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Choice and Autonomy in Everyday Life for Eight Adults with Physical Disabilities

A dissertation submitted to the University of Dublin, Trinity College, for the degree of Doctor of Philosophy

2009

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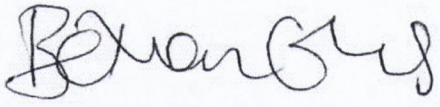

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Summary

This research seeks to explore the daily life experience of eight adults with significant physical disability, with a particular focus on their experience and perceptions of autonomy and choice in everyday life. It involves detailed description of the lives and lifestyles of each of the individuals, their life history and their experiences and views of autonomy and choice. Also explored is the literature within psychology, rehabilitation, occupational therapy and disability studies, concerned with autonomy, choice and other relevant areas.

Two distinct descriptions of autonomy have been presented within the psychological literature; these being self-governance autonomy and agentic separation autonomy (Hmel & Pincus, 2002). In both cases, there is an agentic core, but they differ in that self-governance is positively interpersonal in nature, and agentic separation autonomy is characterised by interpersonal separation. Within rehabilitation, disability studies and occupational therapy, the term "autonomy" is frequently used, but it appears to overlap with other concepts, such as independence, control and choice.

All of the participants in this study have significant physical disability such that they require assistance for some or all personal self-care tasks, and all use a wheelchair for mobility. Four live in the community with personal assistance, and four live in residential settings. They range in age from 28 to 58 years; there are two men and six women, and they have different histories of impairment: three have congenital disabilities, two first experienced disability in their teens and have progressive conditions, and the remaining three acquired disability in adulthood, two having progressive conditions.

Information is collected and explored using a variety of techniques, including: life history narrative; detailed description of daily occupations, captured through interview and diary; discussion with the participants to explore their views of autonomy and choice and description (through a semantic differential scale) of current and ideal lifestyles. The research is based primarily on qualitative methodologies, and includes both descriptive and interpretative findings.

Each of the participants engage in a variety of self-care, productivity and leisure occupations; one works full-time in paid employment, two are involved in education and a fourth does sessional and voluntary work. The patterning of daily occupations varies

between participants, partly due to environmental and institutional structures, and partly due to individual preferences. The amount of time spent at home or within the residential setting varies, ranging from two participants only leaving the home/residential setting once in the week in which the diary was kept, to two who left their home every day. Participants report enjoying most of their activities, and actively choosing to do things that they do enjoy; the amount of control that they have in daily occupations appears to vary between participants.

The extent to which the participants describe feeling autonomous and having choice varies, as does the importance of these concepts to them. Autonomy, for the participants, seems to relate to control; for some it is positively interpersonal, and for others it may not be. Some of the participants, particularly those with acquired disability report that their choice and autonomy are restricted, due to disability, whereas others feel autonomous because they make decisions and remain in control of their lives.

Different psychological reactions to perception of choice and autonomy are discussed; some participants value autonomy and strive to be autonomous; others feel limited in their choice, due to disability, but fundamentally autonomous as they make decisions, and for yet another, the strategy appears to be not thinking or considering autonomy or choice in daily life. It seems that life experience influences a person's perception of their autonomy and choice.

Integration of the literature with the findings of this work enable the description of a new framework to describe autonomy for adults with physical disability. Within this framework, autonomy is characterised by one making choices and governing oneself (with or without influence or support from others); individuals differ in both the extent to which they feel autonomous and their desire for autonomy. Autonomy is developed throughout the life-span and change in function, rather than level of function, is hypothesised to have an influence on a person's sense of autonomy. A key consideration is the person-environment fit to support an individual's own desire for autonomy.

This work poses some key areas for future research and implications for service provision, education and occupational therapy. Future work should include investigation of the proposed autonomy framework, and the relationship between autonomy, control, choice, independence and well-being.

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1. Introduction

Focus of the Research

This research seeks to explore the daily life experience of eight adults with significant physical disability, with a particular focus on their experience and perceptions of autonomy and choice in everyday life.

This research explores the meaning of the notions of autonomy and choice for the eight respondents and investigates the importance to them of autonomy and choice both as goals and values. Because the respondents use assistance from others to accomplish many of the routine and intimate tasks of daily living, this research places special emphasis on the issue of how the practical realities of everyday life may or may not be negotiated in order to sustain a sense of autonomy and control.

This research, therefore, involves detailed description of the lives and lifestyles of each individual, their life history and their experiences of independence, choice and autonomy. It also involves discussion of their views about what the concepts of independence, autonomy, control and choice mean in daily life. The information is both descriptive and interpretative; descriptive findings are presented in eight individual case studies (Chapters 6 & 7), followed by the interpretative findings exploring and comparing the issues among all of the participants (Chapters 8 & 9).

Another key element of this exploration is the review and synthesis of literature from a variety of sources pertinent to this research, presented in chapters 2 – 4.

As with many exploratory studies, there is no specific research question; rather there is the specified purpose as described above. It is envisaged that the exploration will give rise to a number of questions for future research. The results are limited in that they can not be generalised to other people with disabilities, they provide a "snapshot" of the lives of the eight individuals rather than a longitudinal exploration, and the number of participants is comparatively small. However, it is felt that the results of this exploration pose some key questions for both academic study and service provision in the future.

All of the participants have significant physical disability such that they require assistance for some or all of their personal self-care tasks, and all use a wheelchair for most or all of their mobility and/or for seating. Four of the participants live in the community with personal assistance, and four live in residential settings; they range in age from 28 years to 58 years of age; there are two men and six women, and they have different histories of impairment. The participants are described individually in detail in Chapter 6, Description of Participants.

Information from the individuals is collected and explored using a variety of techniques, including life history narrative, detailed description of daily life, including daily occupations (self-care, productivity and leisure), captured through interview and diary, interviews with the participants about their views about their lives and lifestyles and their description (through a rating scale) of current and ideal lifestyles. The methodology employed is fully described in Chapter 5). It is felt important that these different methods were used to provide the detail required about the lived experience, which in turn allows participants' perceptions of their daily lives to be put into context.

The focus of the research arose primarily from the researcher's experience as an occupational therapist and within the disability movement in Ireland, rather than being drawn directly from the literature. Literature related to this exploration has been brought together from a number of sources, as there appears not to be a comprehensive and integrated discussion of the most relevant issues within the areas of occupational therapy, disability studies or psychology. The literature reviewed is presented in the next two chapters and is followed by a synthesis of this information as it relates to the current investigation.

The research focus was also developed in response to the strong trend in policy and legislation within Ireland and worldwide, which can suggest that maximal independence and maximal autonomy are important and healthy; there is the apparent inference that successful living is autonomous and agentic in nature. Arguably, this influential societal backdrop is founded on a political/ideological value system rather than on hard evidence about how these aspirational concepts actually relate to the daily lives of people with physical disability.

Influences on the development of the research focus

Several influences affected the focus of the research. Immediately prior to beginning the research, the researcher worked as an occupational therapist in a long-stay setting / "slow rehabilitation" unit for adults with physical disabilities, referred to by the health services as the "young chronic disabled" (ERHA, 2003). Concurrently, the researcher was also actively involved in the "disability movement" in Ireland.

During the time when working as an occupational therapist, it was observed that a number of "residents" demonstrated a lack of initiative and motivation to do age-appropriate tasks and engage in paid or unpaid work. It seemed that these adults were settling for a life with minimal autonomy or choice – some did not choose their clothes, toiletries, what they ate or when they got up etc., and this in the absence of any significant cognitive impairment. This was not universally true, but when asked, those who showed a lack of autonomy or control, or interest in engaging in activities outside the hospital seemed to perceive that they were not physically able to do more (Collins & Leonard, 2002).

The researcher was also heavily involved in the disability movement in Ireland. It was observed that people with what could be described as objectively equivalent disabilities to those in the residential setting (in terms of nature and severity of the disability) lived their lives in a very different way compared to those in the residential setting. Most lived in the community, many engaged in paid or voluntary work and also had an active social life. It was observed that the nature of assistance varied greatly between those in residential settings and those living in the community; in residential settings assistance for self-care activities was provided by nursing staff within a medical ethos, those living in the community worked with personal assistants which meant that it was possible for them to be assisted in non-self-care activities. The priorities of the people within the disability movement seemed to be the enactment of rights, the need for autonomy, choice and dignity as well as a need to discover a positive "disability identity" (Forum of People with Disabilities, 2004).

It seemed apparent to the researcher that the differences in the sense of, and in the striving for autonomy observed between the two groups could not possibly be due to physical ability or disability alone. Initially several questions arose as to what may cause

the observed differences, such as how the environment in which a person lives affects a person's autonomy, or whether it is primarily a matter of difference in personality. Other questions arose such as whether there is a difference in satisfaction between people living in different environments, with different experiences of choice, control and autonomy in their lives. Central to the investigation was whether people with very different life experiences perceive that they have choice and autonomy in their everyday lives.

A literature search exposed a paucity of information about the lived experiences and occupational patterning of adults with physical disability in Ireland. A key element of the research, therefore, is to gain an understanding of the lived experience of some adults with physical disability, in order to contextualise the respondents' views of their own sense of autonomy and experienced level of choice. In order to understand what they seek in the way of autonomy and what they mean by it, it is important to investigate the routine constraints on choice and independence experienced by these respondents every day.

Background

The landscape for disabled people in Ireland, and worldwide, has changed dramatically since the 1990s. In Ireland, 1990 saw the formation of the first disability lobbying organisation, entirely run for and by disabled people, the Forum of People with Disabilities. This organisation was to have a profound influence on several policy and legislation changes during its lifetime, between 1990 and 2007 (DESSA, 2007). This contrasts with other countries where there were disabled lobbying groups in the mid 1970s and earlier (e.g. UPIAS 1974 - 1976) in the UK, and the CIL in the USA (Gillinson et al, 2005)).

In 1994, the Commission on the Status of People with Disabilities was established, which worked, through consultation, with disabled people, family, carers and other stakeholders, to produce its report, published in 1996 (O'Reilly, 2007). The Commission's report, "A Strategy for Equality" contains numerous recommendations to improve the lives of disabled people in Ireland. Some of these recommendations have been acted upon; others are still awaiting attention (O'Reilly, 2007).

1.3.1. Legislation

A key recommendation of the Commission's report (Commission on the Status of People with Disabilities, 1996) was that rights-based disability legislation should be enacted in Ireland. Since its report, a number of pieces of legislation have changed the situation for disabled people in Ireland. Around the turn of the century new equality legislation (namely the Employment Equality Act 1998 and the Equal Status Act 2000 and 2004) was enacted. This legislation prohibits discrimination under any of nine grounds, one of these grounds being disability. The legislation, like many international instruments, provides for "reasonable accommodation" for persons with disabilities, indeed the legislation defines discrimination against disabled people partly as non-provision of reasonable accommodations (Acts of the Oireachtas, (Equal Status Act) 2000, 2004 section 4).

In 2001, the first "Disability Bill" was published. This was partly in response to the call for legislation specifically around disability, which contains positive rather than merely negative rights (as in equality legislation). Several disability groups came together in protest at the legislation, because it did not contain justicible rights for people with disabilities (Get your Act Together conference proceedings, 2002). This legislation was withdrawn, and the "Disability Legislation Consultative Group" (DLCG) was established by government, to work on a framework for appropriate legislation. Their report, "Equal Citizens" was produced as a template of what the relevant stakeholders wanted in disability legislation. The current Disability Act was published in 2005 (Acts of the Oireachtas, 2005), but several groups continue to describe unsatisfactory aspects of the legislation (DESSA, 2007).

The current research, particularly the data collection phase involving interviews with the participants, took place during the time when discussions over the disability legislation were ongoing. The hopes and aspirations for rights-based legislation are described by one of the participants and although it may not form a direct part of data collected with other participants, the broader debate on proposed disability legislation is likely to have had an impact on several of the other participants.

1.3.2. Changing Priorities

An influence of both the Forum of People with Disabilities and the Commission on the Status of People with Disabilities, aside from changes in legislation, has been the change in attitude and priorities of disabled people. There has been an increasing recognition of the "right" of people with disabilities to live autonomous, independent and dignified lives. The Centre for Independent Living (CIL), together with other similar organisations, has taken a lead role in this movement.

"Rights, choice and identity" was the motto used by the Forum of People with Disabilities (Forum Strategic Plan, 2004). This relates to the perception that disabled people were limited in the choices that they had, that their human rights were being undermined and that there was rarely a sense of pride in, a "disability identity". These views were based mainly on anecdotal information and discussion among disabled people themselves, since rights, choice and identity are issues which have attracted limited research within the Irish context.

The Centre for Independent Living (CIL) established its first Irish centre in 1992, "with the main aim of ensuring that people with disabilities achieved independent living and full participation in society" (Murphy et al, 2006). It offered an advocacy and campaigning representation role, "striving to bring about a social model of service delivery, and to ensure policy decisions would include input from those whose lives were actually affected." (NAG Strategic Plan, 2005 p. 7).

CIL, at its core, adopts what it calls the "principles of Independent Living", which are "choice, rights, empowerment and control" of disabled people in their own lives, so that they can live as they choose (Dixon, 2006; Gillinson et al, 2005). CIL has grown enormously since 1992 and has earned a reputation of acting as a campaigning and advocacy organisation to promote its principles. In 2007 there were 27 CIL centres around the country.

These changes in policy and practice have transformed the landscape for disabled people since 1990. It is reasonable to conclude that there is now greater recognition of the rights

of disabled people and a greater focus on enhancing lifestyle choice and independence for disabled people.

1.3.3. International Instruments

On the international front, the United Nations Convention on the Rights of Persons with Disabilities is a very significant development. This Convention is in the process of being ratified by the state parties, and has been since March 2007. The Convention builds on the previous "Standard Rules for the Equalisation of Opportunities of Persons with Disabilities", which, in itself, was an important document. This Convention is based on the principle that all humans should be seen as equal, and equally enjoy all human rights and fundamental freedoms.

The preamble to the Convention (UN, 2007) recognises:

> "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices"

The Convention itself specifically states that its principles include, "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons" (UN Convention on the Rights of Persons with Disabilities, 2007 article 3.1.a). However, this statement, and the principle that autonomy should be respected are stated within the convention without definition of the key terms such as autonomy and independence.

Autonomy and Independence for disabled people: service providers' views

Despite the lack of clarity of definitions of independence and autonomy, it appears to be generally accepted that autonomy and independence are highly valued by society, for disabled and non disabled people alike (Kagitcibasi, 1996).

The values of independence and choice in society, and to a lesser extent, autonomy, appear to be pervasive in the mission statements of those providing services to people with disabilities.

The Centre for Independent Living defines Independent Living as:

> "The right of all persons regardless of age, type or extent of disability to live in a community; to have a similar range of choices as everybody else in housing, transportation, education and employment; to participate in the social, economic and political life of our communities; to have a family; to live as responsible respected members of our communities with all the duties and privileges that this entails, and to develop their potential."

The Independent Living philosophy is described as going beyond physical achievements, to "political and socio-economic decision-making". The Independent Living movement focuses on personal and economic choices, and its goals are "self-determination, choice, control, and responsibility" (National Access Group, 2005). Self-determination, however, no more than the other linked key concepts, is not defined by CIL.

The Irish Wheelchair Association describes itself as, "the national organisation dedicated to the achievement of the full social, economic and educational integration of people with disabilities as equal, independent and participative members within the general community" (IWA, 2007). In a document about volunteering, the following is stated:

IWA standards and practices are underpinned by the following guiding principles:

> "Person centred; Consultation; Choice; Partnership; Self determination; Equality and fairness; Inclusion; Quality; Accountability; Dignity, and Respect"

There seem to be a large number of guiding principles, and it is not clear how or if these principles are evident in action. As with many service providers, it appears that terms such as "choice", "self determination," "person-centred" and "dignity" are used, without definition or description.

One service that is provided by the Irish Wheelchair Association is the "Assisted Living Service", which provides personal assistants to people with physical disability. The service is reported to facilitate, "community participation, access to education/employment and improved quality of life" and, it is claimed, "enables users to have maximum control of their own services".

The Assisted Living Service describes the role of the personal assistant as follows:

> "A Personal Assistant carries out tasks that the person with a disability might find difficult or impossible to do in their daily lives. Assistance is tailored to the wishes and needs of the person with a disability".

Two different types of service are available, one being self-directed, or "leader-managed", whereby the disabled person manages the employment of the personal assistants themselves, including recruiting the PA, managing time / rosters, arranging for holiday leave and so on. The alternative is where the Association manage the day-to-day service for the disabled person. Participants in this study who were living in the community used self-directed or "leader managed" personal assistance services. In both cases, the personal assistant is paid for by the IWA, unlike in countries such as the UK, there is no direct payments system (see chapter 3).

Another organisation that provides services to people with physical disability is the Cheshire Foundation. Cheshire Ireland aims to, "be a provider of quality, person-centred services which facilitate people with disabilities to live a life of their own choosing" (Cheshire Ireland, 2003). The primary services of the Cheshire Foundation are to provide residential services, respite and other services to disabled people.

Within their strategic plan, Cheshire Ireland quote the ideals for a Cheshire home, as follows:

> "A Cheshire Home should be a place of shelter physically and of encouragement spiritually; a place in which the residents can acquire a sense of belonging, and of ownership, by contributing in any way within their capabilities to its functioning and development; a place to share with others and from which to help others less fortunate; and a place in which to gain confidence and develop independence and interests; a place of hopeful endeavour not of passive disinterest. (Singapore Declaration)"

The Cheshire Ireland Strategic Plan (2003 – 2006) outlines some of the aims of the foundation; the goal is to focus on choice of the individual, in an attempt to implement the independent living ideals. The Plan, by way of explicating core values, quotes the founder as follows:

> "give each individual person the greatest possible choice as regards all aspects of living"
> "everything possible should be done to help the person concerned to achieve maximum independence"
> "the goal should be defined as freedom to choose"

(Cheshire, 1981, as cited in the Cheshire Ireland Strategic Plan, 2003)

Up until the mid 1990's, all of the supported living accommodation took the form of traditional residential settings, but since then, the foundation has aimed to move more into supported living (Cheshire Foundation, 2003). The strategic plan (2003) suggests that all accommodation is akin to supported living services, rather than traditional residential settings.

The term "autonomy" does not appear in the core values of Cheshire Ireland, but there does appear to be a written focus on the importance of providing choice to service users.

There are several residential settings, some of which were approached with a view to recruiting participants for the current study. In the statements of some, there is reference to an ethos whereby the independence of residents is fostered as far as possible. The specific policy statements for individual residential settings are not referenced here, as this could breach the confidentiality of participants in the study.

A question arises whether these statements of intention or value are realised in any form for those using the services.

In 2002, the then Eastern Regional Health Authority recognised that a "problem" group, in terms of service provision existed for health service providers, these being adults with physical disability, termed the "young chronic disabled". A report was produced, outlining service requirements of this group (ERHA, 2003). The report stated that:

"The degree of physical disability can have little to do with the aspiration to live independently. Many people with significant physical disability and significant support needs live very independent and full lives."

The report reviewed 26 cases, with a view to understanding service requirements. It reports that:

> "Among the 26 reviewed case histories were two service users who chose Independent Living as a lifestyle option. Both persons will require twenty - four - hour support for this to be feasible."

It is interesting that only 2 of the 26 case histories chose independent living options, and the question arises about where the remaining 24 live, and whether they have chosen their "lifestyle option".

Within documentation of the Health Service Executive, whose description of its services is quoted below, there appears to be less strong endorsement of the importance of independence and autonomy when compared with that of specific service providers and disabled people themselves.

> "The Health Service Executive (HSE) is responsible for providing Health and Personal Social Services for everyone living in the Republic of Ireland. As outlined in the Health Act, 2004, the objective of the Executive is to use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public."

Accommodation options for people with physical disability

> "It is now thirteen years since the Personal Assistance Services started in Ireland. Before that the only options open to disabled people, who needed assistance, was to rely on family members or go into residential/institutional care. True, there was a service called the Care Attendant Scheme and the Home Help Scheme, but these were focused around family relief and/or bare minimal assistance. None of these options or services provided significantly disabled people with the opportunity to aspire to a quality of life that everyone else took for granted."
> (Murphy et al, 2006)

The Health Service Executive provides services (sometimes via charitable and independent service providers) for people with physical disabilities. In 2002, a review of services for the "young chronic disabled" was undertaken by the then Eastern Regional Health Authority (ERHA, 2003). In relation to accommodation for disabled people, they found:

> "Of immediate concern to Health Service Providers is the lack of appropriate accommodation for people who fall into the young chronically disabled category. At present some people are living in inappropriate accommodation such as Nursing Homes where the emphasis rests on nursing care rather than on social input, and in the community where geographical location and inadequate transport contribute to social isolation. It follows that many young chronically ill men and women are unable to enjoy a full life. A substantial number of those living in the community are living with their families, who experience enormous pressure due to the limited support available to them." (p. 5).

The ERHA began work in 2001, together with representatives of service providers, to assess the current situation and to make recommendations for improvements in service provision for people with physical disabilities between the ages of 18 and 65. Their work

culminated in their report, "A Survey of Services Available to Young Chronically Ill and Physically Disabled People Aged between 18 – 65 years". As part of this review, the types of accommodation that people with physical disabilities live were categorised. The categories were as follows: Independent Living; Supported living; secondary rehabilitation; comprehensive continuing care [residential settings] and challenging behaviour services. The current study began by aiming to invite participants from the independent living, supported living and residential settings; those in secondary rehabilitation were not considered, as this is a transient process, and people with challenging behaviour were not included as part of the population of interest (see chapter 5).

The findings of the ERHA (2003) work concluded that there are many people awaiting appropriate accommodation. The report states that there were 674 people awaiting placement in appropriate accommodation at the time of the initiation of the current research in the region, which covers the Greater Dublin area.

The ERHA (2003) found that the personal assistant scheme was inadequate, and was not available to people living in nursing home, hospital or other residential settings. It reports that the demand for the service greatly exceeds its capabilities, and that employment issues are an obstacle for some disabled people. Additionally, it is reported that ancillary services, such as home help services are insufficient. It was found that regular crisis management services are required for disabled people living in the community, and their carers, due to a lack of respite services.

The report also highlighted that although disabled people report preferring independent living and supported independent living options, that there are no objective measures of the success of these arrangements (ERHA, 2003).

The ERHA (2003) report recommended that a range of accommodation services is required for people who have chronic physical disabilities; standards are required for service provision, and that in all services / accommodation options, the individual should have the option to live as "independently" as possible. Specifically, it is suggested that within residential settings, there should be emphasis on enabling service users to move to alternate accommodation if they wish; for independent living services in the community,

there should be increased provision for personal assistants, and a policy of lifetime adaptable housing should be in force.

The ERHA (2003) document also recommends the use of assistive technology as a support for people living both in the community and in residential settings.

> "There has been huge investment into the benefits of new technology that benefit disabled and elderly people and assist them to control their living environment in other situations. The availability of such technologies not only enhance the autonomy of disabled people but also lesson the dependency on staff to do simple tasks such as operating Television Sets, lights, Personal Computers, opening and closing doors/curtains etc. The Working Group recommends that the Authority invest in making environmental controls/smart house technology available in all new accommodation and support services." (p. 15)

Reflexivity: The researcher's influence and perspective

Throughout this work, I have included reflexive elements; that is my examination of how my own personal attitudes, values and experiences may be shaping my interactions with participants and my approach to methodology and interpretation. The requirement for reflexivity in qualitative research is well-established. For example Jewiss and Clark-Keefe (2007) state:

> "The necessities and benefits of reflexivity are now well laid out in the broader social science literature... disciplined self-reflection can help students examine personal perspectives that surface during the research process and monitor bias. Failure to develop and maintain a reflective stance can result in a variety of ethical and practical dilemmas."
> (Jewiss & Clark-Keefe, 2007 p. 334)

These reflexive elements are important as a way of contextualizing the research for the reader and informing him or her about the researcher's motivations and particular biases, but equally they are important to the research itself. It is an essential aspect of achieving rigour in qualitative research that the researcher reflects on his or her preconceptions, attitudes and values and how these impact on the research process. In keeping with the following views of Webb (1992), I have written these sections for the most part in the first person:.

> "With regard to research in the qualitative, critical and feminist paradigms... the use of the first person is required in keeping with the epistemologies of the research and in the pursuit of reflexivity.... and where an author is giving a personal judgement arrived at on the basis of reasonable evidence."

(Webb, 1992 p. 747)

In this section, I look at how I arrived at the choice of research focus – in other words why did I choose to study autonomy and choice for people with significant disability? In sections in the Methodology chapter, I explore my influence on the choice of methodology. The importance and use of the reflexive aspects of this research are further discussed in the final chapters

I arrived at this particular topic, as already described (see sections 1.2 and 1.3), from experience both as an occupational therapist and as someone who was active in the disability movement in Ireland - as a member of the Board of Directors of one disability lobby group, as a broadcaster on national radio and television and in other capacities. This does not necessarily imply that I myself am disabled. However, the fact is that these interests are indeed linked to my situation as a blind person . When considering the research question, I thought about conducting work with people who are blind or vision impaired – an easier option in that I am blind, know a lot of blind people, and am active in the blind community. I decided not to do research with blind people, because I was concerned that my very strong views would influence the research too much. I wanted to do research that was primarily professionally motivated, though also inevitably coloured by my own experience of disability. I was not working as an occupational therapist with people who are blind or vision impaired, but those with physical disabilities so this latter group were the natural focus of my professional research interest. Initially, I regarded the focus on physically disabled people as an aid to greater objectivity and rigour in the research process. The idea was that I would be stepping outside my own disability group and would thereby potentially free myself from ingrained attitudes and emotional reactions which shape my own thinking about independence choice and autonomy for people with a similar disability to mine.

Through the course of this research, I have become increasingly aware that my "blind views" are highly transferable and transferred quite readily to other impairment groups, such as people with physical disabilities. I have concluded that the specific impairment itself is irrelevant to the larger concepts and discussions of the meaning of independence, or autonomy or choice or control. The idea that exploring the issues for people with disability experiences that differ to mine would make it easier to be "objective" or "reflexive" has time and again been shown to be invalid. My original assumptions may

have been naïve but discovering this certainly highlights the central role of reflexivity in qualitative work of this kind.

My own views of independence, choice and autonomy in the context of disability have been shaped in important ways by my education as an occupational therapist and by my wider reading in the area as well as by my experience as a disabled person. As an occupational therapy student, I became acquainted with the work of Rogers (1982), where the description of independence as comprising of autonomy and competence appears. This work was like a light-switch, and highlighted many of the deficits that I saw in the profession that I feel passionate about. It seemed to me that occupational therapy all too often focused solely on the competence part of independence – my physically disabled friends spoke of horror stories of OTs coming to them to teach them to put their socks on, when all they really wanted to do was go to College, get a job, have a boy/girlfriend or whatever. I remember so many debates with my disabled friends trying to advocate for a profession that they perceived to be obsessed with bathing.

I reflected also on my own experience, what made me an independent person? As someone with a degenerative impairment, I went through a period where my measurable competence (or ability to see, read, get around etc) was reducing significantly, but I felt more and more independent, I was having a great student life, I considered myself to be doing well in College, had future plans, I was more independent, but less competent. So, the independence, for me arose from a number of factors. I had supportive friends. I had a reader to read print information onto tape, and so for the first time I could decide what I wanted to read based on its content rather than on the size of print or how tired I felt. Rogers' (1982) words, other readings from disability studies and my disabled friends' words seemed to ring true for me – independence depends on having (and exerting) choice or autonomy.

Upon graduation, I worked clinically, in a number of areas. Avoiding the temptation to teach people how to put their socks on, I worked with a group of people who were young, had significant physical disabilities and were living in a residential setting. When I asked them if they would be interested in working or going to college, they tended to tell me that they couldn't, because they were not physically able to do so. Their social outlets seemed restricted to organised activities within the setting. At the same time, my friends in the disability movement were working, attending meetings and regularly going to the pub to socialise. I remember one friend, a leader of a PA, directing the PA to renew her car tax,

to pay certain bills and to get some shopping. This friend, in "functional ability" was no different to the people with whom I worked, but their lives were poles apart. My friend made choices, took control, and considered herself independent and autonomous. The people with whom I worked felt incompetent, dependent and not in control.

These observations in my professional and personal life stimulated my interest in independence, choice and autonomy in the lives of physically disabled people and especially in the processes by which people with similar levels of "function" can end up with such very different lifestyles and levels of lived independence. This research, therefore, aims to explore the meaning of autonomy to a number of people with significant physical disability. I could easily have asked the people I knew from within "the movement", the "old guard" of the disability movement in Ireland, as one activist calls us, but this would have given a very limited and perhaps a one-sided view. I wanted to also invite people who were living in different settings, be they residential or in the community, but who may not be involved in the movement, where autonomy is a staple of coffee time discussions.

I was interested to explore what autonomy means to people who don't make choices about their environment, about what time they get up, about their clothes. I was concerned to discover if this concept, autonomy, is relevant only to those who have fought to be autonomous, and so, almost certainly have thought hard about what independence and autonomy mean to them. I was concerned to explore what autonomy means to different people and whether it is as important and as relevant as I have found it to be in my own life, and as central to peoples lives as some occupational therapy and psychological literature suggests.

The issue of autonomy is very much the focus of this research, but the focus is also on attempting to gain insights into the role of independence, choice and autonomy in the life stories of the participants and in the grounding context of their reality of daily experience, For example, the issue of the need for assistance to go to the toilet is sometimes an elephant in the room. Such basic issues are often brushed under the carpet when independence, choice and autonomy are under discussion. Indeed, such discussions can tend to resort to rather ethereal and idealistic concepts of independence, choice and autonomy that do not relate to mundane reality. On the one hand, the discussion and debate in disability studies tends to skate over the practical daily experiences of impairment, on the other the more medical literature focuses on competence to perform

these tasks. I am interested in knowing how people manage daily life, including assistance, how the need for assistance affects perceptions of autonomy and independence, whether use of assistance increases independence or whether it is seen as an indication of a person's inability to be independent – and most of all, how people view their own lives when these lives involve an inevitable degree of dependence alongside opportunities for constrained but real independence.

Governmental policy and the mission statements of many service providers suggest that maximal independence is important. I am interested in investigating the views of independence and autonomy of the potential beneficiaries of these evidently enlightened policies. Are independence, choice and autonomy relevant to everyone? In the same way? What does autonomy actually mean, in a practical and theoretical way, to people with significant physical disability?

Overview of Methodology

This research reports on an exploration of eight individual case studies of people with significant physical disability. It focuses on their life history, daily lived experience and perceptions of autonomy, choice, control and independence.

The methodology employed is integrated (as described by DePoy & Gitlin, 2005)with qualitative information and detailed descriptive information. The stages in data collection are as follows:

Individuals were initially interviewed using a semi-structured interview, and life history narrative approach.

- The participants were interviewed to collect detailed information about their daily self-maintenance routines. This is to explore the daily experience, and the extent to which they have choice and control in personal self-care occupations. It also provided a description of the disability experience of the person, and avoided repetition in subsequent data collection.
- A 7-day diary was kept by each participant, outlining activities performed and other details, such as whether or not these are performed with other people, whether they are chosen, important or enjoyable for the participants.

- The final interview involved specific discussion of the participants' views of choice and autonomy, their perceptions about their daily routine, week of diary entries and lifestyle in general and a semantic differential-type scale for participants to rate their present lifestyle compared to an ideal.

Important aspects of the research process involved reflexivity, collection of data using a number of methods (akin to triangulation) and strategies to promote rigour.

A full description of the methodology used in this study is contained in Chapter 5. The information gleaned from the process is presented in Chapters 6, 7, 8 and 9, and is followed by discussion in chapter 10.

Definitions

As Cresswell (2007) describes, qualitative studies rarely have detailed definition lists, as the interpretations and meanings of the participants are of most importance. However, it was felt that the definition of a number of terms would be useful. Below a number of terms are defined, as used in this research.

Disability / disabled people / people with disabilities.

People with disabilities and disabled people are used interchangeably in this study, although it is recognised that they have different connotations, with "disabled people" being a term more commonly used by activists using a social model of disability, while "people with disabilities" has medical model connotations (Shakespeare & Watson, 2002).

The definition most appropriate to this study is that found within the UN Convention of Rights of Persons with Disabilities (2007):

> "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."
> (UN Convention, Article 1)

For a more detailed discussion of definitions of disability, see Chapter 3.

Significant Physical Disability

The participants in this research all experience "significant physical disability", meaning that they all use a wheelchair most or all of the time for mobility, all require some personal assistance and / or the use of specialist adaptive equipment in order to perform self-care tasks on a daily basis and they all have physical impairments.

Autonomy

As definition (or description) of autonomy is a core element of the work of this research, it is not entirely appropriate to provide a definition in this section. However, it is worth noting the variety of definitions found within the literature. These are discussed in more detail in Chapter 2 (section 2.5).

Hmel & Pincus (2002 p278) write that,

> "Despite this significance to the human experience and its prevalence in the literature, autonomy is a construct lacking theoretical homogeneity as well as a consistent and common operational definition. The autonomous individual has been described as both psychologically adjusted (Deci & Ryan, 1985) and prone to psychopathology (Beck, 1983), related to others (Blatt & Blass, 1996; Koestner & Losier, 1996) and indifferent to others (Hirschfield, Klerman, Gough, Barrett, Korchin, & Chodoff, 1977), self-ruling (Haworth, 1986) and defensively separated (Robins, Ladd, Welkowitz, Blaney, Diaz, & Kutcher, 1994). An intriguing challenge that arises from such diversity lies in the interpretation of numerous autonomy theories and research endeavors.".

In their study exploring the different conceptions of autonomy within psychological research, Hmel and Pincus (2002) conclude that there are two valid, distinct meanings to autonomy within the literature; that of autonomy meaning self-governance (autonomy II) and that of autonomy meaning agentic inter-personal separateness (autonomy III). Self-governance autonomy is characterised by an individual making choices, governing oneself, being in control of their actions, with or without the help or collaboration of others. It is also described as "reflective autonomy" (Koestner & Losier, 1996) and autonomy as described within self-determination theory (Chirkov et al, 2003; Koestner & Losier, 1996; Ryan & Deci, 2000). The second form of autonomy distinguished by Hmel and Pincus (2002) is autonomy meaning agentic interpersonal separation (autonomy III). This form of

autonomy is similar to the "self governance" autonomy, in that there is an agentic dimension, but differs in that a person makes choices in isolation from other people; research has shown that in this form of autonomy an individual is unlikely to heed advice from others or be influenced by others (Koestner & Losier, 1996). The interpersonal separation autonomy is also described as "reactive autonomy" (Koestner & Losier, 1996). There are similarities in both constructs, but the greatest difference is in the relationship with other people.

While recognising Hmel and Pincus' (2002) work, other descriptions of autonomy are found within the literature, particularly when research from the fields of disability and rehabilitation are considered in addition to the psychological literature. Some of these descriptions include:

- The concept of "Autonomy I", which is autonomy as a psychological vulnerability, associated with depression (Beck, 1983).
- The "liberal theory of autonomy", as described by Agich (2003), which consists of a set of qualities, relating to independence, or non-interference from others.
- "Decisional" and "executional" autonomy, proposed by Cardol et al. (2002), Decisional autonomy is described as the ability to make decisions without external restraint and executional autonomy is described as the ability to act as one wishes, typically as a result of the decisions made.
- Proot's (2000) description, that autonomy consists of: self-determination (described as choices, decisions and freedom of choice); independence (described as physical, psychological and social) and self-care (the activities of daily living).
- Agich (2003) describes "actual" or "phenomenological" autonomy; which is not an end-state, but rather a process of continual engagement with the world, in which a person exercises their autonomy partly through making choices that are meaningful to them, and which are a reflection of the self-concept and a description of their unique life history (Agich, 2003).

Epistemological and Ontological perspectives

This research is situated in a relativist ontological perspective, that is, the belief or assumption that each person is a "relational being", interdependent on others (Mauthner &

Doucet, 2003) and that there are several "realities", each of which entwined in cultural, societal and individual norms and experiences. The aim of this research is to understand and uncover the realities for each of the participants, rather than trying to uncover one positivist "truth". There have also been elements of reflexive or cultural bracketing in the method and approach (as described by Gearing, 2004).

Alongside the ontological standpoint, the epistemological perspective has been inquisitorial in nature, the researcher sought to observe, discuss and then interpret findings with the aim of re-configuring information to create a fuller understanding of the issues of autonomy and choice. This exploration, epistemologically, is underpinned by the post-modern assumption that there are many realities, and that the social context and research method itself is likely to affect the findings, as Mauthner and Doucet (2003) describe, the research process may enhance some voices and silence others.

Limitations

This study has a number of inherent limitations, as described below.

Information is collected with a small number of participants. The small number was due to a number of factors, including the large volume of data collected with each individual. It was felt important to concentrate on quality information from a smaller number of participants rather than less detailed information from a large number. Eight participants are included in this research, however incomplete data collection took place with a further eight individuals (see Chapter 5, Methodology for details).

All individuals were living within the greater Dublin area. This was done to facilitate data collection, and means that a geographic spread is not achieved. However, as each of the individuals are described separately, and as comparison or inference is not part of this work, geographical spread was not considered important.

The data collection methods were novel, created specifically for the purpose of this research. If existing, reliable and valid tools were available to support the work, they could have been used. The tools used were, however, to some extent based on existing methods and tools that were adapted to a greater or lesser extent to specifically explore

issues in this research. The creation of appropriate data collection methods, rather than using pre-existing tools is also thought to be more in keeping with the qualitative approach used.

The data collection process did not necessarily reach the point of saturation with each individual. Data collection to the point of saturation may have ensured more completeness in the data, but ethically, further data collection with the individuals would have been more burdensome for the participants.

The results, to some extent, depend on the reliability and honesty of participants as self-observers and reporters of their information. Strategies were used to try and improve trustworthiness of the information, as described in Chapter 5.

The topic under discussion is highly complex, which poses difficulties for both the researcher and the participants. The complexity of the subject results in an inability to categorically differentiate between influences of the environment, innate personality traits, aspects of the participants' life history and experience of disability. The information is presented as is, with discussion of the various influences, but it is not a purpose of this work to make such differentiations, simply to explore the experiences of a number of individuals.

This research, due to its scale and method is not transferable to other individuals with significant physical disability. Its purpose is not to provide transferable findings, rather to explore and document the situation, both in concrete and abstract terms, of a number of individuals with significant physical disability.

Structure of this report

An extensive review of literature from a number of fields was conducted and is presented in the next three chapters (Chapters 2, 3 and 4).

The methodology used is described in detail in Chapter 5.

The results are presented in chapters 6 – 9, beginning with the case-studies in chapters 6 (description of participants) and chapter 7 (Daily Occupations). The following two results chapters present comparative and interpretative results and results of explorations into the autonomy, choice and control that participants have in their daily lives (chapter 8) and the meaning or interpretation of autonomy, choice and control of the individuals and their views about their lifestyles (Chapter 9).

The results are discussed with reference to the literature in the final chapter, Chapter 10.

2. Literature Review Part 1
3.

Introduction

This research seeks to explore the daily life experience of eight adults with significant physical disability, with a particular focus on their experience and perceptions of autonomy, choice and independence in everyday life. This chapter is the first section of the literature review, which aims to embed this work within the broader literature.

The literature review is divided into three parts:

- firstly, this chapter will review information primarily from the discipline of psychology, providing a backdrop to the psychological factors considered in this work;
- the second section (chapter 3) focuses on disability research and theory, which provides a parallel backdrop, relating to the researched lived experiences of people with disabilities, and
- the third section (chapter 4) aims to synthesise the key parts of the literature that relate to this work.

While the focus of the research arose primarily from the researcher's experience, certain theoretical concepts also influenced the work. The questions that inspired this research appear primarily to be psychological in nature, and include issues such as the extent to which motivation impacts a person's experience of independence and autonomy; how some individuals appear to strive to achieve, whereas others appear to view themselves as helpless, or settle for the lifestyle that they have; how autonomy is conceptualised within psychology, and what influences a person's autonomy or desire for autonomy; how some individuals seem to strive for control and choice, whereas to others these appear unimportant, and how individuals create lifestyles that are meaningful and happy in spite of adverse circumstances, and others appear not to create lifestyles of their choice. Psychological literature about these concepts is reviewed in this chapter.

As described in the introductory chapter, it appears that policy and legislation suggest that maximal independence and maximal autonomy are important, are healthy and are

constituents of successful living. The evidence supporting or negating these suggestions is sought from within the psychological literature.

Motivation

Motivation is a major area of investigation within the field of psychology (Eccles et al, 1998), therefore a comprehensive discussion of theoretical approaches is considered beyond the scope of this review. However, as this research is concerned with exploring the lived experience of the individuals, with a focus on their autonomy and choice, it is considered important briefly to overview pertinent theories, particularly relating to intrinsic motivation and self-determination theory.

There are many theories about motivation within psychology (Eccles et al, 1998), from the "grand theories" such as behaviourism and psychoanalysis to more modern theories, including self-determination theory (Ryan & Deci, 2000), the theory of optimal experience, or "flow" (Csikszentmihalyi, 1988) and self-efficacy theory (Bandura, 1982). These, as with many aspects of psychology are supported by experimental results with non-disabled people.

There seems to be little investigation into the relevance or applicability of some aspects of theories of motivation to disabled people, such as the drive for mastery; research in psychology has tended to focus on specific areas of disability rather than exploring the relationship of psychological theories to disabled people (Tate & Pledger, 2003). The application of some of these theories appears within occupational therapy literature, such as the work of deCharms as found within the Model of Human Occupation, (Kielhofner, 1996; 2008),

Bandura (1989; 1978) describes the explanation of human agency within social cognitive theory. Humans are perceived to be neither fully autonomous nor mechanistic, but that a system of reciprocal determinism, or "emergent interactive agency" occurs. Within the theory of reciprocal determinism, humans are viewed as being able to influence and be influenced; personal factors, environmental factors and self-governed influences all contribute to determination. An important influence on human agency is cited as the capacity for forethought, whereby a person can anticipate future situations and

consequences of behaviour, set goals and plans of action to achieve desired outcomes, resulting in self-motivated behaviour (Bandura, 1978; 1989; 1982).

Within social cognitive theory, people are seen as both agents and objects, as they act on the environment and on the self (Bandura, 1989). The concepts of human agency are compatible with determinism, which is seen to mean the "production of effects by events" (Bandura, 1989). Both the environmental and self-generated influences affect behaviour, so in the same environment, people who have acquired the skills to regulate their motivation and behaviour do better than those who have not (Bandura, 1982). It is assumed that better performance relates to better adaptation to the environment. Relating this to disabled people living in different settings, it could be further assumed that those that can regulate their behaviour to suit the particular environment will do better.

Self-determination theory

> "Despite the fact that humans are liberally endowed with intrinsic motivational tendencies, the evidence is now clear that the maintenance and enhancement of this inherent propensity requires supportive conditions, as it can be fairly readily disrupted by various nonsupportive conditions... our theory of intrinsic motivation... examines the conditions that elicit and sustain, versus subdue and diminish, this innate propensity."
> (Ryan & Deci, 2000, p.70)

Deci and Ryan (1985a; Ryan & Deci, 2000) describe "Self-Determination Theory" (SDT), which combines two theories relating to motivation. The theory comprises of two sub-theories, these being "Cognitive Evaluation Theory", which describes three basic psychological needs, which, if met, promote intrinsic motivation, and Organismic Integration Theory, which describes a continuum of motivation and regulatory styles for different levels of motivation along that continuum.

Cognitive-evaluation theory (CET), was proposed by Deci and Ryan (1985). This theory proposes that intrinsic motivation is innate, but is either fostered or hindered by the social environmental surrounds. It suggests that if three basic needs are met, then intrinsic motivation is possible. These basic psychological needs are competence, autonomy and relatedness. It is suggested that the environment can affect the fulfilment of the three basic psychological needs. Intrinsic motivation is possible or enhanced when the three

needs are met. It is clarified that people will only be intrinsically motivated to perform activities that are valued and interesting to them.

Aspects of the cognitive evaluation theory are highly relevant to this research, in particular the presentation of autonomy as a basic psychological need, and also the definitions and differentiations of the three needs; autonomy, competence and relatedness. Discussion of each of these is contained later in this chapter.

The second sub-theory within SDT is organismic integration theory (OIT) proposed by Ryan and Deci.(2000). This theory describes the regulation of behaviour along a motivation continuum, from amotivation at one end to intrinsic motivation at the other end. Along the continuum, the regulatory styles change, as does the degree to which the value of the task is internalised and integrated, with internalisation being the extent to which the value is adopted by the person, and integration the extent to which the person views the value as their own (Ryan & Deci, 2000).

Ryan & Deci (2000, p. 71) differentiate between extrinsic and intrinsic motivation as follows:

> The term extrinsic motivation refers to the performance of an activity in order to attain some separable outcome and, thus, contrasts with intrinsic motivation, which refers to doing an activity for the inherent satisfaction of the activity itself.

There are several forms of extrinsic motivation described within organismic integration theory, depending on the regulatory style. The regulation styles are placed along the continuum, from external to internal regulation. There are a number of discrete points along the continuum, these being:

> External Regulation; the Perceived Locus of Causality is External and the Relevant Regulatory Processes are Compliance, External Rewards and Punishments.
> Introjected Regulation; the Perceived Locus of Causality is Somewhat External and the Relevant Regulatory Processes are Self-Control, Ego-Involvement, Internal Rewards and Punishments.
> Identified Regulation; the Perceived Locus of Causality is Somewhat Internal and the Relevant Regulatory Processes are Personal, Importance, Conscious Valuing.
> Integrated Regulation; the Perceived Locus of Causality is Internal and the Relevant Regulatory Processes are Congruence, Awareness, Synthesis With Self.
> (Ryan & Deci, 2000, p. 71)

The regulatory styles are environment-specific (Ryan & Deci, 2000), and so it would be interesting to examine whether people with physical disability living in different situations

(such as residential settings compared to independent living) experience different regulatory styles, and therefor, whether motivation is qualitatively different.

Intrinsic motivation

> "Perhaps no single phenomenon reflects the positive potential of human nature as much as intrinsic motivation, the inherent tendency to seek out novelty and challenges, to extend and exercise one's capacities, to explore, and to learn"
> (Ryan & Deci, 2000, p. 70)

Within self-determination theory (or more specifically cognitive evaluation theory, it is assumed that intrinsic motivation is innate. Being innate, the environmental surroundings catalyse intrinsic motivation, rather than create it (Ryan & Deci, 2000).

It is argued that feedback, if positive, can help to foster a sense of competence, which in turn can lead to increased intrinsic motivation, provided that the three basic psychological needs of autonomy, competence and relatedness are supported. This theory relates in some ways to that of self-efficacy (Bandura, 1982), but differs from it in focus and also in that the self-determination theory suggests that perceptions of competence are not enough to promote intrinsic motivation; a sense of autonomy is also required (Ryan & Deci, 2000). This sense of autonomy required is similar to the notion of an internal locus of control, or "origin-like" behaviour (deCharms, 1968).

DeCharms (1968) describes the difference between intrinsic and extrinsic motivation not in terms of competence or perceived competence (as within self-efficacy theory), but in terms of regulatory style, "the crux of the distinction between extrinsic and intrinsic motivation lies in the knowledge or feeling of personal causation" (p. 328). The construct of personal causation, and the work of deCharms provided a foundation to other theories of intrinsic motivation, including SDT and the theory of "flow"(Csikszentmihalyi, 1988).

DeCharms (1968) found differences in school-children, that he described in terms of whether or not they felt that they had control of their lives. He described those that had control as being "origins", and those who did not have control as "pawns" (deCharms, 1968), which led to the theory of personal causation. An interesting feature of the "origins" in deCharms' (1968) work is that they appeared to experience intrinsic motivation to a much greater extent than the "pawns". The "origins" also seemed to take ownership of, or

responsibility for behaviour, and were more independent of outside forces. DeCharms (1968) first suggested that if people initially chose to engage in behaviour, and were subsequently rewarded for this behaviour, their intrinsic motivation decreased. This finding has been replicated a number of times and incorporated into other theories of intrinsic motivation (e.g. Csikszentmihalyi & Csikszentmihalyi, 1988; Ryan & Deci, 2000).

Csikszentmihalyi (1988) describes the sense of "flow", as optimal experience of engagement, which occurs when a person is engaged in an intrinsically motivated task. The focus of the flow theory is the subjective experience of the person. This focus differs from that of Deci and Ryan (1985a), in that the focus within SDT is on what factors promote intrinsic motivation, and how intrinsic motivation affects behaviour, rather than the experience of being intrinsically motivated.

Csikszentmihalyi (1988) describes "flow" as a technical term in intrinsic motivation to describe the optimal experience. Csikszentmihalyi's work began by observing artists who were intensely engaged in their work, despite an apparent lack of external reward for their work (Csikszentmihalyi & Csikszentmihalyi, 1988).

Csikszentmihalyi (1988) describes the "flow" experience as an autotelic experience, because the experience itself is motivating, rather than any future consequences. The structure or nature of flow is similar regardless of the activity in which the person is engaged, although a person is more likely to experience flow when engaged in some activities, such as those that are structured and challenging, and provide feedback, compared to other activities. Csikszentmihalyi (1988) argues that "flow" is a pan-human experience, and its structure is constant across cultures.

Csikszentmihalyi (1988) found that there are a number of preconditions that allow for flow experiences; one of these is that a person needs to perceive that there is a challenge, but a challenge which is possible. It is also suggested that while all people can experience flow, some personalities are more likely to do so, partly due to in-born traits, and partly due to experiences where the preconditions for the experience have been learned (Csikszentmihalyi, 1988).

The experience of engaging is the central focus for the theory of flow (Csikszentmihalyi, 1988). While experiencing flow, the person finds the activity deeply enjoyable; their

concentration is highly focused, to the extent that awareness of the self is suspended (or transcended); they perceive that the outcome is within their control, not due to fate; there is a distorted sense of time and problems or other concerns are lost during the experience.

Flow, in itself is a rewarding experience, which can act as a motivator for a person to engage in more activities, which in turn develop competence (Csikszentmihalyi 1988). The experience of flow is only likely to be present when there is an optimal level of challenge (Csikszentmihalyi, 1988), or the "just right" challenge, as described in occupational therapy literature (Rogers, 1982)

The optimal experience requires an environment / task that provides the appropriate level of challenge. It is not clear how this may apply to people with significant disability, who frequently live within a world where the environment does not support independent action. Does this mean that flow experiences are more difficult?

A number of studies have described the benefits of flow to well-being (Csikszentmihalyi & Csikszentmihalyi 1988), as well as the experience of intrinsic motivation (e.g. Ryan & Deci, 2000).

Competence

There are a number of theories describing competent performance. This section aims briefly to outline those proposed by Masten and Coatsworth (1998); the theories within self-determination theory (Ryan & Deci, 2000) and within occupational therapy literature.

Actual competence is only part of the picture; a person's perception of their competence can be as important as their actual level of ability (Bandura, 1982). Theories of the development of a person's perception of their competence, such as self-efficacy theory (Bandura, 1982) are also presented. The area of competence is potentially very large, and a detailed discussion of measuring competence from an occupational therapy perspective is considered beyond the scope of this review. However, given that this research focuses on the daily lives of adults with physical disability, discussion of concepts of competence is considered necessary.

Actual Competence and resilience

Masten and Coatsworth (1998) describe competence as referring to,

> "a pattern of effective adaptation in the environment, either broadly defined in terms of reasonable success with major developmental tasks expected for a person of a given age and gender in the context of his or her culture, society, and time, or more narrowly defined in terms of specific domains of achievement, such as academics, peer acceptance, or athletics" (p206)

They further describe the two implications of competence, these being that there is a history of competent or effective behaviour, and that there is likely to be future competent or effective behaviour. They also suggest that "competence", as a concept refers to good adaptation, rather than to excellence.

Within occupational therapy literature, competence, or the ability to do, is frequently synonymous with the term "occupational performance", which is seen as the interaction between the person, environment and the task (AOTA, 1995). In psychology literature, competence is, according to Masten and Coatsworth (1998), dependent on both the person's abilities and on the environment. It is possible that the task aspect of the occupational therapy definition or understanding is taken as part of the environment, but there appears to be no specific mention of the influence of the task in relation to competence.

Masten and Coatsworth (1998) describe the importance of the environment's influence on a child's competence. When supported, children can perform at a higher level, whereas in an unsupportive environment the same child may be considered incompetent.

Resilience refers to demonstrable competence where there are significant challenges to adaptation or development Masten and Coatsworth (1998). Masten and colleagues have studied children who are considered to be "resilient", in an attempt to understand whether these children have unique qualities enabling them to overcome the challenges and achieve competence in a situation where others fail.

It is interesting that the discussion of resilience refers to children, and it is questioned whether the same theories hold true for adults. It also appears that the research has focused on children in environments that thwart development and adaptation, rather than children who have disabilities, where a "normal" environment is unsupportive to them, whereas it may be considered fully supportive of a non-disabled child. For a child to be classified as "resilient", it is necessary that the environment is considered "high-risk" and that adaptation or development is good Masten and Coatsworth (1998).

This study investigates the experience of adults with physical disabilities of autonomy, and independence. The history of development of competence is important to consider, and further to explore differences between those who have had the opportunity to develop competence in supportive environments.

Masten and Coatsworth (1998) highlight the importance of an understanding of how competence is achieved in adverse situations, especially if disadvantage affects a large number of people. Their work concentrates on the achievement of competence in children at risk, and it is not known to what extent the findings are applicable for adults with physical disability. It is reported that the development of competence and resilience have been studied in a wide variety of settings (Masten & Coatsworth, 1998), all of which seem to be environmental risks. It is interesting that disability (of the child rather than of a parent, which has been studied) seems not to constitute "risk" or has been overlooked in this research.

Masten and Coatsworth (1998) suggest that, if children's competence is to be improved, a multi-fold approach is needed; the level of ability can be increased and the environment can be made more supportive or changed to produce better fit. In occupational therapy literature, the concept of the "just right challenge" is frequently proposed (e.g. Rogers, 1982; CAOT, 1997; Kielhofner, 1996). This is viewed as the environment and task which best supports change and improvement in occupational performance, or competence.

There are a number of context-specific methods suggested for occupational therapists to improve competence of individuals, whether this be by improving personal capabilities, such as physical, cognitive or affective components, simplifying or adapting the task and providing a supportive physical, social, cultural and institutional environment (AOTA, 1995; CAOT, 1997).

Fundamentally, it is proposed that there is an innate interest or desire for mastery in humans, observable in the manner in which people engage with the environment and derive pleasure from doing so. This need or desire for mastery is viewed as a motivating factor in facilitating the development of competence. The environmental and internal characteristics that have been seen to be strong in resilient children (and adults) have consistently been found to be "relationships with caring, pro-social adults and good intellectual functioning" (Masten & Coatsworth, 1998 p. 212).

Within self-determination theory (Ryan & Deci, 2000), the basic need for competence is seen as a reason why people seek stimulation and challenging activities. Competence, along with a sense of autonomy or internal locus of control, is essential for intrinsic motivation, which in turn can be reduced by external control or negative competence feedback (Ryan & Deci, 2000; Eccles et al, 1998). For competence and autonomy to be present and to promote intrinsic motivation, there must either be a supportive environment that promotes both needs, or previously acquired "inner resources" (Ryan & Deci, 2000 p.70).

Competent behaviour is thought to promote well-being in daily life (Reis et al, 2000; Ryan & Deci, 2000), as well as adaptation to the environment (Bandura, 1982). Persistent non-conpetence is thought to lead to undesirable outcomes, such as learned helplessness (Seligman, 1975).

Research has highlighted the importance of early childhood development as the foundation for future competence (Masten & Coatsworth 1998). Factors such as parenting styles have been linked to the development of social skills, rule-governed behaviour and good self regulation. Pro-social behaviour has, in turn been linked to better achievement and higher intelligence (IQ) and positive peer reputation to social competence, achievement in a variety of domains, higher self-worth and better mental health (Masten & Coatsworth, 1998).

Findings showing increased competence seem to relate to the assertion within self-determination theory that relatedness is a basic psychological need, promoting the development of competence and autonomy. It is unclear, however, how these social factors influence competence, whether pro-social behaviour leads to heightened

perceptions of competency (e.g. increased self-efficacy) or whether the social environment supports performance by providing a suitable environment.

The importance of high intelligence for competence has been highlighted – children who have succeeded despite a high-risk environment have frequently been found to have "strong intellectual skills" (Masten & Coatsworth, 1998, p. 212). Bandura (1989) reports that analytic thinking results in higher accomplishment. Interpretations of why intelligence (and language skills) appear so crucial have included that in adverse situations higher cognitive functioning promotes better problem-solving, and that intelligent children are likely to be able to elicit a variety of information processing skills that can also be used when dealing with an adverse situation.

When faced with adverse environments, Bandura (1989) argues that a strong sense of self-efficacy enables a person to remain task focused, and that people who believe that they have good problem-solving skills can remain efficient in complex situations, unlike those with less confidence in their ability to problem-solve. Relating this to the importance of problem-solving in resilient children, reported by Masten and Coatsworth (1998), it is questioned whether resilient children's belief in their ability to problem-solve, as well as their actual ability to do so combine to produce more positive outcomes than those with either poorer ability or less confidence in that ability.

Perceptions of competence: Self-efficacy

Marsh and Hau (2003) report that people are more likely to achieve more if they feel competent in what they do, are self-confident, and feel positively about themselves. It appears that perceptions of competence may be as important as actual competence in determining success or failure. One example of a theory about perceptions of competence is self-efficacy theory, proposed by Bandura (1982).

> "Self-percepts of efficacy influence thought patterns, actions, and emotional arousal. In causal tests the higher the level of induced self-efficacy, the higher the performance accomplishments and the lower the emotional arousal... Perceived self-efficacy helps to account for such diverse phenomena as changes in coping behavior produced by different modes of influence, level of physiological stress reactions, self-regulation of refractory behavior, resignation and despondency to failure experiences, self-debilitating effects of proxy control and illusory inefficaciousness, achievement strivings, growth of intrinsic interest, and career pursuits."
> (Bandura, 1982 p 122)

Bandura's (1982; 1989, 1994) theory of self-efficacy is concerned with personal judgements of capabilities and how these judgements of efficacy affect behaviour, motivation and performance. It is suggested that a person's level of self-efficacy positively influences thoughts, actions and inversely affects emotional arousal (Bandura, 1982). Self-efficacy beliefs can vary in strength, generality across different tasks, and for either difficult or easy tasks (Eccles et al, 1998).

Self-referent thought is described as the mediator between knowledge (for example how to perform a task) and action (the performance). If the person has low expectations of success (or poor self-efficacy) it is more likely that they will not act positively even when they know what has to be done (Bandura, 1982).

The formation of self efficacy beliefs is described as a complex process whereby the person judges the value of a range of sources of information, and then integrates them to create a sense of efficacy in a given situation (Bandura, 1982). The sources of information about self-efficacy include: previous experience of mastery or failure; vicarious experience, where a person compares their own capabilities to another person's; social influences, such as verbal feedback, and also physiological information (Bandura, 1982; 1989).

A person acts, based on their self-efficacy judgements, and this action produces further information, either confirming or negating the original judgement. This experience is then used as the person re-evaluates their efficacy (Bandura, 1982).

A person develops self-efficacy beliefs, which lead them to develop expectations for the outcome of their performance. Distinction is made between two types of expectancy beliefs, the expectancy that a particular action will result in an outcome, and the expectancy that a person has the ability to perform that action (Bandura, 1982; 1989). The latter, self-efficacy belief is considered more influential on a person's choice of activity, environment, goal setting and willingness to expend effort (Eccles et al 1998; Bandura, 1982).

Sustained high levels of self-efficacy require success in tasks perceived to be difficult and which require sustained effort (Bandura, 1989), as if a person is used to only succeeding at "easy" tasks, immediate reward is expected, resulting in reduced perseverance in more difficult situations.

The ways in which efficacy beliefs are formed, in the case of people with physical disabilities, is interesting. The first way that efficacy judgements are formed is through action. The importance of the environment in supporting action must be particularly important, as the physical ability of a disabled person, is, by definition, limited in some way.

Of particular interest to this study, and other research with disabled people, is the role of vicarious experience, where a person compares their expected efficacy with that of another. Bandura (1989; 1982) specifies that a vicarious role model is best when the person appears similar to the individual, and the individual can make judgements, such as, "if they can do that, so can I", or conversely, "if they can't do that, I won't be able to either". When it comes to disabled people, the social environment, and the person's self perception are likely to be important. If a disabled person is living in a residential setting, for example, surrounded by other people with similar disability, then it is likely that a "like" role model for vicarious self-efficacy judgements will be available; if a person has little contact with disabled people, who acts as a similar model? Whether or not a disabled person considers a non-disabled person alike enough to act as a vicarious model is presumably dependent on their own self-perception, and whether or not the disability experience is perceived to be relevant. Further research about vicarious formation of self-efficacy beliefs by people with physical disability would be helpful, particularly as the role of disabled advocates or role models appears to be assumed to be positive.

Masten and Coatsworth (1998) suggest that the development of competence leads to the formation of a person's identity and autonomy, and that aspects of identity (such as values) affect expectations for competence. Within the disability community, there is increasing acknowledgement of the importance of identity, in terms of disability identity, and also that common stereotypes of disability or general understandings can lead to lowered expectations for competences of disabled people.

Verbal encouragement and other social influences that reinforce a person's ability or inability can be effective in forming efficacy beliefs (Bandura, 1982). The social context in which disabled people act is often described as "disabling" (e.g. Oliver, 1990). Due to stereotypes and stigma, disabled people are often not expected to have abilities by others in society (e.g. Johnstone, 1998; Oliver, 1990; Barnes et al, 1999). In order for a disabled person to develop accurate, positive self-efficacy beliefs it seems likely that a positive supportive environment is needed so that a person can experience success, (as well as failure).

It is suggested that behaviour relates to the level of changed self-efficacy, irrespective of how the change was induced. In experiments, it was shown that the higher the level of self-efficacy, the better the performance, and the more likely that people are to continue with efforts to succeed (Bandura, 1982). Self-efficacy beliefs are also thought to determine a person's level of motivation (Bandura, 1982).

If competency beliefs are developed over time (Bandura, 1982), and if early childhood is essential for the development of competency (Masten & Coatsworth, 1998), then it is likely that there may be differences in perceptions of competence between people who objectively have similar abilities but developed disability at different stages in life. A child who is not disabled is likely to develop "normal" competence, and beliefs in the importance of competence. Thus, when such a person becomes physically disabled, their reference point remains that sense of competence as a non-disabled person, and the social values of competence are likely to be present. If on the other hand, a child is disabled, their reference point is competence with disability. Whether or not the value of competence is internalised must depend on the social environment in which they develop.

The view that self-efficacy can determine motivation and effort contrasts with self-determination theory, in which it is argued that competency beliefs alone cannot promote more intrinsic motivation, but that autonomy is also required (Ryan & Deci, 2000). It is argued that people settle for mediocre results if their sense of efficacy is low, whereas those with a strong sense of efficacy are more likely to be persistent to strive for a more positive outcome (Bandura, 1989).

It is considered important that a person should have a positive sense of self-efficacy for achievement and well-being, to persevere and sustain the effort needed to overcome

normal life challenges (Bandura, 1989). It is normal that, amid difficulties, self-doubt results, but Bandura (1989) highlights that it is the recovery of self-efficacy rather than the doubt that most influences future action.

In relation to self-determination theory research, it has been found that high levels of perceived competence and environmental support for competence promote internalisation of extrinsic rewards (Ryan & Deci, 2000). Extrinsically motivated behaviour is even more likely to be internalised when a high level of perceived competence is also coupled with a sense of relatedness, that is, when it is thought that the activity is valued by the social group. Internalisation of a socially valued activity is less likely to occur if the person does not feel competent (Ryan & Deci, 2000).

Low levels of self-efficacy result in increased levels of stress and depression in difficult situations, which can affect behaviour directly and through changes in thoughts that can increase the perceived threat of the environment (Bandura, 1989).

Futility and learned helplessness

Anxiety, despondency and feelings of futility result in situations where a person feels that they cannot influence events or the environment, or produce desired outcomes (Bandura, 1982). Whereas efficacious people are likely to persist and even intensify efforts to produce results, people with low self-efficacy tend to give up easily (Bandura, 1982).

Within self-efficacy theory (Bandura, 1982) distinction is made between two sources of futility: the judgement that a person does not have the competence to achieve necessary results; or the judgement that they have the competences, but that the environment is negative, meaning that results will not be achieved. Either judgement can result in a person ceasing efforts, but the cause and ways of improving the situation are different. If the person feels inefficacious due to a lack of perceived competence, then competence and belief in one's competence need to be improved. If, on the other hand, a person believes that they have the capacity to achieve the results, but the environment prohibits achievement, then it is necessary to change the environment (Bandura, 1982).

Distinction is also made between results of failure – apathy and despondency. Apathy and resignation arise when a person does not perceive that they have the abilities to achieve, but others in the same environment with greater skill can achieve. This leads to self-criticism (Bandura, 1982; 1989). People become despondent when they believe that they have the ability to produce results, but that the environment is not supportive – this often results in anger and frustration (Bandura, 1989).

The theory of learned helplessness (Seligman, 1975) suggests that people become inactive and depressed if they are unable to produce change or results. People then avoid action, believing it to be futile, even when it is likely that they have the necessary competence (Bandura, 1982). Central to learned helplessness is the judgement of what caused failure. Judgements relate to internality (whether or not the failure was due to factors internal or external to the person), stability (whether the reason for failure is enduring or transient) and generality (whether causes occur in multiple situations or only specific situations (Bandura 1982). If a person attributes failure to personal inefficacy, which is enduring and general (rather than situation-specific) it is likely that they will perceive themselves as highly inefficacious.

For the current work, exploration of both what people do on a daily basis, and their perceptions of this behaviour, with reference to their perception of their autonomy is sought. Perceptions of the barriers to engagement in occupations, particularly if people are less active would be interesting to explore, in the context of lerned helplessness.

The judgements that are made about failure in the theory of learned helplessness also relate to Weiner's attribution theory of motivation. In this theory, success or failure attributions are made within three domains: locus of control; stability, and generality (Eccles et al, 1998).

While the research surrounding learned helplessness seems to relate to non-disabled people, it is highly relevant to those with disabilities. Physical competence is highly valued by society (Oliver, 1996; Barron, 2001; Reindal, 1999), and frequently people believe that their inability to physically perform relates to their overall competence. If, according to theories of learned helplessness, failure is attributed to personal inabilities (such as physical disability), which are enduring (highly likely for most impairments/conditions) and are generalised, then the result is almost necessarily learned

helplessness. Yet, not all people with physical disability exhibit signs of learned helplessness. Further research to explore these individual differences, specifically in people with disabilities may be helpful – for example it would be interesting to examine whether those who do not experience learned helplessness have more supportive environments or whether there are internal mechanisms, such as altering the value (accommodating) of the task in hand.

Choice of environment for competence

People will tend to choose environments and tasks in which they perceive themselves to be efficacious and avoid those that they perceive to be too demanding (Bandura, 1989; 1982). If a person selects an environment in which they feel competent, then it is likely that the influences within that environment will continue to support positive perceptions of self-efficacy (Bandura, 1989). The constructs within the environment are likely to continue to support competences, values and interests long after the initial choice of that environment has been made, thus initially small decisions about choice of environment can strongly affect the life-course of individuals (Bandura, 1989).

Selection of environments seems particularly important for disabled people, from a physical and social perspective. If people with objectively similar levels of function choose different environmental settings, it would be interesting to find out whether the choice of a more protective environment is associated with lower self-efficacy beliefs, or a greater value being placed on the importance of actual physical ability.

Bandura (1982) suggests that when in a given environment, people with poor-self-efficacy tend to dwell on personal limitations and view difficulties as greater than they objectively are. Difficulties tend to spur action and effort in people with high self-efficacy. In some circumstances, then, a person may choose a given environment: those with low self-efficacy are more likely to avoid challenging environments, and when in an environment will tend to view their limitations and the challenges as greater than they may necessarily be. Those who have high self-efficacy beliefs, tend to choose more challenging environments and increase effort to overcome challenges.

Theories of self-efficacy are not without their critics. Eccles et al argue that the theory can be criticised for its over-simplification and mechanistic description of human behaviour and motivation; others, such as those within the self-determination tradition have argued that a perception of one's own competence is simply not enough to explain aspects of motivation, but that the other two psychological needs (relatedness and autonomy) must also be supported.

The next section will briefly describe another of Ryan and Deci's (2000) basic psychological needs, relatedness.

Relatedness

Within the framework of self-determination theory, a basic psychological need is relatedness (Ryan & Deci, 2000). This is described as the building of close and supportive social relationships. In the presence of supports for autonomy and competence, relatedness influences the extent of intrinsic motivation.

Relatedness is seen to support intrinsic motivation from early childhood – children show more exploratory behaviour (which is suggested to be evidence of intrinsic motivation) when they are attached to a parent (Bowlby, 1979 as cited in Ryan & Deci, 2000). Self-determination theory hypothesises that similar attachment, or relatedness is necessary over the lifespan.

Relatedness helps to internalise motives for actions that are not interesting in themselves (Ryan & Deci, 2000). Behaviours that are not intrinsically motivated are initially performed because they are modelled, prompted or highly valued by significant others.

Relatedness is not only important in the development of internalised motivation, but it also supports the development of competence. Mastden and Coatsworth (1998) suggest that infants' competence is "embedded in the caregiving system" (p. 208), and that the power that infants have to secure help enables them to develop skills in response to environmental demands and in facilitating their future development. Developmental psychologists, according to Masten and Coatsworth (1998) have described competence in

terms of the mother-infant pair, with the infant's competence in seeking help only being efficient if the mother responds appropriately.

The importance of relatedness continues throughout life (Ryan & Deci, 2000). Children can influence their own development by their choices of who they relate with – pro-social children are more likely to socialise with pro-social peers (Masten & Coatsworth, 1998).

Social factors have already been discussed in relation to the formation of self-efficacy judgements. It may be possible that a sense of relatedness affects the mechanism through which vicarious learning of efficacy beliefs occur. Maybe the fact that role-models who are perceived to be similar to individuals are more effective (Bandura, 1982) is because people feel a sense of relatedness to the role-model. Similarly, since verbal encouragement or other social affirmation can also change efficacy judgements (Bandura, 1982) the change in competency beliefs may be due to a sense of relatedness.

There seems to be little information on the impact of relatedness on disabled people's functioning, sense of autonomy or competence. It has been found that autonomy combined with a sense of relatedness led to increased well-being in nursing-home residents (Ryan & Deci, 2000). Whether this is also true of adults in residential settings is unclear, as is the impact of relatedness in isolation of autonomy.

It is questioned how much the sense of relatedness can impact on identity and self-concept, thus affecting activity and environmental choices. As relatedness affects the internalisation of social values, norms and behaviours, it is possible that disabled people (as well as non-disabled people) may strive to behave according to those internalised values and norms. In the specific case of disabled people, relatedness to those who value physical ability and expect behaviour to comply with social norms (i.e. taking a medical model view of disability) could potentially undermine self-determination rather than promote it.

In studies with people who have experienced misfortune, connections with others have been shown to be important. For example, Taylor (1983; Taylor, 1984) found that people with cancer made social comparisons as one of a number of mechanisms in order to cope with their situation, particularly comparison of oneself to a less fortunate person.

Reis et al (2000) found that the social environments that best promote the satisfaction of relatedness needs were those where individuals felt understood and appreciated by others, and when they could engage in meaningful conversation. Given this information, it is questionable what the relative effect of different social environments of disabled people living in different situations is to the satisfaction of relatedness needs. For example, a person living in a residential setting who appears not to have meaningful conversations with others may experience less relatedness when compared to a person living in the community.

The difference between interpersonal relatedness (the need to establish close relationships) and self-definition (a differentiated, stable sense of self) are highlighted by Shaher et al (2003). They highlight research that shows that interpersonal relatedness is a requirement for the development of a coherent self-definition. A synergistic relationship occurs, whereby the presence of close interpersonal relationships fosters self-definition, which in turn enhances interpersonal relationships, such as a child's primary caregiver being experienced as a secure base, enabling the child to explore the environment and develop a more autonomous sense of self (Shahar et al, 2003)

Chirkov, Ryan, Kim and Kaplan (2003) describe the role of culture on sense of relatedness and autonomy. Within self-determination theory it is assumed that the more a person can assimilate the surrounding culture, the better for their well-being. Chirkov et al (2003) then question whether some cultures are easier to internalise or assimilate. The reason why it is suggested that internalisation is important is partly because it supports relatedness needs. It is highly questionable whether or not specific sub-cultures, such as those within a residential setting for adults with physical disabilities are easy to internalise, and what effect such assimilation may have on individuals.

An interesting area of study within self-determination theory is that of situations where autonomy and relatedness are co-supporting. Hodgins et al (1996) undertook such a study, where autonomy assessed using the General Causality Orientation Scale (GCOS) (see section below) was found to lead to more positive, open interactions with others.

Of the three psychological needs proposed by Ryan and Deci, (2000), autonomy is that which requires most attention in this study, as the study aims to discover the lived

experience of autonomy of a number of individuals with physical disabilities. The following section will detail various theories of autonomy, followed by experimental results demonstrating the impact of a sense of autonomy on an individual's well-being.

Autonomy

This section will outline theoretical approaches to autonomy, particularly those within the psychological literature, relating to non-disabled people.

In a study exploring the different conceptual frameworks of autonomy within psychological literature by Hmel and Pincus (2002), the researchers administered 15 self-report assessments of autonomy to 290 college students. Their aim was to clarify aspects of autonomy, and to place descriptions of autonomy on the Interpersonal Circumplex. Hmel and Pincus (2002) conclude that there are two valid, distinct meanings to autonomy within the literature, that of autonomy meaning self-governance and autonomy meaning agentic separation from others. There are similarities in both constructs, but the greatest difference is in the relationship with other people.

This also relates to the propositions of Kagitcibasi (1996), who suggests that autonomy consists of two interdependent factors, these being the agency dimension, and the interpersonal closeness-distance dimension.

While recognising the work of Hmel and Pincus (2002), other descriptions of autonomy are found within the literature and also warrant description in this section.

Autonomy : the debate over definitions

As is evidenced within the wide variety of literature about "autonomy", there appears to be a lack of clarity about what the construct means, in either theoretical or practical terms.

Hmel & Pincus (2002, p. 278) write that,

> "Despite this significance to the human experience and its prevalence in the literature, autonomy is a construct lacking theoretical homogeneity as well as a consistent and common operational definition. The autonomous individual has been described as both psychologically adjusted (Deci & Ryan, 1985) and prone to psychopathology (Beck, 1983), related to others (Blatt & Blass, 1996; Koestner & Losier, 1996) and indifferent to others (Hirschfield, Klerman, Gough, Barrett, Korchin, & Chodoff, 1977), self-ruling (Haworth, 1986) and defensively separated (Robins, Ladd, Welkowitz, Blaney, Diaz, & Kutcher, 1994). An intriguing challenge that arises from such diversity lies in the interpretation of numerous autonomy theories and research endeavors.".

The concept of autonomy, in its simplest form, appears to relate to self (auto) ruling (nomous), and dates back to a Greek political ideal (Hmel & Pincus, 2002; Reindal, 1999). Discussion of autonomy can be found In many different academic disciplines, such as philosophy (e.g. DesCartes, Sartre), sociology, law, psychology and disability studies; in each discipline it appears that there is a different focus.

DesCartes described "autonomy" as a cardinal value, the goal of each person. The autonomy that he was speaking about arose from the master-slave relationship from ancient Greece, it related to freedom, choice and the ability to govern oneself, not to being separated from others. This idea of autonomy seems to have perpetuated and appears within the psychological literature, which is the focus for this literature review.

From their review of the literature, Hmel and Pincus (2002) describe "at least three" views of autonomy within the psychological literature. These are:

- Autonomy as self-governance, which is described by others as "Autonomy II" or "reflective autonomy";
- Autonomy as interpersonal (or agentic) separation, also known as "Autonomy III", or "reactive autonomy", and,
- Autonomy as a psychological vulnerability, associated with depression, also described as "autonomy I".

Other descriptions of autonomy have been found in fields other than psychology, particularly within disability and rehabilitation literature, that also have differences in meaning.

As Hmel and Pincus (2002) describe, the heterogeneity of the construct of autonomy is not helpful, as it hinders meaningful discussion of the issues involved. Hmel and Pincus

(2002) attempt to provide common terminology and a means whereby the different constructs can be separated.

The "liberal theory" of Autonomy

Agich, (2003) describes the "liberal theory" of autonomy, arising from the areas of politics and law. He describes this liberal theory of autonomy as consisting of a set of qualities, relating to independence, or non-interference from others.

> Autonomy is a central value in American society; it gives expression to a basic set of legal and political ideals that have gone under the name of liberalism. Central to political liberalism is the idea of individual freedom or autonomy. The term autonomy refers to a broad set of qualities that are generally, though not universally, regarded with approval in Western societies. Central to its treatment in political contexts is the concept of independence or what has been termed negative freedom, the freedom to be left alone
> (Agich, 2003 p. 14).

This liberal theory is limited in its practical utility (Agich, 2003); the theory relates to abstract ideals, and according to Agich (2003), these are difficult to apply to the concrete daily lives of individuals, particularly, older people in long-term care, which is the area of concern to Agich.

A full discussion of the philosophical and legal interpretations of autonomy is considered beyond the scope of this review, particularly considering there is an abundance of literature within psychology that is directly related to daily experience.

Autonomy as self-governance: the "Autonomy II" construct

One of the constructs that Hmel and Pincus (2002) found to be a valid description of autonomy is the concept of self-governance, described as "autonomy II", reflective autonomy (Koestner & Losier, 1996),. Kagitcibasi (1996) classes this form of autonomy as high in the "agency dimension", and close to others on the "interpersonal closeness-separation" dimension of autonomy.

The concept of autonomy as self-governance is the construct of autonomy described within self-determination theory (e.g. Ryan & Deci, 2000). According to Ryan and Deci (2000), "the term autonomy literally refers to regulation by the self. Its opposite, heteronomy, refers to controlled regulation, or regulation that occurs without self-endorsement" (p. 74).

Hmel and Pincus (2002) suggest that Autonomy II, or self-governance is an inter-dependent form of autonomy, supporting work (including that within the self-determination theory tradition) that this form of autonomy is a "marker of psychological adjustment", and is positively interpersonal in nature.

The self-governance, interdependent form of autonomy is, according to Hmel and Pincus (2002), assessed using the General Causality Orientation Scale (GCOS), which was created by Deci and Ryan (1985b), and is sometimes therefore referred to as "GCOS-Autonomy". Another measure for the self-governance form of autonomy is the Worthington Autonomy Scale (WAS) (Hmel & Pincus, 2002). This scale includes four sub-scales relating to family, emotions, behaviour and value, and focus on freedom, self-control and responsibility (Hmel & Pincus, 2002). Each of the sub-scales is designed to assess autonomy in aspects of the persons life, for example, the family autonomy refers to freedom from "binding" by the family; emotional autonomy is the desire for self-control, emotional independence and to achieve interpersonal competence; behavioural autonomy is the freedom to act as one wishes, and to take responsibility for actions and value autonomy is the ability to make moral decisions. According to Hmel and Pincus (2002), the WAS is a newer instrument, whereas the GCOS has been extensively tested.

A major difference between the self-governance and agentic separation constructs of autonomy is the relationship to others, or their position in the "interpersonal closeness-separation" dimension (Kagitcibasi, 1996). Chirkov et al (2003), using the self-determination theory framework, suggest that a person is autonomous when their behaviour is perceived to be willingly enacted, when the person takes responsibility for and fully endorses their action. They describe people as being most autonomous when they act in a manner that fits with their values and desires. With this description, it is clear that the opposite of autonomy is the situation in which one's actions are controlled by others or not in accordance with one's own values, wishes or desires, described as heteronomy.

According to the self-governance framework, a person whose behaviour is willingly enacted is seen to be autonomous, regardless of whether or not there has been outside influence (Chirkov et al, 2003). For example, a person can be willingly dependent on another person and be considered autonomous or, conversely, can be independent of others and not be autonomous. Equally, a person can experience a lack of autonomy when they feel compelled to do something or follow more generalised social norms with which they do not agree or identify, or when one adheres to tradition or obeys orders out of fear of punishment (Chirkov et al 2003). When a person fully identifies with the broader cultural and social norms, and willingly acts in accordance with them, they are still considered to be autonomous (Chirkov et al, 2003).

Ryan and Deci (2006), quote Ricoeur (1966), who argued that autonomous or self-determined acts are those endorsed or owned by the self, and are congruent with the person's own values. Thus an autonomous act may be one that has been requested by another person, or influenced by another person, provided that the individual takes responsibility for the act, endorses it, and it fits with their value system. In this analysis, autonomous acts are not restricted to those independently chosen by the individual, but are also external demands to which the individual fully consents. Autonomy, therefore is not the absense of external control, but the person's endorsement of their actions (Ryan & Deci, 2006).

Hmel and Pincus (2002) describe Wiggins' (1997) description of self-governance autonomy, stating that it exists on a continuum from passivity to agency, thus the opposite of this construct of autonomy is passivity, rather than heteronomy, as described within self-determination theory (Chirkov et al, 2003; Ryan & Deci, 2000). Wiggins' (1997) description, according to Hmel and Pincus (2002) of "passivity" reflects the impact of external influences; a passive individual is controlled by outside forces (rather than the term "passive" being the opposite of action, it is described as the opposite of agency).

Hmel and Pincus conclude that the view of autonomy as self-governance is "congruent with the origin of the construct, and is represented within the theoretical and empirical formulations" (pp. 279-280).

Hodgins et al (1996) investigated the relationship of self-governance autonomy to the daily interpersonal relationships of individuals using diary-type information. It was

hypothesised that autonomy (as measured by the GCOS) would positively affect social relations. Two studies supported their hypothesis; the authors found that high GCOS autonomy scores were linked to more positive and honest reactions, whereas the perception of being controlled related to more defensive interactions (Hodgins et al 1996).

A number of studies (e.g. Koestner & Losier, 1996) have explored the impact of a person's autonomy on their acceptance or denial of expert advice. Individuals with "reflective" or self-governance autonomy were reported to accept advice from "experts", whereas those who appeared to have "reactive" autonomy did not, at times to their detriment (Koestner & Losier, 1996; Chirkov et al, 2003; Hmel & Pincus, 2002).

Hmel and Pincus (2002) review a number of studies and conclude that the self-governance framework of autonomy has been found to have positive correlations with good interpersonal relationships, openness, self-awareness and being "emotionally tuned-in". They also found that people with high self-governance autonomy were more likely to be open to considering new ideas, reconsidering existing values and showed a lack of dogmatism; they also found that people with high self-governance autonomy are less prone to boredom (Hmel & Pincus, 2002).

As cited in Ryan and Deci (2000), research has shown that satisfaction in life roles depends on how much that role supports autonomy. Studies have found that, in educational settings, more autonomy was linked to more engagement, and better performance. Ryan and Deci (2000) also cite other research that showed that supports for autonomy and relatedness promoted greater well-being among nursing home residents.

Autonomy II and III (self governance and agentic separation) have some commonalities, primarily that both are agentic in nature (Hmel & Pincus, 2002). There are, however significant differences, particularly relating to interactions with other people.

Autonomy as agentic separation: the "Autonomy III" construct

A possibly more traditional view of autonomy is characterised by the description of autonomy III, agentic separation autonomy.

A number of authors have suggested that this is a distinctly different conceptualisation of autonomy to the self-governance autonomy previously described (e.g. Koestner & Losier, 1996; Hmel & Pincus, 2002). This form of autonomy is characterised by both agency and interpersonal separation, or independence from others. Thus, according to the conceptualisation presented by Kagitcibasi (1996), this form of autonomy is high in the agency dimension, and separated in the interpersonal closeness-separation dimension of autonomy.

Agentic separation autonomy has its roots within the work of social-cognitive theorists, such as Bandura (Hmel & Pincus, 2002). Bandura (1989) describes autonomy as action that is independent of external influence. This argument leads to the conclusion that it is impossible for any action to be entirely independent of the external social influences, thus that autonomy does not, or can not exist in reality (Hmel & Pincus, 2002). Without the construct of autonomy, Bandura (1982; 1989) suggests that motivation and agency are controlled by self-efficacy judgements, and beliefs about the likelihood of certain outcomes of behaviour. There are a number of critics of this approach (e.g. Ryan & Deci, 2006; Hmel & Pincus, 2002; Chirkov et al, 2003), primarily as self-efficacy does not address the reason for action, nor does it differentiate between engagement that is autonomous or alienated.

Hmel and Pincus (2002) describe agentic separation autonomy as focusing on individuation and separation from others. They found that this concept of autonomy as separation is contained within the literature, and that it is measured by a number of scales, most notably the Adjective Checklist (ACL), created by Gough and Heilbrun (1983), as cited in Hmel & Pincus (2002).

The agentic separation construct of autonomy, as measured by the ACL has been associated with a number of negative outcomes for individuals, which contrasts with correlates of the self-governance (GCOS) autonomy (Hmel & Pincus, 2002). These include poor social adjustment and negative perceptions of daily events (Koestner & Losier, 1996). ACL autonomy has been linked to leaving school early, the need for self-directed careers, and dissatisfaction with and poor performance in teamwork (Hmel &

Pincus, 2002). It appears that this form of separation autonomy is characterised by the need to do, be and think independently of others.

Iyenger and Lepper (1999) studied school children's dedication to and motivation to participate in a number of tasks, some self-chosen, others chosen by an experimenter and others reported to be chosen by the child's parent. Their findings showed that particularly Asian-American children were equally motivated to participate in tasks which they believed to be chosen by a parent as those that they chose themselves, whereas Anglo-American children were more motivated to participate in activities that they had chosen themselves. It was suggested that autonomy was not a universal need; for people from Eastern cultures, relatedness may be more important than autonomy.

Chirkov et al (2003) criticised the work of Iyengar and Lepper (1999), but it appears that the two sets of authors are using different definitions of autonomy. While not explicitly stated, it appears that Iyengar and Lepper (1999) were describing agentic-separation autonomy, and Chirkov et al (2003) self-governance autonomy.

The issue raised by Iyengar and Lepper (1999) that agentic separation may be more desirable or valued in some cultures may be worth considering. Chirkov et al (2003) reference Oishi (2000), who suggested that in all but a few individualistic Western cultures, people who are autonomous are no more satisfied than those who are less autonomous; a claim disputed by the authors. Again, the difference appears to be in the definition of autonomy.

Hmel and Pincus (2002) call for further research to fully understand and explore the similarities and differences between agentic separation autonomy and self-governance autonomy, particularly as the impacts on health and well-being appear to differ greatly.

Autonomy as vulnerability: the "Autonomy I" construct

Hmel and Pincus (2002) identified a third description of autonomy, depressogenic vulnerability or Autonomy I. This is reported to be based on the work of Beck and colleagues, and suggests that autonomy is a personality construct, and the highly autonomous individual is at risk of developing reactive depression. According to this

construct, autonomous people have "an excessive investment in personal freedom, mobility, achievement and individuality and tend to be hypersensitive to events that threaten these values" (Hmel & Pincus, 2002 p. 285); when they fail, or obstacles to freedom are encountered, these individuals are highly vulnerable to reactive depression.

The vulnerability model of autonomy has been assessed using a number of self-report instruments, developed by Beck and colleagues, including the original Sociotropy-Autonomy Scale (SAS), developed by Beck and colleagues in 1983 (Hmel & Pincus, 2002). The SAS and similar scales consist of three sub-scales, these being "excessive perfectionism", "need for control" and "defensive separation from others" (Hmel & Pincus, 2002).

According to Hmel & Pincus (2002), research about the vulnerability model of autonomy has been mixed, with no conclusive results. The link between this view of autonomy and negative affect has not been confirmed.

Hmel and Pincus (2002) conclude that only two of the descriptions of autonomy that they present are valid constructs of autonomy.

> "Factor I (Depressogenic Vulnerability) lacks the essential agentic core that would be necessary for an autonomy construct. We therefore conclude that it is inconsistent with conceptualizations of autonomy and in need of a label more consistent with its nature."
> (Hmel & Pincus, 2002 p. 304).

Reactive and reflective autonomy

Another categorisation of autonomy was presented by Koestner & Losier (1996), in which autonomy was differentiated into reflective and reactive forms of autonomy.

Reflective autonomy appears to be similar to self-governance autonomy, also called "interpersonal autonomy" as measured using the GCOS, whereas reactive autonomy, assessed using the ACL appears to be similar to the agentic separation form of autonomy (Koestner & Losier 1996). Reactive autonomy is described as an orientation to act independently of others, and reflective autonomy as the experience of "choicefullness" about one's actions (Koestner & Losier 1996).

Koestner & Losier (1996) established that the two forms of autonomy described are only loosely related to each other. They also investigated the behaviour patterns of people who scored highly in GCOS / reflective autonomy and those who scored highly in ACL / reactive autonomy. They found differences in the individuals' experience of daily affect and the strategies used to regulate mood; specifically, it was found that those with high reflective / GCOS autonomy experienced more positive affect during daily activities.

The biggest difference between those with high reactive versus high reflective autonomy was found to be in interpersonal relationships. It was found that overall, those with high reflective autonomy related more positively to people, had more intimate and positive peer interactions, and were willing to accept advice from experts or authority figures; those with high reactive autonomy, on the other hand, had less positive relationships with others, and more strikingly were opposed to taking advice from authority figures, even to their own detriment (Koestner & Losier 1996).

Koestner and Losier (1996) conclude that their studies highlight the importance of distinguishing between the two forms of autonomy. It would be more helpful if the terminology used were compatible with other terminology used, such as describing reflective autonomy as self-governance autonomy and reactive autonomy as agentic separation autonomy.

Other classifications of autonomy

Apart from the three conceptualisations of autonomy described by Hmel and Pincus (2002), there are other descriptions of autonomy within the literature, particularly within the area of disability and rehabilitation.

Cardol et al (2002) propose a different classification of forms of autonomy. They distinguish between two types of autonomy, these being decisional and executional autonomy. Decisional autonomy is the ability to make decisions without external restraint and executional autonomy is the ability to act as one wishes, typically as a result of the decisions made.

Clapton and Kendall (2002) support the distinction between decisional and executional autonomy, stating that, regardless of the language used, autonomy consists of both the ability to choose and the ability to perform the chosen activity.

The distinction between decisional and executional autonomy, while initially appearing helpful, does have a number of inconsistencies and difficulties. These distinctions do not seem to be reflected in other literature, in that it appears that much of the literature describes autonomy in terms similar to those used to describe "decisional" autonomy; executional autonomy is similar to competence (the ability to do).

According to Clapton et al (2002), competence, or "the physical conditions which allow chosen action to be carried out (p. 702) is essential for decisional autonomy, arguing that restrictions can reduce a person's expectations, which, it is argued, undermine decisional autonomy (i.e. the ability to choose and make decisions is undermined). External (or indeed internal) forces undermining expectations of performance may lower a person's sense of self-efficacy (Bandura, 1982), but it appears that this concept of decisional autonomy has also been confused with the concept of self-efficacy.

One concern is that the terms "decisional autonomy" and "executional autonomy" are unclear and confused with other terms. Neither term appears to be within the main body of psychological literature. It is also unclear whether either decisional or executional autonomy is related to agentic separation or self-governance constructs of autonomy, or

where either of these fit in either the agency or interpersonal closeness-separation dimensions.

The distinction between decisional and executional autonomy may mirror what Rogers (1982) describes as "independence", which comprises of autonomy (deciding what to do – as in self-governance) and competence (the ability to do).

Proot's (2000) review of the literature suggests that autonomy relates to self-governance, self-awareness and what they describe as "actual autonomy". It appears that the self-governance theme is consistent with other descriptions of autonomy; the term "self-awareness" may be likened to a person's sense of self-efficacy, and that what they describe as "actual autonomy" relates to being able to perform occupations alone (as in competence).

One exploration of autonomy is proposed by Proot et al (2000). They argue that, in relation to people who have experienced a stroke, autonomy consists of: self-determination (described as choices, decisions and freedom of choice); independence (described as physical, psychological and social) and self-care (the activities of daily living). This description is in addition to the description previously cited as resulting from a literature review, and is, according to the authors, based on the interpretation of findings of their study interviewing individuals who had experienced a stroke.

It is difficult to understand the logic of such a description of autonomy, as in the case of other descriptors, autonomy is a discrete psychological need (Deci & Ryan, 1985a), or a psychological constituent that can be mapped on the interpersonal circumplex (Hmel & Pincus, 2002). The term used by Proot et al (2000) appears to relate to a wide variety of psychological factors

The term "self-determination" used appears to relate to choice, therefore could be taken to mean self-governance autonomy. "Independence" appears to relate to competence, or the ability to do. Neither of these terms are described in the same manner within the bulk of the psychological or disability literature. The inclusion of self-care occupations in a description of autonomy appears inadequately justified.

Proot et al (2000) distinguish between "individual" autonomy, describing this as the competence to perform activities alone, and "social" autonomy, being the environmental characteristics that support independent functioning. These also seem to be misnomers – how can autonomy (for example, as characterised in the bulk of the psychological literature) be anything but individual, whether it is a sense of agency or self-governance or separation from others. The idea of social autonomy is not clearly justified or explained, but is understood to mean the environmental factors that support autonomy, or independence, which seems to be a more appropriate name for the construct being discussed.

Proot et al (2000) developed their components of autonomy based on a study of people who had experienced stroke and who were in a nursing home. Some definitions of "independence" relate to the ability to perform occupations, typically self-care, alone, and the notion of "executional autonomy" could also relate to occupational performance. It is understandable, given the situation, that self-care activities appeared important to participants in Proot et al's (2000) study, but it nevertheless appears inconsistent that the performance of these is considered to be a constituent of autonomy.

Agich (2003) describes a need for a fuller description of autonomy as it relates to the lived experience of individuals, his work focusing on those who live in nursing home settings. He describes "actual autonomy" being more complex than the liberal or abstract theories commonly discussed in psychological and other literature. Agich (2003), argues that one needs to understand the "concrete" person, as a unique being. The unique person develops autonomy through the life-span, in conjunction with the desire to control and the development of competence (Agich, 2003). Autonomy is described not as an end-state, but a result of continual engagement with the world. This engagement in the world leads to the formation of a self-concept, which is in turn inextricably linked to a person's sense of autonomy. A person exercises their autonomy partly through making choices that are meaningful to them, and which are a reflection of the self-concept and a description of their unique life history (Agich, 2003). It appears that Agich (2003) also does not differentiate between different forms of autonomy in the literature, and that his construct relates closely to the construct of independence described by Rogers (1982).

Agich (2003) reports that an understanding of autonomy requires investigation into the history of the person, and it may only be developed or sustained through the provision of choices and opportunity for action that are meaningful to the individual.

Agich (2003) criticises the presentation of autonomy in all but the concrete "actual" autonomy that he presents, suggesting that the presentation of autonomy within the literature assumes a competent individual, capable of making choices. This may not necessarily be the reality for older people living in nursing homes, who may have physical and cognitive impairment as well as being bound by aspects of the physical and social environment.

Importance of Autonomy

There have been a large number of studies emphasising the impact of autonomy on human well-being, particularly the benefits of self-governance autonomy. Only a brief description of some of these findings is presented in this section, as they could relate to the participants in the present study.

Hmel and Pincus (2002) review research that assessed autonomy using the GCOS (i.e. assessing self-governance autonomy). The research has shown that autonomous individuals have increased self-awareness, were more likely to be high in self-esteem and ego development and were less likely to be self-derogatory or to experience negative emotions such as hostility, shame, and guilt (Deci and Ryan, 1985b). Other research showed that individuals with high GCOS-autonomy were high achievers, rarely experienced boredom and were more focused and persistent in goal-directed behaviours. "In its totality, GCOS research suggests an adaptive quality to an autonomous causality orientation" (Hmel & Pincus, 2002 p 281).

Within self-determination theory research, it has been found that performance is enhanced by an autonomy-supportive environment, particularly requiring flexible, heuristic or creative capacities or if the task is complex (Ryan & Deci, 2000).

Autonomy, of the self-governance form has been found to facilitate attachment to others, intimacy and higher quality of relationships, and that people are most attached to those who support their autonomy (Ryan & Deci, 2006).

Chirkov et al (2003) found that there was a link between autonomous function and well-being. They report that their assumption was a causal relationship – that autonomy promotes well-being, but state that this may not necessarily be the case; high well-being may cause people to view their behaviour as autonomous. This, of course, assumes the self-governance construct of autonomy.

Several studies have considered achievement in school, and generally findings suggest that high self-governance autonomy leads to higher achievement. For example, Tanaka and Yamauchi (2000) reported that students with high autonomy and low sense of being controlled were more adaptive learners, and achieved highly, compared to those who perceived that they had little autonomy and were being controlled.

Lambe (2006) studied the impact of adult education, and found that employment status and academic qualification are important influences upon a person's sense of self-governance, agency or autonomy.

Strategies to enhance autonomy

Clapton and Kendell (2002) warn against over-valuing autonomy for disabled people, as they argue that it is based on "western, male, white, middle-class and ablest ideas of personhood". However, this appears not to be supported by literature on self-governance autonomy, which has been described as pan-human (Chirkov et al, 2003). Cardol et al (2002) report that autonomy is the ultimate aim of rehabilitation, because it is a pre-requisite for participation in society.

Within rehabilitation literature, it appears that autonomy, despite the lack of definition, is an important value, and as a result there are a large number of studies describing strategies to enhance autonomy of disabled people. Studies within health care in general also show that when autonomy is supported (for example, by the therapist), there is greater involvement, adherence to programmes and change is maintained for longer (Ryan & Deci, 2006).

Studies of health care and therapy similarly attest to the importance of practitioners' support for autonomy. Studies show that autonomy support leads to greater program involvement, adherence, and maintained change in specific behaviours.

Ryan and Deci (2006) suggest that in order to enhance autonomy, it is important that the social environment is supportive; controls, evaluation, rewards and punishments can affect motivation and consequently sense of autonomy, frequently without the person being aware of it. Coersion and use of rewards can undermine autonomy.

There are a number of different concepts of autonomy, and the applicability of these to adults with physical disabilities seems to vary. Chapter 4 will attempt to synthesise some of this information in relation to this study, and in light of other literature reviewed. However, an initial tentative conclusion can be that central to a concept of autonomy is agency, or the ability for an individual to exert control in their lives.

Choice

Koestner and Losier, (1996) describe reflective autonomy (or self-governance autonomy) as the experience of choicefulness about one's actions, which is as described within self-determination theory (Ryan & Deci, 2000; 2006). So how, then, does the construct of choice differ from that of autonomy (self-governance and agentic separation autonomy)?

Iyenger and Lepper (1999) state that the assumption that choice is always beneficial, desirable and powerful pervades psychological theory and research. The ideal of choice, or the perception that a person always has choice was a tenet of the writings of French existentialist, Sartre.

A number of theories exist about how individuals make choices, particularly choices of activities to perform in the short term, or career choices in the longer term. Some of those relating to activity choice appear to be within the motivation literature, and seem to relate to concepts such as self-efficacy (Bandura, 1982), and suggest that a person's sense of efficacy and perception of the task difficulty or likelihood that they will be competent to succeed at the activity will affect activity choice; those with higher self-efficacy are likely to choose to engage in more difficult tasks (Bandura, 1982; 1989).

Eccles and colleagues developed an expectancy-value model of achievement-related choices (Eccles et al, 1998). Building on the work of others, such as Lewin, the model focuses on the social and psychological influences on choice and persistence at a task. Both negative and positive characteristics affect choices, and all choices have costs, because one choice rules out other options. The theory suggests that the relative value of tasks and the likelihood of success will influence the choice, especially for achievement-related choices, be they activity performance or career selection.

Similar to the theory of self-efficacy, expectations of performance are assumed to directly affect performance, persistence and choice of task, but so too does the value that the tasks have for the individual. The cost is viewed as part of the value of the task – a choice that is too "costly" will not be as highly valued. Within the expectancy-value model, values are created through more stable perceptions of the self and identity; choices are made, but these are not necessarily the result of conscious or rational decision-making (Eccles, 1998).

It appears that there are many theories about the benefits of choice for an individual, for example in deCharms' (1968) work with school-children, he found that those who were more engaged, and intrinsically motivated, described as the "origins", appeared to perceive that they had more choices, and furthermore were free to make choices, compared with the "pawns", who did not appear to perceive that they had choice. DeCharms' (1968) theory of personal causation is strongly related to the importance of having choice.

Within self-determination theory (Deci & Ryan, 1985a; Ryan & Deci, 2000), the availability of choice, and consequently a person's ability to act in accordance with their choices and values are considered important in supporting the basic psychological need for autonomy, and consequently can improve intrinsic motivation.

Iyenger & Lepper (1999) proposed a contradiction to the mainstream view that choices are necessarily positive and increase a sense of control, personal causation and intrinsic motivation, and that these states of control and intrinsic motivation have been associated with physical and psychological benefits. They propose that these views of choice as necessarily being a good thing are culture-specific, and that most of the research has

been conducted in America, where choice appears to be highly valued. They report a number of findings, including a study comparing different cultures whereby they found that American students reported higher values for choice, having more choices and wanting more choices than their Japanese counterparts.

Iyenger and Lepper (1999) argue that choice may have less intrinsic value in other cultures and that in some situations choice can be undermining, for example if a person's choice were at variance with that of their social group. Other studies reported by Iyenger and Lepper (1999) include consumer studies, where shoppers who were given more choice were found to buy less, thus they conclude that providing this choice was unhelpful to the consumers.

Schwartz (2000) also questioned the value of choice, suggesting that too many choices can be overwhelming, and can increase stress, and that not all choice increases freedom, findings also echoed by the work of Iyengar and Lepper (Iyengar & Lepper, 2000; 1999). Others have argued that making choices is energy draining or ego-depleting (e.g. Baumeister et al, 1998 as cited in Ryan & Deci, 2006).

Ryan and Deci (2006) have criticised the arguments of both Iyenger and Lepper (1999) and Schwartz (2000), stating that they both fundamentally misinterpret self-determination theory, which is not merely about providing people with many different choices, but facilitating a sense of choicefulness. They argue that even though tasks involving lots of choice are more challenging (and in the case of the consumer test, result in less buying), their studies find that people still appear to enjoy exercising that choice. Ryan and Deci (2006) do not, however, fully address issues raised in Iyenger and Lepper's paper, particularly that choice may be valued differently in different cultures.

Ryan and Deci (2006) argue that the confusion from the mixed results is due to definitions or explanations of what choice is. They argue that many options, or choices, do not necessarily facilitate autonomy, that instead people may feel overwhelmed and resentful, due to the challenge posed by too many choices. They then argue that if a person has only one option, fundamentally meaning no choice, but they wholeheartedly support this choice, then they are acting autonomously, as has been previously discussed (see section 2.5 above) autonomy, within self determination theory is self-governance autonomy, and

the important factor is the extent to which the person fully supports their action, rather than the presence or absence of external forces.

Ryan and Deci (2006) conclude that if choice is meaningful, it can facilitate self-determination, as it could potentially allow a person to find options which are fully endorsed (therefore autonomous); if, on the other hand, it is not meaningful it can reduce self-determination and cause confusion or fatigue, in which case fewer choices may support self determination and/or competence.

Control

> "During the past three decades, psychologists have made a major contribution in addressing the question of how individuals gain and maintain a sense of control in their lives. Several control-related constructs have been developed and explored... Hundreds of studies and dozens of books have been devoted to the theory, research, and applications of a variety of personal control strategies to numerous health care and psychotherapeutic concerns."
> (Shapiro et al, 1996 p. 1213).

There have been a number of approaches within psychology to address issues of control; why some people have greater or lesser desire for control (e.g. Burger, 1985) and to describe the effect of control on individuals (e.g. Shapiro et al, 1996).

The research about control mirrors, in some ways, that for topics such as competence; there is a body of knowledge surrounding actual control, surrounding perceived control, the behavioural implications of control or the lack thereof, and of the desire for control.

A number of studies have found that "normal" individuals (i.e. those without mental health issues) have a greater perception of their own control than do those with conditions such as depression; "normal" individuals exaggerate their control and their ability to achieve control in a given situation. Equally, they underestimate risk (Shapiro et al, 1996).

The earliest research in the area of control, according to Shapiro et al (1996) demonstrated a linear relationship between control and positive health benefits – it was assumed that the more control a person has, the better. Studies, including one with nursing home residents (Rodin & Langer, 1977), found that those who had control over

external variables, such as deciding on meals and television watching, lived longer than a matched group that did not have such controls.

