An Evaluation of Personalised Supports to Individuals with Disabilities and Mental Health Difficulties

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Foreword

This evaluation is unique in Ireland in terms of its scope which is across disability and mental health; with multi-stakeholder perspectives; across multiple sites in Ireland and over multiple points in time. While this breadth across different dimensions is important, perhaps the greatest strength of this study is its focus on the person; on listening to and documenting their stories; on carefully measuring, based on the person's own assessments, how their life has changed as a result of the supports they have received to move to a more independent life. We in Genio are delighted to see the completion of this significant piece of work, which provides important evidence on policy implementation in Ireland.

Prof. McConkey and his team, along with the research associates, went above and beyond what was expected to complete this work comprehensively and to a high standard, through building relationships with the individuals involved, their relatives and the organisations and staff supporting those individuals.

We are very grateful to the individuals and their relatives, who gave of their time and shared their own stories with us. We are also grateful for the cooperation of the organisations who participated along with their staff and we acknowledge the time involved in such an undertaking.

We owe it to the participants, and the many more individuals with disabilities and mental health difficulties who still do not have the life of their choosing, to act on the findings in this report. Genio will use these findings to inform how people with disabilities and mental health difficulties can be supported to live independent and included lives in their own communities, while receiving more cost-effective supports from disability and mental health services.

Fiona Keogh, PhD

Director of Research and Evidence, Genio

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This report

This report gives an overview of the findings from an evaluation of 23 projects that Genio grant-aided in 2010 and 2011 to facilitate personalised housing and support arrangements for persons with intellectual disabilities, mental health difficulties and physical disabilities.

This report on the findings has been written primarily for service providers and commissioners. The more technical aspects of the research that was undertaken are available in a series of technical reports which are available on request from Prof. McConkey. Our aim is to make the findings accessible and to identify the implications for future decision-making with regard to transforming and extending current accommodation and support arrangements in Ireland for persons with disabilities and enduring mental health difficulties.

Project Team

Professor Roy McConkey directed the evaluation. His chair in developmental disabilities at the University of Ulster is a joint appointment with the Health and Social Care Board for N. Ireland. A psychologist by training he previously worked at the University of Manchester, in Dublin with St Michael's House and in Scotland with the Brothers of Charity. He has undertaken numerous research and evaluation projects nationally and internationally.

Rachel Stevens was appointed as part-time Project Manager. She has worked in the field of human rights and social justice for the majority of her career, supporting projects and individuals in the areas of disability and mental health, psychosocial support, advocacy, youth projects and homelessness. Until December 2010 Rachel was Manager at the Centre for Disability Law and Policy, at the National University of Ireland, Galway, and Chairperson of the Galway Advocacy Service. At the start of 2011, she founded and now directs Empower All, a private organisation with the intention and purpose to empower individuals and organisations to instigate positive social, economic, civil, political and cultural change.

Professor Brendan Bunting holds a chair in psychology at the University of Ulster and was the founding Director of the Bamford Centre for Health and Wellbeing. He has worked with Harvard Medical School on prevalence rates of classified mental health conditions and the economic costs of posttraumatic stress disorders and is part of a 28 country consortium examining inequalities in mental health.

Dr Edurne Garcia Iriarte Following on from her doctoral studies in the USA, Edurne came to Trinity College Dublin in 2009 and has extensive experience of working with intellectual disability services across the Republic of Ireland and the formation of an

Inclusive Research Network. She is a lecturer in the School of Social Policy and course director of the Masters in Disability Studies.

Dr Finola Ferry is a research associate at the University of Ulster specialising in health economics. She received her training from the Centre for Health Economics at the University of York and from the European Study of the Epidemiology of Mental Disorders (ESEMeD) Group at the University of Leipzig and the University of Barcelona.

1. Context of the Evaluation

1.1 The international context

Recent years have seen a radical shift in thinking about disability and chronic ill-health. Medical models of 'care' have given way to new approaches that emphasise removing the social barriers to citizenship and equality of opportunity as embodied in the United Nations Convention on Rights of Persons with Disabilities (2006). Article 1 summarises its purpose:

*"to promote, protect and ensure the full and equal enjoyment of **all** human rights and fundamental freedoms by **all** persons with disabilities, and to promote respect for their inherent dignity".*

Furthermore Article 19 states:

> *Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*

Likewise in mental ill-health, recovery-orientated practices share similar aspirations (Department of Health and Children, 2006).

> *Interventions should be aimed at maximising recovery from mental illness, and building on the resources within service users and within their immediate social networks to allow them to achieve meaningful integration and participation in community life (p.8).*

Inclusion International (2012) brought together the experience of self-advocates with intellectual disability and family members across 95 countries to review the international application of Article 19 of the Convention. They concluded:

> *In high income countries where service infrastructures have been developed they continue to be professionally driven, modelled after institutional care; segregated and isolating. Governments must introduce a reorganization of the service delivery system which requires a paradigm shift by all actors (disability and other service providers, public policy actors, families, employers, educators etc.) towards a system which is directed by the needs and aspirations of people with disabilities (p.136).*

But for this to happen, major changes are required to the way support services are financed and delivered and that better outcomes are likely as a European Commission report (2009) noted:

> *There is strong evidence in support of transition from institutional care to community-based alternatives (deinstitutionalisation). These can provide better results for users, their families and the staff while their costs are comparable to those of institutional care if the comparison is made on the basis of comparable needs of residents and comparable quality of care (p.6).*

However this transition is more than merely changing where people live. A position paper prepared by the International Association for the Scientific Study of Intellectual Disability (Mansell and Beadle-Brown, 2010) noted:

> *It is important to note that shifting from institutional to community-based models of care is not simply a case of replacing one set of buildings with another. Successful community based services need to be carefully planned around the needs and wishes of individual people and then continually monitored and adjusted as people's needs and wishes change (p.109).*

A European Expert Group produced guidelines on the transition from institutional to community-based care (2012) in which they identified four key lessons that have emerged over the years:

> *• the importance of a vision; • the need to engage with civil society; • the need to bring all the stakeholders on board; and • the crucial role of leadership in driving this process.*

Likewise studies of the de-institutional experience in Europe (Mansell et al, 2007) have demonstrated that the required transformation of services is not easily achieved unless there is political will, reallocation of resources and defined alternative models.

1.2 The Irish context

In Ireland, there are signs that such changes are coming. Recent policy documents have also described and recommended a way of supporting people with disabilities which involves a reframing of provision from services towards individualised supports.

The review of disability policy (Department of Health and Children, 2011) recognised that:

> *"there is a gap between the policy objectives and what is provided by many disability services. While current policy objectives emphasise 'full and independent lives' the available information shows that many disability services are not organised or provided in a way that supports this goal" (p.3).*

This conclusion was further underlined in the Value for Money and Policy Review of Disability Services in Ireland (Department of Health 2012).

> *The findings from the public consultation conducted as part of the VFM Review clearly show that people are now looking for more choice in disability services and control over how they access them. They are looking for flexible services that meet their individual needs and systems that vest more control with the service user and, where appropriate, their families. These features are not generally available in the existing system, particularly to people with intellectual disabilities (p.xxi).*

This report recommended that the goal of full inclusion and self-determination for people with disabilities be pursued *"through access to the individualised personal social supports and services needed to live a fully included life in the community."*

Moreover the review proposed that:

> *The HSE should drive migration towards a person-centred model of services and supports through the Service Level Arrangement (SLA) process. Demonstration projects should be initiated by service providers as proof of concept and run in parallel with current services, and their suitability for wider application subsequently evaluated (p. xviii).*

The report of the Working Group on Congregated settings (HSE, 2011) spelt out how this vision could be realised for people currently living in institutional settings.

> *The Working Group is proposing a new model of support in the community. The model envisages that people living in congregated settings will move to dispersed forms of housing in ordinary communities, provided mainly by housing authorities. They will have the same entitlement to mainstream community health and social services as any other citizen, such as GP services, home help and public health nursing services, and access to primary care teams. .... People will get the supports they need to help them to live independently and to be part of their local community (p.3).*

The challenge is formidable given that over 4,000 persons are currently resident in congregate settings and the variation that exists across the country in the shift away from congregated settings. McConkey et al (2013) in their analysis over a ten year period of information contained on the National Intellectual Disability Database concluded:

> *Marked variations across the eight (former health board) areas were found in the overall numbers of people in residential accommodation, the proportion of persons living in congregated settings and the extent of changes in the numbers of people in each type of accommodation. Moreover, fewer than 15% of people had relocated nationally from congregated settings over the 10-year period and the number of new admissions to this form of provision remained high in certain areas (p.969).*

Self-advocates in Ireland National Institute for Intellectual Disability (2009), as well as internationally, have pressed for greater opportunities in housing, employment, education and leisure. McCormack and Farrell (2009) undertook a review of the personal outcomes achieved for over 250 adult persons with intellectual disability across 22 service providers and concluded that there was:

> *the need to develop more integrated services, to maintain people in their local communities rather than remove them into special settings and develop more reciprocal relationships with communities (p. 300).*

The HSE report (2012) on Day Services echoed the same change in direction as for residential provision.

> *This new approach to adult day services will be known as New Directions. The range of supports to which individuals will have access should equip them to:*
>
> - *make choices and plans to support personal goals;*
> - *have influence over the decisions which affect their lives;*
> - *achieve personal goals and aspirations; and*
> - *be active, independent members of their community and society (p.16)*

Although the evidence-base remains weak in Ireland for the impact of these new styles of services, there are growing indications that they do produce better outcomes. For example, families have appreciated the gains that resulted from their relative moving from institutional settings to community-based accommodation (Doody, 2012).

> *Overall, families expressed positive thoughts about the move to the community houses believing life was better for clients in the community compared to the institution expressing their preference to remain in the community setting and an intention of 'not going back' to the former congregate care facility. Families appreciated the setting as more flexible and responsive to their individual preferences (p.51).*

1.3 Personalisation

Internationally there is growing evidence of how personalised supports allied with greater opportunities for community inclusion can improve the quality of people's lives (McConkey et al., 2009). Personalised or individualised supports are those which address the unique needs of the individual focusing on their strengths and abilities, which are chosen by the person and which are delivered in the community fostering inclusion and participation. The key characteristics of personalisation are an emphasis on self-determination and tailoring supports around the specific needs of the person. Personalised or individualised supports have been described in the following way (Genio, 2012):

- *planned and delivered on the basis of a consideration of the wider needs and potential contributions of the person, moving away from a focus on deficits;*
- *a response to one person rather than group-based;*
- *chosen by the person with a disability or mental health difficulty (or their or advocate as appropriate);*
- *delivered in the community fostering inclusion and participation rather than in segregated, stigmatising settings;*
- *inclusive of family and community supports and mainstream services;*
- *reliant on paid professionals only when necessary;*

1.3.1 Personalised budgets

A favoured approach of late internationally is the move to individualised housing and support options allied with personalised budgets so that people can have more control over the type and forms of support they receive (Lord and Hutchison, 2003). A review of the Australian experience reported largely positive outcomes (Fisher et al., 2010).

> *All respondents said that individual funding had improved their control, choice, independence and self-determination in their lives. Using a standard measure of personal wellbeing, scores on all domains ... were similar or higher than the scores for the broader Australian population, except for personal health and future security. The scores of people using individual funding were also higher than normative data for Victorians with intellectual disabilities in the domains of personal health, achievement in life and personal safety, but lower in personal relationships, community connectedness and future security (p. viii).*

A similar review in England with over 1,000 users of personal budgets also noted gains, but identified certain conditions for success (Hatton and Waters, 2011):

> *...it seems that personal budgets are likely to have generally positive impacts on the lives of all groups of personal budget holders and the people who care for them. The likelihood of people experiencing a positive impact from a personal budget is maximised by a personal budget support process that keeps people fully informed, puts people in control of the personal budget and how it is spent, supports people without undue constraint and bureaucracy, and fully involves carers. Under these conditions, personal budgets can and do work well for everyone (p.4).*

As yet a firm empirical base is lacking as to how these services can be developed, managed and sustained (Carr, 2009).

> *Reliable evidence on the long-term social care cost implications is not yet available. This is an area which needs urgent attention to sustain confidence (p.1).*

A further concern has been the applicability of personalisation to individuals with different disabilities and illnesses as many of the initiatives to date have focussed on care of the elderly. For example, Mencap (2010) is fearful that people with higher dependency needs may not get the supports they need if the funding is capped.

> *There is also concern surrounding the local authority resource allocation systems. Anecdotal evidence suggests that some local authorities set an upper limit of around £50,000 for an annual individual budget. Besides being illegal, this means that in some areas, people with higher support needs or profound and multiple learning disabilities cannot afford to enter the world of personalisation.*

Likewise Cobigo and Stuart (2010) identified the relative dearth of experience in relation to persons with enduring mental health difficulties:

> *Mental health community-based supports and services that are person-centred and recovery-oriented hold considerable promise, but they are not widely available nor have they been widely evaluated (p.453).*

Nonetheless, in Ireland the Government's Programme for National Recovery pledged to ensure that the quality of life of people with disabilities is enhanced and that resources allocated reach the people who need them. Moreover this commitment was made:

> *we will move a proportion of public spending to a personal budget model so that people with disabilities or their families have the flexibility to make choices that suit their needs best. Personal budgets also introduce greater transparency and efficiency in funding services (p.54).*

However, such services need to be attuned to the particular funding and service delivery contexts within a country as well as taking into account the historical and cultural influences that may be present. This is especially pertinent in terms of the workforce available to provide personalised supports (Manthorpe et al., 2008). Hence it is vital that a study is undertaken in Ireland of personalised support models to determine the extent to which international experience is applicable here, as well as identifying possible unique characteristics to successful implementation of such approaches and the transformation of existing provision (Tyson, 2009).

1.4 Outcomes

A critical issue is the outcomes for the individual delivered by their support services. As Schalock et al. (2008) argue, the concept of Quality of Life provides a succinct framework for assessing the effectiveness of service supports to persons with disabilities. Their review of past literature identified three core factors underpinning Life Outcomes: namely Independence; Well-being and Social participation. Verdugo et al. (2012) also note that:

> *There is a close relationship between the core quality of life domains and the 34 Articles (contained in the Convention of Rights of Persons with Disabilities). Furthermore, the current status of these Articles can be evaluated through the assessment of indicators associated with the eight core quality of life domains (p.1036).*

Furthermore Walsh et al. (2010) demonstrated the applicability of a Quality of Life framework in identifying the differential impact of various accommodation options post-deinstitutionalisation.

> *Post-deinstitutionalization studies provided consistent evidence for greater choice, self-determination, and participation in community-based activities in smaller settings, but no evidence for greater physical health or material well-*

being, and little evidence for a relationship between type of setting and employment (p.137).

However, suitable outcomes measures remain a subject of debate, especially in reflecting changes over time. In particular the subjective opinions of the people receiving service supports need to be obtained rather than relying on third party reports, as has often been the case particularly with people who have intellectual disabilities (Perry and Felce, 2002).

Also convincing evidence of causal relationships between service supports and outcomes is lacking due to the dearth of longitudinal studies and the need to control for other confounding variables such as the characteristics of the persons supported and other forms of support that may be available to them (Gardner et al., 2005).

Nonetheless, purely statistical methodologies need to be complemented with more qualitative approaches in order to gain a full understanding of the processes underpinning the provision of effective supports across persons with diverse needs and aspirations.

However the gathering of empirical evidence per se is usually insufficient to produce major changes in service provision in the short and even medium term. Rather the major stakeholders – the people supported, their supporters, service providers and commissioners - have to be actively engaged in using the data gathered to inform their advocacy and decision-making.

1.5 Aims of the evaluation

In this context this evaluation was concerned with identifying:

1. The outcomes for people with disabilities and mental health difficulties receiving individualised supports; particularly on indicators of social inclusion and quality of life, but also in relation to their individual aspirations, including assessing changes over time as people move from congregated settings to more personalised arrangements;

2. The processes which have led to effective change and transition in terms of personal outcomes and the delivery of individualised supports;

3. The direct costs of providing the personalised support for service users and how these costs have changed as a result of the changes in support provided;

4. The implications for the further development of personalised services in an Irish service context.

2. Methodology

The procedures used in undertaking the evaluation are described here. These were initially outlined in the tender bid to Genio by the University of Ulster team, but they were refined through the participation of Dr. Fiona Keogh, Director of Research and Evidence with Genio, as a member of the project management team and in consultation with the Genio International Research Advisory Committee. In addition, consultations were held with stake-holders groups organised by Genio.

2.1 Project Personnel

The project management team consisted of Professors McConkey and Bunting from the University of Ulster and Dr Edurne Garcia-Iriarte from Trinity College Dublin.

A part-time Project Manager – Rachel Stevens - was appointed to co-ordinate the data gathering and liaising with projects and Genio.

Marie Wolfe, a self-advocate in intellectual disabilities and a service user joined the management group as a paid adviser.

A team of nine experienced Research Assistants from around Ireland were recruited to assist with data gathering. This approach enabled us to employ personnel who lived close to projects and who often had direct experience of working in or with services. They were linked with specific projects for the three data uplifts.

2.2 The sample

The evaluation uniquely involved 24 projects from across Ireland including services for people with intellectual disabilities, people with mental health difficulties and people with physical disabilities. As noted previously the evaluation was centred around the people being supported in the projects; in all 197 persons were involved in the evaluations as shown in Figure 2.1. The diversity among the participants was a strength of the evaluation, although it raised challenges in terms of the way information would be gathered.

Figure 2.1: The Sample

2.3 Projects included in the evaluation

In all, 23 Community Living projects were grant-aided by Genio in 2010 and 2011. In addition a further project not grant-aided by Genio was also included, which had a history of transforming their services to more personalised arrangements. Of the 24 projects:

- 13 served people with intellectual disabilities: 12 voluntary organisations and 1 HSE managed service.
- 8 served people with mental health difficulties: 7 were HSE managed and 1 was a voluntary organisation.
- 3 served people with physical disabilities all voluntary organisations although one served people with a range of disabilities.

The number of persons participating in each project ranged from 1 to 34 with a median of 14 persons. Section 3 gives further details of their characteristics.

Table 2.1 identifies the number of individuals who participated in the projects based on Genio records and those who agreed to participate in at least one phase of three data gathering phases of the evaluation. In addition, a sample of 15 persons with intellectual disability was recruited from a service that was not funded by Genio.

Table 2.1: The number of persons involved in the Genio Projects and in the Evaluation.

Impairment Group	Number known to Genio	Number Left Project	Not included in Evaluation or declined	Data gathered at one or more time point
Intellectual Disability	127	14	18	101 (plus 15)*
Mental Health	98	27	12	64
Physical Disability	34	6	12	17
Total	259	47	42	182 (plus 15)*

**In the additional, non-Genio project*

Overall, around 18% of persons (N=47) included in the original plans for the projects left the projects over the course of the evaluation through their choice, those of family members or through death. For a small proportion of them, data at one or two time points had been gathered.

In all, 42 persons either declined an invitation to participate in the evaluation or they had replaced a person who had left after the data gathering for the evaluation had commenced. They represent 19% of the total number of persons who were actively

involved in the project. Thus, in total around 197 persons (approximately 60% with Intellectual Disability) participated in the data gathered.

2.4 The design

A longitudinal design was used with three data uplifts conducted over a 20 month period to monitor changes in participants' support and lives.

Figure 2.2: Evaluation design

The data gathering took much longer than originally anticipated in certain services as various operational difficulties had to be overcome, notably the delayed start to some projects and the availability of support staff for interview.

Also the data gathering was extended at each time point so as to capture as many people who changed accommodation in that time period. Ideally, the evaluation could have been conducted on a rolling basis – following people as they moved – but this would have required repeat visits to the same project and this was not possible within the available resources.

2.5 The informants

The primary informants were to be the people supported by the projects. We recognised the challenges this presented for persons with intellectual disabilities in particular but the team had expertise in this area and the data gathering materials were designed accordingly.

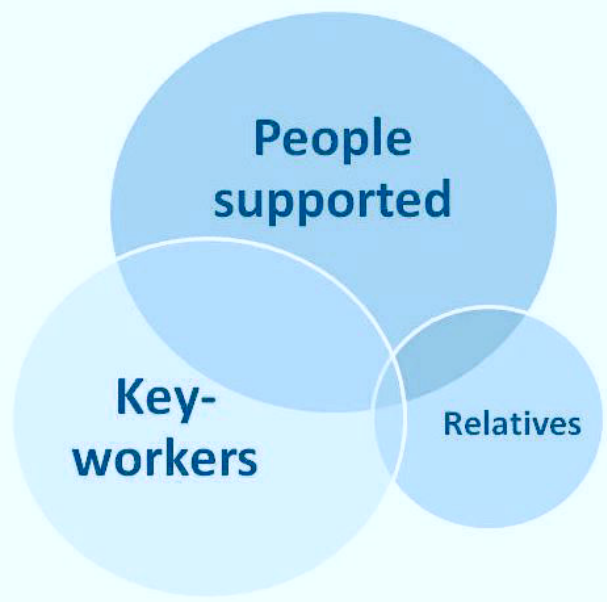

Figure 2.3: The Informants

In addition, we were eager to capture the experiences and insights of key-workers; the support staff who were most closely involved in supporting the individual. Also we wanted to obtain the reactions of relatives who were available and had on-going involvement with the person. However, the permission of the person to do this was sought.

2.6 Data gathering tools

With each group of informants three types of information gathering tools were used. The information was gathered mainly through face-to-face interviews held in a location chosen by the informants, usually their place of residence. However, some relatives were interviewed by phone and key-workers self-completed some ratings scales. The data gathering tools for each group are described here.

Figure 2.4: Data gathering tools

2.6.1 People supported

A structured interview pro-forma[1] was developed based mainly around the criteria that Genio had used in selecting projects, but also incorporating questions derived from past research and evaluations of personalised options. These formed the domains around which changes in people's lives could be assessed and possible indicators that could be used within each. The indicators were further validated through the literature review plus they were expanded to include Healthy lifestyle as shown in Figure 2.5.

Figure 2.5: Domains of Change

Within each domain, questions were developed to indicate the person's situation at each time point[2]. The analysis of data gathered at Time 1 further verified suitable indicators by contrasting those that best discriminated between people living in personalised as opposed to congregated settings.

Based on the data obtained at Time 3, latent class analyses were undertaken to identify within each domain the indicators that best discriminated the grouping of individuals according to the

[1] All pro-formas developed were refined in the light of pilot testing.
[2] Copies of the pro-formas used are available on request.

moves they had or had not made during the course of the evaluation. The results of this analysis are described in section 4.1 of the results chapter.

Further analyses were undertaken to establish if these 16 indicators could be combined into one scale; thereby providing a single composite indicator against which individuals could be assessed. However the internal consistency of the single scale was poor (Chronbach's alpha 0.625) and an exploratory factor analysis (promax rotation with maximum likelihood estimation) identified six factors. Thus these 16 items are better thought of as a profile for assessing people's present lifestyle or changes in it.

In addition ratings scales relating to Quality Life and Indicators of Personalised Supports were developed based on previous literature, which were adapted and shortened for this study. For the quality of life scale, ten items indicative of quality of life were identified from the literature and past research: for example: physical health, respect, control, relationship with staff and the place they lived. For each item, respondents were given three choices: 1 – Not Good 2 – OK 3 - It's Great. If required, people supported were presented with three cards of smiley faces so they could indicate their choice non-verbally if they preferred.

The second rating scale consisted of 10 items reflective of individualised support, for example: support staff take time to get to know N; they help N to do what N wants to do; N has support staff to go out to where N wants to go; N knows how to make a complaint. Respondents rated each item on a three point scale: 1 This does not happen for N; 2; This is happening but improvements are needed; 3. This happens and I can't think of any improvements. People supported were interviewed and key-workers self-completed a written pro-forma. A high score was indicative of greater levels of individualised support.

These rating scales not only provided further confirmation of any changes experienced by participants but they also enabled comparisons to be made between the ratings given by the people supported and by their key-workers and relatives who completed the same two scales independently from the person. With people supported the scales were completed through interview whereas key workers[3] and relatives self-completed a written pro-forma. Both scales were completed at Time 1 and again at Time 3 so that changes over time could be detected. Findings from the rating scales are reported in section 4.4.

Cost data collection: Detailed information on service use and benefits received was collected to inform the cost analysis. This information was supplemented by the key-worker if the person supported did not have the available details. In this way the following categories of costs were obtained:

- **Direct Support Staff costs:** For people in traditional accommodation options such as congregated settings and group homes, this data was based on the

[3] For people who moved, their key-workers may have changed. This could mean an additional source of variation in the responses.

'resource usage groups' as presented in the Value for Money Review undertaken by the HSE. However for individuals in personalised arrangements and those receiving support while living in family settings, these costs were calculated on data provided for each individual by their key-worker.

- **Community service costs**: When people move from specialist services into more personalised arrangements they may make more use of community health and other services. Information was obtained on the usage of these services for all participants across the five groupings as a result of moving. The costs were computed using the indicative costs provided by HSE[4].
- **Hospital services costs:** Likewise, people living in community settings may make more use of acute hospital Accident and Emergency and inpatient services as well as having readmissions to specialist provision. Again, service use data was captured for people supported across the five groupings and costs were computed using the unit costs data supplied by the HSE.
- **Income from social security benefits**: People living in personalised arrangements usually qualify for a range of social security benefits and indeed these can be a major contribution to the funding of these arrangements.

Qualitative data collection: Semi-structured interview schedules were devised to obtain the person's perspective on their living arrangements and changes that had taken place. The use of semi-structured interviews helped ensure some uniformity in approach across the different interviewers although the intention was to make these as conversational as possible. All the interviews were audio-recorded with permission for later transcription. At each Time point, the people supported were individually interviewed using a series of structured prompts that were adjusted according to whether or not they had changed their accommodation. From this rich source of qualitative data, we were able to create the personal stories of participants in the evaluation with quotes of their own words. Moreover, a substantial and unique archive of material has been assembled that could be used to investigate particular themes around the lives of people with varying needs in future data analysis.

The full complement of data gathering tools was deployed at Time 1 and Time 3 with all participants. At Time 2, this was only done for people who had changed their accommodation and support arrangements since Time 1 and with others shortened versions of the pro-formas were used.

2.6.2 Relatives

At each time point of the evaluation, the view of relatives of the person supported were sought if they had known relatives and if the person gave their consent for us to approach a nominated relative. Over the course of the evaluation we made contact

[4] Our thanks to Valerie Walshe, HSE Economist for her assistance with this and other information.

on at least one occasion with the relatives of 112 persons (57% of the people supported). They came from 19 of the 22 participating projects (86%).

Around one third of the interviews were conducted in the relative's home or the home of the person supported and a similar proportion were in service settings. Others were conducted by telephone. Fewer relatives agreed to take part in a second interview mostly on the grounds that they were too busy and had already expressed their views.

A basic demographic profile of each relative was collected and they were also asked to complete the same rating scales on quality of life and personalised supports as the person supported. This required the relatives assessing the person's quality of life and the type of supports they were receiving.

The semi-structured interviews conducted with the relatives at Time 3 followed the procedures used for interviews with the people supported, and included questions relating to their perceptions of the support provided and the benefits it had brought to the person as well as for themselves. We also enquired about possible improvements they would recommend.

2.6.3 Key-workers

Information was collected from the key-workers by means of a structured face-to-face interview and a self-completed pro-forma at Time 1 and Time 3. The procedures for the interview were the same as described above for the people supported. The key-workers provided corroborating information on that provided by the person supported and also completed the same rating scales on quality of life and personalised supports as the person supported. This required the key-workers assessing the person's quality of life and the type of supports they were receiving.

2.6.4 Senior management in participating organisations

Representatives of the participating projects were invited by Genio to attend one of two focus groups held in Mullingar and in Dublin with Roy McConkey as facilitator. Those who were unable to attend either took part in an individual interview with Roy (N=2) or completed a written pro-forma (N=3). In addition two of the group participants made additional written comments. In all 18 of the 24 services (75%) were represented in this data set.

A series of trigger questions had been developed based on previous literature and insights gained from service visits and information supplied by persons supported and their key-workers. The questions included:

- Why did you seek funding from Genio?
- What three factors contributed most to the success of your project?
- What were the three main barriers you encountered?
- How different is the role played by support staff in the new arrangements?

- What has been the impact of the project, if any, on the wider organisation?
- What partnerships, if any, have you developed with community agencies as part of the project?
- What advice would you give colleagues embarking on a similar project next year?

The focus groups and interviews were transcribed and together with the written comments, a rich data set was available for analysis.

2.7 Methods

The project manager made initial contact with all the participating projects and visited most personally to meet the mangers/leaders to explain the evaluation and discuss with them the best options in relation to gathering the required information.

The research associates were allocated to projects based mainly on their geographical location. They were accompanied by a member of the project team on the first visit to the service. The project team member conducted the first interviews with the research associate observing and recording answers and then they swapped roles for the second set of interviews and the research associates were given feedback on the interview techniques and recording or answers. In this way we aimed to ensure some consistency in the data gathering across the interviewers.

The interviews were usually conducted in a private room in the person's residence. The person supported had the option of a member of staff being present or a relative as appropriate. Key-workers and relatives were interviewed separately.

The interviews with people supported generally took around two hours with breaks as needed but they could extend to nearly four hours. Those with key-workers generally took under 45 minutes with relatives somewhat shorter although certain relatives took much longer as they had a great deal to say.

Data collection was a complex and challenging undertaking made possible through careful planning and the active co-operation of many people. On the whole the procedures worked well as indicated by the high level of recruitment to the study and the retention of participants over the 20 month period.

2.8 Data Analysis

The data recorded on pro-formas and rating scales were coded into SPSS files. Unique code numbers were used in doing this and only the project manager had access to link code numbers with names of participants. Statistical analyses were undertaken that described the participating samples and compared the responses across accommodation options and over time. Latent Class Analyses were used to identify the main discriminating variables between congregated and personalised settings.

Regression analyses were used to identify the main predictors of difference and changes over time. Comparisons could also be drawn between ratings given by people supported and their key-workers. Sections 4.1 and 4.3 give the results of these analyses.

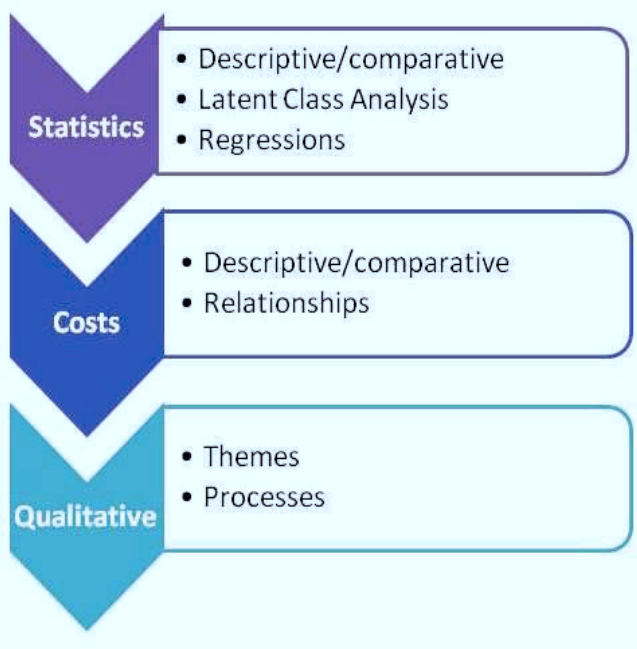

Figure 2.5: Data Analysis

The rating scales on Quality of Life and Indicators of Personalised Support were completed at Time 1 and again at Time 3 so that changes over time could be detected. Exploratory and confirmatory factor analyses were conducted on this data with one main factor accounting for around 60% of the variance across both scales and both groups of respondents. Likewise Cronbach's alpha values were generally around 0.8 which is acceptable but also suggestive of some inter-item variation within the scales[5]. The maximum score on all scales was 40 with minimum of 0.

Information on support costs and service usage was contained in the pro-formas and this data was used to calculate costs, supplemented by the cost information contained in the recent exercise undertaken by the HSE for the Value for Money (Department of Health, 2012). Also an attempt was made to relate direct support costs with benefits in terms of quality of life and indicators of individualised support. Further details are given in Section 4.7.

The interviews were transcribed verbatim and thematic content analysis used to identify the core themes and the processes that had facilitated or hindered moves to personalisation. The perspectives of people supported are summarised in a series of case studies (see Section 5); of relatives in Section 5.5, of support staff in Section 5.8 and of service mangers in Section 6.

2.9 Ethical approval and informed consent

Ethical approval for the evaluation was obtained through the University of Ulster Ethics Committee (ref REC/11/0088). In addition the Ethics Committee of the School of Social Work and Social Policy at Trinity College, Dublin approved the procedures for Master students undertaking secondary analysis of the data gathered as part of the Genio evaluation.

[5] A technical report on these analyses is available on request.

The participating services had agreed to participate in the evaluation in accepting the grant from Genio so no further approaches or approvals were sought from local ethics committees.

An easy-to-read information sheet describing the evaluation was prepared along with a consent form. These were sent to projects prior to the data gathering commencing in the hope that they would be distributed to people supported, staff and relatives ahead of the first interviews. This did not always happen. Hence all participants were talked through the Information Sheet and signed consent obtained before the interviews commenced.

