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A case study analysis of Person-Centred-Planning for people with intellectual disability following their transfer from institutional care.

Donal Fitzsimons, RNID, BA (hons), MBA

Ph. D. **2012**

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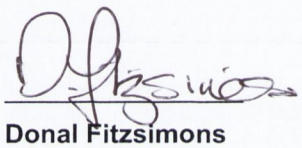

Donal Fitzsimons

Summary

Person centred planning (PCP) has an essential part to play in ensuring self determination for the lives of people with intellectual disability. It is typically taken as an indicator to the quality of services and it is regarded as especially important when considering its effectiveness in impacting on the lives of people with intellectual disability. Robertson's et al (2005) six indices of PCP efficacy of social networks, community involvement, scheduled day services, contact with friends, contact with family and choice are regarded as a standard measure. This research examined the PCP process and its impact on the reality of the life of the person with intellectual disability. It considered the understanding of various stakeholders in the PCP process and investigated whether PCP brings added value to the lives of people with intellectual disability in community settings. Finally, it explored the relationship between the theory, policy, and outcomes of PCP for ongoing practice.

Using a qualitative case study approach this study examined the lives of ten people who were selected from a list of people with intellectual disability who were removed from their families and placed in institutional settings and later transferred to community residences. Semi-structured face-to-face interviews based on Robertson's six indices of PCP efficacy took place with the three stakeholder groups including the person with intellectual disability, their family member and their key worker (thirty interviews). For each focus individual further information was collected from relevant professionals such as day service staff, social workers, psychologists and speech and language therapists. Finally, one PCP meeting was attended for each individual (10 in total). This informed a descriptive account of each case which were based on the following structure: background and content, current status, the PCP process and comment and anlaysis which resulted in an individual case study for each of the ten people with intellectual disability of this study.

Recurring themes emerged from a detailed cross case study analysis. A key theme that emerged was the legacy of institutional care and practices. The study found the structure of the PCP meeting to be over formal with a limited understanding of the aims and impact of PCP by all concerned. Different factors led to resource limitations for each of the stakeholders resulting in a reliance of special services combined with a fear of additional costs and routine activities in PCP. This study also found that there was an emphasis on duty of care that led to risk aversion in PCP goal setting with individual differences and local variations impacting on the efficacy of PCP. The PCP's in this study were found to promote community presence but did not lead to community participation. This study also found that there are some positive impacts to having a PCP in place for people with intellectual disability.

This study did not find evidence for true person centeredness in the community residences but it found that the community residence service model (which is in affect a smaller version of the institutional model) still lacks flexibility in providing people with intellectual disability lives of their own determination. In considering PCP this study found that the community based residence model acted as a barrier to Robertson's standards of PCP efficacy as the goals of the PCP simply

did not include actions that would lead to community participation, enduring family involvement or any element of real choice. It did find that when people with intellectual disability moved from the institution to a community setting the PCP delivered on an increased range of hobby activities, typically in the context of special service settings and special service networks.

This study found the need to introduce a fresh look at improving the PCP by in service training on the philosophical basis of PCP, guidance for families, accessible formats for the people with intellectual disability to take on ownership of their PCP's, deeper consultation with families as well as introducing standard measures and ongoing monitoring of PCP. This is important as we know from the National Intellectual Disability Database (NIDD, 2010) that 26,484 people with intellectual disability are in receipt of services. In addition there are over 4000 Irish citizens with intellectual disability who continue to languish in large institutions who need to transfer to a community setting (HSE, 2011) while a further 4,088 individuals reside in community residences.

As well as concluding that the PCP's examined in this study were flawed it is also evident that there is a need to challenge the premise of the congregate care model of service provision as inherent in this is segregation and lack of valued social roles. Optimal individual service design (OISD) is one such way of challenging the outdated 20th Century service model which is perpetuated by a reliance on grouping people based on their disability in both day and residential services. In an effort to be truly person centred this study sets out to challenge services and policy makers on the the individual and citizenship rights of each person with intellectual disability and questions whether PCP has the power to act as a conduit in the structuring of person centred support which ultimately can only be done for one person at a time.

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Dr John O'Brien an Internationally renowned author, pioneer and lifelong advocate on PCP has worked zealously in partnership with people with disability to build more just and inclusive communities. Dr O'Brien is affiliated with the Centre on Human Policy at Syracuse University, New York, USA and the Centre for Integrated Education in Toronto, Ontario, Canada. His interest and international perspective has brought a high degree of expertise to this research. He has been reassuring and affirming and a sense of inspiration that this research was worthwhile and that change is inevitable in the way services are delivered for people with intellectual disability in Ireland. Dr O'Brien, thank you for your overwhelming inspiration and for signposting the way forward towards an inclusive society for people with disability.

Dedication

This thesis is dedicated to Deirdre Gordon. Deirdre worked as a Ward Sister in Orchard House, St Saviour's Hospital, Jersey, Channel Islands. She dedicated her working life to supporting people with intellectual disability ensuring the people in her care led meaningful and dignified lives. I had the pleasure of knowing and working with Deirdre in the Channel Islands from 1997 to 1999 and during this time Deirdre instilled in me a deep understanding of personalisation and to see people with intellectual disability as individuals with a valued role to play in society. Coupled with this, she had the foresight to recognise that we all had a part to play in ensuring that society embraced people with intellectual disability; accepting them as participating equals and not burdens in society that required resources and support. In hindsight, I now recognise working under Deirdre's leadership and management instilled in me the true meaning of what is person centredness. Deirdre, you have led me on a journey bringing change in how we support people with intellectual disability – this has been a remarkable journey – thank you.

Deirdre passed away in 2007 at just 46 years of age. She leaves behind a legacy of instilling in the many people that had the pleasure of working with her from around the world a true person centred approach and reciprocal respect for people with intellectual disability. This thesis is to honour her memory.

Chapter 1

Introduction

1.0 Introduction

One of the aims of this research is to establish the efficacy of person centred planning (PCP). To fully understand this and by way of introduction it is important to briefly consider the historical context of intellectual disability service provision in Ireland. Over the past 20 years there have been radical changes in how services for people with intellectual disability are delivered. In particular there has been an emphasis on people moving from institutional care to community care.

Person centred care has been a concept used to improve service delivery, often driven by the process of person centred planning (PCP). It is important to trace the development of intellectual disability services with a particular reference to an Irish context. For this research attempts have been made to shed light on the relevance of PCP against a back drop of de-institutionalisation, movement to community services, participation and inclusion in the mainstream of society for people with intellectual disability.

What follows is an early historical perspective on care and education, early Government service development, the influence of religious organisations in the care of people with intellectual disability, the initiation of the parents and friends associations, the development of specialisations, current Government policy, a description of the transfer programme and a description of the three congregate care settings involved in the transfer programme.

1.1 An early historical perspective on the care and education of people with intellectual disability in Irish society

The late 1800's and early 1900's saw the introduction of the asylum and workhouses for people who were described at that time as lunatics. Robins (1992) cites Kirkpatrick (1931), in his early writings on the 19th century Ireland and reported on inhumane practices whereby people with intellectual disability were banished in locked in rooms, chained to beds and held in baskets, which further exacerbated already complex needs. Moylan (1938) argues that before Irish society decided to respond to disability in a particular way, it had first to decide that having a disability was a problem. He believes that Irish society in the 19th and 20th centuries responded in several ways such as fabricating stories and developing myths to explain the disability. This often resulted in the child with disability being kept out of sight and away from the community or by allowing the child wander the streets and being forced to protect itself from society. He further alludes to the fact that in the 1900's in Ireland many children with disability did not have a long life expectancy. He attributed this to poor housing, poor hygiene and the lack of medications such as antibiotics to treat infections. More alarmingly, he makes reference to the practice of infanticide and wilful neglect with preference to non disabled off spring.

The establishment of the primary school system in Ireland in the 1830's introduced to the Irish society the notion of the 'slow learner' (Byrne, 1979). Byrne details that a child at this time could be expelled from school for failing to grasp basic academic skills. Byrne continues that the slow

learner concept was also seen as a formal judgement of intellectual disability before intelligence quotient (IQ) tests were developed. Many children born with intellectual disability are also likely to have other challenges including epilepsy, physical and sensory disabilities and with one in four exhibiting behaviours that challenge (Emerson, 1985). Families struggled to cope with such complex needs. The task of caring for the person presented serious difficulties which often resulted in responses which were far from adequate or ethical.

The asylums and workhouses then developed into special hospitals and institutions for people with intellectual disability during the second half of the 20th century. This subsequently shifted to care in the community and the introduction of the group home model as being the preferred option as we approached the 21st century. The group home model which was developed from the de-institutionalisation movement in the USA (Wolfensberger, 1981) was an approach that saw the acquisition of ordinary housing in the community, whereby people with intellectual disability were grouped on the basis of a common level of support need. The community group home model was a good model of its time. Living in a group home provided many advantages over living in an institution. However, in the early years of the 21st century alternative models of care are gradually starting to emerge. The newer models advocate that people are supported to live independently in the community in ordinary housing with tenancy agreements, mortgages and shared ownership. These evolving models recognise the person with intellectual disability as having the same rights as everyone else in society to be part of the community in which they reside. It is predicated on the person with intellectual disability being able to access locally any required supports while also being afforded the opportunity to offer something meaningful to society.

1.2 Early Government service development

Byrne (1979) argues that a key Government decision taken in the early 19th century in Ireland was to refuse to offer relief to families caring for people with intellectual disability in the home. If a decision was taken by the family to keep the person with intellectual disability at home, they received no support from the state. The only way a family could receive state support for the person with intellectual disability was for that person to enter a workhouse. Each workhouse had a small number of 'lunatic cells' at the back of the complex specifically for people with intellectual disability. By the end of the 19th century there were twenty-two workhouses or asylums in Ireland, each providing services across two or three counties where both staff and inmates lived with little contact with the outside world. Byrne believes that this isolation removed any outside influence and also gave staff unchecked powers which allowed a potential for abuse to thrive. Coupled with this, Byrne believes that it allowed society to be happily ignorant of how fellow human beings were being treated and therefore society could ignore the need for improvements in these conditions.

In Ireland, in the 1800's, there were a few prominent Dublin citizens who lobbied for government funding and for voluntary donations in order to set up specific institutions for people with intellectual disability. This reflected similar developments that were beginning to emerge in the United Kingdom, and was based on the notion that these children could be cured or a least taught to lead

a useful life. In keeping with this Stewarts Hospital opened in 1869 and was known at the time as 'Stewarts Institution for idiot Children'. Stewarts Hospital still exists as a service for people with intellectual disability and is located in Palmerstown, Co Dublin. At the onset this institution was intended for one hundred children who were deemed educable. The assumption was that once the person reached eighteen years of age they would return to their families 'trained' and ready for life. As the service received voluntary donations, donors were allowed to elect children for entry to the institution. Over time, more severely disabled children were accepted, most of whom did not return home at eighteen years of age. This limited the availability of vacancies and the demand for the service increased accordingly throughout Ireland (Byrne, 1979). In response to the ever increasing demand for education and rehabilitation of people with intellectual disability religious orders began to respond.

1.3 The influence of religious organisations in the care of people with intellectual disability

Robbins (1992) reported that the number of people in the 1800's being admitted to the workhouses or asylums was spiralling out of control and alternatives were needed. A funding decision was taken by the Government at the turn of the 20th century to provide accommodation away from workhouses or asylums. This move towards housing people with intellectual disability away from workhouses and asylums saw the opening of St Raphael's Hospital in Youghal and St Ita's Hospital in Portrane in the early nineteen hundreds. These hospitals provided units specifically for people with intellectual disability. Similarly, a home and school for children with intellectual disability under the management of the Daughters of Charity was opened in Cabra in 1926 following the abolition of the workhouse in 1923. The Daughters of Charity took over an estate in Clonsilla (1943) and the Guinness house in Glenmaroon (1950) which also provided services to people with intellectual disability. Other religious orders followed suit and special centres for people with intellectual disability were opened across the country at various locations in Blackrock (1931), Stamullen (1942), St Mary's, Drumcar, Co Louth (1946) and St Raphael's, Celbridge, Co Kildare (1952) by the St John of God Brothers. The Brothers of Charity opened a centre at Glanmire in Cork (1939) and in Kilcronan, Galway (1952). The Sisters of La Sagesse founded Cregg House, a service in Co Sligo (1955) and the Sisters of Charity of Jesus and Mary opened Moore Abbey in Monasterevin, Co Kildare (1946) and St Mary in Delvin, Co Westmeath (1954). This saw the start of the specialisation of the education and support service to people with intellectual disability, a practice that continues in Ireland to date.

Robins (1992) discusses the belief-systems underlying the work of religious orders that were funded by the state in order to provide care and education to people with intellectual disability during the early to mid 1900's. The religious perspective viewed the person with intellectual disability as being 'special', 'innocent', 'angel-like' and 'close to God'. Robins argues that, in a religious context, 'special' meant 'apart'. The religious orders viewed their services for people with intellectual disability as Gods work which they undertook by removing people from everyday life and spared them from the demands of the broader society. Bequeath with large period dwellings

and in an effort to make charitable use of these buildings religious orders developed services in the large country manors miles from towns and villages. This became the norm throughout Ireland. This trend formed the foundation for many services for people with intellectual disability and currently persists. In the 1950's many families began to resist the offer of residential schooling for their family member with intellectual disability as these services were frequently in the context of large institutional settings long distances away from home. This initiated consumer group advocacy.

1.4 The initiation of the Parents and Friends Associations

The 1950's saw the emergence of the first parents and friends groups in Ireland. These groups began to advocate for the provision of local services for people with intellectual disability (Robinson 1987). One of the first promoters of change was Mrs Patricia Farrell. Mrs Farrell placed a notice in the *'Irish Times'* (1955) to announce a public meeting in Dublin on the topic of disability. Following this initial meeting, a cohort of parents of children with intellectual disability continued to meet regularly and the movement gathered momentum. A public meeting in the Mansion House was announced in 1955 for interested parties. A large crowd gathered for this meeting and a committee was established which saw the birth of an Association of Parents and Friends of Mentally Handicapped Children (*Irish Times*, 1955, pg 19).

Similar groups of 'Parents and Friends of the Mentally Handicapped' continued to emerge throughout Ireland often with the aim of ending the segregation of people with intellectual disability in institutions and seeking more of a partnership with professionals such as teachers, nurses and psychiatrists, rather than handing over the care of their family member. They also wanted to change the prevalent idea that parents, families and communities had little or no role to play in the development of the child with disability (Robinson 1987).

As parents and friends groups flourished throughout the country the National Association of the Mentally Handicapped in Ireland (NAMHI) was established in 1961. The role of NAMHI, now known as Inclusion Ireland was and is to advocate for the provision of local services that support people to have fully inclusive and self determined lives. At the same time, many special services were also changing in important ways. Keen to provide the best support services with the most highly skilled and professional workforce led to the development of many specialised services throughout Ireland.

1.5 The development of specialised services

The development of services for people with intellectual disability in the latter half of the 20th century saw the beginning of a process of specialisation. The Commission of Inquiry on Mental Handicap (1965) described the existing status of services for people with intellectual disability in Ireland. It called for greater equity and fairness and inspired the development of local facilities across the country. Special centres and special schools were developed in the 1960's which also

introduced the development of a range of specialised professions. These included registered nurse mental handicap (RNMH, now RNID), special education teachers and other professionals such as occupational therapists (OT), speech and language therapists (S&LT), physiotherapists, psychologists, psychiatry and social workers.

A range of therapies were devised that required special equipment including hydro-therapy pools, multisensory rooms and snoezelen rooms. The underlying assumption in specialisation was that people with intellectual disability had special needs. The model was that more sophisticated and varied specialisations led to a service that could respond to a broad range of special needs in a highly sophisticated and nuanced manner. Local parents and friends groups were guided by the zeal of the specialist movement that something special was better than something ordinary.

In order to promote full citizenship of people with intellectual disability Irish Government policy at the time began to acknowledge the importance of inclusion, participation in mainstream society and the significance of valued social roles for people with intellectual disability (Robins, 1986).

1.6 Current Government policy and the development of the transfer programme

Throughout the twentieth century, in Ireland, home for many people in care with intellectual disability was in a large residential centre, institution or psychiatric hospital. These facilities were situated on the outskirts of large towns with the 'inmates' hidden away, protecting the community from the 'insane', 'mentally sick' and 'retarded' (Robins, 1992). By 1981, the census figures showed that there were approximately 1,900 people with intellectual disability in the care of psychiatric services (Mulcahy & Reynolds, 1984). Others were placed in the care of religious orders and in later years in the care of Health Boards, the first Health Board facility in Ireland being St Peter's Centre, Castlepollard, Co Westmeath.

A report of the study group on the development of psychiatric services *'The Psychiatric Services - Planning for the Future'* (1984) recommended that people with intellectual disability would not in the future be admitted to psychiatric hospitals and that those with intellectual disability already living in a psychiatric hospital be separately catered for from those with a mental illness. It also recommended that some of this cohort be considered for placement in specialised community services with adequate back up facilities.

The *'Needs and Abilities – A policy for the intellectually disabled'* report of 1990 to the Minister for Health outlined the best approaches to meet the needs of and realise the abilities of people with intellectual disability (Department of Health, 1990). The report recognised that people with intellectual disability have the right to live as others in the general community. This vision placed an onus on the Government to respond positively by planning to provide community based services with an emphasis on positive quality outcomes for the people concerned.

The two centres, Lough Sheever Centre in Mullingar and Alvernia House in Portlaoise were de-designated under the Mental Treatment Act 1945 and these centres became part of the community care programme offering services to people with intellectual disability. For the purpose of this research the focus is on these two centres and St Peter's Centre, Castlepollard which were all part of the former Midland Health Board (MHB) area where in 1989 and in line with *Planning for the Future*, (1984) areas of the two large psychiatric hospitals were separated from the psychiatric services and devoted to the care of 150 adults with intellectual disability.

The Midland Health Board (MHB), as part of its 1998 service plan, established a project team to review the future direction of service provision for the large numbers of people with intellectual disability who continued to live in its three large residential centres (N=206). As a result of the recommendations of the project team the transfer programme was subsequently established (MHB, 2001). The Midland Health Board's transfer programme secured ring fenced funding to re-house the 206 people with intellectual disability from the three large residential centres located at: Lough Sheever Centre, Mullingar, Co Westmeath, Alvernia House, Portlaoise, Co Laois and St Peter's Centre, Castlepollard, Co Westmeath to community based settings

The transfer programme was also in keeping with the Irish Government's Health Strategy *"Quality & Fairness – A Health System for You"* (2001) which states *"complete programme to transfer people with intellectual disability currently in psychiatric hospitals to appropriate accommodation as soon as possible and not later than the end of 2006" (pg 83).* The Quality and Fairness strategy further endorsed policies previously outlined in *'Planning for the Future'* (1984). *Quality and Fairness* (2001) is a recent blueprint to guide health policy makers and service providers towards the vision of a health system in the field of intellectual disability comparable to the best examples in other countries. One of its principles is that all new service developments will be co-ordinated through Person Centred Planning (PCP) with the principles of community integration at its core. In 2011, the HSE published a long awaited document entitled *'Time to Move on from Congregate Settings'* a strategy calling for the continued transfer of people with intellectual disability still residing in congregate care settings in Ireland (N=4000). This strategy describes it as essential for current programmes to include PCP, advocacy, support for community inclusion, in-home supports, community based primary care and specialist supports and a right to work and lifelong education.

As described above, disability service provision in Ireland has gone through a process of evolving change through the years, with religious organisations being the predominant service providers for the last fifty years. Specialised services for people with intellectual disability were developed in earnest throughout the 1960's and it was from this process of specialisation that the notion of normalisation was introduced into Ireland. *Planning for the Future* (1984) was an attempt to separate people with intellectual disability from people who had a psychiatric illness, and made recommendations to move people with intellectual disability from large psychiatric hospitals to community services. *Quality and Fairness* (2001) reiterated the recommendations of Planning for the Future, and so community intellectual disability services continued to develop. In the MHB region the transfer programme (2001) started a process of de-institutionalisation for 206 people

with intellectual disability from three large institutional settings. As part of the de-institutionalisation process in the midlands, person centred planning has been utilised with the stated aim of making the services about the person rather than about the services. The challenge today is not only to effect closure of the large institutions but also at the same time to continue to meet the support needs of the individuals as they move to community living.

1.7 Conclusion

In the context of this historical overview of intellectual disability services in Ireland and with particular reference to the three centres described let us consider the role of person centred planning. Good practice guidelines at the time encouraged services to ensure that each individual had a PCP in place. The above three centres initiated training in PCP for all staff. The training was initiated to ensure a high standard of PCP and included everything from getting to know the person, a background in the philosophy of O'Brien's five service accomplishments and the importance of aims, goal setting and skills teaching about meetings. This training and preparation led to an assumption that the PCP's were of a high standard and that when people with intellectual disability transferred to community settings it was vital that the PCP went with them. An assumption was made that the function of the PCP was to provide an encyclopaedic source of information for staff who did not know the individual. The naivety of that assumption was that all staff had to do was read a person's PCP and they had all the knowledge required to fully understand and care for the person. It was also assumed that the PCP would provide a rich source of guidelines for true community living with valued social roles for each individual with intellectual disability. Furthermore, it was assumed that families had been included in the process as they were assumed to have been involved with the person prior to their move to the community, but this was never verified.

While many people would like to believe that transfers were decided by the choice exercised through their own PCP, the reality was that the large centres were closing and people were moving regardless. People moved with their PCP and this was seen as a safety net to ensure that their lives were continually monitored and that any deficits would be readily corrected.

In a professional capacity the researcher became Project Manager of the Transfer Programme of the three Midland centres. Because of firsthand knowledge of the people and the places in question also came a personal interest and imperative to ensure that people's lives improved when moved from the large centres. I had a deep professional interest and personal desire to establish whether PCP really contributes to the lives of people in the community. I found myself questioning to what extent PCP has a role in safeguarding and improving their lives. It was of particular importance to ensure that people's lives actually improved and that there were no deleterious effects on their lifestyle as a result of their move. A stated concern and indeed belief of some people was that because the standard of healthcare and social well being in the institutions was high it would be impossible to replicate this standard in the community. With this given stated concern it was important to consider the efficacy of PCP in the process of transferring people with

intellectual disability to community based settings. How effective was it? Were any of the assumptions correct or were there naive assumptions made about the power of the PCP?

Chapter 2

Literature Review

2.0 Literature Review

2.1 Introduction

The overall aim of this study is to examine the efficacy of person centred planning (PCP) for people with intellectual disability who have moved from large congregate care settings to community residences. In order to illustrate how the PCP movement influenced service delivery, this chapter will consider the traditional models of care for people with intellectual disability. The literature review then considers alternative philosophies with particular reference to person centredness and human rights. By way of definition concepts such as O'Brien's service accomplishments merit consideration here as these is the essence of the concept of person centredness. ***Community Presence*** is defined by the service user's presence in the community and is supported by their actual presence in the same neighbourhoods, schools, shops, recreation facilities and churches as ordinary citizens. ***Choice*** is defined by the service users being supported in making choices about their lives thus helping them to act in their own interest in everyday issues like who to live with or what work to do. ***Competence*** is defined by the service user developing competence by increasing skills and attributes that are functional and meaningful to decrease dependency. ***Respect*** is defined by service users developing and maintaining a positive reputation. It should ensure a choice of activities, locations, forms of dress and use of language that promotes the perception of people with intellectual disability as citizens. ***Community participation*** is defined by service users participating in the life of community by supporting people's natural relationships with families and neighbours to widen their network of relationships (O'Brien & Tyne, 1981).

The work of Wolfensberger and O'Brien led to the birth of PCP with a description of the value changes that underpin this philosophy. From here we move to a new model of care in the form of PCP.

The spread of PCP as a global movement is described. This leads to a redefinition of the outcomes of service provision reflecting how PCP actually demands a different approach to thinking about outcomes and the five service accomplishments. The literature review will critique PCP in practice with particular reference to possible limitations in achieving its outcomes. Research on PCP will be examined, in particular, systematic attempts to evaluate what PCP is telling us. We will find that the evidence base is limited and inconclusive and thus this study will attempt to tell us more about the reality of PCP in an Irish context. What follows is an account of how the Irish system engaged with the PCP agenda and concludes with the aims of the present study. The following topics will be dealt in this section:-

- The move out of the institutions
- Alternative philosophies – person centredness and human rights
- A new model of care – person centred planning (PCP)
- The spread of PCP
- Redefining outcomes of service provision

- Critiques of PCP
- Research evaluations of PCP
- PCP in the Irish context
- Description of aims of this current study

2.2 The move out of the institutions

This section examines services for people with intellectual disability in large residential institutions. Many people with intellectual disability were placed in large institutions for a variety of reasons including the belief that education and training would rehabilitate them, that they need protection from themselves and the hazards from a broader life in the community (Byrne, 1979). In 1970 there were over 2000 people incarcerated in one midland psychiatric hospital with no distinction made between psychiatric illness and what was then known as mental handicap (Mulcahy, 1975). The legacy is that this large institutional type model of service for people with intellectual disability endures despite efforts to seek the closure of this outdated model of service provision. We know from the report 'Moving on from Congregate Settings' that 4000 people with intellectual disability in this country continue to reside in these out dated facilities (HSE, 2011).

Through the 1950's, 60's and 70's there was an assumption that people with intellectual disability could be trained to improve their social and life skills and as such could return to their families in their own communities rehabilitated (McCormack, 2004). The harsh reality is that the effects of moving someone who was already vulnerable due to their intellectual disability from their family home further impinged on the likelihood of success of innovative programmes available at that time. People became dependent on institutional solutions to meet what was the perceived problem of disability. As the Irish population increased it was seen as good practice to develop more and more specialist intellectual disability facilities. At the same time, the process of de-institutionalisation has been occurring at a slow and gradual pace.

De-institutionalisation has been the subject of extensive research and debate over the last number of decades (Allen, 1989, Birenbaum, 1999, Felce & Toogood, 1989, Emerson, 1985, Allen, Pahl & Quine, 1988, Kendrick, 2001 & Fleming, 1996). Walmsley (2005) explores the notion that in order to understand de-institutionalisation, it must be first understood what preceded it, that is, institutionalisation. She explores institutions as a 'social policy solution' to the problem of the then termed feebleminded in early twentieth century Britain and beyond. She states that, for many of those who lived in institutions, they were unpleasant and restrictive places at best, abusive at worst.

De-institutionalisation in England and Wales between 1969 and 1993 saw the specialist hospital population fall by over 70% (DHSS, 1971, Emerson & Hatton, 1994) a change that has been mirrored in North America, Australia and in several Western European countries (Hatton, Emerson & Kiernan, 1995, Larkin, Prouty, Anderson & Sandlin, 1997, Parmenter, Cummins, Shaddock &

Stancliffe, 1994). Emerson et al (1997) found that community care is far superior to institutional care.

Is simply moving people from institutions to community residences always the best alternative to institutional care? Researchers question the adequacy of replacement community services for people with intellectual disability. Johnson and Traustadottir (2005) demonstrate that one of the difficulties faced as the de-institutionalisation process rolls out is that people with intellectual disability continue to be managed in the community rather than allowed to be individuals with preferences and particular needs. A place in the community is offered to people with intellectual disability but it may not necessarily be what the person wants or needs (Felce, 1998, Emerson 1985). Johnson and Traustadottir (2005) argue that this may be attributed to lack of resources and having to manage large groups of people. In their experience, people who listen to and help people with intellectual disability are family members, and to a lesser extent, staff members supporting the person with intellectual disability. However, they argue that the family agendum can be mixed, and can at times run counter to the interests and needs of the person with intellectual disability.

Contemporary thinking on service provision for people with intellectual disability internationally is based on the school of thought that services should be delivered locally in community settings and should be based on individual need, concepts that Nirje (1969), Wolfensberger (1972) and O'Brien (1981) have been expounding since the 1960's, 1970's and 1980's. Kendrick (2007) argues that although many of us think we are responsive to people and their needs, the reality of much every day service practice is not at all consistent with this self image. He argues that the vast majority of service models are designed without reference to the service user and usually at a point well before the person seeks support. This, he argues, significantly diminishes the likelihood that the services available are the best option for the person with intellectual disability. People with a vested interest in congregate care are opposed to this contemporary way of thinking and advocate for the traditional institutional residential type accommodation that endorses the concept that people with intellectual disability should be protected from society. In his study, Freckleton (2005) puts forward two perceptions for this which he believes lead people to think that institutions are suitable places. These include the view that people with intellectual disability are dangerous and cause problems for society, and they should be looked after and cared for in ways that would help them to live happy lives locked away from the reality of society.

Rimland (1997) in his research demonstrates that institutions have been under sharp attack for decades, a finding endorsed by Johnson and Traustadottir (2005). This, Rimland believes to be spurred by revelations of deplorable, neglectful and abusive conditions thus resulting in calls from well meaning advocates for people with intellectual disability to close the institutions. But he describes as naïve and euphemistic the belief that moving into smaller group homes equates to living in the community. Rimland argues that the cure of closing the institutions is often worse than the disease and he sounds a note of caution where he considers some group homes and some institutions as 'snake pits'. He argues that millions of American people with intellectual disability

are at risk from poor quality care, questionable and even criminal management practices by service providers and lack lustre monitoring by public health and welfare agencies. He argues that a disturbing pattern of abuse, neglect and fiscal mismanagement has emerged in community group homes. He attributes this to under trained, poorly paid and an inadequately screened workforce charged with the responsibility of caring for people with intellectual disability who may have additional physical, mental, psychological and complex needs (Rimland, 1997).

Johnson and Traustadottir (2005) give accounts of 'warm relationships between residents in institutions and staff members' (p. 21). However, they are superseded by the memories of abuse and neglect of people with intellectual disability in institutions. They found that the abuse was part of the system that had to be 'borne rather than resisted' (p. 21). They concluded that it is too simplistic to think by simply closing institutions that the problem of abuse in intellectual disability services is curtailed and that the person with intellectual disability lives an inclusive life in the community. It is worth noting that one in four people with intellectual disability experience abuse irrespective of their circumstances (Murphy, 2000).

Strauss and Kastner (1996) call for the careful management of the de-institutionalisation process based on their finding that the death rate was higher when people moved to non institutional settings than it was in the hospital settings. They sound a further note of caution that the closure of the institutions and their replacement by care in the community is not a simple task. They believe that it is a complex process that needs to be carefully planned and managed with an inbuilt system of monitoring and constant review.

Johnson and Traustadottir (2005) found that some people continued to live in the institutions, not because of their disability but because they were 'useful'; that is, necessary to the maintenance of the institution. People with challenging behaviour were not in locked wards because of their intellectual disability but because management decided that they were a risk to themselves and others. They found that their challenging behaviour was not seen as something that may have been due, at least in part, to their life experiences but was seen as integral to the intellectual disability. They argue that challenging behaviour, poverty, abuse and family problems led many people with intellectual disability to be taken from their community and placed in institutions. They also document ongoing tensions within institutions between the need to care for and protect people with intellectual disability and efforts to control and exclude them as possible dangers to the wider community.

These complex issues have led to the unresolved perpetuated perspectives of institutions and are cogently debated by people loyal to the institutional model. Rimland (1997) argues that he is not opposed to group homes. He believes that some are excellent, just as some institutions are excellent. He argues that he has seen both models which boast outstanding programmes, committed and well trained staff members and happy residents. He argues that this does not mean that either type should be shut down but that both models must be improved upon and be vigilantly monitored. He holds that it is time to replace de-institutionalisation with a 'common sense'

approach that acknowledges the diversity of people with intellectual disability with this cohort requiring the need for institutional care, group homes and other options.

Irish exposés such as Mary Rafferty's Primetime Investigates Programme 'Behind the Walls' (2011) and Annie Ryan's 'Walls of Silence' (1999) further discredited institutionalisation for people with intellectual disability. These examples reinforced an understanding of people with disabilities as a disadvantaged and segregated minority and fuelled the move to develop comprehensive services in local communities. The fact that many professionals continued to defend institutions and advocate for congregate services and segregated special education opened deep questions about the legitimacy of the professional perspective (Birklen & Bogdan, 1976). According to Blatt (1981) it is possible for well meaning professionals to unknowingly destroy lives by the way they choose to tell people's stories and recommend or refer people to congregate settings.

How did normalisation alter professional perspectives? Acceptance by governments of the normalisation concept worldwide, led to the closure of long stay institutions beginning in earnest (Wolfensberger, 1972). One would question if the closure of institutions alone equate to improved quality of life for people with intellectual disability. "Advocates of de-institutionalisation have implicitly assumed that the happiness of people with mental retardation is inevitable when they are transferred from an institution into community residential and day service programs" (Harner & Heal 1993 pp. 222). This is a questionable assumption as suggested by research (Pratt, Luszcz & Brown, 1980). "Just as large-scale institutions have been shown to vary considerably in the care they provide, community-based facilities vary also" (Pratt, Luszcz & Brown 1980, p. 188). One can conclude that the move to a community setting is, in itself, no guarantee of a person centred inclusive life for the person with intellectual disability.

In contrast, Emerson and Emerson (1987) argue that community services are more conducive to the delivery of quality services than traditional or relatively new institutions. They believe that the conditions which typically exist in community houses facilitate the development of greater independence and autonomy, while conditions in institutions promote a culture of dependency. On the other hand, advocates of institutional care believe that residential centres or institutional care can offer people with intellectual disability greater specialist care, training and more security (Freckleton, 2005). Felce and Toogood (1988) found that adults with intellectual disability living in small group homes used community amenities significantly more than they did when living in institutions and also significantly more than residents of larger community residences. They also found that a major strand in the argument for replacing institutional care with community care are the opportunities created for integration, participation in the community and the maintenance of family and other social relationships. This is further endorsed by Emerson and Emerson (1987) where they identified a range of significant barriers in institutional settings which prevented the implementation of successful rehabilitation programmes.

Schalock et al (1981) demonstrated that the use of community amenities was high for people with intellectual disability who resided in independent community places. People with intellectual

disability based in the community without the support of intellectual disability agencies have grown more independent with time (Edgerton & Bercouici, 1976; Edgerton, Bollinger & Herr, 1984). In contrast to this, adults who have a more severe intellectual disability living in staffed community settings have been shown to differ markedly in restrictiveness and levels of involvement in community life (Bjaanes & Butler, 1974; Moore, Butler & Bjaanes, 1976; Birenbaum & Re, 1979).

Bratt and Johnston (1988) looked at five adults with intellectual disability before and after moving to a smaller community setting and found improvement in quality of life in terms of residents going out more and engaging in less inappropriate behaviour. However, closer scrutiny of the data revealed a lack of substantive community integration. Opening up opportunities for more fulfilling lifestyles is considerably more difficult than changing buildings and it is here that Felce (1998) queries some policy makers belief that community resettlement will prove a panacea for many of the problems which people with intellectual disability encounter in their daily lives. He sounds a note of caution to this idea in that "Newly provided services have not always embraced the full extent of envisaged reform leaving the quality of life of those served diminished compared to what could otherwise be achieved" (Felce, 1998 p. 4).

In a study carried out by Felce and Perry (1995) the extent of resident engagement in activity was observed and they found that it was related to their ability levels. If the person had the skills to be independent he/she could occupy himself/herself for the majority of the time. The study also found that the people who were severely disabled were often disengaged for most of the time. Bratt and Johnston (1988) in describing new staffed houses in England, found little evidence to suggest that the residents were being supported in ways that increased their competence. Jahoda et al (1990) assessed the social activity of people moving from long-stay hospitals to the community and found that this led to very few opportunities for them to meet people without intellectual disability, a view further endorsed by Felce (1999) where he observes that most people with intellectual disability live on the fringes of society and do not take part in many community activities.

Emerson and Hatton (1994) consider that people with intellectual disability tend to express high levels of satisfaction with their current provision, irrespective of actual environmental conditions (Emerson & Hatton, 1994; Hatton & Emerson, 1996; Felce, 1999). People with intellectual disability may be slow to express dissatisfaction with institutional living because it is all they know. Furthermore they may be afraid that they would be punished in some subtle way if they complain and they may also have a fear of the unknown. The majority of people with intellectual disability resettled from the National Health Service's (NHS) mental handicap hospitals into small community based provision expressed a clear preference for their new support arrangements. Few residents resettled into small community based provision expressed a wish to return to the institution (Emerson & Hatton, 1994). This finding was further endorsed by Johnson and Traustadóttir (2005) where they demonstrated that although people had moved from an institutional setting they did not want to return to the institutions even when they faced problems living in the community. They state that "Sometimes their lives are good: people talk about meeting up with families, walking,

going on holidays and doing fun things. But they also talk about the loneliness and not having meaningful work or choices in their lives" (Johnson & Traustadóttir, 2005, pp. 14-15).

The approaches that appear to be critical for the success of the community care model include: choice, independence, use of community amenities, increase in family contact, the size of the residential venue and the staff ratio (Emerson & Hatton, 1994; Hatton & Emerson, 1996; Felce, 1999). In the United Kingdom, where the philosophy of community care and resettlement programmes has been implemented, large hospitals have discharged the majority of their "patients" into local communities (Fernando, Kohen, Sebaratnam & Mathew, 1997). Researchers argue that there is an overall marked improvement in individuals' communication skills, social interaction and a decrease in stereotyped behaviour for people who are resettled in the community. They posit that these improvements may be related to the higher staff/resident ratio in the community setting, which gives more opportunity for staff to engage in constructive activities with the resident (Fernando, Kohen, Sebaratnam & Mathew, 1995).

Finnerty and McCormack (1997) suggest that people with intellectual disability who have experienced both disempowerment and subsequent empowerment are the people best placed to describe what they have gained from the experience. In the traditional model, the service managed the person's disability, funding drove the interventions and professionals determined the desired outcomes. A number of innovative strategies have been developed by services in recent years which support the empowerment of the person with intellectual disability by really listening to what they have to say about their life and aspirations. These strategies include person centred planning (PCP), optimal individual service design (OISD) and the promotion of self-determination, inclusion and self-advocacy for people with intellectual disability.

2.3 Alternative philosophies – person centredness and human rights

Person centredness, with its underpinnings in Wolfensbergers principles of normalisation which he describes in 1996 included the good things in life, dignity, respect, acceptance with a sense of belonging. This he believes can be achieved through education and the development of one's capabilities with a voice in the affairs of one's community and opportunities to participate. This can be achieved by ascribing to people marginalised by intellectual disability a decent standard of living, including a normative place to live with opportunities for work and self expression.

The reality of the ineffectiveness of person centred service provision in very large groupings became highly questionable with good practice dictating that services for people with intellectual disability should be provided in small community based settings. The use of community based alternatives to institutions, focusing in particular on small staffed houses and group homes is widely documented. Exponents of transferring people with intellectual disability from large congregate care settings to community based residences argue that people with intellectual disability are entitled to as normal a life as possible and that living in an ordinary house (in this case a group

home) in the community offers people many opportunities and benefits (Wolfensberger, 1972, Emerson, 1985 & Felce, 1999).

With the aim of considering person centred outcomes, research interests moved to considering the success of community living for people with intellectual disability. De Kock et al (1988) demonstrated that use of community amenities for people with intellectual disability was greater among residents of ordinary housing services than residents of larger community services. Felce and Repp (1992) showed that residents were more constructively occupied in smaller community settings. Felce and Perry (1997) found small size to be positively associated with normalisation ratings among residential settings in Wales. In the United States, Stancliffe (1997) found small size predicted greater resident choice and Thompson et al (1996a; 1996b) showed ordinary housing services were more homelike and that homelike provision, service philosophy and resident behaviour were positively associated. In Norway, Tossebro (1995) found smaller settings (five and below) were more homelike than larger settings and that residents in such homes had greater self-determination.

Johnson and Traustadóttir (2005) looked at the full process of deinstitutionalisation in the context of PCP. By this, they mean looking full circle at this process from institutional life, moving out, living in the community and future possibilities. They highlight that earlier works (Blatt & Kaplan, 1966, & Wolfensberger, 1969) on deinstitutionalisation focussed on the negative side of institutional care and as community care gathered momentum studies emerged on the analysis of community living and the process of deinstitutionalisation (Booth, Simons & Booth, 1990, Tossebro, Aalto & Brusen, 1996, Felce, 1999, Emerson 1985, Emerson & Hatton, 1994). They further indicate that an increasing number of studies have started to describe issues relating to the inclusion of people with intellectual disability in the community. Johnson and Traustadóttir (2005) found that those who remain longest in institutional care are those with higher support needs, are older, and are judged as 'most at risk'. With the increasing emphasis on rights for people with intellectual disability, the focus on care has shifted to one of inclusion. It can be argued that the control previously exerted on people through locked doors and high walls has now translated into the more subtle discourse of risk management and risk assessment (Rose, 1998, 2000; Johnson & Tait, 2003).

The human rights movement has been influenced by the rights based agenda of marginalised populations including people of colour, ethnic and religious minorities, women, children and refugees, to the rights of what is termed 'invisible, under protected minorities', particularly people living with HIV/AIDS, homosexual men and women and persons with physical and mental disabilities. The promotion of human rights has come to be recognised as a universal value with internationally recognised meaning (Herr, Gostin & Koh, 2003). Herr et al (2003) found that each of these minority groups have traditionally been hidden from society and have long been subjected to widespread discrimination, which has never been well chronicled or subject to sustained public scrutiny or criticism. People with intellectually disability ranked among the World's most vulnerable and at risk populations as they are regarded as different and because their disability renders them less able to either assert their rights or to protect themselves against blatant segregation (2003).

In common with others with a variety of disabilities, a large proportion of the world's population of people with intellectual disability still live in horrifying conditions (Herr, Gostin & Koh, 2003). Robinson (2000) indicated that it is well known and documented that people with intellectual disability frequently live in deplorable conditions and face physical and social barriers, which sadly eludes person centred practices and prevents their integration and participation in the community. Robinson (2000) remarks that millions of people with intellectual disability throughout the world are segregated and deprived of virtually all of their rights and sometimes lead wretched and marginalised lives. She argued that, because of their incapacity to protect or even to understand their own interests, people with intellectual disability are at the greatest risk. She made reference to the many mental institutions and psychiatric hospitals worldwide that she believes stand in dismal conditions where patients have to contend with inhumane and unsanitary living conditions, where they are treated as subhuman prisoners receiving little or no medical care. She posits that article one of the Universal Declaration of Human Rights (2000) declares that all humans are born free and equal in dignity and rights and national and international organisations share a joint responsibility to ensure that the rights proclaimed in international norms and national legislation are translated into genuine and concrete improvements in the lives of people with intellectual disability.

It is documented by Herr (2003) that human rights workers need to learn how to help people with intellectual disability to speak up for their own rights and to integrate the language, tools, strategies and networks of the international human rights movement into their daily struggle for dignity, equality and justice. Such a pattern began to unfold where advocates have first sought to reconceptualise disability as a human rights issue and only secondary as a medical issue. Reflecting the true essence of PCP Robinson postulated in her address to the International Disability Foundation (2002) the most important tool in tackling inequality is to enable those experiencing it to remedy the power relationship and to take some control. She believes that this is a concept of rights that requires that those who are furthest from the cabinet table own the rights that inhere to them by virtue solely of their humanity. She continued in her address that ownership of this kind enables people to describe their condition, then to challenge it and then to ensure that any decisions taken in the organisation and the ordering of their lives are made 'by and with' them, not 'about and for them' (Robinson, 2002). In Ireland the use of instruments designed by Wolfensberger yielded the information that provided the evidence base for changing the structure of the services to a more person centred practice.

Wolfensberger's (1972 & 2011) principles of normalisation were extremely influential in the development of quality tools to measure the huge disparities between the life conditions of people with intellectual disability and the ordinary population. Wolfensberger and colleagues developed the Program Analysis of Service Systems (PASS; Wolfensberger & Glynn, 1975), which was updated in 1983 (PASSING; Wolfensberger & Thomas, 1983). These measures had a very dramatic impact in the dawning of the realisation that institutions were highly inappropriate for people with intellectual disability to spend their lives and were tantamount to the violation of human rights. Although revolutionary, they did not consider subjective psychological variables such as satisfaction and happiness, which are regarded as essential for person centredness in practice.

From influences such as Wolfensberger's principles of normalisation and the human rights movement PCP has emerged as one unifying concept regarded by all stakeholders as a necessary action required to safeguard the overall well-being of the person with intellectual disability.

Through the lens of PASS, the originators of PCP learned difficult lessons, including seeing opportunities for improvement that was ignored or dismissed by the people who managed the services. The people who managed the services were part and parcel of the services and until they had at their disposal the PASS instruments had no capacity to evaluate their practice and were restricted in their understanding of how to progress services in a person centred way A shortcoming of the PASS evaluation, useful and all as it was at the time, was restricted to looking at the context of service delivery such as the buildings, the location and the modes of transport used, commenting whether these situations were either normative or not.

Mansell et al (2009) describes Person Centred Active Supports (PCAS) as a value to action approach which stems from O'Brien's (1981) five accomplishments of community presence, choice, competence, participation and respect. The PCAS approach distinguishes between engagement in meaningful activities about the person's life such as participation in meal preparation and all activities of daily living versus disengagement which is characterised by individual's lack of participation such as a person waiting for daily activities to happen to them. The essential components of PCAS conclude that every moment has potential for involving the individual. Graded assistance is used to ensure successful participation by providing just enough help for the individual to experience some successful participation. A key principle of PCAS is helping people to engage 'little and often' so they build up experiences of success and enjoyment that increase their motivation, maximising choice and control.

PCAS highlights the importance of listening to the individual with intellectual disability to what they are saying, how they are saying it and considering what they are not saying. It calls for in-depth discussion with the person including the use of alternative communication such as object cues, picture exchange communication system (PECS), lámh (Communication Augmentation Sign System) and assistive technology with the object of trying to establish the individual preference for activities and support styles. Mansell and Beadle Browne (2009) would concur that you can provide PCAS across the spectrum of service settings such as day services, community residences and the persons own home. Kendrick (2009) would argue that you can never be truly person centred when people with intellectual disability are grouped together on the basis that their disability can be serviced by support staff because they have similar levels of need. Kendrick (2009) introduces the Optimal Individual Service Design (OISD) model based on the notion that true person centredness is based on the individual's specific needs and aspirations. The model for the OISD is derived from what Kendrick calls the normative/universal needs including nutrition, healthcare, a place to live, a place to work, financial autonomy, a valued reputation and respect, valued social roles and images, social inclusion, mobility, safeguards, lifelong learning and personal growth, transportation, recreation, communication, spirituality, identity and culture, relationships and the respect for and capacity to exercise civil rights.

Kendrick challenges service providers to think of crafting service provision in new and individualised forms in order to maximise true person centredness. Ironically, Kendrick illustrates that when you approach people with intellectual disability one by one the net effect is a service that is not only better for the individual and their families but also less costly and closer to the person centred ideology.

2.4 A new approach to supporting people with intellectual disability influenced by person centred planning (PCP)

The continued forum for refining and developing new ways to understand and explain the relationship among disability, community and organised services led some to explore alternative ways of framing the search for service quality and PCP. O'Brien (2002) refers to three innovations in the process of normalisation teaching that were of significant importance in the development of PCP. These include time spent on thoughtful discussion of the overall situation of the person with intellectual disability of which deep listening is a vital component. Simple questions he believes guide this discussion and include what are the individual's most important needs and how these can be met in the least restrictive and most inclusive way. In his person centred practice O'Brien advocates the use of straightforward language rather than professional jargon.

In an intellectual disability context, person centred planning (PCP) is a broad term that describes a concept developed from the work of John O'Brien with a community of practitioners in the USA with its origins rooted in Wolfensberger's principles of normalisation theory (1972). The concept of normalisation has significantly affected the lives of people with intellectual disability and was premised on the assumption that people with disabilities could live lives as near to normal as possible. Wolfensberger postulated that normalisation theory if rigorously and coherently utilised as a culturally valued means then devalued people have the best chance of living socially normative lives and gaining socially valued roles.

What followed from Wolfensberger's principle of normalisation was his theory of Social Role Valorisation (SRV). This new understanding of supporting people with intellectual disability emerged from a deep consideration of the importance of relationships espoused by O'Brien as one of the five service accomplishments. The cases in this study document the lives of the people who had been institutionalised for the most part of their lives and consequently their social roles, as family member, neighbour and friend, had been removed. For Wolfensberger SRV focuses on transacting social value into human relationships and human services (Wolfensberger, 1983, Lemay, 1995). Wolfensberger defined SRV as "the application of what science can tell us about the enablement, establishment, enhancement, maintenance and/or defence of valued social roles for people" (Thomas & Wolfensberger, in Flynn & Lemay, 1999 p. 125). The basic concept of SRV is that people are much more likely to experience the good things in life if they hold valued social roles than if they do not (Wolfensberger, Thomas & Caruso, 1996). One of the major objectives of SRV is to create or support socially valued roles for people in their society because if a person holds valued social roles, that person is highly likely to receive from society those good things in life

that are available to that society and that can be conveyed by it, or at least the opportunities for attaining these (Osburn, 2006).

Wolfensberger and Thomas (2005) believe that SRV is especially relevant to two classes of people in society: those who are already societally devalued and those who are at heightened risk of becoming devalued. In any society, there are groups and classes who are at value risk or already devalued in and by their society or some of its systems. Devalued individuals, groups or classes are far more likely than other members of society to be treated and to be subjected to a systemic and possibly lifelong pattern of such negative experience and include being perceived and interpreted as deviant due to their negatively-valued differences including disability (Osburn, 2006 pp. 4-13).

Kendrick (1994) argues that in reality not all people are positively valued in their society and that is what makes SRV so important. He believes that SRV can help to prevent bad things from happening to socially vulnerable or devalued people and can also increase the likelihood that they will experience the good things in life. He argues that the good things in life do not usually come to people who are devalued in society. For people with intellectual disability most good things in life are beyond their reach and are denied or withheld. Osburn (2006) holds that the probability that a person benefits from a socially valued role depends on efforts to improve both their image and their competencies. He stresses the urgency of moving SRV from the academic realm of social science theory and research to every day practice. He believes that because people with valued social roles go on to lead desirable lifestyles and thus having an enhanced self worth and competency. This concept of normalisation and SRV principles led to the recognition by stakeholders of the need for more normalising services for people who were marginalised by disability. But does this in itself enhance the person centredness for individuals with intellectual disability?

In contemporary intellectual disability services, the emphasis is on promoting person centredness and independence whereby the person with intellectual disability can perform essential activities of daily living in order to live as full and normal a life as possible of their own crafting (Mansell et al, 2009). The Department of Health in the UK (1998b) state its aim is the joint health and social care strategy which is responsive to individual needs, is person centred and promotes people's independence through a flexible and diverse spectrum of provision. Emerson and Hatton (1994) found that the implementation of a "person centred active support" resulted in providing residential supports when and where it was needed. This led to increased levels of expressed satisfaction with accommodation, day activities and choice. According to Emerson and Hatton (1994) the number of hours and days per week in which service users had regular and predictable access to structured day activities was positively associated with levels of expressed satisfaction with accommodation, day activities, friendships and relationships.

Johnson and Traustadottir (2005) argue that in order for people with intellectual disability to live successfully in the community they need strong advocates to listen to what they have to say about themselves and what they want from life. They posit however, that if people have high support

needs or challenging behaviour they are at risk of ending up in new institutions only this time in community based residences.

Hatton and Emerson (1996) found that increased friendships and relationships were associated with people having a greater proportion of people with intellectual disability in their social networks. These findings are consistent with the existing literature, which indicates that few people with intellectual disability in residential care have meaningful relationships with people who do not have intellectual disability, outside of their immediate family or employees paid to be with them. Developing relationships is an important aspect of the person centred process, which enjoys widespread favour in all service settings for people with intellectual disability. There is little academic evidence to suggest that such meaningful relationships develop over time for people living in community based provision without active intervention (Lowe & de Paiva, 1991; Evans, Todd, Beyer, Felce & Perry, 1994; Rapley & Beyer, 1998). In any event, people with intellectual disability themselves place significant value on their friendships with other people with intellectual disability and the staff paid to be with them (Atkinson, 1987).

Person centred active supports (PCAS) are also required to enable people to reap the benefits of living in their local community. PCAS according to Beadle-Brown (2012) is a way of supporting people with intellectual disability which puts the person at the centre of their own lives and focuses on enabling and empowering people to experience a range of activities but new and familiar, in a wide range of different contexts, with just enough help and support so that people grow in independence, have real choices and control their own lives and become a valued member of their community. McConkey (1998) highlights the many barriers that face people with intellectual disability when they attempt to integrate with local communities. He found that these include social isolation, lack of friends and negative attitudes towards them. Notwithstanding this, Johnson and Traustadottir (2005) demonstrate that few people want to return to the institution and in most cases people's lives have improved in the community. They give an account of people with intellectual disability having more activities, increased family contact, peaceful lives and something meaningful to do during the day. This finding is also in keeping with the finding of Robertson et al (2005) where they found that the main areas in which PCP was effective were social networks, community involvement, scheduled day services, contact with friends, contact with family and choice. However, Johnson and Traustadottir (2005) argue that not everyone is happy in the community; life in the community for people with intellectual disability can be lonely, yet for some the threat of re-institutionalisation remains a 'shadow', a 'fear' or a 'nightmare'. They also argue that people with intellectual disability are not part of the planning process when moving out of institutions as they often have no choice of where to live or with whom.

In Canada, Kendrick (2001) argues that the Community Based Option (CBO) has been the largest growing system of care and has extensively helped over the last number of decades, to reduce the Provinces' reliance on outdated institutional care. The CBO is distinctive in being a system of "small options", which includes small group homes or community residences for three or less people (Kendrick, 2001). Similar contemporary approaches world-wide have seen a successful

step in which people with intellectual disability were "custodialized" and excluded from society. However, Kendrick (2001) argues that a good deal of paternalism still exists which stands in the way of allowing people with intellectual disability to have the level of control of their own lives. Typically families find it difficult to visit their family member in large institutional settings.

Felce et al (1980) demonstrates that the provision of local community services resulted in more frequent family contact for people with severe and profound intellectual disability compared to groups in traditional institutions. Felce and Toogood (1988) found that adults living in small homes experienced significantly more community amenities. There were increased levels of community and family contact experienced by adults with severe and profound handicaps after transfer to small, local homes, compared to the levels experienced in their previous mainly institutional, residential settings. Higher levels of community involvement of adults living in small homes compared with those in larger community based units were also shown. The small homes had greater autonomy and flexibility in their domestic and catering arrangements, and greater budget control (Felce & Toogood, 1988). The impact of size of residence on residents' opportunities for choice was examined for Australian adults with intellectual disability who lived in staff supported community residences housing one to five residents. Significantly greater choice was exercised by individuals living in smaller groups (Stancliffe, 1997).

In keeping with new approaches to supporting people with intellectual disability influenced by PCP individuals living semi-independently not only reside in smaller settings with less staff support but also typically have more skills (Harner & Heal,1993, Hill, Larkin & Bruininks, 1988; Stancliffe & Wehmeyer, 1995; Voelker, Shore, Brown-More, Hill, Miller & Perry, 1990) and fewer challenging behaviours. There is also some evidence that individuals with fewer challenging behaviours exercise more choice (Schalock, 1994). Hatton and Emerson (1996), Connealy, Boyle and Smyth (1992), and Maisto and Hughes (1995) all noted positive changes in adaptive behaviour of residents in such community settings.

Felce et al (1998) found residents in small houses were getting direct contact from staff for an average of only thirteen minutes every hour, although it was still higher than in traditional settings which averaged at five minutes per hour. Hatton and Emerson (1996) found the use of community based services were typically associated with greater presence in the community, with people making greater use of ordinary community facilities than their institutionalised counterparts. Fernando et al (1997) found that there was an increased level of activity and contact for people with intellectual disability within the local community after they had moved there. Hatton and Emerson (1996) commented that although most had relationships with people in the community that were neutral or positive, very few had friends outside the service. Fernando et al (1997) report similar findings although they noted that levels of participation appeared to have reached a plateau when followed up later.

Schalock et al (1989) reported that lower staffing levels were strongly associated with a more person centred quality of life. Stancliffe and Wehmeyer's (1995) views are consistent with the

proposition that continuous staff presence may inhibit choice. Interestingly, despite the fact that people with more severe intellectual disability require more support from staff, residents with lower levels of independence, adaptive behaviour or intellectual competence have been found to receive less attention, less training and stimulation, and more routine custodial care than their more able counterparts (Dailey, Allen, Chinsky & Veit, 1974; Ducker, Boonekamp, Brummelhuis, Hendrix, Hermans, Leeuwe & Seys, 1989; Grant & Moores 1977; Pratt, Bumstead & Raynes, 1976).

Hatton and Emerson (1996) found generally higher levels of participation in meaningful activities within community based services than in institutional settings. They noted that people in community based settings were likely to have a greater direct contact with staff than in institutions. The general pattern of greater participation or engagement in community settings in comparison to institutional settings was generally confirmed (Connealy, Boyle & Smyth, 1992; Felce, Grant, Todd, Ramcharan, Beyer, McGrath, Perry, Shearn, Kilsby & Lowe, 1998). However, the level of engagement in many community settings was still often low and indeed in some instances, very low (Rapley & Beyer, 1998). Hatton and Emerson (1996) found residents with greater skills got more staff support. In other instances, the level of staff contact was low or variable, with little evidence of practical assistance or encouragement (Rapley & Beyer, 1998).

Kroese et al (1998) reported that the competencies of people with intellectual disability, following a move to the community, did not increase unless structured staff procedures were implemented. Even in studies where increased activity levels were found, such a result may have depended on the internal organisation of the setting rather than the increase being a general consequence of the move. The extent of assistance received is probably the key to participation in activity for people who lack independent abilities (Perry & Felce, 1994). McGill and Toogood (1993) and Emerson & Hatton (1994) have argued that the implementation of a PCAS model, with clearly defined structures for planning staff and resident activity and for the delivery of the practical help to people with intellectual disability, is of the utmost importance. The problems of social isolation and being unoccupied for much of the time tend to intensify with the severity of the intellectual disability (Perry & Felce, 1994). Planning activities for people with intellectual disability, outlining staff responsibilities and giving training to staff in how to assist the person who is more severely disabled can all increase activity levels. Felce (1999) believes that supporting people with severe intellectual disability is not an intuitive skill and good management and the adoption of effective working methods aligned with staff training should result in the delivery of appropriate support.

The appeal of the new approach for people with intellectual disability through PCP was universal and rapidly became the widely favoured modus operandi for supporting individuals to have dignified lifestyles characterised by community participation and the support that they require to maintain socially valued roles guided by their personal choices. The inarguable success of PCP has led to global application.

2.5 The Spread of PCP

The English White Paper: *Valuing People* (2001), which promotes the person centred principles of choice, independence, rights and inclusion, could not be further removed from its early twentieth century equivalent, the 1913 *Mental Deficiency Act*, which is characterised by segregation, labelling and coercion. *'Valuing People'* was founded on the twin principles of self-determination and social inclusion. This strategy promotes a person centred vision for people with intellectual disability in the mainstream of life. To achieve this goal, it seeks to integrate a wide variety of elements, in which PCP is one.

Johnson and Traustadottir (2005) found that life in institutions was difficult for many people despite the 'good intentions'. They concluded that in congregate settings PCP became impossible calling for reform guided by person centred aims of individuals. In England, current policy initiatives place considerable emphasis on the empowerment of and consultation with the consumers of health and social care services including people with intellectual disability (Department of Health, 1996). The growth of consumerism and the importance attached to the voice of the individual in human services has been reflected in the increasing importance attached to involving the person with intellectual disability in the audit, inspection and evaluation of their residential supports, and in judging the quality of these supports on the basis of the levels of satisfaction expressed by them through their PCP (Emerson & Hatton, 1994; Hatton & Emerson, 1996; Kroese, Gillot & Atkinson, 1998; & Turner, 1998).

The spread of PCP in the UK has been influenced by care philosophies in the USA and the Scandinavian countries (Nirji, 1969; Wolfensberger, 1983). The outcome was the acceptance by the English Government of the need to promote community care for various groups including people with intellectual disability (DoH, 1989 & DoH, 1991) in a person centred way. In an effort to promote PCP, given our understanding that the larger the service setting the less person centred it can be; a policy focus shifted to unit size with an increasing emphasis on small group community living for adults with intellectual disability. In 1994 in the United States, there was a national average of 4.9 people per residential setting as compared with 22.5 in 1977. In 1994, almost half (47%) of all recipients of residential services lived in settings for one to six people (Mangan Prouty, Polister & Larkin, 1995). However, very large differences between states regarding residence size continue to be evident (Larkin, White, Hill, Bruininks & Wright, 1990; Mangan Prouty, Polister & Larkin, 1995). Although there is a trend towards smaller residence size based on the assumption that person centredness is more achievable in smaller settings, there is considerable disagreement, in practice, about the appropriate size range. Larkin et al (1990) called for national policy to make community living in small settings more uniformly available across the states. Schalock (1994) provided more detailed findings and reported that size was a significant predictor of choice, a key component in PCP, but that the level of residential supervision was not. In an Irish context the HSE report from the working group on congregated settings (2011) calls for dispersed housing of not more than four people with intellectual disability choosing to live together in one location. The important assumption here is that individuals with intellectual disability exercise their

choice of how to live, with whom to live, and where to live in a way that reflects person centred practice.

Mittlers (2003) demonstrates the profound impact of PCP which has had the effect of shifting the thinking in how support services are delivered. Mittler believes that there should be a world trend towards an internationally agreed human rights perspective which would redefine intellectual disability as residing not in an individual handicap, but rather, in the limitations imposed on the individual by social institutions. Mittler describes the worldwide shift of emphasis from custodial segregated services to community based services with PCP to the core. Mittler also refers to the global self-advocacy movement and more effective partnership between service providers and service recipients. Mittler sees the key issue for the future as the promotion of self advocacy and inclusion which is also in keeping with O'Brien's service accomplishments. This is endorsed by the Irish government and is a key recommendation in the HSE report 'Time to Move on from Congregated Settings' (2011).

The spread of person centred practice in the area of intellectual disability is often evident in the personal style of individuals who behave in person centred ways. They encourage a focus on the individual stress the importance of developing deep relationships. Although John O'Brien borrowed the term 'person centred' from an approach to economic development in the Asia-Pacific region, specifically from Korten's person centred development (1981) the spread of PCP has been because of its universal appeal, the roots of which is in the mutual benefit of psychological and personal growth for and with the person with intellectual disability.

The antithesis of PCP is expressed globally when people with intellectual disability are offered and receive existing services into which they are required to fit. In addition, they are expected to fit into a service where someone else, usually a staff member, decides on how they should act, think or feel in relation to the service received (Howel, 2004). Howel argues that the longer individuals with intellectual disability are expected to comply with the rigours of formal services provision the further removed they become from O'Brien's formulation of person centeredness.

Wolfensberger (1969) used a history of intellectual disability services to vividly sketch the powerful and mutually reinforcing connection between how society sees people with disability, the shape of the services that the professionals consequently offer and the impact of these services on the lives of the people who rely on services. He illuminated the practical differences it makes to understand people with disabilities as citizens and developing persons rather than as 'sub-human, menaces, 'objects of ridicule, sick, burdens of charity, eternal children or holy innocents'. This perspective offers a powerful tool for deconstructing common service practices and points to a way to improve life conditions by emphasising 'personhood, citizenship and development potential', a principal that appeared along with the first written expression of normalisation (Nirje, 1969). This person centred process contributed to the social and legal changes for people with intellectual disability, who may have been excluded from schools and removed from society to exist in institutions (Kindred, Cohen, Penrod & Shafter, 1976).

According to O'Brien and O'Brien (2000) PCP, like other efforts for social change, has been used and misused, complicated and simplified, lengthened and shortened, trivialised and legalised in an attempt to aid those who use the model to improve the life or people with intellectual disability. They noticed that agencies wanted to benefit from the PCP process and often acted as if PCP was a sort of 'tool box of techniques' that staff could be trained to use in workshops by studying protocols, hearing about ideas and perhaps trying out new techniques. O'Brien was involved in the development of many different formats that guide the principles of PCP including essential lifestyle planning (ELP) and planning alternative tomorrows with hope (PATH). He emphasised the importance of intention in PCP and cautioned against PCP becoming a system driven requirement and urged personal commitment to action in order to resist social pressures to exclude people from ordinary lives and activities. He asserts that every PCP should be unique to the individual. Notwithstanding this over two thousand formats for PCP emerged since the 1970's which put a framework on PCP. These include Personal Histories, New Hats, Getting to Know You, Individual Design Sessions, Families First, Essential Lifestyle Planning, Personal Futures Planning, Group Action Planning, PATH, MAPS, 24 Hour Planning and Personal Outcome Measures. Many more variations, with O'Brien's service accomplishments to the forefront of PCP have developed as a growing number of practitioners and service providers have adopted the approach to new circumstances and developed their own methods.

In considering the spread of PCP in Ireland the National Disability Authority (NDA) describe PCP as 'a way of helping people or their families/parents of very young people or people with high dependencies, think about what is important to them, how they want to live and what support they want' (NDA, 2004 p. 11). Ritchie et al (2003) states that PCP is good planning leading to positive changes in people's lives and services. O'Brien (2004) reminds us that PCP is "listening to and learning from what people want from their lives, by helping people to think about what they want now and in the future and by working together with the person to make this happen" (p. 11). O'Brien sees the potential in every human being and sets out the task for the key worker to assist in actively searching for a person's gifts and capacities in the context of community life rather than specialising their disability. He believes done right that PCP strengthens the voice of the person with intellectual disability and those who know the person best. PCP should tell the story of the person's life accounting for their personal history rather than file entries logging incidences. He believes that PCP looks at the individual's present lifestyle with an eye to considering the valued experiences and social roles the individual enjoys, always looking towards a positive future (Mount, 1992). Through PCP the importance of re-engaging families in the lives of the person with intellectual disability is paramount and in direct contrast to the message given to families when their family member was institutionalised many years ago (Robinson, 2005).

As PCP gathered momentum it was intended to positively change the way families engage with service providers and for communities to think about positive futures for people with intellectual disability. This is a contrast to the approach where people with intellectual disability were supported in programmes that already existed, whereby the person moulded into the culture and practice of that programme away from their families of origin. PCP on the other hand turns the

focus away from the system and practices of exclusion and places it on the individual and their natural circle of support. The PCP ideally mobilises a different kind of action with the most important feature being the vision of a positive future for the person with intellectual disability that involves all stakeholders in the person's life thinking and acting creatively (O'Brien, 2000).

According to O'Brien (2000) PCP is intended to reflect the unique circumstances of the individual person with an intellectual disability both in assessing and in organising what should be done for the person. PCP emphasises three other characteristics. Firstly the aspirations and capacities expressed by the individual or those speaking on behalf of the individual are considered rather than the deficiencies of the person. Secondly, PCP attempts to include and mobilise the individual's family and wider social network, as well as to use resources from the system of statutory services. The third distinctive characteristic is that PCP emphasises the importance of providing supports required to achieve goals, rather than limiting goals to what services typically can manage to achieve (Cambridge & Carnaby, 2005).

As PCP spread worldwide there was a growing impetus for change and for service providers to be more person centred. O'Brien's five service accomplishments have been the cornerstone for PCP as referred to earlier. These five service accomplishments challenge service providers to work towards inclusion and placing the person with intellectual disability at the centre of the planning process, thus seeking valued experiences for people with intellectual disability. In the practical application of PCP, the main thrust is the promotion of normalisation which aims to provide valued experiences for the focus person in areas of dignity, choice, relationships, ordinary places and by contributing to society. The basic principle that underpins PCP is that it is planning from the perspective of the individual with intellectual disability. According to Mansell and Beadle-Brown (2004) it is the individual with intellectual disability around whom planning is conducted and where his/her wishes are taken as the single most important reference point for the entire planning venture albeit that this can be difficult for service providers to realise.

Falvey et al (1994) indicates that all PCP approaches share basic features. The person's family and connections within the community are more important than the specialised services available to the person with intellectual disability. They state that planning must be done with the person with intellectual disability and by people who know the person very well and who are committed to helping the person achieve his/her goals. The features of PCP have developed because people with intellectual disability often find it difficult to get the kind of basic services, opportunities and experiences that most other people without disability take for granted (NDA, 2004).

O'Brien (2004) indicates that PCP involves a Circle of Support made up of the focus person with a disability, his or her key worker/advocate, the focus person's parents and family members who formally meet with service providers and others as frequently as needed to develop and implement a future vision for the individual. Staff training in the process is essential and is part of a typical training course. The profile of the individual is developed using a 'profile poster' of the individual concerned. More information is gathered and a 'vision poster' is compiled incorporating the

positive aspects of the individual, his/her competencies, strengths and attributes. Past interests which may have been ignored or not known about hitherto are also taken into account. This PCP process is a contrast to traditional approaches which tend to focus on the deficits and on ways of helping the person cope with negative aspects of his/her disability where protection and safeguarding from risk taking overshadows the uniqueness of the individual.

According to Ritchie et al (2003) there is a growing body of international evidence to suggest the beneficial effects of PCP for people with intellectual disability. Felce (2004) cautions that there is no guarantee of a better life for the person with intellectual disability simply as a result of the implementation of the PCP process. PCP seems to have been adopted in British policy as the central strategy for driving the development of support for people with intellectual disability. PCP is enshrined in the English white paper *'Valuing People'* (2001), in Wales *Fulfilling the Promises* (2001), in Scotland *Same as You* (2000) and Ireland *Quality and Fairness* (2001).

The strong support worldwide for PCP has resulted in it being endorsed in many countries. Felce (2004) agrees with the findings of Mansell and Beadle-Brown (2004) that PCP has rather a weak evidence base for the centrality of its position in policy. Consequently the rational for this current study is to add to the evidence base on the efficacy of PCP. Claes et al (2010) conducted an in-depth analysis of the international research on the effectiveness of PCP. The conclusion reached was that in order to get a better understanding of the different components of the PCP process and their effects on the outcomes practitioners will be well advised to look at practice driven evaluation. While PCP has its origins in guiding people to craft individualised service plans it has also been found to provide valuable information on the effectiveness of PCP as an intervention (O'Brien, 2007). Proficient PCP requires investment in the long term, regular and face-to-face sharing of activities, stories and questions that build examples of good practices that are able to create models relevant to today's opportunities and challenges. O'Brien (2000) believes that such conditions are necessary for real changes in the lives of people with intellectual disability. Many exponents of PCP are aware that rapid attempts to train staff and spread PCP as a toolbox of techniques are likely to have limited benefits.

Cambridge and Carnaby (2005) believe that service managers and practitioners cannot hope to develop PCP services simply through introducing the device of PCP. At one level it is evident that PCP cannot successfully operate in isolation of other work and at another level that it has the potential to provide a vehicle or at least a route for fostering person centred initiatives and action. User participation is now not only desirable or feasible, but essential at all levels of service and resource organisation, providing a prerequisite to successful PCP and a wide range of user outcomes following from PCP. The use of PCP is widespread worldwide in service delivery and reflected in social policy. In Ireland the HSE service plan for service provision for people with intellectual disability highlights PCP as a performance indicator. This poses the intriguing question as to the position of PCP in the Irish context.

2.6 PCP in an Irish Context

In Ireland in the 21st century, PCP is widely considered to be central to the provision of the highest attainable standards of care for individuals with intellectual disability. PCP focuses on the positive aspects of the person along with positive outcomes for him/her, rather than dwelling on past problems and service shortcomings. Many services endeavour to use PCP as central to planning every aspect of the individual's life including family involvement, updating the Intellectual Disability Database (IDDB) information and discussing the implications of change on the individual's life (NDA, 2005).

The last two decades in Ireland has seen a shift in ideas, from a position in which people with intellectual disability had limited opportunity to be involved in making decisions about their lives, to a now more consultative era. This shift has been influenced by the importance of the equality agenda, the de-institutionalisation process and quality of life (Department of Health & Children, 2001). The concept of quality of life is an over-arching principle that is applicable to the betterment of society as a whole in a time of social and economic change. The shift in service provision for people with intellectual disability with a focus on community-based services and quality outcomes has challenged disability service providers in Ireland to respond positively. The four principles of equity, people-centeredness, quality and accountability which guided the development of the Health Strategy (Department of Health & Children, 2001) also place an onus on service providers to comply with the aspirations for quality and fairness for all in a person centred way.

The current thinking in an Irish context is that people with intellectual disability are supported based on the level of support needed to live a self determined life of their own crafting. Separating them from their families and their community in order to provide them with special services is not the preferred option (HSE, 2011). This fact contrasts with the reality that Ireland was ranked extremely low in the process of deinstitutionalisation in the twentieth century, being the third lowest of fifteen European countries with the second highest rate of institutionalisation (Emerson, 1997). This provides direction for Irish Government policies to endorse a shift from institutional care to care in the community at the same time being mindful that people with intellectual disability having moved reap the benefits of increased opportunities in the community (HSE, 2011). This was also seen in many countries, including Wales, where a shift from institutional care for people with intellectual disability to community care has been closely monitored. Felce (1999) foresees an end in sight of such organised exclusion of people with intellectual disability from the mainstream society.

There is a dearth of academic studies on the use and impact of PCP in Irish settings despite the fact that PCP is a common every day practice in Irish services. What has happened in Ireland in every day practice is that various service providers have been interested in different forms of PCP such as personal outcomes measures (POMS) and as such they have engaged the Council to provide training and monitoring of POMS in their service settings. For the implementation of POMS a good practice guide (2008) was developed that itemises twenty three good practice outcome measures under the broad headings of 'my self', 'my world' and my 'dreams'. Examples from my

self include; 'I am connected to my natural support networks', 'I have intimate relationships', 'I am safe', 'I am free from abuse and neglect' and 'I decide when to share my personal information'. Examples of outcomes from my world include; 'I choose where and with whom I live', 'I choose where I work' and 'I live in integrated environments'. Examples of outcomes from my dreams include; 'I choose and realise personal goals', 'I participate in the life of the community' and 'I have friends and I am respected'. In the former Midland Health Board area in 1999 in preparation for the de-institutionalisation process a working group compiled a care plan and PCP format. The idea was to specifically itemise all of the individuals medical care needs as a platform for their PCP. Similarly to elsewhere in Ireland, training in PCP was made available in the institutions to all staff in preparation for transfer and to equip them to carry on training in PCP at an in-service level.

In a survey carried out in Ireland in 1996, Fleming found that individuals with intellectual disability who moved to small community houses became more independent, regardless of their level of intellectual disability. Those who lived in either large or small institutions became more dependent. These findings offer strong counter-indications to those who argue that some people, especially those with severe or profound intellectual disability, need institutional care to reach their full potential. Those who live in the community in smaller groups of six or less with one or occasionally two staff on duty at any one time experienced considerable benefits (Fleming, 1996). He sounds, however, a note of caution that people who live in the community tend to be more isolated and lonely. The important thing that Fleming notes is that people's lives improve because they are supported in a person centred way and that they have the benefit of home cooked meals and relating with a smaller number of staff.