More recent research has shown that there is not necessarily a linear relationship between the amount of control a person has and health or behavioural outcomes (Shapiro et al, 1996). This later research has found that more control is not necessarily better. For some people there are "mismatches" between the amount of control available and personal factors, including: the competence of the individual; their belief in their competence; their willingness to take responsibility and their desire for control.

Shapiro et al (1996) describe two conditions where more control can be damaging: the first where there is control available in the environment, but where a person does not want control or is unable to use it; the second is where a person wants control and could use it, but when the environment does not afford the opportunity for the individual to exert control. In these cases, the construct of control is linked to concepts of learned helplessness and self-efficacy.

Burger and Cooper (1979) introduced the notion of desire for control, which is a stable personality trait reflecting the extent to which individuals generally are motivated to control the events in their lives Burger (1985). Those with a high desire for control tend to make their own decisions, take action to avoid loss of control, try to assume leadership in group situations and take on responsibility. Burger (1985) developed a scale to measure an individual's desire for control, and behavioural outcomes based on whether or not a person exhibits a high desire for control.

The desire for control construct is only loosely correlated with locus of control and self-efficacy concepts (Burger 1985). This suggests that the desire for control is significantly different from actual exhibition of control behaviours and perception of control. According to Bandura (1989):

People who believe they can exercise control over potential threats do not conjure up apprehensive cognitions and, therefore, are not perturbed by them. But those who believe they cannot manage potential threats experience high levels of stress and anxiety arousal. They tend to dwell on their coping deficiencies and view many aspects of their environment as fraught with danger. Through such inefficacious thought they distress themselves and constrain and impair their level of functioning.

Studies have found that there needs to be a match between a person's desire for control, their amount of control (overcontrolling / assuming too much or yielding / assuming too little control), and their sense of themselves as a positive source of control versus others as a positive source of control (Shapiro et al, 1996). The ideal intervention strategy is one that matches the person's control profile with strategies to better match it with the environment, such as teaching assertiveness skills to people that are yielding in environments that afford control or teaching people to manage overcontrolling behaviour or excessive desire for control.

The relationship between the constructs of control and autonomy are inadequately explored in the literature, and further investigation of these concepts would be helpful. Does autonomy mirror control in that there may be a difference in personal desire for autonomy? Are there particular environmental characteristics that support different levels of desire for autonomy? Further exploration is also needed about the ability of adults with physical disabilities to exert control in their lives, with a particular focus on the different environmental contexts.

Happiness and well-being

Lyubomirsky (2001) describes the "two millennia-old argument that happiness is the whole aim and end of human existence" (p.239). She notes that what actually makes up "happiness" differs between cultures, but nevertheless, happiness is a goal for all cultures. This goal has also been shown to have positive by-products, for the happy individual, for their family and for the wider society. Lyubomirsky (2001) describes happiness as being synonymous with well-being.

Within psychology, until the 1990's, focus was on unhappiness and negative emotions, rather than positive ones (Sheldon et al, 1996). Studies found that negative moods interfere with concentration and sense of control; and that dysphoria has been considered a trait that is a vulnerability for depression and other psychopathology, rather than a condition that can affect anybody at different times (Sheldon et al, 1996).

Ryan and Deci (2000) describe self-determination theory as a means to explain the factors that promote well-being:

> In a nutshell, SDT addresses what people find interesting; why they value certain things; why they join certain groups; how they internalize social practices; and why they develop insecurities, psychopathologies, or maladaptive patterns... The theory argues that people are most alive, motivated, and vital when they satisfy basic psychological needs... Thus, relationships, groups, and cultures that provide supports and opportunities to fulfil basic needs are more enhancing of well-being.

Self-determination theory aims to describe happiness in terms of the environmental support for the basic psychological needs of autonomy, competence and relatedness, suggesting that without these needs being met well-being is diminished (Chirkov et al, 2003; Ryan & Deci, 2006). It is recognised that other factors may also enhance a persons happiness, but nevertheless it is suggested that the three basic psychological needs need to be met for sustained well-being (Chirkov et al,2003; Ryan & Deci, 2006).

Self-determination theory provides an alternative explanation for happiness, which typically has been studied in terms of differences between people, in trait-like terms (Reis et al, 2000). However, the theory does not explain, for example, why some people appear to be happier generally, and others less happy, except in terms of whether the psychological needs have been met.

Lyubomirsky (2001) describes the limitations of many studies where inter-personal differences in innate happiness levels are studied. As it is not possible (nor ethical) to change a person's innate level of happiness, the studies to date have only considered correlations between environmental and intra-personal factors and the level of happiness.

A summary of research to date has found that the factors expected to promote well-being, such as objective circumstances, life events and demographic variables, have only a marginal effect on overall happiness (Lyubomirsky, 2001). It is reported that even extreme and unexpected life events, such as winning large amounts of money or acquiring significant disability, can have weak effects on current happiness or predictions for future well-being (Lyubomirsky, 2001). The reason for such findings is suggested to be that a person cognitively processes information, such as life events, thus filtering the experience through their own perspective. The manner in which events are processed is due to a pre-existing level of happiness.

Lyubomirsky (2001) argues for a "construal theory" of happiness to understand why some people are happier than others. This theory promotes an understanding of the cognitive and motivational processes through which life events and situations are filtered, which in turn either maintain or enhance the person's level of happiness, and also their moment to moment mood or affect.

Lyubomirsky (2001) describes the construal theory of happiness as exploring "hedonically relevant psychological processes"; these being social comparison, dissonance reduction, self-reflection, self-evaluation and the person's self-perception.

There are a range of studies that suggest that happiness and satisfaction are enhanced when goals are intrinsic, self-concordant, realistic, valued by one's culture and not conflicting Lyubomirsky (2001). To relate these findings to a self-determination framework, goals that are intrinsic, not conflicting and self-concordant could be seen to be supportive of self-governance autonomy; those that are realistic supportive of competence and those valued by one's culture supportive of both self-governance autonomy and relatedness. Lyubomirsky (2001) also suggests that studies have found people to be happier when they aim for success, rather than avoiding failure, are committed to their goals and believe that they are being successful in goal-oriented behaviour.

Lyubomirsky (2001) reports studies showing that the coping mechanisms, or cognitive responses to situations vary between people who are happier and less happy. Happier people have been found to use optimistic strategies and biases: they perceive their circumstances more positively; they expect positive situations in the future; they feel that they have control, and they feel confident about their own abilities Lyubomirsky (2001); they also have high-self-efficacy beliefs. People who are less happy are more likely to remember negative aspects of events and to dwell on oneself and problems (Lyubomirsky 2001). Studies have also shown greater well-being among people who are optimistic about their extent of control; who take positive meaning from negative situations; who use humour, spirituality and faith when faced with adversity, and who use social comparisons favourably (Lyubomirsky 2001).

Lyubomirsky (2001) found that people who rated themselves as happy seem to be less sensitive to social comparison than people who are unhappy, particularly when the information about themselves is unfavourable. Differences were also found in "post-

decisional rationalisation": happy people tend to view the range of options open to them as good with the option that they chose or were given as very good, whereas unhappy people consider all of the options as mediocre, and the option that they chose or were given as "the best of a bad lot".

The overall results and theory presented by Lyubomirsky (2001) suggest that people interpret, remember and experience situations (whether real or hypothetical) in a way that reinforces their innate dispositions on the happiness continuum. It has also been found that the differences found between happy and unhappy individuals have been shown to be largely independent of optimism and self-esteem. This finding appears to contradict previous studies cited by Lyubomirsky (2001) in which the coping strategies or psychological mechanisms of happy and unhappy people differed in that happy people tended to have optimistic views.

Reis et al (2000) suggest that the study of happiness has concentrated on distinguishing between inter-person differences in happiness, but that more emphasis is needed on intra-person, daily fluctuations in happiness. They suggest that the daily variations in a person's happiness can be described in terms of how much the basic needs of autonomy, competence and relatedness are supported. This finding was derived following a study using daily activity records and self-assessed well-being reports, where the individual differences between participants were controlled for.

Sheldon et al (1996) also undertook a diary study within the self-determination theory tradition, to establish whether support for the psychological needs promotes daily well being. Sheldon et al (1996) compared the participants' results and suggested that those with higher autonomy and competence tended to report better days. The intra-person results showed that participants felt that they had good days when they felt autonomous and competent in the activities when compared to their own baseline.

A number of theories have been suggested to describe happiness as related to occupational performance, such as the "activity theory", which suggests that participation in pleasant activities promotes general happiness and well-being; people who are less happy engage in fewer pleasurable activities, and expect activities to be less pleasurable (Sheldon et al, 1996).

Csikszentmihalyi and Csikszentmihalyi (1988) have reported the results of studies on "flow", in which it has been found that flow is a highly pleasurable experience. People who experience flow on a regular basis are reported to be generally happier than those who do not, and people are most happy themselves when intrinsically motivated (Csikszentmihalyi & Csikszentmihalyi, 1988).

Fredrickson (1998) also studied the link between participation in activities and positive affect. A positive affect prompts a person to engage with their environment and participate in activities, which in turn may promote happiness. She created the "broaden and build theory" of positive emotions, stating that positive emotions can broaden people's repertoires for participation in activities, and that this then builds personal resources, through learning. Positive emotions were also found to build psychological resilience. Thus, the "broaden and build" theory goes beyond traditional views that suggest that positive emotions promote well-being and immediate behaviour, but also provide a long-term, more important role, that promote growth and development (Fredrickson, 1998).

Other studies in positive emotions and affect include those by Folkman and Moskowitz (2000). They cite studies that have shown that positive affect can promote creativity, flexibility in thinking, problem-solving and can enhance interpretation of information about the self.

While it is beyond the scope of the current study to explore how happy individuals are, theories of happiness and well-being are pertinent to understanding participants' interpretations of their life situation. This is particularly important where the overlap between occupational performance and happiness, and autonomy and happiness are considered in the literature. Will the participants who are most engaged in occupations that they report enjoying be happier overall? Do the participants who report greater autonomy report being happier?

Equally the theory that happiness is affected to a surpriningly small degree by major life events (such as onset of disability) is of interest. This will also be further discussed in the next chapter.

Coping Mechanisms

Folkman and Moskowitz (2000 p. 647) state that

> "Research on coping over the past 30 years has been dominated by contextual models that emphasize coping by a person situated in a particular stressful encounter or stressful social condition... Studies based on these conceptualizations vary in the weight they give to the influence of antecedent factors such as personality, individual and social resources and development over the life span."

Summarising the main conclusions from research on coping, Folkman and Moskowitz (2000) suggest that: coping has multiple functions for the individual, including management of distress; the manner in which a person copes with a situation depends on the stressful situation itself, such as its controllability, and how a person copes with a situation depends on personality dispositions and social resources.

Boemer and Jopp (2007) identify three major lifespan theories that attempt to explain the mechanisms used to enable a person to cope with or adapt to major life change, loss or trauma, and highlight the commonalities between these. They argue that the different theories point to two central processes, one being improvement / maintenance and the other being reorientation.

"Improvement / maintenance" is the first adaptational process described by Boemer and Jopp (2007), in this process, the person pursues existing goals, even if this is difficult. This process is generally used when the person can actively change aspects of the situation, such as improving their own skill. The "improvement" and "maintenance" categories differ greatly in that improvement relates to learning new skills, adaptation and enhancing development, whereas "maintenance" focuses on preventing further loss. The commonality between these, according to Boemer and Jopp (2007) is that they both relate to goal engagement.

"Reorientation" processes are the second category described by Boemer and Jopp (2007), in which a person changes their goals and values to reflect their change in circumstances, so that the goals become feasible. The reorientation processes usually occur when the person can exert no control, or the situation cannot be altered. This process differs from "improvement/maintenance" because it is characterised by goal

disengagement, in that the person changes, re-evaluates or re-values goals (Boemer & Jopp, 2007).

Boemer & Jopp (2007) argue that, following onset of disability, both of the processes can occur at the same time; the person can learn new skills, maintain current levels of functioning and concurrently change their value system, so that previous goals become less important, and new, feasible ones more important.

The three models described by Boemer and Jopp (2007) are: Brandstadter's assimilation / accommodation model; the SOC model proposed by Baites and Baites, and Heckhausen and Schulz' lifespan theory of control.

In Brandstadter's dual process model, coping is described as taking one of two forms; the assimilative mode, which is akin to adaptation and learning and the accommodative mode, which relates to adjusting goals and values. According to this model, the likely sequence of events is that a person initially attempts assimilation (goal engagement), and then if this fails, accommodation (goal re-orientation) (Boemer & Jopp, 2007).

Baltes and Baltes' selection, optimisation and compensation (SOC) model is the second to be reviewed by Boemer and Jopp (2007). Selection refers to the principle that gives direction to development, optimisation is where an individual aims to improve development, and compensation is the use of alternative means to maintain function in the face of developmental loss. A person initially selects goals, which can be elective selection, where a person actively chooses a goal, or loss-based selection, where a person may need to give up on a goal. Once the goal is selected, optimisation occurs, which is the coordination of resources and the building of capacities to meat the goal. Compensation involves changing the manner in which the goal is reached, as a result of loss, such as using an alternative strategy to achieve a goal. If the goal is not feasible following optimisation or compensation, then loss-based selection occurs, where a new goal is formed. The different parts of the SOC model work dynamically as a unit. Boemer and Jopp (2007) apply the SOC model to their framework stating that elective selection, optimisation and compensation all relate to goal engagement, and are therefore forms of "improvement / maintenance", whereas loss-based selection is "reorientation".

Heckhausen and Schulz' lifespan theory of control is the third model of coping described by Boemer and Jopp. This theory defines two types of control; primary control, where action is used to change the external environment, and secondary control, which is concerned with the adaptation of the self to external situations. It is suggested that the potential for primary control needs to be enhanced for positive development in the long term Both primary and secondary controls can be selective or compensatory. Boemer and Jopp (2007) relate this model to their categories by stating that selective primary control, selective secondary control and compensatory primary control are adaptive, goal-engagement strategies, and so form part of their "improvement / maintenance" construct. Goal disengagement occurs in compensatory secondary control mechanisms, which are a "reorientation" process.

Significant differences in the theories are presented by Boemer and Jopp (2007), including the scope and focus of each of the models. They argue that the explanation for the type of strategy used by a given individual is well described in the dual process model; this model suggests that assimilative and accommodative modes are partly due to learned or habitual tendencies, meaning that a person is more or less likely to use one or other strategy, based on previous experience. Dispositional differences are also described similarly for the lifespan theory of control, whereas in the SOC model, Boemer and Jopp (2007) state that there is no explicit description of whether dispositional factors affect a person's tendency to use one mechanism rather than another.

Boemer and Jopp (2007) also state that coping mechanisms change over the lifespan. The dual process suggests that later in life, or following the onset of disability, accommodative strategies are used, similarly compensatory secondary control mechanisms, as conceptualised in the lifespan control theory, are used later in life.

Boemer and Jopp's (2007) model appears to highlight similarities of the three theories described in a simplified manner, but it has not been wholeheartedly welcomed. For example, Riediger and Ebner (2007) suggest that their overlapping of the theories, in that they all include engagement and disengagement processes as developmental-regulatory mechanisms is useful, but that combining improvement and maintenance in one group does not make sense, as these are clearly different processes and should be separated. They argue that the three theories reviewed are significantly different and that Boemer and Jopp (2007) should have focused on the differences in scope of these theories (Riediger & Ebner, 2007).

Greve and Wentura (2007) similarly argue that Boemer and Jopp's two-function framework is over simplistic, and that the differences between the theories should be further highlighted. They further argue that the division of processes into improvement / maintenance and reorientation is in itself misleading, stating that these are different theoretical layers rather than different processes, for example, a person may use reorientation to maintain or improve well-being (Greve and Wentura 2007). It is argued that while there may be overlap, the three theories are describing different layers of coping strategies, thus simply merging the ideas into two categories is over-simplistic and could be confusing; a completely new understanding of coping mechanisms would be rather more helpful (Greve and Wentura 2007).

Taylor (1983) described five mechanisms that were used by people to cope with adverse situations, these being: comparison of oneself with another less fortunate individual; focusing on factors that make the person feel advantaged; imagining worse situations; imagine benefit from the adverse situation and creating standards of adjustment that makes the individual's coping seem superior. In another study (Taylor et al, 1984) it was found that women with breast cancer did not use all of these strategies, but the most commonly used was the comparison of oneself with less fortunate others.

Schneider (2001) described results of studies of optimism, and found that optimistic people had better coping strategies. These "better" coping strategies consisted of more active coping, and less avoidance or denial of the situation. One disadvantage of optimists, as described by Schneider (2001) is that they were found not to take preventative action in light of risk.

Bandura (1989) describes people who cope better in adverse situations as those with high self-efficacy beliefs. People with low self-efficacy beliefs were found to reduce effort or abandon their goals early, and are likely to settle for mediocre results. People with a high sense of efficacy are found to exert greater effort to master a challenge, and that perseverance usually results in greater accomplishments. Self-efficacy beliefs are also viewed as being protective, as daily life is full of difficult situations and potential failures, a robust sense of efficacy enables a person to sustain effort and to recover quickly from set-backs. High self-efficacy is therefore linked to resilience in engaging in challenging activities (Bandura, 1989).

Bonauno (2005) describes resilience as a pattern of disruption following adversity, that differs from other patterns. Other patterns include: recovery, where "normal" functioning is suspended, but returns after a period of time; chronic disruption which remains over time; delayed disruption, which occurs some time following the adverse event. In resilience, normal functioning remains throughout an adverse event. Bonauno (2005) studied resilience, and concluded that it is common, but largely ignored by psychology as those who meet the attention of psychologists are frequently people with inferior coping mechanisms.

Folkman and Moskowitz (2000) state that while psychologists have described different coping mechanisms, they have done little to address the question of how coping enables individuals to minimise the negative effects of adverse events. Their concern is with positive affect in coping situations, and they conclude that positive affect can co-occur with distress, it enables adaptation and that some coping processes generate and sustain positive affect, these involve the creation of meaning or understanding of the event. Folkman and Moskowitz (2000) argue that psychology has been too focused on negative affect, and that further study of positive affect when it co-occurs with adverse situations, how positive affect is maintained and its role in long-term adjustment and well-being is needed.

The participants in the current study are likely to all use some forms of coping mechanism to manage daily life, particularly those with acquired and degenerative disabilities. Do participants who feel more autonomous cope using goal engagement strategies to a greater extent than those with lower perceptions of their autonomy and competence? How do participants deal with the frustrations of daily life? Given that there is a lack of literature linking coping strategies to autonomy, or control of individuals with disabilities, this is an area for further research.

The Self in adverse situations

There are numerous theories about "the self" within social, developmental and personality psychology, thus a review of these is considered beyond the scope of this review. However, as will be described in the next chapter, within the disability movement, there has been an increasing focus on "identity" and its role in the lives and adjustment of

people with disabilities. This section will briefly consider the impact of development of self-concept and self-esteem on performance,

Marsh and Hau (2003) highlight the importance of the development of self-concept, and that this has been related to a variety of areas, including education, health (both mental and physical), development, industry, social services and sports. They claim that self-concept is an important outcome variable in itself, as well as influencing the development of a variety of other psychological outcomes.

It appears that results of research into self-concept mirrors that from self-efficacy, in that it is a mediator of goal involvement, and that it is situation-specific, so a person can have a positive self-concept in one area, and a negative self-concept in another area, resulting in inaccuracies in any attempt to use global measures of self-concept (Marsh & Hau, 2003).

Aspects of identity, including self-concept and self-worth are developed throughout the lifespan, in response to environmental stimuli and processing of this information, as well as the different roles that people play In social interactions (Scheieir & Carver, 1980).

Covington (1992) described the mechanisms by which individuals aim to maintain their self-worth, including adopting causal attributions for success or failure. This theory has primarily been related to education, where an individual may attribute success to effort, and failure to a lack of effort, and if failure is predicted will not expend effort with a view to maintaining their sense of self-worth.

There are a number of theories about the development of self-esteem (Ryan & Deci, 2004; Pyszczynski et al, 2004). Ryan and Deci (2004) differentiate between self-esteem that occurs in the presence of anxiety, this being described as contingent self-esteem; they describe "true" self-esteem as being based on satisfaction of the three psychological needs within the self-determination theory formulation (these being autonomy, competence and relatedness).

The contingent form of self-esteem has been described as a buffer mechanism to protect the self in times of anxiety or alienation, where people aim to feel significant in an attempt to find solace in the face of adversity (Ryan & Deci, 2004; Pyszczynski et al, 2004).

Issues with self-esteem are most likely to occur, according to Ryan and Deci (2004), when the psychological needs are not met.

Conclusion

This chapter reviewed some of the literature, primarily from the field of psychology, which helps form central questions within this research, particularly relating to autonomy, choice and control.

While this psychological backdrop is considered essential to the current work, it does not provide a detailed insight into the lives or lifestyles of people with physical disability. The next chapter will address disability theory, and research about disabled people. It is then followed by a synthesis of both this chapter and the next.

4. Literature Review Part 2

Introduction

As this research seeks to explore the daily life experience of eight adults with significant physical disability, with a particular focus on their experience and perceptions of autonomy, choice and independence in everyday life, it is thought necessary to undertake a comprehensive review of literature pertinent to the lives of adults with physical disability.

The previous chapter provided information on current thinking in relation to the psychological factors inherent in this work; this chapter concentrates on the researched lived experiences of adults with physical disability.

This review begins with an exploration of disability theory and models of disability, including their influence on thinking, research and policy. It then includes information about different accommodation options for disabled people, iincluding residential settings and independent living. More specific research focusing on occupational performance issues for adults with physical disability, independence, well-being and social influences are presented in this chapter. The chapter concludes with discussion of the different approaches to research in the area of disability.

There is a large volume of published material relating to adults with physical impairments, but a limited number of studies directly relevant to this work, and a paucity of literature about adults in Ireland. Thus, this literature review presents information in relation to key concerns of the work, sourced from academic journals and books, policy documents, and literature from disability organisations.

Following this chapter, there will be a focus on integrating material from both this and the previous chapter, and relating the material directly to the current work.

Disability Theory and Models

> "It is estimated that there are 650million people with disabilities in the world, of which 194 million of them are children... In the next 20 years there will be a high increase in the numbers of people with disabilities... within the next 25 years disabled people aged 15-29 will increase by 55%; aged 30-64 by 150% and aged 60 and over by more than 200%. With this calculation, by 2025 there will be 900 million people with disabilities globally and 650 million in developing countries alone"
> (Khalfan, 2007 p.3)

It is frequently recognised that it is very difficult to "count" the numbers of people with disabilities in the world (e.g. Johnstone, 2001; Oliver, 2002; Khalfan, 2007). Nevertheless, estimates are that up to 10% of the population may be disabled.

> "Disability is the product of definitions and practices. ..[it] is what the "disablist" society decides so to call. ..it is not the internal nature of the disability but the labelling process which categorises people in relation to the dominant structures and values of the society.."
> (Bury, 1996 p.25)

The definition of "disability" is a complex area, subject to different viewpoints. As Oliver (, 2002) states, depending on the definition of disability, it theoretically would be possible to have 0% of the population disabled, or 100% of the population categorised as disabled. The problem of defining disability is symptomatic of the debate in the social sciences, between methodological individualism and social theories (Oliver, 1990).

The definitions of disability relate to the "disability model" used, and therefore it is worth examining the models of disability.

Oliver (2004) describes the models of disability as a way of translating ideas into practice; the models exist within a structure of legislation, social values etc. The models of disability appear to be explanatory and descriptive in nature.

Llewellyn and Hogan, (2000) argue that the models have their place within the discourse on disability. They describe the models of disability as an abstract system that can be used as a means to present a theory, They differentiate between models and theory, but argue that the models of disability serve a role in providing representations of the situation from which hypotheses can be generated (Llewellyn & Hogan, 2000).

There are a number of distinct models of disability, Kirby (2004) differentiates between them as follows:

> "A number of divergent conceptualisations of disability emerged in the twentieth century, including those of "the biomedical model," "disability as social construction," "disability as difference," and "disability as potentially universal experience." Proponents of the biomedical and social construction models have squared off against each other from seemingly incompatible and highly polarised standpoints... an analysis of all four conceptualisations reveals that each has something of value to offer in the exploration and handling of justice issues of relevance to disability."
> (Kirby, 2004. p. 229).

The Medical Model

Johnston (1996) describes the medical model as the primary approach historically taken to disabled people. He reports that it arises from the disease model used in medicine, where all disability is physiological in nature, and is a defect, disease or abnormality in need of treatment.

The medical model is generally considered to be based within the previous WHO International Classification of Impairment, Disability and Handicap (WHO, 1978). The definitions are as follows:

> Impairment -
> In the context of health experience, an impairment is a loss or abnormality of any psychological, physiological or anatomical structure or function.
> Disability -
> In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
> Handicap -
> In the context of health experience, a handicap is a disadvantage for a given individual resulting from an impairment or disability, that limits or prevents fulfilment of a role (depending on age, sex, cultural and social factors) considered normal for that individual.

The aim of a medical, or bioethical model is to "fix" the person / impairment, so that the person functions "normally" for the species (Kirby, 2004). The view that to be disabled is to "suffer" is inherent within a medical model approach, thus the most appropriate action is to remove the impairment, therefore the suffering (Silvers, 1995).

Within the medical model, the person is viewed as alterable and flexible; society is not (Llewellyn & Hogan, 2000). From a justice perspective, the medical model has led to approaches of re-distribution of wealth to aim to decrease inequality among people, but with minimal disturbance to the social norms, or status quo (Kirby, 2004). This could include, for example, payments to people with disabilities or impairments who are not working (such as the Disability Allowance in Ireland); they, in effect, recognise that an individual is different and unable to participate in society, without changing the social construct; which could enable a person to participate (e.g. to work).

A widely cited problem with the medical model of disability, as encapsulated within the WHO definitions (ICIDH) is the reference to a "normal". It is argued that "normal" is societal, and does not take account of difference (Abberley, 1996).

There have been many critics of the medical model (e.g. Oliver, 1990, Swain et al, 1993; Shakespeare & Watson, 2002 etc). The objections to the medical model of disability began with the disability movement, when a number of groups of disabled activists (such as the Union of Physically Impaired Against Segregation (UPIAS) and Disabled Persons International (DPI), among others) sought the right to define disability themselves (Llewellyn & Hogan, 2000; Cooper, 1999; Driedger, 1989)

> "...the traditional way of dealing with disabled people has been for doctors and other professionals to decide what is best for us. It is of course a fact that we sometimes require skilled medical help to treat our physical impairments... We may also need therapists to help restore or maintain physical function, and to advise us on aids to independence and mobility. But the imposition of medical authority, and of a medical definition of our problems of living in society, have to be resisted strongly. First and foremost we are people, not "patients", "cases", "spastics", "the deaf", "the blind", "wheelchairs" or "the sick". Our Union rejects entirely any idea of medical or other experts having the right to tell us how we should live, or withholding information from us, or take decisions behind our backs.
> 15 We reject also the whole idea of "experts" and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the "psychology" of disablement. We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down to - far better than any able-bodied expert. We as a Union are not interested in descriptions of how awful it is to be disabled. What we are interested in, are ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top our physical impairments by the way this society is organised to exclude us. In our view, it is only the actual impairment which we must accept; the additional and totally unnecessary problems caused by the way we are treated are essentially to be overcome and not accepted. We look forward to the day when the army of "experts" on our social and psychological problems can find more productive work "
> (UPIAS, 1976, sections 14 – 16).

This activism gave rise to an alternative view of disability, encapsulated within the "Social Model" (Oliver, 1990).

The Social Model of Disability

The disability activist group, Union of Physically Impaired Against Segregation (UPIAS) was established and produced a position paper in 1974, which was subsequently amended in 1976 (UPIAS, 1976). In this paper, disability was re-defined as follows:

> Impairment -
> "lacking part of or all of a limb or having a defective limb, organ or mechanism of the body."
> Disability -
> "a disadvantage or restriction of an activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities."

UPIAS (1976), described its aim, in its initial position paper as follows:

> "The Union [UPIAS] aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society. These arrangements must include the necessary financial, medical, technical, educational and other help required from the State to enable us to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives."

The UPIAS definition of disability differs greatly from the definition in the ICIDH (WHO, 1978), which characterises the medical model of disability. The UPIAS definition is considered to characterise the social model of disability, where the "cause" of disability is firmly placed within society – people are disabled by the social constructs, rather than their impairments (Oliver, 1990).

Understanding the basic principle that the problem is not the individual or impairment, but the way society has chosen to respond to it, turns middle range theory on its head (Oliver, 1996) and has transformed the lives of many hundreds of disabled people (Germon, 1999 p.82)

Oliver (2004) describes the main characteristics of the social model of disability as follows:

- The focus is not on impairment or functional limitations as the origin of problems; rather difficulties arise due to the "disabling barriers, environments and cultures"
- Problems are seen holistically, as a result of a number of environmental factors. For example, access to education is not simply about internal organisation of schools or universities but relates to a cluster of related areas, including transport, housing, technology, financial support etc.
- The social model of disability does not negate or exclude individual level modes of intervention at the expense of collective action.

> "The social model focuses on the experience of disability ... it considers a wide range of social and material factors and conditions, such as family circumstances, income and financial support, education, employment, housing, transport and the built environment, and more besides. At the same time, the individual and collective conditions of disabled people are not fixed, and the experience of disability therefore also demonstrates an 'emergent' and temporal character. This spans the individual's experience of disability, in the context of the overall biography, social relationships and life history the wider circumstances of disabling barriers and attitudes in society, and the impact of state policies and welfare support systems."
> (Barnes et al, 1999 p.31)

The model is reported to take a "materialist" approach, in that it starts with the viewpoint that there are structures external to the person (such as the physical environment, regulations etc), and these structures shape the experiences of the individual (Oliver, 2004).

The social model of disability is certainly not without its critics. Thomas (2004) argued that there are many limitations with the social model, most notably that theorising about diversity needs a far more sophisticated approach than is contained within the social model of disability, and that this theory should attend to issues of how individual identities are created and maintained. It is also argued that individual disabled people are also part of other sub-groups which are culturally formed, such as social class, ethnicity etc.

Possibly one of the most fundamental criticisms of the social model is that there is no coherent concept of a "social model" of disability (Harris, 2000). Harris (2000) proposes that a dimension of the social model that is claimed by its advocates is that if social barriers were removed, then no disabling factors remain, which does not make sense. Instead, it is proposed that recognition of the social implications of physical and other disabilities needs to be recognised, but that the cause of disability remains the impairment itself (Harris, 2000).

Personal experience is removed from a social model of disability, as it focuses on individual aspects of disability, and frequently highlights the "personal tragedy" view. The individual experience or "personal tragedy" approach is described by Oliver (1990, 2004) as a distraction, it moves attention from the social and physical barriers that disable people, and reinforces the linear relationship between impairment and disability, thus was not a constituent of the social model theory.

Thomas (2004), however, among others, argues for a re-evaluation of the social model of disability. She argues that aspects of human experience (such as the psycho-emotional dimension) need to be brought back into a model of disability. She argues that this personal experience of impairment is equally as political as any experience of barriers, be they social, physical or of whatever form.

It is argued that a postmodernist approach would suggest that a clear separation between the social disability and biological impairment is unhelpful, because both are mediated by factors both within and outside the person, and are affected by discourse, for example, the definition of impairment and normality is contained within medical discourse, as there is no clear non-disabled character that is created outside of discourse. Others, e.g. Abberley (1996) argue that impairment itself can be a social product, in that war, pollution, poverty and countless other social situations can result in disability.

Hughes et al (2004) argue that the separation of the "self", or identity from the physical, sensory body (the disabled body) is nonsensical, as the manner in which a person experiences the social world includes all aspects of the person, the disabled body and the psychological sense of self. Whether this separation is, in fact a tenet of the social model, is debatable. It is not necessarily true that the impairment or "disabled body" is ignored or separated from identity within the models.

Other authors (e.g. Harrison & Kahn, 2004; Crowe, 1996) have also called for a re-thinking of the social model. Crowe (1996) highlights the difference between the disability movement and other civil rights movements; skin colour, ethnicity or sexual orientation are neutral conditions, whereas impairment can cause pain, fatigue and is not a neutral characteristic, thus the disability movement needs to re-introduce the importance of impairment. She hypothesises that the reason why impairment was excluded from

discussion is that it may weaken the argument that disability is created by social and physical barriers.

Hughes (2000) also criticises the materialist approach of the social model, suggesting that it reduces the importance of culture, as a lens through which disability, from both an individualistic and a collectivist perspective are created. Whether this is necessarily true, is possibly debatable, but Shakespeare & Watson (2002) argue that culture needs to be added to the explanation of disability in a re-think of the social model of disability. They argue that disabled people, within an emancipatory framework, also need to take greater account of the influence and role of culture.

Morris (1991) suggests that disabled people create their own culture; immersion into a disability culture, which celebrates difference and challenges the non-disabled representation of disability, is the primary vehicle for changing the societal attitude towards disability.

Occupational Therapy Models

According to Townsend (1993 p.176), the,

> "foundational features of Occupational Therapy are consistent with the foundational features of social justice... Occupational Therapy's vision is to promote social justice by enabling people to participate as valued members of society..."

Townsend's (1993) argument suggests that occupational therapy would fit most snugly within a social model of disability, but this frequently is not the case. There are a number of generic practice models within occupational therapy, each of which appears to reflect a different theory of disability.

Possibly the most generic of occupational therapy models is that whereby the occupational therapist focuses on occupational performance, or doing, and that this is the interaction between the person, the environment and the occupation (AOTA, 1995) or the P-E-O framework. In this framework, the "cause" of dysfunction, or inability to do, can be a result of performance deficits of the person which can be remediated or compensated for (as in the medical model), environmental barriers (as in the social model), or the task or occupation in which the person engages. The focus on the occupation as a potential

cause of performance deficit appears to be unique to occupational therapy, and could fit within either a social or a medical model of disability.

The Model of Human Occupation (MOHO) (Kielhofner, 2002; 2008) is one of the generic models of practice within occupational therapy. Its aims, or "concerns" are described as:

> :"...to understand how persons are motivated toward and choose to do the things that fill their lives... the recurrent pattern of doing that makes up everyday life [and] ... how are people able to engage in such a wide range of physical, cognitive and social actions"
> (Kielhofner, 2002, p13).

The Model of Human Occupation (Kielhofner, 2002; 2008) describes the lived body experience of disabled people; the later versions of this model describe one of the human sub-systems as, "Performance Capacity", which includes both the objective physical/cognitive components and the individual's subjective experience. In MOHO, the emphasis is not on the actual components, but on the "subjective experience and its role in shaping how people perform" (Kielhofner, 2002, p.23). People who have objective limitations (or abilities) in physical, cognitive or affective areas also have subjective experiences of those limitations or abilities. These experiences are the focus in MOHO (Kielhofner, 2002).

The model also describes the role of the environment in both affording opportunities for individuals to engage in occupations, and presses, or forces people to exert behaviour in certain situations.

The Model of Human Occupation, as a description of theory, has developed significantly since its first and second version. The change in focus, including description of the lived body, subjective experience of disability along with interaction with the environment is more similar to a social model approach than a medical model approach; however the individual focus remains.

Another generic model of practice used within occupational therapy is the Canadian Model of Occupational Performance (CMOP) (CAOT, 1997); Townsend & Polatajko, 2007). This model can provide a framework for individual and social change, and is described as a means to promote health, well-being and justice, through people's occupational performance (Townsend & Polatajko, 2007). Within the CMOP, there is a

focus on the potential of the environment, including physical, social, cultural and institutional elements, to either enable or disable a person's occupational performance.

The Canadian Model of Occupational Performance (CMOP) and the Model of Human Occupation (MOHO) both straddle an individual – society model or view of disability. Being a health profession, it is not surprising that many of the frames of reference and theory associated with occupational therapy have some root within a medical model. However, it does appear that the more recent theories, particularly as encapsulated within the generic models, and theories such as occupational deprivation (Whiteford, 2000), are taking a more social perspective.

Other theories / models of disability

Kirby (2004) differentiates between four models of disability, the biomedical, social, one he describes as "disability as difference", and finally a model described as "disability as a potentially universal experience".

Kirby's (2004) description of the "disability as difference" approach appears to draw from aspects of the medical and social models of disability. He describes the approach as drawing on feminist theory. Disabled people are likened to women as conceptualised within some feminist theory, in that they are construed as being dependent and passive (Kirby, 2004). This "disability as difference" approach appears to differentiate in clear terms, between those who are different, disabled, and those who are able, forming part of the norm in society. The "abnormal" (disabled) people are then likely to be oppressed by the social organisation (Kirby, 2004).

This "disability as difference" theory appears to draw on aspects of both the medical and social models of disability, in effect appears to be a composite of both. The difference being norm-related is similar to the description of disability within the medical model; difference being socially constructed and likely to lead to oppression is as in the social model of disability.

The final theory described by Kirby (2004) is that of "disability as a potentially universal experience", which he acknowledges is not referred to as such in the disability literature.

Smith (2001) argues that the notion of independence is a myth, despite it being generally considered to be a valued goal. In this "disability as a potentially universal experience" approach, it is taken that all people become sick, and elderly at some point in time, and so at that point, in effect become "disabled" (Kirby, 2004).

Tate and Pledger, (2003) describe the need for a new paradigm of disability, related to psychology.

> "... the current mainstream of psychology has tended to relegate disability and chronic illness to a peripheral area of concern and to subspecialties such as rehabilitation psychology. This practice has posed a significant challenge for psychology because they are in an environment where the consumer is increasingly challenging policymakers, demanding that providers be knowledgeable about disability, and questioning systems that deny access and prevent integration of individuals with disabilities into the community."

They argue that the new paradigm, or "integrative socioecological conceptual framework" of disability should contain four types of variables, these being:

- the environmental system, including physical setting, organisational factors, human aggregate, and social climate;
- the personal system;
- mediating factors (described as appraisal, activation and adaptation), and
- health status.

(Tate & Pledger, 2003)

It is stated that both the environmental system and the personal system can have an impact on disability experience either with or without mediating factors.

It is questionable what this new paradigm will or has contributed to the literature about disability.

Occupation

This research seeks to explore the daily lives of the participants, with a particular focus on their experiences of autonomy and choice. Within occupational therapy theory, daily life is made up of a variety of occupations, activities and tasks (Hagedorn, 1997; Levine & Brayley, 1991). As this research has a strong occupational therapy focus, and indeed investigates the participants' lived experience in terms of occupational performance and patterning, it is considered necessary in this section, to explore the concept of occupation.

The anthropologist Bateson (1996) describes occupation in a literary, analagous manner, as the "web and woof" of the tapestry of daily lives, which weaves together work, pleasure and a sense of identity that form a unique individual's life (Bateson, 1996).

More conventionally, occupation has been described as: the commonplace, ordinary tasks that are performed every day (AOTA, 1995); the things that make us what we are (Hagedorn, 1997); a complex, multifaceted construct (Polatajko, 1994), and is the "totality of productive purposeful action (Hagedorn, 1995 p. 79).

Occupation appears to have been defined in a variety of ways in the occupational therapy literature, (for example, Christiansen, 1994; Nelson, 1988; Yerxa, 1998; AOTA, 1995) Commonalities from these definitions include that occupations: a) form patterns, collections or "chunks" of named, organised activities; b) occur throughout the life-span; c) occur in time, in daily life, d) are what humans engage in, or occupy themselves with; e) are meaningful, with cultural and social significance, and f) fulfil a purpose for the individual (Collins, 2000).

Occupational performance is seen as the interaction between the occupation itself, (as Nelson (1988) describes, the "occupational form"), the environment and the person (AOTA, 1995; CAOT, 1997).

Occupation is commonly classified as self-care (also known as personal activities of daily living), productivity / work, and leisure / play (AOTA, 1995; Hagedorn, 1997; Christiansen, 1994; CAOT, 1997). Within this classification, work and leisure are frequently seen as opposites. There have been a number of critics of this classification (including Hagedorn,

1997), and it is highlighted that classifications are personal; the same activity could be considered self-care by one person, productivity by another and leisure by yet another person, so the need to examine the meaning of an activity for each individual is highlighted (e.g. Kielhofner, 2002).

Critique of the classifications of occupation also occurs outside the fields of occupational therapy and occupational science. For example, Csikszentmihalyi (1988) reports that flow studies have found that work and leisure are not necessarily opposites; and that rather than ascribing an activity as leisure due to its nature, it would better be defined by the quality of the experience.

This study will explore the daily lives of adults with physical disabilities, and through diary methodology investigate their daily occupations. It will be interesting to investigate how they describe their occupations, and what differentiates self-care, productivity and leisure occupations.

Within occupational therapy theory, and occupational science (particularly in the 1990's, (e.g. Levine & Brayley, 1991), it was suggested that a balance of self-care, productivity and leisure occupations are health-promoting (Hagedorn, 1997). It is argued that rather than balance of occupational classifications, balance in terms of the purpose and meaning of occupations would be more useful (Hagedorn, 1997).

Participation in occupation is also thought to be health promoting (Christiansen et al, 1999; Wilcock, 1998; Wilcock, 1999; Whiteford, 2000). Failure to participate in a variety of different occupations can have negative impacts on an individual's mental and physical well-being (Hagedorn, 1997). While these views are widely cited within the occupational therapy literature, there appear to be a limited number of empirical studies describing such results.

Another area of study within occupational science and occupational therapy is the issue of time use and patterning of occupations. Fricke and Unsworth (2001) investigated time use and the importance of instrumental activities of daily living for older adults living in the community. They report that the older people tended to spend significant time at home, and spent over half of their time undertaking instrumental activities of daily living; another

finding was that the priority or importance of tasks for the older people related to the meaning that they attribute to these tasks.

As this research seeks to explore, in some detail, the patterning of the participants' occupations, it is considered worthwhile to review research into the lived experience and self-care, productivity and leisure occupations. The next section will review literature pertaining to independent living and institutions, followed by an exploration of how and whether occupational therapy has engaged with the independent living philosophy. This is followed by three sections reviewing self-care, productivity and leisure occupations.

Independent Living and Residential settings

The participants in the current study have been selected such that some live in the community, with personal assistance, and others live in residential settings.

In the introductory chapter, an overview of the options available to people with significant physical disabilities in terms of accommodation and assistance was given. This section reviews literature about the independent living movement and also examines some of the literature about residential settings.

Residential Settings

> "An institution is a social psychological laboratory. The experiments which take place there are naturally occurring experiments in the psychology of social interaction, social roles, inter group attitudes, conflict and cohesiveness."
> (Orford, 1982, p. 293).

Brookes (1983) describes institutions as originally being built "by those who assumed that a protected environment staffed by objective caretakers would lead to better lives for vulnerable people" (p. 293). Brookes (1983) highlights that the problems caused by institutions for disabled people were not recognised for decades, arguing that this may be because early institutions probably did provide better accommodation than what was available outside the settings. Brookes (1983) argues that researchers have a

responsibility to investigate the daily lives and actual living arrangements of disabled people to explore whether institutions do provide best care.

Much of the literature about residential settings (or "institutions") dates back to the 1980s or earlier. For example, Orford (1982) provides a précis of the characteristics of institutions, highlighting the differences in social behaviour that occur there, when compared to non-institutional environments. He describes important features of institutions being their size, the location, the opportunities for individuals to engage in a variety of different activities within the institution, and the internal environment. He argues that institutions create different social norms and behaviours: behaviour exhibited in institutional settings is likely to be different to that exhibited in community settings.

One of the key features of residential settings highlighted in the literature is that restrictions on choices occur for residents. Orford (1982 p299) provides the following examples;

What time to get up and go to bed
What to wear
What to eat for breakfast and other meals
Planning future meals
Whether to make a drink or snack
Whether to visit the local shop
Whether to go to work
Whether to go to the pictures
How to spend own money
When to have a bath
When to have a haircut
Whether to have medicine
Deciding on arrangement of own room
Deciding decoration of own room
Whether to smoke
Whether to play the radio or tv
When to have friends in
Whether to have a sexual relationship with a friend

Numerous pieces of research have been conducted exploring the influences that affect institutional climates. Orford (1982) describes the influence of the institution's ideology or philosophy, but despite the "pervasive influence" it can be totally missed by staff. Tizard et al (1975) investigated the influence of staff autonomy on institutions. They report that staff who can make choices about the way an individual ward or area is run tended to have better interactions with the clients or patients in that ward.

The influence of staff attitudes has also been investigated: these are affected by the organisation of the institution, but are also affected by personality factors (Orford, 1982). Important considerations for people living in residential settings are the behaviour of the staff and staff-client interactions (Orford, 1982). Other important factors include the physical layout and also the other clients availing of services; however less investigation has been undertaken about the influence of other residents (Orford 1982).

In 1972, Miller and Gwynne undertook an investigation of a number of residential settings for people with physical disabilities. In this work, detailed description of the nature of the settings is given. They contrasted two ideologies that they propose exist within residential settings, these being "warehousing" and "horticultural" ideologies.

Warehousing, as an ideology for residential settings involves emphasis on physical care needs. It highlights the medical and care needs of the individual, and emphasises dependence of residents and power or autocracy of the service providers (Miller & Gwynne, 1972).

The alternate ideology proposed by Miller and Gwynne (1972) is the horticultural ideology, whereby the emphasis is on the development and "nurturing" of the residents. The focus is on fostering service users' interests and abilities, and the style of management is less autocratic.

Miller and Gwynne (1972) highlight that there are difficulties with both types of ideology: in warehousing, residents dependence is exacerbated, and they become institutionalised, in a horticultural ideology, there is the fear of setting unrealistic expectations for service users.

In order to investigate the atmosphere in hospital wards, Moss (1974) developed the Ward Atmosphere Scale. Using this scale, his research demonstrated that the higher the "adult status" of residents, allowing them to have autonomy, be spontaneous and express their anger and frustration, the more satisfied the patients appeared to be. Autonomy, in the context of Moss' (1974) work, is described as how self-sufficient and independent patients are encouraged to be in their personal affairs, in their self-care and how much they are allowed or expected to be self-directed and take responsibility.

The work of Moss (1974), Gwynne and Miller (1972) and others highlight the effect of the institutional policies and organisation on the residents, in this case, disabled people. Different mitigating factors have been proposed to improve residential settings for disabled people, and indeed the outcomes for residents. However, the independent living movement argues that independent living is the only option that provides real autonomy for adults with physical disabilities (DeJong, 1983).

The work of Miller and Gwynne (1972) has been rejected by the disability movement and disabled people, and criticised as oppressive and demeaning (Shakespeare, 2006). Indeed non-disabled researchers investigating residential settings or the lifestyle of disabled people, when they do not espouse the values of the disability movement have been described as parasites for disabled people (Branfield, 1998).

The independent living movement, and disability organisations have long campaigned for deinstitutionalisation, including UPIAS in its 1976 paper (UPIAS, 1976). However, unlike the campaigns for deinstitutionalisation for people with other disabilities (such as those with intellectual disabilities or mental health issues), DeJong (1983) argues that people with physical disabilities are "latecomers" to the campaign, and arguments of cost savings are less easy to make for people with physical disabilities (DeJong, 1983).

Those within the independent living movement challenge the use of residential settings, suggesting that they will never promote the rights of individuals, because of the persistence of the "impaired role" (DeJong, 1983). The impaired role, according to DeJong (1983) occurs when the premise of the medical model (search for a cure) is weakened by time, and disabled (or impaired people) and the responsibilities of daily life are removed from the disabled person. This evolves into the "dependency-creating" features of institutional settings, where staff "exercise a substantial measure of social control with little outside interference... patients are encouraged to follow instructions, rules and regulations. Compliance is highly valued..." (DeJong, 1983 p. 18).

The research about residential settings, particularly that studying the social psychology of residential settings seems to have been concentrated in the 1970s and 1980s. There is very limited evidence of literature since 2000 about residential settings, particularly suggesting benefits of these settings for disabled people. While no conclusions can be

drawn from this apparent lack of literature, it does contrast sharply with the volume of literature discussing details of service provision within an independent living framework. Is it that the disability movement lobby has been so vocal that researchers are unwilling to conduct research into the impact (including potential benefits) of living in residential settings for people with physical disability?

Given that the focus of this research is on the participants' sense of choice and autonomy, investigation of whether or not they feel autonomous on a daily basis and whether those in independent living settings are more autonomous than those living in residential settings will both be issues of concern.

Independent living

> Independent Living does not imply a life led in self-sufficient isolation. It means that a person with a disability is afforded the same right to choice and self-determination within the wider community that all other adults take for granted. These choices often require that a disabled person be supported, either by assistive technology, environmental adaptation or by the physical help of another individual. It is the element of choice and the fact that it is the disabled person who chooses and directs his or her own support services, which underpins the Independent Living approach to disability.
> (Dixon, 2006, p.17)

The independent living movement began in the 1960s in the US, where groups of disabled people, including veterans of the war in Vietnam, began seeking equal civil rights (Campbell, 1996), and concurrently students with physical disabilities forming a group in Berkeley University, to campaign for equal access and less segregation (Dixon, 2006). In Ireland, Independent Living, as a movement, began in the early 1990s, with the first centre being established in 1992 (Dixon, 2006).

Independent living (IL) is described as being based upon four fundamental premises: that each life is valuable; each individual has the ability to make choices; individuals have the right to exert control in their lives, and the right of each disabled person to participate fully in society (Morris, 1993).

In the early years of the independent living movement, advocates campaigned for what were described as the eleven basic needs, these being: housing; personal assistance; mobility/transport; access; peer counselling; information; technical assistance;

employment; education and training; income/benefits and advocacy (Dixon, 2006; Gillinson et al, 2005).

Independent living centres and movements are now worldwide, e.g in Korea (Kim, 2008) China (Fisher & Jing, 2008), Japan (Yamaki & Yamazaka, 2004; Hayashi & Okuhira, 2001) and throughout the US and Europe.

As a philosophy, DeJong (1983) argues that the independent living movement is more than a campaign for rights: it also aims to "reshape" the thinking of professionals working with disabled people and disability researchers, with a view to promoting new forms of service delivery and research.

The independent living philosophy asserts that environmental barriers are "at least as critical as personal characteristics in determining disability outcomes" (DeJong 1983 p. 24). While the work of DeJong (1983) and others can be described as somewhat dated now, the key issues of environmental barriers, transport difficulties, unmet needs for personal assistance and the need to adopt patient or impairment roles remain salient within more modern IL literature.

A key feature of the independent living movement campaigns are for a broader examination of outcomes, rather than a simple focus on self-care activities, as is argued to be within the rehabilitation or residential environments (DeJong, 1983). As Zola (1983), a founder of the independent living movement states:

> "The Independent Living Movement argues that it is more important for us to have full control over our lives than over our bodies. We will give up doing some things for ourselves if we can determine when and how they are to be done."
> (Zola, 1983 p. 58).

This philosophy, and focus on multiple outcomes for individuals is reported to differ from rehabilitation, which stresses the importance of performance of self-care tasks, mobility and full employment without assistance from others.

> "Independent living emphasizes the importance of living arrangements, consumer assertiveness, outdoor mobility, and out-of-home activity. In some instances, the IL paradigm would reject the significance of self-care as an outcome. The fact that a disabled person needs more assistance from a human helper does not necessarily imply that he or she is more dependent. A person who can get dressed in fifteen minutes

> with human assistance and then be off for a day of work is more independent than the person who takes two hours to dress and then remains homebound.
> (DeJong, 1983, p. 25)

Shakespeare (2006) criticises the IL movement for focusing on autonomy and choice as outcomes, when these may not necessarily be the most important for all disabled people. While oppressive residential settings do need to be resigned to history, Shakespeare (2006) calls for a more pluralistic approach to service profision, where the individual needs and desires of the person are paramount.

Stewart (2004) suggests that there are two aspects to housing in independent living: the first being the practical "bricks and mortar", the aspects of the home environment that either enable or hinder access and use of the area. .The second, more complex aspect is the manner in which accessible homes are funded, and the potential for dependence on the welfare state. Adaptations to dwellings are expensive, and Stewart (2004) suggests that the prevalence of adapted housing within social services fosters dependence. A solution to this issue could be the improvement of building standards for accessible, life-time adaptable, inclusive building design, so that minor adaptations to promote accessibility for people with significant disabilities will not be too costly. However, many other authors (e.g. Morris, 1993; Zola, 1983 and others) have highlighted the importance of personal assistance to independent living.

The independent living movement is not simply about the physical accessibility of housing, rather more on the manner in which people live their lives, including use of personal assistance (Frieden, 1983).

Shakespeare (2006) reports that the findings about independent living and direct payments for services are generally positive, but he argues that there are disadvantages to independent living that have to be considered.

Morris (2004) argues that, while the disability movement has made progress in its aims to enable disabled people to have the right to independent living, the structure of service provision means that this is rarely a reality. Issues such as financial incentives to place disabled people in residential settings, and the lack of services to support activities other than self-care make true independent living an aspiration rather than a reality (Morris, 2004).

In a study of young people with physical disabilities, Hill (1993) found that only 38% of those studied either were or planned to live independently in the future. 35% of the young people felt that their physical disability was such that they would not be able to live without parental care within the family home. 90% of the parents interviewed stated that they did not feel that their son or daughter would be able to live independently (Hill, 1993). Hill (1993) concludes that information and a range of accommodation and personal assistance options need to be made available to people with physical disability and their parents from a young age, so that it may be possible for choices about style of living to be made.

The participants who live in the community in this study all avail of independent living services, (such as personal assistance or peer counselling), but the extent to which their living situations can be described as independent living arrangements will be interesting to investigate

Priestley (2004) differentiates true independent living from simply living in the community. He argues that independent living focuses on more than care or support at home, but should allow for true involvement in work, leisure and community activities, whereas care in the community focuses on simply providing assistance with self-care and personal needs (needs which are usually ascribed rather than self-defined).

In the current work, part of the methodology will explore the daily lives of the participants, and so the extent to which they are supported in engaging in community, work and leisure activities will be investigated. Do the participants in this study feel that the assistance that they receive, be it in the community or in residential settings meets more broader needs than simply self-care?

One critique of the manner in which assistance has been provided through independent living paradigms is that rather than clearly evaluating a service user's needs, it simply provides financial resources, and then leaves the disabled person to decide how to use these (usually less than adequate) resources in terms of support for self-care, home management and other activities (Priestley, 2004). Priestley (2004) suggests that community supports and peer counseling are also needed to support IL service users to manage their assistance requirements.

Within community care systems, the independent living philosophy has been "watered down", so that disabled people are in the situation where they need to manage situations within a social structure that still values self-care tasks over community integration (Priestley, 2004; Morris 1993). This has the effect of negating the control and independence promised by the IL movement, and a devolution of responsibility from service providers to disabled people, with the power (of resources) remaining in the welfare state model (Priestley, 2004; Morris, 1983).

The aim of independent living is held back by an ideology at the heart of community care policies, which does not recognise the civil rights of disabled people but instead considers them to be dependent people and in need of care. (1993: 38)

Another difficulty with community care systems is that community care assessors and disabled people have different purposes for assessment of need, thus communication and power relations remain with the service providers and their "view of the world" having power over the individual (Priestley, 2004).

Another, more modern concept is that of Integrated Living (e.g. Priestley, 2004), which includes the central features of independent living (such as choice for the individual), but recognizes that of central importance is that disabled people can become integrated into their community and engage in a variety of occupations of their choice.

As previously noted, the majority of the research about residential settings found in the literature was published prior to the mid 1980s. Since that time, the literature reviewed seems to strongly advocate independent living as a paradigm, and the research has seemed to focus on the barriers to independent living.

Shakespeare (2006) agrees with the independent living movement in their call for services to support disabled people that maximize choice and minimize the risk of abuse and paternalism, but he questions whether the independent living movement is the solution to these issues. He argues that independent living provides the solution when the issues are about autonomy and independence, but argues that these may not be the central concerns for all disabled people. Some disabled people may seek security and care rather than control.

The commentary of Shakespeare (2006) highlights the central issue in service provision to people with physical disabilities: that is, the meaning of and values associated with the concept of care.

Morris (1991) argues that "care" for disabled people has led to the social construction of disabled people, for example, as a burden on carers. The feminist literature, according to Morris (1991) has also led to the conceptualization of care as burdensome, negating the rights and wishes of carers, who were for the most part, women. She argues that this perception of caring did not only construct roles for women, but also for disabled people (Morris, 1991). The reaction of the feminist movement to care is to suggest communal arrangements (Shakespeare, 2006; Morris 1991), however this is not in line with the independent living movement.

Morris (1993) argues that the concept of a disabled person as necessarily dependent or helpless needs to be questioned: she distinguishes between social and physical dependence. While disabled people may need support to perform certain tasks, the key to independence is that the disabled person has control over how tasks are performed.

Shakespeare (2006) argues that a person's preference for care reflects their view of "what a good life may involve". He argues that there is equally the potential for harm within "arrangements based on autonomy and individualism" as there is in residential settings. He suggests that the more restrictive forms of housing and care, such as residential settings, do have some advantages: they are likely to provide the individual with more social contact, security and less responsibility.

The preference of the person, and their construction of an ideal life appears to be almost absent from the independent living literature, where IL is seen as a right, and should be available to all. The arguments of Shakespeare (2006) appear to be the exception to this, and present the possible advantages of residential settings. These views seem to mirror psychological studies, such as the work of O'Connor and Vallerand on nursing home residents, which found that there needs to be a person-environment fit between the amount of choice and control allowed in the environment, and the person's desire for choice and control.

A review of the literature does suggest that in the past two decades, research has focused on aspects of independent living, and very little work has been done in relation to residential settings. The current study recruits participants who live in the community and who live in residential settings, and so their satisfaction with their living arrangements and an exploration of what each option offers the individual will be interesting.

Occupational Therapy and Independent Living

This section aims to compare and contrast some of the occupational therapy literature with that of the disability activists and the independent living movement. While much of the literature about health professionals within the disability literature is quite negative (Shakespeare, 2006; Kielhofner, 2005; Abberley 1995), it is thought helpful to reflect firstly on why this is so, and secondly whether there is or could be a more positive future for Occupational Therapy (OT) as a profession.

Models of practice within occupational therapy have previously been presented (see section 3.2.3, and while the different models presented (PEO, MOHO and CMOP) do seem to vary in focus, it can be concluded from more recent occupational therapy theory, that the profession is moving more towards a social basis of intervention. (Kielhofner, 2005)

Kielhofner (2005) states that disability studies scholars challenge occupational therapists to re-consider practice, education and research with a view to becoming more aligned with social model ideals. However, there is much evidence that in its history, occupational therapy has worked very much within a rehabilitation framework.

Literature both within occupational therapy and outside, for example in disability studies, paints a very different picture in terms of practice. A brief review of the contents of core Occupational Therapy journals over the last five years has shown a preponderance of articles focusing on impairment and practice to cause change in people, rather than addressing societal barriers. Even a "Special edition" of the American Journal of Occupational Therapy on Disability Studies and Occupational Therapy (2005 volume 5) includes work on specific impairments and for the most part seems to fail to address key

questions of whether or not occupational therapy, at its essence perpetuates oppression or helps to dismantle the barriers to inclusion faced by disabled people.

The purpose of this section is not specifically to critique occupational therapy, merely to provide a backdrop of challenging and contradictory influences that have occurred in the context of this study. As will be described in the methodology chapter, the researcher was influenced by research and theory within occupational therapy, and so exploration of this is pertinent at this point.

In 1993, the American Occupational Therapy Association (AOTA) produced a position paper about Occupational Therapy and Independent Living. In this, it was suggested that the two philosophies run parallel, and that the aims are concordant. However, on deeper examination of this position paper, it seems that the AOTA do not go anywhere as far as the IL movement in describing the importance of rights and choice. AOTA (1993) seem not to have fully embraced social model ideals, nor positioned the disabled person as the expert in intervention (Taylor, 1999).

Abberley (1995) undertook a study of occupational therapists' practice with disabled people, whereby therapists were asked about the nature of intervention, what formed success and failure and the pressures on the professional. His general conclusion was that the manner in which occupational therapy services are provided is likely to disempower disabled people (Abberley 1995; 2004).

Abberley (1995) argues that occupational therapy's philosophy relates to a concept of independence related to doing alone (see section 3.8 later in this chapter for a discussion of concepts of independence). Are these assertions valid?

In a study of student occupational therapists' perceptions of independence and empowerment (Taylor 2001), it was found that definitions of independence (doing alone or having choice) can act as a potential source of conflict between the disabled person and the occupational therapist. Taylor (1999; 2001) cites much literature within occupational therapy that supports the view that occupational therapy focuses on a "doing alone" or functional concept of independence. However, as is noted by Taylor (2001), there is also literature that supports a more social, client centred view of disability.

In Taylor's (2001) study, she investigated the development of students' ideas about independence throughout their occupational therapy education, hypothesising that in the beginning, a "doing alone" attitude to independence would prevail for most students. This appears to have been the case, with students describing functional aspects of independence for potential clients. A striking feature of Taylor's (2001) results is that occupational therapy students described their rationale for action with potential clients as helping the clients to behave "normally". Taylor (2001) found that there was progression in thinking throughout the three years, with most of the students showing some flexibility and client-centredness in their thinking by the end of their studies. However, two of the student group (of 10) still were somewhat rigid in their thinking and promotion of normalising, function-centred rehabilitation practice.

As Taylor (2001) highlights, the responses of some of the students in her study could be seen as an indictment of occupational therapy education. Despite rich and laudable values and theory including client-centred practice and social ideals, some students were unable to express these ideals, and some retained functional values for much of their occupational therapy education.

The work of Taylor (1999; 2001) seems to justify Abberley's (2004) claim that occupational therapy can be disempowering. In his study, Abberley (1995; 2004) argues that the structure within which occupational therapists work, and the manner in which intervention is evaluated puts pressure on therapists to intervene in a way that disempowers clients. He states that even occupational therapists who do not wholeheartedly endorse self-sufficient ideals justify their work and maintain their professional status through promoting functional rehabilitation (Abberley 2004).

Assessment has also been described as oppressive (Gillman, 2004), primarily because the therapist decides on what will constitute assessment, and typically assessment focuses on function and impairment.

Kielhofner (2005) suggests that a major barrier to occupational therapists truly engaging with disability studies is that interventions, such as the elimination of social barriers may not be feasible, nor may this work be paid for.

Abberley (2004) and others within the disability activist literature argue that therapists view their assessment and intervention as based on an objective reality, and that if goals of intervention include changing the client's perception of their situation, or modifying "unrealistic" expectations, then this can be oppressive practice. Kielhofner (2005) also highlights the importance to occupational therapists of understanding the impact of their interventions on clients' perceptions – when there is a concentration on rehabilitation, this can affect a person's self-image, and identity as a disabled person, thus leading to oppression.

Abberley (2004) concludes that, in the context of disability, the "caring professions", including occupational therapy should either be abolished or should work towards a more collaborative relationship with service users, otherwise the oppression of disabled people will be perpetuated.

Kielhofner (2005) calls for the profession to become more reflective in its work, integrating the work of disability studies scholars more into practice, education and research. He highlights a number of aspects of contemporary practice and research that embrace disability studies. These include client centred practice, and the research focus on narrative and case-study approaches to understand the lived experience of disabled people.

Client-centred practice has been a theme within occupational therapy for over a decade, originally based on Rogerian psychology, it has been articulated by Law (1998) and others. Kielhofner (2005) suggests that one way that occupational therapists can engage with the disability movement, and change practice to adopt more social model ideals is by engaging in client-centred practice.

Another force within the occupational therapy practice is the need to seek evidence to support practice (Holm, 2000), and to evaluate outcomes of intervention. The outcomes of practice are frequently defined by the occupational therapist, rather than the disabled person (Abberley, 2004). Thus, what defines "successful" practice and "failures" are dependent on therapist, not client perceptions.

Shakespeare (2006) suggests that the disability movement needs to become allies with professional service providers, including therapists. He too, highlights the negativity within

the disability literature towards professional practice, but suggests that this, in some cases, is unwarranted.

While it is clear that occupational therapy practice, in particular, has many challenges ahead to enable it to empower rather than oppress disabled people, there is grounding within its theory, emerging areas of research and education practices that can promote disability activist ideals.

The paradox within occupational therapy seems to be that while the theory does approach a social model approach to intervention, practice seems not to reflect this theory. The challenge for occupational therapists, researchers, educators and theorists is now to translate those ideals into practice. This research seeks to understand aspects of occupational therapy and psychological theory (namely choice and autonomy) for people with physical disabilities, and it is hoped that the information gleaned will help to guide future work to improve practice and education.

As the core feature of occupational therapy is its focus on occupation (as described in section 3.3 in this chapter), the next three sections will review literature that seeks to understand, from both a medical / rehabilitative background and a rights perspective, the reality of daily self-care, productivity and leisure occupations.

Self-care occupations

As described in section 3.3, self-care occupations are those needed to maintain health (CAOT, 1997), and frequently include washing, dressing, grooming, bathing, toileting, functional transfers, functional mobility and feeding. Instrumental activities of daily living, or instrumental self-care tasks may also be included, such as budgeting/money management, shopping, household activities etc.

There is a range of published studies outlining the effect of particular disabilities on self-care task performance, such as those assessed using the Functional Independence measure or Barthel Index (Grimby et al, 1996; Judge et al, 1996). There appear to be a very large number of such studies, so a review of these is considered beyond the scope of this work. However, it is noted that when function is assessed in terms of ability to

perform self-care activities alone, there appears to be consensus that different conditions result in varying levels of disability. Also in the literature are a number of studies examining methods to improve self-care function.

Other studies have highlighted the importance of assistive technology and equipment (Mann et al, 1995; McDonald et al, 1996) and personal assistance in enabling people with physical disabilities to engage in daily occupations. For example, Hagglund et al (2004) highlight the importance of personal assistant services to support people with physical disabilities. The use of personal assistants was found to enable people to engage in education, work, and participate in social events. This participation, enabled by personal assistance, means that people with disabilities can become included in the social community (Hagglund et al, 2004), already described as having an important impact on well-being in general. Despite the recognition that personal assistants are central to a disabled person's participation, it appears that financial pressures create difficulties in the provision of such services (Hagglund et al, 2004; ERHA, 2003).

A study of how women with physical disabilities adapt to disability emphasised the importance of habit formation in enabling them to engage in daily occupations (Macdonald, 2002). The study found that the formation of habits, through practice, repetition and reinforcement, enabled occupational integration, i.e. the patterning of different occupations in daily life (Macdonald, 2002).

Personal Assistance

Adults with significant physical disability are likely to require assistance with activities of daily living, thus, a review of literature about personal assistance is considered relevant.

The nature of the provision of personal assistance is central to independent living philosophy, and differs from a medical-type approach of either working with an individual to improve self-sufficiency in self-care tasks, or provision of assistance organised by non-disabled professionals. Within the independent living philosophy of personal assistance, the central tenet is that the disabled person is the "leader"; he or she controls and chooses the nature of assistance provided.

There has been some investigation of the effects of personal assistance schemes in Ireland, including a survey undertaken by the National Disability Authority and a review of the PA service in Ireland (Murphy et al, 2006). In Japan, a study investigated the relationship between users of personal assistance schemes and their assistants, reporting that relationships had functional, interpersonal and collective dimensions (Yamaki & Yamazaki, 2004). This suggests that while assistance is necessarily task-focused (functional dimension), the relationship is also similar to that of employer-employee (interpersonal).

The role and exact activities performed by a personal assistant are also discussed; those within the independent living movement suggest that assistance should be entirely directed by the individual, and anything less is oppression – this argument is highlighted by Batavia (2001), who reports that some advocates call for personal assistants to perform any tasks, including being able to assist with suicide.

O'Shea and Kennelly (1996) discuss ethical and cost-effectiveness of personal assistant services, in relation to whether or not these services can have an economic benefit in terms of enabling disabled people to enter education or employment. They attempt to discuss a framework whereby issues of efficiency and cost-effectiveness of personal assistance schemes can be discussed and evaluated (O'Shea & Kennelly, 1996).

The key question in relation to personal assistance, or other assistance appears to concern the choice or control that the individual disabled person has.

A survey of 93 disabled people in receipt of rehabilitation services in Southern England found that they reported unmet needs, most commonly for adaptations to their homes, equipment, physiotherapy and wheelchairs, rather than for other services to support their participation in intellectual or social activities (Kersten et al, 2000). The authors conclude that, despite the participants being engaged with social services, they still had basic unmet needs, and that if these needs were met, participants may then be more able to participate in a wide variety of activities and be more fulfilled in other areas of their lives (Kersten et al, 2000).

In terms of the type of support provided to severely physically disabled people, one study found that the nature and quantity of the assistance varied across and within diagnostic

groups, and that the assistance provided could not be related directly to need (Phillips, 1995). This finding, it is argued, suggests that there is a need to systematically review the provision of services to support people with physical disabilities with self-care activities, with a view to promoting equity (Phillips, 1995).

Another study into service provision for young people with physical disabilities in London found that the level of service did not necessarily correlate with need for services (Doyle et al, 1994) In both Phillips' (1995) study and that of Doyle et al (1994) it was found that the majority of participants were living with informal care-givers, who were supplementing the support for personal self-care activities provided by the state.

Helgoy et al (2003) report the findings of a study examining service provision for physically disabled people in Norway, which involved interviews with disabled people and service providers. This study found that service providers appear to categorise individuals in terms of their independence, and disabled people assume roles in interactions with service providers. These roles and categories may impact the nature and quantity of assistance provided (Helgoy et al, 2003).

There are a number of different methods of organising personal assistance services used throughout the world (e.g. Gillinson et al, 2005; Murphy et al, 2006; Barron, 2001; Priestley et al, 2007). In Ireland, personal assistance schemes are provided through service providers, rather than the direct payment scheme used in other countries (Murphy et al, 2006). This approach has been criticised as not being as true to the central values of independent living, but that it also does mean less management for the individual leaders (Murphy et al, 2006).

In the UK, the system of direct payments came into force in 1996, but a national review has shown limited and uneven take-up of these services (Priestley, 2007). One study that investigated users' satisfaction with a system of direct payments for personal assistance services found that users experienced a broad range of benefits, including increased self-esteem and control and greater opportunities for engagement in vocational and lifestyle activities (Stainton & Boyce, 2004). Another study found that those in receipt of direct payments also availed of health services (such as physiotherapy, chiropody and wound dressings) from their payments, rather than simply using them for personal assistance (Glendinning et al, 2000). As with reports from other work, (e.g. Stainton & Boyce, 2004;

Doyle, 1995), it was found that those recipients of direct payments reported more independence over their lives, and wanted to have the flexibility to avail of the wide range of services (Glendinning et al, 2000).

Productivity / Work

All of the participants in this study are adults with physical disabilities who are of working age. Whether or not the participants engage in paid or unpaid work will be sought through diary information, so it is felt important to examine the literature about work for adults with physical disabilities.

It is widely recognised that disabled people have fewer opportunities for employment, that disabled people experience ongoing barriers to work, and that the proportions of disabled people working is lower than the proportion of non-disabled people of working age in employment (Johnstone, 2001; Roulstone, 2004; Hurstfield, 2004; Fitzgerald, 2005; Gannon & Nolan, 2004; Gannon & Nolan, 2005).

According to Roulstone (2004), in the UK, 47% of people of working age with a disability were in employment, compared to 87% of the general population. Of the disabled people who were economically inactive, it is reported that 33% said that they would like to work, if they had the opportunity. It is also highlighted that disabled people are more likely to be in the lower three social classes, working part-time or self-employed than non-disabled people (Roulstone, 2004).

Fitzgerald (2005) outlines the statistics of disabled people in employment in Ireland, highlighting that disabled people are less likely to be in employment than their non-disabled peers, across all age-groups above the age of 20, and for both genders, and also the more significant the disability, the less likely they are to work. The difference is quantified as disabled people are 2.5 times less likely to be in employment in Ireland than non-disabled people. Of those not employed, it is reported that most state that they are unable to work rather than unemployed. Of those who specified that they have difficulty with working, 87% state that they are not working, but disabled people who do not describe themselves as having difficulties in work situations are also less likely to be employed when compared with non-disabled people (Fitzgerald, 2005).

In terms of differences in employment of people with different disabilities, it is reported that only 16% of people who have difficulty "dressing, bathing or getting around inside the home" are employed (Fitzgerald, 2005 p.14). There is no reported difference in the type of work undertaken by disabled people when compared with non-disabled people (Fitzgerald, 2005), but this finding requires further investigation, particularly for people with significant physical disabilities, as it may be unlikely that these would work in construction, for example.

Even when disabled people are in employment, it is reported that they earn less, on average, when compared to non-disabled people (Gannon & Nolan, 2005). No explanation is given for this finding. The findings of Roulestone (2004) that disabled people are more likely to be self-employed or work part time are replicated in Ireland (Gannon & Nolan, 2004).

It is argued that restriction in employment opportunities are a follow-on from the protectiveness of previous medical model approaches to disability (Johnstone, 2001). Prior to 1944, in the UK, disability was assumed to mean non-employability, which may have been partly due to the nature of industrial jobs (Roulstone, 2004). Following the war, there was an Act of Parliament, which brought in the 3% quota (Roulstone, 2004), which is still in existence in countries outside the UK, such as Ireland, within the Disability Act (2005). This quota suggests that 3% of the public sector workforce should be disabled people.

Negative attitudes of employers can be one factor that reduces the opportunities for disabled people to gain employment, including an undifferentiated view of disabled people, as all being the same, and unemployable (Roulstone, 2004). This attitudinal barrier in the present time is argued to constitute oppression (Johnstone, 2001). In conjunction with attitudinal barriers, there are also difficulties with the physical environment, rendering buildings inaccessible to people with physical disability, providing an additional hurdle that limits the opportunities for disabled people to participate in employment (Roulstone, 2004). Evidence suggests that people with visible disabilities are more likely to experience negative reactions to their job applications (Roulstone, 2004).

Disabled people who are highly educated have been found to be more likely to be employed (Johnstone, 2001), but barriers to education exist. A person with a physical disability is less likely to have been in formal, valued education or training (Roulstone, 2004). Martin (2005) reports that there are supports available for people with physical disabilities in education and training, but that these supports are no longer available when people enter the workforce.

It is reported that equality and disability legislation have made a positive difference to disabled people's opportunity for employment (Roulstone, 2004). In Ireland, the Employment Equality Act (1998) requires that employers make "reasonable accommodation" for persons with disabilities; a similar facet exists within legislation in other countries, such as the Disability Discrimination Act (DDA, 1995) in the UK. The Irish Disability Act (2005) also requires all public bodies to make buildings accessible for persons with disabilities. A review of the UK legislation found that barriers still exist, and that there needs to be more work to enable legislation to be more effective, and to examine other non-legislative supports for disabled people in work (Hurstfield, 2004).

Under Irish law (Employment Equality Act, 1998 – 2004), it is against the law to discriminate against a person due to their disability. Murphy and O'Leary (2005) report that there are only a limited number of cases being brought by disabled people for discrimination on the grounds of disability. These cases have included issues with physical access, and it is reported that people with physical disabilities are more likely to take a case of discrimination than people with mental health or intellectual disabilities (Murphy & O'Leary, 2005).

In an English study by Doyle et al (1994), it was found that only a small proportion of those with physical disabilities were employed, even though over half had undertaken formal education and examinations. Few of the participants in the study had received career advice, and those from different ethnic backgrounds felt that the combination of disability, poverty and ethnic background greatly reduced their opportunities to gain paid employment or be fully included in their wider community (Doyle et al, 1994).

One barrier that makes employment difficult for people with significant disabilities in Ireland is the lack of a formal structure whereby workplace-based personal assistants can be provided (Martin, 2005). Martin (2005) highlights that people with physical disabilities

experience additional costs associated with working when compared to non-disabled people, such as increased transport costs, and state benefits such as the Disability Allowance are withdrawn, thus, he argues, the financial benefits of working are significantly less for people with physical disabilities when compared with non-disabled people.

Martin (2005) undertook a study to examine workplace-based personal assistance schemes that are available for people with physical disability. He highlights that there is no formal system of personal assistance in the workplace for people with physical disabilities, and that FAS and the Department of Enterprise, Trade and Employment state that personal assistance is a health issue, and the Department of health and Children state that it is a work issue. He reports that some people and their employers have used other sources of funding, such as the Employment Support Grant (which is generally used to compensate employers for reduced productivity of disabled staff) as a means to employ personal assistance, but he criticises the lack of formal provision of this service (Martin, 2005). He recommends that the Irish Government look to best practice in the UK and Sweden, where personal assistance is available to people in the workplace (Martin, 2005).

Despite Martin's (2005) call to replicate services in the UK, it appears that issues of equity of opportunity in employment exist in countries with better practice, as already outlined. Danieli and Wheeler (2006) argue that a fundamental change in policy is needed, in line with the independent living movement's ethos and values to promote work opportunities for disabled people. Another study also suggests that the single most important factor that will enable a person with a significant physical disability to work is the availability of personal assistance in the workplace (Nosek & Foley, 1995).

Ville and Winance (2006) investigated the chronology of processes which affected people with "severe motor disability" to employment. The study used interviews to understand the decisions made by participants, their subsequent actions and the consequences and feelings following decisions and actions. It was found that there was significant diversity in the chronologies of events and decisions that have resulted in participants either working or not working (Ville & Winance, 2006). The study reports ongoing barriers to employment experienced by disabled people, and it is suggested that rather than simply considering whether or not a person works, it is more important to understand the meaning of or reasons behind the situation for that person.

Barnes and Mercer (2005) also highlight the importance of understanding the meaning of employment for people with disabilities. They argue that the analyses of social policy and employment trends undertaken have been superficial in that they have not focused in enough depth on the social and environmental barriers experienced by disabled people (Barnes & Mercer, 2005).

The impact of working for disabled people has also been studied. For example, in one study, it was found that an increase in time spent working resulted in less time spent in household chores for people with systemic sclerosis (Sandqvist & Eklund, 2008). Those who spent more time working reported greater satisfaction with daily activities and a greater sense of well-being; thus the authors conclude that work is an important factor in promoting life satisfaction and well-being for this group (Sandqvist & Eklund, 2008).

Leisure

Apart from work, it appears that participation in other occupations may be somewhat restricted for people with disabilities. Disabled people's opportunity to participate in general leisure activities is reduced by many factors; economic, environmental and cultural (Carr, 2004).

There appear to be a variety of studies examining leisure participation, particularly physical activity, for people with specific conditions, such as cerebral palsy (Maher et al, 2007), spinal cord injury (Beringer, 2004; O'Brien et al, 2008), multiple sclerosis, stroke and arthritis (Gignac, 2003). There are a number of studies that investigate the impact of physical exercise on specific conditions, and studies to establish the validity and reliability of the PADS assessment (the physical activity and disability survey) as a measure of physical activity in people who have physical disabilities (Rimmer et al, 2001). These studies, for the most part, are beyond the scope of this review, which simply aims to highlight research investigating leisure participation in more general terms for people with physical disability.

Rimmer et al (1999) investigated the levels of physical activity and exercise in African-American women with physical disabilities, using the PADS measure. They found very low levels of physical activity, with only 8.2% of the participants taking part in physical leisure activities, and 10% taking part in any aerobic exercise three or more times per

week (Rimmer et al, 1999). They conclude that this lack of physical activity in leisure time poses an increased risk of secondary medical conditions for the sample. Further discussion of secondary health issues is included in section 3.8.2 of this chapter.

Maher et al (2007) investigated the leisure habits of adolescents with cerebral palsy, and found that the physical activity levels of those with cerebral palsy were related to their level of "gross motor function", and declined with age. Their level of participation in physical activities was generally lower than the population levels, and the type of physical activity was different, being less structured and less intense for those with cerebral palsy. There was no significant difference in the level of non-physical lesure activities, such as watching television and playing computer games (Maher et al, 2007).

In a study of people following stroke, it was found that the quality and quantity of participation in activity outside their home, particularly leisure activities, decreased following stroke (Trigg et al, 1999). This reduction in participation had negative impacts on the participants' social interaction (Trigg et al, 1999), which has been described as a key factor in determining quality of life and well-being (e.g. Albrecht & Devlieger, 1999; Alaszewski et al. 2006).

A small study to establish the extent to which young adults with physical disability engage in occupations outside a long-stay residential setting in Dublin found that the levels of participation were lower than those found for the general population, particularly participation in the arts (Collins & Leonard, 2002). The five activities performed by the largest number of residents in the sample in the year prior to data collection were shopping (81%), eating out (62%), cinema (47%), going to a pub (24%) and going on holidays (14%) (Collins, 2001). It was found that most of these outings were organised by the hospital staff, for example, only 9% of the sample went to the cinema on a trip other than an organised outing with a number of residents and volunteers or hospital staff, and that 48% of the participants had been shopping only on an organised hospital outing. It was found that the levels of satisfaction with the level of participation in activities outside the hospital was not necessarily related to performance, that the lowest levels of satisfaction were found in those who have a moderate level of participation (Collins, 2001; Collins & Leonard, 2002). The participants were most dissatisfied that they did not have the opportunity to go on holidays; to the cinema; to art galleries, museums or exhibitions; engage in work or training and to go shopping (Collins, 2001). This study found that the factors that residents felt limited their occupational performance included transport; their

own motivation; money; a person to accompany the resident and physical access (Collins, 2001).

One study found that participation in leisure following a spinal cord injury assisted in the individual's rehabilitation, including their functional independence, quality of life and community integration (Beringer, 2004). Another study found that participation in leisure had positive effects on mental health of men with physical disability, but that level of depression was "predictive" of leisure activities, thus those that were depressed participated in fewer leisure activities (Elliott, 1995). Another study investigating participation in physical activity of people with arthritis also found that it increased well-being, when the activity was appropriate for the individual (Gignac, 2003). It has also been found that participation in and satisfaction with leisure activities is the most important single factor that promotes well-being of adults with physical disabilities (Kinney & Coyle, 1992).

Other studies have focused on the experience or meaning of leisure participation, rather than any effects that it has on the individual's health or well-being. Henderson and Bedini (1995) undertook detailed qualititative interviews with women with mobility impairments to explore the meaning of physical activity for them. They found that the meanings of the physical activity included participation as leisure, as therapy, as a means to maintain their physical abilities, or that it had little value (Henderson & Bedini, 1995). Henderson and Bedini (1995) also found that the factors that mediated participation included: pain and energy levels; the availability of transport (or lack thereof); social fears; social support, and access issues.

There have been a number of studies investigating ways to improve leisure participation (including physical activity) for people with physical disabilities. Spivock et al (2008) investigated whether there is an association between environmental supports for adults with physical disabilities to participate in leisure (such as accessible and adapted facilities) and actual levels of leisure performance (Spivock et al, 2008). This study found that leisure participation was significantly higher when there were "environmental buoys", or accessible facilities, but that further analysis found that the presence or absence of transport was not significant (Spivock et al, 2008).

White and colleagues (1995) undertook a small study to investigate whether improved access / egress within the homes of people with physical disabilities improved their level of participation in community activities. Two-thirds of the participants reported an increase in the frequency of outings into the community, but the scale of the study, and other environmental barriers may make conclusions difficult. Nevertheless, it appears that facilitating home access and egress could be an important aspect of facilitating leisure activities for some adults with physical disabilities.

In terms of non-physical activities, one study found that the presence of a mentor, (a person with a physical disability) enabled young people with physical disabilities to participate in community activities, and that those provided with a mentor reported higher self-efficacy, community knowledge and confidence compared to a control group who were not provided with a mentor (Powers et al, 1995). The study also found that parents of those with a mentor reported that they believed that their young adults with physical disability were more confident than did the parents of those who did not have a mentor (Powers et al, 1995).

Thus the literature on leisure participation seems to suggest that: a) participation in leisure has a number of health and social benefits; b) people with physical disabilities have been found to participate less in physical leisure (exercise), and, c) that environmental support (including accessibility and mentoring) can facilitate leisure participation.

Independence

Independence is often a concern for disabled people, and the perceptions of what makes an individual "independent" are based within the model or view of disability (Goble, 2004). Given that independence and autonomy are intertwined, a review of intormation about independence is necessary.

Reindal, (1999 p 353) expresses difference in the views of independence:

> "Professionals tend to define independence in terms of self-care activities. So, independence is measured against skills in relation to performance of these activities. Disabled people however, define independence as an ability to be in control of and make decisions about one's life. Independence is then not linked to doing things alone or without help, but by obtaining assistance when and how one requires it"

Apart from the difference between independence as control, or choice over the environment (reflecting a social model of disability), and independence as competence, or doing alone (reflecting a medical model of disability), there are additional, more complex theories or models of independence found within the literature. These are described in this section.

One limitation found within the literature is that independence and dependence are rarely defined clearly (Gignac & Cott, 1998; Nosek & Fuhrer, 1992a). This lack of a clear definition has hampered the development of services to support the independence of disabled people (Nosek & Fuhrer, 1992a) and has also led to the production of many assessment tools that focus on physical and cognitive abilities, rather than other issues, such as environmental barriers (Nosek & Fuhrer, 1992a). This specific focus on physical and cognitive function has led to a reduction in the quality of life of individuals with physical disability (Nosek & Fuhrer, 1992a).

Gignac and Cott (1998) state that within the literature, Independence and dependence are treated as antonyms; with independence being universally desirable and dependence being a negative consequence of disability. The different frameworks provide for very different concepts of independence.

> "By definition, a person with a physical disability lacks adequate tools for certain physical behaviors, but there is no necessary relationship between those missing or impaired physical tools and the ability to meet the demands of higher social, psychological, and cognitive tasks"
> (Kerr & Meyerson, 1987, p. 175).

Independence as autonomy and competence

In occupational therapy literature, independence, of disabled people, has been described as consisting of a mixture of autonomy and competence (Rogers, 1982). For a disabled person to be classed as "independent" there is a need for a level of physical, cognitive and affective competence as well as the ability to decide, or autonomy.

It has been argued that, in the past, there was an over-emphasis on the importance of competence when describing an individual's independence. More recently, it has been recognised that the physical or cognitive ability to do is not enough to enable a person to

be independent; the person needs to be able to decide what they want to do as well as physically do it (Rogers, 1982).

This concept of independence comprising of autonomy (choice) and competence is evident in a number of occupational therapy frameworks. It appears to straddle the medical and social model views, that a person is independent if they can have choice or control over the environment and that they are independent if they can perform tasks alone.

Independence as self-reliance, or doing alone

Certain service providers appear to view independence as Reindal (1999) describes, in terms of abilities to perform self-care tasks alone, or without assistance. In some settings, the approach to promoting independence is to improve competence in self-care tasks so that disabled people can do tasks without assistance. Although this approach is widely criticised from within the disability movement, (e.g. Oliver, 1996; Goble, 2004) it appears to pervade health service provision.

A number of measures of independence, such as the Functional Independence Measure (FIM) are used to rate a person's independence, in their ability to perform self-care and mobility tasks without assistance. In the FIM, for example, a person is rated as less independent if assistive devices are used to perform tasks, and even less independent with increases in the amount of support or assistance required. It is assumed that independence, for these measures, refers to doing alone, or self-reliance.

Several authors have criticised this "professional" approach to independence (e.g. Goble, 2004; Nosek & Fuhrer, 1992a; 1992b; Oliver 1990 etc). Goble (2004) describes the professional view of independence as being central to the professional's approach to the individual; their aim is to improve "independence" by using assessments and technical skills so that an individual can approximate "normality" in the performance of specific tasks.

It is argued that, for a person with significant physical disability, physical competence may be irrelevant to the individual's definition of their independence (Wilkerson, 1982 as cited

in Nosek & Fuhrer, 1998). Thus, within the disability movement, a different definition of independence, not related to physical ability has been created.

Independence as control

> "Independence does not refer to someone who can do everything themselves, a feat that no human being can achieve whether they have an impairment or not, but indicates someone who is able to take control of their own life and to choose how that life is to be led It is a thought process not contingent on physical abilities."
> (Barnes, 1994, p. 129 as cited in Johnstone, 2001, p. 62).

Within the Independent Living Movement, Independence has been re-defined, to focus on a person's choice and control of their environment. As Reindal (1999) describes, within this formulation of independence, the emphasis is not on doing alone, but on having the control and choice to seek assistance when and how a person wants it.

"Independent Living is a philosophy and a movement of disabled people who work for equal rights and equal opportunities, self-respect and self-determination" (Ratzka, as cited in Gillinson et al, 2005 p.17). Independent living is based on four principles, these being: that every person's life is equally valuable; that everyone can exert choice; that people disabled by society have the right to control their lives and that disabled people have the right to participate fully in society (Gillinson et al, 2005).

Thus, from an independent living perspective, a person is independent if they have the opportunity to exert choice, control their lives and participate as fully as they wish in society. The factors that render a person not independent relate to a physical environment that does not support this choice, control and participation.

The independence described by the movement requires 12 pillars, or supports, these being: full access to the environment; an accessible transport system; technical aids and equipment; accessible housing; personal assistance; inclusive education and training; an adequate income; equal opportunities for employment; accessible information; advocacy; peer counseling and appropriate and accessible health care (Gillinson et al, 2005 p. 21). These supports are the practical aspects of the environment that will enable a person to participate in society, to control their life, to exert choice and to feel valued, thus enable independence.

The difference in definition between professionals, concerned with functional ability, and disabled people, concerned with control and the ability to make choices, has resulted in continuous conflict with respect to service priorities (Nosek & Fuhrer, 1992a). Disabled people, particularly within the Independent Living Movement, have called for changes in policies so that choice and control are emphasised, thus meaning that daily tasks can be performed with assistance so that energy can be used performing occupations that are truly interesting or worthwhile to the individual.

Nosek & Fuhrer's (1992) model

Nosek and Fuhrer (1992a) describe creating a theoretical construct to describe independence coupled with an assessment tool to evaluate an individual's independence (1992b). This tool is known as the PIP (Personal Independence Profile). The purpose of developing the PIP, according to Nosek and Fuhrer (1992a) was to create a measure that comprehensively and concisely assesses psychological, social, functional and environmental constructs of independence for people with a wide variety of disabilities. The hope is that the PIP will form part of service planning and delivery that are specific to the needs of individuals (Nosek & Fuhrer, 1992a).

In previous research cited by Nosek and Fuhrer (1992a), it is reported that the physical abilities of people with orthopaedic disabilities were not significantly related to their level of what the authors describe as psychological and social independence. The research found that psychological factors, particularly being able to control the environment were important determinants of a person's productivity, social engagement and independence. Based on this previous research, Nosek and Fuhrer (1992a) conclude that physical ability is not related to social independence. The difficulty with their argument is, however, the lack of a very clear definition of independence – it appears that the construct being described is similar to self-governance autonomy, and is described as independence based on the Independent Living Movement's definition.

The model presented by Nosek and Fuhrer (1992a) is described as being based on the independent living approach to independence. Four essential components of independence are described in the model, these being: perceived control of one's life; psychological self-reliance; environmental resources, and, physical functioning.

In their model, perceived control relates to the ability to make decisions and act to achieve desireable outcomes, and includes self-control and control of the environment. The self-control aspect includes aspects of competence (as described by Haworth (1986), cited in Nosek & Fuhrer, 1992a) and self-efficacy. The environmental control relates to concepts such as locus of control. The model describes control being enabled when a situation is predictable and when the individual has the information to enable them to plan for future events.

The psychological self-reliance construct relates to the ability of the person to make decisions, be emotionally autonomous, confident and cope with varying situations. This construct, within the model, appears to draw on a number of seemingly different areas, such as ego-integrity, assertiveness and decision-making. It is described as the psychological or "instrumental" aspect of performance, including the ability to manage different new situations.

The physical functioning aspect of the model is possibly more straightforward; it consists of the ability to perform tasks alone, such as moving around, self-care activities and processing sensory information.

The environmental factors part of the model includes all physical and social elements external to the person that can either help or hinder the person's performance. An important part of the model is the individual's perception of the resources available, the perception of resources is more important than the actual availability or non-availability of resources.

Psychological self-reliance is used to engage or use environmental resources to support impairment in physical functioning. The component of control has been found to be the least related to physical functioning, but has the greatest influence on a person's eventual level of independence (Nosek & Fuhrer, 1992b).

This model is reported to be based on the independent living philosophy of independence, but broadens it significantly, including physical function, environmental resources and psychological self-reliance in addition to concepts of control. It is also more detailed than the "professional", or independence as competence framework, although it includes these components as well. It also includes aspects of Rogers' (1982) framework, where

independence is viewed as autonomy and competence – the autonomy aspect appears to mirror both the psychological self-reliance and control dimensions, and competence the physical function component of Nosek and Fuhrer's model.

There is also empirical evidence supporting the model, which was used to develop a comprehensive assessment of independence (the PIP) (Nosek & Fuhrer, 1992b). This assessment method is significantly different from the traditional "professional" approach, which focuses solely on physical functioning. The results of a study using the model and PIP assessment are described in later sections of this review.

Gignac & Cott's (1998) model

Gignac and Cott (1998) identify a difficulty within the literature surrounding independence, this being the lack of a clear definition of what independence actually is.

Gignac and Cott (1998) describe a difference between physical independence and dependence, in that they are separate and "multiply determined constructs". The same person, within this model, can be "independent", "dependent", "not independent" or experience "imposed dependence" in different situations. This model describes "physical independence", although the authors recognise that there is also the potential for what they describe as psychological, behavioural and social independence (Gignac & Cott, 1998).

The different aspects of independence / dependence described in this model relate to assistance required by and provided to the individual to perform specific tasks.

According to this model, a person is "independent" if they do not need assistance and they do not receive assistance; they experience "imposed dependence" if they do not need assistance, but receive it; they are "not independent" if they need assistance but do not receive it; and are "dependent" if they need assistance and receive it (Gignac & Cott, 1998).

These descriptions of independence and dependence differ greatly from those in Nosek and Fuhrer's (1992a) model, and as conceptualised within the Independent Living Movement; they more closely relate to the professional view, of independence meaning competence.

There are, according to Gignac and Cott (1998), factors that determine whether or not a person will be independent, not independent, dependent or experience imposed dependence. These factors relate to different domains of disability, the subjective perceptions of the individual, demographics, the environment, personal resources and the nature of the assistive relationship.

The domains of disability described refer to different occupational performance areas, such as self-care, mobility, household tasks, community mobility, valued activities, caregiving of others and employment.

The model suggests that people respond to external situations, and actively affect their own independence or dependence. It states that independence and dependence is more than the need for and receipt of assistance, as it depends on the type of task involved and the person's perceptions of these tasks in relation to whether or not they believe that they need assistance. The model also includes discussion of the nature of independence.

Gignac and Cott (1998) suggest that some domains of disability are more important from an independence/dependence perspective. One such example given by the authors is personal self-care, as it is not feasible for a person to be "not independent", because the task is essential, so if a person requires assistance, they must receive it. It is also stated that due to the personal nature of the tasks, it is unlikely that a person will request assistance if it is not needed, and therefore is unlikely to experience "imposed dependence" (Gignac & Cott, 1998).

It appears that this model, and description is based on assumptions, rather than empirical evidence. There is no evidence referenced to support the claim that those who require assistance with personal care will necessarily receive it and that it is unlikely that a person will request assistance that is not required. There are also assertions within this model that are questionable, thus further research on such statements would be helpful.

This model of independence / dependence clearly lies firmly within the "professional" view of independence, despite claims of the authors suggesting that it resembles a social model approach. The focus of the model is on the assistance required to perform physical tasks; thus it does not relate to the Independent Living view of independence as the ability to control one's life, with or without assistance.

Independence – some further thoughts

The descriptions of independence and dependence vary significantly, but can generally be split into those arising from the "professional" view, and those arising from the Disability movement, or Independent Living Movement. Nosek and Fuhrer's (1992a) model, and that of Rogers (1982) have aspects of both approaches, containing elements of both physical function (competence) and choice, control and autonomy.

Independence of disabled people has been of central importance, and has shaped aspects of research and debate about the lived experience of disabled people. The following sections will describe some of the research concerning the lived experience of people with physical disability.

Well being and Quality of Life

There is a large body of literature describing quality of life issues and well-being of people with disabilities; primarily this literature is concerned with health-related quality of life, as measured using any of numerous scales. A discussion of quality of life and well-being of people with physical disabilities, in general terms, is considered beyond the scope of this work. However, a brief discussion of some issues affecting quality of life and well-being are presented.

Section 2.7 in the previous chapter briefly describes some of the psychological literature pertinent to the area of happiness and well-being. A summary of this research, which, in the main, is conducted with non-disabled people, finds that objective circumstances have a surprisingly small effect on a person's happiness and sense of well-being; that a person has a set of predispositions, and they process information about objective circumstances, thus filtering the information, reducing its impact on their overall level of happiness or unhappiness (Lyubomirsky, 2001).

Several studies have found that, in general terms, disabled people report a similar level of well-being and quality of life to non-disabled people, but that there are certain factors that specifically affect the quality of life for disabled people. For example, Schulz and Decker (1985) studied people with spinal cord injury many years after the injury. They compared the quality of life scores from the general population to those from their sample of people with spinal cord injury. Their primary finding was that the quality of life as rated by those with spinal cord injury did not differ significantly from that of the general, non-disabled population, which was a result that they did not expect to find. A lower sense of well-being was found for people with very recent injury, when compared to the norms for the tests used. Specific factors affecting quality of life and satisfaction with life for the participants with spinal cord injury were the amount of social support that a person has and the amount of control that they have over their lives. Self-blame for the injury and belief about whether or not disability could have been avoided were important immediately after injury in determining satisfaction with life, but became far less important many years post-injury (Schulz & Decker, 1985).

A literature review of qualitative studies examining quality of life for people following spinal cord injury was conducted, and found that ten concepts emerged from the literature as affecting quality of life (Hammell, 2007). These concepts were that problems with body and body functions and a sense of loss can decrease quality of life, that people feel that they need to change their values and perspectives after injury and feel that they can contribute and take control of their life in order to maintain well-being. The concepts that are related to good life experience include positive social relationships, a sense of self-worth and a sense that their "self" continues, before and after injury. It was also noted that the environmental context can affect well-being, particularly negatively when not supportive, and that the sense of well-being changes as people have good and bad days (Hammell, 2007). In this research, the importance of a qualitative approach to researching well-being is emphasised (Hammell, 2007), but there are a limited number of papers that use such qualitative methods.

Schulz and Decker (1985) found that participants with spinal cord lesions that had higher levels of well-being were generally younger, became disabled at a younger age, blame themselves for their disability and feel that they could have avoided the injury. The issue of whether or not the injury could have been avoided is, according to Schulz and Decker (1985) contrary to others' findings which suggest that those who cope with disability better blame themselves, but feel that the injury was not avoidable. For the well-being of participants many years post-injury, it was found that both self-blame and perceptions of the avoidability of injury are less important.

Overall, Schulz and Decker (1985) highlight that their results showed that over time, the key determinants of well-being are the person's present situation, the social support and control a person has in their life, rather than the nature or circumstances of injury.

Similarly, Sandstrom (2007) found that the overall life satisfaction for people with cerebral palsy is similar to that of the general population. The condition, cerebral palsy is significantly different from spinal cord injury, in that it is a congenital disability that changes slowly, if at all, in the course of the life-time. Sandstrom (2007) reports that the factors that determine well-being for participants with cerepral palsy were related to pain and deteriorating function. It was found that well-being was not related to the person's level of function, it was just reduced if a person was experiencing reduced function. Further investigation of these issues would be helpful, but it appears that the findings

mirror, those of Schulz and Decker (1985) in that it is the present circumstances rather than general health or function issues which affect well-being.

Alaszewski et al. (2006) found different results when studying people who had experienced stroke. The stroke, for many of the participants, had an impact on well-being. Results showed that following stroke, the participants were more anxious about performing tasks at home and outside the home; they were afraid of further strokes, and tended not to make long-term plans. For many, their social standing was negatively affected. A variety of strategies were used by the stroke survivors in Alaszewski et al's (2006) study: they focused on short-term goals and actions, some living from day to day and others creating a range of short term goals aiming to improve their social standing.

While the finding that the well-being of participants with stroke is poorer than that of the general population differs from findings for people with other conditions (e.g. cerebral palsy and spinal cord injury as described above), the results may have some commonalities. The biggest differences between the study of people with spinal cord injury and the study with those with stroke are the time interval between onset of disability (many years for the spinal cord injured, recent onset for those with stroke) and the potential for disability to "strike again", possibly causing death, in the case of the people with stroke. Anxiety about their future was a finding of Alaszewski et al's (2006) study, which was not relevant in other studies.

The strategies used by the participants with stroke are interesting, when compared with the factors that increased well-being in Schulz and Decker's (1985) study: participants aimed to live in the present and re-establish their social standing Alaszewski et al (2006). Schulz and Decker (1985) found that the present circumstances of the person and the social support were the main factors that impacted on well-being.

Alaszewski et al. (2006) report that the priorities for people with stroke differ from those of the professionals working with them: people with stroke concentrated on re-constructing their lives and social networks, whereas professionals were found to concentrate on safety, and reducing the risk of further strokes. Based on the literature, it may be plausible to suggest that the strategies to re-construct social supports and meaning in life may be more effective at enhancing well-being than the approach to promoting safety.

Albrecht and Devlieger (1999) undertook a study exploring the apparent "disability paradox", where people with "serious and persistent disabilities" report that they have a good or excellent quality of life, when observers state that people with disabilities live undesirable lives, full of frustration and limits on performance.

In their study, Albrecht and Devliedger (1999) found that 54.3% of their sample of people with serious disabilities rported that they have a good or excellend quality of life, which compares with about 80% of the non-disabled population (Albrecht & Devliedger, 1999).

External observers find that people with disabilities cannot rate highly on health-related quality of life measures; they are assumed to be limited in function with lower life satisfaction and they may also be stigmatised and underpriviledged. This assertion contradicts the findings that people with disabilities report similar levels of quality of life to non-disabled people. However, at the same time, people with disabilities report that they have serious limitation in daily activities, experience discrimination and have problems performing social roles (Albrecht & Devliedger, 1999).

One difficulty that may give rise to the disability paradox is that there is no consensus on what constitutes quality of life – there are many conceptual models of quality of life, and many of these have health-status components. These may not be appropriate for people with disabilities. People with disabilities have argued against these, suggesting that quality of life is more than simply absence of disease and functional ability (Albrecht & Devlieger, 1999). The participants in the study reported that well-being involves acknowledging the presence of impairment, but being in control of their minds and bodies. They also reported the importance of being able to perform social roles, having purpose and meaning in life and having a positive "can do" attitude to life. Another important factor identified in quality of life was a sense of satisfaction when comparing oneself to others in similar situations (Albrecht & Devlieger, 1999).

Participants in Albrecht and Devlieger's (1999) study who reported low quality of life were those who experienced pain and fatigue, and an inability to control or predict their ability to perform tasks. Pain and fatigue were found to disorganise, which coincided with a sense of hopelessness and no clear purpose in life. It was found that people who have poorer quality of life had unpredictable lives, lack the resources to engage in social activities and support. Another factor in reducing quality of life was found to be when there is a

significant difference between what a person wants to do and what they can do, or between what they used to do and can now do. The final key finding was that those with lower quality of life, typically were unable to become "agents" in their own world; either due to the type of impairment or the environmental surround; they are unable to take control (Albrecht & Devlieger, 1999).

The conclusion to the study is that quality of life, or well-being, depends on a balance within the self and on establishing and maintaining positive social relationships (Albrecht & Devlieger, 1999). These findings, particularly the importance of social support, are mirrored by other studies, including those by Schulz and Decker (1985) and Alaszewski et al. (2006). However, Albrecht and Devlieger (1999) also suggest that high reports of quality of life could be due to a secondary gain, occurring when a person adapts to new conditions, and finds meaning in this process.

O'Connor and Vallerand (1994) studied the well-being of people in nursing home settings. Unlike the results from Schulz and Decker (1985) and Albrecht and Devlieger (1999), they did not find that increased control necessarily leads to improved well-being. They found that residents with high self-determined motivational styles did best in nursing homes when there was opportunity for choice and freedom, but they also found that residents with low self-determined motivational styles were better adjusted in settings where there was more constraint. They recommend the use of person-environment congruence to determine the best means to improve well-being in nursing home residents.

O'Connor and Vallerand's (1994) study is interesting in that it highlights personal differences as being important in determining the type of environment that is most likely to support well-being. It would be interesting to conduct research to establish whether or not their findings are applicable to other settings, such as young disabled people living in residential settings, or in the community. This finding could have significant importance, as it is assumed, (for example within the Independent Living Movement) that the more choice and control a person has, the better.