In consenting it was made clear to participants that they could refuse to answer any questions without giving a reason and they could terminate their participation at any time. They were assured that all their information would be kept private and no one, and no service would be identified in any reports.

Garda clearance was obtained for all project personnel who had contact with participants in the evaluation.

3. Details of sample

3.1 Description of participants in the evaluation

Table 3.1 summarises the characteristics of the participants in the evaluation broken down by the three impairment groupings.

Table 3.1: The characteristics of participants in the evaluation by disability grouping

	Intellectual Disability (N=121)	Mental Health (N=64)	Physical Disability (N=12)	Total (N=197)	Significant Difference
% Male	47%	67%	67%	45%	p<0.05
% Female	53%	33%	33%	55%	
Under 40	36%	47%	25%	39%	NS
40+ years	64%	53%	75%	61%	
Special School	50%	10%	60%	36%	p<0.001
Ordinary school	50%	90%	40%	64%	
No Educational Qualifications	77%	21%	30%	53%	p<0.001
Educational Qualification	23%	79%	70%	47%	
Irish	95%	97%	90%	95%	NS
Non-Irish	5%	3%	10%	5%	
Single	99%	90%	100%	96%	NS
Married/divorced/ widowed	1%	10%	0%	4%	

Notes: The differences between the three groups were tested by Chi Square.

This data shows that more females than males were included in the evaluation; three-fifths were over 40 years of age (total age range 16 to 73 years); nearly two-thirds had attended ordinary schools although fewer than half held an educational qualification; nearly all were single with few non-Irish nationals.

There were three significant differences in the characteristics of people by disability and mental health. More females with intellectual disabilities were involved in the projects whereas there was a predominance of males in the other two groupings. Not surprisingly, people with mental health problems had attended mainstream rather than special schools and more had obtained educational qualifications. While persons with disabilities had mostly attended special schools, people with physical

disabilities were more likely to have attained educational qualifications than those with intellectual disabilities.

3.2 Housing and support arrangements

The main focus of the evaluation was on changes in the accommodation and support arrangements for the individuals across the different projects and particularly in contrasting personalised with group settings. Table 3.2 shows the number and percentage of persons within each impairment grouping by their housing and support arrangements at the first data uplift.

Table 3.2: The number and percentage of persons in different accommodation arrangements at Time 1.

Living at Time 1		Impairment grouping			Total
		Intellectual Disability	Mental Health	Physical	
Personalised	Count	29	14	7	**50**
	%	24.0%	22.2%	58.3%	**25.5%**
Family (incl. foster family)	Count	25	1	2	**28**
	%	20.7%	1.6%	16.7%	**14.3%**
Group Home	Count	4	13	0	**17**
	%	3.3%	20.6%	.0%	**8.7%**
Congregated	Count	63	35	3	**101**
	%	52.1%	55.6%	25.0%	**51.5%**
Total	Count	**121**	**63**	**12**	**196**
	%	100.0%	100.0%	100.0%	100.0%

(NB data missing on one person).

Personalised arrangements: Overall one quarter of persons in the evaluation were already living in personalised arrangements; 26 of whom (52%) had moved as part of the Genio project but before the evaluation commenced. Typically these arrangements took the form of rented accommodation in ordinary houses or apartments with people either living alone or with a partner of their choosing. The tenants often chose the property and location as well as deciding on furnishings. They had support staff visiting their home at agreed days and times for a set number of hours per week in accordance with their needs.

As Table 3.2 shows, these arrangements were proportionately more common for people with physical disabilities at Time 1.

Family carers: A second grouping of persons were living with family carers as certain projects aimed to relocate people from their family home to other arrangements. This was especially so for persons with intellectual disability. As reported later, a range of relatives were involved in the person's care but rarely would support staff work in the family home. Rather the support staff were employed to link

the person to activities and resources in the community. These arrangements rarely applied to people with mental health difficulties.

Group Homes: A small number of people resided in Group homes; more commonly people with mental health difficulties. These were ordinary housing in the community shared by up to six persons with support staff available during day-time hours or in some instances on a 24 hour basis. People had limited choice of co-residents. At Time 1 for people with mental health difficulties these arrangements tended to be described as 'low support hostels' which were an intermediary step from hospital to independent living.

Congregated settings: These included campus accommodation of separate bungalows and houses on a shared site as well as hospital wards. In such settings people had little choice over whom they lived with; they shared communal bathing facilities, dining and sitting rooms and even though some may have had their own bedroom, others had shared sleeping arrangements in ward-like accommodation. Staff were available 24 hours a day although different staff may work across the various housing units and wards. In all, over half the sample of persons with intellectual disability and those with mental health difficulties were living in such accommodation at Time 1.

A note of caution though: within these broad groupings, there were variations in the style and nature of the accommodation as well as the support arrangements that were in place for each individual.

3.2.1 Changes in housing and support arrangements at Time 1

Prior to the start of the evaluation, 42 persons in the sample had already moved in the previous year to new arrangements. Of this number, 23 persons (55%) were in Mental Health Services with 17 (41%) in Intellectual Disability services and 2 (4%) in Physical Disability services. The ten different changes in accommodation among this group are summarised in Table 3.3.

Table 3.3: The number of people who had changed accommodation prior to Time 1 interview (N=42)

Previous Accommodation	New Accommodation			Total
	Personalised Arrangements	**Group Home**	**Congregated setting**	
Independent	1 (Relatives)	1	0	**2**
Family	9	3	1	**13**
Group Home	10	0	3	**13**
Congregated	7	3	4	**14**
Total	**27 (64%)**	**7 (17%)**	**8 (19%)**	**42**

Overall nearly two-thirds moved to personalised arrangements (i.e. living alone; with a partner or non-disabled friends). At the time of this first move, people in mental health services were more likely to move to group homes ('low support hostels') or to more individualised accommodation in congregated settings such as a small house in the grounds of the hospital (i.e. 12 of 15 persons living in group homes or congregated settings). This was seen as preparation of a move to more personalised arrangements.

Three-quarters of this sample considered that the move had made things better for them; 19% thought it was the same and 6% were unsure. No one was considered worse off as a result of the move. Three-quarters also reported that they had chosen the place where they live (higher in personalised and group homes than for congregated settings).

3.2.2 Changes in housing and support arrangements from Time 1 to Time 3

Over the 20 months of the evaluation, more people changed their accommodation. Figure 3.1 summarises the number of persons in each type of accommodation option at the end of the evaluation period – Time 3. Tables A3.1 and A3.2 in Appendix 1 detail the various types of moves that took place from Time 1 to Time 2 and then overall from Time 1 to Time 3.

In all 86% of the movers felt it had made things better for them, 5% the same and only 3% felt it had made things worse (one in personalised and one in group home) with 6% unsure.

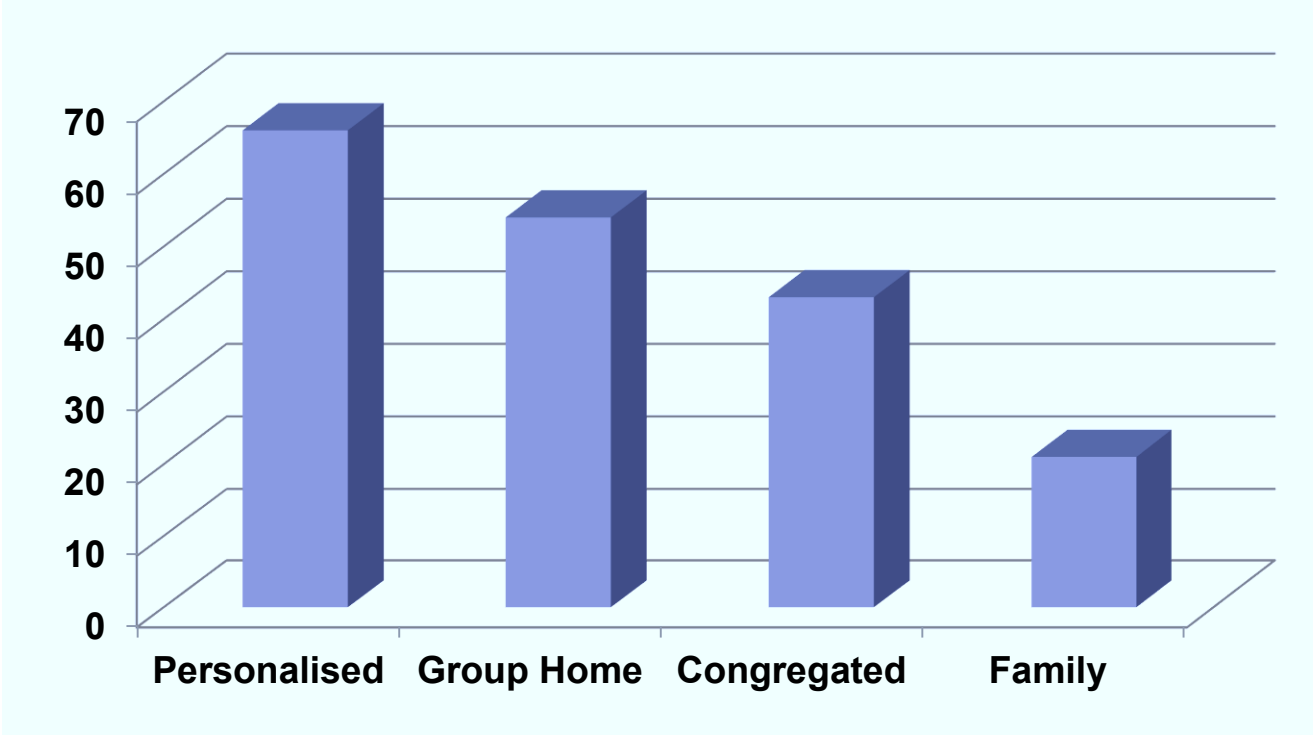

Figure 3.1: The number of persons in each accommodation option at Time 3

3.2.3 Comparisons between Time 1 and Time 3

For the purposes of monitoring changes within the evaluation sample, comparisons can be drawn for five main groupings as shown in Table 3.4[6].

Table 3.4: The number and percentages of movers and non-movers between Time 1 and Time 3 for each impairment group.

Living arrangements at Time1 and Time 3		Impairment grouping by service			Total
		Intellectual Disability	Mental Health	Physical	
Personalised at T1 and T3	Count	26	9	5	**40**
(NB Having moved prior to T1)	%	24.8%	20.0%	50.0%	**25.0%**
Congregated at T1 and T3	Count	29	13	0	**42**
(NB Had not moved by T3)	%	27.6%	28.9%	.0%	**26.3%**
Family at T1 and T3	Count	17	1	2	**20**
(NB Remained with family)	%	16.2%	2.2%	20.0%	**12.5%**
Move from Congregated at T1 to Personalised at T3	Count	5	15	3	**23**
	%	4.8%	33.3%	30.0%	**14.4%**
Moved from Congregated T1 to Group Home T3	Count	28	7	0	**35**
	%	26.7%	15.6%	.0%	**21.9%**
Total	**Count**	**105**	**45**	**10**	**160**
	%	100.0%	100.0%	100.0%	100.0%

Throughout this report, the results are presented for the following five groups that emerged in the course of the evaluation. Those who were in:

- Congregated settings at first interview (T1) and moved to personalised arrangements by Time 3 (T3) (n=23);
- Congregated settings at T1 and moved to group homes by T3 (n=35);

[6] This grouping excludes people who were living in Group Homes at Time 1 and continued to do so at Time 3 (n=10) as well as two people who moved from family to a group home and one person who had moved back to congregated settings from personalised arrangements due to ill-health).

- Remained in congregated settings in the course of the evaluation (n=42). This group can also form a comparison with those who move from congregated setting.
- Remained with their family in the course of the evaluation (n=20). This group is of interest as they were being prepared by the projects for a move at some point in the future;
- Already moved to personalised arrangements at T1 and who remained there for the course of the evaluation (n=40). This group can also be compared with those who have recently moved to personalised settings.

Further comparisons are possible with those who continued to live in group homes who likewise might be being prepared for a move to personalised arrangements although the number in this grouping is small (n=10).

As Table 3.4 shows, the moves to personalised arrangements from congregated settings were more common for people with mental health difficulties whereas moves to group homes featured more for persons with intellectual disabilities. People with physical disabilities form a small proportion of the total sample (6%) due the small number of participating projects and drop-outs from the evaluation.

The five groupings were also distinguished by the length of time people had lived in that type of arrangement. By definition, all the movers had resided in the new arrangements for less than two years as had 89% of those who remained in personalised arrangements (11% had been there for five or more years but they came from the non-Genio service included in the evaluation). However of those remaining in congregated settings, 85% had been there for five and more years and for those living with families, the comparable figure was 80%.

3.3 Characteristics of persons in the five groupings

These five groupings are used to compare the participants throughout the report. Table 3.5 summarises the percentages of persons within each grouping on various demographic characteristics with the significance of differences across the five groupings tested using Chi Square tests.

	Personalised T1 and T3	Congregated T1 and T3	Family T1 and T3	Congregated to Personal	Congregated to Group Home	Sign
Female	45%	64%	55%	22%	37%	p<0.05
Male	55%	36%	45%	78%	63%	
< 40 years	41%	14%	100%	58%	36%	p<0.001
40 + years	59%	86%	0%	42%	64%	
Intellectual Disability	65%	69%	85%	22%	80%	p<0.001
Mental Health Difficulties	23%	31%	5%	65%	28%	
Physical Disability	12%	0%	10%	13%	0%	
Special School	30%	14%	38%	10%	20%	p<0.001
Ordinary School	70%	86%	62%	90%	80%	
No educational qualifications	48%	62%	54%	35%	77%	p<0.05
Educational qualifications	52%	38%	46%	65%	23%	
Irish	91%	95%	100%	100%	97%	NS
Non-Irish	9%	5%	0%	0%	3%	
Single	94%	95%	100%	95%	97%	NS
Married/Divorced/widowed	6%	5%	0%	5%	3%	

Table 3.5: The characteristics of participants in the evaluation by the five groupings of changes in accommodation and support arrangements

As the above table shows, the characteristics of persons varied across the five groupings in terms of gender, age, type of impairment, schooling and educational qualifications. To an extent the latter two indicators are confounded with the impairment grouping.

In sum, males were more likely than females to move to new settings. Older persons were more often found in congregated settings and people with mental health

difficulties were more likely to move to personalised arrangements rather than to group homes whereas it was the converse for people with intellectual disabilities. There were no differences between the groupings in terms of nationality or marital status.

3.4 Other indicators

Other pertinent information about the participants had also been gathered on the participants. This included the level of support they required with daily tasks, their physical and mental well-being, and the presence of epilepsy, autism and challenging behaviours.

Levels of support: Each participant rated themselves on the amount of support they needed to complete 13 items related to daily life; such as doing household chores, using public transport, shopping for groceries and filling in forms and key-workers were asked to make the same ratings on the person supported. Subsequent data analysis identified that 10 items best discriminated the participants into three broad groupings: those requiring low support and able to do most items by themselves; those requiring some support and those who needed high levels of support with most tasks. Table 3.6 shows the percentages of persons within the five groupings by their support needs.

Table 3.6: The percentages of participants in the five groupings of changes in accommodation and support arrangements by their support needs.

	Personalised T1 and T3	Congregated T1 and T3	Family T1 and T3	Congregated to Personal	Congregated to Group Home	Total
High support	29%	33%	27%	20%	42%	32%
Some Support	11%	24%	46%	27%	35%	26%
Low Support	61%	43%	27%	53%	23%	43%

Overall the differences were not statistically significant although those persons moving to group homes were rated as having the highest support needs. More pertinently, people with varying support needs are found in all accommodation options.

Additional disability: The percentages of persons reported to need on-going support because of epilepsy and autism are shown in Table 3.7. Higher proportions of persons moving to group homes and those in congregated settings or living with families had epilepsy with much lower proportions in congregated settings or those moving from congregated settings to personalised arrangements (Chi Sq $p<0.01$). However, the differences for autism were less marked with the highest proportion reported for people moving from congregated settings to group homes.

Table 3.7: The percentages of participants with epilepsy and autism in the five groupings of changes in accommodation and support arrangements.

	Personalised T1 and T3	Congregated T1 and T3	Family T1 and T3	Congregated to Personal	Congregated to Group Home	Total
Epilepsy	24%	6%	28%	5%	39%	21%
Autism/ASD	9%	3%	6%	5%	23%	10%

Health: Participants also rated themselves on a standardised tool: EQ-5D Health Questionnaire which has five items relating to mobility, self-care, things you want to do, pain/discomfort and feeling down or worried. Low scores are indicative of good health with higher scores of indicating poorer health.

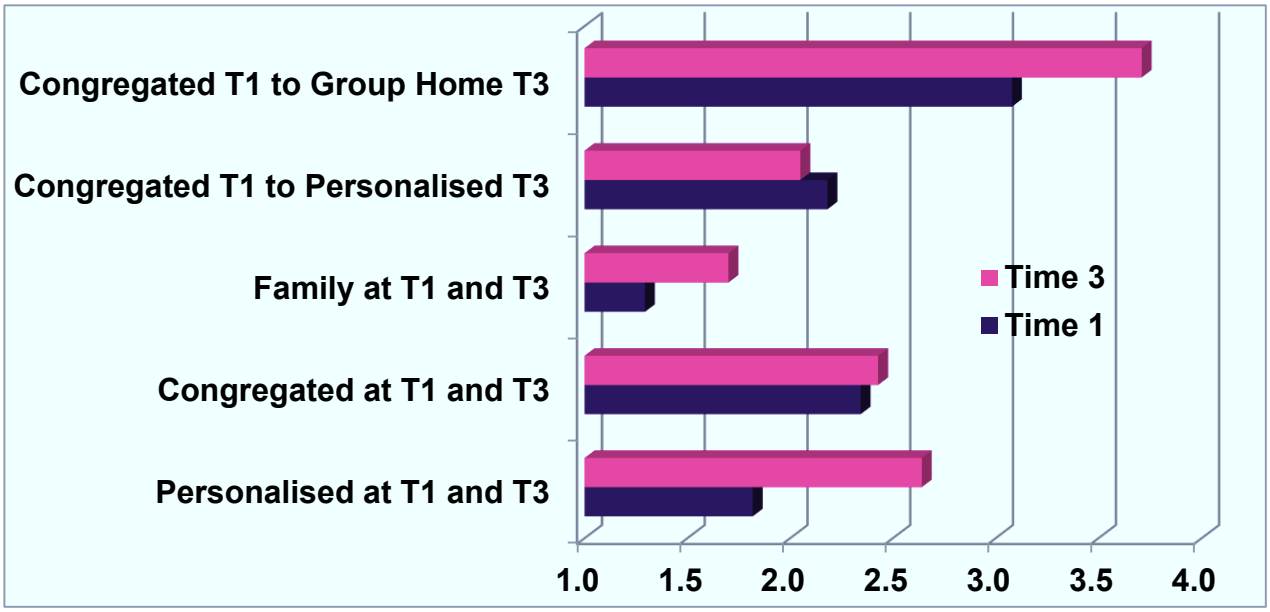

Figure 3.2: The mean scores on the ED-Q5 measures for the five groupings of changes in accommodation and support arrangements at Time 1 and at Time 3

As Figure 3.2 illustrates, the differences across the five groupings were significant at both time points but more marked at Time 3 with people in congregated settings generally reporting poorer health. For the five groupings the differences from Time 1 to Time 3 were generally not significant although that for personalised arrangements approached significance ($p<0.06$).

Smoking and Use of Alcohol: Table 3.8 summarises the percentages of people who smoke and use alcohol at least once a week across the five groupings. For smoking the differences were statistically significant ($p<0.01$) with most smokers occurring among people who moved to personalised arrangements and least among those living with family members.

Table 3.8: The percentages of participants who smoke and use alcohol weekly in the five groupings of changes in accommodation and support arrangements.

	Personalised T1 and T3	Congregated T1 and T3	Family T1 and T3	Congregated to Personal	Congregated to Group Home	Total
Smoker	27%	29%	5%	50%	15%	25%
Use alcohol weekly	16%	20%	15%	30%	9%	17%

The differences in use of alcohol were less. Alcohol use was also highest in people who moved to personalised arrangements and least in group home settings where presumably people had less opportunity to access alcohol.

Challenging Behaviours: Participants were also asked to self-rate themselves in response to the question: "Do people say that you have challenging behaviours" (with the explanation that these were behaviours that hurt or bother you or other people even if you don't mean to cause hurt). Figure 3.3 shows the percentage of people answering 'Yes' in all of the five groupings at both time points. The differences across the five groupings were significant at both time points (Chi Square: $p<0.05$).

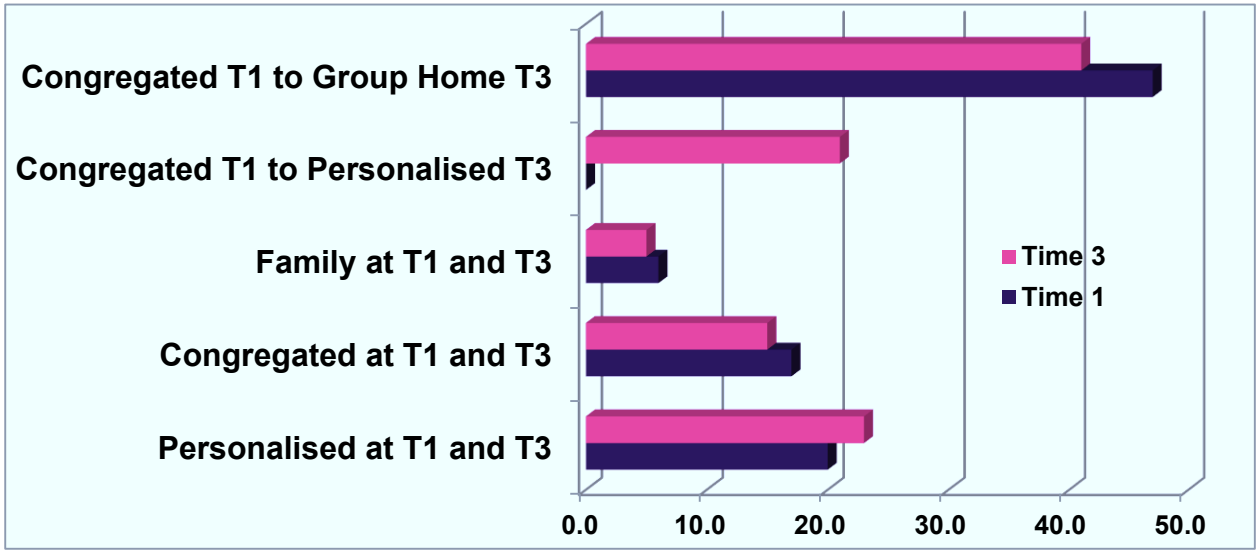

Figure 3.3: The percentage of persons self-reporting challenging behaviours in the five groupings of changes in accommodation and support arrangements at Time 1 and at Time 3

Again, more people living in congregated settings who moved to group homes tended to report having challenging behaviours with the least occurring for people living with families. The percentages were broadly comparable from Time 1 to Time 3, except for persons moving from congregated to personalised settings when a higher proportion of persons reported challenging behaviours. This may perhaps arise from an under-estimation prior to their move or a genuine increase arising from

the move, or it may be due to a greater awareness of the challenges faced by the individual and a reinterpretation based on the exposure to personalisation.

Support with medication: At Time 1 and Time 3 people were asked if they needed support with taking their medication. Figure 3.4 shows the percentages of people replying yes. The differences among the groups were significant at Time 1 ($p<0.01$) with more people in congregated settings and those who moved from there to group homes requiring support than those in personalised arrangements. By Time 3, the proportions had increased in some settings and reduced in others although the reasons are not that clear.

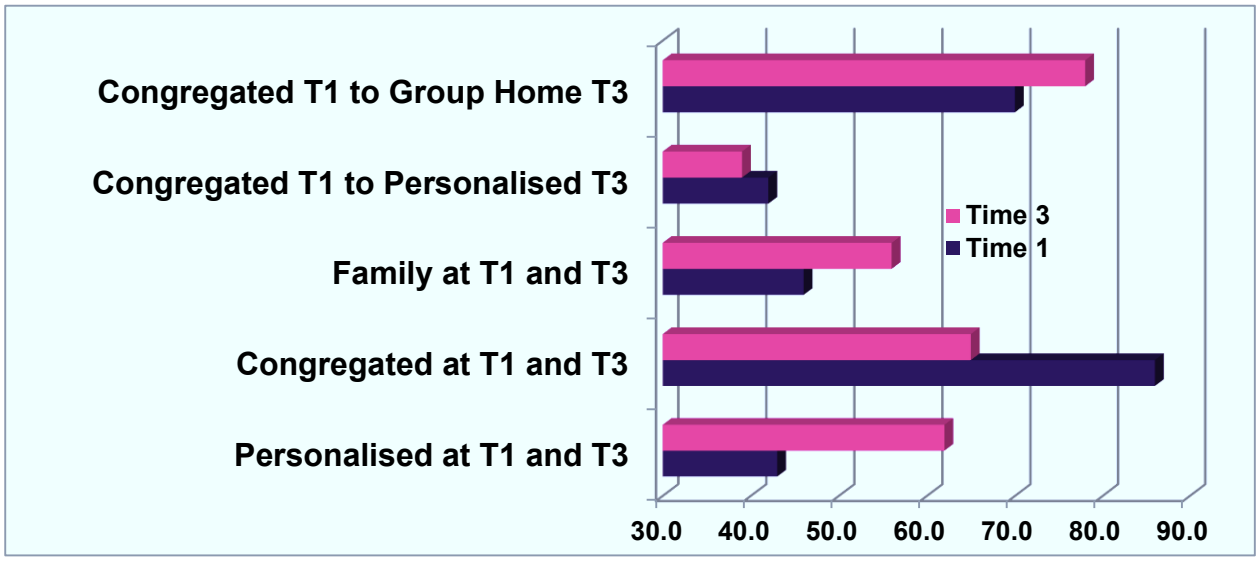

Figure 3.4: The percentage of persons requiring support with taking medication in the five groupings of changes in accommodation and support arrangements at Time 1 and at Time 3

3.5 Performance of projects

One way of judging the performance of the projects is in terms of achieving their goal of relocating people to new arrangements. Of the 24 projects involved in the evaluation, one had received no grants from Genio and a further one was funded in relation to direct payments, hence both were discounted from this analysis; leaving 22 projects. These projects varied in terms of the number of persons involved in the project, the client population they served and their organisational status (i.e. HSE and voluntary organisations).

Table 3.9 summarises the performance of the 22 projects in terms of relocations. This is based on data provided by Genio in July 2013 and includes relocations that occurred before the evaluation commenced and persons who declined to take part in the evaluation. Hence, this data is not directly comparable with that reported in other sections but it does give a more complete picture of relocations.

In sum:

- Six projects had relocated all the nominated individuals. Three of these were projects centred on one or two people and two projects involved supporting people to move due to the closure of the residential centres involved. In all 42 persons had moved in these projects.

- Of the nine projects in which more than half the nominated persons had been relocated, 28 persons had moved in mental health services and 22 in intellectual disability services.

Table 3.9: The performance of the projects participating in the Genio grant-aided programme.

Projects' achievement	Type of projects
All persons relocated	6 projects (Four intellectual disability projects; one mental health and one physical disability project).
More than half of all persons relocated	9 projects (Five mental health projects and four intellectual disability projects).
Less half of all persons relocated	4 projects (Two intellectual disability projects; one project for people with physical disability and intellectual disability; one mental health project)
No persons relocated	1 project in intellectual disability
Projects withdrew from the Genio programme	2 projects (One mental health and one intellectual disability project each with only one person participating)

- The four projects that together had relocated 11 of the 42 nominated persons consisted of two community support organisations who were not providers of residential accommodation but aimed to assist people find personalised accommodation and support. Two organisations were established providers of accommodation and they relocated five out of 21 nominated persons.
- The one project with no relocations had 10 persons in congregated settings[7].
- The two projects that withdrew each had one person participating in the project.

Hence the majority of projects (68%) had either achieved their target relocations or were close to doing so. This included services provided by HSE and voluntary organisations and also across the different client groups although mental health services tended to have higher proportions of relocations. In all 92 persons had been relocated by these projects by the close of data collection in June 2013.

[7] Since the data collection was completed three people have successfully moved to personalised arrangements.

4. Results

4.1 Analysis of indicators

The indicators for domains of change have been described in section 2.6.1 (Figure 4.1 below). Based on the data obtained on these indicators at Time 3, latent class analyses were undertaken to identify within each domain the indicators that best discriminated the grouping of individuals according to the moves they had or had not made during the course of the evaluation (see Table 4.1)[8].

These analyses serve two purposes. Firstly, they identify the most salient indicators of difference associated with moving to more personalised arrangements for the services taking part in this evaluation. These 16 indicators are summarised in Table 4.1 and a series of figures illustrate the changes across the groupings by movers and non-movers in the following section 4.2. It should be stressed though that the relatively small numbers may have precluded the differences on other indicators from becoming statistically significant. Also this data is particular to the projects participating in the evaluation and may not be applicable to other services and their clientele for whom other indicators could be more salient.

Figure 4.1: Domains of Change

Secondly, when taken together, the indicators summarised in Table 4.1 could form a 'bench-marking profile' to assess the extent of personalisation achieved for each individual. This aspect is described further in this Section along with the regression analyses that were undertaken in order to assess the possible impact that other factors may have on people's lives in addition to changes in their accommodation – such as their impairment (i.e. mental health and intellectual disability) and the level of support the person required.

[8] A technical report giving details of these analyses is available on request from Prof. Roy McConkey.

Table 4.1: Indicators of personalised support

(NB: The indicator that was the best discriminator is shown first and in bold.)

Domain	Significant indicators
Personalised accommodation	• **Has a key to the house** • Free to come and go as you please
Personalised supports	• **Chooses own support staff** • Had training in advocacy • Has individual plan
Relationships with people not paid	• **Friends visited for a meal** • Friends stayed over • Neighbours have provided help • Made new friends in past year
Valued roles in the community	• **In paid employment** • Has done voluntary work in the community • Helped neighbours
Healthy lifestyle	• **Less anxiety** • Average weight
Use of mainstream public services	• **Participates in sports, swimming, fitness**
Use of specialist disability services	• **Does not attend a day centre**

4.2 Changes over time

4.2.1 Personalised Accommodation

Two indicators highlighted differences in the accommodation domain: having a key of the house and being able to come and go as you please. The Figures below give the percentage of respondents in the five groups who replied yes to these indicators at Time 1 and Time 3. (Note: The differences between the five groupings were statistically significant at both time points: Chi-Sq $p<0.001$). In the following Figures the main comparisons of interest are the differences at T1 and T3 for movers either to personalised arrangements or to group homes; and the comparisons with personalised and congregated arrangements at both time points. Thus as Figure 4.2 shows, a higher percentage of people had a key to the house when they moved to personalised arrangements but this did not happen for those moving to group homes.

Very few people remaining in congregated settings had a key compared to those already in personalised arrangements or living with family carers.

A similar pattern is discernible for those able to come and go as they pleased although in this instance people moving from congregated settings to group homes had a higher increase as did those living with families.

Other indicators in this domain did not discriminate across the groupings: namely having own bedroom, feeling safe and having special equipment available which suggests that these features are present in all the accommodation options.

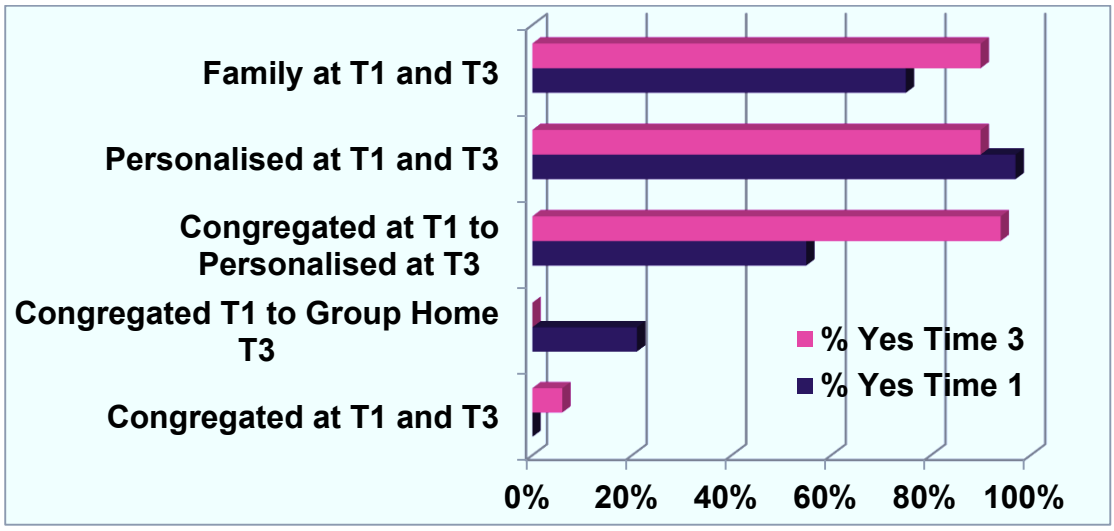

Figure 4.2: The percentage of persons in each grouping reported to have a key to their house at Time 1 and again at Time 3.