As stated earlier the Irish Health Strategy 'Quality and Fairness' (2001) makes reference to the resettlement of people with intellectual disability in more appropriate settings by 2006. Regrettably this was not realised for the people with intellectual disability who continue to reside in congregate care settings (N=4000). The National Review Group on congregate care (2007) was established to report on the future provision of residential care for people with intellectual disability in Ireland. The group submitted an interim report to the HSE recommending that no new development funding should be used to provide residential accommodation in an institutional or congregate care setting of ten or more people. However, the de-institutionalisation agenda is still not driven by legislation in Ireland.

The Irish Government endorses the health strategy set out in 'Quality and Fairness' (2001). It is a widely held assumption that PCP will guide services to deliver on their commitment to provide quality services for people with intellectual disability. In addition, the National Standards for disability services make explicit reference to PCP as a key reference point for the development and delivery of services for people with intellectual disability in Ireland (National Disability Authority Standards, 2005). The IDDB collects information annually on all levels of service provision to people with disabilities in Ireland. One of the many questions 'is there a PCP in place?' This simply captures whether or not a PCP is in place for the individual but it does not probe in any detail on the content or quality of the PCP.

In an Irish context in the twenty first century the overall objective is to close out-dated institutions and re-integrate people with intellectual disability into community settings (HSE, 2011). This ideology is also evident in countries that have a legislative framework to protect people with intellectual disability. In Ireland, such plans and strategies are dependent on funding being made available, which appears to be happening at a much slower pace than some other countries in Western Europe.

In 2011 the Federation of Voluntary Bodies hosted a major seminar 'Challenging Times' which acknowledged the current Irish economic situation but at the same time convinced that PCP could continue to flourish. This forum learned from John O'Brien who posed the question 'where do we get more from'? He went on to explain that there are many resources that heretofore have not been accessed. Where more comes from, according to O'Brien, is from the individual with intellectual disability and their many talents and capacities that may have been overlooked in the past. Another untapped resource that O'Brien points out is from families themselves who may have a greater interest in participating in the support of their family member. Furthermore O'Brien looked towards communities with unemployment levels at an all time high. There is an unprecedented availability of people willing and able to be deployed in a person centred way. O'Brien provides inspirational direction but more importantly that PCP can happen especially in times of recession. The enduring question is not around the popularity of PCP but around how effective PCP is in delivering on the personal aspirations of the individual with intellectual disability.

2.7 Critiques of PCP

Felce (2004) posits that leaders in the field of intellectual disability services are embarking on the process of PCP, not out of evidence that people receive better support and live enhanced lives as a result, but rather because they are convinced that PCP is a logical and necessary approach to knowing people well. This, he believes enables them to make the necessary support arrangements that meet individual requirements also taking into account the preferences and lifestyle choices of the person with intellectual disability (Felce, 2004). He further questions whether PCP has the potential to improve people's lives pointing out that policy should identify the conditions under which the widespread implementation of PCP would be possible without impacting on the process (Felce, 2004). Felce believes that when PCP is done well it is a time consuming process that produces good results. However, he points out that service systems do not calculate the real cost of this time consuming process.

Connolly (2001) states that much of the effectiveness of PCP would seem to rest in the way it is conducted. Although it would seem that well developed plans that are acted upon can make considerable differences to individual's lives, it is important to also bear in mind that currently few good quality systematic evaluations of person centred planning exist.

Mansell and Beadle-Brown (2004) posit concerns about the possible impact of the systematic introduction of PCP across services for people with intellectual disability in the UK. This is based

on the argument that there is still insufficient evidence that investing in PCP will be of benefit to people with intellectual disability. They argue that there are a number of reasons as to why PCP may fail and they believe that addressing the structural problems around the process would be of greater benefit rather than actually investing in PCP. They discuss the similarities between PCP and previous approaches to individualised planning. They state that PCP is presented as making a fundamental break with previous methods of individualised planning. Proponents of PCP question whether all previous methods of individualised planning have failed or become irrelevant (Mansell & Beadle Browne, 2004). They do agree however, that PCP has been an evolutionary step in the gradual move towards individualised services for people with intellectual disability.

Emerson and Stancliffe (2004) argues that the new way of working through the PCP approach has much in common with existing practices in intellectual disability services and could lead to the reintroduction of institutional practices and behaviours in a community setting. Felce (2004) highlights that change within intellectual disability services is often presented in a manner that denies the possibility of historical continuity and thus people's personal histories may be eradicated.

Felce (2004) is mindful of the importance of PCP and its influence in strategic planning acknowledging the resources required for it to be effective. It is clear that there will be limited benefits if services embark on a significant PCP agenda without making the investment which may be required to meet the services and supports produced. O'Brien (2004) states that policies such as 'Valuing People' (2001) do not make simplistic assumptions about the effects of PCP. He goes on to say that changing individual planning procedures will not automatically change people's lives. He argues that ignoring resource constraints or failing to address the need to improve services will marginalise the PCP process. He states that PCP can only succeed in a context of comprehensive and systemic approaches to challenging the current local and national practices. O'Brien (2004) further states that PCP is only one aspect of a multi-pronged strategy needed to change the role of specialist and mainstream services.

In the context of coming to a greater understanding of PCP, Cambridge (2005) points out that there are two common assumptions that can lead people to believe that they are on the right road in terms of effective PCP. These assumptions are that because PCP has worked in another jurisdiction that the methodology can be replicated and that the learning reported from the individual case studies can also readily transfer. Cambridge cautions therefore against making the assumption that all you have to do is emulate the method reported on in other situations because if PCP is to be successful it has to be driven by the individual and by their very unique support network.

A note of caution is that If PCP was to be implemented system wide in the true sense of what person centredness means, then the process could place a very high demand on scarce intellectual disability resources. As Holburn and Vietze (1999) state, change needs to begin by starting PCP with a small number of people and gradually building on the process of further

implementing the plans, incrementally to ensure adequate resources, as agreed by the service planners and budget holders are in place. Emerson and Stancliffe (2004) further endorse the notion from Holburn and Vietze by sounding a note of real concern in that system wide adoption of PCP may be characterised by overzealous promotion of the purported benefits without sufficient attention to the difficulties and the necessary changes to system architecture to ensure that those involved in PCP have the authority or resources to achieve their aims. If this is allowed to happen, PCP may well become another passing fad, with stake-holders becoming ever more discouraged, disheartened and alienated by a system characterised by rhetoric rather than meaningful action.

Felce (2004) demonstrated that it is worth noting that effective PCP must lead to person centred action. PCP, if it is to engender real change, largely depends on who holds decision making power in services. Service architecture is the array of policies and practices related to authorising and contracting services and supports. Relocating power and control to service users at local level is deemed vital for the success of PCP. Holburn and Vietze (1999) state that in order for PCP to survive in an agency, it needs support from the very system that it views as holding the power and that it seeks to change. The alternative is to adopt the rhetoric of person centredness in systems that do not change. This can occur in large institutions and community based settings where people espouse to being person centred and at the same time failing to engage in true person centred practice (O'Brien et al, 2005).

2.8 Research evaluations of PCP

The population of people with intellectual disability includes many individuals with severe disabilities and high levels of dependency. Their disability places restrictions on their capacity to communicate and their relationships are based on their dependency making it difficult to evaluate the effectiveness of their PCP. Interested in this concept, Mansell, et al (2002) in a national study in the United Kingdom sent questionnaires to the managers of every non statutory residential service asking them to provide information about the people whom they served. The findings from this study found that 43% of people with intellectual disability had major communication difficulties, 63% of the same cohort had impaired social interaction and 35% had had severe challenging behaviour. Each of these findings alone and in combination with others presents substantial challenges for the implementation of effective PCP. A further consideration is that Bradshaw (2001) found that staff often misjudge the receptive language ability of people with intellectual disability. Similarly, the extent to which people with intellectual disability can understand choices and decisions is often limited and requires careful assessment (Arscott, Dagnan & Kroese 1999). This in itself presents a very unique research challenge but nonetheless attempts to evaluate PCP continue.

What do systematic attempts to evaluate PCP tell us? In this context the work of Robertson et al (2005), a large scale evaluation of the outcomes of PCP in the UK, will be considered. The study of Robertson et al (2005) incorporates both qualitative and quantitative research methods. It was commissioned by the Department of Health as a follow up to 'Valuing People' (Department of

Health, 2001). This longitudinal study looked at the efficacy and costs of introducing PCP for ninety three people with intellectual disability across the United Kingdom over a two year period. The first part of the study involved development work with the organisations to prepare policies and procedures around the introduction of PCP's for people with intellectual disability. A lot of resources were invested in training for both management and staff of the organisations. Staff spent, on average, 84.5 – 100 hours in training while managers spent 53.5 -100 hours in training. In the second part of this PCP evaluation ninety three people, over a one year period participated in the study, sixty five of whom had a PCP developed during the life of the study. Participants included people with low support ranging to high support needs and people who were aged between sixteen and eighty six years. Some were noted to live in the most deprived areas in the United Kingdom (Robertson et al, 2005).

He described the different instruments used to gather information such as 'The Social Network Map', 'Index of Community Involvement', 'Adaptive Behaviour Scale' and 'Client Service Receipt Inventory'. Most of the information was gathered from the person's key worker using a combination of self-completion questionnaires and structured interviews. The information gathered included age, gender, ethnicity, ability, challenging behaviour, syndromes associated with intellectual disability and residential history. At three month intervals information on the person's community activity levels and social networks was gathered from the key worker. At six month intervals information on the person's mental health, their challenging behaviour and accidents were collated from the key worker using instruments like the 'Strengths and Difficulties Questionnaire' and medication receipts. This stage of the study has provided one of the few quantitative studies available on the impact of PCP.

Emerson et al (2005) commenting on Robertson's work pointed to the paucity of research on the impact of PCP. They further comment that the quantitative approach adds to the small number of qualitative research studies. Emerson (2005) commented that "over the past decade numerous position papers have outlined the potential benefits of PCP. However, there have been few attempts to formally evaluate the benefits and cost associated with the adoption of PCP" (p. 8). The work of Robertson (2005) has evaluated PCP and has included a qualitative piece in order that the voice of people with intellectual disability and staff could be heard. People with intellectual disability who could answer for themselves were interviewed using a questionnaire specifically designed for the study (my life interview). PCP facilitators were also interviewed on a six monthly basis using semi structured interviews. Questions included "facilitators characteristics, the reported impact of PCP for the participant, barriers to goals set for the participant being met, attitudes towards PCP, organisational barriers to PCP, commitment to PCP and perceived self-efficacy" (p. 26). The main area of focus in analysing the data was to determine if PCP was efficacious and effective for people with intellectual disability. They found that the main areas that PCP was efficacious were; "social networks, community involvement, scheduled day services, contact with friends, contact with family and choice" (p. 44). They also concluded that PCP was effective in the following four areas: "community involvement, contact with friends, contact with family and choice" (p. 44).

While the above is not an exhaustive list of research that has been undertaken it is nonetheless comprehensive and points to the need for a larger PCP evidence base, especially in the Irish context. The research currently available falls short of informing us whether PCP is effective in promoting O'Brien's five service accomplishments. In this study the impetus is to establish whether the PCP's for people following their move to the community embrace the same five service accomplishments, ensure some certainty that person-centred lives are led and also driven by their person centred agenda.

There has been significant investment by the Irish Government through the HSE in order to ensure that every person with intellectual disability has a PCP in place. Mindful of this investment to date and with a commitment from 'Time to Move On from Congregate Settings – A Strategy for Community Inclusion' (HSE, 2011) that a further 4000 people with intellectual disability await transfer from institutions to community based settings. This places an imperative on social policy makers to establish whether PCP has the desired impact on the lives of people with intellectual disability based on the findings of Robertson et al (2005). This Irish study aims to provide an evidence base on the efficacy of PCP with a view to guiding every day practice and social policy.

2.9 Aims of the Current Study

This study will examine the efficacy of PCP for people with intellectual disability following their transfer from institutions. It will build on the work of O'Brien (2000) and Robertson et al (2005) and will add to the evidence base. Specifically the study will: -

1. Consider the lives of people with intellectual disability, prior to their institutionalisation, while in the institution and examine how person centred their current lifestyle is in community settings.

2. Examine the PCP process with particular reference to the PCP meeting, the contribution of the person with intellectual disability, the participation of the family member and the role of the key worker and how effective this process is in achieving person centred action.

3. Investigate whether PCP brings added value to the lives of people with intellectual disability in community settings by considering PCP in light of O'Brien's five service accomplishments (2000) and the findings of Robertson et al (2005).

4. Explore the relationship between the outcomes, theory and practice of PCP to establish an evidence base on the efficacy of PCP in order to inform future social policy.

Chapter 3

Methodology

3.0 Methodology

3.1 Introduction

In order to establish the efficacy of PCP for people with intellectual disability following their transfer from institutions, the study questions led to a systematic exploration through this research. This led to a consideration of the relative merits of various research methods. The researcher considered the distinguishing features between two approaches of data collection and analysis namely: qualitative and quantitative (Gilbert, 2001). Deciding between the applications of these two approaches and selecting of one over the other can be challenging.

The range of research options are explored in this discussion with a view to finding the best fit to answer the research questions. This chapter will describe the methodology that was utilised in this study to evaluate the efficacy of PCP for people with intellectual disability who moved from institutions. The qualitative method for conducting this research, case study is then described including the theory, rationale and benefits of such a method.

3.2 Research design

This study examined the efficacy of PCP for people with intellectual disability following their transfer from institutions. It built on the work of O'Brien (2000) and Robertson et al (2005) and will add to the evidence base. For reasons discussed below, a qualitative research method was selected. Parahoo (1997) defines qualitative research as "Collecting data from respondents often in their natural environments taking into account how cultural social and other factors influence their experiences and behaviour" (p. 59). One assumption in qualitative research is the belief that phenomena must be studied from the individual's perspective and in the context in which they happen (Parahoo, 1997).

Creswell (2003) also believes that one undertakes qualitative research in a natural setting where the researcher is an instrument of data collection that gathers words or pictures, analyses them inductively, focuses on the meaning of participants and describes a process that is expressive and persuasive in language. He defines qualitative research as *"An inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting"* (Creswell, 1998, p.15).

Denzin and Lincoln (1998) define qualitative research as *'Multi-method in focus, involving an interpretive, naturalistic approach to its subject matter'* (p. 3). In other words, people carrying out qualitative research do so in the subject matter's natural settings, attempting to make sense of, or interpret, phenomena in terms of the meaning people bring to them. Similar concepts are found in Parahoo (1997) and Creswell (1998 & 2003).

Qualitative research is inherently multi-method in focus (Brewer & Hunter, 1989). However, the use of multi methods, or triangulation, reflects an attempt to secure an in-depth understanding of the phenomenon in question. Qualitative research can be difficult to define clearly as it has no theory or paradigm that is distinctively its own (Denzin & Lincoln, 1998). It appears to be used in many separate disciplines. In addition, qualitative research does not have a distinct set of methods that are entirely its own. Qualitative researchers use semiotics, narrative, content, discourse, archival and phonemic analysis, even statistics.

According to Denzin & Lincoln (1998), qualitative research has a long and distinguished history in the human disciplines. They highlight from a sociological perspective the 'Chicago School' which established the importance of qualitative research for the study of human life in the 1920's and 1930's. Qualitative research is interpretive. It is a critical social science (Neuman, 2003) and is concerned with the "discovery of meaning through observation, description, decoding and translation" (Ahearne, 2000, p. 15). John Creswell (1998) examined five traditions of qualitative research, biography, phenomenology, grounded theory, ethnography and case studies. He then compared them to six phases of research design. These six phases include philosophical or theoretical perspectives, introduction to a study (including the formation of the purpose and research questions), data collection, data analysis, report writing and standards of quality and verification (Creswell, 1998). Qualitative research became well established and was employed in other social science disciplines including nursing, social work, education and communications. As the research question is about the phenomena of the individual's lives documented in the case studies that will follow, their biographies and an attempt to understand the human life scenarios is clearly a good fit with application for the method selected for the current study presented. The history and context of intellectual disability research has been about quantifying where people are, how they function, what kind services we think they require versus what they really have to say. This research puts the person with intellectual disability at the centre by using the qualitative case study method and the direct interview with the person themselves in order to formulate their case study. Not much is known about the perspective of the person with intellectual disability, his or her family or that of direct support workers. This research will add to the knowledge base. As the research question relates fundamentally to PCP and qualitative research methods are primarily about the human experience, qualitative methods were particularly suited to this research design.

There are many methods and approaches that fall under the category of qualitative research and include such techniques as interviewing, participant observation and visual methods. Denzin & Lincoln (1998) demonstrate that qualitative research operates in a complex historical field that crosscuts five historical movements namely; traditional (1900-1950), the modernist or golden age (1950-1970), blurred genres (1970-1986), the crisis of representation (1986-1990) and post modern or present moments (1990-to present). Denzin & Lincoln (1998) further argue that all five operate in the present and argue that any description of what constitutes qualitative research must work within this complex historical field.

There has been a long debate on the efficacy of using qualitative approaches to research as opposed to the quantitative approach. In the past qualitative research was regarded as less scientific than quantitative approaches (Denzin & Lincoln, 1998), subjective (Parahoo, 1997) and lead some researchers to prefer quantitative measurement (Agar, 1980). However, as qualitative measures have become rigorous their credibility is regarded as equally scientific. Carey (1989) adds that the positive sciences of physics, chemistry, and economics are often seen as the crowning achievements of Western civilisation and in their practices it is assumed that the "truth" can transcend opinion and personal bias (p. 99). He believes that qualitative research can be regarded as "an assault on this tradition" (p. 104). Examination of the protocols of both research approaches led some to assume that the methodologies were mutually incompatible. In more recent times it is agreed that both research approaches can complement each other (Gilbert, 2001). Most would accept that quantitative and qualitative research or a mixed methods approach share a common goal: an understanding of the world we live in (Parahoo, 1997).

The qualitative approach is the approach deemed most suitable for this study because the researcher saw the benefit of going straight to the source for their unique perspective. This is against the background that people with intellectual disability are not only marginalised by systems and services but also by researchers who despite their best intentions did not position themselves to capture the thoughts, feelings and views of the various stakeholders. The reality is that quantitative data would not have the power to lend itself to the type of data collection that may not have the potential to yield a deep understanding of the research question. The benefits of qualitative case studies abound. The popular notion that quantitative research deals with quantity and numbers and that qualitative research deals with quality and descriptions is viewed by some as too simplistic (Parahoo, 1997). Broadly speaking, quantitative researchers rely on a positive approach to social sciences (Neuman, 2003) and Ahearne (2000) sets out that qualitative research "describes and categorizes information and tests assumptions" (p. 13). The quantitative approach is described as deductive, with the research producing empirical evidence to test or refute theories (May, 2001). Quantitative research also adopts a reductionist approach in that it aims to reduce complex phenomena to simple units that can be observed or recorded (Hammersley, 1993). This approach may restrict the resolution of the research question.

As this research is about people's life experiences and the research interest is in these subjective experiences, the qualitative method may give an opportunity to harvest insights rooted in the individual's own system of experience and values. Qualitative research methods have the potential to yield valuable information on the outcomes of the efficacy of PCP within the research parameters. Given that the researcher has twenty years experience working with people with intellectual disability; this has accrued an enhanced knowledge base of the service systems but more importantly an understanding of the lifestyles of people with intellectual disability in a range of settings. Opportunities arise in this study to employ ethnographic methods such as spending time with the person with intellectual disability in their own home as a bona fide method of gaining an insider's perspective. There are a range of options within the realm of qualitative methodologies to select from to find the best fit in terms of application to the research question.

This study will examine the efficacy of PCP for people with intellectual disability following their transfer from institutions. It will build on the work of O'Brien (2000) and Robertson et al (2005) and will add to the evidence base. Specifically the study will: -

1. Consider the lives of people with intellectual disability, prior to their institutionalisation, while in the institution and examine how person centred their current lifestyle is in community settings.

2. Examine the PCP process with particular reference to the PCP meeting, the contribution of the person with intellectual disability, the participation of the family member and the role of the key worker and how effective this process is in achieving person centred action.

3. Investigate whether PCP brings added value to the lives of people with intellectual disability in community settings by considering PCP in light of O'Brien's five service accomplishments (2000) and the findings of Robertson et al (2005).

4. Explore the relationship between the outcomes, theory and practice of PCP to establish an evidence base on the efficacy of PCP in order to inform future social policy.

To elaborate on the objectives contained in the aim of this study various qualitative research options will be reviewed.

3.3. Biographical, phenomenological, grounded theory, ethnographic and case study approaches.

Creswell (1998) defines a ***biographical study*** as *"the study of an individual and her or his experiences as told to the researcher or found in documents and archival material"* (p. 47). Denzin (1989a) defines the biographical method as the *"studied use of and collection of life documents that describe turning point moments in the individual's life"* (p. 69). A biographical study is used irrespective of the type of life the person has or has had. A biographical study includes individual's biographies, autobiographies, life histories and oral histories.

Phenomenology focuses on individual's interpretation of their experiences and the ways in which they express them (Baker, Wuest & Stern, 1992). It focuses on describing how the individual experiences phenomena. Creswell (1998) defines phenomenology as "the meaning of the lived experiences for several individuals about a concept or phenomenon" (p. 51). Phenomenology as a philosophy stresses the notion that only those who experience the particular phenomena are capable of communicating them to the outside world and that the researcher's empirical observations are limited in understanding people's perceptions (Parahoo, 1997). The researcher's task is to describe phenomena as experienced and expressed.

Phenomenology as a research method is especially suited to the study of illness and the care received. The approach requires the researcher to take the perception of each person into account. The primary tool of data collection in a phenomenological study is the interview, during which the researcher seeks to gain insight into how respondents make sense of their experiences. The emphasis is on allowing or facilitating respondents to speak freely about a topic and questions are asked in an attempt to seek clarification, illustration or further exploration (Parahoo, 1997). As with ethnographical studies, phenomenological data can be analysed by searching for themes, patterns or trends and findings which are often presented in responses.

Grounded theory was first introduced in 1967 by Glaser and Strauss. It is regarded as an inductive approach to research whereby hypothesis and theories emerge out of, or are grounded in, data. The central aim of grounded theory research is the development or generation of a theory closely related to the context of the phenomenon being studied (Creswell, 1998 & 2003). It is in itself not a theory but a description of theories developed in this way. Grounded theory is useful for studying phenomena for which little or no theory has been developed. Grounded theory usually involves the researcher conducting 20-30 interviews based on several visits to the field to collect interview data to saturate the categories (Creswell, 1998). A category is regarded as a unit of information composed of events, happenings and instances (Strauss & Corbin, 1990).

Ethnography is concerned with studying human behaviour in the cultural and social context in which it takes place. This means that the ethnographer has to spend some time in the company of those being studied. The ethnographer has to participate, overtly or covertly, in the people's lives for an extended period of time, watching what happens, listening to what is being said, asking questions; in fact collecting whatever data are available to throw light on the issue with which the researcher is concerned. Observation and interviews are the two main data collection tools in ethnography (Spradley, 1980) and the researcher uses the senses as much as cognition as primary data gathering tools to characterise important physical and social features of a given field of human behaviour (Hughes, 1992). Ethnographic data analysis involves the researcher analysing and synthesising data during interviews and participant observations.

Creswell (1998) defines a ***case study*** as "an exploration of a 'bounded system' or a case (or multiple cases) over time through detailed, in-depth data collection involving multiple sources of information rich in context (p. 61). This system is bounded by time and place and it is the case being studied such as a programme, an event, an activity or individuals. Sources of information include observations, interviews, audio-visual material, documents and reports. Case studies can be single or collective, multi-sited or within site, focused on a case or on an issue (Stake, 1995; Yin, 1989 & 2008).

Yin (1989 & 2008) delineates six types of information in a case study; documentation, archival records, interviews, direct observations, participant observations and physical artefacts. The types of analysis of these data can be a holistic analysis of the entire case or an embedded analysis of a specific aspect of the case. Bowling (2004) argues that the case study approach is based on

unstructured interviews, observations and document analysis. Through this data collection, a detailed description of the case emerges as does an analysis of themes and an interpretation or assertions about the case by the researcher (Stake, 1995). When multiple cases are chosen, a typical format is to first provide a detailed description of each case and themes within the case followed by a thematic analysis across the cases, along with an interpretation of the meaning of the case. Kane & O'Reilly-De Brun (2001) argue that life history is a special kind of case study, in which patterns that are being identified and understood are manifested in the contexts of someone's life story.

3.4 Choosing the right qualitative method

Bowling (2004) adds that the focus in case study research is on the circumstances, dynamics and complexities of a single case or a small number of cases (p. 403). Numbers in case study research are usually small as the cases are retrospectively intensively explored in-depth, currently and sometimes over time through detailed observations, interviews and details from records. Case study research holds a long distinguished history across many disciplines (Creswell, 1998 & 2003). It is an ideal fit for this study because it allows the researcher to deeply listen to the account of the individual, to give their voice through the presentation of the case study and with an ethnographic style allows for the researcher to witness and give an account of their life experiences. It further allows for consideration of the multiple perspectives on the complex process of PCP. This current study involves three groups of stakeholders; the people with intellectual disability, the family members and the key workers. Case study research is also a valuable method for the study of complex social settings (Bowling, 2004).

Yin (1989 & 2008) recommends participant observation in case study research. The technique of participant observation will be relevant when considering the PCP meetings for the people presented in the case studies. Participant observation is a widely used research method and is associated with flexible designs (Robson, 2002), particularly suited for the topic of this research. Omidian (2000) describes that during participant observation researchers get to see what the informants "routinely do and how they routinely interact" (p. 46). In keeping with Omidians comments on participant observation this aspect was used for this current study as the researcher also spent considerable time in the company of each of the three stakeholder groups.

The case study research to follow will focus on the circumstances, dynamics and complexities of the lives of ten people with intellectual disability, who were removed from their homes, were institutionalised and subsequently de-institutionalised. The case studies will be intensively explored in-depth, retrospectively, currently and over time through detailed observations, interviews and scrutinising of case notes. Further to this, large volumes of archival records were scrutinised to verify and authenticate current case notes and relevant past histories.

3.5 The Study

In keeping with the Department of Health and Children in Ireland's policy on deinstitutionalisation (1984) a local project team was established in the former Midland Health Board (MHB) in 2000 to report on suitable community residential options and to oversee the closure of three large residential centres in the area. It was also envisaged that in so doing ensuring that as people moved to community based residences that O'Brien's (1981) five service accomplishments were realised through PCP. Prior to moving from the large residential centres described below all the individuals had PCP in place. It was envisaged that this would provide the person with intellectual disability and their support staff with an understanding of the person with the PCP acting as a touchstone to promote O'Brien's accomplishments.

3.5.1 Residential Centres

To fully realise the context of residential services and the lifestyles of the individuals who are the focus of this research, the history and the description of the three centres are of a particular interest to this study as they provided a context for considering the lives of the people whose case studies are presented here.

St. Peter's Centre, which was purchased by the Midland Health Board in the early 1970's, is situated on the outskirts of the village of Castlepollard; set in its own grounds it comprises a main hospital building, a period manor house and a six-bedded chalet. The period manor house was the former home of the Pollard family who resided there from 1716 to 1914. The house was vacant for twenty two years until 1936 when the Sisters of Charity of the Sacred Heart purchased the property and added the main hospital building and a small fever hospital (now the Health Centre). The Sisters of Charity of the Sacred Heart ran an orphanage and a home for unmarried mothers. This provision ceased in the early 1970's.

In 1973, forty seven children and adolescents with intellectual disability were transferred to St Peter's Centre, Castlepollard from the children's ward of St. Loman's Psychiatric Hospital in Mullingar. Dr. S. O'Daly and a team of psychiatric staff nurses and student psychiatric nurses transferred to St Peter's Centre from St Loman's Hospital where they developed and expanded the intellectual disability service (Midland Health Board, 2002).

In 1976 St. Peter's Centre was formally recognised as the first centre in Ireland caring for people with intellectual disability and managed by the Health Board. Referrals for admissions were accepted from the Midland Health Board Area and some from outside the area leading to a quadrupling of the population over a twelve year period. A review of the services in St Peter's was commissioned in 1985. This review utilised the *"Programme Analysis of Service Systems"* (PASS) and recommended the purchase of ordinary houses for the transfer of residents to the community. This recommendation was in keeping with Government policy articulated in Planning for the Future (1984). The services emanating from St Peter's continued to expand and currently provides

institutional and community based residential services to over one hundred people with intellectual disability.

Lough Sheever Centre was established in July 1989 as a residential centre for people with intellectual disability when it was de-designated from St. Loman's Psychiatric Hospital, Mullingar, Co Westmeath by the Department of Health. The Midland Health Board, at its meeting on 19/1/1989 adopted the proposal that an opportunity existed to develop a de-designated centre for the mentally handicapped in the hospital building, which would accommodate mentally handicapped persons already resident in the hospital (Midland Health Board, 2002). In affect this meant an area of the former psychiatric hospital was no longer designated under the Mental Treatment Act (1945) as a place where persons with intellectual disability could be treated or detained under the Act (Planning for the Future, 1984). In reality however, such de-designated units remained within the campus of the psychiatric hospital, and generally staffed by registered psychiatric nurses from the psychiatric hospital.

Ninety four people with intellectual disability were discharged from the psychiatric service and transferred to Lough Sheever Centre. They were accommodated in three separate units: St. John's unit for male residents, St. Colman's unit for female residents and St. Augustine's unit for a mixed group of younger people displaying difficult and challenging behaviours. The purpose of this change was to provide a more appropriate setting and range of services for people with intellectual disability but who did not have a psychiatric illness.

In 1990, within a year of the de-designation of the centre, a PASS evaluation team was established by the Midland Health Board to examine the services provided in the centre. A number of recommendations were put forward by the evaluation team, which included the development of an individual planning process (IPP) for residents, and advocated person centred planning (PCP) and the development of a community residential programme. The recommendations of the PASS evaluation team were adopted by the Management Team of the Midland Health Board and Lough Sheever Centre, and have underpinned their subsequent service development.

In 1990 a disused area of Lough Sheever Centre (St. Camillus') was set up to provide a workshop and activation unit for the residents. This unit has continued to expand and has become a sheltered work environment for a number of residents of Lough Sheever Centre and for some people with intellectual disability living at home or in community residences in the area. In 1995 due to service development and an increased demand for placements, this day unit relocated and became the Mullingar Resource Centre (MRC). The development of the MRC enabled Lough Sheever Centre to develop activation, recreation and social programmes for service users with a different range of needs. These programmes are provided to the residents of the Lough Sheever Centre on a sessional basis. Some people attending intellectual disability services also access the MRC programme when their own day service close.

The community residential programme to transfer residents of Lough Sheever Centre to a community setting began in 1995 when two community houses were opened in the Mullingar area. In addition to this, in 1996 a supported living project was set up to provide support for people with intellectual disability who wished to live independent lives in homes of their own in the community. In 2003 the transfer programme continued to see the commissioning of a further four community residences. By mid 2012 Lough Sheever will be completely closed and their services will be community based. During the transfer process efforts were made to enable individuals to choose where to live, and with whom, in a variety of housing options, for example a rented house, a private apartment, or the person's own home. Services and supports are built around the person based on their needs or choice (Midland Health Board, 2002).

Alvernia House was established in 1989 as a residential centre for thirty-nine people with intellectual disability when it was de-designated from St. Fintan's Psychiatric Hospital, Portlaoise, by the Department of Health. The residential service is provided on three floors of a building built in the middle of the 19th century adjacent to the psychiatric hospital. An Occupational Therapy unit for residents is located on the third floor of the building. A day activation service is provided on the second floor of an adjacent refurbished building. The accommodation for sleeping mainly consists of large dormitories with a small number of individual rooms. The living area consists of large day rooms and dining rooms. Similar to many other psychiatric hospitals, the service was run primarily by psychiatric nursing staff.

In 1990, within a year of the Alvernia House de-designation, a PASS evaluation team was established by the Midland Health Board to examine the service provided in the centre, benchmarked against the Midland Health Board's policy on services for person with intellectual disability and the needs of individual residents. A number of recommendations were put forward by the evaluation team which included the development of an individual planning process (IPP) and advocated person centred planning (PCP) and the development of a community residential programme for residents. An IPP was designed to ensure that high standards of care were in place for the person with intellectual disability. While IPP endeavoured to incorporate all the care needs of the person it lacked a capacity to be responsive to the person as an individual and was not designed to promote PCP. PCP on the other hand aspired to incorporating O'Brien's service accomplishments which had the person with intellectual disability as the driving force. The recommendations of the PASS evaluation team were adopted by the Management Team of the Midland Health Board and Alvernia House, and have underpinned subsequent service development at this location (Midland Health Board, 2002). To date one community has opened but it is envisaged by the end of 2012 all services will be community based resulting in the closure of the institution at Alvernia House.

3.5.2 Source material

In order to gain an understanding of the efficacy of PCP it is essential to look at the three predominant stakeholders. First and foremost the most important stakeholder is the person for

whom the PCP is actually designed to help - the person with intellectual disability. Given that people with intellectual disability can have significant support needs it is vital that they are guided in conducting their PCP by their key worker who also acts as an advocate. Family members are also integral to the process as they form the basis of the most significant life relationships.

The source of the material utilised for the formulation of the case studies for each individual with intellectual disability includes:

- Archival and current file study
- Study of all documentation relating to the individuals PCP
- Interdisciplinary consultations
- Interview with Directors of Nursing
- Interview with people with intellectual disability and spending time with the person in a range of their settings including where they live, where they spend their day and their family home
- Interviews with the family members
- Interviews with the key workers
- Attendance as participant observer at PCP meetings

3.5.3 Research interest

It is important to illustrate that the researcher is currently employed in the HSE under the auspices of the community care programme as Manager of Disability Services with responsibility for the midland area of Ireland. This role is not an operational role but one of strategic planning, commissioning of services, quality and governance with an eye to value for money for individuals with disability. The research interest that inspired this project grew from life long practical work in the field for the previous twenty years. The value base of this work has been set firmly in an understanding of the person first, their human and civil rights and the importance of promoting O'Brien's five service accomplishments. This rights based approach has meant that information has been collected, analysed and interpreted with a view to considering its effect on the person's basic human rights and civil liberties.

The researcher approached this project first and foremost as a Doctoral student from the school of Social Work and Social Policy of Trinity College Dublin. Efforts were made to ensure that those partaking in the study were not aware or influenced by the managerial post which in fact did not govern them in any way and was quite separate to the hands on delivery of service. Very distinct and separate managerial structures actually govern service settings where the participants of this study were recruited. It was helpful to the researcher to have knowledge of the service settings and possibly some of the people but many of the service settings were viewed and the people therein met for the first time as part of this study.

3.5.4 Getting access

The Directors of Nursing of the three large residential centres were written to first with the purpose of the consultation and were then met separately and interviewed in their offices of the large centres. The purpose of the meetings was to seek their interest, and co-operation and from their knowledge base to assist in the formulation of a list of potential people with intellectual disability, their family members and key workers who could be considered as potential subjects for this study. A list of a total of twenty two people with intellectual disability who had already moved to a community setting was formulated. A random sample of fifteen names was drawn in a lottery fashion and this list became the working list for the research project. For the purpose of this study a description of the intent of the study was communicated in verbal dialogue face-to-face with service managers who were in daily contact with the fifteen people with intellectual disability.

The range of settings where these people resided or attended day programmes included day and residential settings. The managers of these services facilitated a face-to-face meeting with the interviewer and the potential subjects. During these brief meetings the atmosphere was convivial and every effort was made to establish a good working rapport with the potential subjects. The location where the researcher met with the people with intellectual disability was familiar to them and in settings where they were comfortable and supported by familiar support workers in order to ensure that the person did not feel threatened in any way. At the point when the individual indicated a willingness to participate a pre prepared participant information sheet and consent form was introduced (see appendix I). As many of the potential interviewees were preliterate or had low levels of literacy a carefully constructed pictorial information package and consent form using the Bristol Guidelines was presented to the individuals. The opportunity was taken to systematically read through the documents with the individual in an effort to ensure their informed compliance and consent. When interviewees were agreeable they signed or marked the consent forms with the understanding that at any time during the course of the process for this study that they wished to relinquish their agreement to participate that they could.

In an effort to further ensure people's understanding and to ensure that their consent was congruent each consent form was co-signed by the person's key worker or service manager. This has had the added advantage of providing emotional support to individuals who are not typically asked to participate in research. Following this process two of the potential participants declined to participate for personal reasons. One of the participants declined on the basis of an anxiety around anything that they might say and how this may be interpreted as a complaint and a fear that this would negatively impact on them. The second person declined because of a recent bereavement and said they did not feel up to it.

3.5.5 Selection criteria and recruitment of sample

For the purpose of this study an inclusion and exclusion criterion was developed for the three study groups. The inclusion criteria for the first study group were that people would have an intellectual

disability according to the WHO classification. According to the World Health Organisation (WHO) intellectual disability can be classified according to a person's level of intelligence quotient (IQ). In order to satisfy the criteria for intellectual disability the condition must be within the developmental period (0-18yrs) and the condition must be life long. It must affect the person's social, educational and social functioning. The subcategories of IQ range within intellectual disability are borderline (IQ, 71-84) which affect 10% approximately of the general population and usually means they have learning difficulties. The next category is mild intellectual disability (IQ, 50-70) which results in the person having limited cognitive skills. While they are typically undistinguishable from the general population they do require support, guidance and assistance especially when life is stressful. People with moderate intellectual disability (IQ, 30-50) can acquire academic skills up to second class resulting in very basic academic standards. They require assistance in most activities of daily living for which they require supervision and support. People with severe intellectual disability typically fall into the IQ range of 30-20. This cohort requires a high level of support in all aspects of daily living (DSM-IV-TR, 2000). The person with profound intellectual disability has an IQ classification of less than 20 with severe limitations in self care, mobility, continence and communication with accompanying neurological disorders. The above descriptors highlight an awareness of the vulnerability of the restrictions that intellectual disability imposes on individuals. Therefore, given the vulnerability it is even more important to consider the ethical issues and to ensure that every safeguard is put in place.

Further to this, the person with intellectual disability would have resided in an institutional setting for a minimum of ten years of their life. For this study group they also would have transferred from the institutional setting to a community based setting within the last ten years. It was essential for this study group that the participants had a PCP in place prior to and on discharge from the institution to the community setting. This was essential as the aims of the study were to consider the efficacy of PCP in the context of institutional care and upon transfer to community care. Others factors considered important in this study was to capture a gender and age balance, to look at individuals who varied in terms of their capacity and support needs in order to ensure an ability mix. Their consent to participation, their level of interest and their cooperation with the study was also a factor in their inclusion. People with intellectual disability were excluded from the study if they had not been part of the transfer programme or did not have a PCP.

The second study group refers to the family of the person with intellectual disability, inclusion and exclusion criteria were also developed. Included in this study were people who were actively involved in the life of their family member with intellectual disability. The exclusion criteria were those who declined to be involved in the PCP process and those whose family members remained in the institution.

The third study group refers to staff members with the dual role of key worker. The inclusion criteria for this group were that they have worked in the field of intellectual disability for a minimum of five years and a requirement that they had attended one or more of PCP meetings. In addition they had to have an availability to participate in the interviews for the research. Key workers were

excluded if they had not been working in the field of intellectual disability for a minimum of five years and if they were not working directly with the focus person with intellectual disability in this study.

File entries listed a next of kin for each of the thirteen potential participates and they were written to as the family member deemed most in contact with the person with intellectual disability. Each family member was sent an information pack including an introductory cover letter, a participant information sheet specific to their role in the study and a consent form for them to sign to give their personal consent to be part of the study (see appendix II). Also included in the pack was a stamped self addressed envelope for ease of return of the consent form within a two week timeframe. Telephone contact was also made to each of the thirteen family members in case there was any question or ambiguity about the request to participate. Of the thirteen people who were contacted two people were inaccessible by telephone and one person redirected the researcher to another family member. Of the thirteen family members eleven consent forms were returned documenting their consent to participate in the study. Two family members declined to participate in the study with one family member not returning the consent form. A second family member said they were not participating and declined to give permission for their family member to be part of the study.

The Directors of Nursing of the three centres provided the researcher with the list of names and contact details of the key workers for the eleven remaining participants. The key workers were contacted individually by letter detailing an overview of the study. A participant information sheet and consent form was also provided (see appendix III). In order to establish rapport with the key workers telephone contact was made subsequent to them receiving the information. This was also an opportunity to seek clarity on the research. One staff member who was new to the services declined to be part of the study as she could not commit to participate due to upcoming maternity leave.

At the end of this process the researcher had ten people with intellectual disability who had consented to be part of the study. In addition, their family members and key workers had also consented to participate in the research project. All thirty participants had the benefit of familiarising themselves with the research project through the provided literature and interview with the researcher plus telephone consultation.

3.5.6 Demographic details of the triangulated research participants

Table 1 contains background and descriptive information about the people with intellectual disability who participated in this study. All names used are pseudonyms to safeguard the personal integrity and privacy of these real life individuals. Of the ten participants 60% were male and 40% were female. The majority of the participants were between 40 and 60 years of age; the youngest being in his 30's and the oldest in the 70-80 age range. While actual ages are known from case files an approximate age range is cited here in order to further safeguard the indentification of the

participants. Only two of the participants of this study were diagnosed with a known syndrome and intellectual disability at birth despite the fact that 100% of the study group are currently in receipt of intellectual disability services at level III and level IV as per the Supports Intensity Scale (2004). The types of support are rated to reflect the nature of the support the person currently has available to them. The support type ranges from none which equates to 0, monitoring which equates to I, to intense which is full assistance and equates to IV. Considering the participants of this study 80% spent long periods of their life detained in psychiatric hospitals at a very young age.

Table: 1 Demographics of person with intellectual disability

Person with Intellectual Disability										
	Colette	*Ronan*	*Lee*	*Anna*	*Teresa*	*Gary*	*Killian*	*Ryan*	*Margy*	*Paddy*
Gender	F	M	M	F	F	M	M	M	F	M
Age	60's	50's	40'	70's	40's	50's	30's	50's	50's	70's
Diagnosis of ID at birth	No	No	Yes	No	No	No	Yes	No	No	No
Diagnosed with physical disability	No	No	No	Yes	No	Yes	Yes	No	No	No
Level of supports received	IV	IV	III	IV	IV	IV	III	IV	IV	IV
Resided in psychiatric hospital	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes

Table 2 contains the background and descriptive information on the family members who participated in this study. There were equal numbers of male to female participants with an age range from 40 – 80 years with 60% in their 60's and 70's. For the family members and estimate was taken of their approximate age range based on the details gleaned during interview and their presentation. Considering this study group 80% were siblings with 50% brothers (Br) and 30% sisters (Sr) with one mother (Mo) being in her 80's. The level of contact refers to the frequency of face-to-face contact between the person with intellectual disability and their family member, with 0 indicating no contact, 1 referring to contact of approximately once a year, 2 referring to bi-annual

contact, 3 being monthly contact and 4 being weekly contact. As indicated in table 2 one participant of the study group had no family contact while 40% had contact once a year, 20% had contact twice a year with 30% having monthly contact. No participants of this study had weekly contact with family members.

Table: 2 Demographics of the family member

	Family Member									
	Colette	*Ronan*	*Lee*	*Anna*	*Teresa*	*Gary*	*Killian*	*Ryan*	*Margy*	*Paddy*
Gender	M	F	F	M	F	M	F	F	M	M
Age range	60's	60's	40's	70's	40's	50's	50's	80's	40's	70's
Nature of relationship	Br	Sr	Sr	Br	Sr	Br	Mo	Mo	Br	Br
Level of contact	0	3	3	1	2	1	3	2	1	1

Table 3 contains the background and descriptive information on the key workers who participated in this study. Of this study group 70% were female and 30% were male with an age range from 20 – 60 years. For the key workers approximate age was gleaned from information given to the researcher during interview by comments such as 'I am due to retire next year' and 'I qualified as a nurse two years ago'. Of the key worker participants of this study group 50% were staff nurses (SN) with 30% being care assistants (CA). The remaining 20% were equally divided, one at clinical nurse manager (CNM) level and one as a social care worker (SCW) level. The number of years that this staff member acted s key worker for the individual with intellectual disability ranged from 2 - 6 years.

Table: 3 Demographics of the key worker

Key worker										
	Colette	*Ronan*	*Lee*	*Anna*	*Teresa*	*Gary*	*Killian*	*Ryan*	*Margy*	*Paddy*
Gender	F	M	M	F	F	M	F	F	F	F
Age range	50's	30's	30's	50's	50's	40's	20's	60's	30's	50's
Level of employment	CA	SN	CA	CNM	CA	SN	SCW	SN	SN	SN
Number of years as key worker	2	5	6	3	5	3	2	6	4	2

3.5.7 Consent and ethical considerations for this research project

Inclusion Ireland (2010) makes reference to the fact that it is actually wrong to assume that a person with intellectual disability lacks capacity and therefore cannot consent. Understanding a person with intellectual disability depends on effective communication being available to them. Capacity depends on understanding and even if a person is deemed to lack capacity they still have a right to have accessible information. Consent can be made behaviourally and capacity can vary in the same person from different decisions and can fluctuate over time. It is worth noting that in Irish law no one can consent on behalf of another adult therefore in this case a family member cannot consent for the person with intellectual disability but a family member's opinion nonetheless is worth considering just as is the opinion of a staff member who knows the individual well.

One of the first ethical issues confronting the researcher was the issue of the individual with intellectual disability's capacity to consent to participate in the research study. In this case where people demonstrated the cognitive skills to make the determination themselves and where their capacity was such that they could sign their own name on a consent form and they were agreeable, this was taken as consent. However, as is the case for half of the subjects of this study when their cognitive restrictions was such that they did not have the skills to write their name and their understanding was restricted the researcher relied on their cooperation with the process as an indication of their consent but also on the views of the other stakeholders as a source of verification that this less able group were assenting to the process.

It is well documented that many people with intellectual disability will acquiesce to what they perceive the interviewer expects from them (Perske, 1995). Therefore extra measures are required to ensure that the person's agreement to participate is in their best interest and not just a matter of them acquiescing to the request. In this case the perspectives of the family members, key workers, Directors of nursing and the interdisciplinary professionals involved were sought. Fundamentally the researcher's own code of practice was such that no unwilling participants would have been considered.

Another ethical consideration is the importance of upholding the confidentiality and privacy issues of the person with intellectual disability's personal and sensitive information and that of their families. Every effort was made to show respect for the privilege of holding information on people's lives and upholding their dignity at all times. This privileged access was undoubtedly made easier by the position held by the researcher within the HSE. Notwithstanding this position written permission was sought from the highest level within the HSE.

In the context of interviewing people for this study a range of disclosures were made to the researcher including accounts of physical punishment and sexual abuse. In each disclosure the researcher was vigilant in ensuring that the appropriate protocols and policies were adhered to. The researcher was satisfied that they were investigated appropriately using the available protocol for that time. In the case of some interviews issues that were outside the remit of the discussion on

PCP emerged. These issues were serious for the individuals and as such suggestions were made for onward referral to appropriate sources.

By being mindful that due consideration was given to the many and various ethical considerations approval was sought and received from the Research and Ethical Approval Committee (REAC) of both the Social Work and Social Policy Department of Trinity College Dublin and the Research Ethics Committee (REC) Dublin Mid Leinster Region of the Health Service Executive (HSE). A standard REAC form was submitted to TCD and they took a decision to seek clarification from the researcher with regard to six queries. Upon clarification of these six issues the decision to proceed was granted (see appendix IV). Parallel to this process three application forms were submitted to the REC of the HSE and correspondence to proceed was granted (see appendix V).

3.5.8 Preparation for interviews and research process

Miles and Huberman (1994) discuss the use of conceptual and empirical matrices where data can be transferred to spreadsheets. Considering this a template was developed in order to log the detailed information required in data collection (see appendix VI). This template listed invaluable information for the organisation of the fieldwork such as phone numbers of the various stakeholders, locations of the families as well as specifics of the individual's PCP that would prove vital in analysing the status of the PCP's. In total there were forty two variables on each subject for future analysis.

An individual checklist was also designed to capture the range of steps required for each person with intellectual disability in order to ensure their full participation in the development of the individual case study including their consent, interview and attendance at their PCP meeting.

In order to glean a comprehensive understanding of the life trajectory of the individuals, access to archival information filed on each of the ten individuals was sought from each person with intellectual disability. Access to these files was facilitated by the Directors of Nursing in each of the three centres. Participant archival files were reviewed in the offices of the Directors of Nursing at the three centres and further to this current files in the ten individual community residences were also reviewed as were current case notes to ensure an accurate compilation of case histories.

The next step was that the researcher read the ten participants PCP documents. The participants PCP documents were reviewed to gain an understanding of the status of their PCP as it evolved over time taking into consideration their lives in the institution and how they were influenced by the PCP to their current PCP.

Consultation took place with a range of other professionals in the field. Speech and language therapists were conferred with on their opinion on the information package for people with intellectual disability and on the use of the Bristol Guidelines. Psychologists were consulted with

for their opinions on levels of intellectual disability and capacity to consent. Social workers were consulted with in order to discuss family's participation and family status.

An interview schedule was developed specifically for people with intellectual disability (see appendix VII). This schedule was designed based on Robertson et al (2005) six indices of PCP efficacy. This interview schedule was a comprehensive stocktaking of the persons past and present life and included questions such as: 'How is your life at the moment?', 'what is good in your life?' (with an emphasis on social activities and social roles), 'what is not good in your life?' (with an emphasis on life in the institution towards life in the community), 'tell me about your PCP?' (with an emphasis on relationships with family, friendships and staff), 'tell me what you are proud off?' (With an emphasis on life achievements) and lastly 'what would you know like to do in life?' (with an emphasis on future planning).

A specific family interview schedule was designed based on Robertson et al (2005) six indices of PCP efficacy (see appendix VIII). Some examples of the questions crafted for this interview schedule were 'how do you perceive your family members life now?', 'how is life different now since they left the institution?', 'what is your understanding of PCP?' and 'how do you find the PCP process?' Their opinion was also sought on the merits of PCP in terms of its capacity to set goals, ensure family participation, community participation, social networks, choice and a full life for the individual. Further to this a question was posed around PCP creating an opportunity for optimal individualised service design (OISD).

An interview schedule was designed for the key worker with similar questions posed (see appendix IX). These include 'what is your understanding of PCP?', 'how long have you known the person?', 'how long have you been key worker?', 'what is the role of the key worker?', 'do you regard PCP as the perfect way to get to know someone?'; 'does PCP enhance family relationships, community participation, social networks, choice and a full life for the individual?' The key workers opinion was also sought on whether they saw PCP as leading to more OISD.

3.5.9 Conducting the interviews for the research project

Thirty face-to-face interviews were carried by the researcher with the three respondent groups. The interview schedules described above were used as a format to guide the interview which were all recorded using an Olympus DSS for transcribing at a later date. Each of the thirty interviews varied in length from one to two hours. At all times the person being interviewed selected the time, date and venue for the interview. Prior to each interview telephone contact was made with the interviewee for consultation to agree a mutually suitable time and date for the interview to occur. This was then followed up by a letter in order to confirm agreement and act as a reminder.

The first face-to-face individual interviews were conducted with the people with intellectual disability in either their day service or their community house. People with intellectual disability were interviewed first as they are central to the PCP process and it is evidently important to know them

before interviewing family members and their key workers. The plan to see them in a familiar environment was in order to maximise their level of comfort and relaxation as it was thought that bringing them in to an office or clinic setting may have had the adverse effect of creating stress and tensions. As the individuals with intellectual disability varied in their capacity and as some were restricted in their expressive language support staff were close by in order to provide clarity. All of the ten individual interviews with the person with intellectual disability were digitally recorded. These were later transcribed by the researcher for the record and analysis in compiling the case studies. This process enhanced the first hand knowledge of the researcher of the life of the person with intellectual disability. An example of a transcribed interview with the person with intellectual disability is contained in appendix X.

Individual face-to-face interviews were held with family members. These interviews were held in a range of locations including two in the community residences, three in the day service settings and five in the family members own home. Eight out of the ten interviews with family members were digitally recorded and later transcribed by the researcher. Two family members declined to allow digital recording of their interview but did consent to the researcher taking hand written notes. An example of a transcribed interview with the family member is contained in appendix XI.

Individual face-to-face interviews were held with the key workers. Key worker interviews were held in either the day service setting or the community residence. Nine out of the ten interviews with the key workers were digitally recorded and later transcribed by the researcher. One key worker declined to allow digital recording of her interview but did consent to the researcher taking hand written notes. An example of a transcribed interview with the key worker is contained in appendix XII.

3.5.10 Detailing of the PCP meetings attended

The researcher attended each of the ten participant's most recent PCP meeting as a non participant observer in an ethnographic style. The PCP meetings typically lasted between one and two hours with eight to ten people present. Refreshments were served at the end of the meetings. These PCP meetings were held either in the person's day service or at their community house. Nine of the ten PCP meetings were digitally recorded and were transcribed for the record and later analysed. Before each PCP meeting prior consultation took place with the individual and the service setting manager to ensure that the researcher's presence at the meeting was agreeable to all parties. An invitation for the researcher to attend was either received by telephone or letter. An example of a transcribed PCP meeting is available in appendix XIII.

3.5.11 The formulation of the case studies

The formulation of the case studies was a lengthy and intricate process. For each of the ten people with intellectual disability of this study case studies were formulated by meeting the person with intellectual disability and giving them an opportunity to talk about their lives. This was further

enriched by a systematic review of the archival files and current files. This was followed by a detailed analysis of the four transcripts on each person including the interview with the person with intellectual disability, their family member, their key worker and the PCP meeting. The case studies were then crafted following a systematic format which contained an introduction, a description of their current situation, a detail of the PCP process concluding with a comment and analysis section. The case studies are presented in chapter 4 and an example of a fuller case study can be found in appendix XIV

The rationale for following this format was that the introduction contained a description of the person's life with their family prior to their institutionalisation, followed by a consideration of their current situation and lifestyle. This gave an overview of the significant life events experienced by the person before they were institutionalised; during their time in the long stay institutions, and their life subsequent to their discharge to community based services. The PCP process is also included in the case studies with reference to how the PCP is perceived by the individual, their family and key worker. In order to establish the common themes a detailed comment and analysis of each case study is formulated.

3.5.12 The steps taken to analyse information from each of the cases and the formulation of the common themes

The cross case study analysis involved detailed consideration of emerging salient themes. Each theme was considered in light of the extensive literature reviewed for this study against a background of current trends in service development and PCP. This study uses multiple data sources including for example semi-structured interviews with the person with intellectual disability, the family members and key workers in order to reap the harvest that it abounds from triangulation analysis. Case study research has been found to provide a richer set of data that promotes transferability of the study findings (Yin, 2008) The process of triangulation involves corroborating the data from multiple perspectives to enhance the depth of understanding of the specific themes and to provide verification (Creswell, 1998). This study uses case study research because of the benefits from using multiple cases to add confidence in the findings (Miles & Huberman, 1994). The evidence from multiple cases is considered more compelling and the overall study is regarded as more robost. The multiple cases in this study allow for exploration, description and explanation in each case as well as across the cases to help provide 'lessons learned' (Creswell, 1998, p 249). This study benefits from the application of both triangulation and multiple case studies that ensures quality criteria in the conducting of qualiatative research that is transferable, dependable, credible and objective (Creswell, 1998).

As Yin (2008) recommended when he described the six types of information in a case study this study drew on archival records, interviews with the three focus groups, participant observation at the PCP meetings and direct observation of the individual with intellectual disability. The ultimate aim was to highlight the central themes. The researcher in order to provide a format for thematic analysis set out a spreadsheet for each case study. The spreadsheet contained identifying

biographical details such as age, service setting and family contacts. The themes that emerged from each of the participants were systematically itemised on each of the individual's spreadsheet. The themes were drawn from the comment and analysis section of the individual case studies. The common themes were then coded and the codes that were found to be universal across the case studies were then refined to the ten overarching themes.

The most robust themes were discussed in order to explain the relevance and to elucidate on how to improve the individual's life through PCP in the future. As O'Reilly-De-Brun (2001) argues, patterns can be identified and understood as they are manifested in the context of someone's life story and life histories can be a powerful source of material. The case studies yield a very powerful source of material to further our understanding of each of the ten individuals with intellectual disability. This study drew on three primary sources to address the research question. These sources include the person with intellectual disability, the family members and the key workers. Separate spreadsheets were designed to capture information from these three sources. The researcher was mindful of the quality criteria for conducting qualitative research including transferability, dependability, credibility and objectivity.

The cases are presented in chapter 4, with a cross case analysis presented in chapter 5. Chapter 6 contains a discussion on the salient themes of the case studies, drawing on Yin's (2008) application of case study research.

3.6 Conclusion

There is a strong and compelling rationale for choosing a qualitative approach to understanding PCP for people with intellectual disability as detailed above. As we know there is a dearth of evidence base regarding the efficacy of PCP and further exploration on the topic is needed. Qualitative research presenting a detailed view of PCP will add to this body of research. In addition, case study and ethnographic research was chosen for this study as described by Yin (2008) it was vital to capture some of the six styles to case study research. Much of the available literature on PCP is theoretical and anecdotal, describing PCP as an ideology rather than focusing on qualitative outcomes of the process has resulted in a limited and sometimes contradictory evaluation of the process to date. Within the PCP movement and given that PCP is not an intervention in itself, there has always been a critical debate around finding a better way to ensure people with intellectual disability have person centred lifestyles.

What follows is a description in case study format of the ten cases that tell a story from the perspective of the person with intellectual disability from the beginning of their lives, through to their institutionalisation, and transfer to community based residences. The researcher will consider their understanding of PCP as well as that of their family members and key workers. This will be followed by a description and analysis of their PCP meeting. The research will consider their understanding of PCP as well as that of their family members and key workers. This will be followed by a description and analysis of their PCP meeting.

Chapter 4

The Cases

A consideration of the lives of ten individuals with intellectual disability who were institutionalised and later transferred to community based residences. Their PCPs through case study format are examined. All names used are pseudonyms to safeguard the personal integrity and privacy of these real life individuals.

Colette

4.1 Colette

4.1.1 Background and Context

Colette was born in a midlands town in the middle of the twentieth century. Colette was the second eldest of a large family. She stated that she enjoyed her early days at home with her parents and her siblings. Colette had positive family relationships but her parents passed away when she was a young adult.

> "Home was lovely; we always had the best of everything. We had a good mother and a good father, but unfortunately they died".
>
> Interview with Colette.

While she was protected somewhat by her extended family, nonetheless there was no evidence of an intellectual disability. She enjoyed good health and there were no concerns about her physical health. To this day, Colette has a good relationship with her surviving siblings. Her younger sister also has a life long intellectual disability requiring residential care and lives close by in a neighbouring village. Colette makes a point of visiting her sister as often as she can.

Colette attended the local religious run school. She progressed to the local secondary school but experienced learning difficulties and left school at fifteen years of age. She stated that she hated doing her homework but she felt she had to do it. This was the first time in her life that she experienced learning problems at school. She recalls having a good relationship with one nun who she viewed as 'like a sister to me' and is glad that she learned to read and write. She does however recall her school experience as 'terrible' and she stated that she never liked school as the nuns used to 'beat the hell out of me' and in particular one specific nun.

> "Jesus I will never forget them. The beatings I got was unbelievable. One of the teachers there used to wallop the hands of me. I had a very bad time of it in school".
>
> Interview with Colette.

Colette alludes to the relatively poor living conditions when she was a teenager and spoke of her parent's decision to immigrate to the United Kingdom.

> "The whole lot of us moved to Birmingham, but what me father done was he went over first and he got a house. He seen the landlord and me mother went over along with him but what me father didn't tell him was that there was also five kids to go into it".
>
> Interview with Colette.

At this stage in Colette's life she was gainfully employed in a variety of low paid, unskilled factory settings. She stated that her job was:

> "Packing the pancakes, putting them in sixes, putting them in a dish and putting them on a conveyor belt, then they would all fall onto another conveyor belt and get wrapped with paper. It was a good job. I got great money for it and I enjoyed it".

Interview with Colette.

In the early 1970's Colette met and married a local English man. He worked as a barman and was involved in the music business. Colette recounts that she sang in various Cabaret acts around England, managed by him. She recalls not having a stable home life during her marriage and had feelings of being diminished due to the demands placed on her to perform at cabaret acts at his will. She reported that they started to argue and her husband started to see other women.

> "I got married to a good for nothing yoke. He couldn't do anything that way. That was partly why I split up with him. He used to blame me but sure it wasn't me at all it was him. I couldn't stick that so I went to the Doctor and I got myself checked out and the Doctor said to me there was nothing wrong with me in that way".

Interview with Colette.

Colette's brother reported that Colette was doing fine up until she got married. He stated that:

> "Well, her life was good until she married that man. He was a bad b*****d to tell you the truth".

Interview with brother.

During this time, with her random performing music schedule Colette reported that she was unable to hold down her factory jobs. What became clear when Colette reflected on her nine year marriage was that she lacked control over activities, an absence of financial autonomy coupled with feeling marginalised and a sense of feeling unloved. The couple divorced and subsequently Colette stated that she had a 'nervous breakdown' during which she was hospitalised in England. She recalls having had electroconvulsive therapy (ECT) twice which she says 'made her feel a bit better'.

The next part of Colette's life is patchy in that she was found in a 'bewildered state' in a train station in the Irish Midlands. At this time in the early 80's she was admitted to the local psychiatric hospital for treatment of depression. File entries describe Colette as 'a chronic schizophrenic and

depressed'. She was admitted and discharged four times over a five year period to this psychiatric hospital. She was never discharged after her final admission.

She transferred to a new intellectual disability service in 1989 when it became de-designated from this psychiatric hospital. She lived on a Ward with thirty five other people with intellectual disability in open plan day rooms and in dormitory style sleeping accommodation. Colette recalls spending her days walking up and down the corridor. Many aspects of institutional living such as tasteless food, central laundry, being told what to wear, fixed meal times and fixed bath times were a source of complaints. She recalls the lack of facility for her personal affects and memorabilia. She spoke of the ward routine at night where she was 'tormented by the sound of other patients crying and calling out' while she recalls 'lights left on in the long corridors and staff moving about jingling keys'. She articulated an objection to the ever present smell of disinfectant, other unpleasant odours. She poignantly continued to protest her hospitalisation.

> "I was kept there for a long time. The authorities wouldn't let me get out of it. I didn't like the women in it. They put you to bed at half eight and then you would have a big long night ahead of you. They made you wear clothes that you didn't like".
>
> Interview with Colette.

During this period her opportunities to visit her loving home were scant. She did have regular visits from her younger brother to the ward, however, she reports this as being frustrating as other patients would surround them looking for his attention, cigarettes and sweets. She remembers her brother fondly.

> "He is dead now you know. He used to take care of my mother and bring her places. The last words she said to him were to make sure his sisters were alright. He came every day to the ward. He used to walk sometimes all the way to see me".
>
> Interview with Colette.

4.1.2 Current Situation

Colette moved from the large intellectual disability residential centre to a community house in the same midlands town as part of the HSE transfer programme in 2003. She lived in this community house with five other people with intellectual disability. While Colette was very pleased with this move, as she had her own bedroom and enjoyed the home prepared meals, she still yearned for a place to live on her own. She continued to advocate for better living conditions. Colette was moved by management to another community house with four other people with intellectual

disability outside the town where she currently resides. When asked do you like your new house? She replied: 'I do, I like the house, I just don't like the people out there'.

She perceives her move to the new community house as an improvement in her living conditions and she commented on her accommodation by stating:

> "I have my own bedroom out there, it is very small. I do have all my own things in it. No I don't have a key to my house nor to my room either. It doesn't bother me though there is always staff so we don't need a key".
>
> Interview with Colette.

When asked whether she regarded the current community house as ***her home*** now. Colette replied:

> "No I do not. I see it as a dump. There is too much favouritism. One or two gets everything from the staff".
>
> Interview with Colette.

When asked how she spends her leisure time in the evenings. Colette replied:

> "I sit down and smoke cigarettes one after the other, if not I go to the tap and drink loads of water. I am happy to sit the way I am. I am 61 now and all I want is peace and quiet".
>
> Interview with Colette.

As the intellectual disability service developed in the community Colette's many talents became evident when she started to attend modular day services in the residential centre doing art and music which she reports as being very important to her. She now attends a part time day service of her choice in the town five afternoons per week. The community inclusion modules give her an opportunity to utilise facilities in the town where she goes to the hairdresser, clothes shopping, restaurants, cinema and other community activities that interest her.

Typically, when Colette is brought to her day service venue her money and cigarette allocation is given to her day service staff by her residential care staff. She commented:

> "I came in, in the morning with five cigarettes in an envelope to do me the day. The staff came with €25 in an envelope to give to day service manager every Monday for me to use for the week. I have

a bank account but I can't use it because they have the card. I wouldn't go mad buying clothes, as they think".

Interview with Colette.

During the interview with Colette's brother he noted that Colette looks physically well. He has observed that since she has moved to a community house and has something constructive to do during the day she seems a lot happier, stating:

"She is a lot smarter and looks well dressed. She is like a yank home on holidays. She looks a lot better than when she was in the hospital. She has lost weight, she was a lot stouter".

Interview with brother.

4.1.3 PCP Process

Colette's understanding of PCP is confused. When asked how your PCP is going she stated: 'there is a one that you need to go to, to see about my care plan' indicating that she sees a care plan and a PCP as one of the same. When asked what a PCP means she stated:

> "It means that I can go on a Share-a-Break, that's all I know about it. It keeps a medical record".
>
> Interview with Colette.

When asked about her goals at her PCP meeting and what this actually meant to Colette she replied:

> "Jaysus I don't know.....where they mark down whether you have been good or bad".
>
> Interview with Colette.

Colette's brother spoke of his own limited coping skills stating that he is unemployed, does not drive and has a history of alcohol abuse. When he was asked 'do you go to Colette's PCP meeting? or 'whether he was aware of PCP? He stated:

> "No, the nurses do all that; they know what is best for Colette. I think trained nurses are better at that".
>
> Interview with brother.

Colette had no family support at her PCP meeting. Her brother declined an opportunity to be involved in all aspects of planning her life, regarding her as being:

> "Well looked after. There were too many of them in the hospital, God it was a bad place. There are small numbers now where she lives. I have been to the house a few times, it is a grand house".
>
> Interview with brother.

When Colette was asked where the PCP information was held she stated that 'the staff would have it. It is down in the office. I don't have it'. Colette commented that she was at her PCP meeting a couple of months ago and stated:

> "I told them it was about time that they got me a place of my own as I am a long time looking for it now. I put in for it but I can't understand why I didn't get a place. That is going back now to last year or the year before".

Interview with Colette.

Colette's key worker describes her relationship with Colette as extending for about fifteen years including the time she resided in a hospital setting. But 'I am her key worker for two years now'. She noted that Colette can be 'very difficult sometimes' which she attributes to her not realising her ambition to reside in her own accommodation.

> "Colette for the past couple of months was shouting and roaring at me saying 'you didn't get me a flat'. But at the end of the day I am not the one that can get a flat. She blamed me because I was her key worker".

Interview with key worker.

Another difficulty the key worker alluded to was the advice Colette received from the many varied staff and advocates that she should have a flat of her own.

> "They just come in and work with her for a few hours and then they go again and it is left high and dry. I can see Colette's point in that everyone is telling her that 'she should have a flat' and then nothing happens about it".

Interview with key worker.

As part of the research process I attended Colette's most recent PCP meeting which was held in her day centre. This meeting was attended by Colette, a care assistant as her key worker, two staff nurses from her group home, the Clinical Nurse Manager (CNM), day service manager, two support workers and an independent advocate. Colette's PCP meeting opened with her key worker speaking in the first person giving a synopsis of Colette's life story. A summary of the last meeting held in 2009 was presented in the context of the modest goals that were achieved. These included visiting her sister, attending her day service, going on an overnight stay with a staff member to a hotel and having three overnight Share-a-Breaks. Colette stated:

> "I love going on my Share-a-Break, I go off out to the middle of nowhere and I like it. I love peace and quiet and that is why I want my own flat. So I can be alone".
>
> Colette speaking at her PCP meeting.

There was a general chat on how life has been for Colette since her last meeting. It was acknowledged that one of her brothers had passed away and that she was supported to attend the funeral by staff from her community house. There was no further discussion on this and was brushed over as incidental.

In Colette's PCP documentation there is a long term goal for Colette to live more independently in a flat. 'Her number one goal is moving to a flat'. Colette remarked:

> "Yeah that's right, that's all I want. But it is not what I want, it is what I get".
>
> Colette speaking at her PCP Meeting.

This statement from Colette was trivialised and she was asked 'so what would you like'? At this point Colette adjusted her request and reconciled to something more achievable by stating 'I would like to go for a drink every second weekend and to continue with my Share-a-Break'.

While the intricacies of the PCP process may somewhat elude her, nonetheless she has a compelling sense of her own life goals which means getting a place to live on her own. Ideally, the key worker's role is around person centred active supports in assisting Colette to realise this ambition which she repeats at every opportunity. When Colette spoke of her desire to live in a flat on her own, staff typically responded by telling her why this was not achievable.

> "Well, I want to say something that I know Colette won't like me saying this, but most of the time you wouldn't be able to live on your own. I found cigarette butts behind the bed and the locker. I know you are great and that you are out and about. The early part of the day I don't think that you would be able to manage without somebody at least coming in and assisting. As you know you are reluctant to get up in the morning and you are reluctant to go to bed at night. I am not giving out I am just telling you the way things are".
>
> The CNM speaking at Colette's PCP Meeting.

Further to this the staff spoke about money management and whether she would be able to manage her own finances and stated:

> "You like to spend any money you have in your purse. Straight away it is gone. So, realistically do you think that you would be able to manage your finances? I mean really and honestly".
>
> Staff nurse speaking at Colette's PCP Meeting.

Colette responds 'Well it all depends on how much the rent is. I am able to manage my own money and I can count, I might be a bit slow at it but I can do it'.

A further debate on the topic ensued with a discussion with the staff present on how it would not be possible for Colette to have a flat. The notion of a supported living scheme was discussed with staff commenting as follows:

> "There are no vacancies in supported living and none are envisaged in the near future. I spoke to the manager who said that there isn't anything really coming up and that you wouldn't be able to manage on your own. You require a lot of staffing. With staffing the way it is at the moment it would not be possible".
>
> CNM speaking at Colette's PCP Meeting.

Colette responded by stating 'the manager told me that she was going to get me a flat, a good flat. It would be something that I want and that I can choose'. The staff conceded remarking that:

> "Maybe you could think of a granny flat attached to a community house. This is where you would still live with the support of the staff attached to the community house, for your medical needs. You have huge medical needs and you can get sick very quickly. You know yourself; you don't be well nearly overnight. Would that be a compromise?"
>
> Key worker speaking at Colette's PCP Meeting.

Colette responded with 'Ah, I don't think so'. To which staff replied 'you don't know when you are well off'. Colette stated: 'You see I don't think that I am well off. You see I am just there and the whole lot is getting me down'. Staff asked Colette how she felt about her current residential placement:

> "The majority of the time I feel I could go mad. I don't want to be there. But then I settle down. I have my cup of coffee and I am alright. It takes me a couple of hours to get that way".

Colette speaking at her PCP Meeting.

The staff at the PCP meeting defended the community residence model. Instead of taking on Colette's goal of having a place of her own staff continue to defend the community group home model to the extent that it drowns out her voice. Colette holds on to her goal despite staffs comments.

> "Do you really think living on your own would make any difference? When you are with the rest of us you can bounce things of us. You have someone to talk to and some one to listen to. If you were on your own like, you would be on your own. It can be lonesome, but if that is what you want that is fine. But like it is an awful lot to be on your own".

Staff nurse speaking at Colette's PCP Meeting.

Colette retorted:

> "Some people like living on there own. You get so far in life and you just like to be on your own. You get to a certain age and you just like to be on your own. Do you understand?"

Colette speaking at her PCP Meeting.

Again Staff tried to convince her of the many difficulties she may encounter saying 'it is a lot of extra work. You have to cook for yourself and everything'. She responded by saying 'that is no problem I can do that'.

It became evident during the course of the PCP meeting that Colette's considered opinion was being disregarded. This was most evident in her response to her stated desire to having her own flat. But further to that when she was asked whether she wanted to participate in the special leisure buddy scheme she declined forcibly three times. Interestingly staff kept returning to this theme perhaps because if she had agreed to a leisure buddy as a PCP goal that this was achievable and then there would be a successful outcome.

Staff interjected yet again disregarding Colette's plea to have a place of her own by discussing holidays, stating:

> "I think we all need a holiday once a year. Colette really enjoys it, going shopping and then going back to the hotel to unwind. Would you like to go on holidays again before the end of the year?"
>
> Key worker speaking at Colette's PCP Meeting.

Colette replied 'the question is do I have the money to go?' Staff then respond by stating 'well don't worry about money'. To which she replied 'well I do worry about money'. Again this was dismissed and staff moved onto her day service and asked her 'what about your day programme here Colette, are you happy with that?' She was handed her day service agenda to read aloud to the group which she did in a perfunctory manner.

Her day programme is about keeping her occupied. She has no opportunities to earn money or to contribute back to society. A goal in her last PCP meeting was to maintain contact with her sister who has intellectual disability.

> "Just to mention that one of the things that Colette wanted last year was to have contact with her sister. This is happening every second week and we drop her to her sister. She visits her sister while the others go to the therapeutic pool".
>
> Day service manager speaking at Colette's PCP Meeting.

At her PCP meeting opportunities were taken to illustrate Colette's perceived reliance on staff even in her day service.

> "You can see from her timetable most of her programmes are one to one because she needs the space. Sometimes it is not always possible in that if we don't have the staff today we would ask Colette if she would like to do this or this and she is always very obliging. The staff have given a little report here to say that Colette 'works well in the kitchen' and she appears to 'love her job in the kitchen'. She does require supervision but we love having Colette here".
>
> Day service manager speaking at Colette's PCP Meeting.

Staff reported to the PCP meeting 'the many friends that Colette has made'. They went on to list the names of four paid members of staff who work in day services who were reported as Colette's friends. Interestingly, it was not Colette that gave an account of these people as being her friends but that of the staff. Staff stated 'Colette is busy while she is here and I think she really enjoys being in day services. Don't you Colette?' Colette replied 'sometimes, it depends on how I feel'.

The focus of the PCP meeting changed to her medical needs once the advocate had questioned what was agreed regarding her stated desire to have her own flat. Staff said:

> "She is on an awful lot of tablets, 13 or 14 each morning and she has a lot of hospital appointments as well. Her diabetes is controlled and is going well, it is the behaviour that sends it high and then it is a worry for us".

Staff nurse speaking at Colette's PCP Meeting.

It seems the concerns over her health and in particular managing her diabetes made those caring for Colette disinclined to assist her in furthering her goal of independent living. This may stem from fear or anxiety arsing from her current mental health challenges and the fact that she may not always be reliable in monitoring her own diabetes. The nursing staff fears that Colette 'could go into a diabetic coma'.