Another study of quality of life of nursing home residents has a different focus from that of O'Connor and Vallerand (1994). In this study, (Luleci et al, 2008), it was found that residents who were independent (in terms of being able to perform alone) in activities of daily living had higher scores in a quality of life measure used (The WHO Quality of Life

Measure, WHOQOL-Bref). The activities of daily living included bathing, dressing, toileting, transfers, continence and feeding. Quality of life scores were also increased when participants engaged in physical exercise (Luleci et al, 2008).

In another study, a personal account of the lived-body experience of disability is presented, as an insight into one individual's experience of factors that affect quality of life. The paper suggests that the experience of disability is a profound disruption of space and time, experienced through loss of function, such as reduced mobility (Toombs, 1995). The change in perception and emotional reactions to the surrounding space and objects affects a person's relationship with others; the reduction in physical function means a change in temporal experience – tasks take longer to perform. Of most significance to the author is the loss of "upright position", which is reported to diminish autonomy and negatively affects social interactions (Toombs, 1995).

In general terms, research has shown that the quality of life of people with disabilities is not significantly different from that of the general population (e.g. Schulz & Decker, 1985; Albrecht & Devlieger, 1999), but that a number of factors can affect quality of life. The applicability of these factors to the participants in this study will be worth considering.

Secondary Health Issues

A number of studies have reported that people with physical disabilities are more at risk of secondary health issues, due to a range of factors.

Studies examining the incidence of secondary health issues of people with physical disabilities appear to show that there is a greater incidence and risk of health issues with people with physical disabilities (Nosek et al, 2004; Nosek et al, 2006; Rimmer et al, 1999). One study found that 95% of a sample of women with physical disabilities experience interruptions in daily occupations due to pain, and 93% due to fatigue (Nosek et al, 2006). Nosek et al's (2006) study traced women over a one-year period, and also found that other issues included spasticity (85%); weakness (82%); sleep problems (80%), vision impairment (77.9%), and circulatory problems (77.9%).

Another secondary health issue reported in the literature is the risk of obesity, and that obesity is more common in people with physical disabilities compared to normative data (Nosek et al, 2006; Santiago, 2004; Rimmer et al, 1999).

Common problems for people living in the community, and who use wheelchairs for seating include the risk of skin breakdown (White et al, 1996). White et al (1996) suggest that independent living services, rather than health services, may be best placed to manage some of these difficulties.

The nature of the disability has also been found to be related to the nature of secondary health issues experienced, with people with joint and connective tissue conditions reporting more secondary health issues, and reporting greater severity of these issues (Nosek et al, 2006). Nosek and colleagues (2006) conclude that their work has highlighted that secondary conditions are "substantially more problematic than reported previously" and that further research is required in this area.

Social Factors

This section will review research concerned with social aspects of physical disability, including stigma and marginalisation, social comparison and social support.

Social Stigma and Marginalisation

There appears to be a wealth of information about stigma, and the effects of social stigma on persons with disabilities. Goffman, (1968) describes the root of stigma, arising from Greek, meaning a physical sign that suggests lower morals or disgrace. The use of the term has changed somewhat, to now refer to the disgrace itself rather than its bodily exhibition (Goffman, 1968), Stigma relates to a discrediting attribution, and occurs when attributes and stereotypes occur together. Stigmatised people are those who do not fit into the "normal", and so belong to a different category; one conception of stigmatised people is that they are thought to be "not quite human", which can result in discrimination (Goffman, 1968).

Goffman (1968) highlights the difference between the "discredited", those with visible disabilities, and the "discreditable", those with hidden disabilities which are not immediately apparent. People who have physical disabilities, such that a wheelchair is used are "discredited", thus they are always immediately perceived as stigmatised or different, unlike those who are discreditable, and whose aim in social interactions is to manage information about disability (Goffman, 1968).

Using a wheelchair may provide useful mobility, but it also serves as a stigma symbol, meaning that the person is immediately discredited (Goffman, 1968). In her study, of women with physical disabilities, Tighe (2001), found that women felt that people saw the wheelchair before the person. The women in the study also reported that some activities, such as participation in leisure, are not expected of wheelchair-users, and so a "supercrip" stereotype exists for those who do engage in such leisure activities (Tighe, 2001).

Tighe (2001) found that women in the study felt vulnerable, as they felt different, or "the other" from those in power. This vulnerability and sense of difference was managed by the participants by exerting as much control as they could over their environment.

One reason why people with physical disabilities are stigmatised is reported to be because their bodies are assumed to be different (Morris, 1991; Tighe, 2001; Taub et al, 1999). In one study, (Taub et al, 1999) reported that participation in sport and physical recreation is a means to manage the stigma of a physical disability. The participants in this study reported that participation in sports changed people's attitudes towards disability, as it is not expected that a person with a physical disability would be active (Taub et al, 1999). This finding contrasts with that of (Tighe, 2001), whose participants reported that social attitudes changed with the perception that a disabled person is a "supercrip" if they participate in sports or leisure. One possible difference is that Taub et al's (1999) participants were all young males, Tighe's (2001) participants were middle-aged women, so the social groupings and social norms of the reference groups may have been different.

This participation in physical activity, or doing what is not expected of a disabled person, is described by Morris (1991) as the "overcoming all odds" of disability model. While unexpectedly overcoming barriers can lessen the fear that non-disabled people have of disability, according to Morris (1991) it also reaffirms "normal" as "right". Morris argues for

disabled people to reject "normal" and take pride in difference and disability, since attempting "normal" is simply acting, or pretending and will not enable a person to be fully "admitted" to the non-disabled world.

It is frequently assumed that social stigma leads to lowered self-esteem (Crocker et al, 1991), but this may not necessarily be the case. Previously, it had been assumed that the groups to which a person belongs are central in determining self-esteem, and feelings of self-worth, as these are dependent on the social evaluation of the group to which a person belongs (Crocker & Major, 1989). More recent studies have found that some people can ignore negative feedback and attitudes when they can attribute these attitudes to prejudice from people towards their group, and so such feedback is discounted (Crocker et al, 1991). It has been found that this ability to discount negative feedback can protect the individual (Crocker et al. 1991). If a person suspects that another is prejudiced, they may be wary of, or ignore positive feedback, concerned that this may have an ulterior motive (Crocker et al. 1991).

Other authors have written about the strategies used specifically by disabled people to manage stigma (Goffman, 1968; Tighe, 2001; Morris, 1991). Morris (1991), for example, advocates that disabled people to reject the "normal" in society, and take pride in difference; that prejudice arises as a result of the need to manage difference. This management of difference, or "normality" can relate to comparisons between people with physical disability and non-disabled people in society.

Social Comparison and Expectation

Tighe (2001) reports that the predominant feature of the narratives of eight women with physical disability was the need to define themselves, and their health, by "able-bodied standards". The women in the study felt the need to compare their bodies with non-disabled people, and work at fitting in with a social norm (Tighe, 2001). This social comparison is reported as conscious – the women were aware that they were comparing themselves to non-disabled women.

In their study, Schulz and Decker (1985), specifically asked participants with spinal cord lesions who they compared themselves to. It is reported that many respondents stated

that they did not compare themselves to other people; when probed 59% of the study said that they compared themselves with people in general, 16% with non-disabled people and 25% of the people in the study compared themselves with other disabled people (Schulz & Decker, 1985).

Despite actively comparing themselves with non-disabled people, the women in Tighe's (2001) study reported finding meeting other disabled people helpful. So, although the comparison remains with non-disabled people, it appears that the people in the study find value in being supported by, and supporting people with similar experiences of disability.

Social Support

A study of women with spinal cord injury investigated the importance of social support for participation in occupations (Isaksson et a;, 2007). Emotional and practical social support was required, and acted as a motivator to enable the women to participate in occupations. Immediately after injury, the women needed to receive support, but after a period of time, it became equally important for them to give support (Isaksson et al, 2007). This study is interesting in that the need to give support is discussed, whereas the majority of studies appear to focus on an individual's need to receive support.

In an earlier study of people with spinal cord injury, it was found that people who had high levels of social support, good social contacts and control over their lives reported high levels of well-being (Schulz & Decker, 1985).

Nosek and Fuhrer's (1992) study

Nosek and Fuhrer (1992b) undertook a study using the Personal independence Profile (PIP) to describe the difference in independence of 200 participants with different disabilities, using their heuristic model. Their study included 56.5% females, the mean age of the sample was 37.9 years of age, and a range of disabilities were represented, including spinal cord injury, cerebral palsy, head injury and arthritis. Only 5.7% of the participants lived in residential settings; the remainder in private accommodation, alone, with family, friends, hired assistants or a combination of these. Only 3.2% of their sample rarely left their place of residence, and nearly half owned and drove their own car.

The participants in Nosek and Fuhrer's (1992b) study had a range of education, including college/university, with all but 7% having finished school. Despite the high level of education, 61% of the group were not in paid employment. Other participants were involved in education, voluntary work, home-making and leisure activities.

Participants in the study were asked to rate their overall level of independence, which was defined as, "control over one's life based on choice of acceptable options that keep to a minimum reliance on others in making decisions and in performing everyday activities," 76% rated their independence as high or very high (Nosek & Fuhrer, 1992b).

The authors found three distinct groups, relating to different styles of independence: profile A were described as independently minded, less disabled; B independly minded more disabled and C non-independently minded.

Profile A participants (40%) reported high levels of independence, and had high scores on scales testing for psychological self-reliance, control and functioning. They tended to feel in control of their lives and had the highest productivity (Nosek & Fuhrer, 1992b).

The profile B participants (24%) reported high levels of independence, and were found to have high scores in tests for psychological self-reliance and control, but low levels on physical functioning. These participants were also productive, but had significantly different levels of impairment, compared to Profile A.

Profile C participants were significantly different from those in the other groups. These had low scores in control and psychological self-reliance, but very variable levels of physical functioning. This group reported the lowest level of independence and health, and were the least productive.

Nosek and Fuhrer (1992b) report that the analysis of the data shows that there is little relationship between physical ability and independence on the psychological and control scales. Physical ability was not related to productivity, as the least productive group (profile C) were those that were "non-independently minded"; the most productive were the independently minded – be they more or less physically disabled (profiles A and B).

Of the three groups, the two that were found to be most similar were profiles A and B, i.e. those that were independently minded, but with different levels of disability (Nosek & Fuhrer, 1992b). Regardless of the severity of the disability, those who reported themselves to be most independent had highest scores on the psychological self-reliance and control scales, regardless of physical ability.

A conclusion drawn by Nosek and Fuhrer (1992b) is that people in each of the different profiles will have different service requirements: it is argued that those who are non-independently minded would benefit from support to change their attitudes and skills in self-management; those who are independently minded with significant physical disability would require further support, such as personal assistance and transport; those who are independently minded with a relatively high level of physical ability may need support to manage additional barriers to enable them to engage in productive occupations (Nosek & Fuhrer, 2006b).

Nosek and Fuhrer's model and study (1992a; 1992b) provide an interesting and informative description of the experience of independence of a number of people with physical disabilities. It is assumed, however, that productivity and independence are necessarily a good thing, for example, the suggestion that the best intervention for the non-independently minded is to support them becoming independently minded. It appears that there have been no studies about the satisfaction or quality of life of the different groups; it is assumed that productivity and perceived independence are positive, and that this must lead to well-being.

Independent-mindedness, or the opportunity to take control and be psychologically self-reliant appears to be similar to the concept of self-governance autonomy. The assumption that this autonomy is best does not appear to fit with other research. While the concept of autonomy as a psychological need is contained within self-determination theory (Ryan & Deci, 2000), research has found that the desire for control (a component of independent mindedness) is a more or less stable personality trait (Burger, 1985), and that people who are in environments demanding control have lower well-being than those in an environment that fits their innate dispositions (O'Connor & Vallerand 1994).

Researching disability

As this research involves disabled people, a review of literature about research within social model paradigms is important to include. Further discussion of the methodology, and influences on the selection of the methodology is included in the Methodology chapter, Chapter 5.

Emancipatory and Participatory research have been described, and differentiated within the literature on disability research (e.g. Zarb, 1992). Prior to the emergence of emancipatory research methods, it was argued that disability research had little or no effect on changing policy or oppression that affect disabled people (Oliver, 1992).

Emancipatory research, in the field of disability, was first described in the early 1990's, as a research method with rather than on people with disabilities, where the primary focus and outcomes of research should be to investigate and challenge the oppression experienced by disabled people (Barnes, 1992; Oliver, 2002; Oliver, 1992).

Disability research has differed from research with other groups, such as in the area of feminism, race or sexuality, both in the quantity and focus of the research; disabled people have been researched as objects by non-disabled people, particularly in medicine, the therapies and rehabilitation (Mitchell, 2002). The "professional" researchers have considered disabled people as deviants, and studied the deviance, rather than the social or cultural organisation that surrounds disabled people (Mitchell, 2002).

Emancipatory and participatory research have evolved as a response to the perceived difficulties with traditional research on disabled people. Participatory research is criticised (Oliver, 2002), as it fails to target the key concern of the disability movement, which is oppression. Oliver argues that frequently participatory research simply involves including a token disabled researcher or disability organisation, without the fundamental change of focus that the disability movement calls for (Oliver, 2002).

It is argued that, rather than being a methodology per se, emancipatory (and to a lesser extent, participatory) research focuses on the control of the research, and means putting disabled people at the forefront of the research, as active agents rather than objects.

Barnes (1992) suggests, however, that qualitative research is fundamental to emancipatory methodologies.

Morris (1992) argues that feminist theory has a lot to offer disability research, but disabled women's experiences have not found their way into feminist literature. Her views appear to be somewhat more radical than those of Oliver or Barnes, in that she advocates a cessation of research on disabled people, undertaken by non-disabled people, but recognises that this is unlikely, so calls for non-disabled researchers to re-focus their research to address issues of oppression.

The value of investigation of the meaning and interpretation of phenomena to disabled people is discussed in the literature; Barnes (1992) highlights that this promotes an understanding of the lived experience of disabled people, thus can enable a greater understanding of the situation (oppression) experienced, whereas Oliver (2002; 1992) argues that recording the experiences of disabled people is simply not enough, documenting a situation does not necessarily promote change.

Barnes (2003) highlights the change in discourse about emancipatory research that has occurred in the decade since its first description. In the early 1990's, emancipatory research was seen as quite radical, and had at its core the social model of disability (Barnes, 2003). In 2003, he argued that the rhetoric of the social model of disability and emancipatory research methods had been assimilated into the language of non-disabled service providers, which in effect has led to a watering-down of core concepts and values.

Whether or not emancipatory research, in its purest sence is undertaken, it appears that authors within the disability movement have called for a change in research: from professional control and power to promoting disabled people's involvement and control; researchers researching with disabled people rather than on subjects; disabled people commissioning research and generating ideas for research, and finally that the product of disability research is of value and benefit to disabled people, rather than to medical or other professionals (e.g. Beresford & Evans, 1999).

Emancipatory research is not without its critics, including those from within the disability movement. Despite high hopes, emancipatory research has not necessarily produced the societal changes that were hoped for. Barnes (2003) outlines issues associated with this

form of research, including the lack of accountability and difficulty in promoting rigour. There have also been suggestions that aspects of emancipatory research lead to collusion, rather than presenting genuine research findings.

The methodology employed in this research is described in Chapter 5, but it cannot be described as emancipatory research. A concerted effort was made to engage with disabled people at the outset, thus the work does have participatory elements.

Conclusion

This chapter has presented literature specifically concerned with disability, including: disability theory; occupational performance (in terms of self-care, productivity and leisure) of people with physical disabilities; theories of independence and research into well-being and social support for people with physical disabilities.

The next chapter will attempt to synthesise the literature from this chapter and the previous, to relate the most salient concepts to the current research exploring choice and autonomy of adults with significant physical disability.

5. Synthesis of literature: Autonomy and Choice

The previous two chapters reviewed literature from psychology and from within disability studies, rehabilitation and occupational therapy. As a variety of material was reviewed, it is thought helpful to relate the literatures to each other and directly to this study. The aim of this chapter is briefly to present a synthesis and application of the literature as it relates to this work.

The key concepts that are relevant to this work include those of: autonomy; choice; independence and control, as well as theories that describe well-being and coping mechanisms for people with physical disability.

Autonomy and choice are the concepts at the centre of this work. There are a number of descriptions of autonomy found within the literature; the extent to which these concepts overlap with, and are similar to the concepts of independence, control and choice will be explored in this chapter.

The concept of autonomy is of concern to several different academic disciplines, but the information reviewed for this work is primarily that found within psychology and rehabilitation.

Kagitcibasi (1996) proposes a theory that the concepts of autonomy can be differentiated by how they deal with the issues of agency and interpersonal relationships; she describes these as the "agency dimension", and the "interpersonal closeness-separation dimension" of autonomy. Hmel and Pincus (2002) argue that two theories are valid concepts of autonomy; these being self-governance autonomy and agentic separation autonomy. Both of these forms are high in agency, but they differ in that self-governance autonomy is characterised by interpersonal closeness, and agentic separation autonomy by interpersonal separation.

Within the literature that relates to disabled people, however, the concepts of autonomy are presented in a significantly different manner. For those theorising about disabled

people, it would appear that the concept of competence (the actual ability to do or to enact one's decisions) is also salient. This is seen in the work of Cardol et al (2002), which describes decisional and executional autonomy, and that of Proot (2000), which includes the ability to perform self-care tasks as a component of autonomy. Why is this so? Why is it, that within the psychological literature, the concept is clearly and necessarily related to agency (Hmel & Pincus, 2002), whereas in the rehabilitation literature it is suggested that competence is centrally important in autonomy?

Within self-determination theory, for example, autonomy is seen as a basic psychological need, fulfilment of which promotes intrinsic motivation. The focus of study within SDT theory is the environmental support (or lack thereof) for autonomy. The views of autonomy within the rehabilitation literature appear to focus on disabled persons themselves, rather than the environmental surrounds. Could this be mirroring the medical/social model of disability debate? As self determination theory is not concerned specifically with disabled people, the "problem" or "issue" of autonomy is considered within an environmental context, whereas in rehabilitation, there appears to be the assumption that physical function must be important, and further that the "problem" or "issue" of autonomy is different for a disabled person, and located within the person?

Chirkov et al (2003) suggest that a person is autonomous when their behaviour is perceived to be willingly enacted, when the person takes responsibility for and fully endorses their action. They describe people as being most autonomous when they act in a manner that fits with their values and desires. This is yet another slightly different description: autonomy is the endorsement of, rather than the selection of action (although choice of action may also be involved). It is more difficult to fit this description with the presentations of autonomy found within the rehabilitation literature, because of the issue of competence. If autonomy is primarily endorsement or taking responsibility for action, then how can competence be relevant?

Clapton and Kendall (2002) warn against over-valuing autonomy for disabled people, as they argue that it is based on "Western, male, white, middle-class and ablist ideas of personhood". However, this appears not to be supported by literature on self-governance autonomy, which has been described as pan-human (Chirkov et al, 2003). Cardol et al (2002) report that autonomy is the ultimate aim of rehabilitation, because it is a pre-requisite for participation in society. It seems that the different concepts of autonomy warrant further study, particularly as there appear to be different outcomes reported for

different concepts, such as self-governance and agentic separation autonomy (Hmel & Pincus, 2002).

The varying concepts of autonomy appear to closely relate to and overlap with other concepts, such as control, independence and choice. For example, Rogers (1982) proposes that independence comprises of autonomy (the ability to choose) and competence (the ability to do). This seems strikingly similar to the descriptions of decisional autonomy (Rogers' autonomy) and executional autonomy (Rogers' competence), as presented by Cardol et al (2002). Could it be that Cardol et al (2000) and Rogers (1982) are speaking of the same concept, but that one describes it as "autonomy", and the other as "independence"?

There appear to be significant overlaps between the concepts of autonomy and independence, particularly within the rehabilitation literature. This overlapping is not helped by the frequent lack of definition of either concept.

It appears that there are two fundamentally different explanations of independence, with other theories (such as that of Rogers, 1982 and Nosek and Fuhrer, 1992a) bridging the two. The two theories are that of independence as control (the Independent Living perspective) and that of independence as competence, or ability to do alone (the professional perspective) (Reindal, 1999).

There is much literature about the professional view of independence as competence, and the focus of this literature varies somewhat. For example, some studies investigate the extent to which specific tasks can be performed alone; others investigate strategies that can be used to promote independent (competent) performance, and yet others (such as that of Gignac & Cott, 1998) investigate the situations in which a person may or may not be able to perform tasks alone (thus the times when a person is "independent", "dependent", "not independent" or experiences "imposed dependence"). All of these assume, or define, independence to be the ability to undertake tasks alone.

The professional view of independence appears to have little connection with autonomy. According to the self-governance framework of autonomy, a person whose behaviour is willingly enacted is seen to be autonomous; regardless of whether or not there has been outside influence (Chirkov et al, 2003). For example, a person can be willingly dependent

on another person and be considered autonomous or, conversely, can be independent of others and not be autonomous.

Independence, according to the Independent Living Movement, is the ability to make choices, and control one's life. It is difficult, then, to differentiate the concept of independence as control from the concept of autonomy, particularly self-governance autonomy.

The two "bridging" theories of independence provide more clarification in the attempt to differentiate autonomy from independence. Rogers (1982), as previously stated, presents a conceptualisation of independence as being both autonomy and competence; a person both needs to have and make choices, but also needs to have a certain level of competence to be independent. Nosek and Fuhrer's (1992a) "heuristic model" of independence is somewhat more sophisticated, whereby independence has four components: perceived control of one's life; psychological self-reliance; environmental resources, and physical functioning. The model is said to describe psychological, social, functional and environmental constructs of independence (Nosek & Fuhrer, 1992a). It is suggested that the perceived control and psychological self-reliance elements of this model could be likened to autonomy, and the physical functioning to competence, and the environmental resources is an additional factor not clearly linked to other theories of independence.

Nosek and Fuhrer (1992a; 1992b) describe one of the features of independence as "independent-mindedness", and found that independent-minded individuals, regardless of the level of physical ability, were more productive than those who were not independent-minded. Could this concept of independent-mindedness be similar to self-governance autonomy?

Whether or not it can be synonymous with independence, it appears that autonomy also relates to control and choice.

There are a number of theories of control, focusing on both the desire for control (e.g. Burger, 1985) and the extent to which people feel that they have control and the impact of control on an individual's life (Shapiro et al, 1996). A conclusion from the literature, as presented by Shapiro et al (1996), seems to be that for optimal well-being, the

environmental opportunity and demand for control needs to be matched with the individual's desire for control.

Nosek and Fuhrer (1992b) undertook research using their personal independence profile, and concluded that one of the components of independence, control, was least related to a person's physical functioning, but had the biggest impact on their overall level of independence and productivity.

The ability of an individual to exert control over one's actions and in an environment has been highlighted as important, particularly for disabled people and in the independent living movement. One study by Tighe (2001) also found that women with physical disabilities aimed to exert control over their environment as a strategy to manage feelings of vulnerability and differentness, or being "the other" to those in power.

Modern studies within psychology have suggested that an environment that matches a person's desire for control best promotes well-being (Shapiro et al, 1996). O'Connor and Vallerand (1994) found that residents with high self-determined motivational styles did best in nursing homes when there was opportunity for choice and freedom, but they also found that residents with low self-determined motivational styles were better adjusted in settings where there was more constraint. They recommend the use of person-environment congruence to determine the best means to improve well-being in nursing home residents.

The relationship between control and autonomy are not fully clear within the literature. Further work to investigate these concepts would be helpful, particularly as it is suggested that self-governance autonomy is a pan-human psychological need (Chirkov et al, 2003), whereas the desire for control is a relatively stable personality trait (Burger, 1985); self-governance autonomy is thought to be health-promoting, whereas control is not necessarily healthy (Shapiro et al, 1996).

Choice appears to be clearly linked to autonomy; in self-determination theory in particular, autonomy is described as a sense of choicefulness (Ryan & Deci, 2000). The debate within psychology about choice appears to relate to whether or not choice is a cultural concept; whether choice can be harmful, stressful or whether it is always positive, and the

importance of meaningful choice in the promotion of well-being (Ryan & Deci, 2006; Reis et al, 2000; Iyengar & Lepper, 1999; Iyengar & Lepper, 2000).

Choice appears to be very highly valued by the independent living movement; choice of disabled people is seen as a right, and choice is viewed as necessarily positive. There is, however limited discussion within disability studies about what enables or constrains choices of disabled people, nor does there appear to be any significant robust critique of the value of choice. Agich (2003), however, suggests that choice is over-valued, and that there is the assumption that people are able to make choices, which may not necessarily be true.

Lyubomirsky (2001) describes the construal theory of happiness as exploring "hedonically relevant psychological processes"; these being social comparison, dissonance reduction, self-reflection, self-evaluation and the person's self-perception. Some of these concepts, particularly the influence of social comparison have been found to be relevant to people with health issues (Taylor, 1983; Taylor et al, 1984), but less so to people with physical disability.

Several studies have found that, in general terms, disabled people report a similar level of well-being and quality of life to non-disabled people, but that there are certain factors that specifically affect the quality of life for disabled people.

In research with people with disabilities, there appear to be a range of factors that are thought to promote well-being and quality of life, including: social support and the amount of control a person has over their life (Schulz & Decker, 1985); a deterioration in function (rather than overall level of disability) (Sandstrom, 2007); secondary health issues, pain and fatigue (Nosek et al, 2006; Albrecht & Devlieger, 1999), and research with people with different disabilities has found different results, most notably that if a health issue could recur (as in the case of a CVA), this, in itself has a negative impact on well-being (Alaszewski et al. 2006).

Albrecht and Devlieger (1999) undertook a study exploring the apparent "disability paradox", where people with "serious and persistent disabilities" report that they have a good or excellent quality of life, when observers state that people with disabilities live undesirable lives, full of frustration and limits on performance. The conclusion to the study

is that quality of life, or well-being, depends on a balance within the self and on establishing and maintaining positive social relationships (Albrecht & Devlieger, 1999). These findings, particularly the importance of social support, are mirrored by other studies, including those by Schulz and Decker (1985) and Alaszewski et al. (2006). If these results were compared to well-being within self-determination theory, it could be suggested that the emphasis on the importance of the social context is the satisfaction of the need for relatedness.

It seems that the concepts of choice, control, independence and autonomy are all interconnected. A major weakness of the vast majority of the literature is that these concepts are not specifically defined, resulting in debates over semantics, rather than exploration of the meaning or relevance of these concepts. Also, there appears to be a gap between the psychological literature and that found in disability studies and rehabilitation.

Contribution of concepts of autonomy from the literature: The theoretical strand of the Autonomy and Choice Framework.

A proposed outcome of this exploration is to develop a framework to synthesise the concepts of autonomy, albeit in a draft format. The literature reviewed provides information that could inform such a framework, and the strands to be included in the framework are outlined below.

Within a framework of findings for this work, the first element that will need to be included is a description or definition of what autonomy means, integrating concepts from the literature with the views of the participants.

- Do the participants, in their views and experiences of autonomy reflect the psychological literature in the need for an agentic core to be present?
- Does physical function, the ability to perform or enact choices affect autonomy? (i.e. can the participants in this work contribute to the debate about social and medical model views of the role of impairment in autonomy?)
- Is the concept of autonomy meaningful to the participants?

The second area where the literature has provided further questions for this study are about whether or not autonomy is "pan-human", that is a universal need, goal or value, and how important or relevant is it to the participants in the study?

A third element is the management of autonomy: Do participants exert autonomy and choice, do they make decisions, do they feel "autonomous"? How do participants manage these feelings and experiences? Within this aspect of the work, the development of autonomy and choice throughout the lifespan, and the daily life experiences of autonomy for the participants will be important. Do the participants differ in what they do, and how much autonomy they have over their lives?

There are a number of relevant psychological theories, including self-determination (Ryan & Deci, 2000) self-efficacy (bandura, 1982) learned helplessness (Seligman 1975) and theories of choice (Iyengar & Lepper, 2000) and control (Burger 1985). To what extent do any of these theories mirror the concept of autonomy for the participants in this study? An exploration of these concepts in relation to participants' lives and perceptions of autonomy forms a fourth strand to a framework.

A final essential strand for any new framework involves consideration of the environmental factors that either support or negate the participants' daily experiences of autonomy and choice and their perceptions of these concepts.

Thus, from the review of the literature, a framework needs to contain at least five strands, including: the meaning of autonomy; whether or not autonomy is a need, goal or value for the participants; what daily experience of autonomy (or lack of autonomy) is "like"; whether concepts of autonomy overlap other psychological theories and the impact of the environment on autonomy and choice.

Additionally, the literature reviewed has posed many more questions for future research that cannot be adequately addressed in the current work. The primary among these is whether autonomy and choice do promote well-being, whether people in independent living settings are more autonomous, and consequently have greater quality of life. While it may be possible to extract anecdotal information about these topics from the current work, a larger, more quantitative approach is needed to address links between autonomy, living situation and quality of life.

The next chapter will present the methodology used in the current work. It is followed by the descriptive results, then the interpretative results, and finally by a discussion, in which this draft framework can be presented in more depth.

6. Methodology

This research seeks to explore the daily life experience of eight adults with significant physical disability, with a particular focus on their experience and perceptions of autonomy, choice and independence in everyday life. The focus also involves detailed description of aspects of daily life for each participant. This chapter describes the methodology used in this exploration.

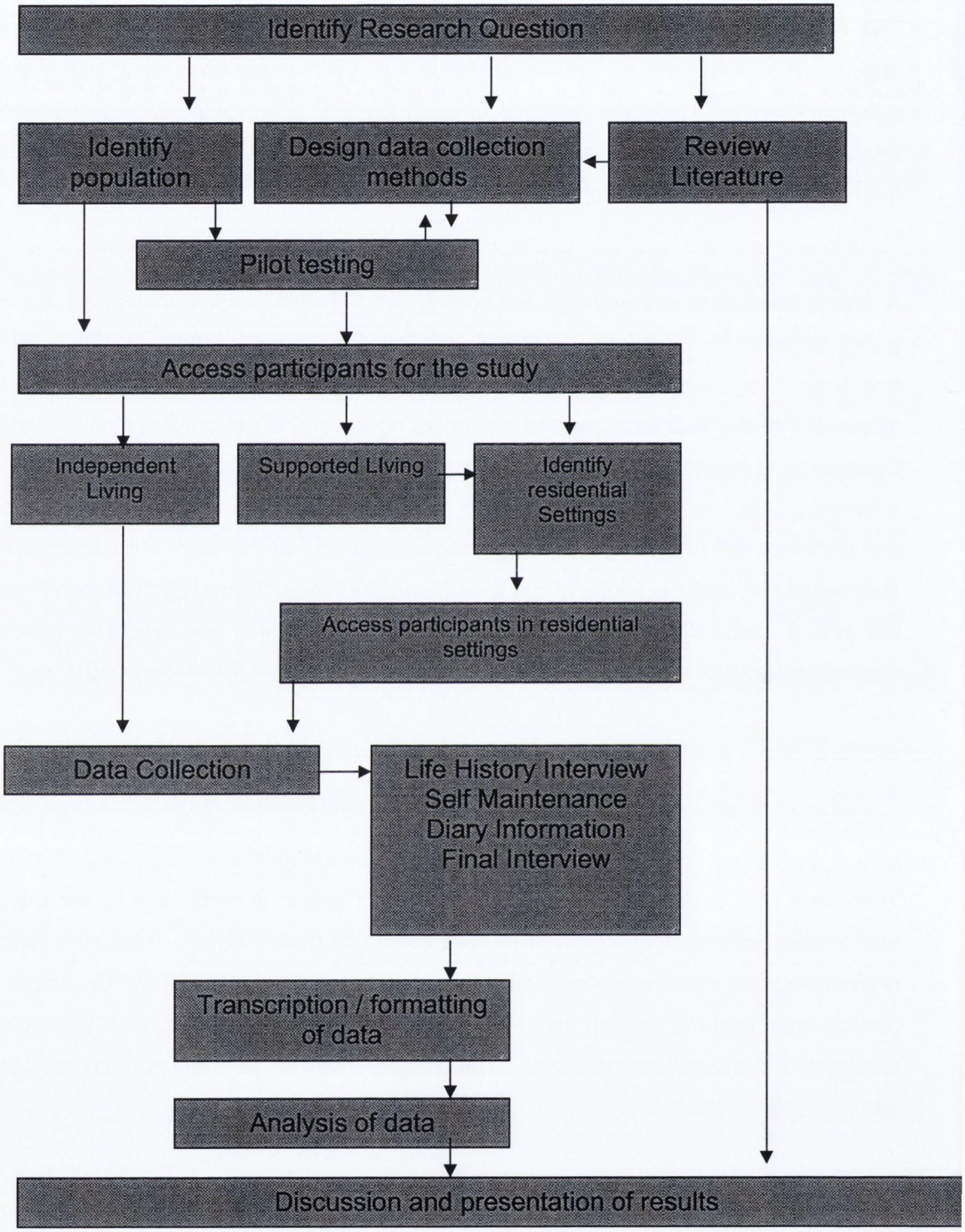
A description of the overarching methodology and epistemological standpoint are initially given, followed by description of the stages involved in preparation, data collection and analysis. There is a section on the reflexive standpoint of the researcher, and finally a discussion of the methods used to maximise rigour and trustworthiness of the research. Discussion of trustworthiness and rigor are provided at the end of the chapter; not as an afterthought, but to enable the reader to judge the rigour and trustworthiness aspects of the work with full knowledge of the procedural aspects of the work. Ethical issues are also described, and decisions made throughout the research are highlighted in relation to the ethical and political standpoint, with a view to enabling the reader to assess the evaluative rigour of the work (as described by Kitto, Chesters & Grbich, 2008).

Overview of the methodology

This study was undertaken over the course of six years. It involves a mixed qualitative and detailed description approach to data collection and analysis. The work forms two distinct sections, one being descriptive (life history and description of the daily lives of the participants), and the second being interpretative, where interpretations of autonomy and choice are drawn from the data. The stages involved in the research process are summarised in Figure 5.1.

> It is incumbent upon each qualitative researcher to understand the ontological basis of their research and to make explicit the decisions made in terms of methodology and method (Mason 2002, Holloway & Todres 2005).
> (Bradbury-Jones, 2007, p. 291)

Figure 5.1: Key stages involved in methodology.



This research is situated in a relativist ontological perspective, that is, the belief or assumption that each person is a "relational being", interdependent on others (Mauthner & Doucet, 2003) and that there are several "realities", each of which entwined in cultural, societal and individual norms and experiences. The aim of this research is to understand and uncover the realities for each of the participants, rather than trying to uncover one positivist "truth". There have also been elements of reflexive or cultural bracketing in the method and approach (as described by Gearing, 2004).

Alongside the ontological standpoint, the epistemological perspective has been inquisitorial in nature, the researcher sought to observe, discuss and then interpret findings with the aim of re-configuring information to create a fuller understanding of the issues of autonomy and choice. This exploration, epistemologically, is underpinned by the post-modern assumption that there are many realities, and that the social context and research method itself is likely to affect the findings, as Mauthner and Doucet (2003) describe, the research process may strengthen some voices and silence others.

A fuller description of the axiological issues involved with the research, including the reflexive and trustworthiness elements are discussed at the end of this chapter, and briefly in reflections in chapter 10.

Qualitative methods were considered essential to explore the "lived experience" of disabled people with a view to exploring differences in perceived choice, autonomy and the factors that enable or limit a person's ability to do. The qualitative aspects of the methodology involved semi-structured interviews, primarily focusing on life-history and explorations of concepts of autonomy and choice. Thus, both descriptive and interpretative qualitative methods were required.

Detailed description of the individuals' lives is undertaken, as a legitimate part of the exploration, and also so that the meaning of autonomy can be explored for the participants in real terms. This was undertaken primarily by participants maintaining a diary with questions specifically focused on the amount of choice and autonomy that they have in their daily life. This description, and the manner in which the data are used would not ordinarily form part of a purely qualitative study.

Thus, the methodology is based within a qualitative paradigm, but uses an integrated approach to data collection (as described by DePoy and Gitlin,2005). This integrated approach, it is felt, grounds the work within occupational therapy and occupational science, and is thought to enhance the qualitative aspects of the work.

In line with a relativist ontological standpoint, it is assumed that the concepts under study are extremely subjective and the experience of autonomy is likely to be multi-faceted and dependent on a variety of factors. To facilitate variety in experience and perceptions, it was considered imperative that a diverse group of individuals were sought for the study. Participants were sought who live in different settings, with a mix of gender and age (but between the ages of 18 and 65). The specifics of participant selection are described in section 5.6 below.

Rationale for overall choice of methodologies

> "An increasing number of researchers are using multimethod approaches to achieve broader and often better results"
> (Fontana & Frey, 1994, p.636)

This study involves an integrated method (DePoy & Gitlin, 2005), with elements of both qualitative methodology and descriptive methodologies. There were a number of influences on the design of the study, including qualitative approaches, such as ethnography and phenomenology, but it was considered neither feasible nor desirable to use one single approach. The primary rationale for mix of methodologies is to capture the views and ideas of the participants, but also the concrete information about their actual (as opposed to perceived) lived experience.

DePoy and Gitlin (2005 p.32) describe integrated methodologies as being:

> "based on its own philosophical foundation of pragmatism, draws on strategies from both experimental-type and naturalistic inquiry traditions and may involve multiple and varied thinking and action processes."

As described by DePoy and Gitlin (2005), integrated approaches draw on aspects of different research traditions, producing a combination of methods whereby one compliments the other.

Integrated methodologies are differentiated from mixed method or multi-method research approaches in the extent to which the different strategies are combined to create a whole. For example, a mixed-method research approach includes several different strategies to answer different aspects of research questions, or different questions (DePoy & Gitlin, 2005; Steward, 2006). It is felt that the integrated approach best describes the current work, because different strategies are used to access different aspects of knowledge about the same question: different methods are integrated to complement each other and create a more comprehensive and complete whole.

A number of different approaches were considered. As the individuals are unique, aspects of case study approach were used. The case-study approach was used for descriptive information, and also includes aspects of narrative approaches.

> "Case study evaluations are valuable where broad, complex questions have to be addressed in complex circumstances. No one method is sufficient to capture all salient aspects of an intervention, and case studies typically use multiple methods "
> (Keen & Packwood, 2000)

The first section of the results are divided into two chapters (Chapters 6 and 7), and these form the descriptive element of the work. These chapters present the core results related to life history information, disability experience, and the daily life of each of the participants separately, in a case study format. Data are analysed and presented using a descriptive (rather than interpretative) method. The second section of the results, chapters 8 and 9, form the interpretative part of this work, where findings from all individuals are integrated.

Pope, Ziebland and Mays (2000) describe case study approaches (in health care settings) as focusing on a limited number of settings, to explore phenomena, particularly when there are complex interrelated issues. In this research, issues of choice, autonomy, independence and control are the focus of data collection, so it was considered essential to adopt an approach whereby these issues could be discussed with participants. Mays and Pope (2000) describe case studies as potentially explanatory, exploratory, descriptive or a combination of these. The individual participants' information is primarily descriptive, with exploration of issues such as experience of autonomy. The descriptive aspect of the case studies is considered highly valuable, as a means of embedding the explorations in a lived reality.

While the case-study approach was used, influence was drawn from life-history narrative approaches (Cresswell, 2007; Kielhofner & Henry, 1988). Narrative research approaches involve "expressed lived and told stories of individuals" (Cresswell, 2007), and can use metaphor to describe the life shape or experiences of an individual as described by them (Kielhofner & Henry, 1988; Kielhofner, 2008). This approach was considered useful as a means to describe the individuals. Discussion of the usefulness of combining case study approaches and narrative approaches, and whether the narrative content provides helpful information is included in chapter 10.

Grounded theory, as an approach to understanding or interpreting the experiences and perceptions of the participants was considered. However, it was felt that this was both impractical and undesirable for the present study. Within grounded theory, all explanations of autonomy would have come directly from the participants' accounts. With concepts such as autonomy, choice and control, there is extensive literature, and are already a number of theoretical frameworks (see chapters 2 and 3). It would not be desirable to "ignore" such theories, nor create new ones; rather these can be used as a means to interpret findings from the participants. Insights from the participants are presented alongside an awareness of the existing theoretical descriptions of the constructs under study. Barbour (2001) explains that many studies claim to use grounded theory as an approach to data analysis and reporting, but that this is rarely the case.

Part of the data collection method involves semi-structured interviews; these were chosen in order to understand the participants' life history and perceptions of choice and autonomy. Qualitative, semi-structured interviews allow the researcher to be interactive and sensitive to the participants' language and concepts (Britten, 1995), and permit a flexible agenda, whereby there is opportunity for participants or interviewer to raise other issues (Britten, 1995). In the course of a number of interviews, different but related issues were raised by participants through this medium.

An important aspect of qualitative interviews is that the issues are discussed in depth, and where possible the interviewer clarifies that the participants meanings were fully understood (Britten, 1995). This was attempted, however several (if not all to some degree) of the participants experienced fatigue as a result of their disability; thus limiting the time available for interview. Ideally, further interviews would have been carried out with participants in order to achieve data saturation. It was decided that it would not be ethically appropriate to engage participants in an even longer data collection process.

Several potential participants withdrew due to the time involved in data collection, thus further data collection with any individuals could have been overwhelming.

The interpretation of data involved elements of analytical and reflexive bracketing (as described by Gearing, 2004), in order to interpret the results with full awareness of potential biases of the researcher, and understanding the interpretations of the participants. Pope et al (2000) argue that taking the participants interpretation can be dangerous, leading to collusion and romanticizing of results. Another difficulty with the typical methods of interpreting and analyzing qualitative data arises when participants are requested to member-check; Pope et al (2000) warn that this can be exploitative, distressing and place an undue burden on participants' time. Considering the time factor involved for participants in this research, the initial data collection process involved "member checking" for interpretation of the life history information and checking the accuracy and interpretation of self-maintenance and diary information This was built into the initial part of the final interview, both as a means to ensure, as far as possible, that the previous information was correctly understood, and also to remind the participant of the information previously provided and the focus of the research topic. Participants were also invited to read the descriptive results and correct any misunderstandings. This is discussed in more detail in sections 5.6.4 and section 5.10 in this chapter.

Reflexivity and consideration of how the researcher would be perceived by the participants in the study (Britten, 1995) were considered. During the interviews, some of the participants made reference to the researcher, in acknowledging or commenting on the fact that she has a guide-dog, is an occupational therapist or has been active in the "disability movement". It is not known the influence of these issues on participants; for some it appeared that knowing that the researcher had been involved in the movement meant that the participant felt that she was speaking to someone who "understood" concepts such as the social model of disability; others commented on the presence of a guide dog as a visible indicator of disability, thus some of the public perception / stigma issues may be similar for the researcher personally. Others were aware that the researcher is an occupational therapist, and at the time of data collection, had recently been practicing clinically with people similar to the participants, thus there may have been a perception that the researcher would "be like" other occupational therapists and have similar views. Wherever it was thought that this may occur, the researcher aimed to ask participants to say what they feel, rather than what they think the researcher wanted to hear. This is discussed further in section 5.12 in this chapter.

Mays and Pope (2000a) suggest that qualitative research can best be judged in terms of its validity and relevance. In terms of validity, it is argued that comprehensiveness is a better indicator of quality than internal validity, and that contradictions can pose further theoretical questions, rather than detracting from a work (Britten, 1995; Mays & Pope, 2000a). An integrated approach was chosen in an attempt to be as comprehensive as possible. The descriptive aspects of the study enable comparison of concrete information between participants, and so that perceptions of autonomy and choice could be understood in a comprehensive, grounded manner.

Mays and Pope (2000b) state that, "in health services research the differences between qualitative and quantitative methods continue to be overstated and misunderstood". There are parts of the methodology where aspects of both qualitative and quantitative methodologies overlap.

> "Whilst there is nothing inherently wrong with descriptive level studies we, as a scientific community, need to do much more in our current research than describe. Indeed, the most illuminating qualitative findings go far further than description: they interpret, explain, and solve problems... Expert qualitative researchers go beyond the words, see past the obvious, access the underlying and the hidden, and enlanguage the often present yet invisible process/culture/experiences."
> (Cutcliffe & McKenna, 2004)

Initially, a number of quantitative options were considered, including attempting to match participants from different settings; using standardised tests, and collecting data from a large number of participants. These approaches were deemed inappropriate. Matching individuals would have been extremely difficult, unless very crude criteria such as age, gender and the place where the person lives were used. Matching would also be meaningless for a study of such complex concepts as autonomy and choice. Use of standardised psychological tests, including those for autonomy (such as the ACL or GCOS) were briefly considered, as were commonly used occupational therapy instruments, such as interest or role checklists. It was decided that the information from these would be less valuable than discussion with participants and information from their daily life. It was felt that such a quantitative, positivist approach would not have been helpful in the present study.

Reflexive aspects of the methodology will be described in section 5.11, suffice to note at this stage that the political and social views and experiences of the researcher greatly

influenced the overall research design, both in terms of the procedural decisions and the greater epistemological and ontological backdrop within which this work is situated. Axiological decisions, for example, not to ask personal assistants or nursing staff for information were made throughout the process, and required reflexive strategies to uncover the value-laden decisions made.

Preparation for data collection

At the start of the research process, ethical issues were considered, and initial information gathering was conducted to ascertain the viability of accessing individuals to participate in the study. Information about the nature of service provision (such as types of residential settings and the nature of personal assistance) were sought. There was also significant informal contact and discussion with people with physical disability and service providers to enrich the researcher's initial thoughts on the work.

In preparation for data collection, a booklet was produced to inform potential participants about the research (see appendix C). The booklet, entitled "Choice and Autonomy in Doing – Research with people with disabilities" includes the following sections:

1. A bit about the Researcher
2. Overview of the research
3. Your rights as a contributor
4. What the process involves
5. What kind of information will be asked?
6. The interviews:
   Interview 1
   Self-Maintenance Activities
   Diary Information
   The final interview
7. Some more answers to questions
8. Contacts.

Ethical Considerations

At the time that this research began (end of 2002 / beginning of 2003), there was no formal ethics procedure for research within the Health Science Faculty of Trinity College Dublin, therefore ethical approval from the University was not specifically sought. Ethical approval was, however sought from service providers for access to the population.

Several steps were taken to maximise the ethical standard of this research. This was considered essential, particularly given that some of the participants are traditionally considered "vulnerable", such as those living in residential settings.

Informed Consent

The booklet "Choice and Autonomy in Doing – Research with people with disabilities" (see appendix C) was produced to provide potential participants with information on the study. This booklet was designed to give full, clear information about the study and what is involved in participating. It was written following guidelines for Clear Print and Plain English. The booklet was made available in clear print, large print, electronically (via e-mail) and on audio cassette.

Participants were accessed through the various service providers (see section on participant selection below) and given an introductory letter, with a form of interest for them to request the booklet. Participants were assured that requesting the booklet was not agreeing to participate. Those requesting the booklet were sent it in the format of their choice (clear print, large print, electronic or on audio cassette).

One week after sending the booklet to potential participants, they were contacted asking if they were interested in participating, and if they had further questions. A number of people decided not to participate in the research upon receipt of the booklet, due to the lengthy nature of data collection.

At the start of the first interview, participants were asked if they had further questions, were reminded of their rights as contributors and permission was sought to record interviews. Their verbal consent was taken as consent to participate. As a significant proportion of participants or potential participants' physical disability is such that they would be unable to sign a consent form, it was thought that this format for seeking consent was inappropriate.

Anonymity of Participants

To protect the anonymity of the participants, those who completed the data collection process and whose information is used in this research were assigned a number, e.g. "Anna", "Bart" and so on.

The setting where the person lives was not included in the data. Participants' living circumstances were described, such as "living in the community" or "living in a residential setting".

The information given to participants in the booklet about their anonymity was as follows:

> You will remain anonymous.
> As a participant, your information will be assigned an identification number. Your name, the place where you live, or other personal details will not be recorded at all with your information.

Confidentiality

This study provides detailed description of the participants. This is thought necessary as a means to interpret their information. However, such detail does have an impact on the confidentiality of findings, and more particularly how identifiable participants are. This is particularly concerning as the number of people with physical disabilities living in each type of setting is relatively small, and considering that some of the individuals may be identifiable to people in organisations with which the participants are involved.

Strategies to protect the confidentiality of the participants include:

- Removal of details such as where the person lives;
- Removal of specific information, such as names of suburban areas, schools and specific place names;
- Removal of the names of organisations or specific job titles;
- Removal of information that identifies the person specifically, where applicable (such as noteworthy achievements).
- This information was removed as part of the transcription process and descriptors were inserted into the text in square brackets (e.g.[suburban area]).

The transcripts of the material were kept on password protected computer, and hard copies, when printed were kept in a locked area.

In the booklet, participants were also ensured that:

> Your views will not be used for any other purpose.
> Any information, opinions of views that you give during the course of interviews will not be shared with anyone outside the research and will not be used for any purpose other than to inform the findings of this research.

> You have a right to dignity and privacy.
> The nature of research is to find out about people's lived experiences. This research method is designed to collect a lot of information, but should not be too intrusive. Your dignity and rights will be respected, and all information is strictly private.

Participants' right to withdraw

Participants were assured of their right to withdraw from the process at any stage. Some, in fact, did withdraw during data collection.

> You are free to pull out at any stage.
> Pulling out of the research will not affect you in any way.

Harm and beneficence

A key principle of research is the need not to cause harm to participants. It is possible that harm could have been caused due to the nature of questioning. Strategies were put in place to minimise the likelihood of participants becoming distressed, and to manage any distress should it occur. The strategy involved the following steps:

All interviews were conducted by the researcher, who is a qualified occupational therapist with a number of years clinical experience, some of which was working with people with physical disability that could form part of the population. The usual ethical standards of interaction were employed when interviewing.

The participants were informed prior to the data collection, what kind of information would be sought. This was to prepare them to give what information they wish, and so they were not surprised by the line of interviewing. This information was included in the

booklet, and was also given verbally immediately before each period of data collection. Some potential participants chose not to give information about a specific topic. (Where this is significant, such as the participant who did not want to give information on self-care activities, they were removed from the study).

Participants were informed that they could stop the interview at any time. If and when a participant became distressed, the researcher stopped questioning the participant about the particular topic, and where necessary, stopped the interview procedure. Support was available to the participant should he / she become distressed.

Participants

A number of methods to recruit participants for the study were considered. Barbour (2001) highlights that within qualitative research, diversity within a population is sought, rather than aiming to have a statistically generalisable or representative sample.

Convenience sampling was an option to seek participants, and is frequently used in qualitative research, in cases where the population may be difficult to access (Barbour, 2001). It was feared that this would lead to very different groups – the "convenient" people living in the community would necessarily have been somewhat active in the disability movement or organisations of disabled people, for the researcher to come into contact with them. Those living in residential settings would be unlikely to have been part of the disability movement, thus, rather than having a range of people involved, there may have been two groups – "activists" and those living in residential settings.

Theoretical, or purposive sampling was also considered. In this approach the researcher would have sought specific difference amongst participants so that the different accounts could be juxtaposed (Barbour, 2001). At the start of data collection, it was not entirely known what the critical areas of difference would be, apart from demographics, such as age, type of disability or setting. Together with the lack of clarity of the key theoretical differences, very little information was initially known about participants. Therefore it was thought that solely recruiting participants using a purposive method would not have been manageable.

A combination of random sampling and purposive sampling were used, as well as participants self-selection. There are weaknesses in this approach, but given the ontological and epistemological assumptions of the work, it was considered adequate for the work.

As this research seeks to explore the meaning and lived experience of autonomy for people with physical disabilities, participants were selected who:

- Have significant physical disabilities, i.e. those who use a wheelchair some or all of the time for mobility and who require some assistance with self-care activities. The term "significant" physical disability was open to the participant's own interpretation, however, participants were sourced through service providers such that the services provided are those to meet the needs of people with significant disability.
- Do not have cognitive impairment. As the nature of the research topic is somewhat abstract, it was felt necessary to only include participants who are cognitively able to discuss such abstract terms as autonomy, choice, independence and control. This was assessed by an initial informal conversation, through e-mail (1 participant), over the telephone or in person with a number of potential participants. Those that were unable to discuss independence in broad terms were not invited to participate. Despite this initial conversation, one participant's results are not included in the findings, due to a definite inability to discuss abstract concepts and ideas once data collection began. It was found that in residential settings, it was difficult to find younger residents to invite to participate in the study.
- Are aged between 18 and 65 years at the time of initial data collection. This was because services differ greatly for those under the age of 65 and over the age of 65, and age-related disability was not intended to be the primary disability experience.
- Live within a specific geographic area, (i.e. the greater Dublin area). This was for convenience so that the researcher would be able to interview the participants.

Initially, it was proposed to select individuals based on their living circumstances, so that the perceived impact of the environment on their lived experience of autonomy could form part of the exploration. The number of participants means that no comparison of living

situations or causal relationships could be investigated nor was this ever intended; the purpose is to ensure a diverse sample.

Three discreet groupings were initially proposed:

- people living in the community availing of personal assistance;
- those who live in "supported living" or group home arrangements, and
- those living in residential settings.

These groups were identified (along with others, such as those with cognitive impairment or challenging behaviour) as specific, differentiated groups within the Health Service's report on the housing and support needs of the "Young Chronic Disabled" (ERHA, 2003). It was thought that each of the environments would be qualitatively different, thus provide for different experiences of autonomy.

The differences in the environments were expected to relate to:

- the type of assistance provided - those in independent living use personal assistance, and manage the tasks of their assistant; those in supported living were expected to avail of a pool of assistants associated with the setting, and those in residential settings are assisted by nursing staff;
- The physical environment – those living in independent living were expected to live in the community in private dwellings; those in supported living were expected to live in either group home arrangements or self-contained units on a larger site, and those in residential settings were expected to live in single- or multi-bed ward-like rooms, within a larger institution.

During data collection, it was found that the settings that were classified as "supported living" could not be considered qualitatively different from residential settings, as the form of assistance and even the physical structures were very similar to those found in residential settings. It was decided to merge the supported living and residential settings groups. Thus, for data analysis the two different environmental contexts are "independent living" and "residential".

Independent Living Group

Those living in the community were recruited through the provider of the personal assistance service. A random selection of those using personal assistants were sent letters of introduction from the researcher, with a form which could be used to request more information (the "Choice and Autonomy" booklet).

The selection was made by the researcher generating random numbers, and sending these to the service provider, who then selected the service user in the database corresponding to the number generated. The service provider initially filtered the database so that only users living within the geographical area could be selected. 50 service users were sent information about the research, with a request to participate.

"Packs" of information were prepared and forwarded to the service provider by the researcher (containing introductory letters, the form of initial interest, a stamped addressed envelope for participants to return the forms, and a stamped envelope for the service provider to use to send information to potential participants). The service provider sent the packs of information to service users as per the random selection.

Information about the research was published in the magazine of a disability organisation. This was to raise awareness about the research, rather than as a means of recruiting participants. This appeared to generate some interest, and a number of people contacted the researcher seeking more information. This enabled the researcher to have preliminary discussions with disabled people to help form the research focus, and also to better understand the reality of services available for people with physical disability.

Forms of interest were returned to the researcher, who then sent the potential participants the "Choice and Autonomy" booklet in the preferred format. One week after the booklets had been sent to potential participants, they were contacted to find out if they had further questions and if they wished to participate in the research.

Residential Settings

Those living in residential settings or supported independent living were recruited in a different manner to those living in the community.

A list of residential services within the greater Dublin area was drawn up, and information about the services was sourced (such as numbers of residents, age etc. Managers of the services were contacted to ascertain whether there are residents that fulfil the inclusion criteria in the setting.

The researcher wrote to, and met the directors / managers of residential services. Information about the research was provided to these managers. A time to meet residents was requested, and the researcher presented the research and booklets to those interested. In a number of settings, the management also approached residents on behalf of the researcher.

Residents were directly given the "Choice and Autonomy" Booklet, an initial discussion took place (for the researcher to assess whether or not the complex issues could be discussed, and so that the potential participant could know more about the research), and contact details were sought. One week later, residents were contacted again (typically the researcher went back to the setting) and asked if they wished to participate. Times for meeting were arranged.

Participants selected

There appeared to be significant interest in the research initially, especially from those living in the community. However, the nature and length of data collection was off-putting to over half of those who showed initial interest.

It was hoped that the participants from both settings would form a diverse group, in terms of their age, the type of disability / impairment, their educational and social background, and also for there to be a mix of men and women. Thus, for the initial selection, there was

an element of purposive or theoretical sampling, which was made possible following initial contact (phone / e-mail / face-to-face) with the potential participants.

Data collection began with 16 people. Of these, 8 were living in the community and 8 were living in residential / supported living settings.

Four from each setting were male, the remainder were female. Half of the original participants in each living situation had congenital disabilities, the remainder had acquired their disability in their teens or later.

It is not possible to report on all of the initial participants, because:

- Three died either during (1) or after data collection (2).
- The information from one participant was such that it was evident that the person had a cognitive or intellectual disability, meaning that discussion of the abstract concepts was impossible, and the results were not meaningful;
- One moved away during the course of data collection, and so could not complete the process.
- Three did not complete the data collection process fully (typically, diary information was not fully recorded.

A disadvantage of not reporting incomplete participants' results is that a significant amount of information is consequently "lost" to this report.

As part of the data collection involves diary information, the researcher was interested in all diaries being kept at a similar time, to remove differences (such as the summer weather meaning it is more possible for a person to go out etc.) While this approach is more aligned with a positivistic quantitative epistemology, it was felt that social, political and weather factors were worth considering. Therefore, following the withdrawal of some of the participants, no further participants were recruited.

The results of eight participants are included in this report, of these 4 live in residential settings and 4 in the community; there are two men and six women,

A weakness of this research is the relatively small number of participants, and further the complexity or length of the data collection method, which resulted in it being too great a task for a number of people interested in the research.

Development of data collection instruments

As this research seeks to explore the daily life experience of eight adults with significant physical disability, with a particular focus on their experience and perceptions of autonomy and choice in everyday life, and as the literature suggests that autonomy is a highly subjective experience, developed throughout the life-span (Agich, 2003), data collection needed to include background information on participants (life history), a description of their actual lived experiences and also an exploration of the meaning of the concepts of autonomy to the individuals.

Several options for data collection were considered, but finally a four-part data collection method was used. There appeared not to be one tool or method that has been previously used that could be used for this study, and given the epistemological backdrop, it was felt appropriate that the data collection methods were developed by the researcher, concurrently with initial discussions with disabled people and service providers.

Initial interview

It was decided that the initial interview would be semi-structured and qualitative in nature, with the aims of: understanding the participant's life history narrative; gaining a brief description of the participant's experience of their physical and social environment and establishing the best methods to collect further data. The environment in which the person lives was also observed in this initial session. It was also hoped that, through this interview, rapport would be built so that subsequent phases of the data collection could follow.

> "Qualitative interviews are widely and often uncritically adopted for health care research, with little justification of therapeutic value. Although they might provide valuable insights into the perspectives of participants, they represent only a version of reality, rather than "truth" per se. Qualitative research is vulnerable to bias through the

> attitudes and qualities of the researcher, social desirability factors, and conditions of worth. Exploitation, through role confusion, therapeutic misconception, and misrepresentation are particular risks for health care-related research. "
> (Hewitt, 2007)

While Hewitt (2007) appears to adopt a more positivistic epistemology than the current work, the point remains that use of "semi-structured interviews" is widespread and lacks clarity, and the influence of the researcher may be significant (Barbour, 2001)

Britten (1995) differentiates between three types of qualitative interview, these being structured, semi-structured and in-depth. A semi structured interview, according to Britten (1995) is one that has a "loose structure consisting of open ended questions that define the area to be explored, at least initially, and from which the interviewer or interviewee may diverge in order to pursue an idea in more detail". A semi structured approach was chosen for this research for a number of reasons. It allowed the interview to include areas considered central to the question, while also allowing the participant to discuss other areas of concern. It was considered the most time-appropriate method to achieve in-depth information – an unstructured interview may have yielded more in-depth information, but it may have necessitated longer or more interviews; structured interviews may have been shorter, but would not have allowed for as much exploration of issues, or other areas to be raised. Also, as it was the first interview of a lengthy, time-consuming involvement for participants, it was felt that a semi structured interview would most promote rapport and trust between researcher and participant.

The first interview was initially based on the second version of the Occupational Performance history Interview (OPHI-2) (Kielhofner & Henry, 1988), which involves a life history narrative. Following pilot-testing it was found that this interview format was not specific or sensitive enough for the present research, and as large adaptations in the line of questioning were made, it was felt that the interview no longer closely followed the OPHI-2 format. Use of the rating scales associated with this interview were deemed unsuitable, as judgement of an individual's adaptation is required, which is tangential to the research question and was considered methodologically dubious as a constituent of research, rather than a clinical tool.

The interview format was semi-structured, beginning with the question, "can you tell me a bit about yourself". The structure or themes to be discussed are included in Appendix B. Topics such as educational and work history, how the person came to live where they do,

course of their disability were discussed. Participants were also asked, in relation to the above topics, whether they consider that they have choice and autonomy in their everyday lives.

Britten (1995) suggests that good questions in qualitative research are open ended, neutral, sensitive and clear, and that ideally a simple question that is easy for the participant to answer forms the start of the interview. The initial question in this interview was not simple ("can you tell me a little about yourself, please?"); however it was aimed at allowing the participant to describe themselves in their own terms, with minimal influence from the researcher.

The interviews all took place in the setting of the participant's choice, typically where they live. The length of interviews ranged, but were all over one hour. All but one of the interviews was recorded and transcribed. The one that was not recorded on minidisk involved the participant using assistive communication technology, and the time lag meant that recording was impossible. For this interview, notes were taken by the researcher using a laptop computer.

Self-maintenance

The second part of data collection involves self-maintenance information. The research focuses on a person's experience of choice and autonomy, and as all of the participants necessarily require assistance for self-care tasks at least some of the time, it was considered important to capture their experiences in this aspect of daily life.

Combining self-care with other diary information was considered, but it was found that this would be very repetitive for participants (as they would need to record the same daily information multiple times). The decision to separate out daily routine tasks is not to emphasise them; rather to enable participants to focus on non-self maintenance tasks when keeping diary information, while also ensuring that this information is captured for the research.

Apart from the aim of understanding the participants' experience of choice and autonomy in daily self-care tasks, a person's ability to perform such tasks independently has also

been used as a description of the level of disability, such as use of the Functional Independence Measure (FIM) or the Barthel Index. Use of both / either of these tools were considered to form part of the data collection method, but this was thought to be inappropriate as both measures require judgement of a person's ability in performing the self care tasks. The purpose of this work is not to judge a person's ability to perform tasks, rather to understand their experiences of performance, specifically the extent to which they feel autonomous in the performance. It would also have been difficult for the researcher to observe all participants in self-care tasks, and inclusion of others (such as nurses or assistants) was not considered desirable.

It was decided that description of the participants' abilities and how assistance is used would provide the most useful information for this study. Information about the assistance required for self-care was thought to complement observation as a crude indication of disability status. Only a broad description of physical ability was felt necessary, as the focus of the research is on the participants' experiences of choice and autonomy.

The options of asking participants to complete a questionnaire / diary style information or the use of an interview were considered. It was felt that using an interview would enable the researcher to collect more information, and specifically probe participants to describe their experiences of choice and autonomy in the activities. A semi-structured interview was designed, based on a tabulated diary-type format. Participants completed the table, and then this was discussed in an interview.

The key elements in relation to self-care activities relate to whether a person: uses assistance; has choice about the manner in which they are assisted, and feels that they have choice in the way that they perform self-care activities.

Information was collected using the interview and table (see Appendix B) for most of the participants. Some participants completed the tables independently of the researcher, and this was followed by interview. For others, the information was included in the table by the researcher during the course of the interview.

Table 5.1: Self-Maintenance Activities.

NOTE: The formatting of this table has been changed, in the original version, the table appears in landscape format. See Appendix B.

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No

Diary information

The third part of the data collection method involves diary information. As this research focuses on participants' experiences of autonomy and choice, information on participants' lifestyles and occupational patterning was considered important, both in its own right and to enable discussion of participants' perceptions of their lifestyles and sense of choice and autonomy.

As described above, the diary information was separated from the daily self-care activities to avoid repetition.

A number of techniques to get occupational patterning information were considered. It was felt that diary information would yield the most accurate picture of lived experience of the participants, and give a firm foundation from which the concepts under study could be examined. Within the Model of Human Occupation tools (Kielhofner, 2002), a three-day diary assessment is included, namely the Occupational Questionnaire (Smith et al, 1986). This was considered, but three days was not thought to be sufficient information for the purpose of this study.

Additionally, while there are tools based on diary information, the questions of choice and autonomy that are central to this research seemed not to be included. This part of data collection was influenced by other instruments, but it was felt that no existing tool was specific enough, so a new tool was created.

Key elements of the diary information tool include: the proportion of time that is considered to be work, self-care or leisure; whether the person performs occupations alone or with other people; whether they have choice in and control over the occupations in which they engage, and how important these occupations are to the person.

Table 5.2 Diary Activities.

NOTE: The formatting of this table has been changed, in the original version, the table appears in landscape format. See Appendix B.

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Final interview

The final interview seeks further elaboration of self-care and diary information, as well as discussion about perceptions of choice, autonomy and life satisfaction. The primary aim of this final interview is to explore the concepts of choice and autonomy within the context of the participants' lived experience.

The interview has the following sections:

- Participants are asked to verify interpretations of their life history narrative and information in the diary and self-maintenance sections.
- Participants are asked to explain what autonomy and choice mean to them.
- Discussion of self-maintenance activities, as recorded in the interview, in relation to satisfaction with the activities, assistance used, autonomy and choice.
- Discussion of diary information, as recorded by the participant, in relation to how typical the activities are, the participant's enjoyment of the activities, satisfaction with the week's activities, and factors that enabled and hindered occupational performance.
- Discussion of lifestyle in general, including satisfaction with lifestyle, feelings about choice and autonomy in daily life, and deterministic questions about lifestyle.
- Scale based on a semantic differential, where the person is asked to rate their present lifestyle and their ideal lifestyle.

The rationale for the final interview is to "pull together" the various aspects of the data collection method, and to explore the participants' perceptions of their lives, and their sense of autonomy and choice. This interview enables the researcher to move from purely descriptive aspects of the information to a deeper interrogation and interpretative approach.

A secondary aim of the final interview is to check the accuracy of previous parts of the data collection method, such as interpretation of the initial interview, diary information and self-maintenance information.

Several options for collecting information about participants' satisfaction with their lifestyle were considered, including measures of quality of life. A further in-depth interview was not thought to be practical, given the volume of data already collected from participants.

As described in section 5.2, assessments of autonomy were considered, but it was decided that these would not be used. This decision was made partly because there may be physical difficulties for the participants in completing standard assessments, it may undermine trust between the participant and researcher, and also each test has limitations

and relates to a specific concept of autonomy, such as the GCOS relates to "self-governance" autonomy and the adjective checklist (ACL) measures agentic-separation autonomy (Hmel & Pincus, 2002). Thus, the specific tool used would measure the extent to which participants exhibit one concept of autonomy, rather than enabling an understanding of what autonomy, choice and control mean to the participants.

The semantic differential scale was created as a means whereby lifestyle ratings could be captured, and compared between participants. The concepts under scrutiny in the scale are "present lifestyle" and "ideal lifestyle". Fourteen pairs of polar opposite words were placed at either end of a continuum. For each pair, participants were asked to rate their current and ideal lifestyle. Table 5.1 below is an example of the semantic differential.

The words included in the scale broadly fit into the categories of "good/bad", "weak/strong" and "active/passive", as described by Bandura, based on work by Osgood et al (1957). The ordering of the words was randomised, in that some "active/strong/good" components of pairs were to the left, and others to the right. This was in an attempt to reduce the likelihood of judgements being assumed.

Each of the participants completed the form during the final interview. One participant was e-mailed the scales to complete, all others used the researcher's laptop to view the scale and delete the appropriate number, or tell the researcher which number to delete.

Table 5.3 The semantic differential used.

NOTE: The formatting of this table has been changed, in the original version, the table appears in landscape format. See Appendix B.

How would you rate your lifestyle and the things that you do now?						
Varied	1	2	3	4	5	Monotonous
Boring	1	2	3	4	5	Interesting
Bad	1	2	3	4	5	Good
Fulfilling	1	2	3	4	5	Unfulfilling
Sedentary	1	2	3	4	5	Strenuous
Challenging	1	2	3	4	5	Unchallenging
Idle	1	2	3	4	5	Busy
Active	1	2	3	4	5	Passive
In company	1	2	3	4	5	Alone
Outside home	1	2	3	4	5	At home
Satisfying	1	2	3	4	5	Disappointing
Lots of free time	1	2	3	4	5	Little free time
Weak	1	2	3	4	5	Strong
Full of choice	1	2	3	4	5	No choice

Pilot testing

The data collection method was piloted on two participants, both of whom form part of the population. One was male, living in a residential setting and the other was female, living in the community.

The pilot testing revealed that the data collection process is more lengthy than initially anticipated. At the time of pilot-testing, the initial interview was based on the OPHI – 2. It

was following the pilot testing that it was decided that this format was not specific enough to the research question, and that use of the rating scales is inappropriate.

Other issues that pilot testing raised were:

- The sequence of questions in the final interview was not entirely logical, which meant that the interview was somewhat disorganised and didn't "flow" as well as it could have. Following pilot-testing, the final interview questions were grouped into sections, including self-maintenance, diary questions and questions about lifestyle in general.
- The diary information and self-maintenance information is somewhat difficult for participants to collect. Prior to the pilot testing, it was envisaged that the majority of the self-maintenance information from participants would be collected by participants completing the forms independently. The pilot studies showed that interview enabled the researcher to supplement the descriptive information that would have been completed by participants independently with further more detailed information that specifically relates to autonomy, choice and control.
- A method of analysing information was created using Microsoft Access, for the pilot test results. It was found that this approach was labour-intensive, and did not capture the information in an easy to use, appropriate manner. Following analysis of the pilot interviews, it was decided not to use this programme, rather to analyse information by hand.
- There was no mechanism for keeping field notes with the pilot participants, and it was felt that this, alongside a log of the research process would add depth to the process. A format for recording field notes after the first and final interviews was drawn up, and included with the data collection method.

Data collection and maintenance of log

Data collection began in September 2003. Participants were concurrently sought from the community and residential settings, so data collection took place with individuals from both types of setting at similar times.

Participants were typically interviewed where they live, but some interviews also took place outside participants' homes, two in coffee shops and one in a respite centre.

The data collection with each participant took place over a minimum time period of one week. For some participants, the time interval between the first and final interview was up to four weeks. This was to facilitate completion of the diary information and to arrange meeting times that suited both the participant and the researcher. During the intervening week/s, the researcher contacted the participants to find out how they were managing diary information, and also constructed a draft interpretation (with questions) of the life history.

Self-maintenance interviews were conducted with participants shortly after the initial interview, and the information was directly inputted into the tables in Microsoft Word, on the researcher's laptop computer. Participants were encouraged to look at the screen to check the accuracy of the information being inputted. Some participants completed the self-maintenance tables alone, and the content of these was discussed at a later interview.

Diary information was collected by participants, by hand, on computer or in another diary format, to suit the individual.

- Those who kept the diary by hand, completed their information directly onto the diary information tables, which were printed out and given to participants after the first interview. The tables of hand-written information were returned to the researcher prior to the final interview.
- The tables of information were e-mailed to some participants, who kept information electronically. These participants returned the completed forms by e-mail, prior to the final interview.
- Some participants chose to keep the diary information in another format, for example, one preferred to just take notes using her own computer. They all had access to the tables (in printed form) while keeping the information. Information from these participants was collected by interview, the researcher completed the tables on the laptop computer, while interviewing the participant.

The diary and self-maintenance information was checked, and identifying details were removed, to protect participants.

> "The origins of audit trails in qualitative research appear to reside in the work of Lincoln and Guba (1985). In their influential publications, Lincoln and Guba (1985, p. 318/319) regarded audit trails as one of the principal techniques for establishing the 'confirmability' of qualitative findings... We argue that using audit trails as a means to achieve confirmability of qualitative research findings is an exaggeration of the case for method, and may do little to establish the credibility of the findings... Whether included purposefully or otherwise, the rationale underpinning the need for audit trails reflects, at least in part, positivistic concerns and thus can be seen to be addressing claims about lack of control, validity and bias."
> (Cutcliffe & McKenna, 2004)

Despite Cutcliffe and McKenna's (2004) concerns, a log of the research was maintained, but this was not audited by someone outside the research. The purpose of the log was to record the research process, including decisions made. It was felt that the maintenance of such a log also enabled the researcher to be more reflexive throughout the process.

Data Analysis

Pope et al (2000) state that,

> "Transcripts and notes are the raw data of the research. They provide a descriptive record of the research, but they cannot provide explanations. The researcher has to make sense of the data by sifting and interpreting them."

Initially, the information from interviews was transcribed, and tables of information were completed for each participant. This involved creating a large word document with all aspects of data from each participant, labelled "raw participant [number]".

This section describes the manner in which the data, including field notes, were used and analysed.

Data from interviews

Following reflexive readings (as described in section 5.11), the transcribed interview material was analysed using a number of approaches. There were a number of parts to the initial interview, such as the participant's life history and experience, as well as their account of their disability. The first stage of analysis of the interview material is to extract the demographic-type information. This was summarised and part was included on a separate cover sheet for each participant.

The second stage of analysis of the initial interview transcripts involved identifying themes from the content. Some themes or topics were raised by the researcher in questioning; others were raised by the participants themselves in the course of the interview.

Each interview was initially analysed separately, in a case-study type approach. Themes were created, and excerpts within each theme were included. This was done using multiple Word documents and a "copy and paste" approach. The documents were related to each emergent theme. Within each theme, a constant comparison approach was used, whereby several extracts about a given theme were compared to each other. In some cases, sub-themes were also created. Care was taken to create meaningful themes, as categories for data are considered vital (Orford, 1995), all data were categorised in some manner, avoiding what Good and Watts (1989) describe as "waste basket" categories.

As a narrative approach was being used, particular attention was paid to identifying metaphors used by the participants. The entire transcripts were searched for examples of metaphors, and self-descriptions that support or negate the stated metaphors.

The final interview was also transcribed, where appropriate, and the verbatim extracts of interview material were also themed. This was frequently a simpler process, as the final interview was more structured than the initial interview. Where themes converged with those identified in the initial interview, these findings were included with the analysis of the initial interview.

A mixed method was used to interpret themes. This partly involved understanding the information from the viewpoint of the participant, i.e. inductive analysis (Pope et al 2000). These findings are particularly presented in chapters 6 and 7.

The transcripts were coded and re-coded, although a rigid "code-recode" approach was not used. The data collection and analysis took place over the course of five years, thus necessarily, the researcher needed to re-read and re-review transcripts and themes of information for each participant. As described by Britten (1995), original interpretations of information change throughout the research process. In order to capture this evolving process of interpretation, a number of Microsoft Office files were kept in a "thinking folder".

In these files, thoughts, comments and interpretations were gathered. These were then compared to the themed information directly from the transcripts. Over time, it was found that some of the initial interpretations may have changed somewhat, thus the possible explanations or insights has broadened. As described by Britten (1995), this allowed further exploration and coding of material.

The interpretation of data, as with many qualitative research approaches, also took place concurrently with data collection, as the researcher was meeting and interviewing the participants (Pope et al, 2000; Seale & Silverman, 1997). Insights and ideas formed immediately after the interview, as well as observational data were recorded in the "Field notes". (See Appendix B for full data collection method, including field notes). The field notes from the initial interview, any information from the individual, service providers or staff in residential settings, and observation were used together to form detailed descriptions of the living situation of the participants, described in Chapter 6, for each participant.

The maintenance of field notes and a "thinking folder" of thoughts enabled the researcher to probe deeper if areas after the first interview were unclear. For example, one participant described a role that she had assumed, without providing adequate information to interpret this role; the log and questions arising after the initial interview led to further questioning about this topic at the start of the final interview.

The final part of analysis of the interviews (both the initial and final interviews combined) used a process similar to constant comparison, whereby each description of autonomy and choice are compiled for all of the participants and checked and compared with the information on the theme from other participants, or within other sections of the same participant's interviews.

A significant limitation to the analysis of the interviews is that they vary in length and type, particularly considering one participant used augmentative communication technology to engage in the first interview, and had e-mail conversations for the remainder of the data collection method. Also, as several of the participants experienced fatigue, the interviews may have been shorter or in less depth than ideal. Another limitation to the analysis of information was the accessibility of materials for the researcher – it was necessary to do

all analysis using accessible computer programmes (primarily Word) rather than being able to map or chart qualitative findings as described in the literature.

Using a computer programme to analyse the interview data was considered, but it was decided that this would not be the ideal method. Analysing data by "hand" had several benefits: for example, it allowed the researcher to become very familiar with the content. Another potential difficulty of using computer programmes was the accessibility of the programmes when used with screen reading software.

Self-maintenance information

The information from the self-maintenance section is primarily descriptive. It provides a picture of the participants' daily routine activities in terms of what has to be done, how it is done, how long it takes and the level of assistance used. Of key importance to the research is an understanding of the extent to which participants have choice in how they are assisted, and choice over the activities.

The self maintenance information from interviews and from hand-written records were compiled in the self-maintenance tables (See Appendix B). A mixed method approach was used to analyse these data. The total number of activities listed as self-maintenance were counted. The locations of the activities and times involved are also recorded. For some participants, all self-care activities take place in the same area, for others a variety of locations are used. This information is particularly used in conjunction with the aspects of the final interview where participants are asked for their perceptions of their occupational performance, and the discussion of their perceptions of the environment in the initial interview.

The description of assistance is recorded for each activity. The type and proportion of activities that assistance is used for, and the manner in which assistance is provided is documented. This information is presented broadly for each participant in Chapters 6 and 7 (in case-study format), and is also discussed for the participants together in comparative terms in chapter 8.

During the interviews, a detailed record of the participants' responses was kept, with verbatim comments documented. In some cases, these comments are as useful in exploring the participants' perception of their unique situations as the actual categorised answers. For example, when asked "do you have control over this task", responses of "Of course I do!", and "Yes, I think I probably do", are both recorded as "yes"; whereas the qualitative strength of the statements is very different. Similarly a response of "I have never even thought of it", could be followed by either a "yes", a "some" or "no", but its implication or meaning is different to those who may have been highly concerned about the amount of control that they have.

Following analysis of the information, the self-maintenance tables for each participant were standardised, extra information and identifying details were removed, and the completed tables are presented in Appendix A of this report.

Diary information

A number of methods of analysing the diary information were attempted, before a uniform approach was reached.

Initial analysis of the diary entries is purely descriptive, there is simple counting of:

- The number of activities;
- The numbers of self-care, productivity, leisure and mixed activities;
- The number of activities that are performed alone or with someone;
- The number of activities that the participants find important, enjoyed and had control over.

The time element was only used as an indicator of the total amount of time recorded in the diary, and as a means to compare proportions of time involved in different types of activities. Many of the participants did not keep accurate records of time, so these were not extensively used in the analysis.

Each of the different activities recorded by the participant were entered into a Microsoft Excel Worksheet. Some participants recorded the same activity a number of times. Where exactly the same details pertain to multiple entries, then the number of occurrences is recorded. Frequently, participants may state the same activity (e.g. reading), which is sometimes recorded as leisure and other times as productivity; sometimes is performed in one location and other times in another location; is important or enjoyable in some entries, but not in others. When this occurred, the activity was entered multiple times, to capture the differences.

Final interview

The final interview was structured, and so the researcher took notes, completing these into the computer as the participants spoke. Additionally, the final interviews were recorded and transcribed.

The information from the final interview was initially crudely coded, based on the question. The interview is in a number of discrete sections, including perceptions of autonomy and choice, self-maintenance, diary information and lifestyle in general.

The crude coding involved compiling notes from the computer and transcripts from each section. In the case of diary and self-maintenance sections, this information was collated with information collected at the initial interview and the self-observation material recorded in the self-maintenance/diary tables. This gives a more comprehensive picture of the participants' experience of the tasks involved, and also their autonomy and choice in these activities. A constant-comparison type of analysis was then performed with collated information. The combined information is presented in chapters 6 and 7.

Information about perceptions of autonomy and choice were collated with information about lifestyle in general. An analysis of the initial interview data to draw perceptions was also performed, and these two sources of information were integrated. This gives a more comprehensive view of the person's perceptions, and a constant comparison type of analysis was performed. The participants perceptions of their lifestyle in general, including the meaning of choice and autonomy are presented in chapter 7.

Semantic Differential / Lifestyle Ratings

The scores from the semantic differential lifestyle ratings were recorded directly onto the laptop computer with the participants at the final interview for all but one of the participants. The other participant recorded his results and e-mailed them to the researcher.

The randomised order of the paired words was changed, so that a high value equates to a good/active/strong word, and a low value to bad/passive/weak. This was done for ease of analysis and interpretation.

For each individual, the scores for each pair were recorded. The number and name of "extreme," "some agreement" and neutral responses was recorded, for both the current and ideal lifestyle. This gives a description of the participants' perception of their current and ideal lifestyles.

The difference between the current and ideal lifestyle scores for each participant were calculated, giving an indication of which aspects of the individual's current life differ from what they would ideally like.

The data (scores for current and ideal lifestyles and the difference) for all of the participants were entered into a pivot table in Microsoft Excel for analysis. This was used to analyse the results of the group as a whole. The current lifestyle ratings, the ideal lifestyle ratings and the difference between current and ideal of the individuals were compared. Also, the rating of each semantic pair is analysed.

Interpretation of the ratings is compared with comments from the participants, both that directly recorded after the rating was completed, and information in the interviews and self-maintenance/diary information. The interpretations of the ratings were compared to the other information in a form of constant comparison analysis. For example, if a participant rates their life as being very active, the level of activity recorded in the diary information, and their discussion of their level of activity from the interviews were compared.

Information from the semantic differential / lifestyle ratings are discussed, along with the interpretations compared to the other data, in chapters 7 and 9.

Field Notes

Field notes were recorded shortly after each interview or face-to-face contact with each participant. The format for the field notes was developed, following consultation with literature about ethnographic methods in qualitative research. An example of the format for field notes is contained in Appendix B.

The field notes were used as a reminder for the researcher of the details of data collection. Additionally, the "hunches" and overall themes and feelings that arose immediately after data collection and prior to transcription and analysis of interviews were compared to the themes that arose from interviews following analysis.

Participant Verification

One common approach to promoting rigor is participant verification, or member-checking of data (Pope et al, 2000; Krefting, 1991; Mays & Pope, 2000a) This can take the form of participants reviewing the themes / analysis of interviews or the entire transcripts (Mays & Pope, 2000a).

There are a number of arguments for and against sharing transcripts and data with participants of qualitative research, as a means to improve rigour (e.g. Krefting, 1991; Barbour, 2001; Koch & Harrington, 1998; Curtin & Fossey, 2007) but that may cause distress or undue burden on participants (e.g. Forbat & Henderson, 2005; Mays & Pope, 2000a). Curtin and Fossey (2007) argue that researchers can discover how fair, accurate and valid data analysis is through member-checking.

Providing participants with full transcripts of the interviews was considered, but it was decided that this would not take place, although participants would be provided with transcripts upon request. No participants wanted to see full transcripts.

Mays and Pope (2000a) identify some weaknesses In participant verification. The researcher's account will necessarily be different from that of the participants, simply due to their different roles in the research (Mays & Pope, 2000a). The member checking produces new data, which can be useful in "error reduction", but the new information generated also needs to be interpreted (Mays & Pope, 2000a). Despite these concerns, some form of participant verification was required.

The first form of participant verification that took place was undertaken before the final interview, where the researcher clarified interpretations of the life-history narrative, and also clarified information relating to the diaries. The results of this participant verification were assimilated into the information presented for both the life history and the diary information.

Forbat and Henderson (2005) highlight a number of epistemological and ethical issues with sharing transcripts with participants, and with sharing representations of participants to themselves. Some of these issues, such as the possibility that participants have "moved on" from where they were at the time of the interview are relevant to this research.

Participants were asked to comment on the conclusions and representations made, bearing in mind the time lag between data collection and participant verification. Their comments, where given, are included in Chapter 9 and reflect the changes that have occurred in each of the participants' lives. The purpose is therefore not to ask participants to confirm the content that was spoken or transcript (which raises epistemological issues in itself (Forbat & Henderson, 2005)), but rather assess the accuracy of interpretations and to comment further on the ideas of autonomy and choice.

Reflexivity

This section describes the reflexive elements of the work, the steps taken to improve the reflexivity of the work, and the key reflexive issues that arose. The methods and the outcomes are described in the first person.

> "the importance of being reflexive is acknowledged within social science research and there is widespread recognition that the interpretation of data is a reflexive exercise through which meanings are made rather than found... reflexivity has not been

> translated into data analysis practice in terms of the difficulties, practicalities and methods of doing it. Instead, there is an assumption built into many data analysis methods that the researcher, the method and the data are separate entities rather than reflexively interdependent and interconnected. Most methods continue to be presented as a series of neutral, mechanical and decontextualized procedures that are applied to the data and that take place in a social vacuum. "
> (Mauthner & Doucet, 2003, p.413)

The aim to be reflexive, and to manage and present the data in a reflexive manner, was an ongoing concern throughout the research process. The ability to be reflexive about the data and analysis has greatly been aided by the time difference of several years between initial data collection, transcription and analysis, and the presentation of results in this report.

Epistemologically, this research recognises that the participants' comments are not necessarily "transparent passageways into their experiences" (Mauthner & Doucet, 2003) but rather give an insight into the participants' experiences, the interpretation and construction of which are enabled through the research process and by the researcher, thus is subject to the researcher's management of potential bias. Also, in line with a relativist epistemological perspective, the researcher's interpretations are also viewed as a source of knowledge (Mauthner & Doucet, 2003). The aim in this work is to use reflexive strategies to reconstruct information using multiple data collection methods so that as complete a picture could be created. This required reflexive work, particularly when interpreting interview data.

Methods used to increase reflexivity

The key reflexive tools used were forms of bracketing, including maintenance of a "thinking folder", field notes and reflexive readings of transcripts. These tools were used to heighten awareness of the researcher's bias, and to aid the process of bracketing. These strategies are described in this section, as are some of the key reflexive findings that have shaped the work.

Gearing (2004) maps the "subtle theoretical and philosophical underpinnings of bracketing" (p. 1429) and describes reflexive bracketing as "representing a more modern development in qualitative inquiry" (p. 1448), but with its history in phenomenology. In this form of bracketing, the researcher needs to become self-conscious and thoughtful, to identify suppositions and values, which can enable the researcher to reduce their own influence on the study (Mauthner & Doucet, 2003; Gearing, 2004)

Reflexive bracketing was, to a certain extent used, alongside other measures to promote trustworthiness of this work (described in section 5.13 below). The extent to which reflexive bracketing was used, and the nature of its use in this work are described in this section.

Reflexive bracketing clearly fits within relativism, where the data can be understood from multiple perspectives. Reflexive bracketing allows the researcher to acknowledge that it is impossible to suspend prior knowledge and values, but that these can be made explicit with the aim of being aware of the influences on the research (Gearing, 2004; Ahern, 1999).

The "thinking folder"

Throughout the process, I kept notes about my ideas, and views. In the development of the focus of the work, the data collection methods used – and not used, the experience of data collection, data analysis and the presentation of this report were all included. The notes were maintained in a "thinking folder", to which I referred frequently.

Rather than chronological notes, as kept for a log of discrete events (e.g. wrote letter to service provider, did first interview with Anna etc.), these were themed notes. As time progressed, more notes were added, and additions were made to initial notes.

For example, one note was entitled, "Did you choose your present lifestyle", which is one question in the final interview. After the final interview with the first participant, I was particularly surprised by her reaction to this question, so I noted what had been said, and how I felt about it. For each of the interviews, I noted my reaction and interpretation of this question in this section. I found that this helped me to understand why I was so surprised by both the content of answers and the manner in which respondents answered. Keeping the notes in the thinking folder enabled me to separate my emotional reaction to the participants – which included my questioning of the appropriateness of the question and my emotional reaction to some of the responses, from my intellectual responses, and from the actual responses themselves. For example, I felt that Anna became almost angry with me, as if I hadn't been listening to her, intellectually, I understood that she was trying to make her point clear, what she said was that she had fought for her life, so that of course it was a choice. Intellectually the response "it chose me" did not make sense to me; so I reflected why, and found that my bias, my upbringing, my ethos is very deterministic, being able to put that aside meant that I could listen to "it chose me", and understand what was meant by it.

Another note is "settling or aspiring", which was one of the initial considerations within this work – whether some participants settle for what they have and others aspire to do more. This note included reflection on my views, reflection on findings from the literature, and reflections on the information from participants. It was an exciting note. When information about striving for goals, aspiring or conversely settling for the status quo arose in interviews, in the literature, or indeed in daily life, these thoughts were noted. It was exciting because it was intellectually stimulating, without being an emotionally charged area. Again, my biases towards aspiration and striving were apparent.

The thinking folder approach used in this work does not appear to be described in the literature, it arose naturally as a way that worked for me to be reflexive, and also to contemplate and immerse myself in the work. It, in and of itself is not a robust reflexive method. It was used in conjunction with other methods, but did appear to be the way I uncovered many issues, and became more self-aware and conscious of my influence on

the work. It also worked to excite me about the information from the literature and from the participants; it acted as a series of themed melting-pots.

Notes from the thinking folder were not edited, nor changed throughout the process. Where new thoughts or changes in opinion occur, they were added to the end of the document. This means that the notes are quite cumbersome, and took increasingly long periods of time to work with, but was a very deliberate strategy. I wanted to retain all of the comments, without altering them, in a similar way to keeping a reflective diary, so that the progression in thinking is documented. There was no detailed analysis of the thinking folder notes.

Reflexive readings of interview data

A more standard form of reflexive data analysis used is described in the literature as the "voice-centred relational method of data analysis", proposed by Brown and Gilligan (1992), described by Mauthner and Doucet (2003). At the time that data analysis began, I didn't know the terminology for this form of reflexive analysis, but it became apparent that this approach was being used.

The voice-centred method involves reading of transcribed interviews several times, with different purposes for each reading. One reading, the reflexive reading, involves the researcher noting her own personal emotional and intellectual responses to the individual (Mauthner & Doucet, 2003). In this study, I read transcripts from my own perspective, understanding the information on an intellectual and emotional basis. I also listened to the recordings of interviews several times. The method involved noting reflexive issues as they arose, to increase awareness of these, with a view to presenting the results without unintentionally biasing the accounts of the participants that I was creating. I found that I needed to listen to the accounts several times, and repeat the reflexive approach, because new things kept "popping up". If I had presented the information from only one or two readings, I suspect that I would have presented a skewed report, emphasising small parts that just seemed to jump out to me. I found that the re-reading and noting my reactions – in one or two words sometimes, and other times in big paragraphs, until saturation meant that I could then begin to reconstruct the life stories and views of autonomy in a more balanced way.

Emotionally, I found some of the accounts upsetting, my heart wanted to go out to some of the participants. These emotions were noted. Intellectually, the argument of some of the participants was easier to understand, when there were difficulties, these were noted, and explored. Issues that were frequently raised by this process were my axiological biases, the values that I have adopted from occupational therapy, from my involvement in the disability movement and from my own life history.

> Mauthner and Doucet (2003, p.419) describe the voice-centred method as allowing the researcher to
> "examine how and where some of her assumptions and views might affect her interpretation of the respondent's words, or how she later writes about the person. This reading is based on the assumption that locating ourselves socially, emotionally and intellectually allows us to retain some grasp over the blurred boundary between the respondent's narrative and our interpretation. Failure to name these emotions and responses might lead them to become expressed in other ways such as in how we write about that person.

I found that one single reflexive reading of the accounts, as described by Mauthner and Doucet (2003) was not sufficient for me to become fully aware of my reactions. The first reading raised awareness of the most prominent emotions and intellectual reactions, but subsequent readings enabled me to discover more subtle reactions, which may have influenced the presentation of information further.

Reintegration of reflexive bracketing

The strategies used to increase my awareness of my own suppositions was used to manage the interpretation of the findings. The thinking folder work was reintegrated by summarising or highlighting the key issues (e.g. my bias / assumption that autonomy is valuable), and then re-reading transcript data and literature specifically seeking interpretations other than my own. Summaries were not necessarily written, but rather a heightening of awareness.

The voice-centred reading of the transcripts was re-integrated firstly by balancing my initial reactions, so that I had a more complete and balanced view of my own influence. Then the transcripts were analysed for content (as described in section 5.9). The analysed material was compared with the reflexive comments, and effort was made to understand the participant's meaning.

Outcomes of reflexive work – key issues

The first most apparent influence that I had on the research is the choice or adoption of an epistemological and ontological perspective. In this case, it was more an adoption, or development of the perspectives rather than an active, conscious choice at the outset.

Initially in the work, there were elements of positivism. Prior to the development of the focus as it currently is, approaches such as "testing" to find out if there are differences in experience of autonomy of people living in different environments were considered, with ideas such as "matching" participants for disability experience. I realised very quickly that this didn't "sit right" with me; it appeared incongruent to my world view, without necessarily realising that the world view that I was adopting was pragmatic (as described by Cresswell, 2007), and my view of knowledge and the nature of subjectivity was closely aligned with relativism. My views were underpinned by the assumption that people are influenced by social constructions.

The adoption of a pragmatic world view was expressed in my interest in looking at the what and how of the phenomenon under study (autonomy) (Cresswell, 2007; Gearing, 2004), it probably influenced the integrated approach to data collection. The possible origins of this pragmatism are outlined below.

The research, in an aim to understand my influences, has necessitated deeper consideration of epistemology, ontology and axiology. Theory drawn from feminism, such as the importance of the participant's "voice", and emancipatory ideals influenced the work. For example, I very deliberately chose not to interview others, such as personal assistants or nursing staff for the purpose of triangulation. When reflecting on this decision, it is clear that my rationale was based on the view that it was the voices of the participants that were most important to me, their views, rather than any sense of an outsider's perspective.

Emancipatory research has influenced disability research for more than a decade (Oliver, 2002). This method involves disabled people directly as designers and instigators of research, rather than subjects or objects of research. While this method appealed to me, I was not undertaking an emancipatory piece of work, primarily due to the awareness that this is an academic piece of work for an academic award, rather than research for the

researched. Despite my perceived inability to undertake emancipatory research, it was very important to me that the work be "accepted" by disabled people. Several interesting discussions with disabled people, and with my supervisor helped me to tread the balance between doing a popular study and one that could be academically valuable. I reacted very positively when one of my participants described the work as "revolutionary".

There were several potential drawbacks in the way that I was very involved in the disability movement, particularly at the beginning of this research. Apart from it taking me away from the work, and drawing me down other lines, it did also provide a constraint to what I would and would not do. Choices made throughout, including the choice of autonomy as a focus, needed to be politically correct. The key way that I became more aware of this influence was through supervisory meetings.

A big dilemma throughout the research process arose between joint influences of occupational therapy and the disability movement. The occupational therapist in me wanted to know the daily life events, the self-care issues, exactly how assistance is provided, the patterning of occupations, as a valid and under-researched source of information. The disability activist in me cringed at the thought of asking people about self-care, again, as the view of occupational therapists as people obsessed with bathing was in the forefront of my thoughts.

A wide range of data collection methods could have been used for this study, including formalised assessments of quality of life, autonomy, independence etc. but these were not used, partly because they necessarily represent a definition of the terms that may not be relevant to the participants, and partly because as a researcher, I did not feel ethically comfortable using these tools. I felt that the most important aspect of the work is to understand the participants' perspectives, rather than assess their abilities.

Occupational therapy influences on the research

As an occupational therapist, the professional values and culture necessarily influenced the type of research undertaken. The reflexive processes were used to uncover some of these issues.

Occupational therapy practice, and its contrast with the theory found in books and journal articles was a major influence on the decision to engage in this work at the beginning. These influences are described in the introductory chapter (see sections 1.2 and 1.3). I feel that I am committed to the profession of occupational therapy, and believe in its potential value. Yet, as described in Chapter 3 (see section 3.5), there seems to be a paradox, where theory suggests a more inclusive, social approach to disability and disabled people, and practice shows quite another.

While acknowledging this commitment to my profession, I did not want to undertake "occupational therapy research" per se. I wanted to understand the experiences of disabled people,living in different situations. I was more interested in participatory research, but recognised the limitations of this approach in an academic piece of work.

However, the work that I engaged in is very closely aligned to OT theory. All of my previous research experience was focused on occupational therapy (and health science) research, so it necessarily was a major influence.

Occupational science, as a discipline has also been an influence, particularly in the decisions to explore the everyday lives, the occupations, occupational patterning and meanings derived from the occupations of the individuals in the work. These concepts are central to the area of enquiry of occupational science (Zemke & Clark, 1998; Yerxa 1998).

Probably the greatest influences of occupational therapy on this work is the choice of methodologies to use, and approaches to the research.

The manner in which data were collected, and the focus reflect occupational therapy values, in particular grounding the perceptions within a lived-experience, diary information framework. Asking participants to keep diaries of what they did, is a method used within occupational therapy practice. It demonstrates a focus on occupational performance and patterning. Another profession would probably have investigated thoughts and perceptions more than daily activities.

As an occupational therapist, I valued observation of function probably more than a disabled activist would. I built field visits into the data collection process, spending time

with the participants in their homes and sometimes in other places (like a coffee shop). I noted these observations of their environment, and their function, when it was pertinent, and include some descriptions in the results. This decision was influenced by occupational therapy theory and practice, and also drew influence from ethnographic methodologies and phenomenology..

The inclusion of such information on self-care was a challenge and a difficulty throughout the research, and epitomised the battle that I faced between occupational therapy and disability movement influences on the research. Occupational therapy instruments to measure self-care function were available (such as the FIM and the Barthel Index), but these were not used.

A key influence on the methodology used includes the work of Kielhofner and others (e.g. Kielhofner, 2002; Kielhofner & Henry, 1998), and assessments such as the OPHI-II that focus on narrative. Critique of this methodology is included in the discussion chapter, but at the start of data collection, it was important for me to try and understand the narrative of the individuals involved, to construct metaphor and to understand the development of autonomy and coice.

Influences from a disabled person's perspective

As a disabled person, I have been subjected to many research studies, involving researchers asking seemingly meaningless questions, that have no benefit to my life, and highlight disability as an "oddity", thus worth investigating. Being aware of this, I was keen to involve disabled people to aim not to repeat the same mistakes that others have made. Thus, I began by speaking with a variety of people, most of whom were disabled, to understand where I could position myself on the continuum between truly participant-led emancipatory methodology and "doing to" the research participants.

I consider myself to be an independent person, and autonomy is important to me. It is important to me, personally, that I can choose where to go, what to do, what to wear and so on. Disability (in my case, blindness) may potentially limit aspects of performance, but it is important to me that I can choose to use the techniques, equipment and supports that will enable me to do what I want to do and be who I want to be. In my case, these include

using a guide dog for mobility, using assistive technology and so on. At times, there have been battles, with people who suggest that I can't do things because I can't see. I have typically been motivated by these people to do exactly what they say I can't do. Bringing this personal baggage to a research project, with a focus of deep personal resonance necessitated reflexivity, and strategies to understand my potential influence. I found particularly speaking to those who have a different value system and experiences of autonomy and independence enabled me to further identify my biases; being aware of them in the first place enabled me to re-phrase questions to avoid undue bias.

While the primary focus of the research arose from clinical and life experience, information from the literature did inform the focus of the work, and particularly the interpretations of the data. It was important that the reflexive strategies were used to prevent this experience and knowledge of the literature from distorting perceptions of the data (McGhee, Marland & Atkinson, 2007).

Bias, Rigor and Trustworthiness

Reliability and validity are seen as the measures of rigor in qualitative research (Krefting, 1991), and these are less easy to codify than in quantitative methodologies (Seale & Silverman, 1997). A number of strategies are available to improve the rigor and trustworthiness of qualitative research (Barbour, 2001; Mays & Pope, 2000a; Krefting, 1991; Seale & Silverman, 1997 etc). Some of the strategies used have been described throughout this chapter. Reflexive strategies, as described above were used to promote trustworthiness of the work. Other trustworthiness issues are described in this section.

This research involved both descriptive and interpretative findings. The descriptive findings are presented in chapters 6 and 7, the interpretative findings in chapters 8 and 9. The strategies used to enhance the rigour of descriptive and interpretative findings differ somewhat, thus a variety of approaches were used.

Trustworthiness has been described as,

> "the extent to which the findings are an authentic reflection of the personal or lived experiences of the phenomenon under investigation".
> (Curtin, 2007, p. 88)

Curtin and Fossey (2007) outline six strategies to enhance the quality of qualitative research, these being: evidence of thick description; triangulation strategies; member-checking; collaboration between the researcher and the researched; transferability and reflexivity. Many of these strategies were used in this work; reflexivity and member checking have already been described in sections 5.11 and 5.10 respectively.

Barbour (2001) warns of the ad-hoc use of textbook-style, formulaeic procedures, arguing that they are ineffective unless embedded in a broader, systematic approach to the research.

One method frequently employed to promote rigor in qualitative research is triangulation, where information is collected from a number of sources (Mays & Pope, 2000a; Barbour, 2001). To a certain extent, this was done in the current work; the participants perceptions were sought through interview, self-observation was required for self-maintenance and diary information, and a numerical rating was included to further understand their perceptions.

Triangulation in the form of collecting data in a number of ways was used to provide a more holistic view of the individuals' autonomy, independence and lifestyles (as described by Curtin and Fossey (2007)).

Other forms of triangulation may also have been possible, such as interviewing an assistant or carer. This was ruled out for a number of reasons. Firstly, the research question focuses on participants' own perceptions and experiences of autonomy and choice; information from a third party would not necessarily provide useful information about the participants' own situation. Secondly, the data collection was extensive and possibly intrusive for participants as it stood, the addition of a further element whereby another person is asked to report on the participant may have been too much for some participants. Thirdly, the selection of appropriate informants would have been difficult, as the relationship between personal assistants and leaders is likely to be significantly different to that between nurses and patients in residential settings.

Researcher-observation of participants was briefly considered, but this was ruled out, as it would simply have contributed information about how a person performs tasks, rather than addressing the question of autonomy or choice.

Barbour (2001) highlights some issues with using triangulation as a means to promote rigor in qualitative research, including that data from different methods cannot be directly compared. A strength of the current work is that the different forms of data collection form part of a mixed method, addressing different aspects of the question, rather than acting as multiple sources of the same type of information. The use of a mixed rather than a purely qualitative method enabled a richness of data which also allowed for collection of discreet, concrete information from each participant that could be compared with the other participants. Mays and Pope (2000a) also highlight that triangulation may not be a genuine test of validity, because it is based on the assumption that a weakness in one method will be compensated for by another. The type of triangulation, or mixed approach to data collection used in this research is not seen as a tool to improve the rigor, but does provide a richness of data that would not otherwise have been possible. This comprehensiveness of data, with the ability to be more reflexive and consider other information in analysis is a real benefit of data collection from multiple sources (Mays & Pope, 2000a).

Presentation of results

The results are presented in the following chapters of the research, and are divided into two sections: descriptive findings, in chapters 6 and 7, and interpretative findings in chapters 8 and 9. Descriptive findings are presented in a case-study type approach.

7. Description of Participants – Life history and current situation

This chapter will describe the information from each participant in terms of:

- their life history;
- disability experience, and
- their situation at the time of initial data collection, including living environment.

This information gives a background to each of the participants, and describes their unique situations in some depth. In conjunction with the next chapter, which describes the participants' daily lives, it provides the backdrop to an exploration of their experiences of autonomy and choice in their daily lives.

The information in this chapter is compiled primarily from the initial interview, the researcher's observations (of the living situation) and is supported by information from the other interviews.

The purpose of collecting and reporting the disability experience of each of the participants is two-fold; firstly to give the reader a clear image of each of the participants with which further information can be understood, and secondly as a legitimate factor that influences the person's own individual experience and perceptions.

All descriptions of participants are as at the initial data collection period. As data collection and the research process extended over a number of years, certain characteristics, such as employment status may have changed. Where these are significant, they are reported.

Falsified names are given to each participant.

Anna

Brief self-description

Anna is a 28-year old woman who lives "independently with personal assistance in my own apartment".

> "I am 28, I live independently with personal assistance in my own apartment... I work full-time, I have an active social life, and I am , em, often times, very idealistic and not very perfect, but I fought very hard to get where I am and... well, I would describe myself as first of all, I suppose, an independent woman, disability is a part of my identity but it is by no means the overall, em, you know, of course it shapes who I am and whatever but I would hope that people would, of course they see the wheelchair, but I would hope that people get to know me and whatever and they see me first as opposed to what surrounds me, and my equipment and my technology or my personal assistants . Em, I suppose I would also be em, an an advocate and very much a kind of a, I suppose I've nearly been called a rebel [laugh] in fighting for the cause, so, that would, I suppose describe me fairly accurately."

