DECLARATION

“I declare that this dissertation has not been submitted as an exercise for a degree at this or any other university and is entirely my own work.

I agree to deposit this dissertation in the University’s open access institutional repository or allow the Library to do so on my behalf, subject to Irish Copyright Legislation and Trinity College Library conditions of use and acknowledgement.”

_______________________
Gerry Haslam
Title: Person Centred Planning – the perceptions of Persons with Intellectual Disability of the planning process and its outcomes.

This research aimed to assess the utility of the PCP process from the perspective of persons with a mild/moderate intellectual disability based in the west of Ireland. A qualitative descriptive methodology has been used in this study, and the research has been conducted from a social model of disability epistemology. Data was collected with the use of semi-structured interviews, which were held with 11 individuals and a general inductive methodology was utilised to analyse the raw data.

Significant findings included that the majority of participants expressed feeling greater levels of independence, more confidence and an enjoyment of the process. There was also family involvement in the PCP process of every participant.

It is suggested that these findings are linked to a significant support and training programme given to staff as facilitators, by the service provider.

Recommendations of this study include that the service provider continues to allocate the significant support levels to the PCP process. The study also recommends further research into the utility of the PCP process involving participants with verbal communication difficulties.
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Table 1: Selected studies with prevalence estimates from different countries.

List of Abbreviations

Person Centred Planning (PCP)

Health Service Executive (HSE)

National Intellectual Disability Database (NIDD)

Social Role Valorisation (SRV)

The Union of the Physically Impaired Against Segregation (UPIAS)

Health Information and Quality Authority (HIQA)

Individual Budgets Evaluation Network (IBSEN)

International Association for the Scientific Study of Mental Deficiency (IASSMD)

Appendices

Appendix 1 Interview Guide

Appendix 2 Information Sheet for Participants and Staff (including Language friendly version)
Appendix 3  Consent form for Participants (including Language friendly version)

Acknowledgments

Many people have supported me over the last two years enabling me to complete the M.Sc. in Disability Studies. Therefore I would like to acknowledge in particular:

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My supervisor Colin Griffiths for his insight, guidance and patience.

Finally to my family, wife Maria, children Niamh and Cormac, and Eilis minding us all.
Chapter 1

Introduction
1.1 **Introduction**

Person Centred Planning (PCP) has been described in the literature as an umbrella term referring to a variety of specific approaches to helping people who use social care services, to plan their own futures (Stalker and Campbell 1998).

This research aims to gather knowledge from the lives and experiences of people with intellectual disabilities, to ascertain the utility of the PCP process in their service based in Ireland. The Author is employed as an Area Services Manager with an intellectual disability services provider in the voluntary sector, based in the west of Ireland.

The author is aware that a large number of service users within this organisation are currently participating in a Person Centred Planning process. Whilst review of the goals being achieved takes place, no review of the process and its utility from the perspective of the person with intellectual disability occurs. The literature review has highlighted that there is a paucity of qualitative research specifically related to service users' perspective of PCP. The author has considered when undertaking this research the changes that have occurred in Intellectual Disability Service provision internationally and in Ireland, both on a theoretical and policy level. The author aimed to assess the effectiveness of the Person Centred Planning process, from the perspective of the participants. Upon considering the aims and objectives of the research the author decided that a qualitative descriptive methodology would be appropriate for the study.
Chapter outline

Chapter 1 introduces the reader to the topic under discussion and describes the context and historical background of Person Centred Planning.

Chapter 2 presents a literature review which examines the literature as it relates to Person Centred Planning in Intellectual Disability. The literature review includes areas such as barriers to effective Person Centred Planning, factors that facilitate good Person Centred Planning, legislative considerations both internationally and in Ireland. The CINAHL, Medline and PsychINFO databases were accessed. Phrases accessed included the following: Person Centred Planning, Person Centred Planning process, Service Users Perspective of Person Centred Planning, Service Users Perspective, Person centredness.

Chapter 3 outlines the methodology for the study, which describes the specific objectives of the study and the methodology used to generate the data to achieve this.

Chapter 4 is a presentation of the research findings.