Colette, at this point in the meeting, yet again, realised that her dream of attaining her own place to live was ebbing away. 'I am not going to get my flat by the sound of it'. People at the meeting were aware of Colette's feelings of dejection and they tried to rescue the situation by stating 'I think the idea of a granny flat would be a step in the right direction'. Regrettably, further explanation of where this granny flat would be, what Colette understands to be the arrangement and when this arrangement would transpire was left in abeyance.

Colette was asked by the advocate whether anything had changed for her as a result of the PCP meeting to which Colette replied 'No'. Alarmingly staff cautioned Colette stating:

> "Now Colette there is no point in you going out of here today saying that 'I am after having my PCP meeting and it is the same old thing again'. Sure there's not?"

CNM speaking at Colette's' PCP Meeting.

Colette meekishly replied 'I won't be saying nothing but it is the same old thing again. The key worker reflected on the PCP meeting afterwards and regarded the process as 'still worthwhile' despite the many frustrations for all concerned. It becomes apparent that the key worker did not see her role as a conduit to empower Colette to realise her own personal goals. She in fact took ownership of the goals herself causing her to feel hurt and personally upset.

> "Well it does upset me. I feel that I should have done more but I am not the boss. I should have done more to get the boss to do it. I have to go through the managers, however some managers will say 'go ahead and do it and keep fighting for the flat' and others

will say 'no you can't do that'. They say the same to Colette. She gets confused. You can't tell her one thing then tell her something different. There should be an alternative for her'"

Interview with key worker.

4.1.4. Comment and analysis

It is remarkable when reflecting on Colette's life to recall that she had a reasonably satisfactory life without formal intellectual disability services well into adulthood. She went to her own local school, she emigrated to the United Kingdom, she gained meaningful employment, resided happily with her family and later marrying her husband of nine years, which illustrates a level of self determination and demonstrating independence. What a sharp contrast to her current lifestyle which regrettably lacks many features of the previous lifestyle she enjoyed and clearly continues to seek. This is evident from her many statements where she repeatedly looks for support in finding a place of her own to live. She now admits that as she has aged she needs help, has some limitations, but sees herself as being more independent and capable than the staff acknowledge.

She previously earned and managed her own income but is now at the mercy of staff to give her 'pocket money' from her disability allowance. She also receives a rationed cigarette allowance. There is a very paternalistic style and tone taken at the PCP meeting with an emphasis on controlling rather than empowering. This is further evidenced by telling her that she is unable to manage her finances and the staff controls her bank details and bank card. Colette herself has succumbed to this feeling of learned helplessness to the extent that now doesn't care about not having a key to her own front door.

What is striking is the lack of reference to any safeguards to assist her to be more independent. The emphasis is on telling her that she cannot live on her own or she would not be able to live on her own rather than looking at alternative assistive technologies such as smart houses, meals on wheels and other forms of readily available community support. While it is acknowledged that there are certain behaviours of concern to staff such as smoking in bed and the proper disposal of cigarette butts, these of themselves should not be a barrier to her life goals. Safe guards are available to assist in managing such behaviours.

The key worker has a dual responsibility; on the one hand she is employed as a care worker with responsibility for the efficient running of the community residence. However, superimposed on this role is an additional role and responsibility of key worker. In this case the key worker seems to over identify with the responsibility of promoting an action plan as opposed to prompting Colette's capacity to take the small incremental steps required to reclaim her independence. This perpetuates the status quo and it is evidently frustrating for all concerned with little or no outcome and worse still there is evidence that Colette is silenced.

There was an effort in Colette's PCP to surrender her to the world of 'special services and support'. She lives in a community house for people with intellectual disability, she attends a congregate day service for people with intellectual disability and if that was not enough there was a 'pushing' of achievable add-ons such as the Share-a-Break scheme and the leisure buddy scheme again schemes for people with intellectual disability. The reality is that Colette is never without one or

more paid members of staff. She never has staff free times, yet she frequently states 'all I want to do is to be left alone in peace and quiet'.

What typically works well for staff is when clients are 'compliant' with the daily routine and 'grateful' rather than critical for their services. Staff goals in Colette's PCP meeting are around the efficient running of the group home and conforming to the status quo. Colette's goals are juxtaposed with this and they are not mutually compatible causing frustration and disquiet.

Staff attach a lot of importance to her medication regime which is used as a barrier to not realising her ambition to get a place of her own. Staff are genuinely concerned for Colette's health and well being more so since the onset of her diabetes. It maybe helpful to look at rationalising her medication regime. Good practice indicates monopharmacy versus polypharmacy. Teaching and supporting Colette to self medicate could enable her to manage her health care as opposed to being reliant on staff

The Citizens Information Centre provided the services of an independent advocate at Colette's PCP. Her contribution ensured that the meeting returned to Colette's stated goal of moving to independent accommodation. As an observer at this meeting it was obvious that if this person was not present that this goal would be further obscured. Albeit that her presence did not have an immediate impact it caused the staff to rethink and consider a compromise such as a granny flat.

The summary of Colette's life tells us that she is being treated for diabetes, chronic respiratory problems, urinary tract infections and mental health problems with a range of polypharmacies and other medications. These problems currently define her lifestyle as one that is characterised by twenty four seven staff support which limits her capacity to self determine. Her PCP should be a vehicle for her to move her life on and realise some of her deep personal dreams and aspirations. Colette has many interesting capacities as a woman with borderline low average cognitive ability and despite her psychiatric diagnosis of 'chronic schizophrenia and depression' has many rights as a citizen and with the appropriate supports should be able to lead a life that she chooses. By moving from the legacy of institutional care to a model of self determination Colette's PCP could transform her life.

This case study questions to what extent the institutional practices continued despite her move to the community. One would also wonder that if she had not been in the psychiatric hospital during the period of de-designation and policy change to move people with 'mental handicap' out of psychiatric hospitals as recommended by Planning for the Future (1984), would she have ever been the recipient of day and residential services typically designed for people with moderate, severe and profound intellectual disability? At a minimum, her PCP is exploring the possibility of giving her a granny flat attached to the segregated group home which goes some small way towards a more personal lifestyle. It seems Colette is on a merry-go-round and is going from living in a segregated group home to a special day service. Both Colette and those supporting her lack

an appreciation of how her life might improve if she was given an opportunity to be included in the mainstream of her community.

Ronan

4.2 Ronan

4.2.1 Background and context

Ronan was born in a small town in Ireland during the 1960's. He is one of a sib ship of six. His father and two of his siblings have passed on and his mother continues to reside in the family home although now she has been diagnosed with Alzheimer's disease. He has a good relationship with the remaining members of his family all of whom live local enough to the family home. File entries confirm (1970) that he attended the local national school where he was described as 'a bit slow'. He was then enrolled in the local special school as a day pupil. He attended this special school for approximately two years; however, he states that he never really liked school. Psychometric tests confirm that Ronan has 'a low mild/moderate level of intellectual functioning'. This would indicate that Ronan is functioning at a relatively high level although he has a reported 'mental age equivalence of the five -seven test age' (In summary report, 2004). While Ronan progressed reasonably well in this special school regrettably he was expelled following an incident where he was reported to have 'pushed a resident down the stairs' (file entry, 1972).

Ronan spent the next four years at home on the small family farm. At age sixteen he was enrolled in a day programme for activation and occupational therapy in the local hospital for people with intellectual disability. He was admitted eleven times to the local psychiatric hospital for treatment of 'impulsive behaviour' and 'outbursts'. Prior to his eleventh admission to the psychiatric hospital Ronan attended an Uncles funeral. After the Funeral, Ronan who always had difficulty expressing his emotions appropriately had a behavioural outburst in his local town breaking windows and assaulting people. The family in an effort to cope contacted the nurse in charge of his day programme who came to his home and administered emergency medication and conveyed Ronan again into the care of the psychiatric services. At this point Ronan was told in a threatening manner that 'he would never see his family again' and that he 'would never be let back to his day programme'.

> "I got very upset at the house one day and the Guards came up. The nurse came and said he' wouldn't take me back to the day centre anymore'. Then the guards came and the lady Doctor. They gave me an injection into the bum. Anyway she came up and sent me back to admissions in the hospital. I took a turn and the nurse said I was never going back home".
>
> Interview with Ronan

When Ronan was twenty nine years of age a case conference was held with Ronan's family where they were offered permanent residential care in the new intellectual disability centre that was de-designated from the psychiatric hospital. This hallmarked a welcome reprieve for his family but for Ronan it began a life of institutional care. For Ronan's family the stress of living with the

unpredictability of potential assaults particularly as they were aging and becoming more vulnerable was a factor in their decision to let him go to residential services.

From 1989 to 2004 Ronan resided in various wards in the large residential centre for people with intellectual disability. He lived in this setting with ninety five other people with varying degrees of disability. Because he was relatively capable in activities of daily living, such as being able to walk, talk and self care, he had the opportunity of spending his days across the road in the nearby workshop. He reflects on his days being purposeful in that he engaged in supported work such as landscaping, upholstery and woodwork. Midday, he returned to the ward of the large centre for his medication and main meal. In the evenings, regardless of weather Ronan would spend hours pacing around the walled perimeter of the psychiatric hospital and large residential centre.

He recalled the long corridors and the large dormitories where his sleep was interrupted by the night time activities on the wards. He described how the hospital beds had mattresses covered with rubber that he found 'uncomfortable, smelly and sweaty'. Ronan took prescribed medications three times per day at meal times. A feature of institutional practice is the drug keys, drug round, drug trolley and the administration of medications at mealtimes. This routine was a way of taking attendance and tracking people. While Ronan did not have a lot in common with the other residents, he did however have a friend with whom he lived and worked. This is illustrative of the fact that he had the social skills to make friends and to maintain a harmonious relationship with other people.

A file search revealed three accounts of serious sexual exploitation of Ronan. The first account (1994) he graphically details how one evening when he was out on his usual walk around the perimeter of the centre he was approached by a man who he recognised as a psychiatric patient. He described to the nurse details of the event.

> "Ronan stated to me that the man had oral sex with him. He then said that he 'hit me across the bottom with a stick'. Further on in the conversation about the abuse he told me that 'he would beat me up' if he told anyone what happened".
>
> File entry August 1994

Subsequent to this incident Ronan attended the 'Keep Safe/Stay Safe Programme' for psychological counselling and induction in the hope being that he would be able to ward off any sexual predators while at the same time not lose any of his freedom. An option considered at this time was to place Ronan in a locked ward of the residential centre in an attempt to protect him from any further assaults. He continued to reside on a ward for aging men with intellectual disability and in 2003 he had the opportunity to move to a community residence five miles from the town. It was envisaged that he would continue to have his nightly walks on the country roads and not around

the perimeter of the psychiatric hospital. It became apparent that due to road hazards and traffic volumes that this was not tenable. He stated:

> "I couldn't walk around the area, the cars would knock you down, if I had a house in town I would be happy".

Summary report from Ronan's PCP in 2004

Living in this community residence provided a marked improvement in Ronan's quality of life; however, it was not a good match for meeting his needs. The idea was that this would be a nice quiet house for aging men, many of whom exceeded his age by twenty years. However, one evening after a full day at work landscaping Ronan and his co-residents attended an evening appointment with the dentist. He had an invasive procedure carried out which included extractions. Despite being tired after his days work and at the very least, following an extraction, he would be experiencing some pain and discomfort the scheduled activities of the group continued. Ronan refers to being 'very anxious and afraid of the dentist' and along with heightened stress levels following the dental visit he was brought to a 'special disco' with his co-residents that evening. At this disco he had a behavioural outburst where he was reported to have thrown a glass and a chair. As a means of control and punishment he was immediately returned to the large centre from which he had been transferred three months previous. He recalled:

> "I had a bit of trouble. I was in the clubhouse. I broke glasses. The nurse held me down by the neck on the ground. Then he put me back to the hospital. I had to stay there a good while, a good many years".

Interview with Ronan

He continued to reside on the ward of the large residential centre where he had some personal freedom. During this time he made a second allegation of sexual assault. This time it was in the context of him walking from the large centre to his rehabilitative training programme in town. His walk brought him past a business where the alleged incident was reported to have occurred in a shed.

> "A fellow brought me into the shed. He put the latch on the door. He told me to take down my trousers. He told me he would kill me if I didn't go in. I didn't want him to touch my private parts. I can't go to town now. I am afraid he would catch me".

File entry May 2005

A full Garda investigation was carried out of Ronan's complaint. A file was prepared for the DPP, however, no prosecution followed. His sister recalled:

> "The guards were looking into it and they sent it to the DPP and it couldn't go any further and that was it. It was unfortunate really and I said to the guards 'the law is wrong'. Just because you have a disability you can't be a witness. The law let Ronan down. It is the only thing that I have regrets about".
>
> Interview with Ronan's sister

In an attempt to safeguard Ronan's wellbeing he was escorted back and forth from town by staff. Interestingly, at this point (2005) he reported a third allegation of sexual assault. This time it was against a fellow resident of the large residential centre. The Garda inspector's reports states:

> "The injured party Ronan alleges that Mr X sexually assaulted him in his bedroom on the ward over a period of two months this year. The last incident he states occurred in the chapel on the grounds of the hospital in October 2005".
>
> File entry November 2005

Ronan was prioritised for transfer to the first available community residence. He eventually moved to a newly acquired bungalow in the town. There are however, unresolved issues in relation to his institutionalisation, the reported abuse and staff misunderstanding his needs. Even his sister says 'every time Ronan gets into trouble he always brings the abuse incidents into it'.

In summary, Ronan was initially placed in the psychiatric service but later transferred to intellectual disability services on the same campus. In the intellectual disability service he experienced frequent moves from ward to ward. In all he moved in excess of ten times. He recalls being 'held down by the neck' and given injections 'into the bum' as a consequence of behavioural outbursts. He describes not only many incidents of sexual abuse nature but also abuse of his basic civil rights.

4.2.2 Current situation

Ronan currently resides in a comfortable bungalow in a small development one hundred meters from the psychiatric hospital where he lived on and off since he was sixteen years of age. The house is in walking distance from his sheltered work placement and town. He co-resides with four other male residents whose age ranges from forty to seventy years. He has his own small bedroom with his personal belongings. Staff report that Ronan likes having his own clothes, watch, money and television. He is involved in the local community by going to the pub, the local GAA club, mass and shopping. Other people see him as friendly and a good worker. He likes to go

dancing in the local hotel and he enjoys making his own choices for food, clothing and leisure pursuits. He is a good gardener, dancer and is good at household chores.

> "I go to see country and western bands in the hotel. My key worker brings me for a pint. I wanted to go to the dance last Thursday night but they wouldn't let me go. I kicked up a bit of a racket and they wouldn't let me go. They might let me go next Thursday night because I am very good now so I am. So they might let me go this time".

Interview with Ronan

Ronan's remaining two sisters are dedicated to the care of his eighty seven year old mother. She resides in the adjoining terraced bungalow to Ronan's sister, Mary. Ronan continues to visit home and says that he goes out to visit his mother every Saturday.

> "We have a cup of tea and I stay with mammy for a little while and she gives me money. She is keeping well. She is an old age pensioner. The nurses bring me out".

Interview with Ronan

Ronan has availed of a range of varying day services and training options over the years. He is currently quite pleased with the day service that he is attending particular as it is less arduous. He has left the sheltered work shop setting and now has a more socio-recreational programme that enables him to use the leisure amenities in his area such as bowling, horse riding, swimming and pitch and putt. 'Well I am so happy to be out of the work shop. I didn't like the work shop so I didn't'

As part of this research study an interview with Ronan's family member took place, in this case with his sister Mary in her home. While many professionals are au fait with the rhetoric and language of the PCP process it was striking that from the outset Mary bluntly requested 'If you don't start speaking English there won't be much point to continuing with the interview'. Every effort was made to discuss Ronan's PCP with a view to ensuring that Ronan's sister could comfortably discuss Ronan's life and consider specific issues raised in the PCP. Mary volunteered that Ronan is currently doing very well in his present community house.

> "I see Ronan now since he moved to the last house as never being happier to be honest. He is so contented. He comes home, they bring him out on Saturday to see me mother, but he loves

> going to that house, he just loves it. It is the happiest that I have ever seen him. It is the contentment".
>
> Interview with Ronan's sister

Mary sees the location of this particular house as contributing to Ronan's well being.

> "I think it is because the house is beside the hospital that was Ronan's life. I think it is because it is in the town. He can come out of that house and can walk by the hospital when he goes for his walk and he knows the route. Ronan's heart and soul are stuck in that place".
>
> Interview with Ronan's sister

Mary comments that Ronan likes to go to church 'I know he still goes to Mass because he would go to Mass three times a day if he was let and he answers all the prayers'. Mary is acutely aware of the importance of family and in particular the relationship between Ronan and his mother which she regards as fundamental to his wellbeing. 'We are still trying to keep up the relationship with my mother'.

Mary reflects on Ronan's early childhood and life trajectory. She reflects on the many sacrifices that the family made to accommodate Ronan and his special needs. His parents sold the small family farm and dwelling house and moved to a terraced bungalow in the village within walking distance of his day service. Mary regarded Ronan as having a privileged place in their household because of his special needs stating: 'Ronan is spoiled and was very spoiled when we were growing up more so than the rest of us'. In trying to illustrate this Mary explained:

> "I remember me mother always had a big box of chocolate bars in the house. They were for Ronan only and daren't any of us go near them or we would be killed. If my brother, the youngest, asked for a bar he would be told 'they are for Ronan he is disabled'. Ronan would have heard this ringing out all the time. He was told he was different from the rest of us which was a mistake of course".
>
> Interview with Ronan's sister

Mary holds the view that 'hindsight is a great thing' and that in current times it is likely that people with intellectual disability would be treated with more equality. Mary believes that Ronan should not have been indulged by her parents in the past and she retains this view today. She believes

that pandering to him and acceding to his requests at all times was inappropriate. She relates this thinking back to their childhood days.

> "Ronan would have grown up with the idea that, 'hold on a minute I am different and I would get away with stuff'. He did get away with more than he should have. My mother let him away with things. This caused more rows at home. Everyone else in the house would have missed out on the attention because Ronan was constantly getting the attention".
>
> Interview with Ronan's sister

Mary describes the distress caused by Ronan's acting out behaviours. She recalled an incident when her older brother, who drove a school bus, parked it near the family home.

> "Ronan would break every window in it. God he broke more windows in that bus and you know the money it cost to replace them going back years ago and no one could do anything to Ronan and my mother protected him and he was allowed to get away with it and he would just do it again".
>
> Interview with Ronan's sister

Mary recalled one Saturday evening when the family were all sitting watching a television programme 'Dallas'. During the course of the programme the protagonist JR struck another character.

> "While JR was in a fight, someone gave JR a box in the mouth and just as JR was getting the box in the mouth Ronan stood up and in front of everyone at home gave me father the same kind of box in the mouth".
>
> Interview with Ronan's sister

In Mary's eyes this event led the family to believe that they would require a dramatic intervention in an effort to curtail ongoing property damage and assaults. The family realised they needed help in caring for Ronan at this stage and said 'enough is enough'.

She makes the contribution:

> "When all is said and done it is walking that Ronan thrives on. Ronan loves walking, while the staff are very good to him in that

house bringing him to all those music festivals it is walking that he likes. That would be his biggest thing".

Interview with Ronan's sister

Mary is convinced that the current house is a better match to Ronan's needs because of his familiarity with the locality. Mary also acknowledges that Ronan is doing better now with the small number of peers in the house.

"I would say that the fact that there are only four other people in the house definitely helps. The small groups are great. It is quieter and they get on with one another. I see a difference from a ward setting with loads of people to just a couple of residents and Ronan definitely finds this better".

Interview with Ronan's sister

Mary values the fact that her brother now has privacy. Further to this she acknowledges his freedom and capacity to make choices.

"You can see he can make choices for himself. He can come and go. He can go for his long walks. He has a wardrobe full of beautiful clothes which he did not have when he lived in the residential centre. As you know it was a case of the first up best dressed. At that time he was very dilapidated but it is unbelievable how well he looks now".

Interview with Ronan's sister

4.2.3 PCP process

To Ronan his understanding of PCP is restricted to him being present at his PCP meeting. He has an understanding of a key worker being important in the process. Ronan goes on to say that he attends his PCP meeting 'very often, once a year. About every August, maybe'. Previous meetings were held in his mother's home to make it convenient for the family.

"We had the PCP in my mother's house a couple of times. We talk about how I am getting on in the house and we talk about when I am going to retire".

Interview with Ronan

Ronan displayed a restricted understanding of some of the concepts of PCP and in particular goal setting eluded him. In speaking about his lifestyle and relationships there is a certain amount of confusion in Ronan's mind regarding people roles. Ronan refers to his friends as:

> "All the staff are me friends. Me mother and brothers and sisters as well as all the clients and staff in this house are me friends".
>
> Interview with Ronan

A conversation about the PCP process took place with Ronan in order to give him an opportunity to talk about his lifestyle and current aspirations. He went on to say that his current community residence is his home. 'This is my house, yeah. When I get a bit older I will retire out to my mother'. Sadly for Ronan he does not seem to have any realisation that life will eventually change and he sees life as it currently is as being fixed in time. He has never progressed to full adult status and this is reflected in his disempowerment in every day personal responsibilities. When asked who buys your clothes? He replied 'the staff does'. When asked who picks your clothes? He replied 'the staff does'. When asked who cooks your dinner? He relied 'the staff cooks it'. When asked if he had a key to his front door he replied 'no, the staff has it'. Ronan displayed awareness that having a key to his own front door was important.

> "I should have a key but it is too dangerous, not for me but if the clients got out I would be murdered so I would. That's why the staff have the key".
>
> Interview with Ronan

Ronan was pleased to talk about his interest in gardening with his key worker remarking 'I am helping him out the back there to plant vegetables, onions, spuds and turnips'. He goes on to report that he still enjoys vigorous walks.

> "I go for walks up and down the hospital grounds. I walk on my own up and down and to town on my own".
>
> Interview with Ronan

Given his previous history it is poignant that Ronan harbours anxiety around re-institutionalisation as he stated:

> "If I mess up or cause a racket they said they would have to ring the Guards so I need to be good. I wouldn't like to be sent back. I like it here now so I do. It is more comfortable and I don't want to be sent back. It is a good house. It is a nice house. I don't like

> the hospital so I don't. They would bite the arm off you and beat you up. The nurses would hit you a box. It is a shocking place and I never ever want to go back".

Interview with Ronan

In the context of the PCP Mary has a concern that given Ronan's restricted understanding that he will perceive PCP meetings as a forum for making requests for luxury items.

> "Well it is just that Ronan can get what he wants. He decided he wanted a mobile phone and the staff got him one then and there. If I wanted one I would have to budget for it. Ronan seems to say what he wants to get out of these meetings and it is just got for him".

Interview with Ronan's sister

There are many complexities in the relationship that Mary has with the staff that care for Ronan. She threads very carefully in that she does not want to 'interfere, blame (it is not the staffs fault)', and further more she does not want to make even small decisions without deferring to the staff in the first instance. Mary's attitudes to staff are not conducive to her active participation at PCP meetings. Mary regards the staff as being in control 'if they do something with Ronan they have to control him in some way. It is very tough but they are very good'. What came across at the interview was that she regards the staff who care for Ronan as better equipped to deal with him. This gave the impression that she feels inferior.

Mary represents the family even though her mother, brother and sister are still alive. In terms of her future involvement in PCP for Ronan she commented:

> "I will go to the meetings. God forbid if anything ever happened to Ronan we know where he is going to be buried and he will know that this is his home. His life is now in the town and he knows that we are here at home and until mothers day is over he will continue to go to her and I will continue to watch from a distance".

Interview with Ronan's sister

Mary was specifically asked what she saw as her role in the PCP process. However, she responded to the question by describing her role in Ronan's life.

> "I would say with Ronan that he likes to know that he has a family, do you know? He likes to know that he is not forgotten. He likes to feel that he is working and that he has his own place. I see my role as a support to him and that we are always there for him and when something goes wrong, like in all families we will row in behind him and help to support him as best we can. But he likes his independence and he has his own freedom and I see my role as being family".
>
> Interview with Ronan's sister

Mary does acknowledge the merits of PCP and she agrees that it acts as a conduit for the person to realise their goals. She does not regard the process as tedious. She further states that Ronan will talk in front of people at his PCP meeting. Yet she questions the point at times stating 'I don't think a meeting is required for him to say what he wants. He has everything he wants, his own television, music, he has everything and that wasn't got by having a meeting'. Mary concedes that family participation is fundamental to maintaining relationships 'it goes back to Ronan and him knowing that he has someone there. I think it is vital to know that he has the support of his family'. Mary sees the PCP as aiding community participation 'it's a thing that everyone should be able to go to the shops and buy things and I think PCP helps this to happen'. In terms of using the natural resources in the community Mary sees the smaller groups as contributing to this 'yes it does, it allows for smaller groups to access these things on their own'. In terms of PCP promoting choice Mary holds the view that they should be safeguarded and balanced 'it shouldn't be too easy. Ronan should have to earn things. This is something I will consider saying at the next PCP meeting'. Mary goes on to agree that the PCP ensures a full and active life but her comment is tainted somewhat by her long held view that he is a 'spoiled child'.

> "He gets everything his own way, he gets to go every place he wants to, all he has to say is, 'I want' and he gets".
>
> Interview with Ronan's sister

Ronan's key worker responded during the interview with the researcher with his understanding of what PCP is.

> "Well obviously it is person related. For the client involved it is planning his life and if he is living in the community it is what we do. We plan goals and realistic goals. We involve as many people as possible in his life and an aim is family inclusion. We do a plan out for him for the year".
>
> Interview with key worker

On a positive note the key worker feels in control of goal setting which gives him a certain amount of confidence in approaching Ronan's PCP. Regrettably he does not see it as his role to really listen to Ronan and drive Ronan's goals.

> "I find as key worker I can set realistic goals because I know him and I am aware what he is capable of. His family are so good to Ronan so I can work with them. I can also liaise with the workshop that he attends. So you see I can set realistic goals. I know failure for him means that he can get very frustrated. So I find the PCP is like a good guideline".
>
> Interview with key worker

The key worker uses Ronan's daily activities as a monitor for person centred effectiveness. In reply to how do you follow up and monitor the PCP goals? He replied:

> "Well it is actually in the PCP and his daily activities. What goals have been carried out and what goals have not been met. Some things are not recorded daily, the like of a holiday and things like that. Well it is all in his daily care plan".
>
> Interview with key worker

It would appear that they key worker fails to distinguish the essentials of carrying out Ronan's daily care plan effectively and his role in monitoring Ronan's goals of his PCP. The key worker says in his defence 'generally here it is taken that goals of the people in this house are reached'. Commenting on unmet goals the key worker acknowledged his role in following up by stating:

> "The ones that are not being met, all you have to do is look at them and ask 'why are they not being met?' or maybe do something to alter them".
>
> Interview with key worker

One would have a concern that when goals are not reached that it would lead staff to consider deleting or altering the goals. When you couple this comment with his opening comment about what constitutes realistic goals it is evident that the goal setting exercise can be strongly influenced by what staff feel confident and capable of delivering.

Ronan is a relatively capable man who has previously stated his desire to move back to his home town. He is mindful that he will require supports, but states 'I want to retire back home'. The

question was asked of his key worker about this and if the model of a more optimal individual service design for Ronan could be explored. His key worker did not demonstrate any response that reflected an interest in pursuing Ronan's stated life long ambition.

> "Ronan will need a lot of staff support. The network in the house is good because we have our own staff and the same staff the whole time. Like Ronan it probably has nothing to do with PCP but Ronan cannot distinguish someone being good to him and thinks there is a relationship developing. That's where he sometimes gets confused. An individual service design would be too intense. Whether it would suit him or not, I don't know about that type of set up".
>
> Interview with key worker

Ironically, the key worker manages to side step Ronan's ultimate goal of retiring to his town of origin. Instead of assisting him with this goal he disregards it as unrealistic.

Regarding the PCP mechanism the key worker remarked:

> "Well they are making it shorter. We have all the new stuff now on PCP and it is shortened up again. So it is going from a very long document to what we have for today's meeting, which is even shorter again".
>
> Interview with key worker

One would wonder about the key worker's motivation when he remarks about PCP that 'It is time consuming and it can be bit of a paper exercise'. He does acknowledge that the PCP process helps:

> "To keep a good eye on what is going on in Ronan's life. If you look back on the last month you will see the amount of outings he has gone on and you will see any day programmes that he has attended and all that. So I think that it is good for record keeping. So the likes of his family can know exactly what he is doing on a daily basis".
>
> Interview with key worker

The key worker does acknowledge that the PCP document can be useful in informing uninitiated staff about the life of the individual.

> "If a staff member has never worked here before they can sit down with the care plan and read the PCP. It would give you a good indication of the person, yeah it would. Obviously the more you work with someone the more you get to know them but by reading the PCP you have a good understanding of the person".
>
> Interview with key worker

When asked about family participation at the PCP meeting he does acknowledge that the PCP process has been helpful in supporting staff's interface with families. When asked about the PCP's role in aiding community participation the key worker simply related the fact that 'Ronan attends Mass'. When further questioned on Ronan's level of participation and whether he had any role in the church service or interacting with other parishioners the key worker response contradicted his previous statement saying 'no I don't think he gets much out of it to be honest, no'.

It seems that the key worker has the preconceived idea that because Ronan has a wrap around care service that the need for relationships outside of this care model are not important. He remarks, when asked about the role the PCP process has in promoting friendships and social networks he refers to Ronan's care network. 'Yes I think it does it gives you different opportunities and you get involved with the family and you are involved in his whole care network really'.

In summary, the key worker did not believe that a PCP provides a vital role in promoting choice for people with intellectual disability. Furthermore he believes that when individuals are in state care it is taken as given that the lives that are provided for them are complete and amply fulfilled to such a high standard that adding on to the role of the PCP process in terms of choice and goal setting is in reality redundant. He stated:

> "No it doesn't, obviously when you are in care you are going to have a good life anyway with or without a PCP. They would have a good life with all the care they would be getting. Now with a PCP they obviously get even more. They get goals as well! You know what I mean? They get opportunities to go here, to go there and to go everywhere. They are out and about the whole time. They don't need PCP".
>
> Interview with key worker

The PCP meeting was opened by Ronan's key worker in his community residence. He welcomed everyone to the meeting which included Ronan, Ronan's two sisters, a care worker from his day service, and a care worker from his residential service. The key worker described how Ronan had transferred from a sheltered workshop setting to an activation unit.

It is interesting that the key worker took the opportunity at the PCP meeting to review his day programme. The day service care worker was asked to give an update of his day programme. He went on to describe how Ronan does art, drama and music stating that 'he really enjoys those activities'. The day service care worker went on to describe the activities and their limits saying:

> "We could also bring him out in the evenings. He has requested to do that but with the staffing levels we weren't able to do that".
>
> Day service staff speaking at Ronan's PCP meeting

He restated that the capacity of the day service was to do more and lamented again that 'we can't get him out because of the staffing levels'. At this point the PCP meeting takes a turn. His sister describes bringing him out for his birthday on Saturday stating:

> "Ronan gets very excited around people especially young ones. If there is any encouragement there will always be a problem. Unfortunately the day we had him out there were a few incidences, and young girls who didn't understand the situation. He got a bit carried away with people holding his hand".
>
> Mary speaking at Ronan's PCP meeting

At this point in the meeting there were innuendoes and code talk among the staff and family of potential problems for Ronan that left Ronan on the periphery of the PCP process. These problems seem to stem from a difficulty they attribute to Ronan in discriminating between social contact with people and social contact that may lead to a relationship of an intimate nature. Their concern was that if he was disappointed by rejection that this has the potential to lead to him acting out in an aggressive way as he had done in the past. Coupled with this they have a concern that Ronan could report a sexual activity that they would have to follow up as a sexual allegation. His key worker remarked that 'there haven't been any incidences in a couple of years'. The care staff from the day services stated 'he knows his boundaries in relation to his work'. Throughout this code talk Ronan repeats 'I am being good. Am I going home on Sunday? I am very good'.

The key worker in dismissing the concerns of Ronan's sister brings the meeting back to a discussion on Ronan's leisure activities. A goal of his previous meeting was that he would have regular visits home.

> "He still gets to go home. That's a big thing for him. It is great to have ye in here. It is mighty".
>
> Key worker speaking at Ronan's PCP meeting

Ronan's sister apologises for the absence of their mother at the meeting but concede that 'the PCP is good for me mother as well but that she couldn't come here today because she is a cripple'. It is interesting that during the next part of the meeting Ronan repeatedly questions:

> "Am I going home? When am I going home? Am I going home Friday evening? Am I going home this Sunday"?
>
> Ronan speaking at his PCP meeting

The key worker replies as a matter of fact. 'I don't know Ronan, but don't worry we will sort it out'. The style of communication from the key worker to Ronan is not conducive to Ronan having any degree of certainty and is also dismissive of his immediate concerns. When Ronan asked the direct question to the key worker 'are you here next week?' The key worker replied. 'No. I could be. We will get it sorted. He can always tell me when I am on duty better than I know myself'. The key worker reverts to a discussion on the previous years goals.

> "Last years goals were about activity sampling in the work place. So we just took this to the activation unit where they were trying him with different things and whatever he warmed to they put him into it and they let him at it and if it didn't work out we took him out of it. It was big enough taking him out of the workshop and putting him into activation. It stressed him out a bit".
>
> Key worker speaking at Ronan's PCP meeting

Ronan interjects 'can I still do the walking?' to which his sister replied he does the walking at home as well'. His key worker elaborated saying

> "Oh he has to do the walking. It is quiet here and sure we have the football field and everything around us here. All this stuff and all his possessions are all the same. He wants for nothing".
>
> Key worker speaking at Ronan's PCP meeting

Ronan repeats 'can I still do the walking?' with an anxious tone as he believes the PCP meeting is reviewing goals, and can add and take away previous goals. His sister recollects that 'at the last meeting we were at he decided that he wanted a mobile phone and he got it that evening'. His key worker explained:

> "It didn't work out for him. He would bring it with him and he wouldn't turn it off and it locked on him and then he lost it. He

couldn't work it and then he got stressed over it. He couldn't work it so we just got rid of it".

Key worker speaking at Ronan's PCP meeting

It is not surprising that for Ronan that he harbours a concern that agreed goals will not be sustained given his experience with the loss of his mobile phone. The people at the meeting remark that Ronan is full of energy. His sister stating 'God he has loads of energy'. Despite acknowledging this no one reassures Ronan that he will continue to be allowed to have his evening walks. The key worker recaps again on the previous years goals.

"Last years goals were that for Ronan to attend local dances and cinema. They have been met. Family contact and relationships to be maintained and they have been met. The other one obviously was social inclusion. We go for a drink and he goes to dances".

Key worker speaking at Ronan's PCP meeting

Again the key worker takes the opportunity to flag staffing issues stating:

"The goal of a holiday, this is a no go. There was no holiday this year. It was just with staff and shortages. Now we have put it in to try and get him away. You see he should be getting away, even for one night. I will try and arrange something with the manager to try and get a couple of the boys away. Even for a night or two. I know myself he asked to go away. It is a nightmare you know with the staff but it is a pity that the boys have to suffer".

Key worker speaker at Ronan's PCP meeting

His sister reverts to an issue of obvious concern to her which is his oral hygiene and missing teeth which detract from his presentation. The key worker did not inform Ronan's sister that the PCP meeting was not designed to deal with issues of health care and a good percentage of the meeting was taken up with this topic. When dentures were suggested Ronan quipped 'No, it would be like the mobile phone'. By continuing the discussion Ronan became more and more anxious.

"I am too nervous, I don't like going to the dentist. I don't want to have all my teeth out. False teeth, no I don't think that they would work, they would be too awkward".

Ronan speaking at his PCP meeting

There was an acceptance by those at the meeting that if goals were not reached that staffing levels were the singular reason and there was no attempt to consider how goals could be reached in other ways. Acknowledging that last years goal of a holiday for Ronan had not been reached his key worker went on to itemise this as a goal for the coming year stating; 'and his holiday has not been met but now we are on to next years goals'. Ronan's sisters acknowledged the importance of family contact and concurred that this is an important ongoing goal. When asked if he had any goal to add Ronan stated 'is there no way that I could go on a holiday?' The key worker replied stating 'I will try and sort something out for you on that one. I will talk to the manager'.

Ronan goes on to make a plea for very simple and achievable items to be included as goals such as going for a walk in the football field and the grounds of the hospital. Given all the people at the PCP meeting Ronan was the one person that succinctly commented on his short and long term goals.

> "I used to work five days a week now I am off Monday and Friday. I want to go to the pub on Friday nights. We get chips and sausages. I want to go to church on Sunday and I want to continue to go home. I would like to drive. I drove a lawnmower and I don't want to have my teeth out. When I get older I want to retire to my home place".
>
> Ronan speaking at his PCP meeting

4.2.4 Comment and analysis

Ronan was born into a loving and caring farming family in the early 60's. He had a pleasant early childhood including attending the local school with his siblings. However, when he was identified as being a 'slow learner', his transfer to a special school was a very upsetting event for him. Due to his 'acting out behaviours' his enrolment in the special school was short lived. It would seem that his parents were indulgent and very protective of him as they saw him as different. Their intolerance of his emotional outburst eventually led them to realise their inability to cope and at sixteen years of age they sought outside help for him and for them as a family. Ronan was apprehended and brought to the local psychiatric services with words that he recalls even today ringing in his ears. 'You will never see your family again!' This must have been heartbreaking for all concerned and must have embedded in Ronan a deep anxiety about his loss of family life. Although the psychiatric hospital was relatively close to home he did not have access to his warm and caring family.

The PCP process, while used as an activity summary and service review, does, nonetheless, reflect Ronan's current service as being a better match to his needs. But the way that Ronan sees himself as a person is quite basic in that he views himself as either 'good' or 'bad'. Further to this his family continue to view him as a 'spoilt child' and staff pretty much treat him like a child 'you're a

good boy Ronan'. The key worker takes the position of goal setter at the PCP meeting. He blatantly states 'so you see I can set realistic goals'. The people present at Ronan's PCP meeting fail to listen at any deep level to Ronan's well articulated future vision in favour of maintaining him in the current status quo.

Ronan has experienced significant loss including the death of his father and two siblings as well as the premature death of some of his peers. Yet when his sister died people were very aware of the importance of bereavement counselling for him taking cognisance of the fact that his life had many major traumas with no counselling. For him there is also the loss of opportunities and his PCP failed to pick up on the benefits of social role valorisation for Ronan. Despite his vocational skills which he displayed in the workshop setting he has never had the opportunity to get paid employment of any kind. Unfortunately his PCP does not engage his right to have paid employment. This means that he has never made work colleagues or friends. Because he lived in a hospital setting for most of his adult life he never had the opportunity to have neighbours or friends in the community. Ideally his PCP should be focussing on his skills in developing relationships. Instead, his PCP puts forward a case for him to be protected from becoming involved in the broader community in favour of the use of special day and residential services.
The many moves and harsh methods for managing his behaviour were more likely to cause him further upset and lacked insight into the way he was feeling and to any more progressive ways of supporting his positive behaviour. As articulated by his comments his key worker equates being in care as having a good life and wanting for nothing, 'you don't need PCP'. This comment clearly reflects his understanding of the potential benefits of PCP to promote Ronan's personal agenda.

People who know Ronan will be aware that a recurring theme with him in any conversation is his stated desire to return to the village where he is from when he retires. Further to this, people will know Ronan as an avid gardener who enjoys being outdoors and landscaping. For some reason neither of these two things were addressed at his PCP meeting. At one point in his PCP meeting, his key worker concluded; 'they don't need PCP to reach goals'. He referred to PCP as 'record keeping' and 'paperwork'. The PCP meeting reflected many staff issues for example from the families point of view they referred to 'checking with staff before they would do anything' and their effort to try 'not to annoy them'. They regard the staff as somewhat superior as 'they know best'. As with other families, they saw the PCP as a good review of Ronan's activities and current level of service provision. For the staff they saw the PCP meeting as an opportunity to air staffing issues. They went on to refer to staff who would feel 'confident' in bringing Ronan places and to the 'staffing levels' and to what they regard as 'staff shortages'.

The goals of the PCP were restricted to what staff felt that they could deliver in terms of pleasant or desirable activities over the next year but they did not reflect any steps towards medium or long terms goals. Furthermore, serious account was not taken of the things that Ronan himself said he wanted to do including, 'I want to learn to drive'. While it may not be realistic that he would get a licence and learn to drive a motor car he could engage in associated activities.

Mary holds the view that the PCP process is a mechanism which allows for Ronan to make requests for tangible items that he wants. In reality he does not need to use the PCP meeting to have his wish list fulfilled but should be supported to make these purchases in a person centred active way as a matter of course. There is a missed opportunity here as neither Ronan nor Mary sees PCP as a vehicle for crafting a vision of a positive future that is linked to Ronan's personal ambitions. She believes that the PCP process is keeping alive the image she has of Ronan as the 'spoilt child' and cautions, 'sure he will think that he can have whatever he wants', further indulging Ronan by exceeding to his requests which she perceives may not be in his best interest.

On a positive note the PCP meeting was a format for the family to express their level of satisfaction with Ronan's current service. Ironically, his family have made plans for his end of life and burial. 'We know where he will be buried'. Yet there is uncertainty to how Ronan's life will take shape in the interim period.

Lee

4.3 Lee

4.3.1 Background and context

Lee was born with Down syndrome in the mid 70's to a large family where his father worked outside of the home and his mother was the primary carer. Lee received early intervention services at the early critical learning periods. Lee was described as 'functioning intellectually within the range of moderate mental handicap and as such is eligible for special education' (file entry, July 1978). At the time the identification of his developmental delay equated to an identified need for special services.

Lee was enrolled in the local 'care unit' for preschool children. Here he made steady progress receiving individual teaching and learning basic fundamentals. He was described as 'very stubborn and can have temper tantrums' (file entry, January 1979). At home, Lee slept in a cot in his parent's bed room. At this point he was also noted to have hearing loss and the psychology report indicates that 'his frustration about him not been able to express himself leads to problem behaviour' (file entry, April 1981). At the time he was six years of age and his language development was scored at the two year test age. He was also noted to have recurring chest infections.

At five and a half years of age Lee was promoted from the 'care unit' to the special school on the same site. At this stage while he did not achieve a high academic standard he was nonetheless popular with teachers and the other school children. For the next eight years Lee, was reported by both his family and teachers to have had a happy life, living at home and attended his local school. In 1987 Lee was admitted to a residential school on a temporary long term basis some sixty miles away as his mother was ill with cancer, was having surgery and was unable to continue to look after him. His mother passed away and Lee's placement in this residential facility became more permanent. The Director of Nursing made an urgent appeal for Lee to be considered for a community house as his placement was deemed inappropriate for a seventeen year old.

He spent a total of four years in the residential school. The residential service was primarily for people with severe to profound intellectual disability many of whom also displayed behaviours that challenge. It was noted that he had no peer group as none of the other co-residents had expressive language. Further to this there was a concern that Lee would model some of the social inappropriate behaviours.

There was a further problem in that Lee's family were reluctant to consider Lee being supported to live in the vicinity of the family home because of his challenging behaviours and known pilfering.

> "I am not having that. You can put that out of your mind. I am not having him arriving at the front door and finding no one there and out of frustration having him kicking at the door. He will become

> friendly with the neighbours and pilfer items from them and that we will be left with to deal with".
>
> File entry, June 1991 Lee's father

At a case conference in 1995 the family made some obscure comments which seem to suggest that the family did not want Lee to return home or return to his home town. As a school leaver there was no alternative out of home placement for Lee who continued to reside in a hospital setting. He lived on a ward with fourteen male youths with severe and profound intellectual disability. He availed of weekend breaks with a local family who would take Lee into their home. He also attended a day service programme in a nearby town. He developed an imaginary friend (file entry, September 1995) in an attempt to 'ward off loneliness'. He was also noted to have periods of 'mood swings'. The Director of Nursing continued to lobby the health authorities in support of a more appropriate residential placement for Lee.

In an effort to give him normal living experiences staff and maintenance men were actively encouraged to include Lee in social events and jobs on campus. It would have been common practice for Lee to get into the maintenance van and accompany the workmen during the course of their work. His role models were robust builders, farmers and tradesmen. At some point while Lee was living in the residential centre he made a comment of a lurid sexual nature to the nurse caring for him that he attributed to one of the workmen. This was processed as an allegation of sexual abuse which had an inconclusive outcome. An event which maybe related to this is that his sisters presented to the local Garda station to make a complaint against their father.

> "Three sisters alleged dad sexually abused them as children. Lee becomes upset in the presence of his father and they fear that this may relate to possible similar experiences and wish to report it though no additional information is known at this time".
>
> Garda notification of suspected abuse

The health authorities and Gardai investigated this allegation and found that it was not upheld. Lee's father vehemently denied that any wrong doing occurred and to the contrary stated that 'I have sacrificed everything for my family'. He also asserted that he wanted an out of home placement for Lee because it was his belief that it was character building for Lee and that Lee would learn more from professional staff rather than indulgent family members (File entry, 1999).

Efforts were directed towards sourcing a community residential house in a neighbouring county as his family of origin refused to consider a placement in his home town. When Lee was in his early 20's he was successful in getting a place in a community residence in a neighbouring county. At this point in Lee's life he had spent nine years in institutional care. As Lee embarked on his new life in the community at twenty two years of age he had the opportunity to attend a day service. In

the community residence, he lived with six other people with intellectual disability. All of the residents of the house attended day services in the same town as him. This meant that everyone needed to be up and ready for the mini bus to convey them all from this rural location to town.

For Lee this represented a culture shock and a dramatic change in lifestyle as he would have to be up and ready by 8am and that he would be expected to engage in the provided activity. Lee was not accustomed to the inflexible structure. While he showed interest and tolerance for this programme initially, he gradually became less compliant. He began to show health deterioration and while he was always prone to 'mood swings' these became more pronounced. He was diagnosed with depression which was treated with psychotropic medication; a side effect of this treatment was weight gain. This led to Lee spending more and more time in his bedroom and a pattern of him refusing to get out of bed each morning. Lee continued to gain weight to the extent that he became morbidly clinically obese weighing approximately twenty stone. Lee also had recurring chest infections and skin problems and was attending the eye and ear hospital for treatment of a detached retina.

This cluster of medical and behavioural health issues had the consequence of Lee being moved to another community residence with a higher ratio of staff including nursing staff. Lee's behaviour became more aggressive and nursing staff became increasingly concerned about the health risks of his obesity including the risk of cardiac arrest and diabetes. Because this house, as well as the previous house, was not staffed during the day the decision was taken to again move Lee this time to the large institutional setting. It was also believed that the management of his behaviour would be more easily achieved in an institutional setting.

In the institutional centre Lee resided for twelve months on a ward with sixteen other men with varying degrees of intellectual disability and challenging behaviour. Lee lost many of the privileges associated with life in a community residence because of the structured institutional regimes of; bedtime, bath time, meal time and when to get up. While in institutional care Lee benefited from positive behaviour supports. He rapidly lost a lot of the excess weight and enjoyed his improved physical fitness. He was very proud and took delight in his improved physical appearance and his mood improved. He became more biddable, compliant and less aggressive to staff and his peers. When asked can you tell me what it was like living there? Lee replied 'I don't want to think about it'. All during this time Lee's family maintained a lively interest in his wellbeing and Lee had regular visits home.

4.3.2 Current situation

As Lee had made a remarkable improvement in his overall behaviour and health, coupled with the fact that one of the residents had died in the community house that he had left one year previous, creating a vacancy, Lee was given a second chance to live in the community. Lee returned to live in the community house and he continues to live in this house today with four other people. He has

an outreach day programme from a small community based day service. He has enjoyed a summer holiday on the continent and he is a member of the local leisure centre. His proxy states:

> "Lee goes to the local leisure centre, he is a member there and he is a great swimmer and makes good use of the gym. He also goes bowling and likes going out for a drink and out to the cinema".

Interview with Lee

Lee's expressive language consists of short three to four word sentences. He is noted to reply by affirming or negating what is asked. "Are you enjoying life"? To which Lee replied "yeah". Do you like it here? To which Lee replied 'yeah'. How is life? To which Lee replied, 'fine'. Lee will volunteer information when the subject is of interest to him and at the same time when he gauges that people are receptive to what he wants to say. His proxy stated that Lee enjoys music and to support this interest he was accompanied to attend the Michael Jackson exhibition. Lee stated 'Michael Jackson has died'. When asked about the co-residents in his current house Lee replied by giving the names of the staff as opposed to his peers and he was unable to state how many people he lived with. Despite prompting from his proxy he still seemed unable to answer this question accurately.

4.3.3 PCP process

Lee was interviewed in order to establish his knowledge of the PCP process. This interview took place in his day service. Lee was supported during this interview by an instructor who also acted as a proxy. When asked 'who is your key worker?' Lee replied 'I don't know'. When Lee was asked 'do you know what your PCP is?' He replied 'yeah'. When asked 'what is it?' He replied 'I don't know'. When asked 'where his PCP was kept?' He stated 'I don't know'. When asked 'do you write in the folder?' He said 'I do yeah'.

In order to establish a rapport and set the scene of the interview with Lee non threatening open questions were asked. When Lee was asked 'are you happy at the moment'? He replied 'I am very happy, yeah'. When he was asked 'do you like living in your house'? He replied 'I love the house'. When asked whether he had a 'key to his house' He replied 'yes'. Lee was able to say that he was going on holidays to Spain. When asked 'what choices do you make'? Lee replied 'I make them myself'. His proxy commented:

> "Yes he does. We do things here in picture format and he would choose from that. We used to find that if Lee didn't know what we were doing, like a new activity in the morning he might be anxious. We find if we build up to it every day that it helps".
>
> Day service support worker at Interview with Lee

Albeit that Lees' verbal expressive skills are limited in that he does not appear to be capable of giving a descriptive account of events, nonetheless when he does volunteer comments they are congruent and powerful and certainly ring true. In order to get an understanding of Lee's life in the passed he was asked about the period of time that he spent in institutional care and he said simply 'I don't want to think about it'. This is also reflected in his sister's comments where she acknowledges her brother's lack of capacity to converse freely about events but yet his behaviour reflects a deep long term memory of past events.

> "You know there are all kinds of things that he is familiar with and that he remembers. Yet when you talk to him now, some of the things that happened today he wouldn't be able to talk to you about. But I think that it's more that he is not able to communicate by speaking of it as opposed to the fact that he doesn't have the actual memory. When he is at home and he goes around the town, if he passes the graveyard where our mother is, he will bless himself and say how Mam is in heaven. If he goes by the

clubhouse he does the scout's salute because he was in the boy scouts when he was younger".

Interview with sister

Lee's sister took advantage of the opportunity that presented at her interview to give an account of their childhood. This insight in his sisters comments brought an understanding to the PCP process as to how Lee was treated as a child. She stated:

"My parents treated him as normal. The biggest thing that I can remember of him when I was younger was that he wasn't ever curtailed in terms of freedom and independence. He got involved in everything, like swimming. He always had identification on him with his name, address and phone number. The door was always open so he could go out whenever he wanted. Sure enough we got a couple of phone calls because he went missing for a couple of hours, but eventually we would find him. There was a phone box at the end of the street and he would call 999 and someone would come and collect him. So my parents had the attitude to let him have his independence".

Interview with sister

The significance of this comment is that it illustrates that Lee has always been regarded as 'normal' and as having capacity as making life choices around whatever activity he wanted to engage in. While many families, who have a member with intellectual disability, can be overprotective, in this case there was a more relaxed approach to risk taking and opportunities for Lee's self expression.

"Even like, the key worker taking him clay pigeon shooting and go carting, some people might kind of quiver at the thought of that, where our view is to let him off. If he gets hurt then he gets hurt. People get hurt doing things like that. I wouldn't stop him. I would let him off. His key worker is excellent and is constantly looking out for him anyway".

Interview with sister

She contrasts his current lifestyle with his past institutionalised lifestyle that was in her opinion absent of any real meaning or content.

"His quality of life has improved tenfold since he moved. He is doing far more than the average person. He is better looked after

and people understand him better. Before this to a large extent he was just left to sit there, do you know what I mean? He had very little interaction. But now he has gotten back into himself and he is involved in everything. He is very sociable. Even when he comes home he is out the whole time. He has a lot of activities and a sense of independence. "

Interview with sister

Lee's sister is pleased with his current residential situation and attributes this to his current received level of support to engage in many activities of his choice. She gives a lot of credit to his residential support staff for ensuring that he has plenty of activities and that he is treated with dignity and respect and this in her view has the knock-on effect of his anti social behaviours no longer being a concern. Lee's sister is very encouraged by the improvements she sees in her brother's life and believes that this was achieved through the PCP process. She has an excellent understanding of PCP as illustrated in her following comment:

"My understanding of PCP is that it brings together all the different areas of Lee's life. It's like the people who are working with him in his day service and the people who are working with him from his house, all come together. They plan and focus with him, looking at what he wants, where he is going, and how he can develop further as a person. They look at what is working for him in the house and what is working for him in the day service. Just people coming together and talking about what is working and what is not working can literally make a difference. One can give a helping hand to the other".

Interview with sister

Yet despite her understanding of PCP and Lee's support needs she sees her role in the PCP process as being simply informed as to how Lee is and what he has been up to. She sees PCP as a mechanism for Lee to realise his goals. She regards personal outcomes as only having a potential to be realised through the PCP process. Interestingly, she regards family participation at the PCP meeting as not fundamental to maintaining relationships as much as it is about the opportunity of meeting the range of staff that supports Lee in his life. Lee's sister is positive about the PCP facilitating community participation and alluded to the range of community based activities enumerated in his PCP meeting. Lee's sister believes that Lee believes that he has a lot to offer in the community. 'He is not just there. I think he feels he has a part to play, definitely'.

Lee's sister has a number of questions and issues on the PCP process relating to her and her family's acceptance of his disability and how society will respond to him and how this will reflect on

them as a family. This may stem back to the fact that Lee was taken out of the family home as a boy after his mother's demise and when he finished his residential schooling the family were adamant that he would not be returning to his home or to his home town. On the one hand they talk about promoting his independence and risk taking while on the other have a concern that left to his own devices he would express inappropriate choices that are childlike as they believe he is still in a childlike state.

Lee's key worker despite his enthusiasm for his work interestingly also grapples with society's perception of people with intellectual disability. He uses socially distancing language when he talks about people with intellectual disability referring to them as 'these people' and 'Lee can tag along with us' several times during the course of his interview.

At one level there appears to be an acceptance on behalf of the key worker with regard to Lee's disability but on the other hand this is conditional and contingent on how he looks and behaves. However his comments on PCP are clear and relevant:

> "My understanding of PCP is that it is a plan that is individual and on behalf of the person. It is the person's plan, not what I would like, but what they would like. It is a plan for moving forward. It is a measure of where we are, where we have been and where we are going and how we have done. It is goal related and hopefully it will make the person's life better".
>
> Interview with key worker

The key worker has a cautious regard for PCP that is not something that happens as a natural process stating:

> "PCP has its failings. The way I see it the failing is when it is not done naturally. This is when you just pay lip service to PCP and you just do it because it is a policy thing for your employer. But if you take advantage of natural opportunities to be person centred then it does make a difference".
>
> Interview with key worker

The key worker in his attempt to be person centred with Lee compares Lee's life to his own life as they are of a similar age and from a similar background.

> "I have a plan in my own life. I might not always follow that plan but I know what I am doing and the plan gives me a goal. For me I like to know what I am doing. You see I don't think these people

are any different. Plans can be good guidelines and can bring you back to earth. Even if you loose direction sometimes you know where you are going with this person".

Interview with key worker

The key worker expresses satisfaction with the PCP process.

"I find it good. Lee gets to discuss things with all of us because it is his PCP. He can request something or something that he would like to do and it actually gets done. He wanted to go shooting so we looked into clay pigeon shooting. Lee went clay pigeon shooting. Lee got to do something that was relevant to his age with a group of men and that is what Lee wants and he was at his happiest".

Interview with key worker

In this case Lee's key worker has a range of past times that involve risk taking and are not normally activities that you would associate within a group home. These activities include motorbike racing, go carting, formula one racing and shooting. For Lee and his key worker this represents a win/win situation in that Lee gets the opportunity to experience these exhilarating activities. As the key worker stated 'I can't believe that I get paid for this, something that I love doing'.

In order to establish whether these goals were Lee's person centred goals or whether they were the interests of his key worker, the key worker was asked 'do you think that your interests influence Lee or is it Lee's interests that inspire your activities'? The key worker responded:

"We get to like what we see and then we want to try it. I took him fishing. I took him out on my boat. Now Lee loves engines, motorbikes and go karts. It was great to see a person with intellectual disability driving his own kart. He crashed it but he got the experience. It changed his attitude. It strengthened our bond and our friendship. He comes back from these activities so happy".

Interview with key worker

The key worker perceives the key worker system as working well because 'it is completely focused on the person'. At the same time he laments that in the PCP if the person chooses an activity that the support staff clearly does not enjoy, this lack of enthusiasm can taint the experience for the

individual with intellectual disability. The key worker sees his role in the PCP process as very important.

> "I am Lee's support. I am Lee's friend. I am Lee's voice. I am able to sit back and say to Lee 'it is over to you'. I am second in command to Lee. My role is not as important as the person whom the PCP is for. But it is up to me to drive it forward and to say where we are at and why we are doing stuff and to chase it up".
>
> Interview with key worker

With reference to more optimal individual service design, the key worker perceives the current service model as 'slowly turning a corner and I think that we are on the right track. I think that we have turned a corner. We don't own these people we are here to support them'. The good news here is that the key worker is aware and open to more person centred models of service provision.

There is a parallel between Lee's sister's views of Lee's outward appearance to society and the importance the key worker attaches to the outward appearance of the community residence as seen in his remarks:

> "Really, I look at my house and I am damn proud of my service. My service 'aint half bad' and it is something that my service provider should be proud of. We are part of the community and it is important that we do our bit and that the neighbours can look out and see a house that is well kept. People look at us and we are being judged, so we have to fit in".
>
> Interview with key worker

The key worker sees the PCP process as a secondary to a firsthand knowledge of the person.

> "I think if you are going to carryout a PCP on someone you should know the person really well beforehand. You start by knowing the person and building up their trust. The PCP isn't the only tool for achieving personal outcomes. You have to look for other ways and other things. It's not the bible. It is the assistant bible. It is a very good guide like a clear directional signpost because otherwise people could lose focus. It shouldn't be the be all and the end all and you should have a lot of flexibility to use common sense"
>
> Interview with key worker

The key worker regards family participation in the PCP process as fundamental saying 'it was hard for family's to have a relationship when people were in institutional care'. The key worker believes that the PCP process is about his relationship with the family. 'It is a basic requirement to have positive relationships with their family'. The key worker is equally enthusiastic about PCP aiding community participation. He refers to the activity of going for a drink to the local pub stating 'when Lee is out he will strike up a conversation with people'. When asked whether PCP promotes the use of natural resources in the community the key worker reverts to the personal skills of the key worker. 'The person doing the PCP should have very good networking skills'.

In terms of promoting choice the key worker regards the PCP as fundamental and recalls how Lee selected a package holiday to Spain and he is being supported in planning this trip. He agrees that the PCP ensures a full and active life for the person in this regard.

At the PCP meeting it was noted that this meeting was held in the day service and was attended by Lee, his sister, his key worker, four support staff and the clinical nurse manager. The PCP was presented in PowerPoint format showing pictures. The key worker followed Lee's request to lead with the meeting. The presentation commenced with a photograph of Lee's extended family and he named each person to the staff present at his meeting. This gave an opportunity for Lee and his sister to point out to those attending the significance of his family bonds and in particular the strong bond he has with his nine year old nephew. This was followed by photographs of Lee's various support staff.

The next photographs were of people he works and lives with and of the activities that he had carried out in the last year including the shop where he has part-time work experience. There is an emphasis on community based activities such as Lee in the library and Lee on holidays. In an effort to illustrate his capacity to exercise choices there were a group of slides that consisted of things that he liked and disliked. Lee described the things he liked as 'bowling, Liverpool, swimming, Olympics, gym and Michael Jackson', who he described as 'brilliant'. He went on to mention 'motorbikes (mimicking the movement of handlebars), he further stated that he was going to concerts to 'see bands, and I like bingo, football and refereeing'.

Lee illustrated the things that he dislikes 'oh yes mornings, I don't like getting up until half twelve'. He went on to say 'I don't like peas' and he interjects saying 'do you know what I like, beans, chips and burgers'. He further stated that 'I don't like being told what to do'. This illustrates the fundamental importance of the basics of his personal likes and dislikes for PCP. The next part of the PCP meeting related to the places that Lee had been since his previous meeting illustrating that the goals had been reached. Lee stated 'in the aeroplane with Anne to the sun, oh yeah, Spain and to Cork'.

The next slides showed Lee clay pigeon shooting and Lee enjoyed standing up and demonstrating the shooting action to the group. A further slide showed Lee at the go kart track and his key worker described a near miss incident where Lee passed him out on the first corner and crashed.

"I went running over to him and I thought 'here we go'. Lee took off his helmet and said 'cooooool', but he really enjoyed the experience!"

Key worker at PCP meeting

The next slides were of further activities such as fishing and efforts to promote his independence such as shopping and walking without the support of staff. There was an atmosphere of satisfaction with the standard of Lee's PCP primarily because people regarded him as achieving quite a lot. The PCP meeting viewed a slide listing his goals for 2010 which were primarily the same activities only slightly more developed.

The first goal as agreed by his family at the PCP meeting included visiting his family more often than his current visiting arrangements of once a month. There was a discussion around how during the course of the time that he would spend in Dublin an effort would be made to arrange a meeting with his sister who lives there. Further to this the sister who he goes home to agreed to bring him on a hotel break to Cork to meet up with another sister who lives there.

The second goal also agreed at the PCP meeting was that he would learn to ride an adult tricycle and he has been doing this as part of his day programme. His sister voiced her concern that this was an unrealistic goal in that as a child she recalled that Lee had a BMX with stabilisers but he never managed to learn to ride it. Staff disagreed with her and notwithstanding that Lee himself persisted that 'I want a bike'. His sister eventually conceded but stipulated that he had to learn cycling skills in the first instance.

The third goal was about going horse riding and it was agreed by the staff at the PCP meeting that this would take place as part of his day programme as service users have horse riding on Mondays and Tuesdays and Lee was welcomed to join this group. The fourth, fifth and sixth goals of clay pigeon shooting, archery and watching car racing in Mondello Park were reiterated by his key worker and the meeting was informed that they would continue. The seventh goal referred to was that Lee would be transferring to a new location for his day service and that he would be able to attend this service four days per week.

The eight goal was a trip to a Shrine in Ireland on a coach supplied by the local Parent's and Friends Group with several hundred people with intellectual disability in attendance. Goal number nine was itemised as visiting various towns and cities around Ireland including attending festivals. An objective of the PCP was promoting Lee's capacity to be independent giving him staff-free time and allowing him to walk to a nearby shop to make small purchases.

Lee went on to express his interest in wearing a beard and growing his hair long enough so he could have a pony tail, 'that's it I am growing to grow a pony tail and beard. I am serious. It is my choice'. His sister holds the view that a beard would make his appearance more atypical and draw

unwanted attention to his disability. This underscores her concern that if his appearance would be atypical that he would not have the same opportunity to mix with his nieces and nephews who in her eyes maybe afraid of him and really undo all their efforts down through the years to ensure that he has 'normal' social experiences. Despite Lee's best efforts to self advocate his desire to change his hairstyle a lively debate ensued and Lee was relegated to a childlike role and his sisters opinion overrode his aspiration to grow his hair by stating 'I want him to look neat and tidy, he is not getting a pony tail'.

4.3.4 Comment and analysis

Lee is a thirty seven year old man with Down syndrome and a moderate intellectual disability. His special needs were recognised from birth and from Pre School onward he has been in receipt of special services and therapies for people with intellectual disability. The illness and death of his mother had the consequence of him being removed from the family home at an early age and what followed was ten years of institutional care. However, his core personality remains one of a resilient self willed man who reacts to what he perceives as unfair in life by becoming depressed and aggressive or in mental health terms what is regarded as 'mood swings'.

Lee has also a number of health problems including hearing loss, eye problems and recurring chest infections. He is currently in good health having overcome a battle with obesity. At the moment Lee is medication free and is receiving help for his mood and behaviour through a Positive Behaviour Support Plan

Although nothing was ever substantiated there are two inconclusive allegations of sexual abuse, one referred to his childhood and the other to his adolescent years.

For Lee and his family the presence of his Down syndrome was also an early marker that he was different in his outward appearance to other children and for them this has been a life long issue. Relentless efforts have been made to ensure that Lee's outward appearance is of a high standard and that he is always well dressed and presented. Lee enjoys receiving compliments when people notice his stylish appearance.

People now regard Lee as being at his best in that he is now participating in his day programme and engaging with his peers and people in the community. He visits home regularly and his sister remarks that 'he is a pleasure to be with'.

Lee's PCP is essentially a comprehensive list of his likes, dislikes and favourite activities; it is in effect a comprehensive activity plan. The emphasis is on keeping Lee as busy as he can possibly be and this has the advantage of keeping his weight under control and his mood stable however, it falls short of doing what true person centred planning is really about. There is no evidence in any of the interviews that Lee could exercise any self determination or even be supported to take a modest level of control over his own life. It is essentially about what staff could do and what staff could offer coupled with what his sister could offer and what she saw as appropriate for Lee.

The people at his PCP meeting seem satisfied to build on the activities as goals versus empowering Lee through skills teaching and risk taking which is about him. Given that Lee has restricted speech his PCP was in pictorial PowerPoint format there was little evidence that when he actually did say something that anybody really listened. People were more interested in making their own point at the meeting and did not pick up on or respond to the content of the previous speaker's comments.

At the PCP meeting Lee's sister, with others, saw the PCP as about information gathering. None of the staff at the meeting took the opportunity to harvest any anecdotal stories about Lee's life with his family that were alluded to that might have enhanced their knowledge base of Lee. They completely missed the role of the family member as an advocate and the potential to build on the role of the family member to support Lee to take charge of his own life.

There was no acknowledgement of the fact that Lee and his sister were the only two people at the PCP meeting that were not paid members of staff. Little acknowledgement was given to the formality of the situation where Lee who has a moderate intellectual disability was expected to perform. A lot of the content of the meeting was beyond his understanding and one would question if the potential benefits are not outweighed by the possible detrimental effects of the stress this caused to Lee.

Anna

4.4 Anna

4.4.1 Background and context

Anna was born in a small country hospital in Ireland in the mid 1930's. She is one of a large family who lived in an isolated part of rural Ireland. The family lived in a small cottage where they managed their subsistence farm. It was a time of political unrest and between the two world wars where poverty and deprivation were widespread. From the onset it was recognised that Anna had a physical disability of a foot deformity, Talispes Equinovarus, more commonly known as club foot. As a young child she attended her local national school despite the fact that she had a developmental delay. There are reports that Anna allegedly was disruptive in school and was expelled. It is unclear what age Anna was at the time of her expulsion from school.

The next piece of information about Anna's childhood is that at nine years of age she was removed from the family home and entered to what transpired to be a life of institutional care. It is unclear as to the actual reasons for the detachment from her family. It is known that her mother passed away around this time and that her siblings were all divided among her father's siblings who lived in the area. Anna's father had a sister who was single and worked as a nurse abroad. When he passed away this sister returned home to help run the farm with her nephew, Anna's brother.

Anna's brother believes that she went to Dublin for residential care and education for 'troubled children'. It is unclear from her family and from file entries as to the location of this service. Her family report that she spent these fourteen years of her life in 'Cappagh', which was, and still is an orthopaedic hospital. This account from Anna's family is plausible as she did have an underlying physical disability and that she may have required orthopaedic surgery and ongoing physical therapy. In addition Cappagh Hospital at this time was 'to provide a school for poor children and as a convalescent home for underprivileged children who suffered from the diseases of poverty such as rickets, tuberculosis and malnutrition were transferred to Cappagh for continuing treatment' (Cappagh Hospital Website, 2011).

On the other hand a file entry reports that these fourteen years of Anna's life, although very vague name this location as 'Cabra'. This is also plausible as St Vincent's in Cabra was and still is a dedicated facility for people with intellectual disability including challenging behaviour. Her siblings have no recollection of ever visiting or even seeing their sister for holidays from the time she was nine years of age until she was a young woman in her mid twenty's.

Anna's family hold the view that 'she got too old for the children in Cappagh and she out grew that school'. At this time in 1958 it is believed that she transferred to St Brendan's psychiatric hospital in Grangegorman in Dublin. Her family had no control or say in her life.

> "She would have been seen by the specialist in Cappagh at that time. She would have been properly assessed but the information

> is missing from Cappagh hospital. There is nothing there. You would think that the hospitals would have had some communication between them but they don't. The information is missing. We have children of our own and we would like to know her complete history but we don't. You are talking about sixty five years ago".
>
> Interview with Anna's brother

It is striking that their belief is that Anna had the best of 'expert' care and assessments yet they are frustrated by this missing chapter in her life and unfortunately Anna cannot give an account of this part of her life herself.

The documented account of Anna's life begins when she was discharged following a two week stay in St Brendan's hospital and transferred to a large psychiatric hospital in her county of origin. According to her file notes in her PCP she was reported as being unmanageable as she was 'attacking the smaller children' in St Brendan's hospital. At this point in her life she was a petit woman of diminished stature. Her gait was atypical but she was not dysmorphic nor had any outward signs of an intellectual disability. She was referred to a psychiatric hospital as opposed to a special centre for people with intellectual disability which was also in her locality. The psychiatric hospital, apparently, was the first port of call as the primary issue was the management of her behavioural challenges.

Anna was admitted to her local Psychiatric Hospital in the late 1950's, a young woman of twenty three years of age. The hospital at the time was a large self sufficient citadel with over two thousand patients residing on campus. Wards consisted of large open plan living areas and thirty bedded dormitories. Anna spent her days working in the hospital's large laundry and would have had adequate freshly cooked meals and provisions. When people refer to this period in her life they refer to her as 'top dog' and 'in-charge' and 'competitive' with a desire to always be in the 'limelight' regarding the other people with whom she lived. She was known to be colourful in her language and exert her authority over more subdued residents.

Family contact recommenced. At this stage her siblings were all adults and as such had the capacity to re-engage with their sister, who was now residing in the town where they lived and shopped frequently.

While Anna had a busy day and her basic needs catered for she was still an involuntary patient detained in a locked ward in a psychiatric hospital. This meant that she could not leave of her own free will and needed permission from the psychiatrist to get 'parole' for any outward excursions or visits to her. Her family recall such visits and their impact on them particularly seeing her sad restricted life.

"Well there was nothing nice about it and there was nothing nice about seeing someone in an institution like that. It was an awful big building and there was nothing nice about it. The institution was terrible. It was like, no, worse than a prison".

Interview with family

As Anna's life in the psychiatric hospital progressed she became more and more institutionalised and disempowered. She spent twenty four unpaid years working daily in the laundry. When Anna was fifty seven years of age she ceased working in the laundry of the hospital 'she spent most of her day unoccupied on the ward with the exception of carrying out simple chores for staff' (PCP, 2010). Anna remained in the care of the psychiatric services until 1989.

After thirty one years in a psychiatric hospital and at fifty four years of age Anna was moved to the newly created intellectual disability service, under community care which de-designated from the psychiatric hospital. This intellectual disability centre is adjacent to the psychiatric hospital which did not represent any improvement in her living conditions. Despite being under the community care programme she continued to reside in a large eighteenth century hospital setting in large single sex wards and dormitories. She lived with eighteen other female residents with varying levels of intellectual disability and behavioural challenges. She attended day services on site on a sessional basis where remedial teaching was available. In 2004, due to a decrease in her mobility and balance Anna began using a wheelchair. She transferred to a community house near her town of origin in September 2007 at age seventy two as part of the Midland Health Board's Transfer Programme.

4.4.2 Current situation

Anna is now seventy six years of age and currently resides in a five bedroom bungalow in a small village. She now has her own bedroom and personal affects. She lives with five other men and women who also transferred from the same centre. Despite years of institutionalisation Anna retained a sense of pride in herself and her appearance. She is known for her love of fashion and style and enjoys looking well and wearing jewellery. Staff are familiar with her many likes and dislikes and do their utmost to support her in a very personalised lifestyle.

Anna requires assistance with one of her favourite activities - taking a bath each morning. This is a daily indulgence that she likes to take time with and relax. It is followed by her having her hair styled and a leisurely breakfast of her choice. She is pleasant and easy to be with when she has staffs undivided attention. She dislikes sharing their attention with her co-residents and has demarcated her own space in the communal areas of the house. This maybe a hangover from institutional living which in Anna's case consisted of forty nine years of being in an institutional setting.

Her family find it much easier to visit her now that she is living in an ordinary house where she has the benefit of enjoying many ordinary activities in the community such as going to the shops and having meals out. She enjoys home comforts such as watching the television, listening to music, spending time on her own, thumbing through magazines, going for drives and watching people go by. Relaxing in a recliner chair in the front sitting room provides a relief from her wheelchair. She is however, selective about her television viewing and does not follow current affairs or topical programmes. While she is not aware of sporting or political events she is visually aware and is attracted to items such as mobile phones, watches, rings, necklaces and colourful things such as nail varnish and lipstick.

Anna looks younger than her seventy six years and yet she takes medication for a thyroid condition and high cholesterol. She is administered neuroleptic medication as a tranquilizer in an attempt to stabilise her mood. She continues to require a wheelchair although she can stand and take faltering steps. Her exercise, consequently, is very limited yet she has maintained a stable weight. As a medical card holder she rarely makes a visit to her GP. Anna is reported by her key worker as enjoying her current lifestyle and is eating and sleeping well. While she has never had any formal diagnosis her current level of support needs are high.

4.4.3 PCP process

An interview was held with Anna in order to establish a rapport and glean from her an understanding of her PCP. Anna was met in her community residence mid morning. She was supported at this meeting by the clinical nurse manager (CNM) who also acted as proxy. Anna knew that she has a PCP and while she was pleased to have a conversation where she answered 'yes' and 'no' to specific questions it was clear that she had difficulty comprehending questions and responding to them in a meaningful way. Her expressive language consisted of short sentences.

> 'Are you going to fix my knee?..... It is very sore.....yeah!
> No!..... Biddy takes me out..... I got a new chair.....
> Are you going to bring me on the bus?..... She gave me that necklace..... Isn't that a nice scarf?

Interview with Anna

It became evident that Anna was not relating to the content or purpose of the interview on PCP but she did have awareness that she did have a PCP and seemed to associate this with family members visiting her. While Anna had a proxy present at the meeting her presence did not add value to the content or topic but served only to correct any erroneous comments that Anna made. She corrected Anna on her statement on her brothers saying:

> "Anna has a brother a Priest Fr Pat but she always calls him Matt but Matt is the eldest of the family. Matt is not the Priest. Anna keeps saying that Matt is the Priest. Fr Pat is the Priest Anna".