When asked what being "an independent woman" means to her, she states that,

> "It means, being able to take control of my own life and make decisions and mistakes like everybody else and be able to take responsibility for my own actions."

This desire for control and choice appear to be central to her narrative, and are discussed in further detail in the following chapters.

Life history

Anna grew up in a rural environment, and went to mainstream school until the age of 9, when she describes making the decision to go to a special school, where she would not feel different to others. While in that school (until the age of 18), she was in effect in a residential setting. Living in a residential setting was a major force that made Anna decide that she wanted to live independently in the future, and to begin her "fight" for independent living.

Anna went to University in a different city and completed a degree.

> "I lived ...[on campus] and I was a rebel student and it was brilliant and then basically I was unemployed for a year because I didn't have transport and I didn't, I was

> basically stuck in a rut because I was going through my phase of I don't want to work in disability just because I am disabled..."

Following her period of unemployment, Anna started working in a charity respite service for disabled people, "which is a dreadful place". She did not enjoy this work particularly, and alongside the work started doing disability awareness training with another disability organisation. She found that she enjoyed giving presentations and speaking in public, and so decided to do a higher diploma,

> "which I did, and really enjoyed, and made friends and then moved up the career ladder from there."

Throughout her life-history, Anna describes determination as being of primary importance. She describes currently having a "madly busy" full-time job, in which she feels that she can use her disability to her advantage, and an "active" social life.

Metaphors used in her narrative include "fighter" and "rebel"; she strongly asserts that she has taken control and shaped her life.

Disability experience

Anna has a congenital disability (cerebral palsy) that she describes as,

> "a mobility issue that ... puts certain constraints on my life but I don't see why it should allow that. So basically while my disability is with me, it is an integral part of my life, but it doesn't take over my life."

Anna reports her disability having changed, "quite significantly since I was a child..." She reports being able to weight-bear and walk with assistance until the age of twelve years, when "my feet collapsed basically underneath me and my legs couldn't carry me any more and then I developed scoliosis of the spine". She describes this change in her disability as having greatly affected her requirements for assistance and her functional ability, from being able to transfer and be "very mobile" to now, where she describes being "not mobile at all".

Anna uses a powered wheelchair with lateral support and tilt-in-space. During the interviews, there was evidence of poor trunk control and athetoid movements. She has poor hand dexterity.

Living situation

Anna lives in her own apartment, located near the city centre. The apartment is open-plan in style.

Anna is satisfied with the environment because it is designed to meet her needs. She describes having a lot of influence in the design of her home environment and that this has made a big difference to her.

> "From the very initial stages I had an impact into the design of this apartment... Well a major thing in my home environment is being able to get in and out of my own front door. I have an automatic front door, and that wasn't easy to insist on. Also my actual, the height of things, the height of anything from my dressing table to the counters are at my level. And, I mean, I would review it often, and be very insistent that it be the way that is most comfortable for me. "

Anna describes the difficulties that she experiences outside her home environment:

> "But outside of this environment, I become very uneasy like, simple things like going on holiday is so frustrating... like you have to think of everything from can I get the hoist under the bed, to can I get into the shower, is there enough circulation space in the bathroom to does the PA have enough circulation space in the bedroom to move me without injuring herself... out of my environment I am very uneasy... Outside of my own environment, I am a totally different person, my temperament and everything changes... I couldn't go away for a weekend and think that I mightn't be able to have a shower..."

Anna has designed her home environment to enable her to use equipment to assist with daily occupations. In relation to this equipment, Anna reports being,

> "very satisfied, because I monitor it all myself and if I need new equipment or technology I would contact the community OT or whatever and usually it might take a while to get what I want or need, but usually, you know, they know I'd put a good rationale together..."

Anna lives alone, but has a number of personal assistants that work with her, more or less on a 24-hour basis. She is provided with a set number of hours assistance, from the personal assistance service provider.

Anna decides, and has control over the times and type of functions that the personal assistants perform. She reports taking total responsibility for managing her personal assistants in terms of when they work and what they do. She describes "fighting" to maintain the hours of assistance that she has available to her.

> "I am one of the very lucky ones in a sense that I have what I need, and very few people have that now... the service providers are constantly trying to cut back... and they even rang me two weeks ago asking me... [to reduce the number of hours assistance] ... but I said no, and I had to give them a breakdown of my tasks basically about how I use every hour, you know, yeah, basically, that's how bad it is now. "

She describes this as frustrating, but feels that she is in a stronger position to "fight" for what she needs,

> "there are people who that are not as confident or articulate as me and they are being bullied and humiliated. "

Bart

Brief self-description

Bart is a 30 year old male living independently in "an extension my mother built for me" with personal assistance. At the time of the initial interview, he was planning to move out into a new purpose-built apartment in the City Centre. At this time, he was also in the process of looking for a job, having just completed his University degree.

He considers himself to be bright, and witty, but easy-going, without serious concerns or worries about his future, despite frustrations about his work situation and significant delays and difficulties in his new flat becoming available.

Life history

Bart, at the time of the initial interview was seeking employment, having just completed a University degree. He had previously attempted two other courses, but reports that he "hated" the other two, and leaving in the case of one, and failing the other. The university degree took more than the usual length of time (7 years for a typically 4 year degree), due

to disability. One of the difficulties identified by Bart in college, and in his future world of work is the pace or speed at which things move, which disadvantages him due to his method of communication being slower than verbal speech or typing.

Initially, it seemed that Bart had no clear idea of what he wanted to do in the area of work, apart from wanting to work in the area of his degree. During the course of data collection, Bart started working with a disability organisation.

While in University, Bart lived in campus accommodation, which he enjoyed and found reasonably accessible. He reported that moving back home was a "shock", and that he is keen to move out into his "own place". He intends moving to a purpose-built flat closer to town, primarily to facilitate the social aspects of his life.

Disability experience

> "I have significant cerebral palsy. That means I can't manually walk or talk. To combat this, I talk through a voice synthesizer and I have three fulltime personal assistants. The internet and email are important to me. They are one of my vital connections to the public. I live independently but there are always times when I am not [independent]."

Bart has cerebral palsy, resulting in spastic quadriplegia. While his condition is congenital and his disability experience has not changed significantly, he has experienced an increase in difficulties with digestion over the past few years.

Bart has no speech; he uses a computer or lite-writer with switch-controlled scanning to communicate. He uses switch controls that are mounted on a D-frame around his neck, which are activated by chin movement. During data collection, a PA was present, he called for the PA using backwards jerking movements of the head. At times, the personal assistant interpreted the meaning for the interviewer.

Bart displays athetoid involuntary movements in both upper and lower limbs. He uses a manual wheelchair with ramped seat base, which is propelled by an assistant.

Living situation

At the time of data collection, Bart was living in "an extension my mother built for me". This is a self-contained extension to the family home, with ramped access from outside. His mother's house is in a suburb, requiring transport to the city centre.

Bart had recently moved back home from living in campus accommodation while he was in college.

Bart was in the process of arranging a move for himself to a purpose-built apartment in the city centre. This move is to facilitate the lifestyle that he wants, such as making access to work and social activities easier.

Bart is happy with the physical environment of his home. He sees the accommodation living with his mother as temporary until he can have his "own place".

Bart has three full-time personal assistants. He manages their times / rotas and the activities that they perform himself. Personal assistants provide 24 hour assistance.

Bart uses personal assistance for all tasks, as he has minimal functional movement in his body. He also uses technology, notably communication technology.

Cathal

Brief self-description

Cathal is a 46-year old man who is living in a residential setting. He describes himself as follows:

> "... I've been in here nearly two years, in fact just over two and I have been in hospital two years. I have MS... up to a few years ago I was quite mobile working and living a normal life with the odd symptom here and there but... the last few years I have come very much down hill... I live in a hospital, which is a huge turnaround, because I used to be very active in different spheres, and I had a busy job."

Life history

Cathal had been working with a major national non-governmental organisation, as "stationery storekeeper", with responsibilities for all of the nationwide offices of the organisation. He describes the job as being very busy and with significant responsibilities. He also was involved in a school sports club as committee member and treasurer, actively involved in a political party and,

> "like any responsible parent, I was taking my proper place, if you like, in helping to raise my children".

He has four children, the youngest of whom was 15 at the time of the initial interview, and one grandchild.

During a relapse of MS, where Cathal became unwell and unable to move from his bed, he was admitted to an acute general hospital. He was transferred from the acute hospital to the residential setting in which he now lives, following a prolonged stay. He reports not having choice in his transfer to the present setting, and describes the transition as follows:

> "it was put to me that I would probably be better off going to the [current setting] from [acute hospital], because [it] is an acute hospital. This is a long-stay hospital and so I had to be released from [acute hospital] because that was freeing up a bed which they obviously need...The move didn't bother me as such, but the one thing that did hit me was I, all the time I was in [acute hospital] it was in my head that, a discharge date sometime in the future, and I thought that, I felt okay about that. When I came in here, no fault of here, I suddenly felt, "this is it" for the rest of my life and that hit me hard. I found that hard to cope with. And I wouldn't say that I am alone in that. Just the idea, that this is where I am for good."

Cathal reports being offered an option of going to live in "independent living" a year prior to the initial interview (just over a year since admission to the residential setting). He reports that he was initially "delighted with the idea", "...but having looked at it, I knew in my mind that there was no way I would be able for it, and as it happens, the people who were offering it didn't feel I'd be able for it either." His concerns about independent living were that he would be living alone with inadequate support, because "there is so much that I need help doing now, there's no way I could cope".

At the time of the initial interview, Cathal was undertaking a college course four days a week in computers. He intends to progress and choose a more advanced college course, but has no clear idea about what course he would like to do, or what he would like to do after the course. His previous job (which he left over six years ago) is still open to him, but he says that he would not be able to do it now.

> "I would have to be a lot more physically able because I wouldn't be able to cope with the demands. If I was in my present state, there is no way, because I mean... now I can't even stand up, so there is just no way."

Disability experience

> "I have MS, I have had it for a long time, my first symptom was in 1975, I was diagnosed in 84, and up to a few years ago I was quite mobile working and living a normal life with the odd symptom here and there but, eh, the last few years I have come very much down hill and I am now full-time in a wheelchair can do very little for myself and eh, and, as you can see I live in a hospital,"

Cathal uses a powered wheelchair with tilt in space. As he describes above, he has multiple sclerosis (relapsing remitting). His last relapse was three years prior to data collection, after which he was unable to walk. He has reduced trunk stability. Cathal has good upper limb dexterity, but describes weakness in his arms. His speech and swallow are unaffected.

Cathal describes experiencing significant fatigue as a result of having multiple sclerosis. It was evident that the participant became tired at the end of each interview. The interviews took place beside Cathal's bed in a shared room. The curtains around the bed were pulled, but there was limited privacy. Cathal chose this location for each interview.

Living situation

> "It's a nice place here. There are always people to help you."

Cathal lives "in a hospital", which is a large residential setting. He shares a five-bedded ward-like room, with adjoining bathroom. He has a small amount of space, a wardrobe and bedside locker for his personal belongings. He has his own TV and DVD player with headphones beside his bed. Along the corridor from the participant's room is a large dining area where food is served.

Nursing staff provide the assistance to Cathal for the majority of his daily routine activities. When he is in college, assistance is provided by people in the college. He does not have a personal assistant. Cathal uses a hoist for all transfers.

Deirdre

Brief self-description

Deirdre is a 52-year old lady, who lives in a residential setting.

> "Well I am in this [name of residential setting] since 1998... I'd say that I am a quiet sort of a person but I am interested in lots of things, in art and literature, history, bird-watching and nature, but I am not deeply interested in any of them."

When asked, Deirdre says that she would

> "love to be able to go out, as I was, and cope, and be able to walk and write and things like that, and I try hard but it doesn't seem to be enough."

She reports that she perceives that independent living is not an option for her, because she would need personal assistance or nurses. Her hope is in scientific research, so that she can regain physical function, "I think the stem cells will be the answer for me".

Deirdre does not engage in employment or education. She reports her primary purpose in the setting as aiming to regain movement in her affected side, so that she can return to live in her apartment.

Life history

Deirdre experienced a cerebro-vascular accident (CVA) which resulted in left hemiparesis. She reports living in the setting because,

> "I had a stroke and I was completely paralysed on one side and I had to live here because my own apartment is not is not wheelchair accessible even though it is on the ground floor… so that's why I am not out there."

She perceives the residential setting as an interim measure, and her long-term goal initially stated is to return to her apartment, and live independently. She says:

> "I always looked at it like that. [living in residential setting]"
> B: Looked at it or, still look at it?
> "…I don't know, I do want to, I'd love to be able to go out as I was and cope, myself, be able to walk and write and things like that, but I think, I try hard, but it doesn't seem to be enough. [pause], but I think the stem cells, the stem cells will be the answer for me."

Deirdre reports being happy to move to the setting initially, because it had a good reputation for enabling people "to be able to do things for themselves to be able to cope with themselves." Now, having lived in the setting for a number of years, she reports that while there are lots of things to do, she becomes "bored" and frustrated with her situation,

> "I say, My god, how many years, when will I be able to walk or use have the use of my left paralysed side so that I can do things again."

Prior to her CVA, Deirdre worked in a busy medical setting. She was an administrator, and reports her work as being busy,

> "it used to change every day, you would have a different lot of people in… even if you had the same crowd every week, it still was different, and you would have a different lot every day… I enjoyed that very much and I also I liked the job too, even though it became crazy busy at it, you hadn't a minute to spare, but still it was interesting."

She reports particularly enjoying the social aspects of her work, working with other people.

Deirdre tries to keep herself busy, reporting that she has little free time. She participates primarily in structured, organised activities within the residential setting, but also enjoys being alone in the grounds of the setting.

> "I like going out around the grounds, and eh, and I have found the cats, and I feed them and look after them as best I can, and they have come on, they have grown into nice cats, good cats now. Not wild scrawny things now... I want to do it for the cat's sake... I know sometimes it is not very nice, like today and some days going out in the wet, it might be cold or very wet and windy, but otherwise, I do, I like it a lot... and the garden outside there I like to do a little weeding or dead-heading, nothing serious out there when I have time."

She reports having "hardly any free time at all", mostly because of the organised activities, occupational therapy and physiotherapy. The only day she is not busy is Saturday; "there is nothing at all on Saturdays, which is a pity, we could do with something, some sort of a group or something on a Saturday or at the weekends"

Deirdre is single, she typically spends some time at weekends with one of her siblings, with whom she describes being close, stating that, "they are good to me".

Disability experience

Deirdre had a cerebro-vascular accident, which resulted in left sided hemiparesis. She also has some perceptual difficulties (left inattention). Prior to the CVA, she was non-disabled.

Deirdre alternately uses a powered wheelchair and a manual "hemi-drive" wheelchair for mobility. When interviewed each time, she was using her powered wheelchair. She can transfer herself independently from chair to chair. Deirdre wears ankle and wrist orthoses.

She requires minimal assistance for most tasks, and undertakes eating, the majority of grooming activities and functional transfers independently. Deirdre lives in a residential setting, so all meals are provided.

For each of the interviews, the Deirdre was met near her bed or in a day-room, and she went with the interviewer to a private room, of the her choice for the interviews. Deirdre was very keen that the interviews be conducted in a private location.

Living situation

Deirdre lives in a large residential setting, and shares a room with four other residents. There is an adjacent bathroom.

The residential setting is very large, with a number of wards. Deirdre lives in a unit designed for younger adults with physical disability, which comprises of a number of rooms, mostly of 5 beds, a large dining area and access to a garden area. Within the setting, there are a number of day rooms, a garden in which Deirdre has her own raised bed and the grounds are quite extensive.

Deirdre is generally dissatisfied with the setting, in terms of the physical environment, she finds the bathroom "depressing".

Assistance is provided by nursing staff and care assistants. There is a medical ethos, and the amount of assistance provided to each resident is decided upon by the staff, based on the individual's assessed needs.

Deirdre's biggest difficulty with the residential setting relates to the social environment, both residents and more particularly the staff.

She describes finding it difficult living in the setting,

> "I mean, there's no going home at five o'clock, for us, you know. I can't say, ohh it's five o'clock or four o'clock, it's time to go home and get away from the whole thing for the night you know, and come back in tomorrow like they do in at work"

She describes serious difficulties with the social environment:

"There's somebody beside me now, and she actually physically beat me up a few times... Oh she was so near me, yeah it was awful, but she was moved then, somebody else put in the bed next to me, and she was moved so, when she starts to [pause], row now, I just ignore her. And I'd love to answer her, but you know, I can't anymore... I don't answer her, it would start off a new war... That's with one in particular, but I mean, I was really hit, banged three times, banged ... Let me think, I went to [ward manager], I went and I told her. Well what do you want me to do about it [ward manager] said. Well I said, well I, I said I'm not a nurse here or a sister, you know, how would I know what you should do about it? That's what I said to [manager]... then a while later she moved the girl, and the first fall she moved I spoke to [other manager], the other sister about it and she said, you keep away from her, but you can't keep away from somebody who's not that far from you, you know, the bed is that far from you... [pause], it was, it was awful, [pause], but that's over now. So she got the board up, the board put up between the two of us... she got a wardrobe pushed down between the two beds, [quiet chuckle]... It creates a bad atmosphere"

Emily

Brief self-description

Emily is a 37-year old woman who lives in a residential setting. She describes herself as follows:

"outgoing person, jolly, I mix well with people, disabled and non disabled, young and old. My disability is cerebral palsy, from birth and, so when I was a young child I was able to do more so, more things than umm, than I am now, because your body is more flexible... I want to show people that I'm just as normal as anyone else. I try and communicate in the same format as the other person, not as a disabled, disabled person, I talk normally, emm, keep up the conversation, emm, and also explain please don't look at the chair, look at the person within the chair.... lot of disabled people would be of, attach themselves onto me as such, because when you're in a place like this, you are one, family, you're like a family of disabled people when you're living in such a home, so some have clinged onto me... they know that they can talk to me, in confidentiality, and I have done that role before, so I'm used to that."

The role of advocate or resource to disabled people appears to be very important to Emily, but it was not clear how she enacts the role.

Life history

Emily moved to the residential setting after the death of her mother, who was her primary care-giver.

Prior to her moving into the residential setting, she had lived in the community, in the family home all of her life. She reports making the choice to go to a residential setting because there was difficulty with her siblings taking turns to care for her, and she did not want to disrupt their lives. Emily reports that it took her about a year and a half to settle into living in a residential setting because it was very different from her previous home life, the primary difference being that

> "you have to abide by the routine of the home, the responsibility of staff and inform them... you have to work around these areas."

Emily has a congenital disability (cerebral palsy) and attended special school at primary and secondary level. She reports feeling "very angry" about her educational experience, she suggests that her education was not as good as she would have liked, because there were low expectations for students and too much of an emphasis on therapy.

After school, Emily initially went to work in sheltered employment.

> "Unfortunately, like everyone else in the special schools they said you would be better off in a workshop...I told my mother that that wouldn't be for me that wouldn't be my personality. I felt a bit trapped... It's very hard work and they don't get paid very much... So, I did workshop for a couple of years and I said enough."

Since leaving the sheltered workshop, she has not had formal employment or education. She describes a role that she has created for herself as being a mentor or helper for other disabled people. She reports doing disability awareness work in schools "off and on" and that she sees herself as an advocate for disabled people.

She reports doing some courses, but has not specified what these are. She also aspires to go to University, but has no clear idea of what she would like to do or what this would involve.

Disability experience

Emily has cerebral palsy, a congenital disability. She reports having more physical ability when she was younger, and being more flexible as a child. She reports that her physical abilities vary, depending on the time of year and the weather.

"my disability to me is free going, like, it allows me to do the things I want to do with limitations, but say if someone questions my judgement or it gets me frustrated or angry then it plays up then I am fighting a battle within me. With CP, that's cerebral palsy, you get a lot of spasm so if anyone really got me angry or really upset me I would find my disability worse than usual, but I am, I am medium as they say in medical words. I have, I try and do as much as I can to try to keep my disability as loose as possible"

Emily uses a large powered wheelchair with tilt-in-space. Athetoid movements in her upper limbs were observed during the data collection interviews, and it was evident that she has limited trunk control or sitting balance. Her speech became slurred on occasion during the interviews.

Living situation

Emily lives in a residential setting. She shares a room with three other residents. There is a bathroom adjacent to the room, and a larger bathroom further down the corridor.

There are a number of communal areas in the setting, and there is a large dining area in an extension-like building.

Emily reports being "very happy" with the environment in which she lives. She describes the environment as accessible, which, to her, means that she is "more at ease" with self-care tasks.

Emily considers it imperative that she retains control of how the self-maintenance activities are undertaken. She reports being generally satisfied, but strongly dislikes the need for equipment to be used.

> "Don't like too much equipment around me. Equipment makes disability more apparent in mind."

Assistance is provided by nursing and care staff. It seems that the routine of the setting has a significant impact both on what and how self-maintenance tasks are undertaken. Emily reports that the assistance may result in changes to her self-maintenance tasks: an example of when an activity may change is if a staff member is out sick.

Freya

Brief self-description

Freya is female and describes herself as follows:

> "I'm 40, I'm single, but I'm open to offers, umm, I work part time doing some disability awareness training... I live in a two storey mid terraced house with my mother... I suppose I would like to see myself as a person of intelligence, a person of compassion, umm, a person of common sense, and a person with a sense of humour. My life is too short just to sit back and whinge and whine about life you know"

Freya describes enjoying living with her mother, who is elderly and experiences a number of age-related health problems. She describes an important role for her being that of carer for her mother, as Freya manages many of the household matters. The role of carer is important to her,

> "I like, I think we all need to be needed, whether we'll admit it or we won't, I think we do, and I have to admit I do enjoy being needed"

Freya does sessional work in the area of disability awareness training. She also spends a lot of time doing voluntary work with a large charity.

Freya describes herself as stubborn, and describes finding ways around the difficulties that her disability cause, these primarily being self-care and household activities. She reports preferring to do things for herself rather than using assistance, but is looking forward to moving into a new purpose-built bungalow which will have an environmental control system, enabling her to do tasks on her own (such as opening and closing windows).

Life history

Freya describes herself as coming from a poor background; her family was supported by a local charity when she was younger. The support of this charity has had a great influence on her, fuelling her desire to "give something back"; she now spends a lot of time volunteering and doing charity work.

> "the old cliché of putting something back, giving something back is really important to me, umm, I suppose that was my driving force in joining [the charity] 25 years ago. I said I'd do it for 18 months and heh!... I was 15 years old [when she joined] and I said right, go for it... and I was the youngest by about 30 years"

Freya went to the local mainstream school. She describes being clumsy and having difficulties in school, but at that stage her disability had not been diagnosed. She left school at 16.

Once she finished school, Freya started work in a shop, but found this very tiring and needed to take a lot of time off. She describes leaving the job before she was fired. Shortly after leaving the job, she was diagnosed with her disability.

Since leaving work in a shop, Freya has been involved in part-time work and voluntary work, but she has not since worked full-time.

Disability experience

Freya was diagnosed with her disability, which is a rare rheumatological condition affecting collagen, at the age of 21. She describes the diagnosis as a relief, because she had been experiencing clumsiness and difficulties for a number of years, but found that people didn't believe her that something was wrong. She describes having difficulties in school, particularly with writing and fine motor tasks. She also reports experiencing significant fatigue on an ongoing basis. The fatigue is partly due to respiratory difficulties associated with the condition.

> "It turns out it's been there since birth, because it's a genetic, I was always one of those very clumsy children, you know, always dropping things, falling, the usual stuff, and I never enjoyed taking part in sport and games and that kind of thing. Umm, and I really started dislocating at the age of about 18, having, I always had pain in my muscles and my joints. I was just very, very lucky, after referral to about five orthopaedic surgeons I found one who instantly diagnosed me, as soon as he shook hands with me, my bones are inclined to collapse in my hand when you, actually, if you squeeze my hand you see what I mean. Squeeze my hand slightly, feel the way the bones, no you won't hurt me, feel the way the bones collapse? So he actually shook hands and said, ahh, you've got [condition]. Umm, and I have to admit, I came out of there, being told that I had a life limiting and life shortening disability with a grin on my face like a Cheshire cat. "
>
> B: Why was that?
>
> "It was such a relief [with great emphasis], to finally have a reason, because I was constantly being told you're imagining it, would you care to see our psychiatrist?... you're almost, you're afraid to seek medical assistance then, I actually became frightened of seeking medical assistance, because I knew somebody was going to upset me"

Freya reports frequently dislocating joints of her body, particularly her shoulders. She reports an increased risk of falling.

Freya uses a large powered wheelchair for all outdoor mobility. This has a tilt in space function, and suspension. She reports that suspension is vital to her, as she experiences ongoing pain.

Due to the physical environment in her home, she is unable to use powered mobility indoors, so uses a manual wheelchair. She is able to transfer independently, although she fears falling.

Freya reports that the most significant impact of her disability is the fatigue that she experiences, and she plans her daily and weekly activities to manage the fatigue. She also experiences difficulties on a day to day basis with reduced dexterity.

In terms of her view of her disability, she says:

> "I would see it as a part of my identity, I would never see myself as a disabled person. I see myself as a person with a disability. It's a part of my life, a big part of my life, not all of my life."

Living situation

Freya lives with her mother in a council mid-terrace, two storey house. This is unsuitable for her needs. She says that it is, "not very disability friendly, umm, even the bathroom's a nightmare, you know", and describes difficulties accessing the house and moving internally, as well as finding it difficult to perform occupations (such as cooking) due to the physical layout of the kitchen. She reports having difficulty getting through the front door; she has difficulty getting around the house as she cannot use her powered wheelchair indoors due to lack of space, so uses a manual wheelchair; she uses a stair-lift to get up and down the stairs and is in constant fear of falling. Freya describes a constant fear of the house going on fire during the night and her being unable to get out.

> "There is a stair lift in the house, but I have huge concerns about sleeping upstairs, in the event of fire, I have great concern there I have to admit... I have to admit I'm a bit freaky about that, [pause], I am by religion a devout coward... It's always a worry, umm, you're always double checking to make sure you unplug things and, umm, I don't allow smoking at all in my home, apart from the whole problem about respiratory problems, I just think it's dangerous."

Freya manages the difficult environment by adapting her occupations. She needs to get out of her wheelchair and push it through the front door, as there is such limited space. This increases her fear of falling, and also is tiring for her.

> "Exhausting, so you, you don't go in and out too often, what you try to do when you go out the door is to go out and do things, you do everything that needs doing and then go home for the day."

Freya is also aware that her mother is elderly, and is experiencing age-related disability and ill-health. She reports also being concerned that the home environment is increasingly difficult for her mother to manage.

Freya's county council are building a bungalow for her and her mother. She describes having a large say in the design of the bungalow so that it will meet both her and her mother's needs. Freya chose to apply for a purpose built bungalow as her physical abilities reduced, due to her disability.

> "Yes, we are actively choosing to change it, ahh, I was very lucky in that umm, a few years ago I started, really having major respiratory problems and my GP decided, you know you really need to use a power chair rather than a regular one, it was getting a bit much. Also I was dislocating my shoulders constantly [due to pushing a manual wheelchair], which wasn't, I wasn't very popular at [the local] hospital by that stage, you know. Umm, so, she sat down with my mother and I and went through our needs, and she was saying well maybe an extension on the back of the house would be sensible, but then with it being a mid terraced, quite narrow, it wasn't really practical to do that. So while I would prefer to stay in that house, I also have to consider my mum, and really at her age I don't think it's a great idea for her to be trotting up and down stairs either, so, when the county council offered to purpose build a bungalow for us we just grabbed it with both hands. So that is the choice."

In terms of support, Freya is most frequently assisted by her mother. She also has personal assistance and a regular home help, who primarily does household chores.

Grainne

Brief self-description

Grainne is a 48-year old woman who lives in a residential setting.

> "I came from [suburban area] a really poor background ... I'm a fighter. But I find it very hard to live here, I find it very hard to live with, I know it sounds awful, people who that are really desperate and very low down. You can't talk about anything"

Initially, Grainne was told that she would be living in supported independent living bungalows on the site, with assistance, but that did not happen.

"I live here and they said it was going to be little houses that we live in and that was going to be great. I spent a whole year, a really hardship, trying to go to toilet on your own, trying to get dressed on your own, for a whole year, and then they decide it's, apartments all together, so you no peace, know what I mean. I would just like to be on my own... afraid to open the door, there's always someone outside, I don't like that, I like my own space."

Grainne describes not having any privacy and limited freedom living in the setting; she reports wanting her own front door that she can close. She reports finding life in the residential setting very difficult, primarily as there is not enough academic or cognitive stimulation – "I call it a romper room, an adult romper room because it's just like being in a kindergarten".

Grainne uses her computer to write short stories and poems, and describes the importance of friends, some of which she has since her school days.

She reports enjoying going out with family and friends and spending time in the grounds, feeding the wild birds. Her ideal life would be living alone with animals,

> "I'd have a field with a house and my health and with loads of animals, I'd be happy."

Life history

Grainne recalls a very happy childhood, "You know we were poor as in money, but like he [her father] sang us or told us stories, we had a great life".

Grainne went to mainstream school, and most of her education was prior to the onset of her disability. She reports doing well in school, gaining nine honours in her Inter cert and nine honours in her Leaving cert. She reports coming from a poor background, so she.

> "went out and got a job, at [the age of] nine, in a guesthouse, paid for my own uniform, books for school, brought all the tips home."

She describes herself as being a determined person, and the reason for her getting a job throughout school was this determination.

Following school, Grainne did a secretarial course, which she describes being good at and quick. She began working as an administrator in a large organisation, but found the work easy and became bored,

> "so they gave out hell to me one day, they said we're not keeping you because people are finding it so hard, and you're finding it so easy and you're keeping people from doing their work. So, that was that... they were right, I was talking the whole day."

Grainne then went to University and did three years of a four-year course, leaving because she became "sick". At this point, her disability had progressed such that she used a wheelchair full-time and was struggling to manage in the family home.

Grainne has been living in the residential setting for 11 years, she moved there when she realised that her mother could not manage assisting her in the family home any more. Initially, it was intended that she stay in the residential setting for only part of the week, but as her mother aged, she began to live in the setting full-time. Grainne reports choosing to live in the setting because it was close to her family, and because she knew that the family were not managing at home. She describes her family as being very unwilling for her to go into the residential setting because they thought that neighbours would think that they were unable to look after her.

Disability experience

> "Well I have a rare disease, it's called Freidrich's Ataxia and there's only one in every quarter of a million, that have it. So unfortunately I was one of them, and but I'm the only one of our family which is very unusual, and em, they go deaf, dumb and blind. But I haven't, so far"

Grainne has a neurological condition. She first became aware of difficulties when she experienced clumsiness and tripping at the age of 16. In her late teens, she was diagnosed with Friedrich's Ataxia, a degenerative neurological disorder. She reports trying to hide reduced physical ability throughout her early twenties, pretending that she was just clumsy and had a sprained ankle. During the course of a University degree, she became "sick" and couldn't manage, and began to use a wheelchair.

For many years, while in school and college, Grainne tried to hide her disability from others, as she was embarrassed.

> "I was moving from one thing to another And then. I don't know, I always liked to keep changing, I think it was part of the disease and all, when I got, I was trying to pretend that I wasn't getting worse... Just tripped, I was tripping a lot. I just went and they, my mother just said it was being awkward, look where you are going and you won't be falling. But I knew it was more than that... I was trying to pretend that I wasn't getting worse... But it was... slowly it got worse... It just came, crept up on you, but I would pretend. I broke both legs, my arms, I've concussion, broke my nose, trying to keep out of wheelchair. And I had a sprained ankle for three years, everyone said "what's wrong with you?" "Oh" I said "oh, a sprained ankle" So my mother said just don't tell anyone, and I felt then that I better not tell anyone, so I never did tell anyone...Yeah, oh I was so embarrassed"[starting to use the wheelchair]"
> Were you? Why was that?
> "Why? Would you not be?"
> [pause] I don't know,
> "If you're working around an office and you're in a wheelchair, and everyone ohhh, everyone was drawing a breath when they saw you. What happened to you? What happened to you? People didn't know"

Grainne also has a number of medical conditions, including insulin-dependent diabetes. She has also had problems with her eyes. Grainne uses a supra-pubic urinary catheter.

Currently, Grainne uses a powered wheelchair for mobility. She uses assistance and a hoist to transfer. She has reduced strength in her upper limbs. Another disability-related difficulty is that she experiences fatigue. It was evident during data collection that she became tired during interviews.

The data collection took place in a quiet room in the setting.

Living situation

Grainne lives in a residential setting, described as "supported independent living". As already described, Grainne was told that this accommodation would comprise of individual, self-contained bungalows, but these were never built, and instead the extension wing of the setting was built. The disappointment that she feels about the type of accommodation is very prominent in the information that she gave the researcher.

The accommodation that Grainne lives in comprises of single rooms with en-suite toilet facilities. There is also a large bathroom that is shared. Each room leads off a corridor,

with some open space. This is close to the back door of the setting, which is automatic, and there is an automatic gate to enter the setting beyond this (outside). Grainne reports preferring to use this back door and gate to access the setting, and after one interview, she showed the researcher out this way.

In Grainne's room, as well as her bed, wardrobe etc, she has her computer, stereo system and a television. She has a dog, which sleeps in her room. It is not clear if this dog belongs to her, or the setting, but she certainly feeds, walks and generally takes care of the dog.

Food is provided in the setting, in a large dining room at the other end of the residential setting.

Grainne reports general dissatisfaction with where she lives, she would like to be living on her own rather than in the residential setting, where there are others around her all of the time. The physical area where activities are performed is accessible, but some activities (such as eating meals other than breakfast) take place in communal areas, these she describes as an "adult romper room", because other residents are talking "rubbish". She manages this frustration by spending as little time in the area as possible.

Honour

Brief self-description

Honour is female and lives in the community, with personal assistance.

> "I'm single, I'm 58, Irish born and I suppose yes I would be a disabled person now, yes, that is one of the things I suppose I have a tremendous problem with, coming to terms with it..."

Honour lives in a local authority house, which she describes as "totally unsuitable" for her needs. She is currently on a waiting list for an apartment which will be accessible to her. She lives with a personal assistant.

Honour's main passion is, and always has been reading. She said that she can't remember not being able to read;

> "I must have been reading by the time I was four though, and that was one of the things that kept me sane I suppose for a very long time... they let me into [name of] library...I had books for every member of my family, dead and alive you know... simply reading and learning new things has always been important to me, I just, that's what I like doing. In some ways I suppose my life isn't too bad because that's what I can do, and that's what I like doing, I mean, I suppose if I wanted to I could just sit back and read for the rest of my life and I would to a certain extent, be content... what I'd really like to do is sort of be a University Don in Oxford or Cambridge, and just sort of, live with books you know, and that's what I want to do... I'm really quite happy with my own company or you know with sort of books."

Life history

Honour describes being a "sickly child", meaning that she missed a lot of school. Her family moved abroad, during which time her father left her mother. On return to Ireland, Honour reports starting work to help to support her two younger siblings. She left school early, and worked in a number of different jobs as a shop assistant, all of which she "loathed".

She went to the UK and began a course in nursing, but due to the development of her physical disability (arthritis), and an incident where she could not manage manual handling, she had to leave nursing.

She then got a job in a large firm as an office manager, and worked there for a number of years until she started to have significant difficulty managing, particularly with mobility, so she returned home, and found herself caring for her mother.

Following a number of years looking after her mother, who began abusing alcohol, Honour decided that she wanted to do something for herself, and began a University degree as a mature student. She hopes to complete this, but needed to defer her place during the second year when she became unwell.

The primary reason why Honour decided to go to college was to do something for herself,

> "I still felt that I was an absolute failure at life, and I'm, I can give an impression of being fairly self confident and that but I'm not, I'm always shaking inside, so... I wanted to go to university and I wanted to do sort of more or less what I'm doing...I started [university degree] the following year and I was very happy, umm, except that I found going in and out, I got very, very tired..."

Honour's ambition is to return to college, finish her degree and she would ideally like to do postgraduate studies in the area. She has not returned to college for three years as her consultant and the college doctor say that she is currently unfit to do the course.

> "If I, if it takes me until I'm a million or however long that I live, I am getting the damn degree, and I'm progressing on if they let me stay there, I just, you know I that I got so stubborn about it now that I feel that I want to achieve something. I feel that my life, probably a lot of it through my own fault, has been umm, most unsuccessful a mess, I feel rather guilty about it and umm, I just would like to achieve something."

Disability experience

Honour was born with a physical disability (spina bifida) and describes her left leg and foot as being deformed, but this was surgically corrected at the age of eight. In her thirties, she was diagnosed with a mental health difficulty, and has experienced mental health issues throughout her life. At times, the mental health difficulty was very severe and she

describes one serious suicide attempt. She also describes being affected by sexual abuse.

During her late 20s and 30s, Honour developed significant arthritis, which may be connected to her congenital disability. Honour experiences severe arthritis and other rheumatological conditions, resulting in pain and swelling in joints, and there are systemic effects.

She began noticing that her disability was affecting her significantly in her thirties,

> "I was in my 30's that I started, I always had been in a lot of pain with my back now, sort of bones and things but it just was a background thing with me, I just accepted it and got on with things... anyway, my ribs went and when they x-rayed me they found my back was in a horrible state, much worse than it sort of looked on the surface and I also had the arthritis, so that was the end of the nursing... I worked for some more years... but then I couldn't manage the tubes or anything any longer... I was crumbling myself I was in a lot of pain and finding it quite hard to walk."

Honour describes feeling "horrified" at her physical disability progressing over the years. She describes one of the hardest things she has come to live with is the experience of being physically disabled.

Honour uses a wheelchair for most mobility, although she is able to walk short distances and transfer with minimal assistance. She uses either a powered wheelchair or powered scooter for outdoor or long-distance mobility. She describes being unsteady on her feet, has fallen frequently, and fears that she is at risk of falling. She describes having poor hand function.

Living situation

Honour lives with her personal assistant in a council house, described as an old cottage. The cottage is close to the city centre, towards the end of a cul de sac. The cottage has two main rooms, one of which the PA uses and the other is a kitchen / living room that Honour uses – her bed and all of her books are in that room. There is also a small bathroom.

The house is described as totally unsuitable for Honour – it lacks space, and it is impossible for Honour to use powered mobility in the house.

> "it's supposed to be adapted for a disabled wheelchair user, but it isn't, at all, this is because it's umm, an old cottage that has been sort of semi adapted, but can only be taken so far so it wasn't, if you like, purpose built or enough, planning perhaps put into it you know, and umm, they're not planning to do anything else with it, so, I guess what you have is what you get sort of, until I can get somewhere better."

Honour is very dissatisfied indeed with her home environment. She reports being unable to access the bathroom facilities using a wheelchair. This has led to her needing more assistance and falling on occasion. The lack of accessibility leads to an increased fear of falling.

Honour is waiting to be re-housed in an apartment, which, she hopes, will resolve the access issues and make self-maintenance activities easier and safer to perform. Assistance is provided by a full-time personal assistant.

Reflexive Elements

The content of this chapter is distilled from many hours spent with each of the individual participants, primarily the recorded interviews, but also the time they took showing me where they live and spend their time. It is very difficult not to react emotionally and logically to the content of personal histories. Rather than ignoring my reactions, or trying to be "objective", I noted my reactions during and immediately after the interviews.

My own reflections, from immediately after the interviews, and now, some years later are described here. This section is also derived from some of the voice-centred relational methodology used (see section 5.12.3 for a description of this), thus it is attempted to raise the potential issues that were raised by the reflexive strategies in the reconstruction of the participant descriptions. .

Anna, while I didn't know her personally prior to data collection, I could understand "where she was coming from" in her description of independence and the battles that she has in her life, and the need to be a fighter. I had heard similar discussions before – not that I

had "heard it all before", but I had an "in", I had some understanding of where she was coming from, we had common friends and allies in the disability movement. Throughout the interview, she says, "you know what I mean" – and I did. During the interview, I nodded, or agreed, and only when transcribing, or when coming to analyse the interview did I realise that a reader may not know what she means.

I instinctively had a sense of admiration, not patronising "isn't she great" admiration, but a recognition that she has achieved, has fought, and in many cases has won her battles. Anna, throughout data collection raised a number of issues way beyond the scope of this research, but are noteworthy and important aspects of her life. She helped me to remember that there is more to life than autonomy or independence, but that these are nevertheless worth fighting for, for her.

Bart has limited information in terms of words, but the information is succinct and insightful. There were obvious communication issues with Bart. I arrived at his home to do the first interview, to find that my plans to record the interview simply would not work, due to the pace of communication. I needed to ask a lot more questions, and got short answers. As a qualitative researcher, I was dealing with the reality of not having the lengthy transcripts that I hoped for or expected, but instead have contracted versions of information, that nevertheless provide a clear insight. Much of the data was collected by e-discussions – he probably hated getting e-mails from me!

Prior to interviewing Cathal, I knew some information about him, that he had disclosed when we made our appointment for me to interview him. I initially found it harder to understand why someone would not want to be "independent", and why someone who relatively recently had had his life massively changed by moving into a residential setting would not want to live in the community. His information really enabled me to think about my presumptions. Cathal also enabled me to think more deeply about the secondary mechanisms that are used to manage change and unfavourable situations. I was surprised that Cathal chose to be interviewed beside his bed – we pulled the curtain around, but there was limited privacy and multiple interruptions.

I found that I had the most emotional reaction to Deirdre and Grainne's stories. For both, I wonder how they manage their life in circumstances that they describe as so imperfect. In the case of Grainne I could really associate with the lack of academic stimulation – to be living in an "adult romper room". Deirdre describes not fitting in, as well as difficulties with

assistance. She used the phrase that "you need to have grey hair and a smile to get on in here" – that really made me consider the social influences. As well as describing being hit by other residents. I am interested in how both of these participants manage their situations - both coincidentally feed cats in their local area, but react differently. Grainne tries to get away from people as much as she can, Deirdre goes to groups and organised activities, and spends her time with those who she feels she can help, or be good company to.

Emily "talked the talk", but I found her difficult to "pin down", it seemed that the things that she was saying were words, as if she was putting on a front. I found it difficult to know whether to take what she says at face value, or how much to probe. It felt to me, like she had learned the rhetoric of rights and independence, but I didn't know if she fully understood them. Maybe, for this case, my prior experience, and my belief that I do understand aspects of the independent living philosophy, that I have considered myself an "activist" actually made it harder for me to both build rapport and to fully engage or understand Emily.

Freya and Honour live in the community, but I have a sense that they are balancing on a knife edge, the same knife edge that probably was the situation prior to Emily and Grainne moving into residential settings. I reacted somewhat angrily to the lack of services, and empathised with the fight that they need to engage in, in their lives, just to do the simple things. Anna differs in that she appears to have the energy and will to fight, I don't know if Freya or Honour do. "We're not asking for much are we?" said Freya when we spoke about the possibility that she may have assistance.

Honour describes her life as a failure, and her goal to rectify that failing is to do a degree in a college. I felt privileged that I have had the opportunity to engage in education, and questioned the role of health service providers, who had suggested that she was not well enough to do her degree, when that dream is what is keeping her hopeful.

Conclusion

This chapter introduced each of the eight participants in the study, in terms of their self-description, brief life history, their living situation, disability experience and occupational performance. The information from this chapter was collated from the initial interview, the self-maintenance interview and the diary information from each participant.

The next chapter forms the second part of the descriptive results. It describes what the participants do, their occupational performance on a daily basis.

8. Daily Life experiences

Introduction

This chapter is the second part of the descriptive results, and focuses on the daily lives of the participants, in terms of occupational performance. Combined with the previous chapter describing the participants, it forms the background for the interpretative findings in the next two chapters.

Information for this section is compiled from:

- the diary information, each participant kept a 7-day diary;
- the self-maintenance interview, and
- information from the first and final interviews.

Thus, as well as the information from interviews, this section is also based on participants' self-report and self-observation.

There are two key questions that underpin this chapter:

- What do the diaries tell us about each individual?
- What do the diaries tell us about the group as a whole (in terms of similarities and contrasts?

This chapter is presented in such a way as to address both of the above questions, presenting firstly the information from each individual, and second, brief comment on the diaries of the group as a whole, including some differences and similarities in the diaries of the eight participants.

The terms "self-care", "self-maintenance" and "daily routine" activities are used interchangeably in this chapter. These terms refer to those activities that are performed daily in order to maintain health (CAOT, 1997), and typically include washing, dressing, bathing, grooming, food preparation and eating, toileting and mobility.

An exploration of the manner in which self-care activities are performed was thought necessary for a number of reasons. It further describes the disability experience in terms of functional ability; it enables the separation of daily activities from lifestyle activities; it gives an insight into the lived experience of disabled people in terms of "ordinary" things, which is rarely, if ever, clearly documented. It is possible to compare this exploration with the experiences of participants in general "lifestyle" activities, and as a means to compare different individuals' responses.

There are differences in the occupational performance of the participants. A description of each person's productivity and leisure occupations, both in terms of what is done, and in terms of their perceptions of choice and control, are described.

Diary information for each participant

Anna

As described in the previous chapter, Anna is a 28-year old female, who lives in her own apartment with personal assistance.

Anna recorded her self-maintenance activities and the diary information on her computer. The blank tables (appendix B) were e-mailed to her, and she e-mailed the completed ones to the researcher. (See appendix A for completed tables).

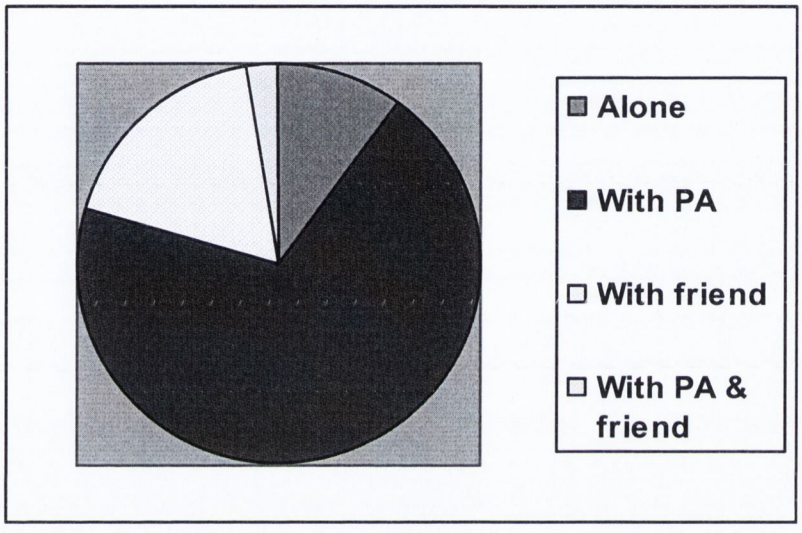
Anna included 39 items in her 7-day diary, which accounted for 90 hours in total. She also included four items in her self-maintenance record (see "self-care" below).

Her diary information was broken down into:

- 13 self-care activities, which included getting up and going to bed (included for some but not all days); chatting with friends; cooking either with her PA or a friend.

- 5 productivity items, including going to work and going to a training course.
- 19 leisure items, including reading, watching television, chatting to friends, listening to music, using the internet and e-mail, making telephone calls, going to the cinema, pub, coffee shop, art exhibition and going shopping in the city centre.

Figure 7.1.1 Breakdown of self-care, productivity and leisure activities by number of diary entries



In all entries (39) the participant reports that she has control over the activity. (To the question, "Did you have control over this activity?" where the possible answers are "yes", "some" and "no", the participant responded "yes").

The participant reports enjoying 30 of the diary entries, with a "n/a" given to the remaining 9 entries (all of which are self-care activities). 31 of the 39 entries are important to her, 2 are "a little" important (both watching television) and 6 are not applicable (all self-care activities.

Occupational Patterning

The diary includes week-end and week days. For week-days, the pattern of the occupations is reported as follows:

- getting up at about 7 a.m. on work days;
- starting work at 9.30 and ending at 5.30;
- cooking dinner with PA at 6.30;
- beginning leisure activities at 7.30 (including watching television, reading, using computer and telephone, going to the pub with friends);
- going to bed between 10.30 and 11.30.

There is a less clear pattern for weekend activities. Anna reports getting up later in the morning (between 10.30 and 12 noon) than week days. The only time reported as being alone is at weekends, apart from one productivity activity (see below). The activities in the centre of town (apart from one trip to the pub) in shops or venues other than home or workplace all take place at week-ends. The diary entries for the weekends suggest that this time is busy, active time for Anna.

Four of the 39 items are reported as being performed alone; one of these is in a productivity activity, where it is assumed that other people were around (i.e. the participant was not entirely alone). Other activities listed (35) were either with a personal assistant (27), with a friend (7) or with both a friend and a PA (1). In total, 7 and-a-half hours during the 90 hour time period described are reported as being alone (excluding the productivity activity).

Self-care (daily routine)

In terms of her daily routine:

> "...I get up early in the morning, sometime between 7 and 7.30 depending on what time my first appointment is of the day, and then shower and dress, and then I would have ... breakfast ... and it's a story trying to watch the clock and organise and get me out to work. Then I have an adapted vehicle which I don't drive myself, but my personal assistant drives and we go to work."

Anna described four daily routine activities, these being: getting up, washed and dressed each morning; toileting; cooking, and going to bed.

Anna uses personal assistance and equipment for washing/dressing, toileting, transfers, cooking / home management and going to bed. Once set-up, she can feed herself independently. All of her self-care activities are undertaken in her own home, and, in the case of toileting, also in the work-place. For all of her self-care activities, she reports having control and choice over how these are performed.

Anna notes that the morning routine of getting out of bed, having a shower and getting dressed usually takes in excess of 50 minutes, and that she ensures that she has one and a half hours for the routine. The most time-consuming aspect of her morning routine are the transfers. She reports being satisfied with the time that morning self-care takes because she reports having chosen to structure her routine so that it is not stressful in the mornings.

> "It wouldn't take everybody that time to get up and get out in the morning em, but in order to be comfortable and not be stressed going out the door, I would have to give myself that amount of time but I have it structured into my day, so it is routine now, so that the average tasks of showering, getting dressed and whatever, they do take a bit longer but you, I have become so used to it that it is not a problem."

The critical factor in whether self-care activities take longer is whether the personal assistant is used to her routine and the way that she likes to be assisted.

> "Most of the time it is average but there might be times where it may be longer due to change in staff personnel, by that I mean personal assistants, PAs. By that I mean if somebody is new and they may have worked with somebody before but they may not have, it very much depends, but then it would take longer than average, you know, to get them into my routine."

Anna reports being totally satisfied with managing the activities that need to be done, as she reports not having "any particularly medical routines".

Initially, Anna reports being "very satisfied" with how she manages her daily routine, "because I monitor it all myself". It appears that her having control over her routine is the major factor that leads to her satisfaction. Having control over the routine includes managing her personal assistance and the equipment that she uses.

Productivity

Anna reports work as being important to her. Her initial description of herself in the first interview included that she works full-time, and her worker role seems to form an important part of her identity.

Anna works with disabled people, She describes her role as follows:

> "...My job would be to put whatever relevant supports each person needs and to seek funding for those supports, and to em to provide em support and training for staff around around disability issues, around equality issues...part of my job, especially at the moment is lobbying the department...So, it's very broad."

She describes her job as "madly busy", and reports that she "enjoy[s] it immensely". She states that she enjoys it because she has a particular interest in the area, and because, "I believe that there is a huge need to develop it there from my own experience and from experience of my colleagues and friends having been through the system as people with disabilities".

A key feature of how Anna organises her work is that she reports taking control of the environment, and of the support she uses. This taking control, and ensuring that her environment is appropriate to her is, she reports, a choice and an she is active in ensuring that she has control.

Her control and adaptation of the work environment relates to the physical environment, she gives examples including sourcing the most appropriate desk for herself and asking for adaptations to the toilets to facilitate her.

It is less easy for Anna to control the social environment in which she works. She describes the need to challenge the social environment, and that by so doing she is working towards changing attitudes and reducing barriers.

> "...I would always be challenging people's perception of disability, no matter what it is, no matter what label it is. I sometimes shock people in meetings when I have never met anyone. Suddenly ...[Anna], wheelchair user arrives and it's like, sometimes I have to explain the role of my PA, and how it works and all that kind of thing. Sometimes, people's, the biggest challenge I think... is sometimes around myself but sometimes around... people's perceptions...Yeah, but then I start talking" [big smile and giggle]

Anna describes how she changes the environment, and that the social environment becomes more supportive when people get to know her. In order to challenge the social environment, the "images or perceptions that are out there in their head" about disability, she reports the need to be "open" and willing to listen to the attitudes. Anna reports that through experience, "you get very good at doing that", skill in challenging increases, and it becomes easier to observe potential barriers, "by their body language, and by their tone of voice and by the way they speak...[attitudes] not about me because they don't know me, but about issues in general, and then it's to challenge that without being offensive and also to listen to their perspective and find a happy medium."

Anna describes the difference between having a "visible" disability and a hidden disability, suggesting that there is more stigma for people with hidden disabilities, particularly as they sometimes are not believed. "For people with dyslexia or mental health issues, society has a long way to go around that... and it's only now that I am getting into my job, I see the whole stigma around it."

When asked what makes Anna good at her job, she reports that:

> "well obviously being open and non-judgemental is a primary factor. Also being a good problem-solver and trouble shooter, also in this kind of a job, and my colleagues would probably back me up in this, my in a way, and it's kind of unusual, but having a disability actually works to my advantage [smile] Because if you have, say a [client] that is going through a very difficult time, or is finding it difficult to cope, or isn't co-operating with staff in a way that would benefit them... they listen to you because you have a disability yourself and maybe you can talk to them more frankly and openly, and we can... I think...what I try to do is to make them realise that I don't have all the answers, they have, they actually have it within themselves they just have to realise it and I think that's the kind of trick to being successful at this kind of work."

When asked about negative aspects of her job, she reports that it sometimes takes up "more [time] than it should", and that, "I get very frustrated with the bureaucratic system that we work in, and sometimes I can find it difficult to switch off".

Anna has also described how she has used resources granted to her to support her at work to supplement personal assistance.

> "...at work [service provider provides] twenty hours [of personal assistance], that covers two days... when I started in my last job... I had to re-apply for that funding..."

She describes the mechanism for the provision of such funding, which is usually given to compensate an employer for a disabled person's reduced productivity.

> "so all this lack of productivity, now I wasn't buying that so I twisted it around and said alright, I will be completely unproductive if I don't have this [funding]... my manager was very supportive, but we fought for weeks to do that, but we got it in the end..."

She describes the mechanism of the funding of the assistant for the hours, reporting that she is "in total control of that".

Leisure

Anna reports having childhood leisure activities that included horse-riding and riding her bicycle. These activities are no longer possible for her, due to the deterioration in her physical ability.

Currently, Anna reports her favourite leisure activities as follows:

> "Cinema, I love cinema and... the theatre, and... I like pubbing but I don't really like night-clubs I like late bars... and concerts, I love concerts, all kinds."

In the diary information, leisure activities included: going to the cinema; going to the pub; going to a coffee shop; shopping in the city centre; reading; watching television,; chatting to friends; listening to music; using the internet and e-mail, and making telephone calls.

The leisure activities listed are all either quiet recreation (e.g. reading, listening to music, watching television) or social recreation. When asked, Anna reported that she would like to engage in active (sporting) recreation, particularly swimming. She reports that she had planned to go swimming, but her ability to go depends on the availability of a personal assistant who is willing and able to assist her in the pool, as well as the pool being accessible and having the appropriate equipment, such as a hoist. She reports some frustration about not being able to go swimming for a period of time, due to difficulties with personal assistance. When asked if there was anything that she would have particularly liked to do in the period during which diary information was recorded, swimming was the one activity that she spoke about.

One of the key themes that emerged in relation to her leisure activities was the amount of planning and organisation that is required to do any leisure activity.

> "...firstly it's not that simple. Lots of times it is but most of the time it isn't. Okay, I have at the moment, a number of PAs so I have to manage their times, their rosters and all that kind of thing so and lots of them do part-time hours for me so we have to kind of say what time, if I do this, what time will such and such a person come on, what time will such and such a person come off. It's not so bad if something's on within the city centre because I don't need a driver, you see not all my PA's can drive and I don't have an open insurance policy because it's too expensive at the moment, so they are named drivers on my Dad's policy. Em, so, and they have to be over 25, so that's very restrictive, so, actually, well one major restriction is in having to plan if I am to go outside the city centre."
> So the skill, from your personal point of view for you to organise an active social life involves a lot more planning than for a non-disabled person?
> "Absolutely, everything from access to the toilet facility which is a huge issue to em, things like, ok, ok, I only have a certain amount of hours, and that's the way it works. So, if I go out on a Saturday night I may have to pay my PA a little bit of money because she will have to stay out later she may also have to be a driver, etc etc. There's ways around things that you have to take into consideration plus, em physical access to buildings and, is an issue because, you know, before you go anywhere you have to, you have to check everything out "

Anna reports that going out and engaging in leisure activities is, "a lot of work". When asked what motivates her to do the work, to "go through all the hassle" (interviewer's words) she reports strategies such as not thinking about the hassle, or not considering the need to organise to be "hassle". It seems that including the need to organise assistance and access is routine, so easier to deal with.

> "Because, well, because I, well 9 times out of 10 I don't even think about it, I just do it. It's just part of life and it, like, I, thankfully I don't even view it as hassle, it's just something you have to do, and I think that's if I did view it as hassle, I wouldn't have come as far as I have come because you have to where possible surmount these obstacles..."

Bart

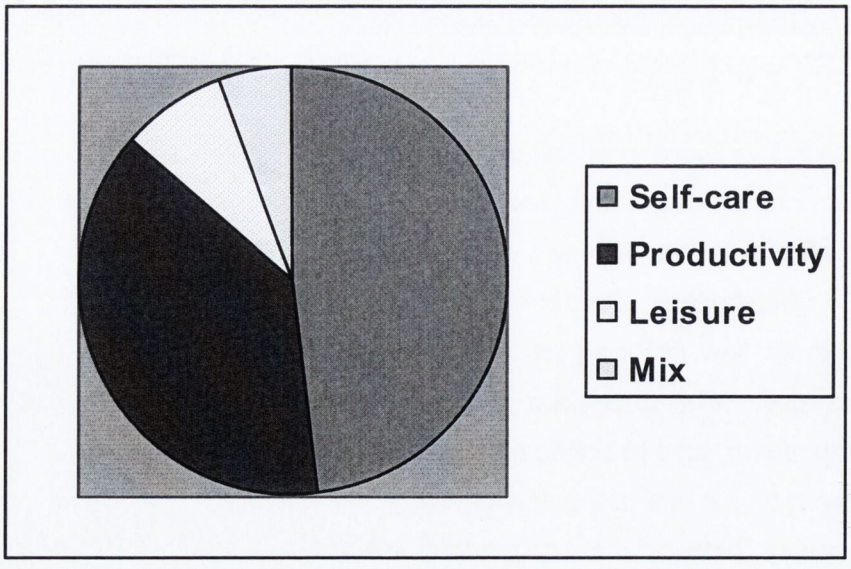
As described in the previous chapter, Bart is a 30-year old male, who lives in an extension to his mother's house, with full-time personal assistance.

Bart recorded the activities on his computer, and e-mailed the responses to the researcher. (See Appendix A for completed diary and self-maintenance information).

Bart recorded a total of 74 activities in the 7-day diary. He also recorded three self-maintenance activities separately – the diary information included daily routine self-care activities. In terms of the diary entries:

- 35 of these he regards as self-care;
- 28 productivity;
- 6 leisure and
- the remaining activities are a mixture, 3 are self-care and leisure, one is leisure and productivity.

Figure 7.1.2 Breakdown of self-care, productivity and leisure activities



Occupational Patterning

In terms of routine, there does not seem to be a clear pattern or routine for the days in the diary information, other than on six of the days he reports getting up / doing his first activity (frequently choosing his clothes) at 9.00 a.m. and the final activity finishes at around 1.00 a.m.

There is some time spent alone each day, but the vast majority of the day is spent in the company of a personal assistant. The tasks that are performed alone include giving the PA a break, watching a DVD, reading an e-book (3 reports), checking e-mail (3 reports).

During three of the days, all of the activities take place in the participant's home (or the adjoining home of his mother). Other locations include a large shopping centre, the local "village", a pub and a church.

Self-care (daily routine)

Bart lists the following self-care activities: brushing teeth; taking a dump and choosing what to wear (as with all entries, the participants own words are used). He also records more self-care activities in his diary information, such as eating, laundry, shopping and washing his van.

Bart uses full assistance for all activities of daily living, including washing, dressing, toileting, eating etc. In terms of toileting, he describes the assistance as,

> "Assistant lifts me onto the toilet chair and inserts an enema into my rectum".

Bart is happy with the amount of assistance provided.

He describes the need for routine, and that he sometimes feels overwhelmed by the routine of personal assistants. He reports that each PA has his/her own routine, and that he needs to get used to each PA, but that he always endeavours to remain in control.

Bart reports not particularly considering the time involved in his self-maintenance activities. He reports the time as being slightly more or similar to the time taken by a non-disabled person because of his personal assistants.

Productivity

At the time of data collection, Bart was not in paid employment. He had recently completed a University degree and was looking for work in the area of his degree. Subsequent to data collection, he did commence employment with a disability organisation.

The activities listed as productivity in the diary information were as follows: eating family dinner (also leisure); washing van (also self-care); checking e-mail; phone-calls; giving PA a break; taking a walk (also leisure); putting clothes in wash; buying a voucher; reading an e-book; going to the pub; family get-together and e-mailing timesheets to PAs.

There were at least two productivity items each day – including those that are both designated productivity and leisure or self-care, one day had two productivity activities, two had three productivity items, one had four, one five and two days had six productivity items included.

Bart's categorisation of occupations as "productivity" may be different to that expected, or that others may make, for example, "going to the pub" may typically be considered a leisure, rather than a work activity.

Bart did not give a description of the productivity items in detail in the course of data collection. In the initial interview, he spoke about his hope to get a job in the area in which he had completed his degree, but had no further, more specific plans or ideas about what that role would involve. One important factor in his ability to choose his job is described as the pace of work. As the participant uses augmentative communication technology (a lite-writer or computer), his communication is slower than verbal speech. He needs a job that he can perform at his own pace.

Leisure

Bart listed the following activities as leisure: eating – breakfast, lunch etc.; watching a DVD (2 entries); choosing what to wear (2 entries as leisure and self-care, other entries as just self-care); masturbation; taking a walk; watching television; going to a party and listening to the radio.

He includes no leisure activities on two days, one on one day, two on one day and three leisure activities on three of the days in his diary.

It seems that many of the leisure activities (watching television, DVD etc) are performed alone.

Cathal

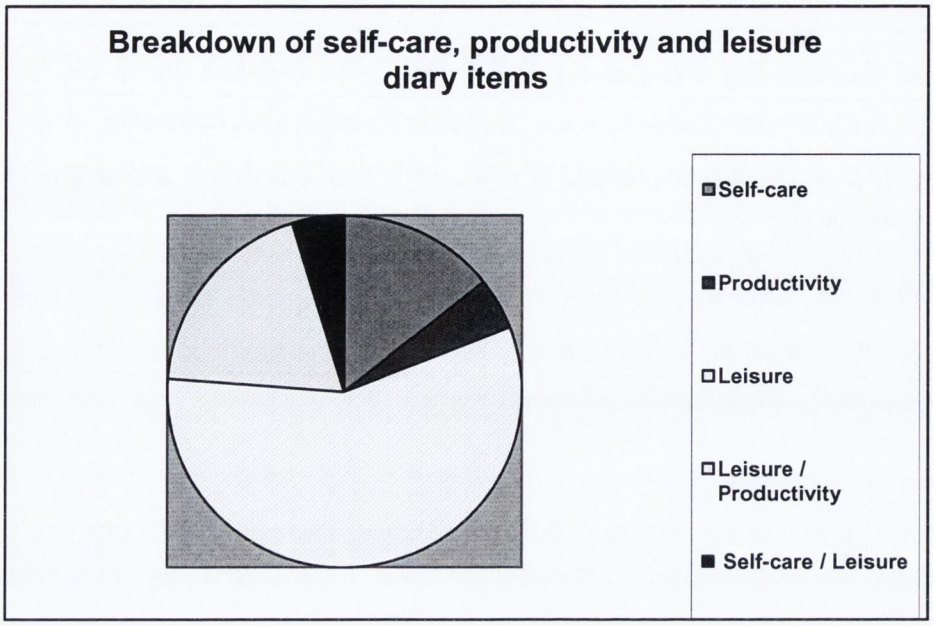
Cathal, as described in Chapter 6, is a 46-year old man, who lives in a residential setting.

Cathal recorded the activities on a computer, and they were discussed during the final interview.

Cathal included 21 activities in his 7-day diary,

- 3 of these were self-care
- One was productivity
- 12 leisure items
- 4 were leisure and productivity (these were all "Going to college", four times in the week), and
- One was a mixture of self-care and leisure.

Figure 7.1.3 Breakdown of self-care, productivity and leisure activities



Cathal reports the week as being fairly typical of his weeks. He reports that he used to go to football matches very frequently, and particularly supported one club. Recently, he has been unable to do this because he did not have transport or anyone to go with him.

> "My weeks tend to be very much the same one after the other... It's not a problem, it's just the way it is. Every once in a while there is something different, but most weeks are all the same."
> Are you happy with your weeks?
> "Em, happy, within the fact that I can't do an awful lot of what I used to be able to do, but, eh, there's a lot of things that I would like to do and can't, simple as that."
> Is that because of your physical disability?
> "Well, I actually only found out yesterday, I actually want to go into town to get a birth cert to apply for a passport, and I was only, last night I was told, and I don't know how correct or otherwise this is, but the office where they do birth certs, steps up to the door, which means somebody like me, forget it. And in this day and age, it's a government building, in this day and age there is no way it should be inaccessible."
> So, what are you going to do?
> "My mother is going to get me my birth cert, and I have asked her to just have a look when she's there if there is a ramp or an anything. And if there isn't I'm going to get onto the radio and say, what's the story, what's going on?"

Of the things that he does do, from diary entries, nine items are classed as important, six as a little important and four as not important to the participant. In terms of his enjoyment, he reports not doing activities that he does not enjoy.

> "I suppose most of the activities that I do at the moment are passive, I enjoy listening to music and watching people performing music and DVDs. They don't require any action, I am just listening and watching... I don't do activities as such that I don't want to do...A lot of the time it is a conscious decision not to follow something. You are given an option, do you want to or not and if you decide you don't want to, then, if you like, you have made a decision, you have been in control that you are not going to take part."

In the diary entries, there are 9 activities listed as being enjoyable, seven as a little enjoyable and three as not enjoyable.

Occupational Patterning

On four of the week-days, Cathal goes to college. He leaves at 10.00 and uses the transport of the residential setting. He returns at around 3.30. His leisure activities typically take place after 7.00 p.m.

On the days when Cathal does not go to college, he reports getting up later, and finding the days harder to fill.

On two of the days, Cathal reports going to bed early. This is described as necessary if he experiences fatigue due to his disability.

Self-care (daily routine)

Cathal records seven daily self-maintenance activities, which are: getting up; eating breakfast; shaving and brushing teeth; toilet; lunch; tea, and going to bed.

Cathal reports not even thinking about the self-care activities or how they are performed. When questioned further, he says:

> "Most things I have to, I need help with, which usually doesn't bother me until every so often when I think about how things used to be, when I used to do everything on my own, and it gets you a bit down. But the way it is now.."
> What is it about getting assistance that gets you down?
> "What?"
> What is it about getting assistance that gets you down?
> "Well, I used to do so much on my own. Now I can't. So I don't have a problem with people helping me, I have a minor problem with not being able to do it on my own any more."

Cathal reports spending longer performing self-care tasks, but also highlights the amount of thought that is required to do simple tasks that typically would be routine.

> "I'd say I spend longer doing very simple things that even me when I was able-bodied, little things, for arguments' sake, like washing my face, that, could be done without thinking about it. Now I have to think about everything and do it, specifically think about things, and sometimes I am not able."

He records each activity as taking 30 minutes, but says "it depends" for eating tea and going to the toilet, he does not specify a length of time.

Cathal reports being satisfied with the environments in which he performs his daily occupations. The majority of the activities take place in the bathroom next to his ward, or beside his bed. He also uses the toilet facilities in his college.

Cathal uses assistance for washing, dressing, showering and using the toilet; this assistance is described as "full assistance".

> "I am washed by them" it would take me two days to have a shower."

He reports using some assistance when getting food – the assistance is that the food is brought to him rather than him cooking or preparing food for himself. Cathal reports that when his arms are weak or he is feeling particularly tired he "sometimes needs help with the spoon", but reports "rarely" needing assistance with eating. He does not use assistance for shaving or brushing his teeth.

Nursing staff provide the assistance to Cathal for the majority of his daily routine activities. When he is in college, assistance is provided by people in the college. He does not have a personal assistant. Cathal uses a hoist for all transfers.

> "I would love to be able to require less help, but I know I need assistance all the time. See the chart up there on the wall there, that's about needs. And basically if I have to be moved at all, we'll say bed to chair, chair to toilet, anything, anything at all it's all hoist. I can't do anything at all on my own. That at times bothers me… I suppose like everybody, I get days when I wonder what the hell are they doing but that's moments. It is fine."

The living environment is such that staff are available to assist Cathal at particular times, as they need to provide assistance to other residents in the setting. Cathal is aware that he needs to decide when to get up and go to bed to fit in with the routines of staff.

Meals are provided in the setting, Cathal reports that if he really wanted to, he could go to a shop and buy food and ask for it to be cooked for him, but that he has never done this.

Productivity

In his diary information, Cathal recorded "going to college" as partly a productivity activity, and partly leisure. He also recorded a weekly physiotherapy session as partly productivity and partly self-care. He recorded only one occupation that is solely productivity or work.

Cathal goes to college four days a week. He does not engage in paid employment since he retired from his job some years previously. He reports still being employed, so his college course is more of something to do to fill in time. He describes this as follows:

> "I am studying computers, but I would still call myself a beginner... there's a course called "College Start" which is introducing people back into college life, I mean people that have been for one reason or another, out of the schooling system for a long time. And that, that includes me, obviously. And, so I go to college, and college start is, if you like, a variety of things, and while you are doing college start, you are then encouraged to pick a course and embark on that course within that college..."
> Do you plan to pick a course, do you plan to go on?
> "Yeah, I do, but I still haven't made up my mind what I want to do... that caused them a problem when I first went into college. Most people who go to college are looking towards a career move of some description or another. But, I just wanted to learn computers. I had no interest, really in finding a new career path, because I am still employed... It fills a big, big gap in the week, and I am learning something that I would like to learn."
> So, is it like work, does it replace work for you?
> "In some ways, yes. It means that I am not sitting looking at the walls here and slowly going mad. I am doing something with my day..."

Cathal, in the diary entry reports that college is important to him, he enjoys doing it, particularly checking his e-mail and that while he chose to do the course in the first place, he has less control over it now because of the transport. He also reports enjoying the activity – stating that he has a new computer teacher and feels that he is learning a lot.

Cathal reports having some control over the activity of going to college

> "Only time when I don't have control is going and coming, I have to be ready for when the driver is ready, the driver decides what time because there are other pick-ups."

In the final interview, he reports frustration at needing to use the transport of the residential setting, as one day he needed to return early from college, due to the transport.

When in college, he reports having control, because "They won't push if I am having a bad day through MS", so he can take the course at his own pace.

When asked about his former employment, he describes it as a demanding, responsible job that he would now not be able to do. When asked if he would like to return to something like his former job, he says:

> "Em, I am still employed...and if there was a miracle and I got better next week, they'd welcome me back, but they would then have the problem of finding me work to do, because naturally, I am out of there nearly six years or somewhere around six years, so my job has been filled a long time, em, so I would have to, they would have to, as my boss when I was retiring said to me, if you got better, if something brilliant happened and you got better, and you were able to come back the problem of finding you work would be ours. Eh, that I wouldn't have a problem, they would. They would have to find something for me."
> When you say, "Get better" do you mean more physically able?
> "I would have to be a lot more physically able because I wouldn't be able to cope with the demands. If I was in my present state, there is no way, because I mean, when I retired from work, I actually left there, I was walking with a walking stick, and I was able for it. Now I can't even stand up, so there is just no way."

It seems clear that Cathal believes that the reason why he can't return to work, or engage in paid employment is because he "can't walk", because of his physical disability.

An aspect of the work that he misses is the social contact, which was important to him.

> "A couple of weeks ago I was in [location] for a presentation... I was presented with a silver badge and scroll, framed, em, just to, just to acknowledge my service and my contribution over the years... I enjoyed the day to day activities and being in contact with other people who are like minded. Without being pretentious, it's people with the same raison d'etre. I know I have lost a lot, but it is nice to be in touch with [like-minded] people."

Leisure

In his diary, Cathal records at least one leisure activity each day. Leisure activities include: Having Visitors (2 entries); watching a DVD (3 entries); going to the pub; going for a walk; meeting and going out with family; listening to music (2 entries), and watching TV (2 entries).

He describes his leisure activities

> "I listen to a lot of music. I watch quite a few DVDs. I have a DVD machine behind me here, and I watch quite a lot of DVDs and television. "

He reports that he used to go to football matches very frequently, and particularly supported one club. Recently, he has been unable to do this because he did not have transport or anyone to go with him.

> "Recently I haven't gone to matches of Shamrock Rovers. I used to go a lot, but haven't been recently. I find, You find, that you miss it... I used to go all around the country following Shamrock Rovers and I find I miss it. When you get onto the coach, you have, first of all the supporters, and you can have some craic."
> Why is it that you haven't gone to any of the matches recently?
> "Because you need transport to get from A to B. My father would be willing to bring me, but he is 82, and he is not getting any younger. Somebody who has got my disability needs a lot of physical helpand he is not able for it any more"
> Do you ever think that there may be a way of getting someone and transport to go to the matches?
> "Em, I am sure there is, I just haven't done anything about it"

Another factor that limits Cathal's ability to perform the leisure activities of his choice is the physical environment. He hopes that a new expected football stadium will be accessible for him, enabling him to go to more football matches. His perception of the lack of physical access causes significant difficulties for him.

> "the actual lack of accessibility is frightening, when going out, but things have improved a lot. Even here, down the road from here, there are a couple of pubs em, they don't have any facilities for disabled, which is crazy in this day and age... I find, in general nowadays that whenever anybody starts talking about going so and so place, doing such a thing, the first question I always have to ask is, "is it accessible". Usually people haven't even thought about it, and say, "oh, I don't know, I'll have to check that out", and often they come back and say, "no, it's not". But that's just, the country we live in."

An aspect of leisure that is important to Cathal is contact with other people. In his diary entries, he describes having visitors as both leisure, but also that it is important for him, for his mood; he describes social contact as, "therapeutic".

He describes the activities that he most enjoys as being leisure activities that he performs alone, and doesn't need assistance to do.

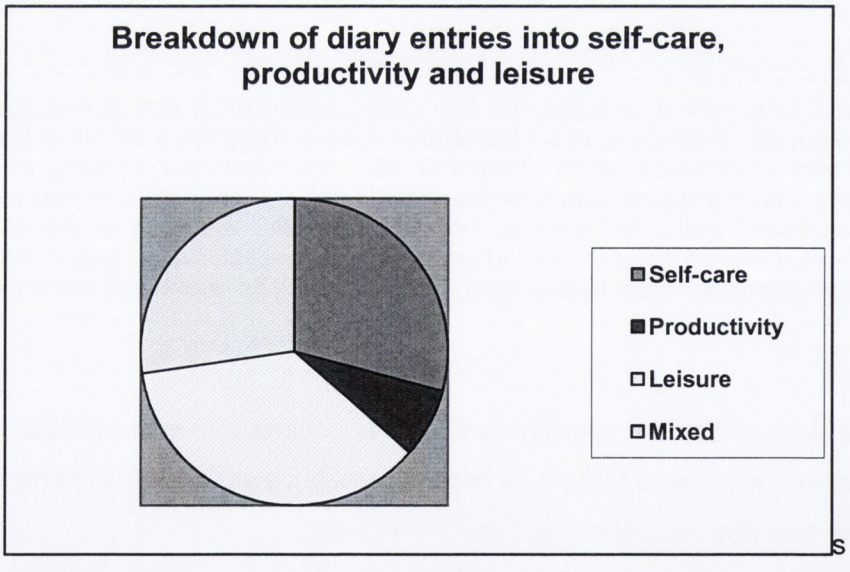
Deirdre

Deirdre, who is 52 and lives in a residential setting, recorded 55 diary entries, which included 31 different activities. These can be broken down as follows:

- 16 of the activities are self-care;
- 4 productivity diary entries
- 20 leisure entries.
- 15 activities were a mixture of self-care, productivity and leisure.

The majority of activities that Deirdre records are activities or groups organised in the residential setting. In her information, she also includes groups or activities that were in fact cancelled on the week that she kept the diary. (These are computers and an exercise class).

Figure 7.1.4 Breakdown of Deirdre's activities into self-care, productivity and leisure



Deirdre reports that 24 activities are important to her; 5 activities are a little important and 2 activities are not important to her.

She reports enjoying 17 activities, enjoying 10 a little and not enjoying 4 activities.

Deirdre reports having control over 12 activities,; she reports having some control over 16 and no control over 3 of the activities listed in her diary information.

She reports being generally happy with the week in which the diary was kept, in terms of what she did. She states that a church service that she attended would not be typical of a week, and that she usually has more physiotherapy. Other than those activities, she reports that the week that she kept her diary was fairly typical.

The things that enabled Deirdre to engage in the occupations during the week she kept the diary are reported as being: the use of the powered wheelchair, without which she says she would "curl and sink into the ground", and warm clothes.

Occupational Patterning

In terms of her daily routine, Deirdre reports:

> "Well, I get up in the morning and wash and dress and then go out and have breakfast as quickly as I can, to groups we have and I like going out around the grounds, and eh, and I have found the cats and I feed them and look after them as best I can"

In her diary information, she reports staying within the residential setting (including the grounds) for 6 of the seven days. She uses different rooms / areas of the setting, as well as going around the grounds. Deirdre is not satisfied with the proportion of time that she spends in the residential setting – she would prefer to go out more. She said that she particularly wanted to go to the local village, but is not allowed out on her own.

On four of the seven days, Deirdre reports spending some time alone. The other days, she has no time alone at all.

Deirdre reports that she never finds time hard to fill – if there are no activities organised, she reports listening to the radio and reading.

Self-care (daily routine)

Deirdre listed eight daily self-maintenance activities and a further two that are not performed daily were discussed (bathing and showering). One of her daily self-maintenance activities is going out to feed the cats – this she says is self-maintenance because it is giving her some fresh air. In the final interview, she reported that she particularly enjoys looking after the cats.

In addition to the eight activities discussed in the self-maintenance interview, Deirdre also includes a further 15 self-care tasks in her diary information. These are: physiotherapy (3 entries); prayer meeting; looked after the cat (3 times); Legion of Mary (2 entries); social work; quiz; current affairs group; bowling; relaxation; looked at books (2 entries); go out to pick some weeds and dead head; sister came, went down to the village and bought a few things and we went for lunch; exercise cancelled; shower, and art.

Deirdre reports being satisfied with what has to be done. Her dissatisfaction is in the manner and the location in which self care activities take place.

Deirdre describes herself as spending more than average time doing self-care activities, time which she would prefer to use doing other activities. She says that she would prefer to use assistance with some tasks, such as getting dressed and having breakfast, to save time.

> "I'm up about half nine or ten to breakfast, I suppose about half eight, [self care activities take] about two hours for me any how"

Deirdre reports using some assistance for washing and dressing, "if I can't put my bra on"; showering/bathing; on occasion for toileting, and at breakfast "if I can get it".

She reports that the ethos of the residential setting is to encourage people to do self-care tasks alone, without assistance. She describes being frustrated, particularly at breakfast, when she would prefer to use assistance. In general, she would "like some more", and feels that staff are "trying to make me more independent" – the kind of independence that she does not want. Deirdre explains that she would prefer to use assistance for washing, dressing, breakfast and other tasks so that she has more time to spend "with the cats", or doing what she would like to do.

"maybe with the nurses, they're trying to make you do as much as they can, and you try and do as much as you can but it's just not enough... Like you know, dressing, and maybe tidying up"

She also has difficulty with the types of self-maintenance tasks that she is asked to do:

"Well, I mean, I'm not, being in here to be paid, I'm not being paid to be here to work, they're being paid [very quietly]"
So you don't feel that you should clean up or do anything like that?
"A little but not, as much as I'm able to but not try and over do it with somebody, you know"

The participant describes it a struggle to get assistance, so she also tries to use assistive devices.

"And sometimes, say if I couldn't put on my bra, it's a big bone of contention for me... Well if I can't put it on, ahh, I have to wait for somebody to do it, and there's so much fussing and rushing and giving out about this bra, that I think, if they say if they tied the back of it first, rather than leave me there half an hour fiddling with it myself trying to do it, it'd be a lot of time... That's up to very lately now, one of the OTs got a, kind of a, Velcro, I'm the Velcro woman, on the back, you know, and at the same time they have to use a hook or something, and it's a bit of a puzzle, but, I guess I get my bra on every morning now any how."

The type of assistance is described as, "autocratic... [she must] take it or leave it... [the assistance] makes me feel kind of annoyed and frustrated". She describes assistance as being provided in an "off-hand" and sometimes "grumpy" manner, although some of the nursing staff are "great... pleasant manner", others lack "basic common courtesy".

"To be quite honest with you, I say they, I often wonder if, why the hell they ever applied for the job, if they don't want to do it now"

She reports needing to be "in with the nurses" to be able to get assistance.

"unless you go over some, be really nice and a bit of a lick, that's the only way. I used to think at one stage the only way I'd get on in a place like this is to, if you're really old, have grey hair and a big smile on your face and say everything and everybody's lovely."

In her diary information, she describes an incident whereby she was woken up at 6.00 in the morning by nursing staff, who removed the bedclothes from her. She reports that while this was for medications, she feels that there was "no need to leave me without duvet". She reports not enjoying it – she was very angry it happened.

Deirdre reports changing the occupations that she does due to a lack of assistance. In relation to breakfast, she reports choosing porridge, because she doesn't have the assistance to get other breakfast cereals.

> "[pause], oh if I can get it [assistance with breakfast] I do, of course I do, but... I got around the breakfast thing, by umm, ohh trying to think what I want, porridge, there's not much you can do with porridge, what I'd have to do is just throw sugar on it and a bit of warm milk."

She says that "it's a good thing" that she likes porridge, because that is the only breakfast item that she feels that she can manage without assistance, and assistance is not provided.

Productivity

Deirdre reports 4 productivity activities, these are: looking after the cats (3 entries); Mass; Computers (but was not on) and art. Deirdre reports engaging in productivity occupations on three of the days. The productivity items are frequently classed as also self-care or leisure, and in the case of feeding the cats, it is considered to be self-care, productivity and leisure on different days.

Since the onset of disability, (when she had a CVA), Deirdre has not been involved in paid or voluntary work. It seems that engaging in the activities in the setting have become her major productive role. She also considers looking after the cats, and to a lesser extent, speaking to other residents as productive roles.

> "Yeah, well there's one or two people that I do, I go down to see, or something, a few people I go and see, and talk to you know like that, down at, the other end, of... I go down to some people like that down there, and ahh, people who can talk then I go to them too, down, older people.. they like that and I like listen to them you know... I know I like it and they like it too, that's why I do it, and other times, I spose I, the cat is a duty, a duty to the cats, cause nobody looks after them any more"

As described in her life history, above, prior to her CVA, Deirdre reports having a busy job, working in the office as an administrator and managing bookings in a large medical setting. She reports enjoying the work. She also reports that she did, and still does, enjoy keeping herself busy.

Leisure

Deirdre recorded 20 leisure activities in her 7-day diary. These were: Prayer meeting; cats; bingo; quiz; current affairs group; bowling; relaxation; church service; looked at books and / or papers (2 entries); coffee; go out to pick some weeds and dead head; Mass; rang sisters; lunch with sister; computers but was not on in O.T. ; met friend; exercise class (cancelled); art and pottery. Some of the above activities are also considered self-care, productivity or both.

Leisure activities take place every day. The majority of the leisure activities are groups or activities that are provided for residents in the setting. She also reports doing some things alone, such as going to look at books.

> "at these groups yeah, and then I have, I read and I listen to, try and listen to, I have a little small radio, and I bought a CD player, and I listen to some CDs."

Deirdre reports the importance of leisure, particularly as a means to get away from either (or both) the people on her ward and/or the residential setting itself. She reports preferring to go out for a longer time, such as a weekend, rather than simply out for a meal. "I said that if I don't get out of here I'm going to crack up".

Deirdre reports being significantly restricted in her ability to engage in leisure, due to the constraints of the setting.

> "well I, wanted to go down to the village and there was nobody available to come down with me, they wouldn't let me go on my own you know... Ahh, it's a pity, fair enough if they hadn't anybody, what can you do about it, but still it was a pity from my point of view that I couldn't, [pause] because I'd love to go... [have the] Independence, to go down and look around ... if you saw a book you liked or something or... Yeah, whether it's to look at the ducks or stroll around the bookshop or, look in at the houses and apartments that are for sale in Portugal or Spain [hearty laugh!]"

She reports that, when she is out with someone, she feels that she can't do what she wants to do, she feels responsible for the person with her, so that she doesn't make them tired by walking around too much.

Emily

Emily is female with a congenital disability and lives in a residential setting.

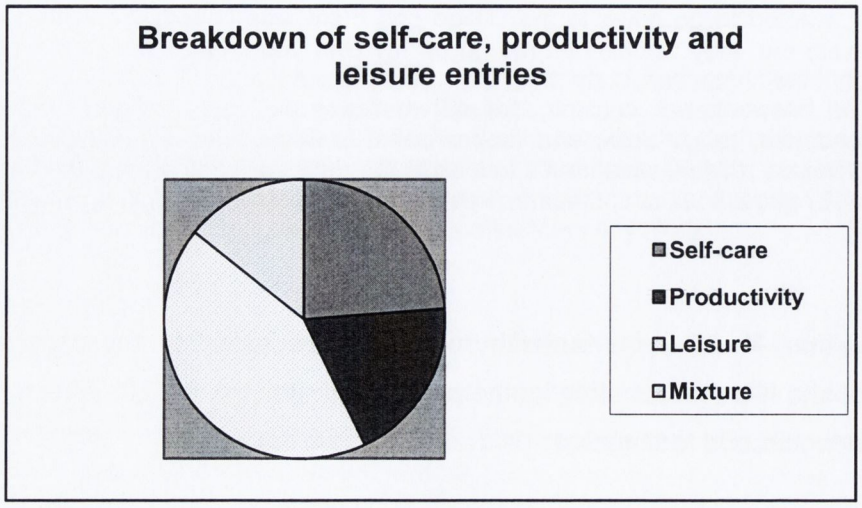
Emily records 18 diary entries over the seven-day period. There are 5 self-care activities, 4 productivity activities, and 9 leisure activities

Emily considers 4 activities to be a mixture of self-care, productivity and leisure. These are: going to the library (2 entries); using her computer; sitting in the garden (2 entries), and walk to enjoy nature.

14 activities are considered important to Emily; 4 are a little important and none of the activities in the diary are considered "not important".

Emily reports enjoying 13 of the activities; enjoying 3 a little, and not enjoying 2. During the final interview, she reported enjoying "talking to staff and residents", going to the garden and, most of all, going to the library. There are no diary entries with "talking to staff and residents", but it is possible that these are frequent, short activities that the participant chose not to record. She reports enjoying going to church the least, but that this depends on the priest.

Figure 7.1.5 Breakdown of self-care, productivity and leisure diary entries for Emily



She reports having control over 12 of the activities; having some control over 4 and no control over 2 of the diary entries.

Emily reports that the week in which she kept her diary was busier than usual, she typically does not do a number of the activities. She describes it as follows:

> "Little bit busier than usual. More active, was outgoing and interacting more. I was so good because I can't go overboard because of my back. Last week I was in good form because of my back, If you don't know of your limitations, it can hinder you."

In terms of what she did, she reports being:

> "Very happy because I was in very stable mood when it comes to my illness with my back, I was able to do more. Maybe if I don't push myself. Nice to go back to the library."

Emily reports that nothing hindered her from doing anything that she wanted to on the week she kept her diary; good weather and her "mood" about her back enabled her to perform the occupations.

Occupational Patterning

Emily reports having time alone in all but one of the days. She reports performing the following occupations alone: went to the bank; went into town after bank; went to library (2 entries); went to the doctor; used computer (2 entries); visited a friend; went to Mass; sitting in the garden (2 entries); went to mothers grave, and went for a walk to enjoy nature.

In four of the activities listed above, Emily started out alone but met with others during the outings.

On two of the days, Emily reports being in the residential setting and grounds all day.

It is somewhat difficult to determine Emily's routines from the diary information kept. She does, however tend to get up at a similar time each morning (8 – 9 a.m.), lunch is served

around noon, and there is "tea" in the evening, shortly after 5.00. Her activities occur between these times.

Self-care (daily routine)

In addition to the diary entries listed as self-care, in the interview, Emily outlined five self-maintenance activities, these being: getting up and dressed (this includes all grooming); washing her hair; eating; going for walks and using the toilet.

Emily uses assistance for all self-care activities, except for going on a walk, which she does alone (using her powered wheelchair). She uses minimal assistance for eating, but also uses equipment, such as "dycem", adapted cutlery and a plate guard.

She reports being satisfied with what has to be done, but highlights that she frequently goes swimming, but that this had not taken place recently.

Emily reports being satisfied with the amount of assistance that is provided.

> "Enough but not too much don't like to be overrun with staff wanting to do things for me."

She describes the assistance for getting up, her first activity as follows:

> "I get up early around 8.30 or 9... I choose the time, can change to a late time if I want... use a ceiling hoist... staff come in at a given time... [they] only assist with the things that I need help with... would be frustrating if they did everything...have better communication with a staff member you know for a little longer... Can relate more to them... Personally I am more comfortable with staff that known for a number of years. Takes a number of months to get used to new staff. They have a new thing so that all staff have to work in a particular area so you don't know who will assist you... Have to accept whoever is there to assist. They have to use equipment. Equipment is necessary because it is the routine of the house, and you have to respect routine and abide by it."

The manner in which assistance is given changes, depending on the day and the staff member. This is somewhat unsatisfactory for Emily, but she reports managing it by remaining in control.

> "Need to always be in control... Can say stop."

Emily reports being "very happy" with the environment in which she lives. She describes the environment as accessible, which, to her, means that she is "more at ease" with self-care tasks.

One of the activities listed as self care is:

> "Going for walks and enjoy nature"

She describes these as self-care, because it is:

> "Important to do at least once a week to calm down and relax."

Emily reports spending an average amount of time undertaking self-care activities. She is happy with the time involved.

Emily describes having a bath, from her diary information, as follows:

> "Thursday is my bath day, like I find it more, ehh, I find it more easy to take a bath than a shower because I have a severe back complaint and they have a Jacuzzi. You know, one of them bubble yokes, and, I find using that bath and the bubbles the effect of the elasticity would stay in my back for some time and I wouldn't stiffen up"

The biggest difficulties that she has with self-care tasks are the need to use equipment and the need to comply with the routine of the house. The activities can be particularly difficult if there is a need to change, or there is a change in staff. She reports being more comfortable with staff that she has known for a number of years.

Productivity

In her diary information, the following were listed as productivity: went to bank; library (2 entries); computer and Mass. These accounted for 7 hours of time. There is no specified pattern of productivity. Activities considered productive occur sporadically on day one, two three four and seven.

Since leaving the sheltered workshop, Emily has not been involved in continuous paid employment. She describes going to schools to do disability awareness training, but it is not clear how this occurs, or in what capacity she goes. It is simply described as follows:

> "But I find also good about talking about the disability, it, I do, I do talk and do awareness from, you know, disabled awareness in schools. I've done it for five years, Off and on, and you go in to primary and secondary, and you completely be honest with the young people, now you have to change the format, with that because of the age difference, with the more older children I get more, more interesting answers, and, the basic answers as well, now can you do this, you know, can you walk, can you sit up, can you do that, and... Yeh, and they say, they would tell me also that, do you get angry when you see people like me, able bodied, walking around and, you know, using their limbs, I would say to them for that question, I would say well, I was a bit annoyed when I was younger but you can't change what you are. So, I, have great imagination so, I, you know, I come across as if I was walking"

She also reports her assumed role of advocate for other disabled people, but similarly, it is unclear how this role is played out. She gives an example:

> "a lot of people would have fear using them [public transport] and I would try and educate people. I met an old man, he was in a wheelchair, I knew him, I've often seen him up and down [name of suburb], and he's in a power chair, and he was waiting at the bus stop and I stopped to say are you getting on the bus, you know with the ramp and he said no, I have never tried it. You know you never tried it, so I said, umm, I use it all the time, so, when I explained what happened, he was very interested, because he has people that he knows outside [suburb] probably in town that, and that would help him bring relations closer to him, if he could use the bus service, or DART, and it was amazing to see the difference when I was communicating, his eyes were wide, you know, really excited, you know, couldn't wait to try the bus... they [disabled people], they kind of show a way, you know if they don't feel comfortable around another disabled person, you know, if they don't know them, and they wouldn't know how to communicate and I would say, you know, I, you know, if I was in a group and there was a new person that I knew would love a conversation with another disabled person and, I would show the person that, there's no difference, there's actually the same kind of talk and same kind of body language, same kind of everything you know and once, once they can see how the role works, then they do it for themselves, But they have to be shown that first, and what I also would love to see for the near future, that the children that are born disabled now are going to have more quality of life. They're going to have more, ehh, no more difficulties as such, they go to a normal school, they get more equipment than we did when I was a child, they, and they will have better access to colleges to places than I had, and if you keep educating yourself by college or by whatever means you do, and then it would, it would widen your awareness of yourself as a person"

In terms of the information in her diary, she reports particularly enjoying going to the bank, because she may meet another disabled person.

Leisure

Emily accounts for 25 hours of leisure in her 7-day diary. The activities that she includes are: going into town; going to the library (2 entries); going to the cinema; using her computer (2 entries); visiting a friend; sitting in the garden (2 entries); going to mother's grave; having a friend visit her, and going for a walk to enjoy nature.

Leisure time occurs every day, in the morning, afternoon and the evening.

Emily, during the interviews speaks about her enjoyment of going for walks around the grounds.

Freya

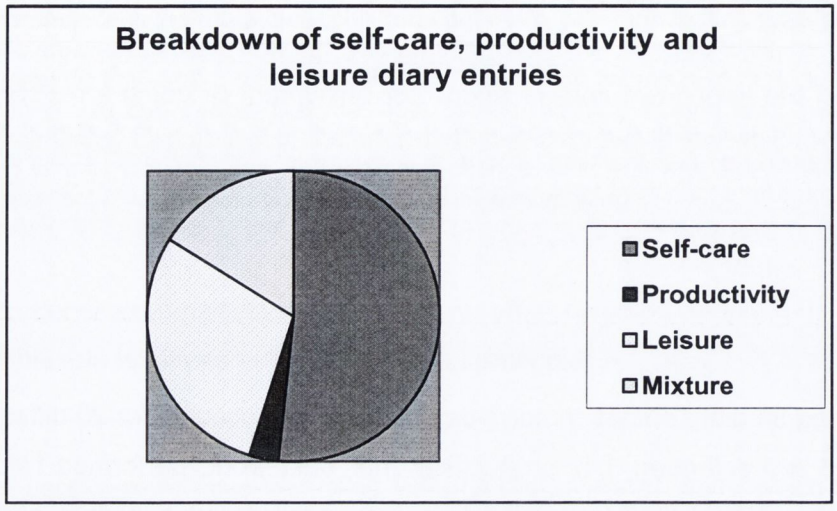
Freya reported 84 diary entries in her 7-day diary. This accounts for 26 different activities. Of these: 16 are self-care; 1 is productivity (her paid work, performed twice)and 9 are leisure. Two activities (both occurring twice) are considered a mixture of self-care and leisure, these being shopping and visiting the library. Three activities are considered a mixture of productivity and leisure. All three are related to her volunteering.

Freya reports that 77 of her diary entries are important to her, none are a little important, and none are not considered important. For 7 of the activities, the importance is not specified.

Freya reports enjoying 61 of the activities, enjoying 3 somewhat and not enjoying 13. 7 do not have the enjoyment recorded.

Freya reports having control over 72 activities, she has no control over 3 and the level of control for the remaining 9 is not specified.

Figure 7.1.6 Breakdown of self-care, productivity and leisure diary entries for Freya



Occupational patterning

Freya spends some time alone each day. Fifty of the diary entries are reported as being performed alone, the remaining activities are performed with someone, but the person is not specified. Activities performed once or more with someone are: prepare and eat breakfast; go to bed; reading; watching TV; going shopping; visiting library; preparing and eating dinner; writing letter; phone calls; voluntary work; visiting friend & dinner; having coffee; credit union visit; work lunch; visit to the hospital and bathing/showering and moisturising.

Freya leaves her home every day. She reports performing leisure occupations every day, and productivity occupations every day. One activity that she performs frequently is shopping.

> "I'm very fond of my fresh fruit and veggies, so I would be shopping at [location] almost, most days anyway I would, umm, then I suppose all the usual bits and pieces that everybody else does, like the cooking, or I'm a big bookworm."

Typically, Freya engages in paid work on a sessional basis, frequently twice per week. She is also very involved in doing voluntary work, which occurs several times per week.

When describing her routine, Freya reports that she needs to be careful to plan her days, as fatigue is a major part of her disability. She organises her time and occupations so that she can manage her fatigue.

> "I tire very, very, very easily, umm, I don't have huge amounts of energy, umm, I'm fine in the morning but get me at nine o'clock at night and I just want my bed... You know, I'm just not a night owl. Umm, if I need to go out at night I need to grab a few hours sleep in the afternoon... [she needs to plan] Very, very much so, umm, I very rarely say would go out to dinner with somebody, I'd go out to lunch, umm... If I'm, say I fancy going to a play, we're in Bewleys on Grafton Street now so I would often go to the lunchtime theatre here, ahh, rather than go out at night, umm"

She also reports needing to prioritise her occupations.

> "things that would probably come highest, umm, I suppose making sure that for a start my mother is safe and happy, you know, if I get up in the morning and Mum is not too well, she is my priority. You know, I suppose everybody would prioritise their life like that, umm, you prioritise what needs to be done as opposed to what you want to be done. I'm very lucky in that my late grandmother had the expression, the house needs to be clean enough to be healthy and dirty enough to be happy. So what's important is, cleaning the cooker, cleaning the food surfaces, cleaning the bathroom, what's not important is taking down the curtains, you know, [chuckling]"

Self-care (daily routine)

In addition to the diary information, Freya recorded her self-maintenance activities by hand in the form provided, these were: getting up; wash and moisturise; get dressed; use nebuliser; prepare food; shopping; having a bath; getting to bed; toileting, and preparing drinks, snacks etc.

In terms of her perceptions of what has to be done, and how it is done, she says:

> "I suppose what has to be done has to be done and I suppose I'm satisfied in that I can do them, I just wish it didn't take so flipping long... how I do them on a lot of occasions is just about manageable, for me, in that when I go about doing things, by the time I've gotten half way through them I'm so flipping frustrated that I'm probably dropping more things than usual or whatever, so I get pretty fed up as I said... In an ideal world I would just have, umm, a battery power pack attached to me to speed everything up, or a gorgeous guy to help me do them. You don't know of a saint who's looking for a partner do you?"

Freya, in discussion, says that the manner in which she needs to do self-maintenance activities is frustrating, due to her physical disability and a lack of assistance.

> "well my fine motor skills are pretty dreadful, so, just even doing basic things, like umm, even opening bottles of shampoo to wash your hair, or going to get dressed even, umm, and I've, by the time I have picked up the things that I've dropped for the fourth time, you know, it's, it does take me an awful lot longer to do everything."

How do you feel about that?
"Frustrated! And bloody annoyed! I can think of better things to be doing with my time"

She speaks about the importance of technology to assist her in self-maintenance activities, not only disability-specific equipment, like a bath lift that she uses, but also generally available technology both for personal hygiene and for other household activities. She gives examples of electric toothbrushes, microwaves and steamers for vegetables. The technology sometimes is the difference between her being able to do or not able to do, but sometimes the difference is more subtle.

> "It would definitely be the difference between doing it properly, umm, I would say my tooth brushing would be down from, if I was doing it with a regular toothbrush to do properly you would probably be talking 20 minutes, whereas I can probably do it in five. What a difference! And also, you feel you've done it properly too."

Productivity

Freya does sessional work for a company which provides disability awareness training for people working in the public and private sector – usually to large companies or organisations.

> "[the training] it covers all areas both of disability awareness, all kinds of diversity awareness training. And I would go in maybe for an hour, hour and a half as a guest speaker, and we would discuss everything from physical access, umm, all the way through to attitudinal barriers to using a service, umm, and also, umm, field any questions, comments or what ever... I think the important skills I suppose is an awareness of disability issues, and not just around one's own disability. Umm, I'm sure you've seen it yourself Bethan, the number of people who are wheelchair users and who think the world ends and the whole area of disability ends around wheel chair users and their needs. But, umm, I'd like to think that I've got an awareness of issues around other disabilities as well and perhaps the fact that I do have a disability myself does help. Also I think when I roll in to discuss areas of physical access it helps that I'm sitting in a wheelchair, people take me a little bit more seriously."

In terms of her motivation to work, she reports that it is not solely for financial reasons.

> "it's important that I feel I'm contributing something to society. Umm, even if it is just awareness of issues that surround disability, I feel that I'm contributing umm, an awareness and understanding, and if one person out of the 10 or 12 or 14 people who are sitting there go out with a little bit more knowledge and, I suppose with the intention of just putting in a little more thought into their working lives, if it's going to make a difference to just one other person with a disability I feel I've made a contribution...well let's face it Bethan, most of us at some stage or other have been, on the receiving end of other people's efforts and we only enjoy a lot of the rights we enjoy because of the efforts of people such as ourselves. So it's important that we make an effort as well."

She reports enjoying the work, because she feels that it is important and of value to society.

Another important activity in Freya's life is volunteering with a local charity. She explains that her family were greatly helped by this charity when they were growing up, and that she was always committed to supporting it. She goes to weekly meetings and visits hospitals and nursing homes a number of times a week. Freya describes the role of volunteer as being very important to her, and that she values spending time doing voluntary work that she would not like to be paid for.

> "my Mum raised us on her own, and the local [charity] were very, very, very good to us, when I was growing up. I wouldn't have had a holiday were it not for them, they were helpful around Christmas and first Communions, that type of thing. And I always felt that I wanted just, to give something back to [charity], so when the opportunity came up, umm, I actually joined a hospital visitation conference, umm, I don't know why it appealed but I was 15 years old and I said right, go for it. Ahh, so I joined this particular conference, and I was the youngest by about 30 years [chuckling], [laughing now], I was the only female, which didn't impress one of the founder members, he wasn't overly impressed at all [chuckling again], with umm, women coming in, but... we have our [charity] meetings on Sunday mornings, about quarter to 11, then after that we break up and we visit the different hospitals that we visit and umm, literally we would go in, particularly concentrate on those who don't have many visitors, and umm, I'm sure you've seen the situation many times where there are umm, particularly older people who have family and the family don't bother. You would have seen that a lot, ummm, so we would go in and we literally provide the hand of friendship, and it could be anything from just sitting and chatting about what's been on TV or there's one particular lady who loves politics and I'm a real political animal as well, so we could spend two hours sitting there, discussing politics"

> [She goes to work with the charity] "Every Sunday, yeah, and an awful lot of other days in between too, because if somebody needs an extra visit, I'm going to make it... the whole work aspect, yes, it is valuable work that needs to be done... no I would not like to be paid for it, no, no I would hate to be paid for it"
> Why is that?
> "it removes the whole beauty of volunteering! Totally removes that!... if I was paid for it, I could see myself as going and doing it because it provides a pay cheque at the end of the month, umm, whereas now, I'm doing it because I want to do it!"

When asked, Freya is emphatic that she chooses to volunteer, while it has become a routine, it is still an active choice that she makes and she really wants to do the work. She chose hospital visiting rather than home visiting or another activity because there are no access issues.

Leisure

Freya reports the following leisure activities in her diary information: writing letter; reading (3 entries); phone calls (2 entries); TV (2 entries); napping; coffee with guest; credit union visit; visit friend & dinner and shower/ moisturise.