Chapter 5 provides a discussion of the findings in light of literature available and outlined research aims.
1.2 **Demography of Intellectual Disability in Ireland and Internationally**

There were 26,484 people registered on the National Intellectual Disability Database (NIDD) in December 2010, representing a prevalence rate of 6.25 per 1,000 population. The prevalence rate for mild intellectual disability was 2.09 per 1,000 and the prevalence rate for moderate, severe or profound intellectual disability was 3.69 per 1,000.

The numbers registered on the NIDD in December 2010 were reported as follows:

- 25,936 people with intellectual disability were in receipt of services, representing 98% of the total population registered on the NIDD.
- 287 people (1% of those registered) who were without services in 2010 and who were identified as requiring appropriate services in the period 2011–2015.
- Of the 25,936 people who were in receipt of services in 2010:
  - 8,213 (31.2%) were in receipt of full-time residential services.
  - 25,857 (99.7%) people availed of at least one day programme in 2010. Of this group, 8,152 were in full-time residential placements.
  - 21,803 (84.1%) people availed of one or more multidisciplinary support services.
Sixty-five per cent of those registered on the NIDD (17,112 individuals) lived at home with parents, siblings, relatives or foster parents in 2010.

Inclusion of individuals with a mild level of intellectual disability is sought if they are in special classes or special schools for children with intellectual disability, or are attending an intellectual disability service as adults, or if they are considered likely to require such a service within the next five years.

**International comparison**

Maulik and Harbour (2012) in a review of selected studies with prevalence estimates from different countries found that there was a wide variance in incidence of intellectual disability in the selected studies; there was also a variance in the disability definitions utilised, and significant difference in population sizes sampled.

In comparison to the figure quoted for the island of Ireland, 6.3 per 1000 population (McConkey *et al.* 2006) in what is the largest sample size, the average for the 10 studies is 7.57 per 1000 population. The figures vary however, from 3.9 in an Ethiopian study (Fitaw *et al.* 2006) to 14.3 in a recent Australian study (Leonard *et al.* 2003).

Maulik and Harbour (2012) found that while among adults, the rates vary between 3-6/1000, among children the rates are between 3-14/1000. Almost all the studies report that the prevalence of intellectual disability is higher among
males than females, especially among children less than 15 years of age. For mild intellectual disability, males have about a 1.5-fold greater prevalence.

Table 1

<table>
<thead>
<tr>
<th>Country (Reference)</th>
<th>Source of study population</th>
<th>Definition used</th>
<th>Total study population</th>
<th>Prevalence per 1000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia (Beange &amp; Taplin 1996)</td>
<td>Administrative data on 20-50 year olds</td>
<td>ASSR classification</td>
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<td>3.3 Male = 3.4 Female = 3.2</td>
</tr>
<tr>
<td>Australia (Leonard et al. 2003)</td>
<td>Administrative data on children 6-15 years</td>
<td>DSM-IV TR</td>
<td>240358</td>
<td>14.3</td>
</tr>
<tr>
<td>Canada (Bradley et al. 2002)</td>
<td>Administrative data and population study on 14-20 year olds</td>
<td>ICD 10</td>
<td>35485</td>
<td>7.2</td>
</tr>
<tr>
<td>China (Zuo et al. 1986)</td>
<td>Survey of 0-14 year old children</td>
<td>AAMR definition</td>
<td>7150</td>
<td>7.8 Male = 7.9 Female = 7.9</td>
</tr>
<tr>
<td>China (Xie et al. 2008)</td>
<td>Household survey of children aged 0-6 years</td>
<td>Specific disability criteria</td>
<td>60124</td>
<td>9.3 Male = 10.1 Female = 8.3</td>
</tr>
<tr>
<td>Ethiopia (Fitaw et al. 2006)</td>
<td>Population based study on adults</td>
<td>ICF</td>
<td>24453</td>
<td>3.9</td>
</tr>
<tr>
<td>Finland (Rantakallio et al. 1986)</td>
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<td>ICD 9</td>
<td>12058</td>
<td>5.6 (Mild) 6.3 (Mod/severe)</td>
</tr>
<tr>
<td>Ireland (incl N.I. UK) (McConkey et al. 2006)</td>
<td>Administrative data of adults</td>
<td>ICD 10</td>
<td>3961701</td>
<td>6.3</td>
</tr>
<tr>
<td>Norway (Stromme et al. 1998)</td>
<td>Administrative data on specific birth cohort of children</td>
<td>DSM-IV</td>
<td>30037</td>
<td>6.2 Male = 8.4 Female = 5.7</td>
</tr>
<tr>
<td>USA (Murphy et al. 1995)</td>
<td>Administrative data on 10 year old children</td>
<td>DSM-III</td>
<td>89534</td>
<td>12 Male = 13.8 Female = 10.1</td>
</tr>
</tbody>
</table>
1.3 **History of intellectual Disability Service Provision in Ireland**