Interview with Anna

Anna's family's understanding of PCP revolves around staff efforts to maintain a high standard of care but have no understanding that they have a role to play. While at the same time they are somewhat disconcerted because they have had to deal with so many different staff members down through the years a practice that still continues. Anna's brother remarked:

> "I think they are just trying to ensure that what they are doing is the best they can do for Anna, from her point of view, wouldn't that be it? Well the meeting here today was just to let everyone know that they are doing the best that they can. It was very nice. We got to see the same person because sometimes it is hard when you see different staff members all each time you come. We don't have a huge role to play in her life anyway, but we try and keep in touch, what more could we do?"

Interview with family

While Anna's family are very appreciative of her current standard of living they are also aware that their sister is very much a unique individual in her own right who craves staff attention and dislikes competing for that attention with her fellow housemates. Anna has a long history of doing better when she is in receipt of individual attention and does not seek the company of her peers. Her family acknowledge this and would see her doing much better in her own home but are reticent about articulating this.

The family regard the PCP as a worthwhile exercise and as a mechanism for Anna to realise her goals and a great reciprocal learning opportunity. 'In a perfect world the goals should be reached anyway but they probably wouldn't happen if it wasn't for the PCP'. The family minimise their importance in the PCP process and lack clarity around their role. 'There is not an awful lot we can do but for us it is good. We hope that it is helpful for Anna'.

At this point in Anna's life the family questions the benefit to her being involved in community based activities and agree with the sanctions imposed by her staff. 'I am no expert but at seventy five does she need to go to Mass? I don't think so if it is upsetting for everybody else'. The family's only hope for Anna is that she be treated with tolerance and kindness. Not only do they minimise their own potential contribution at the PCP meeting but they also minimise Anna's contribution. 'She wasn't at her meeting, but it wouldn't have mattered because she wouldn't have participated

anyway'. The family conclude the interview on PCP by surmising that the most they can do is to be regular visitors to their sister.

The key worker gives an impressive verbal account of her understanding of PCP by stating:

> "Well it is about the person, that you look at the person as a whole and that any plan can impact on their life. You look at the whole person and the PCP is devised around the whole person"
>
> Interview with key worker

The key worker stated that she knows Anna for twenty one years and she has been her key worker for her for the last three years. The key worker concurs that PCP's are substantially about activities when she states:

> "It means that you have responsibility for overseeing the activities that are planned out in the PCP. The files are updated and these must have a positive impact on the person's life".
>
> Interview with key worker

The key worker does strive towards building the team around the person adding:

> "Well the key worker is responsible for organising the PCP, but all staff working with the individual should be involved in implementing the goals. All staff have a valuable input".
>
> Interview with key worker

In the key worker's mind there is a blurred distinction between the PCP and the care plan.

> "I think that the PCP overlaps with the care plan. The care plan speaks volumes and is the core of the person's life. To me I wonder why we have a care plan for Anna, and then we also have a PCP, when we could have it all in the one. You see it's a problem to have the care plans and the PCP's separate".
>
> Interview with key worker

The key worker speaks about the detailed information gathered during the PCP process and questions the merit in this. She doesn't see the relevance of the history of Anna's life and queries why this is included at all in the PCP. She believes that maybe it should be considered in short bullet points. She contrasts the physicality of Anna's life in the community based setting versus the

institutional setting and acknowledging that it is easier to implement PCP's in community settings. She points out:

> "Anna now has her own room. When she lived in the institution she lived in a big day room and she had no choices or opportunities like she has here. In this house the presses are open and she can choose whatever she likes. She can pick out the clothes she wants to wear. She can choose whether she has a bath or shower. There is a lot more time here and staff have a lot more time to give Anna. It is easier and there is no strict regime. Anna can get up when she wants to whereas in the institution everybody had to be up by ten o'clock and were left sitting looking at each other for the rest of the day".
>
> Interview with key worker

She is dismissive about the paperwork associated with PCP's by stating, 'it can be written on the back of a cornflakes box. It is not just a white folder thrown into the press and taken out once a year. It is about implementing the goals'. The key worker acknowledges the importance of having Anna's likes and dislike documented especially for new staff that are unfamiliar with the residents. The interesting thing is that she refers to the care plan and not the PCP. The key worker makes the point that PCP's in themselves are not the way ordinary people typically plan their lives.

While the key worker is mindful that Anna has to have her personal affects as an integral part of her PCP she disregards the importance of Anna having a key to her front door of her house. 'Well I have a key as the CNM II but Anna doesn't need a key because the doors are always opened here'. The key worker believes that the PCP is a conduit for Anna to realise her goals but laments Anna's incapacity to self advocate. Regrettably, there was no independent advocate invited to attend Anna's PCP meeting. The key worker agrees that the PCP process is a perfect way to get to know Anna because 'when you start doing a PCP on someone you do a lot of research on the person and you get to know them better than their own families'. This comment is paradoxical as on the one hand it is encouraging that the key worker sees the PCP as a good way of getting to know someone but on the other hand the key worker does not take cognisance of the fact that seventeen years of Anna's life is sketchy and unaccountable. Even Anna's family does not know where she was for these seventeen years.

The key worker alludes to the PCP being a vehicle for personal outcomes for the individual 'because it is the only detailed format that we have'. She believes that family participation at the PCP is fundamental to maintaining relationships and allaying fears that families may have with regard to the process.

> "When you see the people here that lived in the institution, where they had very little family contact because people didn't like going into the big old institutions. Now that we are out here we see a lot more of the families. But the families may be frightened because some of them think that the PCP is about them taking the person back home to live with them again. I think that it is a fear around the fact that they have not been involved in the person's life for many years and all of a sudden they are getting involved in the person's life again and it is a fear of what might be expected of them. But by having the PCP meeting and if the family's come we can talk to them about this".

Interview with key worker

The key worker remarks that:

> "Family contact is better now that they have moved out of the institution but it is starting to slacken off. Obviously this is because the families see that they have a better life here and they say things like 'I will never worry about him again'. They are happy with it".

Interview with key worker

The key worker regards the PCP as facilitating community participation 'unless there is community involvement we might as well have stayed in the institution'. She attributes the broader community as being very welcoming to the special needs of the residents. The key worker concludes that the PCP is a conduit for promoting the choices of the person and comments that 'it is all about choice, we are looking at the whole person'.

The researcher attended Anna's most recent PCP meeting which was held in the dining room of her community house. It was attended by her brother and sister-in-law, the clinical nurse manager of the house who was also her key worker, a staff nurse and two care staff. At the onset of Anna's PCP meeting she was removed from the dining room and she was wheeled into the sitting room. When Anna was removed from the area the key worker opened Anna's PCP meeting by welcoming those remaining. Her first comments related to what she knew of the vague details of Anna's early life. The PCP meeting went on to discuss Anna's personality style and support needs. Her family concurred 'yeah she likes a lot of attention'. This relentless attention seeking behaviour thwarts the relationships that Anna has with her co-residents.

> "She did like John for a while until she realised that he was going every where with her. So that changed because she resented that".
>
> CNM at PCP meeting

Sadly one staff after the other related negative stories about Anna, taking little cognisance of her behavioural status and emotional needs. They did not display sensitivity to the fact that her brother and sister-in-law might be embarrassed and hurt by staff's descriptions.

> "When we come in in the morning and if we don't automatically go straight over to Anna and say 'hello, how are you' she goes mad and starts shouting and will say 'I don't like you. I am going to tell on you. I am going to tell Mary and Pat' (her friends). They are only up on a pedestal for a while but they soon get knocked off. It depends on her mood and her mood changes. As the day goes on she cops on that the day staff are going off duty and the night staff are coming on duty so she knows that she can't manipulate them".
>
> Support worker at PCP meeting

The PCP meeting heard that an agreed goal in her previous PCP meeting she was brought on a hotel break with a co-resident. However, Anna enjoys time with staff on her own and is noted to dislike having to compete with others for staff attention. This impacted on her capacity to benefit from the hotel break.

> "While she enjoyed the build up to going away, when she got there she resented John being there. She was very distressed and I would have to say that she ruined John's holiday. He didn't enjoy it and he refused to go on holiday with her this year".
>
> Support worker at PCP meeting

While the discussion seemed quite negative, staff acknowledged that they are growing in their understanding of what works and doesn't work for Anna.

> "We learned that she liked to be in the house and that when she went shopping that she liked to bring her things back. We listen to what she says when she says what she wants to do".
>
> Support worker at PCP meeting

As part of a long list of negative events the staff went on to describe Anna's behaviour at Mass. They described how the Priest would take the time to give Anna attention by saying 'hello' before Mass but then describe how Anna would persist in calling out across the church 'how are you Fr Jim?' The family interjects 'oh no way, how embarrassing' and staff report that Anna goes on to say 'good man Jim' and then when the Priest picks up the wine at the consecration Anna reportedly shouts 'good man Jim, drink it all, good boy Jim' and staff say that that goes on all through the Mass.

At some point in the PCP meeting it seems that the four staff members may have started to empathise with Anna's family and there was a shift in the tone of their comments.

> "I used to actually love bringing her to Mass because I actually felt that she was one of the ones that actually got something out of the Mass. I really felt that, it wasn't a wasted trip for her. She even held the leaflet in her hand. She was following the whole Mass and she knows every single bit of the Mass. When the box came around for the money she didn't want to part with her coins".
>
> Key worker at PCP meeting

The key worker suggested that the first goal of this years PCP could be to bring Anna to church on her own but not for Mass. The meeting concurred that this was a good idea because of their concerns that other people would not be disrupted. The key worker announced the second goal as 'a trip to the shop, maybe once a month. This trip to the shop will be with the support of two staff.' The meeting discussed what her key worker construed as the ultimate PCP would be 'I am sure if Anna could say what she wanted she would say that she wanted an apartment on her own with just staff staying with her the whole day. That would be her lottery. That would be her life!'

The staff started to reflect on the positive aspects of Anna's current life stating that 'she can choose her own clothes in the morning and what she eats for her breakfast'. They regard the skills that she learned when she worked in the hospital laundry as standing to her now.

> "I always see her in her room tidying it. I think it is great, she will get you to open the door of her wardrobe and she will get you to pick out what she wants to wear. As vocal as she is we have to adjust to her rather than her adjusting to us. You get to know her".
>
> Support worker at PCP meeting

Her family comment that there is a frequent turn over of staff. 'I seldom see the same person twice. Staff seem to be constantly changing. That, in itself must be confusing to Anna'. The family

acknowledge the importance of knowing Anna well if she is to be supported in a person centred way. The manager concedes.

> "It would be better if we had regular staff. We need consistency and continuity of care. But there is a moratorium on recruitment and some shifts have to be filled through agency staff and we don't know who we are going to have from day to day".
>
> CNM at PCP meeting

Her family questioned this practice. 'We understand but back years ago, Anna knew all the staff that was in every day'. Her family then ask about her general health.

> "She sure doesn't look her age. She was always well cared for and it is standing to her now, but her feet are gone aren't they?"
>
> Brother at PCP meeting

Staff agree remarking that she is 'rarely on an antibiotic, she is really healthy'. The family stated that she was 'very ill requiring hospital admission sevens years previous' but yet there was no follow up information about her condition. The house manager reported that she was on medication for a thyroid condition and high cholesterol. When they questioned why she was on Largactil and what it was for they were told:

> "It is a tranquilliser but she is only on small doses of that and the psychiatrist would not want to decrease it, he would be increasing it, if anything".
>
> CNM at PCP meeting

The family replied in exasperation 'so she can never come off it?' In a light hearted way the staff commented that Anna describes herself as 'Ms Murphy' and as being 'high up on the pecking order'. Anna's family conclude the meeting by stating 'that was very good, that was very informative'.

4.4.4 Comment and analysis

Anna is a seventy six year old woman who started life with the disadvantage of having a physical disability. This combined with her mother's illness and early onset of disruptive behaviour in national school resulted in her being removed from her home at nine years of age. For a period of fourteen formative years she had little or no family contact. During this period she lost both her

parents. At twenty three years of age she was deemed to be mentally ill and was returned to the 'mental hospital' in her county of origin. For the duration of her adult life she was institutionalised and laboured in the laundry of the 'mental hospital'.

It is likely that in the locked wards she was subject to institutional practices and harsh conditions. As well as being deprived of the benefit of family life during childhood and adolescence she was also deprived during her adulthood of opportunities to establish meaningful lifelong relationships. Despite this, she retained her sense of self and has an innate pride in her appearance. She is self willed, assertive and has survived the legacy of institutionalisation.

While her siblings reengaged in her life when she returned to the local 'mental hospital' they set the bar low in terms of their expectations of services for their sister. All they want for her is that people will be kind to her. As well as there been vagueness about the time she spent in Dublin there continues to be a vagueness around her diagnosis. She spent thirty one years in a psychiatric facility and then bizarrely and inexplicably was moved to intellectual disability services at fifty eight years of age in the absence of an intellectual disability diagnosis.

The staff justified the PCP as something they perform on the person rather than it being a conduit to provide a more fulfilling life for the individual. The family are uncertain about how they can be part of Anna's life. For part of her life they had no contact with her and were not inclined to visit when she was in the psychiatric hospital. Now they know they can visit at any time yet are uncertain as to whether visiting is actually good for her. At her PCP meeting the staff think that her family regard the PCP's as suggesting the possibility that they bring their family member home to live with them again. The staff, who admit many institutionalised practices, describe Anna as not having a voice yet she does have a voice and part of the problem is that she is loud and boisterous to the point of embarrassing them. Just as she was removed from her home as a child she was removed from her own PCP meeting. While she was out of the room the privileges of community living were scaled back and removed from her because her voice is 'loud'.

While Anna is comfortably positioned in a recliner in the sitting room her meeting takes place in another room and the fact is that she does not have the motor dexterity to move independently from this position to attend her meeting, which is tantamount to physical restraint.

Teresa

4.5 Teresa

4.5.1 Background and context

Teresa was born prematurely in the mid 1960's and weighed less than three pounds. This low birth weight placed her at risk of developmental delay. She lived with her father and mother in their small home situated on the outskirts of a rural village. Teresa's case notes indicate that her parents had 12 children. When she was three years of age she was placed in a large children's ward, of the local psychiatric hospital. She was placed there because, according to her mother, she was 'completely unmanageable at home'. Teresa's sister, who had spina bifida and severe intellectual disability also resided in the same ward. According to Teresa, she was told that she was sent there to 'mind her sister', Mary. However, following a file search it seems that Mary had died at 12 years of age some two years prior to Teresa's admission to this hospital.

When Teresa was six years of age, she was moved to a special residential and education centre under the care of an order of nuns. She was reported as doing 'reasonably well' in school, acquiring basic academic skills. During this period from 1971 to 1983 she did not have the benefit of normal family life. She was regarded as a relatively bright pupil but case notes from this time describe her as 'stubborn' and 'argumentative'.

When Teresa graduated from 'special school' it was envisaged that she would attend a residential rehabilitation programme. However, this did not transpire due to her unwillingness to go to yet another residential facility. Teresa returned to live at home with her family. Teresa reported that she was very happy during this stage of her life. It is noted that she displayed some adjustment difficulties at home which took the form of temper tantrums and acting out aggressively towards others. As a result of these behaviours, Teresa's parents sought an out of home placement for her. Teresa was admitted to a large residential centre for people with intellectual disability in 1985. Shortly after her admission to the centre, her mother passed away. Some ten years later her father died, thus making it increasingly unlikely that Teresa would ever return home in the absence of her parents. Her life became inextricably bound to the formal intellectual disability service provision.

In the large residential centre where Teresa resided there were many institutional practices such as dormitory style accommodation of twelve beds, central meal preparation and central laundry. Residents were expected to conform. There were set unit meal times, waking times, bed times, shared leisure activities such viewing the same television programme, going for walks and communal personal hygiene practices. Teresa, while in the large residential centre, made three abuse allegations where she reported to the staff that her brother allegedly 'fondled her' while at home for the weekend but declined to make a statement to the Gardai. She also reported that a staff member working in the psychiatric hospital had 'run around after her' and again she declined to make a statement to the Gardai. She made a further allegation against another service user but again declined to make a formal complaint to the Gardai.

After about a year living in this residential centre, during which time there was an external Programme Analysis of Systems and Services (PASS) evaluation of the Health Board service which subscribed to the underlying philosophy of normalisation, Teresa was removed to a group home in the area. Teresa moved to the group home with women that she had been residing with in the large residential centre. Because of the move Teresa now had her own bedroom, participated in meal preparation and her lifestyle was more conventional. She was also given a day placement in the occupational therapy unit in the psychiatric hospital where she resided as a child, working in supported employment in the laundry. Initially Teresa got on well in her community residence but was frequently returned to the large residential centre in response to 'bad behaviour'.

Teresa has had numerous psychological assessments carried out throughout the course of her life, from the onset of her special education through to her most recent full psychometric review in 2008. She consistently functions within the middle of the range of mild intellectual disability. Teresa has always displayed impressive verbal skills with a good basic working vocabulary, enabling her to carry on a lively discussion on a range of topics, for instance, her hobbies such as local sport, in particular following her favourite hurling team and popular music. In the past, Teresa was active in cross country running and has numerous medals for running in the Special Olympics. She enjoyed playing pitch and putt and going to the golf range and more recently, swimming.

4.5.2 Current situation

Teresa currently resides in a community residence, approximately four miles on the outskirts of a large town. She attends a day service in this town on four days per week and an activation unit in another part of the town for the fifth day. Teresa reports that she is now happy in this house and also with her day service. During her day programme Teresa reported that she engages in many activities such as art therapy, reflexology, community inclusion including going for coffee, shopping, using local amenities such as the swimming pool, church or cinema. Teresa reported that she finds these activities very enjoyable and satisfying. Staff reports that in the context of the house what works well for her is the smaller number of residents and the high staff ratio plus the relative spaciousness of the house. Teresa has her own bedroom and can move freely around the house and gardens when she perceives that she needs to be on her own. Staff commented that Teresa feels secure in her community house. A similar observation was made by Teresa's sister who said 'Teresa needs space for her mental state of mind'.

Teresa stated that she has feelings of not being listened to, of her voice not having power, views of others being taken as fact whilst her views are discredited in her eyes. When one asks Teresa 'how are you, Teresa' she will reply 'the staff say I'm very good' or for instance it is noted that she is in good form, she is likely to reply 'the tablets are working' or 'I went to the doctor and he told me the tablets are working'. This is a classic feature of institutionalisation where a person with intellectual disability relinquishes control and responsibility for their own lives and to have an over reliance on medical opinions.

When Teresa is treated unfairly in a punitive manner she is more likely to engage in acting out behaviours and that her reputation as 'difficult' is fulfilled. Teresa, like many people with intellectual disability are often seen as being in a state of 'eternal childhood' and are treated with strategies reminisant of the past where children were punished when they were perceived as being 'bold'. More enlightened protocols around positive behaviour supports can be found in Teresa's care plan so she can be supported to have a more self determined lifestyle versus the more restrictive and punitive behaviour management strategies of the past. Teresa does not see herself as being trustworthy or having ordinary entitlements such as a key to her own front door. She states 'I might lose it'. Her leisure pursuits are restricted to 'special' events. These include attending the local Special Olympics and the monthly parents and friends disco for people with intellectual disability.

When asked if she participated in buying groceries for the house she stated 'Well we shop online using the internet for groceries'. When probed about her participation in this activity she stated 'no I can't use a computer. I am not that good at it. I think the staff do it. The food is delivered to the house. It is a great service'. When Teresa was asked if she participated in preparing and cooking meals in the house she replied:

> "The care assistants do that. We don't go near it because we are not allowed go near the cooker, we're not let. I would help to serve out the dinner but I am not allowed near the cooker".

Interview with Teresa

When Teresa was asked whether she participated in doing her own laundry she replied:

> "Well if I was shown how to use it and if I got it started. I wouldn't mind learning. I do help by clearing up the table, emptying the dishwasher, bring the clothes off the line, sweep the floor and set the table, things like that".

Interview with Teresa

Teresa attributes her current level of happiness to the successful role of medication and to her care plan. She states 'the key worker says the care plan is working' and 'the doctor says the medication is doing its job'. Teresa spoke of herself in an objective way for example stating 'takes me' and 'handover' about herself. She continually spoke of herself in the third person. She referred to her peers as 'clients' and states that when she goes on Share-a-Break 'another client goes with me'. When planning seasonal breaks she describes herself as being at the mercy of her sisters to 'take' her home. She describes her brothers as having 'no interest in my life'. When reflecting on her past life she remarked:

> "I have lived in three institutions and I didn't like any of them, you would have to share dormitories and I didn't like the food, you didn't get out much and there was nothing to do other than do messages for the staff".

Interview with Teresa

Teresa also commented that while she is currently happy in her house she is in she does feel insecure. She attributes this to being moved many times without consultation, even in the recent past she left her community residence one morning to be brought by the staff to a different house. This was done to facilitate another service user who was terminally ill. She said:

> "Well I had to move to another house the reason being was that another resident was sick. You see he was very sick and they needed a single room for him and I had to give him my room. You see I didn't mind, but sure what could I do. I had no choice".

Interview with Teresa

Teresa described being moved without her knowledge as 'very upsetting'; however, Teresa made the comment that she is now 'very happy with her life'.

In the interview, Teresa's sister perceived Teresa as now having a 'wonderful life'. She emphasised the importance of 'dignity and respect for people with intellectual disability'. She stated that Teresa 'does not like being spoken down to and that this causes her to get stressed'. She alluded to another community placement where Teresa was unhappy. She was moved there without her knowing to free up a room. This caused great distress in her life and she believed that her sister was 'heading for a breakdown. She was on anti-depressants and was suicidal. I live in fear that they will do that to her again'.

She believed other community houses to be 'cold' and 'impersonal' and that Teresa was always 'just a number'. She was 'ringing my house everyday in an absolute state'.

> "We will be told then to take her out and look after her. I wouldn't be able to cope with her full-time. We are working and we have the baby. This is my biggest fear. I am not judging the staff. The majority of staff are wonderful and they have a hard job, but things that I want to say I am afraid to say because I would be told to take her out".

Interview with Teresa's sister

She made the point that space is vital for Teresa and her current placement clearly represents an improvement over her previous residential settings. Teresa's sister also remarked that 'they were all born and reared in the country and that Teresa is not able to cope with living in a town'. The location of the service is seen as excellent for Teresa. She noted that it is important for Teresa to have 'choice' in her life and that she should decide herself what 'she wants to do'.

Teresa's sister points out that Teresa's lifestyle is not very person centred in that Teresa lacks any real choice in her daily activities. She had some reservations with regard to Teresa's level of activity. She doesn't think that she should be told what to do. She stated that Teresa is 'told to do art, but if she is not in the mood to do art, it doesn't matter, she still has to do it'. She remarked that in the past being sent back to the large residential centre when Teresa became difficult as 'not very professional'. She articulated again, however, a sense of reservation about 'saying too much' because of an underlying fear that following any criticism 'I would be told to take her out' implying that she would have the responsibility for Teresa's care if she was critical of the quality of her current service provision.

She welcomed being invited to her current house for 'parties' and 'Masses'. She would like to take her 'out more' but there is a lot going on in her life at the moment. She stated that Teresa knows where she is and that if she is ever feeling down that she can ring her and she believes that is a 'great comfort' to Teresa.

> "I always say to Teresa that even though I may not be talking to her everyday or that I don't see her every week that if there is ever anything that she needs never to feel alone. I know that you have staff and you have your own friends but always remember that family is crucial".
>
> Interview with Teresa's sister

4.5.3 The PCP process

Teresa displays a relatively good understanding of the mechanisms of the PCP process. She has some difficulties with the deeper philosophical constructs of the process. In the interview with Teresa she describes the PCP as 'This is Your Life'. She did not see the PCP as something that she owned. She went on to describe it as a 'white folder that staff took notes and wrote in'. She stated that she 'did not have permission to read the PCP' and it is stored in a locked filing cabinet that is not accessible to her. When asked to give more information about the PCP Teresa commented:

> '"Well it is about your life, about how you are getting on, about going places with your key worker and co worker. About daily activities, you know and things like that".
>
> Interview with Teresa

Regarding the frequency of PCP meetings Teresa notes 'a PCP meeting is due now, but they haven't decided when it will be'. She attributes the manager of the house with the responsibility of convening her PCP meeting and again when asked who is involved she describes many staff members.

Teresa has a limited perception of the things she has control over, for example, while saving for a holiday she went on to say that the 'staff haven't decided where we are going yet'. When asked 'who sets the goals'? Teresa stated 'well we do, the staff, whatever staff does be there on the day looks at the goals on the care plan'. While in the past Teresa was able to visit her sister in the USA alone she now perceives this as being beyond her reach as she now would not only have to have a staff member with her she would also be required to pay for this staff person's expenses. As it happens this was set as a goal at her last PCP. When questioned about her realising her goals from her last PCP Teresa stated that while a return visit to the USA was planned it did not happen. When asked why she made the following statement:

> "Because of the finances. The money end of it. I didn't have enough money to go. Then you have to pay for a member of staff to go with you. I wouldn't be let go. I know that I went the very first time on my own but I wouldn't want to go on my own now. I am 45 now the first time I went I was younger. You know my sister would meet me in JFK the other side and then you see the fist time I went I was handed over to the air hostess but they don't hand over passengers anymore".
>
> Interview with Teresa

Another example from her most recent PCP meeting was that her bedroom required a chest of drawers. However; a staff member selected this item in the absence of consultation with Teresa. When asked 'how did you select your chest of drawers'? Teresa stated:

> "You see the staff have ordered it. I didn't pick it I wasn't there now. I was at my day service so the staff picked one for me so they will make it and assemble it you know".

Interview with Teresa

Teresa's sister stated 'I don't really understand person centred planning' and she believes that she doesn't really have a role to play in it. She further stated 'Teresa's happiness is crucial' and that regarding Teresa, 'we need to give them back their voice'. She did note a deterioration in Teresa's personal and oral hygiene, and she also noticed recently that 'Teresa doesn't read the paper any more'. She remarked that these issues are a real concern to her but went on to make the startling statement:

> "I feel intimidated when I bring up things like this. I would hate for Teresa to be given false hope with regard to unrealistic goals and I wonder who has the power to say what is going to happen".

Interview with Teresa's sister

She further remarked that she could not say anything negative about the PCP process but was of the opinion that the PCP was not a requirement for people with intellectual disability to realise their goals as the activities 'would probably happen anyway'. She agrees that family participation is crucial at PCP meetings in order to try and maintain relationships with staff. She doesn't believe that the PCP process promotes the development of family, friendships and social networks, however she agrees that PCP does promote the use of natural resources in the community. She doesn't believe that PCP promotes choice for the person with intellectual disability.

> "I think that they could be given the chance to make more decisions for themselves and if it is the wrong choice it is the wrong one but their choice none the less".

Interview with Teresa's sister

Teresa's key worker described the PCP as a 'white folder' that contained information on 'the whole life of the person and what they want from life'. While it is very helpful to familiarise yourself with the content of the PCP it is not intended as a replacement for spending time or getting to know the person with intellectual disability. She further remarked that 'they tell the story themselves, if they can' and that what is within the care plan/PCP is 'usually correct'. The key worker acknowledges

that the crafting of goals in PCP is a skill that requires both knowledge of the individual and what is realistic for them. It is vital that the goals are the focus person's aspirations and set within the 'realms of likely success'. The key worker was of the opinion that the PCP was a document designed to aid her to formulate goals for the focus person as opposed to actively supporting the person with intellectual disability to craft their own realistic goals. 'You can build a profile and then you can set goals'

Typically, a paid member of staff would be responsible for assisting the person in all activities of daily living incorporated into day and residential programmes. Yet the key worker remarked:

> "One of the problems with this is that people with intellectual disability in community residences are on a restricted income and they have difficulty affording the cost of a lot of elements of day programmes such as art therapy and aromatherapy. The ones that can speak up for what they want get the most".
>
> Interview with key worker

Ideally the role of the key worker would be to promote the person with intellectual disability in their own decision making particularly around choice of activities and how they spend their disposable income. Another aspect to this is around self determination and self advocacy.

The key worker stated that people with intellectual disability are often viewed as 'children' who can't make decisions for themselves. She believes that the key worker should 'be a friend, like a sister, advocating for the person' and that she sees this as her role as key worker. She stated that in the past there has been a lot of 'abuse of power' and feels helpless at times when decisions are made by management that are out of her control. She spoke of a specific incident where Teresa went to her day service one morning and a decision was taken by management to move Teresa to another community residence without involving her in that decision. This was in order to facilitate another service user who was ill to have a single room. From this experience the key worker firmly believes that there is a huge role for advocacy.

She spoke of the lack of feedback and monitoring of the PCP's. She stated that 'staff require help with the procedural aspect of PCP's'. She also stated that staff can use 'the whole goal thing' as objectives that they can reach versus what is required for the individual.

> "The key worker system is a way of getting things done but that you don't have a choice of who to be key worker for, you are given someone to do a PCP on and that as a key worker, I try to be a friend but I get paid to be here".
>
> Interview with key worker

The key worker reflected that there are merits to the PCP process as it now exists. She believes that it may be helpful to enumerate the merits and the disadvantages of the current system. Someone needs to 'monitor the PCP process'. She believes that it is not just a matter of making sure it happens. It is making sure that it is in keeping with the 'person centred philosophy'. In endeavouring to ensure the person has a full and active life she states 'I don't think PCP it insures it or is it the whole thing. It is part of it and it is a good thing'.

Teresa's PCP meeting opened with a general take on how life is at the moment for her. Teresa reported that she is very happy with everything at the moment and that life is 'wonderful'. An apology for the delay in setting up the meeting was noted namely; the meeting was supposed to take place yearly, the last meeting was two years ago. Apparently, the meeting was postponed on numerous occasions due to the non availability of staff. The PCP meeting was scheduled on a Sunday (which is unusual) to suit Teresa's sister travelling from Galway to another event. The implication of this is that people who work with Teresa during the week were not available. Those in attendance were Teresa, Teresa's sister and Teresa's key worker. The goals from Teresa's previous PCP meeting were reviewed and included Teresa to run the mini marathon, Teresa to visit her sister in the USA, Teresa to establish a friend through the Buddy system, to go on day trips, go to concerts, and to continue with the Special Olympics.

There was an emphasis on attributing Teresa with direct responsibility for achieving her own goals. Teresa did not run the mini marathon but it was emphasised that this was because she did not partake in the pre-marathon training regime. Her key worker made the comment:

> "Last year we decided Teresa that we were going to do the mini marathon and why did that not happen'? Teresa replied 'Because I did not do the training'".
>
> Key worker at PCP meeting

Teresa did not go to the USA but this was because she had not saved the money required. The key worker offered her opinion as to why this goal was not achieved:

> "Your goal was to visit the USA and part of that action plan was to keep in contact with your sister there and to start saving. The key worker was to follow up on that which is me. That didn't happen, did it Teresa? There were a few reasons for that wasn't there Teresa? Financially I think maybe the money was an issue. Wasn't your sister home? What happened? Oh yeah, didn't your brother die? That stopped the process. Ok, well we might look at that again in a couple of year's time".
>
> Key worker at PCP meeting

Her key worker went on to say 'an action was that you would use your travel pass to go new places and go dancing. So has that happened this year or over the last two years'? Teresa responded to this complex question by stating 'well yeah, I went with the staff and she asked me out dancing tonight if I am not too tired'. The key worker remarked that:

> "I suppose Teresa you have gone new places and you use your travel pass, well you have with me anyway. We went to Dublin. That was fantastic, we stayed overnight in a hotel. We had a great time. The weather was brilliant the music was brilliant wasn't it Teresa"?
>
> Key worker at PCP meeting

Teresa responded by stating 'yeah, I like to go to concerts'.

The buddy scheme, a volunteer that is matched with a service user was unsuccessful at this time. The key worker states that 'we had this set up but that it didn't work out. Why do you think Teresa that it didn't work out?' Teresa commented that 'because she was married and had children to look after and that was the reason'. The key worker interjected:

> "I think a lot of it was that she didn't understand. I think for Teresa she would need a very special person to work with her to understand and it just didn't work out".
>
> Key worker at PCP meeting

Teresa went on to state 'I love Share-a-Break, yeah I do and that is going well'. The key worker said 'you go training with the Special Olympics, you go training once a week for that'. Teresa informed the meeting that she goes training on a Tuesday night. Her sister articulates concern 'you don't feel it is too much pressure?' Teresa replied 'no I don't'.

Teresa stated her aspirations at the PCP meeting.

> "I'd like to go to a West life Concert and to see River dance. I'd like to go to a hurling match to see my local team and to football matches".
>
> Teresa at PCP meeting

Staff availability, their rosters and personal likes all determine whether or not Teresa gets to go to these matches and events or not. Teresa asserts that she enjoys many activities in her day service.

> "I like the staff and clients. I like going up the town and mixing with people. Socialising and having tea up the town. I like to go to the cinema and do other entertaining things. I like the music lessons as well, the drums. I have drums. I like doing that. I like getting me feet done on a Thursday afternoon. I love activation, I do yeah".

Teresa at PCP meeting

The key worker displayed a vision poster to the meeting (this is a graphic illustration of the focus person's life trajectory and future aims) and commented to Teresa:

> "So we will have a look now at your last vision poster. We haven't the new one done yet. That's what we would say, it is in production. So I am just having a look at this one Teresa. You tell us, this is yours".

Key worker at PCP meeting

Teresa responded by reading the poster headings 'home, family, personal possessions, friends and relationships, 9-5, what will happen and leisure time and local community'. The key worker asked Teresa:

> "Do you think that all these things that are mentioned on your vision poster, do you do them, or would you like to do more? The 9-5 is your day programme and what you have told us already is that it seems to be working and going well".

Key worker at PCP meeting

Teresa replies 'yeah it is'. The key worker mentions community involvement and goes on to say 'yeah so you like dancing and things like that'. Teresa says 'community involvement and I go dancing and things'. The key worker asks Teresa 'ok do you think maybe you could do more with that'? Teresa responds 'yeah I would'. The key worker then remarks:

> "Unfortunately, the house Teresa lives in has a client that requires 2:1 staffing and it is always difficult to get the extra staff to cover,

so that prevents others from going out. The Parents and Friends Association are very good and she can get a taxi".

Key worker at PCP meeting

The key worker reverts to Teresa's sister to whom she remarks 'you have to agree she can be a little bit more independent'. Concerns were expressed about Teresa's capacity to express herself as she would need to. Towards the end of the meeting her sister remarked:

"I think that it is important that Teresa is able to express herself, you know. Maybe sometimes she doesn't express herself appropriately depending on the situation she is in. Do you know what I mean?"

Teresa's sister at PCP meeting

At this point in the meeting it was clear that a separate discussion had taken place prior to the PCP meeting between the key worker and Teresa's sister. This may have been to protect Teresa from having her feelings hurt in the event of the topic being embarrassing in content. The key worker offered her interpretation of Teresa's behaviour by commenting:

"She doesn't like to hurt people's feelings and she says what they might like to hear for example around the swimming she didn't express herself about the pressure she was under and her blood pressure went up".

Key worker at PCP meeting

Many people with intellectual disability acquiesce. They frequently state things that they believe will please others and gain them popularity. Her sister reflects:

"So I think if there are things that are bothering her maybe she could learn to express these properly and tell her key worker".

Teresa's sister at PCP meeting

This clearly specifies the view that Teresa needs active support in promoting her capacity to state her needs in a way that commands an appropriate response, the role of the key worker. Her sister tells Teresa, 'I would like if you were able to talk to me or others about how you are feeling'. Interestingly, the key worker saw her role as trying to solve the problems on Teresa's behalf whereas it might have been more expedient if she helped Teresa to self advocate. The key worker responds directly to Teresa reinforcing her opinion that people with intellectual disability are in a

state of 'eternal childhood' thus ensuring that they don't grow in their own capacity to deal with every day life issue:

> "At the end of the day Teresa I am your key worker and I take a very special interest in you and you are my priority. So if there are things bothering you I will do my best to help you solve it as there are always solutions".
>
> Key worker at PCP meeting

The key worker directs a comment to Teresa's sister 'so you are happy that things are going well'? To which she replies 'yeah I really am'. The key worker remarks 'and that's great you are so approachable'. The meeting ends with the key worker thanking those who attended and reassuring Teresa that every effort will be made to help her realise the goals discussed.

4.5.4 Comment and analysis

The puzzling part of Teresa's life narrative is trying to understand why she had to be hospitalised for behaviour management difficulties. It is evident that these problems led to her being removed from her family home at a very young age, yet the benefit to Teresa was questionable given that her parents were alive in a functioning household. The descriptors of her used in the case notes are pejorative in tone such as 'stubborn'. The communal life style in the institutional setting would have provided her with some level of order and consistency but would also more than likely have impacted negatively on her sense of self and her whole identity formation. What was hoped in the whole philosophy of the group home movement of the 1980's was that people with intellectual disability would have a more normal lifestyle, yet we now understand that there is nothing normal with grouping people with intellectual disability together in group settings for housing purposes.

While Teresa had periods of contentment and satisfaction residing in the group home, it seems that returning her to the large residential centre became custom and practice as a mechanism for managing her behaviour. One would question the benefit to Teresa from moving her from a small group home back to a large residential centre. Teresa described this as a very difficult time and 'unfair'. Her sister remarked on the injustice of meeting her needs in this manner and regarded it as 'unprofessional practice'. From the review of her case notes a recurring theme is that the residential centre equates to a punishment for behavioural outbursts such as 'becoming high spirited'; 'being rude to staff'; 'being ungrateful'; 'being mean to the others' and 'giving out' as well as throwing things and breaking things such as delph, furniture and windows. In attempting to understand what Teresa was going through at this time one could conclude that she must have felt marginalised, disempowered and misunderstood which is a frequent side effect of institutionalisation?

Her PCP contains many good practice rules of thumb in what works well for her but there is a recurring theme of the service users being differentiated such as comments like 'were not let' 'going with other clients' and 'staff say I am good'. While her key worker maintains that she knows her so well it is baffling that in her conversations she is not succinct or specific in what she is asking of Teresa. The key worker asks many compound questions. She also includes a number of statements for verification from Teresa that events took place. The regrettable element is that Teresa is responding to the agenda of questions versus offering her own ideas. At the PCP meeting one question contained four elements so this must have been confusing for Teresa to answer. Teresa in turn has adopted 'staff lingo' like instead of saying she had no money she said 'because of the finances'. Teresa can feel somewhat disempowered and is noted to acquiesce and agree with what the staff state they can reach on versus holding on to her own personal goals and objectives. Teresa has characteristically relinquished control of her life to others, particularly staff.

From her PCP many of the goals were funnelled through special events such as Special Olympics, Share-a-Break and Special Buddies. All of these activities and outings are in the context of special services with paid members of staff versus natural community inclusion and natural circle of

support. Notwithstanding the benefits of special service to Teresa there are a direct contradiction to normalisation principles and true person centredness. There was a patronising tone taken evidenced by listening to Teresa but instead of going with the desires reflected in her statement informing her that they will be dealt with later. On a positive note the key worker did say that she learned a lot about Teresa's history. Also it gave her an opportunity to express her opinions such as people with intellectual disability are 'occupied too much'. She also stated that 'you don't have a choice of who you are key worker for'. She talked about the role for advocacy in order to strike a balance in the power relationship. She called for staff training on the procedural aspects of PCP and the need for monitoring.

Rather than taking ownership for the fact that some of the ambitious goals had not been realised there seemed to be an effort to attribute responsibility for this failure directly to Teresa. The art of goal setting was not at a very advanced state. Instead of having running a marathon as a goal it may have been more worthwhile to break this goal into smaller more realisable actions. The PCP is clearly very much **about** Teresa versus being **for** Teresa. Ideally if the PCP was for Teresa it would be coaching her to set realisable goals with small achievable steps that her key worker could share in the joy of Teresa's success.

Teresa's sister on the one hand reflected that she now has a 'wonderful life' yet further into the conversation her remarks contains many indicators of an underlying anxiety such as 'she will be left with you if you complain' and 'I live in fear that they will tell me to take her home'. The language that professionals use may be socially distancing for the layman such as when staff talk about community inclusion when they mean ordinary activities. Teresa sister said 'I don't know about PCP' yet her other responses reflected a deep understanding of the importance of family relationships and involvement.

There is a simplicity about Teresa' sisters remarks at the PCP meeting 'if Teresa could learn to express herself' that this would somehow enable the key worker to make the changes to alleviate the situation. This is not an achievable goal or end in itself yet it absorbed a proportionate amount of time at the PCP meeting. A lot of the conversation was around getting her to understand the notion of trying to express herself but the reality is that she has no direct control in her life.

Teresa has, however, a sense of fair play and justice and responds well when treated with dignity and respect. She has achieved some of her life's goals in that she continues to enjoy going out socially with staff, going to concerts and visiting her family.

Gary

4.6 Gary

4.6.1 Background and context

Gary was born in the winter of the mid 1950's, the third son to Ann and Paddy who resided in a small midlands town. The couple went on to have two more sons. Gary was born at home and as he developed it became clear that he had a pronounced curvature of the spine. Unlike his older brothers he was notably delayed in reaching developmental milestones. His oldest brother Jack recalls how much of his early childhood was spent in the direct care of Gary. 'We used to feed him; he used to be able to start to feed himself but then he needed help'. Gary's intellectual disability became evident to the family when his parents decided to enrol him in formal education. His brother Jack recalls:

> "He didn't go to school then, it was the dark ages then, the 1960's, it really was the dark ages and families didn't publicise that they had a child like that".
>
> Interview with brother

Another difficulty for Gary was that he presented as being very anxious and nervous and Jack recalls that 'he had an inherent fear of everything'. Another concern was most likely a consequence of his skeletal deformity and he was noted to have 'a bad chest'. This led his carers to protect him by keeping him indoors because he was 'delicate'. Gary did not develop expressive language and so his vocabulary was restricted to short concrete utterances such as 'cup of tea'. He did not have an opportunity to acquire any basic academic attainments.

A redeeming feature of Gary's early life is the presence of his loving maternal grandmother who resided nearby and took an active role in the rearing of the five sons of Ann and Paddy. Jack recalls 'my father was a very quiet man. Our Granny reared us from day one and that's how it was years ago'. Sadly for this family Gary's father a labourer passed away suddenly when Gary was ten years of age. As well as dealing with the loss of their father this was a turning point in other ways for the family. Shortly after their father died their mother entered a second relationship and married a local man Tom.

Tom and Ann were interested in starting a new life together and the maternal Grandmother took over the care of Gary's brothers, but despite the protests from Gary's family Tom took the unilateral decision to place Gary in the local psychiatric hospital.

> "My Grandmother fought tooth and nail for Gary to remain at home, but eventually Tom put him into the mental hospital and since then there has been a split in the family. We were stopped from having anything to do with Gary. The four of us were reared

by our Grandmother. She took the four of us and Gary went to the mental. That's when the split arose".

Interview with brother

Gary was admitted at ten years of age to the local Psychiatric Hospital a week before Christmas in 1969. Jack, Gary's brother recalls that Tom coaxed Gary into his car stating 'we are going to a football match'. Gary, who always required assistance with eating and drinking, had a favourite spouted beaker with him at the time. Jack remembers that Gary was clutching this beaker when he was brought from the family home to what he and Gary were told was the football match nearby. In fact, Jack later found out that Tom had Gary incarcerated in the local psychiatric hospital. When Jack reflects on the time that he was involved in caring for his younger brother he remembers how significant the beaker was to Gary. During his time in the psychiatric hospital Gary refused beverages from anything other than a spouted beaker. It was quite possible that for Gary the beaker was the only link with home onto which he clutched.

Retrospective file entries in preparation for the de-designation of intellectual disability services from the psychiatric hospital verify that Gary was 'abandoned' (1986, Case notes). From 1969 to 1989, a period of twenty years Gary resided in various wards in the large psychiatric hospital. Initially Gary resided on a ward for adolescent boys who were referred to at the time as 'emotionally disturbed'. There were up to sixty adolescents on this ward at any given time. Families were discouraged from visiting as they were seen as upsetting the residents. From Jack's account, their step father insisted 'we stay away and have nothing to do with him'.

During this phase of Gary's life he did not receive any formal education despite being of school going age. He spent many empty hours sitting in an un-stimulating environment in a locked ward. Gary who was noted to be a somewhat nervous and deeply anxious child was subject to the many institutional practices of communal showering, communal mealtimes and complete lack of privacy for personal care. Amongst his peers then there was a hierarchal order and given that he had restricted capacity and little strength, he was in the lower echelon and lacked a real voice for himself. This would have compounded his difficulties, was exceedingly stressful and thwarted his development.

As a young adult Gary was moved to a ward for men with high dependencies and nursing care needs. Again this would have imposed a limit to his access to the community as such people were not typically brought for excursions outside the hospital. In 1989 the service for people with intellectual disability residing in the psychiatric hospital was transferred to community care and a large de-designated centre was commissioned on campus for this cohort. He lived on the male ward with twenty one men with varying degrees of intellectual disability and behavioural challenges. At this point Gary was diagnosed with an anxiety disorder and was reported as being afraid of the other residents.

> "Like when he was in that place he used to stand behind a chair the whole time. It was like the chair was his safeguard. He was so frightened of the other people there".
>
> Interview with Nurse in Charge

For Gary the benefits of moving to the large intellectual disability centre was that for the first time in his life, at thirty two years of age, he was being provided with special services for people with intellectual disability. He spent time off the ward in the occupational therapy room doing simple desk-top activities and received a day service on a part-time basis where he engaged in multi sensory activities and community outings.

In his thirty eight years of institutional care there are three file entries that indicate family visits. In 1999 his mother and half brother visited him for the first time since his admission to institutional care following the death of his step father and to mark his fortieth birthday. In 2004 for the first time in thirty three years Gary was brought home to celebrate his forty fifth birthday. In 2006 there is a file entry that states 'Gary's mother visited the hospital and gave a present to the nurse for Gary but that declined the opportunity to see her son'.

4.6.2 Current situation

After residing in the large intellectual disability centre for eighteen years Gary finally transferred to a community residence under the transfer programme. This five bed roomed bungalow is situated along a canal which has many pleasant walkways. The house has an extensive garden and many nice views of the countryside. Gary now has a much more personalised lifestyle including his own bedroom and personal artefacts. He has improved in his general health in that he has gained weight and looks more robust. He is more relaxed and settled and does not display previously noted symptoms of anxiety.

> "When he was inside he used to sleep with his head propped up on his elbow, as if afraid he was going to be pounced on by another resident at night. Now he lies down flat and he is relaxed when he is in bed. It was worry and fear. He was worried about something".
>
> Interview with nurse in charge

He was taken off all medication previously prescribed while living in the institution and is now medication free. He has also acquired self care skills and is now doing more for himself. While he was reliant on taking liquids from a beaker for years in institutional care he has learned to drink

liquids from cups and glasses. This in itself means that Gary can enjoy restaurant experiences without drawing attention to his special needs.

Gary now has a more varied an enriched lifestyle. The things that bring him enjoyment and satisfaction are the simple every day activities that he finds pleasant. Since moving to his new home Gary loves to sit in the sitting room and listen to his music. He enjoys a foot massage and has a full body massage once a month. He loves going for walks by the canal with staff and he loves sitting in the garden. Gary enjoys going to the supermarket with staff to do the grocery shopping.

He goes to Mass each Sunday in the village and participates in saying the prayers. He enjoys going to restaurants for meals and the odd pint in the local pub. Because of the legacy of his institutional care he retains an anxiety about people milling around him and making unexpected movements. Those caring for him are vigilant about ensuring that he doesn't experience ongoing stress by going into crowded places. He enjoys having a lie in each morning and really enjoys the practice of taking a daily shower in privacy. Gary now uses single words, short sentences and gestures to make his needs known. He is speaking a lot more since his move to the community house.

His mother at this stage who was aging with significant health problems was delighted with the fact that her son finally had an opportunity to realise a life that she herself wasn't able to provide. Sadly, after Gary moved to his new home his mother passed away. Staff from Gary's new home brought him to his mother's funeral. At this juncture, the family who were united in their grief were pleasantly surprised and impressed as to how well Gary looked. His four brothers seeing him for the first time in many years were so overcome with delight and emotion seeing his participation at Mass insisted that he sit with them where he belonged as an equal family member and a chief mourner. Jack states that this was the realisation for them as an estranged family that they could re-engage with Gary and that they had a role to play in his life. It is important to recall that when Gary was institutionalised his family were told that they had no role in his life and 'to stay away'. Now, they see him as a person in his own right with whom they can re-establish a loving and meaningful relationship.

In summary, Gary's current situation is a dramatic improvement in many of his quality of life domains. He has a comfortable community residence where he is obviously contented and thriving. Despite the fact that Gary resides with smaller numbers of people it is important to realise that his needs are always considered against the backdrop of the needs of the other people he lives with. For example;

> "When Gary moved out at first he did have his own bedroom. Unfortunately, one of the other residents passed away. The person that replaced the resident who had died was a woman. In order to give her her own room we had to move Gary from his

single room to a double room that he now shares with another man".

Interview with nurse in charge

4.6.3 PCP process

Gary's expressive language is restricted to his capacity to utter social phrases such as 'cup of tea', 'hello', 'goodbye' and 'thank you'. Because his comprehension is about immediate things such as meals and activities, it became evident to the interviewer that his understanding of PCP would not lend itself to interview. Gary was present at the PCP interview and questions on the process were answered by proxy, in this case by the clinical nurse manager (CNM). From the transcript of the interview with Gary he answered all questions with the stock phrase 'cup of tea'. The interviewer asked Gary, 'hello Gary how are you keeping?' To which Gary replied 'cup of tea'. The interviewer asked Gary, 'did you get a cup of tea?' To which he replied 'cup of tea'. By way of illustration on Gary's interaction style Gary replied to several questions by simply smiling and saying 'cup of tea'. Gary's support staff volunteered the comments on his current lifestyle by stating:

"Do you know his whole life has changed since he moved here? I see a massive difference in him. He is just brilliant. I would bring him anywhere. He likes contact now as before he was just too nervous. He is so happy now".

Interview with CNM

The interview takes a slightly different format to other interviews because of Gary's restricted capacity. His support worker volunteers information about his PCP and related activities emanating from his PCP.

"His PCP states that one goal will be that he visits his mother's grave once a month. This is incorporated into a visit home. A second goal is that he goes out for a meal once a month and he does that. Another goal is that he goes to Mass once a week".

Interview with Proxy

The proxy advocates for a more person centred approach particularly smaller groupings of people. As she moved from the large congregate care setting and now works in a community residence she has gained an understanding of how this setting influences person centredness. She states with a lot of passion:

"I would love to see that big place closed. I would love to see chains blocking the doors going into it. It is disgraceful. It is full of people ready to move into houses. It is absolutely disgraceful. You have people in that place begging and pleading to get into a community house".

Interview with CNM

In an attempt to clarify her own thinking on how institutional settings exists to this day she further reflects:

"Staff in that big place are worried about their roles and worried about the demarcation between domestic duties and traditional institutional roles. This is a big myth. I don't see myself out there cooking dinners and cleaning floors, I see myself supporting people to live dignified lives as independently as possible".

Interview with CNM

In a further exploration of the elements of institutional practices and in the context of this interview on PCP the interviewer took the opportunity to try and establish how her thinking had become more person centred. She then reflected:

"There are psychiatric nurses that don't understand community living. They all want to promote the institution. Because they themselves are institutionalised they need the institution as a place of work to do there job as they see it. Keys and drug trolley's are so important to them".

Interview with CNM

She then reflected that a psychiatric nurse from the institution was rostered to do a shift in the community residence. When she came on duty she questioned 'where is the drug trolley?' She remarked to her stating:

"Drug trolley? There are drugs in the press there and that meets An Bord Altranais's guidelines. Why would you look for a drug trolley with six people living in a house? It was clear to me that she would rather work inside where there was a drug trolley rather than this lovely house".

Interview with CNM

The CNM in her interview gave many accounts of how she believes Gary's life to be more person centred. She sites one example as follows:

> "Well for example he never ate breakfast inside. He was too scared. Now he eats eggs and he enjoys home cooked food. Sure look how well he looks. Now he has the courage to ask for his favourite foods. He asks for jelly and pears after his dinner. Sure isn't that great".

Interview with CNM

At the end of the interview Gary's support worker and in this case proxy concluded by reassuring Gary 'you better go into the kitchen so you can get that cup of tea'. To which Gary replied 'cup of tea'.

An interview was held with Gary's oldest brother Sean who is two years his senior and has a vivid recall of Gary as a child. The purpose of this interview was to gain an understanding of his perception of PCP, but before this could be embarked on Sean at the onset of his interview sought a moment to clarify the underlying intent of his participation in his and his other brother's re-engagement in Gary's life. He sought clarity around any direct responsibility for Gary's care that might be displayed by any tacit participation by him or his siblings and extended family. The clarification on these issues was vital to their future participation in PCP. While the ultimate aim of his question was to establish whether any family member would be expected to take over the direct care, Sean asked:

> "What is the status of Gary's current placement in this house? Does he have a right of residency? Is it permanent? Do you expect us to take him home full time? Because if you do, we can't be involved".

Interview with brother

Part of the role of the PCP is to have an understanding of the person's entire life. Often family members are the only ones who can contribute information on the person's life prior to their institutionalisation. Sean went on to describe the historic aspects of the family care arrangements referred to above in the background and context. He told how this resulted in their alienation from their brother Gary and a lack of opportunity in their lives for them to get information or a clear indication as to how Gary was doing. The PCP provided them with an opportunity to learn about Gary and re-engage.

> "We have never had a chance to discuss this with anybody. I was 15 or 16 at the time and I was in the army. I then went on to get

married and I had 11 children of my own so I was very busy. But there was always this 'common denominator' of our step father; he never wanted Gary back in our house. At this stage the first family were pushed away. This has come to light since my mother died. The second family don't want to have any thing to do with Gary, but we do".

Interview with brother

Ultimately Sean's concern was more about the legalities of Gary's current status rather than the PCP process. He sought clarity around

"In the last couple of years now since mother died I have been trying to figure out legally where we stand and whose responsibility Gary is? Who is Gary's legal guardian? After all his step father never wanted anything to do with him".

Interview with brother

When Gary's status as an adult with the same rights as any other citizen was clarified for Sean, he remarked that 'it is time for us to step up and see if there is any thing we can do to help. I want to be of help, to be able to assist in whatever way I can, with the girls here.

He further stated that in his mind there was never any reason why Gary was 'put away' and added that 'in my mind he could have been looked after at home'. The interviewer asked Sean to reflect on Gary's current living and care arrangements and Sean concluded:

"Yes, sure it is lovely out here and it is easier to come and visit here. It is much easier than going to the mental with locked doors and everything. His life at the moment is excellent, I will be perfectly honest with you, it is absolutely first class".

Interview with brother

Sean reflects that during the time that Gary resided in the 'mental' that he really only saw him the once that he was taken home to his mother's house. This must have been a bewildering experience for Gary, as during these infrequent visits he was brought to visit his mother's new family consisting of half siblings whom he has never met or lived. At this stage Sean's only role was providing Gary with some semblance of a previous life in the hope that he would recognise his brother.

Regarding the PCP process at this time Sean goes on to declare his interest in learning more about the process stating:

> "As and from today's PCP we are one hundred percent on board. We are going to sit down tonight as a family and we are going to see what we can do as a family to help out and to come and visit more often. That is my aim and that is what I intend to do".
>
> Interview with brother

It becomes evident in Sean's remarks that because Gary has improved since he moved they realise the benefits to Gary and to themselves of more involvement in his life. When Sean was asked about his understanding of the PCP process he stated:

> "It is individually based and from what I see here it means they are planning activities to suit Gary's needs rather than the needs of the general population here".
>
> Interview with brother

When asked about the role of the family members in the PCP process Sean replied with a certain degree of inspiration.

> "I see it as the time we can dedicate to Gary. Gary has everything that he needs but it is the time that he has with family that has been missing in his life. So from now on we can make up for this".
>
> Interview with brother

In the context of the PCP process facilitating Gary in realising his personal goals, his brother remarks:

> "That his inherent fear in the past blocked his involvement in any new activities. But since his move to the community group home he has improved one hundred percent, no two hundred percent. I think the PCP process is very fulfilling. The PCP process is a perfect way to get to know my brother".
>
> Interview with brother

With regard to personal outcomes being reached through the PCP Sean describes the improvements in Gary as evidence that outcomes have been reached stating 'I think you need the

PCP to achieve all this, especially in Gary's case. He really has changed so much you know'. Sean believes family participation in the PCP as fundamental to maintaining family relationships. On the topic of PCP and community participation Sean concludes:

> "Gary has established a good relationship with those caring for him. They seem to love him here and they bring him everywhere. I think that if I had Gary out somewhere I would be afraid that I would not be able to manage him. The staff are great with managing him".
>
> Interview with brother

The important question of the PCP process promoting the development of family, friendships and social networks is answered in a resounding way by Sean stating:

> "Hopefully this is the first day of the rest of our lives. I want to get involved one hundred percent whenever I need to get involved with Gary and I will be guided one hundred percent by the staff".
>
> Interview with brother

In terms of the PCP promoting choice for Gary, Sean agrees that 'Gary is doing exactly what he wants to do and the staff have him well sussed out. They know his likes and his dislikes and he is finally living life on his terms'.

To conclude Sean agrees that the PCP ensures a full and active life for Gary.

> "Yea I agree wholeheartedly. It is great to see him so active. I am seeing him for the first time in a long time with so much to do. He is up in the clouds. I am so proud of him".
>
> Interview with brother

Gary's key worker Pat seems to have a natural affinity for Gary and further to this he has a person centred perspective on his work practice that is remarkable because in it he reflects his understanding of true person centredness on how PCP can go from rhetoric to practice. Pat describes that he has known Gary for five years and that he has been his key worker for three years. Pat regards the role of the key worker as pivotal and sees PCP as working and driven by the key worker.

> "PCP can work really well but it is only as good as the person delivering it and the person who is there to support the individual.

> Some people would say that the key worker should carry out all the goals but I don't believe that".
>
> Interview with key worker

Pat is more interested in ensuring that modest goals such as going to Mass are reached consistently, irrespective of who is on duty, rather than setting more ambitious goals. It is his priority as key worker to work on ensuring that all staff are comfortable in supporting Gary in realising his modest goals of going to Mass or going out to lunch on a very regular basis versus these modest things only happening when he, as the key worker, is on duty.

Pat is mindful of his role as key worker in empowering others saying 'I think we need to remember that it is Gary's PCP not the staffs PCP'. He illustrates how he brings people on by modelling and quietly encouraging rather than trying to champion Gary's cause in an insistent manner. Pat remarks on what he would describe as text book 'PCP stuff'.

> "One of Gary's goals is that he gets to listen to Irish music and go to more local events. Well the home of Irish music is on our doorstep in the local hotel. The woman on the door knows him by name and while he might not get up and dance he really does enjoy being there. To top it off he even collects the posters from the concerts he goes to and he has them all hanging in his bedroom. It is a lovely kind off memorabilia and reminds him that 'yes I was there, I was at that concert on that date' and this is a goal that he has achieved".
>
> Interview with key worker

Despite the fact that Pat acknowledges Gary's significant intellectual disability and lack of capacity to formulate his own goals he describes, that by giving Gary a range of opportunities it is possible to discern from him what he really enjoys and what he doesn't. He believes that this gives Gary a framework for goal setting and really it is Pat's preference in keeping them modest and achievable and that by investing his energies ensures all staff see the benefit of true person centredness and the broader horizons of community participation. Some of Pat's remarks reflected a realisation that there is still a lot more work to be done to instil true person centredness across the board.

> "The key workers role is fundamental but then if you have staff saying 'we better do this because the key worker is on duty'. But this is losing the whole point. It is not for the key worker, it is for

> Gary. But if that is what delivers a PCP goal well that is fair enough".
>
> Interview with key worker

The key worker acknowledges that a lot of the PCP goals should be part of Gary's every day life but at the same time he recalls when Gary moved from the large centre that:

> "We had to start from scratch. The things that you and I take for granted, like going to Mass was something that Gary never ever did. So we were really at the bottom of the ladder here"
>
> Interview with key worker

Pat speaks positively about the role of Gary's family in the PCP process.

> "The family now want to get involved in Gary's life which is great. It was their mother's wishes that they would be part of Gary's life again. The fact is, there were three of Gary's brothers here today and that is great. I believe that they feel quite comfortable coming here to the house rather than going to the large institution".
>
> Interview with key worker

Pat contrasts this with a recollection that he had of Gary's family's effort to visit while residing in the institution.

> "I was told that the family were there in the visitor's room. I was told to bring Gary down there to this special room for visiting, just like they have in prisons. It would have been nice if they had come up to the ward to see where he lived and slept. But that couldn't happen. So you can imagine how formal and off putting it must have been for families to visit in comparison to what we have seen here at today's PCP meeting. Families need to feel free and comfortable and if they don't the wont want to come again".
>
> Interview with key worker

He added that because going to Mass was a goal of Gary's PCP he was then able to attend a funeral of a family member and he was able to participate without being afraid. His other family members introduced him as 'this is our brother' and they felt 'proud of him'.

When the question of optimal individual service design from the interview schedule was posed to Pat he stated 'at the end of the day anything is possible'. Pat reflected that Gary likes peace and quiet acknowledging that sometimes his current environment falls short of meeting his needs. Pat did not place limits on Gary nor did he see his current placement as a final destination. Further to this Pat strongly agrees that the PCP acts as a tool for Gary to realise his goals.

Pat concurred that the work behind the scenes of the PCP can be tedious and unfulfilling but that it is fulfilling when you see things being achieved. He shares the belief that the PCP process is the perfect way to get to know, Gary 'basically you get to know dislikes and dislikes, but it is not the only way'. He further states personal outcomes can be achieved in lots of ways. 'We could decide that something could happen in Gary's life that is not part of the PCP process. So it is not the only way. It is a structured way to go forward. But you do have room for things to happen outside the PCP'.

Pat agrees that the PCP is fundamental to maintaining family relationships. 'That is evident here today, three of his brothers came'. Pat agrees that the PCP promotes the use of natural community services and further sheds light on the importance to the community of having contact with people like Gary. 'Like if he had a job in the community you would see more benefit from his presence'. Pat strongly agrees that Gary now does have more choice because 'he does make his needs known. While choice with him is two way 'do you want to go on the bus or do you want to listen to music'. He will say 'go on the bus'. Pat views the PCP process in ensuring a full and active life for Gary in that 'there are new things for Gary to try that he has never done before'.

The interviewer attended Gary's most recent PCP meeting as an observer. This was also attended by Gary, his key worker Pat, the nurse in charge, a care assistant, three of his brothers and his sister-in-law. The meeting opened by the key worker welcoming every one to Gary's new home and to the PCP meeting. The atmosphere was relaxed and convivial, chatting socially over a cup of tea.

The key worker reviewed the four goals identified at the previous PCP meeting held a year ago. These included; visiting his mother's grave, to attend Mass once a week, an overnight stay in a holiday destination and identifying a Christmas present that Gary would regard as personal.
Because of Gary's restricted functioning at the PCP meeting he is not forthcoming with high level or ambitious goals. As stated already, when Gary is given choices in life, those who know him will readily conclude whether he enjoys these activities or not. The purpose of his second goal was to give him an opportunity to practice his religion by going to Mass. This also has the advantage of giving Gary a visible presence in the community and a social role as a parishioner. His family now value this role that Gary has and his brother stated:

> "We believe that Gary is now able to grasp the concept of religion through Mass. He is saying his prayers and he did say 'In the name of the Father, Son, Holy Spirit, Amen' the other day".
>
> Brother at PCP meeting

Pat reflects on this stating 'I think that it is good to keep this up despite how much or how little Gary gets from the experience. We hope we are supporting him as best we can'. Pat is mindful of Gary's concerns around being in crowded places and is sensitive to Gary's needs to be supported but believes that he is growing in confidence 'he is now much more confident than when he first moved out'. As well as recognising the benefits of Gary going to Mass his key worker is keen to illustrate the benefits to Gary in helping him overcome his trepidation of crowds.

> "Even though it may seem a minor thing going to church, it can help him in the long run. Gary seems to be getting over his fear of crowds and he seems to now enjoy some of the things that large crowds bring about. He was able to go to his mother's funeral because he was used to going to Mass every Sunday. When he hears the choir or the organ it doesn't shock him anymore".
>
> Key worker at PCP meeting

Gary's brother concurs "Yes it makes sense, he hears the choir in the church and he hums along to the music".

The key worker reported to the meeting that last years goal of a one night holiday break was achieved and stated that 'Gary enjoyed his trip to Galway'. The features of his Galway break included 'plenty of meals out and plenty of bus trips'. His final goal was to get a Disc Man for his Christmas present. 'Unfortunately Gary wouldn't tolerate the head phones, but he still enjoys listening to his stereo in the sitting room and this suits him much better'.

In terms of setting goals for the coming year there was an agreement at the PCP meeting that it was important to retain an emphasis on the goals from the previous years as an integral part of his PCP. Even though the goals were relatively modest his key worker was keen to get the support of every one attending in cooperating with the basic goals of going to Mass, making sure that Gary has music of his choice to listen to, making sure Gary has regular walks, outings for meals and regular bus trips. The trajectory of the meeting followed by staff members recounting to Gary's family of the many incidental activities that he benefits from since he moved to this house.

Staff remarked that Gary enjoys a good appetite and is in very good health seldom requiring any medical attention. His family concur, with his brother stating, 'God we really see an improvement in him. I have never heard him say so much. I know he can't tell us but from observing him we know

he is very happy'. The nurse in charge adds 'Gary is very much a success story. He spent most of his life in an institution and now he has really adapted well to community living and appears to be in a very happy place at the moment'.

The key worker was very much aware of the family's involvement and the relationship that Gary would have had with his mother. The key worker recounts:

> "The time your mother was sick, I took Gary to see her in ICU. I knew that day she was very sick and wasn't going to make it. What I did was to gather a few photographs of Gary in the house. She was planning to visit in the springtime, don't you know. I brought her the photographs and she took them and she looked through them and said 'I am very happy now because I know that Gary is in a very happy place'. Unfortunately, she never got to visit".
>
> Key worker at PCP meeting

Gary's family observed at the PCP meeting that he is using a lot more words and is more conversant. His key worker states that 'we encourage him to say more words you know'. The key worker in summary outlined the renewal of the same goals the coming year asking the family 'can you think of anything that you would like Gary to do. Tell us and we will take it on board'. To which Gary's brother replied:

> "To be perfectly honest you know him better than we do and you know what is best for him. What you are doing here is fantastic. We think ye are great".
>
> Brother at PCP meeting

While this is an encouraging positive comment it may have been spurred more by the ambience of the meeting rather than a deep knowledge of Gary's current service. The key worker responds by thanking people for coming to Gary's PCP meeting stating:

> "Fair play to ye all for coming out here today to Gary's PCP because it is important to have a family presence at these meetings".
>
> Key worker at PCP meeting

An ideal opportunity has been missed here to rearticulate the role of family members in Gary's more person centred life as clarified by the family at the beginning of the meeting. Interestingly,

family participation is not itemised as a goal or in any an objective in his PCP and the key worker clearly disregards the importance of developing family participation and developing relationships to 'family presence'. The key worker concluded by saying:

> "Gary has managed to achieve a whole new life since he moved out here. He is still a young man and hopefully will have many a more good day".
>
> Key worker at PCP meeting

4.6.4 Comment and analysis

Gary who is a man in his fifties moved to a community residence three years ago from a large hospital setting where he lived for thirty eight years. Despite his obvious birth defect and developmental delay he was part of a loving vibrant family who looked out for him in a somewhat overprotective way. It was the family's intention to provide for Gary in terms of his home schooling and meeting his direct care needs. Unfortunately, Gary's father passed away suddenly when Gary was a young boy. This event, combined with his mother's second marriage and the fact that she went on to have another family resulted in Gary's 'abandonment' and the complete loss of his family.

In the institutional setting he did not receive an education nor did he receive any special support services such as Speech and Language Therapy and Occupational Therapy that would have been readily available in an appropriate setting. Upon his institutionalisation Gary appeared to have lost some of his basic skills such as he stopped talking and was described as being 'hunched' and 'fearful'. His brother describes the 'locked doors' of the institution and family members were advised 'visiting would only upset the patient and to stay away'.

Gary was first incarcerated in a ward for emotionally disturbed children in the 'mental hospital'. There were approximately sixty children co-residing in this setting. Given Gary's small stature and scoliosis he was even more vulnerable to bullying and domination by others. This coupled with his already nervous and anxious disposition further thwarted his development. His last eighteen years in the hospital setting were improved by the de-designation from the psychiatric service to community care. This led to Gary having more opportunities for activities and excursions off campus.

Finally, he had an opportunity to live in an ordinary house, this time with five other people with intellectual disability. His life is better in that he is healthy, confident and more engaged and while his mother has passed on he has had the opportunity to re-engage with his siblings from whom he had been estranged for thirty eight years.

At the onset of the PCP meeting his family members spoke of their fear of being involved in the PCP process if it implied in any way that they would be required or viewed as capable of taking on any of the direct care or responsibility for Gary. They asked questions about their legal responsibilities, if any, and were happy to be involved in his life once it was understood that they now had their own lives and Gary's care needs were not up for discussion by them. This illustrates the point that as family members they were not given information and did not have any understanding of their role as a family member in Gary's PCP. They came to the meeting with a certain amount of nervous apprehension and fear as to what was required of them. From Gary's case study it is clear that the role of family members in the PCP process needs further exploration.

The key worker seems very enthusiastic and focussed on immediate and achievable goals in Gary's PCP. Yet he may be disempowering the family in active participation in small things in Gary's life such as taking a walk or going to a restaurant by saying 'these things require staff'. The family are not empowered to do any suggested activities with Gary and surprisingly there are no aims or goals set that involve them.

While there is an overwhelming acknowledgment by everyone at Gary's PCP meeting that his life is better, this does not equate to it being perfect and there are ample opportunities for his life to be more person centred. Initially, Gary had his own bed room in his new house but this was short lived as due to the needs of others and because of his lack of an advocate his single room was taken from him. Because of his intellectual disability and the fact that he is in a service setting for people with intellectual disability with five others he is still at the mercy of how staff prioritise his support needs.

As Gary's expressive language is restricted to lines of humming popular songs, responding to prayers and asking for his favourite beverage 'cup of tea', his interview on the PCP process and his participation at the PCP meeting was by proxy of his support staff. But this still left him in the position of not having the benefit of any independent or objective voice. He is still in that abyss of being totally overshadowed by staff, who the family naively perceive as 'perfect'. Again while the key worker had a good understanding of the PCP process he attributed the PCP process as being a conduit for Gary to engage in community based activities such as going to Mass and going to a restaurant. He viewed all PCP goals as requiring 'more staff input' and goals were only as good as 'the staff person delivering them'.

The key worker did not make any obvious accommodations to Gary to facilitate his participation and involvement in his PCP. One would expect at a minimum that there would be visual aids and object cues so that Gary would be able to contribute to his PCP.

The essence of PCP is about the person and the basic requirement for it to function is a deep knowledge of that person characterised by a corresponding respect for that person's choices, lifestyle, dreams and aspirations. The family in this case revert to the staff. When asked about their opinion on furthering his goals they are lost and sadly acknowledge that the staff 'know him best'.

In this case, as in others, the PCP goals were restricted to deliverable activities that they saw as requiring staff and were not based on any more personalised vision of what Gary's life could be like. Ideally, his PCP should include a more visionary perspective on what his life has the potential to be, including; supporting Gary in spending time with his brothers away from a service setting, learning new skills, having a socially valued role in society or developing new relationships outside of 'special settings'. Opportunities such as those mentioned above were lost.

Killian

4.7 Killian

4.7.1 Background and context

Killian was born pre term during the 1980's. He had a very low birth weight and his chance of survival was questionable. His family were advised at that time to prepare for the worst. He spent the first part of his life in an incubator on a paediatric ward in a Dublin hospital, a good distance away from his family who resided in a small midlands town. When he was eventually discharged to the care of his parents it became clear that he was experiencing developmental disability. The early intervention team involved with him at the time disputed whether his primary disability was one of physical disability in that Killian carry's a diagnosis of 'Cerebral Palsy and Spastic Diplegia' or physical and intellectual disability.

Killian lived at home with his parents who went on to have two other healthy children whose care needs were prioritised over Killian's. He remembers fondly the time he lived at home and still regards his parent's house as 'home' even though he has not lived there since he was ten years of age, some twenty one years before the interview.

Killian's family were happy for him to avail of services in the local pre school for people with intellectual disability. The family were relieved that he would receive his therapies in this special facility, relieving them of the responsibility of having to bring him to appointments. As he became older his mother recounted that they were unable to meet his physical needs at home given that he was non ambulant. 'I wasn't able to look after him full time. We wouldn't be able to look after him'.

When Killian was ten years of age he was sent to a Residential School in Dublin for children with physical disabilities, coming home only for the major holiday intervals. It is worth noting that at this time Killian was denied access to his local school because of his physical disability. He continued to live in this residential school for nine years. While resident there Killian attended special education class each day. Despite this, his academic achievements were very limited in that he never really learned to read or write. At this time it became apparent that Killian's intellectual disability was underestimated.

Killian's extra curricular activities included horse riding and swimming. He slept in an open plan ward which generally had eight regular residents with physical disability plus four temporary residents in respite care. His main interests at the time involved resting on his bed, listening to music and rambling around the corridors and buildings with the use of his walking frame. He vaguely remembers not having any friends while he lived in Dublin and he describes this part of his life as 'a bit fuzzy'.

In keeping with policy, students from this special school graduated at eighteen years of age and were required to leave the boarding school. At this juncture, his family indicated to the local health authorities that they were not in a position to provide him with the care that he required as a young

adult in their home. A case conference was held in Killian's local town with representations from the local intellectual disability service providers and the staff from his special placement in Dublin. Recommendations from this case conference identified that a community residential placement in a local group home was the most suitable option with the proviso that he attends a day place in a local activation unit for people with intellectual disability.

The following year a discharge meeting was held in Dublin to implement the agreed recommendations for Killian's future residential and day placement. At this meeting it was identified that there were no group home vacancies in his town and unfortunately a proposed community residential house was not available. The only remaining option was to place Killian in a large residential centre for people with intellectual disability, thirty miles from his parent's home. This placement was deemed inappropriate but was agreed by the Multi Disciplinary Team as an interim measure while awaiting the development of a community group home for people with intellectual disability in his locality.

> "I never wanted him to go to that residential centre; it was all they had at the time. He had to leave school in Dublin and it is what we were given".
>
> Interview with Killian's mother

Psychological reports from this time indicate that Killian functions within the upper moderate range of intellectual disability. His mental age equivalency is quoted at the six year test age approximately. Upon his return from the special residential school Killian was admitted to a bungalow on the campus of the large residential centre for people with intellectual disability. It became clear that the confines of the bungalow, which was not wheel chair accessible, restricted Killian's movements. After a brief period there he was transferred to a ward in the main hospital building. The ward at the time was home to twenty five people with intellectual disability and complex care needs including, people with severe challenging behaviour and people who were psycho geriatric with intense care needs. Killian shared a dormitory with five other people who were life long residents. He was subject to the institutional lifestyle practices including set communal meal times, set bed times, little room for his personal belongings and the authoritarian behaviour management regimes. He commented 'I didn't like it there because that nurse guy was very loud, you know very strict, you know very bossy'

During his three years sojourn in the large centre, Killian was relentless as a self advocate for moving out of the institution to a community group home. He frequently commented to people 'I want to get out of here, I want to get out of here, can you help me get out of here?'