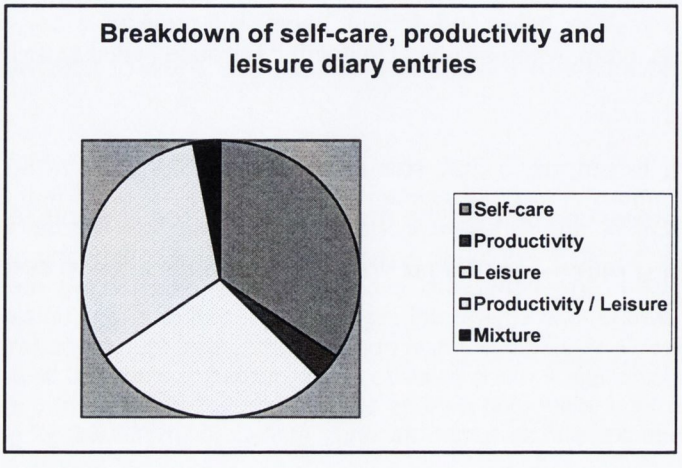
Freya reports being a "bookworm", and enjoying politics, but she doesn't describe leisure activities in detail; it could be that, for her, leisure is combined with her role as volunteer and certain self-care tasks.

Grainne

Grainne, a 48-year old woman living in a residential setting, reported 32 entries in her diary information, which were 17 different activities. Of the diary entries, 11 are self-care; 1 is productivity (which is using the computer); 9 are leisure; 10 are a mixture of productivity and leisure and one is a mixture of all three.

Of the diary entries, 13 are important to her, 18 are a little important and 1 is not important to her. She reports enjoying 15, enjoying 13 a little and not enjoying 4. She reports having control over 15, some control over 14 and not having control over 3 of the entries in her diary.

Figure 7.1.7 Breakdown of self-care, productivity and leisure diary entries - Grainne



Occupational Patterning

Grainne described the week of her diary entries as being typical. The only difference is that she had to make a visit to the local hospital, but she reports that this will be a more frequent occurrence due to disability-related complications that she is experiencing.

Grainne reports leaving the residential setting on three of the seven days. One of these days, it is a visit to the hospital, and on the other two, it is a visit to the local suburb. The purpose of one trip is not specified, the other trip to the local suburb is reported to be for the participant to meet her sister in law and her children. A striking feature of the diary information is the amount of time spent by the participant in her own bedroom – there appears to be minimal use of communal areas, which is unsurprising considering that she reports disliking being with others in the setting. On six of the days, Grainne reports going out to the grounds of the setting, to "feed the animals" and/or "walk the dog". The only day that this did not occur was one where she reported feeling unwell, and needing to spend the day in bed.

She reports getting up at about the same time each morning, and that her morning routine usually lasts from 7 a.m. to 8.45 a.m.. The exceptions are the days (on one day in this diary period) when she has a Jacuzzi, on those days, she stays late in bed.

Self-care (daily routine)

She describes her first self-maintenance activity, getting up as follows:

> "I'm really slow to get ready, I get up in the morning and everyone now they have to do my eye and...then I get dressed. Well, they get the hoist and into the wheelchair, it takes a good hour to get ready... Well they bring the breakfast to the bedroom because I have to eat the minute I do the blood, take the tablet and then eat"

Grainne described six self-maintenance tasks, these being: getting up; eating, using the toilet, managing her catheter, bathing and getting around. She also described other tasks that need to be done on a daily basis, such as testing her blood sugars – these formed part of the other tasks (such as getting up includes testing blood sugars; eating includes taking medication).

Grainne doesn't like the need to use a urinary catheter, and the management of the catheter / catheter bag are self-maintenance activities that she does not like doing. She also describes having difficulty getting around because her powered wheelchair is unreliable, she has had difficulties with its batteries.

In terms of the manner in which activities are performed, the participant reports using assistance, having tried for a period to undertake tasks solely with the use of equipment. She did this in the hope that she may be able to live in supported independent living bungalows in the grounds of the residential setting. She describes that the plans changed, and no such accommodation was available to her, so she gave up trying to undertake tasks alone. Performing self-maintenance tasks without personal assistance was impractical, tiring and difficult, but Grainne said that it was worth trying if she had the option of her "own front door".

Assistance is provided by nursing and care staff. Grainne can request what times she is assisted in the mornings and evenings, but the time that she gets up is generally a regular time, due to the need for her to take medication and eat at the same time every day. In terms of feeding, she uses assistance only to bring food to her to eat, and she uses adapted cutlery and a plate-guard. She uses a powered wheelchair for mobility, but as this has broken down and is unreliable, she sometimes requires assistance for mobility.

Grainne reports being generally happy with the assistance that she gets, she is more aware of the importance or value of having assistance having tried to manage self-maintenance tasks alone previously. She describes the assistance as "ok, it's grand", but that she is careful not to be too demanding on staff, as she is aware that they need to provide assistance to other residents.

Productivity

Grainne does not engage in any paid or unpaid work. In her life history, she describes going to work at a young age, to buy all of her school books and uniform. She reports having had a number of jobs, and leaving one to take up a university degree, which she did not complete, due to the degeneration of her physical ability.

Grainne reports engaging in activities that are either purely or partially productivity on six of the seven days she kept her diary.

Of the diary entries, only one is purely productivity for Grainne. This is using the computer. She describes writing stories and poetry using her computer, and also accessing information using the internet.

Grainne also included 10 diary entries which she considers to be a combination of productivity and leisure. These activities are: feeding the animals (5 times), walking the dog (1 time), using the computer (3 times) and going into the local suburb (1 time).

Leisure

Grainne recorded 9 entries as purely leisure, in addition to those that are a combination of productivity and leisure previously described. There is also one activity which she describes as a mixture of self-care, productivity and leisure, this being "feeding the birds and other animals" on the first day of diary information.

The activities that are purely leisure include: going around the grounds of the residential setting; using the computer (2 entries); friends coming in to visit (3 entries); meeting her sister-in-law and her children; watching television (2 times), and family coming to visit.

There are leisure occupations performed every day.

Honour

Honour included 114 diary entries in the 7-day period. These entries comprise of 19 discrete activities or related groups of activities (e.g. washing/dressing, morning hygiene etc are one group). The manner in which she kept her diary (see appendix A) meant that grouping of some activities was necessary, and some entries consisted of multiple activities, e.g. "using laptop, rest, reading", which the researcher considers different

activities, so these were separated. It appears that the participant recorded time rather than activities.

In her diary. Honour recorded:

- 8 different self-care activities, totalling 32 diary entries. These include: Lavatory/ Shower; Sleep /Rest/ Try to sleep; Reading; Meals /Breakfast /Lunch /Tea/ Dinner; Exercise; Night routines/ Bed preparation; Washing/drying machine; Arrange/pack for respite.
- 12 different productivity activities, totalling 22 diary entries, and
- 5 different leisure activities, totaling 12 diary entries.

She also included the following, which are a mixture of two or more categories:

Self-care and productivity:

- Study (2 entries)
- Sleep /Rest/ Try to sleep (2 entries)
- Morning hygiene/ Dressing /Personal hygiene/Lavatory/ Shower (2 entries)
- Meals /Breakfast /Lunch /Tea/ Dinner (3 entries)
- Arrange/pack for respite (1 entry)

Self-care and leisure:

- Meals /Breakfast /Lunch /Tea/ Dinner (5 entries)
- Washing/drying machine (1 entry)
- Reading (4 entries)
- Morning hygiene/ Dressing /Personal hygiene/Lavatory/ Shower (2 entries)
- TV (1 entry)
- Sleep /Rest/ Try to sleep (4 entries)
- Study (1 entry)
- Exercise (1 entry)

Productivity and leisure:

- Reading (4 entries)
- Study (1 entry)

- Meals /Breakfast /Lunch /Tea/ Dinner (2 entries)
- TV (2 entries)
- Laptop (2 entries)
- Videotapes (2 entries)

A mixture of self-care, productivity and leisure:

- Dog care (2 entries)
- Exercise (2 entries)
- Meals /Breakfast /Lunch /Tea/ Dinner (2 entries)
- Reading (2 entries)
- Sleep /Rest/ Try to sleep (2 entries)
- PA duties/ Discussion with PA (2 entries)

As is evident from the above lists, there was significant inconsistency about the designation of activities as self-care, productivity or leisure.

Honour reports that 97 activities are important, 16 are a little important and only one activity is not important to her.

She reports enjoying 36 activities, enjoying 39 a little and not enjoying 39 activities. In the final interview, she says that the most enjoyable activities are:

> "Reading and studying. Without a doubt, a shadow of a doubt, I noticed you know when you circled the yeses or the nos... I mean some things I do, but I don't enjoy... I suppose I least enjoy umm, things like, the basic routines of life if you like. I have to try to sort of fit in, umm, rest, which I don't enjoy having to do but it's necessary, because otherwise I won't function very well, and pain will just sort of overcome me, and I'll take too many painkillers"

Honour reports having control over 64 of the diary entries, having some control over 47, no control over 2 and not specifying whether or not she has control over one.

She reports some dissatisfaction with her week. One of the activities that she was doing was powered mobility training with an occupational therapist. She said that her inability to get out and about without the powered wheelchair was limiting her.

> "Well, I'd like to have umm, been out, I mean I'd have like to have just been able to simply go to the shops, and that wasn't considered advisable,"

Previously, Honour had been using a powered scooter for mobility, but this was not considered safe, due to her decreased physical ability and risk of falling when transferring. She also experienced severe pain when using the scooter.

Occupational patterning

Honour reports that the week when she kept the diary was fairly typical, although she was preparing to go into respite.

> "A new brain is what I need, umm, well it would be, it wouldn't be as typical as I would like it to be but it's been typical certainly of the last year. It was an average [week], except for the wheelchair practice, that's one of the reasons, I was stuck... it was pretty typical as I said for about the last year, in that all of my time really was spent at home except for short brief periods out, umm, on the first day, in the afternoon I had two hours wheelchair practice in local area streets with umm, an OT, so that was from two till four pm, so that wasn't typical. Umm, what would have been typical in that before that, before May, before I was left without anything, I would have been out, right you know, I'd have been out on the scooter or something like that so, you know, probably in the morning, and then of course when I was going to college it would have been totally different altogether."

Honour has changed her routine, since it has been increasingly difficult for her to get out. She describes her routine:

> "I used to do a certain amount of shopping, and now I do it on the laptop, so that was sort of the last six months that I haven't been going out with the dogs, [PA] has been doing that, so as I said, it's sort of morning hygiene, study, breakfast, usually reading, business affairs, dressing then, exercise, lunch, stuff like that, then the evening's just, I don't really have any social life outside"

She reports being significantly dissatisfied with not being able to get out. In her diary information, she only left her own home (a small cottage) once in the week, and that was for powered wheelchair training with an occupational therapist.

> "not happy really with that at all [time spent at home], no, that will have to change definitely. I'm not happy with the umm, lack of social activity, now I don't want to go partying, I don't, but I wouldn't mind sort of umm, meeting a few people, I wouldn't mind sort of being able to have someone in for dinner occasionally, or go out for dinner occasionally or something like that you know. Which really isn't possible at the moment."

As she describes above, she also has limited social contact. The only people that she reports doing any of the activities with in the week she kept her diary are her personal assistant and the occupational therapist.

A striking feature of Honour's diary is the length of her days. She begins activities early in the morning, and is frequently late going to bed – entries continue until after 4.00 a.m. on several of the days, and 2.30 a.m. is the earliest time she reports going to sleep.

She explains:

> "I do, I might get [PA] to put the washing in, and then I'd go out and switch it off when the thing comes on you know, and then sort of take it and I can use my picky stick now...go out and dry it and sort of stuff like that because I sleep in bursts... and I wake up and I go to the loo a lot, and I'm in kind of pain, so I wake up lot, so it isn't really a problem for me, it frightens the life out of [PA] because he's convinced I have fallen once or twice...but you really have to kind of preserve a certain degree of independence and for what you want to do you know."

The diary information suggests that she does rest, sleep or try to sleep during the day, most days.

Self-care (daily routine)

Honour recorded her self-maintenance activities by handwriting details in a form given to her. She recorded the tasks both in her usual routine, and when in respite care. These are in addition to the self-care tasks described in her diary information (listed above)

Honour lists ten self-maintenance activities. These are: hygiene, washing, hair, etc.; breakfast; dressing; lunch; visits to the lavatory etc.; housework, cleaning; bed making: air mattress, quilt cover changing etc.; dinner; high tea, and showering.

Honour describes being dissatisfied with the daily routine tasks that have to be done, primarily because she feels that there are so many things that she cannot do independently. She reports that daily tasks are "awkward", they take a long time, cause fatigue, and she is concerned about her safety, as she has fallen a number of times.

Honour tries to minimise what has to be done on a daily basis, and minimise the difficulties that she experiences by modifying the occupations. She chooses not to wear make-up and to keep her hair very short to minimise the amount of time and effort that self-maintenance activities take up.

> "like you take it down very much to the basics of staying clean, staying presentable so that you're not absolutely kind of frightful, frightening to the horses, and if there's sort of personal things that interest you, I'm interested in skincare... you do tailor your wants and your needs... you have to manage them to a degree that you wouldn't do if you were just able to walk around."

Honour is also dissatisfied with the manner in which self care activities are performed, because she feels that she needs assistance. When assistance is not available or sought, she is also dissatisfied with how she undertakes the tasks, as she feels awkward and they take too much time and energy.

Honour uses assistance for eight of the activities, sometimes uses assistance for one (using the toilet) and she does not use assistance for one task (morning hygiene). She clarifies that she does not use assistance to eat, but requires assistance to prepare foods. She sometimes requires assistance with toileting when she is ill and has a flare-up of irritable bowel syndrome. She transfers independently, although in some environments requires supervision to reduce the risk of falling.

> "Dressing... I use the PA... And I need help with dressing, I can't now any longer, umm, I can't get my bra fastened, I need help sort of getting trousers and pants and that over my feet, I can pull them up after that, I can get a top on usually alright, unless my shoulders and neck have gone... sometimes can be a bit stiff, and I definitely have to have someone to put my shoes and socks on."

Assistance is provided by a personal assistant. She is satisfied with the amount of assistance that she receives, The type of assistance is appropriate, but a disadvantage is that the "PA talks back". In an ideal world, and in relation to the manner in which assistance is provided, a more robotic form of assistance would be preferred by this participant, that doesn't "talk back".

> "Well, it's pretty good, pretty good, but I'm fairly precise in what I want done. So I can sort of say you know, I want it done this way, that way or the other way, the unfortunate thing is that my PA, knowing me so well, is inclined to talk back a bit, "

Most of the tasks listed take the participant around 20 minutes, except for showering, which takes 45 minutes.

When performing activities, it is estimated that simple actions, such as a shower "take three times as long" for Honour. As described previously, she modifies tasks, such as not wearing make-up and having short hair, to reduce the time involved in self-care activities.

> "Well, when it comes to taking a shower for instance, I require assistance for that, but it would take an awful lot longer, I mean, another person could hop in and out of a shower, but whereas for me, it's a three quarter of an hour activity really... I'd say it's about three times [as long as it would take a non-disabled person], I remember I would used to fly in and out of a shower in about, less than 10 minutes I suppose."

One interesting point that Honour makes is that her self-care activities are changed by the rest of her routine, particularly productivity. She describes now doing the minimum, and explains this by saying that she is staying at home, so she feels that she doesn't need to dress up.

> "if you were in a situation where perhaps you were going out to work or whatever every day you probably would take a lot more care with appearance and with umm, buying clothes, instead of just wearing T-shirts and trousers and stuff like that, you probably would go in for smarter outfits"

Productivity

Honour lists the following activities as purely productivity or work: study (8 entries); business affairs (2 entries); wheelchair practice (2 entries) PA duties/ Discussion with PA: dog care; phone; laptop (2 entries); Meals/Breakfast /Lunch /Tea/ Dinner; shopping etc.; arrange/pack for respite: reading and writing.

There are a total of 85¾ hours of activities that are considered productivity, that includes those that are purely productive and those that are considered a mixture of productivity and self-care and/or leisure.

There is at least one productivity activity performed each day.

Honour's main productive role is that of student. Although she is currently not attending college, due to health and disability issues, she still spends time studying. She is particularly interested in ancient history. Her dream is to return to University to do her Bachelor's degree, and then continue to higher degrees. Her dream is to eventually have a PhD.

Honour began the college course a number of years before the initial data collection took place, and she has completed one year, and part of the second year. She describes herself as different from the school-leavers in the class, because she wants to be there – she reports that all she wants for her life is to be immersed in books.

Initially, she reports feeling lucky, that what she wants to do is possible for her to do, but then she does describe some disability-related difficulties:

> "I have found, lately that large books are difficult for me, and as I just don't have the room to sit at a desk, umm, it's a bit of a problem, so that because I'm sort of propping things up on a pillow in the bed so that if I want to and some of my books are whopping great things, you know reference books can be quite large, umm, the laptop is ok, it's bigger than yours but I can, I can manage it,"

Honour initially decided that she wanted to start the college course when she had improved mobility, so that it would be physically possible for her to get in and out. Her reduced physical ability over time was a major contributing factor to her inability to continue with the course.

> "I remember it was about nine years ago now since I first bought a scooter, and when I realised that I was really getting to a stage that I was becoming very shut in because of disability, and I just went off and bought one, you know, I didn't sort of know anything about them, that there were different kinds, or there were OTs to advise you or anything, and I was quite lucky really, and it got me around terrifically, that's why I got up sort of you know, finally got the courage to approach [University] and that"

Another important productive role for Honour is managing her finances, and "business affairs". She describes this as being important to her, as she likes to be in control.

Leisure

In her diary, the following are activities that are considered purely leisure: reading (4 entries); Meals /Breakfast /Lunch /Tea/ Dinner (3 entries); Sleep/Rest/Try to sleep (3 entries); Videotapes and TV.

The total time for leisure occupations, including those that are purely leisure, and those that are a combination of leisure and self-care and/or productivity is 66 hours. Leisure activities occur every day.

As previously described, the activities that the participant most enjoys are reading, and studying, most frequently these are also considered productivity. She describes herself as someone who doesn't get bored, and always has something to do.

> "This may seem very, very strange, but I'm not a person who ever gets bored. I find myself frustrated certainly... I would decide, there would be things I want to do, I'd want to go to the theatre, I'd want to do this that or the other, and it's just impossible, and umm, so frustration can come in. Boredom, no, I don't, I find it very, very hard to even understand the concept, because umm, I, I know what it's like when everything shuts down, when you literally can't concentrate, when you can't think, so that for me every moment that everything is up and working mentally is just absolutely terrific, and really, that overcomes anything, other things can be an irritant, they can be frustrating, they can be annoying, but once the old mind is ticking over, I don't mind. If nothing else you can actually sit and think, lions think and go over things you know, so, but that is a big bonus for me, I suppose I'm very fortunate."

What do the diaries tell us about the participants as a group?

The previous section described each participant's diary and self maintenance activities, and also included some comment from the participants about their information. This section gives an overview of information gleaned from the diaries for the group as a whole. As there are only eight participants, it is not thought helpful to make generalisations. However, an overview of what the detailed information provided tells us about the participants as a group is thought useful.

The eight participants kept diaries of activities that they performed over a seven-day period. The number of activities recorded differed greatly, with the total number of diary entries ranging from Emily's 18 to Honour's 120 entries. Some of the difference in numbers of entries may be an interpretation of what the researcher was looking for – Honour accounted for practically every hour, whereas in Emily's diary, there are large amounts of time where no diary entries occur. She tended to record activities other than just being around her residential setting, such as going out.

Occupational Patterning

Overall, it appears that the group all engage in a variety of self-care, productivity and leisure occupations, although there is significant difference in the nature of their performance, in terms of the environments in which occupational performance occurs and occupational forms elicited.

Routine was highlighted by a number of participants as important. Bart states that routine is important, but that it is sometimes overwhelming for him, as it is imposed by personal assistants. However, his diary entries demonstrate little routine, except for times of getting up and going to bed. Emily describes the need to "abide by" the routine of residential settings. There appears to be clearer routine in terms of getting up and going to bed, of the four participants who live in residential settings (Cathal, Deirdre, Emily and Grainne,). This is particularly the case when week days are compared to weekend days.

Honour is striking in the lack of routine, even in terms of hours of sleep that she has; all other participants appear to go to bed and get up at similar times on some of the days.

There appear to be key contrasts in the routines of participants. It does appear that certain environments impose structure, such as the time assistance is available in residential settings, or the need to go to work or other regular commitments. The contrasts are not only in the evidence or lack of evidence for routine, but also in the manner in which participants use or do not have a routine. Anna and Deirdre appear to have clear routines: for Anna, this is possibly imposed by her working full-time; for Deirdre, it is a conscious strategy to go to different groups and activities in the settings.

Anna and Bart, in particular, report having little time alone; Anna reports that 4 out of the 39 activities are performed alone, which comprises of 7.5 out of 90 hours accounted for; Bart is alone for 6 out of 74 activities. For both of these participants, most of the activities are performed with a personal assistant. This is significantly different to some of the participants who live in residential settings.

There appear to be significant differences in the amount of time participants spend outside their home or residential setting. Deirdre and Honour report only leaving the setting / home once during the week. Both cite difficulty with mobility, either that Deirdre is not allowed to leave the grounds unattended or Honour who does not have a powered wheelchair that she can use. However, these participants contrast in that Deirdre does go to different rooms in the setting, and goes out in the grounds. Honour literally did not leave her small cottage, except for a couple of hours with an occupational therapist who was doing powered mobility practice. Both would like to leave the setting/home more often.

Other participants appear to leave their home significantly more. Anna and Freya leave their homes every day; Cathal and Emily leave the residential setting most days.

Self-care, productivity and leisure occupations

Table 7.1 on the following page gives the number of diary entries and the proportion of activities that are categorised by the participants as self-care, productivity and leisure.

It is important to note that table 7.1, and indeed the interpretation of diary information relates solely to diary entries, regardless of the amount of time involved. For example, Anna includes 5 productivity items, compared to Bart's 28 and Honour's 22, yet she is the only participant who, at the time of data collection, was working in paid employment full-time. Therefore, the time involved in productivity would appear very different to the total number of diary entries.

It appears that Freya has the highest proportion of diary entries as self-care (75%). A possible explanation for this is that she included 16 entries (19%) that are disability-related, medical tasks, such as visits to the hospital and using a nebuliser. Cathal reports

the lowest number of self-care activities, this may be as he did not include the daily self-care tasks in the diary. The variation of self-care tasks is at least partly due to some participants recording all self-maintenance activities in the diary, as well as in the self-maintenance record/interview, and others not.

In terms of time involved, the self maintenance / diary entries of the group as a whole may suggest that self-care tasks take several hours. While some participants did not include detailed time involved in activities, discussion and the time that is given suggests that some of the participants feel that their self-care takes longer than what they expect for a non-disabled person. Freya and Deirdre specifically report that self-care activities such as washing / dressing particularly take a long time.

Anna reports that getting up and dressed takes in excess of 50 minutes, but that she needs to leave herself more time so that she is not stressed or rushing in the morning. As with several of the other participants, she reports that the morning routine takes much longer when there is a new personal assistant. Therefore, a commonality is that the familiarity of the assistant with the person and their routine significantly affects the time it takes participants to undertake self-care activities.

Table 7.1 Breakdown of diary entries into self-care, productivity and leisure																
	Anna		Bart		Cathal		Deirdre		Emily		Freya		Grainne		Honour	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Total	39	100	74	100	21	100	55	100	18	100	84	100	32	100	120	100
Self-care	13	33.3	35	47.3	3	14.3	16	29.1	5	27.8	63	75	11	34.4	32	26.7
Productivity	5	12.8	28	37.8	1	4.8	7	7.3	4	22.2	2	2.3	1	3.1	22	18.3
Leisure	19	48.7	6	8.1	12	57.1	20	36.4	9	50	13	15.5	9	28.1	12	10
S / P	0	0	0	0	0	0	0	0	0	0	0	0	0	0	10	8.3
P / L	0	0	1	1.4	4	19	2	3.6	0	0	3	3.6	10	31.3	13	10.8
S / L	0	0	3	4.1	1	4.8	9	16.3	0	0	4	4.8	0	0	19	15.8
None	0	0	0	0	0	0	1	1.8	0	0	0	0	0	0	0	0
All three	0	0	0	0	0	0	3	5.4	0	0	0	0	1	3.1	12	10

As a group of adults aged between 28 and 58, only one is in full-time, paid employment. The other participants do engage in productivity tasks, and Freya does sessional work. The participants report a variety of occupations as being productivity.

All of the participants engage in leisure activities, both inside their home / residential setting and outside. Six of the participants report watching television or DVD at some point in their diaries (Deirdre and Emily do not).

The nature of assistance used by the participants will be discussed in more detail in the next chapter. The nature of and availability of assistance does, however, appear to affect occupational patterning, particularly in terms of ability to go to different places and flexibility in routines.

Description of participants' perceptions of their diary information, both as outlined in the diaries themselves, and as discussed in the final interview are presented in the next chapter.

Contribution of Descriptive Results to a potential Choice and Autonomy Framework

Chapter 4 (section 4.1) highlighted some of the issues to be considered in a Choice and Autonomy Framework that arose out of the literature. What do the descriptive results tell us that can inform the framework?

As described in Chapter 4, a choice and autonomy framework needs to contain at least five strands, including:

- the meaning of autonomy;
- whether or not autonomy is a need, goal or value;
- what daily experience of autonomy (or lack of autonomy) is "like";
- whether concepts of autonomy overlap other psychological theories, and
- the impact of the environment on autonomy and choice.

The descriptive findings give us a picture of the daily lives of the participants, and some information about whether or not they exert choice and control in their daily lives. It contributes most to the third and fifth strand of the framework: the description of what autonomy is like, and the environmental supports/barriers. However, these findings provide the backdrop to the investigation of all strands through the interpretative results.

Clearly, there are differences in the extent to which participants exert control over their lives and life situations. This is evident in the histories that they gave (in chapter 6), and in the differences in their daily occupations. Thus, the experience of autonomy in daily life could differ between the participants.

The issue of routine seems to be a potential factor affecting choice and autonomy: too much routine could minimise autonomy, but so too could too little. Further interpretation of these findings could elucidate impacts of habits and routine on a person's sense of autonomy. Likewise, as discussed in the previous section, the nature of assistance could have an important impact on an individual. This will be discussed in the next chapter, where comments from the participants will be interpreted.

It is clear that physical and social environments are both controlled by participants (for example, see Anna's descriptions) and act to influence the experience of autonomy. For example, several participants reported physical access issues as hindering their occupational performance. Is this perceived to limit autonomy? Further exploration and interpretation of how the participants manage both physical and social situations will be included in the next chapter.

From the descriptive findings, it is not possible to conclude that certain environments support autonomy more than others, as is suggested by literature within the independent living movement (see section 3.4 for description of this literature). While the influence of the environment will be interpreted in the next

two chapters, a simple link between accommodation and autonomy does not seem likely at this point.

Conclusion

This chapter presented the diary information of the participants, with brief comment about some similarities and differences. This concludes the descriptive results.

The next two chapters focus on the interpretative results, investigating, in more detail, the perceptions of the participants, with a particular view to exploring the meaning of autonomy and choice to them.

9. Autonomy, choice and control in occupational performance

Introduction

This chapter presents the first part of the interpretative findings of the research. It focuses on the participants' experiences of autonomy, choice and control in their everyday lives, and occupational performance, building on the descriptive information in chapters 6 and 7.

The previous chapters described each of the participants in terms of a brief life history and the actual nature of their lives and occupational performance. In the previous two chapters, detailed information is provided to present the reader with information about each of the individuals. This chapter looks deeper into the differences between and similarities among the participants' experiences and views about their circumstances, with a focus on autonomy and choice. As this is interpretative and comparative, it is structured under themes, rather than in a case-study approach. Reference is made to direct quotes and information presented in the previous two chapters, to limit the need to repeat information.

This research describes the situations of eight very different individuals. The differences and individuality of each participant are very likely to have an impact on their "view of the world". This section begins with a look at the different life experiences that the participants have, with a view to understanding their perceptions of their occupational performance. Then, the different perceptions of life situations will be explored from the viewpoint of autonomy, choice and control.

Throughout the presentation of these results, there is comment from the researcher and integration of concepts from theory and the literature reviewed. These first interpretative findings aim to provide some background and critical areas to be included in an emerging choice and autonomy framework for adults with physical disabilities.

Self-descriptions

Each of the participants were first asked, "can you tell me a little about yourself". The descriptions given varied greatly.

Some participants described features that they consider that they have, for example, Bart described himself as, "bright, witty and outgoing"; for him, an important aspect of how he sees himself is that he is the "master of the ship". Emily began by describing herself as an "outgoing person, jolly, I mix well with people...". Unlike Bart, whose description of disability only came in the final interview, (objectively he could be described as having the most significant physical disability), Emily immediately describes her disability, and states:

> "I want to show people that I'm just as normal as anyone else. I try and communicate in the same format as the other person, not as a disabled, disabled person, I talk normally, emm, keep up the conversation, emm, and also explain please don't look at the chair, look at the person within the chair."

This emphasis of being "as normal as anyone else" and her suggestion that she is there to educate others about disability appears to be a theme running through the data collected with her. This idea of being an educator, or "advocate" as she describes herself seems to greatly colour the information she gives.

Anna, as described previously lives with personal assistance in the community (see section 6.2.1). Central to this description is that she is "an independent woman". Anna's self-description includes similar features to that of Emily; it includes a description of her personality and the influence disability has on her life. Anna says that she "hopes" that people see her rather than the wheelchair, whereas Emily wants to "explain" to people to look at her rather than the wheelchair. Both participants also describe their assumed role as "advocate" or "fighter".

The three participants that began describing themselves with attributes all have cerebral palsy, a congenital disability.

Honour has primarily an acquired disability (although she did have a congenital disability that was surgically corrected), which has resulted in physical deterioration over time. Unlike Anna and Emily, whose self-descriptions suggest a certain self-confidence or acceptance of disability, Honour begins by stating that she has difficulty accepting that she is now "a disabled person".

Cathal and Deirdre both have acquired disabilities, in the case of Cathal it is a deteriorating condition. They both live in residential settings, and begin by describing how long they have been in the setting.

The difference in Cathal and Deirdre's description of themselves is that Cathal describes the course of his condition and what he used to do; Deirdre immediately describes what she is interested in. For Cathal, the change in his physical ability obviously has a profound effect on his life, and so his way of describing himself, who he is, seems to be the course of his physical disability and how he has come to live in the setting.

Both Freya and Grainne have disabilities that began in their teens, and have progressed throughout their lives. They begin differently, but both introduce themselves by describing what they do, or have done. Grainne describes doing Law in college, whereas Freya describes her part-time work in disability awareness training.

Freya then describes where she lives, and herself using adjectives, similar to the manner in which Anna, Bart and Emily did.

Initially, it appears curious that the descriptions of participants with the same type of disability seem to have features in common, but this may be related to the broader sense of how a person views him- or herself. As Anna describes,

> "I don't believe in feeling sorry for, you know, for myself or for anybody with a disability because it's not an illness. I would regard it very much... in terms of the social model paradigm."

The above quote appears within her response to the question to describe herself, implying that central to her self-description is an adherence to the social model of disability. This

necessarily implies that an inability to do is due to the surrounding environment, rather than any medical issue (Oliver, 1990; Morris, 1993).

Cathal is probably the most directly opposite to Anna; his self-description suggests a medical model viewpoint, his description of himself reads like his medical history. It is probably not surprising that much of the rest of the information from these participants appears to contrast sharply.

While there seems to be an absence of information about how people describe themselves within the literature, the issue of disability identity is certainly evident, and can be related to the initial descriptions. It is clear that Anna has assimilated a disability identity, expressing herself in terms that are congruent with disability activism. This identity remains consistent throughout her information. Cathal appears to have acquired a "impairment identity" (as described by DeJong, 1983) Further description of the formation of identity, and the impact of disability on identity will be discussed later in this section.

Disability, course and type

The experience of disability differs within the group of participants, and this is evident even from the initial self-descriptions.

Anna, Bart and Emily have congenital disabilities; they all have cerebral palsy. While their experience of impairment may have changed somewhat, it is evident that they have always been disabled. Equally, for these participants, it is unlikely that their impairment will change significantly in the future. In other words, for these three participants, the *status quo* is being disabled.

Freya and Grainne both began noticing difficulties with physical function in their teens, and were diagnosed with their disabilities in their late teens or early twenties. Both have experienced deterioration in their level of physical ability over their life-time, and also it is quite likely that their level of function will continue to decrease. Objectively, it appears that Freya has a greater level of function at present. Both found that their disability had a negative impact on their education, and to a certain extent, were not surprised when their

disabilities were diagnosed. For the majority of their lives (all of their adult lives), both participants have lived with a disability.

Cathal, Deirdre and Honour all have acquired disabilities, although Honour also had a congenital disability that was surgically corrected. Cathal and Honour both describe some level of difficulty coming to terms with disability, and in particular the need for assistance with self-care tasks. Deirdre describes a hope that medical research will provide a cure for her, but does not report difficulties with the need for assistance as much as do Cathal and Honour. Both have degenerative conditions, whereas Deirdre's condition is stable; she hopes that with continued physiotherapy her level of function may in fact improve. Deirdre is also the only participant whose disability occurred suddenly, she had a CVA. All other participants were either born with disability, or disability developed over a period of time.

The participants who have non-congenital disability, particularly those who acquired disability in adulthood describe different reactions to their change in function. Freya reports being "relieved" when she actually had a name to put on what she was experiencing. Prior to the diagnosis, she felt that people didn't believe that there was anything wrong, she was just considered "clumsy". Grainne also describes feeling clumsy, but she reports being embarrassed about her disability, and did whatever she could to stay out of a wheelchair for as long as she could (see her comments in section 6.7.3)..

When Honour begins her self-description, she initially describes her difficulty coming to terms with disability. She describes being "horrified" at the deterioration in her physical abilities, and is frustrated and dissatisfied with the manner in which activities are performed.

Cathal describes his disability as not having a major impact on his life until fairly recently, immediately prior to his admission into an acute hospital. He doesn't appear to describe how he has come to terms with disability, but it could be inferred that he compares his present state to his previous abilities. It is possible that, for Cathal, disability has meant a huge change in life and lifestyle.

Age

The participants range in age from 28 (Anna) to 58 (Honour). The average age is 42 years, with a standard deviation of 10.5 years. The average age of those living in the community is younger than those living in residential settings (39 compared to 46), but both the youngest and oldest participants are living in the community (standard deviation is 14 years). The participants with congenital disabilities are, on average, younger than those with acquired disabilities (31 years compared to 49).

Difference in chronological age is relevant, but even more important is the difference in life experiences that have arisen. Anna and Bart are beginning their careers, whereas Cathal, Grainne and Honour in particular have a career history behind them; they have worked, and gave up work due to disability. Anna seems to describe life plans ahead of her; the older participants, who all have acquired disabilities appear to be "looking back".

Cathal is different from the other participants in that he has been married, has children and a grandchild.

Education

Of the eight participants described, three did not complete school to leaving certificate level (Emily, Freya and Honour), three completed the leaving certificate and went directly into work (Cathal, Deirdre and Grainne) and the other two have degrees (Anna and Bart), one of whom also has post-graduate qualifications.

Cathal was undertaking a course in a college specifically providing courses for disabled students, and two participants started university courses as mature students, but did not finish in the case of Grainne, or has not finished (Honour despite not having completed the leaving certificate).

In terms of secondary education, three of the participants went, for at least part of their education to a special school – these being the three participants with congenital disabilities. All others attended mainstream schools.

Anna attended the local mainstream primary school in the rural area until third class, at the age of 9. She describes having felt "different" and been bullied in the mainstream school. She reports clearly remembering that she, at the age of 9 decided that she "couldn't handle it anymore", and chose to go to a special school for disabled children in the nearest city.

When she began in the special school, she reports noticing a huge difference in culture and attitude, "it shocked me, totally totally shocked me". She reports there being a difference in attitude and expectation for the children, and that children were "sheltered".

> "For somebody coming from a totally open environment exposed to everything to somebody.... I think I went into shock at the way people were sheltered, at the way people didn't have any expectations for themselves, even at a young age"

Anna describes how she perceives that teaching staff were institutionalised, "sucked into the system", particularly that they had low expectations for students and that she feels that they judged people solely by their physical ability, without taking account of intellectual ability.

Anna reports feeling "lucky" that her teacher was "straight out of teacher training", and was not as institutionalised as those who had been there for many years. This meant that she was pushed academically, following the standard curriculum (unlike others in the school).

Emily also describes her schooling, but to a much lesser degree. She reports being "very angry" about her schooling. Like Anna, Emily also went to a special school for children with physical disabilities. She reports that there was a lack of expectations for disabled students, and that she feels that, now, there are more opportunities for education. Upon leaving school, Emily went directly to work in sheltered employment.

Family circumstances

All of the participants were single at the time of data collection. Cathal is separated, and has children and a grandchild. Honour spoke of a long-term relationship that she had, but is no longer in.

Two of the participants live with, or adjacent to their mothers, these being Bart and Freya. Bart lives in an extension which is self-contained, whereas Freya lives with her mother, and her mother provides assistance to her.

Anna spoke about the influence of family on her upbringing, both the manner in which her parents treated her the same as other children, and a certain rivalry between her, her siblings and her cousins which motivated her to do her leaving certificate and go to college, as they were, rather than following an expected route for a disabled person.

The issue of partnership and family were not a major part of this research, and so information was not directly sought about this.

Possible impact of life history on current situation and views of autonomy, choice and control

It is suggested that the marked differences in life histories may have an impact on the participants' perceptions of their choice, autonomy, independence and control. One significant difference appears to be between those with congenital disability, particularly when the disability is static, and when the participant became disabled in adult life, and their level of impairment decreases over time. Two such contrasting life histories are those of Anna and Cathal.

Anna has always been disabled, although at the age of 12 her level of physical ability decreased. All of her teenage and adult life, she has been a disabled person, she describes herself as a disabled person. She now lives independently, and states that,

> "the life I thought I could never have, I now have".

The information from Anna suggests that she has a "disability identity" as described by the disability activists and within the independent living movement (DeJong, 1983). She has fought to live as she does, and so the ideals of independent living (as described by Zola, 1983 and DeJong, 1983) have largely influenced her life. It can then be expected that the value of autonomy and independence (choice) are important to her.

Cathal, on the other hand, states, "I live in a hospital, which is a huge turnaround, because I used to be very active in different spheres, and I had a busy job". He recalls a life which was not significantly affected by disability. Cathal demonstrates an impairment role, where the reason for his difficulties is attributed to physical disability: a medical model approach (Oliver, 1990).

The two participants look back to different life histories, particularly comparing previous living circumstances. Anna has lived in a residential setting; Cathal used to live independently, and his previous living arrangements only changed with change in disability.

Anna reports that, the experience in a residential setting has shaped her life, not only that it made her want to strive to live independently, but it also fuelled her "passion for communicating", particularly with disabled people who do not use verbal language,

> "and that's stayed with me. So it [the experience living in a residential setting] does appear to have shaped my life fundamentally".

Prior to watching a television programme about IL (which influenced Anna greatly), Anna had not had any exposure to independent living or the Independent Living Movement. The programme resulted in her believing that it is possible to live independently – this meant for her that if she could live independently she would be able to go to University.

> "it gave me a goal because I knew it was possible OK, it wouldn't be easy, I mightn't be told yes the first time but I knew it was possible to actually do it and I wanted to go to college but didn't know how to do it, it gave me a goal to work towards and it and I got my points and all that stuff and I, and so I said that's what I have to do, so they can't say, you know, because education was one of my rights and it didn't matter what supports I needed I was going to get them and I was going to go to the edge of the earth and the European Court of Human Rights (smile, arm movements, excited tone) if I had to"

She also describes herself as a "trouble-maker", which appears similar to the "rebel" metaphor. She particularly used these self-descriptors when describing her "fights" to request improvements to physical access. While on the one hand she describes her "fight" as "difficult and frustrating", on the other it seems apparent that these are central characteristics. It is also apparent that her self-perception is of a fighter that, with determination and effort, ultimately wins the fight rather than someone who fights and doesn't succeed.

Anna describes fighting for her life as it is now; she fought to live where and how she is now. Cathal, on the other hand describes looking back at a life, in which he was an active participant in "several spheres". He had his own home and his level of physical ability was significantly greater than it is now. This is the account of how Cathal came to live in the setting and it contrasts starkly with Anna's accounts of similar processes:

> "it was put to me that I would probably be better off going to the [current setting] from [acute hospital], because [it] is an acute hospital. This is a long-stay hospital and so I had to be released from [acute hospital] because that was freeing up a bed which they obviously need...The move didn't bother me as such, but the one thing that did hit me was I, all the time I was in [acute hospital] it was in my head that, a discharge date sometime in the future, and I thought that, I felt okay about that. When I came in here, no fault of here, I suddenly felt, "this is it" for the rest of my life and that hit me hard. I found that hard to cope with. And I wouldn't say that I am alone in that. Just the idea, that this is where I am for good."

The tone of Cathal's account differs from that of Anna – she describes fighting for her rights, he describes being moved rather than choosing to move, he describes moving to free up a bed in an acute hospital that was needed by others. There may be a sense of being moved out of the way about Cathal's sense of his experience.

The limited recent work on residential settings means that it is difficult to relate these findings about Cathal to other work about people who live in residential situations. The question about how important choice may be in terms of accommodation will be described in the next section.

Marsh and Hau (2003) highlight the importance of the development of self-concept: a positive (realistic) sense of self is an important outcome variable for health; it mediates goal involvement and is situation specific for each person. Self-concept is developed throughout the life-span in response to environmental stimuli and the processing of these stimuli, as well as interactions in social situations (Schieir & Carver, 1980). Clearly, throughout Anna's life, she has developed a self-concept of herself as successful, an "independent woman", who has a physical disability. Her interactions in social situations and with the environment have generally led her to win her battles. Thus, her self-concept remains intact. Cathal, on the other hand, presumably developed his self-concept as a non-disabled person, who was physically active in "several spheres". Disability, for him, must have affected his self-concept, he is no longer who he used to be. Thus, it is not surprising that they describe themselves differently.

Covington (1992) describes the mechanisms by which people maintain their sense of self-worth, including that they attribute different causes to success or failure. The Anna is likely to succeed in her "fights" and clearly does attribute this success to her own action: Cathal attributes his current situation as due to his physical ability.

Further discussion of the role of identity and self-worth will be included as it relates to living situations in the next section.

Autonomy, choice and control in living situations

How the participants came to live where they do

An important part of this research is to include people from different living arrangements, i.e. those living in residential settings and those living in the community. Four of the participants in this study live in residential settings (Cathal, Deirdre, Emily and Grainne), the others live in the community.

Participants living in residential settings

Those who live in residential settings moved there for a variety of reasons. In the case of Cathal and Deirdre, the move was directly from an acute hospital, following an exacerbation of his condition in the case of Cathal, and following the onset of disability (in the form of a CVA) in the case of Deirdre. Deirdre states that she still hopes to move out of the setting, and that she first went there in the hope that the rehabilitation available would enable her to regain function. Cathal describes being resigned to living in the setting for the rest of his life.

Deirdre, on the other hand, initially states that she still hopes that she will move on to live in the community, but with further questioning, her hard work to try and rehabilitate herself "is never enough", and she then suggests that medical research is the "answer for me". With the further questioning, it seems clear that Deirdre, while she hopes that she may live in the community again, is somewhat resigned to living in the setting. She reports significant dissatisfaction with the setting.

The other participants living in residential settings moved there when family could no longer assist them. In the case of Emily, it was following the death of her mother, her primary carer. Grainne moved to the setting when family could no longer manage, due to ageing of the primary carer coupled with the deterioration of Grainne's condition.

Grainne moved to the residential setting, believing that small, supported independent living bungalows would be built and that she would live in one of these. She speaks of the huge disappointment when this form of accommodation was not built, and instead a new wing of the residential setting was built. She reports having tried hard to be more independent with self-care tasks so that she would be able to live in the supported bungalows.

Cathal reports being offered independent living, but deciding that he did not want it, because he feels that there is no way he could manage, due to his physical ability. A factor that has resulted in Cathal's settling for life in the residential setting could be that he actively chose not to move to independent living accommodation, albeit that he felt he had no choice, and would be unable to cope. This contrasts with Grainne, who felt she was being offered a similar opportunity, but the offer was taken away, resulting in her being left in the residential setting.

Grainne reports that her family were embarrassed with her moving to the setting. She reports that they were concerned that neighbours would think that they couldn't look after her. She initially moved in on a part-time basis, but as the health of her mother deteriorated, she needed to remain there full-time. It is possible that her move to the setting and her disappointment with the type of accommodation contribute to her dissatisfaction with her living circumstances.

Emily reports choosing to live in the residential setting, this choice was made following the death of her mother. Family also had an influence on her decision, but the influence differs from the experience of Grainne; Emily decided to move as family were arguing over who would care for her, and as she describes, trying to take on the role of her mother. When directly asked about the choice to live, Emily is emphatic that she wanted to live in the setting, and that it provides her with both the assistance that she requires and the independence that she wants. She reports being happy with her living situation.

Emily's satisfaction with her living situation echoes Shakespeare's (2006) assertions that independent living is simply not for everyone, and is not the only answer to support for disabled people. The independent living movement, right back to the UPIAS statement in 1976, have been adamant that residential settings should be closed. For Emily, she reports choosing this form of accommodation, and liking the support that she has available to her on an ongoing basis. As Shakespeare (2006) suggests, autonomy and control in living situations are not necessarily the goals of every disabled person.

Participants living in the community

As already described, Anna very clearly reports fighting to live where she does, and how she does. Bart also describes making choices about where he lives and has lived – he chose to move out and live in campus accommodation while he was in college; at the time of the initial data collection, he was actively arranging for a flat for himself in the city centre. Both of these participants have more or less full-time personal assistance, and manage the work of their assistants.

Participants 6 and 8 [Note should not these labels be changed to names?] were, at the time of initial data collection, also looking to move to different accommodation as their homes are not accessible enough for them. Freya does not describe actively choosing to live with her mother, she never moved out of home, but she does report enjoying living with her mother, and enjoying her company. She describes the mutually supportive role that they have.

Honour was housed by the council in the small cottage where she lives. She doesn't describe actively choosing the location, but she does describe how her personal assistant came to live with her.

A summary of the reasons why and means whereby participants came to live where they do is below.

- Anna very actively chose (and "fought") to live where she is.

- Bart chooses to live independently. He is currently aiming to move out to a flat; this is a choice, and he is taking a lead role in making sure that the layout of the new apartment will meet his needs.
- Cathal did not specifically choose to live where he does, it was suggested to him that he would be "better off" there. He chose not to try independent living because he feels he would not be "able for it".
- Deirdre agreed to move to the setting, with the hope or belief that it would be a temporary arrangement, so that she can become more physically able.
- Emily chose where she is living now, but following the death of her mother. In other words, she chose the setting and to move into a residential setting when her circumstances had changed.
- Freya never moved out of home, but is actively involved in arranging to move to accommodation that better suits her needs.
- Grainne chose to move to the setting, believing that it would be independent living bungalows, but it is not. She did not choose to live as she does now, but feels that she has no other option.
- Honour did not specifically choose to live where she does, and is hoping to move to more accessible accommodation.

The participants' perceptions of their choices in terms of their living accommodations may be affected by personality factors. For example, Lyubomirsky (2001) found that people who are happier tend to be less sensitive to social comparison, and tend to view their choices as good, or the best choices. Anna, Emily and Freya report that (despite difficulties in physical access for Freya), their living situation is good, it is where they want to be. While Cathal, Deirdre and Grainne did choose (to a greater or lesser extent) their accommodation, they are far less happy with it: they could be seen as viewing their choice as the best of a bad lot – mirroring the work of Lyubomirsky (2001).

Experiences of living situation

Grainne and Deirdre both discuss significant disappointment and difficulty with their living circumstances, whereas the others living in residential settings seem to accept their living situation.

Deirdre reports that staff try to "make" her independent, by not providing assistance. She would, theoretically like to live independently, but seems resigned to living where she is.

Deirdre describes significant difficulties with the setting. These primarily relate to the social environment, both staff and other residents, although she does also describe the bathroom as "depressing". In the initial interview, Deirdre describes being physically hit by another resident; she describes a battle to get assistance, particularly with self-care tasks, and states that she is frequently being "given out to" by staff, for not being "good" – when further discussed, this makes her feel like she is a naughty child. She reports being told to "keep away" from the resident who hit her, but then states that it is difficult when the beds are so close together, and there is little space between them. It appears that the physical environment exacerbates the difficulties that she has with the social environment.

The way that Deirdre deals with the difficulties in her environment are to go out with family at weekends, to spend time away from the ward and around the grounds, to participate in organised activities, and to visit other, older people living in the setting, to keep them company.

Her behaviours could suggest avoidance of difficulties that she finds within the social environment. While an in-depth analysis of the residential setting was not undertaken, the accounts of Deirdre are interesting when compared to the literature on such settings. Some of the aspects of the setting seem to mirror Miller and Gwynne's (1972) "warehousing ideology". But, the experience of the setting as described by Deirdre does not closely match the warehousing concept. A similarity between her description and warehousing is the authoritarian manner of control, but there are differences, including staff trying to make her independent. This will be further discussed later in this chapter, in relation to the provision of care or assistance.

Deirdre's coping strategy is also interesting. When it comes to self-care activities, there is very clear evidence of goal disengagement – she avoids situations wherever possible (similar to an avoidance mechanism, as proposed by Boemer and Jopp, 2007).

Deirdre is clearly dissatisfied with her living situation, and if her description is compared to other work, such as that of Moss (1974). Moss suggested that "adult status" of residents was positively correlated with satisfaction. Adult status is demonstrated by autonomy, the

ability to be spontaneous, and being allowed to express anger and frustration. While there is clearly an attempt to make Deirdre self-sufficient in her daily tasks (a component of Moss' autonomy), she describes not being allowed to take responsibility for her own actions (like where she goes or how she is assisted). Deirdre's accounts of her living situation clearly suggest that she experiences a lack of adult status.

Grainne states:

> "I'm a fighter. But I find it very hard to live here, I find it very hard to live with, I know it sounds awful, people who that are really desperate and very low down. You can't talk about anything you know, they talk like children, they all talk like three year olds... No stimulation at all. So I go down and I lock the door and I get more out of the cat and the dog."

Grainne describes significant difficulties with the setting in which she lives, particularly with the social environment, but her difficulties are different to those described by Deirdre. Grainne describes a total lack of cognitive stimulation in the setting, which she describes as, "an adult romper room". She does criticise staff, but her situation is significantly different to that described by Deirdre. Her main way of managing the frustrations of the social environment is to try to be alone, with her cat and dog, and using her computer. She also speaks about the importance of frequent visits from family and friends.

Again, the descriptions given by Grainne suggest goal disengagement as a coping strategy. Her disengagement takes a different form to Deirdre, but her dissatisfication arises from a different cause. Applying self-determination theory (Ryan & Deci, 2000), to Grainne's situation, could suggest a lack of relatedness in the setting.

Reis et al (2000) found that the social environments that best promote the satisfaction of relatedness needs were those where individuals felt understood and appreciated, and where they could engage in meaningful conversation with others. The accounts of Grainne in particular include several examples of where she lacks the ability to have meaningful conversation, and there is no evidence of her feeling understood or appreciated (but this information was not directly sought by the researcher). Deirdre manages her situation by building links with others: she describes going to have conversations with other residents to support them, and she has created a role for herself whereby she feels needed by the cats.

Grainne describes the setting as being very "male", that the staff are more interested in assisting men. Another difficulty that Grainne describes is the assumption that because she is articulate, she doesn't need to be included in, or asked if she wants to participate in organised activities.

> "I mean, I know, I know this may sound, you know, stupid but, I feel that I'm missing out because they go along to everyone "would you like to come here? Would you like to go there?" And they never ask me. Never, you know, I was going to speak today about it and then she was rushing, and I didn't, but like, The Furys were on on Sunday and they were at it. I would have loved it. I love The Furys And I really feel that I'm left out a lot. "

The diary information supports this radical difference between Deirdre and Grainne. Despite both having frustrations with the social environment, Deirdre gets involved in as many organised activities as she can to be busy, Grainne keeps to herself, away from other residents. The different strategies could have come about because Deirdre seems to find staff more frustrating than other residents; Grainne experiences the opposite. Both have an interest in animals and getting out around the grounds, and coincidentally, both feed cats on the grounds of their residential settings.

Cathal and Emily report fewer difficulties with the social environment in the residential settings. Diary information suggests that these participants also report spending more time outside the settings than do deirdre and Grainne.

Emily describes how she interacts with other residents in the setting where she lives – by describing herself as an advocate for them, wishing to be seen as a person who others can speak to, and who will speak up for others.

When it comes to reports of staff, Cathal is complimentary, reporting that staff are always available to assist him, Emily reports needing to take an active role in managing how she is assisted. Deirdre is the least complimentary about staff, and Grainne just states that assistance provided is "grand".

It seems that participants who live in residential settings are more concerned with the social environment than the physical environment, in that this aspect of the environment was reported as being more difficult. The literature about institutional environments and residential settings does suggest that this aspect of residential living would be the most

problematic. For example, Orford's (1982) description of residential settings as social psychology experiments: behaviours within institutions may not be seen outside such settings. Orford (1982) also describes the likelihood that there is less choice available in residential settings. This is evident from the accounts of all of the participants who live in residential settings.

Some of the participants living in the community report the converse to be the case, i.e. that physical environments can be problematic.

Two of those living in the community report significant difficulties with the physical environment, and three of the four planned to move out of their current accommodation at the time of the first interview.

Freya and Honour both live in what they describe as unsuitable accommodation, owned by the local authority. The accommodation in the case of Honour is too small, meaning that she can't negotiate the house effectively using a wheelchair. The bathroom is also unsuitable, which increases both the incidence of, and her fear of falling when undertaking self-care tasks. Freya, at the start of data collection lived with her mother in a two storey house, which meant that she needed to transfer onto a stair-lift to access her bedroom. She, in the first interview, spoke about her great fear if there were ever a fire or an emergency, as she would be unable to leave the building. She also reports mechanical difficulties with the stairlift. She also reported difficulties accessing the house using her powered wheelchair. Both of these participants' situations were significantly difficult for them.

Bart planned to move out into a flat at the start of data collection. This was not because of access issues, more so that he could improve his social life. At the time of data collection, he was living "in an extension my mother built for me".

Anna is the only participant who reports being totally satisfied with where she is living, in terms of both the physical and the social environment. She reports having significant influence in the way her flat was designed, so that she can access it easily. She describes fighting for the accommodation, and assistance that makes it possible for her to live where and how she does.

> "The physical environment would be one that I am constantly challenging. I challenged greatly five and a half years ago when I insisted on having a very large involvement in the design of this apartment. A few people would have done it, but I would have been one of the first to actually have insisted. From the very initial stages I had an impact into the design of this apartment, well a major thing in my home environment is being able to get in and out of my own front door. I have an automatic front door, and that wasn't easy to insist on. Also my actual the height of things, the height of anything from my dressing table to the counters are at my level. And, I mean, I would review it often, and be very insistent that it be the way that is most comfortable for me." (Anna)

When asked directly whether she has control of the physical environment, she says, "yes"; whether she takes control, "yes", and whether this is a decision, "absolutely".

It is possible that, from a very basic view, the environmental challenges for most of the participants depend on their living circumstances: some of those living in residential settings report challenges with the social environment, and some of those living in independent living settings report difficulties with the physical environment, unless, as in the case of Anna, they "fight" for, and have significant influence on the design of the environment. (The three participants who were planning to move from the accommodation described are all involved in the design of the new accommodation.).

This breakdown of physical difficulties in the community and social difficulties in residential settings are reported throughout the disability studies literature. Several accounts exist of problems with physical access (e.g. Steward, 2004), and social issues with residential settings are also well documented (Orford, 1982).

It could also be suggested that either difficulties with the social environment or with the physical environment could potentially restrict the choices that the participants have in relation to their occupational performance. Deirdre is limited by the social or institutional environment, in that she is "not allowed" to leave the grounds alone; Grainne is limited because she feels that she is not included in outings; Honour is so restricted by her physical environment that she has difficulty leaving her front door, so all but one of her days reported in her diary were entirely spent within her cottage; Freya has such difficulty getting in and out that she needs to pattern her occupations to make sure that she only needs to go out and come in to her house once a day.

Two of the participants report being happy with their living situation: Anna and Emily, both report that they chose to live where they do, and had (or have) control over their living

circumstances. Bart and Freya are choosing to take control of their move to different accommodation, to improve access for Freya and social life for Bart. Even considering these changes, both Bart and Freya are happy with the general choices that they have made in relation to their accommodation.

Independent living literature (e.g. Morris, 1993; 1991; DeJong, 1983) and that of the disability movement in general (e.g. Oliver, 1990; Shakespeare, 2006 highlight the importance of choice for disabled people in where and how they live. Typically, though (with the exception of Shakespeare, 2006), this leads to a conclusion that independent living is necessarily better, because it means ongoing choice and control for disabled people. However, further investigation about the impact of the initial choice of living situation) on satisfaction with this situation would be helpful.

From a psychological perspective, having control over fundamental decisions such as living situations is likely to have positive consequences, particularly for those who actively seek control (Shapiro et al, 1996). However, as previously described, the attribution of causes for people to be living in their current situation could also be affected by pre-existing personality differences, such as happiness (Lyubomirsky, 2001).

The coping mechanisms and psychological attributions of the different participants are interesting. Those for Grainne and Deirdre have already been mentioned, Lyubomirsky (2001) cites several studies that the cognitive responses to situations vary between people who are more or less optimistic and happy: those who are generally happier perceive their circumstances more positively, they feel that they have control and feel confident about their abilities. This seems to describe both Anna and Emily. While the other three participants in residential settings do describe significant difficulties (albeit that Cathal attributes these negative aspects to his own physical disability rather than to the environment), Emily reports her environment as being positive, and that she has and does exert control over her life. Her diary entries, observation and her description of her lifestyle do not suggest any significant differences in living situation that would give rise to such perceptions, so why do they occur? Is it personality-led? Lyubomirsky (2001) also reports that people who are happier describe more favourable social comparisons – Emily certainly describes herself as different to other disabled people, and there is evidence that she compares herself positively to others – she wants to advocate for others.

The nature and impact of assistance used

Assistance required

Objectively, there is a difference in the amount of assistance that the participants require, and the tasks for which assistance is needed.

Objectively, Bart requires the most assistance – he has minimal controlled physical movement in his body. He communicates using technology and a chin-switch; he uses a manual wheelchair propelled by an assistant. He requires assistance for all self-care tasks, including feeding and toileting. Freya objectively reports having the least assistance; she has intermittent assistance from her mother and a carer, but does not have personal assistance on a daily basis. She uses a powered wheelchair for mobility, but is able to walk very short distances if supported. She can perform most self-care tasks alone, albeit with difficulty, with the exception of bathing, moisturising her skin and washing her hair.

The difference between assistance "required" and "used" depends on the participants' situation, and what is available to them. As no formal testing of level of function was conducted (nor considered appropriate), the level of impairment and consequently the objective need for assistance can only be inferred. Table 8.1 below describes the assistance used by participants.

Table 8.1 Assistance used for self-care tasks

Code: A = always use assistance. S = Sometimes uses assistance.
A blank in both A and S means that no assistance is ordinarily used.

	Participant															
	Anna		Bart		Cathal		Deirdre		Emily		Freya		Grainne		Honour	
	A	S	A	S	A	S	A	S	A	S	A	S	A	S	A	S
Washing	✔		✔		✔			✔	✔			✔	✔		✔	
Dressing	✔		✔		✔			✔	✔			✔	✔		✔	
Grooming	✔		✔			✔			✔				✔			
Transfers	✔		✔		✔			✔	✔			✔	✔			✔
Feeding			✔			✔				✔				✔		
Toileting	✔		✔		✔			✔	✔			✔	✔			✔
Bathing	✔		✔		✔		✔		✔		✔		✔		✔	

Choice, control and autonomy in assistance

A qualitative difference between living in the community and living in residential settings appears to be the nature of assistance available to the participants. This echoes work found within disability studies, such as that of DeJong (1983) and Brookes (1983).

Four of the participants (those living in residential settings) are assisted by nursing staff. Assistance is provided in the residential settings, and communal facilities (such as the bathroom) are used. One of the participants has her own room, the others share, so are assisted in the shared room, with curtains around their beds as the privacy measure.

Anna and Bart have a number of personal assistants that work given hours, in both cases, this is more or less full-time. The participants manage the assistance in terms of what and how it is provided to them. Honour has one full-time, live-in personal assistant, and Freya has assistance from her mother, an assistant and a home help that do not come on a daily basis. The personal assistants are provided by an organisation; each individual is provided with a set number of hours assistance.

Participants who have personal assistants (particularly Anna and Bart) manage their assistant's time and how they are assisted. Both describe (either in the interview or in diary information) sending timesheets to the assistants.

Anna is satisfied with the amount of assistance that she has. She reports taking total responsibility for managing her personal assistants in terms of when they work and what they do. She describes "fighting" to maintain the hours of assistance that she has available to her, and that the service providers are always wishing to cut down on hours. She describes this as frustrating, but feels that she is in a stronger position to "fight" for what she needs,

> "there are people who that are not as confident or articulate as me and they are being bullied and humiliated".

Anna reports having choice in the manner in which she is assisted in all of her self-care tasks. She reports having control over all of her self-maintenance tasks. Choice and control are vitally important to her, she is keen to maintain both in all activities.

Initially, Anna reports being "very satisfied" with her daily routine, "because I monitor it all myself". It appears that her having control over her routine is the major factor that leads to her satisfaction. Having control over the routine includes managing her personal assistance and the equipment that she uses.

Bart reports being satisfied with what has to be done, but reports that

> "sometimes I feel that their [personal assistants'] routine is overpowering, but it works out for me in the end".

He reports being an "untidy" person, and wanting his PAs to tidy up after him. It is a source of frustration when they do not tidy up after him. He reports that each PA has his/her own routine, and that he needs to get used to each PA, but that he always endeavours to remain in control.

Bart uses the metaphor of "captain of the ship" to describe how he takes control of self-care activities. He describes the need to be the "master", to direct the personal assistants so that he is satisfied with his routine.

He doesn't reply clearly as to whether he has choice and control, stating that some tasks, such as "taking a dump" are daily needs, and so neither choice nor control are applicable.

Honour reports that her personal assistant tends to "talk back" to her. She manages the need for assistance by being precise about what she wants and how she wants things done – this appears to be similar to the approach taken by Anna.

Honour, unlike any of the other participants, describes also availing of regular respite in a residential setting. When in respite settings, Honour is less likely to call for assistance, because of a fear that staff are busy with people who need the assistance more. She reports that the relationship between the person and the assistant is central to satisfaction with assistance provided. In a residential setting, she feels much less in control of the

assistance she uses, not only because she tends not to ask for as much assistance, but also in the manner in which it is provided.

> "I feel that because you're in ahh, a medical environment, that there's always the feeling of, well, we really know best... you are in a hospital environment really, so that it, you feel that the medical model definitely applies here, and umm It makes you feel more like a patient, than a, a, a person, umm, say on a holiday, or whatever respite is exactly supposed to mean, you know. I suppose one would rather not, you would rather just feel you were having two weeks break from the routine or what have you, but, you're not really, you're rather a bit more as if you were just kind of going into hospital, and you know, they will kind of come and say, sort of umm, as if you kind of wallowed in dirt or something at home you know, never had showers and that sort of things like that... You know the way that, nurses can kind of go on.. so sometimes just for a peaceful life, you will you know... have what you get. And it's, obviously, it's their routine that you're fitting in with as opposed to what you would prefer yourself you know. Ideally, it would be more pleasant to sort of go on two weeks break in a hotel or something, just you would still need somebody, I mean you can't just be asking the chambermaid to sort of shove you into your knickers or what have you, you know "

This need to fit in with the routine of nursing staff when she is on respite appears to mirror the experience of participants who live in residential settings. Whereas when a person has a personal assistant, they have more control over who assists them, when and how.

Those who use nursing staff are assisted among other people, and there is a need to "fit in" with others. There is also limited control over who will assist the person each day. Emily describes:

> "You need to accept who comes in, because if you do not accept it then the issue of staff member being frustrated with you, and then the tone of voice can change, and they will put anything on you you are not in trouble like, , but they say you don't like me and this and that and the other. You know what I am trying to get at?"
> Do you think you have control over when you get up?
> "Yes, that's one good thing I have, I have always kept that going. Because if I stopped doing that role, then I would feel they can take over and get me up even if I don't want to get up and I, no, from for my disability I need to be able to know when I can get up myself rather than them "

The manner in which assistance is given changes, depending on the day and the staff member. This is somewhat unsatisfactory for Emily, but she reports managing it by remaining in control.

Of the five activities listed by Emily, she reports having control over three and some control over the remaining two. She reports being satisfied with the amount of control that she has, and that she strives to maintain control in the activities.

Cathal also lives in a residential setting, but appears to have an entirely different approach to managing the assistance that is provided. When asked whether he has choice in how he is assisted, Cathal says,

> "Never even thought about it... Choice in as much as the staff wouldn't do anything if I said, 'no, I don't want that'. I need assistance anyway, so I don't have choice in that and that's not their fault."

In relation to getting up in the morning, he reports choosing his clothes, but not having choice about the toiletries that he uses, stating that this is because of infection control measures in place in the setting. He reports having limited choice about what time he gets up in the morning, because staff "don't like to go past 9.30 or 10.00".

> "I've had a few run-ins because I find Friday mornings I'm not going to college on Fridays and they are here first thing. On Mondays, I have to ring for assistance because they have forgotten that I am getting up to go to college.. at times it can be a bit annoying...I have what you would call limited control, I could have said this morning 'could you give me another hour', and they would have, but I didn't think to ask."

Cathal reports having no choice at all in toileting. He is assisted at set times, hoisted onto the toilet and left, the staff return after a period of time. Should he want to use the toilet at a different time, he can ask staff for assistance, but they are "often busy".

> "I don't look to have control or choice. I have to be hoisted anyway, so I don't look to have choice or control."

Cathal reports having some choice about (and control over) what time he goes to bed.

> "Staff have a tendency to ask if you want to go to bed maybe at 9.00. And at 46 years old, I am a bit reticent to go to bed at 9.00 or half nine or whatever... They allow you to have control... there is nobody saying you have to go to bed. The only pressure is their break time comes around 11.00 or half 11. And that, there is pressure there, if I haven't got into bed before the break time then, if you like, I have to resign myself to being put into bed after. Because I think to expect them to forgo their break is a bit selfish."

Cathal reports that he, in theory, could have choice over what he eats if he went to the shop and brought whatever he wanted to the kitchen, but otherwise his choice is limited. He reports that people who are "physically able" can make their own breakfast and have more freedom, he says that he would prefer to have control over what he eats for breakfast and the choice to make his own breakfast if he so wished.

The only two self care activities that he reports having full choice in are what he eats at lunch in college, shaving and how he brushes his teeth. He reports having control over shaving, "in the sense that if I didn't feel like shaving I wouldn't be hounded to shave". It is interesting that control, for a 48-year old man is described as not being hounded to shave.

In relation to control over activities, Cathal states that, he has some control over the amount of assistance he gets because there are always people around to provide assistance,

> "People here appear always to be on-hand, If you are having serious trouble when you need assistance, they will offer it."

The experience of people always being available to provide assistance is different to the experience of Deirdre, who also lives in a residential setting.

Deirdre reports that the ethos of the residential setting in which she lives is to encourage people to do self-care tasks alone, without assistance. She describes being frustrated, particularly at breakfast, when she would prefer to use assistance. In general, she would "like some more", and feels that staff are "trying to make me more independent" – the kind of independence that she does not want. Deirdre explains that she would prefer to use assistance for washing, dressing, breakfast and other tasks so that she has more time to spend "with the cats", or doing what she would like to do.

> "maybe with the nurses, they're trying to make you do as much as they can, and you try and do as much as you can but it's just not enough... Like you know, dressing, and maybe tidying up"

She also has difficulty with the types of self-maintenance tasks that she is asked to do: Deirdre describes it a struggle to get assistance, so she also tries to use assistive devices. The example of her getting her bra on is given in chapter 7, which is described as a "bone of contention" for her.

The type of assistance is described as, "autocratic... [she must] take it or leave it... [the assistance] makes me feel kind of annoyed and frustrated". She describes assistance as being provided in an "off-hand" and sometimes "grumpy" manner, although some of the nursing staff are "great... pleasant manner", others lack "basic common courtesy".

> "To be quite honest with you, I say they, I often wonder if, why the hell they ever applied for the job, if they don't want to do it now"

She reports needing to be "in with the nurses" to be able to get assistance.

Deirdre reports changing the occupations that she does due to a lack of assistance. In relation to breakfast, she reports choosing porridge, because she doesn't have the assistance to get other breakfast cereals. She says that "it's a good thing" that she likes porridge, because that is the only breakfast item that she feels that she can manage without assistance, and assistance is not provided.

Deirdre says that she "[doesn't] have a lot [of autonomy]... would like some more" in self-maintenance activities, and that the amount of choice she has is, "not a whole lot".

Out of the eight self-maintenance activities listed by Deirdre, she reports having no control over the manner in which she is assisted in four of the tasks, has some choice in how she is assisted in two and answers "yes" to the question of whether she has choice in how she is assisted for the remaining two activities. Those that she has no choice in how she is assisted are: getting dressed; doing her teeth and hair; putting her splints on and using the toilet.

Deirdre says that she would prefer to have more control over her self-maintenance activities, if she had more control, then, "they [nursing staff] might listen to the way I want it". It appears that the largest issue is that what tasks she will have assistance for, and the manner in which assistance is provided to her is decided by staff, she has little say in the decision.

While there are differences in the structure and assistance (institutional environments) in the settings in which the participants live, this difference does not account entirely for the different perceptions of the participants.

Cathal and Deirdre, for example seem to have fundamentally different interpretations of assistance. For Cathal, it is more like a necessary evil: he doesn't want to need

assistance, but does, and so does not think about controlling it. His perfect situation would be to not need assistance in the first place. Thus, the cause of his problem is his own physical ability. Deirdre, on the other hand, does want assistance, so that she can spend her time and energy doing the things that she wants to do – she certainly considers her assistance, and would like to take more control. For her, the problem is with the institutional environment, whereby her "needs" are decided upon by professionals. This situation of needs being ascribed has been discussed as an oppressive aspect of rehabilitation (Abberley 2006). This situation, where a person does not have control of how they perform self-care tasks has been described as oppressive by those in the independent living movement (e.g. Batavia, 2001; DeJong, 1983; Zola, 1983).

All of the residential settings seem to be places whereby routine is important, and participants all noted that staff need also to assist other residents. The focus on these self-maintenance aspects of care and authoritarian management reflects the warehousing ideology proposed by Miller and Gwynne (1972). However, some of the situations, particularly that of Deirdre, differ somewhat from the concept as described in the original work. For example, in a warehousing situation, typically patients are encouraged to be passive recipients of service: dependency is fostered (Miller & Gwynne, 1972; Orford, 1982). Deirdre's situation is different, she is not encouraged to be dependent. Staff have taken the trouble to assess her needs, and to introduce strategies to promote her self-sufficiency, which could be argued to be to foster her abilities (as in a horticultural approach). However well-intentioned the assessment of need and subsequent actions are or were, it is clear that these cause significant dissatisfaction for Deirdre.

The impact of using assistance, including the coping mechanisms used by the participants will be described in the next sub-section.

Freya has less assistance than she would like, but she is living in the community. Unlike Deirdre, where it appears that assistance is not given to “make me independent”, the situation with Freya appears to be that she does not have the resource of enough personal assistance on a daily basis. She lives with her mother, and reports being slightly loath to ask for assistance from her mother. When her mother does assist her, she feels that this is empowering, and she does have control.

> “I would have great control over that because Mum is always very sensitive to how I would need assistance and in what way, umm, yeah, I would have good control over that though, that would not be an issue at all.”

The issue for her is the lack of personal assistance. She is unsure how she would effectively manage more hours per week, as she feels that she needs intermittent assistance, but she feels that she does need more assistance with self-care tasks than she currently has. Her ideal would be a flexible arrangement, where she could arrange with an assistant a day or so before, so that she can arrange assistance for times when she needs to be out at work in the mornings. Freya was asked how she does manage, in light of the lack of assistance available to her.

> "I manage by allowing more time than I think that I need for each activity. If I think I need an hour then I'll make it an hour and a half, so that I'm not delaying anybody, you know if I'm to meet somebody or to go do something. So I'm kind of very, I'm inclined to allow myself extra time for everything."

The lack of assistance also has an impact on her sense of how much choice she has.

> "probably I wouldn't have a great amount of choice, because I don't umm, I don't, I have difficulties doing things and living my life in the way I would like to, so, umm, I mean there are lots of things that I would like to do with my life, but I often don't have the energy because of everything that is taken up with everything else."

While on paper, Freya could be described as living independently, the reality for her is that she is living in the community with unmet needs (as differentiated by Priestley, 2004). The experience of disabled people living with unmet needs is widely reported in the literature. The most common unmet needs found by Kersten et al (2000) was home adaptations, equipment, physiotherapy and wheelchairs. Of the above list, it seems that only home adaptations (such as environmental controls) are what Freya lacks: services to support intellectual or social involvement were described as less likely to be a problem by Kersten et al (2000), but due to the lack of personal assistance, Freya feels that she can't engage in more of these types of tasks.

Philips (1995) suggests that a systematic review of service provision to support people with physical disabilities is needed, to promote equality of service provision. Difficulties with the management of service provision, including the ascription of need have been discussed in chapter 3. Whatever the difficulties with the organisation of personal assistance services, Freya's situation seems to echo the findings of Philips (1995) and Doyle et al (1994), that her mother is supplementing support – but is providing the majority of support to Freya. The long-term success of this situation, given that her mother is

elderly and has health problems must surely be questioned. In contrast to Philips' (1995) work, though, Freya suggests that the home adaptations in place (particularly her move to a purpose-built bungalow with assistive technology) and assistive devices are the difference between managing and not managing for her.

The reason why Freya lacks the assistance that she could need should be questioned. Freya herself is unsure of how much she would be able to use more assistance, yet it is clear in her diary entries and in her accounts that assistance with self-care tasks would greatly improve the choices that she has. Possibly she has never asked for more assistance, and service providers assume that, since she is managing, she will continue to manage Helgoy et al's (2003) work suggests that service providers categorise individuals, and disabled people assume particular roles with service providers, both of which impact on services provided. Does freya adopt an "I can manage" role with service providers?

All of the participants also use assistive devices, equipment or technology to assist with self-care tasks. These include a hoist for transfers, bath lifts, and other large equipment, as well as small devices such as adapted cutlery, dycem and plate guards. All of the participants use a wheelchair for mobility some or all of the time. They all use powered mobility, with the exception of Bart, whose personal assistants push his manual wheelchair.

Some of the participants, particularly Anna and Emily, report difficulties with using equipment. Emily says that,

> "Don't like too much equipment around me. Equipment makes disability more apparent in mind."

Anna initially reports being satisfied with the equipment that she uses:

> "very satisfied, because I monitor it all myself and if I need new equipment or technology I would contact the community OT or whatever and usually it might take a while to get what I want or need, but usually, you know, they know I'd put a good rationale together..."

Upon further discussion, however, it appears that Anna finds the need for equipment undignified, particularly the need to use a hoist to transfer.

Freya, on the other hand reports being happy to use equipment, both disability-specific and generic technology. A possible reason for this is that her situation is different to Anna and Emily in that she has minimal personal assistance, so that the equipment is very enabling for her.

The impact of using assistance

> "...human assistance... it's great and I wouldn't be without it...but it can also be em, frustrating and the most frustrating thing for me is having to ask for assistance to go to the loo ... one of the greatest obstacles that I had to overcome in relation to my disability... was having to use equipment such as a hoist... the way I worked it all the way I got myself in some way to learn to live with it because I don't believe you accept these things, I believe you find coping strategies and live with them and get on with it ...The way I overcame it was to say, ok, this will allow me to access people to use this equipment to allow me to live my life the way I want to. It will also allow me to, to to go where I want to with whatever. So that was the most difficult thing, but, then in another sense having a machine perform certain tasks can be quite undignified." (Anna)

Anna describes the struggle with needing assistance, and the need for coping strategies to deal with these everyday activities. Her strategies appear to be two-fold, firstly, as described in the quote above, viewing the need for assistance as enabling her to do the other things that interest her and make up her lifestyle. The second coping strategy appears to be taking very direct control of how each action is performed. Her initial response was to suggest that she is very satisfied with self-care activities, it was only through further probing that the issues of dignity and the need to cope with rather than accept the need for assistance arose.

Using Boemer and Jopp's (2007) categorisation of coping mechanisms, Anna is using goal engagement strategies. She works to "maintain" her status by taking control of the situation. At the same time, there is a certain amount of reorientation – she both is active in managing the assistance and also minimises the importance of performing alone. As has already been discussed, Anna clearly identifies with the independent living movement philosophy, in that she prioritises choice and control over physical abilities. This is probably necessary for her, given the very real physical limitations imposed by impairment. However, her account provides depth rarely seen in IL literature: she acknowledges that using assistance can be difficult in itself. Until recently (e.g. in the work of Shakespeare and Watson, 2002) impairment seemed not to be acknowledged as an important aspect of disability: it was characterised as a neutral feature (e.g. Zola,

1983). Shakespeare and Watson (2002) argue that impairment is not neutral, like other characteristics, and so needs to be included in an understanding of disability experience.

As reported in Chapter 5, Anna describes herself first and foremost as "an independent woman". How does this self-perception fit with her daily experiences? Independence, to her, is "being able to take control of my own life and make decisions...". She initially reported being satisfied with her self-care activities because she does take control and decide what, how and where these activities are performed. The belief that a person doesn't accept the need for assistance, but develops coping strategies may also be important. Using assistance (be it human or mechanical) can affect dignity and presumably her self-perception. It may be possible that her definition of independence is created to support the coping strategy that she uses – deciding is the most important part of independence.

It is interesting that Anna reports the hardest thing about being disabled is the need for assistance (including equipment) with personal self-care activities, particularly given that these activities are essential and must form part of every day. The coping strategy of focusing on her lifestyle, using equipment, "to allow me to live my life the way I want to" deflects attention from the act, therefore it is not surprising that if her identity is centred around being an "independent woman" that her lifestyle in general is so important to her.

Outside her home environment, she reports experiencing access issues, but equally there is evidence of loss of control, and needing to think about self-care activities. The participant reports that her coping strategy is to "get on with" managing self-care so that she can live the life that she wants to. When in an unfamiliar or inaccessible environment, it seems that that strategy is undermined as self-care activities increase in prominence, as they are far more difficult. It is evident that she avoids situations where this may happen, she avoids going on holidays:

> "simple things like going on holiday is so frustrating - it's things like that non-disabled people take for granted".

Given that Anna describes the need for assistance and to use equipment as being the hardest thing about disability, it is understandable that the need to "fight" for that very assistance causes some frustration. It could be expected that fighting for equipment and hours of assistance may also affect her dignity (rather than being a frustration), but this does not seem to be the case. When describing how she has managed assistance and

equipment, the metaphor of "fighter" appears strongly. She appeared more comfortable speaking about the need to fight for services than when describing the assistance. It could be that when the need for assistance is discussed in distant terms, needing to justify hours and "fight" with service providers, this may reinforce her self-image as a person that takes control, that fights and makes decisions, who, in her own words, is "an independent woman".

Emily also reports that the need for human (and equipment) assistance can be undignified. The actual words "undignified" and "dignity" were not as apparent in the interviews with the other participants, but it is not justifiable to interpret this lack of discussion as meaning that the participants do not have similar views and issues. Alternatively, it may be that the participants have different secondary mechanisms for managing the need for human assistance.

Cathal, when discussing the need for assistance, and the manner in which assistance is provided, reports, "never even think of it". It appears that his way of managing the need for assistance is simply to not think about it. This is evidently a goal disengagement strategy, if using Boemer and Jopp's (2007) categorisation of strategies. .

Bart appears to have a strategy that is a mixture of that described by Anna and Cathal: he emphasises the importance of control and actively managing his personal assistants, as with Anna; but he also reports not really thinking about assistance, particularly for self-care, daily activities, that he describes as "just routine".

Deirdre and Freya report not having enough assistance, for different reasons. It is possible that the lack of appropriate assistance is in itself undignified. It could be suggested that the difficulties described by Deirdre in relation to her putting her bra on could compromise dignity, although this is not explicitly stated. She does describe feeling like a naughty child, which again, could suggest a lack of dignity.

Further description, within the literature, about how people manage assistance, and exploration of the coping strategies would be helpful. While the author thinks that this may not be popular within the disability movement, as some may argue that it would be akin to a personal tragedy approach (e.g. as described by Oliver, 1996). However, the reality of the situation for the participants of this study is that there are a wide number of

strategies used. Maybe a better understanding of the strategies could enable services to adapt and support the needs of disabled people in managing personal assistance support.

In terms of autonomy, it seems that the participants who use personal assistance have positive interpersonal relationships with their assistants: interdependence occurs. This may suggest that, if they do have positive personal relationships and are willing to use support of others effectively, that they will have self-governance, reflective autonomy (Autonomy II), rather than agentic separation autonomy (Hodgins et al, 1996; Koestner & Losier, 1996).

Autonomy, choice and control in occupational performance

Variety of diary information

The diary information has been described in the previous chapter, with brief comment on what the diaries tell us about the group as a whole. Further description of the diary information at this point would be repetitive.

In the previous chapter (see section 7.3), some commonalities and differences were highlighted that occur in the diary information. Differences included the manner in which diaries were maintained and the detail kept therein, and also actual differences in occupational patterning. These differences and similarities will be interpreted in this section, with reference to the literature.

Importance of activities

In the diary information, each participant was asked to rate each activity in terms of its importance, stating whether it is very important, a little important or not important at all. Table 8.2 on page 322, gives the importance ratings for each of the participants.

Anna, Bart, Cathal, Deirdre, Emily, Freya and Honour recorded 70% or more of the activities listed in their diary information as being very important. The highest of these is Freya, who reported that all of her activities were either "very important" (92%) or not given a rating.

Cathal and Grainne appear to report the importance of the activities that they perform differently from the other individuals. Both of these report that less than half of their activities are very important to them.

Anna, Bart, Emily and Freya report no activities as not being important to them, however both Anna and Freya do not specify the importance of some activities.

The value of asking participants whether or not what they do is important to them is twofold: it gives a picture as to relative value of different occupations to them, and it also can give some information as to how important their overall occupational performance is. For example, for Anna, most of the diary entries are important to her, the ones that are a little important are more passive activities that she does in her own home, such as watching television, and she doesn't give an importance rating to self-care tasks. Thus, her diary information supports what she has described: that engagement in occupations, such as work and socialising are important to her. Grainne has the highest proportion of activities that are a little important or not important; which raises questions about her life satisfaction.

There seems to be a lack of information within the literature that investigates the importance of occupations to disabled people. Further research in this area would be useful. As described above, it provides information to help to understand occupational performance priorities for individuals. Further research looking at how or whether engagement in meaningful occupations (rather than activity per se, as suggested by Sheldon et al (1996) could be an important area for occupational science.

In their investigation of diary information, Sheldon et al (1996) look at what makes a day "good" and relate this to activity theory, and perceptions of autonomy and competence: those who experience more competent and autonomous activity are more happy with their daily experiences, compared to when the same people experience less competence or autonomy. (Autonomy is as per the self-determination theory formulation i.e. Autonomy II). Are there links between not only control of activities (autonomous choice) but also how important and valuable the occupations are? For the motivational style to be intrinsic or integrated (Ryan & Deci, 2000), a person needs to value the activity. How does this rate with the importance of he activity? Does performing "important" activities promote well-being, or conversely engaging mostly in "unimportant" activities reduce well-being?

Enjoyment of activities

Table 8.3 (on page 322) presents the numbers and proportion of diary entries that are enjoyed, enjoyed a little or not enjoyed by each participant.

There is some variation in the proportion of diary entries that the participants report enjoying. Freya reports enjoying the largest proportion of her diary entries (79%), followed by Anna (77%) and Bart and Emily, both reporting that they enjoy 72% of the activities recorded in the diary entries. Honour reports enjoying the smallest proportion of activities (only 30%), Cathal and Grainne both report enjoying 47%, and Deirdre reports enjoying 53%.

Anna appears different to the others, in that she reports enjoying 77% of the diary entries, and not reporting the enjoyment levels of the others, all of which are self-care tasks. It appears then, that for the entries where a level of enjoyment is given, Anna actually reports that she enjoys all of her diary entries. In the final interview, she reports most enjoying meeting friends and going to the theatre or pub. With no differentiation in her answers contained within the diary information, it is difficult to create a picture of how happy she is with her activities, apart from taking all information at face value, in that she enjoys everything. This enjoyment of all of the activities also mirrors her control over the activities that she does (see section 8.3.4 below).

Freya reports enjoying the highest proportion of her diary entries (79%), but she also reports not enjoying 17%, which is the second highest proportion, and she enjoys 4% of her diary entries a little. With Freya, there seems to be the biggest difference between enjoy and not enjoy; with few entries in the middle ground. She most enjoys her voluntary work, and least enjoys the health-related tasks, including a hospital visit.

Table 8.2 Diary entries – Importance of activities to participants

	Participant															
	Anna		Bart		Cathal		Deirdre		Emily		Freya		Grainne		Honour	
	n	%	n	%	n	%	N	%	n	%	n	%	n	%	n	%
Total entries	39	100	74	100	21	100	55	100	18	100	84	100	32	100	120	100
Important	31	79.5	54	73	9	47.4	24	77.4	14	77.8	77	91.7	13	40.6	97	85.1
A little important	2	5.1	9	12.2	6	31.6	5	16.1	4	22.2	0	0	18	56.3	16	14
Not important	0	0	0	0	4	21.1	2	6.5	0	0	0	0	1	3.1	1	0.9
n/a or not specified	6	15.4	0	0	0	0	0	0	0	0	7	8.3	0	0	0	0

Table 8.3 Diary entries – Participants' enjoyment of activities

	Participant															
	Anna		Bart		Cathal		Deirdre		Emily		Freya		Grainne		Honour	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Total entries	39	100	74	100	21	100	55	100	18	100	84	100	32	100	120	100
Enjoyed	30	77	53	72	9	47	17	53	13	72	61	79	15	47	36	30
Enjoyed a little	0	0	9	12	7	36	10	32	3	17	3	4	13	41	39	40
Not enjoyed	0	0	1	1	3	16	4	13	2	11	13	17	4	12	39	40
n/a or not specified	9	23	11	15	0	0	0	0	0	0	7	8	0	0	0	0

Honour reports enjoying only 30% of her diary entries, and not enjoying 40%, (the remaining activities are enjoyed somewhat), thus she enjoys fewer activities than she does not enjoy. She also records the largest number of activities in her diary information (120), and includes a number of self-care tasks. These self-care tasks, and resting are some of the entries that she reports not enjoying. She describes her enjoyment of activities, in response to the question, "which of the activities do you enjoy most?" she answers that this is reading and studying, with least enjoyment of taking rest and the self-care tasks. (See chapter 7 for her exact words). She describes not enjoying sleeping, but that this is necessary for her to manage ongoing pain.

The above description of the proportion of activities that Honour enjoys gives one side of a picture; the other side is somewhat different. When based on time spent doing activities, it seems that she does spend more time doing the things that she enjoys most, reading and studying, compared to the time that she spends on self-care activities (with the exception of resting). The significant discrepancy between time use and lists of activities, and the difference between her list of activities and others (most particularly Emily) is that she records by far the most activities, and accounts for practically all of her time each day. If other participants had recorded all of their time, then it is likely that others would have also presented a different balance between activities enjoyed, enjoyed somewhat and not enjoyed.

Cathal reports not doing activities that he does not enjoy; this is an active choice.

> "I suppose most of the activities that I do at the moment are passive, I enjoy listening to music and watching people performing music and DVDs. They don't require any action, I am just listening and watching... I don't do activities as such that I don't want to do..."

Cathal possibly gives the most clear account of making choices not to do activities that he does not enjoy; this differs from the account of Honour, for example, who states there are things that she needs to do that she does not enjoy. The amount of enjoyment that participants report in activities appears to be related to their control, or choice over what they do and do not do (as well as the actual reporting of enjoyment as discussed above).

Emily reported enjoying "talking to staff and residents", going to the garden and going to the library most. There are no diary entries with "talking to staff and residents", but it is possible that these are frequent, short activities that the participant chose not to record. She reports enjoying going to church the least, but that this depends on the priest.

The information about how enjoyable diary entries are for participants is also valuable, in that it also provides information about their value system, and also can be used in conjunction with other information to inform discussion of their lifestyle. For example, again, it appears that self-care tasks are least enjoyable; while this is not surprising, having the participants' perceptions, rather than making assumptions is useful. It could be hypothesised that leisure would be more enjoyable than productivity, but this does not seem to be the case for the participants.

This study cannot make conclusions about such information, but the rating of productive items as enjoyable, for the vast majority of diary entries is interesting, and suggests that further research into the value of productivity occupations would be interesting. This is particularly so, given that leisure items, proportionally, do not seem to be reported as enjoyable.

Obviously, the participants' experience of, and assignment of activities as self-care, productivity or leisure is subjective, and as most of the participants are not in full-time or paid employment, this may affect what is considered to be work.

Sandqvist and Eklund (2008) found that people with physical disability who work in paid employment spent less time in tasks such as household chores. Those who spent more time working reported greater satisfaction with daily activities and a greater sense of well-being; thus the authors conclude that work is an important factor in promoting life satisfaction and well-being for this group (Sandqvist & Eklund, 2008) Whether it is simply work that promotes well-being, as is argued, or whether it is that participants who work are more likely to be engaged in occupations that are important, meaningful and possibly enjoyable is questioned.

While the current study does not aim to make conclusions about the impact of engaging in enjoyable or important activities on well-being, there is some evidence to support such a hypothesis. While Cathal doesn't seem to value his college course greatly, he does describe it as preventing him from "slowly going mad".

Intrinsically motivated occupations are intensely enjoyable (Csikszentmihalyi, 1988). How many of the participants' activities could be described as intrinsically motivated? The

answer to this is not clear from the diary information, nor from the interview material, but, as described in chapter 2, further work on the experience of flow for disabled people, where it may be difficult to include aspects of typically flow-inducing occupations (such as physical movement) would be worth investigating. What has been found, is that those who engage in more intrinsically motivated (and therefore enjoyable) occupations report generally greater senses of well-being (Csikszentmihalyi, 1988).

Control in occupations – selection and patterning

Table 8.4 on the following page presents the number and proportions of diary entries that the participants report having control over.

All of the participants were asked to rate the extent to which they have control in each of their diary entries. An interesting feature of the results to this question is that half of the participants (4) did not specify whether or not they have control in a number of the activities; the amount of control was not specified in 44% and 28% of the entries by Deirdre and Freya respectively.

The responses to the open questions also show a great difference between participants, in attitudes to control, particularly between Anna and Cathal. Anna reports very actively taking control, and that this control is imperative to her managing her lifestyle and where she lives. She reports having control over all of her activities. Similarly, Emily reports that being in control of her activities are important to her, she reports being in control of 67% of her diary entries. As already noted, Anna appears to perceive that she has control in all of her diary entries.

Cathal reports having control over 24% of his activities, and having some control over 48% (the remainder are unspecified). The concept of control appears to be somewhat alien to him. This was also the case when discussing the self-maintenance activities. In several cases, he clarifies what he means by having some control; typically this is that he has the choice to do or not to do the activity. For one activity, having visitors over, he reports that:

> "If [he] thought about it [he would have] a degree of control... don't wish to have control"

Another description of his views about control are as follows:

> "A lot of the time it is a conscious decision not to follow something. You are given an option, do you want to or not and if you decide you don't want to, then, if you like, you have made a decision, you have been in control that you are not going to take part."

The participants who report having control over the highest proportion of their activities are Anna, Bart and Freya, all reporting being in control of more than 80% of their activities. These three live in the community. Emily and Grainne report having no control over 11% and 9% of their diary entries respectively. These both live in residential settings.

It is not possible to make inferences about living circumstances and amount of control, but this information does provide an interesting insight that elaborates information from the qualitative interviews. The diary entries are suggesting patterns, that appear to be supported by discussion with participants. If autonomy is likened to control, for example, it could be hypothesised that Anna, Bart and Freya experience autonomy (or control) in their daily lives, whereas this appears to be less true of Cathal, Deirdre and Grainne.

Shapiro et al (1996) suggest that there needs to be a match between the environmental support for control and personal factors. One such personal factor is desire for control (Burger, (1985). Cathal does not seem to want control in his daily life, he reports not thinking about it. He makes choices, but when these are "put to" him, be they whether or not to live in the setting, whether or not to go to college, whether to take part in activities and so on. The description of his living situation seems to be that he is not required to take control, so it could be hypothesised that there is a good match. Equally, Anna and Bart both wish to take control, and their living circumstances demand this action, particularly in relation to management of personal assistance services.

Table 8.4 Diary entries – Participants' control of activities																
	Participant															
	Anna		Bart		Cathal		Deirdre		Emily		Freya		Grainne		Honour	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Total entries	39	100	74	100	21	100	55	100	18	100	84	100	32	100	120	100
Control	39	100	60	81	5	24	12	22	12	67	72	85	15	47	64	53
Some control	0	0	12	16	10	48	16	29	4	22	0	0	14	44	47	39
No control	0	0	2	3	0	0	3	5	2	11	3	4	3	9	2	2
n/a or not specified	0	0	0	0	6	28	24	44	0	0	9	11	0	0	7	6

Deirdre craves more control than is available to her in the residential setting. She wants to have more control over where she goes, whether or not she can leave the residential setting, what she has to eat and how she is assisted with self-care tasks. There seems to be a mis-match between her desire for control, and the nature of the setting. This mis-match could account for some of her dissatisfaction with her living situation.

Shapiro et al (1996) suggest that desire for control is not the only personal factor that is important in determining the match between the person and the environment. Other salient factors include the competence of the individual; their belief in their competence, and their willingness to take responsibility.

A person's belief in their competence is said to affect their perceptions of control (Shapiro et al, 1996), but also people who believe that they can exert control over situations experience less stress about their competence, and believe that their environment is more supportive than those who do not believe that they can exert control (Bandura 1989).

For Cathal, he seems to believe that he does not have competence (in a physical manner) and so does not look to exert control, but in his interviews, there is also evidence of apprehension of physical inaccessibility wherever he goes. He gives several examples of wanting to do things (such as get a birth certificate, go out with his colleagues in college, go to the pub etc), where he does not go, because of fear of inaccessibility. Thus, he has limited desire for control, he is fearful of access issues in the environment, and he does not challenge the environment. This seems to be a persistent state of feelings of lack of competence and lack of control: could this be leading to learned helplessness, as is suggested by Seligman 1975)?

Anna perceives herself to be "independent" and competent: she appears to have a high desire for control, she "challenges" the physical and social environment, and fights, as previously described, she tends to win her battles. Thus, she seems to be in a positive spiral of control and competence.

Alone / with someone

Participants were asked whether their diary entries were performed alone or with someone, and were asked who activities were performed with. The majority of the responses did not specify a person or people, so there is inadequate evidence to describe with whom participants spend their time. Those that did report with whom they spend time, (particularly Anna and Bart), perform the majority of activities with a PA.

Anna reports that 4 of the 39 items are performed alone; one of these is in a productivity activity, where it is assumed that other people were around (i.e. the participant was not entirely alone). Other activities listed (35) were either with a personal assistant (27), with a friend (7) or with both a friend and a PA (1). In total, 7 and-a-half hours during the 90-hour time period described are reported as being alone (excluding the productivity activity). There is no time alone in five of the seven days. As will be highlighted in the next chapter, the time alone is one of the features of her current lifestyle that Anna would like to change: in interviews, she says that she would like more time alone.

Bart spends some time alone each day, but the vast majority of the day is spent in the company of a personal assistant. The tasks that are performed alone include giving the PA a break, watching a DVD, reading an e-book (3 reports) and checking e-mail (3 reports). These typically appear to take place in the early evening.

Cathal spends time alone each day, typically in the early evening, with tasks such as watching DVDs or television. He differentiates between tasks which are performed with a carer or one-to-one person who could assist him with tasks if necessary, and activities such as going to college, where people are around, but he is not specifically with someone.

On four of the seven days, Deirdre reports spending some time alone. The other days, she has no time alone. The time spent alone is small, compared to the overall number of hours in her day. Deirdre spends time alone going around the grounds of the residential setting and feeding the cats.

Emily reports having time alone in all but one of the days. She reports going to the bank, into town, to the library, to the doctor, visiting a friend, going to mass, sitting in the garden, visiting her mother's grave and going for a walk alone.

Grainne reports doing 17 of the 32 activities alone (53%), including feeding the animals, and using her computer. Those performed with people are typically when she uses assistance to get up in the morning or meeting family and friends. This is consistent with the previously reported difficulties with the social environment.

Honour describes all except for one activity as either being performed alone or with her PA. This is a striking lack of contact with other people evident in her diaries.

There seems to be a lack of information about proportions of time spent alone or with other people in the literature, however, it is likely that people who live independently with personal assistance will spend a lot of time with a PA. Investigation of this would be useful, particularly what happens when there are difficulties between the PA and leader.

Social contact has been described in huge detail in social psychology, and comparison of much of this literature is beyond the scope of this work. However, the relatedness concept is pertinent - relatedness helps to internalise motives for actions that are not interesting in themselves (Ryan & Deci, 2000). Social comparison (including vicarious development of self-efficacy beliefs) seem also to be relevant, but there is limited evidence within the current work to make such links with participants' self-reports or diaries.

The contrasting mechanisms that Deirdre and Grainne use to manage difficulties in the social environment in their residential settings are interesting. Maybe Deirdre's engagement with others in the setting enables her to make positive social comparisons, which support her coping mechanisms (as described by Taylor, 1984). Further investigation into Grainne's diaries and interview material is that continued interaction with former school friends and her extended family are really important for her.

Occupational patterning

Routine and habits of the participants are difficult to deduce from the diary entries, but the interviews also provide information about the participants' routines and how they pattern occupations. These are described in section 7..

Anna is the only participant who works full-time. She describes a clear routine with a regular time to get up, go to bed etc. Cathal attends college four days per week, and similarly describes a clear routine with regular times to get up and go to bed on those days at work/college. The other participants either don't work, or do sessional work (in the case of Freya).

Previously in this chapter, the potential benefits for disabled people of working, and the links between work and satisfaction have been alluded to. Of a group of eight adults of working age, one in full-time employment (in the years of the Celtic Tiger in Ireland) seems less than what would be expected for the general population.

It is widely recognised that disabled people have fewer opportunities for employment, that disabled people experience ongoing barriers to work, and that the proportions of disabled people working is lower than the proportion of non-disabled people of working age in employment (Johnstone, 2001; Roulstone, 2004; Hurstfield, 2004; Fitzgerald, 2005; Gannon & Nolan, 2004; Gannon & Nolan, 2005). This is certainly true for the participants of this study. The question arises about why only Anna is in full-time employment.

Ville and Winance (2006) report ongoing barriers to employment experienced by disabled people, and it is suggested that rather than simply considering whether or not a person works, it is more important to understand the meaning of or reasons behind the situation for that person. The situation for each of the participants is different.

Bart was seeking work at the time of the first interview, and did begin work in the course of this study. He had just completed a University degree course, and was clearly looking for work. The barriers that he describes are the need to manage the speed of communication and pace of work in different settings, due to his use of a chin-switch and switch technology for communication.

Cathal has a previous history of working, and has left work due to his physical disability. While he is undertaking a college course four days per week, he has no intention or expectation to return to work due to physical disability. Deirdre, also, worked prior to onset of disability, and she does not expect to return to work due to disability. Grainne gave up work, and then a University course due to disability, and while the prospect of her being in paid employment was not actually discussed at any length in the interviews, it is expected that she does not expect to return to work, due to disability. She does, however, spend time writing stories and poetry on her computer, which appears to fulfil a productive role for her.

Honour has a history of working, and left work due to deterioration in her physical disability. She then began a University course, which is full time. However, despite very evident motivation to continue with this course, she has not returned to University for two years, because doctors have said that she is not well enough to return. For Honour, work involves reading and studying, and her aspiration is to return to University, finish her degree and go on to post-graduate studies.

Emily worked briefly in sheltered employment, but gave it up, stating that it is not her "personality". She has no real ambition or expectation of working.

Thus, the stories that have brought people to their current employment situation are quite different – such differences were also found by Barnes and Mercer (2005). The experiences seem to support findings, such as those of Fitzgerald (2005), who suggested that 16% of people who have difficulty "dressing, bathing or getting around inside the home" are employed (Fitzgerald, 2005 p.14).

The two most highly educated participants (Anna and Bart) are the ones working, or seeking employment: Johnstone (2001) reports that more educated disabled people are more likely to be employed than those with less education. Martin's (2005) findings about the difficulties of providing resources (such as a personal assistant) for work are exactly as described by Anna. She describes how she has to use funds in an alternative way to fund the PA that she requires for work.

Bart seems not to have a clear routine in his diary information, apart from getting up and going to bed at similar times on six of the seven days.

The most prominent routine feature of Deirdre is that she reports staying within the residential setting (including the grounds) for 6 of the seven days. She uses different rooms / areas of the setting, as well as going around the grounds. The participant reports not being satisfied with the proportion of time that she spends in the residential setting – she would prefer to go out more. She said that she particularly wanted to go to the local village, but is not allowed out on her own. She reports that while each day is different, she tends to do similar things on the same day each week (i.e. has a Monday routine, a Tuesday routine, and so on.) Emily also reports being in her residential setting / grounds all day, and Grainne reports being in her setting on four of the seven days.

Macdonald (2002) found that for women with physical disabilities, routine and habit formation was an important factor in enabling participation in daily occupations. The only participant in this study who seems to lack routine is Honour.

People will tend to choose environments and tasks in which they perceive themselves to be efficacious and avoid those that they perceive to be too demanding (Bandura, 1989; 1982). Bandura's (1982) suggestion that the selection of environments based on self-efficacy beliefs does not fully explain the occupational patterns found within the diary entries of the participants. For the participants in this study, real physical access issues impact on choice of environments. This is particularly true for Honour and Cathal, who actively restrict the places where they go due to being unable to move around (Honour) or fear that the environment may be inaccessible.

For Deirdre, however, the selection of environments is imposed upon her: on one of the days she reports that she wanted to go to the local "village" shops (in a suburb of Dublin). She was unable to, because there were no staff available to accompany her. Reasons given for not allowing her to leave the residential setting are that she is not safe using her powered wheelchair outside, and so she could injure herself. She appears to accept this, but describes a longing to feed the ducks at a local park and look in shop windows. Zola (1983) describes the core rights embedded in independent living as the right to take risks. It seems that the setting in which Deirdre lives does not allow her to take such risks.

If a person selects an environment in which they feel competent, then it is likely that the influences within that environment will continue to support positive perceptions of self-efficacy (Bandura, 1989). The constructs within the environment are likely to continue to support competences, values and interests long after the initial choice of that environment has been made, thus initially small decisions about choice of environment can strongly affect the life-course of individuals (Bandura, 1989). Anna, in particular, describes feeling lucky, because she had the opportunities that non-disabled people have, she has built up confidence and feels confident in a number of environments. However, she does describe difficulties, for example, when she is on holiday and there are accessibility issues. As a result, she avoids going on holiday, because it is "too stressful".

All of the participants engage in leisure, and the types of leisure activities performed seems to mirror research findings. These include passive, rather than physically active activities. Anna and Emily both stated that they want to go swimming, but have limited opportunity to do so. Such a lack of participation in active leisure is suggested can increase the likelihood of secondary health issues Rimmer et al, 1999).

Honour seems to lack social leisure. She states that she is not happy with her situation, wishing that she could have friends around to dinner or go out to dinner once in a while. Such a lack of leisure has been found to have negative impacts on social interaction (Trigg et al, 1999), which has been described as a key factor in determining quality of life and well-being (e.g. Albrecht & Devlieger, 1999; Alaszewski et al. 2006).