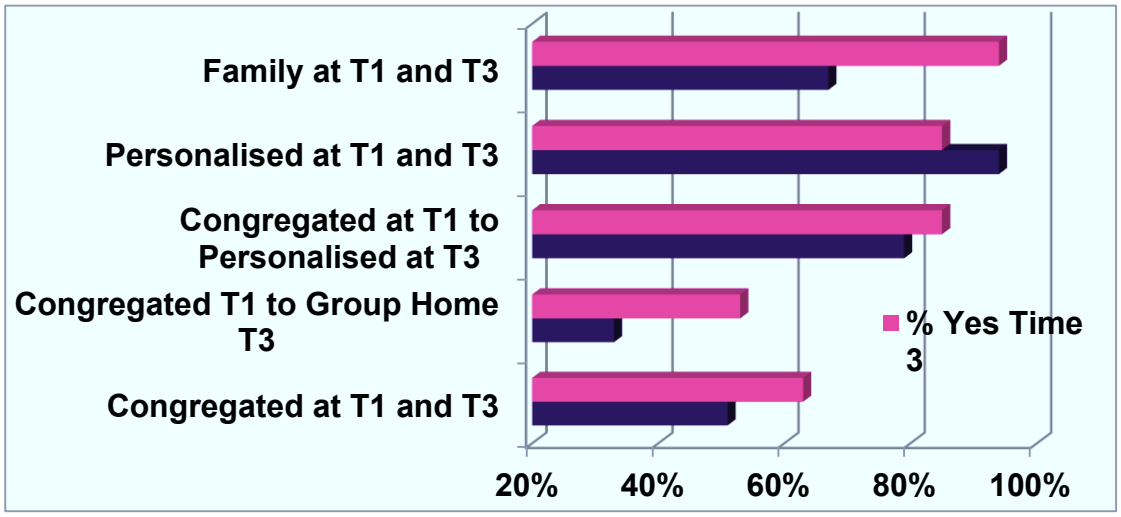

Figure 4.3: The percentage of persons in each grouping reported as able to come and go as they please at Time 1 and again at Time 3.

4.2.2 Involvement of the person in planning

Three indicators best discriminated the groupings. As Figure 4.4 shows, people living with families showed the largest increase in their choice of support worker although this option was more common for people living in personalised arrangements than for those in group homes or congregated settings at both time points.

Access to training in advocacy followed a similar pattern, with those living with family carers having had great access to training by Time 1 (see Figure 4.5). There is also the suggestion in the data that training in advocacy preceded moves to personalisation arrangements.

Having an individualised/person-centred or outcomes plan was most commonly reported for those who moved to group homes or were already in personalised settings and less so for those living with family carers (see Figure 4.6).

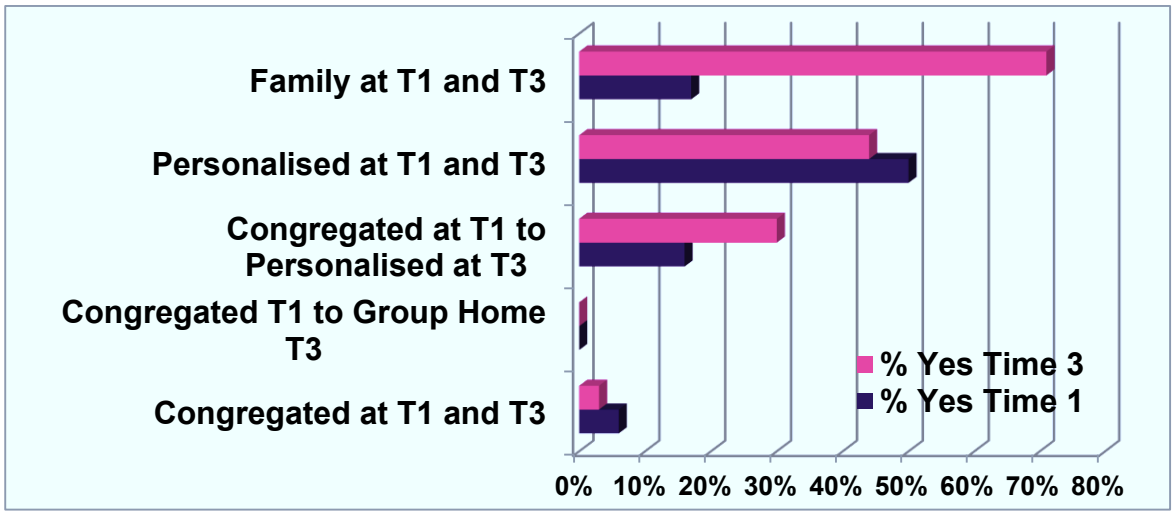

Figure 4.4: The percentage of persons in each grouping who chose their own support staff at Time 1 and again at Time 3.

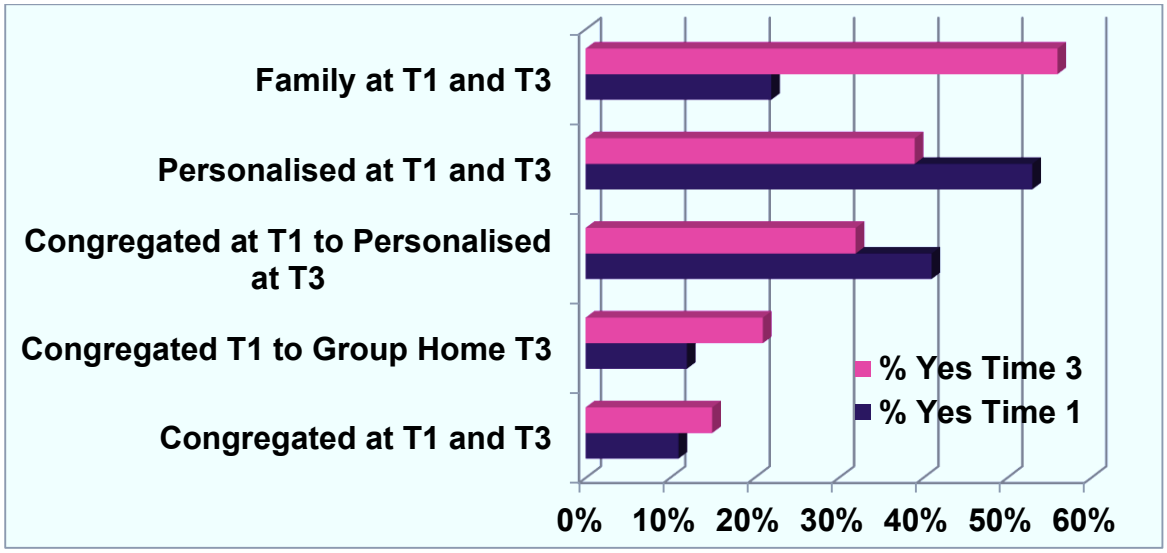

Figure 4.5: The percentage of persons in each grouping who had training in advocacy at Time 1 and again at Time 3.

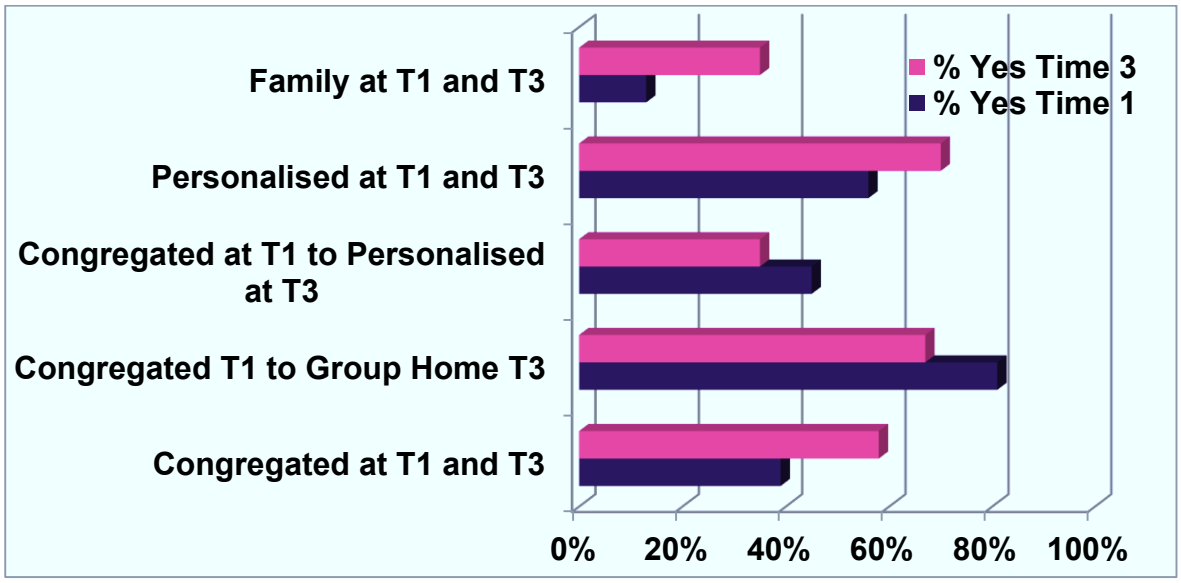

Figure 4.6: The percentage of persons in each grouping who had an individual plan at Time 1 and again at Time 3.

The other indicators in this domain that did not discriminate between the groups included the person having a key-worker, attending planning meetings, having an advocate, belonging to an advocacy group and having an individualised payment.

4.2.3 Relationships with people who are not paid staff

Although people with disabilities and mental health difficulties can require on-going support, this need not be provided solely by professional staff. Equally, social relationships with friends and family are a core characteristic of living a full life in the community. Hence, an outcome of community-based, personalised accommodation

should be increased opportunities for people to form relationships with people who are not paid to support them. The following figures (4.7 to 4.10) illustrate the four main indicators of changes in friendships and contact with neighbours that distinguished the groupings over time.

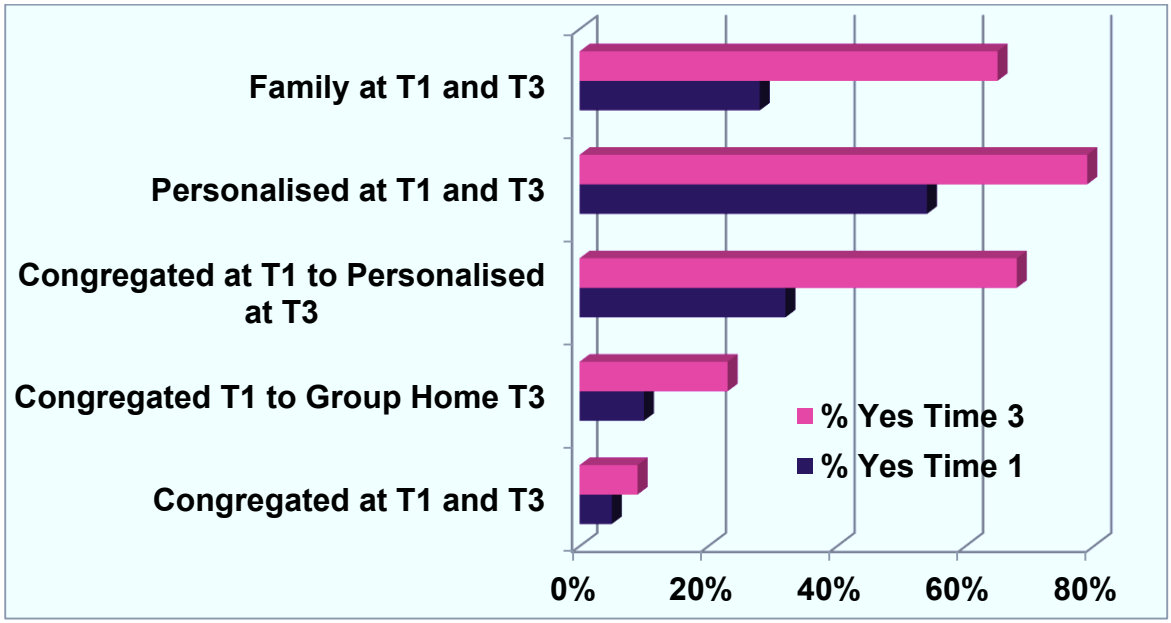

Figure 4.7: The percentage of persons in each grouping whose friends came to their home for a meal at Time 1 and again at Time 3.

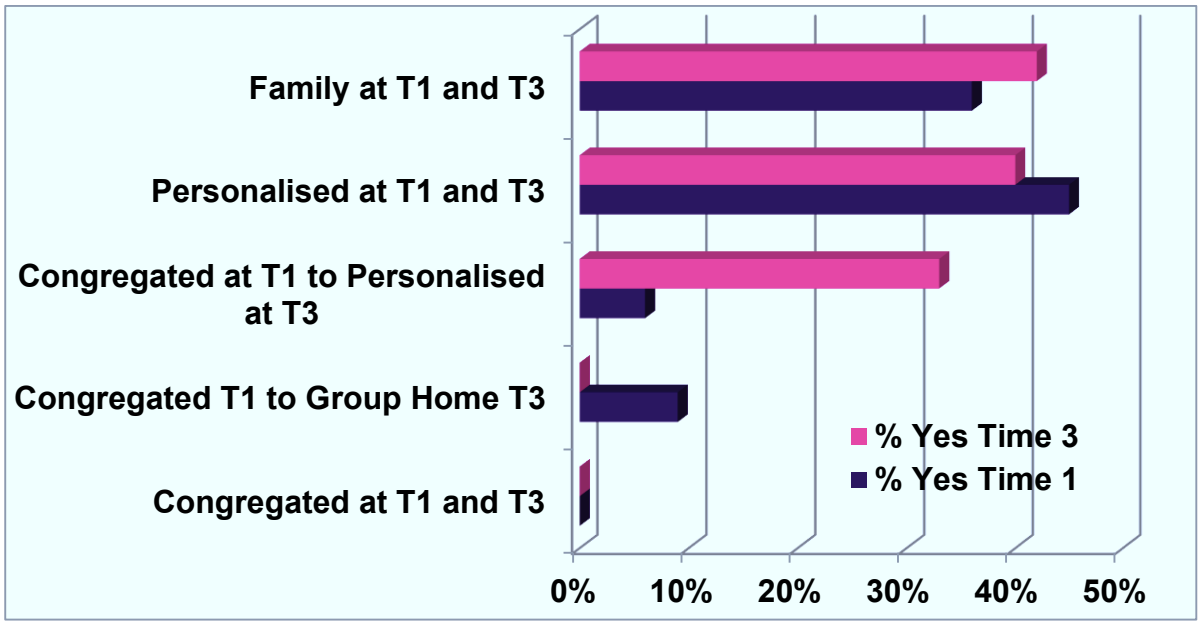

Figure 4.8: The percentage of persons in each grouping whose friends stayed overnight at their house at Time 1 and again at Time 3.

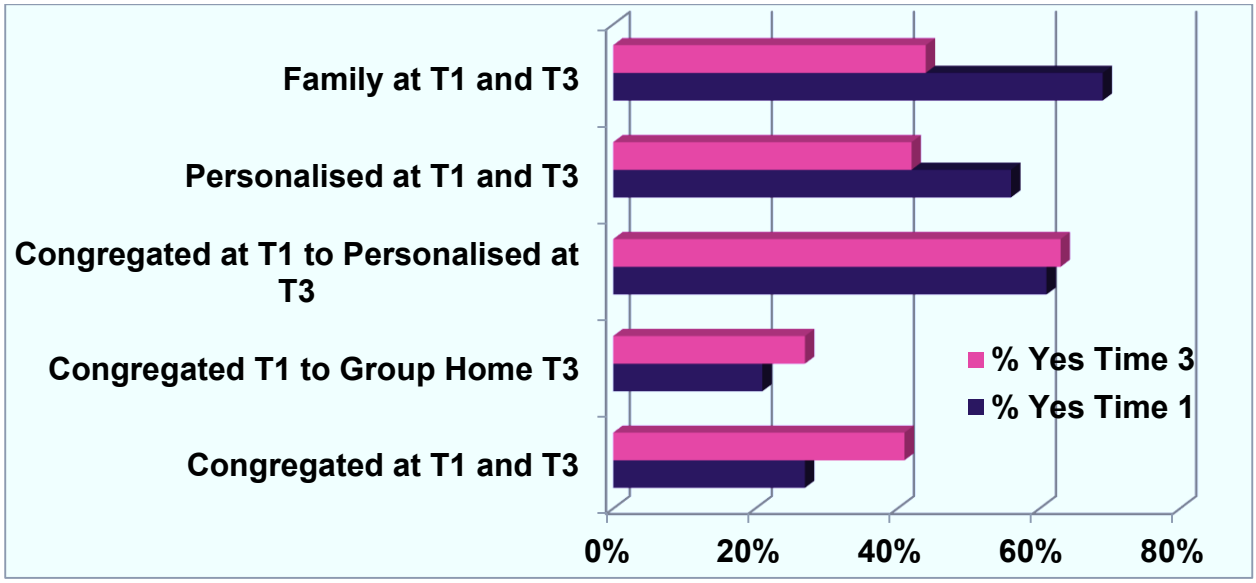

Figure 4.9: The percentage of persons in each grouping reported to have made new friends at Time 1 and again at Time 3.

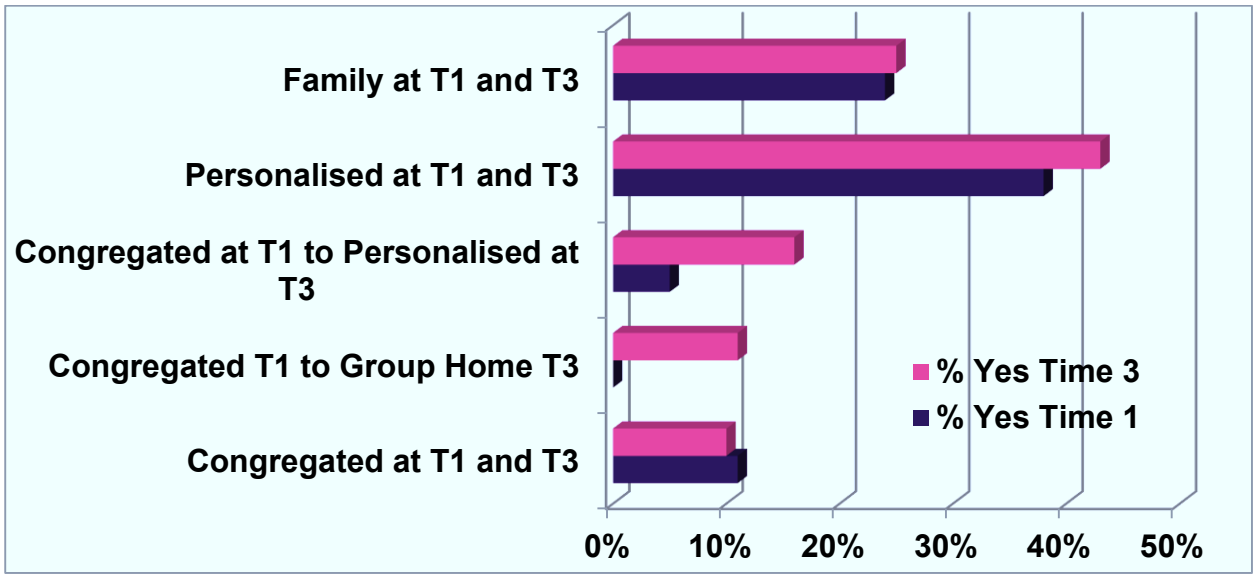

Figure 4.10: The percentage of persons in each grouping who received help from neighbours at Time 1 and again at Time 3.

The indicators that did not discriminate across the groupings were the frequency of contact with relatives, having a circle of support and the frequency of contact they have with their friends.

4.2.4 Valued roles in the community

A further aspiration of providing personalised support is that people with disabilities or mental health difficulties will be enabled and empowered to fulfil valued roles in the community. The following figures focus on the three indicators that differentiated the groupings, such as paid employment. As Figure 4.11 shows, people living with family

carers and in already established personalised arrangements were significantly more likely to be in paid work. It is possible though that paid employment facilitates placement in more individualised accommodation rather than the converse. However there were few differences on this indicator over time.

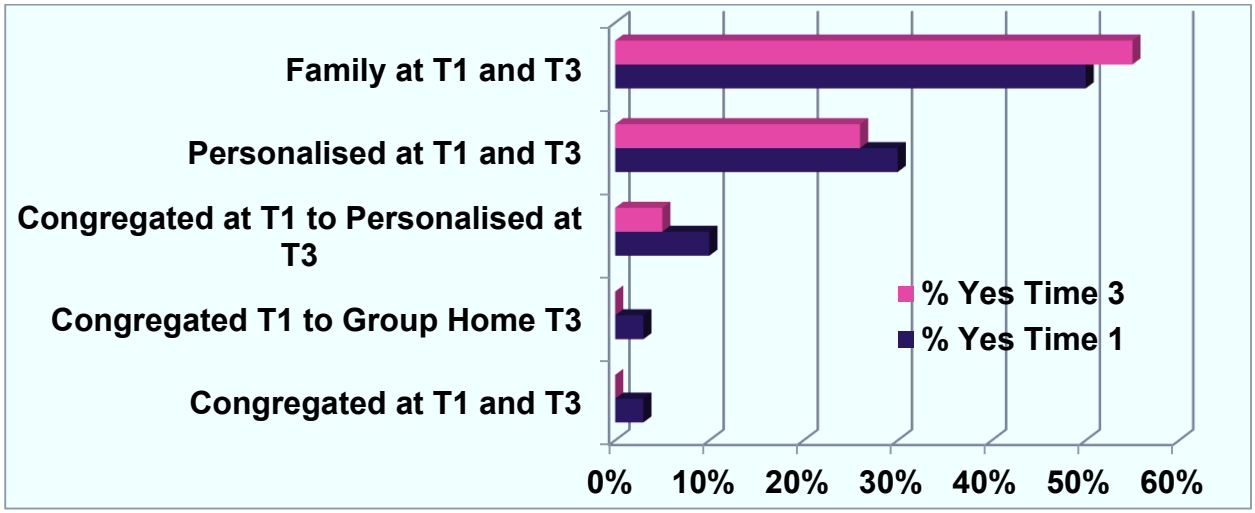

Figure 4.11: The percentage of persons in each grouping who were in paid employment at Time 1 and again at Time 3.

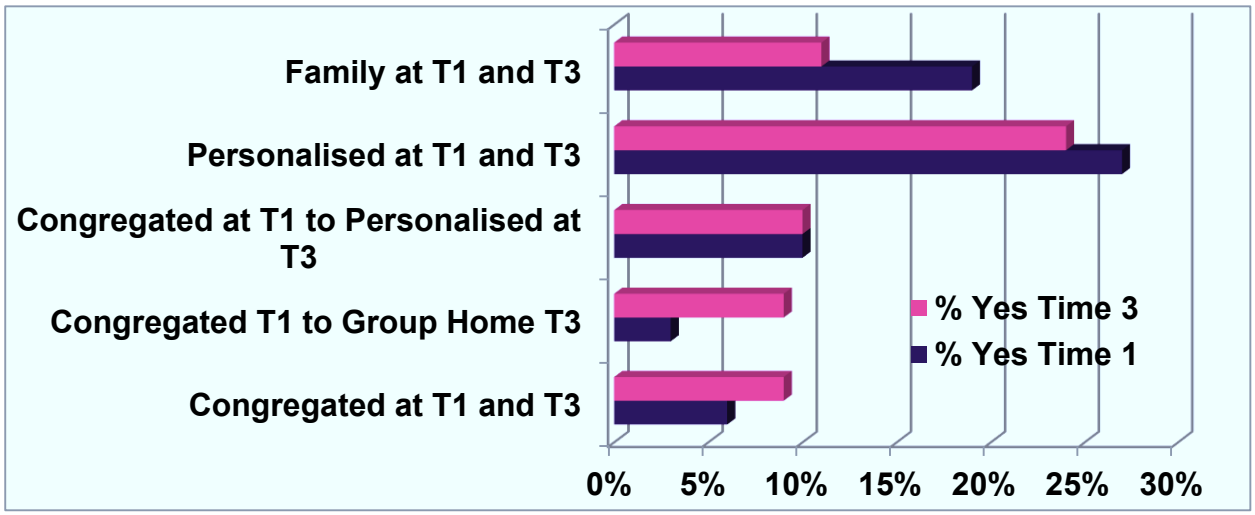

Figure 4.12: The percentage of persons in each grouping who undertook voluntary work in the community at Time 1 and again at Time 3.

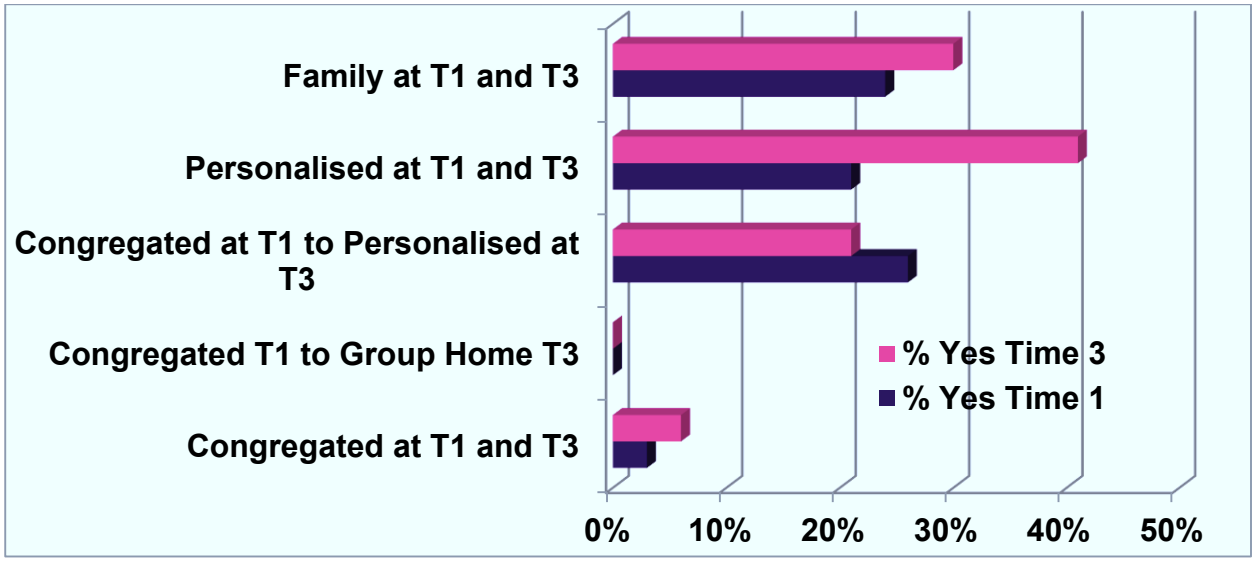

Figure 4.13: The percentage of persons in each grouping who provided help for their neighbours at Time 1 and again at Time 3.

A similar pattern was also present in the proportions of people undertaking voluntary work although the differences among the groupings were less marked and with little change over time (see Figure 4.12).

Also as Figure 4.13 shows, higher proportions of people in personalised arrangements and living with family carers were more likely to provide help to their neighbours, which rarely happened for people in congregated settings or group homes.

Other indicators that were not associated with the groupings were being a home owner, having a tenancy agreement, their marital status, owning a car and having undertaken work placements.

4.2.5 Healthy Lifestyles

Good health is an important component of Quality of Life. A move to more personalised support may not necessarily improve a person's health as people can be well cared for in other settings. Equally it is important to ensure that such moves do not result in dis-improvements in people's health and emotional well-being. Two indicators distinguished the groupings. Figure 4.14 illustrates the proportion of people who considered themselves to be overweight more notably at Time 1 than Time 3 and for people living in congregated settings.

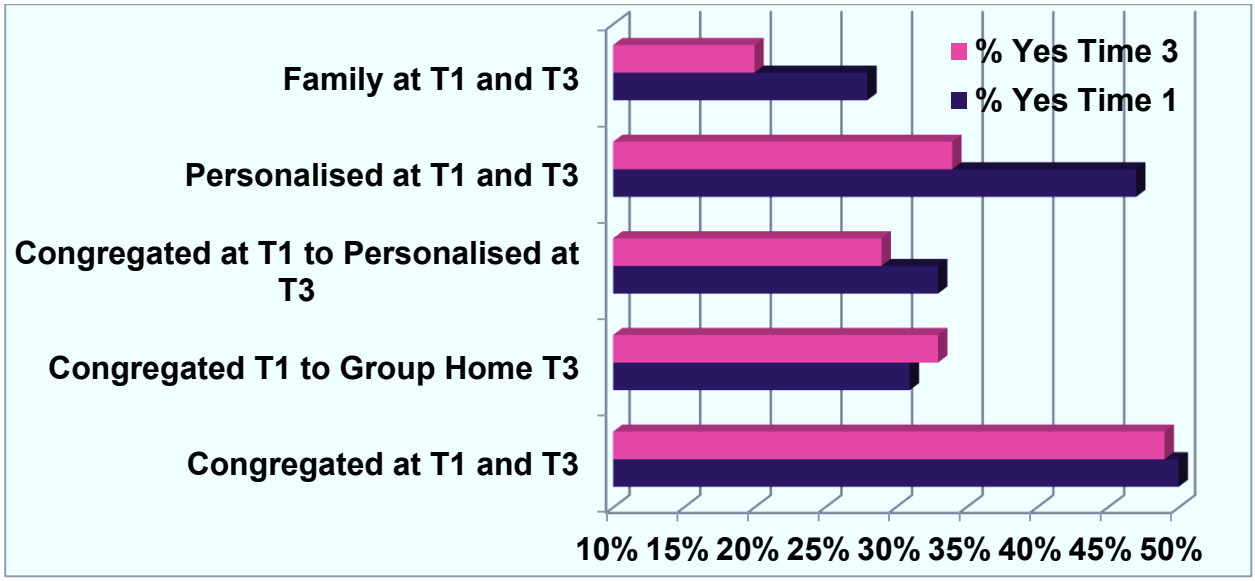

Figure 4.14: The percentage of persons in each grouping who considered themselves to be overweight at Time 1 and again at Time 3.

The second discriminating variable related to feeling nervous, anxious or on edge during the past two weeks. As Figure 4.15 illustrates the differences among the groupings was more apparent in the changes that had taken place over time, especially those who had moved or were living in personalised arrangements, whereas fewer persons living with family carers reported feelings of anxiety at Time 3.

The indicators that showed no differences by groupings were self-reported diet, use of alcohol, smoking and taking regular exercise.

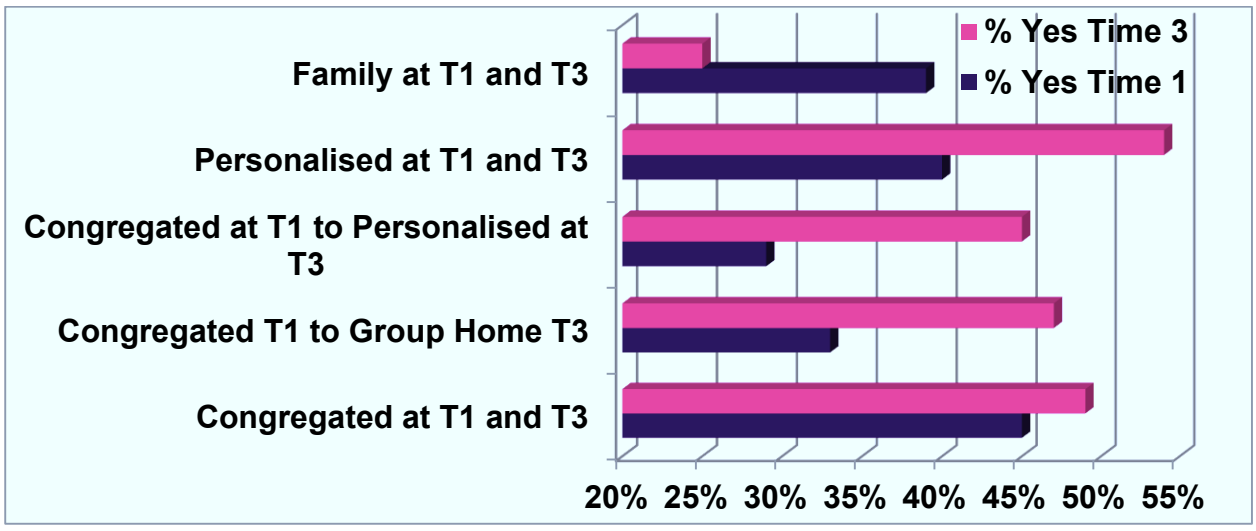

Figure 4.15: The percentage of persons in each grouping who considered themselves to be anxious at Time 1 and again at Time 3.

4.2.6 Use of mainstream recreation

Of the many indicators included in the data gathering on the use of mainstream recreation only one proved to discriminate among the groupings: their participation in sports, swimming or fitness clubs as shown in Figure 4.1.6. These pursuits were more common among those living with family carers or in personalised arrangements and less so in group homes and congregated settings.