Local intellectual disability services worked and developed a more appropriate residential placement for Killian. He was eventually discharged from the large residential hospital setting in 2001 and moved to a new community group home nearer his county of origin with five other people

with intellectual disability of similar age and ability. He also commenced a day service programme with a local service provider at this time.

4.7.2 Current situation

Killian is living in this community residence for ten years now and the house is within walking distance of a small rural town in the Midlands. He speaks positively about his current living arrangements. 'Eh, it is good in that I have my own room and all that. I am living with a few housemates'. This detached two storey house is equipped with modern amenities but given Killian's restrictions half the house is inaccessible to him. He is a very sociable young man and likes to meet people, yet he said:

> "No friends ever visit me here and I don't get to visit the neighbours as I would not be allowed. You wouldn't like to be invading someone else's house".
>
> Interview with Killian

In Killian's mother eyes the services he currently receives are far superior to those of the large residential centre and 'when he is happy, I am happy'. When asked do you see a difference in his life now she remarked:

> "Oh God yes. I never wanted him to go there. It was all they had at the time. He had to leave school in Dublin and it is what we were given. I wasn't able to take him home full time. We wouldn't be able to look after him".
>
> Interview with Killian's mother

The day service where Killian attends five days a week is located in a disused convent in the middle of the same town where he lives. Albeit that the service is located in the middle of the town it is quite isolated form the community and the campus is also occupied by other socially marginalised groups. The residents of his house also attend this day service along with him. The implications of this for Killian are that his opportunities to interact with new and different people are restricted. Similarly, the personnel employed in both day and residential settings are from the same service provider. Again this limits the number and nature of social contacts. 'They are all staff'. Killian states that he enjoys going to his day service, 'Eh it gets me out of the house'.

Killian refers to his day service as 'work' and he does engage in some activities that have a work aspect such as horticulture. But most of the activities are of a social occupational nature such as swimming and going bowling with people with intellectual disability. Killian referred to a Christmas

play that he was preparing for in the local community theatre. While this was a source of great joy for him it transpired that this play was being presented by fellow service users to fellow service users lacking an element of real community inclusion and participation.

One of the services that the day programme provides is the nursing supervision of his physiotherapy regime. Apart from this there is no element of the programme that focuses on Killian's unique potential for making a contribution to the community. 'I do exercises, mostly stretching exercises'.

Killian states that he goes home to his parent's house every weekend. He travels home on special transport provided by the service, thus he does not have the opportunity to use public transport. The trip home for Killian also incorporates an outing for other individuals with intellectual disability as an activity, 'going for a drive'. Killian looks forward to this and enjoys the time that he is at home. He speaks fondly of his two siblings and enjoys the time they have together, however, when asked what he did when he was at home he stated:

> "I would sit around and watch television, I would go shopping, but you see, my mum does be working like, she's a nurse and hasn't the time to take me. Eh, I would also visit my granny and I would listen to the radio".

Interview with Killian

This is further evidence that Killian's physical needs have circumvented his participation in a more meaningful way in family and community life. He has many empty hours and it seems that he is not valued as a person who has anything to offer. He doesn't work and he does not socialise as one would expect for a 31 year old man. Life at home is about containment rather than promoting Killian's life goals.

When asked if he would socialise with his sisters he alluded to the fact that one of them was in college and one still lived at home. He stated that they do bring him out to the pub but when asked as to where he would go he stated 'no, I wouldn't bother'. He went on to say that he does not drink alcohol stating 'because I don't drink when I am on the tablets'.

4.7.3 PCP process

Killian's sees PCP as being about people meeting and talking about him and his life, 'where you have a chat'. His expressive language is so good in that he repeats what other people say to him and he has some understanding of the comments but this does not extend to a deep understanding. He was unable to say what a goal actually is and in response would typically deflect by changing the subject completely or by asking the same question back to the interviewer requesting comment. When asked do you know what a goal is? He stated 'no I wouldn't'. Further to this Killian can acquiesce and agree with what is being said as if he fully understood it but added 'me head does be gone'.

Killian's mother, who is happy with his current day and residential services, is disinclined to consider the power of PCP to enhance her son's quality of life. She regards PCP as a process whereby she 'learns what he is doing'. She describes PCP as 'it is where they set out plans for the staff to keep people busy'. She sees her role as important in the PCP process as a mother so she knows 'what he is doing'. She seems to judge the success of the PCP to the amount of people present at the meeting, 'all the people that were here for him today'. She added that because Killian has a really good standard or living now and a good standard of care he therefore must have a good PCP. She attributes the PCP process as the only way for 'staff to get to know my son well'. One would wonder why his family are not more ready to engage in raising the bar or setting higher standards for their son and Killian's key worker offers the comment that 'they are happy that he is here and not at home. I think they wouldn't want to rock the boat'.

Killian's key worker defines PCP as 'where the client decides what they want to do. They get to choose what they want from life and we as key workers help them achieve it'. For her there is no naivety about the complexities of the PCP process and she goes on to differentiate between the theory of PCP and practice. To illustrate the complexities that arise when crafting goals that are on the one hand achievable on what staff can offer but on the other hand might restrict the choice the individual has in pursuing their personal aspirations. She questioned:

> "Is there an element of choice when it comes to the PCP or do staff decide beforehand what the goals will be? Would you like that Killian or will we do that Killian? So that the choice that Killian will make is to agree with that or not".
>
> Interview with key worker

She alluded to the fact that staff in a subtle way offer goals to the PCP which are within their control. These would typically be activities that Killian has derived some satisfaction from previously. Sadly, these are activities that should be happening anyway such as using local shops and recreational amenities. They are modest reachable goals within the short term and not visionary long term truly person centred goals. When goals are typically not reached or staffing

levels are typically blamed. 'I have tried to offer choice to Killian. As key worker for him I feel that this is my role, however, I will be told that won't happen because of staffing. If I try to do it I am shot down'.

The key worker during the course of her interview stated that at Killian's last PCP meeting he chose a goal of wanting to do music lessons. It was organised with a local music teacher but it didn't happen because of 'staffing levels'. She added that the truth was that it didn't happen because the manager said it would interfere with the morning regime in the house. She concluded by offering the solution 'could I could come in on a Saturday morning on my own time to take him but I was still told no'. She added a note of caution, 'he has more potential. Management are holding him back and worse still they are let'.

The key worker provided another example of where she believes management have the control and power to say a goal will not happen.

> "He also wanted a Juke Box and management regarded it as too expensive. Goals depend on who the person in control is and as it stands the power to say no can control someone's life".
>
> Interview with key worker

As well as management controlling Killian's spending, the goal of the juke box reflects a restricted understanding of the true essence of person centeredness. There is an evident weakness in the style of crafting goals in this case as in providing material things such as 'a big television, an en-suite and a juke box' versus a person centred vision as to what a better life would look like for Killian.

As a key worker and care worker she articulates a sense of profound frustration with regard to the PCP process. In her opinion the view and style of management can positively impact on a PCP or conversely their view can undermine goal setting and realisation. In this case management's priority is around the efficient day to day management of the house. Managements desire to have an efficient running of the house over rides the individual's personal goals, creating another strand of tension. This adds to the negativity around the PCP process and limits the creativity because of her underlying belief that the process is flawed:

> "It is not right! I find it very frustrating! Killian is given excuses all the time as to why his goals cannot be reached. So don't be fooled by that PCP, it is an act, a paper exercise, all for show".
>
> Interview with key worker

She states that 'I find the PCP process is doing Killian an injustice'. She concedes however, that PCP puts an onus on the staff to make sure that the goals, however basic, do happen. She goes on to say that 'from my experience, I am here seven years and the PCP is the only chance they get to get out'. She further states that the PCP is good in that 'you get to build up a profile of the person, so you do get a lot of information. You get to spend more time with the person'. She believes that the PCP process falls short of enhancing friendships and social networks. 'Killian has no friends other than other service users'. On a positive note she believes that the PCP does enhance the person's use of accessing local amenities, 'people are now starting to recognise Killian and will say hello to him on the street'.

The key worker stated that families can frequently feel under obligation to service providers. Paid staff come on duty for six to twelve hours per day and can attend to Killian's personal needs during their shift time. When Killian is at home he is there for twenty four hours a day over the weekend and his family are not always in a position to give him their undivided attention. In this case the family is very grateful to the service but at times they feel that they cannot compete with the community residence in a material way. This compounds the situation where it leaves them less likely to criticize or try to extend the breadth of the PCP.

The key worker calls for specific policies on the regulating and auditing of PCP's. She goes on to make the point that 'there is a huge potential for advocacy. No paid employees but someone looking out for the person'. She believes that this is the role of the key worker but regrets that 'it should be but it is not working. You are shut down at every turn and you are told who the boss is'. Further to this she is clear that 'you have got to respect people for who they are'.

The key worker denies the possibility of the PCP promoting a full and active life for the person with intellectual disability. 'No way, absolutely no way. If people believe that is what it does they are seriously blinkered'. The interview process may have had the benefit of giving interviewees the opportunity to communicate on themes which have been a source of stress and concern for them. The key worker added that she was grateful for the opportunity to express her tensions and difficulties and ultimately was glad of the opportunity by adding 'it was nice to off load my opinion. I am frustrated with the process'.

Killian's most recent PCP meeting was opened by a member of staff from Killian's day service. He welcomed everyone to the meeting which included Killian, Killian's mother, the manager of his residential house, his key worker and the manager of his day service. The support worker from the day service presented a PowerPoint slide show to the meeting in picture format to assist Killian's recognition and participation in activities related to his goals in 2009. This slide show depicted a number of pictures of Killian engaging in various activities which were all carried out in the context of special services.

The PowerPoint presentation from his day service concluded with a slide show listing Killian's goals for 2010/11. Interestingly these were agreed prior to the meeting and separate from the other

stakeholders. It was noted that having pre agreed goals displayed in such a technical way did not generate any creative ideas in assisting Killian in his own personal goals. This thwarted true participation and minimised the potential contributions that may have come from the other attendees at the PCP meeting.

There are many benefits to Killian being the subject of a vivid PowerPoint slide show depicting him in many enjoyable pastimes. This may help him reflect on the year that has gone by and to recall his personal highlights. The reality is that while this may be a very pleasant way of reviewing his many activities it falls short of being representative of the objectives of true PCP.

The key worker from Killian's community residence presented Killian's PCP on his behalf reviewing his short term goals from 2009. She went on to say that all the goals were reached in 2009 with the exception of him starting music lessons. She spoke in the first person and she paraphrased Killian stating:

> "I was sorry to hear that due to staff shortages I could not do my music lessons but the manager of my house is looking into getting someone to come to the house to give me lessons".
>
> Key worker at PCP Meeting

From observations at the PCP meeting it became obvious to the researcher that there were tensions between the key worker and the house manager as well as tensions between the day service staff and residential service staff. This was evident in the comment about the music lessons which were apparently stopped by the manager but the manager was cited as the person who would eventually realise this goal for Killian.

The key worker then presented the meeting with Killian's short, medium and long term goals for 2010/2011 and these goals included items about activities, holidays and 'special' events. The key worker then asked Killian 'Are you happy with everything in your PCP or is there anything that you would like to change?' Killian nodded saying 'no, all is well'. At this point in the meeting, which had gone on for an hour and a half, Killian was clearly tired and confused. Staff did not have an operational definition of short term, medium term or long term goals and used these words interchangeably. The many interesting activities that they put forward on his behalf were put forward without any reference to time, day or date that they were likely to happen. This places Killian in a more vulnerable position given his intellectual disability.

The key worker acknowledged that a lot of the goals were pre agreed and presented to the meeting and went on to explain to all at the meeting that it is custom and practice in the house that the staff have a meeting with the residents every Monday, 'where they all sit down and plan what they want to do for the week. The custom and practice of having house meetings enables staff to pave the way for person centred practice in the every day life of the residents. It is about facilitating what the

person wants at the end of the day'. Towards the end of the meeting Killian was given the opportunity to express his gratitude declaring simply 'thank you all for coming to my PCP meeting'. He was given very little opportunity to talk at this meeting.

4.7.4 Comment and analysis

Killian who has a dual disability, has limited expressive verbal skills to self-advocate with any degree of authority. Consequently he is more at the mercy of support staff and family members to guide him towards setting goals in the PCP process. During his meeting, things were presented in pictorial format to assist him but he was only asked to affirm or negate what other people had put forward.

His family have a dilemma - on the one hand they don't want to be seen as critical of the service he is currently receiving which they regard as much better than the institutional service he received since he was ten years of age. They are mindful that many people with intellectual disability are still languishing in large hospital settings and at least their son and brother is in a small community residence. But on the other hand they do have hopes and dreams for Killian to have more self determination in his life.

The family do not have access to guidelines or published literature on how families can contribute to the PCP process. This family see their role as being available to attend an annual meeting to learn what Killian is actually doing during the day. They concentrate on what activities he has rather than seeing the PCP as a vehicle to potentially improve his life by them supporting Killian in realising far reaching goals.

Killian's key worker is very cynical, contrasting the text book approach to PCP with the reality of working in a community residence day to day. She views management as a barrier to true person centredness rather than a source of encouragement and support in the PCP process. She is discouraged by this and consequently has less enthusiasm for the process and has given up.

The divide between day services and residential services is one of a competitive nature rather than one that promotes a shared understanding of person centredness. In this case there are two key workers, which is unusual, one from his day service and one from his residential service but they are not mutually supportive of each others role. This means that there is fragmentation and duplication for Killian.

It was obvious that the staff relied on tangible material goals to be able to provide evidence of their achievements. While it is beneficial that he has an en-suite and a new television the reality is that those involved in the PCP process have missed the point that the PCP is essentially about creating a pathway to a positive future lifestyle for Killian. The hallmark of this pathway is not the tangible items but rather the features of Killian's lifestyle that will be noted in community participation, increased usage of community amenities versus special amenities, increased opportunities for Killian to make personal contributions to society and increased opportunities for Killian to engage in life long learning in the community versus in special settings.

It would seem that the trajectory that the staff are on in terms of PCP is one of increasing the variety of pleasant recreational events instead of walking in Killian's shoes and trying to create a vision that is **for and about him**. All Killian's goals were about engaging in various activities and pastimes. Despite the vision of the service to aspire to promoting full participation and inclusion for people with intellectual disability in the broader community; in reality the only events in Killian's life that are not in the context of special services are his weekends at home.

Eventually the financial restrictions, the difficulties of meeting Killian's goals when they are embedded in the context of meeting other service user's goals and the limit to the deliverable activity items that eventually comes about, all result in disappointment and frustration for everyone involved in his life. In fact, if the same efforts were directed towards assisting Killian in small incremental ways in reaching his personal life goals the process would intrinsically be more rewarding and appropriate to the person centred process which is about Killian.

The missed opportunity for Killian was that taking guitar lessons was something that he truly wanted to do in the community that would promote his participation and increase his skills and ultimately enhance his identity as a potential participant in musical events. This did not have an element of providing staff with a level of entertainment or enjoyment and was not in the context of special services. So in reality it was a true person centred goal and ironically the one goal that presented as being insurmountable.

Ideally the PCP should be about looking at a way of enhancing his citizenship, whether it is his contribution to society as an employee, a volunteer or someone with a socially valued role. Where Killian lives is vital to his family and social relationships. While he may require a great deal of support it is not unreasonable that Killian would eventually have his own home, most likely near his family, with his own key to his own front door. This would be in sharp contrast to his present residence in a house owned and staffed by service providers.

> "I don't have a key to the front door though; someone does have to open it. I get to the doorbell and I wouldn't know how to get in anyway (laugh)".
>
> Interview with Killian

This is self defeating and is not in Killian's best interest to perpetuate this. The challenge is how we inspire Killian to craft his own vision while at the same time bringing his staff and family members on board. It is not solely about training the staff that supports Killian or it is not solely about guidelines and policies but rather a value base that promotes respect for Killian seeing him as an equal, with the same rights as any other citizens, a fundamental premise of Killian's PCP.

Ryan

4.8 Ryan

4.8.1 Background and context

Ryan was born in the summer of the late 1950's in a large garrison town. His father is described as a loving and caring man by Ryan's mother. He worked all his adult life in the defence forces providing for his large family. Ryan's mother willingly described the details of her pregnancy with Ryan and the difficult birth. Ryan was born at home after a prolonged and difficult labour, three weeks overdue and weighed over thirteen pounds. She reported that he was breech presentation and deprived of oxygen resulting in brain damage at birth. She recalled the vital role the family practitioner had in both her and Ryan's survival.

> "Ryan was three weeks overdue you know. He was breech and he tore me to pieces. Only for the GP we wouldn't have survived".
>
> Interview with mother

Ryan's mother was intuitively aware of the importance of early childhood stimulation investing a lot of her time and energy in ensuring that Ryan was well cared for and stimulated in preparation for life in general. 'I knew he was delayed and I was determined to work night and day with him. I was going to get him to a level where he would be ready for life'. Ryan's older brother Brian was diagnosed at birth with severe cerebral palsy and was sent to a residential school for children with physical disability in Dublin some sixty miles from his home. Ryan's mother, keenly aware of the importance of a child being able to walk; talk and self care in order to be allowed enrol in the local school worked all the harder on Ryan to keep him in his home and locality.

> "Toilet training became a big issue and he had problems trying to dress himself. He stayed at home with me here until I thought he was ready for school. He started in the convent school when he was six".
>
> Interview with mother

Despite her efforts his local school still was ill-equipped to meet his needs. She recalled:

> "The toilets in the school were in the school yard. Because he used to wander off they wouldn't let him go to the toilet and then he would wet himself. The nun used to send for his sister and she had to clean up the mess. Then she told me to take him home and not to bring him back. I was dumbfounded that the nun could

> decide to send him home and not let him back. Those days the nuns ruled the schools, the children and the parents".

Interview with mother

She persisted in her efforts to keep Ryan at home and educated locally. 'Well I thought Ryan loads and I had loads of equipment here in the house to prepare him'. The family canvassed many professionals for support to continue with this arrangement. Doctors advised against this, referring him to residential special education out of his locality some sixty miles a way and at eight years of age he moved to this education facility. 'In my opinion the best Doctor in the world is a mother'. Ryan's parents reluctantly let him go off to residential services for people with intellectual disability. During his time in residential care he resided in large dormitory style accommodation with approximately sixty other boys with varying degrees of intellectual disability and challenging behaviour. Ryan was expected to comply with the institutional regime of the institution. While he attended special school on campus he did not achieve and academic attainments. His mother laments 'well he went to go to school with the religious brothers there. I was told it was in his best interest. He remained in this facility until he was eighteen years of age'.

At eighteen years of age Ryan was discharged from the care of the brothers and sent home to his family. At this stage Ryan's parents had twelve children, five of whom were still living at home. Albeit that Ryan had ten years of special education he failed to acquire any basic scholastic attainments. His expressive language did not develop beyond that of a three to four year old. Because of his intellectual disability Ryan did not develop an apprehension of hazards or risks in that he could not make appropriate judgements about road safety or show an understanding of social boundaries around property in that he would take items that appealed to him without due consideration to their owners. Apparently his needs for supervision were more than his family were able to give him. His mother lamented:

> "I couldn't take it any more. The Doctor came and took him to the admission ward of the mental hospital. They moved him into a locked ward. It was full of older people. I nearly had a nervous breakdown".

Interview with mother

Ryan was admitted to the local psychiatric hospital in 1977 at nineteen years of age. He was accompanied to this hospital by his father. While his father was aware of the difficulty of providing Ryan with direct care and meeting his needs he also had correspondence from his previous residential service outlining Ryan's needs for future life long care. Ryan's mother recalled:

> "Well he was in that awful place, in that ward in the mental hospital. You used to have to try and get into that place but the

door was always locked and there was no bell on the door. You would be waiting ages for someone with the keys to let you in. There was a lot of bullying going on in that place. So Ryan had an awful life there".

Interview with mother

It became evident that Ryan was misplaced in a long stay psychiatric ward with over thirty people with mental health challenges. While his basic needs for food, clothing and shelter were met, this inappropriate placement really set him up for failure because of the mismatch between his needs and the service objectives of this setting. These objectives included keeping the ward secure, keeping the residents safe and medicated and not to address the special needs of people with intellectual disability. At this crucial period in his life as a young adult he was not only deprived of the benefits of the social experience of community living but he was also deprived of any specialist intellectual disability services that were available such as occupational therapy, speech and language therapy and positive behaviour supports. Ryan spent the next twelve years living on this hospital ward of the adult mental health service and in 1989 when the hospital was de-designated from the psychiatric services he transferred to the new intellectual disability service on the same campus under the auspices of community services.

4.8.2 Current situation

Ryan spent a further fourteen years from 1989 to 2003 in another locked ward in the new intellectual disability service. The sad thing for Ryan was that this ward was specifically for people with intellectual disability with behaviours that challenge. This must have been a source of great stress to him personally. Ryan would have been subjected to the difficult behaviours displayed by his eighteen co residents. These included screaming, biting, kicking, damaging property and other impulsive and unpredictable behaviours. While this environment was stressful it did offer him some improvements such as his own small partitioned sleeping area within the male dormitory and further to this the nurse/resident staff ratio was high allowing for daily excursions from the ward to walks outside, drives and visits home. Along with this Ryan secured sheltered work in a special workshop for people with intellectual disability where he could develop his skills in woodwork and upholstery.

Despite the many difficult situations and environments that Ryan lived through, he has always retained a happy disposition, a sense of playfulness and a love of his family. He has acquired some health problems including diabetes which he needs support in managing. Further to this he has lost some teeth so his speech is muffled and sometimes hard to understand. He was placed on psychotropic medications as a means to managing his behaviours and has to endure the side effects of these medications including polydypsia. Ryan derives satisfaction from contributing in

the work place and affable social engagement found in the work place and he is well liked by the staff who support him.

In 2003, Ryan was selected to move to a new community house as part of the transfer programme. This bungalow is in an established housing estate within the perimeter of the town and near local amenities. It is within walking distance to his sheltered work placement. He has his own bedroom with his own personal effects including; clothes, a watch, a radio, a work shed and tools. He now has more regular family contact and his mother is very pleased with his current service.

> "With Gods help thankfully the Health Board found him a house. His life is good now. It is a hundred percent better than when he lived in the mental hospital. It is much cleaner in the house, he gets out more and he is much happier in the house. I would say it is a second home to him and I am happy to say that".

Interview with mother

Ryan himself is remarkably more contented and secure in his more favourable environment. His physical appearance has improved and he reports enjoying going out for a drink, doing the garden, participating in household chores, going on holidays to Cork and Kerry and visiting home. His life style is now person centred and he offers the following comment:

> "I like it here. I can go home to see mammy. Yeah, I go for my dinner to mammy. I can't do the garden at home, mammy does it. I do the garden here. I drank a pint out in the pub. I see my brother, Bob, he drives a car. I go on holidays yeah, to Cork and Kerry".

Interview with Ryan

Staff note that his days are very enriched and varied in that he now works in the sheltered workshop and attends various classes. He loves spending time in his work shed at the back of the house, playing football, watching TV, going for walks, social outings and looking at books. Staff report that he is actively involved in the community by attending football and hurling matches, attending social gatherings whenever possible such as meals out, visit to family and friends and attending Mass every Sunday. His mother attributes the success of his current residential placement to staff having a better understanding of Ryan and the smaller numbers that staff have to care for.

It in documented in Ryan's PCP that he is making choices for himself such as when he gets up in the morning, the clothes he wears, what he eats or whether he will spend time in the garden. The PCP alludes to his strengths and includes that he can make his bed, that he smiles a lot, that he is

good at digging the garden, that he likes sanding timber and he likes painting pictures. He goes on a least two holidays a year. Ryan's vision is to have more home visits, more social outings and more tools for his shed. The things he would like to happen would be to get lights into his shed, attend more art classes, to paint his shed, to get his own razor and to attend mass every Sunday.

Ryan's mother infers that as Ryan is now living in a community residence that he has a better life and that PCP has been instrumental in securing a better standard of living for her son. One of the benefits she sees with this is that she can actually visit him with ease.

> "The fact that he is out in a house is great. He does love it. The smaller numbers are better. I can actually get into the house when I call to see him now. Not like when he lived in the mental hospital. I am invited into the house and it is lovely".
>
> Interview with mother

4.8.3 PCP process

In spite of Ryan's low moderate/severe intellectual disability it is good practice in PCP to support the person in attending their own PCP meeting to ensure that all attendees are aware of support needs and realistic in terms of goal setting. As Ryan's ability to answer direct questions is restricted and he is not always reliable in his answers that he gives makes it difficult in an interview situation to harvest any more specific information about his PCP. He doesn't really know what a PCP is. He may be able to state the names of the people who come to his meeting and other concrete details for example where the meeting is held but he would not be able to respond to more abstract questions about goal setting nor would he have a knowledge of things such as the role of the key worker and where his PCP is kept. When asked if he had a key to his front door he replied 'I don't know'. He was able to say that 'I drank a pint'. When asked where he drank the pint he stated 'I don't know'. When asked who comes to his PCP meeting he said the names of a staff member and his sister. When asked about what he talked about at his PCP meeting he stated 'Ellen is my sister'. When asked if you talk about things you like to do Ryan said 'Yes'. When asked what they were Ryan said 'I don't know'.

While Ryan's mother enjoyed talking about topics relating to him and to her role as his mother she was more reserved when asked about specific questions about the PCP process. Further to this she is perceived by the staff caring for Ryan as somebody who is self absorbed, self-indulgent and who can be critical of the services and needs to be managed accordingly. She is known to be tangential in her discussions absorbing staff time. When asked specifically about her understanding of PCP, she replied 'I don't know enough about it but I would want to be part of it'. When asked if she attended Ryan's PCP in the past she added 'not that I remember but I know how he is doing. I just don't know what he is doing. I just don't know enough about it'.

When asked do you think that the PCP acts as a mechanism for people with intellectual disability to realise their goals Ryan's mother simply replied 'I don't understand the question'. When asked if she thought the PCP process is the best way for staff to get to know Ryan she concedes 'I suppose it would be'. She goes on to say that 'it would be important for someone from his family to be at the PCP meeting with Ryan'. Ryan's mother infers that the PCP process aids community participation stating; 'well if PCP is about getting the person out there doing more then I agree it does'. Further to this she sees the PCP process as promoting the use of natural resources in the community such as shops, banks and cinema. While Ryan's mother admits that she is uninitiated with the finer aspects of PC she does respond to the question on whether or not PCP ensures a full and active life for Ryan by stating:

> "Yes I believe it does. If PCP is happening for Ryan then I would agree because he is a lot happier with his life and he is doing well in this house. He has his own room. He gets on well with all the

people living and working here. Yes I think it would promote choice".

Interview with mother

In this case the key worker was ill at ease and not agreeable to digital recording. On probing it became evident that this was because of her anxiety of her being unable to answer the questions in a way that would reflect negatively on her professional practice. This was because she believed that there was a right and a wrong way to respond perceiving the interview process as like an examination on her competence relating to this field. The interesting fact is that she has known Ryan for over twenty years and is his key worker for six years and yet she stated that she did not feel confident enough to be digitally recorded. She further commented that she felt insecure of her knowledge of PCP and displayed an anxiety about being 'caught out'. She regards the PCP process as:

"I think it is a great way of communicating with all members of staff. It gives you a great way to record the progress for the person. I find it good, no very good".

Interview with key worker

She describes the PCP as 'the life story of the person'. The key worker sees her role as being about 'acting in Ryan's best interest'. When asked whether there were more opportunities for optimal individual service design for Ryan her reply was reserved but she concede 'who knows what he is really capable off? There is learning in this for all of us". It appears that she is satisfied that Ryan has gone as far as he can go in terms of his independence. While acknowledging that there is learning in it for her she does not take this to the next step of a more optimal person centred service. When asked if she saw the PCP as a mechanism for Ryan to realise his goals she states blankly; 'yes I do. I would strongly agree that it does, it is a good way'. The key worker does not perceive the current PCP process as tedious and unfulfilling but added 'it is a about writing all the information about Ryan in the white folder'.

She reflects that the PCP process is a good way to get to know the focus person well. On the other hand she does not regard the PCP process of a singular way of reaching personal outcomes. The key worker values the role of family participation in PCP meetings as fundamental in maintaining relationships. This is particularly true for Ryan. The fact that he has his family and that they mean so much to him is important to the PCP process. The way she looks at community participation is from the perspective of the benefits to the broader community and their knowledge of people who are 'differently abled', 'people with intellectual disability really exist and have a contribution to make in this world'. She believes that the PCP process promotes the development of family, friendships and social networks and 'families appear to get more involved with the person afterwards'. The key worker gave an account of Ryan's increased presence in the community and

was confident that he was now making more choices in activities of daily living and relating to his person care 'he now chooses the food he eats and the clothes he wears'.

The interview concluded by the key worker remarking that she was pleased with the way the interview went and that she answered the questions to the best of her ability.

Ryan's most recent PCP meeting was held in his community residence. This meeting was also attended by Ryan, his mother, his key worker, a care staff from his house and a nurse in charge of his day service. Again there was a reluctance to have the PCP meeting digitally recorded so a hand written transcript was taken. The key worker opened the meeting by reporting on Ryan's activity level and that he has a very busy schedule. Staff commented 'sure he is great with his hands'. His key worker went on to say that he has a very busy day programme. 'Well he does art, drama and music and dance therapy as part of his day programme'. The key worker comments on the efforts made to personalise Ryan's living environment in a way that match his interests. The key worker reported on the efforts that have been made to enhance Ryan's basic social skills. 'We promote independent living skills here in the house. We are teaching him to use the washing machine, to go shopping, to make his own tea and to tidy the house'.

The key worker went on to review Ryan's 'action plan' for the previous years PCP under standard headings and in a matter of fact manner the key worker concluded that this goals were reached and that person centeredness for Ryan had been achieved. However, the six goals enumerated were characterised by their simplicity and include items such as 'family contact to continue, maintaining a healthy diet, going for daily walks, getting a new CD player'. It became obvious that the previous years PCP had been minimised to a 'to do' list of items and that had to be seen to be done. When Ryan had stated that he wanted a CD player, the staff reported 'we managed to get him this'. For Ryan this was a missed opportunity to budget for the desired appliance, to shop for it, select it and to purchase it himself. The key worker concluded:

> "So all in all he is doing plenty and is well activated. He has his own bedroom here which is good for his own piece of mind. So that's his PCP for last year and as we can see it really went very well. Has anyone anything to add before we move on to the action plan for the coming year?"
>
> Key worker at PCP meeting

His mother attempts to interject at this point but the manager cuts her off and states:

> "Ryan is doing very well in this house. We talked to him last night about what he would like for the next year because he doesn't like

talking in crowds. So he told us last night what he wanted. Isn't that right Ryan?"

CNM at PCP Meeting

The key worker railroaded ahead with five pre-agreed items for the coming year. The various activities listed such as going to the cinema to increase Ryan's community presence, purchasing his own clothing in local men's stores and shopping for healthy food for people like him who have diabetes were all linked to one-to-one staffing in order for them to happen.

As one of the objectives was to increase family contact his mother spoke of some of the other family members who currently reside in other parts of Ireland. When his key worker asked 'is there anything else you would like Ryan?' Ryan replied by naming some of his siblings. When he was asked 'you are going shopping next week Ryan, what are you going to buy?' He replied 'don't know'. He later asked 'is Santa Claus coming?' and went on to talk about a Christmas play 'we are starting a play'. Cleary Ryan made very valiant efforts given his low level of expressive language to contribute to his PCP meeting and to generate conversation that was of interest to him such as talking about his family, talking about his activities and taking about his love of the Christmas period. There was no cultivation of this and must have been frustrating and disappointing for him - an antithesis of person centredness.

The key worker hastily brought the PCP meeting to a conclusion in a manner that staff later admitted was a pre agreed strategy to ensure that Ryan's mother spent the least amount of time in the house.

"Ok then, so that is the end of the PCP meeting. Thank you all for coming. Thank you Ryan's mother. Betty will drop you home now. She is ready to go isn't that right Betty".

Key worker at PCP meeting

After the PCP meeting when Ryan's mother had been dispatched the key worker explained:

"To me you can't let Mrs X say too much at the meeting. She will take over the whole thing. The PCP meeting then becomes all about her and not about Ryan. That's why we went through everything so quickly".

Key worker at PCP meeting

4.8.4 Comment and analysis

Ryan is a 53 year old man with a moderate intellectual disability with restricted expressive language and health problems. Ten years of his childhood were spent in special residential schools and left with few if any measurable educational achievements. He went on to spend a further 26 years in psychiatric hospitals and de-designated units. Yet he is still a contented and reasonably well adjusted gentleman who clearly deserves dignity and respect.

His life has improved dramatically in the last seven to eight years in that he now has a place in a HSE community house, however, he still does not have a key to his own front door. His mother is seen as an annoyance by staff to be managed rather than a person who should be supported in making an ongoing and valuable irreplaceable contribution in Ryan's life.

The staff employed to support Ryan go through the PCP process in a dutiful manner but miss many opportunities to make the process more about the person for whom it is designed. They include many items that should be in his care plan and not in his PCP. They fail to use any visual aids to make the meetings and process more meaningful to Ryan.

Ryan's PCP meeting was used as a vehicle by staff to justify increased staff ratios. This was requested in order for the staff to carry out activities with Ryan, who has high dependency needs. This approach at a PCP meeting is regrettable because it became about staff issues and not true person centredness. Some of the staff suggested goals that should have been taken as a matter of course in his care plan and in his day-to-day activities.

They attempt to inflate the merits of the every day activities that he does by referring to them as therapies. People who know Ryan know that he always enjoyed gardening and painting. These activities are now described as 'art and horticulture therapy' and they endeavour to make 'specialisations' out of Ryan's every day hobbies.

While his current situation is a dramatic improvement on the residential care he received for forty five years of his life it still falls short on current thinking on individual service design and visionary person centredness. This case study suggests that Ryan's life is not destined to change, develop or improve but rather to stay at this current plateau where the staff have taken a covert satisfaction in the fact that they have enabled him to reach what they regard as his full potential.

Margy

4.9 Margy

4.9.1 Background and context

Margy was born in the mid 1960's in a large Maternity Hospital. She lived with her parents in a small seaside town with her three older male siblings. At some point in her early childhood her parents left her three older brothers in the care of her paternal grandmother. At this time Margy was taken into foster care. She believes this was because she 'wet the bed'. Later, when her parents decided to move to England they removed Margy from the foster home. Margy accompanied her parents to England and was enrolled in a special school. Around this time her parents had their fifth child, a younger brother to Margy.

Margy's early childhood was chaotic and unstable as both her birth parents drank alcohol very heavily and frequently moved from one rented house to another. When Margy was a teenager and still living in England her parent's separated and her mother developed a new relationship with a man from the Midlands of Ireland. This man had a reputation for being a heavy drinker, aggressive and possibly violent to women. Her father returned to the seaside town with Margy's younger brother leaving him in the care of his grandmother where his older three brothers had been left prior to Margy moving to the UK with her mother and father. Margy's father emigrated to America where he started a new life. Margy's mother and her new partner along with Margy returned to his family home in Ireland. They resided in a small rural cottage that had not been modernised and lacked amenities.

Margy availed of day services for adults with intellectual disability in the area. There was an expectation that attendees would be able and capable of productive participation in sheltered work activities such as working in food preparation in the canteen. Along with this there was the expectation that people would be attentive to their personal hygiene and present in clean attire each day. For Margy this was a challenge as she did not have the wherewithal to maintain the standard of personal hygiene required or to even launder her clothing to a satisfactory standard. A white mini bus collected her and dropped her off every day but she was frequently locked out of home and left outdoors while she awaited the return of her mother and her mother's partner from the local public house each evening. Margy reflects that she spent many hours playing with the pet dog in the front garden, 'cold and hungry'.

When Margy was twenty years of age her life took an unplanned turn. A combination of factors including the death of her mother, the substandard conditions that she was living in and the recognition that she had a life long intellectual disability resulted in the manager of her day service seeking help from the local psychiatric hospital. She was admitted to the female admissions ward. Given Margy's history of association with intellectual disability services, she was transferred from the female admissions unit after a brief period to the de-designated unit on campus.

When Margy moved to the de-designated area, it emerged that the name that staff used for her and that was on her admissions record and file was incorrect. It became clear that her mother enrolled her in services under the name of her mother's partner's surname which was unusual as they were not married. For Margy this must have been confusing. Margy argued for the use of her original surname as she saw it. At this juncture she was assessed as functioning in the mild range of intellectual disability, with a reading age of 10.5 years with good functional skills in literacy and numeracy which were relatively high in comparison to her co-residents in the congregate setting.

Margy was confined to a locked ward with sixteen people with challenging behaviour. In keeping with the ethos and understanding of the time it was broadly accepted that the role of such facilities was one of protection from potential harm, not only of the residents but for the broader society. Margy continued to reside in this inappropriate setting for seventeen years. 'I was shifted to every ward, St A's and St B's'. She recalls that really her saving grace while residing there was the relationship that she had with one nurse who she describes as 'loving her'. When asked about the relationships she had with her peers she described them as 'bullies'.

At different times during her incarceration, Margy reported three accounts of sexual encounters with staff. In attempts to establish the veracity of these claims the named staff members were interviewed at the time and one named staff member readily admitted to 'fondling her' stating that he perceived Margy as 'willingly and consenting' (file entry 1995). In the absence of specific guidelines of abuse of adults with intellectual disability it was custom and practice to use the health board's guidelines on sexual abuse of children for adults with intellectual disability. This initiated a preliminary screening. A decision was taken by the authorities that no legal action would be taken. This led to Margy being more closely supervised at all times and given the label of being 'promiscuous' and the assumption that society needed to be protected from her. In Margy's account she was not promiscuous but rather she bartered and offered sexual favours in exchange for cigarettes.

During this time there were efforts to personalise her lifestyle. Staff recognised the many attributes of her understanding and as such they tried to bring her out for social events in the community. They included her in individual activities such as bringing her out to lunch, a privilege specific to her. Many staff registered concern because of the restrictions placed on Margy residing in a locked ward and while they did their best to give her things to look forward to. The situation continued over seventeen years until such a time that Margy had the opportunity to move to a community residence in 2003 as part of the transfer programme when she was thirty seven years old.

4.9.2 Current situation

Margy is now forty six years of age and currently resides in a five bedroom bungalow in a midlands town. The house is within walking distance to local entertainment amenities and shops. She shares this house with four other people with varying degrees of intellectual disability. Margy has

her own bedroom and personal belongings such as television, clothes, bank account and a mobile phone. Margy enjoys the fact that she can go outside to a gazebo to have a cigarette. 'I do like it, because I am happy there, but it is a place where there are a load of clients. I do have a lovely bedroom, I love it'. When asked about whether she had a key to her front door she replied, 'I used to have a key one time to let myself in but now I don't. There is always someone there to let me in'.

Although Margy likes living in her community house she still yearns to return to her county of origin. In her mind, the Midlands town where she currently resides is irrevocably linked to the town venue where she spent seventeen years hospitalised in a locked ward. The legacy of her institutionalisation is that she is distrustful of others and frequently very saddened and dispirited about life in general.

Due to a physical decline in her health, Margy appears much older looking than her chronological age. In recent times, she has developed a severe kyphosis finding it difficult to deport herself. She attends the adult mental health service and is on a cocktail of polypharmacy. Her smoking behaviour has left her vulnerable to frequent throat and chest infections requiring antibiotic treatments. However, she still has a healthy appetite and likes the odd beer.

In terms of her social contact Margy prefers the company of staff and continues to have a longing for social contact with her cousin and brother. Margy has had correspondence from her half sister in America whom she recently met for the first time. Margy does not perceive herself as a co-resident with intellectual disability requiring care but rather as a co-worker requiring a social life. From a review of her PCP Margy has stated that she would like to continue to go to the cinema and shopping and to visit her mother's grave. Margy reported that she likes having her own bedroom and loves chatting to staff at night when the other residents have all gone to bed. All these comments lead to an understanding of Margy as a person who does not perceive herself as having the same needs as the other service users. Margy states that she 'does not like people making fun of me'. She perceives the people that she lives with as old and states that 'I do not like living with old people or living in this town'. She also comments 'I do not like myself'.

In terms of promoting Margy choices her PCP documents that she chooses what she wants to wear and what to eat and drink. She chooses when to go to bed and the places that she likes such as visiting her mother's grave and visiting her cousin and brother. She also chooses the programmes she watches on television. She says that she did not make the choice with whom she lives with or the location of her residence. She does not make her own medical appointments or any appointments for that matter. The staff decide when she can visit her family and for how long. The staff remark that she is smart, good at house work and has a good memory. Staff say that Margy has 'lots of opportunities at present'. She likes to read and has bought books that she likes with pictures and 'big writing'. She now has her own money which is very important to her.

Staffs perception of Margy's life achievements include moving to a 'nice community house'. She attends a day programme and likes that there are young people at the day programme. It is

documented on file that she goes out for meals, drives and drinks now that she has moved from the institution. Staff state that she goes 'home every eight weeks or so with one of the staff to visit her brother and her granny'. Staff report that her family contact has 'really improved' with her meeting her niece for the first time. She had not previously been aware of her existence. She also met with her aunt and uncle. They were reported as being 'delighted to see her', showing her photographs of their children, and explained their plans for Margy's introduction to them. Staff believe that Margy's family contact is increasing and report that she is 'really happy about that'. Margy continues to report 'I feel lonely at times'.

Margy's PCP lists that she has positive qualities and staff say 'she has nice hair, is good looking with a lovely smile and a good sense of humour'. Margy adds that she would really like 'to see my family more often' and would really like to 'have a group of friend's similar to my own age that I could go out with'. She states that she would also 'really love to live with people her own age'. Margy continues to yearn for her native county at every opportunity and longs for the day that she can live on her own. 'I can walk down the street on my own to visit my brother and my granny'. She further states that she would like to travel to America to visit her half sister. She has indicated that she 'would like to meet a good man and get married, stop fighting with people and to work in the tobacco factory'. The things that Margy states that she must have are 'cigarettes, my own money, and my own clothes with pockets so I can carry my belongings'.

4.9.3 PCP process

Margy's understanding of the PCP process is clearly more about the care planning aspect without a deep understanding of the person centred approach. When asked if she knew what a PCP was she responded by saying 'it's a plan'. Margy, who has a mild intellectual disability stated that she did not want to talk about the actual plan but had a desire to use the interview to talk about herself. She reflected 'I wish I was left alone and I just want to be loved. Well it is all about me and it is not fair because people are around me all of the time. It is my life, you know that". This illustrates her feelings of exasperation and frustration. She states that on the one hand she is happy with the venue of her services 'I like it here in the day service, I love the day service. I like my house also', on the other hand, she has a low threshold for tolerance of other service user referring to them as 'bullies' and 'always in me face'. She comments, 'I can't bare the bold clients in there and they are all too old in the house'.

Margy's knowledge of the role of the key worker is clear in that she knows who her key worker is and she sees her key worker as 'she makes sure you are alright, she looks after me'. However, in this case her key worker is due to go on leave and this has led to Margy again feeling abandoned and confused. When asked who would be taking over the role of her key worker Margy replied angrily 'why do you have to ask all those bloody questions? Your like the rest of them, talking sh*t'. It became evident during the course of the interview with Margy that when she did not have the knowledge to answer a question she responded in a hostile manner.

Margy knew where her PCP was kept stating that it was 'in the filing cabinet, with all the care plans'. Here she uses PCP and care plans co-terminously and made no distinction between them and sees them as having the same function. The interesting thing is that when she spoke of the people who would be attending her meeting she described all the paid employees as:

> "All me friends go to it. I do have a meeting and they do all come to it. I don't mind going to the meeting when all me friends are there".
>
> Interview with Margy

In terms of content, the PCP meeting is an opportunity for Margy to talk about how she perceives her life. She has taken on the rhetoric of PCP and in spite of her tendency to move and side track from the topic she offers the following comment:

> "We talk about my life and that is all it is about, right? It is about how happy I am. I just want to be happy; I just want to be loved. Do you understand? I just want to be loved? It is my life and I am

quite happy and it is not fair to me now. I am the boss, you know that".

Interview with Margy

Margy's younger brother was interviewed in his home. This man has never shared his home or life with Margy at any time yet he is documented as her next of kin. When asked about his involvement with his sister through PCP he said:

"I haven't a clue, it is not up to me to say, the nurses are doing their best for her. I really don't know anything about her. I can't handle her. She switches on and off. She does me head in when she comes to visit".

Interview with brother

Margy's brother perceives any contact with service providers as implying a subtle undertone that suggests he likes a more direct role in her care. He believes that he has devoted a good portion of his life caring for his elderly grandmother and is disinclined to get involved in his sister's life primarily because she has obvious care needs.

"She thinks this is her home but I have done my f**king time looking after people. I was fifteen f**king years looking after me granny in this house. I can't f**king take on another one. They bring her here, they usually ring beforehand. They drop her off and they go for a couple of hours".

Interview with brother

When asked about her PCP he replied blankly. 'What are you talking about, never heard of it'.

When asked about Margy's current living accommodation in a community residence he did concede:

"Well she does appear a lot happier in the house but I know that she is still not happy there. She wants to live here with me and I find the pressure too much. She can't communicate right".

Interview with brother

By contrast when he remarked that when she was living in the large congregate setting he said 'that hospital was f**king horrific. It was a hell hole. I hated going there'. He perceives his any

involvement with PCP as leading to him having to spend more unwelcome time with her. He is happy enough for her to visit him every six months as an agreed goal of her PCP meeting stating 'I am her brother'. He is disinclined however, to have any additional involvement and did not accept invitations to her PCP meetings.

> "When she comes here she says 'I will come to live with you here, at home', this is not her f**king home. She was brought up with the mother in different places".

Interview with brother

Margy's brother became upset at this point of the interview and he broke down and cried. He did however wish to continue and he concluded the interview stating:

> "Well what do you want me to say? I have given up my life to look after me granny. I can't handle it again. I do not want to get involved. Jesus we are a f**king disaster of a family, a f**king disaster".

Interview with brother

While this gentleman is her brother and officially her next of kin he has never lived with Margy as they were raised apart. He has made it explicit that life has been difficult for him and is not interested or capable of extending himself to include Margy in furthering their relationship. He has also stated that he is not interested in attending her PCP meetings.

The key worker stated that she knew Margy for three years and was key worker for her throughout this time. She described PCP as:

> "Basically it is a plan that lets the clients kinda decide what they want to do with their life. It has all their information in it that you need to know about them and whatever goals they want to achieve, their care plans, their history. So it is a plan around them. It is their care plan and it is based around them".

Interview with key worker

The key worker commented on the PCP process in a positive light stating:

> "Yeah I think it is good like, once you keep the focus as to what is in it and that you don't get side tracked with unrealistic goals and

that you know that it is what they are capable of what they are achieving. Then it works".

Interview with key worker

It was clear that the key worker sees it as her role to craft goals that are within the staff and Margy's capacity to reach. From the onset she was attempting to influence the type of goals that were for discussion at the PCP meeting by attempting to restrict the discussion to the activities that were on offer in special services and that she could reach on. She sees the meeting as having the checks and balances 'It is a good guideline and you can keep an eye on what is said and what is being done'. The key worker perceives her role as one of safeguarding Margy's interests. The key worker is keen to justify restricted goal setting and realisation for Margy with limited financial resources, as well as staffing issues.

"I don't think that it is always possible. In an ideal world maybe, but you have so many things restricting, like finances and whether the service would be suitable".

Interview with key worker

The key worker sees her role as filtering Margy's aspirations and when Margy generates ideas that may challenge she counter argues with Margy.

"I think sometimes that just because someone wants something it may not always be the best for them and it may not work out for them".

Interview with key worker

She agreed that in the PCP process some of the responsibility for goal setting lies with the individual. She concludes that 'it is not just a team of people deciding on what Margy should do. It is her meeting and she is well able to vocalise what she wants'. Because Margy can actually articulate and consent to suggested goals she perceives that the PCP process as beneficial 'Margy is able to say what she wants and a lot can't'. She says 'One would wonder if it is just what the staff think and not what the person wants'. The key worker believed that in this case that she has an in-depth knowledge of Margy because of the PCP process. She stated that 'it gives you everything you need to know about the person". The key worker holds the view that personal goals can be reached with or without a PCP but are dependant on staff motivation to ensure the outcome for the person.

The key worker perceives family involvement as not fundamental to the PCP process. 'I think it is nice to have family at meetings but it is about the individual. You can still have family contact without having them at meetings you know'.

The key worker links Margy's level of community participation and choice with well crafted goals.

> "Every thing you do to help people achieve their goals should be in the community. In using the community you integrate them into the community. This is what the PCP is supposed to do. It gives the person an opportunity to say what it is they want out of their life and sometimes to help them to achieve it".

Interview with key worker

At least in theory the key worker has a positive understanding of the potential of the PCP process as one of well crafted goal setting and having the power to improve the person's quality of life.

Those attending Margy's most recent PCP meeting included Margy, three staff from her community house and two staff from her day service. At the onset I was asked by the key worker what were my expectations of the meeting. I took the opportunity of stating 'that I was here to observe the meeting'. I gave the advice that they should carry on as if I were not there. The key worker opened the meeting and proceeded to review the goals set at the meeting in the previous year. This is uncharacteristic of most PCP's where at the beginning of meetings there is usually a reflection on the person's life trajectory and milestones. The first reference to a goal was made with regard to promoting independence for Margy. This was equated to her using a taxi to attend her day service. This was regarded as an achievement because it happens on a regular basis and she was seen as a measure of her independence.

The meeting quickly moved on to her second goal which was around enhancing relationships. In order to reach this goal it was decided to increase her Share-a-Break visits. Margy states 'I love going to Share-a-Break, don't I'. The staff at the PCP meeting minimise the importance of relationship building. By distilling relationships down to increased Share-a-Break visits that they actually insinuate that the goal had been achieved. They moved swiftly along with the process. Some discussion followed about a formal friendship group that Margy was supposed to join in one of the hotels in town. However, there was some confusion around times and venue and this never came to fruition. A good proportion of the time of the meeting was devoted to this fruitless discussion.

Another goal was to increase her day programme and this was again seen as achieved as she now attends 'on a Friday afternoon because she has nothing on Friday's. She now goes Monday, Tuesday, Thursday and Friday afternoons'. The key worker described her fourth goal and the only goal that was not embedded in special service systems. This was her weekly attendance at

Weight Watchers. This goal was discontinued because the staff perceived the weekly fee for attendance at the meeting, weigh in, socialising with other people, refreshments, one to one interaction and talks on healthy lifestyle as too expensive for Margy. The group discussed among themselves other options for Margy such as weighing her in a pharmacy in town at a much lower cost. Margy did not follow the logic of this suggestion. She was asked for her approval. It was explained to her by her key worker that she could continue paying for Weight Watchers but that 'other things would have to go if you want to continue, cigarettes maybe'? Margy who was clearly upset, conceded to the request and was disempowered. The key worker then hastily attempted to summarise the goals. She struggled to itemise the list of goals that Margy had achieved over the past year.

> "Yeah, so mmm, well her summary is all about what I am after saying. Yvonne and her Share-a-Break and with Claire. She went on her friendship evening just at Christmas. She went to all her parties and everything else. That's kinda it, there is nothing major".
>
> Key worker at PCP meeting

The key worker after this rudimentary summary requested the other staff at the meeting to offer any goal suggestions for the coming year. A request was put forward by a staff in her day service for her to continue with the equestrian assisted learning that she had sampled over two sessions. This was something that she regarded as both therapeutic and beneficial for behavioural issues with Margy in mind.

> "Well Margy has done two sessions with me in the equestrian assisted learning. It is actually very good for issues around behaviours and we just decided how it would go. As I said there was two sessions and Margy herself can tell you how she got on with Elvis the donkey"?
>
> Day service staff at PCP meeting

The staff member displayed ten photographs of Margy with Elvis the donkey stating:

> "There was a lovely connection with Margy and Elvis. It was lovely and quiet there was no one else there. It was Margy's time with Elvis and she loved it. She loves that one to one time and it is quiet and peaceful".
>
> Day service staff at PCP meeting

Discussion took place on the funding of this service which staff reframed as 'therapy' and as such should be funded from management's budget. The key worker took on the task of referring this goal to her line manager for approval.

> "Actually it is good therapy for her and we discussed it with the line manager given the state of her finances. The line manager discussed it with senior management and it was agreed that payment for this service would come from a central fund".

Key worker at PCP meeting

Discussion on her financial situation took place in a matter of fact style without reflecting on how this may have made Margy feel. 'The biggest issue is the money, it is slowly going and she won't have anything left by Christmas'. She quite flippantly turned to Margy and asked her if she had anything she would like to include as a PCP goal after reminding her that she had no financial resources to back up any additional requests. The key worker replied to her own question stating 'Yeah we need to arrange to go and see your brother again, don't we'? She went on to say 'so we will kinda still try to maintain that family contact'. To which other staff commented 'well with you back on day duty it may now happen'. Without giving Margy an opportunity to comment the key worker posed questions to day the service staff who recapped on her programme of excursions such as going to the cinema on Friday afternoons.

The key worker directed a comment to Margy 'you are very busy anyway, but is there anything that you want to do that you are not already doing'? Margy replied 'well I am not that fussy anyway'. A staff member then volunteered to bring Margy to an aerobics class through music on Wednesday and Friday evenings. To which Margy replied 'I would like to do it'. The key worker registered her concern around her physical well being and in particular concern around her Kyphosis. The nurse reported that she had brought her to a medial consultation to a Dublin hospital where consideration was given to surgery. There was confusion as to what the follow-up to this consultation was, if any. There was agreement that further follow up with the local GP would be pursued by the nurse. In actual fact these items should be considered in the context of best practice when reviewing her medical care plan and should not be the subject for consideration at an annual PCP meeting. Further to this Margy had been referred for Physiotherapy but it was clear that she had missed several appointments. On further discussion it became clear that the staff were confused around her appointment regime and the professionals involved.

Rather abruptly the meeting concluded when the key worker asked Margy 'well is there anything else you want to say? To which Margy replied 'well I am young, I am happy and what more can I say'.

4.9.4 Comment and analysis

Margy has restricted understanding as she functions within the range of mild intellectual disability. She had a very difficult developmental period during which time she moved frequently and was separated from her siblings. It is a tribute to her that after all she has endured that she has retained some resilience and interest in her family. Margy's life was punctuated by dramatic barriers to opportunities for a life she longed for. While many twenty year olds would be out and about, meeting people, engaging in recreational activities and clubs Margy was confined to a locked ward. Therein she had restricted opportunities to meet people and form adult relationships.

She has had no opportunity to work or to access life long learning. She has mental health challenges that include intermittent delusional thoughts. 'I am the boss'. She has a tendency to perceive other service users as 'bullies'. There is also a mixed message that comes from the content of her statements typical of Margy such as 'I wish I was left alone' and 'I just want to be loved'. This all had the net effect for her of not developing positive relationships. Margy has an unmet need for unconditioned love and acceptance. Margy's rhetoric of love from her mother which she uses in attempt to have these needs met are noted in her frequent statements 'all I want is for someone to love me'.

On meeting her most people regard her as cantankerous and irritable. It is like that she is trying to distance people because she has been disappointed by so many people coming and going over her forty six years. Her emotional life could be compared to a busy train station with people constantly moving in and out over which she has no control. No one has ever spoken to her about her own disability and as such she has a very limited understanding of other service users who she regards as 'bullies' with whom she competes for staff attention. Staff placate her telling her that 'yes I do love you' and 'yes you are staff' which further confuses an already chaotic situation.

Margy craves acceptance and has a longing to be part of what she perceives as a normal life 'I would love to meet a really good man and get married'. Margy does not perceive herself as having an intellectual disability despite cognitive restrictions and she lacks insight into her mental health challenges. There is a repetitive loop in her thinking and her manner 'I just want to be left alone, I am the boss and you're doing me head in'. This has the effect of further distancing people from her and prevent the development of peer relationships.

There is an assumption that family members have the capacity and willingness to participate and contribute to the PCP process. This often taken for granted and when you consider the plight of Margy's brother. Such an assumption is definitely questionable because of his life circumstances and personal issues. He is both unwilling and incapable at this point of making a meaningful contribution to the PCP process for Margy. He believes that the professionals are in a better position than he could ever be and does not want to be forthcoming in declaring any interest in her future life as he was not involved in her past life. The sad reality is that Margy sees his home as her grandmother's residence and as such her home as well. She pleads with her brother during

her visits 'I want to live here with you'. This completely overwhelms him and puts him in a position where he has to distance himself from her even more.

The staff compiling her PCP have the zeal for identifying achievable goals and making sure that things are happening for Margy. However, these goals are limited to very superficial items that should be happening anyway and staff did not really capitalise on the potential of the PCP process to be life altering and instrumental in enhancing Margy's quality of life. Further to this there is a very distancing and patronising attitude taken which is ultimately demeaning for Margy. There was a lack of preparation and planning for this meeting as evidenced by the lack of notes, posters, visual aids and uncertainty of staff around the day-to-day personal issues for Margy. It seemed to be possible to get funding for her to avail of time with the therapeutic aspect of spending time with a donkey but out of her reach to spend time and her money in the one activity that was in the community. The patronising tone was also evident in the analysis of the content of the conversation as staff were really speaking to each other in Margy's presence rather than speaking to her.

The key worker equates documentary knowledge of the history of a person with a deep knowledge and understanding of the person. While she espouses to the language and rhetoric of PCP yet in practice doesn't demonstrate the underpinning values of PCP and the goals set fall short of being any way visionary for Margy. Furthermore while Margy's brother is ill-equipped to participate in the PCP process there is a lack of understanding by the key workers of the importance of having a support person from outside the intellectual disability system (usually a family member) to participate in and critique the process.

It was evident during the interview with Margy's brother that at no point did any one counsel or attempt to describe to him what is involved in the PCP process which he perceived as an attempt to displace some of Margy's care on to him. This is a common theme amongst families where their family member has an out of home placement and a challenge to service providers to overcome this erroneous assumption.

The blurred distinction of what a PCP is versus what is typically covered in care plan causes ongoing concern and may, inadvertently, lead to neglect. For example in this case physiotherapy appointments were missed and there was uncertainty around follow-up orthopaedic consultations.

By stating that she is 'the boss' it seems that Margy is trying to give the impression that she is in authority and in control of her own life. Ironically, this is the one thing that most people have which Margy does not have and that is control of her life. The objective of PCP is to support people in achieving the life that they want. This includes meaningful relationships and a degree of self-determination.

The outstanding question is whether this was a PCP meeting for the sake of having a meeting or a PCP meeting aiming to further Margy's personal goals.

Paddy

4.10 Paddy

4.10.1 Background and context

Paddy was born in a small local hospital in the mid 1930's. His early life was spent at home with his mother and father and three siblings. Paddy began his educational career in the local junior national school which he attended from age four and transferred to the Christian Brother's boy's school at age eight years. He was noted to be a 'slow learner' and his family reported that he was corporally punished due to relatively low academic achievements. While his parents worked on the small family farm providing for their four children it wasn't unusual for older children to leave school early in order to take up unskilled employment to help with the gross family income. Paddy completed his primary education at age thirteen and quickly took up full time employment as a farm labourer in a large country house estate. He was regarded as a punctual and trustworthy employee who had many complex responsibilities in his work such as felling trees, planting and harvesting crops and rearing turf on the bog.

Paddy continued to reside in the family home with his two brothers and while his sister married and lived nearby their parents passed away when Paddy was twenty one and twenty two years old respectively. For the next twenty four years Paddy continued to work locally and resided with his brothers in the family home. During this time Paddy had no association with any formal educational, mental health or disability services. He was getting on with life in a problem free way. The three brothers had an arrangement whereby one of the brothers stayed at home during the working day and took care of the small holding. This brother also looked after the household such as meal preparation, shopping and laundry. Paddy and his other brother continued working outside the home as reliable employees and 'bread winners'. The brothers enjoyed socialising locally and at weekends attended local events such as football and hurling matches, garden fetes and car shows.

When Paddy was forty six years of age he required a dental procedure that necessitated the removal of all his teeth. This was a very painful and distressing event for Paddy. File entry's report that at this juncture Paddy ceased talking and became 'very agitated and withdrawn'. A family member noted:

> "You see he was normal up until he got his teeth out. Then the ones that he was working with said that he couldn't talk anymore and it just got in on him".
>
> Interview with Niece

He was diagnosed with depression and hospitalised for treatment in the local mental hospital (file entry, 1983). Paddy was taken from the family home and began a period of hospitalisation that ultimately lasted for twenty four years. The first six of these years were spent in the 'mental

hospital'. Paddy continued to reside on a ward for a further eighteen years until 2007. During this time, Paddy, an already shy and traumatised individual was subjected to many undignified institutional practices. These practices included communal showering, complete lack of privacy in communal toilets and dormitories, regimental mealtimes and lack of food choices, staff practices and the stresses of co-residing with people with challenging behaviour and a range of mental health challenges. Despite the best efforts of his family to keep in contact with him, Paddy had a very lonely existence in this hospital setting.

> "Me mother and father (*Paddy's sister and brother-in-law*) and myself used to go to see him all the time. I used to take me mother and father but we used to hate going there. The doors would be locked. There were a whole load of them there all walking around. We hated it, we hated it for Paddy. In that place he never spoke to you. If you asked him something he wasn't able to answer. I think he was afraid in that place, afraid of the other people living there".
>
> Interview with Niece

Paddy was admitted to the psychiatric hospital for depression and was noted to be a 'poor scholar' but he was never diagnosed as having an intellectual disability. To this day he presents as a shy, quiet and retiring gentleman with no obvious appearance of an intellectual disability.

4.10.2 Current situation

In 2007, as part of the transfer programme Paddy was chosen to move to a community group home with five people with intellectual disability. This house is located in a picturesque rural town land with pastoral scenery and many pleasant river and canal walks. Paddy has the opportunity to feed the birds and he goes on many leisurely country strolls along the canal line. Interestingly, Paddy is now more relaxed and self-reliant and has re-engaged with his immediate surroundings to the point where he is now talking again. While Paddy does not have a lot in common with his house mates, he is enjoying a more individualised lifestyle and in particular socialising with staff with whom he chats freely. Sadly one of Paddy's brothers passed away three years ago (2008) but Paddy continues to have a relationship with his married sister and her family and his bachelor brother who continues to reside in the family home.

In the five bedroom bungalow Paddy has his own large single bedroom. He has selected and purchased his furniture and personal items to a very high standard. Paddy has personal pride in his investment and choices which gives him a pleasant sense of ownership and responsibility. His current lifestyle reflects a modest level of self determination in that he can decide when to go to bed in the evening and when he gets up in the morning along with deciding what to wear and food

choices. 'I like to have a lie in in the mornings, I do. I like to take me time in the morning, I do. Yes I really like it here'. This is a marked contrast to his previous life in the institution. Paddy speaks with a certain amount of pride and satisfaction about his life.

> "I am keeping well; I am keeping great thank god. I have my own choice now, what I want to eat and I have more to do during the day".

Interview with Paddy

His family remark on how well he is doing since he moved to the community house.

> "He has never been as good as he has been now. It's great. When he got out he blossomed, do you know? I think well, it is the fact that he is living with smaller numbers of people and it is nice and peaceful and quiet. He has lots in his life. It was just when he got his teeth out that time; he was never the same after that. They had a great life at home until that happened".

Interview with Niece

Paddy now enjoys regular visits and is developing relationships with his extended family. 'It is a lot easier to come here. The doors aren't locked. There are fewer people'. When Paddy was asked about his visits home he volunteered the remarks:

> "My sister celebrated her eightieth in a restaurant near the home place. I had a great time. There were twenty two of us out for a meal. Me and me brother were talking about different people. It was a great night. My brother lives on his own. He comes to visit me here. He was here at Christmas and I go to visit him. I was talking to me sister on the phone yesterday and we had a chat about this and that".

Interview with Paddy

When asked about his time in the hospital Paddy declined to speak about this time in his life and stated 'I prefer it here. I don't want to go back. It's nice and quiet here'.

4.10.3 The PCP process

Paddy was given the opportunity to respond to questions about his view of the PCP process. While Paddy can be very conversant on topics with which he is familiar such as talking about his family and social life he is more reticent when talking directly about service issues. His remarks consisted of replies like 'no problem', 'I did', 'I did enjoy it', 'there was yes', 'yes it is', 'yes I really like it', 'I see', 'I do yes', 'I do I like the house', 'yes I do', 'yes I did' and 'I got all that'. These responses suggest that Paddy, although polite and courteous, was anxious to acquiesce and he did not display an understanding of the concepts involved in PCP.

In the interview with Paddy's participating family member (in this case his niece Mary) she outlines her understanding of the PCP process as 'I think it is good because he is able to tell you what he wants and we are happy about that'. While Paddy has the capacity to share his views he does not do it in the context of the PCP meeting. Mary expresses her and her families desire to have a role in PCP for Paddy. Mary views the PCP as a mechanism for Paddy to realise his personal goals. However, Mary uses goals co-terminulously with Paddy acquiring material comforts such as his own bedroom and personal effects. 'Whatever he wants now he can get'.

Mary does not perceive the PCP process as tedious but states to the contrary 'Oh God I think that it is good because he is getting on better than he ever did'. She concurs that the PCP process is the perfect way for staff to get to know Paddy. When Mary was asked about her view of personal outcomes being reached through PCP her reply was 'I think it is a good way to do it. Meeting up once a year is no harm. You can look back on the year and what he has achieved'. Mary perceives family participation at PCP meetings as an important vehicle for the family's knowledge base on Paddy's life. Mary contrasts Paddy's level of community participation from past to present and considers the PCP as aiding Paddy's use of local amenities. 'He goes shopping and he does what he wants to do. But when he was in the other place sure he never done anything. He is doing more now'.

Mary expresses delight with that aspect of the PCP which promotes the development of family, friendships and social networks stating simply 'Well yes we are all here today and it has done that' Regarding the PCP promoting choice Mary again contrasted his previous service to his current service when she stated 'I'd say he chooses now. He never did before'. In conclusion when asked if the PCP ensured a full and active life for Paddy she concluded 'he is good now anyway and we cannot complain'.

Paddy's key worker demonstrated knowledge of the rhetoric used in discussing PCP as we find in the following statement:

> "Primarily we are here to enhance the life of Paddy. The PCP should be incorporated in to his day to day life, like the nursing care plans. The PCP should be incorporated into our daily write

up and should be followed through and looked at on a daily basis. And as I said, everything we do can enhance the life of Paddy. We are here to make his life as happy as we can in this house".

Interview with key worker

The key worker describes the PCP process as a panacea to all of Paddy's issues by stating 'We are here to meet all his needs and to ensure that he is happy'. She describes how she has known Paddy for two years and she has been his key worker for the last year. In response to questions on the PCP process she is optimistic. 'I think it is wonderful. Primarily we are here for Paddy. We are here for all the clients'.

She equates her role as key worker to the good rapport that she has with her work colleagues. 'We have a very good rapport here with colleagues. If I can't do it someone else will pick up the goals'. The key worker instead of responding to the essence of the question deviates. She concedes that it is part of her role to 'ensure that all the goals are set and followed through on'. Regarding the key worker role in linking with families she regards this as 'totally up to me, very much so, to initiate links and I will do so'. The key worker equates individualised service design with one to one staff ratios. 'Paddy thrives on one-to-one for his activities'. As quoted, she believes that it is about doing individual activities with a person rather than the more progressive empowerment of the individual to have a lifestyle that is optimal and in which they have control and less staff dependant. The key worker in her estimation holds that Paddy lacks personal initiative. This lack of personal initiative may have its roots in the twenty four years of Paddy's institutionalisation which is a common feature of people subjected to institutional regimes where they actually lose their self esteem and lack motivation to actively engage. The key worker sees this as a barrier to Paddy doing anything of his own volition. 'Absolutely not, he could not take any kind of initiative. No, no he wouldn't be capable; you see he would be so scared'. She then goes on to disregard any discussion of Paddy moving on or living in any other circumstances.

"Oh my God, no, no, no. He loves it here. This is his home you know and further more I had to reassure him twenty times over that this PCP was very informal and that there was no threat that he would be moved on from here".

Interview with key worker

The key worker recognises the role of PCP as a mechanism for her as key worker and for Paddy to set goals. 'Yes, at his meeting we are just going to sit down and discuss things that would enhance his life and make his life better'. The key worker does not regard the PCP process as tedious but rather as productive. 'I think that I get an awful lot out of it. I will get an awful lot out of it to see Paddy happier'. She regards the PCP process as the perfect way to get to know Paddy and sees the PCP template as a useful format for recording Paddy's many and varied activities.

The key worker regards family participation at PCP meetings as fundamental to maintaining family relationships.

> "I think that it is vital, because we get input from Paddy's family and that input I will take on board and give very serious consideration to it, you know. Who knows Paddy better in the world than Paddy's family?"
>
> Interview with key worker

The key worker believes that the PCP aids community participation and recounts that 'the priest will come and have five minutes with him before Mass, because he is a lovely Priest'. She regards the PCP process as a way of promoting the development of family, friendships and social networks but also regards this as an opportunity for her to develop her relationship with family members. 'Visiting Paddy's sister with him for tea once a month helps me to get to know her and for her to get to know me'. It seems that the key worker is investing a lot in her relationship which may compromise Paddy's opportunities to grow and develop his personal relationship with his own family. It is not about her relationship it is about promoting and nurturing Paddy's relationships with his family.

The key worker believes that the PCP promotes the use of natural resources in the community and that he is well known at the cinema, supermarket and Mass. In this case the key worker is restricted in her understanding of the potential for Paddy to express choice.

> "Like he told us that he does not like chips. He told us that he does not want to go swimming. He was going to go to play golf but now he does not want to go to golf. So of course he has choice. Paddy is choosing what he wants to do and that is how it should be. It is Paddy's life. It is Paddy's home".
>
> Interview with key worker

While it is encouraging that he is exercising simple choices around food and activities it is disappointing that the potential for the PCP to reflect deeper lifestyle choices is not considered by his key worker. The underpinning function of PCP is not about whether someone likes chips; it is about personalised lifestyles which are regrettably absent for Paddy. The key worker affirms that because he is activated he has a full an active life.

At a superficial level the key worker is engaging in the PCP process, however, there is an absence of any critical reflection on the choices Paddy is making which are all immediate to his care needs. There is a distinct absence of any reference to deeper and more critical real opportunities for Paddy to be empowered to formulate his personal view.

Paddy's most recent PCP meeting was attended by Paddy, Paddy's brother, nephew and niece, his key worker, a staff nurse and the clinical nurse manager. It is notable for Paddy's PCP there was three family members present. The meeting was held in the dining room of his community residence. The key worker opened the meeting and welcomed everyone. She referred immediately to the fact that time was spent with Paddy prior to the meeting as preparation as to what things Paddy would like to do for the following year.

> "Primarily this meeting is about making Paddy as happy as possible in the house, if not even happier. Paddy spent an hour with us yesterday and he ran through a couple of things that he would like to do. Didn't you Paddy?"
>
> The key worker at PCP meeting

The key worker tried to get Paddy to read out and list the things that had been discussed prior to the meeting, as if to perform. He was clearly uncomfortable with this request. Further to this, she misunderstood the role of the researcher as an observer and tried to shift this role to one of participation requesting of Paddy:

> "Do you want to start telling Donal? Go ahead, tell the things you do like and the things that you don't like and I will help you out. Do you want to read this out to Donal or do you want to talk? So Donal this is what we came up with. It is pretty simplistic but that is how it needs to be you know".
>
> The key worker at PCP meeting

There was an uncomfortable long pause and Paddy eventually stated "No, you do it". At this point in the interview the researcher interjected stating:

> "Sorry, this is Paddy's PCP and as I said earlier I am here to observe the process".
>
> The researcher at PCP meeting

At this point the key worker instead of reverting to Paddy turned to Paddy's niece and directed the ensuing conversation about activities towards her requesting her approval to do so and at the same time marginalising the other attendees at the meeting. 'Ok so Mary, we will go through the activities with you. Is that ok?' to which Mary replied 'yes that is ok'.

Paddy's verbal contribution at his PCP meeting consisted primarily of short utterances that affirmed his agreement or otherwise to specific activities such as, 'I do, yes, I, oh no, yes I would, I do yes,

alright, oh god no'. Despite the fact that Paddy in ordinary circumstances is well able to have a full conversation, he forgoes the opportunity to participate more fully out of some underlying deference to staff. For people who have been institutionalised and have lost the opportunity to make decisions it must be very difficult for them to understand that finally their voice can be heard or alternatively they may lack the confidence to speak in group situations.

The key worker goes on to inform the meeting of the activities that she perceives that Paddy would enjoy. Interestingly, she also includes the staffing ratios required for Paddy to do ordinary things.

> "One of the things that Paddy loves to do is go to Mass on a Saturday night, preferably with just Pat and himself on a one to one. You do love that don't you Paddy? That is something he really looks forward to and another thing he really loves is to rest on a Sunday morning. Don't you Paddy? Maybe not even to get dressed but to come down in his dressing gown and kick back and watch television. You just like that don't you Paddy? Another thing that Paddy likes to do is to sit out there on the swing. I think you like that don't you?"
>
> The key worker at PCP meeting

The key worker adopts a somewhat patronising tone and continues to describe Paddy's everyday demeanour.

> "And another thing he loves is to just sit back in the house itself. This is his home and we let Paddy enjoy the fact that this is his home and this is where he belongs. Paddy is here three years now and it is only in the last couple of months that Paddy has expressed to us the things that he likes. It is fantastic. He is even going to the fridge and pouring his own milk and buttering his own bread. He has asked us for his own wallet and he has asked to go shopping and he uses that wallet to buy stuff. Its fantastic and a big step isn't it Paddy?"
>
> The key worker at PCP meeting

These things should be occurring as a matter of course in any service setting and it is disappointing that a man is bereft of these basic requirements. He is provided with a beautiful house to live in. The key worker addresses a comment to Paddy.

> "We will go out Paddy once a month, me, you or Pat and you can bring your own wallet and pay for your own meal. Would you like that?"
>
> The key worker at PCP meeting

In the normal course of good service practice people with intellectual disability are ideally supported by staff to make purchases that affect them such as the food they eat and the clothes they wear. In this case Paddy's participation in shopping is discussed at his PCP meeting as if this shopping activity was a privilege to him as seen in this remark.

> "Another thing that Paddy has expressed is that he would like to go with the staff on Fridays as it is our shopping day, what we try to do is to let Paddy go with one of the girls that work here. And then there is a little coffee shop and we can let him stop here for and hour and have a scone and a coffee. You would love that wouldn't you Paddy. And just have one to one time. Sometimes after that we could go for a little drive, weather permitting of course".
>
> The key worker at PCP meeting

The key worker shifts the discussion to Paddy's food choices remarking:

> "Another thing that Paddy told us is that he likes small portions of food. He likes his food very tender. He doesn't like chips. He is able to make choices now. He is going to the fridge buttering his own bread and pouring his own milk. Now he is able to say what he wants for breakfast".
>
> The key worker at PCP meeting

One institutional practice was to have personal services such as hairdressing, massage, aromatherapy and reflexology delivered in the congregate setting. Disturbingly, a lot of the activities for Paddy that could be delivered outside the community residence are now brought to his community residence in keeping with institutional practice.