In Ireland, religious and charitable / voluntary organisations have played a crucial role shaping the role and model of service to be provided. The usual historical model in Intellectual disability was to be found in large congregated, segregated services such as those in Kilcornan/Clarinbridge and the John Paul Centre provided by the Brothers of Charity, Lisnagry, Limerick and St. Anne's, Roscrea – Daughters of Charity, also Moore Abbey – Sisters of Charity of Jesus & Mary.

The emergence of what the author would call the ‘family and friends’ organisations in the 1950’s and 60’s started to bring about a change in focus, as a lot of these groups were rurally based and the need was felt for small localised services. Examples of this type of organisation include Western Care in Mayo, Kerry Parents & Friends Association in Co. Kerry, North West Parents & Friends Association in Sligo, and CoAction in West Cork.

From the 1980s onwards, the thrust of policy and practice has been moving towards community inclusion for people with disabilities. Public policy in Ireland over the past 20 years has been directed towards the development of community-based services; Needs and Abilities,' the policy for people with intellectual disabilities (1990) made detailed recommendations to discontinue residential provision that was not domestic in size. It proposed a range of community-based alternatives, and supports for families to enable them to maintain their family member in a home situation. The Review Group on Health
and Personal Social Services for People with Physical and Sensory Disabilities, “Towards an Independent Future” (1996) also signalled a move away from large institutions, towards small living units and mainstream housing accommodation. The Report of the Commission on the Status of People with Disabilities “A Strategy for Equality” was also published in 1996 which has been an important building block for the National Disability Strategy (2004) which gives effect to the Government’s mainstreaming policy, which includes the mainstreaming of housing provision for people with disabilities.

Sheerin and McConkey (2008, p.127) write that “Whilst many of the longer-established services, in keeping with the practice of segregation, were located away from urban centres, newer services have tended to be driven by a philosophy of inclusion, and have consequently developed in urban areas, with community group home models predominating.”

The services provided to people with an intellectual disability from the 62 services under the umbrella of the National Federation of Voluntary Bodies are founded on the values as set out in the O’Brien (1987) Principles of Inclusion, Choice, Dignity, Respect, Participation and Contribution. They are rooted in the rights based perspective that people with intellectual disability have the right to live full and active lives, and be active participating members of their own community.
Chapter 2

Literature Review
2.1 Introduction

The British Institute of Learning Disabilities (2002) defines Person Centred Planning as a way of assisting people to work out what they want, the support they require and helping them get it. It further states that Person Centred Planning has the person at the centre, is carried out in alliance with friends and family and is focused on getting real lives for people. It requires a fundamental shift of thinking from a 'power over' relationship to a 'power with' relationship. Duffy (2004) argues that individuals want more control; families want more control; the self-advocacy movement wants people to have more control and central government sees the increasing personalisation of social care as an important goal.

When considering this fundamental shift required, it is worth noting the theoretical model which Irish service provision has come from, and where it is heading to. It can be argued that in Irish Intellectual, Physical and Sensory Disability service provision the services were run based on the medical model theory of disability.

2.2 The Medical Model of Disability

The medical model of disability is one that is primarily concerned with the justification of disability. It sees disability purely as a problem of the individual, without any discrimination between the impairment faced and the disability itself.
(Swain et al. 2003) wrote that the medical model viewed any economic or social deprivation encountered by disabled people as being located within the individual and their impairment.

In the early 1970’s there was a concerted move towards the formation of a political pressure group controlled by disabled activists. (Barnes and Mercer 2004) argue that the origins of this group, The Union of the Physically Impaired Against Segregation (UPIAS) lay in a letter from Paul Hunt which was published in The Guardian on 20th September 1972 that called on disabled people to form their own organisation. UPIAS produced a Policy Statement and constitution in 1974. Two years later, it expanded on its thinking in the Fundamental Principles of Disability (UPIAS 1976). It can be argued that this politicisation of disabled activists led to the creation of the Social Model of Disability.