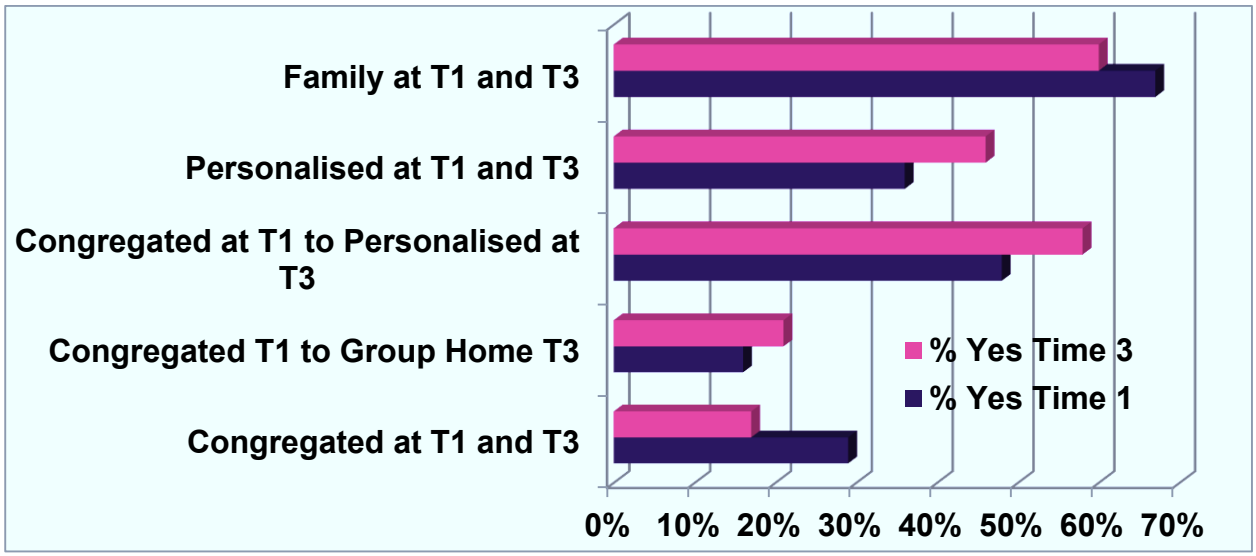

Figure 4.1.6: The percentage of persons in each grouping who participated in sports and fitness at Time 1 and again at Time 3.

The indicators that showed little difference were going to pubs, attending church, cinema, dances, social clubs and educational classes.

4.2.7 Use of specialist services

Conversely, the use of specialist disability services would be expected to decline when people are accommodated in more personalised arrangements. For example attendance at a day centre was the significant indicator (see Figure 4.17) although this seems more common for people with intellectual disability which accounts for the reduction when these people moved from congregated to group homes. In the other types of accommodation, less than one third of persons attended a day centre.

The other indicators that showed no difference were attendance at special clubs and at sheltered workshops.

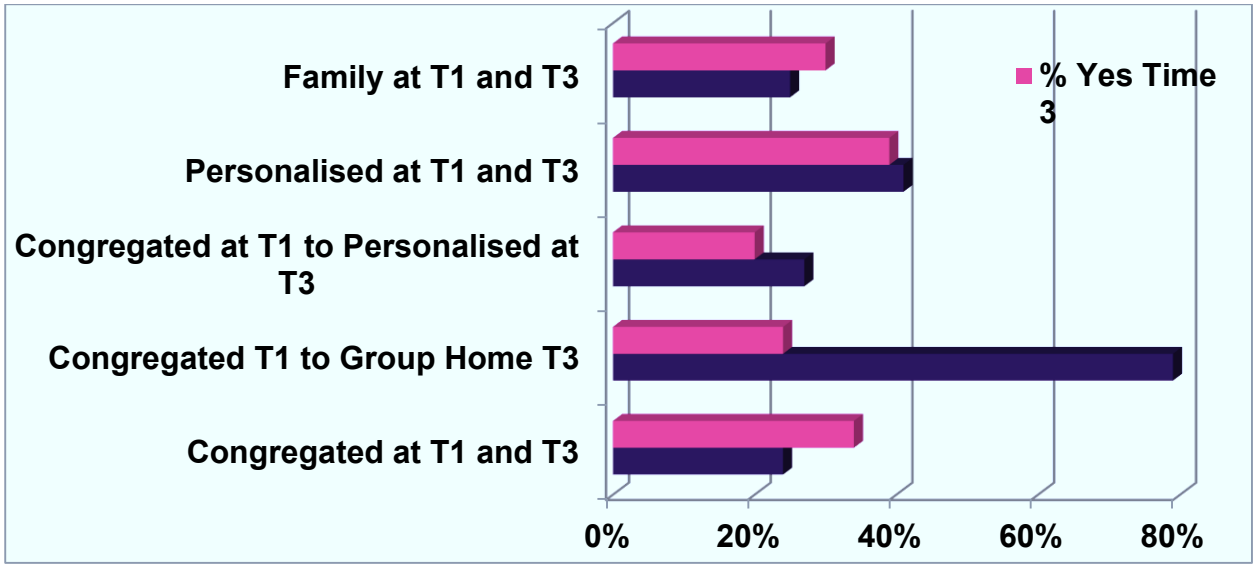

Figure 4.17: The percentage of persons in each grouping attending a day centre at Time 1 and again at Time 3.

4.3 Regression Analyses

The data presented thus far do not take into account other factors that could also account for the changes reported over time and which are confounded with the groupings used in the above analyses. As reported in Section 3.3, the person's impairment – intellectual disability, mental health and physical disability – varied across the groupings. An analysis of the data gathered with this sample identified other confounding factors (see below). Other possible factors as detailed in Section 3.3 proved not to be significant such as gender, type of schooling, educational attainments, nationality and marital status.

A statistical procedure – Binary Logistic Regression – was used to identify the contribution that these factors made to the indicators of a better life as noted in Table 4.1 and reported in the previous section. However, for each of the seven domains, only one indicator was used: the one that best discriminated the groups in order to avoid repetition and reduce the possibility of statistical significance arising from chance.

In these analyses, people living with family carers at both time points were excluded so as to maintain a focus on type of support and accommodation which was subdivided into two groupings: people in personalised arrangements and those in congregated or group homes. People with physical disabilities were also excluded due to small numbers.

The regression analyses were replicated for Time 1 (including people in grouped accommodation prior to moving) and at Time 3 (when more people had moved to personalised arrangements). The same predictor variables were used throughout as

prior analysis had indicated that they were significantly related to one or more outcomes:

- Personalised versus Grouped accommodation (Accommodation).
- Intellectual Disability versus Mental Health (Impairment).
- No assistance required with 13 everyday tasks[9] versus some assistance (Support).
- People aged under 40 years and those 40 years and over (Age Group).
- People resident in the accommodation for less than 5 years versus resident for 5 and more years. (Time resident).

The Binary Logistic regressions identified the likelihood that the above variables contributed to the variation on the chosen indicators. Table 4.2 summarises the predictors that contributed significantly to the indicator variable at Time 1 and Time 3 (NB A blank indicates a non-significant relationship)[10].

[9] Items included: looking after their personal care, shopping for groceries, using public transport, making telephone calls, filling in forms and taking part in activities in the community.

[10] A technical report describing these analyses is available on request from Prof. Roy McConkey

Table 4.2: The predictors that were significantly related to the indicator variables in the Binary Logistic Regressions at Time 1 and Time 3.

Indicator	Time	Accommodation and Support	Impairment	Support	Age Group	Time resident
Key to house	Time 1	Personalised				
	Time 3	Personalised		None needed		Less 5 years
Friends for meal	Time 1		Mental health			Less 5 years
	Time 3	Personalised				
Choose own staff	Time 1	Personalised				
	Time 3	Personalised				
Participates in sports	Time 1				Under 40 yrs	
	Time 3	Personalised				
Paid employment	Time 1	Personalised				
	Time 3		Mental health			
Feeling anxious	Time 1	Personalised				Less 5 years
	Time 3					
Average weight	Time 1					
	Time 3					

In relation to most indicator variables, it was the type of support and accommodation that made the most significant contribution to the regression at one or other time points or both. This data should be treated only as indicative due to the small numbers within the analyses (especially on paid employment and average weight), however they do suggest that the type of accommodation has a stronger influence on these indicators than other possible variables.

4.4 Rating Scales

Two rating scales were also developed as part of the evaluation; one focussing on the person-centred support received and a second on quality of life. These not only provided further confirmation of any changes experienced by participants, but they also enabled comparisons to be made between the ratings given by the people supported and by their key-workers who completed each scale independently from the person. With the people supported, the scales were completed through interview, whereas key workers self-completed a written pro-forma. Both scales were completed at Time 1 and again at Time 3 so that changes over time could be detected.

4.4.1 Quality of Life Ratings

The quality of life rating scale has been described in section 2.6. Ten items were rated of a scale of 1-3, with higher scores indicating better quality of life ratings.

Figure 4.18 gives the mean scores for each of the five subgroupings at Time 1 and at Time 3.

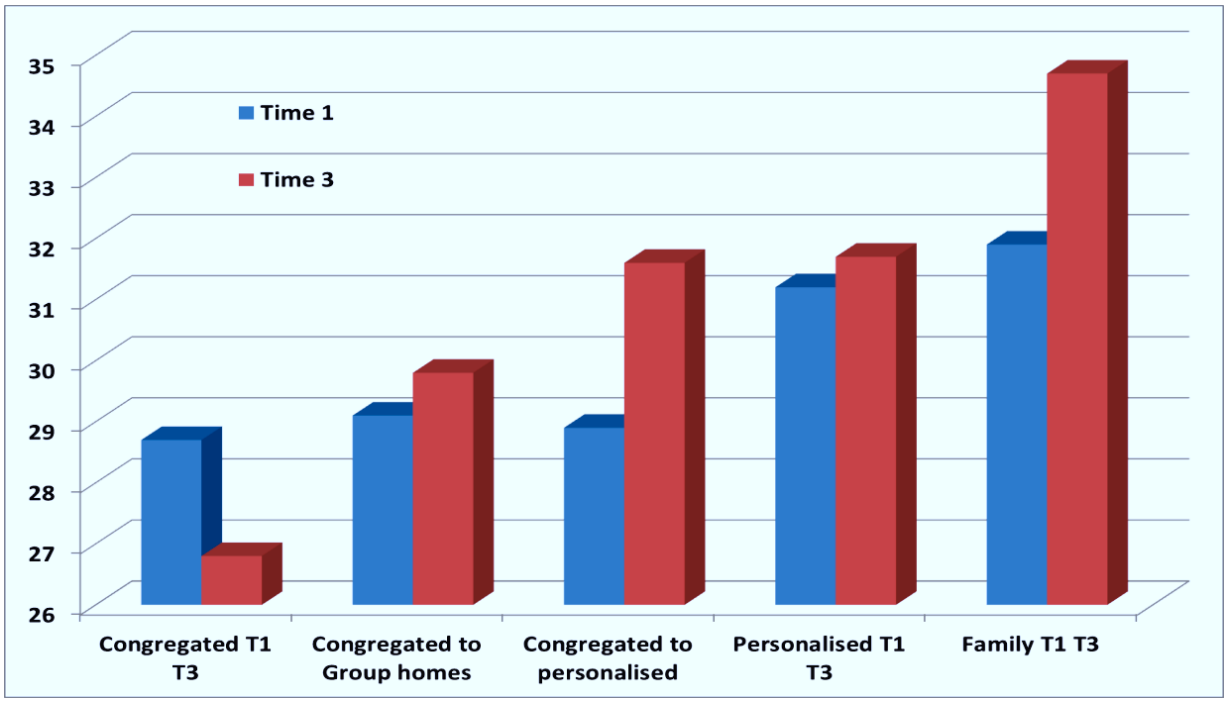

Figure 4.18: The mean scores on the Quality of Life Scale completed by persons supported in each grouping at Time 1 and again at Time 3.

The differences across the five groupings were not significant at Time 1 but they were at Time 3 ($p<0.01$). Those who continued to live in congregated settings gave lower ratings of their Quality of Life at Time 3 than they had given at Time 1. Also at Time 3, people living with families gave higher quality of life ratings compared to those in congregated setting. The changes were not significant for the other

groupings although the variation in scores remained high throughout, which reflects the individuality of people's experiences.

The comparable ratings given by key-workers are shown in Figure 4.19. These differed significantly across the five groupings at Time 1 but not at Time 3. Key-workers were more likely to consider that the person's quality of life had improved for those who moved from congregated settings, whereas their ratings tended to be unchanged for those who remained in the same accommodation. Their ratings of quality of life of those in family or personalised settings tended to be lower than those given by the person.

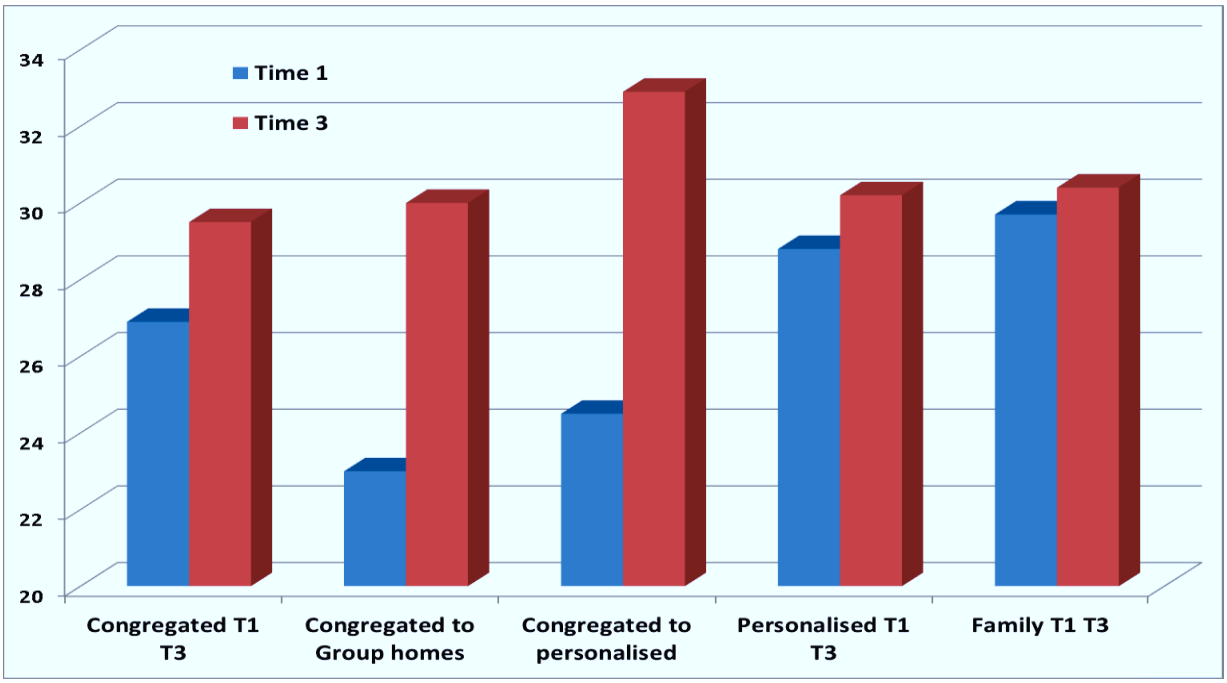

Figure 4.19: The mean scores on the Quality of Life Scale completed by key workers in each grouping at Time 1 and again at Time 3.

4.2.2 Indicators of individualised support

The second rating scale consisted of 10 items reflective of individualised support each rated on a scale of 1-3. A high score was indicative of greater levels of individualised support.

Figure 4.20 gives the mean ratings given by the person supported in the five subgroups at the two time points. The difference across the five groups was significant at Time 1 ($p<0.05$) but not at Time 3. However, the largest change in ratings was for people moving from congregated to personalised settings and those living with family carers, where higher ratings of personalised support were given.

Individualised support was rated lowest for those living in group homes. The ratings completed by key-workers are summarised in Figure 4.21. Again the differences

across groups were significant at Time 1 ($p<0.05$) but not at Time 3. Individualised support was rated lowest for those prior to transferring from congregated settings to group homes. By contrast individualised support was rated higher for people in personalised arrangements and family settings. By time 3, key-workers tended to rate individual support as similar across the various settings and in a comparable way to the persons supported, with the exception of those in family settings who rated their support more personalised than the key-workers.

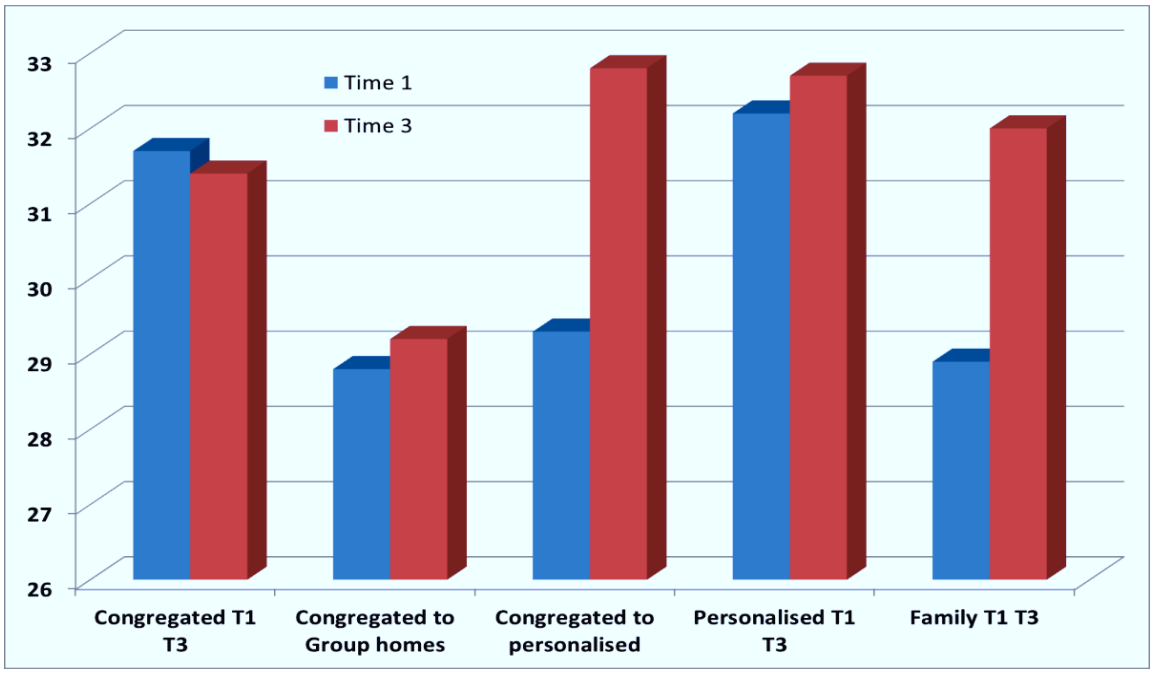

Figure 4.20: The mean scores on the Individualised Support Scale completed by persons supported in each grouping at Time 1 and again at Time 3.

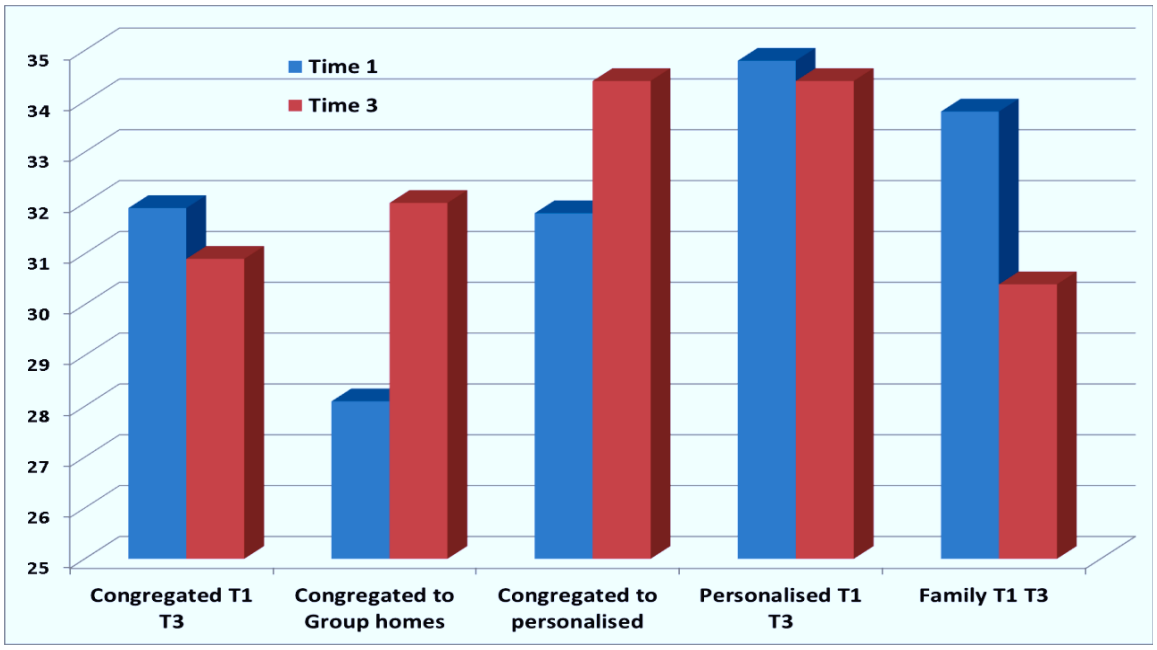

Figure 4.21: The mean scores on Individualised Support Scale by key-workers in each grouping at Time 1 and again at Time 3.

4.5 Findings from relatives

Over the course of the evaluation we made contact on at least one occasion with the relatives of 112 persons (57% of the people supported). They came from 19 of the 22 participating projects (86%).

The majority were relatives of persons with intellectual disabilities (N=79: 65% of sample of persons with ID in the evaluation). In all 23 relatives of persons with mental health difficulties were contacted (36% of persons with mental health difficulties) and 10 relatives of persons with physical disabilities (59% of this grouping in the study).

Table 4.3 shows that relatives had persons in each of the accommodation and support groupings used throughout the evaluation. Proportionately more relatives had persons supported living with them at home with the least proportion coming from those in personalised arrangements.

Table 4.3: The number and percentages of relatives with people supported in the accommodation and support options.

Living arrangements at Time1 and Time 3	Relatives	% of total in grouping	Total and % overall (N=160)
Personalised at T1 and T3 *(NB Having moved prior to T1)*	15	38%	40
			25.0%
Congregated at T1 and T3 *(NB Had not moved by T3)*	25	60%	42
			26.3%
Family at T1 and T3 *(NB Remained with family)*	17	85%	20
			12.5%
Move from Congregated at T1 to Personalised at T3	12	52%	23
			14.4%
Moved from Congregated T1 to Group Home T3	26	74%	35
			21.9%

Just under half of the relatives were parents (mostly mothers were interviewed) with sisters or sisters-in-law forming just under a quarter of the sample and a similar proportion were brothers or brothers in law. The remainder were aunt/uncle or foster carers.

4.5.1 Relative's ratings

The two rating scales developed as part of the evaluation - one focussing on the person-centred support received and a second on quality of life - were also completed by relatives during their interview. However, some relatives found these

difficult to complete and they had insufficient knowledge on which to base their ratings. This meant a marked reduction in the number of relatives completing the scales especially as fewer agreed to be interviewed at Time 3. Hence, the following data should be treated as suggestive in that it may not fully reflect the views of all the relatives of persons in the evaluation.

Because of the reduced numbers the ratings are presented in terms of contrast between persons living in personalised arrangements versus those in congregated settings.

4.5.2 Individualised support ratings by relatives

Figure 4.22 shows the mean scores given by relatives at Time 1 and Time 3 on the individualised support scale for each of the three accommodation options. Shown for comparison are the mean scores given by the key-workers in lighter shading.

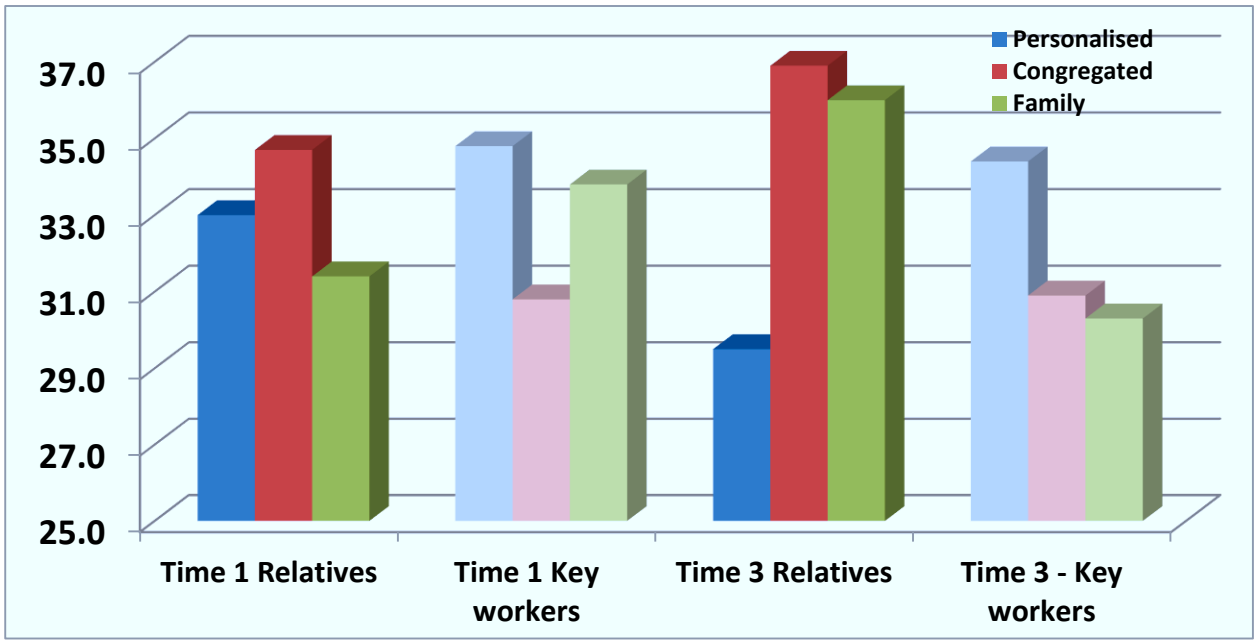

Figure 4.22: The mean scores on Individualised Support by relatives and key-workers (lighter shade) for the accommodation options at Time 1 and again at Time 3.

Although none of the differences between the relatives' ratings by accommodation and support options and over time were statistically significant, there were contrasting changes in their ratings. At Time 3 they rated personalised settings as providing less individualised support, whereas their ratings for such support to people living with families had increased as it had in congregated settings. It could be that relatives had an overly optimistic view of the support provided in congregated settings as the ratings by key-workers for congregated settings were lower at both time points than those given by relatives. Conversely, the key worker ratings of personalised care tended to be higher than relative's ratings.

4.5.3 Quality of Life ratings by relatives

Figure 4.23 similarly displays the mean ratings on the Quality of Life Scale. Again the differences in relatives' mean scores across the accommodation and support options and over time were not statistically significant, but there are some interesting contrasts with the mean scores given by key-workers.

At Time 3 relative gave even higher ratings to persons living in congregated settings than they had at Time 1, but the key-workers did likewise. This may reflect a hope from both parties that congregated settings do offer a reasonable quality of life to persons even though there are plans for them to move out. The ratings for the other accommodation options were broadly similar at both time points and the two sets of raters. These ratings contrast with the comments of many relatives of people who had moved, who recognised the difference in quality of life between the personalised and congregated setting.

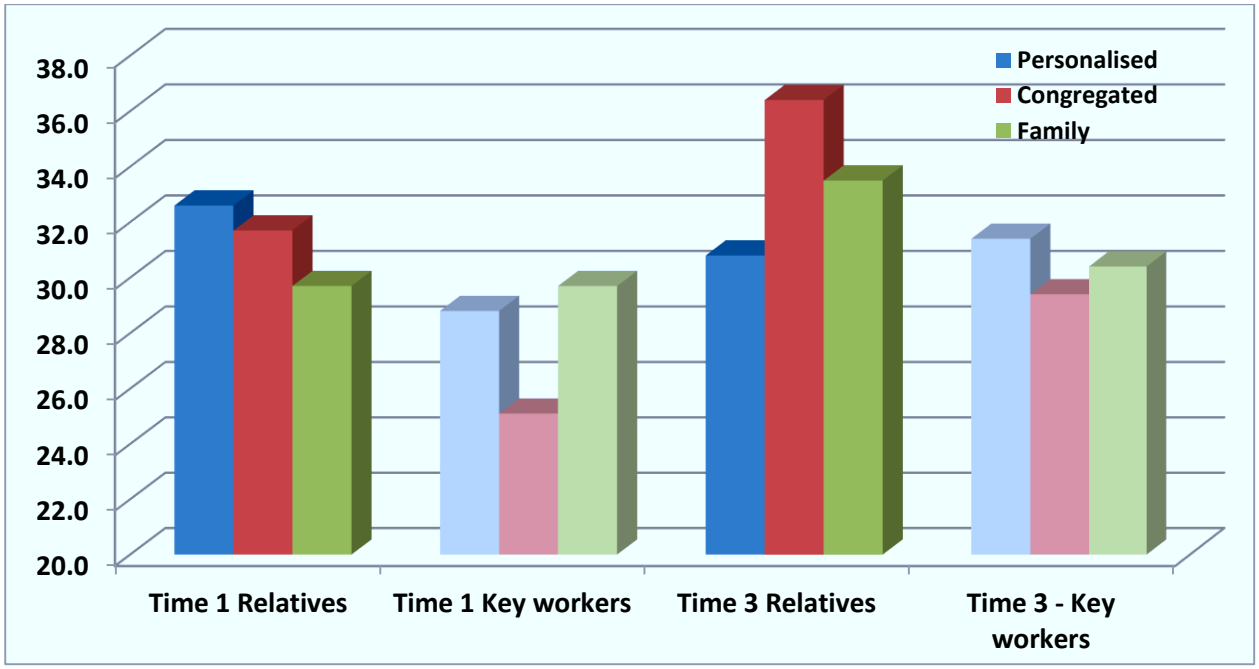

Figure 4.23: The mean scores on Quality of Life Ratings by relatives and key-workers (lighter shade) for the accommodation options at Time 1 and again at Time 3.

4.6 Findings from staff

Information was collected from the key-workers by means of a structured face-to-face interview and a self-completed pro-forma. At Time 3, information was supplied by 144 key-workers: 87 (60%) employed by intellectual disability services, 50 (35%) in mental health services and 7 (5%) in physical disability services.

This number is smaller than the number of people supported in the evaluation as some key-workers supported more than one person and some of the people supported did not wish a staff member to be interviewed or they did not have a key-worker. Moreover, small proportions of informants declined to provide some of the information requested. Thus this data is not necessarily indicative of the staffing complement within the participating services, although it may be indicative of the staff who 'know best' the individuals participating in this study as we had used this phrase to identify the key-worker, even if the staff member did not have such a title.

4.6.1 Staff characteristics

The data presented in this section was collected at Time 3 when most people had moved and hence the profiles of staff are those working in the new arrangements as well as the longer established ones. The staff characteristics are summarised for the four types of settings noted in Table 4.4.

Table 4.4: The percentage of staff within the four types of accommodation options*

Staff characteristic	Personalised	Family	Group Home	Congre-gated	Overall
% Nurses and care staff	28%	7%	41%	41%	31%
% Support workers ***(N=128 all staff)***	72%	93%	59%	59%	69%
% Irish national ***(N=125)***	91%	93%	71%	90%	86%
% Higher education ***(N=123)***	82%	79%	74%	82%	80%
% Female ***(N=128)***	75%	71%	54%	74%	70%
% <40 yrs ***(N=122)***	48%	64%	44%	28%	44%
% Fulltime work ***(N=122)***	91%	86%	81%	89%	86%
% Permanent job ***(N=126)***	83%	71%	59%	71%	74%
In present post 5+ years ***(N=128)***	46%	43%	29%	52%	43%
In disability/health work < 2 yrs ***(N=124)***	77%	71%	56%	70%	70%
% Training individualised support ***(N=124)***	80%	79%	86%	69%	78%
% Training Genio ***(N=130)***	51%	75%	37%	40%	46%

** Due to missing data the numbers on which percentages are based varies across the staff characteristics. Figures have been rounded to the nearest whole figure.*

Given the relatively small numbers in these analyses, none of the differences were statistically significant ($p<0.05$) on the staffing characteristics as shown although there were some trends that will be highlighted below.

4.6.2 Job Titles

Staff could be grouped into two broad categories: namely qualified nurses plus care assistants and those classed as support workers which included a variety of job titles including life coaches, coordinators, community support workers, mentoring support worker, instructors and personal assistants. This variation seems to be indicative of services creating new job roles for which there is no uniform staff grading. There were no significant differences in these job roles across the three types of service agencies, i.e. mental health and intellectual disability[11].