> "Another thing that Paddy has asked for is his massage. He loves having his massage. He had his massage here yesterday and then he usually has a rest for an hour or two afterwards".
>
> The key worker at PCP meeting

Encouragingly Paddy has started to assert that he wants to be consulted on whether he wants to participate on group excursions from the house.

> "Paddy has expressed to us that he wants to be asked where he wants to go and where he doesn't want to go. He doesn't want us to say 'come on now Paddy, we are all going such and such a place'. Now he is able to say 'no, I don't want to go on the bus with everyone'. He likes to spend time back in the house when all the others are gone out. He has a great relationship with all the staff".
>
> The key worker at PCP meeting

The key worker during the PCP meeting does her best to extrapolate on potential activities for Paddy.

> "Pat suggested that when the evenings get long, that please God, we get him a fishing reel and go down to the canal and do a bit of fishing (Paddy laughs at this). I was asking Paddy if he would like to go to the fishing farm in the spring. What you do is you pay and go in and fish for two hours and you are guaranteed to catch a fish or two. Sure we might try that in the spring time, when the evenings get long. But it is lovely to take a ramble and very often we take Paddy for a ramble down by the canal".
>
> Nurse at PCP meeting

The PCP meeting moved to a discussion about Paddy's family involvement. The key worker directs a question to Paddy's niece requesting permission for Paddy to visit his brother and sister. She also requested permission for Paddy to ring his sister every two weeks.

> "And what we are going to do, once a month, if that is ok with you, is to go with him home to visit home on a one-to-one. You know we will give you a call the week before. Paddy will have a one to one. We will come over and have a cup of tea. You would like that wouldn't you Paddy? And Paddy told us that he would like to talk to his sister every two weeks on the phone. Isn't that right Paddy?"
>
> The key worker at PCP meeting

The key worker does not wait for an answer either from Paddy or his niece but she goes on to discuss another activity about going to the cinema. 'Paddy has expressed to me that he would like to go to the cinema, to see old matinee films'. For the first time in the meeting Paddy's brother comments, remarking:

> "He used to go years ago, he loved it. He loved cowboy films. Isn't that right Paddy? Bang bang. John Wayne or somebody. I remember the time that he was at the cinema and he was pretending to shoot people. He had a great time. That was a good while ago. It must be twenty years ago now. Me and Paddy used to go all around the country looking at hurling and football matches. I used to drive a car. I had a Fiat 127. Do you remember them? They were very easy on Petrol. He has been to Croke Park with me. The 1957, no, the 1967 Leinster final. We went to see Laois and Longford. Laois were beaten by four points. It was the Leinster final and Longford beat us by four points. Me and Paddy used to go to the dogs and then we used to get ice cream. You remember that Paddy don't you?"
>
> Paddy's brother at PCP meeting

Paddy's brother Lar provides the meeting with a rich and vivid account of many pleasurable reminiscences of the range of accounts of a past life shared with is brother. How sad for Lar who had a simple country life with the companionship of his brother Paddy who was taken away. Lar uses this meeting to share the memories of the many pleasant activities of hurling matches, football matches and cinema. Unfortunately, the relevance of this is missed by the staff attending the meeting who now take ownership of providing Paddy with what they perceive as a good life. Instead of responding to Lar's reflections staff shift the conversation back to services that they provide. This may be because the key worker struggles with what Lar has said and its relevance to Paddy's life.

> "He loves to stroll and feed the birds here in the garden. We have a bird feeder here now and you love feeding the birds, don't you Paddy? And of course Paddy the parker bath, you love that don't you Paddy, a bubble bath. Tell them Paddy that you love the parker bath and the bubbles. And he will go into the sitting room and look at the hurling and football on the television and he will be able to tell you exactly who is playing and what team and whether it is football or hurling. You still like ice cream don't you Paddy, but not all the time though".
>
> The key worker at PCP meeting

The key worker then asked 'is there anything else you would like to have Paddy?' To which he replied 'well sure, ah no. Sure I enjoy me life'. As if coached, the key worker asks 'do you enjoy your life **here**?' Paddy replies 'I do enjoy me life here. I do like the people here. I enjoy my life'. In a patronising tone again, the key worker adds 'that's all that matters - that's what we are here for Paddy to make sure that you keep enjoying your life'. She then went on to talk about the possibility of organising a holiday for Paddy. She alluded to a couple of overnight stays in a hotel that he had had the previous year. Vague accounts of these breaks were given to all present. He was asked if he would like to go on another break to which he was non-committal.

> "I might not bother. I will decide myself and see. I would like to be able to phone my sister before I go away".
>
> Paddy at PCP meeting

The key worker, in a further attempt to impress the family states:

> "Paddy has us spoilt here. He pulls the curtains here at night and puts on the lamps. He is good as gold, aren't ya Paddy? So there is nothing else we can do for you here Paddy, is there?"
>
> Key worker at PCP meeting

The family concur with the key worker that Paddy's life is so much better 'Sure he is looked after very well. We see a big change in his life. We thank you for all you are doing'.

4.10.4 Comment and analysis

Paddy's family are very relieved that he is in a better living environment than his previous institutional placement. "The doors aren't locked here. We hated it in that place. He never spoke to us. He was afraid". The family, who are appreciative of his current arrangement, do not have a shared understanding of how things could be better for Paddy but are satisfied that his environment is much better. They themselves are disempowered by staff that are keen to impress them with the view that Paddy has 'a full and active life'.

In this case study we need to remind ourselves that Paddy had a full and active life prior to his admission to the psychiatric hospital at forty six years of age; following a dental procedure he lost his voice, became depressed and lost the life he knew and enjoyed. His brother's contribution provided an inkling as to what this life was like and shared the happy times.

Paddy was never diagnosed with an intellectual disability. He was admitted to mental health services after his teeth were removed following which he did not speak for a considerable amount of time. In hindsight, he may have experienced post traumatic stress disorder as consequent of the painful dental procedure. The treatment in the 'mental hospital' may have compounded his stress related illness. He was in the de-designated community disability services, and thus began his treatment in what was known as services for people with mental handicap. He still has no formal diagnosis of intellectual disability and a lot of his support needs now stem from twenty four years of institutional care. His support needs are confounded by staff issues and interestingly the key worker admits 'it is because of you Paddy that I have a job here today'. All of her contributions to the PCP meeting and her individual interview are peppered with staff speak, 'one-to-one, patients, expressed, interact with him'. Further to this staff speak around time frames, 'once a month, every second Thursday and once a fortnight'. This is not a conversational style that lends itself to developing relationships with families or the person with intellectual disability.

While Paddy has now moved into a comfortable environment the research has revealed that ample opportunities for community inclusion were missed. Staff played lip service to person centredness but in reality many practices transferred from the large institution to his community residence. These are referred to above and included such activities as 'massage, and the use of a parker bath' and an over cautious attitude towards risk taking and a complete reliance of one to one staff to do ordinary activities. Paddy, a person who had his own home and job until he was forty six years of age is now in a situation where he never has staff free time in his life. Ordinary activities, such as visiting his sister, are seen as requiring one to one staffing. This is both a waste of resources but also a barrier to him having a person centred ordinary life. It is not about his life but more about staff priorities.

Paddy is put in a subordinate position and his life choices are contingent on staff availability. "She takes me out and she is good to me'.

There is no evidence of skills teaching or effort to empower Paddy to visualise and articulate his own goals. There is no element of person centred active supports whereby the emphasis is on supporting Paddy in doing every day things rather than doing every day things for him such as meal preparation, shopping for his own food and clothing.

Paddy is non-committal about going on a holiday. This would be a holiday that would typically be decided by staff. One of the reasons may be that people who have experienced institutionalisation realise that when they leave to go home or on a holiday break, their place is often filled by the next person in need. They are dispossessed and their possessions are often misplaced. Paddy would naturally have a concern about leaving, even for a short time, for fear that someone would move in.

When Paddy was asked about his reflections on his life in the institution he simply stated 'I don't want to talk about it'. It is clear from Paddy that he was afraid when living in the institution. He didn't speak while there and would still prefer not to talk about this part of his life. A reasonable inference, given the institutional practice regimes, is that he was subject to unpleasant events. 'Is it any wonder that he didn't talk in that place'? A presenting question is whether Paddy would benefit from professional counselling with regard to the time he was institutionalised?

It is clear from Paddy that his home is still as he sees it 'the home place' that he was removed from in 1983. Yet the staff insist to him that the community residence where he has a residential service is now 'his home'. He does not have a key to his front door and he shares the house with five other unrelated people with intellectual disability, which is staffed at all times. At a minimum there are nine adults in this house at any given time. Albeit that this is a marked improvement on his previous living arrangement it still lacks a home like atmosphere and is, in fact, clinical in nature.

While the PCP has brought people together to review Paddy's activities and interests and included his family the fact remains that ample opportunities were missed to be truly person centred. The key worker overlooked the potential for more family involvement by insisting all activities for Paddy were 'one-to-one'. There was a failure to build on the recollections of Paddy's brother to achieve a true sense of Paddy's independent past life. Staff claimed an ownership of Paddy's PCP making him happy with a range of activities that are engaged in and supported by staff.

Chapter 5

Cross Case Study Analysis

5.0 Cross Case study Analysis

5.1 Introduction

This chapter endeavours to develop from primary qualitative cases thematic categories that resonate across all the cases. Themes of the case studies are analysed and described. Further to this the themes that emerge from the cross case study analysis of the person centred planning process will be considered with the overall aim of analysing the PCP process in its entirety from general to specific.

The true essence of person centred planning (PCP) for people with intellectual disability is that the individual focus person's life, support needs and aspirations are considered in depth from that person's perspective. The various stakeholders such as the focus person, their family, the key worker and their support staff should have a shared understanding of the focus person, the process of PCP and the philosophical underpinnings of PCP as a foundation on which to build a positive inclusive future determined by the individual with intellectual disability.

There were many topics that emerged as meritorious of further exploration such as the number of people that were admitted to residential care for special education for whom it transpired that this equated to life long residential care in intellectual disability services. A number of people made allegations of physical and sexual abuse. All of the people in this study were incarcerated and as such removed from the mainstream of society, isolated from ordinary community living especially family life and subjected to institutional regimes and practices, an infringement on their basic civil rights. All of these topics seem to warrant further research.

This study is on PCP. It focuses on the efficacy of PCP for people with intellectual disability in community services following the transfer of these people from institutional care to care in the community. Robertson et al (2005) concluded that PCP was effective in "social networks, community involvement, scheduled day services, contact with family, friends and choice" and through this research efforts will be made to illustrate this reality for the ten people considered in this study. Specifically the study will consider the lives of ten people with intellectual disability in entirety, prior to their institutionalisation, while in the institution and how person centred their current lifestyle is in community settings. What was derived from a consideration of the lives of the ten people and an analysis of the interviews with them, their family member, their key worker and the content of their PCP meeting will be described here.

5.2 Recurring themes

From the qualitative cross case data analysis themes were clearly identified and include:

- The legacy of institutional care and practices has an impact on the PCP process
- The structure of the PCP meeting is overformal

- There is a limited understanding of the aims and purpose of PCP
- Different factors lead to resource limitations for each stakeholder in the PCP process
- The consequence of resource limitations are reliance on special services
- Fear of additional costs and routine activities
- Emphasis on duty of care leads to risk aversion in PCP goal setting
- Individual differences and local variations impact on the efficacy of PCP
- PCP promotes community presence but falls short of community participation
- Positive impacts of PCP.

5.2.1 The legacy of institutional care and practices has an impact on the PCP process

This section will deal with how the legacy of institutional care and practices impact on the PCP process for the person with intellectual disability, their family member and key worker. Table 4 below summarises the issues relating to the legacy of institutional care for the ten people reported on in the case studies.

Table 4: Summary of the legacy issues of institutional care

	Person with intellectual disability	Family members of the person with intellectual disability	Key worker for the person with intellectual disability
The legacy of institutional care and practices has an impact on the PCP process.	▪ Alienation from family & community life – antithesis of PCP. ▪ A loss of personhood & control of their lives. ▪ Relinquished to patient status. ▪ Acquiescence. ▪ Loss of confidence and self esteem. ▪ Restricted to the menu of special services. ▪ At the mercy of staff that are paid to be with them.	▪ No control in their family member being taken into care. ▪ Years later it is assumed that they can or will participate in PCP. ▪ This leads to confusion, anxiety and fear. ▪ The concern that if they display any confidence that they will be expected to engage in direct care. ▪ Afraid to complain or really say what they think. ▪ Deference to staff.	▪ Attitude of ownership to people in state care. ▪ Institutional practices persist in community houses. ▪ Institutional hierarchy of conflicting roles.

The legacy of institutional care for people with intellectual disability led to their alienation from family and community life simply because they were removed from their homes and placed in large institutions. This led to a loss of personhood and instead of being a family member the person became a patient who lost control of their life. This led to a loss of confidence and self esteem. Their lives were relegated to what was available in the hospital settings restricted to the menu of special services. Throughout the case studies there was ample evidence of the early life

experiences profoundly impacted on the subsequent developmental trajectory for the person with intellectual disability. From the work of Bowlby and others on attachment theory, it is now recognised that adverse experiences in childhood can affect brain organisation, future relationships and lead to the development of maladaptive patterns of behaviour.

For the family members institutionalisation of their family member was done without engagement of all the family members and worse some were told not to visit as it would only upset the person. Now that the person is living in community based residences families are now asked to engage in the PCP process without prior consultation, leading to their confusion, anxiety and fear. This study found that families displayed a concern that if they appeared to the staff to have capacity that they would somehow be expected to engage in direct care. At the same time there was a reluctance to complain or to say what they really thought in case this would impact on their family member. Some family members deferred to staff and saw them as having superior ability to care for their family member.

The key worker for the person with intellectual disability exercised control over the lives of people in their care as if people in state care are owned by the service provider. When staff move from the institution to the community residences institutional practices also moved with them. This study found that the institutional hierarchy that exists meant that there were differing roles among staff. This meant in effect that people who held higher status jobs could be more effective as key workers as they held the decision making power.

People with intellectual disability who have been institutionalised carry with them many deleterious effects. Many family members would have been unaware of the lifestyle of the person in the institution. PCP meetings serve to share information on all aspects of the focus person's lifestyle. An example of this was at Gary's PCP (case 6) when information was shared with his family members as to aspects of his life when he was living in the large institution. He showed signs of fear of falling asleep by propping himself up tensely on his elbow as a safeguard making him ready to respond to any intrusion thus having a fitful night sleep. Staff now report that Gary sleeps very comfortably and undisturbed throughout the night. Shortly after Gary was admitted to institutional care he stopped speaking and for decades people presumed that he was mute. Surprisingly, when he moved to his new community residence and after a period of settling in, he started to speak again, asking for certain foods and preferred activities. Gary's family found this new information astonishing and it enhanced their appreciation of his current service.

Another example was in the case of Colette (case 1). As a young woman she was married and employed and due to marital breakdown became more vulnerable. This led to her hospitalisation and detention in a psychiatric setting for decades leading to a complete loss of her self confidence, self esteem and liberty. Colette's expectations of her life and her PCP are quite low 'so I am not getting my flat then'. Similarly for Ronan (case 2) the graphic account that he presented on his institutionalisation where he was physically removed from his loving home left an indelible mark on his personality. This led to him being incapable of making any new and trusting relationships and

relegated him to a life of special services. Margy (case 9) was institutionalised because the staff in her day programme held the view that her family were neglectful of her needs. An essential part of PCP is supporting people in having satisfactory relationships. Missing her family life and craving affection Margy gained a reputation of being promiscuous so her personal liberty was restricted in an effort to protect society and she spent the best years of her life in a locked ward. This is the complete opposite of what one would expect from a person centred service.

While PCP endeavours to signpost the way towards a good life in the case of these ten individuals what is also needed is a strategy to try and undo some of the legacy issues of institutional care in order to re-empower people with intellectual disability to lead lives of their own crafting in a person centred way. While the PCP process endeavours to do this, people with intellectual disability have not as yet experienced the support they require to make and have friends or indeed have intimate relationships. All ten people in this study are single and describe their 'friends' as the staff that are paid to be with them. Half of the study group reported abuse of a physical and/or sexual nature while living in the large institution.

In a truly person centred service people would have ownership of personal possessions. A study question was posed to the individuals with intellectual disability "Do you have a key to your front door?" This study found that alarmingly none of the individuals had a tenancy agreement or even a key to their front door and worse still they did not perceive themselves as having the responsibilities associated with key ownership and tenancy contracts.

Given the age profiles many of the family members comprise brothers and sisters with only three people in this study group with one or more parents still alive. As previously stated at the time of their family member's institutionalisation these siblings were children themselves and as such had no hand, act or part in their brother or sister going into care. Furthermore, some families were discouraged from visiting and were asked to stay away for fear of upsetting the person in care. Now that people are living in community based residences with PCP's in place we are going to these same families and asking them to be involved in PCP having distanced them for decades. As part of the PCP process family members are now invited to PCP meetings. This is done in the absence of any systematic way of informing them of what is required of them and what their involvement is in practical terms in the PCP process will look like. As one sibling put it 'I don't know a lot about PCP but I do know a lot about my sister'. Sadly, some individuals stated prior to them being interviewed that they had a fear if they agreed to be interviewed and participate in the PCP process that this would somehow mean that they would be expected to re-engage and that the person would be sent home to them to care for. In one case the family admitted that they lacked information or understating of the PCP but they did state that they realised that his current service is relatively good by comparison to the service of those who continue to reside in large institutions. Gary's brother (case 6) was hesitative about being interviewed until he clarified for himself and his siblings what was expected of them as a family. He made the following comment:

> "What is the status of Gary's current placement in this house? Does he have a right of residency? Is it permanent? Do you expect us to take him home full time? Because if you do, we can't be involved".
>
> Interview with Gary's brother

At least in the case outlined above, by seeking clarification there was an opportunity to allay this fear but notwithstanding that, for other families there was a reluctance to participate and the lack of clarity on the role of families in PCP from the beginning may lead them to conclude that the PCP is about exploring the families capacity to be more involved and in providing direct care. Some of the families made statements such as "I would never manage him at home, I have a family of my own now and I do all that I can for him". Some family members behaved as if the person with intellectual disability was a child incapable of participating in any decision making and viewed the PCP meeting as a place where they would hear from staff as to the conduct of their family member. In the past, the only time that families were conferred with was when the individual had done something that warranted punishment for which they might be sent home. Family members accepted the authority and power of staff to make decisions for and on behalf of their family member. As Ronan's sister (case 2) stated 'I don't interfere, staff know best and they know him well'.

There is evidence from this study that individuals with intellectual disability are still controlled in their lifestyles and are frequently disempowered by staff who 'knows best'. In the context of institutional care the medical model prevailed. Clearly people's basic needs for food, warmth and medication were well met in this context albeit that their personal lives were stolen from them. Now in community based services instead of providing people with complete wrap around care an objective is to support them to lead a life of their own crafting. In keeping with this theme an objective of PCP is that staff relinquish their control in favour of supporting the person to have competence, confidence and control of their own life. An example of this not happening was where Killian (case 7) aspired to learn to play the guitar that he had purchased. Guitar lessons were sourced locally by his key worker and available to him on Saturday mornings. However, the lesson time was regarded as inconvenient to the staff and the efficient running of the community residence. So this personal goal of Killian's was controlled by staff and thus Killian's aspiration was secondary to the Saturday morning routine of his community house. Another example was where Colette (case 1) gave a litany of reasons why she wanted to live alone in a flat and each of these requests were counter argued by staff who regarded themselves as 'I know best'. The control that staff place on the focus person, not only undermines the individual's capacity to self advocate, but also further disempowers the person and results in learned helplessness and their relinquishing to 'staff know best'.

Staff working with people with intellectual disability in residential care settings make the assumption that because their care needs are so well met that other overlays are superfluous. There may be evidence of relative deprivation at work. This is a psychological theory that people evaluate how

wealthy or deprived they are relative to others. Status and wealth are not absolute but are judged by reference to the surroundings. In this case staff might be seeing such an improvement from the institution that they judge further improvement as unnecessary. As people have been in care for the preponderance of their lives there was little or no attempt to see them as in control of their lives. It was as if the key worker owned the focus person. This is an institutional position that is assumed by all stakeholders so much so that the recent HSE report on congregate settings (2011) stated that "neither the HSE nor the service provider own the client, but have the responsibility to maximise their independence" *(A time to move from congregate settings. A Strategy for community inclusion. pg 3).* The reality is that people with intellectual disability who are in care are at the mercy of the staff that are paid to support them in situ.

The key workers are in a quandary that is linked to their job status. On the one hand there is an expectation that as key worker they will facilitate the person with intellectual disability with their personal goals and objectives yet they themselves have to report through a chain of command including their line manager, unit manager and overall service manager. What this study found was that the key workers with the higher employment status, the more power they had to expedite the personal objectives of their focus person. At the same time while they are key worker for one person they also had to juggle meeting the care and support needs of the other dependent people who lived in the community house.

5.2.2 The structure of the PCP meeting is over formal

The PCP meeting is a structured format for reviewing old and agreeing new person centred goals. The PCP brings people together with the sole purpose of focusing on the individual with intellectual disability. Table 5 summarises the key points that emerge within the theme of the PCP meeting being over formal.

Table 5: Summary of over formal PCP meeting

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
The structure of the PCP meeting is over formal.	▪ Competing with others to make their voice heard. ▪ Not listened to. ▪ Loss of control over the PCP. ▪ It is not their meeting. ▪ Marginalised by the extent of their disability. ▪ Information not accessible. ▪ Expected to perform. ▪ Emphasis on preparation.	▪ Confused as to their role. ▪ Informed of activities obscuring the person centred aims. ▪ Overwhelms and unknowingly intimidates families. ▪ Use of staff jargon causes a barrier to open communication. ▪ Unaware of the potential benefits of PCP. ▪ Cautious about staffs perceptions and judgements of them. ▪ Made to feel grateful for services.	▪ Excessive control of the process. ▪ Performance anxiety leading to check listing. ▪ Used for the purpose of self-justification or discipline. ▪ Over representation of staff with eight to ten people at a PCP meeting overpowering the individual with intellectual disability. ▪ Lack of active listening. ▪ Meetings comprised mostly of paid staff.

This study found that the structure of the PCP meeting is over formal involving eight to ten people. For the person with intellectual disability this meant that they had to compete with staff and family members to make their voice heard. In fact there was a loss of control over the PCP meeting which in effect meant that it was not really their meeting. To a greater or lesser extent the effect of their disability impacted on their capacity to participate. The information presented at meetings was not accessible to them and the meetings were characterised by the expectation that if they did

participate it had the sense of the person with intellectual disability performing as if on stage. As the emphasis is on the preparation for the meeting, the person with intellectual disability was frequently left with the impression that the PCP was about their PCP meeting as opposed to how person centred their life became as a consequence of the PCP meeting.

The family members of the person with intellectual disability saw the PCP meetings as information sharing on activities and behaviours which obscured the person centred aims. Family members experienced confusion, anxiety and uncertainty about what role and function they had in the PCP process. The preponderance of staff members and the use of staff speak and jargon further intimidated families. This study found that families of the individuals with intellectual disability were unaware of the potential of PCP and were confused about what PCP actually is, their responsibility in the context of PCP and they are anxious about how they are perceived by staff caring for their family member. In the past when people were admitted to psychiatric hospitals, as is the case of eight out of the ten individuals in this study, families were told to stay away and not to visit as it would only upset the person and make them more difficult to care for. Home visits from the psychiatric services were known as the person being on 'parole'. Families were held at arm's length and seldom consulted or conferred with in relation to significant life decisions. This is in direct contrast to current best practice.

By contrast, at PCP meetings there is the expectation that family members will not only know the philosophy and rationale of PCP but also to participate in a process with person centred outcomes. Furthermore, some family members hold the view that their knowledge of the person supersedes the person with intellectual disability and staff and as such they can have the final say in any decision making. An example was where Lee (case 3) expressed an interest in growing a beard he was told that he wasn't allowed by a family member. This is very reminiscent of a child centred approach.

In other cases it was evident that families were encouraged to feel sub-ordinate to staff and they were therefore uncritical of service provision. They were also made to feel grateful for the fact that their family member was in care. There was very little attempt to embrace families who were themselves marginalised in their capacity to contribute due to ageing and/or mental health challenges. An example was where Ryan's mother, a seventy year old woman (case 8) attended her sons PCP meeting. Staff provided transport for her to leave the meeting prematurely which was a pre organised strategy to limit the presence and participation at her sons PCP meeting. In this case, instead of giving direction and support and taking cognisance of the fact that despite her shortcoming she is still his mother and as such has a unique and irreplaceable relationship with her son which should be supported.

Unwittingly, staff spoke to families using service and group speak jargon to describe the person's support needs 'he is a two to one when he is out', 'you need two up on nights', 'community inclusion', 'PCP' and 'goals'. What do these terms really mean to an uninitiated family member? There was evidence of many missed opportunities where families showed a loving interest but

didn't have the current knowledge or social skills to participate. If we were truly person centred these skills, such as staff recognising the potential for families heart felt participation would be utilised to improve relationships.

This study found that the key workers for the person with intellectual disability were in charge of the PCP meetings. The key workers demonstrated excessive control over the process. While the key workers were in control they also had a great deal of anxiety which led to them check listing and thwarting any spontaneous creativity. This control also led the key workers to use the PCP meeting as an opportunity to showcase the range of available activities. This study found that the key workers used the PCP meetings as a means of social control and to maintain discipline. An example was where Colette (case 1) was told by the clinical nurse manager (CNM) towards the end of her meeting 'now Colette, you are not to be going out of here saying you didn't get what you wanted, you know you can't live in a flat. You can go on holidays for a few days and that will do you'.

At the PCP meetings over half the attendees were paid members of staff significantly out numbering the family and the individual with intellectual disability. This straight away led to a lack of balance and made it difficult for the person with intellectual disability to have their voice heard. PCP meeting involved mostly paid staff. The person with intellectual disability lacked formal tuition in PCP. Key workers were inexperienced in conducting formal meetings which mean the person with intellectual disability was relegated to the position of a token participant. They continue to lack the support required to determine what happens to their personal information. In this study the PCP is described as 'a white folder' filled with personal information on the individual 'kept by the staff'.

There was an obvious lack of listening to the individual with intellectual disability at the PCP meetings that resulted in no response or a negation of the individual statements made by the person such as 'I want to grow a beard', 'I want my own flat', and 'I want to retire'. While it was likely that people were listened to in their everyday lives, within the confines of the PCP meeting this study found that there was a demonstrable absence of active listening. To be person centred requires an in-depth knowledge of the focus person. To understand another human being in terms of their thoughts, perception of the world, ideas about the future direction their life requires as a first step active listening to what the person is really saying.

A theme from the PCP meetings was one of token listening. In one extreme case, Anna (case 4) was removed from her PCP meeting as she was characteristically vocal and as such was perceived as hindering and interrupting the process rather than contributing her perspective. Further to this there were patronising tones and interjections from staff at the meetings who appeared to view the person's contribution as insignificant, unimportant and childlike. At two PCP meetings staff behaved opportunistically and used the PCP meeting to speak in coded dialogue to one another that left the focus person of the PCP meeting in a state of anxiety. This anxiety was caused by the person with intellectual disability being aware that they were being spoken about but

not being able to decipher the content and thus becoming really unnecessarily upset. While some people were included in their PCP meetings in only two incidences did staff use simple language and/or picture format to assist the individual's participation. The contradiction is that on the one hand the PCP is supposed to empower individuals to self determine while on the other hand it is inconvenient and presents challenges for the PCP meeting to really hear what individuals are saying.

Meetings typically took place in service settings lasting between one and two hours per meeting. There were missed opportunities to make use of ordinary places such as community centres, libraries or hotels to promote community inclusion, presence and participation. For the majority, the focus person had the benefit of and support of a family member. Typically, staff were represented from both day services and residential services varying from management to direct care staff. The number of staff outweighed the number of other participants at the PCP meetings and there was dominance at the meetings of paid staff members and a lack of inclusion of other people from the person's social network such as, friends, neighbours, and extended family members.

At some meetings, there was evidence of another agenda that was addressed in an obtuse way such as staff wanting to discuss issues but to exclude the individual with intellectual disability from the discussion. This maybe because people feel that there are issues unrelated to the PCP that require discussion. At the same time, they want to take advantage of the fact that everyone is present for the PCP meeting. For the person with intellectual disability this is confusing as it excludes them and is not very person centred. An example was where Ronan (case 2) was confused at his PCP meeting when his family and staff were talking in code around his behaviour and he thought that they were planning not to facilitate a home visit. Ronan who has an excessive anxiety around his dental care made the erroneous assumption that they were surreptitiously planning to take him to the dentist.

Many of the key workers described their sense of anxiety around having to perform at PCP meetings. Some complained that it was a 'bureaucratic exercise' and that they were 'going through the motions' to establish if goals were reached since the previous meeting. There was a lack of enthusiasm and almost a despondency that was unhelpful to the desired aims of the process. The key workers saw it as their role to focus on reporting on the goals that had been reached since the last meeting and list new reachable goals for the next year but in the absence of facilitating person centeredness of the lifestyle of the focus person.

There was an expectation that the key worker would inform those attending the PCP meeting as to what goals had been achieved in the preceding year and while the focus person was present (with the exception of one PCP meeting) there was little investment in preparing the person to give their own account of events. There was a tendency for the key workers to behave as if they owned the goals and to set goals that were at times of mutual benefit to them and to the focus person. An example is where the key worker set a goal of attending a rock concert of her choice rather than

Teresa's choice (case 5). Further to this, when goals were not reached the key worker invested in a blame game by putting the responsibility back on to the individual or back on management. An example was when a goal was set for Teresa to run the mini marathon and it didn't happen the reason put forward by the key worker was that Teresa did not partake in the necessary training and preparation for this event thus it was her fault. When Colette (case 1) did not get her own flat it was explained by the key worker as management's fault and when Margy (case 9) couldn't go to weight watchers 'finances' were blamed by the key worker.

5.2.3 There is a limited understanding of the aims and the purpose of PCP

This section will deal with the limited understanding displayed by the various stakeholders of the aims and the impact of PCP (summarised in table 6).

Table 6: Summary of limited understanding of aims and purpose of PCP

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
There is a limited understanding of the aims and purpose of PCP.	▪ As the person with ID has limited understanding and have no training in PCP they have little input into the process. ▪ Erroneous assumption that the PCP meeting is about whether they have been 'good or bad'. ▪ A learned helplessness that continues despite a PCP being in place. ▪ Rights as citizens limited. Limited understanding of SRV.	▪ Tend to view the meeting as a test of their interest. ▪ Distorted view of their formal status *vis-à-vis* the focus person. ▪ As family members have little exposure to PCP their responses can result in anxiety and fear.	▪ Mechanical attitude to PCP. ▪ Focus on activities rather than goals. ▪ Little creativity or initiative in crafting goals.

While the PCP concept is appealing to most, because it is about the focus person, it is very evident from this research that the various stakeholders came to the meetings with hugely different

understandings of the nature, purpose and responsibilities of PCP. These ranged from a passing acquaintance to an assumed knowledge but all were characterised by the lack of knowledge of the deeper philosophical rationale of true person centeredness. To illustrate this point the perception of one staff member was that because Ronan (case 2) was in care in a community residence that PCP goals were superfluous as his basic care needs was so well met. "Sure isn't he in care, and he has PCP as well". For PCP to work in the way it was intended people like Colette and Margy would not find themselves in stressful situations. Colette (case 1) looked to move to her own flat with support staff rapidly dismissing her telling her 'that you do not know when you have it so good'. Likewise, Margy (case 9), who clearly was enjoying her weekly attendance at weight watchers, was encouraged by staff to give up the activity in favour of a staff set goal - visiting an equestrian centre in order to have the therapeutic benefit of spending time with the animals.

The individuals in this study believe and know that they do not own their PCP. The folders containing the PCP's are usually located in a staff only accessible filing cabinet. Consequently, the person does not feel at liberty to read their plan or indeed write into their plan. When Colette (case 1) was asked what is a PCP she replied 'it is where they write down whether I have been good or bad'. When the research question, 'what is a PCP?' was posed none of the focus individuals gave accurate answer. Their answers reflected a naivety such as 'the white folder in the kitchen', 'I don't know' and 'goals'. There is training on PCP for staff but none for individuals with intellectual disability. They are expected to understand and know terminology and staff references to PCP.

As the focus person for the PCP people with intellectual disability in theory should have the greatest contribution to make to their PCP and to the meeting. In theory, when a PCP is in the process of formulation the individual should be supported in directing the process. The individual's interests and personal aspirations should be the foundation for the PCP and a source for signposting the future aims. However, this study found that the people with intellectual disability had little or no input into the process and staff offered goals based on what was to hand. Individuals cognitive restrictions some made the erroneous assumption that the PCP meeting was a vehicle for informing others about their behavioural status. Some individuals detailed a catalogue of recollections where they were invited to meetings only to investigate a misdemeanour or to give bad news such as someone has died or they will be moving to a different ward.

This study found that people with intellectual disability had very low expectations for any real change. One would wonder if this is a consequence of the fact that their voice has never really been heard. In the institutional setting one conformed to the regime and yet today we expect these individuals to be in a position to know and say what they hold dearly and what they want out of life. It is very understandable for people who have been institutionalised to be sceptical of the motives of the people who are caring for them.

This study found that there was a huge variation from the family member's perspective in understanding the aims of PCP. O'Brien (2000) espouses that family members should be included to give the family perspective on the individual and to energise the process given their interest in

the focus person. As Teresa's sister (case 5) stated 'I don't know much about PCP, but I do know my sister'. The confusion about their status ranged from siblings who behaved as if they were acting in *loco parentis* to those who had little or no involvement prior to the institutionalisation and were now being recognised as having a role to play in the PCP for their brother or sister. Furthermore some family members felt that if they demonstrated capacity and interest at the PCP meeting that they could be asked to take on more direct responsibility leading to further confusion, anxiety and fear.

This study found that family members required clarification around the aims of the PCP meeting because they had no source for any other information other than to ask staff. Some families felt that attendance at PCP meetings was a measure of their level of interest in their family member's life. Many family members were brothers and sisters and as the legal status of the next of kin is unclear. There was evidence of a distortion of their formal status. An example of how grossly distorted this view was, was where Margy's brother (case 9) stated 'I have cared for my granny for 15 years, I have my time done caring for people so I am not taking Margy'. In contrast to this was where Lee's sister (case 3) viewed herself as having total control of the aims of the PCP and her brother's choices of PCP goals.

Many staff take the time to talk to the focus person about their PCP. However, there is no consistent format or and no way of ensuring that the individual has grasped the concept as many people with intellectual disability acquiesce giving the impression that their understanding has greater depth. Some key workers have had the benefit of formal training in PCP while others have not. Notwithstanding this fact, some trained people continued to focus on the mechanical aspects of completing the information, recording activities in 'the white folder'. The perfunctory nature of some of the PCP meetings gives little deference to the aims and impact of PCP.

This study found that people are offered a range of PCP personal goals by their key worker and/or family member. Individuals did not set their own personal goals but had some personal gain from the varied activities that emanated from their PCP meeting. At PCP meetings the key worker revised the goals prior to and at their annual meetings in an exchange that reviews domestic participation and community presence. The key worker set activities rather than goals that were achievable with the aim of illustrating when the list of accomplishments were complete with limited understanding or creativity in goal crafting.

There was no evidence that the ten participants of this study exercised their rights as citizens, such as voting. Social role valorisation theory points to the importance for the individual's identity of having different purposes and functions in society from which one can derive their identity. For this cohort this is a piece of work that has yet to be considered. This study found an absence of goal setting around the importance of supporting people in new relationships and valued social roles. This deficit reflects missed opportunities to support personal freedom and social integration.

5.2.4 Different factors lead to resource limitations for each stakeholder in the PCP process

This section deals with the different resource limitations for each stakeholder in the PCP process and table 7 below summarises the many factors associated with this theme from the perspective of the various stakeholders.

Table 7: Summary of different factors that lead to resource limitations

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
Different factors lead to resource limitations for each stakeholder in the PCP process.	▪ Limited income. ▪ No control over income. ▪ Reliance on state benefits. ▪ Lack of security in housing.	▪ Multiple competing interests. ▪ Families are expected to comply with meetings scheduled.	▪ Group home with numerous people to care for 'a juggling act'.

Person centred aims with socially valued roles are important to all of us in terms of our well being and include relationships, financial, health care, residential, what you do during the day and socio-recreational pursuits. This research found that because the ten people are in full time care these domains, which able bodied take for granted, are compromised for the individual by the service context and staff behaviour. An example with regard to personal finances is that the ten people of this study do not have access to their own personal finances. Albeit that they have bank accounts and debit cards in their name in reality they are not at liberty to use them. Staff have direct control of the person's use of money.

In terms of choosing where they reside the individuals of this study availed of the opportunity to transfer to better living arrangements but in fact had no part in determining the location, type of residence, with whom they lived, or the staff that supported them. This also had an impact on their relationships. While people had interesting things provided in the special day services none of the ten individuals had supported employment or any job prospects. All the participants of this study are unemployed and as such rely on state disability allowances. This places them on the poverty threshold and therefore all ten people of this study group are technically living in poverty (CSO, 2011). All people lacked an opportunity to exert a real choice in how their day is structured and how they spend their free time. Interestingly, there is no time when these individuals have staff free time. People are brought to a range of day activities and day services. While it is good that they are active during the day their time and daily routine are orchestrated by staff with little input from the individual themselves.

For the person with intellectual disability there is an uncertainty about the permanency of their residential status. There has been a history of repeated moves within the system, primarily to accommodate the needs of others. All the respondents in this study demonstrated this concern. An account that highlighted this rather dramatically was given by Teresa (case 5) who told the researcher that she left her community residence one morning to attend her special day service but the provided transport brought her back to a changed location later that evening. She found that all her personal belongings and affects had been packed for her and she was expected to re-establish herself in a completely different house in a completely different location with completely different people. This was done to suit the needs of another client who, due to ill health required the use of a single room, Teresa's single room. This was verified by Teresa's sister and key worker who gave testimony of the unsettling impact that this action had on all parties.

Families vary and this study found that three of the ten had very elderly parent's surviving with significant health restrictions. Siblings of the focus person of this study were seen as successors to their parents and as such are invited to PCP meetings. Many siblings had busy lives including careers and families of their own. These factors served to limit their availability to participate in PCP and in the lives of their family member with disability. Key workers scheduled meetings at times that suited staff to be rostered and in venues that were easily accessible by staff but little accommodation was made to hold meetings at times and venues that might have suited family schedules better. Despite the harsh economic climate, families were happy to incur personal costs to be part of the PCP process. Some families demonstrated an enduring commitment despite institutionalisation.

Examples of person centred lifestyles in community residences would be supporting various lifestyle choices such as when a person goes to bed at night, when to get up in the morning, what foods they are supported in preparing for their mealtimes, and what community activities they are engaging in specific to them. There was evidence that some institutional practices continued when the focus person transferred to a community residence. The efficient running of the community residence which is based on the commonality of the level of support that the person needs is paramount to individual person centeredness. For the key worker this means that they have to juggle the competing needs of the other house mates with the person centeredness of the focus person which is an impossible task. A difficult dilemma, as one role seems to cancel out the other?

5.2.5 The consequence of resource limitations are reliance on special services, fear of additional costs and routine activities in PCP

Table 8 below summarises the consequences of resource limitations including reliance on special services, fear of additional costs and routine activities in PCP.

Table 8: Summary of the consequences of resource limitations

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
The consequences of resource limitations are reliance on special services, fear of additional costs and routine activities in PCP.	▪ Relinquished to special services. ▪ Lack of experience of using mainstream services, venues and activities due to limited finances. ▪ Frequently subsidise the costs that staff and others incur.	▪ Satisfied with routine activities within special services. ▪ Due to a limited investment in PCP training for family members there is a lack of belief that the person with intellectual disability has a right to access life in the mainstream.	▪ Focus on achievable activities rather than aspirational goals. ▪ Limited by what they view management to be compliant with. ▪ Reliance on the comfort zone provided in special settings.

Special services exist for the life span for people with intellectual disability. These include special pre schools, special schools, special workshops, special sporting and recreational events and even special retirement programmes. People with intellectual disability and staff working with them derive a certain comfort and security from familiar contexts and familiar people within these settings. Using special services is often very practical, convenient and self perpetuating. While special services have a palpable comfort zone for family, staff and service users they are in fact an example of how people with intellectual disability have been systematically segregated since the inception of institutions. PCP, which should include goals that reflect community inclusion, can act as a conduit to reduce the reliance on special services and increase the opportunities for community participation. In current practice the system of special services for people with intellectual disability co-resides with the philosophical aspiration that people with intellectual disability be included in the mainstream of society.

This analysis demonstrates that the link to community inclusion is a weak and tenuous one. An example of this is where Killian (case 7) described how he was participating in a drama group in the local theatre in his town but yet on probing it transpired that he did this with a group of people

with intellectual disability for family members and other people with intellectual disability as opposed to for the general public. Even when people went out for an evening meal it was typically with other service users supported by a minimum of two staff. Likewise when they attended religious services in the local parish they did so with other people with intellectual disability. They were brought in special vehicles and were supported by care workers and nurses.

The value base espoused by Robertson (2005) points us in the direction of the use of mainstream facilities and services as opposed to special settings and services promoting inclusion of the individual in an ordinary life in the community. Yet we still have a backdrop of segregation and reliance on the use of special places and services. This is evidenced in the goals configured in the ten PCP meetings under scrutiny for this study. It can be concluded that the appeal of special services lie in what is familiar because it protects and minimises any challenges. It also has the benefit of keeping people safe, reducing the risk and protecting them from perceived dangers. Regrettably, by retreating to special services this has the undesired affect of keeping people with intellectual disability at a distance from mainstream society and as such deprives them of their civil liberties.

Robertson et al (2005) saw PCP as having a day service component as important and in all of these cases people had something to do during the day. The individuals in this study were exposed to a range of activities in order to enhance their skills and provide them with meaningful hobbies. It is quite possible that these skills and hobbies can readily be applied to community based settings. If someone can do horticulture in the therapeutic farm in the special day service venue it can easily transfer to gardening in a community allotment. While people have the skills to engage in activities it is now about enabling them to display these skills in the mainstream of ordinary life. A finding of this study is the challenge of how to prompt a movement from special services to true participation within the community for the individual with intellectual disability through PCP.

This study found that the cost associated with activities that were represented as goals of PCP had to be borne by the person with intellectual disability. An example of this was where Teresa's PCP goal (case 5) was to attend a concert. While Teresa required supports in order to attend this concert all costs including the ticket for the key worker were subsidised by her. This practice affects the key workers decisions around goals which are limited by the restricted income that the individual has as they have to also bear the associated costs for the support staff they need. Furthermore, the relationship is tainted by the absence of the normal reciprocal social dimension that would you find in typical friendships where people take turns in hosting activities and where there is a balance in covering costs. An activity goal of simply going out for a meal results in the person with intellectual disability also covering the cost of what the support staff consume making this an expensive activity which was found to be a common goal in all the PCP's of this study.

For family members of people who have been in life long care there is an expectation that all living costs are free at the point of delivery. An example of this was where Paddy (case 10) who lived

independently at home for the most of his life but ended up in institutional care following the traumatic removal of all his teeth. For the occasion of his sisters eightieth birthday Paddy was brought to an event as a patient with the nurse manager who also took part in the celebrations. By her very presence Paddy was not seen as an autonomous individual capable of participating without support. This further marginalised him and limited his participation and contribution to the event. The family members in this case were left to feel grateful that the staff took the time to bring Paddy to the party with no expectation that Paddy had the capacity in his own right. Ideally, if he had been supported in a person centred way he could have been guided in making a financial contribution to the event and the support staff could have minimised the style of support given to enable him to in some way fulfil his role as a family member versus that of a patient.

The practice of the key worker setting special goals seems to be a pattern. Individuals tended to be offered goals that were in the context of special services which in effect limited their community participation and kept them within the confines of special services. In this study, for instance, where Anna (case 4) who attended Mass regularly and had a vocalising behaviour but was no longer brought to Mass by support staff as they perceived her to be upsetting the other people in the group and as such religious services were brought to her in the residential setting. Another example was where Margy (case 9) attended a local community group but this involvement was discontinued by staff as they believed that she could not afford it and was instead brought to special services. This has the consequence of limiting inclusion and participation in society and further distancing the individual from community inclusion and participation. There was evidence of a range of missed opportunities. It seemed that there was a mismatch between the staffs philosophical value base which reflected maintenance and the further development of special services versus Robertson's (2005) conclusions of the importance of community inclusion and participation.

A common goal identified by the key worker at the PCP meetings was the activity of arts and crafts. If a member of the general public decides to pursue arts and crafts they register for the course with the local VEC, however, the individuals of this study were found to be attendees of arts and crafts programmes with other people with intellectual disability in special disability day centres to which there were no fees attached. Likewise, people who were interested in swimming typically attended with the Special Olympics group rather than attending the public sessions. The discos and dances that this research group attended were those run by the local parents and friends of the intellectually disabled versus those in night clubs and cabaret acts in hotels, entertainment centres open to the general public and leisure centres. This has the disadvantage of further segregating people based on their disability. It limits their opportunities to meet other people in their community. At one level they don't have to pay for these activities yet at another level it limits their social role as a customer but makes it more convenient for the key worker. For the key worker these activities are all achievable. They are things that can be pointed to and that they can actually say it is done but this style of goal setting does not reflect any deep aspirational personal goals set by the individual.

5.2.6 Emphasis on duty of care leads to risk aversion in PCP goal setting

Table 9 below summarises the emphasis placed on duty of care that leads to risk aversion in PCP goal setting.

Table 9: Summary of emphasis on duty of care

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
Emphasis on duty of care leads to risk aversion in PCP goal setting.	▪ Little or no 'dignity of risk'. ▪ Emphasis on keeping the person safe and cosseted rather than exposing them to new and different opportunities. ▪ No opportunities to self medicate. ▪ No key to their front door.	▪ Over reliance on professionals 'who know best'. ▪ Families need permission from staff to engage with the person with intellectual disability.	▪ PCP becomes confused with the care plan. ▪ Struggles with competing roles. ▪ Contented with performance.

The people in this study are well cared for and nurtured from a physical perspective but because families and staff regard this population as being 'childlike' and 'not capable of making decisions' they are not afforded the dignity and respect accorded to a non disabled person. Staff perceive the service settings as hospital like and where nursing care is prioritised over supporting people to having meaningful lifestyles. There is trepidation, characteristic of staff caring for people with intellectual disability, around offering them the dignity of risk taking, albeit in very simple things. An example is Teresa (case 5), who in the past made international flights independently, and is now dependent on staff who perceive her as requiring their assistance to access the town. This is understandable but it has the consequence of limiting her personal freedom. Another example was where Colette (case 1) wanted to live in her own self contained apartment but was regarded by staff as incapable due to her medical frailty. So rather than considering what supports Colette needs to realise her life goal of living independently staff reverted to insisting that Colette's needs could only be met within the medical model of their service provision. This illustrates how staff avoid the dignity of risk for Colette in favour of more restricted lifestyle. This provides a sheltered cosseted regime of care that has the consequence of reduced exposure to new and different opportunities for the individuals.

This study found that many of the individuals appeared to be systematically disempowered to the extent that they lost life skills and were deflated when articulating their own personal goals. The life skills lost include competencies in activities of daily living such as food preparation, laundering clothes and home craft. They make use of their immediate environments moving freely around their house with staff placing restricted access to the kitchen areas. An example was where Teresa (case 5) stated regarding domestic activities 'sure we are not allowed to go near the cooker', yet Teresa would have been capable of cooking and baking safely.

It is encouraging that people in this study have good health and are secure and safe in their community residence. This study found that there is an emphasis on keeping the person safe and well. This takes precedence over giving people the dignity of taking small calculated risks directed at building their confidence and skills. They are currently experiencing continuity of care in their residence, a sharp contrast to their previous live experiences where they were moved frequently from ward to ward. The expectations of all the stakeholders in PCP are set very low. Some families present as satisfied with the level of service to their family member. They expressed delight because of the improvement in their current living circumstances over the previous endured institutional care.

While all stakeholders are pleased with their current standard of living the emphasis on maintaining their care status leads to risk aversion. In this case there is trepidation about moving people to more person centred lifestyles. An example was when Ronan (case 2) stated at his PCP meeting that he wanted to retire to his home village. His family members disregarded this stating that he 'wouldn't manage' and 'staff knows best'. In the case of Gary (case 6) his family were distanced from him as they were growing up and they lost all sense of participation in his life. They had unquestioning trust in the perspectives of the professionals and assumed that they had to ask permission to be with their brother.

This study found that none of the individuals in this research project were assessed regarding their capacity to self medicate. This is another example of where the duty of care leads to risk aversion. There are current trends in intellectual disability services to assess individual's capacity to self medicate which was missed in these cases. Efforts to self-medicate are helped by pharmacists who will issue medications in very convenient blister pack colour coded format to make it easier for individual's to understand the mechanistic process of date, times and correct dosage. Regrettably for this population the international consensus on good practice guidelines (1998) on the use of polypharmacies appears to have been ignored. These guidelines are very clear and give helpful step by step instructions on the use of psychotropic medications for people with intellectual disability. In reality their healthcare is overseen by staff nurses. As they are all medical card holders their choice of GP is contingent on local practitioner's capacity and willingness to take them on thus restricting their choice of doctors.

With a certain degree of circumspection it is encouraging that this group gave no accounts in their current community residences of physical or sexual abuse. However, considering the UN Charter

on Human Rights there are examples of people's rights being limited. The staff that support them restrict them in the name of protecting them from hazards to the extent that most of the individuals in this study reported not owning a key to their front door, another example of risk aversion.

This study found that the key workers confused the care plan with the PCP as they are two documents within one folder. The care plan comprises directions on all aspects of care for the individual with intellectual disability. It is an itemised list of all the requirements to keep the person healthy and well from a clinical perspective. The care plan for these ten individuals is merged with the PCP despite the different ideology, the care plan being medically based and clinical whereas the PCP is not a clinical tool but rather philosophical and aims to promote the individual's self determination and socially valued role. In practical terms as the care plan and PCP are merged within one folder it is understandable that key workers struggle with the distinction as the care plan comes first and it influences the content of the PCP so that the medical care needs overshadow the more person centred aspirations. Furthermore, the key worker for the individuals PCP also has direct care duties for others that typically take precedence over the more person centred agenda for the individual for whom they are key worker.

5.2.7 Individual differences and local variations impact on the efficacy of PCP

Individual differences and local variations that impact on the efficacy of PCP are summarised in table 10 below.

Table 10: Summary of the differences and local variations on the efficacy of PCP

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
Individual differences and local variations impact on the efficacy of PCP.	▪ The higher cognitive functioning person can make verbal contributions and participate in their PCP but goals not always realised. ▪ The higher functioning person can put forward a more mainstream personal agenda. ▪ Through PCP visits arranged to siblings home but not the persons home.	▪ The greater the capacity and freedom from other commitments of the family member the more participation in family life is possible. ▪ Confusion on the status of legal guardian. ▪ Confusion on the status of next of kin. ▪ Seen as a patient requiring care not as a citizen with full participation.	▪ The status of the key worker affects their power to deliver on the specific activity goals. ▪ The status of the staff as key workers varies. The power and control lies in the hands of the staff and they decide whether a goal is realised or not. ▪ Personal characteristics influence the PCP. ▪ Key workers will edit goals in line with what they can deliver on. ▪ Limited use of IT and TC at PCP.

Three of the ten participants of this study had restricted expressive language. They lacked a capacity to make a verbal contribution to their PCP meeting illustrating the variation in the contribution style of the individuals. However, even for those seven of the ten participants who had expressive language their contributions to their PCP meetings went unheard. Despite being able to describe their own personal aspirations there was little evidence that their remarks were taken seriously enough to impact on the efficacy of the PCP. An example was where Margy (case 9) has repeatedly protested being made to live with other people with intellectual disability stating 'I am not

like these, I am not handicapped'. Yet she spends her days and nights in congregate settings for people with intellectual disability. Anna a non verbal older woman (case 4) always enjoyed going to church but because she has the tendency to vocalise loudly staff regarded it as inappropriate to bring her to Mass so she now misses out on this opportunity.

This study found that the higher functioning person can put forward a more mainstream personal agenda. Despite their capacity to articulate ordinary aspirations 'I want guitar lessons', 'I want to go to weight watchers' and 'I want to grow a beard' the realisation of these simple goals was not a priority of the key worker and eluded the person.

Four of the ten participants had regular visits home or to the home of siblings. A further two had visits to the homes of family members with staff supervision. It has to be acknowledged that when staff accompany a person with intellectual disability on a visit that this impacts on the quality and texture of the visit. One consequence is that a conversation takes place over the head of the person with intellectual disability rather than with them and the visit is on the terms of the staff and their rostered duty hours.

While some family members demonstrated a tremendous love and interest there is role confusion about their status in relation to their family member. Some parents of adults with intellectual disability perceive themselves as their legal guardians but in Irish law this is not the case. This means that in effect parents cannot legally make decisions on behalf of their family member with intellectual disability. Individual differences noted that some of the siblings who were the next of kin for the individuals of this study held the view that they acted in *loco parentis* and as such held the erroneous assumption that they had the decision making power over the lives of their family member. Worse still is when the service provider viewed the subjects of this study as 'their patients' rather than autonomous citizens.

Another individual difference is that some of the key worker had the benefit of training and/or someone to mentor them in PCP. In some cases the position held by the key worker in the services seemed to influence the quality of the PCP. If the person felt that they had decision making powers without having to go to senior management to arbitrate on things this led to ease in developing reachable goals. Whereas if the key worker was low ranking in the services they would have to ask for permission to undertake activities related to goals because of their sub-ordinate position. This confounds the PCP process because it becomes more about what the system can support rather than what the individual with intellectual disability aspires to. In reality, when goals are not endorsed by management they are typically edited until the system has the capacity to deliver on them. An example was Killian's goal (case 7) to take guitar lessons which were available to him on Saturday mornings. However, this goal was deemed unreachable because of the staffing levels. Instead of questioning this, it was accepted at every level from the person themselves, to the key worker, to the family member and to management.

The personal attributes of the key workers interviewed seem to suggest that if the key worker possess characteristics such as confidence, decision making skills, a positive outlook and an underlying person centred attitude then the PCP is likely to be a better fit with the focus person. An example of this was Lee's key worker who stated "I can get on with it, once it is in Lee's best interest, it is alright, no one interferes with us and we have a great time". Because the key worker's interests lie in outdoor pursuits such as clay pigeon shooting, carting, fishing and archery he believes Lee has the benefit of experiencing all these things with him and Lee himself can choose afterwards whether or not he wishes to pursue them. The next logical step in PCP would be for Lee to avail of these activities without his key worker as the key worker's role now is to build on the activities that Lee has chosen and the natural circle of supports should take over with people who have similar interests engaging with Lee and hopefully providing him with the support he requires at that time. This is the direction that PCP should be going.

Individual differences and local variations were found in the use of technology at PCP meetings. While some individuals do have some voice in that they have a basic working vocabulary the key worker fell short (with the exception of Killian and Lee's PCP meeting) of providing an alternative such as picture format, sign language and assistive technology. There was only evidence of this being used in Lee's PCP meeting which was presented in a PowerPoint presentation and Killian's PCP meeting which was presented in picture format. The other factor is that when people lacked the insight to speak in a manner that would be readily understood by the focus person, such as speaking slowly, using simple rather than complex sentences, and in using a de-jargonised vocabulary that would be familiar to the person. Good practice indicates that Total Communication (TC) should be used in everyday discourse with people with intellectual disability who have restricted language. This approach suggests using signs and gestures such as LAMH (hand signing and gesturing) and the simple spoken word supported by pictures (photographs or line drawings). There was no evidence of TC being used by the key worker at any of the PCP meetings which really limits deep reciprocal communication with the person with intellectual disability. One could conclude that the key worker sees themselves as 'knowing best' and their preoccupation with providing wrap around care acts as a barrier to any effort to engage at a deep level and to get to know what the person is actually thinking.

It transpired that during the course of this study that the lucky few individuals who had an adept key worker assigned to them ended up with more robust and personal PCP's. Despite the fact that key workers are represented at all levels of employment ranging from care staff to nurse managers, an overriding theme was that the personal attributes of the key worker is helped by the status they hold within the hierarchy of the organisation. However, a finding of this study is that PCP's typically reached a plateau of a circular flow of activities in special places for special people confined by risk aversion and the maintenance of the status quo.

5.2.8 PCP promotes community presence but falls short of community participation

Table 11 below summarises the many factors associated with PCP promoting community presence but falling short of true community participation for people with intellectual disability.

Table 11: Summary of PCP that promotes community presence but not participation.

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
PCP promotes community presence but falls short of community participation	▪ Activity driven with an emphasis on increased activation. ▪ Special places equates to a place apart. ▪ Institutional practice limit lives. ▪ More personalised objects in their lives. ▪ Domestic participation increased.	▪Has brought families together in venues that are more socially desirable. ▪Happy and uncritical with current community lifestyle that lacks community participation. ▪Easier to be involved.	▪ Key workers have done a good job in creating opportunities for activities. ▪ Satisfied with token community presence. ▪ Choice promotion at micro but not macro level. ▪ Community presence perceived as the ultimate achievement. ▪ Institutional practices in the community continue to limit lives.

Robertson (2005) eloquently articulates a function of PCP as promoting community presence and community participation. However, in these cases there was an ongoing reliance on special service settings. While people's houses were located in the community, this gave a community presence but because the activities listed as goals in the PCP were by in large limited to special settings this acted as a barrier to community participation. This service practice contradicts one of the functions of PCP and demonstrates that albeit that people have physically moved from the institution to the community the fact remains that many institutional practices continue to limit their lives.

PCP meetings heard that people participated in purchasing food when they went shopping, participated in food preparation of their choice, eating healthily and enjoying mealtimes. This

represents a huge improvement over the institutional practice of central cooking and people being served the same meals at the same time and in the same place irrespective of individual's preference. This finding confirms that for the ten people of this study they have achieved domestic participation. Albeit that PCP's ensure a high level of activation and community presence the reality is that people still live in special houses that are a place apart from the community. They spend their days in special centres which have moved from the institutional settings to the community but they remain separate special facilities. This study found that PCP promotes community presence but there is ample evidence that it falls short of community participation.

Families reported finding it easier to be involved with their family member now that they had moved from the institution to places in the community. An example was when Paddy's niece (case 10) reported how difficult it was for them as a family to visit him in the institution but now that he is living in a community house they find it a lot easier 'it was like going into a prison, now we enjoy coming to his PCP meetings, even my brother visits him here now'. This study found that the institutional regimes were abhorrent to family members. When the people in this study moved to the more familiar group home context of service provision, families were delighted with their increase in community presence. They were uncritical of the lack of any demonstrable community participation and were so appreciative of the improvement of their family member's current lifestyle that they made little demands for further improvement. All family members of this study stated that they were happy with everything that their family member was being provided.

The key workers have succeeded in increasing the level of community presence in so far as this study found that individuals with intellectual disability were brought to a range of varied and interesting places. They were brought to use restaurants, pubs, cinema and points of interest. Further to this the range of activities with other people with intellectual disability in community settings also increased. In the context of the community residences there was a positive emphasis on promoting choice at a micro level in that they could chose what to eat, what to wear and what to watch on television but not at a macro level of choice such as where they live, with whom they live with and how they spend their time. This study found that the key workers did not make the distinction between community presence and community participation and they regarded it as adequate that people were now in the community, a big improvement from the institution and in their eyes this is the ultimate achievement.

5.2.9 Positive impacts of PCP

Table 12 below summarises the many positive impacts that PCP had on the lives of the ten people of this study. All of the people considered for this study had PCP in place that had moved with them from the institution to their community based residence and there are records of annual PCP meetings occurring for each individual.

Table 12: Summary of the positive impacts of PCP

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
There are positive impacts of having a PCP in place	▪ Personalised items to hand. ▪ Improved lifestyles. ▪ Holidays. ▪ Person with intellectual disability attends PCP meeting. ▪ People lead busy lives and are occupied. ▪ Benefits to the person in preparing for their PCP meeting. ▪ Outings are life enhancing.	▪PCP first point of re-engagement. ▪Happy about improved circumstances. ▪On a learning curve about PCP. ▪Learning about contemporary approaches and recovering from the legacy of institutionalisation.	▪ They spend time considering the person. ▪ Meetings act as a prompt for staff. ▪ They do more in the community. ▪ Learning curve about PCP. ▪ Realise the benefits of offering choices to the person. ▪ Realisation of the potential of PCP. ▪ Incremental improvements in the quality of the PCP.

This study found that in the context of the PCP meetings it was reported by staff that people with intellectual disability now took a certain amount of pride in their possessions in that they could store them safely in their bedrooms knowing that they would not be touched or damaged. Efforts were made to support the person in personalising their room with photographs and memorabilia. This is reflected in Anna's PCP meeting (case 4) where it was reported that she now has pictures, jewellery, handbags, makeup and money. While these may appear trite, to go from having no personal possessions to owning your own personal affects represents a huge personal gain for the individual and is a first step towards person centeredness.

There was evidence from this study that the PCP have led to improved lifestyles and clear evidence of increased opportunities to engage in new and different activities. All of the ten people

have had a holiday of some sort and for Lee (case 3) he has had a continental holiday. Family involvement is at a very elementary stage but hopefully as family members attend PCP meetings they will come to learn more constructive ways of adding value to the relationships dimension in the person's life which was negated in the past.

In this study the PCP meetings for the individuals with intellectual disability did serve to enhance the status of the focus individual by virtue of the fact that nine out of the ten individuals were in attendance at their PCP meeting. This is an improvement in the way that business was conducted in the past where discussion was about people rather than with them. While the focus of the PCP meetings was on activities and a perception on staff's performance this is an essential first step in building on person centredness. There was evidence from this study that PCP acted as a prompt for staff to think about the range of activities available to the individual and there was some evidence that people got to experience and try new things in the community. An example is that Lee (case 3) enjoyed riding a quad bike with his key worker and other adventures. Teresa (case 5) got to a rock concert with her key worker and people were brought to hotel breaks. The PCP meetings generated a varied list of activities and events for the purposes of keeping the individual occupied and with interesting things to look forward to. The fact that people were typically brought out on excursions away from the community residences such as going shopping, going out for meals, going to Mass and visiting points of interest was in itself life enhancing. There is no doubt that this has enhanced their community presence illustrating the positive impact of PCP.

The positive impact of their increased community presence is that people with intellectual disability are beginning to be recognised, albeit peripherally such as a person going into a shop with staff and seeing members of the public, However, ideally this should be seen as their first step as customer, parishioner, neighbour and friend. The PCP meeting acknowledges the need for people to have privacy and personal affects that reflect their individuality. One of the findings of this study is that the individuals are all living with smaller numbers of people with more privacy and people tend to have their own room or at most to share with one other. All the people in this study now have their own personal possessions including items of clothing and personal hygiene products along with personal memorabilia such as family photographs. These tangible items add to the understanding, individuality and personal integrity of the individual. It is unclear whether this is as a result of PCP or is simply a consequence of living in a more comfortable domestic setting with smaller numbers of people.

For this study eight of the ten families of the focus person were in attendance at the PCP meeting. For some, coming to the PCP meeting was the first point of reengagement with their family members since they left the large institution. The families were not initiated into the PCP process. The information that they were given was limited to the key workers verbal account of his/her understanding of their participation of PCP meetings. As the PCP process is rolled out it is gaining momentum with families. It is being viewed by them as an opportunity to learn about their family member's activities, interests and current lifestyle. They are also learning more about the potential of their involvement in PCP. Further to this they are learning about the contemporary approach to

improved service provision and service systems. While many families had tremendous personal disdain for the institutional approach to caring for their family member this study found that they displayed a renewed trust and appreciation for a person centred approach. An example is in the case of Gary (case 6) whose family initially, defensively sought to clarify what was expected of them but later in the process, having attended meetings and gaining clarity and understanding of PCP, were 'more than happy to be involved in his life'. For the individual with intellectual disability this is a very important step in their life and a relationship that hopefully will be built on and developed with them central to their future.

On another positive note, the PCP meeting does bring together a wide group of people with a stated objective of being person centred. The key workers moved from the institutions to the community based residences. These were the same people that carried out PCP in the institution. It was difficult for these key workers to see the benefits of PCP in an institutional setting but now that they have moved to a community setting this study found that some key workers are finding the process satisfying and as a result the quality of the PCP are improving. While key workers endeavour to offer people choices it has to be acknowledged that these choices are currently limited to basic choices such as 'porridge or cornflakes' rather than choices of where and with whom they live. By way of preparation for the PCP meetings key workers typically spend time considering the person's life in detail with the focus person in an informal and unstructured way. This research found that there were benefits accrued by the individual in the preparation for and the lead up to the PCP meetings. There is an effort to make sure that the focus person is relaxed, informed and well presented for their meeting. The PCP meeting did illustrate an important role in information sharing if only about basic functional aspects of the individual's life. Many key workers have the benefit of in-service training and education on the principles of PCP. As they gain experience in developing PCP for people with intellectual disability the quality of the PCP should improve. As services develop so too will the in-service training.

Chapter 6

Discussion

6.0 Discussion

This study followed the lives of ten people who resided in large congregate care intellectual disability settings prior to and after their transfer to small scale community residences. A chief aim of this study was to consider how the lives of people with intellectual disability have benefited from having a PCP particularly in the context of their new lives in the broader community. This research has shown that being born with a disability can in itself impose dramatic challenges for the individual and their support network. But what happened to the ten individuals of this study, in the name of actually helping them, was that they were placed at a further disadvantage on their removal from the family and the mainstream of society. This practice was in keeping with policy in Ireland at that time where individuals with intellectual disability were deemed better off and treatable in institutional settings (Robins, 1986). Already vulnerable they were placed in circumstances that left them exposed to risks of maltreatment and abuse (Johnson et al, 2005) in an institutionalised atmosphere where institutional practices were the antithesis of PCP.

For the group of ten people with intellectual disability included in this study life events have cast a shadow on many aspects of their lives such as their capacity for happiness, their personal security and paucity of opportunities to develop socially valued roles. In reality, the lives of the people in this study were marred first and foremost by their disability coupled with events such as the death of a primary carer, their challenging behaviour, mental health issues resulting in institutionalisation early in life. Already vulnerable, they were removed from family life and subjected to harsh regimes of care practices, disempowerment and depersonalisation within an institutional setting.

The Government of Ireland published a review of the psychiatric services entitled Planning for the Future (1986) which recommended that people with intellectual disability then residing in psychiatric services move to de-designated services under the community care programme. This change in government policy resulted in the majority of this cohort moving to designated intellectual disability services in 1989 and in this study this move was to a building adjacent to the psychiatric hospital. For many subjects in this study this led to their languishing in inappropriate settings.

In the present circumstances the person centred process requires the previously institutionalised cohort to direct their own lives. The PCP process has the expectation that families would re-engage. In the past they were deterred from being involved believing that this would upset or confuse the individual with intellectual disability. These families are now asked to participate in a person centred way. This dramatic shift in policy and practice brings with it a complex array of unresolved questions and issues for the person centred process.

A file search coupled with individual accounts revealed that seven out of the ten participants reported being beaten and punished for simple things such as not been able to perform at a basic academic level. Some people also reported through their PCP the use of corporal punishment as sometimes excessive. This practice was common in Ireland prior to the ban of corporal punishment in the early 1980's. Almost half this sample gave accounts of sexual abuse occurring

in the institutional setting and elsewhere. While these accounts of abuse span from the 1940's to the late 1990's they were processed and dealt with according to policy and practice of the time. It is only in recent times that we have the benefit of a precise protocol in reporting, screening and investigating allegations of abuse of vulnerable adults (HSE, 2009).

The practices and policies at the time called for the institutionalisation of people who were different by way of what was then known as 'mental handicap' and 'mental illness'. The current thinking in person centredness enshrines the concept of promoting choice and self determination (O'Brien et al, 1981). It is interesting to note that none of these people had a choice of what happened to them when they were removed from their families. They were the subject of decisions based primarily on their disability which were deemed as needing treatment in special facilities available at that time. The reality was that for this study group their personal identity was fractured not only from their families but also their communities. One of the functions of PCP endorsed by SRV theory (1983) is to help the person with intellectual disability reconstruct a personal and social identity enabling them to now live a life of their own, crafted by removing physical exclusion barriers of imposed segregation.

The people in this study all had PCP's while living in an institutional setting. This study considered the robustness of the PCP now that all these people had moved to a community setting using Robertson's (2005) six indices of PCP efficacy. These are 'increased activities, scheduled day services, contact with family, contact with friends, social networks and promoting choice'. The findings of this study concur with Robertson's theory in relation to some of the six indices that he expounded. In considering PCP for the ten people with intellectual disability in the cross case study analysis it is encouraging that all ten individuals have current PCP's in place living in a community setting. These PCP's generate a varied list of activities that bring added value to their lives by increasing community presence, as also found by Robertson et al (2005), and provided interesting things for them to do, thus enhancing their quality of life. The PCP's bring people together including staff and family members to assist in crafting new goals from one year to the next. They also provide a format for families to engage or re-engage in a constructive life enhancing way for the person with intellectual disability which is also in keeping with the findings of Robertson et al (2005). The cross case analysis for this study found that for people with intellectual disability there are some beneficial affects of having a PCP. For the ten focus people PCP has stimulated the establishment of a sense of community presence.

For people with intellectual disability this study found that their understanding of PCP is limited to a very tangible reality of the 'white folder'. Further to this, when the focus person speaks at PCP meetings their contributions are often not considered as important. Instead of the key worker building on their comments, efforts are made to redirect the individual towards agreeing goals that the service can easily deliver on. This strategy obscures the person's personal self-direction. This strategy is a contradiction of the good practice guidelines put forward by the PCAS (Mansell, 2009).

In keeping with Schalock's findings (1994) this study also found that as well as moving people from the institution many institutional practices moved with them as one would expect when staff and residents move together from institutions to community settings. Regrettably, institutional practices in the community blur the objectives of true person centredness. This is borne out by the finding that the people in this study are not in control of their lives, a finding that mirrors Kendrick's (2007) assumption that people congregated on the basis of their disability are robbed of opportunities to self determine as their lives are controlled by paid staff. There is an externalisation of control and the reality is that the staff determine the lifestyles for the ten individuals considered here.

This study of the PCP process also saw that many of the goals set were set in the context of special activities and special facilities, 'special goals' for 'special people'. This practice negates the opportunity for people with intellectual disability to enjoy mainstream activities and share in the ordinary life of the community. SRV theory refers to this as Image Juxtaposition holding that society knows people by the groupings they present with. Staff opt for the convenient choice of 'special services' and 'special venues' but for the individual who is the focus person of a PCP this comes with a heavy loading in that this limits their access to mainstream opportunities and perpetuates their personal image as a service recipient. This study found that the PCP process undertaken for the ten individuals overlooked the significance of supporting the person to have valued social roles.

PCAS recommend that the individual focus person be supported in the nuances of the reciprocal aspects such as supporting the person in doing things for their friends and family members the same as a non disabled person. After all, who of us would develop a friendship with somebody who never reciprocated? With PCAS the person can be supported to behave in a balanced and mutually supportive manner. While families were invited to attend PCP meetings there was no evidence of supporting individuals to enhance their relationships with their family in a reciprocal manner and as such lacked authenticity - also noted in Kendrick's findings (2007).

It is encouraging that people with intellectual disability are residing in comfortable domestic scale houses. However, this study found that irrespective of the care setting, people with intellectual disability provided with these residential care arrangements continue to lack personal control and security. This finding is in keeping with O'Brien (1994) that you are vulnerable when you live in a house where you have no legal ownership or tenancy agreement. He found that what typically happens is when other people need services or the person becomes more disabled through age related illnesses they are involuntarily moved. Some of the individuals in this study reported that they were moved from house to house without prior consultation with them or their families. The fact remains that people with intellectual disability in residential care are on the receiving end of decisions that are system-led rather than directed by the person centred agenda. While security of residence is important to all of us it is all the more important for the people with intellectual disability of this study who are marginalised and who have previously experienced maltreatment and abuse.

The good thing is that people are engaging in the process of PCP with a degree of enthusiasm involving all of the stakeholders. PCP is something that is in every day conversation and people are confident that they know what PCP means and aspires to. Because the words are simple and straightforward it belies the deeper philosophical challenge of knowing the focus person and empowering that person to self determine. PCP calls on a range of people to partake in the process in a way that is going to be mutually beneficial for the focus person. While PCP's by their nature should be unique to the individual and display a variety of styles so should the role of key workers, families and support workers. This study found that there was a distinct confusion about how a key worker could exercise the potential of their role. This confusion was also evident in the families understanding of their role in PCP and in some cases their participation was conditional. An example was where one family requested confirmation that they would not be expected to take on direct care if they participated in the PCP process. Most of the families thought that their role was to attend the meeting in order to learn about the activities and behavioural status of their family member.

This confusion confounds the PCP process especially as families also struggle with the many other issues that ensue on foot of the person's disability such as anxiety, guilt and worry. In the literature on PCP there is a dearth of information on the role of the key worker and family members in the PCP process. This maybe because of the philosophical assumption that each PCP should be unique to the individual so there is no rule book on how to do it as this would lead to uniformity and conformity in plans which O'Brien held out as undesired. If it was only as simple as turning the light switch of person centredness on! This study found that the key workers were typically very good at the mechanics of PCP including record keeping of goals and attainments, crafting goals that were concrete and attainable in the short term and goals that involved the focus person in activities that were both familiar and novel. The role confusion became evident by the absence of any goals that were a direct response to the aspirations articulated or otherwise by the individual. Goal setting at PCP meetings was about itemising, on behalf of the individual, activities that were in the scope of the key worker and special services to deliver on. They were typically restricted to safe and self perpetuating activities. Staff have a duty of care to ensure that the individuals entrusted to them are at all times safe and protected from hazards and danger. The duty of care extends to promoting good health and limiting as far as possible all risks. While on the one hand this offers the ultimate in safety and protection it has an undesired side effect of limiting the natural risk taking from which we all learn. There was evidence that the people in this study group were not afforded any dignity of risk taking mainly because the duty of care was carried out to such an extreme. It is as if PCP is about what the key worker or family wanted for the person with intellectual disability rather than what the person wanted themselves. The study found that there was a very low exposure to dignified risk taking in favour of overprotecting people and keeping them safe.