Contribution of findings to emerging choice and autonomy framework

As has been already presented, this work involves consideration of a choice and autonomy framework, as a means to explain and elucidate findings. This choice and autonomy framework needs to contain at least five strands, including:

- the meaning of autonomy;
- whether or not autonomy is a need, goal or value;
- what daily experience of autonomy (or lack of autonomy) is "like";
- whether concepts of autonomy overlap other psychological theories, and

- the impact of the environment on autonomy and choice.

This first set of interpretative results provide more information about the second, third and fifth strands of the framework.

Strand 1: The meaning of autonomy

The descriptions of autonomy will be interpreted in the next chapter, but there is now a lot of description to draw upon to create an understanding (or several understandings) of autonomy for the participants

Strand 2: Whether or not autonomy is a need, goal or value

The descriptions and interpretations of the participants' choices, decisions, autonomy and independence in everyday life, and as developed throughout the life-span suggest that the participants differ in the extent to which they value or prioritise control and choice. Some participants clearly report making choices from an early stage in life, and, further, enacting those choices (for example, Anna and Bart). Others seem not to make decisions as readily or take less control of situations (for example Cathal). Further interpretation of these findings will be conducted in the next chapter, but from the evidence so far, for these participants, choice and control are not equally sought or valued by all participants. Does this directly relate to autonomy? This strand of the framework requires further interpretation, but is likely to need to include a concept about the person's values, goals or desire for control, choice and possibly autonomy. [This last sentence is weak. The whole paragraph fails to answer the question in the title because it shifts to choice and control from autonomy and only drags autonomy back in as the last word in the paragraph. Is autonomy a need for all the participants, despite the fact that they have very different attitudes to choice and control? Is it a matter of different people defining their own area or meaning of autonomy differently?]

Strand 3: What daily experience of autonomy (or lack of autonomy) is "like";

The daily experiences of choice, control, independence and autonomy, or lack of these, seem to differ greatly between participants. The experiences differ, but so

do the participants' perceptions of their situations. Examples, such as the different reactions for similar needs for assistance, different reactions to controlling residential settings and to the nature of physical disability highlight that in what can be considered somewhat similar situations, there can be very different interpretations and reactions. Theories within psychology, such as self-efficacy, happiness self-determination theory and control have been used to partially describe possible causes for such differences, but further interpretation will be undertaken in the next chapter. It is clear, that this strand of the Choice and Autonomy framework needs both to consider the actual experiences, and also how people perceive these experiences.

Strand 4: Whether concepts of autonomy overlap other psychological theories

Parallels have been found within a range of the psychological theories, such as control and self-efficacy; happiness and choice; choice and self-efficacy; coping mechanisms and control etc. The concept of autonomy may overlap some of these theories, particularly theories of control. Further interpretation will be presented in the next chapter to explore which concepts overlap with autonomy.

Strand 5: The impact of the environment on autonomy and choice

The interpretations in this chapter suggest that the description of the role of the environment within psychological theories (such as the theory of control and self-determination theory) may be helpful in understanding choice and autonomy. For example, the argument that there needs to be a person-environment fit for optimal well-being seems to make certain sense when directly applied to some of the participants in this study. As with other strands, it seems not simply to be a case of objective environmental circumstances that are solely of relevance, but also a person's perception of the environment.

Conclusion

This chapter presented the first part of the interpretative findings, and described the different experiences of the participants in terms of their histories, and the autonomy, choice and control that they have in their daily life/living situations and in their occupational performance. There appears to be a significant difference in the past and present experiences of the different participants, highlighting the fact that they are eight individuals, each providing an interesting insight into their daily experiences of choice, autonomy and control.

The following chapter describes the participants' perceptions of their lifestyles, and their rating of their current and ideal lifestyles using the scale based on a semantic differential. It concludes the findings, with a more detailed examination of the meaning of autonomy and choice for the participants.

10. Perceptions of Lifestyle and Meaning of Autonomy and Choice to participants

Introduction

This chapter concludes the presentation of results from participants. It presents interpretative findings, focusing on participants' perceptions of their lifestyles and a description of the stated and inferred meanings of autonomy and choice to the participants.

The information for this chapter is largely based on that gleaned in the final interview, with reference (where applicable) to the initial interview, self-maintenance and diary information sections.

Perceptions of lifestyle were recorded through a semantic differential scale, results of which for each participant are presented in this chapter (section 9.2). The perceptions were also discussed with participants, thus the ratings and interview information are discussed and comparisons between participants are made (section 9.3).

The descriptions of autonomy and other concepts are presented, as stated by each participant, and these perceptions are discussed in relation to other information from the entire data collection process. This will provide further information to inform the emerging choice and autonomy framework, which will be discussed in the final chapter.

This chapter concludes with final remarks from participants, once they had reviewed information presented in previous results chapters, with an update on their current situation, some years after the information has been collected.

Lifestyle Ratings

The results for each participant are presented separately. Each participant was asked to rate aspects of their current lifestyle and an ideal lifestyle, based on a semantic differential scale. See sections 5.6.4 and 5.9.5, in the methodology chapter, for a description of the scale and analysis of the results respectively.

The current lifestyle ratings are presented first, followed by ideal lifestyle, and finally a comparison of current and ideal ratings for each participant. In the figures, the "good/active/strong" half of the pair is the first in the pair. On the Y axis, the pairs are listed (e.g. Varied/Monotonous, Strong/Weak, Strenuous/Sedentary, and so on), and the bars represent the rating given. Ratings of 5 indicate responses that are "good/active/strong", and 1 that are "bad/passive/weak". In comparisons of ratings, a "-" suggests that a person would like their life to be higher in the "good/active/strong" domain.

Anna

Anna rated her lifestyle as varied, interesting, good, fulfilling, busy active, inc company, outside home, satisfying, with little free time and full of choice. It is moderately strenuous and challenging. She gave no mid-way ratings.

An interesting feature of these ratings is the extremes; 11 of the 14 items are rated at the extreme. Another interesting feature is that the present lifestyle is reported as being positive, with extremes at "good, interesting, fulfilling, satisfying". There is also high rating of activity, "active, outside home, and little free time" are all at the extreme.

Numerically, the total score for Anna is 67 (where the maximum rating of 70) , indicating high ratings of semantic pairs in the "good", "strong" and "active" spheres.

Her ideal lifestyle is described as varied, interesting, good, challenging, busy, active, outside home, satisfying with lots of free time and lots of choice. It is moderately fulfilling, strenuous, in company and strong.

As with her current lifestyle, the ideal lifestyle also shows extremes in the "good" and "active" spheres. Curiously, the ideal life is not at the extreme of fulfilling. In the ideal life, there are no mid-way ratings given, potentially indicating preferences for a certain lifestyle.

Numerically, the ideal lifestyle has a score of 61 out of 70, which is high in the three domains of "good", "active" and "strong", but is less than the rating given for the current lifestyle.

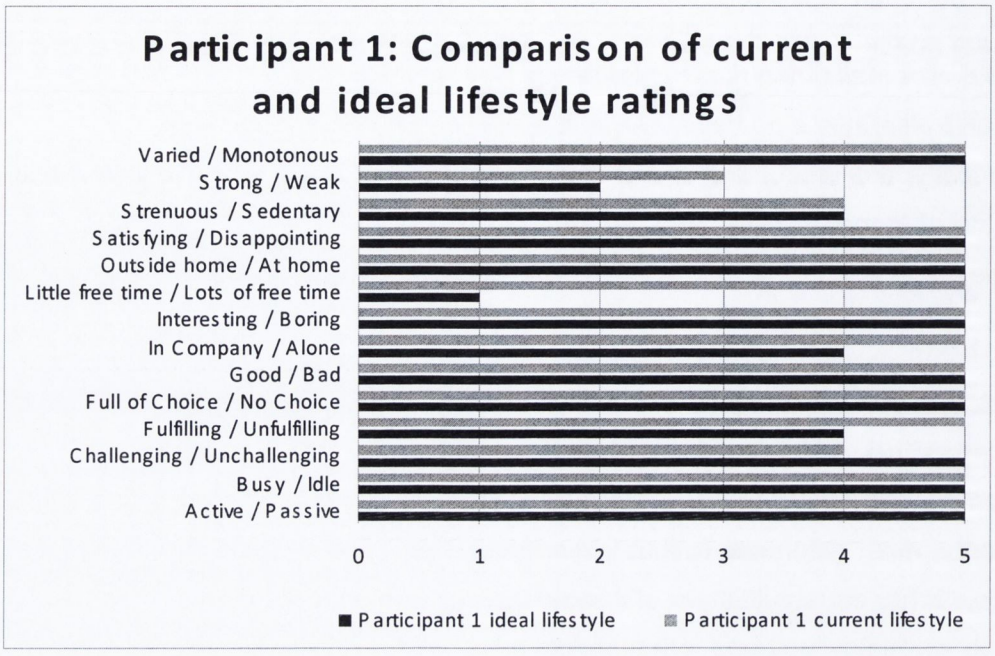
The description of the present lifestyle is very similar to that of the ideal lifestyle. Differences include that her ideal lifestyle would be more challenging, less fulfilling, less in the company of others and stronger. Six descriptors have a different rating, the one that shows the most difference is that in her ideal lifestyle, she would like "lots of free time", whereas in her current lifestyle, she rated the extreme opposite of this ("little free time").

In numerical terms, of the possible total variance score of 56, Anna scores the variation between her present lifestyle and her ideal as 8.

Table 9.1. Anna - Comparison of Lifestyle ratings

Semantic Pair	Current lifestyle	Ideal lifestyle	Difference
Varied / Monotonous	5	5	0
Interesting / Boring	5	5	0
Good / Bad	5	5	0
Fulfilling / Unfulfilling	5	4	-1
Strenuous / Sedentary	4	4	0
Challenging / Unchallenging	4	5	1
Busy / Idle	5	5	0
Active / Passive	5	5	0
In Company / Alone	5	4	-1
Outside home / At home	5	5	0
Satisfying / Disappointing	5	5	0
Little free time / Lots of free time	5	1	-4
Strong / Weak	5	4	-1
Full of Choice / No Choice	5	5	0
Total Variance			8

Figure 9.1 Anna – Comparison of Lifestyle Ratings



When both sets of scores were shown to Anna after she had rated them, her comment about her ideal lifestyle was,

> "it's like it is now... it would be a tiny bit different".

Bart

Bart rated his lifestyle as moderately good, boring, sedentary, at home with free time and choice. He gave no extreme ratings and mid-way ratings to: Varied/Monotonous; Fulfilling / Unfulfilling; Challenging / Unchallenging; Idle / Busy; In company / Alone; Satisfying / unsatisfying and Weak / Strong.

A feature of this rating is that there are no "strong agreement" items, and there are more ratings at the mid-point than some agreement.

The numerical value for this rating is 47, and there are some ratings moderately in the "passive" domain (boring, and sedentary). From the ratings, it seems like there is no clear descriptor of his lifestyle; it is rated as fairly good, with some choice, outside home and with little free time. It is also rated as fairly boring and sedentary.

The ideal lifestyle is rated as moderately varied, interesting, fulfilling, strenuous, challenging, busy, active, outside home, satisfying, strong with little free time and some choice. Mid-way ratings were given to good/bad and alone/in company.

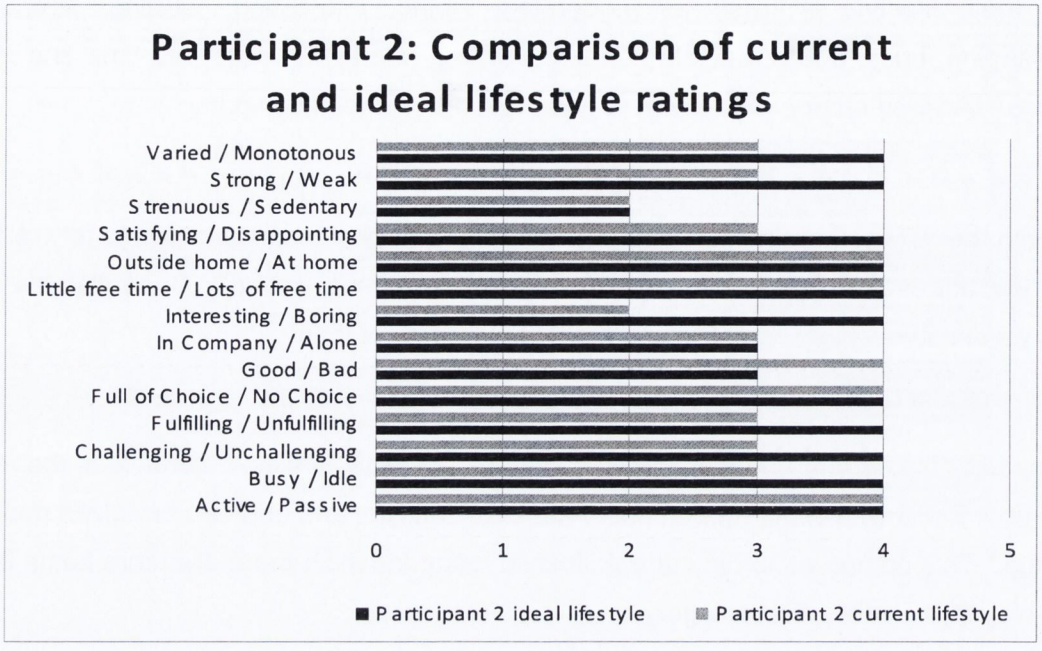
As with the rating of his current lifestyle, Bart does not give maximum ratings for his ideal lifestyle, not even to "good" (he gives good / bad a mid-way rating). Generally, his ideal lifestyle is active, (busy, variable) – but not at extremes of these.

Comparing his current and ideal lifestyle ratings, the most striking difference is that there are more items with some agreement in his ideal lifestyle, and only two are given mid-way ratings. This compares to his current lifestyle rating in which there are more items in the mid-way than in any other category.

Table 9.2. Bart – Comparison of ratings

Pair	Current	Ideal	Difference
Active / Passive	4	4	0
Busy / Idle	3	4	-1
Challenging / Unchallenging	3	4	-1
Fulfilling / Unfulfilling	3	4	-1
Full of Choice / No Choice	4	4	0
Good / Bad	4	3	1
In Company / Alone	3	3	0
Interesting / Boring	2	4	-2
Little free time / Lots of free time	4	4	0
Outside home / At home	4	4	0
Satisfying / Disappointing	3	4	-1
Strenuous / Sedentary	2	2	0
Strong / Weak	3	4	-1
Varied / Monotonous	3	4	-1
Total Variance			9

Figure 9.2 Bart – Comparison of lifestyle ratings



There appears to be a fairly small numerical and contextual difference between Bart's current and ideal lifestyles. The ideal life is rated as fairly busy, challenging, fulfilling, varied, strong and fulfilling, whereas in the current lifestyle, these are rated at the mid-point.

Cathal

Cathal rated his lifestyle as moderately fulfilling, strenuous, passive, at home and satisfying, with mid ratings given to: Varied / Monotonous; Interesting / Boring; Good / Bad; Challenging / Unchallenging; Busy / Idle; In Company / Alone; Little free time / Lots of free time; Strong / Weak and Full of Choice / No Choice.

Nine of the semantic pairs are rated in the mid-range, with the remaining five with some agreement. There are no maximum values given. There seems to be a neutral response to strong/weak pairs and active/passive pairs, with greater agreement with good pairs (satisfying, fulfilling).

In numerical terms, the rating for Cathal's current lifestyle is 48 out of 70, and appears not to show maximum ratings. The lifestyle is rated as fairly fulfilling, strenuous, passive and

satisfying, and outside home. All other ratings are mid-way, suggesting no outstanding features of the lifestyle for the participant.

Cathal rates his ideal life as fulfilling, strong and full of choice. It is also moderately varied, interesting, good, strenuous, challenging, busy, active, in company outside home and satisfying. He gives a mid-way rating to lots of free time / little free time.

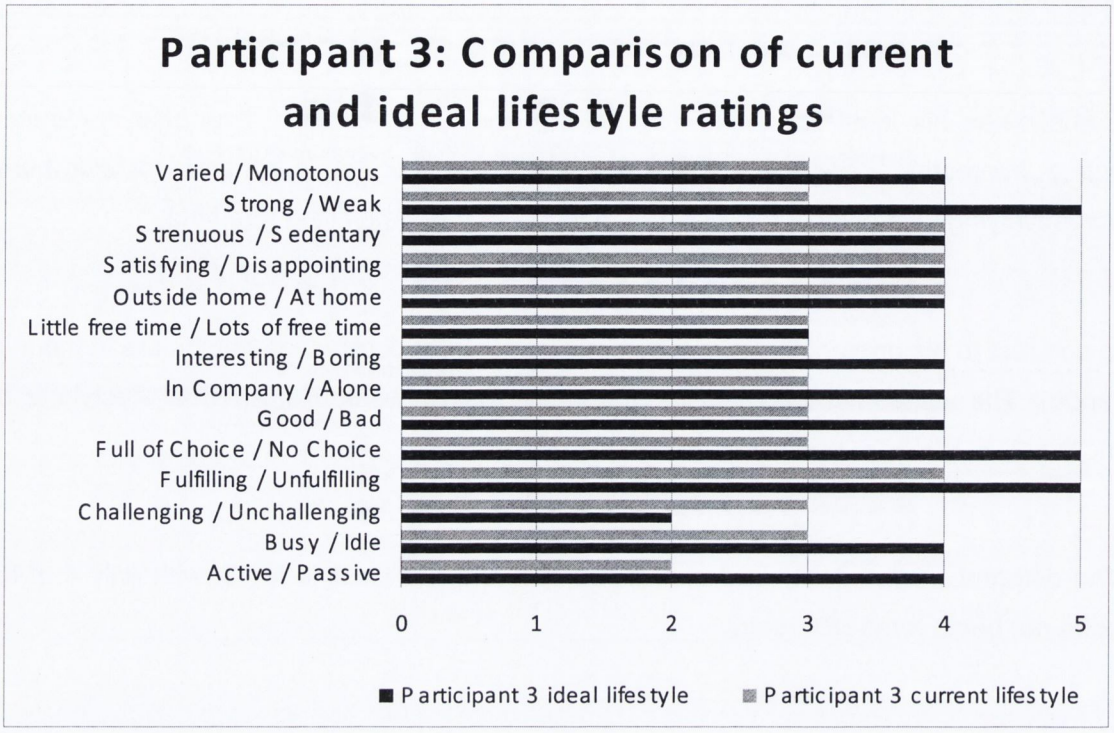
In contrast to his present lifestyle ratings, only one of the fourteen variables are in the mid-range. The values assumed from his rating is that he would like an ideal lifestyle to be more active, stronger and better.

The difference numerically between his current an ideal lifestyle is 13, with only 4 of the pairs not being rated differently.

Table 9.3. Cathal comparison of current and ideal ratings

Pair	current	ideal	difference
Active / Passive	2	4	-2
Busy / Idle	3	4	-1
Challenging / Unchallenging	3	2	1
Fulfilling / Unfulfilling	4	5	-1
Full of Choice / No Choice	3	5	-2
Good / Bad	3	4	-1
In Company / Alone	3	4	-1
Interesting / Boring	3	4	-1
Little free time / Lots of free time	3	3	0
Outside home / At home	4	4	0
Satisfying / Disappointing	4	4	0
Strenuous / Sedentary	4	4	0
Strong / Weak	3	5	-2
Varied / Monotonous	3	4	-1
Total Variance			13

Figure 9.3 Cathal – Comparison of lifestyle ratings



Deirdre

Deirdre rated her current lifestyle as in company and at home. It is moderately bad, challenging, busy, active, disappointing, with little free time and moderately full of choice. Mid-ratings were given to varied / monotonous; interesting /boring; fulfilling/ unfulfilling; strenuous / sedentary and strong / weak.

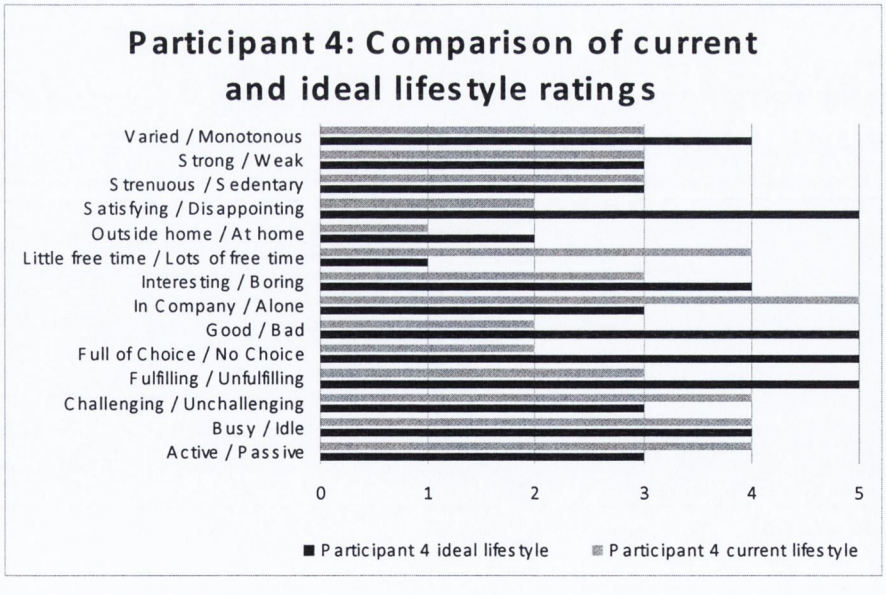
Deirdre's overall numerical rating is 47, but there is variation between the domains of "good/bad", "active/passive" and "weak/strong"; she appears to rate her life as active, agreeing with challenging, busy and active, but she also appears to rate her life as bad – agreeing with "bad" and disappointing".

The only maximum value given by Deirdre is for "in company"; her descriptions of her lifestyle, both in the diary information and during the interviews suggest that she does spend a lot of time in the company of others.

The ideal lifestyle ratings contrast with the current lifestyle in that the "good" domain pairs are more highly rated; "good", "fulfilling" and "satisfying" are all given maximum values. The "active/passive" domain seems to be less valued in the ideal lifestyle.

Table 9.4. Deirdre – Comparison of lifestyle Ratings			
Pair	current	ideal	difference
Active / Passive	4	3	1
Busy / Idle	4	4	0
Challenging / Unchallenging	4	3	1
Fulfilling / Unfulfilling	3	5	-2
Full of Choice / No Choice	2	5	-3
Good / Bad	2	5	-3
In Company / Alone	5	3	2
Interesting / Boring	3	4	-1
Little free time / Lots of free time	4	1	3
Outside home / At home	1	2	-1
Satisfying / Disappointing	2	5	-3
Strenuous / Sedentary	3	3	0
Strong / Weak	3	3	0
Varied / Monotonous	3	4	-1
Total Variance			21

Figure 9.4 Deirdre – Comparison of lifestyle Ratings



The variance between the current and ideal lifestyle (21) seems to be numerically large, and this seems to be primarily accounted for in the "good" domain. The ideal lifestyle is given maximum values for good, full of choice and satisfying, whereas the current lifestyle

is rated as moderately bad, no choice and disappointing; the ideal lifestyle is fulfilling, whereas the current lifestyle is only moderately so.

Emily

Emily rates her current lifestyle as: "strong"; "good"; "satisfying"; "challenging" and "busy". Numerically, the rating is 56, suggesting fairly high scores in all three domains of "good", "strong" and "active". The ratings given by Emily are given in table 9.6.

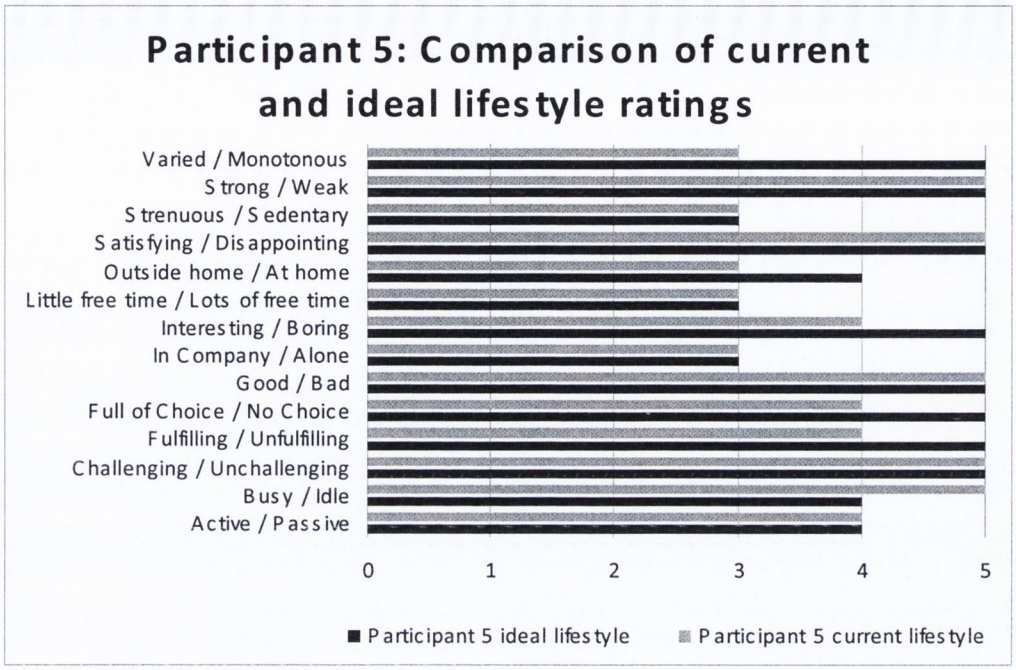
Her ideal lifestyle appears to be rated highly in the "good" pairs, such as "good", "fulfilling", "interesting" and "satisfying"; there is also relatively high activity. Thee values given mid-way ratings are: Strenuous / Sedentary; In Company / Alone and Little free time / Lots of free time.

When comparing her ideal and current lifestyles, it appears that the difference is fairly small. Only one of the pairs was changed by more than one, that is she rated her current lifestyle as mid-way between varied/monotonous, but in her ideal life, she would like a varied lifestyle. Eight of the fourteen pairs were unchanged.

Table 9.5. Emily – Comparison of Lifestyle Ratings

Pair	current	ideal	Difference
Active / Passive	4	4	0
Busy / Idle	5	4	1
Challenging / Unchallenging	5	5	0
Fulfilling / Unfulfilling	4	5	-1
Full of Choice / No Choice	4	5	-1
Good / Bad	5	5	0
In Company / Alone	3	3	0
Interesting / Boring	4	5	-1
Little free time / Lots of free time	3	3	0
Outside home / At home	3	4	-1
Satisfying / Disappointing	5	5	0
Strenuous / Sedentary	3	3	0
Strong / Weak	5	5	0
Varied / Monotonous	3	5	-2
Total Variance			7

Figure 9.5 Emily – Comparison of Lifestyle Ratings



Freya

Freya's current lifestyle is: busy; challenging; fulfilling; strong, satisfying; interesting; in company and with little free time. Numerically, this is a rating of 60 out of a total possible rating of 70, thus suggesting that she rates her lifestyle highly in all three domains of good, strong and active. There are no mid-way ratings given.

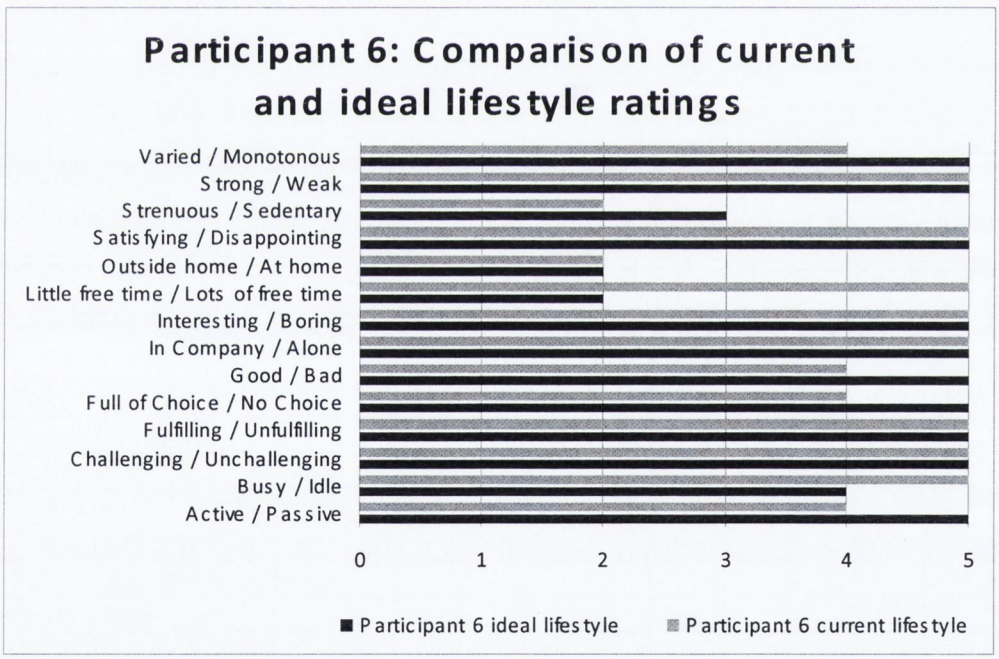
Similarly, her ideal lifestyle is rated highly in the domains of good, strong and active, but includes lots of free time. It also includes one mid-way rating – strenuous ./ sedentary.

The description of the ideal lifestyle as: Varied; Interesting; Good; Fulfilling; Challenging; Active; In company; Satisfying; Strong; Full of Choice; Varied; Interesting; Good; Fulfilling; Challenging; Active; In company; Satisfying; Strong and Full of Choice – being the majority of the "good", "active" and "strong" pairs.

The comparison between current and ideal lifestyles are presented in the table and figure below

Table 9.6. Freya – Comparison of Lifestyle Ratings			
Pair	Current	Ideal	Difference
Active / Passive	4	5	-1
Busy / Idle	5	4	1
Challenging / Unchallenging	5	5	0
Fulfilling / Unfulfilling	5	5	0
Full of Choice / No Choice	4	5	-1
Good / Bad	4	5	-1
In Company / Alone	5	5	0
Interesting / Boring	5	5	0
Little free time / Lots of free time	5	2	3
Outside home / At home	2	2	0
Satisfying / Disappointing	5	5	0
Strenuous / Sedentary	2	3	-1
Strong / Weak	5	5	0
Varied / Monotonous	4	5	-1
Total Variance			9

Figure 9.6 Freya – Comparison of Lifestyle Ratings



The most noteworthy difference between the current and ideal lifestyle as rated by Freya is that in her ideal lifestyle, she would have more free time. There is difference in other pairs, in terms of the strength of agreement, but the variance is quite small, with a numeric value of 9.

Grainne

The only maximum value given by Grainne is in "in company". With moderate ratings, she describes her life as: bad; sedentary; monotonous; disappointing; unchallenging; with no choice and at home.

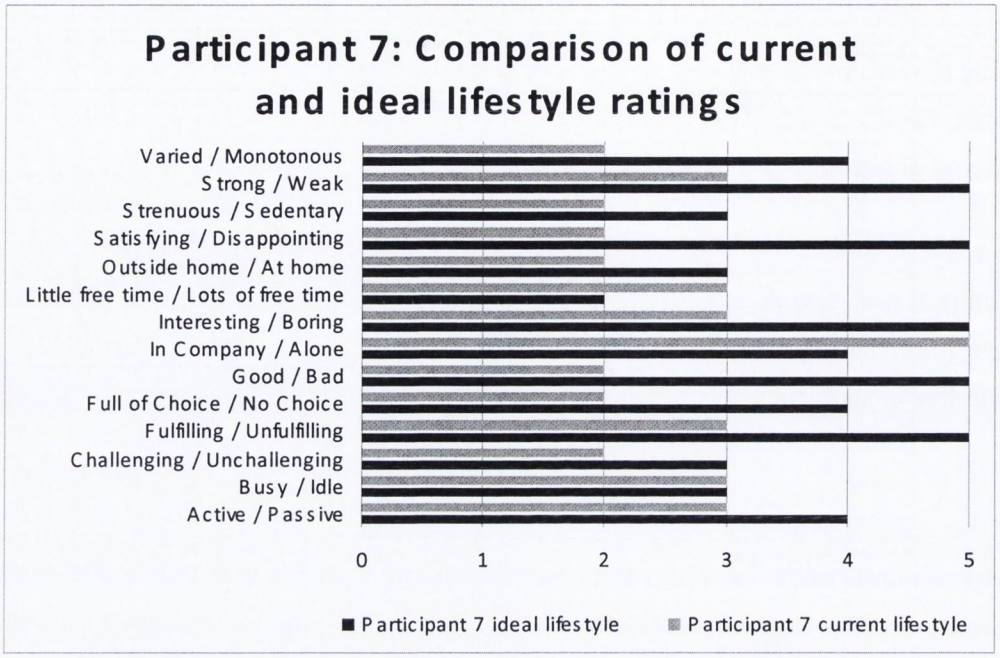
Her rating of her ideal lifestyle is quite different, being rated as: fulfilling; good; interesting; satisfying and strong. The ideal lifestyle is rated highly in the "good" domain, and less highly in the "active" domain.

When the current and ideal lifestyles are compared, it seems that there is a big difference. The two semantic pairs that show the greatest difference are good/bad (moderately bad in the current lifestyle, and very good in the ideal), and satisfying / disappointing (moderately disappointing in the current lifestyle and very satisfying in the ideal). Both of these are in the "good" domain, as is fulfilling/unfulfilling, which is also rated more positively in the ideal lifestyle.

Table 9.7.3 Grainne – Comparison of Lifestyle Ratings

Pair	Current	Ideal	Difference
Active / Passive	3	4	-1
Busy / Idle	3	3	0
Challenging / Unchallenging	2	3	-1
Fulfilling / Unfulfilling	3	5	-2
Full of Choice / No Choice	2	4	-2
Good / Bad	2	5	-3
In Company / Alone	5	4	1
Interesting / Boring	3	5	-2
Little free time / Lots of free time	3	2	1
Outside home / At home	2	3	-1
Satisfying / Disappointing	2	5	-3
Strenuous / Sedentary	2	3	-1
Strong / Weak	3	5	-2
Varied / Monotonous	2	4	-2
Total Variance			22

Figure 9.7 Grainne – Comparison of Lifestyle Ratings



Honour

Honour rates her current life as busy, boring, at home and sedentary. It initially appears difficult to understand how a lifestyle can be both boring and busy, but this appears to relate to the participant's understanding of the words – as will be described later in this chapter, she views her life as boring because she has very limited social or leisure contact, but she doesn't feel "bored" at all. The rating of boring appears to relate to how she perceives others would view her life, showing a limited range of occupations, rather than her being bored by her activities.

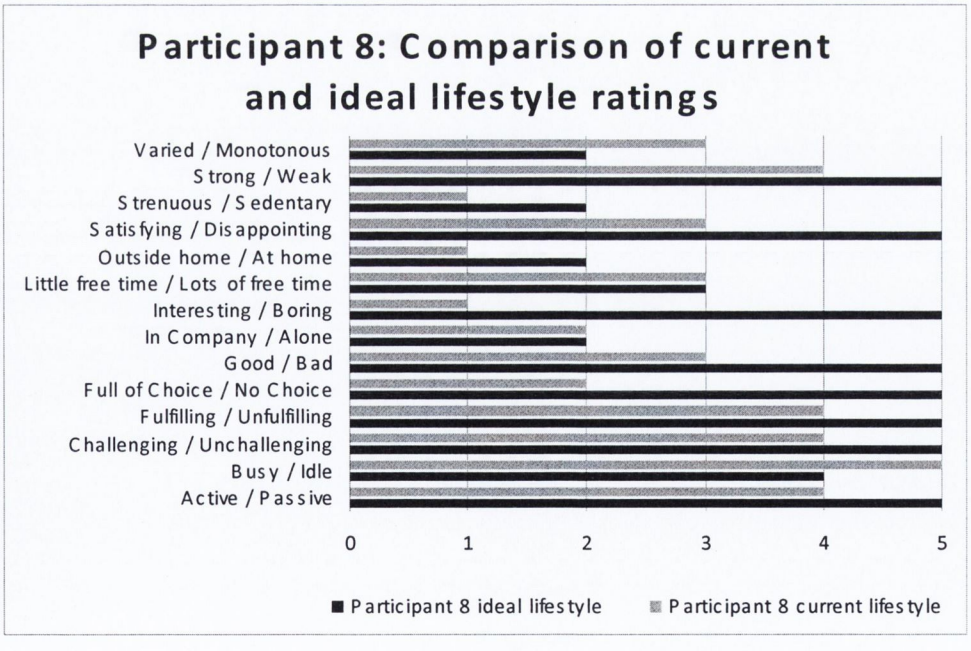
The ideal lifestyle is described as: active; challenging; fulfilling; full of choice; good; interesting; satisfying and strong.

The comparisons of current and ideal lifestyle ratings are presented in table 9.8.3 and figure 9.8.3. The comparison shows difference in most of the pairs, particularly in interesting / boring, which goes from an extreme at boring to an extreme at interesting. The only pairs where no difference in rating is exhibited is alone / in company and little free time / lots of free time.

Comparatively, the ideal lifestyle is more active, challenging, fulfilling, with more choice, better, and more satisfying, than the current lifestyle.

Table 9.8.3 Honour – Comparison of Lifestyle Ratings			
Pair	Current	Ideal	Difference
Active / Passive	4	5	-1
Busy / Idle	5	4	1
Challenging / Unchallenging	4	5	-1
Fulfilling / Unfulfilling	4	5	-1
Full of Choice / No Choice	2	5	-3
Good / Bad	3	5	-2
In Company / Alone	2	2	0
Interesting / Boring	1	5	-4
Little free time / Lots of free time	3	3	0
Outside home / At home	1	2	-1
Satisfying / Disappointing	3	5	-2
Strenuous / Sedentary	1	2	-1
Strong / Weak	4	5	-1
Varied / Monotonous	3	2	1
Total Variance			19

Figure 9.8 Honour – Comparison of Lifestyle Ratings



Comparison of Participants' ratings

This section will present the ratings of the participants as a group. Table 9.9 presents each participant's rating of each semantic pair for their current lifestyle; table 9.10 presents the ideal lifestyle ratings, and table 9.11 presents the differences. Please note that in the tables, participant initials are given, rather than full names.

Table 9.10 Participants' Current Lifestyle Ratings

	Participant								
Pair	A	B	C	D	E	F	G	H	total
Active / Passive	5	4	2	4	4	4	3	4	30
Busy / Idle	5	3	3	4	5	5	3	5	33
Challenging / Unchallenging	4	3	3	4	5	5	2	4	30
Fulfilling / Unfulfilling	5	3	4	3	4	5	3	4	31
Full of Choice / No Choice	5	4	3	2	4	4	2	2	26
Good / Bad	5	4	3	2	5	4	2	3	28
In Company / Alone	5	3	3	5	3	5	5	2	31
Interesting / Boring	5	2	3	3	4	5	3	1	26
Little free time / Lots of free time	5	4	3	4	3	5	3	3	30
Outside home / At home	5	4	4	1	3	2	2	1	22
Satisfying / Disappointing	5	3	4	2	5	5	2	3	29
Strenuous / Sedentary	4	2	4	3	3	2	2	1	21
Strong / Weak	3	3	3	3	5	5	3	4	29
Varied / Monotonous	5	3	3	3	3	4	2	3	26
Grand Total	67	47	48	47	61	66	44	48	392

Of all of the semantic pairs rated, the participants rate their current lives as most busy, with a score of 33 (out of a possible 40), followed by "fulfilling" and "in company", which both have an overall rating of 31.

The participant who gave the highest numerical rating (which simply indicates high scores in the good, active and strong domains, rather than value judgements) is Anna, with a total of 67. The participant with the lowest numerical rating is Grainne.

Table 9.11 Participant Ideal lifestyle ratings									
	Participant								
Pair	A	B	C	D	E	F	G	H	Total
Active / Passive	5	4	4	3	4	5	4	5	34
Busy / Idle	5	4	4	4	4	4	3	4	32
Challenging / Unchallenging	5	4	2	3	5	5	3	5	32
Fulfilling / Unfulfilling	4	4	5	5	5	5	5	5	38
Full of Choice / No Choice	5	4	5	5	5	5	4	5	38
Good / Bad	5	3	4	5	5	5	5	5	37
In Company / Alone	4	3	4	3	3	5	4	2	28
Interesting / Boring	5	4	4	4	5	5	5	5	37
Little free time / Lots of free time	1	4	3	1	3	2	2	3	19
Outside home / At home	5	4	4	2	4	2	3	2	26
Satisfying / Disappointing	5	4	4	5	5	5	5	5	38
Strenuous / Sedentary	4	2	4	3	3	3	3	2	24
Strong / Weak	2	4	5	3	5	5	5	5	34
Varied / Monotonous	5	4	4	4	5	5	4	2	33
Grand Total	61	54	59	54	66	67	62	63	450

For ratings of the ideal lifestyle, the three pairs most highly rated are: satisfying; fulfilling and full of choice, all receiving a rating of 38 out of 40 – only two participants in each case did not give maximum values. It is reasonable to expect that most people would wish for a good, satisfying and fulfilling ideal lifestyle, (good was rated 37). The issue of choice is potentially more interesting to this study. From these ratings, it could be predicted that all participants value choice, and would like a life that is full of choice.

Table 9.12 Comparison of current and ideal lifestyle ratings									
	Participant								
Pair	A	B	C	D	E	F	G	H	total
Active / Passive	0	0	-2	1	0	-1	-1	-1	6
Busy / Idle	0	-1	-1	0	1	1	0	1	5
Challenging / Unchallenging	-1	-1	1	1	0	0	-1	-1	6
Fulfilling / Unfulfilling	1	-1	-1	-2	-1	0	-2	-1	9
Full of Choice / No Choice	0	0	-2	-3	-1	-1	-2	-3	12
Good / Bad	0	1	-1	-3	0	-1	-3	-2	11
In Company / Alone	1	0	-1	2	0	0	1	0	5
Interesting / Boring	0	-2	-1	-1	-1	0	-2	-4	11
Little free time / Lots of free time	4	0	0	3	0	3	1	0	11
Outside home / At home	0	0	0	-1	-1	0	-1	-1	4
Satisfying / Disappointing	0	-1	0	-3	0	0	-3	-2	9
Strenuous / Sedentary	0	0	0	0	0	-1	-1	-1	3
Strong / Weak	1	-1	-2	0	0	0	-2	-1	7
Varied / Monotonous	0	-1	-1	-1	-2	-1	-2	1	9
Grand Total	8	9	13	21	7	9	22	19	

In the ideal lifestyle ratings, the semantic pair with by far the lowest numerical value is little free time / lots of free time. All bar one (Bart) of the participants rated their ideal lifestyle as having lots of free time, or were mid-way between values.

The participant who rated the biggest difference between current and ideal lifestyles was Grainne, followed by Deirdre. As described in the previous chapter, and as will be further discussed in this chapter, both of these participants are living in residential settings, and both describe many difficulties with their current lifestyles. Thus, it is not surprising that this level of difference exists. From the discussion with the participants, it is expected that both of these participants would be dissatisfied with their current lifestyle, and thus would rate it differently to an "ideal".

Participants rated their ideal lifestyles as being "full of choice", and this is the variable that shows greatest difference in ratings, between current and ideal ratings for the participants. Thus, it could be hypothesised that participants both wish for lives full of choice, but also they view a lack of choice in their current lives. The issue of choice, as it is central to this work, will be discussed below, in section 9.3.2. The semantic pairs with the next greatest difference in ratings are interesting/boring, good/bad and lots of free time / little free time.

These ratings in and of themselves only give part of a picture of the participants' lives; but they do help to enrich the story told by each participant. Using the scale, we have discovered certain themes that are important to each participant, and how the perceptions vary.

Methodological issues with the semantic differential scale

The purpose of using the semantic differential scale is not aimed at being a quantitative tool (although it is indeed quantitative), but rather to deepen the understanding of the qualitative data. From this scale, it is possible to identify descriptors of both the current and the ideal lifestyle of the participants.

As a quantitative tool, the reliability of a semantic differential may be questioned. For example, Bart did not give any maximum values at all, in either the current or ideal lifestyle. This could be due to personality, but no comparisons of relative amounts of choice, free time, level of activity etc can sensibly be made. The value of the tool is both as it enables descriptors to be used (as described above) and to compare current and ideal lifestyle ratings of the participants individually.

The meaning of Autonomy and Choice

This section presents the results of interview material, concerned with developing an understanding of the meanings of the concepts of autonomy and choice to the participants. It draws primarily on discussion with the participants in the final interview, but other information collected throughout the data collection process is also used.

Autonomy

Each of the participants gave a definition of autonomy. These are listed below:

Anna

> "freedom to make choices and decisions, the right to take risks and make mistakes"

Bart

> "Autonomy, or independence as they call it, involves being in control of my life while at the same time knowing to accept a certain incontrollability."

Cathal

> "Autonomy is when somebody or something is looking after itself. There is one individual control."

Deirdre

> "Autonomy, means to me [pause], power, something or somebody who has power over you [pause]"
> Someone who has power over you?
> "Yes, that's what I think about it"

Freya

> "Having control over what you do and when you do it, having control of your life really."

Grainne

> "Being in control"

Honour

> "Well autonomy would mean having control of yourself, your life, your circumstances, what you want to do."

Emily initially reported that she did not know what autonomy is, but then went on to describe "independent mindedness", as follows:

> "Independent minded by asserting yourself in a community, it is like being independent. It depends on the situation that I am in, I can challenge myself by being more aware of my assistance, if I wanted to say, do this or try new equipment.
> The independence of going to important things and not having to rely on staff or friends "

A striking theme of the participants' descriptions of autonomy is the importance of control: five of the eight participants specifically describe autonomy in terms of control.

Anna describes autonomy as freedom to choose, thus rather than associating autonomy with control, she associates it with choice, and the ability to make mistakes.

Deirdre does not use the word control, but describes power. Interestingly, she describes autonomy as an external force exerting power over an individual. The other participants relate autonomy to personal control, independence or freedom.

In terms of concepts of autonomy from the literature, this theme of control and choice coincides with the agentic core that Hmel and Pincus (2002) argue is central to the concept within psychology. None of the participants, in their initial description give information about the relationship with others, except for Deirdre, who possibly describes "authority" rather than autonomy.

In addition to asking participants to define autonomy, they were also asked if they feel autonomous in everyday life, and why.

Anna appears to be the participant most assured of her own autonomy. In her self-description, she describes herself as an "independent woman", which,

> "means, being able to take control of my own life and make decisions and mistakes like everybody else and be able to take responsibility for my own actions."

This desire for control and choice appear to be central to her narrative, and mirror her views of autonomy. It could be hypothesised that, for Anna, independence and autonomy are synonymous.

Bart explicitly states that autonomy and independence are synonymous. He reports feeling autonomous in his lifestyle, and describes the sensation of autonomy as "living life to the fullest", whereas a lack of autonomy is "being a doormat". The participant reports not feeling autonomous, "when my lightwriter is out of battery or broken", suggesting that communication is central to the participant's feeling autonomous. He reports that he feels that he has autonomy because he enjoys life.

As previously outlined (see section 6.2), Bart uses the metaphor for himself as "captain of the ship". This metaphor suggests control and autonomy; in response to the question of how he feels autonomous, he responds, "My PAs see me as captain of the ship." The lightwriter or computer are the means whereby he communicates. If these are not working, he uses facial expression and eye movements to communicate, and typically, the PA needs to go through an alphabet, the participant moves his eyes when the appropriate letter is reached, and so on, until the letters, words and intentions are reached. In order to be captain of the ship, it may be important for him to be able to give commands to the crew, thus if technology is not working, this ability is reduced.

Bart does not describe an impact of physical ability or disability on autonomy, nor does he explicitly suggest that autonomy relates to doing, as well as deciding to do (as in Cardol et al's (2002) description of executional and decisional autonomy). However, the description of the situation where he feels that his autonomy is curtailed is when the technology he uses does not enable him to do what he wants to do.

When Cathal was asked if he feels autonomous, his response was,

> "Don't know. I make decisions. Not in relation to physical things".

Autonomy, for Cathal seems to be related to physical ability, it is possibly closely linked to independence in the sense of doing alone. His description of autonomy also echoes this, suggesting self-sufficiency. He describes that, on the one hand, he does make decisions, but that he does not feel autonomous in relation to "physical things", thus, for him, autonomy must be broader than simply deciding (Cardol et al's (2002) decisional autonomy), having choice or control (Autonomy II or III as described by Hmel and Pincus, 2002), but actually enacting this choice (executional autonomy (Cardol et al, 2002)).

Deirdre responds to the question about whether or not she feels autonomous in her daily life as follows:

> "To a degree, but not entirely, the bit of choice, about what I go to and where I go to, and if I go out, if I want to talk to a cat or a bird or something"

This answer links her definition, as given above, about someone having power over another person, and the responses of the other participants, relating to choice. It appears that Deirdre feels that she is most autonomous in being able to choose where she goes within the residential setting. Thus, her description of autonomy is akin to decisional autonomy (Cardol et al, 2002).

Further discussion with Deirdre revealed that, for her, autonomy also links with being able to do what she wants to do, she can make choices, but can't always enact these choices. Unlike Cathal, this does not seem to relate to her own physical ability, but more to her social environment. More autonomy, for her, would mean more control over self-care tasks, and also being allowed to go to places outside the setting alone; she is currently not allowed to leave the setting unattended, due to safety concerns. A question arises whether the restrictions in what she is allowed to do have had an impact on her overall definition of autonomy, relating to power.

> "I don't have a lot, I'd like, we'd like, I'd like some more [autonomy]"
> How could you have some more? What, what would that mean, how would that change things?
> "Well, they might listen to the way that I'd want to do it... Cause it'd make it easier for me, [pause], to if I had it that way... which reminds me of something, there... well I, wanted to go down to the village and there was nobody available to come down with

me, they wouldn't let me go on my own you know. They hadn't anybody to release, to let me go down to the village"
How do you feel about that?
"Ahh, it's a pity, fair enough if they hadn't anybody, what can you do about it, but still it was a pity from my point of view that I couldn't, [pause] because I'd love to go."

She further describes that she would like to just go down to the local village, and look in shop windows, or catch a bus into the city centre. Autonomy and independence have very practical implications, in that needing to have someone with her makes her feel that she is unable to do what she wants to do; she can decide and choose what to do, but feels that she cannot enact these choices because of another person. Her perceived lack of autonomy relates both to the institutional constraints of the setting in which she lives, but she also feels that her autonomy is curtailed as a direct result of having a physical disability.

"[long pause] it's not just the place, it's the disability, it's you know, I notice that if I'm out with people even in shops or anything, if we're going by something I'd love to see something over there, in the other, I can't just, I loath to say it to them, will you bring me over there, I want to see that, because I don't want to be killing them altogether, bringing me around as it is"

It is noteworthy that the aspect of autonomy that Deirdre most values is that both experienced and curtailed; that is, the ability to go where she wants to go and look at what she wants to look at. She both describes feeling autonomous most when she can go out and talk to "a cat or a bird or something"; and least when she is unable to look at what she wants to in shops, or indeed go to the shops when she would like to. The most important aspect of autonomy appears to be related to mobility.

As with Cathal and Deirdre,, Honour suggests that her autonomy is limited, because of her physical disability. When asked why she feels that she doesn't have as much autonomy as she would like, she says:

"Well I think that's probably just down to the disability and there isn't an awful lot I can do about it, umm, "
Autonomy, what does that mean again to you?
"Well, autonomy is control, yes, ok, umm, control over my body, I don't have as much as I would like so that does impact on, activities, so, well, I don't think that anybody who umm, is disabled, particularly if they have lived life as a non disabled person, is ever going to be satisfied."
Ok, ok but, the autonomy that you're talking about relates to autonomy, controlling your own body, as opposed to controlling the situation?
"Yes, and your own activities can't umm, you can't suddenly say, oh, I'm just going to go into town now and you know, I'm going to go into a bookshop, or I'm going to go into BT's so you know, I'm just going to do something, you just can't. That's gone. You have to fit in with, how you've got to organise it, you've got to organise transport,

you've got to organise your PA, you've got to you know, so many got to's that sometimes you say, the hell with it, it's more trouble than it's worth, you know."

In a similar manner to Deirdre, Honour highlights the impact of physical ability on autonomy; that there is no point in making decisions if these cannot be enacted due to physical disability, and that the ability to control one's body is central to actually experiencing autonomy. Thus, Cardol et al's (2002) concept of executional autonomy again seems to be important.

In discussions with Anna, the issue of the amount of "hassle" involved in going out to different places was raised. Anna has a very different perception of the situation, she does not consider the organisation required as hassle, and admits that if it were hassle, she probably would not go out as much. Anna describes the situation, in the first interview, as follows:

How do you decide that you want to go to the cinema or to do something, do you say, "right, I'm going to do it" or...
"Em, firstly it's not that simple. Lots of times it is but most of the time it isn't. Okay, I have at the moment, a number of PAs so I have to manage their times, their rosters and all that kind of thing so and lots of them do part-time hours for me so we have to kind of say what time, if I do this, what time will such and such a person come on, what time will such and such a person come off. It's not so bad If something's on within the city centre because I don't need a driver, you see not all my PAs can drive and and I don't have an open insurance policy because it's too expensive at the moment, so they are named drivers on my Dad's policy. Em, so, and they have to be over 25, so that's very restrictive, so, actually, well one major restriction is in having to plan if I am to go outside the city centre."
So the skill, from your personal point of view for you to organise an active social life involves a lot more planning than for a non-disabled person?
"Absolutely, everything from access to the toilet facility which is a huge issue to em, things like, ok, ok, I only have a certain amount of hours, and that's the way it works. So, if I go out on a Saturday night I may have to pay my PA a little bit of money because she will have to stay out later, she may also have to be a driver, etc etc. There's ways around things that you have to take into consideration plus, em physical access to buildings and, is an issue because, you know, before you go anywhere you have to, you have to check everything out"
So it's a lot of work to plan to go out?
"Yes"
What motivates you to want to go through all that hassle?
"Because, well, because I, well 9 times out of 10 I don't even think about it, I just do it. It's just part of life and it, like, I , thankfully I don't even view it as hassle, it's just something you have to do, and I think that's if I did view it as hassle, I wouldn't have come as far as I have come because you have to where possible surmount these obstacles and you know if you really want to do something."

Anna, unlike Honour, describes herself as a "fighter", so she fights to be able to do what she wants to do; taking control and managing the various aspects of her social and work life could potentially be viewed as reinforcing that identity that she has created, of an independent woman, who is in control and is a successful fighter. The conversation

quoted above goes on, and she describes a role of educating others whenever she experiences obstacles, thus furthering her autonomy and control. This perception of autonomy as making decisions, managing, and the identity of a fighter appears to dramatically change her perception of the organisation required to engage in a social life, when compared to Honour, who is not a fighter, she struggles to "come to terms with" disability, and appears to consider physical disability as a primary obstacle to her being able to do what she wants to do.

Another point of note raised by Honour is the difference between people with acquired disability and those with congenital disability. She states that those who have been non-disabled are unlikely to feel autonomous if they do not have control of their bodies. The participants who did relate autonomy to physical ability are Cathal, Deirdre and Honour, all of whom have acquired disability, Cathal and Honour also having degenerative conditions. While Honour did have a congenital condition, this was corrected surgically, and her experience of physical disability only began to have a significant impact on her life in her 30s.

In terms of how autonomous she feels, Honour says:

> "[pause], ohh, I'd say probably about, 70 percent"

She feels autonomous in that she is able to choose to do the things that she is still able to do, particularly studying and reading, but the lack of physical ability affects her autonomy and then her choices, which lead to a certain amount of dissatisfaction. Below is an extract from the conversation linking choice and autonomy:

> "umm, [pause], my access to the outside world if you like and ahh, leisure activities, social activities, definitely yes. I need to stop being so isolated, I've got to make some friends and you know, stuff like that… I think I had better start being a bit more pro-active."
> Is that as a result of what we've been talking about? [autonomy and choice]
> "Yeah, it's kind of making things clear to me that I think you're doing a bit too much sitting back and umm, just letting life glide by and all, I've been saying to myself, perhaps you'd better just sort of pick up and start ahh, [pause], you know, motivating yourself a little bit more or something, you know."
> How do you feel about those kind of thoughts?
> "[sigh], [pause]…as I said, it could, choices could sort of get terribly philosophical I mean you know, you can't really, nobody can say that they're in control or they have a choice you know."

The discussion of autonomy broadened out with Honour, as in the section quoted above, to include issues such as whether or not she is autonomous if she is not pro-active; if she is not "actively" making decisions and doing things (such as socialising), then, while she does report feeling 70% autonomous, she begins to doubt whether or not this is true. Thus, there appears to be the connection between activity and autonomy; that she can't actually be autonomous unless she is actively engaging in activities. The participant then questions whether or not people in general have choices or control, as quoted above. This will be further discussed below, in relation to choice and satisfaction with lifestyle. Within the literature in psychology, there does not seem to be this link between autonomy and activity in that concepts of autonomy relate to the features of activity (or inactivity), i.e. whether someone is agentic and their relationship to others, rather than whether or not they are actually active. This focus on actual action is most aligned to Cardol et al's (2002) concept of executional autonomy – but it is not the same. Executional autonomy is the ability to enact decisions (Cardol et al, 2002) which is not necessarily related to whether or not they do enact the choices.

Thus, Honour seems to present a different concept of autonomy: that is the need to continually be engaged in occupations, for her to be socially active, in order to be autonomous.

Anna reports that she feels autonomous in her everyday life because she makes the decisions. She feels that she has control over her life, that she has chosen, and indeed fought for it to be the way that it is, and that an important aspect of her identity, as an independent woman, is that she remains autonomous. The autonomy described by Anna is most likely to be the Autonomy II concept: self governance autonomy (Ryan & Deci, 2000; Hmel & Pincus, 2002), where she has positive relationships with others, feels that she has choices, and endorses her actions – also known as reflective autonomy (as described by Koestner and Losier (1996)).

Freya answered the question about whether she feels autonomous in her everyday life as follows:

> "by and large yes, I think so. I mean I'm lucky in that people don't make my decisions for me, I'm very lucky that I have that. I have the capability of making my own decisions, a lot of other people with disabilities don't."

She emphasises the importance of making decisions, and that she has created aspects of her life and lifestyle (such as her volunteering), through conscious decisions. She reports

that self care tasks, in particular, take longer to perform, and reports much frustration with daily living, but that fundamentally, if she makes her own decisions, she is autonomous. This contrasts with the perception of Cathal, Deirdre and Honour, but is more similar to the views of Anna and Bart. Freya also has an acquired, degenerative disability, but she was aware that there was some form of disability in her teens. For Freya, it is the decision-making part of autonomy that, at first, seems most important. However, when choice is discussed (see 9.3.2) the inability to act on these choices is a concern. Thus, again, for Freya, Cardol, DeJong and Ward's (2002) concepts of autonomy both having decisional and executional components seems applicable. When it comes to autonomy, however, it is the decisional aspect (similar to self-governance autonomy as described by Ryan and Deci (2000) and Hmel and Pincus (2002) that is of paramount importance to Freya.

Grainne values her ability to think and make decisions, and that this constitutes autonomy. She responded as follows:

> "Sometimes. At least I can think. I decide to look after the animals and write the stories. I have more autonomy than most of them here."

As with some of the other participants, Grainne highlights the importance of deciding what to do as facilitating her autonomy. She does not make the link between autonomy and physical ability, her views appear to be more similar to Anna and Bart.

The participants in this study present eight different meanings of autonomy, with some common themes. However, it is apparent that, despite the initial straightforward definitions, autonomy means far more than simply having control, choice or making decisions, as is proposed within the psychological literature.

Even though physical ability or disability were not mentioned by some participants, it appears that physical ability or disability does affect autonomy; in the case of Anna, the need to manage and organise supports, assistance, transport etc as a result of disability actually enhances her sense of autonomy, because she feels empowered, in control and managing; the reverse is true for Honour, the organisation involved is not worth the effort for her, so she feels less autonomous, because she feels that she cannot enact her decisions. Bart feels autonomous provided that he can communicate his decisions, so when the supports (assistive technology) break down, this undermines his autonomy. Whether or not this could be classed as "executional autonomy" is not clear: are these

not simply the environmental circumstances in which the participants find themselves, rather than relating to personal competence to perform tasks?

It appears that a sense of autonomy is closely related to the ability to make decisions, and have choices. The participants' definitions of and the meaning of choice will be discussed in the next section.

Choice

As with autonomy, each participant was asked to define choice. The definitions given are as follows:

Anna:

> "Choices means being able to decide between one or two courses of actions or one or two ways of thinking and being able to weigh up the pros and cons of each and being able to make an informed choice based on the information that you have"

Bart

> "It comes with independence and control."

Cathal

> "You do or go for whatever you prefer. It is about expressing a preference and being free to do so."

Deirdre

> "Choice, that you can select, umm, different options"

Emily

> "I have a lot of choice because I can communicate. Choice of eating, choice of clothing, choice of transport."

Freya

> "Being able to live your life in a way that suits you, not somebody else"

Grainne

"Making decisions between things"

Honour

> "Having the umm, ability to choose what you do from day to day, within the social mores of your umm, culture, obviously. It's slightly different to be an Irish person or an Amazonian head hunter, I suppose [laughing]"

Most superficially, the common theme of these descriptions is that choice is the ability to decide between things. The descriptions given, however, also reveal some of the subtleties of what choice means to the participants, including issues of independence, expressing a preference, freedom, lifestyle choice, and linked by Honour with culture. It also appears that choices can relate to doing, or to occupational performance.

There was detailed discussion of the extent to which participants feel that they have choice in their lives, and this was related to autonomy and also to satisfaction with life.

Bart reports not having enough choice in his life, this, he hopes, will be improved when he moves out of home, into his new accommodation.

In relation to choice, in general, Cathal states:

> "To be honest, I never think about it. Although there are many times when I would choose to do more, if I were able, which would suggest that I don't have enough choice...There is an awful lot in my life, and I might have said this to you the last time, whenever people say to do a, b, c or d, the first question I have to ask is, "is it accessible?" And if it's not, then I can't do it. I even had an occasion recently where they were thinking of going somewhere from the college and I asked was it accessible, they checked it out, found out it wasn't accessible so I said, I don't mind if you people want to go ahead, but they just wouldn't do it because I couldn't. it's very nice of them but, I shouldn't have to ask. Yeah, I find people in general, no matter how nice they are, if they are not disabled they don't tend to realise just how much it means to ask whether it is accessible. Now, I have been guilty of that myself when I was able-bodied, so I am not criticising anybody, it's just a part of your life. If you don't have to confront that situation, quite often you don't have to think about it. You find there, when you get there, people that work there would go out of their way to help, but it shouldn't be that way"
> Do you ever feel that you want to do anything about accessibility?
> "Yes, frequently."
> So, what?
> "I don't know. In some of my belligerent moments I would like to sit outside of somewhere to publicise the fact that I can't get in, even if I don't want to, the fact that I can't. I have been seriously tempted to take action, but I haven't, but others may not agree with that."

Cathal, as quoted above, finds that his choice is limited by his own physical ability, and by the accessibility of places that he may choose to visit. A feature of the participant's account throughout is that he reports not thinking about his own level of choice, autonomy or control. These concepts are somewhat alien to him. When asked directly about whether he feels he has choice, immediately the conversation turns to what he would do if he were physically able, and then on to the difficulties with the built environment. It could be argued that, for this participant, choices are made with a non-disabled identity in mind, he chooses to do something (or thinks about doing something), then realises that he is not physically able to do it, or that a place is inaccessible, then feels that he has no choice, because he could not do what he wants to do.

Deirdre reports that it "would be nice to have more choice". She feels constrained in the choices that she can make by the institutional regulations of the residential setting and her physical impairment, as described above in her views of autonomy. She specifically reports that she would like to have the choice to go on the bus, and to leave the setting to go to shops.

As described in the previous chapter, Deirdre also feels that she does not have enough choice in her daily routine activities, or more particularly, in how or whether she is assisted with personal self-care tasks.

This contrasts with Cathal, who also lives in a residential setting, but reports that choice to go to places is more constrained by the external physical environment, whether or not where he wants to go is accessible. Deirdre seems to be one step behind in the decision-making process, she can't or doesn't have the choice to go in the first place, whereas Cathal can choose to go somewhere, but can't or doesn't enact that choice, because of the environment.

Of the other participants who live in residential settings, Emily describes the importance of choice to her. While she primarily speaks of the choices around self-care activities, such as choosing what to eat and what to wear, she also describes, in her diary information, that she does choose to go to different places. She reports that she has enough choice, primarily because she can communicate these choices.

Grainne, like Deirdre, would like more choice in her life. She, in particular would like the choice to be away from people, or the choice of who she meets and spends time with. Also, Grainne feels that her choices are constrained by the social environment in the residential setting. She perceives that because staff feel that she is able to communicate, she is less "needy", therefore opportunities to go on group outings are not offered to her. While both Deirdre and Grainne feel that the residential setting constrains their choice, the nature of that constraint are significantly different, as are the mechanisms that they use to manage the situation in which they find themselves (see chapter 8).

Freya was asked if she has enough choice in her life, and reports:

> "Umm, [pause], mmm, that's an interesting one! Yeah, choice in how I live my life, the decisions I make in my life, yes [enough choice]. My ability to, do the things, follow up on the decisions sometimes that I would make or would have like to have made, ahh, probably no [not enough choice].."
> Ok, so it really depends on what
> "Yeah, on what the circumstances are, yeah at the particular time."
> And what would make it possible for you to have more choice? Was that going back to what we were speaking about earlier?.
> "Yeah, things like, personal assistance, umm, better transport links would be great, you know, to be able to kind of go out and do the things you want to do, do more quickly, do it easier."

Freya cannot clearly state whether or not she feels that she has enough choice, on the one hand she does make the decisions, so therefore has choices, but on the other, she finds her ability to follow through with those choices is limited, due to accessibility. The first part of her answer, that she does make decisions about her life and lifestyle, mirrors the discussion with her about autonomy, and she reports that she does feel autonomous. As already stated, fundamentally, she feels that she is autonomous, because she can make decisions. The situation is less clear for choice, she does make choices, but her ability to "follow up" on those choices is undermined by access, transport and issues of assistance, thus making the choice null and void for her. Whereas she fundamentally feels that she is autonomous, she does not feel that she has enough choice.

The limits on choice expressed by Freya echo aspects of those of both Cathal and Deirdre. Like Cathal, access in the outside world limits her choice, but like Deirdre, in that she does not feel that she has choice in assistance (she has inadequate personal assistance).

Unlike Anna, for example, Freya reports not having enough personal assistance or access to transport. It could be argued that managing the personal assistance and transport enables Anna both to make the choices and to enact them.

Some of Honour's views on choice were presented above, as these were linked to autonomy, but also they relate to her life satisfaction, presented in the next sub-section. It is interesting that she relates choices to culture, and social norms. This was not raised by any other participants, but may be worth considering. Anna, Bart and, to a lesser extent, Freya, feel that they have choices and make decisions, and do not specifically relate these to disability (but they do relate them to the supports used). These are the three participants with congenital disability (cerebral palsy), so all of their lives, they have been disabled people, potentially within a disability culture. The other participants all acquired disability at some point in their lives. Thus, as articulated by Honour, if a person has been non-disabled, it is difficult for them to be happy with the choices and autonomy that are available to a person with a significant disability.

Honour feels that her current lifestyle has been greatly affected by her not having the choices that she would like to make. As described in chapter 6, Honour began a college course, but had to withdraw due to ill-health. She had intended to return in the October prior to data collection, but was told by her doctor and the college doctor that she was unfit to return. While Honour accepts that her health is a problem, she feels that she did not make the choice.

None of the participants reported that they have too much choice in their lives, Those who report not having enough choice report that their choice is curtailed in some way, either because of their own disability or because of the accessibility or institutional organisation of the environment. Iyengar and Lepper (1999; 2000) question the value of choice, arguing that choices are culturally important in Western culture, and are over-valued in psychology. They also argue that too much choice can be demotivating. As none of the participants in this study report too much choice, initially, it seems that the work of Iyengar and Lepper (2000) is less applicable. However, as raised by Ryan and Deci (2006), it is the meaningfulness of choice, rather than the amount of choice that is important in supporting intrinsic motivation and fulfilment of autonomy needs. Some of the accounts of Deirdre, Cathal and Freya suggest that the choices available are not meaningful, because they cannot be acted upon. Could this be demotivating and stressful, as is claimed by Iyengar and Lepper (2000) for too much choice?

Within disability activist and independent living literature, choice is seen as a "right" for disabled people (e.g. Zola, 1983; Oliver 1990). Anna is the only participant who explicitly describes making choices as a right.

Satisfaction with present lifestyle

In addition to the semantic differential scale, participants were asked if they are satisfied with their present lifestyle. Some of the participants, such as Anna, Deirdre, Emily and Grainne are definite about their answers, but others are not so clear. Anna and Emily are happy with their present lifestyles; Deirdre and Grainne are not.

During the course of the data collection, Cathal was asked twice whether he is happy with his present lifestyle, and he gives two quite different answers:

> Are you happy with your present lifestyle?
> "In the sense that, in the sense that it's what I am stuck with, yes."
> What you are stuck with? So you have no control in changing?
> "No [laugh]"
> When you say what you are stuck with, is that to say that you can't change your lifestyle?
> "I don't think there's too much, I don't think that there are too many options, because of my physical disability, I don't think there are too many options. This is my life".

> Are you happy with your present lifestyle?
> "Em, I don't think about it much, but if I was to sit and think about it, I would say no, purely because of the so many things that I used to be able to do as a normal part of living that I can't even think about now... People who have grown up with, for arguments sake, with legs that don't work, or no legs, em, have never known any different. It still doesn't make life easy, but that's the way they have always been... I don't think that being able bodied is something that I should necessarily aspire to, but it would be good if we could have a world where you don't need to think "I can't do that" because of disability."

In both cases, he reports the impact of his physical disability, particularly that it is acquired. In the first answer, he reports being generally satisfied, because he has made the best of the situation in which he finds himself, but there is a very real sense of being "stuck with" his life, and a lack of choice or control. In the second answer, the strategy found throughout the information from Cathal is again revealed: not thinking about issues of autonomy, choice or control, simply because the situation in which he now finds himself is so different to his previous life. Having the comparison between life before disability

and life after disability results in dissatisfaction – if he only considers his current situation (as in the first answer), he can feel somewhat satisfied.

Cathal's dissatisfaction appears to relate to the impact of physical disability on what he can do. There appears to be an emphasis in his life on doing, and being productive, which has been interrupted, and so affects his satisfaction with his life.

Cathal has made an active choice to go to do a college course four days per week. During the interviews, there was discussion of what "should" and what can be done. The participant spoke about his concerns about being in a residential setting that he could "go mad" with nothing to do, and in the same environment, because of a lack of something to do. He describes the role of his going to college to be primarily to fill the large gaps in his days, and that the day he doesn't go to college, he finds the time hard to fill.

Do you think, in general that it is important for people to do something with their days?

> "It's important to do whatever you are capable of doing. Em, without, obviously, without getting too tired, because it's, a condition such as MS, there is fatigue with it, a lot of fatigue, and most of that fatigue is unpredictable, so it's important to be able to do what you can do when you are able."

He is unsure of whether, in general, he finds time hard to fill, except for on the day when he is not in college, when time is hard to fill.

Cathal describes frustration at not being able to do what he wants to do, "I tend to feel at a loss, because I used to do so much". He perceives the need to do things alone, and that the need for assistance is a frustration in itself. The activities that he reports as enjoying most are those with which he does not need assistance.

Cathal appears to view his lifestyle as being significantly constrained by his physical disability, and that his views, or expectations, of what his lifestyle can be are greatly influenced by physical ability. He appears to be almost resigned to accepting things the way they are, or settling for the present status quo.

Honour reports that she is fundamentally dissatisfied with her present lifestyle. She would like to go to college, and as previously described, she feels that the decision about

whether or not she could go was made by medical doctors, and so was not a choice for her. She also describes a lack of social or leisure outlets, and the feeling of being trapped in her own home, because she can't safely get out and move around. Also, in her home, she feels unsafe and is in constant fear of falling. She feels that the assistance is not ideal, and she would prefer a more professional form of personal assistance.

Honour is, however, hopeful that her life will change for the better, and that new powered mobility will make a difference, and that she will be able to return to college, to finish her degree and begin post-graduate research. She also highlights some of the positives of her life, as follows:

> "Ahh, I would decide, there would be things I want to do, I'd want to go to the theatre, I'd want to do this that or the other, and it's just impossible, and umm, so frustration can come in. Boredom, no, I don't, I find it very, very hard to even understand the concept, because umm, I, I know what it's like when everything shuts down, when you literally can't concentrate, when you can't think, so that for me every moment that everything is up and working mentally is just absolutely terrific, and really, that overcomes anything, other things can be an irritant, they can be frustrating, they can be annoying, but once the old mind is ticking over, I don't mind. If nothing else you can actually sit and think, lions think and go over things you know, so, but that is a big bonus for me, I suppose I'm very fortunate."

Deirdre reports not being happy with her lifestyle:

> Are you happy with your present lifestyle?
> "No, I'm not"
> Why?
> "[pause], cause sometimes I feel that life is passing me by, and that a big section of it has been taken away from me"
> Do you feel often, do you often feel like you're not happy?
> "[pause], umm, yep, I do, quite often, sometimes part time, but that's normal under the circumstances I think"
> Under the circumstances of living here? Or of?
> "Of yeah, being umm, paralysed"
> So the difficulties with your lifestyle, they stem from your physical disability, or from the environment that you are in or a mixture of both?
> "Mostly the disability thing"

As with Cathal, Deirdre reports not being satisfied with her life, mostly due to disability. When asked what she would do to change her lifestyle, she says that she would like:

> "Something like this with a little more freedom... being busy, but I need more space. I need space just to get away."

She wants to be in the company of people, and busy, but equally wants to be able to "just get away".

Grainne became somewhat upset when the issue of whether she is satisfied with her present lifestyle was raised, so the amount of probing was limited. She simply responded "no" in a very quiet voice, when asked if she is satisfied. Further probing was not done, considering that she had already described several issues with her current lifestyle, including the accommodation and the people around her.

Emily reports that she is happy with her lifestyle:

> "Yes, I have my independence, choices, quality of life. I am very lucky, I am not a particular disabled I am not in the I don't go out there to show people I let them see me on my terms."

Emily goes on to describe how she is happy because she is living in a setting where she feels safe and supported, comparing it to living in the community.

When it comes to his lifestyle, Bart points out that at the time of data collection, he was at a hiatus in his life, having just finished college and preparing to go to work; having just moved home from other accommodation and preparing to move into his own flat. For these reasons, he suggests that his lifestyle is not as it may normally be. He says that because he is at the transition, he sometimes finds time hard to fill. He reports that previously, he felt that he had too much to do.

> Bart reports that he is happy with his lifestyle,
> "although sometimes I feel apathetic. I am happy with it all in all"

Freya initially responded to the question about whether she is satisfied with her life as follows:

> "Yes, I think so, yes, yeah [pause], that's not to say I'm not on the lookout now for improvements to same, but"
> What kind of improvements would you make if you could?
> "Umm [pause], I suppose it's going to make a big difference when we move to a house that's more disability friendly, that is going to make a big difference, that is, that will be a big choice in my life, umm. And I suppose it all just comes back down to better access to everything, be it buildings, be it transport, be it whatever."
> If you wanted to, could you make changes?
> "I suppose I probably could, but, I suppose the things that I have in my life that could maybe be given up to be replaced by something else, are things that are extremely important, they're probably the most important parts of my life... I love, I could stop

volunteering, that would give me more time to do other things but, that to me wouldn't be a life, that would be an existence."

As previously described, Freya fundamentally feels that she is autonomous, although her choices are limited, by access and physical disability. However, she has created a life that she is happy with, because she can and does do things that are important to her

In the next chapter, there will be discussion of the literature in relation to happiness, satisfaction with life, autonomy and information from within the literature.

Have you chosen your present lifestyle?

Each participant was directly asked if they have chosen their present lifestyle, or if it just happened this way. Honour gives an interesting response to this question:

Do you think that you've chosen your present lifestyle, or has it just happened or?

"[pause], [sigh], [quietly] it's very hard to be ahh, so umm, deterministic, umm, has it happened, have I chosen it? No, I haven't chosen it certainly, whether choices I have made in my life have now brought about, ahh, my life circumstances, that is something that is rather difficult to get rather a bit philosophical on you if you're not careful [laughing], so, but I suppose that for your purposes, probably no, I haven't actually chosen."
So in terms of the way that you plan your days, the kind of things that you do, for this year anyway, weren't
"Weren't what I would have chosen, no"
Just to take that a step further, next year, if we were to do this interview again next year, and all going well you're in college, do you think you'll answer the last two questions differently?
"I think so...I hope to. I hope to very much... I do hope to be more satisfied with my lifestyle, except of course that I'll be a year older, that isn't going to satisfy me one bit at all [laughing]."
But in terms of, if you're in college, you're studying, doing what you want to do, and I asked you do you think that you've chosen your present lifestyle, how do you think you would respond in that case?
"I would say yes, that I had chosen it."

Honour considered the question thoroughly, and, primarily because several choices were made for her, particularly the choice not to go back to college, she feels that she has not chosen her present lifestyle, and that lack of choice has led to significant dissatisfaction. However, she reports that she is making choices, she would choose her lifestyle, but she was told that she could not do what she wants to do, as a result of her physical disability and medical advice. Later on in the conversation (and, indeed informally after the

interviews), Honour highlights the difference between her and other potential participants, stating that, for her, while she is physically disabled, the biggest issues are secondary health problems, such as problems with her immune system and slow healing of wounds, as well as pain and fatigue.

When asked, "Do you think that you have chosen your present lifestyle, or has it just happened this way?", Anna's response is striking and strong:

> "Of course I did, I fought for it!"

The manner in which she responded to this question was emphatic, there was almost anger in her voice that such a question could be asked. Other participants were also quick with their responses.

Bart's response is as follows:

> Do you think that you have chosen your present lifestyle, or has it just "happened this way"?
> "I chose it, although sometimes I feel apathetic."

When discussing changes in his lifestyle, Bart states that he hopes that the change will occur when he moves out. He describes that the change that he most wants is "to get out". This desire to "get out" not only relates to his present accommodation, but to a more general sense.

> "Sometimes I get claustrophobic of being indoors."

Cathal responds as follows:

> "It chose me! It chose me, yeah."
> Did you choose to come and live here?
> "I think I had a part in that decision, but it really was made for me."
> What about in other aspects of your lifestyle. Did you choose to go to college?
> "I was asked if I would be interested and I said definitely."
> What about other things, like football matches and DVDs? Do you choose things now?
> "Em, well, there is a choice that I am making in college. Now, I have to put a portfolio together, which is fair enough, but for years I have been interested in photography, and I used to take a lot of pictures, pictures rather than snaps. I wouldn't pretend that it was good, but it was more like photography. I had an interest in that, and I had the opportunity in the college to put myself forward for that, to do photography and with training, teaching and with a camera, and computers, I could do a lot with that. Not to be famous as a photographer or anything, purely to say, right, I like this, I have done this well, and this is good, even if nobody else thinks it's good if I think it's good."

The difference between the report of Anna and Cathal is striking: one participant describing a very active fight for the lifestyle that she leads; the other being a passive recipient of a lifestyle. Even when probed about choice, as quoted above, Cathal suggests that he simply acquiesced to proposals of others, to live where he does and to go to college; the only active decision appears to be to pursue his hobby of photography.

One possible explanation for the difference between the accounts of Anna and Cathal is that Cathal, in his answer, is suggesting that the lifestyle that he has is as a result of his physical disability; he did not choose to have his disability, he did not have it all of his life, and so his lifestyle has been so curtailed by physical disability that he has been unable to be an active player in his own life. For Anna, being disabled is part of who she is, she has chosen her path in life as a disabled person.

Cathal reports frequently not doing things that he would like to, partly due to a fear of inaccessibility in the environments he wishes to access, partly because he has no transport or anyone to go with him, but also partly due to his personality.

> "It happens to me all the time that I don't do things that I wanted to do. I don't think that's disability, I think that's me. I sort of think I must do so and so, and then forget about it."

The role of personality is certainly of interest, and it would be interesting to further investigate the influence of personality factors on a person's perception of their choice, and their perception of life determination.

Deirdre, in response to whether or not she has chosen her lifestyle reports,

> "It just happened"

As with Cathal, Deirdre reports that her lifestyle has been so greatly influenced by disability, that her ability to choose or shape her lifestyle has been removed from her.

Emily, as with Anna, became slightly agitated with the question. Her response is:

> "I chose this. Remember, I told you"

As with Anna, Emily has always been disabled, so the issue of disability does not enter the discussion in relation to lifestyle choice. She felt that the question was inappropriate, because during the first interview, she described how she chose to move into the residential setting following the death of her mother. She argues that residential settings have a lot to offer disabled people, like herself: she reports having a good mix of the independence that she wants and the assistance that she requires. It appears that she feels the need to justify her choice for living in a residential setting, and comments on the community as follows:

> "It's not all a bed of roses in the community. Some disabled people are caught in the most difficult situations. When you hear their problems and their situations you say I would have lost my mind if that was me."

She appears to be the only participant in a residential setting who is happy with her lifestyle, and feels that she has fully chosen her lifestyle.

Freya reports her situation as follows:

> Do you think that you have chosen your present lifestyle or has it just happened this way?
> "Yeah, I think a lot of it has just happened, yeah, yeah."
> How so?
> "Umm, [pause], because [pause], a lot of the options that would have been open to me where, had I not got [condition], are probably not open to me, because of that, umm, as I say, things like getting extremely tired and umm, everything else that just takes so much longer, we're back to that again, umm".

As with Cathal and Deirdre,, Freya describes the effect of her medical condition on her lifestyle; her choices are being reduced as a result of her physical disability, but without disability, she would have made different choices. However, unlike cathal and Deirdre, she does report making clear decisions about the way that she lives her life, and feels that she could change her life if she so wished.

Grainne appears to give a balanced answer:

> Do you think that you have chosen your present lifestyle, or has it just "happened this way"?
> "It happened, but I have made choices. I chose to live here, but it isn't as they promised. ...I wanted to live in the bungalows. If they provided the bungalows, then it would be better."

Grainne also has an acquired, degenerative condition, and she reports that while she doesn't think that she made an active choice of her lifestyle, she has made choices. The

difficulty for Grainne, as described in chapters 6 and 8, is that what she thought she would have, in terms of accommodation, did not materialise, and thus she finds herself in a social and physical environment with which she is far from satisfied. It is interesting that she reports making choices in her life, yet the difference in her semantic differential ratings between current and ideal lifestyle are the greatest of the participants.

Participants' concluding remarks

This section highlights some of the comments made by the participants following data collection, and once they had reviewed the data about themselves. It also presents an up-date on the participants, several years after initial data collection took place.

Anna

Anna still lives in her apartment, with personal assistance. In relation to the description of her in this report, she states,

> "Thanks so much for your kind words, it means a lot to hear such positive feedback from another disabled woman and fellow activist.
> I felt that the description of me is accurate and there is nothing I would change except perhaps to add:
> IL [Independent Living] is a choice and a right. Rights bring responsibility and I feel thatdisabled people need to be given the skills and the opportunity to make decisions and take gradual control over their own lives. Many disabled people feel that they cannot make mistakes, but we often learn valuable lessons from our mistakes. I feel that this may be part of the reason why many disabled people are afraid to take risks. In conclusion, IL was my dream. I achieved my dream and I will do everything I can to help others who wish to experience IL to do so.
> I hope this make sense, Bethan. Good luck as you tie up the loose ends to the research. Thanks so much for giving me the opportunity to revisit and add to my contribution.

Bart

Bart felt that the description of him was accurate, and had no further comments to add. He has moved into his flat; he began work with a disability organisation, but has since changed job.

Cathal

Cathal moved out of the residential setting, when the option of supported living became open to him. This move seems to have been successful, but it is not exactly clear what form this accommodation takes, but he now does have his own room.

Deirdre

Deirdre still lives in the residential setting. A number of places in supported independent living were made available, but she decided not to apply for these. Her hope remains that she will regain enough physical ability to return to her own home.

She is happy with the presentation of her information, and says that, while there are still difficulties in the residential setting, there have been changes in both residents and staff, and that the situation has improved for her somewhat. She still focuses on feeding the cats and watching birds. She still does not leave the residential setting unless she is accompanied by another person.

Emily

Emily did not actually review the information about her, and it is not clear why this was the case. She, is, however living in the same residential setting, and, overall, reports being happy with her living arrangements.

Freya

Freya moved, with her mother to the purpose-built bungalow. She writes,

> Yep, there are STILL a few problems in the house. We FINALLY got a shower seat. A mere TWO YEARS after we moved in! Also waited the same length of time for a suitable raised toilet seat. The one we were given as a 'Stop-gap' measure didn't have arms, and the grab-rails had been fitted beside the loo were too far apart to be useful. We're STILL waiting for Environmental Controls. Windows aren't reachable from a wheelchair. The front and back doors are REALLY hard to close and lock from a wheelchair. I have to use the Invacare Storm, and as it's quite long, I'm almost falling out of my chair every time I try to close and lock the door. They are the type of locks that only lock with a key. A good idea because you can't accidently lock yourself out, but it makes the whole lack of Environmental Controls... To be fair, our OT has made a report to the County Council requesting that the work be done. We await developments!!!

She was satisfied with the account of her life in this report, and continues to work on a sessional basis, and do voluntary work. Her mother has been unwell, and so she has required further assistance with self-care and household tasks.

Grainne

Grainne chose not to review her information in this report. She still lives in the same residential setting, but has experienced deterioration in her physical ability over the years since data collection. It is questioned whether or not the research process was difficult emotionally for her, but she reports that she simply did not feel that she wanted to read the review.

Honour

Honour was unwell and was unable to review her information in this report. So far, no purpose-built apartment has been provided for her, and so continues to live in a very small cottage which is not suited to her needs. She has spent significant periods of time in hospital since the data collection process, including two injuries following falls in her home. She also contracted a hospital-acquired infection. She has not returned to college.

Contribution of results to the emerging choice and autonomy framework

The results in this chapter provide further information particularly on the first and second strands: what autonomy is and whether it is a need, goal or value for participants. A summary of findings from this section is presented here, but discussion is contained in the next chapter.

Strand 1: The meaning of autonomy

Autonomy clearly means different things to the participants, but central to their description is the need to make decisions and have control. All of the participants describe positively inter-personal enactments of autonomy in their daily lives, that is examples of the exercise of autonomy that depend on an element of assistance by others. This is due to physical disability and the consequent need for assistance.

Participants were divided as to whether autonomy comprises also the executional aspects proposed by Cardol et al (2002). But for all of them, disability, access issues and the availability and nature of support can affect their autonomy.

Strand 2: Whether or not autonomy is a need, goal or value

Interpretation of results in this chapter can enable us to hypothesise that autonomy is directly related to choice and control, but that the experiences of autonomy vary greatly. The same situation (e.g. organising social activities) can either promote a sense of autonomy (as for Anna) or highlight disability and negate autonomy (as for Honour); using assistance can be enabling (as for Anna and Deirdre), or highlight disability (as for Cathal).

Thus, situations must be interpreted through some internal filter, and these interpretations can be positive or negative in their implications for autonomy. Thus a positive sense of and desire for autonomy enable a person to take risks and engage further with the environment, thus promoting in a self-fulfilling way the sense of autonomy, as in the case of self-efficacy (Bandura, 1982). Negative interpretations that emphasize loss of autonomy and dependence and tend to

create frustration and lead to passivity are equally possible. Both positive and negative interpretations, nevertheless point to the existence of a need for autonomy and its important role in motivation and the individual's inner life. However, there appear to be definite differences in the value placed on autonomy. This will be discussed further in the next chapter.

The experience of choice seems to be that choices need to be meaningful, which means that people can act upon their choices. When choices are not perceived to be actionable, this seems to lead to a certain sense of frustration. Previous life history and identity (e.g. disability identity) seem to influence choice-making, and perceptions of reasons why choices can or cannot be enacted.

Conclusion

This chapter concludes the presentation of results, focusing on the participants ratings and perceptions of their lifestyles, and the meanings of choice and autonomy to them.

The next chapter will discuss the key results, and relate them to aspects of the literature. It will also present the Choice and Autonomy Framework that has emerged from this work.

11. Discussion

Introduction

This research sought to explore the daily life experience of eight adults with significant physical disability, with a particular focus on their experience and perceptions of autonomy and choice in everyday life. This chapter will discuss some of the key findings of the research, in relation to the literature and also the implications that the findings may have for academic debate, service provision and occupational therapy practice in the future.

The results of the exploration have been presented in chapters 6 – 9, beginning with detailed descriptions of the participants (in chapters 6 and 7) and followed by interpretative results about their experiences and the meanings of autonomy and choice.

The exploration has raised a number of key questions, including:

- What do autonomy and choice actually mean to the participants? How can the findings of this study be explained in terms of a choice and autonomy framework?
- What can the lives and lifestyles of the participants tell us about them, and how do they compare with participants in other studies?
- Some of the participants have reported that they are dissatisfied with their current lifestyle, and that they feel that they would like to be more autonomous, and have more choice. How do participants in such circumstances manage the difference between what they would like, and what they have, in terms of autonomy and choice?
- How does the overall sense of happiness and satisfaction with life compare with other studies, and is there support for the common perception that successful living is autonomous in nature?

These questions are addressed in this discussion. In addition, the emergent choice and autonomy framework is presented. Reflections on the methodology and the influence of the researcher are given. This exploration presents some key questions for both

academic investigation and service provision; these and recommendations for future action are also presented.

This research has been influenced by relativism; both in epistemology and ontology. Exploration of concepts such as choice and autonomy, within the ontology of relativism, necessarily results in a variety of multi-faceted insights, rather than a positivist "answer" or "explanation" of the phenomena. In light of the complexity of the issues, and of the ontology, this section cannot provide clear answers; however, it can add to current discourse and pose questions for further investigation.

Reflexive Elements of the work

From an axiological point of view, I entered this research with certain assumptions and values; reflexive strategies and indeed reflection on the accounts of the participants helped me first to realise these, and second to question my values.

I had unwittingly assumed that autonomy and choice are essential to well-being, and I thought, at the beginning of this work, that the work would look at the differences in the amount of choice and autonomy people have in different environments, listing the amount of choice, and then maybe suggesting that all people should have more choice and autonomy. I quickly realised that this was an over-simplistic formulation, but I don't think that I expected to be taken where I have been taken in this work. At the beginning of the work, I did not expect to find myself involved in a thorny discussion of what the various concepts, autonomy, choice, independence and control actually mean. When I set out I naively thought that I would be studying and relating the "amounts" of autonomy, choice etc experienced. The complexity and diversity of the participants' experience and understanding of these concepts forced me to abandon my simplistic notions.

I have also reflected on my potential influence on the research; both as a disabled person, as someone who was known to be involved in the disability movement, and as an occupational therapist. Several of the participants noted that I had a guide dog, Nikki. Some asked about the technology that I was using. So, it is clear that participants noted my disability. While some inferences can be made, the true influence of the researcher is not, and can never be, fully known. However, as this research is epistemologically situated in relativism, "knowing" or delineating my influence as the researcher is not a key

issue; what is crucial is the recognition that the information presented are joint constructions of both the researcher and the participants. Reflexive and other strategies (see chapter 5) were used throughout to enable me to recognise and take account of some of the ways I personally may have influenced the research process.

My thinking has changed as a result of this work, particularly as a result of listening carefully to the participants themselves and attending to the valuable insights that each individual participant provided. This evolution of thinking should be apparent within the following discussion.

Methodological issues in this work

This research has not taken the most conventional approach to investigating the autonomy and choice of people with physical disabilities. Alternative, more conventional methodologies were considered. However, the unique focus of the approach adopted here was to explore complex psychological issues against the background of the participants' mundane, practical, daily lived experience and this has produced information and perspectives that are difficult to find within the research literatures of disability studies, occupational therapy, rehabilitation and psychology.

A more conventional quantitative approach to the issues studied in this research could have been taken, for example administering the ACL or GCOS, and possibly some quality of life tool, to larger groups of disabled people living either independently or in residential settings and comparing the results. That would have provided some evidence to support or negate the assumed link between autonomy and quality of life, and provided evidence on how autonomous individuals feel. However, such an approach would not have been informative on what it is like to feel autonomous, or the different ways that autonomy relates to control, power and choice for differently situated disabled people. It would not have provided specific insights into how disability impacts choice, and how people in restrictive circumstances use a variety of strategies to manage their choice and autonomy.

Alternatively, the topics of this research could have been approached by way of a fully-fledged phenomenological study, investigating the true meaning of autonomy and choice to the individuals. While this would have been a valid approach, it would have been limited in comparison to the approach actually taken in regard to learning about the real,

daily occupational performance of the participants and about how they live their lives and perceive their day to day experience in terms of autonomy and choice.

The current work contributes to the occupational therapy literature by exploring occupational performance and occupational patterning alongside autonomy and choice in a fundamentally practical as well as theoretical way. The focus on occupational performance is certainly congruent with occupational therapy philosophy, but the detail about daily life gleaned from this approach is relevant to many other disciplines.

Within occupational therapy, such as the work of Kielhofner (Kielhofner, 2005; 2002; 2008; Kielhofner & Henry, 1988), emphasis has been placed on the use of narrative, including a search for metaphor in the accounts of clients. Kielhofner (2005) argues that this approach could help to promote disability studies and a real understanding of disability within occupational therapy. The use of metaphor was attempted in this work, but it proved of little value in the presentation of results.

Metaphor was found for each of the participants, and frequently this included multiple metaphors, both of their lives and of their situation. (Examples include Anna's "independent woman"; "fighter", "rebel", "advocate"; Bart's "captain of the ship" or "master; and so on). Emily and Anna both described themselves as "advocates"; Grainne, Freya and Anna described themselves as "fighters" but these metaphors mean very different things to each participant. While the metaphor may help to understand the personality or character of the individual, they seemed over-simplistic, and not a useful tool for analysing complex data.

Use of metaphor also seems to be related to education and experience. For example, the concept of "advocate" is one that is popular in disability activism, but maybe less understood in other circumstances. Thus the use of specific metaphorical concepts may give insight into education and cultural experiences, rather than into the phenomena under question. It is suggested that such use of metaphor could oversimplify complex concepts, and as a primary analysis tool, may need to be questioned. While the metaphor is presented in the work, it became evident early in the analysis that it is not as robust as was hoped, thus does not form a central part in the analysis of results.

As with any qualitative research, the methodology employed resulted in very large volumes of disparate information. This included field notes, descriptions of observations of settings and interactions, reflexive work, questions and thoughts as they arose for the researcher, as well as the actual "data" of transcripts, diaries and semantic differential scales. As Finlay and Ballinger (2008) describe, all qualitative researchers need to value, to a greater or lesser extent, the "complex, rich and messy findings of qualitative research" (p. 7). The complex and messy findings of this work enabled more creative analysis. One thread would lead to investigation of themes in the many different places, which enabled further links, and changed previous thoughts along the process. A drawback of such findings is the difficulty in description of the methods to capture this experience, and also the inability to present all of the findings and form a coherent whole. Some findings that were initially of interest, such as the use of language when describing disability compared to when describing life achievements, were removed as they were not key concerns of this work.

While a framework has been proposed within this work, it is done with great caution. This work is an exploratory study, and its aim is not to provide a neat, summary of results that can all be explained in one simplistic formula. Such a formula ignores the complexity of qualitative findings, and could be premature. There are many formulations of concepts such as autonomy and choice within the literature, so any additional framework should be seen as a starting-point for future work, rather than an end-product of this work. It is possible that a different methodology could have better enabled a formation of a framework, had this been the original intent.

A decision was made not to include some of the original participants in this work, due to incomplete information – such as incomplete diary entries. Three of the participants passed away before being able to member-check the information, so that they did not have the opportunity to comment on or correct the reconstruction of their information. While these data were excluded from the final analysis, they undoubtedly influenced the researcher. Processes in this research included many detailed discussions with disabled people, and with service providers prior to data collection. All of this additional information, be it the informal discussions or the information from incomplete participants is “lost” to this report. In future, methods to incorporate such information, that has influenced the work, could be considered.

The ethics of research with disabled people impose certain limits on the ability to explore complex phenomena, when this necessarily requires detailed questioning and potentially stressful and fatiguing, lengthy time periods with individuals.

As described in the methodology section, there appeared to be significant interest in the research initially, especially from those living in the community. However, the nature and length of data collection was off-putting to over half of those who showed initial interest. What does this say? It is interesting that far more people living in the community said that they would not participate right from the outset. In the various residential settings, many of the residents said that they were interested, but when the researcher returned, they had forgotten, not read the information, or said that they were not available on that particular day. By contrast, none of the participants in the community forgot an appointment. .

The methodology certainly has limitations, but the use of an integrated approach to data collection (DePoy & Gitlin, 2005) has certainly been of some value. Different component parts of the methodology can be critiqued, for example the semantic differential scale (see section 9.2.4), use of diary information (see section 10.5.5 on self-representations in diary information) and the use of narrative (see this section). However, as a coherent whole, these methods have provided both detail about the participants, and material that is hoped will enable further work to enhance the experiences of disabled people in the future.

Satisfaction with life

This exploration did not ask participants to "rate" their satisfaction with life, or use any quality of life measures; instead, they were asked whether or not they are happy with their current lifestyle, and some inferences were made when the ideal lifestyle ratings using the semantic differential scale were compared with the current lifestyle ratings.

Participants 1 and 5 [Names here!] report being happy with their present lifestyles; 4 and 7 [Names here!] report not being happy, and the other participants are less clear or direct about their overall sense of satisfaction with their lives. Several studies, outlined in chapter 3, investigate both the extent to which disabled people report good quality of life and satisfaction with life, and the factors that affect quality of life for people with a physical disability.

As highlighted by Nosek and colleagues (2006) secondary health issues potentially have significant negative impacts on the well-being of people with physical disability. Issues that most commonly affect quality of life include fatigue and pain, as these can lead to difficulty in planning life events (Albrecht & Devlieger, 1999; Nosek et al, 2006). Four of the participants (Cathal, Freya, Grainne and Honour) describe ongoing difficulties with secondary health issues, particularly fatigue, and for Honour, pain.

Honour, in particular describes that the effect of fatigue, pain, immune disorder and health issues have had a very significant impact on her lifestyle – she could not return to her college course due to secondary health issues - and also on her daily life, as she needs to rest throughout the day. Freya describes how she needs to plan her days in such a way to manage her fatigue. She also includes several health-related routines, such as using a nebuliser, that need to be performed every day. These participants report that the secondary health issues do impact on their quality of life.

In their study of the "disability paradox", Albrecht and Devliedger (1999) found that over half of their sample of people with disabilities reported that they have a good or excellent quality of life, which compares with about 80% of the non-disabled population. A difficulty with the concept of quality of life is that there is no consensus on what forms quality of life.

In Albrecht and Devliedger's (1999) study, participants reported that well-being involves acknowledging the presence of impairment, but being in control of their minds and bodies. They also reported the importance of being able to perform social roles, having purpose and meaning in life and having a positive "can do" attitude to life (Albrecht & Devlieger, 1999).

The information from participants 1, 2 and 5 [Note should not these labels be changed to names?] appears to suggest that they do acknowledge impairment, are active in social roles and describe some sense of purpose and meaning.

Participants 3 and 8, [Note should not these labels be changed to names?] on the other hand seem to struggle to accept impairment, and have reduced social roles. Honour is seeking purpose and meaning in that she wants to achieve something by working for her degree, but she has not had the control needed to return to college. Cathal describes a

loss of social roles since the deterioration of his physical ability – prior to using a wheelchair, he was involved in a school sports club, a political party, with his family and in his work. All of these roles seem to have diminished since he moved to the residential setting.

Grainne appears to highly value her social roles, particularly that of friend and aunt / relation. It seems that her social contact with people outside the setting is important to her and she derives personal meaning from looking after the dog and the cat. Deirdre, likewise derives meaning from occupations like feeding the cats, but she has involved herself greatly in the residential setting, and created social roles for herself, such as going to listen to other, older residents. Freya very strongly describes purpose and meaning in her occupations, particularly her volunteering.

It could be suggested that people seek to improve their quality of life, as described within work on the "disability paradox" (Albrecht & Devlieger, 1999), and that engaging in occupations that promote social roles, purpose and meaning could be the means whereby these participants promote their own well-being.

The ability to accept impairment, as described by Albrecht and Devlieger (1999), seems to be more difficult for some participants, particularly those with acquired disability and significant secondary health issues.

Another finding from Albrecht and Devlieger (1999) is that the people who have poorer quality of life had unpredictable lives, lack the resources to engage in social activities and support, and experience a significant difference between what they want to do and what they can do, or between what they used to do and can now do. The final key finding was that these people, with lower quality of life, typically were unable to become "agents" in their own world; either due to the type of impairment or the environmental surround, they are unable to take control (Albrecht & Devlieger, 1999). This finding appears to describe, quite well, the situation for Honour and Cathal.

A key question for this exploration is whether or not there is support for the assertion that successful living is autonomous in nature. It seems that the participants who are most satisfied with their life do exert control and have choice; this finding is also supported by Albrecht and Devlieger's (1999) work. It must be assumed that the form of autonomy that

would be described must be self-governance autonomy, which involves positive inter-personal relationships, as the finding that social support and social engagement are important for quality of life have been well documented (Albrecht & Devlieger, 1999; Hammell, 2007; Schulz & Decker, 1985). However, this exploration did not seek to verify or dispute correlations such as level of autonomy and well-being in any definitive manner.

Further study is required in this area., exploring the interrelationship of autonomy and quality of life. An obvious question is, if one were to support a disabled person so as to increase their sense of autonomy, would this have positive effects on quality of life. The literature suggests that interventions that support self-determination, independence and autonomy for disabled people are necessarily positive, but further work to explore the validity of these assumptions would be helpful.

Occupational performance and lifestyle

A large focus of this work involves exploring, and documenting, the actual lived, daily experience of the eight adults with disabilities who participated in this study. These results are presented in chapters 7 and 8.

It is interesting that, despite the large volumes of literature, particularly in the areas of occupational therapy and rehabilitation, that qualitative, descriptive exploration of daily life for adults with physical disability is scarce. There seem to be many studies recounting the effect of one condition or another on specific occupations, most commonly self-care tasks, and there are also studies outlining disabled people's participation in work, social activities, leisure and so on. The current research differs in that the daily experience, and participants' interpretation of their experience is sought, and described.

The methodology used to explore and describe the lived experience of the participants was self-observation, recorded in diary sheets designed specifically for this research. As a methodology, this has a number of inherent weaknesses; it relies on the accuracy, diligence and honesty of the participants, with limited support from the researcher. It was this aspect of data collection that some potential participants found too demanding, and three of the original sixteen participants could not be included in this report due to incomplete diary information.

Another difficulty with diary methodology, as raised in Chapter 7, is that each participant seemed to have slightly different interpretations of what the researcher wanted, and/or some appeared to want to portray or represent themselves, and their activities in a particular way, and so completed the diary to support this representation. Examples of this are highlighted later in this section.

Despite these weaknesses, the complete diaries of the eight participants provide interesting information about one specific week for each person, in terms of what is done, how the participant classifies their occupations, times involved and other factors, such as choice and control In occupations. The diaries are included in Appendix A.

Occupational patterning

In terms of the daily lives of the participants, self-care, productivity and leisure occupations can be described. All of the participants engage in a range of self-care, productivity and leisure occupations, although to varying degrees.

There is variance in the routine described/observable. Cathal, Deirdre, Emily and Grainne live in residential settings, and appear to have fairly clear patterns of occupational performance; they tend to get up and go to bed at regular times, meals are provided at the same time each day and activities form relatively predictable patterns. Anna also appears to have a routine, which she described during interviews. Bart and Freya have less clear routines, but Honour appears to lack any form of routine, even in terms of times when she sleeps.

There are a number of studies describing time use, but the study of most potential relevance suggests that habit formation improves occupational integration, that is, routines and habits make it possible for women with physical disabilities to perform and develop occupations (MacDonald 2002). Anna certainly appears to manage her time in such a way to enable her to engage in occupations of interest to her, and she manages her personal assistance accordingly. Is it possible that the lack of routine observable in Honour's diary exacerbates the difficulties that she has in organising social activities and

occupations outside her own home, as each time she wants to go out, she needs to organise every aspect of that outing?

Deirdre describes a very structured routine, with weekly participation in group activities in her residential setting, and outings with her family on Sundays. She uses the routine of the setting to engage herself in occupations, which, it is suggested, enables her to manage the significant difficulties that she has with some aspects of her living circumstances. When interviewed about her diary information, Deirdre took a dog-eared timetable out of her handbag to supplement what she had noted for her weekly diary, and referred to this timetable. There were disruptions in her timetable, such as no physiotherapy on one day, which did seem to disturb her.