Nurses tended to be more common in congregated settings and in group homes and less so in support of people living with families. However, people who had moved from congregated settings at Time 1 to personalised arrangements at Time 3 tended to receive support from nurses more so than did those persons already in personalised arrangements at Time 1 (42% compared to 13%). This difference was statistically significant ($p<0.01$).

4.6.3 Summary of staff characteristics

As Table 8.1 shows, nearly all support workers were Irish nationals, four-fifths had some form of further or higher education, the majority were female with a median age of over 40 years. Most were employed full-time and had permanent contracts. Nearly three-quarters had worked in disability or health services for 5 years or more and over 40% had been with their present employer for this length of time also.

4.6.4 Training received

Over three-quarters reported receiving training in individualised supports with a similar pattern across the various accommodation options, as the intention was that all these persons would ultimately move to more personalised arrangements. Moreover, half of the key-workers had attended training events organised by Genio.

4.7 The Cost of Services

Data was collected from the person supported and key worker on the following costs (the categories are described in more detail in section 2.6.1):

- Direct support costs
- Community service costs

[11] Comparisons were made between intellectual disability services and mental health services on the staff characteristics. Key-workers differed on only two characteristics: those in intellectual disability services were more likely to be male and to have worked for more than three years with their present services ($p<0.05$ Chi Square tests).

- Hospital services costs
- Income from social security benefits.

The findings arising from the cost data are best treated as indicative rather than definitive for the following reasons.

- Within each grouping, there is wide variation in the costs calculated for individuals included in that grouping. This is especially so when people move. The reasons are varied but they include that people had differing support needs and they lived in different styles of accommodation options. Hence, the range of costs within each grouping along with median costs is reported in this section. This means that, for example, the mean costs of group homes may be lower compared to other options, but some individuals living in a group home may have much higher costs than people in other settings.
- When two or more people shared support staff it was difficult to allocate the amount of support each received using the data available, so the only pragmatic response was to assume they had equal access. For certain individuals this may under-estimate or over-estimate their support costs.
- The data relating to community services and hospital usage depended on recall which is less satisfactory than accessing records of usage. However, it is more likely that these costs are under-estimated.
- Certain information required was not readily available to our primary informants: the people supported and their key-workers. Although we had hoped they could access service records, the required information was not always recorded.
- Because this analysis focused on direct support costs, informal support costs (such as support provided by families) were not included in this analysis. The full costing of informal support would increase the cost of support particularly in the family category.
- The figures presented in this section are NOT total costs as they do not include the managerial and administrative overheads incurred by organisations. This omission was based on the premise that these will remain a constant as long as the person remains within that service. However, if the person were to move to a new provider, this could change. Similarly the costs of food, heating light etc. are not included as these may only change marginally as people change accommodation.

Despite these cautions, the data obtained provides the basis for a more informed debate, as well as enabling us to compile a list of recommendations as to how more accurate cost information can be arrived at for individuals in receipt of services.

4.7.1 Support Staff Costs

It is well recognised that the major costs in health and social service provision are those relating to support staff. Information on support staff for people in personalised

arrangements and those working with persons living in family care was obtained from Key Workers at both time points. Key Workers were asked about the staff that directly supported the participant and specifically about the title and grade of relevant staff to facilitate matching with unit costs. Key Workers were also asked to indicate the number of weekly hours allocated by each member of support staff to the person supported.

Relevant information on staff support costs for individuals living in congregated settings and group homes was obtained from the Value for Money and Policy Review of Disability Services in Ireland (Department of Health 2012). In this Review, the average annual costs of residential services were provided according to 'resource usage groups'/level of support required and by geographical location. Based on the information provided by participants on the level of support and availability of support staff in residential services, individuals were matched with the appropriate annual residential cost from the VFM Review. Residential costs cited within the VFM Review include direct pay costs (which constitute approximately 70%); indirect pay costs (of central management staff that constitute approximately 10%); with the remainder being non-pay costs (which includes administration and overheads). Based on this estimated breakdown, costs of direct support staff for those living in congregated settings and group homes were estimated at 70% of total accommodation costs obtained from the VFM review. This figure was felt to be most comparable to the information collected within the key worker pro-formas for those living in personalised settings or family care.

Unit cost information relating to support staff was obtained from Consolidated Salary Scales and the midpoint of the scale was used unless specific information was given to indicate otherwise (http://www.hse.ie/eng/staff/Benefits_Services/pay/).

On a number of occasions, 'Key workers' were given as an example of support staff but no additional information given as to the type of staff or grade. Furthermore unit cost information was not available for a number of types of support staff mentioned (e.g. Instructor, Co-ordinator, Peer Mentor). Where possible, unit costs relating to these staff members were obtained directly from the service provider. However, for some individuals, staff support costs were omitted due to lack of available costing information. It is likely these costs fall within the range of costs noted.

Figure 4.24 shows the mean annual costs in Euros for each of the five accommodation and support groupings at Time 1 and Time 3.

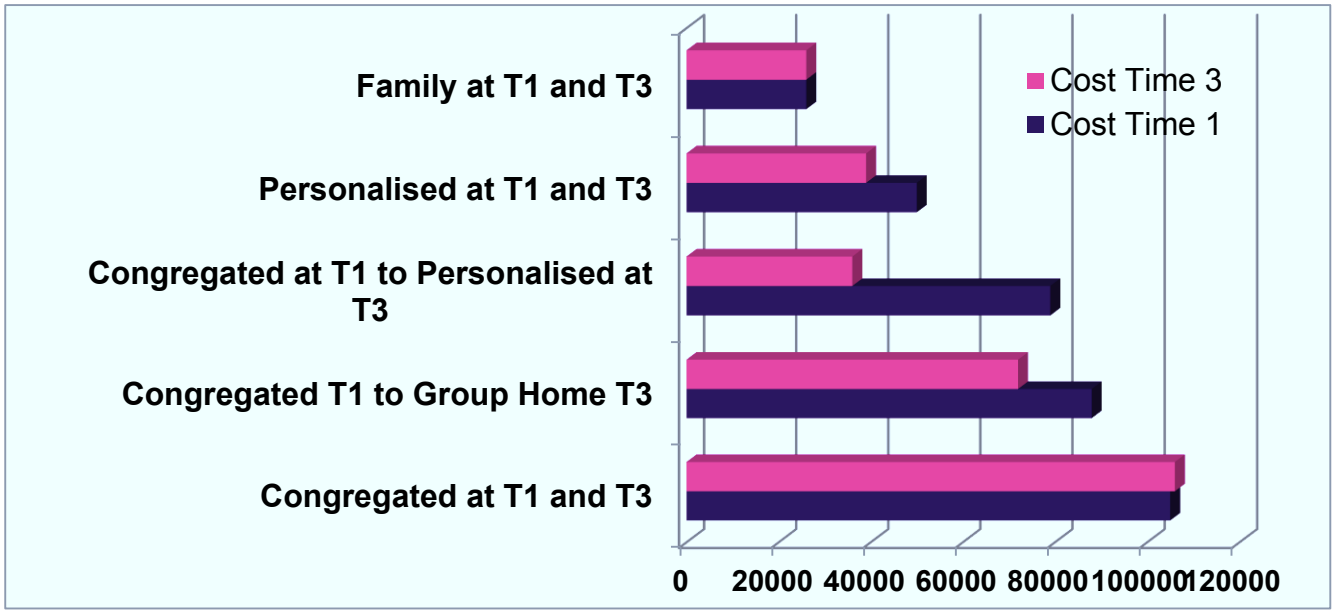

Figure 4.24: The mean annual support staff costs in Euros for each grouping at Time 1 and again at Time 3.

Within each grouping there were marked variations in the staff support costs. This is illustrated in Table 4.5 which gives the median[12] monthly costs across the five groupings also the minimum and maximum costs within that grouping.

Table 4.5: The median, minimum and maximum of monthly staff support costs at Time 1 and Time 3 for people in the five accommodation groupings.

	Personalised T1 and T3		Congregated T1 and T3		Family T1 and T3		Congregated to Personal		Congregated to Group Home	
	T1	T3	T1	T3	T1	T3	T1	T3	T1	T3
Median	€2,121	€1,710	€8,876	€10,348	€2,204	€2,204	€7,365	€2,308	€7,365	€7,365
Min	€228	€156	€2,251	€2,251	€1,292	€1,292	€1,662	€118	€1,212	€1,212
Max	€2,3425	€12,700	€10,348	€10,348	€3,166	€3,166	€10,348	€16,496	€10,348	€7,365

The variation in staff costs in both congregated settings and personalised arrangements was considerable (up to five or ten times the lowest figure). However, significant differences in the average support staff costs were found across the five accommodation groupings at both T1 and T3 ($F=13.40$, $p<0.001$; $F=25.73$, $p<0.01$). Staff costs in congregated settings were around three times higher than in personalised arrangements.

[12] The median is the point at which the group is divided in half – 50% of the values in the group are above the median and 50% are below.

In addition, there were significant differences in costs at T1 and T3 for those persons who moved from congregated settings to personalised living arrangements (t=-2.424, p<0.053) and for those who moved from congregated settings to group homes (t=2.872, p<0.01). However, the costs in group homes still tended to be higher than those in personalised arrangements. The variation in costs from Time 1 to Time 3 in the other groupings did not attain statistical significance.

The lowest direct support costs were in supporting people who continued to live in family care, but this was additional to the hours of care provided by families that are not included in this calculation.

In summary, staff support costs were generally highest in congregated settings for both people with disabilities and mental health difficulties, probably due to the waking night-staff costs which did not occur so commonly in the other options. Overall personalised services did have lower costs for most persons, although the highest staff costs for certain individuals were in personalised arrangements which probably reflected their high support needs.

4.7.2 Cost–benefits

In order to provide an indication of potential cost-benefits, support staff costs could be correlated with the quality of life ratings and the indicators of individualised support as reported in Section 4.4. The ratings of people supported were used in these analyses.

For the sample as a whole at Time 1, the correlations were not significant for both quality of life and individualised support. However, for those persons living in congregated settings, higher monthly costs were associated with higher ratings of individualised support (r=0.611: p<0.01). The other within-group correlations were non-significant.

At Time 3 for the total sample, higher quality of life ratings were correlated with *lower* monthly staff costs (r=0.391:p<0.001). However, the within group correlations were not significant on either of the measures although for persons in congregated settings, higher staff costs tended to be associated with *lower* ratings of quality of life (r=0.394;p<0.06).

This is a somewhat crude method of assessing cost benefits. Nonetheless in general terms, it can be said that the investment of support costs under personalised arrangements bought greater benefits to the people supported than did the investment in congregated care arrangements.

4.7.3 Community Healthcare Costs

An issue to consider in moving people from congregated settings is that some of the costs of their support services may shift to community services. In order to detect whether this happened, participants in the evaluation were presented with a list of services/ healthcare professionals and asked whether they had used the service or visited the healthcare professional within the last six months. Where an individual

indicated they had done so, they were subsequently asked about the number of visits to this provider.

However, this information was misunderstood at Time 1, as informants reported on professionals and services provided through the specialist services. At Time 3 particular emphasis was placed that it was mainstream service usage that was required. (This accounts for the decreased usage reported at Time 3 – see Table 4.6). Nevertheless the usage of specialist services at Time 1 was retained in the following tables as it gives an indicative cost of these services if provided through community services. It also provides a comparison with usage and costs when people changed their accommodation.

Table 4.6: The percentage of participants using community services in the previous six months (at Time 1 and Time 3) in the five accommodation groupings.

Community Services	Personalised T1 and T3		Congregated T1 and T3		Family T1 and T3		Congregated to Personal		Congregated to Group Home	
	T1	T3	T1#	T3	T1	T3	T1#	T3	T1#	T3
GP/Family doctor	62.5	90.0	61.9	40.5	60.0	60.0	60.9	69.6	77.1	74.3
Dentist	45.0	30.0	38.1	26.2	50.0	25.0	34.8	26.1	22.9	14.3
Podiatrist	17.5	30.0	40.5	11.9	10.0	15.0	13.0	26.1	31.4	40.0
Optician	22.5	20.0	26.2	16.7	20.0	15.0	13.0	13.0	8.6	5.7
Community Nurse	30.0	17.5	7.1	2.4	5.0	5.0	13.0	30.4	11.4	14.3
Psychiatrist	17.5	20.0	45.2	2.4	5.0	5.0	26.1	17.4	51.4	5.7
Social worker	12.5	5.0	14.3	2.4	10.0	0	17.4	0	8.6	0
Psychologist	10.0	7.5	21.4	0	10.0	0	13.0	4.3	8.6	2.9
Physio-therapist	17.5	2.5	11.9	2.4	5.0	0	13.0	17.4	5.7	0
Occupational Therapist	12.5	7.5	21.4	0	5.0	0	8.7	8.7	22.9	2.9
Dietician	5.0	5.0	0	2.4	5.0	0	0	4.3	25.7	14.3
Speech and Language	0	5.0	9.5	0	10.0	5.0	4.3	4.3	25.7	0
Home Help	7.5	2.5	0	0	5.0	25.0	0	0	2.9	0
Advocacy Services	2.5	2.5	4.8	4.8	0	15.0	0	4.3	2.9	0
Supported Employment	15.0	0	0	0	5.0	5.0	4.3	0	0	0
Personal assistant	5.0	5.0	0	0	0	0	0	0	0	0

 # These figures may also reflect the use of services provided by specialist agencies.

As Table 4.6 shows, the most commonly used services were GPs, dentists, podiatry and opticians and community nursing. Thereafter the other services were less used and this varied by type of grouping. Also people moving to group homes seemed to

make less use of psychiatric, therapy and psychology services. This may not necessarily be to their detriment as their need for such services may have decreased.

Unit cost information for community healthcare services (with the exception of optician costs) was obtained from Consolidated Salary Scales using the midpoint of each scale (http://www.hse.ie/eng/staff/Benefits_Services/pay/). The unit cost of a visit to an optician was obtained from a previous report Trinity College Dublin on the costs of services for people with Intellectual Disability (McCarron and McCallion, 2009). These were then totalled for each person and averaged over one month. Table 4.7 gives the median, minimum and maximum costs for the five groupings.

Table 4.7: The median, minimum and maximum of monthly costs of using community services each month at Time 1 and Time 3 for people in the five accommodation groupings.

Community Service Costs	Personalised T1 and T3		Congregated T1 and T3		Family T1 and T3		Congregated to Personal		Congregated to Group	
	T1	T3	T1#	T3	T1	T3	T1#	T3	T1#	T3
Median	€151	€48	€77	€21	€83	€22	€53	€61	€76	€42
Minimum	0	0	0	0	0	0	0	0	0	0
Maximum	€1284	€177	€356	€252	€513	€96	€123	€193	€178	€423

 # These figures include the equivalent of community service costs even though they may have been provided as part of a specialist service.

On average people in all groups made relatively little use of community services and there was little evidence of increased usage as people moved to new accommodation options. Once again, there was a wide variation of costs within each grouping which reflects higher usage by certain individuals over a period of time perhaps due to a short-term illness.

4.7.4 Hospital Services

Participants were similarly asked about their attendance at hospital within the previous six months. They were asked specifically about inpatient psychiatric admissions, psychiatric rehabilitation ward stays, general medical ward stays and outpatient visits (psychiatric, day hospital, Accident and Emergency and 'other'). Table 4.8 presents the percentage of persons within each grouping using the specified services. Overall only small numbers of persons had accessed these services with admission to medical wards and outpatients being the most common. Although there was little variation across the five grouping, there were small increases in usage when people moved from congregated settings. Small numbers of people in this sample availed of psychiatric services.

Unit cost information for these services was obtained on request from a HSE Senior Economist, who provided average costs based on the National Casemix Ready Reckoner 2012 relating to 2010 costs and activity. The costs were totalled for each person and their mean monthly costs calculated as shown in Table 4.9. However these costs can be skewed by one or two people having a longer episode of care as appears to be the case for individuals who moved from congregated settings. Acute hospital costs would have been incurred irrespective of a person's place of abode.

Table 4.8: The percentage of participants using hospital services in the previous six months (at Time 1 and Time 3) in the five accommodation groupings

Hospital Services	Personalised T1 and T3		Congregated T1 and T3		Family T1 and T3		Congregated to Personal		Congregated to Group	
	T1	**T3**	**T1**	**T3**	**T1**	**T3**	**T1**	**T3**	**T1**	**T3**
General medical ward	7.5	5.0	9.5	2.4	5.0	5.0	4.3	17.4	11.4	20.0
Outpatient visit	5.0	15.0	16.7	7.1	5.0	15.0	0	8.7	2.9	11.4
A and E	5.0	12.5	7.1	2.4	0	0	0	8.7	8.6	14.3
Day hospital	7.5	5.0	4.8	2.4	0	0	0	8.7	5.7	0
Inpatient psychiatric ward	2.5	2.5	7.1	0	15.0	0	4.3	0	2.9	2.9
Psychiatric outpatient	2.5	5.0	2.4	0	0	0	0	4.3	0	0
Psychiatric rehabilitation unit	0	0	2.4	0	0	0	0	4.3	2.9	0

Table 4.9: The median, minimum and maximum of monthly costs of using hospital services each month at Time 1 and Time 3 for people in the five accommodation groupings.

Hospital service costs	Personalised T1 and T3		Congregated T1 and T3		Family T1 and T3		Congregated to Personal		Congregated to Group	
	T1	**T3**	**T1**	**T3**	**T1**	**T3**	**T1**	**T3**	**T1**	**T3**
Median	€52	€33	€38	€8	€0	€5	€0	€73	€60	€815
Minimum	0	0	0	0	0	0	0	0	0	0
Maximum	€373	€575	€87	€89	€0	€65	€0	€884	€134	€16972

4.7.5 Social Security Benefits Received

At each time point, participants were asked about social welfare benefits they received each week. They were presented with a range of potential social welfare benefits and asked if they received income from these sources. The percentages of people reported to be in receipt of each type of benefit are shown in Table 4.10 for the five groupings.

People in personalised arrangements were more likely to be in receipt of social security benefits. By contrast people in congregated settings and even those who moved to a group home did not receive benefits to the same extent. The information about people living with family carers is most likely incomplete as this was not known by our respondents.

The Unit costs of these benefits were obtained from publically available information on the Department for Social Protection website (www.welfare.ie) and computed on a monthly basis. However the unit costs of rent supplement vary by geographical location and are also dependant on whether an individual lives alone or with others. For each participant in receipt of rent supplement, unit costs were based on the maximum monthly rent limit for their respective county of residence and their living arrangements. These rates are available from www.citizensinformation.ie.

Table 4.10: Percentage of participants in receipt of benefits (at Time 1 and Time 3) in the five accommodation groupings

Benefit	Personalised T1 and T3		Congregated T1 and T3		Family T1 and T3		Congregated to Personal		Congregated to Group	
	T1	**T3**	**T1**	**T3**	**T1**	**T3**	**T1**	**T3**	**T1**	**T3**
Disability allowance	72.5	90.0	83.3	59.5	65.0	90.0	60.9	78.3	74.3	82.9
Rent supplement	30.0	57.5	0	0	0	0	8.7	26.1	0	8.6
Living alone allowance	10.0	25.0	0	0	0	0	0	21.7	0	0
Household benefits package	17.5	55.0	0	0	0	0	4.3	34.8	0	8.6
Fuel allowance	2.0	30.0	0	0	0	0	4.3	21.7	0	5.7
Training allowance workshop	5.0	7.5	7.1	2.4	0	0	17.4	8.7	0	5.7
Disability benefit	0	0	2.4	0	0	0	0	0	0	0
State pension	0	0	0	2.4	0	0	0	4.3	0	2.9
Job seekers A	5.0	0	0	0	0	0	0	0	0	0
Job seekers B	0	0	0	0	0	0	0	0	0	0
Mobility allowance	0	0	0	4.8	0	0	0	4.3	0	0

The monthly amounts in Euro of the benefits received are shown in Table 4.11. These tend to be around 30% higher for people in personalised arrangements and lowest for people in congregated, group home and family settings.

Table 4.11: The median, minimum and maximum of benefits received each month at Time 1 and Time 3 for people in the five accommodation groupings.

Benefit	Personalised T1 and T3		Congregated T1 and T3		Family T1 and T3		Congregated to Personal		Congregated to Group	
	T1	**T3**	**T1**	**T3**	**T1**	**T3**	**T1**	**T3**	**T1**	**T3**
Median	€984	€1096	€786	€776	€662	€812	€664	€975	€756	€802
Minimum	0	0	0	0	0	€815	0	0	0	0
Maximum	€1629	€1502	€815	€1153	€815	€815	€1184	€1968	€815	€1194

NB A minimum cost includes people who were reported to receive no benefits.

4.7.6 Individualised budgets

One of the projects within the evaluation was funded as a pilot in which four people became responsible for managing their own budget for support staff; known usually as personal assistants. (In all other projects, the costs of support staff and their employment were managed by the services from their block grant funding.) This project was an opportunity to assess the procedures for arranging personalised budgets and their out-workings over time. The experiences were broadly positive although initially recipients were somewhat daunted by the responsibilities they had to shoulder.

> The added value of Direct Payments is amazing, the personal assistants are more supportive to me, loyal as an employer instead of to a service. My payment empowers me, strengthens me as an individual. I'm developing skills in budgeting and rostering; skills that are transferable to the workplace. (Person Supported).

> A very important thing to say is that Direct Payments are not for everyone. I wouldn't want to push it on anyone as it's a **** load of work ... I spent all last night and last week doing P60s for tax returns (of my Personal Assistants). (Person Supported).

However, the learning gained through these initiatives allied to that emerging from experiences in other countries, should help to guide further developments in Irish services towards the creation of personal budgets in line with the Government's intentions. Notably this particular project identified four pillars to the success of this approach. Finance (the Direct Payment), Human Resources (including having circles of support and organisation backing for advice and guidance), training in managing the Direct Payment and in Advocacy. The respondents in this project highlighted two other issues to be addressed:

Under the Health Act the HSE cannot fund individuals but they can fund organisations. There is no way round this – it requires a change of law. (Person Supported).

If we were going down the road of Direct Payments they would have to streamline it, and streamline it quite significantly. When you get your disability allowance you don't have to account for every cent of it. In the same manner, why do we have to fill out 50 forms to account for the money we get for our Personal Assistants to account for something we need anyway? The HSE is afraid that I'll go off and do something stupid with the money. (Person Supported).

5. Qualitative findings from interviews

5.1 Personal stories

The goal of all the participating projects was to provide more personalised support and accommodation to the people they support. Thus their success is not to be judged solely in terms of selected indicators and measuring scales. Rather each person has a unique story to tell, not only about the outcomes for them, but also their experiences of the process as they prepared to move and when they made the move.

Limitations of space meant that we had to be selective in reporting on the stories both in terms of their number and content. Our selection aims to convey the variation in experiences as people moved to different types of accommodation options – or not as happened for some - but also to demonstrate the commonality among people's experiences and outcomes. To that end we have selected ten stories of people labelled as having intellectual disabilities, mental health difficulties and physical disabilities. They are presented in this order. We have drawn the stories from different projects across the country. In keeping with our assurances of anonymity, all names used are pseudonyms and we have changed other possible identifying features. The codes after each quotation indicates those that came from the person supported (PS), their key-worker (KW) or a relative (R).

5.2 People with an Intellectual Disability

5.2.1 Margaret's story

Margaret is a 50 year old Irish woman, who moved from a group home which she shared with four others to an apartment in the community where she lived on her own. In the group home she did not engage in any domestic activities and had little participation in community activities. She had no access to her own money.

Margaret had attended ordinary school and following her move she worked in a supported employment scheme two days a week. She had also joined a semi-retirement group with whom she participated in leisure activities.

She described her new apartment as a place where she had freedom and more independence,

> Give me key to the door. You know the front door to (…) I decided to move and I want to be on (my) own. You have the freedom to go 'n all. I like to go shopping and things different, you know. I'm more independent. (PS)

She said she could make decisions by herself and enjoyed the peace in her new apartment,

> If you're in (the group home) you have notices around you 'n all. They don't have to tell me or anything to go to bed; I can go to bed (my) own time, and you don't hear any screaming or anything. (PS)

However, her key worker said that she struggled when she first moved in, asking for permission about different things,

> She has not fully moved in and she's found that tricky and because obviously the rules are different she'd have to ask permission. She struggled with me in her first couple of nights in the apartment. She'd ring and say: do I need to go to bed now? Or is it okay if I cook my dinner? (KW)

Margaret had learned how to use the washing machine and did her washing and ironing, which she had been trained for during her transition to independent living,

> They did (laughing) yeah you know like doing your own washing 'n all. Things like that, your ironing in all you know. Yeah I've learned how to use the machine in all, yeah. (PS)

Margaret's key worker said that after she moved, she was in charge of her own life,

> She's in charge of a lot of things in her life. She's in charge of her medication now which she wouldn't have any... it would have been handed to her (…). Now she goes to the pharmacy and gets the drugs herself. She gets her prescription from the GP (General Practitioner) herself, she attends the GP by herself. And like appointments, she turns up herself. She would be doing her shopping herself which you know and having a choice on to what she eats, when she eats, how she eats. So basically doing her household bits and bobs. (KW)

Her key worker said that the support she provided to Margaret was much more individualised and at the time the study was conducted mainly consisted of helping her with her psychiatric appointments.

> Generally we will visit people once or two times a week for about an hour… and you know assist them with their daily bills not paying the bills but teaching them to go down to the post office to help or to decipher helping to fill out forms, I mean anything else that comes up. It's kind of mixed bag. So it varies from person to person. With Margaret, it will be kind of helping her sometimes with her psychiatric appointments or medical appointments ...and you know basic support of moving her from the (…) service into our service. (KW)

From Margaret's perspective, her support worker was someone that looked after her and made sure everything was alright.

> Very good she comes when (…) she comes to you when (...) when she can 'n all. (…) She looks... she looks after you 'n all. Makes sure everything is alright 'n all. (PS)

Margaret said that she got used to being on her own, although she had missed the company of other residents,

> At first I use to say oh! I miss the company you know and then I got used to it now, you know. (PS)

However, Margaret liked where she lived,

> I like living here and I like the (…) the neighbours. (PS)

5.2.2 Anna's story

Anna is a 54 year old Irish woman who moved from a congregated setting to a shared apartment. She had attended ordinary school and was single with no children. She had lived in a residential institution for approximately 36 years. As a teenager, she was first in an institution run by a religious order of nuns, from where she was transferred to a residential institution for people with disabilities.

Anna had previous work experience in the congregated setting through the workshop and voluntary work she did at a hospital. She was approached by her key worker about moving out to the community,

> (The key worker asked me) 'Would you like to go out to the community?' and I said 'I might and I mightn't, it depends'. And he said 'you're young' and he said 'would you like to give it a go?' and I said 'give me a little bit of time and I'll think about it'. (PS)

She felt that the role of staff would be critical for her to manage in the community and that their help would ease her transition,

> I wouldn't be able to manage it but then when I heard about the staff coming down and doing the cooking and helping us with the shopping and going to pay the bills (…) that kind of eased my mind a bit. (PS)

She had previously shared an apartment with a flatmate that staff had found for her. Problems developed between them, giving Anna enough reason to return to the residential institution. Her first experience moving to an apartment was also marked by the rush to move out. When moving from the institution for the second time, Anna had identified that she wanted her apartment to be near her work place, *I like the places nearer (…) is for me for work* (PS). Her second move, in contrast to the first one, was a paced transition supported by Anna's staff,

> Oh I said (keyworker's name) that's grand and I said I think I'll go down with you one of the days and see. Went down I looked all around, I looked in the bedroom...I looked all around and I thought it was nice you know I said to (my) self 'it's nice'. But when it was done up it was more nicer because the staff

> down there are after coming down and clean it and paint it. And there's a few more bits to be done but you can move into a house, you don't wait for things to be done. (…) And then I used to go from the service down to it in the evening bring (my) friends down too. 'Come on we go down to the house now we'll have a cup of tea or whatever' and (…) going down and coming up, and going down and coming up and going down and coming up because that was the only way (…) I'm getting used to it. And if I just say 'I'll go down today', and not bother going down another day. (PS)

It took a while for Anna to settle in the new place but she soon got in charge of the house, cleaning it and keeping it tidy,

> It's just that when I come in I find it a bit strange at the moment to get (myself) two to three months till I rightly settled you know. (PS)
>
> I get up in the morning and get my own breakfast (…) and then I do a bit of washing. I've done a bit there today and then I tidy up the house, make sure everything's clean and tidy. I don't feel the time going on when I'm here in the house anyway. (PS)

In her new apartment, different staff supported her and they had a communication system that seemed to work for Anna,

> Yeah, well different staff come down, you write them in the folder and if you're stuck they put a phone number. If you need help or anything, something bad, God forbid, you'd have to ring them. (…) We put in today and what we do the next day and the next day. We put them into that folder, (friend) has a folder as well. (PS)

According to her key worker, Anna still needed to develop her social relationships in the new community where she lived. Once her parents had passed away, she had ceased communicating with her family who lived in another county, leaving Anna with a reduced source of social support. Her key worker also pointed out that more support would be needed around the weekend activities.

> If Anna gets used to doing what she's doing, if we can take an hour of our support during the day and maybe use that on a Saturday evening to go out to the cinema or a show or something. (KW)

Meanwhile, a relationship with her neighbours seemed to have flourished naturally for Anna. As her key worker noted,

> She was out having a cigarette and they came along and they started talking and they said 'Sit on the bench there', they have a little bench, 'Sit on the bench any time' so she kind of started a friendship with her neighbours. (KW)

5.2.3 Leo's story

Leo is an 18 year old man who moved from a residential institution back to his family home, something he had desired for a long time. *I got (to) move home* (PS). His key worker said,

> He has been very unhappy in the service that he was getting and all he wanted to do was to return to his home town and his family. So I think he feels like he's been listened to. (KW)
>
> Services have been helping his mother to maintain him in his family home really. So services have just been trying to get him ready for that move and explaining to him I suppose what is expected of him in his house. What his service is going to look like, because Leo had the idea of he won't have any support in his home whereas he does. So, there was a lot of getting him prepared for that and then services help him actually in his home and help him around his behaviours. (KW)

He had attended a special school and when he moved back home had started looking for work. He was also attending an independent living skills course in preparation for a further move to more independent accommodation which he enjoyed very much,

> Yeah, I have the crack here on the course. I have the crack. (PS)

His move to the family home gave Leo the opportunity to join in several activities, and according to his mother,

> Yeah but you see it's just because he's doing so much now he had never done before. Like he's horsemanship course, (…) he's involved in the GAA club, he's doing scouts, and there's camping trips. And you know when he was away in the residential house he didn't have all of these activities outside. (R)

Leo's mother was satisfied with the intensity of the support he was receiving,

> Yeah, he will be still very vulnerable but like the way we're working it now that he always has either me or one of the staff with him. That's, that's working well. (R)

According to his mother, when the support was not available, Leo found himself bored,

> Last Thursday now there was manual handling day and (Laura) rang to see if it would be OK if the lads were alone and we would work without supports that day now. It was fine with me but Leo was very bored for the day because his routine was broken you know. (R)

Leo's mother also expressed that his support was more age appropriate and allowed him to be involved in the community,

> The other two men would've been older men and this person is just twenty our new lad. So I think he'll be kind of more what Leo needs to get involved in the community and you know like to do the young people's kind of stuff and maybe discos or groups or something you know. (R)

5.2.4 Emma's story

Emma is a 62 year old woman who lived in a residential institution for more than ten years. She had attended a special school when she was younger but had not completed it. Emma was about to start a new job the day after the interview,

> I got a new job. I am supposed to be starting tomorrow. (…) Hanging up the hangers, not here, in the job in the afternoon. 12 or 12.30pm. Somebody will give me a lift down to it. (PS)

Emma was unhappy living in the institution and wanted to live in her own house. At the time the study was conducted, she was preparing to move out into a more individualised setting in the community but this had not happened as yet.

> I want to be in my own house (…) I am not very happy (in the institution). The centre is too old. I want to go into my nice house. It's nearly finished anyway. (PS)

Emma's key worker fully supported the idea of her living independently,

> There will be support staff with her all the time and she will have a much better life in this house. Just to reassure her of this. Life will be much better for her I think. (KW)

She was also confident regarding her skills to live independently,

> I do the washing up and drying up and setting the table (…) and I am able to shower myself. (PS)

According to her key worker, there were three of the residents that would be moved to the same house,

> It's a community house. I think there is three of them going there. So obviously it will be much more individualised and much nicer set up than in an institution I suppose. (KW)

However, Emma had not seen the house where she was going to live yet,

> No (I have not seen it) not yet. I have to go down to see it. What day are you bringing me? (PS)

To which Emma's key worker responded, "*I don't know yet Emma. When we know the date we will go down" (KW).*

Her key worker said that, in the institution, she got things done for her even if she was well able to do them herself.