This study found that the key workers perceived their ability to effectively deliver on PCP goals was affected by their status in the organisation. Those who held a high status perceived themselves as having greater power to make things happen within the realm of what was available to them in special services. Those of lower status within the organisation reported greater difficulties in

ensuring that goals were realised. The key worker's role has many layers. The key worker who is also an employee has the responsibility to provide direct care on an equal basis to everyone in their care. By singling out the key worker to provide additional support and interest to one individual over another in a way that is superimposed on to the care role results in a misalignment. This has led to a conflict of interest when trying to meet the care needs and the aspirational needs of the focus person of the PCP. The key workers reported a tension between their on the job role of meeting the competing support needs of other residents in their care and at the same time having a specific role in relation to the person for whom they were key worker. All key workers interviewed in this study were paid members of staff and have a vested interest in keeping the current arrangements in play and demonstrated difficulty in advocating for a positive future for the focus person where they would be supported to live in their own accommodation with help when they needed it to conduct life-enhancing activities. The potential for the key worker to act as an advocate was submerged by their view of the PCP process as a bureaucratic and mandatory exercise.

The good thing however, is that currently services for people with intellectual disability are attempting PCP and this creates a foundation or stepping stone to the future direction of PCP in line with Robinson et al (2005). It has to be said that what we currently have is not very person centred as would be viewed by Kendrick (2007). There are a number of reasons for this and as outlined earlier the person with intellectual disability is regarded by families and staff as being in a state of 'eternal childhood'. Direct supports are placed in areas such as keeping the person healthy, safe, well minded and protected from society versus applying person centred active supports to promoting self determination and empowering the individual. The service settings, while promoting community presence, fall short of promoting community participation and inclusion because it is in itself a 'special' residence and is a smaller version of the institutions that they have left. This finding does not resonate with the argument where O'Brien (1981) puts forward that community inclusion, choice and participation all improved when people with intellectual disability moved to group homes from the institution. O'Brien holds that the institutional setting makes valued experiences virtually impossible. He postulates that community services offer far greater potential for opportunities but if institutional practices follow the individual, as found in this study then opportunities will go unrealised. Where true person centredness is a hallmark of community service delivery O'Brien (1981) holds that they will have far greater opportunities. In keeping with this theme families interviewed in this study reported a greater ease and comfort visiting their family member in their community group home rather than the institution.

All of the people in this study had access to scheduled day services which is in keeping with the findings of Robertson et al (2005). Consequently this meant that they had a focus and a provided purpose to their day where they would also have the opportunity to have social contact with paid staff and other people with intellectual disability in formal day services. They are 'transported' to these special day service venues in the recognisable provided vehicles which is in direct contravention to SRV theory of Positive Imagery which holds that how things look matter a great deal and impact on individual identity. Travelling in special vehicles to special venues further

socially marginalises individuals and contrasts to the general population who travel in private vehicles or on open public transportation to desirable places to recreate. None of this group used personal or public transport. Further to this none of this study group has any form of paid employment thus further limiting their socially valued role. There were many missed opportunities to guide the ten individuals in the reclaiming of their personal and social identity which was a recurring theme in this study and a direct contradiction to the principles of PCAS.

The goals itemised in the PCP study enumerate a range of varied activities both new and old. Contact with friends improved when people moved to the community yet it is difficult to get a true understanding of this as people with intellectual disability describe paid members of staff as 'their friends'. Emerson in his findings (1985) noted that because of people's limited opportunities they had difficulties asking for things and making suggestions about strengthening their social networks thus relying on staff and other people with intellectual disability to be 'their friends'. SRV theory describes this as a form of social segregation and congregation. The PCP process has reintroduced in a positive way contact with families that heretofore were told to 'stay away'. At least now families are invited to annual PCP meetings as well as other social events in the person's life.

Social networks have expanded for the person with intellectual disability but are still largely restricted to community presence versus community participation in that people would go into a shop and be greeted by the shop owner but that was the limit of the engagement. The importance of enabling and promoting choice for people with intellectual disability is highlighted by the PCP but this study found that choice was frequently restricted to simple everyday decisions as what to wear and what to eat for breakfast. Major life choices about where they live, with whom to live and how to spend ones time is reserved for service providers. This finding is similar to that found in the Welch study by Felce et al (1998).

For families considered in this study their role in the PCP process was also unclear and mired by confusion. In the past when each of the individuals of this study was institutionalised families were instructed to stay away as this was thought to be in the best interest of the individual. Today the same families are invited to participate in PCP. For some families in this study they believed that this was an attempt to engage them in direct care of their family member and as a result they were cautious of showing any capacity or availability for involvement. As previously stated for others there was a complete lack of awareness as to what PCP actually means. The only information offered to families is the explanation given by the key worker who was responsible for convening the meetings and inviting the families. Therefore the quality of the information on PCP is not consistent and at best is the subjective view of that key worker communicating to families. This is all against a backdrop of families feeling a sense of loss, a sense of guilt, a sense of anxiety and a sense of failure on them as not being able to maintain care. Now there is an expectation to have them involved and participating in the PCP process yet there is no clear direction for families on what their role in the PCP process actually is and what it means for them. This confusion is perpetuated by the key worker confusion. This study found that most key workers see PCP as

about activities and feel almost compelled to report to families on the activities of their family member. It is not surprising then that families rapidly conclude that a PCP meeting is about staff reporting to them on the activities, behaviour and health status of the individuals.

The individual with intellectual disability associates the PCP as being about the white folder and the meetings where staff relay to their family members what they have done and how they have conducted themselves. This study found that there was no training of the focus person into the principles and philosophy of PCP. People with intellectual disability are expected to understand the specialist language and staff-speak for example 'community inclusion', 'up on nights' and 'PCP'. This study found that there was an absence of any effort to perceive the process from the perspective of the individual. Consequently, the process instead of being enjoyable and very emancipating, the PCP meeting was very stressful, daunting and at times disappointing for the individual with intellectual disability for example a sense of exasperation was articulated by Colette 'so does this mean that I am not getting my flat'. A substantive underlying theme from the literature in PCAS (2009) is the first step of skilled listening at a deep level to what the focus person is saying. This next step is empowering the individual with intellectual disability starting with the utilisation of Total Communication (TC). While acknowledging the inherent difficulties in this if these steps are not taken the PCP becomes about the process rather than about the person. The difficulties are that because the person has an intellectual disability family and staff's expectations are low. At times when they articulate aspirational goals they are seen as unrealistic and beyond the scope of service providers. Notwithstanding this the most important thing is that they are listened to and taken seriously which was not evidenced in this study. Deep listening leads to a different way of service delivery and calls for an openness which will lead to a different way of supporting the individual that is more congruent with PCP. This study heard 'so does that mean I wont get my flat' where as in the future it is vital to look forward to a culturally valued analogue such as the things that other citizens of the same age and location pursue (Kendrick, 2007).

This study concluded that there is a commitment to the process that is at present mechanistic. This study found that key workers are allocated to people with intellectual disability from the existing staff compliment. PCP meetings are scheduled and held in special service venues. Key workers keep adequate records in white folders which are not accessible to the focus person. The preponderance of attendees at PCP meetings are paid staff from day and residential services. This costly process ultimately results in a product that misses the mark of true person centredness. One has to question whether this is the best use of limited resources for the individual with intellectual disability.

Today, we have the benefit of viewing service provision from a human rights perspective. The UN charter on Human Rights (2002) to which Ireland has signed but not as yet ratified enshrines the civil rights of every Irish citizen, able and disable alike. There is no longer a rational for segregating people from separate services from the mainstream of society. The challenge that arises is that the PCP process will go from being a list of activities to a rights based agenda that will add reality to the rhetoric of actively supporting people to realise their own personal goals. In doing so this will

provide real choices in terms of where people live, work and recreate. Further to this it will provide real opportunities for social role valorisation and social inclusion, helping people maintaining and creating friendships including intimate relationships. The PCP process will also empower people to exercise their citizenship right such as voting and participating in community activities that are not associated with special services. Consequently, it will have the added value of building on the dignity and respect in which people with intellectual disability lead their lives.

This study found that the person centred process in Ireland is not at the embryonic stage. It has developed to a point where it brings with it, from the medical model, attention to health care and the importance of a safe environment where people are economically secure and where they report satisfaction with the service. The assumption in the past was that if the institution was well run then the residents had a good life. A note of caution is, if the progress of transferring people with intellectual disability from Irish institutions (N=4000) to the community continues (HSE, 2011) then the importance of being person centred takes precedence over the centre's centredness. It is not just about having a nice house and those tangible things provided by services. It is about the individual self determining their own life. It is about more than keeping people activated; it is about avoiding a never ending merry-go-round that will act as a barrier to true person centredness. The only plausible conclusion which is in keeping with Kendrick (2009) is the imperative for individuals to be considered for more optimal individualised service design which is true person centeredness and the next developmental milestone in PCP.

The study found that PCP was largely activity based and with staff arguing for more staff to do more person centred activities despite the fact that Felce (1997) argues that more staff confounds the situation in that the overriding agenda becomes staff needs and not the individual needs of the person with intellectual disability. Staff's vision appears to be limited to requesting more of what they already have such as more staff, money and transport. There is an apparent failure to look towards other ways of engaging or other means of supporting people to have person centred lives. Rather than asking for more staff, staff need to enhance their skills base so that rather than minding people in the community ad infinitum their attention is addressed to supporting the person to establish relationships in the community that enables them to grow as citizens with ordinary lives. The frustrating aspect of this is that there is little evidence of the next step. It is like swimming in a 'gold fish bowl' and being unaware of opportunities, if manoeuvred correctly, can lead to a world of exciting opportunities. It seems as if the energies of the key worker have been applied almost exclusively to activities of which there is an exhaustible list of potential items. They are hampered by the circular flow of the activities. There is a lack of vision around progressing to more optimal individualised lifestyles. This also has the consequence of the key worker being satisfied by the existing PCP process. This is because they perceive that they have exhausted the range of potential activities for the person with intellectual disability and they feel that their job ends there.

There are deeper issues underlying all of these findings for instance the role of paid staff who traditionally perceive themselves of having to be in control of the household otherwise they may be

deemed as being incompetent. Therefore they have to create a way of working that bridges their challenge of maintaining a functional household while at the same time being mindful of opportunities to promote the individual's humanity and civil rights. Staff typically think they are doing a good job when they are in control of the household and the people who live there. The real challenge is not maintaining the status qou but seeing PCP through the bigger picture which is for the individual to be assisted in crafting a life style that is about their aspirations, their visions and their civil rights as citizens. The question is, how would a staff person know when they are being truly person centred? This will happen when the person with intellectual disability has a life in the community that is reflective of their uniqueness, that sees them participating in the work place and engaging in social activities in ordinary venues for recreation. As well as being supported by paid staff their lives will be characterised by developing friendships and relationships that have a genuine mutual reciprocal basis.

In order for PCP to fully embrace their potential to positively impact on the person's life in a person centred way that is in keeping with O'Brien's' five service accomplishments and Robertson's six indices of PCP efficacy, a decision needs to be made whether the current approach can be rescued and if not perhaps resources can be better redirected. This question can only be answered by furthering the research and evidence base on the efficacy of PCP.

Chapter 7

Conclusion & Recommendations

7.0 Conclusion & Recommendations

7.1 Conclusion

Could the PCP process improve the lives of people with intellectual disability as they moved from the large institutions to the community? What we have seen in reality is that although some people with intellectual disability have physically moved from institutions to community settings many institutional practices and social structures have moved with them. It appears that the weight of these practices and structures, the weight of habit, inertia and resource limitations has channelled the PCP process from its ambitious life-changing course into an easier path of activity driven schedules in service settings.

While some people are now living in smaller settings in the community their lifestyles are characterised by separateness from the mainstream of society. They have no choice about with whom or where they live or how they spend their days. Support staff mechanistically enact the rhetoric of person centredness by offering choices at a very basic level such as choice of breakfast cereal or what clothes to wear. By failing to understand the deeper understanding of promoting self determination, imagining better lifestyles and realising dreams, which are all the essence of person centredness, are the forces at work that will undermine and deflate the full potential for people to live lives of their own crafting. While PCP encourages stakeholders to 'imagine better' and to 'dream' the PCP methodology as applied by people in this study lacks the capacity to deliver or implement actions to help people realise their espoused dreams. This can lead to disappointment as having an idea does not equate to having the authority to deliver on its implementation.

What is obvious is that people have been slotted in to pre-existing service support arrangements rather than generating distinctive and individualised person centred service models. Following a person's dreams will cause a change to conventional practice and should introduce non stadardised responses to people's hopes and dreams. Staff positions, job security and traditional roles override an open-mindedness that would lead to a more creative approach to providing people with the support needs they require to realise O'Brien's service accomplishments. The restrictions are not about staff resources but rather about limited vision and perceptions of people with intellectual disability who are still regarded as childlike and unable to function as citizens in society.

Effective person centredness can only thrive in settings where there is in the culture a broad recognition of the importance of the individual's autonomy. Person centred methods require people to cultivate in themselves a capacity to let the person they are supporting remain at the centre of all of their thinking. When person centredness is attempted, without this philosophical understanding and culture, it is diminished to a bureaucratic, soulless and mandatory process.

It is quite striking that very few service systems that call themselves person centred offer opportunities for service users to redesign their service model. The person with intellectual

disability is expected to fit in to the model on offer. Most services do not provide the opportunity for the individual to access the funding themselves in order to reuse the funding in a more person centred way. While people with intellectual disability were placed in nicer houses in the community creating a community presence they are still nonetheless on the peripherary of society living segregated lives with other people with intellectual disability. Paid support is wrapped around these individuals and it is regrettable that this support is directed at keeping them safe, protected, and minded in a life-limiting style which further diminishes their person centred aspirations.

Paradoxically, given that the goal of PCP is about the individual and the person's individual differences and their capacities, the person centred planning methodology is standardised as 'one size fits all'. PCP is not essential in supporting people to have a better life but if we continue with the person centred process a better match is required between the approach and the individual's support needs. Service models need to change to be more cost effective and individualised. PCP has a role to play in service innovation. Many professionals supporting people with intellectual disability through PCP have a restricted outlook and imagination and are simply unaware of what is possible. While they may be well motivated their loyalty is in perpetuating the current model rather than taking the courageous step of service innovation.

Staff and professionals involved in PCP need to recognise that their presence and possible dominance may act as a barrier to keeping the persons needs central. It is necessary therefore to safeguard against 'staff monopolies' existing in PCP and if continued will only serve to enhance the care plans and keep people occupied. This gives a false sense of fulfilling the higher ideologies of PCP including true community participation, family involvement and people with intellectual disability exercising their citizenship rights.

It is obvious that PCP is not necessarily person centred and it is healthy to be sceptical of the system that has sponsored PCP as a methodology for improving people's lives. What people actually need can be influenced by service options that are available and by the vested interest of others. While it is valid that the PCP has the personal aspirations of the individual at its core, the goals of the individual alone do not lead to solutions. It is important, therefore, to investigate whether the methods used in PCP are sufficiently robust and person centred to offset the vested interest and influences of others. What is essential is that people are supported in life-enhancing activities that bring the individuals vision and dreams to reality. This is a life-long process that requires commitment and investment which may take years rather than short intervals of PCP. The magic of a person centred approach lies inherently in the value system which is ethically complex and recognised in the genuineness of the efforts that need to be verified by evidence rather than a self affirmed opinion.

7.2 Personal journey

From the perspective of the researcher, there was an array of significant life events that took place during the six years of this research dissertation. The challenge of balancing work, home and

research commitments was energising. Despite the challenge that these life events presented there was an enduring quest provided by the research question that demanded engagement and resolution by the author. While many of the research findings about PCP were disappointing; after all the assumption was that PCP was in itself emancipating; the reality was found to be quite different. Ultimately the findings of this study have been enlightening to the extent that the findings have led to a legacy that is influencing current work practices. No longer is it just good enough to slot an individual presenting for services into existing special settings; the challenge that is always there is how we can meet individual needs in a truly person centred way so as not to compound the disability by placing people in restrictive segregated settings. The experience of gathering data and analysing it to find out what you thought you new to be true was based on false assumptions and was personally astonishing. The important thing however, is that the knowledge and the direct application of the information that came from this research has the power to influence the direction of services in a way that is more congruent with the civil and human rights model. The academic engagement with the school of Social Work and Social Policy brought an added dimension to this research and hopefully can act as a catalyst for social policy change.

7.3 Recommendations

What follows is a discussion of the recommendations based on the themes from the cross case study analysis that will be developed from the perspective of the person with intellectual disability, the family member and the key worker for the person with intellectual disability.

7.3.1 Addressing the impact of the legacy of institutional care and practices on the PCP process

Table 13 summarises the recommendations that emanate from the consideration of the thematic analysis on the legacy of institutional care and practices that has an impact on the PCP process.

Table 13: Addressing the impact of the legacy of institutional care and practices on the PCP process

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker for the person with intellectual disability
The legacy of institutional care and practices has an impact on the PCP process.	▪ Safeguard human rights. ▪ Government policy to never institutionalise people because of their intellectual disability. ▪ Support the person to be part of their family and community life. ▪ Support, advocacy and counselling to build on confidence and low self esteem. ▪ Recognition of full citizenship rights. ▪ Give people the tools to make the decisions and to safeguard against acquiescence. ▪ Move from the use of special services to true community participation. ▪ Supported to develop natural friendships including intimate relationships ▪ Pilot study in PCP.	▪Government policy not to institutionalise people because of their intellectual disability. ▪A systematic approach to re-engaging with families in a way that is going to enable their participation that alleviates confusion, anxiety and fear. ▪Provide ongoing information to families with regard to the civil rights and entitlements of their family member. ▪A conscious effort to establish trust and build up confidence with families to move from reliance on and deference to staff. ▪Pilot study in PCP.	▪ Disavow the position of ownership. ▪ Ongoing investment in staff personal development with ongoing education and training. ▪ Reorientation of staff who have worked in institutional settings regarding best practice in community services. ▪ Recognition of the importance of the role of key worker against the backdrop of the institutional hierarchy. ▪ Pilot study in PCP.

People with intellectual disability should not be institutionalised in large congregate care settings because of their disability. This will help safeguard the human and civil rights of people with intellectual disability as citizens of Ireland. In keeping with 'Time to Move on from Congregated Settings' (2011) this study calls for the immediate closure of congregate care settings for people with intellectual disability. As long as these institutions remain open they represent a threat to the family life for people with intellectual disability. Congregate care facilities that remain open pose a risk in that by their very nature decision makers may refer vulnerable people to them. Some would argue that congregate care can have an economic rationale. As part of the PCP efforts should be directed at supporting the person to be part of their family and community life.

Attention must be given to rebuilding self esteem and confidence for the person with intellectual disability who has been subject to institutional practices. Counselling, personal development and advocacy will give the person with intellectual disability the tools to self determine and enhance their person centred life.

In order to achieve community participation it would be helpful if there was a discontinuation of the reliance on the special settings for all activities of daily living. There needs to be a promotion of life enhancing opportunities in the broader mainstream community, such as a chance to make friends and have intimate relationships. This would have the benefit of reducing the segregation of people because of their disability and would have the added benefit of increasing all social roles.

Families who require re-engagement with their family member require flexible support and guidance to re-establish and build on core relationships as part of the person centred approach. Families should be regarded as equal participants in decision making particularly in relation to PCP in order to overcome the current pattern of deference to staff evidenced in this study. In order to allay the confusion, anxiety and fears as evidenced by some family members factual information on the legal status of parents and siblings vis-à-vis their family member with intellectual disability is required. Particularly, the legal status and responsibilities of the next of kin including guardianship legislation.

In order for PCP to be truly effective the institutional hierarchy that moved with the people with intellectual disability to the community setting should be dismantled so that the potential of the key worker in PCP is not contingent on their job status. Coupled with this, there should be an ongoing investment in key worker and all staff training, personal development, and the person centred objective of true community inclusion and participation.

This study was limited to a small number of people in a specific area. Further research is urgently required. It would be helpful to distil the elements that constitute good person centred practice and the current status of PCP in Ireland today. This is important as we know from the National Intellectual Disability Database (NIDD, 2010) that there 26,484 people with intellectual disability registered on NIDD and in receipt of formal services. There are currently 8,213 people with intellectual disability in full time residential care, 4,088 of these people reside in community group

homes and 4,125 continue to reside in large congregate settings including psychiatric hospitals with conditions similar to those of the ten people of this study. An indicator of good service provision is that people with intellectual disability have a PCP in place. This is tracked by the NIDD (2010) where it is reported that 83.2% of the cohort in receipt of formal service have PCP's in situ equating to 6,837. While we have a good evidence base on the numbers there is little current information on the status on the quality of the PCP's. It is known from this study that it is vital that clarity is sought on what constitutes a good PCP. This can be achieved through initiating pilot projects that will identify the precise training needs of the various stakeholders. It is envisaged that standards in true person centredness will develop along with a method and template for PCP evaluation that realistically accounts for the need to move from the rhetoric to reality of person centredness.

7.3.2 Addressing the structure of the PCP meeting that is over formal

Table 14 contains a summary derived from the thematic analysis with recommendations that address the structure of the PCP meeting that is over formal.

Table 14: Addressing the structure of the PCP meeting that is over formal

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
The structure of the PCP meeting is over formal.	▪ Supported to make their voice heard. ▪ Need to be relaxed and own their meeting. ▪ Need to be in control of their PCP. ▪ Support needs to match their capacity level. ▪ Information needs to be in accessible format. ▪ Need to experience success and real change. ▪ The content and quality of the PCP should outweigh the preparation.	▪Need to be versed in their role in the PCP meeting. ▪Needs to be a broader understanding of the objectives and benefits of PCP. ▪An effort to ensure that families are important in the PCP process and that they are supported in their participation with the use of everyday language and open communication thus enhancing relationships.	▪ Relinquish control and restore balance ensuring the person with intellectual disability is at the centre. ▪ The PCP meeting is used to craft person centred realistic goals with equal representation and the use of active listening and open communication.

The person with intellectual disability may benefit from having a PCP in place if they truly own and are in control of their PCP but also in control of their PCP meeting. People with intellectual disability should be supported through education and training in everything from managing their meeting to the purpose, function and objectives of PCP which does not place undue emphasis on preparing them for their PCP meeting but rather ensuring person centred practice in their every day life. There is a broad recommendation that people with intellectual disability should be supported in accessing information in assistive technologies so that their PCP is in a format that is accessible to them that they can easily recognise and use. When a person with intellectual disability is helped to learn to use assistive technology they can exercise more control.

It may be helpful that families have the benefit of access to all relevant information pertaining to the objectives and benefits of PCP but they also need to be supported as equal stakeholders in the PCP process. As evidenced in this study some families may benefit from induction in their role in PCP. It is important that every day language and open communication is used avoiding the use of jargon and professional language that subordinates families. Every effort should be made to enhance the relationship with families which will provide family members with equal status at PCP meetings.

In order for PCP to flourish it may require that the key worker move from a position of controlling the meeting to supporting the individual to be in control of their own meeting. It is important that the person with intellectual disability is deeply listened to in order to harvest goals that are a true reflection of the personal aspirations of the individual.

7.3.3 Addressing the limited understanding of the aims and impact of PCP

Table 15 contains a summary derived from the thematic analysis that addresses the limited understanding of the aims and impact of PCP.

Table 15: Addresses the limited understanding of PCP

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
There is a limited understanding of the aims and impact of PCP.	▪ Ensure that the person has a proportionate input into the PCP process. ▪ More work with the person around the potential benefits of PCP. ▪ Empower people to experience success. ▪ Enhance citizenship roles. ▪ A broadening of their understanding of the importance of their social roles.	▪Information on their formal status vis-à-vis their family member. ▪A focused input on the importance of goal settings at PCP meetings.	▪ Education on the broader philosophical understanding of PCP.

The person with intellectual disability should be empowered to experience the objectives of PCP such as choice, relationships, dignity, respect and full community inclusion. In order for people to exercise full citizenship their PCP should ensure that they have an opportunity to experience enhanced social roles as a neighbour, friend, family member, customer, employee and voter.

With family's accumulating a knowledge base about PCP it is recommended that they be afforded the opportunity to engage in goal setting guided by the person with intellectual disability in order to improve the quality and outcomes of the PCP.

Ongoing in-service training on the broader philosophical understanding of PCP for the key worker is required with the aim of having an improved PCP that will be life enhancing for the person with intellectual disability.

7.3.4 Addressing the different factors that lead to resource limitations for stakeholders in the PCP process

Table 16 contains a summary derived from the thematic analysis that addresses the different factors that lead to resource limitations for stakeholders in the PCP process.

Table 16: Addressing the different factors that lead to resource limitations for stakeholders in the PCP process

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
Different factors lead to resource limitations for each stakeholder in the PCP process.	▪ Should be supported in renting, buying or leasing property in their own name in order to promote security of residence. ▪ Need to be in direct receipt of state benefit and in direct control of their spending with support. ▪ Should have opportunities for paid work with the supports required.	▪ Meetings need to be scheduled to meet family's lifestyles. ▪ Empowerment of the extended family to full participation.	▪ Support a more individualised lifestyle for the person. ▪ Look to the natural support that already exists in the community.

This study found that people with intellectual disability were frequently moved throughout their lives and did not feel secure in the house where they live. This requires actions to ensure that they are supported in acquiring their own home by buying, leasing or renting property in order to promote security of residence. This is achievable when people are in direct control of the spending of their disability allowances, other state benefits or any other income. Through their PCP opportunities to achieve paid work with the supports that they require is an objective in order to graduate them from the dependency of special service and state benefits.

In order to extend the natural circle of support, families may benefit from empowerment to participate and build on the relationships and actions of the circle of support. If this was done in a strategic way then it could serve to safeguard person centred aims that span the quality of life domains including financial, residential, health, relationships, vocational/employment, social

inclusion and family involvement. To ensure ease of family involvement in the PCP process families should have a say in the scheduling of the PCP meeting, such as, venue, time and what family member should be invited.

Key workers may require guidance in taking an in-depth look at the potential within the local community to build on natural relationships and supports with an emphasis on crafting an individualised person centred lifestyle. The PCP should act as a conduit for moving from a position of community presence to that of full community participation.

7.3.5 Addressing the consequences of resource limitations that are reliance on special services, fear of additional costs and routine activities

Table 17 contains a summary derived from the thematic analysis that addresses the consequences of resource limitations that are reliance on special services, fear of additional costs and routine activities.

Table 17: Addressing the consequences of resource limitations that are reliance on special services, fear of additional cost and routine activities

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
The consequences of resource limitations are reliance on special services, fear of additional costs and routine activities.	▪ More exposure to the use of ordinary mainstream venues and services. ▪ Avoidance of the use of congregate settings that segregate based on disability. ▪ Should not have to subsidise paid staff to engage in their person centred goals.	▪Need to be enlightened about the citizenship rights including the right to access mainstream services and activities moving on from the segregation of special services.	▪ A focus on the true aspirations of the person. ▪ A move from community presence to true community participation.

People with intellectual disability will require support to have more exposure to the use of ordinary mainstream venues and services with avoidance of the use of special congregate settings that segregate people based on their disability. The person with intellectual disability should never be in a position to have to financially subsidize a paid member of staff particularly when they engage

in person centred goals. Even when the use of mainstream amenities are more expensive than special settings their use should be encouraged because ultimately the person with intellectual disability may achieve more person centred outcomes.

The family may require support in their understanding of the citizenship rights of their family member including their rights to access mainstream services and activities as they move on from their lifetime of segregation in special services to full citizenship.

The key worker should focus on the true aspirations of the person with intellectual disability. The key worker should continue to support the person with intellectual disability in a person centred way as the focus moves from community presence to full community participation. This would mean that in reality that instead of supporting the person to attend the special swimming session that they attend the public pool used by everyone else in the community. Likewise, the many activities enumerated in their PCP's in similar special facilities such as art, drama and aerobics should take place in mainstream settings.

7.3.6 Addressing the emphasis of duty of care that leads to risk aversion

Table 18 contains a summary derived from the thematic analysis that addresses the issues that arise from the emphasis of duty of care that leads to risk aversion.

Table 18: Addressing the emphasis of duty of care that leads to risk aversion

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
Emphasis on duty of care leads to risk aversion.	▪ Enable people the dignity of risk exposing them to new opportunities with safeguards. ▪ Provide opportunities to take back responsibility for healthcare. ▪ Promote PCP in all quality of life domains. ▪ Promote self determination in a place to live that is truly theirs. ▪ Risk assessment for risk taking.	▪To reduce family reliance on professionals. ▪To harvest the potential of family knowledge by empowering them in their role to be reunited as a family. ▪A greater emphasis on information sharing and flexible supports to promote family engagement. ▪Promote PCP in all quality of life domains.	▪ Education and training on promoting the ideology of PCP. ▪ Distinction between the care plan and PCP with prioritisation of roles. ▪ Promote PCP in all quality of life domains. ▪ Risk assessment for risk taking.

People with intellectual disability should be afforded the dignity of risk that exposes them to new and different opportunities with the appropriate supports and safeguards in place. Through PCP there should be a greater emphasis placed on empowerment of the person with intellectual disability in order for them to take responsibility for their own quality of life, including their own health care. This may lead to more personal autonomy in activities such as self medication, health monitoring, security of residence, financial control and relationships.

One would question the reliance in the past on the professionalization of intellectual disability where family's judgement took second place to what professionals deemed appropriate for their family member. Now there is a greater confidence in a family's capacity to make judgements that support the person centred objectives. Families may benefit from being empowered in their role in PCP. For the subjects of this study the families are functioning as a family through PCP for the first

time in many years. There should be greater emphasis on information sharing and implementing flexibility around supports that promote family engagement.

It may be of benefit that in the context of education and training on promoting the ideology of PCP that PCP is not subjudicated by reverting to risk assessment and avoidance that results in limiting opportunities and exposure to new and different choices. Risk assessment should be about person centred risk taking and not about risk avoidance. It is important to uphold the content of the care plan and that it is followed but the PCP is not the same as the care plan and they need to be seen as distinct in their function and execution.

7.3.7 Addressing the individual differences and local variations that impact on the efficacy of PCP

Table 19 contains a summary derived from the thematical analysis that addresses the individual differences and local variations that impact on the efficacy of PCP.

Table 19: Addressing the individual differences on the efficacy of PCP

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
Individual differences and local variations impact on the efficacy of PCP.	▪ Promote the individuals self expression through Total Communication and skills or activities sampling. ▪ Access to visiting the family home and significant venues from their life history.	▪Information on the legal status and citizenship rights of the next of kin, legal guardian and the consent status of the person with intellectual disability needs ongoing clarification.	▪ Dismantle the many barriers that affect the key worker's capacity to support the person in achieving their personal goals. ▪ Education and training for the key worker in the philosophical underpinnings of PCP and the mechanical aspects of conducting a meeting and using assistive technology and IT. ▪ Consider personal characteristics to ensure a good match of person with intellectual disability and key worker.

PCP requires the promotion of the individuals self expression through the use of Total Communication (TC). Activity sampling and skills teaching should be employed in order to broaden the personal profile of the things the person with intellectual disability can do and choose from. In a

person centred way individuals should be supported in visiting places that are significant to them such as their family home and community.

As all families are different it is important for the PCP process to celebrate differences and to acknowledge that families have an important role irrespective of how they present.

In PCP it is important that the necessary structure is in place to match the key worker to the individual they are supposed to support. Coupled with this the many barriers, that affect the key workers capacity to support the person in achieving their PCP goals, require dismantling. The key workers may require additional training in the skills required in PCP such as conducting a meeting and in the use of assistive information technologies.

7.3.8 Addressing issues of PCP promoting community presence but not community participation

Table 20 contains a summary derived from the thematic analysis that addresses the issues of PCP promoting community presence but not community participation.

Table 20: Addressing the issues of PCP promoting community presence but not community participation

	Person with intellectual disability	Family member of the person with intellectual disability	Key worker of the person with intellectual disability
PCP promotes community presence but falls short of community participation.	▪ Towards greater community participation. ▪ Move from activation in special places to meaningful activities in the community. ▪ Skills teaching to promote active engagement. ▪ Use of person centred active supports. ▪ Careful regard to personal items and affects.	▪Use of local amenities and facilities for engaging the circle of support. ▪Coach families to be more explicit in their views about person centredness.	▪ Choice has to be at a macro level rather than a micro level. ▪ A shift from institutional practices to person centred active supports. ▪ Supported in a move from community presence to full community participation.

Every opportunity should be taken to promote the individuals community participation with a move from an activation of the person in special places to person centred engagement in community activities. This can be achieved by using person centred active supports in mainstream settings.

It may be of benefit to guide families to be more explicit in their views about PCP and their ideas on how their family member can be more included in community life. Circles of support including family members should be encouraged to celebrate the success and joys achieved through PCP.

While the key worker continues to see the benefit of choice at a micro level there should be a renewed zeal of choice at a macro level. This would lead to person centred decisions about major life events and may ensure a move from community presence to greater community participation.

7.4 Recommendation for further research

This study uses an original approach through case study methodology to study PCP. This methodology was found to offer a wealth of deep information on the current status of PCP from the perspective of three different stakeholders complimented by non participant observation at the PCP meetings. Given that this in-depth piece of work captured the reality for ten people it may be helpful if future qualitative research of this style was utilised across a larger population.

As previously stated this study included the important perspective of people with intellectual disability. This is frequently overlooked in contemporary research conducted *'on'* rather than *'with'* people with intellectual disability. The voice of the person with intellectual disability can be found by placing them at the centre of the research process and by promoting participatory research.

7.5 Reflection

This study followed the lives of ten people with intellectual disability who were institutionalised and later transferred to community based residences - all had PCP's in place. At the onset of this research an assumption was made that PCP served to guide and positively influence the individual's life style. Case study research on their PCP enabled the researcher to enter the lives of the ten individuals by way of accessing their personal information, attending their PCP meetings, interviewing them, their families and key workers. The aim was to find individuals who had good PCP's and the assumption was that decisions about their transfer were embedded in their PCP's, but sadly this was not the case. The PCP's for people in this study were merged with their care plans and represented, at best, a paper exercise that led to itemising activities engaged in by the individual in special venues to relatively dismayed family members. While people were well minded and protected when they moved and there was a definite improvement in their living environment, however, very little evidence emerged of any real change in the new style of provision from that provided in the large congregate care setting.

The ideas and concepts from O'Brien and Robertson's work that inspired this study were overlooked by the various stakeholders but especially the key workers who regarded PCP as mechanistic rather than a life enhancing person centred process. There is an overwhelming urgency to promote the efficacy of PCP for the thousands of people with intellectual disability whose lives could be further improved if PCP's were enacted as envisaged by O'Brien and Robertson and would be reflected in their equal participation in Irish society. It is hoped that this study will inform and inspire the need to leave behind the legacy of 20th century practices of institutionalisation. It is hoped that it will guide the future direction of PCP in Ireland well into the 21st century.

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Appendices

Appendix I

Participant information sheet and consent form for people with intellectual disability.

Participant information sheet for people with intellectual disability

A Case study analysis of person-centred-planning for people with intellectal disability following their transfer form institiutional care.

Making sure your voice gets heard!

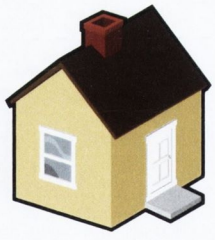
Hello,

My name is Donal and I am doing some research as part of a course in the National Institute of Intellectual Disability at Trinity College Dublin. I would like to firstly ask for your permission to look at your person centred planning (PCP) file so that I can write down what your goals have been before you left the residential centre and what they are now that you are living in a community house. Then I would like to invite you to meet with to tell me about your life. The meeting will be held in a place that suits you and should last about 45 minutes. Your key worker and a member of your family will also be invited to meet with me at a later date.

At the meeting I would like you to talk about your life. If you would like to have someone else that is okay.



I will be asking you where you live and where you have lived in the past.



I will also be asking you what you do during the day.



I will be asking some questions about your person centred plan (PCP).



What you would like to change in your life.



Your dreams and how to make them come true.



I will make sure that the information that you give me will be kept private and will not have your name on it and no one will be able to trace back what you say. I will also be using a tape recorder to record the conversation we have so that I can go over what has been said after the meeting.

Your ideas are important so I will write them down. What you say may help me and other people in our work in the future.



If you change your mind about talking to me then all you have to do is to say that you do not want to go on with being part of our research.



If I hear some things however that makes me think that you are unsafe then I will ask you to meet with another person to talk to them about what has happened and to support you to decide what to do next.



If you are happy to take part in my research, please read the next page and sign the consent form which we will get from you on the day of the meeting.



If you have any questions please contact me on 057 9359915.

Thank you

Consent form for people with intellectual disability

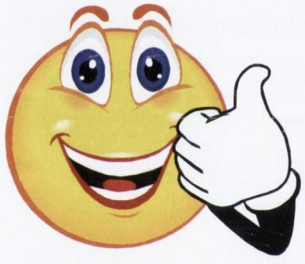
Making sure your voice gets heard

Researcher: Donal Fitzsimons, National Institute for Intellectual Disability, Trinity College, Dublin

This research has been explained to me in a way that I understand..



I have been able to ask questions and have them answered.



I understand what is expected of me.



I can stop being involved at any stage of this project.



My PCP is private and I understand that Donal will not talk about things private to me to other people.



I would be happy to talk to another person if I have any big concerns.



I am happy to have the conversation tape recorded.



I agree to take part in this project.



Signed: _____

Name : _____

Date: _____

Witness: _____

Name: _____

Date: _____

Appendix II

Participant Information sheet and consent form for family members.

Participant information sheet for family members.

Title. A Case study analysis of person-centred-planning for people with intellectal disability following their transfer form institiutional care.

Researcher: Mr Donal Fitzsimons, National Institute for Intellectual Disability, Trinity College Dublin.

Supervisor: Dr Patricia O'Brien, National Institute for Intellectual Disability, Trinity College Dublin (2007 – 2008) followed by Dr Philip Curry, School of Social Work and Social Policy, Trinity College Dublin (2008 – 2012).

Thank you for agreeing to be part of this study. My name is Donal Fitzsimons and I am currently undertaking a part time PhD programme through the Social Work and Social Policy School of Trinity College Dublin. My interest and research is in the area of intellectual disability and the process of person centred planning for people with intellectual disability. I have 20 years experience of working with people with intellectual disability. I have worked directly with people with intellectual disability and their families but I am currently working with the HSE as Manager of Disability Services in the Midlands.

Your family member who uses intellectual disability services has a person centred plan (PCP) in place. I am interested in finding out more about how this PCP impacts on the life of your family member. To find out more from you on your perspective on PCP I would like to meet with you to discuss this topic further. I will be in contact with yu to arrange a mutually time, date and venue to meet. This meeting should last about 45 minutes and I ook forward to meeting with you.

If you are happy to continue in this research, please sign the attached consent form. If you have any queries with regard to any aspect of this research please feel free to contact me by phone on 057 9359915 or email donal.fitzsimons@hse.ie

Consent form for family members

A Case study analysis of person-centred-planning for people with intellectal disability following their transfer form institiutional care.

Researcher: Mr Donal Fitzsimons, National Institute for Intellectual Disability.

- I have had the research explained to me.
- I have been able to ask questions and have them answered.
- I understand what is expected of me.
    - Attend a semi structured meeting.
    - Answer questions on behalf of my son/daughter/sibling.
    - Participate in a discussion on PCP goals and the 'my life interview'.
- **I agree to take part in this research project.**

Signed: _____

Name: _____

Date: _____

Witness: _____

Name: _____

Date: _____

Appendix III

Participant information sheet and consent form for key workers.

Participant information sheet for key workers.

Title: A Case study analysis of person-centred-planning for people with intellectal disability following their transfer form institiutional care.

Researcher: Mr Donal Fitzsimons, National Institute for Intellectual Disability, Trinity College Dublin.

Supervisor: Dr Patricia O'Brien, National Institute for Intellectual Disability, Trinity College Dublin (2007 – 2008) followed by Dr Philip Curry, School of Social Work and Social Policy, Trinity College Dublin (2008 – 2012).

Thank you for agreeing to be part of this study. My name is Donal Fitzsimons and I am currently undertaking a part time PhD programme through the Social Work and Social Policy School of Trinity College Dublin. My area of interest and research is in intellectual disability person centred planning (PCP). I have 20 years experience of working with people with intellectual disability and I am currently employed with the HSE Manager of Disability Services in the Midlands area.

Service providers and staff working with people with intellectual disability have been using person centred planning (PCP) for quite a number of years. Through this research it is planned to look at how PCP impacts on the lives of people with intellectual disability who have moved to community residences from institutional care. Your participation in this research process is fundamental and grately appreciated.

To find out more from you on your perspective on PCP I would like to meet with you to discuss this topic further. I will be in contact with yu to arrange a mutually convenient time, date and venue to meet. This meeting should last about 45 minutes and I look forward to meeting with you.

If you are happy to participate in this research, please sign the attached consent form. If you have any queries with regard to any aspect of this research please feel free to contact me by phone on 057 9359915 or email donal.fitzsimons@hse.ie

Consent form for Key Worker

A Case study analysis of person-centred-planning for people with intellectal disability following their transfer form institiutional care.

Researcher: Mr Donal Fitzsimons, National Institute for Intellectual Disability.

- I have had the research explained to me.
- I have been able to ask questions and have them answered.
- I understand what is expected of me.
    - Attend a semi structured meeting.
    - Answer questions on behalf of the person with intellectual disability.
    - Participate in a discussion on PCP goals and the 'my life interview'.
- Complete a questionnaire
- **I agree to take part in this research project.**

Signed: _____

Name: _____

Date: _____

Witness: _____

Name: _____

Date: _____

Appendix IV

Correspondence pertaining to ethical approval of Trinity College Dublin (TCD) including the Research and Ethical Approval Committee (REAC) form.

School of Social Work and Social Policy

School of Social Work and Social Policy

Research Ethical Approval Form[1]

Forms must be submitted at least TWO WEEKS before a School Research Ethics Committee meeting. If you are a taught MSc student please submit form to your course administrator. If you are a member of staff or MPhil/MLitt/PhD please submit form to Rebecca Casey (rcasey@tcd.ie / Room 3053 / Arts Building)

Title of Project: A case study analysis of person-centred-planning for people with intellectual disability following their transfer from institutional care.

Name of Applicant(s): Donal Fitzsimons

Applicant(s) email address: fitzsido@tcd.ie

Application Date: 30th October 2008

Staff project *(tick as appropriate)* ☐ **Student Project** *(tick as appropriate)* **X**

Project start date: April 2007 **Student Number: 06145256**

Lead researcher: Donal Fitzsimons **Supervisor: Dr Patricia O'Brien (2007 - 2008). Dr Philip Curry (2008 – 2012)**

Title of Course:

Signature of lead researcher *(if applicable)*: _____

Recruitment Procedures

		Yes	No	N/A
1.	Does your project include children under 18 years of age?		X	
2.	Does your project include people with learning or communication difficulties?	X		
3.	Does your project include people in custody?		X	
4.	Is your project likely to include people involved in illegal activities?		X	
5.	Does you project involve people belonging to a vulnerable group, other than those listed above?		X	
6.	Does your project include people who are, have been, or are		X	

[1] This form is an adapted version of an ethical approval form developed by the Cardiff School of Social Sciences. The School of Social Work and Social Policy gratefully acknowledges the generous permission to use and adapt their form.

	likely to become your clients or clients of the School?			
7.	Does you project include people for whom English/Irish is not their first language?		X	
8.	Will you tell participants that their participation is voluntary?	X		
9.	Will you obtain written consent for participation?	X		
10.	If the research is observational, will you ask participants for their consent to being observed?	X		
11.	Will you tell participants that they may withdraw from the research at any time and for any reasons?	X		
12.	Will you give the potential participants a significant period of time to consider participation?	X		

Possible harm to participants and/or researchers

		Yes	No	N/A
13.	Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort?	X		
14.	Is there any realistic risk of any participants experiencing a detriment to their interests as a result of participation?		X	
15.	Does this research pose any risk of physical danger to the researcher?		X	
16.	Does this research pose any risk of mental harm to the researcher?		X	

Data Protection

		Yes	No	N/A
17.	Will any non-anonymised and/or personalised data be generated and/or stored?	X		
18.	Will you have access to documents containing sensitive[2] data about living individuals? If 'Yes' will you gain the consent of the individuals concerned?	X		

[2] Sensitive data are *inter alia* data that relates to racial or ethnic origin, political opinions, religious beliefs, trade union membership, physical or mental health, sexual life, actual and alleged offences.

If there are any other potential ethical issues that you think that Committee should consider please explain them on a separate sheet. It is your obligation to bring to the attention of the Committee any ethical issues not covered on this form.

Checklist

Please attach:

1. Full project proposal ☐
2. Participant information form ☐
3. Consent form ☐
4. Details concerning external funding ☐

If any of the shaded boxes have been ticked please explain, with reference to the number of each question, how the identified potential research ethics issue will be handled. If there are any other potential ethical issues that you think the Committee should consider please explain them here. It is your obligation to bring to the attention of the Committee any other ethical issues not covered on this form.

Re: Q2

The researcher must provide an information sheet and cover letter to the person with intellectual disability, family member and their key worker explaining the process. This information will be distributed prior to the interview date in the form of a meeting with all concerned. The process will be explained verbally and through consultatation. Time will be allowed for all people to consider whether they wish to be part of the research or if they require further explanation or information on the research topic. Written consent will be obtained from each individual prior to any interview taking place. Where capacity to consent is an issue for the person with intellectual disability then consent will be sought from the family member or key worker under the supervision of an independent advocate.

Ten people will be randomly selected with the researcher proposing to carryout semi structured interviews with people with intellectual disability, their family members and their key workers. The person with intellectual disability will have moved from a congregate care setting to a community care setting. If within the interview that it appears that the person is having difficulty understanding the process then the interview will use and an alternative means of communicating

Re: Q9

The researcher will in addition be seeking organizational consent prior to commencing the study. The researcher proposes to write to the Ethics Committee of the Health Service Executive (HSE) to seek approval to contact the people with intellectual disability and the staff working within the organization. Assurances will be given that the process is purely voluntary for both staff and the person with intellectual disability and will not in any way affect the person with intellectual disability or staff if the choose not to participate in the study.

Re: Q13

If the family or the person with intellectual disability become distressed during any aspect of the process the interview will cease immediately. The people involved will be asked to take a break and the option to resume the same day or another day will be offered. The researcher will ensure that a senior employee within the organization will be available to talk to the person with intellectual disability or their family either the same day or at a later date. In addition the researcher has extensive experience of dealing with distress and conflict with people with intellectual disability and their families. In the event that the situation or issues raised by the adult with intellectual disability are extreme the researcher will follow HSE Policy on *"Guidelines for the investigation of allegations*

of abuse of adults with intellectual disability/autism" (HSE, 2002). The Designated Officer for the investigation of allegations of abuse will be contacted immediately and the guidelines will be implemented.

Re: Q17

Personalized data will be gathered during the course of the study and it is proposed that this information will be held centrally at Trinity College in the National Institute for Intellectual Disability department under lock and key for the required amount of time.

Re: Q18

An analysis of the person with intellectual disability's person centred plan (PCP) will be analyzed for outcomes pertaining to their PCP goals. These plans contain sensitive information and the researcher proposes to gain consent initially from the HSE Ethics Committee for approval to contact the person with intellectual disability. Consent will then be sought from each individual to access their files. Where capacity to consent is an issue for the person with intellectual disability then consent will be sought from the family member or key worker under the supervision of an independent advocate.

Supervisor's Declaration

As the supervisor for this project, I confirm that I believe that all research ethical issues have been dealt with in accordance with School policy and the research ethics guidelines of the relevant professional organization.

Signed: _____

Date:

Print Name:

Office Use Only:

Decision of the Ethical Approval Committee

REFERENCE NUMBER	
Research Ethics Meeting Date	
Approved	
To be resubmitted	
Reasons for resubmission	
Date	

Graduate Studies Office, Arts Building, Trinity College Dublin
Ph. 608 3957
Fax. 671 2821
www.tcd.ie/Graduate_Studies

Dean of Graduate Studies – Student Case Decision Memo

To: Student Records Office

From: Dean of Graduate Studies, Prof. Carol O'Sullivan

Date: 22nd October 2008

Re: Transfer from Masters to PhD register

Student Name/Current Reg status:	Student I.D.	Course No
Fitzsimons, Donal / 0	06145256	M.Litt. – 511
Dean's Decision:		
Transfer from Masters to PhD register (509) retrospectively 1st April 2008 . Cess date to change to 1404.		
Fee Implication:		
Fee to be adjusted to reflect the PhD transfer.		

Graduate Studies Office: generaladmin.gso@tcd.ie

Student Records Office: srecords@tcd.ie
jowhelan@tcd.ie
Eilis.Dunne@tcd.ie

Fees Office: jabyrne@tcd.ie

Supervisor/Course Coordinator/Course Director : obrienp3@tcd.ie

Student : fitzsido@tcd.ie

Please Allow 48 Hours for the change to be reflected within our Student Record Database; print out and retain for your records.

Chairperson
Research Ethical Approval Committee
School of Social Work and Social Policy
Trinity College Dublin
Dublin 1

14th April 2010.

Re: Changes to Research Methodology (Ref no. 144)

Dear Chairperson

The Research Ethics Approval Committee chaired by Dr Janet Carter-Anand approved a research proposal (ref no. 144) in February 2009. Since this time the methodology for the research has changed slightly in that I now propose to interview people separately. In the original proposal I planned to carryout interviews in a three person cluster. I believe that this is now not the way to proceed given that the research is focusing on person centred planning outcomes for people with intellectual disability.

I enclose for your consideration a copy of the revised REAC application form together with a synopsis of the steps involved in the research process. I also enclose a copy of the consent forms for the family member and staff.

If you require any further information or clarification please feel free to contact me on 086 8067386 or fitzsido@tcd.ie.

Yours sincerely

_____

Donal Fitzsimons
PhD Student

Appendix V

Correspondence pertaining to ethical approval from the Health Service Executive (HSE) including application form

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Midland Area

Research Ethics Committee – Laois, Offaly, Longford and Westmeath

Application Form

- Please read the guideline document and guidance noted
- Application forms should be typed and include, as applicable, information leaflets, consent forms, questionnaires, topic guides, etc
- A one page CV must accompany each application

Return 3 copies (including your signed original to):

Paul Marsden,
Research Ethics Committee Secretary,
Department of Public Health,
HSE Area Office
Arden Road,
Tullamore,
Co.Offaly.
Paul.marsden@hse.ie

Research Project Ethical Approval Application Form

1. FORM SUBMISSION DETAILS

DATE: 26th November 2008

Please tick if you work for the HSE Midland Area √

Project Originator/Lead/Author:

Donal Fitzsimons

Speciality/Department:

Regional Disability Services, HSE, Arden Road, Tullamore, Co Ofally

Sub-Committee:

N/A

Contact Email & Telephone/Fax Number:

Donal.fitzsimons@hse.ie Phone 0867 8067386 057 9359915 Fax 057 9359936

Project Title:

A case study analysis of Person-Centred-Planning for people with intellectual disability following their transfer from institutional care.

2. PROJECT DETAILS

TOPIC: (please state why this topic was selected & a description of any background work carried out to date)

The author has worked with the HSE as Project Manager with responsibility for the closure of the three large institutions in the area and the development of a community infrastructure for people with intellectual disability. A PASS evaluation recommended care in the community fro all people with intellectual disability and that PCP should be at the core of services for people with intellectual disability. The de-institutionalisation process has commenced in the midland area and PCP has been introduced across the three sites. The author believes that it is now timely to evaluate whether the investment in PCP has made a difference to the lives of people with intellectual disability.

Is this research being undertaken for further education?

Yes ✓ **No** ☐

If yes, please give details:

The research is for a PhD programme through the Social Work and Social Policy Department of Trinity College, Dublin.

Aims & Objectives:

This study will examine the efficacy of PCP for people with intellectual disability following their transfer from institutions. It will build on the work of O'Brien (2000) and Robertson et al (2005) and will add to the evidence base. Specifically the study will: -

How will this study influence your current and/or future work?

N/A

Have you received approval from your Line Manager to undertake this piece of work?

Yes ✓ *Line Manager's Name:* ***Mr Liam O'Callaghan, Local Health Manager,*** *No* ☐

If "no", why not?

3. METHODOLOGY

PROJECT TYPE:

Research ✓ **Evaluation study** ☐

DATA COLLECTION METHODS: (please tick all those that apply)

Qualitative ☐ **Quantitative** ☐ **Both qualitative & quantitative** ✓

Retrospective ☐ **Prospective** ☐ **Concurrent** ☐

Please provide a brief description of how you propose to collect the data:

The three centres that have participated in the move from congregate care to community living and who have implemented a programme of PCP will be invited to participate in all stages of the project. The study has four stages.

1. Analysis of PCP documentation; The PCP files will be made available to the researcher. The researcher will chose two PCP records per participant on or before leaving the institution and the most recent PCP and analyse the documents.
2. The researcher will invite the person with intellectual disability, a family member and a key worker to an individual interview.
3. The researcher will attend a PCP meeting as an observer for each of the ten participants.
4. All interviews willl be recoreded and transcribed.

Please give details of all participants (i.e. clients, patients, professionals, other departments etc.) involved in the research/evaluation, and whether or not they have been (i) identified, (ii) approached or (iii) recruited?

People with intellectual disability will be purposively selected according to the criteria detailed below. The people with intellectual disability will be respectively chosen from the HSE MA three transfer programme sites; St Peter's Centre, Castlepollard, Lough Sheever Centre, Mullingar and Alvernia House, Portlaoise.

Sample Size:

How many participants will be involved?

Ten people with intellectual disability, ten family members and ten key workers.

If quantitative, are these numbers representative of the total population size?

Yes ✓ No ☐

Proposed starting date:

January 2009

Proposed duration of the project:

Four Years

What are the principal inclusion criteria?

The person with ID needs to have been resident in an institutional setting for up to twenty years.
Needs to have transferred to a community setting within the last five years. Have had a PCP in place prior to or upon moving to the community. Part of a gender mix. Part of an ability mix.. Agree to attend, even through proxy, a meeting where the planning process that they have undergone discussed. Have a parent/advocate/staff member willing to be interviewed as part of the project.

What are the principal exclusion criteria?

The person with ID has not been part of a transfer programme. Have not participated in a PCP process. Does not have family member/ advocate/ staff member willing to participate in the research process.

Please provide details of the audience (internal/external/general public/etc.) to whom the report will be made available and how the results will be used. Have you any dissemination plans? If so, please include a brief description of these also.

The report will be made available to the HSE and Trinity College. The results of the research will be presented to senior management of the HSE for information and consideration.

4. DATA PROTECTION

Outline how you propose to ensure the care and protection of the research participants?

If the person with ID or their family become distressed during any aspect of the process the interview will cease immediately. The people involved will be asked to take a break and the option to resume the same day or another day will be offered. The researcher will ensure that a senior employee within the organisation will be available to talk to the person with ID or their family either the same day or at a later date. In addition, the researcher has extensive experience of dealing with distress and conflict with people with ID and their families. In the event that the issues raised are extreme the researcher will make the necessary referral to an appropriate service for follow up.

What measures will be put in place to ensure the confidentiality of personal data?

Personalised data will be gathered during the course of the study and it is proposed that this information will be held centrally at Trinity College in the National Institute for Intellectual disability under lock and key for the required amount of time. A coding system will also be used to ensure anonymity of participants.

Where will the analysis of the data from the study take place? By whom will it be undertaken?

In Trinity College by the researcher.

Who will have control of and act as custodian for the data generated by the study?

The researcher.

Who will have access to the data generated by the study?

The researcher.

For how long will the data be stored? 5 **YEARS** 0 **MONTHS**

Have you addressed all the ethical considerations?

Yes ✓ **No** ☐

Use Ethical Checklist Guide to describe how. Attach the necessary documentation.

5. THIS QUESTION MUST BE ANSWERED BEOFRE UNDERTAKING THE RESEARCH

Will the individual researcher receive any personal payment over and above normal salary for undertaking this research?

Yes ☐ **No** ✓

If yes, outline:

Will individual researchers receive any other benefits or incentives for undertaking this research?

Yes ☐ **No** ✓

If yes, outline:

DECLARATION

- ❖ The information on this form is accurate to the best of my knowledge and I take full responsibility for it.
- ❖ I undertake to abide by the ethical principles underlying the Declaration of Helsinki and the HSE-MA Guidelines on Good Research Practice.
- ❖ I undertake to submit an annual report as per Ethical Approval SOP to the REC.
- ❖ I am aware of my responsibility to comply with the Data Protection Act 1998 and 2003.
- ❖ I understand that research records/data may be subject to inspection for audit purposes if required in the future.
- ❖ I understand that personal data about me as a researcher in this application will be held by the REC and that this will be managed according to the Data Protection Act 1998 and 2003.
- ❖ I will make a copy of my research available to the Regional Librarian on completion.

Date Proposal Form Submitted: _____/_____/_____

Signed (project leader): _____

FOR OFFICE USE ONLY:

Results of proposal discussed by Research Ethics Committee.

Accepted ❒

Rejected ❒ Reason: _____

_____

_____

_____

Chairperson/vice-chairperson

Signature: _____

Date: _____

Research Ethics Committee
HSE –Dublin/Mid-Leinster
HSE Area Offices
Arden Road
Tullamore
Co. Offaly

Telephone: 0579359894 Fax: 057 9359906

13th February 2009

Mr. Donal Fitzsimons
Regional Disability Services
HSE
Arden Road
Tullamore
Co. Offaly

Ref: 030209DF

Re: A case study analysis of person-centred-planning for people with intellectual disability following their transfer from institutional care.

Dear Mr. Fitzsimons,

Thank you for your communication in relation to the queries raised by the Research Ethics Committee that was received by email on the 10th of February.

The Chairperson of the Committee has reviewed your documentation and is satisfied that you have addressed all the issues raised.

Therefore, I am pleased to inform you that research ethical approval has been granted to the above piece of work. Wishing you all the best with your research,

Yours sincerely,

_____

Paul Marsden
Secretary – Research Ethics Committee
On behalf of
Dr. Una Fallon
Chairperson – Research Ethics Committee

Appendix VI

Template for systematically recording information from files, case notes and PCP meetings.

Audit of Person Centre Planning Phd Research Project

Title: A case study analysis of person-centred-planning for people with intellectual disability following their transfer from institutional care.

Name:	Colette
Date of birth:	X
Current address:	X
Home address:	X
Male/Female:	Female
Level of Disability:	Mild?
Diagnosis:	Colette was admitted to X Psychiatric Hospital during the 70's for depression. Colette suffered a nervous breakdown after her marriage broke down in England. She was hospitalised in the UK and was receiving ECT. Memo stated that Colette had a lot of problems namely: Schizophrenia, Diabetes, Anaemia and Depression.
How long did they live in the institution:	Admitted to St X during the 1970's. Colette then transferred to X in 1989. X was de-designated from St X in 1989. It is estimated that Colete was over thirty years living in an institutional setting.
When did they leave the institution:	Colette moved to a community house in 2003.
How long are they living in community:	Colette is 6 years living in a community setting.
How many PCP's Have they done:	
How many PCP's	

were done in the institution:	
How many PCP's have been done in the community:	
When was the first PCP done:	
Was it before the person left the Institution:	
Key Worker name:	Ms X
How long known to the person with ID	
Address:	X
Phone number:	X
Family member Name:	Mr X
Address:	X
Phone number:	X
Audit carried out by:	X
Phone No:	X
Date of Audit:	X

General Information				
		Yes	No	Specify
1.	Is there a PCP folder in place	X		It is called My Person Centred Plan
2.	Is any other document used to record/present PCP information?		x	
3.	Is this information current and up to date?	X		A PCP meeting is recorded as taken place in 2009.
4.	Pages 1-10, are all sections completed?	X		There was problem here in that there is no date on this information or when this information was updated. It is therefore difficult to access dates that the person transferred to a community setting or movement within the community. Possibly consider updating annually and signing.
5.	Are notable life achievements listed (page 8)?	X		Again there was a problem with when this information was completed. Information was vague and it would be helpful to have more detail information in this section.
6.	Is information form vision reflected in Action Plan?		X	The information from the vision sheet is around the nice things in life i.e. what people say about Collette, things she enjoys and wants to do (visit brother, go to a fashion show, and go on holidays).
7.	Does the person with intellectual disability answer for themselves?			Collette can speak for herself but it is unclear from the PCP whether she answered for herself.

Person Centre Planning Meetings				
		Yes	No	Specify
1.	Was the person with intellectual disability there?	X		Colette was present along with her key worker. Four other people were at the PCP meeting including CNM II, Day Service Manager, Staff Nurse and Independent Advocate.
2.	Has a meeting take place in current year?	X		A PCP meeting is recorded as taken place in 2009. The page My Person Centred Planning Meeting is vague and clarity around what is to be recorded here would be helpful. On Colette's PCP file there is a list of names a date and a ticked checklist.
3.	Is Key Worker named on page of last meeting?	X		Yes
4.	Is date of meeting noted?	X		2009
5.	Are family members present?		X	There is no evidence to suggest that they were invited. Maybe worth considering amending My

				Person Centred Planning Meeting to include a section for who was invited and who could not attend.
6.	Is an Advocate present?	X		The titles of people present at the meeting have not been included. It is therefore difficult to decipher who is who.
7.	Are all areas of checklist ticked?	X		The relevance of this is unclear. The checklist is ticked as been updated but in the absence of a signature and a date on pages 1 – 10 one can only assume that it has been done. The action plan has been updated, however, the By what date? Is not filled. Again a signature on this page would be helpful. The Summary page has been completed and dated. Again a signature would be helpful.
8.	Is there evidence that this has been done? i.e. (database changed, additions made)		X	It is not clear from the checklist whether the database information has been updated and who is supposed to have updated it.
9.	Was vision poster used at meeting?		X	There is no reason outlined in the PCP why there is no vision poster being used. One would assume that Colette can speak and therefore does not need a visual prompt.
10.	Was new summary page completed?	X		The summary page has been completed and the date of the last PCP meeting has been recorded which is very helpful. Again a signature and date of completion would be beneficial here. The previous meetings Action Plan sheet would be useful to have here as the summary sheet does not list the previous meetings goals.
11.	Was new summary page reviewed at meeting?	X		The checklist has been ticked as being discussed but there is no evidence to suggest that it was discussed. The summary page outlines what Colette did within the last year (as per goals?) These appear to be based on her likes.
12.	Was this information (from personal profile) used to formulate "Action Plan"?	X		This would be very important if it was the first PCP being carried out as it details a lot of information on the person with intellectual disability. In its current format it is not clear from Colette's file whether it has been updated as My Life Achievements and Vision are vague and are more on history and likes and dislikes.
13.	Was annual review record discussed?	X		This record outlined that Colette had bloods taken and what tests were carried out. This record also

				recorded Colette's weight. The remainder of the record was not completed and again there was no signature.
14.	Have previous "meeting" pages been archived?		X	The record section of the PCP file was empty. Should consider revising the record section with a named storage place for archived PCP notes.
15.	Where have the previous meetings pages been archived?		X	It is not known at this time where such records are archived. There is a real danger here that valuable information on a person's life will be lost.

Action Plan/Goals				
		Yes	**No**	**Specify**
1.	Are there goals set for current year?	X		There are three goals recorded for 2009. **Goal 1** – To enhance Colette's community participation by working 1 or 2 hours per week in a charity shop. **Goal 2** – To increase Colette's competencies by having to cook meals for herself and attend to household chores. **Goal 3** – To facilitate choice by the possibility of shared family living Colette in the coming months.
2.	Are goals clearly defined in terms of expected outcomes?	X		See above.
3.	Do goals promote Robertson et al 6 indices of PCP efficacy? **1. Social Networks** **2. Community Involvement** **3. Scheduled Day Services** **4. Contact with Friends** **5. Contact with Family** **6. Choice**	X		
4.	Are actions planned to facilitate Goal achievement?	X		**Goal 1** – Action 1 – Enquire in shops if a position maybe available for 1 – 2 hours per week for Colette to work. Action 2 – To agree a time that the day service staff will be in a position to support Colette with this Goal. Who is responsible? – Day Service Staff. **Goal 2** – Action 1 – Colette to prepare and cook her own breakfast Monday to Friday. Action 2 – Colette to prepare and cook a lunch in her day service once a week. Action 3 – Colette to learn

				to use dishwasher, washing machine, etc. Who is responsible? – Staff and CNM's. **Goal 3** – Action 1 – Contact Head Social Worker to seek family suitable for Colette. Action 2 – If a family is found Colette to spend one week or so to se how it works out. Who is responsible? – Social Worker and Staff.
5.	Is there any evidence in the plan of these actions/activities Being used?	X		There is a record sheet called Peron Centred Plan Action Record. This is a monthly record sheet and if complete is an excellent summary of goal achievement. There is only one monthly record sheet in Colette's PCP file for May 2009. This record has been subdivided manually to include June and July and is not being filled in correctly. This record sheet is supposed to be a tick box record but it has been completed using words and sentences. This record states that in May Goal number 3 had step 1 & 2 carried out. Step 3 took place on the 17th and 18th May. Goal 2 is documented with step 1 and 2 but there is no evidence that this goal has been carried out. Goal 3 is documented on record sheet with step 1 and 2 numbered, however there is no evidence of Goal 1 been carried out. There are a number of entries on this record i.e. overnight stays and share a break that do not match what the Goals are. There is no evidence of Goal 1 or Goal 2 having taken place as yet.
6.	Were they substituted by other action/activities?	X		Shopping.
7.	Were the actions easily attainable?	X		
8.	Is there any evidence that the actions/activities challenge the person/key worker/service?		X	There is no evidence that this has been a challenge for either the person with intellectual disability/key worker/service. The goals set should and are easily attainable.

Action Steps				
		Yes	**No**	**Specify**
1.	Are actions/steps clear and specific?	X		As above
2.	Are they easily measurable?	X		The PCP Action Record is an excellent template to

				measure the action steps if complete correctly.
3.	Is responsible person named (by name)		X	The "who is responsible for supporting me question"? is complete in Colette's PCP file, however the person responsible is not named by name. For Goal 1 it is recorded as staff. For Goal 2 it is recorded as Staff in and CNM's. For Goal 3 it is recorded as Social Worker and staff.
4.	Is there a clear time span identified?		X	This section of the Action Plan is not complete at all.
5.	Is the previous date of PCP archived?	X		This is recorded on the Summary Page.
6.	Is there a monthly record of actions since last PCP?		X	This is not available in the PCP file. This would be of great benefit if available.
7.	Is the record clear to follow?		X	Not available in PCP.
8.	Does the record reflect the action plan?		X	Not available in PCP.
9.	Is there any evidence of success (or otherwise) of actions?			The summary page highlights the actions of the previous PCP meeting Goals. 1. I visited X regularly over the past year. 2. I stayed overnight on one occasion 3. All Goals were achieved. There is no evidence on PCP file to back up this information.
10.	Did service user benefit/enjoy actions?			There is no record or evidence on Colette's PCP file to infer that Colette enjoyed/benefited the actions.
11.	Was frequency recommended and specified?			Previous PCP Goals are not available.

Action/Steps Not Carried Out				
		Yes	**No**	**Specify**
1.	If action did not take place is reason given?	X		On the Summary Sheet there is a record that Colette went to the X Arms to a dance instead of going to the dog track. It is reported in this summary sheet that she did not enjoy this and would prefer to go to the dog track.
2.	Is this page clear and easy to interpret?		X	This page is not complete in the PCP file. Query where the archived pages are.
3.	Is it clear for whom this page refers?		X	Not complete
4	If action/activity did not take place was it replaced by another goal?		X	Not complete

Summary Page				
		Yes	**No**	**Specify**
1.	Does it reflect audit findings?		X	PCP Audit for previous meetings was not available in PCP file.
2.	When was the summary page written up i.e. is it dated?		X	The summary page is undated and unsigned.
3.	Was summary page consulted for meeting?	X		Although undated and unsigned the goals and dreams from 2008 to be put forward to the 2009 are reflected in the 2009 PCP meeting. This would imply that the summary page was consulted.
4.	Is there evidence of this?		X	

AOB

1. There was a database form on PCP file dated 2006
2. When goals are achieved in a given year do they automatically not become a goal after that year? Example, if a goal is set in 2008 that there will be increased family contact and staff will facilitate a home visit every month. The following year when that goal has been achieved that goal is then archived and new goals are set. How do staff ensure that that goal is not lost for 2009?
3. Colette's PCP has day service and residential staff responsible for certain goals, however, there appears to be no link within the PCP outside of PCP annual meeting.
4. There is a Quality of Life Experiences and Activities Record sheet on Colette's PCP file. This record lists a number of activities including Drive, Radio, Hair appointment, Share a Break, Home Visit, Lunch and Beautician. Goal 3 is recorded here as happening on four occasions in July and when cross referenced with PCP action record there appears to be a difference in dates recorded, however, both documents have recorded goal 3 as happening 4 times for the month of July 2009. Goals 1 and 2 are not reflected on this document.

Appendix VII

Interview schedule for people with intellectual disability based on Robertson et al (2005) six indices of PCP efficacy.

List of Questions for the 'My Life Interview'

The 'My Life Interview' will be based on Robertson et al 6 indices of PCP efficacy i.e.

- Social Networks
- Community Involvement
- Scheduled Day Services
- Contact with Friends
- Contact with Family
- Choice

The questions will include

1. **Tell me about your life at the moment?**

   This question will include where the person is currently living, how long they are living there, who they are living with, do they get on with the people they live with, are there staff supporting the person, how do they get on with the staff that are supporting them, do they like where there are living, is it close to a town, have they got there own bedroom, do they have a key to get in and out of the house.

2. **What are the good things that are happening in your life?**

   This question will look at what are all the good things that are happening for the person and will include social activities, social roles within their community, activities for the person, etc.

3. **What are the not so good things that are happening in your life?**

   This question will give the person with intellectual disability the opportunity the talk about things that were or are not good in the person's life. This question will also give the person an opportunity to talk about what life was like in the institution and if there are good or not so good differences since moving to a community setting.

4. **Are there things in your life that you want to happen that are not currently happening for you?**

   This question will give the person with intellectual disability an opportunity to talk about their short and long term goals. It will explore friendships and contact with family members and whether they actually feel of the community they live in.

5. **What have you achieved in your life to date?**

This question will look all the person has achieved in their life. It will focus on choices they have or have not made in determining where it is they are today.

6. **What has got in the way of you achieving what it is you want to do with your life?**

This question will explore any barriers that the person has experienced to achieving what it is they want from life.

The above questions will be used as a prompt to guide the 'My Life Interview' and will be tape recorded for analysis after the meeting. A graphic facilitator will draw up the responses to the interview. The researcher will then present a PowerPoint summary of the PCP goals from the person's last two PCP meetings. Discussion will then open up on the match between the content of the 'my life interview' and the goals of the PCP process. In the third part of the interview depending on the strength of the match there will be an exploration of its drivers, its mitigating factors and/or its relevance.

Appendix VIII

Interview schedule for family members.

Family Member List of Questions

Name: _____

Address: _____

Contact Number: _____

Family members name: _____

Signed _____ Date: _____

List of Family Member Questions

1. How do you perceive your family members life at the moment?
2. How was life with your family member at home?
3. Are you involved in your family member's life?
4. Is there anything that you know about the person's previous life that would help us for the future?
5. Are you aware of any activities/preferences they might enjoy/have?
6. Do you see a difference now that your family member is living in a community house?
7. What is you understanding of person centred planning?
8. How do you find the PCP process?
9. What do you see as your role as part of the PCP process?
10. Are there opportunities for more optimal individualised service design?

a. I find PCP acts as a conduit for a person with intellectual disability realising their goals.

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

b. The PCP process is tedious and unfulfilling?

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

c. The PCP process is a perfect way to get to know the person with intellectual disability well?

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

d. Personal outcomes can only be reached through PCP?

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

e. Family participation at PCP meetings is fundamental to maintain relationships.

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

f. PCP aids community participation

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

g. The PCP process promotes the development of family, friendships and social networks.

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

h. PCP promotes the use of natural resources in the community eg shops, banks, post office, cinema, entertainment, etc.

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

I. PCP promotes choice for the person with intellectual disability

1_____2_____3_____4_____5

Strongly Disagree

Strongly Agree

Comment

_____

_____

_____

J. PCP ensures a full and active life for the person with intellectual disability.

1_____2_____3_____4_____5

Strongly Disagree

Strongly Agree

Comment

_____

_____

_____

Additional Comments

Appendix IX

Interview schedule for key workers.

Key Worker List of Questions

Name: _____

Address: _____

Contact Number: _____

Key Worker for: _____

Signed _____ Date: _____

List of Key Worker Questions

1. What is you understanding of person centred planning?
2. Have long have you known the person with intellectual disability?
3. How long have you been key worker to the person with intellectual disability?
4. How do you find the PCP process?
5. As key worker for the person with intellectual disability, what do you see as your role as part of the PCP process?
6. Are there opportunities for more optimal individualised service design?

a. I find PCP acts as a conduit for a person with intellectual disability realising their goals.

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____
_____
_____

b. The PCP process is tedious and unfulfilling?

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____
_____
_____

c. **The PCP process is a perfect way to get to know the person with intellectual disability well?**

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

d. **Personal outcomes can only be reached through PCP?**

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

e. **Family participation at PCP meetings is fundamental to maintain relationships.**

1_____2_____3_____4_____5

Strongly Disagree — Strongly Agree

Comment

_____

_____

_____

f. PCP aids community participation

1_____2_____3_____4_____5

Strongly Disagree

Strongly Agree

Comment

_____

_____

_____

g. The PCP process promotes the development of family, friendships and social networks.

1_____2_____3_____4_____5

Strongly Disagree

Strongly Agree

Comment

_____

_____

_____

h. PCP promotes the use of natural resources in the community eg shops, banks, post office, cinema, entertainment, etc.

1_____2_____3_____4_____5

Strongly Disagree

Strongly Agree

Comment

_____

_____

_____

II. PCP promotes choice for the person with intellectual disability

1_____2_____3_____4_____5

Strongly Disagree

Strongly Agree

Comment

_____

_____

_____

K. PCP ensures a full and active life for the person with intellectual disability.

1_____2_____3_____4_____5

Strongly Disagree

Strongly Agree

Comment

_____

_____

_____

Additional Comments

Appendix X

An Example of a transcribed interview with the person with intellectual disability.

Transcript of Interview of:	**Ronan (pseudonym)**
Date:	21st April 2010
Venue	Community Residence

Donal	Hello Ronan, How are you?
Ronan	Okay.
Donal	Do you remember the last time that we met we had a chat about you PCP?
Ronan	Yes I do.
Donal	So I am here today in you home to have a chat about your PCP and to talk about how things are going for you.
Ronan	Yeah.
Donal	Can you tell me a little bit about where you are from?
Ronan	I am from a village in the country. I use to be in that big place long ago and I used to work in OT there.
Donal	Did you like working there?
Ronan	(laugh) Ah I did, it wasn't too bad. We got no money though when we would worked there.
Donal	What did you do when you were there?
Ronan	I put lids into yokes there.
Donal	Did you live in the big place at this time?
Ronan	Yes I did.
Donal	What was the name of the ward?

Ronan It was X Ward.

Donal Was there many people living there with you?

Ronan There was 5 clients and 2 nurses.

Donal What else did you do when you lived there?

Ronan Ha?