Finklestein (2002, p.10) writes in relation to models as follows, ‘A model is what social scientists call a ‘heuristic device’ or an aid to understanding. A good model can enable us to see something which we do not understand because in the model it can be seen from different viewpoints… it is this multi-dimensional replica of reality that can trigger insights that we might not otherwise develop.’

2.3 The Social Model of Disability

The British Council of Disabled People (1991) in relation to the Social model regards it as a concept which recognises that some individuals have physical or psychological differences which can affect their ability to function in society.
They argue that the social model suggests it is society itself that causes the individual with these physical or psychological differences to be disabled. In other words individuals are disabled not by their impairments but by the societal barrier existing which do not take into their needs into account. These barriers can be divided into three categories: environmental, economic and cultural.

The aim of advocates of the social model of disability is to shift society’s focus away from individuals with disabilities, and towards the restrictive structural, environmental, social, cultural, political, economic and attitude barriers that prevent people with disabilities from accessing the full range of options available to non-disabled people. Shakespeare and Watson (2002, p.9) write ‘The social model has now become the ideological litmus test of disability politics in Britain, used by the disabled people’s movement to distinguish between organisations, policies, laws and ideas which are progressive, and those which are inadequate.’

Social model theorists and activists describe the oppression of people with disabilities as the experience of social, cultural, political and economic institutionalised discrimination. In order to change attitudes and fight institutionalised discrimination they argue for the involvement of people with disabilities in all aspects of mainstream society, in the design and delivery of services for people with disabilities, and for protection of these services through the establishment of national and international accountable standards and procedures. However, there are some academics such as Shakespeare (2006), who argue that the social model in and of itself has not been the panacea that it
was hoped, and indeed Shakespeare rejects the social model for a number of reasons, including its age – he feels that it is over 30 years in development without any major changes, he also argues that it has turned into a theoretical model, not an active political model as envisaged.

However this researcher would argue that the social model has brought about a greater awareness amongst governments and service providers as to what is an appropriate system to assist and support persons with Intellectual Disability.

2.4 **The Social Model in Ireland**

In Ireland there exists the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability - a national umbrella organisation for voluntary/non-statutory agencies who provide direct services to people with intellectual disability in Ireland. There are 62 Member Organisations (including those family and friends organisations listed above) in the National Federation of Voluntary Bodies providing services to 22,000 people with intellectual disability and their families in the Republic of Ireland and employ 15,500 staff in a wide range of roles. The members account for in excess of 85% of direct service provision to people with an intellectual disability in Ireland. The 62 member organisations espouse the following 4 main principles, which are that persons with intellectual disability have

1. The right to live an ordinary life within their own community.
2. The right to be treated as an individual with dignity and respect.
3. The right to support in developing their maximum potential.

4. The right to participate in the decision making process on issues affecting their lives.

It is reasonable to suggest that if the umbrella organisation for the majority of service providers has signed up to these principles then a significant theoretical shift has occurred, with a movement away from the Medical Model to the Social Model.

2.5 The History of Person Centred Planning

The concept of "normalisation" was introduced and developed in Scandinavia in the 1950s and 1960’s, primarily by Bengt Nirje, and suggests that people with ID should have access to supports so that they can experience patterns and conditions of everyday life that are as similar as possible to those of mainstream society (Beirne-Smith et al. 2006).

Bengt Nirje (1982) addressing an International Association for the Scientific Study of Mental Deficiency (IASSMD) conference in Toronto, stated that “The normalisation principle means making available to all people with disabilities people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society ”.

Normalisation involves the normal conditions of life – housing, schooling, employment, exercise, recreation and freedom of choice. This includes “the
dignity of risk”, rather than an emphasis on “protection” (Bank – Mickleson. 1976). The principle of Normalisation was developed further during the seventies, especially by Wolf Wolfensberger in Canada through the National Institute on Mental Retardation, leading to the emergence of Social Role Valorization (SRV). The theory of SRV is based on the idea that society tends to identify groups of people as fundamentally 'different', and then view them as being of less value than everyone else. Thomas and Wolfensberger (1999, p.125) 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”.