> (…) I shouldn't be saying that but it's kind of political (…) it is totally ridiculous to hurry up things in the mornings and kind of dress her. She is well able to do it herself (…) all those things have been taken from her independence. (KW)

The key worker pointed out that it was a result of being institutionalised and being treated as a group rather than individuals,

> (…) so many of them have been in institutionalised settings for most of their lives. It's not a good enough setting for them. As individuals they are treated like a group and it is not ideal by any means. (KW)

Emma's support worker thought that people with disabilities deserved and should have as good a life as anyone else and that the key workers' role consisted of being advocates for them. He also mentioned the support he provided to her with her personal appearance,

> I kind of make sure she is wearing nice, appropriate clothing because she tends to wear jumpers morning, noon and night and it would be very inappropriate. If you put out nice clothing for her she is happy. Obviously that is our role. I think she is happy then, once she has very personalised support. (KW)

Emma had contact with her family twice a week, when her father called the residential institution and talked to the nurse. Emma's father knew that the move to the community was something very important to her. However, he did not know how he could have been more involved with Emma's move.

> Well, I talk to Emma. When she is back I ring her on Thursday and Sunday evenings and I would be talking to the nurse that would be on with Emma because they bring her to the phone. So I would be in contact twice a week. (R)

Emma's key worker was also hopeful that the move for Emma would make her brothers more likely to visit her in her own house,

> She has two very good brothers. I mean they live in 'X County', they probably come up for open day and can't really come more often because one is a farmer. When they find the location of the house they might feel more relaxed and kind of come more often like a private house. I think that will be ok. (KW)

At the end of the interview with Emma, she was asked if she wanted to say something else about the move to which Emma responded "*What day will that be?"* (PS). Her key worker responded, "*We don't know yet Emma"* (KW).

5.3 People with Mental Health Problems

5.3.1 Matthew's story

Matthew is an Irish man, aged 58, who had moved to a personalised setting from a residential institution where he had lived for about two years. This was his second attempt to move to the community. He had previously moved to another apartment, but it did not work as there were several problems with the accommodation, such as no heat when he moved in winter time. He was very satisfied with his new move, and said it was the best thing he had done in the last few years, although he felt lonely at times.

> The security, the independence, the privacy, the location (…) the serenity because it is in a lovely location and it is peaceful, okay, there is loneliness but the good thing about it is the privacy and the serenity really. (PS)

He said,

> But I was only capable of doing it because I was strong enough and it was the right time, (…) and I needed to be strong enough physically and mentally; mentally in particular so, (...) it wasn't easy but it is the best decision I have made. (PS)

Matthew compared his new accommodation with the residential institution and said that the main difference was,

> My peace of mind, which was very important and most importantly is I have a greater degree of self-worth…because you lose that, you know, you lose a lot of dignity…in the mental institute. (PS)

For Matthew, there was no need to be behind the walls to be institutionalised, "*you don't need to be in behind the walls (…) to be institutionalised, you can actually become institutionalised in (…) your own home" (PS).* The important thing was that the support to move out was available,

> Someone to coach you (…) gently, not to push you out the door, not to tell you 'listen you are going next week!' cause they did with me that before and, Jesus! I had a very severe…a very adverse reaction to it, within 24 hours and they cancelled**.** Ehm so it has to be gentle, progressive thing, but you need that backing from a qualified medical person of encouragement and coaching. (PS)

In fact, the second move worked really well for Matthew, in terms of the support he received from the staff,

> It was a concerted united effort, they weren't dictatorial…it was all inclusive so we discussed everything …My needs were their priority not their needs. (We were) working together towards my betterment and what suited me best, not what suited them. (PS)

5.3.2 George's Story

George is a 45 year old Irish man who moved from a rehabilitation ward in a hospital to a group home where he lived for approximately two years and then to an apartment he shared with another man. He had attended ordinary school and had passed his leaving certificate. He was single and had no children. He felt the new apartment gave him more freedom to do anything he wanted to do.

> Well, there is more freedom. Like we're always moving towards more freedom here, that's one thing I would say about it. (PS)

Compared to his previous accommodation where,

> Everything was sort of monitored, if you know what I mean, in the (hostel) and the rehab ward. But there's no-one there to keep an eye on us now, that's one thing. (PS)

His key worker supported George's view,

> He can have, you know within his commitments, in terms of his course and maybe clinic appointments, he has freedom to plan out his day. His day is very individualised as respects to being on a ward and following routine, and ward routine so, just a whole change of lifestyle really. And he's adapted well to it. (KW)

He had received support from the community mental health nurses on a daily basis for the six months previous to the interview. The support was provided in a group format if it related to the house, or individually if it concerned George's mental health. At the time of the interview, George was receiving two sessions per week. George said that the key workers had helped him with the move to his new accommodation, however, he was dissatisfied with their support afterwards,

> (name of keyworker) did alright, but I don't know. The other workers didn't. Just reading the rules, what they could do. Just telling the rules don't break them or bend them. I don't want to use the lift now because of insurance purposes. They didn't really help us settle in. (KW)

His key worker stated that the support they had provided consisted mostly of preparation and planning for the move.

> I suppose a lot of planning, a lot of preparation, a lot of discussion, a lot of care plan meetings in preparation for it and then he got offered, he had a short period in the (hostel) which is our intensive training programme here in the grounds. So, he spent a couple of nights there and, obviously the sourcing of accommodation, all that was done with staff assistance here. Sourcing, finding it, financing. Welfare Officers, application forms, everything really to do with moving has all been helped. (KW)

Once he moved, George's support consisted of counselling and keeping contact with him,

> Counselling with him to help him with the adjustment. I suppose just, its ongoing support in terms of his mental health. You know, within his new environment, education support, treatment support. And just helping him keep an eye on his physical health as well. (KW)

George's key worker said that following the move, financial matters became a challenge for George, "*Tight. It's tight, it's much less, yeah"* (KW). Also, the key worker noted the need for George to develop some housing skills, as well as better relationships with the staff,

> I would say ongoing contact anyway with us, the Community Nurses. I would see it, I think, he does still need some input from (a support worker) regards cooking, household rotas that sort of thing. For another while anyway, I think. (KW)

On reflection, the key worker mentioned,

> I think the addition of having the support worker from Genio has been kind of invaluable really. That's all I can say, that's my own view on it. Like, having a support worker to do the kind of practical stuff, go down town, source whether it's a TV, set of towels or bed linen that was a huge piece of work that we didn't have to do. If we didn't have the Support Worker, we'd have been doing that on top of everything else so I would say that's been invaluable. (KW)

5.3.3 Elizabeth's Story

Elizabeth is a 24 year old woman who moved from a mental health institution where she lived with 10 other people for about two years to a low support hostel she shared with three others. Elizabeth had attended an ordinary school and had completed to junior certificate level. She was single and had no children. Her key worker described Elizabeth as a very intelligent and funny person with a great personality. This case has been recorded from the perspective of the key worker as Elizabeth did not want to be interviewed, but she gave permission for her keyworker to be interviewed.

The move had provided Elizabeth with more independence and responsibility, as her new accommodation was not staffed at night. Although the change had been positive from the key worker's perspective, she said that Elizabeth would benefit from living in a more individualised accommodation. When asked whether there was a new accommodation plan for Elizabeth, the key worker responded that her name was on the council list but she thought Elizabeth was not ready for the move and the houses were extraordinarily difficult to find. In her words,

> So, we plan things but putting them into practice is very hard. (KW)

According to the key worker, one of the reasons for the delay in moving was Elizabeth's own reluctance to move out,

> There were days when Elizabeth said 'I don't even want to be doing this'. (KW)

The key worker had supported Elizabeth by giving her information, helping her complete forms which she said Elizabeth found very hard. She also went with Elizabeth to places such as letting agencies or the council because Elizabeth would not go on her own. The key worker's perception was that her support had benefitted Elizabeth. She had leant about the steps to move out and had examples about how to do things. She said that key workers needed patience and perseverance in their role.

> She found hard everything, hard going into council (…) hard filling out the forms (…) hard (…) the idea of not being in the service. In her head, the idea of living in a flat is scary. (KW)

Her support needs, according to the key worker, were around communicating with people and she said that Elizabeth needed support to discuss things and not being told what to do. When she was on the housing list, she would need someone to look at places and make phone calls. The key worker said that she would not be able to provide that support because the service was busy and she had her own role that could not leave unattended.

> That was probably my biggest thing, fitting it in, splitting roles. (KW)

The key worker said that both she and Elizabeth had to adjust to the key worker's new role, instead of having a nursing role. They had to stop talking about medication and mental health and talk instead about moving houses. Although the key worker said she would not keep the key worker role on a permanent basis, she valued very positively her experience,

> It changed my attitude towards everyone I was working with (…). It changed my perspective, it gives a lot of ideas about recovery. You learn to pay attention to what people are saying rather than you thinking you know what's best. You learn how to be more supportive and collaborative with people about their future, because it is their future. (KW)

The key worker mentioned that the one-to-one approach with Elizabeth had been difficult for her as she would had to deal with episodes such as Elizabeth shouting at her in public places and dealing with other people's very negative attitudes towards people with mental health problems. On an overall evaluation of her involvement in the process, she said moving out to a different place has to be people's own choice,

> One thing that really needs to change is that we nominated people. And you really have to ask whether you want to do it. (KW)

The key worker thought that while her immediate boss was behind the project, upper management did not have a full understanding of the project and were not as supportive.

5.3.4 Michael's Story

Michael is a 62 year old Irish man who lived in a community hospital for about seven years, according to him, with,

> Approximately 16 people living here, known as the residents. (…) And there are nurses and there are cooks acting as support capacity during the day. At night we have one nurse and one multi-tasker (sic) who does the cleaning and so on. (PS)

He had been previously married and then divorced and had attended higher education. He would have liked to live on his own and have his own space but there were aspects of the institution that comforted him. While he said living in the community hospital could produce depression or alienation, he liked the medical control over his mental health and medication.

> Well, I like the security of it. And it's a place where we can experience uh, you know, depression or alienation? We can be in danger of being sent to hospital, because, you know, they are keeping a close eye on me. And if I deviate one way or the other, either up or down, they will ring the doc(tor) and get a few extra medications, included in my cocktail. I know that sounds a bit draconian but the point I am making is if I was living by myself I could go for weeks without changing my medication and that could be trouble. (PS)

His key worker also pointed at the levels of autonomy regarding the medication management as a key to people living independently,

> Michael really hasn't progressed to level two yet where we can trust that he would take the tablet on a daily basis (…), but really it revolves around that mainly. (KW)

Michael stated that medication was the reason why nothing had been put in place to help him move to a more independent accommodation,

> Because the conventional wisdom as I understand it is I'm not ready to move in to a new place, because I'm not self-medicated. (PS)

Further, he expressed his doubts about moving,

> Moving to my new place? (…) And I'm not even sure if it would be a good idea because I would be more isolated then, living in my own place. I think that there is something to be said for all of its limitations, for community living. Interacting living, you know, supported living. That's what I have to say about that. (PS)

Michael's relative, nevertheless, thought it was a good idea for him to move out to his own place,

> A lovely house, you know, in an apartment, with their own living room, toilet and their own bedroom; which is lovely for them especially when they have been in long-term care for a while. (R)

Michael disliked different aspects of the institution, for example, as his relative said,

He sometimes would not eat the food in the institution for no particular reason other than it is institutional food. (R)

Michael was conscious about the lack of choice people in the institution had,

> The people that live here aren't here by choice, including myself. (…) It's not an intentional community, it's a community of people who would possibly rather be somewhere else but they don't have the choice because there isn't anywhere to go. (PS)

He said that they had monthly meetings but that so far nothing had been discussed at the meetings. He added,

> Well it's boring at night …I'd like some kind of organized night activity, games, stuff like that. I would also like more outings. (PS)

Michael valued the staff of the community hospital and said they provided a cheerful and comfortable environment,

> They liaise with the residents on a cheerful basis. I said earlier on that they sometimes withdraw into their own company, but I suppose they need that too, (yeah) to cope with a place like this. So they have to offer each other support as well as offer us support and by us I mean the residents. (PS)

Michael's key worker noted that an apartment near the community hospital would be suited to his needs,

> So really an apartment that's near here where he can get all the support and where if necessary, as I said he does has a problem with mood swings, we will still offer him a respite bed, so while we would like to see him have a home, or a flat outside, we would also understand that he will need to go back every so often. (KW)

The key worker believed that Michael had not really accepted his mental health problems and that was preventing him from doing activities with other residents,

> He doesn't like to be involved in group things that the 'X Service' or 'other service' would provide because he doesn't like to be with other patients, he is just that type because he doesn't like the association and because he really hasn't accepted his illness. (KW)

However, Michael had started a magazine and an art programme in the community which was really successful. Furthermore, Michael regularly attended conferences about mental health where he gave eloquent speeches according to his relative. His key worker said,

> He initiated the magazine and did a lot of work with it initially and he also initiated (name given) that provides a stage for people who are artistic and they would have a teacher and he really was the person who had the idea about getting it going and he did and is functioning very well and, you know people are delighted with it. He does tend to get involved with anything to do with mental

> health like for example, next Saturday the 2nd there is a conference in 'X Hotel' about mental health and women, I can be wrong but, he now is going down to attend and will bring the magazines down and you know, he'd be very interested in what they say and he travels, he's gone to 'X place' and 'X Place' to these conferences and he would voice his opinion and he would be quite opinionated. (KW)

Michael's contact with his brothers happened every couple of months and for Christmas dinner. All other contact was occasional. He also had contact with one cousin,

> A cousin of ours would meet him in town occasionally for a coffee and that sort of situation for meeting people. That's what he loves – meeting people for a coffee and a smoke. (R)

Michael's relative said that his ideal support worker had to

> …be the boss rather than Michael. Be there to convince him to take his tablets every day and his grub every day. Would also have to be a buddy to him like, yes, a friend too. A guy who is friendly, but at the same time Michael cannot be calling the shots you know? (R)

Michael's relative mentioned that he had had many friends but had lost them over time. Looking to the future, Michael's wished to be involved in further education,

> I want to do a diploma in social studies in 'University' and other things like that. (PS)

For the immediate future Michael will continue to live in the community hospital.

5.4 People with Physical Disability

5.4.1 Lorna's Story

Lorna is an Irish woman who did not want to give her age. She has multiple sclerosis and uses a wheelchair. She used to work, had attended ordinary school and completed her leaving certificate. Lorna moved from a residential setting which she shared with other men and women to a rented flat where she lived independently. In the residential setting, where she lived for 30 years, she felt that the other residents were like her family. At the first interview, Lorna said that the support she had received to move out focused on building her confidence. She did an advocacy course that supported her being the one deciding what she wanted to do.

> I had looked at many houses in the past but they said it was too small or not accessible for disabled people and they suggested me to look at houses in this (town). I said, I don't want to move to (town). I'm very stubborn. (PS)

However, when she saw the place the organisation had found for her she thought it was nice and asked her brother for help painting the apartment. She had also talked

to staff about how she wanted the house to be and asked to make repairs in the apartment including getting rid of one door. The biggest complaint for Lorna about the move was that the process had taken very long, "*It's been taking so long"* (PS). Her sister-in-law also said,

> Lorna's move has been going on for three years. At the beginning it seemed to be very well planned. Then, everything came to stop due to the economic crisis. (R)

Lorna was a bit apprehensive about the move but knew it had to be done. She complained about the everyday rush in the residential setting, which she saw as limiting her ability to do things on her own,

> I don't like being rushed (…) I like to do things myself but they say 'no, you can't do that'. I could make coffee myself, they don't let me. (…) I want things on my way. (PS)

To that she added,

> A good support worker takes care, there is not a right way of doing things, is pleasant, works together. (PS)

Once she moved to her new place, Lorna said she was happy and she made all the decisions,

> The place is working out great. Now the staff work with me one-to-one. I made it my own place. I'm happy. I can decide when I have my meals, and I go shopping for the food. Now I know what is in the fridge now for my dinner. (…) I decide what I want to eat because I'm on a low fat diet. (PS)

Compared to the place where she used to live before, Lorna said,

> Here is better because in the previous accommodation, there were no bells, they had to shout for the nurse to come if she wanted to go to the bathroom. Here you can ring the staff. (PS)

Lorna's key worker said that three support workers supported her for two full days each, but it would be better for Lorna to have her own social network.

The key worker commented on how her role had changed. She thought it was better, less demanding physically, but in all, she felt it was the same job. Regarding the benefits of the one-to-one approach for Lorna,

> Now that I'm doing the one-to-one, from a health point of view, there are many things that may have been overlooked before. She is now thinking about her health now. She takes an interest in the appointments, she wants to know what they are about. (KW)

She also noted that Lorna needed more support from her family.

> She would like more support from the family. I would like to see her family getting more involved. I'd like to see her socialise more. If her condition doesn't

> worsen, she could do very well. She is thinking about holidays… She would like to go to America to see her brother. (KW)

However, Lorna's sister-in-law was concerned about the lack of a plan to make connections in her new community,

> She is going to become dependent on her staff… She doesn't really have any connections with the area. I don't know what kind of plans are in place to do that. We come, we chat… but we are family and there is only so much that family can do. (R)

In all, the support worker thought that the move had really worked for Lorna,

> The last time I talked to you I was very sceptical and I had lots of issues but now I have visited several people that live in the community and they seem to be thriving. (…) They are enjoying their freedom. That's what they have now. (KW)

Her sister-in-law thought the communication about the move had been problematic and she was concerned about Lorna's condition and memory in few years' time.

> I'd had liked to have a more direct communication with the (organisation). They are respecting Lorna's independence but there are some issues that need to be talked through. (R)

She and Lorna would have a discussion after Lorna had looked at an apartment, then Lorna would have meetings with the staff about the apartment to which the family were not party, despite the family having some issues to raise and that decisions were made without them. Lorna's sister-in-law also noted that she wanted to be involved in Lorna's move, but not with her care and she complained about services Lorna did not have anymore,

> We are very happy to be involved without being really involved, so it keeps the relationship more family like rather than caring. The family did not feel affected by the change to individualised support. She had physiotherapy and occupational therapy that now she does not have. (R)

She worried about Lorna's mobility and memory and the organisation's plans to keep up with providing supports as her sister-in-law aged,

> I don't worry about two years' time… I worry in 10 years' time about her mobility, her memory, dementia… What happens when she is no longer suited to independent living? At what stage does she transition back to a communal nursing home? I don't know how (the organisation) deals with older people. (R)

5.4.2 Helen's story

Helen is a 52 year old Irish woman, single and with no children. She didn't like the institutionalised life and moved to an apartment in the community where she lived on her own. She received support from the organisation with her cooking, appointments,

medication, and daily life. According to her key worker, she didn't like institutionalised life because there was too much structure and the new apartment was working

…absolutely brilliant. Her life has improved 2000 per cent since she moved to the apartment. (KW)

Helen's key worker mentioned that she did a lot more for herself, she was more independent, physically and mentally and it had enhanced her quality of life. Helen had privacy, control over her front door and could decide who came in and out, how to arrange the furniture, when she got up and what she was doing that day - all the things that other people take for granted.

Helen's relative, however, said that things had "*slipped back" (R)* or perhaps Helen had lost interest and mentioned issues, such as Helen not knowing what food was in the fridge.

Before moving to the apartment, Helen had sped things up by writing a letter to the CEO of her organisation and obtaining a positive response from the chairman, informing Helen that they had an apartment for her - "*I wrote the letter, even though it took me four hours to write it" (PS).* While Helen loved her new place, she mentioned that she wanted her doorways widened.

Her key worker mentioned that Helen was also using a taxi service that she arranged by herself, attended the health centre, she was in contact with her community intervention team and attended community coffee mornings. One of the activities she had chosen before moving to the apartment was her participation in a local choir. According to her relative, however, that was about the only thing that Helen attended when he was interviewed at the end of this study. He mentioned that there was nothing besides the medical appointments and the Choir that would take her out of the apartment. He said that she was missing "*what makes life fun" (R).* He did mention that budgetary cuts had had a huge impact on Helen's life, first regarding her mobility allowance and secondly, with the lifestyle programme being terminated in the interest of health and safety programmes.

Her key worker also mentioned that she would like to see Helen more involved in the community, widening her horizons, using more natural and non-paid supports, and having more support hours.

Helen praised her key worker who she knew for the last 10 years.

> I think she has been brilliant, for the past 10 years I've known her, except I wish she would learn the computer. (PS)

Her key worker, in turn, described her role as "*an instrument for Helen to live her life the way she wants to" (KW)* and stated how her role had changed completely.

> I was institutionalised and I didn't realise it until I did come out in the community. You are working to a routine. You go in the morning and you know how many people you have to get up, you know how many people you have to give

medication, you know how many showers, how many you have to feed, and it's time, time, time. (KW)

Her key worker said that staff had been initially very worried about their jobs when the idea of independent living came in and consequently they were also worried about the service users. They thought *"Oh my God! How will they manage?" (KW).* She said it was completely different in Helen's apartment as she did not do anything until Helen told her. However, she did mention that it was more stressful as she was the only staff working and had to make decisions on her own. In all, "*I find it brilliant, I'm getting loads, I'm getting great satisfaction and it gives me great happiness to see the world is changing" (KW).*

When Helen was asked what other supports she needed, she responded "*None" (PS).*

5.5 Findings from interviews with relatives

The semi-structured interviews conducted with the relatives at Time 3 included questions relating to their perceptions of the support provided; the benefits it had brought to the person; the benefits it had brought to themselves and possible improvements they would recommend. Using these four headings, the interview transcripts were analysed to identify the main themes within each. These are summarised in Figure 9.1 and sample quotations are provided to illustrate the points listed in the Figure.

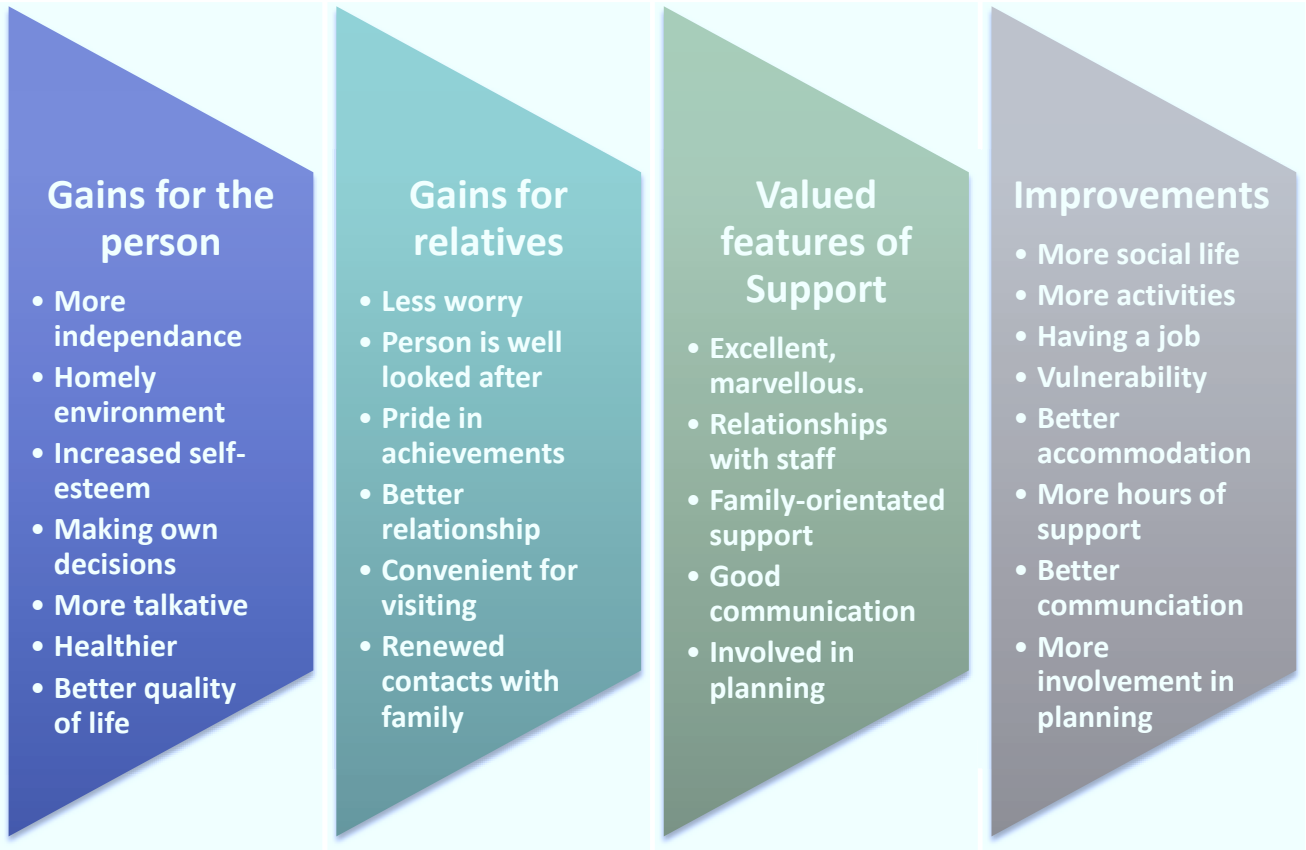

Figure 5.1 The themes in relative's reactions to the supports provided

5.5.1 Gains for the person

I think she has improved a lot since she moved here. Maybe it is because the numbers are not as great as they were in 'the last place'. She is able to do a lot of things for herself – all little things but still it's an improvement. I can see a great change in her since she came here. She would have a better quality of life here. I am not condemning the 'old place' but it was what it was. And this is more suitable for the modern day**.** (Relative)

N is able to take the bus to the centre, go shopping, eat at Eddie Rockets, understand that her money is her own, use the computer to purchase DVDs online, has her own space in the house. (Relative)

They've really brought her out of her shadow quite a lot, regards meeting other people and socialising that type of thing. She was very nervous but I found that her confidence is built up immensely. (Relative)

She's well secure, she's uses the beautiful garden, she's secure outside and she goes out for a few minutes for her fag. Everything is secure and everything about it, I think it's great. I think it's the best thing that's ever happened in her life. (Relative)

She's mixing in the community more and all seem to know her. She has joined theatre, joined bowls but still doesn't want to miss her soaps if things clash. (Relative)

The two boys love it here you know. It's so central... the town is just across that bridge. It's only a couple of hundred yards away. But yet you wouldn't think you're so close to town do you know like, and it's very well kept. There is a committee and there is a care-taker and I mean you'd never even see a sweet paper outside. (Relative)

It's more of his own choice now, because when he was there, he had to do what was asked for each day and what staff could do, but now if he doesn't want to do something he can say he doesn't want to do it and you know he has his own two staff. (Relative)

5.5.2 Gains for relatives

It's terrific for families. As a married couple we have more freedom; our quality of life is much improved. (Relative)

I can go to bed at night and sleep – such a load off my shoulders. I'm a worrier but now he's in a more homely place; not saying the other place was bad but this is better. (Relative)

Well the family can go and visit her when they like. There is no restrictions on the visitation because her sisters come down when they want to see her and there is no problem. It keeps the connection together. (Relative)

I couldn't speak highly enough of X service. What N has got has made a huge difference to her and to us and I would say that even though I kind of work in the area of disability myself, so I have a good idea. (Relative)

She is proud of herself. She had the family to dinner and had to clean up the house and set the table and all. The in-laws came too as they wanted to surprise her. (Relative)

5.5.3 Valued Features of Support

The staff treat him as a human being - not just a number. Now he's talking he is able to communicate with them and people will communicate with him. He was withdrawn but that has lifted. He used to be aggressive with all but not now. (Relative)

I've benefitted because I'll tell you why. I benefit because my mind is at rest and at peace and I know that N's given the best possible attention and looked after. Not just because it is a job but they'd look after her with kindness and they'd see her as they should be seeing her and respect her like a human being. (Relative)

We can come in and are welcomed at any time and they can drop in to us (at our house). His health is discussed at length ... they are very observant and looking after his diet very well; trying to keep down his weight. (Relative)

We talk and have tea with the staff. In the institution you waited in the waiting room when you came to collect him and then drop him off but now we engage with the staff. It's a huge difference. (Relative)

5.6 Improvements

Most of the relatives were also able to name ways in which they felt the lives of the person could be improved still further. Indeed, they generally mentioned more aspects for improvements than did the people themselves or the key-workers. Many of their comments related to the person having a better social life and more activities to do outside of the house, including getting a job. A selection of comments included:

She would love to have a boyfriend but her social life doesn't bring her into contact with many males. (Relative)

The other two (support) workers would be older men, you know and they do certain activities with him but they wouldn't. I'm sure he wouldn't like to go to the disco with one of them. You know what I mean. (Relative)

The apartment is very small for even one person. If he got a little house now even a two bedroom house or whatever or a little house for himself I think he'd be grand. I know they say it's up to how long you're on the housing list but, I thought they might have been able to help him that way. (Relative)

I would prefer a male supervisor. N would not give him as much grief as he would to a female. The nurses below would say that and even his ex-wife said that like, especially a fella who might be of a larger stature, so if there was to be a person visiting N, a fella would probably be better. He would also have to be a buddy to him like - a friend too. A guy who is friendly but at the same time N cannot be calling the shots you know? (Relative)

There is very little in the way of consultation with parents ... such as developing person-centred plans which, to me a person-centre plan it's not something that is done to a person, you know, it should be more it should be more about, somebody saying to N what is it that you want, who do you want involved in helping you to make these things happen. Individual funding I think that's definitely one way. I have some concerns about it as well, but I think is one way of giving the ability, the choice, back to the people who need the service rather than an agency making decisions on behalf of somebody else. (Relative)

When we heard that the service she was getting were going to be lost, that caused great upset for her but thankfully that is now changed 'til September. (Relative)

There were issues of support staff leaving early from their shift and you need to keep a watching brief on this. They had to introduce a clocking out system. (Relative)

5.7 Reactions of relatives prior to moving

Within the sample of relatives who were interviewed, were those with people still living in congregated settings. They tended to voice concerns about the impending move in the following terms:

- The security of the person within the community given their vulnerability.
- The level of support available to the person in the community.
- The person having enough activities to keep them occupied.
- What happens if it doesn't work out?
- The amount of information and say that relatives have in any move.

There's a lot more staff here (in congregated settings) It's a safe environment with 200 staff – there's better support for N.

N needs constant supervision and stimulation to stay active and get up and get washed and clean and fed. Living independently in the community would not be good for him he's too vulnerable. He likes to go on buses and would go with anyone anywhere. I would be very worried if he had too much freedom.

I wouldn't mind so much if there was housemother with them but they will be living without such support.

> If she moves it could give her a new lease of life involved in the community and new friends. But it would be devastating for her if it all went wrong – she'd be back in the institution.
>
> We have no say in where N will live.

However another relative spoke of the need for families to make themselves better informed.

> I remember when the move first came up, families being very resistant. Staff were worried and they were motivating the residents to say no to the move. Relatives should not rely on staff members to tell you what is happening or to tell you what your relative wants. Go and find out for yourself.

5.8 Findings from interviews with staff

The responses given by staff in the interviews were analysed by themes under three main headings: 1) the changes they had experienced in the role and nature of their work, 2) the personal benefits they had gained and 3) aspects of the job that were not so good for them. The overall impression was that staff who were interviewed were enthusiastic about their new roles using words such as *'brilliant; great; love it'*. Quotations are used to illustrate these themes.

5.8.1 Changes in role and nature of the work

The core change that staff reported was a shift away from managing groups of people towards a focus on individuals. Associated with this was an emphasis on supporting people to doing things for themselves rather than being cared for and a change of mind-set about their capacity to learn.

> The key-worker has opened my eyes to the types of people who were institutionalised: they have a lot more potential than recognised. Key-working has changed my approach – to expect more from them. They are capable of a lot more than I had realised. (Key Worker)
>
> I'm coaching him to do a lot more things for himself. I set them up but then step back giving him responsibility for himself rather than me doing things for him. (Key Worker)

They spoke too of how their work was more centred around relationships, as one worker said: *"it's all about listening to people".*

> You learn to pay a lot more attention to what people say they want, as opposed to thinking you know best, being a bit dogmatic at times, you learn to be supportive without being directive and be more collaborative with people about their future, because it is their future. (Key Worker)

They mentioned having more time to spend with people on a one-to-one basis that was not possible before. Others spoke of the trusted relationship that had grown up

with the person and how their relationships were more like those of a family than of the workplace.

> The support she needed initially was very hands-on now it's moved on to regular day-to-day life. Your relationship changes as you get to know the person. She can be very private, she is very anxious about people knowing about her mental health status. Now she is more comfortable with me, she will say "I hear voices" so it is easier to access the support she needs. (Key Worker)

> I was in a nursing role before so this is more relaxed. Less like work and more like a family – they become like a family to you. (Key Worker)

However as support workers, they also needed to challenge the people they supported.

> My role has changed completely and it's been brilliant as well. Learning to stand back and watch and see what people's capabilities are, and going with them, not pushing them too much, working with them rather than making them do things. Taking chances, small chances to see what they are capable of. (Key Worker)

The theme of relationships also extended to partnerships among staff working together as a team and with the families of the people they supported; in some instances helping to re-instate connections with the family.

> Now I do deeper work with the mother. There's been a lot of emotion and it has taken time to build up rapport but this lets you in further. (Key Worker)

> Being involved with families is great – the family look to you for ideas which is nice and vice versa. It gives family a sense that the new ideas are theirs. (Key Worker)

The wider range of responsibilities placed on staff was another theme to emerge, but this was stated more as a gain rather than a complaint, as was their increased links with the community

> It's a lot more responsibility than was on the nursing side – getting involved in community now and also running the household, food, meals, health and planning the day. It's like a family responsibility. (Key Worker)

> I love my job because we moved much more from care point of view to social model – looking for connections between N and the community. Looking for skills; discovering her skills and abilities. It's more about finding resources and matching them with N's skills. (Key Worker)

> The move itself - that's what the focus was on initially - and now it's more into relationships and work and pastimes and those kind of things. (Key Worker)

Staff also spoke about having more autonomy to make decisions and that their confidence had grown to try out new things.