Donal What else did you do?

Ronan Not much really. I went into town sometimes, went for a walk and went on outings.

Donal Would you go with staff or would you go on you own?

Ronan With staff yeah all them. I went to dances and things and to parties as well.

Donal Did you go to dances and parties when you were living in the big place?

Ronan Yeah

Donal Did you like living there?

Ronan I liked living there yeah! I like living in the big place so I do, beside Mammy.

Donal So after you lived in the big place, where did you go?

Ronan I got very upset out at the house one day and the Guards came up and the nurse came up and he said that he wasn't taking it anymore. He said I won't be going back to the big place beside mammy anymore. Then the guards came and the lady Doctor, what do you call her? She does be with Dr. X, what do you call her, the lady Doctor? Anyway she came up and sent me back to Admissions, Admissions in the mental hospital.

Donal What did you say that you did again while you were at home?

Ronan Ha?

Donal What did you do in the house that the Guards came?

Ronan Eh, I took a turn so I did and the nurse came up and gave me an injection and said I would never be going back to the big place and he would never be taking me back.

Donal So at this time you went to the psychiatric hospital and you were there for a while.

Ronan Thats Right yeah.

Donal Where did you go then?

Ronan I used to work down in the old woodwork unit putting lids on yokes.

Donal Were you living in the psychiatric hospital at this time?

Ronan I was yeah.

Donal Did you like living there?

Ronan It was nice in there yeah.

Donal Who were you living with there?

Ronan Ha?

Donal Who was there with you?

Ronan I was in the admissions ward then I went to another ward and then they moved me again to another ward.

Donal So you got round all the Wards?

Ronan And the Admissions Ward?

Donal Did you like living there?

Ronan I liked living there and I was in that other ward as well, em what do you call it, eh, (Ronan named another ward).

Donal Which one?

Ronan — I used to go home every second week and I used to get the bus there beside that workshop there beside Admissions, eh, what do you call it? Anyway I used to get the bus there and the nurse would have me arranged and they would give me money and then I would go home on the bus to me mother every second weekend.

Donal — What would you do when you were at home?

Ronan — Well I would just lie in bed, then get up and just walk about, go for a pint and go to mass and go for a drink with me mother.

Donal — Would you ever go for a pint on your own?

Ronan — No, I would go with my mother.

Donal — Where would you go?

Ronan — Down town to the pub.

Donal — Do you go to any of these places now?

Ronan — No.

Donal — So then tell me, you moved out of the psychiatric hospital.

Ronan — Yeah.

Donal — Where did you move to?

Ronan — Well I was in the big place for a good while then I moved to X when it opened up then and the nurse got me into a community house.

Donal — Did you like living in the house in the coutry?

Ronan — I liked it, yeah.

Donal — How come you are living in this House now?

Ronan — Well eh, eh. I had a bit of trouble. I was at the dance and I broke glasses and the nurse had to hold me down on the ground at the dance by the neck. I got very annoyed at the dance and I broke a glass of beer at the dance on the floor. The nurse had to hold me by the neck until I settled

down and he put me back to the big place. I was there for a while, no a good while, a good many years and then this house opened up then, the nurse mamanger decided to put me up there then.

Donal — Did you look to move to this house?

Ronan — I did yeah. I told the nurse, could I come here and the nurse manager says she would look about it she says.

Donal — So you asked to move to here and here you are? Do you like it here?

Ronan — I like it here yeah.

Donal — Do you have your own bedroom?

Ronan — I have me own room yeah. It's down there (pointing to the end of the corridor). I love the staff here too, so I do.

Donal — How many people are living here with you?

Ronan — There are 5 of us living here and there are two nurses on night duty and two nurses on day duty.

Donal — What do you do during the day?

Ronan — Well I used to work in the centre there but I don't work in the centre anymore. I work in the other place.

Donal — When you were in the centre what did you do?

Ronan — Everything, gardening, carpentry and jobs like that. I was with the staff every Friday.

Donal — Did you enjoy that?

Ronan — I did enjoy that.

Donal — Why did you look to move to the other day service?

Ronan — Because I don't like the staff anymore.

Donal — Alright, okay. Do you walk into town on your own from here?

Ronan — I do walk constantly into town here on my own. The staff mighten trust me anymore then. There trying to get a mini bus to bring me down to the centre in the mornings to save me walking because the two mornings it is very hard. I have asked the nurse to organise to get me the bus to collect me here in the morning.

Donal — Is the nurse working on that for you?

Ronan — She is yea. I do ask her and I will ask her again on Friday. She said she would let me know next week she says.

Donal — Can you tell me a little about your PCP?

Ronan — Hagh!!

Donal — Can you tell me about your person centre plan?

Ronan — Yeah, 'Mary' used to be my key worker long ago. She was a care assistant a care worker, a key worker.

Donal — Who is your key worker now?

Ronan — The nurse

Donal — Do you have a PCP meeting?

Ronan — Very often yeah, every year.

Donal — Can you tell me a little bit about that?

Ronan — Well about every August maybe.

Donal — Can you tell me a little bit about what happens at your PCP meeting?

Ronan — Eh, we used to have it here one time and we had it in my mother's house a couple of times. My other sister that died there before Christmas, me oldest sister died. What do you call the month before Christmas?

Donal — November.

Ronan — I, November, she died in November.

Donal	Oh sorry to hear that. What was her name?
Ronan	'Bridgid'. She was married with two kids and was living in the village. She died of cancer.
Donal	Were you at her funeral?
Ronan	I cried at the removal and I cried at the funeral so I did. Me mother and me sisters were all crying at the removal and the funeral. She died very young you know.
Donal	What age was she?
Ronan	She was only 40.
Donal	God that is very young. Okay are you okay to move on and talk some more.
Ronan	Yeah, I am.
Donal	Okay, so going back to your PCP, can you tell me a little bit about it?
Ronan	Eh
Donal	Who comes to you PCP meeting?
Ronan	Just me mother and me sisters would come to the house.
Donal	Which sisters?
Ronan	'Josie and Ellie'. Brigid' used to come one time, before she died.
Donal	What would you all talk about?
Ronan	Well we would talk about everything.
Donal	Like what?
Ronan	Well we would talk about how I am getting on here, this house and we talk about when I am going to retire.
Donal	Are you planning on retiring, surely not, you're only a young lad?

Ronan Not yet no, we talk about loads of things and we talk about how I was getting on in the centre.

Donal Do you look at your gaols?

Ronan Hah

Ronan My key worker takes me out to his house every couple of weeks to see the goals and the sheep and the hens and ducks and the horses and cattle and pits and that. He brings me out a bit when he is on day duty. He brings me to see his farm.

Donal Right. Tell me Ronan what are the goods things that are happening for you at the moment?

Ronan Now you mean?

Donal Yeah.

Ronan Well I am so happy to be out of the centre I didn't like the staff so I didn't. I didn't likeit, I didn't like it, I don't like it.

Donal So it is good that you are not there.

Ronan Yeah.

Donal Is there anything else that is good?

Ronan I like some of the staff, I am fond of some of them but I don't like the others so I don't. I don't want to ever go back to the big plce so I don't.

Donal Tell me do you go out at night?

Ronan I go out to see John Hogan and Declan Nerney to the hotel. What do you call that big hotel out the Dublin road?

Donal The X Hotel.

Ronan That's it, the X Hotel. Sometimes we would go to that place outside town. What do you call that big hotel outside town out the Dublin road? I go there often.

Donal So you go to see bands playing.

Ronan Yeah, that's right bands playing and dancing.

Donal Do you take a drink?

Ronan I do yeah, I would take a coke or the nurse takes me for a pint very often. I do go over there to the Club to the dancing every so often. I wanted to go to the dance last Thursday night and they wouldn't let me. I kicked up a bit of a racket and they wouldn't let me go the dance, so they wouldn't. They might let me go Thursday night because I am very good now so I am. They might let me go this time.

Donal Do you ever go out to your mother now at all?

Ronan Every Saturday.

Donal Oh you go home every Saturday.

Ronan yeah, every Saturday.

Donal Do you stay the night or do you come back?

Ronan Oh I just go out for a couple of minutes, have a cup of tea and stay with Mammy for a few minutes and she gives me money. She is keeping well. She is an old age pensioner.

Donal Does someone bring you out?

Ronan The staff here, the nurses bring me out. I do go home for holidays for Christmas, Halloween, Paddy's day and Easter.

Donal Very good and would you stay the night?

Ronan No, just for the day. At Halloween I would go home for a couple of minutes, for Christmas I would go home for the whole day. The nurse brings me and me mother up to my sisters house for Christmas dinner. Up to my sisters house for the whole day on Christmas day. I go home for the whole day on Paddy's day to my sister, I watch the parade and come back in that night then. Then I go out at Easter for the whole day, no two hours. I visit the two graves and then I come back in again. I'll have a sup of tae in the house and then they will give me a bath then.

Donal Do your family come to visit you in this house?

Ronan They do yeah, very often.

Donal Does your sistercome in to see you?

Ronan She does yeah, and my other sister comes too. My sister comes in to bring me home often.

Donal Is there anything with your life that you are not happy with?

Ronan No. I am just not happy with up there in the centre. That is the only thing.

Donal Is there anything that is not happening for you at the moment that you would like to happen?

Ronan No just not up there in the centre.

Donal Who are your friends?

Ronan All the staff are me friends. Me mother and brothers and sisters as well and all the staff and clients in this house.

Donal Have you any friends outside of all that?

Ronan I know all the neighbours so I do. I know the most of them so I do. A nurse lives there (pointing) another staff lives down there. A retired nurse used to live over there but he left long ago.

Donal Do you ever call into see them or to have cup of tea?

Ronan No, but I know a lot of the staff from the centre and the hospital that live in here.

Donal Do you see this House as your home?

Ronan This is my home yeah. When I get a bit oulder though I will retire out to my mother in the home place.

Donal Okay so, so your long term plan is that you are going to retire to home.

Ronan	Yeah that's right when I get a bit oulder.
Donal	Does everyone know that and is it part of your PCP?
Ronan	PCP. When I get a bit oulder I am going to move home with mammy. I'll come in once a month to the clinic for them to make sure that I am okay and the nurses will call once a month to see if I am okay. What do you call that when the nurse calls to check on you?
Donal	Oh yeah, as part of the supported living?
Ronan	That's right, she will visit me once a month and she will organise the taxi to bring me into see the doctor once a month.
Donal	God, you have it all sorted. Tell me this do you go shopping for your own clothes?
Ronan	I go shopping yeah, I went shopping yesterday morning with the nurse and she and I put the stuff into the trolley then I put it into the car and I took out the money out of the yoke.
Donal	Who buys your clothes?
Ronan	The staff does.
Donal	Do you pick your own clothes?
Ronan	No the staff does.
Donal	Do you help cook the dinner here in the house?
Ronan	No the staff cooks it.
Donal	So you are happy with everything at the minute?
Ronan	Yes I am.
Donal	Where is your PCP kept?
Ronan	The nurse has it.
Donal	Have you a key to your front door?

Ronan — No, the nurse has.

Donal — Why haven't you got a key?

Ronan — I should have but, it is too dangerous. If the clients got out I would be murdered so I would. That is why the staff only have the key. If I had the key and clients got out I would be murdered.

Donal — So is there anything else you want to tell me?

Ronan — No, but I am not happy up there but I went to get a job in town.

Donal — The nurse is looking into that for you isn't she?

Ronan — She is yeah. She told me probably next week. She said she would also look at where the other lads works.

Donal — Is there anything that you want to do that you are not doing at the minute?

Ronan — No I am helping the nurse out there to plant vegetables.

Donal — Very good.

Ronan — Onions, spuds and turnips.

Donal — Fair play to you. Do you like that kind of work?

Ronan — I do yeah.

Donal — I might have a look at your garden before I go.

Ronan — Yeah, I will show you. I go for walks up and down the grounds of the mental hospital. I walk on my own. Up and down the town on my own. If I mess up there in town or cause a racket the nurse said she would have to ring the Guards so I need to be good. I wouldn't like to be sent to the mental either. I like it here so I do. It is more comfortable and I don't want to be sent back.

Donal — What do you like about here?

Ronan — It is a good house it's a nice house.

Donal — Is it nice and quiet?

Ronan — I don't like the menatl , so I don't. They would bite the arm of you and they would beat you up. The nurses would hit you a box. It is a shocking place so it is and I don't ever want to go back. It is a shocking place. That's why I have to be good. You see if I am bold they will send me down to the ward. So I have to keep good. I told the nurse one Saturday morning that I was going to hit the care staff a box in the mouth.

Donal — You wouldn't do that would you?

Ronan — No I was only codding. I told the nurse that I was only codding but he said I will send you back.

Donal — Is there anything else you want to tell me about your life?

Ronan — No nothing. When will I see you again?

Donal — Well you will see me around. Do you want to show me around your house and garden?

Ronan — I will.

Donal — Thanks very much Ronan for all your help.

Appendix XI

An example of a transcribed interview with the family member.

Transcript of Interview of:	Jack (Gary's brother)
Date:	12th October 2010
Venue:	Community Residence

Donal — Thank you Jack for agreeing to meet with me and allowing me to interview you with regard to Gary and yourselves as a family.

Jack — That is no problem but before we start I would like to give you a brief background to put everything in context, if that is okay with you.

Donal — Yes that is fine please go ahead.

Jack — Well there is a spilt in the family, well me grandmother reared me, Gary and my other brother initially the grandmother reared us and he was the baby at the time. Mother unfortunately got married and eventually got a house. We all lived together at that time, anyway her new husband Tom came on the scene so he didn't want to deal with us.

Donal — So he was your step father.

Jack — Yes that is right.

Donal — Where was your father?

Jack — Our father had died quiet young and when Tom came on the scene he didn't want us. I remember going back to the 1960's or the very very early 1970's and at the time the old Midland Health Board had an allowance of a small amount at the time, however, Tom wanted Gary out of the house at the time. My grandmother fought tooth and nail for him to remain at home but eventually Tom put him into the mental hospital and since then there has been a spilt in the family because we were all stopped from having anything to do with Gary. The four of us out there are all full brothers.

Donal — So basically when ye were all small your father died and your mother re-married. Her new husband didn't want any of you and basically Gary was admitted to the psychiatric hospital and the rest of you went to live with your grandmother.

Jack

Yes that is right. Well actually our granny was rearing us from day one as years ago that's how it was. So she took the three of us and Gary went to the mental. That is where the spilt arose. We have or I have never discussed this with anybody and I am now glad to be getting opportunity to discuss this with you know. We were more or less shut off from Gary. I was young getting on with life. I was 15/16 at the time; I was in the army, got married and had 11 children of my own. But there was always this common dominator of the step father. I only found out today when talking to my brother that he (step father) never wanted Gary back in the house, at any stage we as the second family were always pushed aside and now it has come to light since mother died that they don't want anything more to do with Gary what so ever. My step brother would come to visit, he is not a bad lad.

Donal

Your step brother?

Jack

That is right, he would be a step brother, my mother went on to have another three children two girls and a boy. I would have not contact with the girls. They would go through my mother for everything. That's how they would do it. In the last couple of years now since she died I have been trying to set up legally where we stand and who is responsible or who is Gary's legal guardian as the step father never wanted anything to do with him.

Donal

Gary is an adult and has rights the same as any adult.

Jack

I know, I understand. It is more around where the responsibilities are and who is contacted and who is given the information. It is time for us to step up at this stage see if there is anything we can do from a help point of view and also to see what is required of us or me in particular, to help. I want to be of help or be able to assist in whatever way I can with the girls here.

Donal

I think the fact that you and your brothers are here today is testament to that, to see how well he is doing and the fact that he looks brilliant. I know Gary from old when he was in the residential centre and he just looks great now.

Jack

I know, there was never a reason in my mind why he ever had to be put in. In my mind, he could have been looked after at home. That is the hard thing and that is a hard thing to deal with.

Donal I understand, but I wouldn't beat yourself up over it. Things happen in life that we are not able to control. I think the issue for you is that you are here now. That you are looking to get involved in Gary's life now is the important thing and developing that going forward.

Jack And yeah, sure it is lovely out her and its easier to come to visit her. It is easier than going to the mental with locked doors and everything.

Donal That leads me on nicely to the questions that I want to ask you, Is that okay?

Jack Yeah, absolutely, belt away.

Donal How do you perceive Gary's life at the moment?

Jack Excellent, I will be perfectly honest with you it is absolutely first class. He couldn't be catered for as well, in my opinion, in any other house. He would not get this level of care if he lived in my house. The staff here, and I have only met them 4 or 5 times, are perfect. You couldn't get better and they really and truly love their job.

Donal Would you have had much contact with Gary when he lived in the residential centre or has that contact started again since he moved to this house?

Jack On the few times that he came home I would have seen him there. But I was away with the army and had 11 of my own children. Before that they would ask me to come home when he was there because they thought that we would recognise me, I am going back years now.

Donal How was life at home with Gary?

Jack He was a perfect baby, other than the curvature. I assumed that was all that was wrong with him. He was very active. In the years following and before moving into the mental he was okay, he was fine. He was trying to talk and you could actually understand what he was saying but then again you were with him every single minute of the day you would be able to perceive what it was he was trying to say. As I said the Grandmother would have reared myself, Gary and our other brother He would have got the same as us, the communication wasn't great. We used to feed him, not necessarily feed him everything. He used to start eating and we would end up having to

feed him then. While he was with us in the Grandparent's, he had a good run of things if you know what I mean. He wasn't full care if you know what I mean. As I said the biggest thing that I thought at the time was the curvature of the spine.

Donal — Did he go to school at that time?

Jack — No, even though he was school age he didn't go. Normally at that time families didn't, I am not saying families used to hide them away, but they didn't necessarily publicise it that they had a child like that. I am talking about the dark ages. I know it wasn't that long ago and I am not much older than Gary but it was the dark ages.

Donal — Are you involved in Gary's life at the moment?

Jack — As and from today yes, 100% because we are going to sit down and have a family meeting afterwards not necessarily today but tonight or tomorrow and we are going to see what we can do as a family to help out here and come and visit more often. I was in Dublin this morning and I was on the phone nearly the whole way back to here to the boys in general. That's my aim. That's what I intend to do anyway.

Donal — Is there anything that you know about Gary's previous life that may help us for the future?

Jack — Honestly, what the staff are doing here is absolutely brilliant because, he is at a level that he understands. I think what they are doing for him is first class. I don't think there is anything we could do to improve. When he lived in the residential centre he was more hunched up and appeared more nervous he is not like that out here at all, it is brilliant. He is shining, shining.

Donal — Do you see a difference now that Gary is living in a community house?

Jack — Absolutely, yeah, without a doubt, yes 100%.

Donal — What is your understanding of person centred planning?

Jack — It is individually based from what I see there and I mean they are planning to suit his needs rather than the general population needs here. I think it is a brilliant way to go and it needs a hell of a lot of

dedication from the staff here and fair play to them that they are doing it. I can say with my hand on my heart, I don't know how much they get paid but it is not enough for the work that they are doing. They obviously do it for the love of the job. It shines out. I am sure you see it because I see it every time that I am here. It is not a half hour thing and then go away. I have never seen such a happier bunch of people. It's great, it is absolutely fantastic.

Donal — How do you find the PCP process?

Jack — I am very happy with it and from what I witnessed there today it is fantastic. I can see no downside to it whatsoever, it is all positive.

Donal — Do you see that as your time or what do you see that as?

Jack — I see it as time and from talking to the nurse earlier he has everything he needs. I see it as time and support the staff whatever way possible. I think that is the best way.

Donal — Do you think PCP is a way for Gary to realise his goals.

Jack — Absolutely yeah, 100%.

Donal — Why?

Jack — Knowing Gary, he had an inherent fear of nearly everything at one stage and by bringing him out and introducing him to new things he has improved 100% no 200% different to the time that I remember him last. I don't that I remember him last. I don't thing that I have ever heard him blessing himself. It might sound simple but it is a hell of a step for Gary and unfortunately the way things have worked out, I would have loved to have been more involved all along the line, but from this day onwards, I will have no problem with it.

Donal — Do you think the PCP process is tedious and unfulfilling?

Jack — The only thing that I would say is that it may be tedious on the staff themselves. But I think that is very fulfilling. What I am saying is for the person to get X to do A and B and bring him alone must be hard on that particular person but to get him to do that must be 100% fulfilling.

Donal — Do you think that the PCP process is a perfect way to get to know Gary well?

Jack — Absolutely. You see it there yourself today.

Donal — Do you think personal outcomes can be reached through PCP?

Jack — I think you need the PCP to achieve that especially in Gary's case anyway. He really has changed so much, you know.

Donal — Do you think family participation at the PCP meeting is fundamental to maintain relationships?

Jack — Absolutely, 100%. Today has been brilliant there for us. It was totally informal. It was a chat more than anything else and it is a great atmosphere to be in and it would definitely entice you to come back. I want to talk to the nurse about whether I can pop in and out as I pass the top of the road and before today I was always in the background but that changes today. I can do it now and I can do it whole heartily. You see I see it as always been me and Gary. The next brother down never was too bothered.

Donal — Is he out there?

Jack — No, just for the record, there is another brother and he lives in the local town well he never learned to read or write but he is the cutest boy you will ever meet. He is the finest. He lives in a sort of a Walter Mitty state. He is 100% physically and mentally.

Donal — Do you think that PCP aids community participation?

Jack — Do you mean that it helps get them out and about in the community?

Donal — Yes.

Jack — Well absolutely, it is obvious from him there today that he is more switched on a lot more than he ever was and he gets on great with the staff. They seem to love him here.

Donal — Do you think that the PCP process promotes the development of family, friendships and social networks?

Jack — Yea 100%. Hopefully this is the first day of the rest of out lives. I certainly 100% will get involved with whatever I need to get involved with and I will be guided 100% by the staff here.

Donal — Do you think that PCP promotes the use of natural resources in the community e.g. shops, banks, post office, cinema, entertainment, etc.

Jack — Yeah I think it does. I think that if I had Gary out somewhere, I would be anxious that he would run a muck and how would I deal with it. The staff are great in that they can deal with that.

Donal — PCP promotes choice for the person with intellectual disability.

Jack — Yeah, exactly because your only doing exactly what it is that he wants to do and they have him well sussed out here on what he likes and doesn't like.

Donal — Do you think PCP ensures a full and active life for the person with intellectual disability?

Jack — Yeah, I agree. I remember him out home years ago when he would come out of the mental and he would just come in and sit with nothing out of him and you look at him here and there is no comparison. It is great that they have got him to this level. I am seeing him for the first time at this level in a long long time and he is up in the clouds and I will be singing the praise of staff for a long time.

Donal — Thanks for giving me the time to talk to you about Gary.

Appendix XII

An example of a transcribed interview with the key worker.

Transcript of Interview of:	Key Worker (KW)
Date:	07th July 2010
Venue:	Day Service

Donal Thank you for agreeing to meet with me regarding PCP. The interview will last approx 20 minutes and I will ask a number of questions about your thoughts on PCP

KW That's okay, no problem.

Donal What is your understanding of PCP?

KW What is my understanding? Well, to look after the needs of the person, what they want, their goals

Donal How long have you known the person with intellectual disability for whom you are Key Worker?

KW I have known her a long time. I am only a care staff for the last 7 years but I have known Colette when she was in the residential centre for about 15 years. I have only worked with her directly since she moved out to the house. So I am key worker for Colette for 2 years now.

Donal How do you find being Colette's Key worker?

KW Well Colette can be very difficult; It can be very hard sometimes. Last year when we had her PCP she didn't get her flat, as you know it didn't happen. Colette then for the last couple of months was shouting and roaring at me saying you didn't get me a flat but at the end of the day I am not the one that can say that she can get a flat. Do you know what I mean? She blamed me and she blamed the nurse but mostly it was me because I was her key worker. Also though it was people telling her things like that she should have her flat. They just come in and work with her for a few hours and they go again then it is all there left high and dry. I can see Colette's point in that everyone is telling her she should have a flat and then nothing happens about it. She gets down then and I could see that happening again at the end of the PCP meeting. It was the same last year and we are constantly told we have no money, there is no money. I really do think that she should get something. It is one of her goals

and I really think she should get something. She shouldn't be promised something and then not have it carried out.

Donal Do you think that Colette looking for a flat needs to be reached within the year or would you see this as a long term goal that follows a process over a number of years?

KW I think so Donal. I do think that it is way down the line. I think a granny flat attached to a community house is a good idea to start with whereby there is staff nearby to show her how to take her own blood sugars. But the living on her own may take years and years. It would be a good start and not just to leave it again and we are back to the same next year again as to where are now. She does have a lot of care needs and she is quite slow in the morning's b by the afternoon she is perfect. They do have plans for the house where she currently lives.

Donal How do you find the PCP process?

KW Well it is worth doing but for Colette nothing happened. She wanted a flat and didn't get it. I am to blame? who is to blame

Donal Do you feel then as Key worker that if something doesn't happen for the person that it is your fault?

KW Well, it does upset me. I feel that maybe I should have done more but yet the CNM is the boss. I should have done more but yet the CNM is the boss. I can just go in and say hold on. I have to go through the Managers. Some Managers will say yes KW keep fighting for it and others will say or no you cant do that. They say the same to Colette. She gets confused. You can't tell her one thing then tell her something different. But I do think she needs something. There should be an alternative there for her.

Donal How do you find the PCP process generally?

KW Well okay.

Donal Well there has been a lot of preparation for the PCP meeting.

KW Well yes I think it does work we have set a good few goals for Colette.

Donal Did Colette talk to you beforehand to discuss what it was that she wanted from the meeting?

KW Oh yes. I met with Colette beforehand. I was working on Sunday and we spent most of the day chatting about her goals. She told me what she wanted and what she would like.

Donal Do you think it is good that Colette sits within a group to talk about her life and what it is that she wants from her life?

KW Oh yes I think it is very good for Colette.

Donal Do you think there are more opportunities for more optimal individual service design

KW I suppose there is.

Donal How do you propose that this happen?

KW I don't know.

Donal As key worker can you call a meeting with the CNM to say look here is a goal that Colette set? She wants to move into a flat and how can you help me to realise that goal for Colette.

KW Who does that, I suppose as key worker that is up to me. Is it?

Donal I don't know, I am just asking you do you think as key worker that is your role. The goals of the flat. How does that get fed back to the CNM? Or further up the line?

KW The Manager would normally bring the information with regard to the PCP and requirements.

Donal Is there a minute taken of the PCP meeting?

KW No

Donal Is there no record of the meeting other than the goals that are set?

KW Yeah that is it, just the goals.

Donal So the Manager takes that information to the Director of Nursing?

KW Yeh, yeh

Donal What happens after that then?

KW If the Director of Nursing wants to see me then she will ring me and arrange to meet me. I think on foot of this I will have to arrange a meeting now with her. I think yeh that is the way to go about it. You have left me thinking now.

Appendix XIII

An example of a transcribed PCP meeting.

Transcript of PCP Meeting:	Colette
Date:	07th July 2010
Venue:	Day Service
Present:	**Key Worker (KW), Colette, Staff Nurse (SN), Staff Nurse 2 (SN 2), Day Service Manager (DSM), Manager (M), Support Worker (SW), Support worker 2 (SW 2) and Advocate.**

KW I would just like to welcome everyone here today to Colette's PCP meeting. Colette asked that I speak on her behalf, isn't that right Colette?

Colette It is indeed.

KW Will I start so (KW speaking on behalf of Colette read from her PCP as follows). My name is Colette, I was born in the midlands. I enjoyed my childhood when my mother and father were alive I used to take trips from home to town frequently with them. I had no ill health then. I attended the Convent of Mercy School, at the age of 5. From there I went to the Technical College to the age of 15 years. I completed first and second year. My school experience was terrible. I never liked school as the nuns beat the hell out of me, in particular 'Sr Bridgid'. My favourite nun was 'Sr Martha'. She treated me like a sister. I hated doing my homework but felt I had to do it. I went to Bermingham after I left school at the age of 16 years where I worked in a bakery supply pancake factor for about 2 years and then I worked in a bread factory for about 5 years. I worked in a carpet factory in England for about 9 months. After that I moved to London and worked in a café. After this I moved home and worked in a local hotel. I became unhappy at home and moved to America where I lived in Manhattan and Boston where I worked in pubs and hotels. My favourite place to work was Boston as the people there treated me very well. I earned loads of money and loved buying clothes. I had loads of choice. I keep a nice flat and I managed well on my wages and I got plenty of tips. I now live in a community residence and I live with 4 other residents.

There I have my own room. I also have my own clothes, cosmetics and jewellery. I have may own bank account. I get up in the morning and I go to the day centre at midday. In the evening I come home and I can go for

a drive after my dinner or I can relax watching television. For my leisure time I can relax at home or go for drives, shopping, outings. I can visit my sister in the other centre or go to see my brother in the home place. I can go to the dogs and the beauticians. Since moving to the community house I don't know many of my neighbours and I am not interested in getting involved in the local community. I enjoy watching the cars going up and down the road. I am a small woman with blond hair and glasses. Staff see me as helpful but they say that I can be attention seeking where I talk about my parents and give out about certain things. I like to go shopping for clothes and jewellery, like going to the dogs and also going to the pub for a drink. I like necklaces, bracelets, watches and I like going to the pub for a drink. I like getting my nails painted and I like going to the beauticians. I enjoy eating out and my favourite food is steak and onions. I enjoy going out for a drink at the weekends. I don't enjoy books or television. I don't like carrots or coleslaw. I don't like snails and creepy crawlies.

Choices

I choose my clothes each morning I choose the place I like to go and what I like to eat.

Choices other people make for me

Medical appointment, dental appointments, eye appointments, holidays and whether I visit my family.

Strengths and abilities

I look well, I have my hair done. I keep myself well and I like having my face done up. I like ironing and I like helping around the house.

Opportunities

I go to the dogs once or twice a month. I go to difference restaurants. I visit my family; I can go shopping for groceries and clothes. I can spend money on nice things. I look forward to holidays. I can enjoy my birthday. I have my jewellery and clothes. I love watching the traffic go by.

My life achievements

I got married in 1961 and was married for 9 years. My first 4 years of marriage were happy then things started to change. We started to fight and he started to see other females. We eventually divorced in 1971. I had a nervous breakdown following my divorce and was hospitalised in England. I had ECT twice leaving me feeling a bit better. I returned to Ireland in the 70's and went to live with my parents. I stayed there for

about 4/5 years my condition started to get worse and I was admitted to the psychiatric hospital suffering from depression. I remained there for 9 years and was later transferred to the residential. I then moved to a new house 4 years ago. I lived there for 2 years and 2 years ago I then moved to a different house and I have my own home. I love living with the other people there and I love going to my programme each day. I am in close contact with my brothers and sisters.

Vision

Nice things that people say about me. People say that I dress very well, that I am good at holding conversation with people. People say I am very funning.

Things I would like

I would like to go away on holidays.
I would like to go home more frequently.
I would like to visit my brother and stay overnight.
I would like to go to a fashion show.
I would like to move to a flat.

Things I must have

Clothes, lots of clothes, jewellery, cigarettes.

Things I must not have

Sweets or anything with sugar as I am a diabetic, very little alcohol

Summary page

Last meeting was April 2009.

Goals

1. Visit my sister
2. Attend day service from 12 – 4.30
3. Went to Sligo with staff and stayed overnight
4. Went on an overnight stay with Share-a-Break 3 times

The summary pages was a summary of all activities from April 2009 to date

- Share-a-Break
- Socialising
- Visiting family
- Shopping

Colette's brother passed away in November and she was supported at the funeral by staff.

New Goals for 2010

1. Visit brothers more often and stay overnight.
2. Continue with Share-a-Break (once a month)
3. Continue attending Day Service 9.00 am – 4.30 pm Monday to Friday
4. Go on more social outings and to go out for a drink at least once a week.
5. Move to a flat on my own with support.
6. Visit the family grave more often.
7. Go to Sligo on holidays at least twice during the year.

Colette's big ambition and long term goals is to move to a flat.

Colette	Yeah, that's right, that's all I want.
KW	Her big goals, her number 1 goal is moving to a flat.
Colette	Yeah that's right.
DSM	You had another goal, didn't ya? What would you like to do?
Colette	It's not what I like, it's what I get.
KW	So what would you like?
Colette	Well I would like to go out and have a drink every second weekend.
KW	Right.
Colette	I would like to stick with Share-a-Break.
KW	Right.
SN	Do you enjoy your Share-a-Break?
Colette	I do.
SN	When do you go?

Colette — Every month I go on a Friday evening and come back on a Saturday evening.

KW — What do you do when your on Share-a-Break, do you go shopping?

Colette — I do yeah.

DSM — Who do you meet? You made friends on that Share-a-Break, haven't ya?

Colette — I have and I love going on my Share-a-Break, I go off out to the middle of nowhere and I like it.

SN — Well that is what you prefer. Colette is to be off out in the peace and quiet.

Colette — Yeah, I love peace and quiet and that is why I want that flat on my own. So I can come alone and have my own peace and quiet in the flat.

M — You like having 1:1 with staff and going places that is nice and quiet. You don't like being in crowded places.

Colette — That's right.

M — You love watching television and particular watching ladies fashions. She loves watching TV3 in the morning to look at all the style. The higher the shoes the better, isn't that right Colette.

Colette — Ha ha.

KW — Oh I forgot to say as well that you want to visit the family grave.

Colette — Yes, I intend to do that this weekend. If I can get going this weekend. I intend to buy something for the grave.

KW — What, A bunch of flowers?

Colette — Yeah – flowers or a little statue of our lord for the grave.

KW — Okay and you want to stay for an overnight with Share-a-Break host family.

Colette — Yeah.

KW Then you want to move to a house or flat and share with one or two other women.

Colette No, not two women. Two women never get on in a house.

SN Yes and we have seen that before when you lived in the other house. You get on much better in this house where there are less women.

M Well I want to say something and I know Colette that you wont like me saying this but most of the time you wouldn't be able to live on your own. I know that you are great and are out and about but for the early part of the day I don't think that you would be able to manage on your own without somebody at least coming in assisting. As you know yourself you are reluctant to get up in the morning and you are reluctant to go to bed at night. I am not giving out to you now, I am just telling you the way things are.

Colette I hate going to bed.

M I know you do, and you do be smoking in the bed as well.

Colette No I don't.

M Well I found cigarette butts behind the bed and locker on occasions now.

Colette Well that's going back now a couple of months.

SN But if you were living on your own Colette what would you do?

Colette I wouldn't do it if I was on my own. I wouldn't smoke if I was living on my own as I could put the house on fire it doesn't bother me down there, sometimes I wish the house would go on fire.

M It wouldn't bother you then to throw a butt at the side of the bed. How do you think that you would manage in a flat, realistically, you talk about shopping, managing your money because you do like to spend any money that you have in your purse is gone straight away. So realistically, do you think that you would be able to manage your finances? I mean really and honestly.

Colette Well it all depends on how much the rent is and all that.

M You asked me to talk to the nurse regarding supported living.

Colette Yeah.

M Now she has no vacancies in her supported living, but I did talk to her and she has no vacancies and she doesn't envisage a vacancy coming up in the near future. That's not to say that something wouldn't come up in the future but at the minute there is not a sign of that. I also spoke to the Director of Nursing on your behalf and she is saying that there isn't anything really coming up and that you wouldn't be able to manage on your own and that you require a lot of staffing and with staffing the way it is at the moment that it would not be possible.

Colette Well she told me that she told me she was going to get me a flat, a good flat, something that you choose. It will have to be something that you want and not what you get. She said would you like someone to go and live with you and I said that I wouldn't mind.

M Maybe something that you could think off is maybe looking at a granny flat attached to a community house and this is where you would still have the support of the staff attached to the Community House, for your medical needs, because you have huge medical needs as well and you can get sick very quickly. You know yourself that you don't be well nearly overnight. Would that be a compromise?

KW Down the line.

Colette Ah I don't think so; it could be in one way.

KW It could be!

Colette It could be in one way.

M You don't know when you are well off.

KW Do you think that you are well off in the house? Your well looked after – yeah!

Colette You see I don't think that I am well off. You see I am just there and the whole lot is getting me down. Some days you're alright.

SN Well most days you're alright Colette.

Colette And other days I am just like a lunatic.

SN Well we all have our bad days.

M Well in general terms Colette and for these around the table and we wont be telling the manager or anything about what is being said here but how do you feel about living in your house? Like how do you feel about the staff and the other people that live there? I suppose most of the time I think you're happy, but maybe you are not like most of the time you put on a very happy front, smiling and chatting and you know all our family business.

Colette I don't mind that and you get that in every house.

M But you keep well in time with everything that is going on. Tell me how you feel about being in your house.

Colette I don't mind that and you get that in every house.

M But you keep well in tune with everything that is going on. Tell me how you feel about being in the house.

Colette The majority of the time I feel I could go mad. I don't want to be there. But then I settle down and have my cup of coffee or coup of tea and then I am all right. But it takes me a while to get that way.

M It does yeah!

Colette A good two hours or maybe more and the same in the morning. I might be alright and then like a devil.

M Do you really think that living on your own would make any difference that way like, at least when you are with the rest of us you can bounce things off us. You have someone to talk to and some one to list to you and help you through them. Like if you were on your own, like, you would be on your own. It can be lonesome but if that is what you want to do that is fine, but, like it is an awful lot be on your own.

Colette Some people like living on their own. You get so far and you just like to be on your own. You get to a certain age and you just like to be on your own. Do you understand?

SN — It is a lot of extra work for yourself. You will have to cook for yourself and everything.

Colette — But that is no problem I can do that.

SN — But it is difference when it is all handed to you and things like that you know

Colette — Well I can cook.

SN — I know we understand that, but if you are out all day and have to come home and face into that when you're tired, it can be difficult.

Colette — Sure the staff could come up and cook for me.

All — Ha ha ha.

SN2 — I wonder could we try and increase her Share-a-Break. She really enjoys it but there is too long of a spell from when goes to when she get to go again.

DSM — Well we did try with a second Share-a-Break but it did break down as you know. Now I did talk to the social woker and like every other situation they are chocoblock.

SN2 — Well I wonder if there is something else we could do. She loves to go and visit people and who is that girl that works here, em, A.

Colette — Well the lady who does share-a-break has invited me up for a weekend. Not this weekend but next weekend.

DSM — Well we could definitely talk to the social worker and see if there are any other possibilities.

SW — It would be great if Colette had some outside of here to be able to go for a coffee with.

M — Like a buddy.

SW — Well someone close to her own age that she could go wherever with and do nice things. Like she comes to visit my Mam and they have a great chat.

SN Didn't you have a buddy before Colette?

Colette No.

SN Did you not?

Colette No.

KW Are you interested Colette?

Colette No

M Well you are very fond of my house and the first question I am always asked is will your husband be there? I often wonder is it just him she is coming to see. Colette will sit at the back with him for hours and fill him in with all the news. You are very knowledgeable and up to date with everything that is going on and you really get on very well with him and my children as well. What I am saying is that you might enjoy having a buddy. Some one your own age or near enough your own age or women of a certain age, we wont put an age limit on it.

DSM Again there is a lot of a demand on this service and there is a huge backlog. Really the ideal for Colette is someone that she knew in the natural setting as Colette is well able to make friends for herself. So I feel that she needs to be exposed to social settings where she is going to meet people.

M But having said that when Colette goes out socially and after a meal she is not interested in meeting new people and likes to come home. She doesn't like being in crowds. Isn't that right.

Colette Yeah.

SN What about continuing with the holidays?

Colette Yeah that is great. I love having my eyebrows and hair done on holidays.

SN Yeah I think we will do that once a year. She really enjoys it and loves going shopping and then going back to the hotel to unwind. Would you like to go on holidays again before the end of the year?

Colette The question is do I have the money to go?

SN Ah, I wouldn't worry too much about that end of things.

Colette Well I do worry about money.

KW Well would you like to go before the end of the year?The staff nurse will bring you once and I will bring you once.

Colette Ah, yeah.

KW You would?

Colette Yeah

M And what about your day programme here Colette are you happy with it?

Colette Well I am happy enough with my day programme anyway.

DSM Handed Colette a document to read aloud.

Colette I work in the kitchen. Individual programme Colette Monday am, Tuesday am, Wednesday am, Thursday am, Friday am, 12 noon Kitchen, 12 noon kitchen, 12 noon kitchen, 12 kitchen, 12 noon kitchen. Monday pm, outreach with staff.

DSM What do you do with the staff on a Monday?

Colette I go shopping, hair and beauty on Tuesday.

DSM She comes upstairs doesn't she?

Colette She comes upstairs.

SW Well I take Colette and we go out.

Colette That's right everyday. Thursday pm beauty therapy.

DSM Friday is whatever is going on.

M And do enjoy all of those?

Colette I do.

DSM Your work is in the kitchen from 12 to half 1 every day and she gets an allowance every week for this work.

Colette This is something that I can call me own and something I will always have.

DSM There are some days that Colette wouldn't be feeling quiet as well where she might have a little dip in her sugar levels, you know. She might need her lunch a little earlier, you know.

Colette That's right, if I am not feeling well the staff here will tell me to sit down and have a cup of coffee. So I'll sit and relax and have a cup of coffee. The staff would say off you go and dont bother coming back "I can do it on my own" but I don't like to see her stuck and doing it on her own because she is a great worker.

DSM And she is a great help.

Colette She is.

DSM And sure you're a great help.

M Sure you're great Colette you have all these things and helping gout in the kitchen. You also love ironing.

DSM It is very busy down in the canteen at lunchtime, isn't it KW and if some one needs ketchup or something Colette is able to go and get it for them. She is able to read the situation and if I arrive late she will make me a little pot of tea and you know I am looked after very well.

Colette Ha ha, sometimes.

DSM She is very good natured.

M She is.

DSM Colette and myself usually have our lunch together.

M One of the things that people say about you Colette is that you do have a great personality and you are such a lovely person.

DSM Just to mention also, one of the other things that Colette wanted last year was to have contact with her sister in the other residential centre. That is

happening every second week now and we drop her to her sisters and she is going today. She visits her sister while the others go to the therapeutic pool there. She always buys her a present and they sit out the back and they chat. And it is just ideal as you can see from her timetable most of her programmes are 1:1 because she needs the space. Sometimes it is not always possible in that if we don't have the staff today we ask would you like to do this, this or this and she is always very obliging. The day service staff have given a little report in that she works very well in the kitchen and she appears to love her job and that if she is not in the best of form they will encourage her to sit down and have a coffee and fag to relax. She does require supervision and that is to be expected but all in all we love having Coletten here. She has made some really goods friends with the other service users and she has Share-a-Break there with a staff member. She is busy while she is here and I think she enjoys coming here don't ya?

Colette — Sometimes, it all depends on how I am feeling.

SN — Sure that is like us all. I have seen a huge difference in her since she went to her first community house.

DSM — She has made huge progress since she stated coming here. But it really did take the sitting around and discussing things. Do you remember we set in the office Colette and you and I sat down and wrote down everything that you wanted to do and what you would like to do. You had a big long list, remember? We decided that we needed someone to work especially with Colette and that was one staff member in the beginning. That was how it all started.

Colette — She now works in the large centre. I rang her one night and I didn't know it was her. This woman come on the phone and said hello and it took me a while to figure out who it was. She has a little daughter now, she was telling me.

M — One of Colette's favourite parts of the day is 10 or 11 o'clock at night when everyone else is gone to bed and she is there with the staff. She loves that time and loves the chat with the staff.

Colette — I love buying clothes and I always hope that I have the money to continue buying them.

SN — Sure there is no reason that you won't. She is always worrying about

money aren't you Colette?

Advocate — Are you able to manage your own money Colette?

Colette — Ah, I am.

Advocate — Are you able to count money and know the value of it?

Colette — Ah, yeah I am. I am able to count it, I might be a bit slow at it but I can do it.

DSM — She has a great eye for a bargain. She knows them all in there in Dunnes and she can come out with the bargains. She can equally come out of Marks and Spencer's with the bargain.

Colette — I love the bargains.

SW — She will always see the nice stuff which I never see.

SN — Is there anything else Colette.

Colette — No, there is nothing else.

M — Medically you are well.

Colette — Well I was very sick after the death of my brother. I had a chest infection and couldn't get over it.

SN — That's understandable.

Colette — That's why I would like to go down and leave something on his grave.

KW — We will arrange that Colette.

Advocate — What did we agree around her own house?

M — We didn't agree anything, we're kinda walking around it and we don't know where we are going with that.

Advocate — I think it keeps resurfacing itself and it is definitely her wish. I think that it definitely needs to remain on the agenda regardless what the service can provide for her. It is what she actually wants.

SW I have spoken to the S/L officer about it and I have spoken to the Director of Nursing about it. Eh, the big issue at the moment is the amount of support Colette would need to live in that situation and that is why I brought up the annex type situation.

Advocate Is there anyone currently living with an annex type model?

M No, not within out service. It could be looked at and worked out and it could be the first stage of her moving.

SN It could be staged.

M Look, a report on this will be going into the Director of Nursing for her and we can highlight that maybe a room can be converted to a flat with your own front door. And that you will have the back up if the community house as Colette you would agree that you need a lot of support because you are really not able to manage your diet.

Advocate How much support does she get in the house?

M Full support.

Advocate Should some of that report be given back to Colette around preparing her for independent living?

M Colette will go and get what ever she wants and is well able but because of her diabetes that has to be restricted and that will usually end in a row. Generally Colette will tell us what she likes to eat and will help to prepare it but as regards the extra's Colette would love all of that tart or all of these biscuits. Her diet then has an effect on her physical health. Then I worry because I know Colette and I know she would not adhere to her diet.

Advocate Can she take her own blood sugars?

SN Yeah she is.

SW Are you able to do it Colette?

Colette Well I am able to take the box out every night?

KW No she is not able to do it.

Advocate But why aren't you doing it Colette?

Colette	Because no one showed me how to do it.
SW	No Colette, you were, now Colette.
Colette	Well I take out the box and the pen.
SN2	That is right; she is able to hold the syringe.
KW	But you are very fragile in the mornings.
M	We have tried in the passed but she is not able to manage.
SN2	We have tried this in the passed but she is very fragile and tired first thing in the morning and she keeps forgetting to take it. She ends up falling asleep and that is a worry for us. Sometimes they go that low she wouldn't even have time to make a cup of tea and that happened only last week. Even after she had her dinner her sugar levels after her dinner was 2.3. We made her a cup of tea and a sandwich and it shout up to 10.9. Do you know what I mean?
Advocate	And what kind of medication is she on to try and control it?
SN	Oh she is an awful lot, she is on 13 or 14 tables every morning, isn't she? She has a lot of hospital appointments as well.
M	I think maybe the annex maybe a way to go first. That will give your independence but you will have the support of the community house. You know Colette that you will not manage in a flat on your own.
Colette	Mmh
Advocate	I suppose can a programme be put in place to at least start the process for Colette managing her own diabetes. I know you said you tried it before but if we are looking to the future and Colette says she will do it and if everyone is saying we don't think you will be able to do it Colette then it wont be achievable. If the support is put in place around the things that she does need?
SN2	But from experience of working with Colette for years when she wants something she will just go and get it i.e. if she wants bread then she will just get it.

M She then goes high and that is a very big worry for us with Colette and her independent living.

Advocate But that would indicate that her diabetes is not controlled.

M Her diabetes is controlled and is going well it is the behaviour that sends it high and then it is a worry for us.

SN2 It is close monitoring.

Colette I am not going to get my flat by the sound of it.

M Now Colette, your diabetes is a worry or it is a problem. We are all here today for you Colette and what it is you want but we have to be realistic and your diabetes is a concern and it needs close monitoring.

DSM I think the idea of the granny flat would be a step in the right direction. I agree with Advocate and I know with the best will in the world that everyone is working flat out to ensure that Colette's health and well being is being looked after. It is no different than us sitting down here years ago when it was not working and deciding what it was that we needed to do to work. It really did pull on our resources to provide a 1:1. If we are going to go down the road of a granny flat to the Director of Nursing then we would need a very specific programme to be put in place and she would need that 1:1 support to give her the skill to manage her own health issues to the best of her ability like the back up. Say that there are two staff in the house and Colette needs the support, well there is the technology available that are not too costly. I think it has to be the whole package that supports are put in if she gets someone working 1:1 support and they totally take on her health issues. It will have to be the whole package or I believe then that it will work very well.

M So Colette if we, your number one goals is to move to a flat or shared house. So could we tweak that a bit and if we were able to access a granny flat as a stepping stone to your over all goal. Would that be something that you would consider?

Colette Yes it is.

M And then you maybe able to step on from that and maybe start working with you on taking your own blood sugars. We might start in the evening as you have a very bad shake in your hands in the morning.

SN2 She also believes that she shouldn't have to cook for everyone. She likes doing her own and she knows she can do it. Also, is the diabetic nurse linked in with Colette?

SN Yes that is all in place.

Advocate Do you find that a good support Colette?

Colette Yeah I got a book on it.

Advoate Are you learning all about your diabetes Colette?

Colette Yeah I am.

M: Well she is a very independent person and she can do an awful lot for herself, but, unfortunately she does require supervision. You could quite happily leave Colette in the day room but the worry is her sugar levels, generally she is quite happy to go with staff and because she is a 1:1 it is her choice, so if she wants to go out she can.

Colette: Am I going out today?

SN2: You're going to see your Sister

Colette: I was to bring a picture. You see I wasn't told that I was going out Tuesday.

M: Don't worry about it, we'll sort it.

Colette: You see I have a picture to bring out to her and it is not ready.

M: Well you will be going out once more before the holiday and we will be closed then for 3 weeks for Christmas.

Colette: Ok

M: Are you happy with all that Colette? Have you anything now that you want to say after all that?

Colette: Ah, there's not much I can say.

Advocate: Is there anything you want to add Colette?

Colette: No I don't want to add nothing.

SN: And how do you think the meeting went, Colette?

Colette: All right, but not great either.

M: What bit wasn't great now?

Colette: Well it is the same old thing again, isn't it?

M: Like what?

Colette: I have to go down now and get my lunch.

M: What do you want to achieve, Colette? This is what the meeting is about, what you want to achieve. We have already said that we are going to look at getting the Granny flat and we will get that going (Strong Tone).

Colette: That's alright

M: And we will organise for you to stay over night with your two brothers and that they will be happy to have you over night.

Colette: Well I was talking to my brother on the phone yesterday and he was all smiles on the phone. I didn't know what he was laughing at.

M: I don't know what he was laughing at either. Now Colette there is no point in you going out of here today saying I am after having my PCP meting and it is all the same again.

Colette: I won't be saying nothing.

Advocate: Do you think anything has changed for you as a result of this meeting.

Colette: No.

SN: But it just can't change today Colette. We have to look at everything and organise things for you.

Colette: I know, yes.

Advocate: Is there anything that you would like to change.

Colette: Well!

DSM: Will the trip home to her brothers happen.

M: Well we spoke to them and they have committed that they will do it.

DSM: That would be nice if it happened for her over the summer, even if it was just with one of them.

Colette: Well my brother said he was taking me out.

DSM: And the staff are going to talk to the Director of Nursing about the possibility of a Granny Flat for you.

M: And KW will organise another trip to Sligo for you.

DSM: And you will get out for a drink every Friday.

Colette: Is me Share-a-Break still on?

M: Yeah, KW will sort that out for you.

SN Are you happy with that?

Colette: Eh, ok yeah.

Advocate: And what did you say about the best buddy. Are you interested in getting some one?

Colette: No, I'm not.

Advocate: Ok, right.

SN2: I have noticed the Weekend that the other person goes to Share-a-Break that Colette is left behind saying what about me? I should go to a Share-a-Break also even if it was just for two hours.

SN: Well, I can certainly talk to the docial worker to see if there is anything. We could look at the broader Volunteer service and see. There maybe someone out there that has a couple of hours that may be in a position to take her out for a couple of hours because you like getting out don't you Colette?

Colette: Yes, I do.

M: So you have loads to do Colette?

SN: There is quite a bit now, Colette.

KW: I would like to thank everyone for coming.

Colette: Thanks everyone for appearing at my meeting.

SN2: Your more than welcome.

Appendix XIV

This is one example of a fuller case study analysed which was preformed as an intermediary stage in producing the case studies presented in the main body of the text. These fuller case studies were produced for each of the ten case studies included in the analysis.

Colette

Background and Context

Colette was born in a small town in the mid 1940's. Colette was the second eldest of six brothers and one sister. She stated that she enjoyed her early days at home with her parents and her siblings. Colette had positive family relationships but her parents passed away when she was a young adult.

> "Home was lovely; we always had the best of everything. We had a good mother and a good father, but unfortunately they died".
>
> Interview with Colette.

While she was protected somewhat by her extended family, nonetheless there was no evidence of her having a life long intellectual disability. To this day, Colette has a good relationship with her surviving siblings. Her younger sister has a life long intellectual disability requiring residential care and lives close by to her in a neighbouring village. Colette makes a point of visiting her as often as she can.

As a young person Colette enjoyed good health and there were no concerns about her physical health. During the mid 1990's when Colette was in her late 40's she started to develop health problems attributed to her lifestyle and institutionalisation. Colette, a life long chronic smoker who seldom exercised adopted many unhealthy lifestyle practices.

Colette attended the local school run by a religious order. She progressed to the local secondary school but experienced learning difficulties and left school at fifteen years of age, having completed first and second year. She stated that she hated doing her homework but she felt she had to do it. This was the first time in her life trajectory that she experienced problems while at school. She recalls her school experience as 'terrible' and she stated that she never liked school as the nuns used to 'beat the hell out of me' and in particular one specific nun.

> "Jesus I will never forget them. The beatings I got was unbelievable. One of the teachers there used to wallop the hands of me. I had a very bad time of it in school".
>
> Interview with Colette.

Ironically, Colette recalls having a good relationship with one nun who she viewed as 'like a sister to me' and she is now glad that she learned to read and write.

> "I did like school, yes. I liked it yes, but I was no way smart and that like. I know what I had to know and that was it. I never studied much at school".

Interview with Colette.

Colette alludes to the relatively poor living conditions when she was a teenager and spoke of her parent's decision to immigrate to the United Kingdom.

> "The whole lot of us moved to Birmingham, but what me father done was he went over first and he got a house. He seen the landlord and me mother went over along with him but what me father didn't tell him was that there was also five kids to go into it. He didn't tell him that part of it".

Interview with Colette.

At this stage in Colette's life she was gainfully employed in a variety of low paid, unskilled factory settings. She stated that her job was:

> "Packing the pancakes, putting them in sixes, putting them in a dish and putting them on a conveyor belt, then they would all fall onto another conveyor belt and get wrapped with paper. It was a good job. I got great money for it and I enjoyed it".

Interview with Colette.

In the early 1970's Colette met and married a local English man. He worked as a barman and was involved in the music business. Colette recounts that she sang in various Cabaret acts around England, managed by him. She recalls not having a stable home life during her marriage and had feelings of being diminished due to the demands placed on her to perform at cabaret acts at his will. However, she does recall that the first four years of her marriage as being very happy but things started to change after that. She reported that they started to argue and her husband started to see other women.

> "I got married to a good for nothing yoke. He couldn't do anything that way. That was partly why I split up with him. He used to blame me but sure it wasn't me at all it was him. I couldn't stick that so I went to the Doctor and I got myself checked out and the Doctor said to me there was nothing wrong with me in that way".

Interview with Colette.

Colette's brother reported that Colette was doing fine up until she got married. He stated that:

> "Well, her life was good until she married that man. He was a bad b*****d to tell you the truth".

Interview with brother.

During this time, with her random performing music schedule Colette reported that she was unable to hold down her factory jobs. What became clear when Colette was reflecting on her nine year marriage was that she stated that she had no control over her activities and she had no financial autonomy along with feeling manipulated and unloved. The couple divorced and subsequently Colette stated that she had a 'nervous breakdown' in which she was hospitalised in England. She recalls having had electroconvulsive therapy (ECT) twice which she says 'made her feel a bit better'.

The next part of Colette's life is patchy in that she was found in a 'bewildered state' in a train station in the Midlands of Ireland. At this time in the early 80's she was admitted to the local psychiatric hospital for treatment of depression. File entries describe Colette as 'Chronic Schizophrenic and depressed'. She was admitted and discharged four times over a five year period to this psychiatric hospital. She was never discharged after her final admission.

She transferred to a new intellectual disability service in 1989 when it became de-designated from this psychiatric hospital. She lived on a Ward with thirty five other people with intellectual disability in open plan day rooms and in dormitory style sleeping accommodation. Colette recalls spending her days walking up and down the corridor. She complained of the many aspects of institutional living such as tasteless food, central laundry, being told what to wear, fixed meal times and fixed bath times. She recalls the lack of facility for her personal affects and memorabilia. She spoke of the ward routine at night where she was 'tormented by the sound of other patients crying and calling out' while she recalls 'lights left on in the long corridors and staff moving about jingling keys'. She articulated an objection to the ever present smell of disinfectant, other unpleasant odours and she continued to protest her hospitalisation.

> "I was kept there for a long time. The authorities wouldn't let me get out of it, the ward, I never liked it. I didn't like the women in it. They put you to bed at half eight and then you would have a big long night ahead of you. They made you wear clothes that you didn't like".

Interview with Colette.

During this period her opportunities to visit her loving home were scant. She did have regular visits from her younger brother to the ward, however, she reports this as being frustrating as other

patients would surround them looking for his attention, cigarettes and sweets. She remembers her brother fondly.

> "He is dead now you know. He used to take care of my mother and bring her places. The last words she said to him were to make sure his sisters were alright. He came every day to the ward. He used to walk sometimes all the way to see me".
>
> Interview with Colette.

Current Situation

Colette moved from the large intellectual disability residential centre to a community house in the same midlands town as part of the HSE transfer programme in 2003. She lived in this community house with five other people with intellectual disability. While Colette was very pleased with this move, as she had her own bedroom and enjoyed the home prepared meals, she still yearned for a place to live on her own. She continued to advocate for better living conditions. Colette was moved by management to another community house with four other people with intellectual disability outside the town where she currently resides. When asked do you like your new house? She replied: 'I do, I like the house, I just don't like the people out there'.

She perceives her move to the new community house as an improvement in her living conditions and she commented on her accommodation by stating:

> "I have my own bedroom out there, it is very small. I do have all my own things in it. No I don't have a key to my house nor to my room either. It doesn't bother me though there is always staff so we don't need a key".
>
> Interview with Colette.

When asked whether she regarded the current community house as ***her home*** now. Colette replied:

> "No I do not. I see it as a dump. There is too much favouritism. One or two gets everything from the staff".
>
> Interview with Colette.

When asked how she spends her leisure time in the evenings. Colette replied:

"I sit down and smoke cigarettes one after the other, if not I go to the tap and drink loads of water. I am happy to sit the way I am. I am 61 now and all I want is peace and quiet".

Interview with Colette.

As the intellectual disability service developed in the community Colette's many talents became evident when she started to attend modular day services back in the residential centre doing such programmes as art and music which she reports as being very important to her. She now attends a part time day service of her choice in the town five afternoons per week. The community inclusion modules gives her an opportunity to utilise facilities in the town in that she will go to the hairdresser, go clothes shopping, go for coffee, go to the cinema and other community activities that interest her.

Typically, when Colette is brought to her day service venue her money and cigarette allocation is given to her day service staff by her residential care staff. She commented:

"I came in, in the morning with five cigarettes in an envelope to do me the day. The staff came with €25 in an envelope to give to day service manager every Monday for me to use for the week. I have a bank account but I can't use it because they have the card. I wouldn't go mad buying clothes, as they think. I would buy myself a pair of glasses though".

Interview with Colette.

During the interview with Colette's brother he noted that Colette looks physically well. He has observed that since she has moved to a community house and has something constructive to do during the day she seems a lot happier, stating:

"She is a lot smarter and looks well dressed, clothes wise. She is like a yank home on holidays. She looks a lot better than when she was in the hospital. She has lost weight, she was a lot stouter".

Interview with brother.

PCP Process

Colette's understanding of PCP is confused. When asked how your PCP is going she stated: 'there is a one that you need to go to, to see about my care plan' indicating that she sees a care plan and a PCP as one of the same. When asked what a PCP means she stated:

> "It means that I can go on a Share-a-Break, that's all I know about it. It keeps a medical record".
>
> Interview with Colette.

When asked about her goals at her PCP meeting and what this actually meant to Colette she replied:

> "Jaysus I don't know.....where they mark down whether you have been good or bad".
>
> Interview with Colette.

An interview was held with Colette's brother in the family home where he lives alone. He spoke of his own limited coping skills and he is unemployed. He stated that he does not drive and has a history of alcohol abuse. When he was asked 'do you go to Colette's PCP meeting? or 'whether he was aware of PCP? He stated:

> "No, the nurses do all that; they know what is best for Colette. I think trained nurses are better at that".
>
> Interview with brother.

Colette had no family support or back up at her PCP meeting. Her brother declined an opportunity to be involved in all aspects of planning her life, regarding her as being:

> "Well looked after. There were too many of them in the hospital, God it was a bad place. There are small numbers now where she lives. I have been to the house a few times, it is a grand house".
>
> Interview with brother.

When Colette was asked where the PCP information was held she stated that 'the staff would have it. It is down in the office. I don't have it'. Colette commented that she was at her PCP meeting a couple of months ago and stated:

> "I told them it was about time that you got me a place of my own as I am a long time looking for it now. I put in for it but I can't understand why I didn't get a place. That is going back now to last year or the year before".

Interview with Colette.

Colette's key worker describes her relationship with Colette as extending for about fifteen years including the time she resided in a hospital setting. But 'I am her key worker for two years now'. She noted that Colette can be 'very difficult sometimes'. Some of the difficulties may stem from her not realising her ambition to reside in her own accommodation.

> "Colette for the past couple of months was shouting and roaring at me saying 'you didn't get me a flat'. But at the end of the day I am not the one that can get a flat. She blamed me because I was her key worker".

Interview with key worker.

Another difficulty the key worker eluded to was the advice Colette received from the many varied staff and advocates that she should have a flat of her own.

> "They just come in and work with her for a few hours and then they go again and it is left high and dry. I can see Colette's point in that everyone is telling her that 'she should have a flat' and then nothing happens about it".

Interview with key worker.

As part of the research process I attended Colette's most recent PCP meeting which was held in her day centre. This meeting was attended by Colette, a care assistant as her key worker, two staff nurses from her group home, the CNM II, day service manager and two support workers and the independent advocate. Colette's PCP meeting opened with her key worker speaking in the first person giving a synopsis of her life story. A summary of the last meeting held in 2009 was presented in the context of the modest goals that were achieved. These included visiting her sister, attending her day service, going on an overnight stay with a staff member to a hotel and having three overnight Share-a-Breaks. These events should be part of every day life. With reference to a Share-a-Break Colette stated:

> "I love going on my Share-a-Break, I go off out to the middle of nowhere and I like it. I love peace and quiet and that is why I want my own flat. So I can be alone".
>
> PCP meeting.

There was a general chat on how life has been for Colette since her last meeting. It was acknowledged that one of her brothers had passed away and that she was supported to attend the funeral by staff in her community house. There was no further discussion on this and was brushed over as incidental.

In Colette's PCP documentation there is the vision statement and long term goal to Colette living more autonomously in an apartment of her own. 'Her number one goal is moving to a flat'. Colette remarked:

> "Yeah that's right, that's all I want. But it is not what I want, it is what I get".
>
> PCP Meeting.

This statement from Colette was trivialised and she was asked 'so what would you like'? At this point Colette adjusted her request and reconciled to something more achievable by stating 'I would like to go for a drink every second weekend and to continue with my Share-a-Break'.

While the intricacies of the PCP process may elude her somewhat, nonetheless she has a compelling sense of her own life goals in this case getting a place to live on her own. Ideally, the key workers role is around person centred active supports in assisting Colette to realise this ambition that she repeats at every opportunity. When Colette spoke of her desire to live in a flat on her own, staff typically responded by telling her why this was not achievable.

> "Well, I want to say something that I know Colette won't like me saying this, but most of the time you wouldn't be able to live on your own. I found cigarette butts behind the bed and the locker. I know you are great and that you are out and about. The early part of the day I don't think that you would be able to manage without somebody at least coming in and assisting. As you know you are reluctant to get up in the morning and you are reluctant to go to bed at night. I am not giving out I am just telling you the way things are".
>
> PCP Meeting.

Further to this the staff spoke about money management and whether she would be able to manage her own finances and stated:

> "You like to spend any money you have in your purse. Straight away it is gone. So, realistically do you think that you would be able to manage your finances? I mean really and honestly".
>
> PCP Meeting.

Colette responds quite rightly: 'Well it all depends on how much the rent is. I am able to manage my own money and I can count, I might be a bit slow at it but I can do it'.

A further debate on the topic ensued with a discussion with the staff present on how it would not be possible for Colette to have a flat. The notion of a supported living scheme was discussed with staff commenting as follows:

> "There are no vacancies in supported living and none are envisaged in the near future. I spoke to the manager who said that there isn't anything really coming up and that you wouldn't be able to manage on your own. You require a lot of staffing. With staffing the way it is at the moment it would not be possible".
>
> PCP Meeting.

Colette responded by stating 'the manager told me that she was going to get me a flat, a good flat. It would be something that I want and that I can choose'.

The staff conceded remarking that:

> "Maybe you could think of a granny flat attached to a community house. This is where you would still live with the support of the staff attached to the community house, for your medical needs. You have huge medical needs and you can get sick very quickly. You know yourself, you don't be well nearly overnight. Would that be a compromise?"
>
> PCP Meeting.

Colette responded with 'Ah, I don't think so'. To which staff replied 'you don't know when you are well off'. Colette stated: 'You see I don't think that I am well off. You see I am just there and the whole lot is getting me down'.

When staff asked Colette how she felt about her current residential placement she stated frankly:

> "The majority of the time I feel I could go mad. I don't want to be there. But then I settle down. I have my cup of coffee and I am alright. It takes me a couple of hours to get that way".
>
> PCP Meeting.

The staff at the PCP meeting defend the community residence model. Instead of taking on Colette's goal of having a place of her own staff continue to defend the community group home model to the extent that it drowns out her voice. Colette holds on to her goal despite staffs comments.

> "Do you really think living on your own would make any difference? When you are with the rest of us you can bounce things of us. You have someone to talk to and some one to listen to. If you were on your own like, you would be on your own. It can be lonesome, but if that is what you want that is fine. But like it is an awful lot to be on your own".
>
> PCP Meeting.

Colette retorted:

> "Some people like living on there own. You get so far in life and you just like to be on your own. You get to a certain age and you just like to be on your own. Do you understand?"
>
> PCP Meeting.

Again Staff try to convince her of the many difficulties she may encounter saying 'it is a lot of extra work. You have to cook for yourself and everything'. She responded by saying 'that is no problem I can do that'.

It became evident during the course of the PCP meeting that Colette's considered opinion was being disregarded. This was most evident in her response to her stated desire to having her own flat. But further to that when she was asked whether she wanted to participate in the special leisure buddy scheme she declined forcibly three times. Interestingly staff kept returning to this theme perhaps because if she had agreed to a leisure buddy as a PCP goal that this was achievable and then there would be a successful outcome.

Staff interjected yet again disregarding Colette's plea to have a place of her own by discussing holidays, stating:

> "I think we all need a holiday once a year. Colette really enjoys it, going shopping and then going back to the hotel to unwind. Would you like to go on holidays again before the end of the year?"
>
> PCP Meeting.

Colette replied 'the question is do I have the money to go?' Staff then lulls her into this false sense of security stating 'well don't worry about money'. To which she replied 'well I do worry about money'. Again this was dismissed and staff moved onto her day service and asked her 'what about your day programme here Colette, are you happy with that?' She was handed her day service agenda to read aloud to the group which she did in a perfunctory manner.

> "Individual Programme Colette. Monday AM, Outreach.....Tuesday AM, Kitchen.....Wednesday AM, beauty therapy.....Thursday AM, community inclusion.....Friday AM, whatever is going on".
>
> PCP Meeting.

Her day programme is about keeping her occupied. She has no opportunities to earn money or to contribute back to society. A goal in her last PCP meeting was to maintain contact with her sister who has intellectual disability.

> "Just to mention that one of the things that Colette wanted last year was to have contact with her sister. This is happening every second week and we drop her to her sister. She visits her sister while the others go to the therapeutic pool".
>
> PCP Meeting.

At her PCP meeting opportunities were taken to illustrate Colette's perceived reliance on staff even in her day service.

> "You can see from her timetable most of her programmes are one to one because she needs the space. Sometimes it is not always possible in that if we don't have the staff today we would ask Colette if she would like to do this or this and she is always very obliging. The staff have given a little report here to say that Colette 'works well in the kitchen' and she appears to 'love her job

in the kitchen'. She does require supervision but we love having Colette here".

PCP Meeting.

Staff reported to the PCP meeting 'the many friends that Colette has made'. They went on to list the names of four paid members of staff who work in day services who were reported as Colette's friends. Interestingly, it was not Colette that gave an account of these people as being her friends but that of the staff. Staff stated 'Colette is busy while she is here and I think she really enjoys being in day services. Don't you Colette?' Colette replied 'sometimes, it depends on how I feel'.

The focus of the PCP meeting changed to her medical needs once the advocate had questioned what was agreed regarding her stated desire to have her own flat. Staff said:

"She is on an awful lot of tablets, 13 or 14 each morning and she has a lot of hospital appointments as well. Her diabetes is controlled and is going well, it is the behaviour that sends it high and then it is a worry for us".

PCP Meeting.

It seems the concerns over her health and in particular managing her diabetes made those caring for Colette disinclined to assist her in furthering her goal of independent living. This stems from fear due to her current mental health challenges and the fact that she may not always be reliable in monitoring her own diabetes. The nursing staff would fear that Colette could 'go into a diabetic coma'.

Colette, at this point in the meeting, yet again, realised that her dream of attaining her own place to live was ebbing away. 'I am not going to get my flat by the sound of it'. People at the meeting are aware of Colette's feelings of dejection and they really try to rescue the situation and interject stating 'I think the idea of a granny flat would be a step in the right direction'. Regrettably no further explanation of where this granny flat would be or what Colette's understanding of such an arrangement left this notion suspended.

Colette was asked by the advocate whether anything had changed for her as a result of the PCP meeting to which Colette replied 'No'. Alarmingly staff cautioned Colette stating:

"Now Colette there is no point in you going out of here today saying that 'I am after having my PCP meeting and it is the same old thing again'. Sure there's not?"

PCP Meeting.

Colette meekishly replied:

> "I won't be saying nothing but it is the same old thing again".

PCP Meeting

The key worker reflected on the PCP meeting and regarded the process as 'still worthwhile' despite the many frustrations for all concerned. It becomes apparent that the key worker did not see her role as a conduit to empower Colette to realise her own personal goals. She in fact took ownership of the goals herself causing her to feel hurt and personally upset.

> "Well it does upset me. I feel that I should have done more but I am not the boss. I should have done more to get the boss to do it. I have to go through the managers, however some managers will say 'go ahead and do it and keep fighting for the flat' and others will say 'no you can't do that'. They say the same to Colette. She gets confused. You can't tell her one thing then tell her something different. There should be an alternative for her'"

Interview with key worker.

Comment and Analysis

It is remarkable when reflecting on Colette's life to recall that she had a reasonably satisfactory life without formal intellectual disability services well into adulthood. She went to her own local school, she emigrated to the United Kingdom, she gained meaningful employment, she resided happily with her family and later marrying her husband of nine years, which tells us that she is capable of self determining and demonstrating her independence. This is a sharp contrast to her current lifestyle which is regrettably lacking in the many features of the lifestyle she enjoyed in the past and clearly continues to yearn for. This is evident in her many statements where she repeatedly looks for support in finding a place for her to live on her own. She does now admit that she needs help, has some limitations, particularly as she has aged, but sees herself as being more independent and capable than the staff acknowledge.

While she previously earned and managed her own income she is now at the mercy of staff to give her 'pocket money' from her disability allowance. She also receives a rationed cigarette allowance. There is a very paternalistic style and tone taken at the PCP meeting with an emphasis on controlling rather than empowering. This is further evidenced by telling her that she is unable to manage her finances and the staff control her bank details and bank cards. Colette herself has succumbed to this feeling of learned helplessness and so much so she doesn't care that she does not have a key to her own front door.

What is striking is the lack of reference to any safeguards to assist her to be more independent. The emphasis is on telling her that she cannot live on her own or she would not be able to live on her own rather than looking at alternative assistive technologies such as smart houses, meals on wheels and other forms of community support which are readily available. While it is acknowledged that there are certain behaviours that are a cause of concern to staff such as smoking in bed and the proper disposal of cigarette butts, this in itself should not be a barrier to her life goals. Safe guards are available to assist in managing such behaviours.

The key worker has a dual responsibility; on the one hand she is employed as a care worker with responsibility for the efficient running of the community residence. Superimposed on this role is an additional role and responsibility as key worker. In this case the key worker seems to over identify with the responsibility of promoting an action plan as opposed to prompting Colette's capacity to taking the small incremental steps required to reclaim her independence. This perpetuates the status quo and it is evidently frustrating for all concerned with little or no outcome and worse still there is evidence that Colette is silenced.

There was an effort in Colette's PCP to relinquish her to the world of 'special services and support'. After all, she lives in a community house for people with intellectual disability, she attends a congregate day service for people with intellectual disability and if that was not enough there was a 'pushing' of achievable add-ons such as the Share-a-Break scheme and the leisure buddy scheme again schemes for people with intellectual disability. The reality is that Colette is never without one

or more paid members of staff. She never has staff free times, yet she frequently states 'all I want to do is to be left alone in peace and quiet'.

What typically works well for staff is when clients are 'compliant' with the daily routine and 'grateful' rather than critical for their services. Staff goals in Colette's PCP meeting are around the efficient running of the group home and conforming to the status quo, while Colette's goals are juxtaposed with this and they are not mutually compatible causing frustration and disquiet.

Staff attach a lot of importance to her medication regime and they use this as a barrier to her not realising her ambition to get a place of her own. Staff are genuinely concerned for Colette's health and well being particularly with her onset of diabetes. It maybe helpful to look at rationalising her medication regime. Good practice indicates monopharmacy versus polypharmacy. Teaching and supporting Colette to self medicate could enable her to manage her health care as opposed to being reliant on staff

In this case, the Citizens Information Centre provided the services of an independent advocate at Colette's PCP. Her contribution ensured that the meeting returned to Colette's stated goal of moving to independent accommodation. As an observer at this meeting it was obvious that if this person was not present that this goal would be further obscured. Albeit that her presence did not have an immediate impact it caused the staff to rethink and agree a compromise such as a granny flat.

In summary, Colette is being treated for diabetes, chronic respiratory problems, urinary tract infections and mental health problems with a range of polypharmacies and other medications. A file search revealed that Colette has borderline low average cognitive ability. Her psychiatric diagnosis of 'chronic schizophrenia and depression' pre date the psychological evaluation. One would wonder if she had not been in the psychiatric hospital during the period of de-designation and policy change to move people with 'mental handicap' out of psychiatric hospitals as recommended by Planning for the Future (1984), would she have ever been the recipient of day and residential services typically designed for people with moderate, severe and profound intellectual disability?