Beirdre and Honour appear to be polar opposites in their use of routine, but any conclusions from this, particularly the extent to which it supports occupational performance are not justifiable, based on the information available. Further research in this area may be of benefit; however it is suspected that personality will have an influence on the effect of routine on occupational performance.

Self-care and assistance

All of the participants require assistance for some or all self-care activities, the amount of assistance either received or required ranging from Bart, who requires assistance for all tasks, with no exceptions, to Freya, who only consistently receives assistance for bathing and household chores. Differences in assistance provided and required are discussed in chapter 8.

As found by Doyle et al (1994), service provision does not necessarily meet adults' service needs; the reports of participants in this study suggest that service provision, particularly personal assistance does not necessarily meet the needs of the individuals. Doyle et al's study (1994) and that of Phillips (1995) focused on people with physical disability living in the community. Of the participants living in the community, two of the four are dissatisfied with personal assistance; Honour reports that she would prefer a more professional form of assistance, and Freya simply does not receive enough assistance with self-care tasks. Freya relies on her elderly mother to assist her with self-care tasks, while she describes her mother as always being discreet and "good about

that", this is nevertheless not what Freya would like. This experience of assistance being supplemented by informal carers is replicated in several studies, including those cited above. Anna reports being "lucky" that she has enough assistance, but that she has to fight for the hours of personal assistance. This fight is possible because she is articulate and willing to fight, whereas other disabled people may not be.

Prior to this research, the researcher had (subconsciously) assumed that those living in residential settings would have access to as much assistance with daily self-care tasks as required, and that a difficulty with assistance may be the nature of its provision (nursing staff instead of a PA), and the need to fit in with the institutional environment. While the need to fit in with the institutional environment has been described by all participants living in such settings, the assumption that adequate levels of assistance would be provided seems, for Deirdre in any case, inaccurate. As described in chapters 7 and 8, Deirdre reports having insufficient assistance. Staff decide how much assistance she requires, and as she describes it, they try to "make" her independent". No literature was found that suggests that this lack of assistance in a residential setting is experienced by other people. The information given is obviously the perception of the participant, and has not been subject to further scrutiny, but nevertheless, there is one individual who is living in a residential setting who feels that she does not have the assistance that she requires, feels that she is forced into changing her occupations to manage the lack of assistance, and describes personal self-care tasks as a "bone of contention". The impact of this situation on her dignity must surely be questioned.

There appears to be little information about the time taken by members of the (non-disabled) general population to perform daily self-care tasks and activities. It was expected that, due to disability, self care tasks would take longer for the participants than for a non-disabled person. The self maintenance / diary entries of the group as a whole may suggest that self-care tasks take several hours every day. While some participants did not include detailed time involved in activities, discussion and the time that is given suggests that some of the participants feel that their self-care takes longer than what they expect for a non-disabled person.

Some of the participants report that they are satisfied with the time self-care tasks and activities take, while recognising that this may be somewhat longer than for other people. Participants 4 and 6[Note should not these labels be changed to names?] are the notable

exceptions, who report that self-care tasks take far longer, and require more effort than they would like.

As previously described, Deirdre receives what she considers to be inadequate assistance in the residential setting. Freya lives in the community, and has insufficient hours of personal assistance. She reports that all self-care activities, including very simple tasks, take far longer for her than she would like, and that these are exhausting. She reports that use of assistive technology and commonly available devices, such as electric toothbrushes, make a huge difference to her performance. There are some studies that investigate the impact of assistive technology on self-care performance, but these tend to focus on either high-tech devices or the use and abandonment of aids prescribed by an occupational therapist, rather than on commonly available items. A feature of Freya's coping strategy is that sheer determination and creativity enable her to create new ways to perform a range of activities with less effort.

Cathal, as discussed in the section above, reports not thinking about the choice or control that he has in relation to self-care activities. He states:

> I can't do anything at all on my own. That at times bothers me... I suppose like everybody, I get days when I wonder what the hell are they doing but that's moments. It is fine."

The wondering refers to nursing staff when they assist him. This contrasts very sharply with participants (particularly Anna) who use a PA rather than nursing staff. Anna, for example describes very carefully managing assistance. There appears to be limited information about the psychological impact of either controlling or not being actively involved in the provision of assistance, but there are several studies that suggest that the organisation of assistance (for example how the personal assistant is recruited and managed) is important, and that a direct payments system is most in line with independent living philosophy (Morris, 1997; Priestley et al, 2007; Stainton & Boyce, 2004).

Boemer and Jopp (2007) identify three major lifespan theories that attempt to explain the mechanisms used to enable a person to cope with or adapt to major life change, loss or trauma, and highlight the commonalities between these. They argue that the different theories point to two central processes, one being improvement / maintenance and the other being reorientation. In the case of Improvement / maintenance, the key feature is goal engagement; reorientation is characterised by goal disengagement, in that the person changes, re-evaluates or re-values goals (Boemer & Jopp, 2007).

Cathal has clearly re-evaluated his goals, since moving to the residential setting. It appears that he is still in the process of re-evaluation – his two different responses to whether or not he is satisfied with his present lifestyle (presented in chapter 9) are potential evidence of this. A possible interpretation of his accounts is that if he re-orientates, and re-evaluates goals and values, he can be satisfied with his present lifestyle, whereas if he compares his current life to his life before the deterioration of his physical function, he cannot be satisfied. It seems that he is not actively engaging with possible goals of choice or autonomy in daily life, because he views these as impossible, due to his physical disability.

Anna describes always taking control, and the need for her to take control, to be an "independent woman". However, in more detailed discussion, as presented in chapters 7 and 8, she admits that she doesn't think that a person can actually come to terms with the need for personal assistance for intimate self-care tasks, such as going to the toilet. She deals with this inability to come to terms with the need for assistance in two ways; firstly by taking complete control of the manner in which assistance is provided, fighting where necessary for what will be appropriate assistance for her. Her second strategy is to diminish the importance of these tasks, and highlight the importance of the activities and occupations that she can and does perform independently. Anna appears to be engaging with the issue (need for assistance), and uses these two psychological strategies concurrently in order to manage the need for assistance.

In terms of service provision, the lives and lifestyles of the participants raise a number of key questions. The structure of service provision, particularly in terms of personal assistance means that some participants have either inadequate assistance, or assistance provided in a manner which does not suit them. Contrary to the arguments of the independent living movement, accounts of some of the participants in this work could suggest that, for some people, residential settings are more appropriate, but that the physical design of these and the manner in which assistance is provided may need to be examined in more detail.

Productivity

There is a wealth of literature describing access issues of people with physical disabilities to employment, and that proportionally fewer disabled people work when compared to the non-disabled population (e.g. Johnstone, 2001; Roulstone, 2004; Hurstfield, 2004; Fitzgerald, 2005; Gannon & Nolan, 2004; Gannon & Nolan, 2005). Only Anna was working full-time at the time of initial data collection (all are working age); Bart was actively seeking employment, and indeed began working during the course of this research and one worked on a sessional basis (Freya). These three participants live in the community. In addition, one participant was attending a college course four days per week (Cathal) and one had deferred from college, due to ill-health (Honour). The remaining three participants, all living in residential settings, do not work.

In terms of work history, Cathal, Deirdre, Grainne and Honour describe working full-time for a prolonged period, prior to either the onset of disability (Deirdre) or deterioration of physical function. For all of these participants, and Freya, (who only worked for a short time before realising that it was not possible for her to work long hours due to her disability) it was perceived necessary to give up work as a direct result of physical impairment. Given that these participants have all worked in the past, it seems that disability must pose a significant barrier in their ability to work. During work, none of the participants describe any significant supports to enable them to remain in employment, or enter employment again in the future. The availability of supports for work, in terms of service provision must be questioned.

Anna, who works full-time, and requires personal assistance in her place of work, describes the "battle" that was involved in ensuring that she has the necessary support. As presented in Chapter 3, one study found that a significant barrier to employment for people with physical disabilities in Ireland is the lack of formal provision for personal assistance (Martin, 2005). Anna describes using a mechanism, as identified by Martin (2005), whereby she uses a grant that is designed to compensate employers for reduced productivity of disabled people, to pay for a PA at work, suggesting that she had to state that she would be totally unproductive unless she had personal assistance.

Anna firmly believes that she is capable of working, always had this self-belief, and so fought to work. Cathal does not feel that he can work – he stated that he would need to walk to be able to work. Thus, Cathal associates employability with physical ability.

Fitzgerald (2005) reports that most disabled people who are not working describe themselves as unable to work, rather than unemployed, and that the severity of the disability affects rate of employment, with only 16% of those who have difficulty with self-care tasks in employment in Ireland. While the proportion of disabled people in employment is low in many countries, these figures seem particularly small, and raise further questions about supports available, and the expectations of disabled people about their own employability.

Ville and Winance (2006) report conclusions of their study which explored the chronology of events and decision paths of people with physical disabilities who were and were not in employment. They suggest that rather than simply considering whether or not a person works, it is more important to understand the meaning of or reasons behind the situation for the person. It appears that the situation for each of the participants in this study for their employment status is different: Anna, she wanted to work, as part of her identity as an independent woman, and so fought to work; Bart had just finished a college course, and was fully intending to work, although at the time of data collection, he was not fully sure about what exactly he wanted to do; Cathal had had a busy and responsible job, which he left some years prior to data collection due to disability. He does not work now, thinks that it is impossible for him to work due to his disability, but engages in a college course to occupy his time. Deirdre worked prior to her CVA, and has no plans to return to work, for her, being able to regain physical function and return home are her goals. Emily briefly worked in a sheltered workshop immediately after leaving school; she has never worked in open employment, and there is no evidence that she wants to work. Freya does sessional work, she reports that, due to disability-related fatigue, she would not be able to work full-time. Grainne does not work, and has no plans to work, due to physical disability. She has a history of working since adolescence. Honour does not work, she plans to return to full-time college. She left a full-time job due to disability.

The meaning of work was not explored in any great detail with participants, other than Anna. It does, however seem that for all bar Anna and Bart, they perceive that they are unable to engage in paid work due to physical disability.

All of the participants report work or productivity activities in their diaries, the specific activities that are described as productivity seem to vary between participants. Bart, for example, describes a family dinner as work, Honour describes many hours of reading and studying as work.

Leisure

The leisure activities in which the participants engage are presented in chapter 7. As found in a number of other studies, the extent to which they participate in active leisure occupations appears somewhat limited, which, as Rimmer et al (1999) suggest, could pose increased risk for secondary health issues.

Deirdre describes herself as very busy, and her diary indicates that she participates in a wide range of activities within the residential setting. While she reports being frustrated that she can't leave the residential setting on her own, it seems that she fills her days with activities in the setting. This seems to be a conscious effort, a mechanism that she uses to manage her situation in the setting. Grainne, on the other hand, does precisely the opposite. She withdraws from the social environment of her setting, and spends time during the days alone, using her computer, and moving around the grounds of the setting. She does appear to have visitors in the evenings. Emily, like Deirdre, tries to integrate herself into her setting, reporting that she takes on the role of advocate for other residents.

One activity that both Deirdre and Grainne engage in, is feeding cats in their settings. Both look after animals, and feel a sense of responsibility to these animals. The three female participants who live in residential settings all report going around the grounds of their respective settings to "enjoy nature" (Emily); to walk the dog (Grainne) or to feed the cats, watch birds and do some gardening (Deirdre). This time outside appears to be very important to the participants. Whether or not this is a form of escapism is not entirely clear, but this is a plausible explanation for the behaviour. Deirdre, for example, describes this ability to go out around the grounds as the activity in which she has most autonomy, and which she enjoys most; she describes a need to "just get away". Emily describes enjoying nature as a self-care activity, required for her health and well-being, and Grainne likes to get away from other residents. There is no evidence of this behaviour in the male participant who lives in a residential setting.

The participants who live in the community do not have opportunities to engage in organised activities to the same extent as those in residential settings, nor do they have gardens in which they can feed cats and watch birds. Thus, there are necessarily differences in occupations performed simply due to differences in environment.

Participants' self-representations in their diaries

Chapter 7 simply presented the information from participants, as was presented to the researcher, and chapter 8 aimed to draw out similarities and differences in the situations of the participants. However, it seems that, in presenting diary information, participants were also portraying an image of themselves to the researcher, be that consciously or not.

Emily kept her diary herself, and reported its contents to the researcher in an interview. She sat next to the researcher, and watched as the researcher typed the information into the tables on a laptop computer; the participant referred to "notes" that had been taken, the researcher seeking clarification and discussing the activities throughout. Emily did not describe any times where she was talking to other residents; almost all of her entries related to her leaving the setting, and mostly unattended. However, when, in the final interview, she was asked which activity she most enjoys, she said that this was talking to other residents. Why was this not included in the diary?

During the course of the information, the participant reported that she visited a friend in a hospital, and the researcher asked how she travelled to the hospital. The mode of public transport that she reported using was not in service, at that particular time, on weekends, and so the researcher questioned further. The participant became somewhat defensive, suggesting that she may have got the days incorrect, or had the wrong form of transport. The researcher felt that either explanation is somewhat implausible, so asked whether or not the participant was making information up. This question was not directly answered.

While the accuracy of the information provided by Emily may be questioned, the mere possibility that she wanted to present an image of herself as going to several different places, visiting a friend, and doing other presumably socially appropriate activities (like going to Mass and visiting her mother's grave), and doing things for other residents, when this may not actually be true, is very interesting. Throughout, she presents herself as a person who is not disabled like the other residents; is in some way superior to the others, and so has a role to help them. She describes herself as being independent and mixing well with people; as being competent and able, and therefore it could be suggested, that she feels that she needed to include activities to support this self-perception. The influence of the researcher, and the value system around the need to do, and the meaning

of competence and independence could have influenced the participant, and so this particular self-portrayal was given.

The researcher was faced with the dilemma of what to do with the reports of Emily, given that it is highly likely that these are not an accurate reflection of what she actually did during the week. One possibility was to ask her to re-collect the diary information, but there is no guarantee that the same thing would not happen again. Another possibility would be to remove her from the study, but not all of the information from other participants was scrutinised in this way, and it was only the specific knowledge of the researcher, more detailed probing and a slip-up of that participant that raised the question of the accuracy of her information at all. Emily is included in this research, and the reports that she gives are presented at face value, as is done for all of the other participants, but with the purpose of raising the issues discovered with her in this discussion.

It may be possible to learn a lot from the participant's actions, and they certainly raise questions. What was the influence of the research that created a situation whereby a participant may have made information up? What does it tell us about the social and cultural context and the norms of behaviour that potentially influenced the participant to invent those specific activities (as they seem to have been, though this was not definitively confirmed)? How accurate is any of the diary information? What is it about the participant's understanding of independence, and her role in the world that may have influenced her to present the diary information as she did? Were the activities of all of the participants influenced by the fact that they kept diaries during the week?

Another interesting diary entry was made by Bart, who reports engaging in masturbation. The motivation to include this in the diary is the interesting feature of this entry, but also the researcher's reaction to its inclusion. Did the participant include masturbation simply for completeness, or was there another motive? Why did the researcher wish to question the motivation for this entry, and not other entries? If participants had partners and were sexually active, might this activity be included? Where should the line be drawn between including all activities and invasion of privacy, particularly considering the researcher actively sought information on very personal self-care activities.

Other participants presented justifications for or reflections on the activities or lack thereof, included in the diaries. Deirdre is clear that feeding the cats is important because the cats rely on her; she is needed by the cats, and has enabled them to grow into healthy cats.

Freya openly describes the "need to be needed" – she believes that this is a universal need, and states that she is open about this, therefore she chooses to engage, and actively engages in occupations in which she feels needed, be these being with her mother or volunteering.

Honour reflects on her diary, suggesting that she doesn't do anything with her days, except read. She had initially suggested that she only does activities that are enjoyable, but when reflecting on her diary, she found that most things, apart from reading and studying, she actually doesn't enjoy. Having gone from the sensation that overall, she does enjoy her activities, through completing a diary which specifically asks her if she does enjoy each activity, to realising that, actually, she does not enjoy most of the activities, could have potentially had a negative impact on her. During the final interview, Honour became philosophical, and "down" about the state of her life, to the point that the researcher intervened, and used therapeutic rather than research skills, to enable the participant to unpackage the thoughts and so that she could develop a more realistic or positive understanding of her life situation. This raised issues of ethics, and the extent to which probing deeply into an individual's life can have consequences, be they positive or negative, on an individual.

Further research into diary methodology, including its accuracy would be helpful. Also, as previously mentioned, the diary aspect of the research was the most demanding for the participants, and so ethical issues, and intrusion issues also need to be considered.

Self-determination theory, as proposed by Ryan and Deci (2000), aims to understand motivation, in particular intrinsic motivation, as do other theories, including the theory of flow (Csikszentmihalyi, 1988). Is there evidence of intrinsic motivation in the diaries of the participants, or of flow experiences? As questioned in chapter 2, how is flow created for people with significant physical disability?

There are some instances where it appears that the individuals are intrinsically motivated; particularly Honour's reading and studying. She reads, simply for the pleasure and enjoyment of this. Whether participants gave explanations for their actions that mask the motivational style, or whether the information is simply not detailed enough, other examples of intrinsically motivated behaviour are difficult to find in the diaries (with the possible exception of masturbation). The explanations of activities range; Cathal goes to college to fill his time, so he doesn't "go mad" in the residential setting; Freya volunteers

so that she can feel needed; Grainne writes stories and poetry just for something to do, and to be away from other residents.

Focus on doing and occupational performance

There seems to be an overwhelming focus on "doing" in this research. This was undoubtedly influenced, to a greater or lesser extent, by the researcher, and the research focus, but nevertheless, some of the participants seem to equate being busy, and doing to successful living (particularly Anna, Cathal, Deirdre, Emily and Freya), and not doing to being a failure (Honour).

However, in the lifestyle ratings using the semantic differential, the pair "little free time / lots of free time", was rated differently to other pairs, in that it had equal highest level of change, but all change was in the passive direction: all of the participants who rated a change between their current and ideal amount of free time report that their ideal lifestyle would have more free time, the corollary of which could be less activity, or the ability to engage in other activities of special interest. The vast majority of the difference in current and ideal lifestyle ratings, with the one notable exception of free time, across all participants and each pair, is for the change to be in the direction of active/good/strong rather than the inverse.

Thus, there appears to be a contradiction between the value placed on being busy, and activity as relating to successful living, and the desire for free time. The impact of social desirability was not investigated, but would be worth considering. Wilcock (1999) presents the theory of "doing, being and becoming", in which it is suggested that a dynamic balance is needed between "doing" and "being". As noted in chapter 3, this is a theory, rather than evidence-based, but application of the theory to the diary information of the participants would suggest that they focus on "doing". "Being" involves integration of identity (Wilcock, 1999); for some participants, who report dissatisfaction with being disabled people, introduction of "being" may not necessarily be positive.

In Nosek and Fuhrer's (1992a; 1992b) work, using the personal independence profile (PIP), differences were found between level of activity (described as productivity) in participants in the three profiles that they identified. Profile A participants reported high levels of independence, and were described as independent-minded with good physical

function, and were the most productive; Profile B also were independent-minded, but had poor physical function and were mid-range in terms of productivity, and Profile C were not independent-minded with a range of physical abilities; these had the lowest level of productivity (Nosek and Fuhrer, 1992b). Participants in the current study would all be likely to be within profiles B or C, as all have significant physical disability. One of the primary conclusions of Nosek and Fuhrer (1992b) is that independent mindedness (akin to autonomy) is the primary indicator of productive behaviour.

Relating Nosek and Fuhrer's (1992b) work to the current study would result in the hypothesis that the participants that describe themselves as more autonomous are more productive, but this is not entirely accurate for the participants of the current study.

Anna and Cathal engage in close to full-time education or employment, therefore, it could be stated that they are the two most "productive" participants, yet their perception of their independence, and independent-mindedness would be significantly different. The PIP, as created by Nosek and Fuhrer (1992a), was not administered to the participants in this study. While it may have been an interesting tool, it was thought too lengthy and not related enough to the specific focus of this study.

Honour describes herself as doing very little, but, as presented in Chapter 9, this is primarily because she could not return to her degree course in college. She currently reports herself as lacking in choice and autonomy. When questioned, she said that, if and when she does return to college, she would probably suggest that she would have more autonomy and choice. There appears to be a causal inference (although not directly stated), in the work of Nosek and Fuhrer (1992b) that, in order to be productive, one needs to be independent-minded. This causal relationship needs to be questioned in light of Honour's report – her going to college (becoming more productive) she feels, would increase her sense of choice, autonomy and satisfaction with life, without any change in her level of independent-mindedness. However, it could equally be argued that, if she were more independent-minded, and did take control, then she may actually have returned to college prior to data collection. The nature of the link between autonomy or independent-mindedness and productivity warrants further investigation.

There is also a parallel with Cathal. Honour is unable to return to college, despite really longing to return, because she was told that she was not medically well enough, and because she did not have suitable seating/mobility. Thus, it could be argued that there

were inadequate supports in place to enable her to attend college. Cathal was provided with all of the supports, in terms of transport, assistance during the day, and it was suggested to him that he does go to his college, so he simply needed to decide whether or not to do it. It seems that Honour demonstrates more independent-mindedness, yet, due to lack of supports, is less productive.

Another criticism of Nosek and Fuhrer's (1992a; 1992b) work is the importance given to the level of productivity of their participants. There is very limited evidence that suggests that increased productivity promotes the well-being of adults with physical disability, thus a focus on productive action may be misplaced.

Independent Living and Living in Residential Settings

It was considered key to draw participants from a range of different situations for this research, including those who live in different settings. As described in Chapter 5, initially it was thought that there would be three types of accommodation, based on a report into accommodation and service requirements of people with disabilities (ERHA, 2003). However, when participants were sought, the initial meetings with potential participants and service providers in residential settings and supported living settings appeared to suggest that the difference in organisational aspects between these services is difficult to distinguish, so the two groups were amalgamated. Five years on, it seems that some of the services have evolved, but it is likely that the same decision would be made now.

A residential setting was assumed, and indeed found, to be one where there are a number of people with physical disabilities living together, and where supports are provided by nursing or care staff. This seems to be the situation for supported living settings. There are, however anomalies in service provision, for example, one of the original 16 participants lived in a residential setting and also had his own personal assistant. One potential difference between the supported living and residential settings is that in some (but not all) of the residential settings, there are medical and therapy teams in regular contact, thus residents frequently have access to physiotherapy and occupational therapy. In some of the supported living centres, there were weekly physiotherapy classes, and occupational therapy cover. Thus, the differences seem to be insignificant.

Independent living was assumed to be where individuals live in the community, and receive assistance from a personal assistant, whose work is managed by the disabled person themselves.

Independent Living does not imply a life led in self-sufficient isolation. It means that a person with a disability is afforded the same right to choice and self-determination within the wider community that all other adults take for granted. These choices often require that a disabled person be supported, either by assistive technology, environmental adaptation or by the physical help of another individual. It is the element of choice and the fact that it is the disabled person who chooses and directs his or her own support services, which underpins the Independent Living approach to disability.

(Dixon, 2006 p.17)

There are several aspects of the above statement, from Dixon (2006) that could be questioned, based on this exploration. The statement that "all other adults take for granted" choice and self-determination appears, from the literature reviewed not to be necessarily true or accurate; however this exploration did not involve "all other adults". Dixon (2006) defines the key feature of independent living as being the "disabled person who chooses and directs his or her own support services". Is this a reality for any of the participants in this study?

Anna is an advocate of independent living. Following her review of the information she provided for this research, she wanted to emphasise that independent living is a right for all disabled people. Does she make the choices about her support services? It could be argued that, to a significant extent, she does. She manages her personal assistants in terms of their times and what they do and how they assist her. However, she does describe a need to fight for services.

Bart also makes choices and directs the assistants that he uses. The other two participants are less clear. Freya reports simply not having enough assistance; she lives in the community rather than avails of "independent living". She does not have full choice or control over her support; she clearly states that she would like more assistance with self-care tasks. Honour, officially, is a recipient of independent living services, but she describes problems with the personal assistance service that she receives. She would like a more professional service (ideally a robot).

In their investigation of independent living services in Ireland, Murphy et al (2006) raise similar difficulties to those experienced by the participants in this study, particularly the perceived inadequacy of amount of support, and the implications that this has for disabled people. The current exploration also found other issues, namely the inaccessibility of home environments that were causing significant difficulties for two of the participants (Freya and Honour), including increased fear of falling and being unable to safely enter or leave the home environment. Independent living also considers the accessibility of the physical environment. Services, in terms of human assistance, are being provided to people in environments that could be considered unsafe: should a priority not have been the provision of more accessible home environments, to facilitate occupational performance and safety? At the time of writing this discussion section, it is almost five years since interviewing the participants. Freya did move into a more accessible house two years ago, but she still does not have environmental controls so struggles to lock doors and open windows. No alternate (as was promised) accommodation has been provided for Honour.

Key questions about independent living that are raised by this research are whether or not independent living truly exists in Ireland, and whether this form of living would suit most people with physical disabilities. While Murphy et al (2006) report an investigation of independent living services, this work does not present any form of critique of the services or of the information found.

It appears that independent living requires the ability to be autonomous; it requires a person to be able to make choices and manage their lifestyle. It seems that Honour, in her current circumstances, cannot manage her lifestyle in the manner that she wants.

Of the participants living in residential settings, only Emily appears fully happy with her life. Deirdre and Grainne are clearly dissatisfied, primarily about aspects of their social environments. Cathal describes being happy with the environment, but not liking the thought that he would be there for the rest of his life.

It would be interesting to explore fully why some people choose, and fight for independent living and others do not. Another very important aspect of choice of accommodation could be the nature and onset of impairment. Do those with congenital impairment, for whom

the status quo is being disabled, strive more for independent living? If a person becomes disabled in adulthood, is the concept of independent living, where independence is viewed as control rather than self-reliance, so alien to the individual that it is not considered? Is there a need to accept the need for assistance, and be willing to fight, and to take control of that assistance essential for independent living, and if so, is this particularly hard for people with acquired impairments?

Cathal and Deirdre state that they would not be able to manage in independent living, because they would need assistance, but this, objectively is inaccurate. Bart has the most significant physical impairment, and he lives independently. How is it that potential service users seem to have such a misunderstanding of independent living services? It seems that these participants have not actually been given the information to make a choice about their accommodation. They may not be motivated to investigate changes of living situation, but nevertheless, they lack information that may be very important to their ability to consider other options. It is suggested that information about all possible living options is provided to people with a physical disability, so that individuals are empowered to change, or can be content that they have chosen the most appropriate living situation for themselves. .

The three participants who report being most satisfied with their living circumstances are Anna, Bart and Emily; all of whom chose their current living arrangements, to some degree.

The following tentative conclusions can be drawn: 1, people should have the information and be provided with the opportunity and encouraged to choose the kind of accommodation that would suit them best; 2, a form of supported living, a "middle of the road" option between the traditional residential setting and independent living would be useful for some disabled people; 3, regardless of which form of living a person uses, the services should support their preference and desire for choice and autonomy.

Possibly the most important conclusion, that does not seem to be reflected in any meaningful way in the literature, is the substantial impact of individual differences. It is clear, from the findings of this work, that the suggestion that one form of living accommodation (such as independent living) is necessarily better than another, is invalid. A sensitive, person-centred form of assessment, that takes clear account of desire for autonomy, control and choice, and enables person-environment congruence is required.

The meaning of Autonomy and Choice

The preamble to the UN Convention on the Rights of Persons with Disabilities recognises:

> the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.
> (UN, 2007, preamble)

This recognition of autonomy in the UN convention, suggests that autonomy – which is not defined, but can be assumed to be related to the ability to make choices - is a human right for people with disabilities. This exploration sought to develop some understanding of what autonomy and choice actually mean to a number of adults with significant physical disability.

This was not a phenomenological study into autonomy and choice; rather it grounds the concepts in the daily life and lived experience of the participants. Thus, in this study, the actual lived experience of autonomy (for example, as proposed by Agich, 2003), is paramount. However, a detailed phenomenological study exploring, in depth, the phenomena of choice and autonomy for people with physical disabilities would be welcome.

The nature of autonomy, as described by the participants

The participants appeared to relate autonomy to control and choice; that they are autonomous if they have control in a particular situation. Within the self-determination theory tradition, autonomy is conceptualised as a sense of "choicefulness" (Chirkov et al, 2003); this form of autonomy is also described as "reflective autonomy" (Koestner & Losier, 1996), and is the "Autonomy II" concept described by Hmel and Pincus (2002).

However, for some of the participants, particularly Cathal, Deirdre, Grainne and Honour, autonomy is not simply having choices, or being able to make choices, but also relates to the ability to enact these choices. Thus the mere possibility of choice is insufficient for autonomy; there also needs to be the capacity to enact these choices. For some of the participants, particularly those with acquired disability, the reality of their lives is described as lacking in autonomy, because they do not feel that they have the physical ability to follow through with some of the choices that they would like to make.

For other participants, particularly Anna, Bart and Freya, they perceive themselves to be autonomous because they make decisions, and it is the ability to make decisions, rather than any ability to follow through with these, that enables autonomy. Freya feels autonomous, because she can make decisions, but feels that her choice, rather than her autonomy, is restricted as a result of physical disability and an inability to follow through with decisions.

Cardol et al (2002) propose a conceptual framework of autonomy, including decisional and executional autonomy; where decisional autonomy is the ability to make decisions without external restraint and executional autonomy is the ability to act as one wishes, typically as a result of the decisions made. It would appear that some of the participants in this study may experience decisional autonomy, but some struggle to enact their choices, thus have limited executional autonomy.

As described in Chapter 2, this view of autonomy, consisting of decisional and executional components, does not appear in the main psychological literature, and the concepts appear to overlap concepts within psychology, such as self-efficacy and competence. Given that the participants in this study appear to reflect the distinctions proposed by Cardol et al (2002), the question arises as to why this type of framework is not included in

the main psychological literature, or the extent to which this framework applies to non-disabled people.

One may suggest that, as Cardol et al's (2002) theory of autonomy is specifically related to disabled people and rehabilitation, the issues of an inability to perform chosen tasks and occupations significantly affects people with disabilities, as a direct result of disability. Then, it is a logical step to suggest that autonomy is not simply "choicefulness" for people whose ability to perform chosen occupations is limited by disability. Is there, then, the assumption, within the psychological theories that non-disabled people are not limited in their ability to follow through decisions, thus a person is autonomous if their behaviour is "willingly enacted" (Chirkov et al, 2003), assuming further that their will can be enacted.

It seems illogical to suggest that disability is the only situation whereby a person cannot enact their choice or will; there must be numerous reasons why people can't do what they want to do; a lack of money being one simple example. Thus, should autonomy theoretically always relate to both choosing, and then having the ability to enact those choices? Why is disability highlighted as different to other contexts whereby chosen action is not possible?

In the psychological literature, there appears to be little or no mention of the "executional" aspect of autonomy, resulting in the conclusion that the ability to enact decisions or choices is not part of autonomy, as considered within the mainstream psychological literature. The "executional" aspects of autonomy, within self-determination theory, for example, appear to be described as "competence".

Anna, in this study, was most clear about being autonomous; she reports with no hesitation that she is autonomous, because she makes decisions, and can enact these decisions; she has fought for a life of choice and autonomy. Why does she not relate her physical disability to autonomy? Similarly, Bart reports being autonomous, because he is in control; he feels that he is not autonomous when his technology does not work – not due to himself, but due to technology, which limits his ability to communicate. Both of these participants have congenital disabilities, and being disabled is the status quo, it is "normal" to be disabled. Thus, in their "normal" worlds, physical ability is not something that would have an impact on their perceptions of their ability to follow through with decisions. For them, it could be hypothesised, that physical ability or disability are irrelevant when it comes to autonomy.

Comparing both the different views of the participants, and the literature, one potential solution becomes apparent. For a non-disabled person, or a person who has always been disabled, autonomy could mean control or choice. As Agich (2003) describes, a person's sense of autonomy is developed throughout the life-span, through engagement with aspects of the environment. If a person experiences a change in their ability to perform physical tasks, then their perception of autonomy may change, as it has been developed throughout their (non-disabled) life, and so "normal" activities, or "normal" choices become impossible to enact, thus impacting on the person's sense of autonomy. If a person develops their sense of autonomy through engagement as a disabled person, then autonomy could potentially form independently of disability. Thus, it is the change in status, rather than the status itself that may impact on a person's sense of autonomy.

The question then arises whether or not change in other life circumstances, such as redundancy resulting in a dramatic loss of income, for example, could also result in a sense of diminished autonomy? This would suggest that a sense of autonomy is developed throughout the life-span (as described by Agich, 2002), within the social, personal and environmental context. Would any significant change in that context (be it disability, loss of income or another significant event) affect a person's sense of autonomy? Or, is disability a specific factor that elicits change in a person's sense of autonomy?

Within the self-determination theory literature, there appear to be subtle differences in descriptions of autonomy – autonomy can be both the sense of choice (Chirkov et al, 2003; Ryan & Deci, 2006), but also that actions are willingly enacted or fully endorsed by the individual (Ryan and Deci, 2000; Chirkov et al 2003). This latter description, that is, autonomy as support for one's actions rather than choice of actions, appears to reduce the importance of physical ability. However, no individual in this work described autonomy as endorsing one's actions.

It seems fair to conclude that there is a gap in the literature, between conceptualisations of autonomy for non-disabled people, and for people with physical disabilities, where the ability to enact one's will is limited.

As described in Chapter 2, Hmel and Pincus (2002) identified two "valid" forms of autonomy; these being self-governance autonomy (Autonomy II) and agentic separation autonomy (Autonomy III). Which form of autonomy best reflects that experienced by the participants in this study?

Potentially, each of the participants could have been asked to complete an adjective checklist (ACL), to assess for Autonomy III or a General Causality Orientation Scale (GCOS) (Deci & Ryan, 1985) to assess levels of Autonomy II, but this was not undertaken for a number of reasons (see methodology section). While such checklists / scales may appear to provide information about the extent to which participants feel autonomous, they are based on an over-simplified and perhaps confused notion of autonomy and tend to raise more questions than they answer. It was considered far more important to explore the meanings of autonomy to the participants than to "assess" their autonomy and fit them as well as possible into one or other pre-existing description.

The principle feature that distinguishes self-governance from agentic separation autonomy is the relationship that the individual has with others (Hmel and Pincus, 2002; Hodgins, Koestner and Duncan, 1996; Koestner and Losier, 1996), exemplified by the interpersonal closeness-separation dimension described by Kagitcibasi (1996). Research (e.g. Koestner & Losier, 1996) has demonstrated that those with high self-governance (Autonomy II; reflective) autonomy are likely to seek assistance from others, and are positively socially oriented. Anna and Bart describe themselves as being autonomous, and these participants necessarily require, elicit and receive support from others, including personal assistants. They both describe autonomy as making decisions; as being "captain of the ship" (Bart) and managing others, such as personal assistants. This would suggest that the autonomy that they describe is most likely to be self-governance autonomy. Likewise, despite having restricted choices, Freya describes herself as fundamentally autonomous, because she makes decisions, regardless of whether or not she uses assistance.

Cathal reports that his autonomy is reduced because he can't do "physical things." Similarly, Honour describes her inability to do chosen occupations as restricting her autonomy. For these, it is not clear if autonomy relates to doing alone - without assistance - and then whether this could be more closely related to agentic separation autonomy. Cathal defined autonomy as being individual control and as "somebody or something is looking after itself." This suggests that for this individual autonomy involves

interpersonal separation, therefore agentic separation autonomy, that is, Autonomy III (as described by Hmel & Pincus, 2002).

Further study is required to investigate the relevance of the distinction between self-governance autonomy and agentic separation for disabled people, who use and manage personal assistance and who describe themselves as "autonomous." The development of the personal construct of autonomy continues throughout the lifespan but the results of this research point very clearly to the powerful contribution to this development of the experience of disability from birth or early childhood. Development of the personal construct of autonomy and the personal interpretation of how autonomy is implemented will be markedly shaped by the need to use human assistance and to engage with others in order to satisfy needs. Further research from a developmental perspective into the formation of the sense of autonomy for congenitally disabled and non-disabled people would be an interesting area of future work,

Autonomy: A goal or value?

Fundamentally, the current research seeks to explore the meaning of autonomy and choice in daily life for the participants, so a most basic question that it helps address is the extent to which participants experience autonomy as a goal or a value. It appears that there is significant difference between the participants in this respect.

For Anna, autonomy is clearly both a goal and a value. She has fought to be independent and be autonomous in her lifestyle and she lives her life in a manner which emphasises her ability to make choices and take control. Situations, it is argued, are perceived through some internal lens, and are interpreted as mechanisms to enhance her sense of control, efficacy and autonomy. The example of this presented in the previous chapter is her interpretation of the organisation required to have a social life – organising her PA, transport, making sure where she wants to go is accessible and so on - are not viewed as hassle (as was incorrectly suggested by the researcher), but rather decisions that she takes, and evidence of her autonomy and independence. The same situation (organising a social activity) is perceived entirely differently by Honour, who views the organisation needed as evidence of disability, and not worth the work. Thus, the very same situation results in her having a diminished sense of autonomy and choice.

Freya appears to value autonomy and choice, but unlike Anna, being autonomous does not appear to be a goal in her life. She reports feeling autonomous, and working to maintain her choices as far as possible, but does not appear to strive to "become autonomous". Thus, autonomy could be viewed as a value and not a goal for this participant.

Cathal reports not thinking about whether he has control, choice or autonomy in his daily life. He needed significant probing to elicit answers about autonomy, and he reports that he doesn't think about it. It is clear that autonomy is not a goal for Cathal; he very clearly does not strive to become autonomous. Whether autonomy is valued is less clear, but it is suspected that it is not highly valued by him.

Within the self-determination theory formulation, autonomy is viewed as a basic psychological need, along with competence and relatedness (Ryan & Deci, 2000; Ryan & Deci, 2006). While not thinking about autonomy does not necessarily mean that a person lacks autonomy, the responses of Cathal seem to suggest that he perceives himself to lack competence, and that this also affects his autonomy.

A potential explanation derived from his comments is that he feels that he cannot do chosen occupations, due to physical disability, therefore feels that he is not autonomous and, therefore, he has re-oriented his perceptions (cc review presented by Boemer & Jopp, 2007 about re-orientation), to manage this reduction in autonomy.

While self-determination theory, common wisdom, and many documents produced by disabled lobby groups and service providers, and indeed the UN convention, highlight the importance of autonomy, there seems to be limited evidence to support these claims for disabled people. Self-determination theory suggests that autonomy, competence and relatedness are basic psychological needs, and are essential for intrinsic motivation (Ryan & Deci, 2000). However, Cathal, for example, appears to lack both a sense of autonomy and of competence in his daily life. Does this mean that he is unlikely to experience intrinsic motivation?

It cannot be concluded from the results of this exploration that autonomy is universally a goal or value for the participants. This view of autonomy as universally a goal or value was to an extent a presupposition of the current research and was certainly a key focus

for the exploration. This focus, as described in the introductory chapter, was derived from both the personal experience of the researcher and from an analysis of common policy that suggests that maximal autonomy is positive and desirable. Nevertheless the current findings demonstrate a large diversity in the way the participants manage issues of autonomy and manage their need for autonomy. It seems reasonable to conclude that autonomy is a key issue for all the participants but only if it is recognised that individual definitions and perspectives on autonomy are immensely varied.

However, the extent to which a sense of autonomy is health-promoting or positive, and whether maximal autonomy is desirable are moot questions. This research was neither large enough in terms of sample size, nor was the methodology such that conclusive findings about the effect of a person's sense of autonomy on their overall well-being could be made. However, the participants who describe themselves as fundamentally autonomous (Anna, Bart, Emily and Freya) do describe themselves as being satisfied with their lives; other participants (particularly Deirdre and Honour) describe a lack of autonomy, or choice over lifestyle as leading to less satisfaction. These may be coincidental results, but this research has highlighted a need for further study in this area, particularly with reference to the effects of sense of autonomy on well-being of people with physical disabilities.

An issue with the concept of autonomy, as highlighted in chapter 2, is the difference in meanings given to this term. Some of the debate within the literature, (particularly Schwartz, 2000; Chirkov et al, 2003; Ryan & Deci, 2000; Ryan & Deci, 2006; Koestner & Losier, 1996) appears to be semantic, involving fairly abstruse distinctions about what one word means when compared to another or confusions over two uses of the same word. This raises the question of the extent to which the current research has slipped into the semantic mire rather than concentrated on a meaningful exploration of a potentially important concept.

While there is much debate over semantics, this research nevertheless did investigate an aspect of people's lives that is thought to be important. It may not be possible to exactly state which form of autonomy, as described within the psychological or rehabilitation literature is relevant to the participants, but the participants did describe in their own terms the meaning of this concept to themselves, which was a primary concern of this exploration.

Autonomy as control

As described in chapter 9, a striking theme of the descriptions of autonomy of the participants is the importance of control: five of the eight participants specifically describe autonomy in terms of control.

If autonomy is related to control, then it seems plausible that participants may vary in their desire for autonomy, as desire for control varies between people (Burger, 1985; Shapiro et al, 1996). The extent to which a person desires control has been found to be a relatively stable personality variable and research has also established that there is variation between individuals on this dimension (Burger, 1985). Could the desire for autonomy, particularly if it is seen by individuals as almost synonymous with control, be similarly dependent on personality? If so, how does this relate to the view of self-determination theory, which proposes that autonomy is a basic psychological need?

As described in chapter 2, recent research in psychology has shown that the original proposition that there is a linear relationship between control and positive health is not valid, but rather the opportunities for control afforded by the environment need to match the desire for control that a person has. The earlier studies linking more control with better outcomes (e.g. Rodin & Langer, 1977), could have been undertaken in settings where the amount of control typically afforded by the environment is low. In the case of Rodin and Langer's (1977) study, data were collected in a nursing home setting.

Shapiro, Schwartz and Astin (1996) describe potential mismatches between an individual's sense of control and the opportunities available in the environment for an individual to exert control. For example, where there is opportunity for control in the environment, but the person can't or does not want to exert control, and the inverse, where the person wants to exert control, but is limited by factors in the environment. As most of the participants appeared to view autonomy as related to control, it would be interesting to explore the extent to which these theories of control are applicable to people in similar situations to the participants in this study.

Certainly, those living in residential settings have less control over aspects of their lives, including the time that they get up and go to bed, their choice of food, their ability to go to different places and so on, solely due to the nature of a residential setting environment.

Two of these participants, Deirdre and Grainne, appear significantly dissatisfied with their environments. Deirdre, in particular, reports that she would like more control; more control would mean that she be assisted in the way that she wants, and also it would mean that she can leave the residential setting whenever she wants. It appears that the environment is too controlling for her liking. She describes a need to be a passive recipient of assistance to do well in the setting.

Grainne is also dissatisfied with her setting, but it appears not to be the amount of control that she has that is the problem. It is more the constant barrage of people, the lack of privacy and the disappointment about the physical environment that causes her dissatisfaction.

Emily also lives in a residential setting, and reports being satisfied with her surroundings, and that she chose where she lives. For her, living in the residential setting gives her the "independence" that she wants, she makes choices, has the support that she requires, and she feels that this setting is best suited to her. There are differences in the residential settings experienced by the various participants and in the opportunity for residents to exert control. For example, Deirdre and Emily are living in very different residential settings. Nevertheless, Emily has no desire to live in the community; she clearly states that the residential setting supports her, and that the "need to abide with the routine of the house" is something that she is happy with.

Cathal also lives in a residential setting, and as previously noted, he doesn't think about how much choice or control he has. Throughout his self-maintenance and diary information, he reports that he doesn't think about whether he has control over the situation. He differs from both Deirdre, who does desire more control, but cannot exert it, and Emily, who does not desire more control. It is not clear whether the "not thinking" about control is indicative of not valuing or aspiring to have control, or whether it is a secondary mechanism used to manage a lack of control.

Those living in the community are in environments where it is essential, to a greater or lesser extent, for them to be in control. Anna, as already discussed, actively takes control, and the need to control and organise appears to support her sense of autonomy, and desire for control. She appears to be in an environment where she can exert control, and it appears that fundamentally, she has a strong desire for control. Likewise, Bart appears

to take control, and his metaphor of "captain of the ship" supports his perception of being in control.

Freya reports taking control and making choices. The aspects of her life that she is dissatisfied with relate to performance of occupations, particularly self-care activities, and the lack of assistance, rather than control. She reports being fundamentally autonomous, but that her physical disability and lack of assistance restrict the choices that she can make.

Honour, on the other hand, appears not to enjoy taking control. The information that she provided during the research process showed a number of occasions where it appears that she has not taken control, made decisions or organised supports that are required for her to live an "ideal" lifestyle. She reports finding the need to control overwhelming, and so there appear to have been a number of situations in which she has not taken action. This is particularly striking in that she deeply wanted to return to college, but was told that this would not be advisable, and so simply did not go. After one of the interviews, she described waiting for an occupational therapist to supply her with powered mobility, but she did not contact the OT to find out why there were delays. This resulted in her being unable to leave her home. She was resigned to this situation.

Could it be interpreted that Honour does not have a great desire for control, and that her current living situation requires her to take control for her to live a lifestyle with which she would be happy? If this is a plausible interpretation, the question arises as to how best her life and lifestyle could be made more satisfactory.

O'Connor and Vallerand's (1994) study highlights personal differences as being important in determining the type of environment that is most likely to support well-being.

While the literature seems to suggest that autonomy is positive, or a psychological need (Ryan & Deci, 2000), in relation to control, it seems to suggest that, firstly desire for control differs between people and is personality-related, and secondly, that for optimal well-being, the person's desire for control needs to match the opportunities for control in the environment. It appears that there is a difference between the participants' desires for control, and that those whose environment supports their desire for control appear most satisfied, but this research was not designed to establish that such links exist for other

people with physical disabilities. Further research into control, and its relationship to autonomy would be useful to improve our understanding in this area.

Choice

As well as autonomy, this research sought to explore the meaning of choice in the daily lives of the participants, both in terms of their perception of their own choices and also in terms of the choices that they can make on a daily basis.

One of the most influential accounts of the impact of choice is probably the theory of personal causation, proposed by deCharms (1968). His often cited work suggested that people (the original work focused on children) who were more intrinsically motivated perceived that they had more choice, and had the freedom to make choices; these being described as "origins". Those who did not perceive that they have choice were described as "pawns".

DeCharms' (1968) theory of personal causation appears to closely relate to autonomy, in the sense of self-governance, reflective autonomy. Anna described autonomy as, "freedom to make choices",, and in discussion, it appeared that the other participants also related autonomy to choice.

Several of the participants (e.g Cathal, Deirdre, Freya and Honour) describe their choices as being limited due to their physical disability and/or environmental constraints. They may make decisions or choose a particular course of action, but find that it is not feasible due to disability, accessibility or the institutional environment in which they find themselves. Within the literature, there is some discussion of the value of choice, for example, Iyengar and Lepper (1999), question the value of choice, and suggest that too much choice can be ego-depleting and cause stress.

All of the participants were asked directly if they experienced too much choice, and none of them said that they did. Five of the eight participants suggested that they would like more choice in their current lifestyles, but this statement needs to be clarified. When probed further, it appears that participants were suggesting that they would like to enact choices or make choices that they perceive to be unavailable, due to physical disability.

Freya, for example, views herself as fundamentally autonomous, but she feels that she is limited in the choices that she can make due to physical disability or insufficient personal assistance and poor access.

Cathal describes not thinking about choice, particularly in self-care tasks, but yet it is clear that he does make choices; he describes only taking part in what he describes as "passive" activities that he enjoys and which do not require energy. He states that he tends not to do activities that he does not enjoy. For him, there are choices that he cannot take, an example that he gives is a trip out with his friends from college, that turned out to be an inaccessible venue. It appears that an increase in these potentially meaningless choices that cannot be enacted does cause him some stress.

As presented in chapter 2, Ryan and Deci (2006) clarify that increased meaningful choice can promote self-determination; choices that are not meaningful can cause confusion, fatigue and more meaningless choice can actually hinder self-determination. For Freya, for example, theoretically she could have more choice in her life, but these would not necessarily be meaningful without support, such as personal assistance. Thus, for people with physical disability, choice without supports (such as personal assistance or access) may not be meaningful; it may be useful to undertake further study to examine whether such choices are actually harmful.

Concepts of choice, autonomy and control all seem to be inter-related, and it is difficult to separate the meanings of these for the participants. However, for some participants, autonomy relates to the ability to make decisions, take control, and potentially make choices; whereas having choice seems to relate more to how realistic it is for the person to enact those choices. For some participants, particularly those with acquired disability, both choice and autonomy can be affected by physical disability, and the influence of the environment seems to be significant to the participants in how they experience autonomy, choice and control. Further investigation of these concepts is required.

It was not possible, in this research, to differentiate between predispositions or personality factors that affect an individual's experience of choice and autonomy compared to environmental supports / barriers. Further research concentrating on the influence of both personality and environmental supports / barriers would be potentially useful, and could better lead to appropriate provision of services to support people with physical disabilities.

While there is significant debate over the semantics, phenomenological investigation into the meaning of autonomy and choice, specifically for people with physical disability, would be helpful, and may enable the gap between the psychological and the disability / rehabilitation literature to be bridged. It is tempting to re-formulate the concept of autonomy in the light of current research findings, but this would add further to the confusing array of conceptualisations of autonomy. The current research has resisted this temptation and worked within the confines of extant theories and definitions of autonomy. Nevertheless studies that reconcile and synthesise theories currently in the literature and otherwise advance our understanding of the complex issues surrounding autonomy are required and would be most welcome and useful.

The Choice and Autonomy Framework

This work suggests a five-strand framework describing lived experience of choice and autonomy for adults with physical disability, based on the review of the literature and the findings from these participants.

Each of the strands require further investigation, but it is hoped that with further work, the framework could be developed to become a useful resource for service providers, educators, and most importantly, disabled people.

To create a whole picture of autonomy and choice for people with physical disabilities, this work suggests that the five strands are needed together, and each strand needs to be assessed in relation to each person. As is highlighted in several of the strands, a nuanced, subjective understanding of both the characteristics of the experience / environment and of the person's perceptions is needed.

Below, each strand of the choice and autonomy framework will be described, with particular information about how it can be developed in the future.

Strand 1: The meaning of autonomy

Integrating the literature reviewed, and the experiences of the participants, the key characteristic of autonomy seems to be an agentic core: autonomy is about agency, taking control, making decisions and being self-governing. This may occur with or without support from other people.

Within the psychological literature, distinctions are made in types of autonomy, particularly about interpersonal relations – the closeness or separation from others or the extent to which people take advice from others (Kagitcibasi, 1996; Hmel & Pincus, 2002; Koestner & Losier, 1996). While these distinctions may be important, this work has not highlighted the importance of these concepts, particularly as all of the participants need to build relationships with others, some of whom provide personal assistance with self-care and other occupations.

The feature of autonomy that does seem to be important is the distinction between "decisional" and "executional" autonomy (Cardol, DeJong and Ward, 2002) Within the choice and autonomy framework, these concepts are separated: this first strand focuses on decisional autonomy. Executional autonomy, or enacting choices is part of the experience of autonomy (strand 3).

When used to describe an individual, the first strand aims to understand what people mean by autonomy, and presents it as making choices and governing oneself. Relationships with other people, and the management of control all come into a description of autonomy. It is suggested that autonomy needs to be described and defined by an individual in his or her own life.

Strand 2: Whether or not autonomy is a need, goal or value

The participants in this study clearly value autonomy differently: for some it is a goal and value, for others it is simply a value, and for others it is less important.

When autonomy is highly valued, participants may also strive to be (or remain) autonomous: they desire autonomy, and actively seek it in their daily lives. Others value the control or choice that they have, but may not strive to "be autonomous.

More research is needed about whether or not autonomy is actually needed by people, and whether those who strive for more autonomy have greater well-being than those who do not

An important conclusion from this strand is that people differ in the extent to which they value, desire and work for autonomy in their daily occupational lives. Further investigation is required on the extent to which the need/desire for autonomy is a personality trait, comparable to Berger's construct 'desire for control' (Berger, 1988), and, alternately, the extent to which need/desire for autonomy is a complex of experience and learned cognitions.

It is also hypothesised that desire for autonomy and choice in daily life will influence selection of occupations and environments, and will influence interpretations of experiences.

When used with people with physical disabilities, the choice and autonomy framework would need to include examination of the extent to which the person desires autonomy, and whether or not this is a value for them. Understanding this key difference could better enable services to be tailored to the needs and wishes of the individual. It could help with creating an appropriate person-environment fit, and could help individuals themselves to interpret their life experiences and decisions.

It is hypothesised that desire for autonomy is not directly related to situations or experiences of autonomy (strand 3) or environmental contexts. Longitudinal research would be helpful to determine the extent to which need/desire for autonomy changes over the life-time, and the extent to which it is a personality trait.

Strand 3: Experiences of autonomy

In previous sections of this work, the third strand was titled "what daily experience of autonomy (or lack of autonomy) is "like"". This title has evolved, because ongoing experiences of autonomy seem to be more important than a situation-specific account of autonomy.

The first main conclusion of this strand is that people differ in their experiences of autonomy and choice in daily life. The participants experience choice and autonomy, or are thwarted in their choice and autonomy on a daily basis. Certain experiences promote a sense of autonomy (such as success), and others hinder it (such as inability to enact choices). It seems clear that, for a given individual, some situations are more likely to promote certain experiences, be these positive or negative. The most clear example of experiences where feelings of choice and autonomy are negatively affected is where choices cannot be enacted, due to physical disability, inaccessibility or other issues.

This concept of experience of autonomy relates to Cardol et al's (2002) "executional autonomy" – the ability to enact choices or perform given occupations.

Lack of appropriate assistance, particularly with self-care tasks seems to undermine a person's experience of autonomy. This may be the manner in which assistance is provided, a lack of assistance, or even a person's interpretation of

the need for assistance. Appropriate assistance, on the other hand, seems to support autonomy.

Further research is needed on the effect of occupational performance, patterning and engagement on autonomy is required. This may involve research on the role of certain occupations, such as productivity or leisure and the meaning of these, patterns and routines and the extent to which a person feels that they are a part of and contribute to a social network.

It is suggested that feelings of autonomy are situation-specific. For example, even the apparently most autonomous person in this study (Anna) reports not feeling autonomous in some situations. Could autonomy, as an experience, mirror concepts of self-efficacy?

A crucial hypothesis arising from the findings of this research is that people interpret or understand their experiences of autonomy and choice in different ways. So, the same situation can promote feelings of autonomy in one person but undermine them in another. Further research into the development of the thoughts that make people feel autonomous or not would be of considerable value.

The experience of choice seems to be that choices need to be meaningful, which means that people can act upon their choices. When choices are not perceived to be actionable, this seems to lead to a certain sense of frustration. Previous life history and identity (e.g. disability identity) seem to influence choice-making, and perceptions of reasons why choices can or cannot be enacted.

As with other psychological theories (such as self-efficacy), perceptions about "how" autonomous a person feels are likely to be developed throughout the life span (Agich, 2003). Some of the participants have been actively making and enacting choices, and taking control of aspects of their life, which, it is suggested, has led to a sense of autonomy. Others continually experience difficulties in that choices that they want to make are not possible, for example, due to their perceptions of physical disability.

The most noteworthy difference found is that change in situation (deterioration of or onset of disability) rather than the nature of the disability or situation affect perceptions of autonomy more. Thus, as was found in the current work, those with acquired disability look back on a life full of choices, most of which are no longer possible. For a person with a congenital disability, disability is the status quo, so has less of an impact on perceptions of autonomy. On the other hand, the development to a greater or lesser degree of a disability identity can be assumed in people with congenital or long-standing disabilities.

Strand three, then, comprises of perceptions and experiences of autonomy. Certain situations can promote autonomy, but equally important is that individuals may view situations through a filter of their own perceptions of autonomy. A person's perceptions of their own autonomy develop throughout the life-span, and perception of autonomy seems to be situation-specific.

When used with people with physical disability, this strand would focus on identifying situations in which a person feels autonomous, and in control, and when they feel that they are not. It would involve examination of situations throughout the life to enable an understanding of that individual's own concept of autonomy. Such an understanding would enable an individual to better match their desire for autonomy with situations, so that a positive spiral of matching desire and expectations can be developed.

Strand 4: Whether concepts of autonomy overlap other psychological theories

As previously described, parallels have been found within a range of the psychological theories, such as control and self-efficacy; happiness and choice; choice and self-efficacy; coping mechanisms and control etc. The concept of autonomy may overlap some of these theories, particularly theories of control and self-efficacy. This strand needs further investigation, but if there are overlaps with

other concepts, then it would suggest that such concepts are also considered for individuals.

Quantitative research investigating whether there are correlations between factors such as desire for control and desire for autonomy, experience of autonomy and self-efficacy, happiness and perceptions of autonomy, perceptions of a lack of autonomy and learned helplessness, and other concepts is required. Also, the key and fundamental questions whether, when and for whom autonomy is desirable and promotes well-being and life satisfaction should be studied with large samples.

Strand 5: The impact of the environment on autonomy and choice

Similar to concepts within strand 3, this strand involves two central aspects: one is the objective environmental circumstances, and the other is the person's perception or interpretation of these circumstances.

As has been found in relation to control, for example (e.g. Shapiro et al, 1996), findings of this work clearly support the need for a person-environment fit when it comes to autonomy. An understanding of the meaning, importance and desire for autonomy will make it easier to suggest possible environmental features to support the individual.

This research has found that the person-environment match or mis-match of most importance is in relation to living situation. It seems clear that different types of accommodation and assistance suit different people, and a variety of services should be provided for disabled people.

Throughout the data collected, unless people have fought to live where they do (such as Anna) or actively chose it (as Emily did), the participants have "ended up" in environments that may or may not be satisfactory. Have participants been

asked what they want? When considering a person-environment fit, a person's preferences and hopes need to be considered.

People change their environments as well as are changed by them (Bandura, 1989). For some people, the "right" environment may be one that needs some changing, and is fluid and open to change. This, for example, could be the case for Anna – challenging and actively managing the environment promotes her self-perception as an independent, autonomous person. For others, more stable, consistent environments that need little control may be more suitable.

The physical (and social) access issues that arise from poor building design and management clearly affect autonomy of participants. Difficulties in the design of homes and residential settings that offer little privacy or space have been well documented in the literature, and are clearly an important concern of all of the participants in this study. Well designed spaces and people with positive attitudes towards inclusion seem to be central in ensuring person-environment fit.

When used with disabled people, this strand of the choice and autonomy framework would involve an objective assessment of environmental characteristics, coupled with the individual's interpretation of these. This would allow for adaptation of the environment or selection of environments to better meet the needs and desires of the individual. While objective assessment of and adaptation of an environment may seem large, it is possible that very small changes could make a significant difference to participants.

The next few sections highlight the implications of the work, as a whole, for service provision, occupational therapy practice and occupational therapy education.

Implications for service provision

There are a wide variety of implications for service provision arising from this study. These relate to: 1) the nature of service provision, and the extent to which services meet individual needs; 2) the need to aim for person-environment congruence for autonomy, control and choice; and 3) the need for more information to be available and a wider variety of options for living arrangements to be available.

Service provision

It is evident that for the majority, if not all, of the participants, there are difficulties with service provision. For those living in the community, it seems that fighting for services is an unavoidable and difficult aspect of life. This reflects poorly on service provision and attitudes to disabled people striving to live independently.

Similarly, the situations of community-dwelling participants Freya and Honour, in terms of their physical environment, were poor and inadequate and reflect badly on the level of service provided in what is after all a wealthy country. It seems not to be the best use of resources nor supportive of a person's choice or autonomy, to provide services to a person in an environment, which the individuals perceive to be dangerous. Adaptation or re-housing of individuals so that the environment is supportive of their function, and of the work of a personal assistant is clearly necessary.

It seems that the situation for Freya and Honour are somewhat precarious: both are at risk of falling, and, particularly in the case of Freya, depending on informal assistance, rather than availing of a comprehensive service provision package, of which the disabled person has control.

The result that there is one individual, who cannot and does not leave her home, (with the exception of one visit by a community occupational therapist), very clearly suggests that there is inadequate support for this individual. As proposed by Morris (2004), services should be provided that enable individuals to participate in a wide variety of productivity and leisure occupations; not simply the most basic assistance for self-care tasks.

There needs to be planning for and progressive support to individuals living in the community, as their needs change. It is clear that this is not the case for participants in this study. Anna needs to fight for her service provision, and is able to do so only because she is confident and articulate enough to do so: others, such as Freya and Honour and presumably many others, seem not to be able to advocate as effectively for their needs.

This research has also highlighted shortfalls in service provision in residential settings, particularly the impact of the nature of service provision on an individual's sense of autonomy or choice. There needs to be very careful consideration of the potential implications of policies, such as an aim to make all residents perform as many self-care tasks as possible, on the individual.

The power of the professional, in deciding the amount of support an individual requires, and also whether or not an individual can leave a setting must be questioned. There is a clear need for further debate, and research into the human, individual implications of such actions, and whether these can lead to oppression. It seems that if "safety risks" are suspected, professionals have, in some circumstances (such as that of Deirdre), then imposed rules that could have negative consequences for individual autonomy and choice.

Person-environment congruence for autonomy

One notable implication, arising from the key finding that people are very diverse in their understanding of, need for and approach to autonomy, independence, choice and control, is that effort should be made to enable person-environment congruence, that supports an individual's personal desire for autonomy and choice.

Furthermore, there should be more careful investigation of the person's level of autonomy and control, and their desire for autonomy, choice and control, in order to establish, with them, the most appropriate form of personal assistance and living arrangement.

Options for living arrangements

It is recognised that the Health Service Executive plan to reduce the number of people living in residential settings, but, careful consideration of both the supports available in the community for independent living and of restructuring residential settings so that they are more appropriate for those people that do not wish to undertake independent living are recommended.

Three of the four individuals living in a residential setting in this study demonstrated that they do not understand, or have not had access to adequate information about the nature of independent living or alternative arrangements. The three participants suggest that they would need to be more physically able and would need to be able to perform self-care tasks unassisted to live in the community. This is clearly inaccurate, and people with physical disabilities should be fully informed of their options for living arrangements.

The ERHA report highlighted that, although disabled people report preferring independent living and supported living options, that there are no objective measures of the success of these arrangements (ERHA, 2003). The call for such research remains valid and appropriate.

Implications for occupational therapy practice

This research could pose many questions for occupational therapy, including whether or not consideration of autonomy and choice should be core first steps in any intervention programme with adults with physical disability; the impact of the profession's focus on doing, or occupational performance; the impact of certain interventions, such as provision of equipment, and, further, there is a need to re-evaluate the profession's understanding of independence.

Consideration of autonomy and choice

The concepts of autonomy and choice have been central to this work. Occupational therapy, which aims to promote occupational performance should take more account of an individual's autonomy and choice, including their desire for autonomy and choice, and their experience of these concepts.

All of the participants have been, or are in receipt of occupational therapy services, but the extent to which their autonomy or choice have been supported by this intervention is questionable. It is suggested that an understanding of autonomy and choice is important for any occupational therapy intervention with clients, thus further exploration of these concepts within the occupational therapy literature is warranted.

Further development of the Choice and Autonomy Framework will, it is hoped, result in the development of assessment and intervention techniques that may be used to assist occupational therapists in considering the autonomy of individuals with whom they work.

Focus on doing, or occupational performance

This research has presented the daily lives of the eight adults, and has been influenced by the focus from within occupational therapy on doing, or occupational performance. The assumed links between occupational performance and well-being, and between autonomy and choice and occupational performance clearly require further research.

It has been useful to explore the actual daily lives of the individuals in this research and the impact of their lived experience on their sense of autonomy, especially since the findings strongly confirm the need for occupational therapy to recognise and respect the very personalised and individual perspectives on autonomy that people develop over the life span. Further research into occupational performance and occupational patterning, with a view to understanding the relationship between autonomy and occupational performance and developing methods by which occupational therapy could assess and respond to clients' particular needs in respect of autonomy, choice, control and independence would undoubtedly be helpful.

The participants in this research were engaged in a variety of different occupations, some of which were meaningful to the individual. The purpose and meaning of occupational performance should be further investigated, and considered in a clinical context. Of particular interest is the psychological processing of meaning, and descriptions of the purpose of occupational performance in the context of individual identity.

Impact of certain interventions

Some of the participants in this study described the negative impact of equipment on their dignity and sense of self. While equipment, such as a hoist, is clearly necessary in many cases, the over-use of equipment, and more particularly the influence that provision of equipment has on an individual needs to be further investigated. Occupational therapists would be well advised to endeavour to understand the potential impact of equipment on each individual client prior to its prescription.

Deirdre describes occupational therapy intervention to enable her to put her bra on, involving Velcro and a dressing stick. It is clear that the occupational therapist in this situation was working within the ethos of the residential setting, which aimed, in Deirdre's words, to make her independent. It is suggested that occupational therapists should also consider the individual needs and wishes of clients prior to providing such interventions, so that the dignity of the individual is not compromised.

Re-evaluation of the concept of independence

This research has highlighted the variety of views of independence found in the literature. Occupational therapy seems to straddle the professional and control views of independence. As a profession, it is suggested that independence is highly valuable. The value and nature of independence should be carefully considered by the profession as a whole; furthermore, individual therapists should seek to understand the meaning of independence to each client, so as to promote the client's perception of the concept.

Impact on occupational therapy education

This research has implications for the education of occupational therapists in the future. Given the issues raised in the above section, it seems prudent to include measures in the education of future therapists that enable them to include concepts of independence, disability studies and concepts of autonomy as an integral clinical reasoning skill.

Occupational therapy education should involve further exploration of concepts of independence and autonomy in occupational performance and engagement. Studies in the past (e.g. Taylor, 2001; Block et al, 2005) have shown that students can develop their understanding of such concepts through their professional education, and such development is essential to the profession (Taylor, 2001; Kielhofner, 2005).

Conclusions

This research has explored the lifestyles and perspectives of eight adults with significant physical disability, with a particular focus on the meaning of autonomy and choice in their daily lives, where sometimes their level of choice is extraordinarily restricted. This has involved an extensive exploration of the literature, detailed description of the individuals' lives and lifestyles, and interpretation of their accounts of autonomy and choice.

Autonomy has been frequently and variously described within the psychological and rehabilitation literature, but it is clear that a more nuanced understanding is needed. Much of the previous research involves quantitative methodologies that "smooth over" the

details of autonomy. This exploration concludes that there is a gap between literature in rehabilitation and in psychology; that the assertions that autonomy is a pan-human need is an over-simplification and does not highlight the idiosyncratic meaning and value of autonomy to individuals, particularly those with physical disabilities, and that further investigation of the relationship between autonomy, control, choice and independence, and their impact on well-being is required.

Further investigation is warranted into the situations in which autonomy, of any form, is developed. In particular, further investigation into factors such as the impact of congenital or acquired disability on a person's sense of autonomy is needed.

Participants' choice and feelings of choice were investigated. It is concluded that the assumption that choice is always good needs to be questioned. For people with physical disability, choice without supports (such as personal assistance or access) may not be meaningful; it may be useful to undertake further study to examine whether such choices are actually harmful.

The methodology used for this work has enabled many findings of interest to be uncovered. Further investigation of concepts such as autonomy, choice, control and independence, with a focus on daily life for a range of people of different ages and abilities would contribute positively to the occupational therapy, rehabilitation and psychological discourse.

This study has not only identified issues with service provision, but also, to some degree, the effect that these have on an individual's sense of choice and autonomy. Clearly, there is a need to match service provision to the needs of individuals in terms of both their physical ability/disability and also in terms of their desire for control and autonomy.

While there is much debate over semantics, this research nevertheless has investigated an evidently important aspect of people's lives. It may not be possible to exactly state which form of autonomy, as described within the psychological or rehabilitation literature is relevant to the participants, but the participants did describe in their own terms the meaning of this concept to themselves. This was a primary concern of this exploration and there can be little doubt but that, by the participants' own account, autonomy and

related issues of choice, control and independence, albeit in a variety of guises, are of crucial importance in their lives.

It is clear, from the findings of this work, that the suggestion that one form of living accommodation (such as independent living) is necessarily better than another, is invalid as a general principle, however relevant and appropriate it is for certain individuals. What is required is a sensitive, person-centred form of assessment, which is aimed directly at achieving a satisfactory measure of person-environment congruence with respect to the care environment for physically disabled people. Sometimes, listening to the individual's views on their own autonomy, control and choice needs will suggest less than maximally autonomous or independent care provision solutions as most suited to that person. People find their own, sometimes strange and often unexpected, ways to be autonomous and independent.

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Appendices

Appendix A: Raw Data

Appendix A1: Self-Maintenance and Diary Information

Anna: Self-Maintenance (daily routine) activities.

In relation to the specific daily self-maintenance tasks:

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
Getting up/showered and dressed each morning	Own home		45/50 minutes	Yes	PA and equipment	Yes	Yes
Toileting	Own home & work place	3-4 times per day	10 minutes	Yes	PA and equipment	Yes	Yes
Cooking	Own home	Morning & Evening	10 -50 minutes	Yes	PA with guidance/instruction	Yes	Yes
Going to bed	Own home	Each night	20 -25 minutes	Yes	PA and equipment	Yes	Yes

Anna: Diary Information

Day 1							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Showered & dressed	**S**	Home	S- 11.30 F- 12.30	**w PA**	**yes**	NA	**Yes**
Sent e-mails, listened to music etc.	**L**	Home	S- 2pm F- 4pm	**A**	**Yes**	**Yes**	**es**
Met a friend	**L**	City Centre	S- 4.30 F- 7 pm	**W Friend**	**Yes**	**Yes**	**Yes**
Watched TV & made phone calls	**L**	Home	S- 7.30 pm F- 11 pm	**W PA**	**Yes**	**Yes**	**Yes**
Went to bed	**S**	Home	S- 11pm F- 11.15	**W PA**	NA	NA	**Yes**
Day 2							
Showered & dressed breakfast	**S**	Home	S- 7.10am F- 8.30am	**W PA**	**Yes**	N/A	**Yes**
Went to work	**P**	Work place	S- 9.30am F- 5.30pm	**W PA**	**Yes**	**Yes**	**Yes**

Cooked dinner with PA	**S**	Home	S- 6.30pm F- 7.30pm	**W PA**	**Yes**	**Yes**	**Yes**
Watched TV	**L**	Home	S- 7.30pm F- 9.30pm	**W PA**	**a little**	**Yes**	**Yes**
Reading & listening to music	**L**	Home	S- 9.30pm F- 10.30pm	**W PA**	**Yes**	**Yes**	**Yes**
Bed	**S**	Home	S- 10.45pm F- 11.05pm	**W PA**	N/A	N/A	**Yes**

Day 3							
Showered & dressed breakfast	**S**	Home	S- 7.30am F- 8.30am	**W PA**	**Yes**	N/A	Yes
Went to work	**P**	Work place	S- 9.30am F- 5.30pm	**W PA**	**Yes**	**Yes**	**Yes**
Cooked dinner with PA	**S**	Home	S- 6.30pm F- 7.30pm	**W PA**	**Yes**	**Yes**	**Yes**
Watched TV	**L**	Home	S- 7.30pm F- 8.30pm	**W PA**	**a little**	**Yes**	**Yes**
Internet, e-mail telephone	**L**	Home	S- 8.30pm F- 9.45pm	**W PA**	**Yes**	**Yes**	**Yes**
Listened to music, reading in bed	**L**	Home	S- 10pm F- 11.30pm	**W PA**	**Yes**	**Yes**	**Yes**

Day 4							
Showered & dressed	**S**	Home	S- 10am F- 11.30am	**W PA**	**N/A**	**N/A**	**Yes**
Go into town in powered wheelchair	**L**	N/A	S- 2.30pm F- 3pm	**W PA**	**Yes**	**Yes**	**Yes**
Go to hair salon	**S**	N/A	S- 3pm F- 3.45pm	**W PA**	**Yes**	**Yes**	**Yes**
Go for coffee	**L**	City centre	S- 5pm F- 5.45pm	**W PA**	**Yes**	**Yes**	**Yes**
Go around shops	**L**	City centre	S- 5.45pm F- 7.15pm	**A**	**Yes**	**Yes**	**Yes**
Watch TV	**L**	Home	S- 9pm F- 11pm	**W PA**	**Yes**	**Yes**	**Yes**

Day 5							
Showered/dressed Breakfast	**S**	Home	S- 12 midday F- 2pm	**W PA**	**Yes**	**Yes**	**Yes**
Chatted to friend & we cooked dinner	**S/L**	Home	S- 3pm F- 7pm	**W Friend**	**Yes**	**Yes**	**Yes**
Watched TV	**L**	Home	S- 7pm F- 9pm	**W PA & friend**	**Yes**	**Yes**	**Yes**
Went to Pub	**L**	N/A	S- 9.15am F- 1.30pm	**W Friend**	**Yes**	**Yes**	**Yes**

Day 6							
Showered & Dressed	**S**	Home	S- F-	**WPA**	**N/A**	**N/A**	**Yes**
work	**P**	work		**WPA**			
TV/Music/Internet	**L**	Home	S- 2pm F- 6pm	**A**	**Yes**	**Yes**	**es**
Friend visited/order takeaway/chatted	**L**	Home	S- 6pm F- 9pm	**W friend**	**Yes**	**Yes**	**Yes**
Bed/Reading	**S/L**	Home	S- 9.30pm F- 11pm	**WPA**	**Yes**	**Yes**	**Yes**

Day 7							
Showered & dressed	**S**	Home	S- 9am F- 10.30am	**W PA**	**N/A**	**N/A**	**Yes**
Went to Peer Counselling Supervision meeting	**Volunteer P/L**	IWA Clontarf	S- 11am F- 3.30pm	**A**	**Yes**	**Yes**	**Yes**
Went to friends art exhibition	**L**	Botanic Gardens	S- 4.30pm F- 5.45pm	**Friend**	**Yes**	**Yes**	**Yes**
Went for drink with friends	**L**	Glasnevin	S- 6pm F- 7.30pm	**W Friend**	**Yes**	**Yes**	**Yes**
Went to cinema	**L**	City Centre	S- 8.30pm F- 11.30pm	**W Friend**	**Yes**	**Yes**	**Yes**

Bed	**S**	Home	S- 11.45pm F- 00.15am	**W PA**	**N/A**	**N/A**	**Yes**

Bart: Self-Maintenance (daily routine) activities.

Self-maintenance activities are the activities that are commonly performed by most people every day to stay healthy. These may include getting up, washing, dressing, toileting, eating, etc. Please give as much information as you can. (It is easier to think of these in terms of the routine of a typical day).

In relation to the specific daily self-maintenance tasks:

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
Brushing teeth	Either in kitchen or bathroom	Depends on where we are at the time	Two minutes	Yes	Assistant puts automatic brush in my mouth and I spit out into a bowl	Sometimes yes, sometimes no. It's not really a routine.	Sometimes I forget
Taking a dump	In the bathroom	Night time usually. It's routine based.	Twenty five minutes.	Yes	Assistant lifts me onto the toilet chair and inserts an enema into my rectum	It's a daily need	Yes
Choosing what to wear	In the bedroom	Morning	Two minutes	Yes	Assistant selects clothes	Not really. I am slow waking up	They just do it Maybe I'll change the

							task from morning to night

Bart3: Diary Information

Date:Sunday, September 28		**Day 1**					
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Eating breakfast (mother sent out cooked sausages from next door)	L	Kitchen	S-12.30 F-1.30	With PA	A little	A little	Some
Eating Sunday dinner in my mother's	P+L	My mother's kitchen	S-6.00 F-7.00	With PA	Yes	A little	Yes
Washing my van	S+P	Driveway	S-2.00 F-4.00	With PA	A little	Yes	Some
Watching a dvd	L	My mother's sitting-room	S-8.30 F-10.30	With family	Yes	Yes	Yes

Taking a dump	S	Bathroom	S-11.30 F-12.30	With PA	Yes	Yes	Yes

Day 2

Date:Monday, September 29

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Choosing what to wear	S+L	Bedroom	S-9.00 F-9.02	With PA	A little	No	No
Eating breakfast	S	Kitchen	S-9.30 F-10.00	With PA	Yes	Yes	Yes
Checking email	P	Kitchen	S-10.00 F-11.00	Alone	Yes	Yes	Yes
Putting clothes in wash	S	My mother's kitchen	S-10.00 F-11.00	PA	Yes	Yes	Some
Phone-call to Dublin Corporation	P	Kitchen	S-11.15 F-11.30	With PA	Yes	Yes	Some
Eating lunch	S	Kitchen	S-13.00 F-14.00	With PA	Yes	Yes	Yes
Drying clothes	S	My mother's kitchen	S-15.00 F-17.00	PA	Yes	Yes	Some
Eating dinner	S	Kitchen	S-19.00 F-20.00	With PA	Yes	Yes	Some
Giving PA a break	P	Kitchen	S-20.00 F-23.00	A	A little	A little	Yes

Taking a dump	S	Bathroom	S-12.00 F-1.00	With PA	Yes	Yes	Yes
Masturbation	L	Bed	1.00 1.30	A	Yes	Yes	Yes

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Date:Tuesday, September 30			**Day 3**				
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Choosing what to wear	S+L	Bedroom	S-9.00 F-9.02	With PA	A little	A little	No
Eating breakfast	S	Kitchen	S-9.30 F-10.00	With PA	Yes	Yes	Yes
Checking email	P	Kitchen	S-10.00 F-11.00	With PA	Yes	Yes	Yes
Grocery shopping	S	Blanchardstown Town Centre	S-11.30 F-12.30	With PA	A little	Yes	Yes
Lunch	S	Kitchen	S-1.00 F-2.00	With PA	Yes	Yes	Yes
Taking a walk	P+L	From the house to the village	S-2.00 F-4.00	With PA	Yes	Yes	Yes
Dinner	S	Kitchen	S-6.00 F-8.99	With PA	Yes	Yes	Yes
Giving PA a break	P	Kitchen	S-8.00 F-11.00	A	A little	Yes	Some

Watching a dvd	L	My mother's sitting-room	S-9.00 F-11.00	With family	Yes	Yes	Yes
Taking a dump	S	Bathroom	S-12.00 F-1.00	With PA	Yes	Yes	Yes
Date:Wednesday, October 1			**Day 4**				
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Choosing what to wear	S+L	Bedroom	S-9.00 F-9.02	With PA	A little	A little	Some
Checking email	P	Kitchen	S-10.00 F-12.00	With PA	Yes	Yes	Yes
Putting clothes in wash	P	My mother's kitchen	S-10.00 F-12.00	With PA	Yes	Yes	Some
Lunch	S	Kitchen	S-1.00 F-2.00	With PA	Yes	Yes	Yes
Giving PA a break	P	Kitchen	S-2.00 F-5.00	A	A little	Yes	Yes
Checking email and watching television	P+L	Kitchen	S-2.00 F-5.00	With PA	Yes	Yes	Yes
Dinner	S	Kitchen	S-7.00 F-8.00	With PA	Yes	Yes	Yes
Checking email	P	Kitchen	S-8.00 F-10.00	With PA	Yes	Yes	Yes

Watching TV	L	Kitchen	S-10.00 F-12.00	With PA	Yes	Yes	Yes
Taking a dump	S	Kitchen	S-12.00 F-1.00	With PA	Yes	Yes	Yes

Day 5

Date:Thursday, October 2

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Choosing what to wear	S	Bed	S-9.00 F-9.02	With PA	A little	Yes	Yes
Eating breakfast	S	Kitchen	S-9.00 F-10.00	With PA	Yes	Yes	Yes
Checking email	P	Kitchen	S-10.00 F-12.00	With PA	Yes	Yes	Yes
Lunch	S	Kitchen	S-1.00 F-2.00	With PA	Yes	Yes	Yes
Buying voucher in Blanchardstown	P		S- 2.00 F-3.00	With PA	Yes	Yes	Yes
Phone-calls	P	Kitchen	S-3.00 F-4.00	With	Yes	A little	Some
Checking email	P	Kitchen	S-4.00 F-5.00	With PA	Yes	Yes	Yes
Dinner	S	Kitchen	S-6.00 F-7.00	With PA	Yes	Yes	Yes

Giving PA a break	P	Kitchen	S-7.00 F-10.00	A	A little	A little	Yes
Reading an ebook	P	Kitchen	S-7.00 F-10.00	A	Yes	Yes	Yes
Taking a dump	S	Kitchen	12.00 1.00	With PA	Yes	Yes	Yes

Day 6

Date:Friday, October 3

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Choosing what to wear	S	Bed	S-9.00 F-9.02	With PA	A little	Yes	Yes
Eating breakfast	S	Kitchen	S-9.00 F-10.00	With PA	Yes	Yes	Yes
Taking a walk	P	Kitchen	S-10.00 F-12.00	With PA	Yes	Yes	Yes
Lunch	S	Kitchen	S-1.00 F-2.00	With PA	Yes	Yes	Yes
Giving PA a break	P	Kitchen	S-2.00 F-5.00	A	A little	A little	Yes
Checking email	P	Kitchen	S-2.00 F-3.00	A	Yes	Yes	Yes
Reading an ebook	P	Kitchen	S-4.00 F-5.00	A	Yes	Yes	Yes

Dinner	S	Kitchen	S-6.00 F-7.00	With PA	Yes	Yes	Yes
Checking email	P	Kitchen	S-7.00 F-8.00	A	Yes	Yes	Yes
Pub	P	Kitchen	S-8.00 F-11.00	With PA	Yes	Yes	Yes
Taking a dump	S	Kitchen	12.00 1.00	With PA	Yes	Yes	Yes

Day 7

Date:Saturday, October 4

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Choosing what to wear	S	Bed	S-9.00 F-9.02	With PA	A little	Yes	Yes
Eating breakfast	S	Kitchen	S-9.00 F-10.00	With PA	Yes	Yes	Yes
Taking a walk	P	Kitchen	S-10.00 F-12.00	With PA	Yes	Yes	Yes
Lunch	S	Kitchen	S-1.00 F-2.00	With PA	Yes	Yes	Yes
Giving PA a break	P		S- 2.00 F-5.00	A	Yes	Yes	Yes
Checking email	P	Kitchen	S-3.00 F-4.00	A	Yes	A little	Some

Reading an ebook	P	Kitchen	S-4.00 F-5.00	A	Yes	Yes	Yes
Dinner	S	My mother's sitting-room	S-6.00 F-7.00	With PA	Yes	Yes	Some
Party	L	Pilmico	S-7.00 F-10.00	With PA	Yes	Yes	Yes
Taking a dump	S	Kitchen	12.00 1.00	With PA	Yes	Yes	Yes

Day 8

Date:Sunday, October 6

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Choosing what to wear	S	Bed	S-10.00 F-10.02	With PA	Yes	Yes	Yes
Eating breakfast	S	Kitchen	S-9.00 F-10.00	With PA	Yes	Yes	Yes
Listening to the radio	L	Kitchen	S-10.00 F-12.00	With PA	Yes	Yes	Yes
Father's anniversary mass	S	Castleknock church	S-12.00 F-1.00	With PA	Yes	Yes	Yes
Family get-together	P		S- 2.00 F-3.00	With PA	Yes	Yes	Yes
Taking a dump	S	Bathroom	S-3.00 F-4.00	With PA	Yes	Yes	Yes

Dinner	S	My mother's kitchen	S-4.00 F-5.00	With PA	Yes	Yes	Yes
Emailing PA timesheets	P	Kitchen	S-6.00 F-7.00	With PA	Yes	Yes	Yes
Giving PA a break	P	Kitchen	S-7.00 F-10.00	A	A little	A little	Yes
Watching a film	L	Kitchen	S-7.00 F-10.00	A	Yes	Yes	Yes
Taking a dump	S	Kitchen	12.00 1.00	With PA	Yes	Yes	Yes

Cathal: Self-Maintenance (daily routine) activities.

In relation to the specific daily self-maintenance tasks:

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
Get up	Here [in ward, and adjoining bathroom[	8 a.m. most days but later on Fridays and weekends	30 minutes or more	Yes – full assistance Use a hoisr, staff, into chair Washed and shower totally with assistance "I am washed **by them"** it would take me two days to have a shower. That's with assistance, totally with assistance.	Hoist from bed to chair. Full assistance for shower and washing/dressing	Some "Never even thought about it" "Choice in as much as the staff wouldn't do anything if I said, 'no, I don't want that'. I need assistance anyway, so I don't have choice in that and that's not their fault." Chooses clothes, but it depends about soaps etc because of infection control.	Some "I've had a few run-ins because I find Friday Mornings I'm not going to college on Fridays and they are here first thing. On Mondays, I have to ring for assistance because they have forgotten that I am getting up to go to college" At times it can be a bit Annoying Need to ask I have what you would call limited

							control, I could have said this morning 'could you give me another hour', and they would have, but I didn't think to ask.
Eat Breakfast	Dining room in unit.	Around 9.00 a.m. "9 or thereabouts"	15 – 20 minutes	Sometimes "Rarely" use assistance to eat breakfast, but breakfast is given.	Help with spoon, "If my arms are week I would need help with the spoon."	Some "To an extent with the time but they don't like to go past 9.30 or 10.00. Yes over what eat, can buy whatever you want and bring it to the kitchen, but otherwise a small choice	Some "If I felt able to change them, and I wanted to then yes, I suppose I could change things" "physically able" there is a facility where people who are physically able can make their own breakfast". "They have more freedom for time". Prefer to have the choice to make own breakfast.
Shaving and brushing teeth	In ward	9.30 ish	About 30 minutes. Time is dictated by needing to be ready for college. Good to have time deadlines, good to need to have some discipline. Time	No Once set up with electric toothbrush and razor.		Yes Never think about it just do it.	Yes Yes, in the sense that if I didn't feel like shaving I wouldn't be hounded to shave.

			demands remind of work and former need to always check the clock				Choice and control over assistance. "People here appear always to be on-hand, If you are having serious trouble when you need assistance, they will offer it",
Toilet	In bathroom next to ward	Between 9.30 and 10.00	depends	Yes Full assistance	Hoisted plus full assistance. Left once hoisted onto toilet, but staff return soon.	No Don't look to have control or choice. I have to be hoisted anyway, so I don't look to have choice or control.	No
Lunch	In college	1.00	30 minutes	**Yes**	Quite often I would need assistance with eating. There are staff there. Happy with the assistance	Yes **Over what eaten**	Yes **Control over whether assisted.**
Tea as breakfast	In dining room	5.00	depends	Sometimes	As with breakfast	As with breakfast	As with breakfast
Go to bed	In bedroom/ward	Depends – usually after 11.00.	30 minutes	Yes	Hoisting, and full assistance needed.	Some Staff have a tendency to ask if you want to go to bed maybe at 9.00 . And at 46 years old, I am a	Some They allow you to have control, and will give the time, so there is nobody saying you have to go to

						bit retisent to go to bed at 9.00 or half nine or whatever.	bed. The only pressure is their break time comes around 11.00 or half 11. And that, there is pressure there, if I haven't got into bed before the break time then, if youlike, I have to resign myself to being put into bed after. Because I think to expect them to forgo their break is a bit selfish. Have control except at break time.

Cathl: Diary Information

Day 1							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
College	Leisure, not looking to do a job but in some ways replaces work	In the college. Hospital transport to college	Leave at 10, come back around 3.30	No carer or helper, but in a class,	Yes In the sense that Fridays are very long, To fill the day sense of having done something Personality?	Yes Check e-mail!	Chose in the first place, brought on the days
Visitors	Leisure, but also important for mood. therapeutic	here	7.30 – 8.30	With	Yes	Yes	If thought about it a degree of control. Don't wish to have control.
Watched DVDs	leiure	here	8.30 - 1200S- F-	Alone, used headphones	Yes, because watching what I want to watch rather than the tv	Yes	Yes

Day 2							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
college	L / P	College	S- 10.00 ish F- 4.00	W people in college	yes	Yes new computer tutor and she is very good, still learning, and enjoying it.	Some. Only time when don't have control is going and coming, have to be ready for when the driver is ready, driver decides what time because there are other pick-ups. They won't push if I am having a bad day through MS
Afternoon in bed Not chose, but didn't mind because things going wrong.	rest	Bed	S- all afternoon F-	Alone	Never enjoy but felt it helped	NO, but didn't feel good about things	Yes, and indicated when wanted to get up, and did get up for the evening.
Watched DVD	Leisure	Ward / bed	S – 7.30.	Alone	A little	A little	Yes, some. I chose what to watch and listen to.

Day 3							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
College	As with Day 1						
Went to watch football match with son	Leisure	Local pub	6.30 – 9.30	W	Yes	Yes, very much	Yes, in that I decided to go, and on this occasion had someone to bring me
Day 4							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
College	As with Day 1						
Went to bed early and listened to music	Sc L	Bed		A	It is important for my health, but not very important.	No, but it was helpful	Yes, some

Day 5							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Got up late	Self care	Bed		A	A little	Not really, but it is important to rest	It's not something I think about
Have a walk	Leisure	Just around the hospital			A little	Yes	Not really
Watch DVD	Leisure	Bed		A	A little	Yes	Ye
Watched TV	Leisure	Bed		A	No	A bit, it depends on what is on TV	Yes, I have it all set up here.
Day 6							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?

Went for a walk	L	Around grounds			Yes	Yes, mostly but it was a bit cold and the ground was wet for the powerchair.	To a certain extent, yes, but only in accessible locations
DVD	L	In beside my bed		A	A little	Yes,	Yes
Visitors	It's probably leisure but maybe self-care. It's important for my mind too.	Ward and coffee shop		W	Yes	Yes, but it is tiring	Not really, but I don't look to have control in this.
Listen to music	L	bed		A	A little	I did a bit	Yes, in that I listen to what i want to listen to
Day 7							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Go out with family	L	Went out with family		W	Yes	Yes, but i feel tired afterwards	I never even thought of it.

TV	L				No	Not really	I wouldn't really think of control in this.

Deirdre: Self-Maintenance (daily routine) activities.

In relation to the specific daily self-maintenance tasks:

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
Get up, bring water and toiletries clothes out	ward		9.30 2 hours	A little If I can't put my bra on and there is a	If you get assistance, grumpy.	No	What you wear. No
Teeth and hair	ward		Few minutes	no		yes	yes
Splints and cuffs on					OT puts on the splints and cuffs.		No
Breakfast	Dining room		Breakfast bar	If I can get it, but but order	Very useful	yes	no
Physio	Physio department	10.15	Depends, sometimes a long time, other times 45 minutes	Not much	Someone standing beside, transferring, Put the pillows in place Set up on machines	A little	Not complete control
Feed cat to get fresh air	outside	After lunch	no	no		yes	yes

Toilet			no	no		Yes / Some / No	Often a queue, depends on own health
Meals			provided			Yes, but not over when, but when out at weekend, but can get things made up	No

Deirdre: Diary Information

Day 1							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Physio	S	Phsyo gym in residential setting	S 10.30- F- 11.00	W physio / physio aid	Very (Yes)	Mostly a little	Some - leave it up to the physio.
Praywer meeting	Leisure and self-care, and to get away from wards. Feel good and relaxed in it.	Day room	S2.00- F-2.30	W	Yes	Yes	some, can partake in it if you want to. Choose to go
Fed cat	S / P / L All three	Grounds of setting	S- F-	A	Yes And to the cats	Yes	Yes
Bingo	Leisure and social reasons	Next door (Day room in setting	S 6/30 – 8.00- F-	W	Yes	Yes	Some - Choose to go. No choice when there

Day 2							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Physio	S	As with previous day					
Legion of Mary	Self-care	Ladies room	S- 2.00 - 4	W	yes	A little	Choice of whether go, but no choice when there
Social Work	s	Office of social worker	S- 3.00 – 4.00 F-	W social worker	Yes	Yes	A little, to an extent
Quiz	S and L	Room in residential setting	S 6.30 - F-8.00	W	Yes	Yes	Over whether og or not, but no choice once there.
Day 3							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?

Current Affairs	Self-care leisure	Reading room	S- 11.00 F- 12.00	W	Yes keeps you up to date, leisure as well	Yes	Some Control over going
Bowling	Self-care and leisure	Ladies day room	S 1.30 – 3.00- F-	W	Yes like going on a holiday nearly, really relaxed and joking crowd	Yes, very much	Yes
Relaxation	Self-care and leisure	In OT kitchen	S- 3.00 F- 4.30	W	A little	Yes	Some Choice over going
Church service	leisure	Day room	S-just grabbed me! F-	W	Yes	A little	Some Control over where go
Day 4							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Went down corridor Rosary was over	None really	Residential setting		A	No	No	Some – no control that activity was over
Looked at the books	Leisure and self care	Reading room	About an hour	A	A little	A little – just killing time	Yes

Coffee	Leisure	Coffee shop in residential setting	45 minutes	w	Yes – important to get off the ward and talk to people	Yes	Yes
Legion of Mary	S	Day room		W	Yes	Yes	Some – whether or not to go
Go out to the garden to pick some weeds, and dead-head. alone	S and Leisure Similar rto the cats, getting the fresh air	Grounds of setting	About an hour and a half	A	Yes	Yes	Yes
Day 5							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Went to mass	P and L	In residential setting		W	Yes	A little	Some – whether or not to go
Rang up sisters to find out who was meeting me	leisure	ward	10 minutes	A	A little	A little	Yes

Sister came Went down to the village and bought a few things and we went for lunch. Late and lots of places closed. Bought more things	Self-care and leisure	village	2.00 – 6.00	W	Yes very important	Yes	Yes
Day 6							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Went to Computers, but was not on in OT	P / L	OT	9.00 – should have been to 10.00, but went around hospital at 9.15	A	Yes, when it is on	No, because it was cancelled. Usually enjoy it	No But yes if it was on
Met friend	L	Coffee shop in residential setting	11.00 – 11.45	W friend	Yes	Yes	Yes
Exercise cancelled	S L	Hall in residential setting	2.00 and should go on to 3.00	W	Yes, but it was cancelled	No, because it was cancelled. Usually enjoy it	No But yes if it was on

Cats	All three	Grounds of setting	2.30 – 3.30	A	Yes	Yes	Yes
Looked at books and papers	L	Reading Room		A	A little	A little	Yes
Day 7							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Woken up at 6.00 and took the bedclothes off. No need to leave me without duvet. Medication at 6.00 in the morning for seizures	No need to do that, Nurses said it was for self-care	Bed	S- 6.00 F-	W	No	No very angry it happened	No
Shower	S	Bathroom on ward	S- F-	W nurse and assistant to help	Yes	/ a little	some no choice in when
Physio	As with other physio entries						

Art	Self-care, leisure and productivity if my paintings are sold! **Productivity** because you are producing something	OT	S- 10.30 F- 12.00	W	Yes	Yes	Yes A good bit of control, select what you want to paint.. She would allow you to do things differently.
Pottery	L	Day room	S- 2.00 F- 3.00	W	a little	Yes	some
Cat I never knew how important the cat would become.	All three	Grounds of residential setting	S- 3.15 F- 4.00	A	Yes	Yes	Yes

Emily: Self-Maintenance (daily routine) activities.

In relation to the specific daily self-maintenance tasks:

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
Get up	bedroom	Early – 8/30 or 9. Choose time, can change to a late time	30 minutes 31	Yes	Hoist (ceiling) Personal assistant – staff come in at a given time, including dressing. Only assist with the things that I need help with would be frustrating if they did everything	/ No have better communication with a staff member you know for a little longer. Can relate more to them. They have a new thing so that all staff have to working a particular area so you don't know who will assist you. Have to accept whoever is	Yes Always kept control, because if stopped, staff could take over, and get me up even if I don't want to ger up. I want to be able to know when I can get up.

						there to assist.c	
Eating			minutes	Yes / Sometimes / No	Use equipment dycem, plate guard	Yes Choice of food , and whether you have it here.	Yes
Washing hair	If they had something to enable a disable person then would be able to wash hair.	Either in shower or bath	minutes	Yes / Sometimes / is choice in the day, time, and is choice. Need to arrange a time for bath etc.		Yes / Some / No	Yes / Some / No
Go for walks and enjoy nature Important to do once a week to calm down and relax..	Twice a week Not a lot – Stephen's Green Walk or bus	Getting there – an hour, bus, 30 minutes Choose which way to travel.	minutes	Yes / Sometimes / No Go alone, likes own space, sometimes invites friend		Yes	Yes
Toilet	Use equipment, and direct choose how assisted and in control.		minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No Routine is important
Don't want			minutes	Yes /		Yes / Some /	Yes / Some /

want disability, equipment or people to change the level. Don't like too much equipment around me. Equipment makes disability more apparent in mind.				Sometimes / No		No	No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No

Emily: dditional information:

Space time, and everything around equipment. Same for family being over-protective.

Day 1							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Bath is easier than a shower.	S	Bathroom on ward	S- 8.00 F- 8.30	W nurses assist	Yes	Yes	Yes
Went to bank	P essential	Go to Dun Laoghaire – walk 20 minutes in powered chair	S-1500 F- 15.30	Alone,	Yes, very	Yes	Yes
Went into town after bank	L also to find information,	Walk to bus stop and waited for a bus, then got the bus into town.	S15.30- F- 17.00	A	Yes, because end in sight.	Yes but people bump into you.	yes
Day 2							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?

Library	Leisrue and Productivity Also to access email	Walk to the library in Deansgrange back roads	S- F- 30 minutes travelling, in library for one hour, 30 minutes back	Alone	A little	Yes	Depends on people in the library, because assistance is needed and noise etc.
Go to the doctor	Self-care	Walk to doctor down the road	S- F- 1400 – 1600	Alone	Yes	No	some
Went to the cinema	Leisure	DL Walked	S- 1845 F- 3 HOURS LATER	W	A little	No, the film was crap! Then there was a problem with the lift	No, the other person chose the film
Day 3							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Computer	L and P	In own room	S morning - F 2 hours-	A	Yes – assists in other ways, never thought that could use a computer	Yes Broadened my outlook, part of my right arm now, couldn't be without it.	Yes

Visited a friend	L	Visiting the friend in Vincent's hospital. Bus and walking	S- F- 5 hours	A Met someone there	Yes – important to the other person	Yes	Yes
Day 4							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Bath	S	Bathroom in residential setting	S- 8.00 F-8.45	W assistance from nurses	Yes	Yes	Yes
Mass	P	Walk just around the corner	S 10.00- F-11.00	A	A little	A little	Some Choose service and time.
Sitting in the garden	Leisure and SC Relaxation	Residential setting	S- F 2 hours-	More on own but interact with others	Yes	Yes, very much so	Yes, very much so
Went to mothers grave	Leisure	Deansgrange walked,	S- F 1 hour 1 hour and a half-	Went alone sought assistance while there	Yes	Yes	Yes -

Day 5							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Visited by friend	Leisure	Residential Setting	S- 14.30 F- 16.00	With	Yes	Yes, because not seen her in 3 months.	A little
Physiotherapy	Self-care	Residential Setting	S- 18.00 F-19.00	With	Yes	A little It can be a pain at times. Frustrating	No
Day 6							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Used computer	L	Here	S- 10 F- 12	A	Yes	Yes	Yes
Went for a walk to enjoy nature	S L	Grounds of setting	S- 2.00 3.00 F-	A	Yes	Yes	Yes

Day 7							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Went to library	L and P	Library	S- 10.00 F-12.30	A But interacted with people in library	Yes	a little	Yes
Sat in gardens	L	Residential setting	S- 2.30 F-3.30	A	a little	Yes	Yes

Self-Maintenance (daily routine) activities.

In relation to the specific daily self-maintenance tasks:

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
Getting up.	Bedroom.	Morning.	minutes 5-15.	~~Yes~~ / ~~Sometimes~~ / No	—	Yes / Some / No D/A.	Yes / ~~Some~~ / ~~No~~
Wash & Maintain Dead.	Bathroom.	Morning.	minutes 45-~~60~~.	~~Yes~~ / Sometimes / ~~No~~	Applying Moisturiser.	Yes / ~~Some~~ / ~~No~~	Yes / ~~Some~~ / ~~No~~
Use Nebuliser.	Bedroom.	Morning & Evening. Sometimes Afternoon	minutes 15 per use.	~~Yes~~ / ~~Sometimes~~ / No	—	Yes / Some / No D/A.	Yes / ~~Some~~ / ~~No~~
Prepping food.	Kitchen.	Anytime.	minutes 60-120.	~~Yes~~ / Sometimes / ~~No~~	Cutting Veg. Boning Meat.	Yes / ~~Some~~ / ~~No~~	Yes / ~~Some~~ / ~~No~~
Shopping.	The Square, Tallaght.	Late morning/ Early afternoon	minutes 120.	Yes / ~~Sometimes~~ / ~~No~~	Pushing trolley Packing Bags.	Yes / ~~Some~~ / ~~No~~	Yes / ~~Some~~ / ~~No~~
Having a bath.	Bathroom	Anytime, but usually evening	minutes 60	~~Yes~~ / Sometimes / ~~No~~	Washing & Skin Moisturising.	Yes / ~~Some~~ / ~~No~~	Yes / ~~Some~~ / ~~No~~
Getting to bed.	Bedroom.	Night.	minutes 15 Mins.	~~Yes~~ / ~~Sometimes~~ / No	—	Yes / ~~Some~~ / ~~No~~	Yes / ~~Some~~ / ~~No~~
Toileting.	Bathroom.	Anytime	minutes 10 per visit.	~~Yes~~ / ~~Sometimes~~ / ~~No~~ No	—	Yes / Some / No	Yes / Some / No
Preparing drinks Snacks etc.	Kitchen.	Anytime	minutes 10-20 mins per drink/snack.	~~Yes~~ / Sometimes / ~~No~~	Cutting food. Filling cups.	Yes / ~~Some~~ / ~~No~~	Yes / ~~Some~~ / ~~No~~

Diary Information

Date: Saturday 30th Oct.

Day 1

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Rising & Washing.	S / ~~P/L~~	Bedroom / Bathroom.	S- 8.45 am. F- 9.30 am.	~~A~~/W	Yes / ~~a little/~~ No	~~Yes / a little/~~ No	Yes ~~/ some / No~~
Using Nebuliser / taking Meds.	S / ~~P/L~~	Living Room	S- 9.40. am. F- 10.00 am.	~~A~~/W	Yes ~~/ a little/ No~~	~~Yes / a little/~~ No	Yes ~~/ some / No~~
Preparing & Eating Breakfast.	S / ~~P/L~~	Kitchen & Living Room.	S- 10.15 am F- 11.00 am	~~A~~/W	Yes ~~/ a little/ No~~	Yes ~~/ a little/ No~~	Yes ~~/ some / No~~
Dressing.	S / ~~P/L~~	Bedroom.	S- 11.30 am F- 12. noon	~~A~~/W	Yes ~~/ a little/ No~~	~~Yes /~~ a little/ ~~No~~	Yes ~~/ some / No~~
Shopping & visiting Library.	S / ~~P~~/ L	The Square & County Library.	S- 12.15 pm, F- 4 pm.	~~A~~/W	Yes ~~/ a little/ No~~	Yes ~~/ a little/ No~~	Yes ~~/ some / No~~
Preparing & Eating Dinner	S / ~~P/L~~	Kitchen / Living Room.	S- 4.30 pm F- 5.30 pm.	~~A~~/W	Yes ~~/ a little/ No~~	Yes ~~/ a little/ No~~	Yes ~~/ some / No~~
Writing letter & Reading. Phone calls	~~S / P /~~ L	Living room.	S- 6 pm. F- 8.30 pm.	~~A~~/W	Yes ~~/ a little/ No~~	Yes ~~/ a little/ No~~	Yes ~~/ some / No~~
Talking on bath... & monitoring	S ~~/ P / L~~	Bathroom.	S- 9 pm. F- 10.15 pm.	A/~~W~~	Yes / a little/ No	Yes / a little/ No	Yes ~~/ some~~ / ~~No~~
Bed.	S / ~~P/L~~	Bedroom.	S- 10.30 pm. F- 10.45 am.	A/~~W~~	Yes ~~/ a little/ No~~	~~Yes /~~ a little/ ~~No~~	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Date: Sunday 31st October.