> I feel like a support worker and less as a care staff as before. I'm a lot more confident in my job – writing support plans – and we do the medication. (Key Worker)

They also spoke of the need to be flexible, inventive and creative which was often in contrast to how they were expected to work in congregated settings.

> My way of working has totally changed. In the residential settings you had all these rules and regulations. Now you have the freedom to make things happen. (Key Worker)

Mention was also made of being an advocate for the person when they are unable or unwilling to speak up for themselves.

> Families need to learn to accept the person's choices and ideas and lose the attitude that N is a child. They need to see N's abilities. (Key Worker)

> For me I have gained an awful lot of confidence. I'd ring anybody at this stage, I've no shame left. Particularly when it comes to things like landlords; negotiating, being the advocate. I would not have done that this time last year. I wouldn't have had the panazz to do it. I probably have developed a bit of a thicker skin so that is always good. (Key Worker)

In sum, the insights that staff had experienced in their new roles or when working in personalised arrangements, authenticate the attributes of person-centred working that has been reported previously. They stand in marked contrast to the traditional roles which nurses or care assistants have generally fulfilled in congregated settings notwithstanding aspirations towards person-centeredness.

5.8.2 The benefits to staff

Staff named a variety of personal benefits that the new working arrangements had brought to them. Not surprisingly, these varied across individuals according to what was important to them. Hence some staff focussed on the practical gains such as less physically demanding work, fewer people to deal with, having a homely and pleasant working environment and flexible working hours.

> It's a nicer environment – very comfortable and homely. It's nice going up there to work. (Key Worker)

> There's more flexibility in my working hours which suits my lifestyle. (Key Worker)

Many spoke of how rewarding and satisfying they found the work, particularly seeing people change and develop. They appreciated the relationships they had built with the people they supported and the happiness they had experienced.

> I love empowering people and want to give them a good quality of life. I want people to give people the good opportunities I have had. (Key Worker)

> Good job satisfaction and you get a real buzz out of making things happen for people, providing the simple things, the simple things they never had before. (Key Worker)

Others alluded to the changes in themselves such as becoming more patient.

> I'm not institutionalised anymore and I didn't realise I was. It gives me great satisfaction to see N taking control, taking back her life. (Key Worker)

> You cannot be judgemental – you have to look at things from all points of view. (Key Worker)

> I can identify things in them that I see in myself. Helped me to feel better about myself. (Key Worker).

Staff spoke of the new insights it had given them about people and the work.

> Getting to know people differently gives you new insights into their needs. (Key Worker)

> I'm not so worried now about supports that could be available for my relative who has Asperger's Syndrome. (Key Worker)

> People with intellectual disability are seen as valued members of the community. (Key Worker)

> Being a key-worker is a valued role. (Key Worker)

They also valued working as part of a team and the new types of working relationships they had with colleagues.

> We discuss as a group which lets us debate and reflect on issues. (Key Worker)

> New people came on board with new ideas. The things one of the key-workers did are things I wouldn't have done, so you can learn from that. It's always good to have ideas. (Key Worker)

Those working in mental health services especially noted that the work was now less intense.

> Probably the work is less intense because his mental health is better he has needed less support, And he has been able to do a lot more things for himself; things we would have had to do for him or with him in the past. (Key Worker)

The opportunity to gain new knowledge and skills was also appreciated by staff as had happened through the training they had received. This enabled them to become more confident in their work to the extent that one person talked of feeling *"liberated".*

> It's freer, more liberating. There is much more capacity to use my own skill base, to draw from the different studies I have done in the past. I like the fact that it is a creative process: 'me asking myself what do I do in response to that person is asking, directly or indirectly? (Key Worker)

On the whole, staff could easily name a range of gains they had derived from their work which no doubt contributed to their keenness to support the individuals with whom they worked.

5.8.3 Improvements to their work

Staff interviewed also recognised various ways in which their work could be better, although more respondents could not think of any improvements. One word more than any other recurred – “frustration”. This centred around their aspirations and actions being thwarted by factors over which they had limited control. Rarely was it attributed to the people they supported, even though they did acknowledge that progress sometimes was slow.

Among the more frequently mentioned responses was a change in the attitudes of other work colleagues especially among those who were still working in congregated settings. Their negativity to change could sap morale.

> Without support you can get burnt out. You need to steer away from the negativity of others and there’s been plenty of that. (Staff Member)

> You are battling against an old clinical model and you can and do meet a lot of resistance to the work you are doing; that can make it more of an uphill task. (Staff Member)

A resistance among some staff to working alongside personnel from other disciplines also featured.

> Some nurses feel threatened by other disciplines becoming involved but I think we can’t be jack of all trades, we need help and we need to be open to that. It’s hard to put all these buzzwords into practice and let people in. (Staff Member)

The attitudes of some managers also posed problems for some respondents, allied to a lack of clarity about future planning,

> Sometimes the goal-posts keep changing and it’s not from higher management it’s from in between. I would be very clear about my role –you’re supporting them, teaching them life skills – but sometimes you get: oh no you can’t do that with her. (Staff Member)

> In the past I would have been a support worker but more so in accommodation settings but, when I look back you know it was more maintenance. I used to say, they’ve only one life and they should have more of a chance to do stuff but, it wasn’t part of the ethos of where I worked. (Staff Member)

The lack of sufficient staff cover was another issue that arose across some service settings, especially with more dependent persons. They valued the opportunity for more one-to-one work in group homes.

> The work is more physically demanding. More staff are needed to cope with our people who have. You’re making more decisions and on your own which can be stressful. (Staff Member)

> The lack of service-led clarity about what's happening next. It's a bit frustrating at times not knowing. You feel you are dependent on other people doing their pieces and they're not really doing them. (Staff Member)

Others noted the importance of good communication among the team and examples were given of using emails, team meetings and communication diaries to keep in touch with one another, yet it remained a problem in some settings.

> Communication from the organisation could be better from Team leader down to rest of staff in the house. (Staff Member)

Staff also spoke of the increased stress they felt in the new arrangements. In part, this arose from the strong relationship they had built with the people they supported and finding it difficult to 'switch off' when they finished their shifts. Others recognised the need to balance their work with their personal life.

> I suppose I worry about her more. When she was in X, there were staff there 24 hours a day if anything went wrong. It's a little bit riskier now. (Staff Member)

Another reason was the responsibility they had for making decisions and being unsure if they would be held accountable if things went wrong.

> You're making more decisions and on your own which can be stressful. (Staff Member)

Lone working also created extra stresses for staff, especially when working in certain neighbourhoods. Having access to telephone backup was important.

> Night duty can be very lonely – I'm fearful of local break-ins as people get to know it is a community house and knowing that you have drugs there. (Staff Member)

Quite a few staff alluded to their working hours being an additional source of stress, reporting how they often worked extra hours or dropped in when they were off-duty.

> Loads of hours of work (unpaid overtime) – I hope it won't continue too long. (Staff Member)

> The split shifts took some getting used to but I've accepted that because I am happy about N living on her own. (Staff Member)

Uncertainty about the funding of certain projects was a source of stress for persons supported as well as for staff.

> Uncertainty of the funding; they get anxious about two months before the projects coming to an end and we're explaining it to them that we don't know (if it will happen). Going back to last November, it was extended to February, but then in January people are getting anxious again and at the last minute we were extended again so, that uncertainty isn't great. (Staff Member)

Staff were also concerned that the resources would not be available to provide the necessary support arrangements for people currently living with families.

> You are working with families and you move them away from the idea that N needs to go to a traditional set up and you talk to them about alternatives, but yet I can't provide the alternatives. Even though I think the best thing for N is not to be in a traditional set up ... if something happened to N's parents in the morning I don't have a plan B and in a worst case scenario, N would end up in a traditional set up because there's not plan B for N at the moment. (Staff Member)

Finally some other features were cited by a few staff, for instance, their increased travel time to work, detailed paperwork required, insufficient training and the work not being challenging enough.

6. Making Change Happen

6.1 Overview

Information was obtained from senior staff in participating services who had been responsible for managing the Genio supported projects or who were the most senior manager in the organisation. The aims were to explore the factors that contributed to successful outcomes and to determine the barriers that prevented the project achieving its goals.

Over 85% of the funded services participated and a rich data set was available for analysis.

The metaphor of an engine was used to illustrate how the change agenda towards the personalisation of services was driven forward – see Figure 6.1. Various inter-locking gears are the main drivers of the engine as perceived by the service leaders. The gears vary in power (as represented by the size of the gear) and each can bring its own momentum to the engine or indeed they may retard or stall the overall efficiency of the engine. Each gear will be described in more detail using quotes from the participants but first some overall observations.

Figure 6.1: Service leaders' perception of the engine driving change

- The model applies to services for the various client groups covered by the projects: particularly people with intellectual disabilities and mental health difficulties.
- It holds across voluntary and HSE agencies irrespective of size.
- The drive for change requires some intermediate steps before full personalisation of services is achieved. For example the closure of an institutional building may first result in people living in group homes and later moving to more individual settings.
- The data presented describe mainly the components of the engine but it needs fuelling, tuning and servicing to perform optimally. These factors are inherent in the sub-themes as illustrated but they also include the underpinning values of services; the discourse of rights of persons with disabilities and government policy as noted in the introduction to this report.

6.2 The Central Driver

The service organisation was seen to be the central driving gear in the engine for change. Perhaps this is not surprising given that the informants were the respondents who had led the change process. However, this echoes international experience of resettlement programmes. Indeed given the way services are currently organised in Ireland, the bulk of the resources and associated power resides almost solely with the service provider and therefore much of the power to change resides here also.

However, this is not to say that some of the movement in the central driver might have originally come from the other surrounding gears shown in the figure; such as clients, staff, relatives or Genio. Nevertheless the dominant impression gained from the respondents is that the process was one they had instigated some years back and they continued to drive through, in face of some formidable obstacles they had encountered from the other 'gears' that were slow to get moving or indeed had put brakes on the process.

Respondents identified a number of subthemes that were essential to an effective organisational driver as shown in Figure 6.1. The salience of each varied across services but together they provide a concise summary of the prerequisites of organisational readiness for change.

Culture shift: A recurring theme was the major culture shift that had occurred in the organisation: usually phrased as a shift from "*dependency to empowerment*"; from *"doing things for people to supporting people to look after themselves"*. This is particularly evident in long-established agencies such as HSE services or major voluntary organisations.

> In our experience, it (personalisation) is not something you can do for one person or a group of people in the midst of a bigger group, it has to be an ethos for everyone. People come away from conferences and say "that's all great but

> how can we do it without changing anything" – you have to change. This is all about change. (Manager)

The issue of managing risk was integral to the change in thinking.

> In mental health, risk management is a huge thing and staff not being supported by middle managers to push the boat out in case something goes wrong. Staff didn't feel supported enough by the management team. I think there has to be a more mature attitude to risk because there's also the risk of a life not lived. (Manager)

In several of the agencies the culture shift had started prior to the Genio grant or the person-centred culture was inherent in newer agencies. This may offer an explanation as to why other comparable Irish agencies did not make a bid for Genio funding nor have they made much progress on a cultural shift (see McConkey et al., 2013).

Policy: Linked with the foregoing, various respondents noted how the organisation had developed an explicit policy that summarised the new vision which committed it to new forms of service delivery. This policy had the approval and backing of the Board and financial advisers where relevant, as often there were financial risks to the organisation that had to be managed.

> The Board made a policy decision in 2006 to stop investing in group homes and to try and individualise our services. Around 80% of the organisation knows and sees it as the right thing to do but others are attached to what they know works and is safe – it's a bit of a challenge! (Manager)

Little mention was made of government policy statements as influencing the process; rather they were seen as confirming the organisational policy.

Leadership: Active leadership was viewed as essential in selling the new policy throughout the service and associated stake-holders. This had to come from the Board, CEO and senior managers. Moreover, they had to be prepared to face down the inevitable challenges to culture and practice.

> One of the things that contributed to the success was the clear message that this is going to happen, this is irreversible, this is really non-negotiable. (Manager)

> Leadership was crucial right from the Board of Directors recognising that we were going in a different direction to the one we had done ... to the managers and also recognising the leadership capacity in individuals right across the organisation, It didn't need to be the CEO making all the decisions, what you wanted was kind of empowering people locally. (Manager)

Team: Respondents spoke of the value of having a core team of persons who were responsible for implementing the policy that was separate from day-to-day operations. This should include finance and HR personnel as well as service

managers who knew well the clients. Delegating authority to the team to make decisions was necessary to keep things moving.

> We put together this group that tried to bring together service management, HR, Finance, indeed all of the kind of organisation supports: to bring all of them together as part of the solution.(Manager)

Co-ordinator: Various services had used Genio funding to appoint a co-ordinator to oversee and manage the process; usually an experienced and enthusiastic member of staff; imbued with the vision for shifting values and practices, and who could build trusted relationships with clients and relatives. They also needed the scope to engage with community organisations.

> The Genio funding allowed us to appoint a project manager for a year, which was critical as that was also the time where the single greatest amount of allocation cut was taking place. So we had difficulties just trying to keep the mother ship afloat, and we hadn't got the management capacity to get involved in moving people. They began, I think around January, February last year, and people were in new arrangements late July, August. So that was critical to have a dedicated manager. (Manager)

Learning: Several respondents noted how they learnt as they went along, adapting their plans to the changing circumstances but also that the process involved much more time and effort than they had anticipated.

> We learnt very quickly that there was much more to it than we ever had anticipated. We had a time frame to do it in a year and we realised after nine months of trying to beat the project into the shape we had envisioned, it wasn't going to happen. The process was uncovering a lot more things than people just moving out. (Manager)

Finally, the centrality of the organisation to the change process did not mean that it had to be foremost in people's lives. Indeed one CEO felt that often organisational procedures and reporting requirements worked against the outcomes the new models of services aimed to achieve for clients.

> We have a role in facilitating, we have a role in enabling, but sometimes our role is to just get out of the way (of people's lives) and not be exercising incorrect and undue influence over decisions or resources or whatever it might be; which is very difficult because you have all the accountabilities still. (Manager)

6.3 Other drivers of change

Four further major drivers of change were noted by the participants as well as four more minor ones. These drivers could act to impede changes as well as facilitate them hence effort was needed to ensure these stake-holders were engaged in the process; that they kept moving in the same direction; and that momentum for change was maintained.

6.3.1 Genio's contribution

Genio was recognised by all participants has having played a significant part in taking forward the process of change within the organisations. Its contribution was seen as three-fold.

Status: For some agencies, Genio brought an extra status to their efforts. The review and selection process followed by Genio in the application process, confirmed that their proposals were of sufficient quality to be worthy of funding and brought a national as well as local interest in their outcomes. Also the organisation's arguments for change would be stronger if supported by an agency such as Genio which has support of the HSE and the Department of Health but yet was independent of them.

> Getting funding from Genio... gave a certain status and that was terribly important. Everybody knew that Genio was receiving funding that was asking you to gently turn the ship around. For that reason to get their approval, meant that you had a hand in that - our real goal is to change how money is used. (Manager)

Moreover, service leaders used their accountability to Genio as a reason for ensuring the targets for their service were met.

> I remember having one argument with one line manager and I said, well look, I feel I personally have to respond to Genio. We still have to keep going, we are taking their money, it is in the bank account. (Manager)

Funding: The additional monies made available to projects by Genio was especially welcome when organisations were experiencing *"the biggest single tranche of cost reduction measures over the past 12 years".* The funding could also be used flexibly and in accord with the needs of the project, thereby enabling posts and roles to be filled that could not have happened without funding; such as project managers or community co-ordinators. This was often done in partnership with another organisation or agency.

> We employed community support workers. It was not possible to employ this staff grade through the HSE and support workers were a critical support needed by individuals moving home. (Manager)

> The role of the co-ordinator (in linking people into communities) is a massive undertaking and cannot be done by professionals, on top of our 35 hours, now 37 hours per week job. As a co-ordinator, I had to put in more than 15 hours every week between sourcing the tutors, making sure that they have the knowledge and the support when they are dealing with the participants. The participants as well need the support especially when they are having their doubts: should I continue with the programme or should I not? (Manager)

Training: The training and awareness sessions which Genio organised for their funded projects – such as Endeavour for Excellence - were seen as especially valuable in changing the attitudes of staff and increasing organisational confidence

that their objectives were attainable. Access to knowledgeable personnel within Genio plus opportunities to form alliances with other agencies were also important contributions.

> We were part of an alliance; a loose alliance of organisations who were all interested in doing this and who were sharing examples with each other of things they had done. It was kind of a learning community and the thing that struck us about Genio, apart from the fact that there was money - which was obviously critical - was also this commitment to harnessing that kind of learning community dimension to it. (Manager)

It is worth noting that an outside contribution such as provided by Genio, is not essential as several agencies in the evaluation had commenced a personalisation process prior to or without Genio's involvement. However, an outside agent may be necessary to get the process of change kick-started in less motivated agencies and it accelerated the process with those who had commenced it.

6.3.2 Staffing

A second major theme that occurred among all respondents was the key influence of support staff involved in the process. The attitudes of most staff working with personnel prior to their move were seen as a brake on the process that had to be removed. This was further compounded by Trade Unions whose priority was to protect the employment conditions of their members rather than the betterment for the service users.

> I can understand the Unions position too. They will see it as their duty to defend our workers in that job description or talk about compensating if maybe we were to move them to a different type of grade or job. They didn't do it in a bitter way; I want to make that clear. (Manager)

Three subthemes captured the main issues to be addressed in staffing the new styles of services.

Mind-set: Many spoke of the change of 'mind-set' that was required from staff who worked with clients prior to their move. The phrase 'letting go' recurred in the sense of people doing more for themselves but also in relinquishing control of the person so that they made the decisions.

> We already had put people out in the community from the late 90's but unfortunately they became little institutions, in that we used a social care model of work and what we started to realise was that the social care workers, for all the right reasons, was making all the decisions. It was a huge mind-set (change) for us. It was like we were telling people that worked with us for 20 and 30 years… that we were doing something wrong. (Manager)

A further theme was shifting the staff focus to an individual's strengths rather than their disabilities or illness and also emphasising the developmental potential of

everyone to acquire new skills. The engagement of clinicians in challenging staff attitudes had proved effective in one project.

> The psychologist was crucial ... basically calling the bluff of staff and saying, that is not right. Now he wouldn't say it like that, and he was very straight and very firm about that. He had a professional authority that the staff really couldn't argue with it. (Manager)

There were instances of staff who seemed unlikely to change, becoming strong advocates for the new arrangements.

> We also needed to recognise the potential in staff, some of whom we had kind of put into boxes and said they are no good on this kind of stuff. We were amazed by some people. Like one of our group homes closed, led by probably the last person in the organisation we would have thought would have been able to do it, with a staff team that we thought could never do this. (Manager)

New roles: A new cadre of staff was appointed to the projects which Genio supported and often they had no previous experience of disability.

> The money allowed us to bring in two outsiders. We got one ex-nurse to keep continuity with the staff but one complete outsider. It was the newer workers who started to forge ahead and really develop the project. (Manager)

Their primary roles were two-fold: to empower people to do more for themselves and to connect them into relationships and communities. New job titles, job descriptions and person specifications were required as well as the provision of new practice frameworks to guide staff and for mentoring their performance.

> We are looking for people who like challenges, people who have demonstrated that they are good at relationships and they know how to make friends. (Manager)

Tellingly, one respondent noted that in personalised services, the support workers were no longer perceived as staff but rather as facilitators, allies and friends.

> We employ three Genio support workers. We took them from outside of our own staff and it just meant we could tailor the job to suit the individuals that were going out, rather than the individuals having to suit the HSE. The other major factor for us was that our clients didn't see these people as staff. They had no previous history with them, there was none of that. We have lots of people that we can throw at people Monday to Friday, nine to five, you know and at five o'clock everything in the community shuts down. The fact that we had Genio (staff), we could actually look at evening time, we could look at the weekends and people saw our Genio support workers as something different, something for them, so they took ownership of them. Once they took ownership of it, they flew with it. (Manager)

Training: New and existing staff required training and support in order to work effectively in these new roles. This could come through on-the-job learning especially from the project co-ordinators or managers.

> The support staff needed somebody who had the skill to sit with the circle of support and with the person to kind of say: "ok where are you at now and what was the vision"; and to do that in a way that knew the difference between gentle coaxing to a little shove. It is a very skilled role and that was the capacity building that we were trying to build up. (Management)

Opportunities to attend training courses such as those organised by Genio were also important in (re-)orientating staff to their role.

6.3.3 Clients

The projects had identified named individuals in their funding bids to Genio although these altered as the projects unfolded mostly because people changed their minds about moving. In varying degrees the persons involved in each project had chosen to participate in it and became part of the engine that could drive change. Three subthemes were mentioned by participants as determining the clients' contribution.

Motivation: As the process unfolded people became more motivated for their move to occur. Likewise, when they visited people who had moved to new accommodation they became more enthusiastic about having their own place.

> The conviction of the person themselves, the real want within the person. If they really wanted it (a move) to happen, it could happen. If it was somebody else's idea or even the family's idea or the staff's idea, and if the person wasn't ready or hadn't actually really voiced it; it wasn't as successful. So it is being at the right time at the right place. (Manager)

> I have three people at the moment that would come to my office twice a week and ask me when are they going to their house. They say, you have shown me the house, you have put in the heating, I have the key in the door, why can't I go. And of course we haven't got the worker to go with him, this is the problem, but I suppose he is driving his own project now. (Manager).

Listening: It was vital that people were listened to in terms of their concerns and wishes. Some participants spoke of the baggage that clients had accumulated over the years in traditional services and how this needed to be lessened.

> We thought our job was to get people their own homes and help them in their homes but in fact the job became helping people to discover who they were and how to make choices and what they actually wanted. (Manager)

Giving individuals' choice and engaging them in decision-making was key – including opting out of moving if that was their wish.

> It was such a huge step for people who have always been in that sort of HSE setting. It is very frightening having to support yourself and to have to pay bills.

> Anyone who is in the HSE housing doesn't necessarily have to pay bills but has to pay for the rent on that, so it is a huge step forward for them. Some were very good and wanted to take that challenge and others thought they did but found that half way through they just weren't able to survive and weren't able to do it, they stepped back. (Manager)

The choice of who they lived with was essential as was the client choosing their support staff.

> When they went out, the person chose their own support, which was the first thing. We actually get support through an agency, so we have identified some people who signed up with an agency, but the people choose their own support, that is the first. But you see there is two things for me. We also had co-ordinators who facilitated people to plan differently with the person so it is the quality of the planning and the result, the outcome of the planning because the support people then are hired if you like, by the person to give them the support to do the things that have been well planned for. So if the plan is good and if the person has ownership over the plan, then the person will be able to tell the support staff how to support them basically. (Manager)

Enabled: The emphasis across all clients groups was on 'enablement'.

> Our project is about developing new opportunities for clients and developing new life pathways. It's not about closure but development and opportunity. (Manager)

People were reported to have made "huge leaps" in what they could do for themselves and in their lifestyle. They may still have health needs and disabilities but they seemed better able to manage them in their new surroundings.

> There is a greater understanding that people with serious and complex mental health problems are functionally able to live, work and participate in mainstream activities. In our residences we deskilled them by putting in paid workers. (Manager)

Nevertheless two major challenges remained: unemployment and living in the community rather than being part of it.

> There's the difficulty with becoming *of* the community and not just living in it. Investment of time, peer working, community living will, over time, alleviate this and as we are now focusing in mental health in maintaining people in their own communities it should be less of an issue in the future. (Manager)

6.3.4 Relatives

Participants tended to speak of relatives as initially being an impediment to the process - sometimes fuelled by the negative attitudes of staff - and of families having to be "won over".

> Some families were unsettled and unnerved by the manner in which staff framed the move. This contaminated the family consultation phase – in some cases the closest we could get to family support and consent was a variation of "you'll have to trust us on this". (Manager)

As one participated stated, families were more concerned with their relative's security rather than the quality of service they received.

> Family members were fearful about the vulnerability of loved ones if they were not living in HSE funded housing. (Manager)

Consultations with relatives could be a time-consuming process over many weeks and months but nonetheless was necessary as the goal was to have their active support in making a success of the move and in some senses of re-integrating the person back into their family circle.

Again three subthemes captured the essence of achieving these outcomes with relatives.

Concerns: The concerns of the relatives had to be taken seriously even though they may seem irrational. The service should actively seek out relative's concerns and explicitly explain how they will be addressed. A common concern was that the move was seen as cost saving on the part of the organisation and that the relatives would be left to take over the care of the person.

Honesty: Critical issues had to be put on the table and explicitly addressed rather than ignoring them and hoping they would go away. This included disagreements among families; issues around the person's money; and respecting their choices.

> The mind-set of families is that they actually believe that their sons and daughters are children, they don't fall into the category of adults. And that is our fault as service providers, to have let that happen and not to have challenged that. So not too long ago with a family, I said: "you think your son is a child and that you are his decision maker: I think he is an adult and he can make his own decisions", and she (the mother) said, "he is not". I said, we were never going to get onto the same path until we had this conversation. Now that conversation can be very difficult for younger, untrained, front line staff to have; so we have got to facilitate that at whatever level it requires to be facilitated. (Manager)

Trust: Building a friendly and trusted relationship with relatives was seen a key to bringing them on board and ensuring their active co-operation in the process both in the short and longer term. If an impasse was reached, the service had to be prepared to say: "you are going to have to trust us on this".

> We had a mixed response from the families, and even within families itself. Like if somebody had three or four of their relatives they wanted brought in, within the families certain people who want the person to move on and certain people who don't. Once they came to meet with us, hear that their family member is

> actually going to get more supports ... they were much more reassured. (Manager)

The participating services seem to have successfully won over most families albeit at the expense of diverting energies from other tasks.

6.4 Minor themes

Participants identified four further themes but these featured less prominently in the discussions. They could also be considered more minor in that they did not have the same range of sub-themes as those recounted above. However each of these themes could have major significance for certain organisations at specific points in the process.

Communication: This theme is placed amidst the organisation, staff, clients and relatives parts of the engine, as clear, consistent and constant communication was essential to the success of the process. The vision and rationale for the changes needs to be stated clearly and well-argued cases prepared to counter the criticisms that inevitably arise.

> You need to consult with service users and family carers at all stages as their needs and ambitions will inform the project. (Manager)

Sharing the successes of the process and celebrating the changes in people's lives need to feature in the communications.

> The project has made the wider organisation see that the closure of the institution is a reality and community integration with a valued meaningful life chosen by the clients can be a reality. (Manager)

> When our first client went out to his apartment and people went to see it and they heard about it and the talk and the buzz that was going around; others then saw that and thought: maybe I can do this, they wanted to have a go. (Manager)

> The voices of the clients and of relatives need to be to the fore in the latter.

> The mother's attitude has turned full circle. The lady (whom we supported) had sisters and brothers, but the sisters would have sided with the mother. Eventually they all turned and they are all now a huge support to her to live on her own. They do this kind of 'come dine with me' within the women in the family and she was able to host it in the recent past and it was fantastic for her. (Manager)

It is important that client advocates are also fully informed about the process and their role within it.

> The professional advocacy that I have encountered has tended not to be very alive to the political agendas that are going on and have often allowed themselves to be used to argue in favour of retaining the status quo. They are

very good, well intentioned people but have really allowed themselves to be captured by a particular perspective. (Manager)

Finances: Although funding was not a dominant theme in the process of bringing about change, finances seemed more critical when the discussions shifted towards sustainability. Comments included the on-going cutbacks in health funding; the drop in the value of assets to fund new arrangements; the cap placed on the amount of funding available for each individual in the new arrangements; the costs of running two systems and the need for bridging finance. This necessitated keeping a close rein on expenditure and particularly on individualised staffing arrangements.

Examples were given of reconfiguration in service funding such as the redeployment of day service monies; the reduction in agency staff costs; de-bundling of monies to individuals.

Although we are after getting day service money but actually we are going to use it for something a bit different. We then had to navigate the reporting requirements to the HSE about that. It can be on the edge there sometimes, it does require a bit of creativity, a little bit of resilience and determination. (Manager)

Additional cost pressures on people living in their homes were noted.

There is additional financial strain on individuals following a move to individualised accommodation. There are economics of scale (for individuals) to living in larger residences. (i.e. bills are cheaper when shared among a group of residents) (Manager)

Housing: Certain respondents highlighted the availability of housing as an essential driver in the process either from local authorities or Housing Associations.

The project support worker sourced accommodation from local authorities in consultation with the individual patient. She had dedicated time for individuals to view accommodation and support them in settling into their new homes. This allowed mental health specialist staff from the multi-disciplinary team to use their skills more effectively. (Manager)

Delays with some Housing Associations in delivering accommodation slowed down the process as did the lack of suitable and affordable accommodation in the localities where people wanted to live. The use of private rental accommodation was seen as a viable alternative for some clients. However, cuts in rental allowances created additional difficulties for some organisations.

For us it became a problem to find accommodation that was in the right price range and that the accommodation was suitable. Because there is lots of accommodation out there but a lot of it is not suitable, so that was a big difficulty. Then in the middle of it all, the rent allowance went down, so that was

another big issue because it meant our clients had to have more of their own money invested in it. (Manager)

Community Contacts: This theme was elicited in the focus groups by the facilitator as sparse mention had been made of community connections in the discussion. Participants acknowledged that this aspect was less to the fore in the project with the exception of links with housing associations. Others mentioned having linked with Dublin Bus, the Money Advice and Budgeting service, community based training and employment services and community health services of the HSE.

New community initiatives could also be developed, especially those taking place at evenings and weekends.

> We have partnerships with a project called X. We have given them day centre hours whereby they open the day centre at night. We have no input, but would keep an eye and they can ring us or they can link with us. But they go in there and they run that and our people link into that. Now we are hoping to open it on Sundays as well, from September, with the peer group and we will be there in the background if needed. I think very much that this how we have to go. It's like the workings of a clock: we have to be in the background working away keeping the whole thing ticking. We are no longer at the forefront. (Manager)

The continuing stigma of mental health was cited as a barrier as was poor communication among agencies.

> It is actually the negative attitudes, in mental health it is the stigma. It affects linking with the different services in the community. I can enumerate services that haven't really learned the whole acceptance of the individual's needs as such. So the stigma in mental health is still apparent, there is no doubt about it. Then the communication lapses between inter-agencies and between HSE's and other agencies. It can take a while for us to get even a one line reply. (Manager)

6.5 Stages on the journey

The complexity of the process of change is very evident from the accounts given by the service leaders. Most had embarked on the venture without realising the extent of the task that lay ahead. Yet they had succeeded in varying degrees to making change happen for people with various degrees of disabilities and mental ill-health. The mood throughout was optimistic and enthusiastic; reinforced by the evident improvements they had brought to people's lives and the new sense of purpose they had engendered within their services. However, the journey still needed to be continued both within the participating services but also in the many other Irish services who may wish or need to become more personalised.

If the move from congregated services to personalisation is conceived as a journey, then it follows that there are stages along the road. The service leaders also reflected on this theme especially in relation to the provision of group homes in which up to

four or five individuals shared a house in the community. Certain services had relocated people from institutional, hospital-like settings to such accommodation whereas other services were actively relocating people from group homes to more individualised arrangements. This apparent paradox is perhaps best understood as a staged journey.

The rationale for moving people to group homes was explained as follows,

> This was primarily an initiative to achieve quick closure of a congregate setting. The funding level set for these clients...significantly constrained the potential for individualised 24x7 arrangements. (Manager)

This stage has certain benefits nonetheless.

> The test that the initial post-institution environment had to meet was that of being good enough to provide a better platform within which to get to know the person. Also the best we could achieve in group settings was that of minimising incompatibility. (Manager)

Thus the service made no claims that the group homes were to be the individual's homes for life, as some might have wanted or thought. Rather the move to small group living was better conceived as a "discovery process" that would progress the personalisation of supports.

However, the danger inherent in group homes, is that in earlier attempts at deinstitutionalisation they had become a home for life and in so doing took on the characteristics of mini-institutions: as noted also in international reports[13].

> I was involved probably in the kind of de-institutionalisation in which we went out into the community and we set up little small units. Then gradually, bureaucracy built up around these little units and people were threatened to be restricted again. For example, they couldn't get their money unless two people signed with them and things like that. Environmental Health came in on it, they couldn't any longer go into their own kitchen to cook their food and stuff like that. We were going too much back towards institutionalised care. (Manager)

Thus, a further stage in the journey was the relocation of people from group homes and crucially giving those residents the choice of who they lived with and where they lived. Moreover, there was the need to free them from the bureaucracy that had grown up around services.

> The organisation is a barrier; all the policies and the procedures and the risk assessments, and the service teams: everything has to go through the service team to get the sign-off. So when we started out on the project, we said, ok you are suspended outside the organisation. If you need any of the things that we

[13] European Commission (2009) *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*. Brussels: European Commission Publications.

have as policies and procedures - because clearly you would have to have child protection and all the ones that you have to have - but you don't have to take all the others that we have on board. That just freed up the whole thing and let people just look to the person and see what kind of life that they wanted and try and supply that, without going through all the hoops that we had put in place, for accountability purposes. (Manager)

Even when people moved to their own accommodation, the journey still needed to continue.

> Moving house was never going to be the answer to the person having a good life that just became a platform. But sometimes people were tired by the time they got there and they got stuck. The support staff needed somebody who had the skill to sit with the circle of support and with the person to kind of say: "ok where are you at now and what was the vision". When people came back to, what was the vision, what were we supposed to be doing; they got going again. (Manager)

Thus, the support system around the person needs to be constantly attuned to the growing confidence and competence of the person so that they are free to live full and fulfilled lives.

> It is a lot of work but there is a lot of reward in it. It allows us to work with clients and to do things with clients that we probably wouldn't have done as quick and to see clients who benefitted, their lives have changed, they are independent. It is really worth doing. (Manager)

> It is easier to do it than not to do it. It makes so much sense to do what people want rather than what they don't want. (Manager)

6.6 Cautions and challenges

However, certain cautions and queries were also noted. Is this process suited to meeting the needs of individuals with severe and complex disabilities?

> We have a huge amount of young children with very significant physical and intellectual, and medical problems, coming through our schools at the moment. So can we suggest that they would want to live on their own? There are lots of families I think who think of service land and don't think of an ordinary life for their person. So we need to get those families thinking and we need to figure out the best life also for those persons with significant disabilities. (Manager)

The readiness of managers to embrace change could be an issue when it came to rolling out the personalisation process across services.

> We brought in a lot of decent new people at the direct support level but ultimately we had to integrate them within our line management structure and the line managers don't have the imagination that is necessary, although they are working at it. To an extent we have revved up the enthusiasm of front line

> staff and then we have linked them in with managers who just haven't got it. (Manager)

The prospect of further cost reductions in service budgets could reduce the incentive to change.

> Over the next eighteen months or so, we plan to close three group homes. We believe we can do that in a way that will improve people's lives, do it more cost effectively than we are doing it at the moment. Now what I would love to be saying is - and then we will then reinvest the savings. The reality is what I will be doing is using whatever savings we can accrue to reduce whatever cut is applied to us, because that will be the next kind of emergency that we have to face effectively. (Manager)

And following on from the above, there was a sense of impotence even among the most enthusiastic of proponents to influence national policy and its implementation.

> The thing that strikes me about the policy implementation is that I am kind of sceptical about where this is being led from. So while the policy is right and while the vision for it is right, I am kind of looking on and thinking, who is leading this, where am I seeing the evidence of how this might be enabled and facilitated? Because my experience of it is that we have had to navigate a system while innovating, and I am kind of waiting for the system to have caught up. So I am a bit kind of dubious and I would hope the many organisations who have been innovating, will get to really contribute to the implementation. (Manager)

The information obtained in this phase of the evaluation is striking in two respects. First, the journey towards personalisation was the same across the three client groups – intellectual disability, mental health and physical disability - although ostensibly their needs are thought to be very different; hence the separated service provision that has been traditionally provided. This finding further reinforces the proposition that service systems are primarily designed to meet the needs of the service rather than in response to the needs of individual clients. In one sense this insight is hopeful in that the main focus for change is on systems but it can be also daunting given the heavy investment there is within current service models.

The second strong impression was the unanimity among the respondents in the focus groups, interviews and written comments. Perhaps their 'like-mindedness' is not surprising as they had come together because of a common selection process. Their honest appraisal of the difficulties and shortcomings they had experienced did not assuage their enthusiasm for personalisation or the conviction that this can happen. At present we lack comparable insights into the thinking in those organisations who have yet to embark on a change agenda although a current project at Trinity College Dublin sponsored by the Health Research Board may yield

this information[14]. Even so, it remains to be seen whether the experiences of participants in the Genio projects will influence their contemporaries to instigate a process of change. Their advocacy and potential mentorship could be especially influential.

[14] Moving Ahead Project: Dr Christine Linehan is the principal investigator. Further details at: http://www.socialwork-socialpolicy.tcd.ie/moving-ahead/

7. Conclusions and Discussion

This part brings together the main conclusions to emerge from the evaluation and to discuss the implications for the continuing development of personalised services in Irish health and social services. First though it is worth highlighting the strengths and shortcomings of this evaluation.

7.1 Review of the evaluation

This evaluation had particular strengths and Genio are to be commended for commissioning it so that an evidence base can be assembled that arises from and is especially relevant to the Irish service context. In particular, it includes a sizeable sample of persons with intellectual disabilities and those with mental health difficulties, thus there is shared learning across two client populations that traditionally have had little interaction from a practice or research perspective.

A second strength is the longitudinal nature of the study which allowed comparisons to be made for the same individuals before and after major changes in their lives. Although comparable data is available internationally there is limited information available for Irish services.

Thirdly, we made every effort to obtain information from people themselves rather than rely on third party reports from staff and relatives, although their views were also sought. Moreover, information was gathered across a range of domains to capture a complete picture of people's lives.

Information was gathered primarily through face-to-face interviews undertaken by a hard-working team of Research Assistants who were well supported by our experienced Project Manager, Rachel Stevens. Rachel had personal contacts with the managers and leaders of all the projects and negotiated with them access to the necessary personnel. We believe that the personal relationships we endeavoured to cultivate with all the stake-holders assisted in the high levels of recruitment and retention over the course of the evaluation. Inevitably though, some persons chose not to take part.

7.2 Shortcomings

Despite these strengths there are a number of cautions that need to be recorded. Perhaps the over-riding one is the paradox that lies at the heart of this endeavour. The goal was to personalise the accommodation and support options available to *individuals* and yet the evaluation is predicated on finding differences among *groupings* of persons who experienced apparently similar changes in their support arrangements. The rationale for doing this is laudable and indeed the group differences found represent a strong effect, albeit not holding for everyone. Equally though, there could well be real changes for certain persons in particular situations that are not present for others in the grouping but these are masked by a failure to

find changes for the group as a whole. Much larger samples would be needed to identify these types of changes further.

A second caution concerns the biases that arise from how the projects and their participants were sampled. It is likely that the services that sought funding from Genio differ in some important respects from similar services that had the option to apply but chose not to do so. For example, some already had a greater commitment to personalisation and were comfortable with creating and managing change, although this was not true of all the projects. Likewise, the participants were mostly given the choice about moving and they too may represent a biased sample of more eager and possibly more suitable persons, although again, this was not true of all the participants. Thus, the information obtained is indicative rather than representative data pertaining to Irish services.

Although our choice of questions and measuring scales was guided by past research, consultations with key informants and pilot testing, some of the information we sought was not known to our participants. Moreover, in our interviews with the people supported, they were often unable to supply or recall answers so we have varying degrees of missing data throughout the study that further reduces the statistical power. The lack of suitable measures to assess nebulous concepts such as 'quality of life' is an international challenge that has been recognised (Townsend-White et al., 2012), and which this evaluation attempted to address by including a range of pertinent indicators of quality of life as well as using quality of life rating scales.

7.3 Main Conclusions

Despite the shortcomings that commonly beset evaluations of developing projects such as this one, there are a number of conclusions that can be confidently identified.

Personalised housing and support options are feasible to implement in Ireland.

The evaluation shows that these arrangements could be established across a range of projects in different locations across the country for individuals with a range of difficulties as people with all levels of support needs were found in all accommodation and support options. Both the HSE and voluntary agencies effectively managed these new projects. There were few instances of people having to move back to institutional settings, even though community placements had not worked out for some participants in the past.

Personalisation produces better outcomes than congregated care.

People's experiences were different and arguably better when they were supported in personalised arrangements. This was confirmed by comparing people already living in personalised arrangements with those who lived in congregated setting and in the changes people reported when they move to more personalised arrangements. Taken together, the findings from the indicators and rating scales (Section 4) point towards personalised arrangements producing better outcomes for the people

supported, irrespective of their impairments and level of functioning, than for those who continued to live in congregated settings or in group homes. Similarly people who were supported by projects while living with family carers also reported better outcomes. That the effects were not more pronounced was due perhaps to relatively small numbers of persons within the groups and the confined time in which people had to settle into their new arrangements. Both of these shortcomings could be addressed in future evaluations.

Personalisation can save on costs but not for everyone

The data on costings have to be treated with some caution given the difficulties associated with determining accurate costs for individuals across different services and time points. That said a number of clear messages emerge from the information presented here.

There was evidence that personalisation resulted in marked cost savings for most persons over the traditional service models without incurring undue extra costs in mainstream community and hospital services. Moreover, some of the support costs transferred from health to social security funding.

The data suggests that personalised options are much less costly for the same persons than when they resided in congregated settings although there were instances when these arrangements resulted in the highest monthly cost across all settings. Thus when a move to personalised accommodation and supports is made, it will be less costly for some, roughly the same cost for others and for people with high support needs it will be a more expensive option.

The move to more personalised arrangements including those moving to group homes resulted in greater cost-benefits, as demonstrated through lower support staff costs resulting in greater benefits for participants as reported in Section 4.2. However, this holds more for groupings of persons rather than for individuals as the correlations between individuals' costs and outcome indicators were usually not statistically significant. Further refinement is needed on methodologies for determining costs and outcomes.

On-going staff support costs are mostly much greater than costs involved in using community and hospital services. We were not able to bench-mark the usage of the latter services with a non-disabled population but they do not appear to place an excessive burden on the services available to the wider community.

Given current economic constraints, there is concern that cost reduction becomes the main driver for further personalisation, at the risk of providing less than optimal or indeed essential accommodation and support arrangements, although this was not evident in the projects being evaluated. Such circumstances would threaten the credibility of this model. The emphasis in pursuing personalisation should be on the possibility achieving greater benefits for people supported at lower cost for many. The expertise of those who have been personally involved in implementing the projects should be harnessed in doing this.

Personalised housing and support options can take different forms

Personalised arrangements subsume a variety of options so they can be tailored to the needs and preferences of individuals with many different combinations of accommodation and support arrangements. Current projects have sourced accommodation from private rentals, housing associations and local authorities as well as supporting people in the family home. Likewise the type and amount of support offered can be adjusted to reflect changes in people. That said we were able to identify certain key indicators that most distinguish personalised from grouped arrangements. These indicators could be used for internal monitoring of personalisation and training in it.

Group homes do not offer personalised accommodation

Given the aspirations of the Genio-funded initiative it was surprising to find that people were being relocated from congregated settings into group homes: particularly people with intellectual disability more so than those persons with mental health difficulties. Ironically other projects were funded to relocate people from group homes into more personalised arrangements. For one project, a move to group homes facilitated the speedy closure of an out-dated institution and this seen as a step along the journey to personalisation and has some merit. But the danger is that people may not have the opportunity to move on from the group home. International experience in countries such as Norway, has demonstrated that people can be relocated directly into personalised housing and support arrangements. Moreover, the evaluation shows less personalisation and poorer outcomes for persons in group homes compared to other family and personalised arrangements.

Personalisation slowly changes people's lifestyle

The case studies illustrated the various ways in which people's lives and their lifestyle changed through being part of the projects. Some might be classed as small changes and many were particular to individuals which may explain the limited number of changes that held for groups of people when the different options were compared using quantitative information. Moreover, people who had experienced personalised supports for longer seemed to have fuller lives than those who had recently moved to these types of arrangements.

Community engagement and social relationships need intensive support

The evaluation suggests that changes in accommodation and support have little impact on people's community engagement and social networks although these tended to be greater for persons living in personalised than in congregated arrangements. This seemed to apply to both persons with intellectual disability and mental health difficulties. In part this could arise due to the short length of time people had lived in the new settings. It takes time to make these connections: a truism for anyone moving to a new neighbourhood. However, the availability of support for making such connections may not always be there especially as support staff apparently gave this lower priority than other aspects of their work.

Relatives can be persuaded

The reluctance of relatives to endorse a move for people living in congregated settings can be overcome and indeed when such moves occur, they become enthusiastic about the new arrangements. Indeed as the findings in Section 5.5 show, relatives can become strong advocates of the new arrangements and readily name the benefits for the person as well as for themselves. However, their concerns and worries need to be acknowledged and addressed through their active involvement at all stages of the process, notwithstanding the pre-eminence that must be given to the wishes and aspirations of the person who will be moving.

In order to fully involve relatives, it is important that services have an active communication strategy for informing and involving relatives in the planning process for moving people to new accommodation and to ensure that rumours spread by others are quickly addressed.

New roles for support staff

Support staff are crucial in realising the ambitions of the projects. The interviews undertaken vividly illustrated the core components of their role with a remarkable coherency across client groups and types of services. Their enthusiasm for this new style of working was very evident as was the implicit contrast with staff functions in a more traditional service setting. In retrospect, we probably should have focussed more on the changing nature of their work and role especially as the majority of those who were supporting individuals came from traditional health and social care backgrounds. However, it is a hopeful sign that in these projects many staff did adapt well to the new demands of person-led decision-making and consequent risk-management.

The similarity of responses was striking from staff across the range of services. Their work was the same whether the employer was the HSE or a large or small voluntary organisation. Also staff transferring to new arrangements as well as those who were newly recruited gave comparable accounts. Likewise the role of staff appeared very similar with people who had differing disabilities and mental ill-health. A commonality of role is not surprising when the support is aimed at assisting people with support requirements to live fuller lives in the community, then the staffing functions will possibly vary little by client labels. At a minimum then some consideration needs to be given to the transferability across previously distinct service sectors, of skills and expertise in personalised staff support. But more radically it opens up the possibility of the provision of supports across diverse client groups within a locality by different types of organisations; a cost-effective option that could be particularly attractive in more rural communities.

New arrangements take time to set up

In only a minority of projects grant-aided by Genio had all the persons moved and in most of them there were varying proportions of people who had moved. The complexity of the shift to personalisation was well described by service managers. The process requires skilled and dedicated management. The main reasons for delay were identified but further research could usefully investigate why certain agencies

avoided or ameliorated these problems whereas others did not. Certainly the extra funding available to services via Genio was an important contribution but insufficient alone to drive change.

Longer-term follow-up is needed

The time period for the evaluation in retrospect, was too constrained and perhaps greater insights would have been gained by conducting it over a five year period. Hence consideration should be given to commissioning a follow-up study in 2015 or 2016 with more focussed data gathering using the most relevant and robust measures from this evaluation.

7.4 Conceptualising Personalisation

Perhaps the most fundamental question remains to be addressed. What is meant by personalisation? The findings from the evaluation that encompass both a review of the process followed and the information gained, have enabled us to reflect further on the conceptual framework that underpins the personalisation of health and social care supports; particularly for persons with an intellectual disability or long-term mental health difficulties. The conceptual framework which we outline in this part of the report, builds on some of the debates currently unfolding within the literature as these new ideas are critically examined in the light of evolving experience internationally (Carr, 2013; Hall, 2013).

However one conclusion stands out; personalisation is not merely an alternative way of delivering services. Rather, it is better thought of as a conceptualisation as to how supports are best delivered to persons with certain support requirements.

There are four attributes of personalisation that deserve particular attention as shown in Figure 7.1.

Figure 7.1: Key features of personalisation.

Personalisation is a process not a product.

In the context of this evaluation, the relocation of people from one type of setting to another is better viewed as part of the process in making support services more personalised rather than seeing it as a product that has been achieved. Thus the

preparatory work prior to the move becomes an integral part of individual planning for the person and even more crucially, after the move the process of personalisation has to continue if the supports are to attune more closely to the person's aspirations and needs.

Contrary to traditional care models, personalisation seeks to promote incremental and developmental change while providing stability and security for the person. The real measure of personalisation is the extent to which supports are uniquely designed for each individual and adapted in response to successes and failures. Thus in theory, personalisation could feature across all accommodation options although in congregated settings this can be difficult to achieve without actually breaking them up. Hence moving people to new accommodation options forms a part of the personalisation process that can occur throughout their lives.

Personalisation applies to everyone.

Most Irish citizens personalise their own supports over their life time although most are not conscious of doing so. However, the contrast is stark if the person requires health and social care services. Traditionally, individuality has become subservient to 'group treatments'. In recent years though, tax-payers have become more demanding as consumers of state-funded services and more emphasis is placed on matching services to individual preferences and needs. Indeed the developments in personalised medicine promise more effective treatments as drugs are matched to an individual's genetic make-up. Contextualising personalisation in this way underscores that this approach is not just for groups with certain support requirements but rather emphasises the personhood of the people who happen also to have a disability or a mental health problem. Thus personalisation often responds to the similarity of the needs of all people rather than to their differences. The International Classification of Functioning produced by the World Health Organisation (2002) is an attempt to reframe assessments of disability and illness in this way.

Personalisation is based on self-determination.

This truism may be self-evident but in the context of vulnerable populations it presents particular challenges. Does the individual have the capacity to make decisions? Would professionals and their employers be considered negligent if they did not prevent the person from making erroneous decisions? Again such questions need to be addressed within the process of the personalisation of supports to the individual in which negotiation and shared responsibility feature. In this respect access to effective advocacy is a key feature of personalisation. But a striking finding from many studies and one echoed here too, is the freedom that people experience when they are no longer part of a service system and they take or regain control of their own lives and are able to develop their own individuality and identity (see below). Perhaps personalisation is incompatible with service systems as they are currently managed and funded? New paradigms and arrangements may be required such as service brokerage and circles of care (Dowson and Duffy, 2011).

Personalisation creates identity.

The ultimate goal is to enable persons to enjoy a full and fulfilled life that encourages people to dare to dream and to make those dreams come true. Notions of cure or remediating deficits give way to people living with a condition or illness but not letting it define their identity. Thus personalisation is about supporting people to create and recreate their own individuality and identity; challenging them to be all that they could be – all that they want to be. In a sense it is no different to what parents and educators have been doing for generations of children and young people but it is a new departure for much of our health and social services which unwittingly have reinforced a 'disabled' identity among their clientele. Rather, personalisation is about optimising the developmental capacity of persons despite their disabilities and/or illnesses (Vanier, 2008).

7.4.1 The Uncertainties of Personalisation

Personalisation fits well with the prevailing political mood in many European democracies allied with aspirations for greater cost-efficiencies in health and social services. However, the implementation of this philosophy presents one major difficulty: how to balance equitably the demand for support from different individuals when resources are constrained and all their demands cannot be met. Personalisation per se has no solutions to offer other than to trust that people will not demand more than they need and that their 'true' support requirements deserve to be met by society. Within a State model of finite financial resources, personalisation like other possible competing public demands will realistically always be subject to available resources. However, one would hope that there would at least be a floor (minimum standard) beneath which no vulnerable individual requiring State funded supports would fall.

Governments are disinclined to take on these assumptions and hence various mechanisms have been created to decide among competing demands for personalised supports. These decide not only who qualifies for support but also the extent and duration of that support. Thus a crucial part of both the cost and the effectiveness of personalisation of services lie in these allocation mechanisms. To date this element has been under-researched and formed only a small part of the present evaluation. However, this issue will require careful and prompt attention by the HSE in its role as a service commissioner as well as provider. The ongoing feasibility study commissioned by the National Disability Authority into resource allocation will inform this debate (SQW, 2012).

A second uncertainty relates to the position of disadvantaged groups within society. By its nature and intent, personalisation can reduce the sense of group solidarity that can come from sharing services with other persons with similar difficulties; an aspect that people with disabilities and mental health difficulties often value (Hall, 2010). Furthermore, fewer opportunities for group advocacy could mean that these already

marginalised groups have reduced influence nationally on policy development as well on spending priorities.

A third uncertainty relates to inclusion. Much can be achieved by focussing on the person but their fuller inclusion within society is as much dependent on how society responds to them as in their capacity to become part of society. Merely relocating people into communities runs the risk of their continuing social isolation, perhaps even heightening it as they lose contact with peers and wider staff supports that are found in congregated settings (Power, 2013). Building community acceptance for individuals is arguably less onerous than changing perceptions to marginalised groups known by their disability label. Yet in striving for personalised service supports, little attention may be paid to the shaping of the community in which people will reside; thereby perpetuating a major criticism of existing service systems. However, for all of us, society and the opportunities it provides invariably shapes our identity and developmental potential. Can personalisation contribute to creating a new social context for the people its aims to assist?

The issue of costs and the benefits that derive from it raises a further uncertainty. As Barrett and Byford (2009) noted, cost–benefit analysis is rarely seen in mental health care evaluations because of the difficulties in applying monetary values to mental health outcomes whether they be couched in terms of gains for the individual, such as improved quality of life, or in terms of greater social engagement. Hence there is the risk that costs rather than personal outcomes will drive the personalisation agenda, especially if high levels of support are required by individuals. Arguably it is this thinking that has sustained the provision of congregated care despite its poor outcomes. It is *how* personalisation is delivered that will determine the outcomes not the act of making services more personalised. In that regard there is still much to be learned and certainly beyond the possible honeymoon effect of moving to new settings.

These uncertainties will become more pertinent if and when personalisation is rolled out beyond the current pilot phase.

7.4.2 The contexts of personalisation

Within Irish society as in other European countries, there are long established systems of health and social supports. These structures also need to be factored into the personalisation agenda. Following Bronfenbrenner's (1979) eco-systems approach, Figure 7.2 identifies the systems that influence personalisation from two societal perspectives.

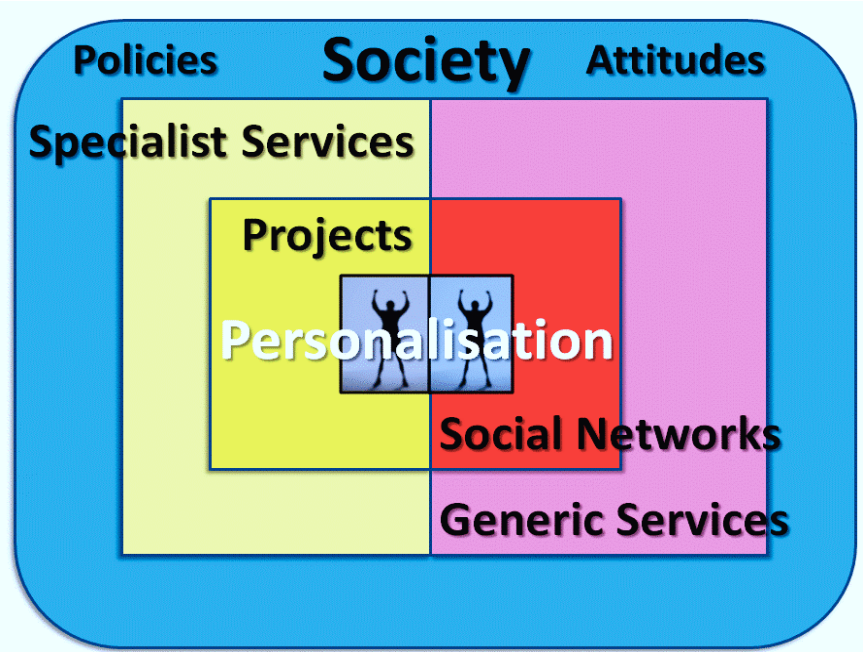

Figure 7.2: The systems impacting on personalisation

On the left-hand side, personalisation is couched within specialist services (in this instance for persons with a disability and mental health problems) which is influenced by Government policies as they relate to disability and health as developed by the Department of Health and the HSE but implemented in the case of this evaluation through discrete projects that relied mostly on specialist support staff.

Conversely on the right hand side of the figure, personalisation is viewed within the perspective that applies to most Irish citizens through their use of generic health services and the person's own social networks of support, that of family, friends and neighbours. It is within these systems that persons often take control of realising their aspirations and meeting their particular needs, for instance as they age. Also past research suggests that social factors make a major contribution to quality of life, health and well-being (Wilkinson and Pickett, 2010).

However, these are not two opposing systems but rather in the case of persons with disabilities and long-term illnesses they should be complementary and hence co-ordinated. Indeed this was the ambition underpinning the Genio projects that the support from specialist services would bridge and connect into the mainstream community. But the potential for this to happen remains to be fully realised in the projects within the current evaluation. The extent of community engagement remained low for some persons who had changed accommodation which also mirrors international experience (McConkey et al., 2009). In part this may due to a lack of focus on helping people to connect with local communities, although encouraging signs were seen for those who had experienced personalised arrangements for longer. Thus far, the focus of policy and the demand for increased resources has come largely from specialist provision rather than on mobilising community resources

instead of, or in addition to, specialist services. However, a more immediate reason could be the perceptions of service staff as to their role and responsibilities in support of the person which may focus overly on care and supervision rather than relationship building. Moreover they, and indeed the people they support, may perceive social contacts to be a risk rather than an opportunity for persons who are considered to be vulnerable. In this context, tackling the stigma of disability and mental illness is a continuing challenge (Link and Phelan, 2001).

However, this conceptual framework suggests that an alternative or complementary strategy would be for generic or community services to be funded to develop personalised services for persons with particular needs within their communities. This has been termed 'natural supports' such as the use of co-workers in supported employment schemes and 'buddies' in leisure and sports activities (Johannes et al., 2013). This would also open up new possibilities in terms of accommodation and support options such as Home Sharing in which members of the community are recruited, selected and paid to provide support for individuals in their home. This has worked well in the provision of short breaks for children and adults with disabilities in Ireland (HSE Working Group, 2012) and to date, Genio has supported 31 projects in disability and mental health to provide such models of alternative respite to over 300 individuals and families. Likewise in other countries it is used to provide longer-term care (Social Finance, 2013) and indeed one of the projects in this evaluation was successfully based on this approach.

In essence therefore, personalisation of service supports demands a societal response underpinned by cross-Government initiatives and collaborative working among specialist and community agencies. It is a truly transformative agenda.

7.5 Looking to the future

This analysis of personalisation raises a number of issues worthy of further debate, reflection and analysis.

- To what extent does the funding of special projects with a focus on personalisation lead to changes in the broader service systems from which they originated? Presumably the premise is that demonstration projects such as these will develop the confidence and expertise of service leaders and managers to extend these approaches to other persons who are receiving 'traditional services'. However, this remains to be tested and this could be done in the coming years for the current projects as well as with new services.
- Equally, to what extent could further changes in government policy and service commissioning lead to transformations in current service provision towards greater personalisation? The Health Information and Quality Authority (HIQA) may have an important function to play in this respect.
- What scope is there to develop mainstream services to meet the needs of persons with intellectual disability as has happened in terms of primary education

for example? Should development grants be made available to existing community services to enable them to make their services more accessible to persons with particular needs?

- Within the evaluation there were examples of specialist agencies forging partnerships with community and mainstream organisations as part of their personalisation process. What actions would support the extension and further development of such partnerships nationally?
- Traditionally different services have been provided according to people's disabilities or long-term illnesses. However, as the focus shifts towards a personalisation agenda, is this separation justified and what would be the advantages of having shared supports across different conditions? This debate may have particular relevance for people living in rural areas thereby making local support services more viable.
- What training and mentoring is required for support staff working within personalised support services? Likewise can their salary and conditions of employment be made sufficiently attractive to recruit and sustain a competent and committed workforce? This dimension to personalisation has received little attention internationally, but if left to 'market forces', the result will be a poorly paid workforce with high turn-over rates.
- Examples are becoming available of the breaking down or 'de-bundling' of block State-funded contracts, into personalised budgets to provide Individual Service Funding. These schemes reputedly have freed up resources to meet increased demand from other users (Hoolahan, 2012).
- The provision of suitable housing is crucial to resettlements from congregated settings as well as meeting the aspirations of persons currently living with family carers. What mechanisms are needed to ensure there is a range of housing options in each area that local people want? This requires an analysis of current supply and projected demand for housing, as well as consultations with people with disabilities and mental health difficulties, their families, carers and other partners about housing needs (Kirkpatrick, 2011).
- Finally, the personalisation agenda extends beyond the health and social care needs of individuals and other Government departments need to join in making a co-ordinated response to unfolding needs and aspirations. Yet how can cross-Government initiatives come about nationally and locally?

Inevitably an evaluation of innovative schemes raises more questions than answers. But at least the questions can be formulated and a debate begun that otherwise would not have happened without the evaluation. Likewise the findings of this evaluation provide much needed encouragement to seek answers, as indeed there appears to be a better way of meeting the needs of Irish citizens with disabilities and mental health difficulties in the modern era.

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Appendix 1

Table A3.1 summarises the changes that had taken place from the first to the second data uplift for all persons in the sample. (A breakdown by impairment grouping can be provided.)

Table A3.1: Comparisons of living arrangements at Time 1 and at Time 2 and the overall percentage of the sample within each combination (shaded areas indicates people who moved).

Living arrangements at Time 1		Living arrangements at Time 2				Total
		Personalised	Family (incl. foster family)	Group Home	Congregated	
Personalised	Count	43	0	1	2	**46**
	% of Total	23.5%	.0%	.5%	1.1%	**25.1%**
Family (incl. foster family)	Count	4	21	0	0	**25**
	% of Total	2.2%	11.5%	.0%	.0%	**13.7%**
Group Home	Count	5	0	11	0	**16**
	% of Total	2.7%	.0%	6.0%	.0%	**8.7%**
Congregated	Count	11	1	29	55	**96**
	% of Total	6.0%	.5%	15.8%	30.1%	**52.5%**
Total	**Count**	**63**	**22**	**41**	**57**	**183**
	% of Total	34.4%	12.0%	22.4%	31.1%	**100.0%**

(NB Data is missing on 13 persons who had left the project and opted not to participate at Time 2).

The largest number of moves was from congregated living arrangements (N=41); mostly into group homes but some into personalised arrangements. Other moves were from group homes and family care into personalised arrangements. Conversely some individuals moved from personalised arrangements into group home or congregated settings due mainly to deterioration in their mental health. However during this time period the majority of the sample (n=130: 71%) remained in the same accommodation.

Proportionately more people with mental health problems had moved between Time 1 and Time 2 as the funding for these projects only became available in 2011 whereas more of the Intellectual Disability projects had been funded from 2010 prior to the evaluation commencing.

Details of the changes that have occurred for persons who moved to more personalised arrangements at Time 2 were given in our second interim report (see Appendices). This was done on the same selected core domains identified in the first report. Some significant changes were found in the characteristics of people's

accommodation but the other domains showed no significant changes, although the trends are in the direction reported previously for personalised arrangements. This suggests that it can take longer for people to experience wider benefits from a move to different accommodation.

Overall 82% of the movers felt it had made things better for them, 7% the same and only 4% felt it had made things worse (i.e. a move to congregated settings) with 7% unsure.

Changes in housing and support arrangements by Time 3.

Table A3.2 summarises the changes that had taken place by the third data uplift some nine months later. By agreement with Genio this data gathering had been delayed so as to include as many planned moves as possible while still completing the evaluation by June 2013. However by this point, of the original 197 participants at Time 1, 12 had left the projects, three had died and eight declined to participate again.

Table A3.2: Comparisons of living arrangements at Time 1 and at Time 3 and the overall percentage of the sample within each combination (shaded areas indicates people who moved).

Living arrangements at Time 1		Living arrangements at Time 3				Total
		Personalised	Family (incl. foster family)	Group Home	Congregated	
Personalised	Count	40	0	0	1	**41**
	% of Total	23.1%	.0%	.0%	.6%	**23.7%**
Family (incl. foster family)	Count	2	20	2	0	**24**
	% of Total	1.2%	11.6%	1.2%	.0%	**13.9%**
Group Home	Count	5	0	10	0	**15**
	% of Total	2.9%	.0%	5.8%	.0%	**8.7%**
Congregated	Count	15	1	35	42	**93**
	% of Total	8.7%	.6%	20.2%	24.3%	**53.8%**
Total	Count	**62**	**21**	**47**	**43**	**173**
	% of Total	**35.8%**	**12.1%**	**27.2%**	**24.9%**	**100.0%**

(NB Data is missing on 23 persons compared to Time 1 who had left the project, died or opted not to participate at Time 3).

The largest group of movers (n=50) was from congregated settings with most moving to group homes; others to personalised arrangements and one person to live with a foster family.

Five persons in the sample moved from Group Homes to Personalised arrangements and four persons from family care to either personalised or group homes. One person who had been in personalised arrangements had been readmitted to hospital.

In all 86% of the movers felt it had made things better for them, 5% the same and only 3% felt it had made things worse (one in personalised and one in group home) with 6% unsure.

However 72 persons (42%) continued to live in congregated settings or with their family or in group homes as they had been doing at Time 1. It could be that in the coming months and years this latter number will decrease further as projects continue to work on relocations.

About Genio

Genio is an independent, non-profit organisation based in Ireland. We are driven by a vision of a society that benefits by valuing all of its citizens. Genio brings together Government and philanthropy to help develop and scale, cost-effective citizen-centred services so that everyone has the chance to live full lives in their communities.

Genio is supported by the Atlantic Philanthropies in collaboration with the Department of Health and the Health service Executive. We work in partnership with all stakeholders to re-configure resources to reform services in order that they reflect national policy and international best practice.

Established in March 2008, Genio Limited is an Irish registered company (Reg no. 454839).

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