Day 2

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Rising & Washing. Dress	S / ~~P / L~~	Bedroom & Bathroom.	S- 7.45am. F- 8.30 am.	A/~~W~~	Yes / ~~a little~~/ ~~No~~	~~Yes / a little~~/ No	Yes / ~~some~~ / ~~No~~
Use nebuliser / Taking Medication	S / ~~P / L~~	Living Room.	S-8.30 am F-8.50 am.	A/~~W~~	~~Yes / a little~~/ ~~No~~ YES!	~~Yes / a little~~/ No	Yes / ~~some~~ / ~~No~~
Preparing & eating Breakfast.	S / ~~P / L~~	Kitchen.	S-9.00 am F-9.30 am.	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Travelling to & participating in SV&P Work.	~~S / P / L~~ L&P.	Bui Chavanhi, Cork St.	S-9.45 am. F-1 pm.	~~A~~/W	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Coffee with guest.	~~S / P~~ / L	Living Room.	S-1 pm. F-2 pm.	~~A~~/W	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Preparing & eating Dinner.	S / ~~P / L~~	Kitchen & Living Room.	S-2.30pm F-3.30pm.	~~A~~/W	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Reading Newspapers, Watching TV, Napping	~~S / P~~ / L	Bedroom.	S-3.45pm. F-8 pm.	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Bath & Mouthwashing	S / ~~P / L~~	Bathroom	S-9pm F-10pm	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Bed.	S / ~~P / L~~	Bedroom.	S-10.30 F-10.45	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Day 3

Date: Monday 1st November

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Getting Up.	S / ~~P / L~~	Bedroom.	S- 7am. F- 7.30am.	A/~~W~~	Yes / ~~a little~~ / ~~No~~	~~Yes / a little~~ / No	Yes / ~~some~~ / ~~No~~
Washing & Dress	S / ~~P / L~~	Bathroom	S-7.30am F-7.55am.	A/~~W~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~some~~ / ~~No~~
Tabulating & taking Meds.	S / ~~P / L~~	Living Room.	S-8 am F-8.15am	A/~~W~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~some~~ / ~~No~~
Planning & Eating Breakfast.	S / ~~P / L~~	Kitchen & Living Room.	S-8.30 am. F-9.15 am.	A/~~W~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~some~~ / ~~No~~
Travelling to and participating in DLG Meeting.	~~S~~ / P / L	Gallagher Partnership Office.	S-10 am. F-12.30 pm.	A/W	Yes / a little / No	Yes / a little / No	Yes / some / No
Travel to Shops & Library. Shopping.	S / ~~P~~ / L	Spar & Library.	S-12.45 pm. F-4.30 pm.	~~A~~/W	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~some~~ / ~~No~~
Preparing & Eating Dinner	S / ~~P / L~~	Kitchen & Living Room	S-5.30 pm F-6.45 pm	~~A~~/W	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~some~~ / ~~No~~
Visit Credit Union	~~S / P~~ / L	Credit Union.	S-7.00 pm. F-7.15 pm	~~A~~/W	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	~~Yes / some~~ / ~~No~~ No
Bath & Moisturiser	S / ~~P / L~~	Bathroom.	S-8.30 pm F-9.30 pm	A/~~W~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~some~~ / ~~No~~
Bed & TV.	S / ~~P / L~~	Bedroom.	S-10. pm F-10.30 pm	A/~~W~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~some~~ / ~~No~~

Date: 2nd November. (Tues).

Day 4

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Getting Up ~~& Dress~~.	S / ~~P / L~~	Bedroom	S-9.00 F-9.30	A/~~W~~	Yes / ~~a little/~~ ~~No~~	Yes / ~~a little/~~ ~~No~~	Yes / ~~some~~ / ~~No~~
Wash Mastrise & Dress.	S / ~~P / L~~	Bathroom	S-9.30 F-10.15.	A/~~W~~	Yes / ~~a little~~/ ~~No~~	~~Yes / a little~~/ No	Yes / ~~some~~ / ~~No~~
Nebulising & Taking Meds	S / ~~P / L~~	Living Room	S-10.30 F-11.00.	A/~~W~~	Yes / ~~a little~~/ ~~No~~	~~Yes / a little~~/ No	Yes / ~~some~~ / ~~No~~
Prep & Eat Breakfast	S / ~~P / L~~	Kitchen & Living Room	S-11.00 F-11.15.	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Travelling to & wait to be Chaumlin.	~~S~~ / P / L	Cook Street.	S-12.00 F-4.30	~~A~~/W	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Visit Friend & Dinner	~~S / P~~ / L	Friends House	S-5.30 F-10.00.	~~A~~/W	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Bed.	S / ~~P / L~~	Bedroom	S-10.30 F-10.45	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Shower & Mastrise

Date: Wendsday 3rd November.

Day 5

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Getting Up.	S / ~~P/L~~	Bedroom	S-8.00am F-8.45 am	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Wash & Moisturise & Dress	S / ~~P/L~~	Bedroom & Bathroom.	S-8.45 am F-9.15 am	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Nebulise & take Meds.	S / ~~P/L~~	Living Room	S-9.15 am F-9.35 am	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Prepare & eat Breakfast.	S / ~~P/L~~	Kitchen & Living Room.	S-9.40 am F-10.15 am	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Travel to & Deliver Dr's Service in Arnotts.	~~S~~ / P / ~~L~~	Arnotts & Taxi	S-10.20 am F-1.05 pm	~~A~~/W	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Travel to and attend Chiropodist & travel home	S / ~~P/L~~	Taxi & Chiropodist	S-1.30 pm. F-4.30 pm.	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Ate light lunch.	S / ~~P/L~~	Arnotts.	S-1.05 pm F-1.30 pm.	~~A~~/W	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Reading, T.V. Phone Calls.	~~S/P~~ / L	Living Room, Bedroom	S-4.30 pm. F-7.30 pm.	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Prepare & Eat Dinner.	S / ~~P/L~~	Kitchen & Living Room	S-7.30 pm F-8.30 pm.	~~A~~/W	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Bath & Moisturise	S / ~~P/L~~	Bathroom	S-8.30 pm F-9.15 pm.	A/~~W~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~a little~~/ ~~No~~	Yes / ~~some~~ / ~~No~~
Bed.	S.	Bedroom	S-9.30 pm F-10.15 pm	A.	Yes	Yes	Yes.
Nebulise	S.	Bedroom	S-11.00 pm F-11.45 pm	A. A.	"	"	"

Date: 14th November (Thurs)

Day 6

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Getting up.	S / ~~P~~ / ~~L~~	Bedroom.	S- 5 am. F- 5.30 am	A/~~W~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~some~~ / ~~No~~
Medication Meds.	S / ~~P~~ / ~~L~~	Living room	S- 5.30 am F- 6.30 am.	A/~~W~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~some~~ / ~~No~~
Daylight Hosp. At E.	S / ~~P~~ / ~~L~~	Dalkeith Hosp.	S- 6.45 am F- 10 am	~~A~~/W	Yes / ~~a little~~ / ~~No~~	~~Yes~~ / ~~a little~~ / ~~No~~ 110.!!	Yes / ~~some~~ / ~~No~~
Travel to + D+ Session in Arnotts.	~~S~~ / P / ~~L~~	Arnotts + Jane	S- 10.30 am. F- 3 pm	~~A~~/W	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	Yes / ~~some~~ / ~~No~~
Eat. Fruit.	S / ~~P~~ / ~~L~~	Living Room.	S- 3.15. F- 4.00.	~~A~~/W	Yes / ~~a little~~ / ~~No~~	~~Yes~~ / a little / ~~No~~	~~Yes / some~~ / No
Bed!	S / ~~P~~ / ~~L~~	Bedroom.	S- 4.30. F-	~~A~~/W	Yes / ~~a little~~ / ~~No~~	Yes / ~~a little~~ / ~~No~~	~~Yes / some~~ / No
	S / P / L		S- F-	A/W	Yes / a little / No	Yes / a little / No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little / No	Yes / a little / No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little / No	Yes / a little / No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little / No	Yes / a little / No	Yes / some / No

Date: Friday 5th November.			Day 7				
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Get up.	S / ~~P / L~~	Bedroom.	S-9.00 F-9.15.	A/~~W~~	Yes / ~~a little / No~~	~~Yes / a little /~~ No	Yes / ~~some / No~~
Wash & Moisturise	S / ~~P / L~~	Bathroom.	S-9.30. F-10.30.	A/~~W~~	Yes / ~~a little / No~~	Yes / ~~a little / No~~	Yes / some / No
Prepare & Eat Breakfast.	S / ~~P / L~~	Kitchen & Living Room	S-10.30 F-11.30	~~A~~/W	Yes / ~~a little / No~~	Yes / ~~a little / No~~	Yes / ~~some / No~~
Take meds & Medication.	S / ~~P / L~~	Living Room.	S-11.40 F-12 noon.	A/W	Yes / a little / No	Yes / a little / No	Yes / some / No
Dressing.	S / ~~P / L~~	Bedroom.	S-12 noon F-12.20 pm.	A/~~W~~	Yes / ~~a little / No~~	Yes / ~~a little / No~~	Yes / ~~some / No~~
Travelling to Square & Library & Shopping & lunch.	S / ~~P / L~~	Square & Library.	S-12.30 pm. F-4.30 pm	~~A/W~~ W.	Yes / ~~a little / No~~	Yes / ~~a little / No~~	Yes / ~~some / No~~
T.V. & Reading.	S / ~~P / L~~	Living Room.	S-5 pm F-6.30.	~~A~~/W	Yes / ~~a little / No~~	Yes / ~~a little / No~~	Yes / ~~some / No~~
Preparing & Eating Dinner.	S / ~~P / L~~	Kitchen & Living Room.	S-7.00 F-8.30.	~~A~~/W	Yes / ~~a little / No~~	Yes / ~~a little / No~~	Yes / ~~some / No~~
Bath & Maintaining	S / ~~P / L~~	Bathroom	S-9.00 F-10.00	A/~~W~~	Yes / ~~a little / No~~	Yes / ~~a little / No~~	Yes / ~~some / No~~
Bed.	S / ~~P / L~~	Bedroom	S-10.15. F-10.30.	A/~~W~~	Yes / ~~a little / No~~	Yes / ~~a little / No~~	Yes / ~~some / No~~

Grainne: Self-Maintenance (daily routine) activities.

In relation to the specific daily self-maintenance tasks:

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
Getting up	Room / bathroom	Morning, usually early around 7.00	A good hour, test blood,	Yes	Hoist Nursing staff	Some Can't be demanding Choose time	Some
Breakfast	Brought to the bedroom because have to eat immediately after bloods and tablets	Straight after get up	15	Only to bring food to me.	Food brought in	No	No
Bath	Jacuzzi, in the big bathroom.	Twice a week, mid-morning	An hour or more	Yes	Hoist and two nurses / care attendants. They clean catheter	Yes	Some
Catheter	Bathroom or bedroom if in bed	Several times a day	5 minutes	Yes	Empty bag and clean	No But it's fine	No It's grand
Toilet	Bathroom		20 minutes, with transfers	Yes	Hoist to transfer	Yes	Yes

			etc				
Mobility Wheelchair is not good, but battery	Transfer in room – then go wherever	Transfer morning and evening	5 mins to transfer	Yes for transfers. Sometimes also when wheelchair is broken.	Transfers, and mobility when chair is broken. Batteries	Some	No, not when chair will break. Control over transfers.
Meals	Dining room, except for breakfast	Lunch and evening	30 minutes – as quick as possible	No	Only to get food, all food is cooked	Yes	Some Hate meal times

Additional information:

Re-collected. Interview not recorded / transcribed fully.

Grainne Diary Information

Day 1							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Get up and breakfast.	S	Bedroom	S- 7.00 F- 8.45	W nurse for getting up A for breakfast	a little/	a little	some
Feed the fish	P / L	Grounds of setting	S- 9.00 F-	A	Yes	Yes	Yes
Feed the birds and other animals	S / P / L All three. Need fresh air too.	Grounds of setting	S- F- just before lunch	A	Yes	yes	Yes
Lunch	S	Dining room	S- 12.30 F-1.00	W	a little	No	some
Walk the dog	P / L	Grounds of setting	S- F-	A	Yes	Yes	Yes
Computer	L	Room	S-after walked dog F- 4.30	A	a little	a little	Yes

Day 2							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Jacuzzi	S	Big bathroom	S- 10.00 F- 11.30	W nursing staff	a little	Yes	some
Computer	P / L	Room	S- 11.30 F- 12.29	A	a little	a little	Yes
Go out around grounds	L	Grounds	S- F-	A	A little	Yes	Yes
Feed animals	P / L	grounds	S- F-	A	Yes	Yes	Yes
Friends come in	L	Bedroom	S- 7.00 F- 9.00	W	Yes	/ a little	some

Day 3							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Getting up etc	As with Day 1						

Meet sister-in-law and her children	L	[local suburb]	S- 10.30 F- 13.00	W But went out alone.	A little	Yes	some
Feed animals	P / L	Grounds	afternoon	A	Yes	Yes	Yes
Watch tv	L	bedroom	evening	A	No	a little	some choose to watch tv

Day 4							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Get up etc	As with day 1						
Feed animals	As with previous days						
Computer	P	bedroom	afternoon	A	a little	Yes	Yes
Family came over	L	bedroom	Evening	W	Yes	a little	some

Day 5							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Jacuzzi	S	Big bathroom	S- 9.30 F- 10.45	W	Yes	a little	some
Computer	P / L	bedroom	until lunch	A	a little	a little	Yes
Rest in bed	S	bedroom	Afternoon	A	a little	No	No
Friend came in	L	bedroom	evening	W	Yes	Yes	Yes

Day 6							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Get up etc	As with day 1						

Go to hospital	S	Hospital – residential setting provided transport		W	a little	No	No
Rest in afternoon	S	bedroom	afternoon	W	a little	No	No
Watch TV	L	bedroom	Evening	A	a little	a little	some

Day 7							
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Get up etc	As with previous days						
Go to [local suburb]	P / L	Suburb	S- 10.00 F- 12.00	A	Yes	Yes	some
Feed animals	P / L	grounds	S- 14.00 F- 15.30	A	Yes	Yes	Yes
Computer	P / L	bedroom	Until tea	A	a little	Yes	Yes
Friend came in	L	bedroom		W	Yes	Yes	Yes

Self-Maintenance (daily routine) activities.

In relation to the specific daily self-maintenance tasks:

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
Hygiene (washing, hair, etc)	Bathroom House OR Respite	6.00 – 6.15 AM	15 – 30 mins	No	N/A	Yes / Some / No N/A	Yes / Some / No Yes
Breakfast *=No help beginning L.TF	Bed House OR Respite	9.00 AM APPROX	minutes 10	Yes / ✓ Sometimes / No	To prepare, serve and clear B'FAST	Yes / Some / No Some	Yes / Some / No Some
Dressing	Bedroom OR Respite WARD	9.15 AM (OR earlier, later.)	minutes 5 to 20 Depending on activity	Yes / ✓ Sometimes / No	Help with underclothes, trousers, socks, shoes etc.	Yes / Some / No Some	Yes / Some / No Yes
*Lunch	Bedroom IN House or Respite WARD	12.30 PM (13.00) RHA Moveable feast at home	minutes 10 – 30	Yes / ✓ Sometimes / No	As Breakfast	Yes / Some / No Some	Yes / Some / No Some
Visits To the Chiropody etc.	Bathrooms IN House OR Respite	Throughout day and night	minutes 5 – 20 usually	Yes / Sometimes / ✓ No	If ill may require help (T.I.S. etc.)	Yes / Some / No No	Yes / Some / No Yes
House work, cleaning.	House OR Respite.	Morning RHD Anytime during day at home	minutes VARIES	Yes / ✓ Sometimes / No	Housework done by P.A.	Yes / Some / No No	Yes / Some / No No
Bed making: Arrangements; Duvet cover, changing etc.	Bedroom IN House OR WARD	Evening	minutes 10 – 20	Yes / ✓ Sometimes / No	Always done by my P.A. even in Respite	Yes / Some / No No	Yes / Some / No No
*Dinner	House	7.30 p.m (19.00)	minutes VARIES	Yes / ✓ Sometimes / No	Food prepared and served, cleared up by P.A.	Yes / Some / No No	Yes / Some / No No
*High Tea	Respite WARD	4.30 pm (16.30)	minutes 10	Yes / ✓ Sometimes / No	As above by Hospital Staff	Yes / Some / No No	Yes / Some / No No
Showering	Bathroom AT Home OR Respite	Times VARY but usually early Afternoon	minutes 45	Yes / ✓ Sometimes / No	Supervision in present failing. Help with shower	Yes / Some / No No	Yes / Some / No No

Diary Information

Date: 02-11-2004 **Day 1** Tuesday

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Morning Hygiene	S/P/L S	BATHROOM	S- 6.15 AM F- 6.30 AM	A/W A	Yes / a little / No yes	Yes / a little / (No) no	(Yes) / some / No yes
Study	S/P/L P	Bed	S- 6.30 AM F- 9.00 AM	A/W A	(Yes) / a little / No yes	(Yes) / a little / No yes	(Yes) / some / No yes
Meals	S/P/L S & L	Bed	S- 9.00 AM; 1.00 PM; 7.30 PM F- 9.40 AM; 1.45 PM; 8.30 PM	A/W A(PA)*	(Yes) / a little / No yes	(Yes) / a little / No yes	Yes / (some) / No Some
Reading	S/P/L P & L	Bed	S- 9.10 AM F- 10.30 AM	A/W A	(Yes) / a little / No yes	(Yes) / a little / No ~~A little~~	(Yes) / some / No yes
Business Affairs	S/P/L P	Bed Telephone, Laptop	S- 10.30 AM F- 12.00 PM	A/W A	Yes / a little / No yes	Yes / (a little) / No [redacted]	Yes / some / No yes
Dressing	S/P/L S	Bed Area & Bathroom	S- 12.00 PM F- 12.30 PM	A/W W P.A.	Yes / a little / (No) NO	Yes / a little / (No) NO	Yes / (some) / No Some
Reading, Emails etc.	S/P/L L	Bed	S- 12.30 PM F- 2.00 PM	A/W A	(Yes) / a little / No yes	(Yes) / a little / No yes	Yes / (some) / No Some
Wheelchair Practice with O.T.	S/P/L P	Local Area Streets	S- 2.00 P.M F- 4.00 P.M	A/W W O.T.	(Yes) / a little / No yes	Yes / a little / (No) NO	Yes / (some) / No Some
Rest (nap)	S/P/L S	Bed	S- 4.15 PM F- 6.00 PM	A/W A	(Yes) / a little / No yes	Yes / a little / (No) NO	(Yes) / some / No yes
Study, Read until T.V. appropriate.	S/P/L P & L	Bed	S- 6.00 PM F- 4.30 AM	A/W A	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No

* N.B. = ALL Meals Are prepared, cooked, Served and cleared up by P.A. I eat Alone, And IN Bed, because of Lack of room in My cottage.

\# 3 Some Assistance, Conversation, etc. with P.A. And Dogs.

Date: 03-11-2004 **Day 2** Wednesday

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Morning Hygiene	S / P / L S	Bathroom	S- 7.00 AM F- 7.15 AM	A/W A	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Rest/Read	S / P / L L	Bed	S- 7.15 AM F- 10.00 AM	A/W A	Yes / a little/ No	Yes / a little/ No (Pain)	Yes / some / No
Business Affairs	S / P / L P	Bed	S- 10.00 AM F- 12.30 PM	A/W A	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Rest/Read Lunch	S / P / L S	Bed	S- 12.30 PM F- 3.30 PM	A/W A	Yes / a little/ No	Yes / a little/ No (Pain)	Yes / some / No
Exercise	S / P / L S	Bed; W'chair; House	S- 3.30 P.M F- 4.00 P.M	A/W W P.A.	Yes / a little/ No	Yes / a little/ No (Pain)	Yes / some / No
Study	S / P / L P	Bed	S- 4.00 P.M F- 7.30 P.M.	A/W A	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Dinner & Videotapes	S / P / L L	Bed	S- 7.30 PM F- 9.00 PM	A/W A	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Personal Hygiene and Bed Prep.	S / P / L S	Bedroom Bathroom	S- 9.00 P.M F- 10.00 P.M.	A/W W P.A.	Yes / a little/ No	Yes / a little/ No (Pain)	Yes / some / No
Reading, Sleep	S / P / L S	Bed	S- 10.00 P.M F- 1.00 AM	A/W A	Yes / a little/ No	Yes / a little/ No (Pain)	Yes / some / No
Operating Washing/Drying Machine - Reading - Lavatory.	S / P / L S & L	Kitchen Bathroom Bed	S- 1.00 A.M. F- Approx 4.45 AM	A/W A	Yes / a little/ No	Yes / a little/ No (Pain)	Yes / some / No

Date: 04-11-2004 Day 3 Thurs Day

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Personal Hygiene	S / P / L S	House Bathroom	S- 6.15 AM F- 6.25 AM	A/W A	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Breakfast	S / P / L S	Bed	S- 7.00 AM F- 7.15 AM	A/W W P.A.	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Discussion with P.A.	S / P / L P	Bed	S- 8.00 AM F- 8.20 AM	A/W W P.A.	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Dog Care Jessica to vet with P.A.	S / P / L P	Bed Telephone	S- 9.00 AM F- 9.15 AM	A/W A	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Study	S / P / L P	Bed	S- 9.30 AM F- 1.00 PM	A/W A	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Telephone, Laptop, Lunch	S / P / L P	Bed	S- 1.00 PM F- 2.00 PM	A/W W P.A.	Yes / a little/ No	Yes / a little/ No	Yes / some / No
Read & Rest Try to sleep	S / P / L L	Bed	S- 2.00 PM F- 4.00 PM	A/W A	Yes / a little/ No	Yes / a little/ No Pain	Yes / some / No
Dogs, Exercise, Dinner	S / P / L L & P/S	House	S- 4.00 PM F- 7.00 PM	A/W W P.A. Dogs	Yes / a little/ No	Yes / a little/ No Painful	Yes / some / No
Personal Hygiene Bed Making Supervision	S / P / L S	Bathroom	S- 8.00 PM F- 8.45 PM	A/W W P.A.	Yes / a little/ No	Yes / a little/ No Painful	Yes / some / No
Read & Rest	S / P / L A	Bed	S- 9.00 PM F- 3.45 AM	A/W A	Yes / a little/ No	Yes / a little/ No Painful	Yes / some / No

Date: 05-11-2004 **Day 4** Friday

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Personal Hygiene	S/P/L S	BATHROOM	S- 6.15 AM F- 6.45 AM	A/W A	(Yes) / a little / No	Yes / a little / (No)	(Yes) / some / No
Study	S/P/L P	Bed	S- 7.00 AM F- 9.30 AM	A/W A	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No
B'fast, P.A.	S/P/L S	Bed	S- 9.30 AM F- 10.00 AM	A/W W P.A.	(Yes) / a little / No	Yes / a little / (No)	Yes (some) / No
Shower & Dress	S/P/L S	BATHROOM	S- 10.00 AM F- 10.45 AM	A/W W P.A.	Yes / (a little) / No	Yes / a little / (No) Painful	Yes (some) / No
Study	S/P/L P	Bed	S- 10.45 AM F- 12.00 P.M.	A/W A	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No
Wheelchair Practice	S/P/L P	My Street	S- 12.00 P.M F- 12.45 P.M	A/W W 2 O.Ts	(Yes) / a little / No	Yes / a little / (No) Painful	Yes (some) / No
Rest	S/P/L S	Bed	S- 12.45 P.M F- 3.00 P.M.	A/W A	(Yes) / a little / No	Yes / a little / (No) Painful	(Yes) / some / No
Lunch, Rest T.V., Dinner	S/P/L S & L	Bed	S- 3.00 P.M F- 8.00 P.M.	A/W A/W P.A.	Yes / (a little) / No	Yes (a little) / No	Yes (some) / No
Night Routine	S/P/L S	BATHROOM Bedroom	S- 8.30 P.M F- 9.15 P.M	A/W W P.A.	(Yes) / a little / No	Yes / a little / (No)	Yes (some) / No
Study, Rest, Sleep	S/P/L P & S	Bed	S- 9.15 P.M. F- 2.30 AM	A/W A	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No

* N.B. Using the New wheelchair has been very painful. P.A. & O.Ts very helpful.

Date: 06-11-2004 **Day 5** SATURDAY

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
USUAL MORNING ACTIVITIES	S/P/L S & P	BATHROOM BED	S- 6.00 AM F- 9.30 AM	A/W A & W.P.A.	(Yes) / a little / No	Yes / (a little) / No	Yes / (some) / No
HOUSEHOLD, SHOPPING, etc	S/P/L P	BED	S- 9.30 AM F- 10.30 AM	A/W A & W P.A.	(Yes) / a little / No	Yes / a little / (No)	(Yes) / some / No
ARRANGE FOR RESPITE	S/P/L P	BED	S- 10.30 AM F- ~~11.30 AM~~	A/W W P.A	(Yes) / a little / No	Yes / a little / (No)	Yes / (some) / No
EXERCISE	S/P/L S	BED & HOUSE	S- 11.30 AM F- 12.00 PM	A/W A/W P.A.	Yes / (a little) / No	Yes / a little / (No)	(Yes) / some / No
REST, LUNCH READ	S/P/L ~~S~~ L/S	BED	S- 12.00 P.M F- 2.00 PM	A/W A	(Yes) / a little / No	Yes / (a little) / No P.M	Yes / (some) / No
STUDY	S/P/L P	BED	S- 2.00 P.M F- 5.00 P.M	A/W A	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No 4/05
READ, P.A DUTIES, SHOWER	S/P/L S/P/L	BED	S- 5.00 P.M F- 8.00 P.M.	A/W A & W P.A.	Yes / (a little) / No	Yes / (a little) / No	Yes / (some) / No
LAPTOP	S/P/L P	BED	S- 8.00 P.M F- 10.30 P.M	A/W A	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No
NIGHT ROUTINE	S/P/L S	BATHROOM BEDROOM	S- 10.30 P.M F- 11.15 PM	A/W W P.A.	(Yes) / a little / No	Yes / a little / (No)	Yes / (some) / No
READ, STUDY, SLEEP, REST	S/P/L L/S	BED	S- 11.15 PM F- 4.45 AM	A/W A	(Yes) / a little / No	(Yes) / a little / No PAIN	(Yes) / some / No

Date: 07-11-2004 **Day 6** Sunday

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Morning Routines	S/P/L S/L	Bathroom Bed	S- 6.30 AM F- 10.00 AM	A/W A	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No
B'fast Respite Activity	S/P/L S/P	Bed	S- 10.15 AM F- 11.00 AM	A/W W P.A.	(Yes) / a little / No	Yes / a little / (No)	Yes / (some) / No
Read, T.V. etc.	S/P/L L	Bed	S- 11.00 AM F- 1.30 PM	A/W A	Yes / (a little) / No	Yes / (a little) / No	(Yes) / some / No
Lunch / Rest / Exercise	S/P/L L/S	Bed & House	S- 1.30 P.M. F- 4.00 P.M.	A/W A & W P.A.	Yes / (a little) / No	Yes / (a little) / No	Yes / (some) / No
TEA	S/P/L L	Bed	S- 4.00 P.M F- 4.30 P.M	A/W A *	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No
Study	S/P/L P	Bed	S- 4.30 P.M F- 8.00 P.M	A/W A	(Yes) / a little / No	(Yes) / a little / No Pain	(Yes) / some / No
Shower, Night Routines	S/P/L S	Bath room Bed room	S- 8.00 P.M F- 9.30 P.M.	A/W W P.A.	(Yes) / a little / No	Yes / a little / (No) Painful	Yes / (some) / No
Reading Laptop	S/P/L L & P	Bed	S- 9.30 P.M F- 12.00 AM	A/W A	(Yes) / a little / No	(Yes) / a little / No Painful	(Yes) / some / No
WATCH V/TAPE	S/P/L L & P	Bed	S- 12.00 AM F- 4.30 AM	A/W A	Yes / (a little) / No	Yes / (a little) / No Pain	(Yes) / some / No
Washing / Drying Machine	S/P/L S	Kitchen	S- 4.30 AM F- 6.00 AM	A/W A	(Yes) / a little / No	Yes / a little / (No) Painful	(Yes) / some / No

Date: 08-11-2004 **Day 7** Monday

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
Morning Routines, Bfast	S / P / L S & P	Bathroom Bed	S- 7.00 AM F- 8.30 AM	A/W A	(Yes) / a little / No	Yes / a little / (No)	(Yes) / some / No
Pack for Respite	S / P / L S	Bed	S- 10.30 AM F- 12.00 PM	A/W W P.A.	(Yes) / a little / No	Yes / a little / (No)	Yes (some) / No
Rest	S / P / L S	Bed	S- 12.00 P.M F- 2.00 P.M.	A/W A	(Yes) / a little / No	Yes / a little / (No) Pain	(Yes) / some / No
Lunch & Study	S / P / L S & P	Bed	S- 2.00 P.M F- 5.00 P.M.	A/W A	(Yes) / a little / No	Yes (a little) / No Pain	(Yes) / some / No
Exercise	S / P / L S	Bed & House	S- 5.00 P.M. F- 5.20 P.M.	A/W W P.A.	(Yes) / a little / No	Yes / a little / (No) Painful	Yes (some) / No
Read & Laptop	S / P / L L & P	Bed	S- 5.30 PM F- 7.30 PM	A/W A	(Yes) / a little / No	(Yes) / a little / No Painful	(Yes) / some / No
Dinner	S / P / L S	Bed	S- 7.30 PM F- 8.00 P.M	A/W A	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No
Study	S / P / L P	Bed	S- 8.30 PM F- 10.30 PM	A/W A	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No
Night Routines	S / P / L S	Bathroom Bedroom	S- 10.30 PM F- 11.00 PM	A/W W P.A.	(Yes) / a little / No	Yes / a little / (No) Painful	Yes (some) / No
Read & Write	S / P / L P	Bed	S- 11.00 P.M F- 2.45 AM	A/W A	(Yes) / a little / No	(Yes) / a little / No	(Yes) / some / No

Honour: Self-Maintenance (daily routine) activities.

[These have been transcribed for clarity]

In relation to the specific daily self-maintenance tasks: Sandra McEntegart

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
Hygiene Washing, hair, etc	Bathroom House or respite RHD	6.00 – 6.15 am	15 - 30 minutes	No	N/A	N/A	Yes
Breakfast * (no help required with eating)	Bed House or respite RHD	9.00 am approx.	10 minutes	Yes	To prepare, serve & clear breakfast	Some	Some
Dressing	Bedroom House or respite RHD	9.15 am (or earlier, later)	5 - 20 minutes (depending on activity)	Yes	Help with underclothes, trousers, shoes, etc	Some	Yes
Lunch * (no help required with eating)	Bedroom in House or respite ward in RHD	12.30 pm (13.00) RHA Moveable feast at home	10 - 30 minutes	Yes	To prepare, serve & clear lunch	Some	Some
Visits to the lavatory etc.	Bathrooms in House or respite RHD	Throughout day and night	5 - 20 minutes usually	Sometimes	If ill may require help (I.B.S. etc)	No	Yes
Housework,	House or	Morning RHD	varies	Yes	Housework	No	No

cleaning	respite RHD	Anytime during day at home	minutes		done by P.A.		
Bed making: airmattress; quilt cover changing etc	Bedroom in House or ward RHD	Evening	10 - 20 minutes	Yes	Always done by my P.A. even in respite	No	No
Dinner * (no help required with eating)	House	7.30 pm	varies minutes	Yes	Food prepared & served, washed up by P.A.	No	No
High tea * (no help required with eating)	Respite ward RHD	4.30 pm	10 minutes	Yes	Food prepared & served, washed up by hospital staff	No	No
Showering	Bathroom at house or respite RHD	Times vary but usually early afternoon	45 minutes	Yes	Supervision to prevent falling. Help with shower	No	No

Additional information:
* No help required with eating

Appendix A2: Semantic Differential Results

Table 9.1.1 Anna - Rating of current lifestyle		
Strong Agreement (Maximum value given)	**Some Agreement**	**Mid-way between points**
Varied Interesting Good Fulfilling Busy Active In company Outside home Satisfying Little free time Full of choice	Strenuous Challenging	Weak/Strong

Table 9.1.2. Anna - Rating of ideal lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
Varied Interesting Good Challenging Busy Active Outside home Satisfying Lots of free time Full of choice	Fulfilling Strenuous In company Strong	No mid-way ratings were given

Table 9.2.1 Bart - Rating of Current Lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
No maximum values given	Good Boring Sedentary Active At home Lots of free time Full of choice	

Table 9.2.2 Rating of Ideal Lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
No maximum rates given	Varied Interesting Fulfilling Strenuous Challenging Busy Active Outside home Satisfying Little free time Strong Full of choice	Good / Bad Alone / In Company

Table 9.3.1 Cathal - Rating of present lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
No maximum values given	Fulfilling Strenuous Passive At home Satisfying	

Table 9.3.2 Cathal - Rating of Ideal lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
Fulfilling Strong Full of choice	Varied Interesting Good Strenuous Challenging Busy Active In Company Outside Home Satisfying	Lots of free time / little free time

Table 9.4.1 Rating of present lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
In Company At home	Bad Challenging Busy Active Disappointing Little free time Full of choice	Varied / Monotonous Interesting / Boring Fulfilling / Unfulfilling Strenuous / Sedentary Strong / Weak

Table 9.4.2 Rating of Ideal lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
Good Fulfilling Satisfying Lots of free time Full of choice	Varied Interesting Busy At home	Strenuous / Sedentary Challenging / Unchallenging Active / Passive In Company /Alone Weak / Strong

Table 9.5.1 Emily - Rating of present lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
Good Challenging Busy Satisfying Strong	Interesting Fulfilling Active Full of Choice	Varied / Monotonous Strenuous / Sedentary In Company / Alone Outside home / At home Little free time / Lots of free time

Table 9.5.2 Rating of Ideal lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
Varied Interesting Good Fulfilling Challenging Satisfying Strong Full of choice	Active Outside Home Busy	Strenuous / Sedentary In Company / Alone Little free time / Lots of free time

Table 9.6.1 Freya - Rating of present lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
Interesting Fulfilling Challenging Busy In Company Satisfying	Varied Good Sedentary Active At home Full of choice	No mid-way ratings

Little free time Strong		

Table 9.6.2 Rating of Ideal lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
Varied Interesting Good Fulfilling Challenging Active In company Satisfying Strong Full of Choice	Busy At home Lots of free time	Strenuous / Sedentary

Table 9.7.2 Grainne Rating of Ideal lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
Fulfilling Good Interesting Satisfying Strong	Active Full of choice In company Lots of free time Varied	Busy / Idle Challenging / unchallenging Strenuous / Sedentary Outside home / At home

Table 9.8.1 Honour -Rating of present lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
Boring Sedentary At home	Fulfilling Challenging Alone Strong No choice Busy Active	Varied / Monotonous Good / Bad Satisfying / Disappointing Little free time / Lots of free time

Table Rating of Ideal lifestyle		
Strong Agreement (Maximum value given)	Some Agreement	Mid-way between points
Interesting Good Fulfilling Challenging Active Satisfying Strong Full of choice	Monotonous Sedentary Busy Alone At home	Little free time / Lots of free time

Figure 9.1.1 Anna - Rating of current lifestyle

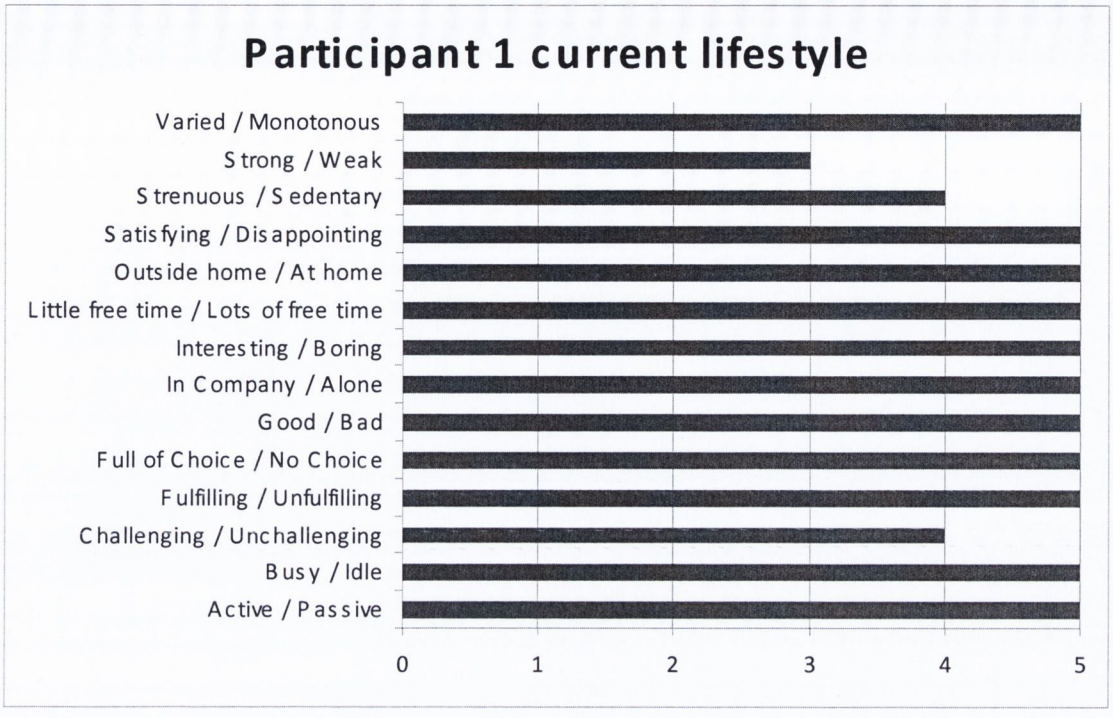


Figure 9.1.2 Anna – Rating of Ideal Lifestyle

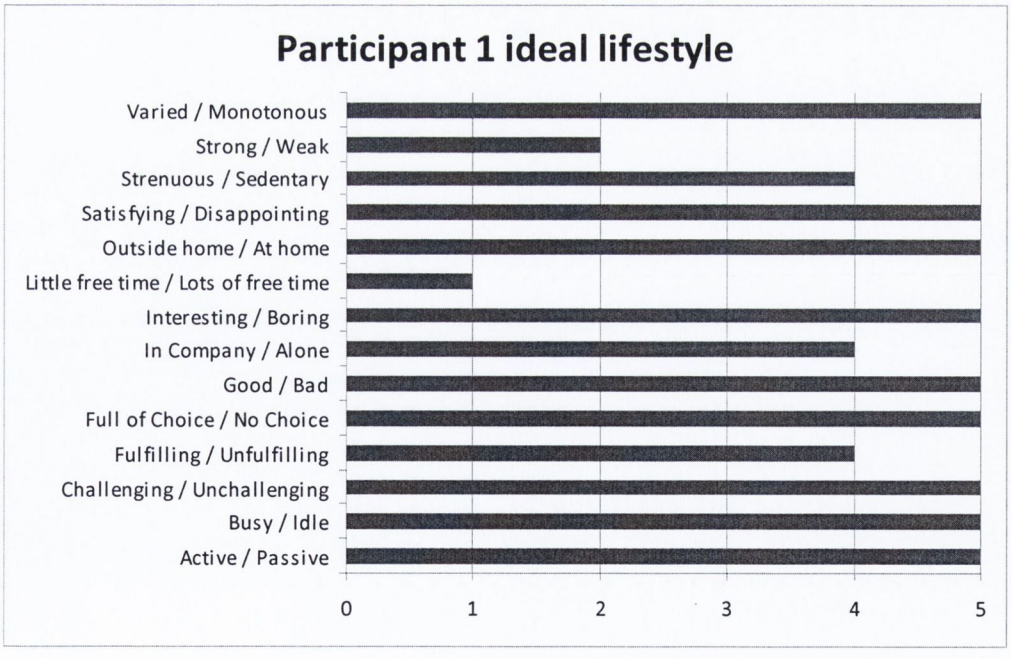


Figure 9.1.3 Anna – Comparison of Lifestyle Ratings

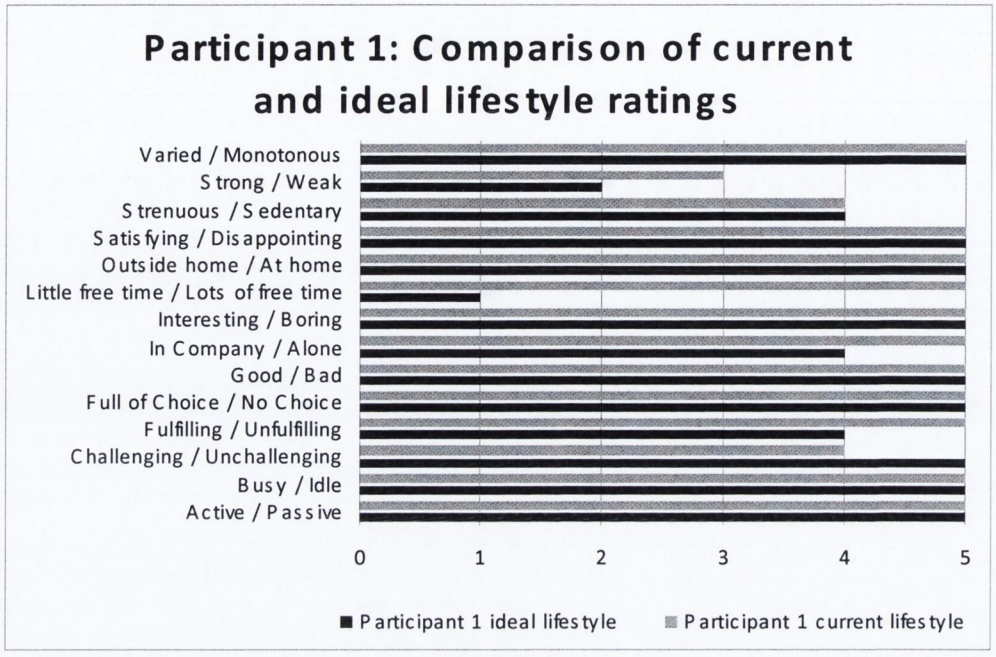


Figure 9.2.1 Bart – Rating of Current Lifestyle

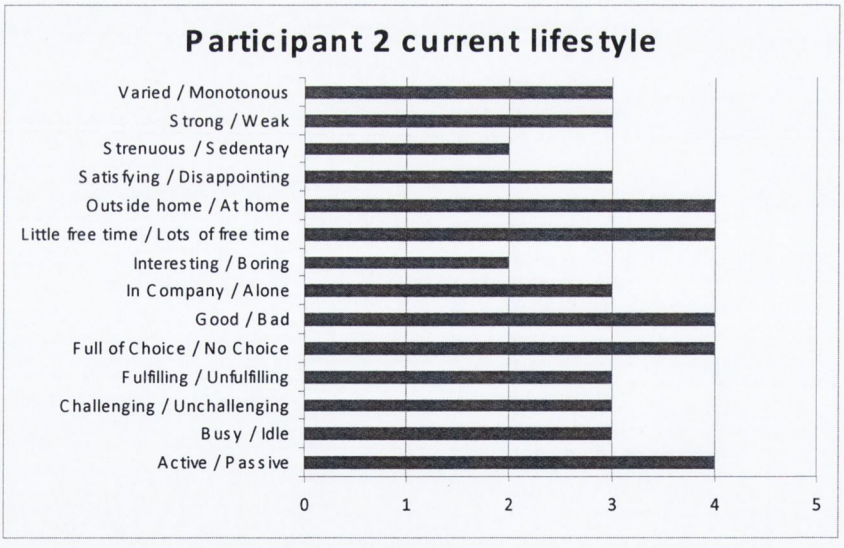


Figure 9.2.2 Bart – Rating of Ideal Lifestyle

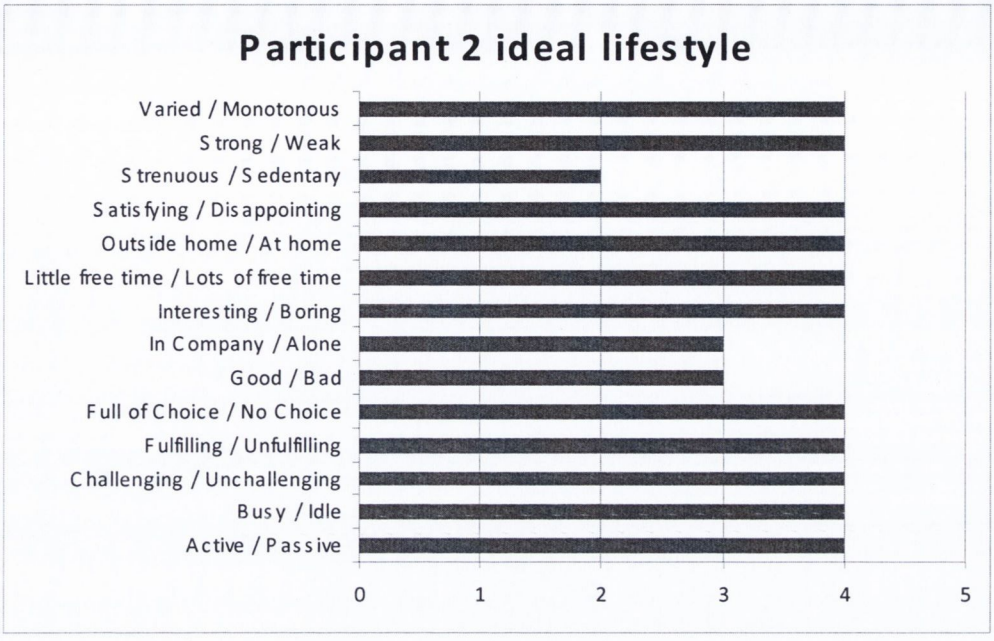


Figure 9.2.3 Bart – Comparison of lifestyle ratings

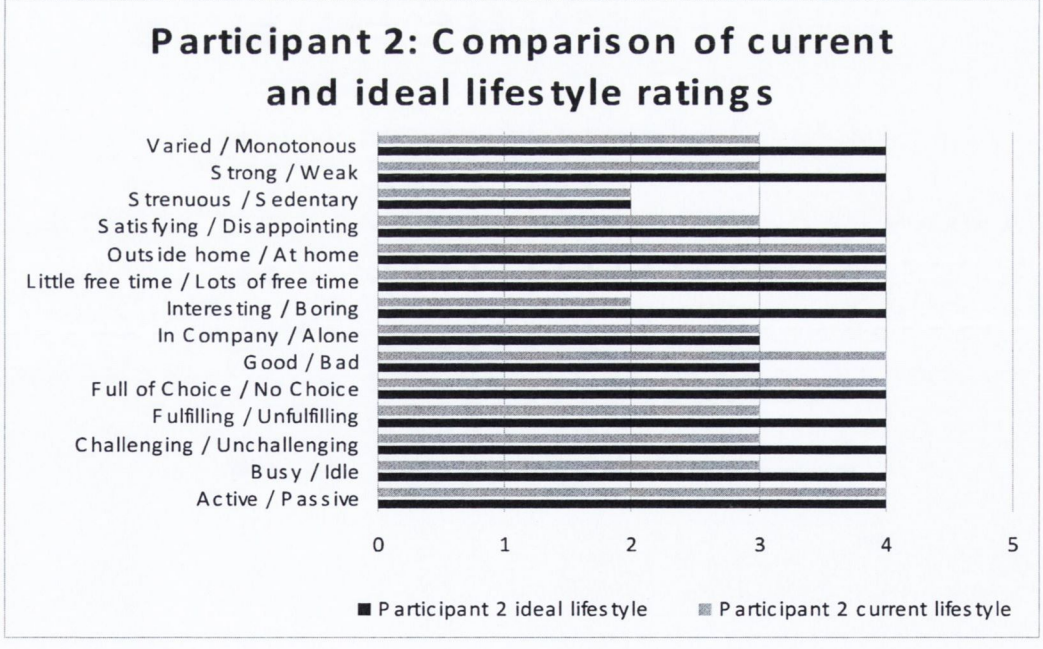


Figure 9.3.1 Cathal – Rating of Current Lifestyle

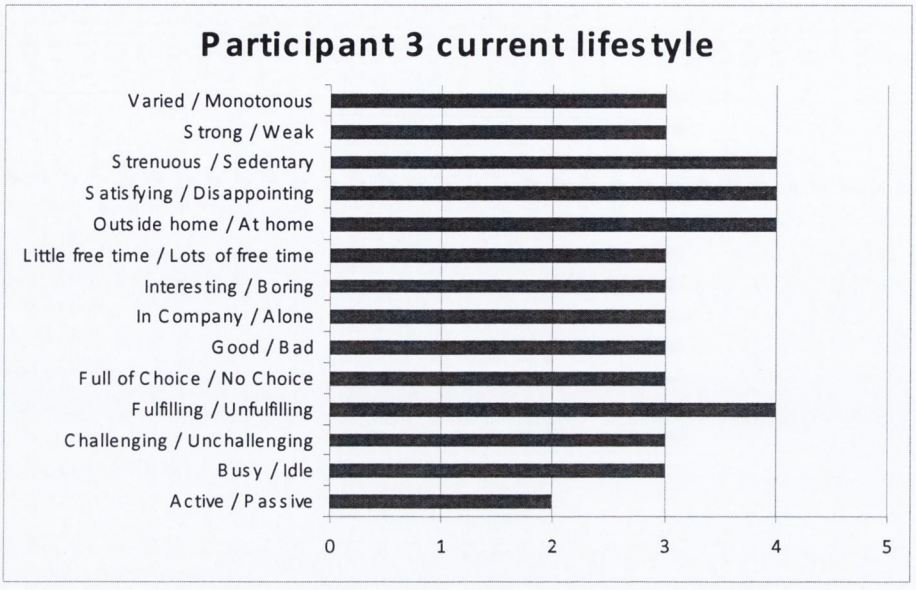


Figure 9.3.2 Cathal – Rating of ideal lifestyle

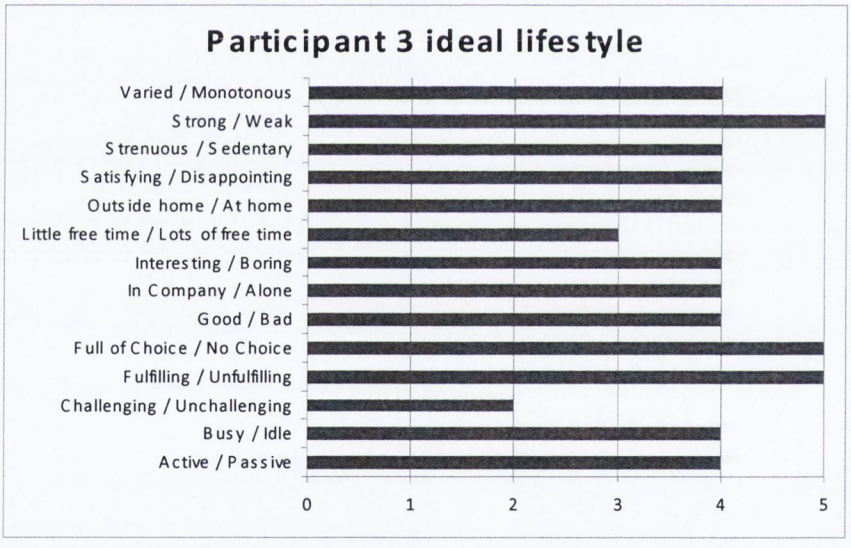


Figure 9.2.3 Cathal – Comparison of lifestyle ratings

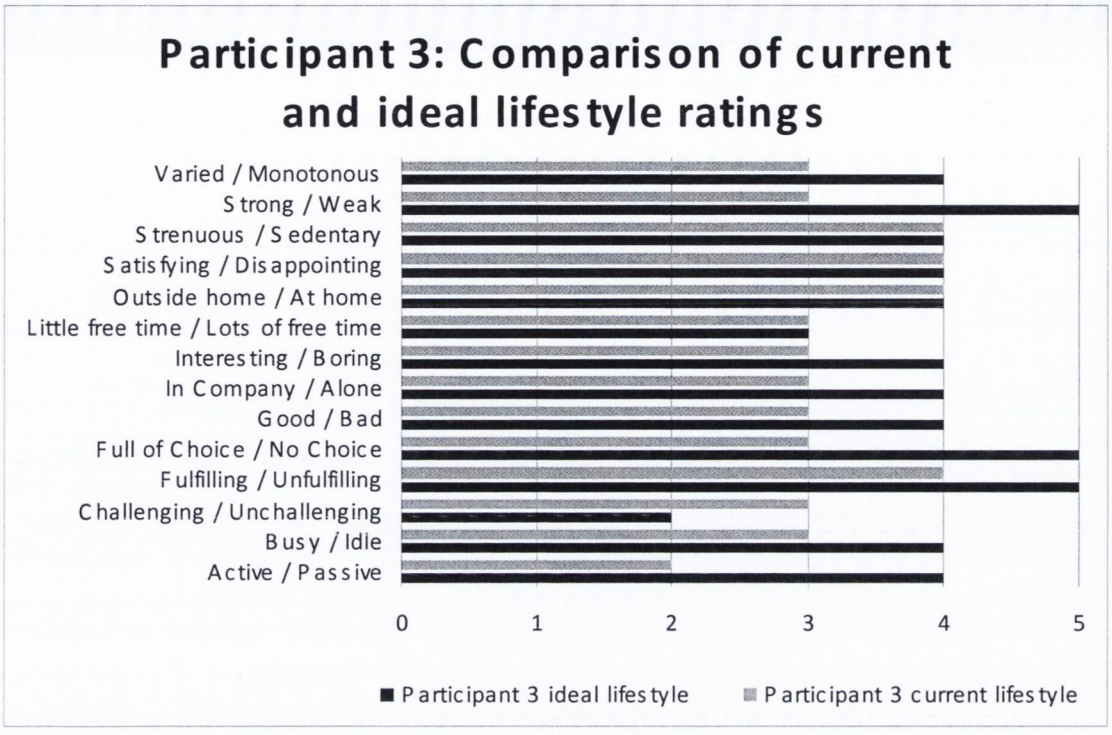


Figure 9.4.1 Deirdre – Rating of Current Lifestyle

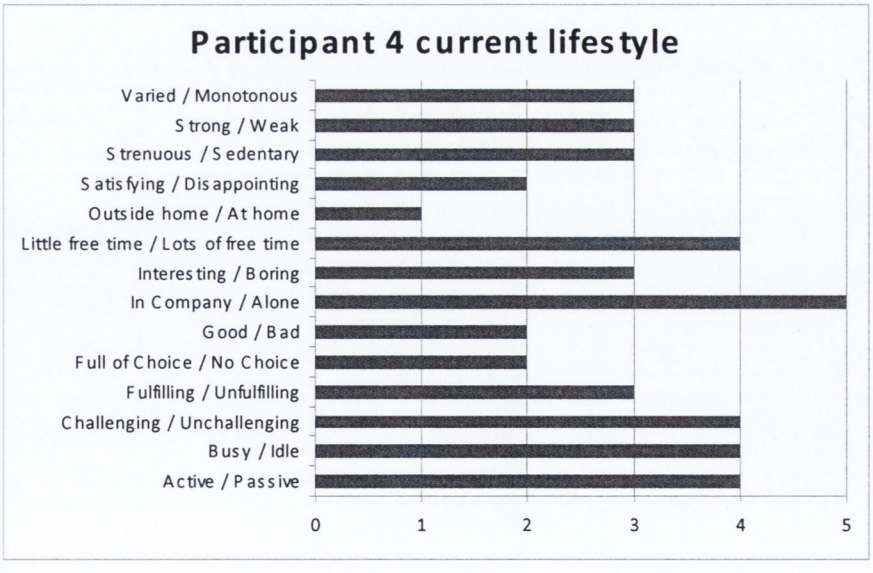


Figure 9.4.2 Deirdre – Rating of Ideal Lifestyle

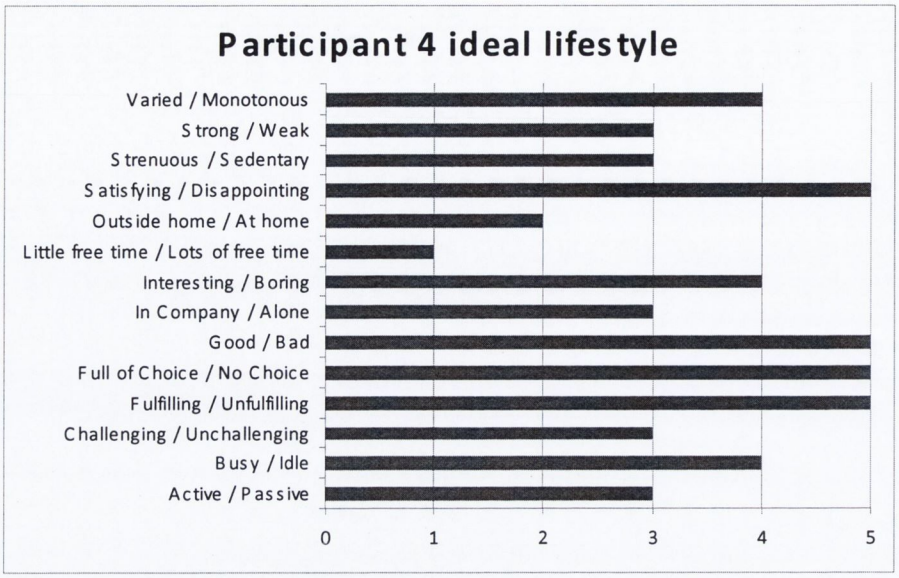


Figure 9.4.3 Deirdre – Comparison of lifestyle Ratings

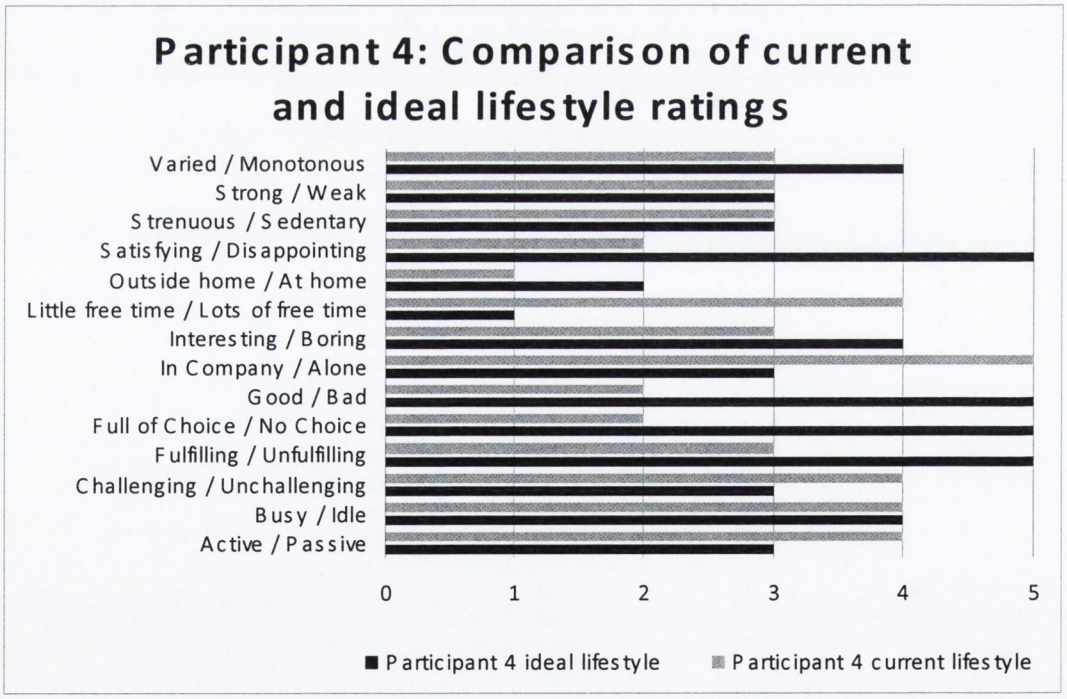


Figure 9.5.1 Emily – Rating of Current Lifestyle

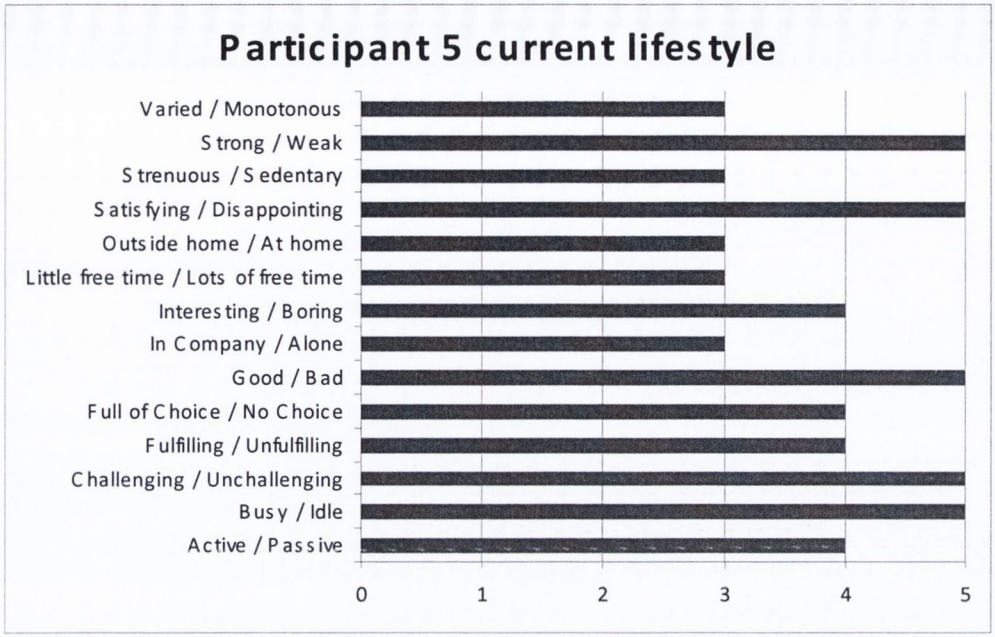


Figure 9.5.2 Emily – Rating of Ideal Lifestyle

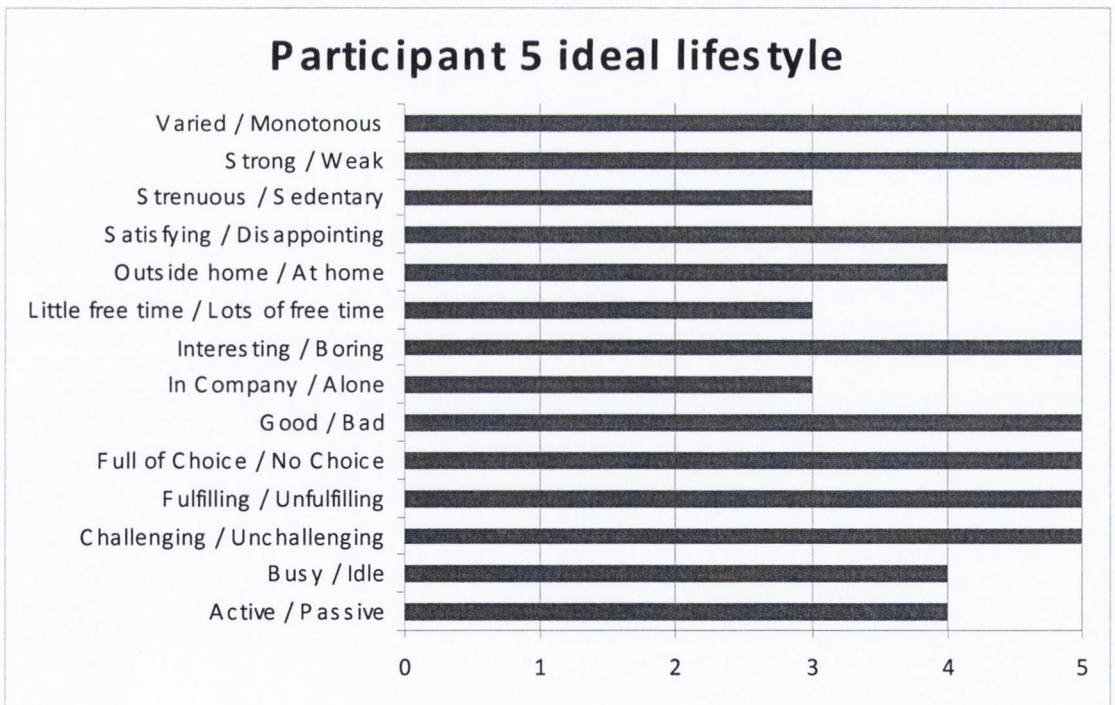


Figure 9.5.3 Emily – Comparison of Lifestyle Ratings

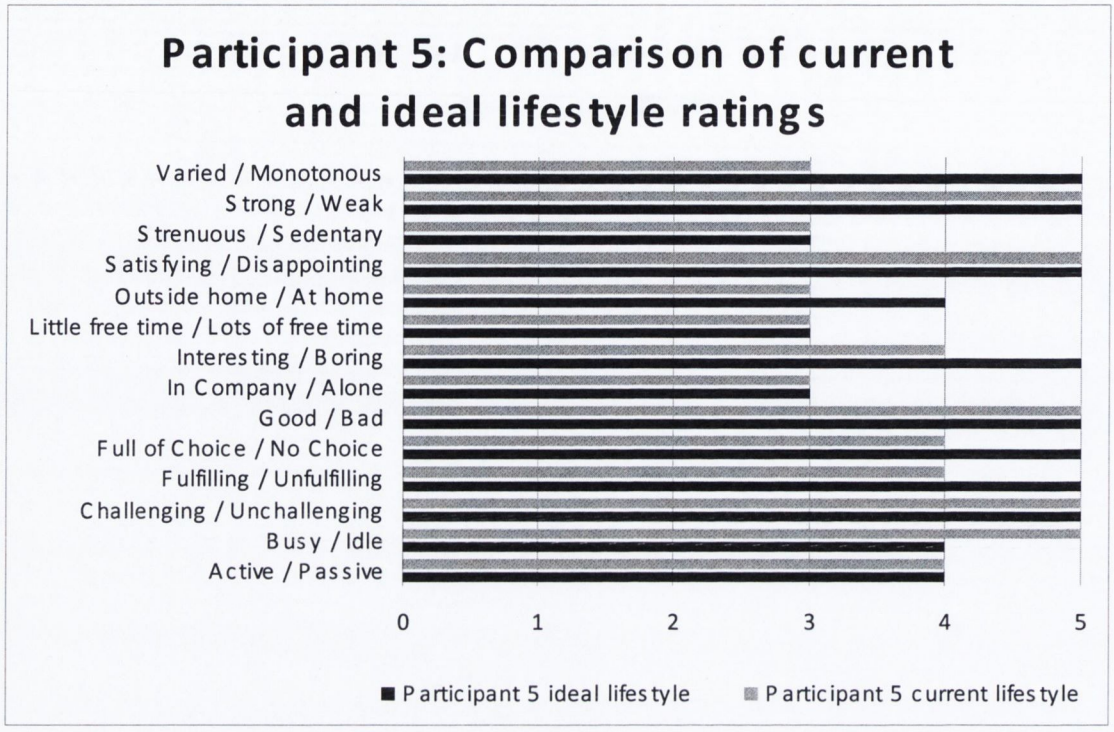


Figure 9.6.1 Freya – Rating of Current Lifestyle

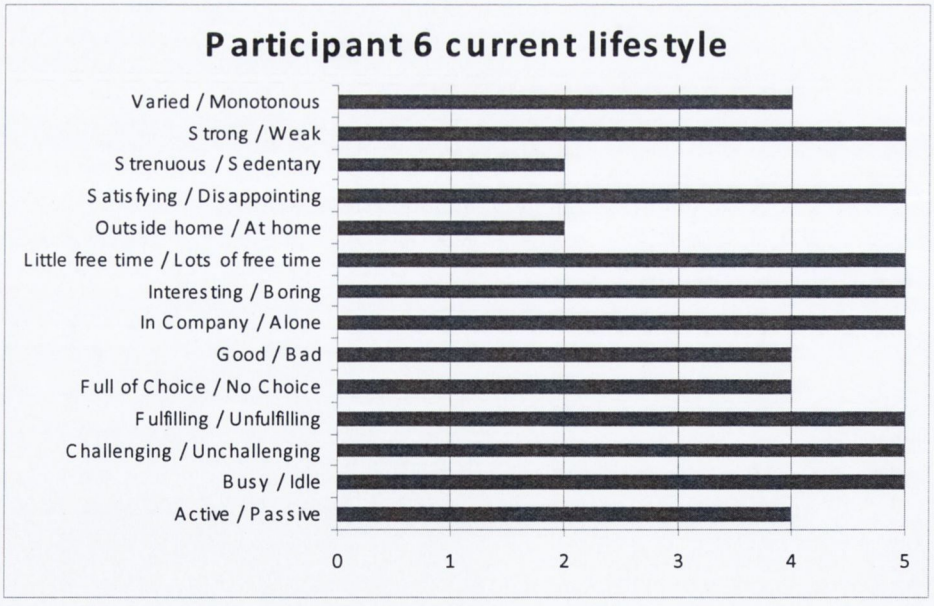


Figure 9.6.3 Freya – Rating of ideal lifestyle

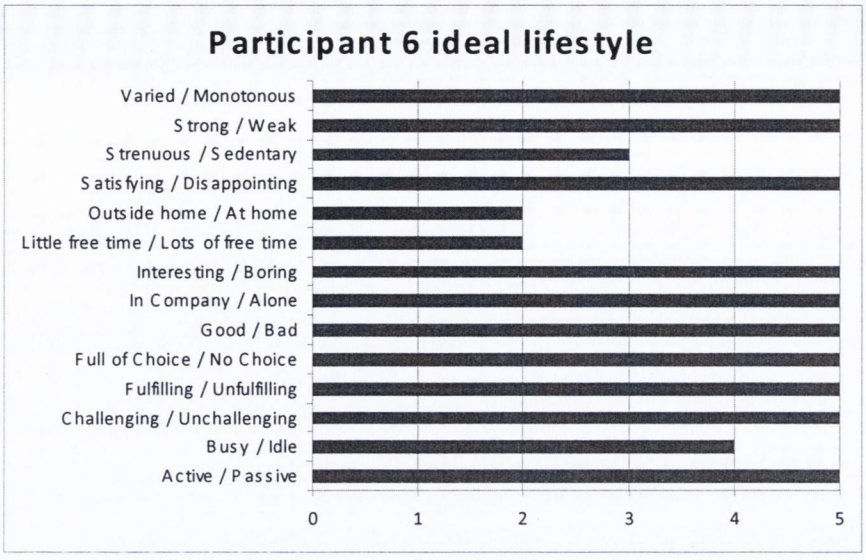


Figure 9.6.3 Freya – Comparison of Lifestyle Ratings

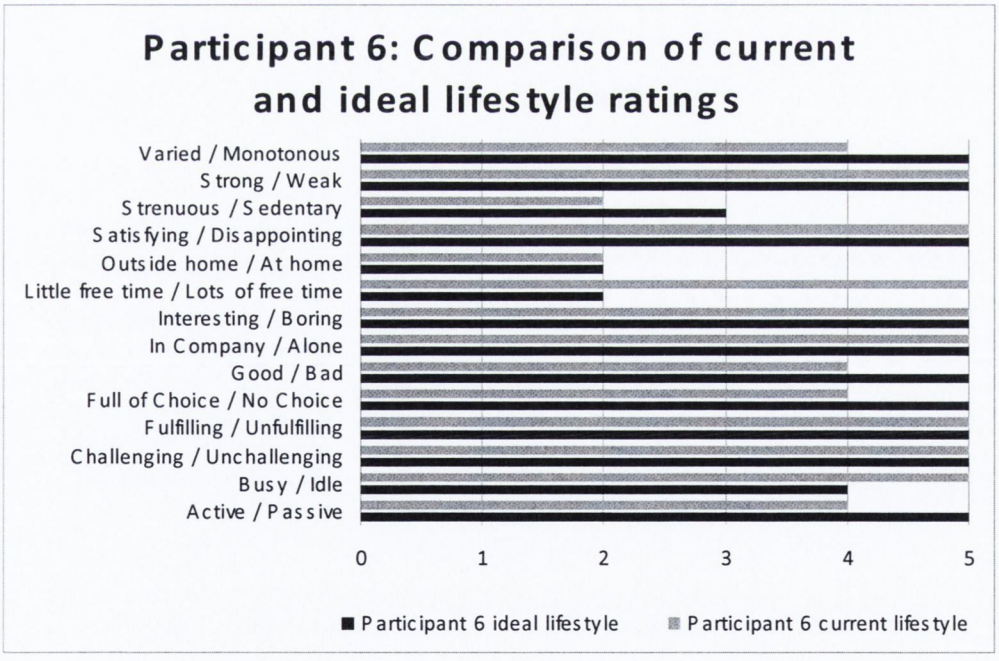


Figure 9.7.1 Grainne – Rating of current lifestyle.

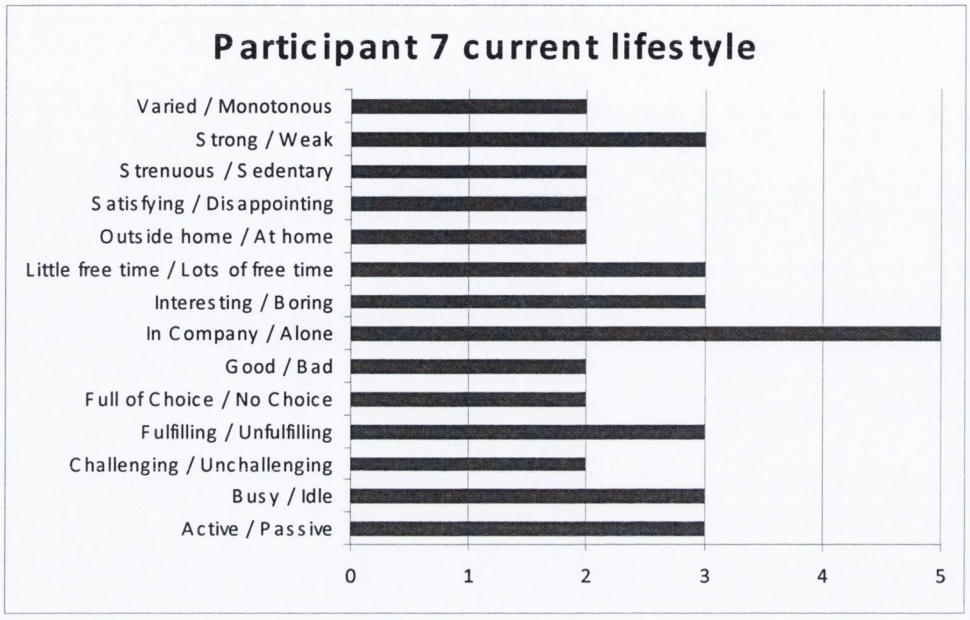


Figure 9.7.2 Grainne – Rating of ideal lifestyle

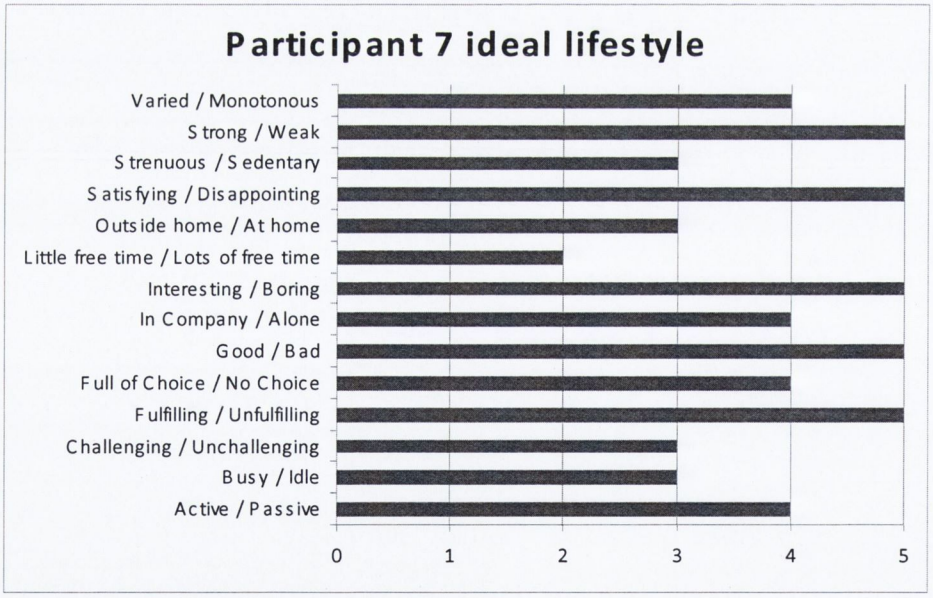


Figure 9.7.3 Grainne – Comparison of Lifestyle Ratings

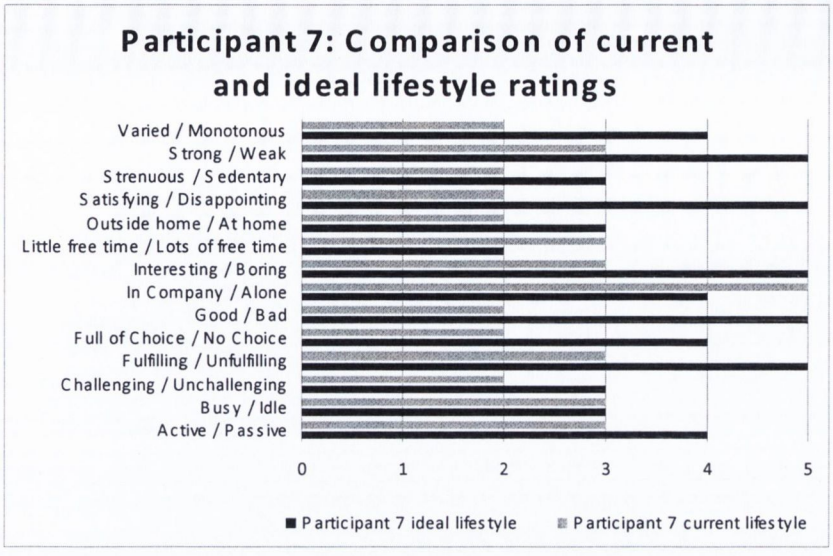


Figure 9.8.1 Honour – Rating of current lifestyle

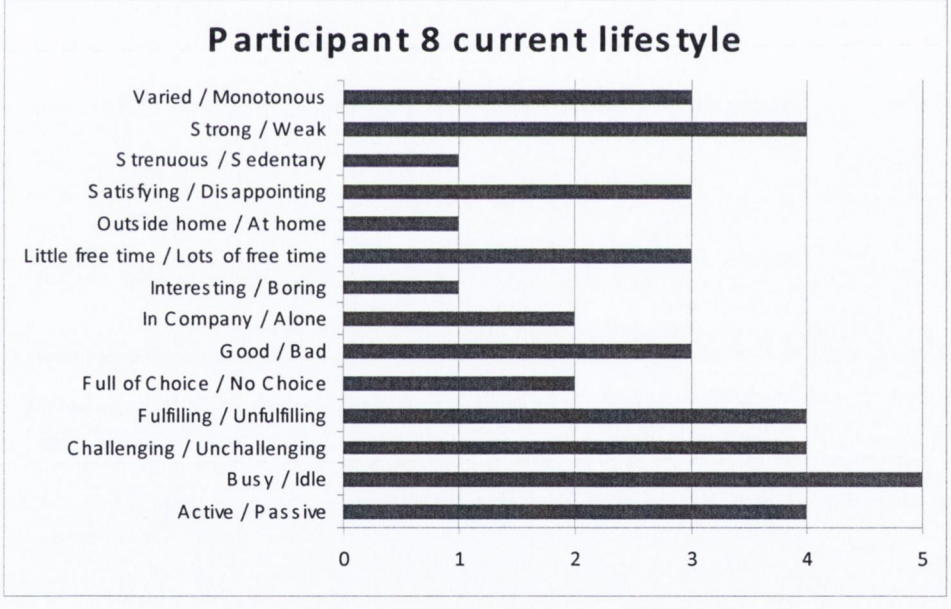


Figure 9.8.2 Honour – Rating of Ideal Lifestyle

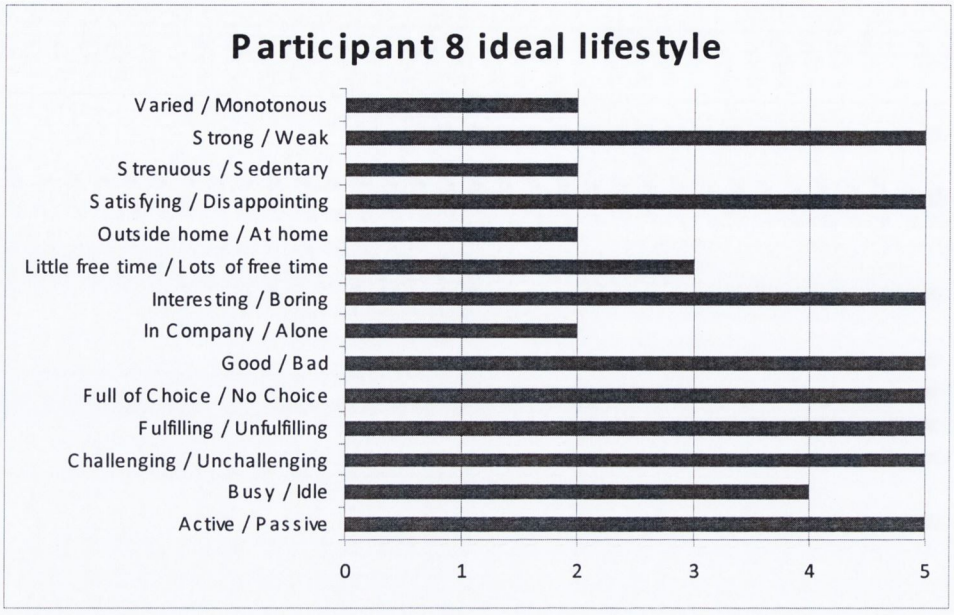
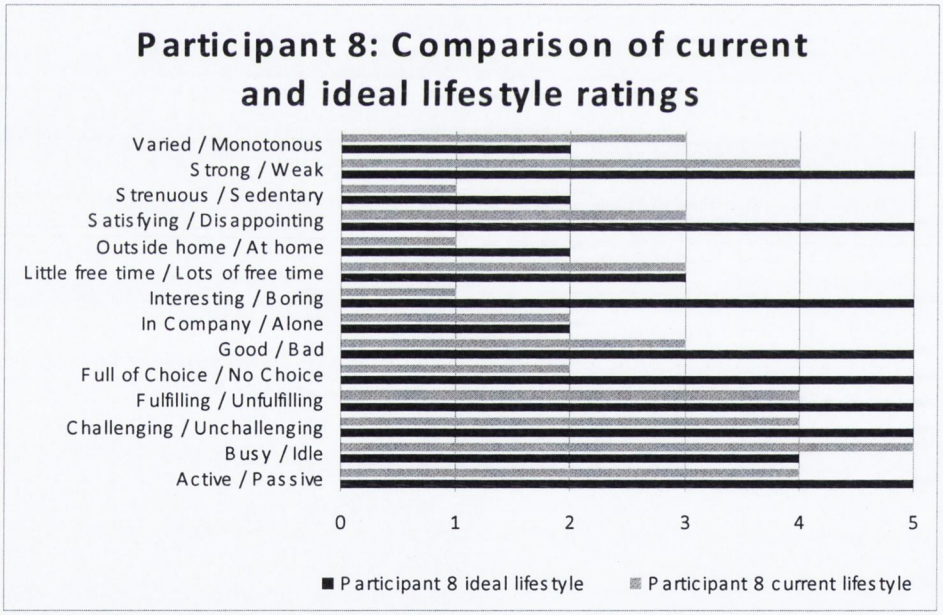


Figure 9.8.3 Honour – Comparison of Lifestyle Ratings



Appendix B: Data Collection Method

Data Collection Summary

Part 1: Background Information

Demographic Information

	ID Number		
	Setting / IL /	Setting ID number:	
	Gender:	Date of Birth: / /19	Age:
	Condition		
	Course of the condition:		
	Observations of Function		

Background Information

How the person came to live in the setting.	
Educational Background:	
Date of first interview:	Date of self-maintenance interview:
Dates of diary week:	Date of final interview:

Semi-structured Interview

Transcript.

Field notes

Code:

ID Number		Initials	
Gender		Age	
Interview type		Date	

Goals
❶
❷
❸

Location

Description of location

Position/Seating
Interviewee
Interviewer

Impact of positioning

Description of Non-verbal behaviour

Interpretation of non-verbal behaviour

Impressions about process

Engagement
Abstract thinking
Consideration of questions

Field Notes Code:
Page 2

Content

Keywords
Focus Topics
Concepts
What stood out

Technology used
Recording
Communicating

Problems with technology

Analysis
Themes
Hunches
Questions

Further Information

Self-Maintenance (daily routine) activities.

In relation to the specific daily self-maintenance tasks:

Name of Task	Where is this done?	When is this done?	How long does it take?	Do you use assistance?	If you use assistance, in what way?	Do you have choice over how you are assisted?	Do you have control over this task?
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes /		Yes / Some /	Yes / Some /

				Sometimes / No		No	No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No
			minutes	Yes / Sometimes / No		Yes / Some / No	Yes / Some / No

Additional information:

Date:			**Day 1**				
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Date:			**Day 2**				
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Day 3

Date:

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Date:			**Day 4**				
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Day 5

Date:

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W)? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Date:			**Day 6**				
Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Day 7

Date:

Name of activity	Is this self-care (S) productivity (P) or Leisure (L)?	Where did the activity take place?	When did you start (S) and finish (F) the activity?	Were you alone (A) or with someone (W) ? Who?	Is this activity important to you?	Did you enjoy the activity?	Did you have control over this activity?
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No
	S / P / L		S- F-	A/W	Yes / a little/ No	Yes / a little/ No	Yes / some / No

Final Interview Notes

Perceptions of Occupational Performance

What does autonomy mean to you? THEMES:
What does choice mean to you? THEMES:
Information from Diary and Self-Maintenance activities verified?
Was last week a good week, an average week, or a bad week? Why?
Self-Maintenance Activities
Are the self-maintenance activities that you outlined for last week typical of every week? If not, what are the differences?
Do you feel that you spend a normal amount of time on self-maintenance tasks, less than usual or more than usual time? How is this?
How satisfied are you with the self-maintenance activities in terms of: What has to be done every day How you do them Where you do them
When outlining your daily activities, you indicated the amount of assistance that you receive to perform the tasks. How do you feel about: The amount of assistance that you use (would you like less or more assistance) The type of assistance The manner in which assistance is given.

In relation to self-maintenance activities, how do you feel about the amount of autonomy you have over what you do?
In relation to self-maintenance activities, how do you feel about the amount of choice you have over what you do?
Activities that are not performed every day, as part of the daily routine
Was last week a typical week in terms of what you did?
Which of last week's activities are rare for you?
Are there any things that you would commonly do during the week that you didn't do last week?
Which activities do you most enjoy?
Which activities do you least enjoy?
How satisfied are you with last week in terms of: What you did How you did the activities The proportion of time that you spent in each place
Did you do everything that you wanted to do last week?
If not, what would you have liked to do?
Last week, what kind of things hindered you from doing what you wanted to do?

Last week, what kind of things enabled you to do what you wanted to do?
Lifestyle in general
On a daily basis, are there periods of time that you find hard to fill?
Do you ever find yourself bored and frustrated because of not having enough to do, or not being able to do what you want to do?
On a daily basis, do you find that you have too much to do and are too busy?
Do you have enough choice in your life? Do you have too much choice? How so?
Are you happy with your present lifestyle?
Do you think that you have chosen your present lifestyle, or has it just "happened this way"? Happened
Do you feel autonomous in your everyday life? How so?
If you wanted to change your lifestyle, could you? How?
What would you change about your lifestyle?
Any further comments:

Final Interview: Transcript

Part 2: Semantic Differential scale: Perceptions of occupational performance

How would you rate your lifestyle and the things that you do now?						
Varied	1	2	3	4	5	Monotonous
Boring	1	2	3	4	5	Interesting
Bad	1	2	3	4	5	Good
Fulfilling	1	2	3	4	5	Unfulfilling
Sedentary	1	2	3	4	5	Strenuous
Challenging	1	2	3	4	5	Unchallenging
Idle	1	2	3	4	5	Busy
Active	1	2	3	4	5	Passive
In company	1	2	3	4	5	Alone
Outside home	1	2	3	4	5	At home
Satisfying	1	2	3	4	5	Disappointing
Lots of free time	1	2	3	4	5	Little free time
Weak	1	2	3	4	5	Strong
Full of choice	1		3	4	5	No choice

Additional Comments:

How would you like your ideal lifestyle to be?						
Varied	1	2	3	4	5	Monotonous
Boring	1	2	3	4	5	Interesting
Bad	1	2	3	4	5	Good
Fulfilling	1	2	3	4	5	Unfulfilling
Sedentary	1	2	3	4	5	Strenuous
Challenging	1	2	3	4	5	Unchallenging
Idle	1	2	3	4	5	Busy
Active	1	2	3	4	5	Passive
In company	1	2	3	4	5	Alone
Outside home	1	2	3	4	5	At home
Satisfying	1	2	3	4	5	Disappointing
Lots of free time	1	2	3	4	5	Little free time
Weak	1	2	3	4	5	Strong
Full of choice	1	2	3	4	5	No choice

Additional comments:

Field notes

Code:

ID Number		Initials	
Gender		Age	
Interview type		Date	

Goals

❶

❷

❸

Location

Description of location

Position/Seating

Interviewee

Interviewer

Impact of positioning

Description of Non-verbal behaviour

Interpretation of non-verbal behaviour

Impressions about process

Engagement

Abstract thinking

Consideration of questions

Field Notes Code:
Page 2

Content

Keywords
Focus Topics
Concepts
What stood out

Technology used
Recording
Communicating

Problems with technology

Analysis
Themes
Hunches
Questions

Further Information

Appendix C: Choice and Autonomy Booklet & Information for Participants prior to Data Collection

Choice and autonomy in doing

Research with people with disabilities

Information Booklet for Participants

Welcome to the research!

Thank-you for indicating that you may be interested in participating in research looking at how a person's choice and the environment can affect how people with disabilities live their lives.

I am grateful to you for taking the time to look through this booklet, and would be very happy to address any queries that you may have. Your dignity, confidentiality and opinions are of most importance, which is one reason this booklet has been produced.

This booklet gives you the information that you need to decide whether or not to participate in the research, and if you do participate, to know what will be asked

What this booklet contains

This booklet has the following sections:

1. A bit about the Researcher
2. Overview of the research
3. Your rights as a contributor
4. What the process involves
5. What kind of information will be asked?
6. The interviews:
   Interview 1
   Self-Maintenance Activities
   Diary Information
   The final interview
7. Some more answers to questions
8. Contacts.

This booklet is available in print and large print, on tape, in electronic format or in another format of your choice should you need it.

1. A bit about the Researcher.

Bethan Collins is conducting this research as part of a PhD in occupational therapy. Bethan graduated with a first class honours degree in occupational therapy from Trinity College Dublin. Before beginning the research, Bethan worked as an occupational therapist in the Royal Hospital Donnybrook. There, she worked in rehabilitation services for older people, long-term care, a dementia unit and with younger adults with physical disability.

Bethan's interest in disability issues primarily comes from experience outside the world of occupational therapy – while in college she was the "Officer for Students with Disabilities" with the Students Union, is an executive member of Irish Blindsports and is on the council of the Forum of People with Disabilities. Of particular interest to her are issues around the individual's right to choice; disability legislation and how the environment affects people with disabilities.

2. Overview of the research

This research is about what people do in everyday life, and how they do these things. It is particularly about how much choice and autonomy people with disabilities who live in different settings have over their lives.

This booklet is about the first part of the research, which will ask a number of people with disabilities what kind of thing they do in their everyday life, how much control and choice they have over what they do, and how happy they are with their current lifestyle.

You have been invited to share some information and participate in the research. Read on to find out more.

3. Your rights as a contributor

You are free to decide whether or not to participate in this research – as with any piece of research. **Participating will not affect you in any other way.**

You will remain anonymous.
As a participant, your information will be assigned an identification number. Your name, the place where you live, or other personal details will not be recorded at all with your information. There will be over 50 other people in the research, so there is no way that you could be identified.

Your answers are confidential
Your answers or views will not be shown to anyone outside the research at any time or for any reason. Results from all participants will be presented together as results of the research, not as information given by one individual. At no point will your answers be distinguishable to anyone other than yourself and the researcher.

Your views will not be used for any other purpose.
Any information, opinions of views that you give during the course of interviews will not be shared with anyone outside the research and will not be used for any purpose other than to inform the findings of this research.

You have a right to dignity and privacy.
The nature of research is to find out about people's lived experiences. This research method is designed to collect a lot of information, but should not be too intrusive. Your dignity and rights will be respected, and all information is strictly private.

You are free to pull out at any stage.
Pulling out of the research will not affect you in any way.

You are entitled to find out the results of the research.
Too often research is "done on" rather than with people with disabilities, and the people who contributed to it never find out what happened to their time. If you participate in the research, you are entitled to ask for, and receive a copy of the findings,

To thank you for participating, you will (if you wish) be entered into a draw to win one of two €100 vouchers.

4. What the process involves

This is the first stage of a research study. It will involve collecting a lot of information from 50 – 75 people about their lifestyle, how happy they are with their lifestyle and how much choice and autonomy each person has.

People who live independently, and in residential spaces are being asked to participate, to find out whether, and how much the environment influences a person's quality of life.

The most important part of the research is finding out your views and opinions about your daily life.

The way that information will be collected is quite long, because your views are so important. It would be too difficult to gather your views if everything had to be pinned down to a short session.

Some people will have less to say, so the process will be shorter for them.

Collecting the information that is needed will be done in four stages. Each stage is described in more detail later on in this booklet.

First, there will be an introduction interview. This asks you broadly about your life.

The second stage involves asking about the routine activities that people do every day – such as getting up, dressing, eating and so on. This is called "self maintenance activities". The focus for this is to find out how much control you have over these activities and how happy you are with the assistance (if any) that you use.

The third section is about all of the activities that are not self-maintenance – everything from hobbies, to work, to watching t.v. – whatever you do. You will be asked to keep a diary of the activities that you do each day for one week.

The final stage is an interview, where you will be asked what your views are about the information that you have given in the previous parts of the research.

5. What kind of information will be asked?

You will be asked quite a lot of information about your daily life, as it is important to have a full picture of the lived experiences and views of people with disabilities.

The questions will primarily relate to a given week in your life.

The questions are about what you do, what you would like to do, what is important to you, what you have control over and how you do the things that are important to you.

The questions are not intended to be intrusive, nor should they invade your privacy. A certain amount of information about what kind of things you do and how you do them is needed to make sure that what you are saying is understood in terms of your life experiences, rather than anyone else's preconceptions.

> *For example, if a person has access to, and uses personal assistance, their comments about the value or role of personal assistance will be different to a person who has no experience at all, but is imagining what it would be like for them. Both views are equally valid, but they come from a different perspective.* **The perspective is very important so that the views are not taken out of context or taken in isolation.**

If at any stage you are uncomfortable answering any question, you have the right to refuse to answer.

You will be asked if you are comfortable answering the questions.

The next part of this booklet will go through the types of questions that will be asked in each part of the interviews.

6. The interviews:

As already described, there are four parts to collecting the information needed. Each of these are described in more detail below.

a. The first interview

Why is this interview happening?
This first interview is to get background information, so that the rest of the information can be put into context.

In this first interview, you will have the chance to ask any questions, and to find out more about the research. If you have any doubts, you can ask for clarification at this time.

What will happen?
The interview will run like a discussion, rather than a list of questions to be answered. It is not a test; your views are the most important thing.

- The first interview will begin by asking demographic information – that is basic facts like your approximate age, gender, what type of space you live in, and will assign an ID number to all of your information.

- A discussion will be held about the kind of things that you do in everyday life, the roles that you have, important things in your life how much choice you have and about what you think about the environment around you (in terms of whether it is supportive, accessible etc.)

- Other information such as how you came to live where you do and what opportunities and experiences you have had of education will be asked.

These sections and the structure of the interview come from an assessment known as the "OPHI-II", which is an occupational therapy interview. The aim of this is to get an idea about the important things that you think shape your life, what is important to you and what kind of things you do.

One part of the research question is to see if the things that people who live in independent living spaces do diffet to the things that people in residential spaces do.
The background information is needed to make sure that comparisons are valid – two people with very different experiences of disability are likely to have different views regardless of where they live. If people with similar disabilities have big differences in what they do then this may be at least partly related to the environment around them.

Why is it being done like this?
This structure for an assessment is tried and tested, and forms part of a "narrative" approach to collecting information. Narratives have been used quite widely in disability research – particularly emancipatory methods, where people with disabilities are actively involved in the research.

This information is being collected to make an account of the differences and similarities that exist in the lived experiences of people with disabilities.

b. Self-Maintenance Activities

Introduction
It is usual that people do certain things every day, such as get up in the morning, wash, dress, eat, use the toilet and so on. These are all to help keep us alive and healthy – the basic functions, and are called "self-maintenance activities"

People with disabilities often manage self-maintenance activities differently to people without disability, such as using adapted equipment or personal assistance. People with physical disabilities sometimes say that self-maintenance activities can take up too much time.

There is very little information available about how having a physical disability affects the way self-maintenance activities are managed.

There is very little, if any information on how the environment and other factors affect how a person with a disability manages their self-maintenance activities.

This part of the research will ask you about how you manage your self-maintenance activities, and will hope to partlyfill in some of the gaps in the information currently available.

What will happen?

The following specific questions will be asked:

- You will be asked to identify and name the self-maintenance activities that are done. (e.g. getting up in the morning, washing, dressing, eating, and so on).
- You will be asked for a general location of where the activity is done, such as "at home", "at work", "in the ward".
- You will be asked when you most commonly do the activity and how long it takes.
- You will be asked if you use assistance, would like to use assistance and how you use any assistance.
- You will be asked whether you have choice over how the activity is done.
- You will be asked whether you have control over what is done and how.

For the example of getting up in the morning,

- *Its name is "getting up"*
- *It may be performed at home*
- *A person may get up at 9.00 a.m., and it may take 30 minutes.*
- *The person may use assistance, and the assistant may help with a transfer from bed to chair.*
- *The person may feel that they have choice, because they can choose what time to get up at.*
- *A person may feel that they don't have much control, because the assistant uses a particular routine.*

Everyone will be very different, and the example above is just to describe what the questions mean.

The exact table where information will be added is at the back of this booklet.

How much information is needed?

You only need to speak about the things that are most important or time-consuming for you. You may group things together, such as including showering with washing and dressing. The most important information is how you do the activities, and whether you feel that you have choice and control over the way that your self-maintenance activities are managed.

Why is it being done like this?
An interview means that you can give the information verbally, rather than needing to fill in forms, which is hoped will be quicker for you.

If filling in the form yourself would be easier, you may do this.

c. Diary Information

Introduction
In the week after the first interview, you will be asked to keep diary information. The information is just to get an outline of the kind of things that you have done over the week

What will happen?
You will be asked which format for diary information would suit you best. The options are as follows:

- You can fill in printed forms like the ones at the back of this booklet.
  If you choose this option, you will be given a form for each day of the week to complete. You will be asked to fill in the information at the same time each day – such as in the evening.

- You can fill in the information electronically
  If you choose this option, you will be either e-mailed or given a disk with a Word Document. The document will contain a table for each day of the week. You will be asked to fill in the table at the same time each day for the week.

- You can record your answers about your diary on tape
  If you choose this option, the questions will be given to you, either in print or on tape, and you will be asked to record your answers onto tape. You will be asked to record your answers at the same time each day. *If necessary, equipment will be loaned, as well as a tape provided.*

- You can be contacted every day and asked to answer the questions.
  If you choose this option, the researcher will phone you each day at an agreed time and ask the questions. The researcher will record your answers, and will show you the information to make sure that it is correct after the week is over.

It is your choice how the diary will be kept – it is designed to suit you.

What will be asked?
The diary information that you will be asked for is in a sheet at the end of this booklet.

The print and electronic versions are in tables, with eight columns and rows where you can fill in your information.

The information that you will be asked is as follows:

1. In the first column, you will be asked to name the activity.

2. The second column asks you to decide whether the activity is self-care, productivity or leisure.
   - A self-care activity could include going shopping for food, cooking food, having a bath – anything that is done as part of self-care that does not form part of your daily routine already discussed. Self-care is often split up into personal self-care activities (grooming, hygiene), functional mobility (getting around) and instrumental activities (shopping, budgeting, planning household chores).
   - A productivity activity is usually paid or unpaid employment, voluntary work, education or household chores.
   - Leisure activities are those done for fun, to relax, for enjoyment. They are often divided into active leisure, quiet recreation (such as reading or watching the television) and social activities.

   It is up to you to decide what is self-care, productivity and leisure for you because it will be different for everyone.

   All you need to do is circle the right letter in the box.

3. The third column asks where you did the activity. All you need to do is write a general place, such as “home”, “work”, “ward”, or whatever in the box.

4. The fourth column asks when the activity started and finished. Next to S write the time hat you started, and next to F write the time that the activity ended.

   This question is asking when you do different things and for how long.

5. The fifth column asks whether you were alone or with someone. Circle A for alone and W for with someone.

6. In the sixth column, you are asked whether the activity is important to you. If it is, circle yes, if it is a bit important, circle "a bit" and if it is not important circle "no".

7. The seventh column asks whether you enjoyed the activity.

   As with the last column, if it is enjoyable, circle "yes", if it is a bit enjoyable, circle "a bit" and if it is not enjoyable at all, circle "No".

8. The final column asks whether you had control over the activity. This means whether you chose to do it, chose where to do it, how to do it, and if you could have not done it or done it differently if you wanted to.

   Circle "Yes" if you feel that it was your choice to do the activity, "Some" if you had some choice or control over the activity, and "no" if you had no choice.

Why is the diary information important?
The diary information is needed to provide a framework to find out your opinions.

It is also to see whether people in different living spaces have different amounts of control, and do different things in their daily lives.

How much information is needed?
You only need to write about the most important or time-consuming things.

You do not need to write about the self-maintenance activities that you have already described.

If you have questions, the researcher will be available to answer them.

d. The final interview

What will be asked?
The final interview asks a number of different questions, relating to information that you have given about self-maintenance and from the diary information.

It will ask you how satisfied you are with the things that you do, and how you do them at the moment. It will ask about how much control you have over how and what you do, and what, if any changes you would like to make.

If you have anything else that you want to say, you will have the opportunity to say it during the final interview.

The very last thing that you will be asked is to rate your lifestyle as it is at the moment using a number of criteria. You will also be asked to rate your "ideal" lifestyle using the same criteria. This is to gauge how happy you are with your lifestyle as it is at the moment, and how, if at all, you would like it to change.

Why is it being done like this?
The final interview is intended to "tie up" all of the information that you have given, to make sure that it is all recorded accurately, as you would like it to be, and to get your views on the situation at present, and how you would like it to be in the future.

7. Some more answers to questions

How long will it all take?
Information will be collected over a one week period. The exact amount of time that it will take will depend on the person. Each interview may take up to an hour, or maybe more. The diary information should only take 5 – 10 minutes every day for one week.

Will my answers be shown to anyone else?
No, all information will be kept within the research.

Why have I been asked to participate?
You have been asked to participate because it is hoped that you can explain what your situation is like. Participants have been selected from a number of settings, so living where you do or using certain services/resources made it possible for us to ask you. You may have volunteered yourself.

What if I don't want to take part?
Then you don't have to.

What if I can't fill in forms?
You don't need to fill in any forms. If you think that you may have difficulty participating in the research due to disability, then the way that your information will be collected can be changed to suit you.

What if I don't want to answer a question?
If you don't want to answer a question, then you don't have to.

What if the most important things to me aren't asked?
There will be time at the end, and during most of the interviews to give other information that you think is important. The questions are only a guide.

Will I get anything out of taking part?
Some people enjoy participating in research, and find that they can think about things more clearly after talking about their life. At the moment there is very little information about the lived experiences of people with disabilities. Participating in this research will mean that more accurate, "real" information is available.
If you wish, you can be entered into a draw to win a €100 voucher for taking part.

8. Contacts.

If you have any queries, at any stage, please do contact me at any of the following:

Bethan Collins

School of Occupational Therapy
Trinity College Dublin,
Trinity Centre for Health Sciences
St. James' Hospital
Dublin 8

Phone: (01) 6083219
087 2060657

fax: (01) 4546363

e-mail: bcollin2@tcd.ie

Thank-you for reading through this booklet

You will be contacted shortly to ask if you are willing to participate in the research.

If you are already a participant, you may keep this booklet for your information. If you have any queries, you may contact the researcher at the above details.