It could be argued that this developing change of focus, and its inherent placing of emphasis on people being treated with dignity, respect and being valued, allied to the emergent Social Model informed the development of Person Centred Planning. O'Brien et al. (2000) write that the genesis of Person Centred Planning occurred between 1979 and 1992. They look at the emergence of person-centered planning from the point of view of communities of practice, a way of understanding how knowledge and skill are created. Communities of practice are “groups of people informally bound together by shared expertise and a passion for a joint enterprise” (Wenger and Snyder, 2000, p.139). Person-centred planning isn't one clearly defined process, but a range of processes sharing a general philosophical background, and aimed at producing similar outcomes.

The term 'person-centred' is used because those who developed it and used it initially shared a belief that services tend to work in a 'service-centred' way.
Ritchie et al. (2003) observe that PCP takes the individual as its starting point as opposed to the service, the service traditionally trying to ‘fit’ the person into their particular service delivery model.

Traditional models have also tended to focus on a person's deficits and negative behaviours, resulting in a labeling of the person and creation of a disempowering mindset from the start. Person-centred planning is designed specifically to ‘empower’ people, to support their social inclusion, and to challenge their devaluation within society. The National Disability Authority in its National Standards for Disability Services says that services must be ‘person centred’. This means they must be designed to suit what the people using the services want.

In the UK Stephen Ladyman (2004), former Parliamentary Under-Secretary of State for the Community, in a speech to the Health and Social Care Advisory Service, stated the following in relation to service provision ‘by ‘person-centred’ I mean we have to move away from mass produced services. .....Services that have too often created a culture of dependency, and move towards a future that seeks to develop the potential that is in every single individual.”

On the mainstream side of the equation in Ireland, the concept of “tailored universalism”, adopted by the partnership body, the National Economic and Social Council (NESC), and deployed in government by agencies such as the Office of the Minister for Health and Children, provides a method for advancing social inclusion in practice. Tailored universalism obliges those responsible for
services to consider who should benefit and ensure that none are denied because appropriate access supports are not provided, i.e., tailoring to include them. Voluntary organisations come into play because they can collaborate with mainstream providers to eliminate possible barriers, and they can help in monitoring the person-centred outcomes from the service.

In the Irish context the Summary of Key Proposals from The Review of Disability Policy (2010, p.2) states ‘In addition, the almost exclusive location of many of the specialised therapy services (e.g. physiotherapy, occupation therapy, psychology etc.) within disability services means that these therapies are not routinely available outside of disability service settings. This drives demand for segregated services which are counter to policy objectives.” It also states in relation to mainstreaming -“Mainstreaming is about people with disabilities having access to the same services as the general population, known as ‘universal services”.

It can be argued the concepts of normalisation and mainstreaming are two of the factors that have brought about a change in policy by service providers, towards Person Centred Planning.

2.6 Defining Person Centred Planning

Person-centred planning is an umbrella term referring to a variety of specific approaches to helping people who use social care services, to plan their own futures (Stalker & Campbell 1998). Person Centred Planning has also been
described as a family of approaches to organising and guiding community change in alliance with people with disabilities and their families and friends. (O’Brien & Lovett 1992).

Sanderson (2000) states that there are 5 key fundamentals to Person Centred Planning:

- The person is at the centre.
- Family members and friends are partners in planning.
- The plan reflects what is important to the person, their capacities, and what support they require.
- The plan will result in actions that are about life, not just services, and reflect what is possible, not just what is available.
- The plan results in ongoing listening, learning, and further action.

Person Centred Planning seeks to craft a vision for a person’s life as part of their local community and/or the broader mainstream of life and describe the actions needed to move it in that direction.

The overall aim of Person Centred Planning is defined as “good planning leading to positive changes in people’s lives and services” (Ritchie et al. 2003).

Ramsey (2004) writing of the PCP scenario in Queensland Australia suggests that planning has to place greater emphasis upon the importance of social
contribution, intentional relationship facilitation, valued roles, disproving negative stereotypes and introducing a more critical thought base into the process. He has suggested that ‘roles-based’ planning is more likely to assist people attain valued roles by intentionally considering:

- Environments.
- Associations/people and contacts.
- Activities that reduce stereotypes.

Sanderson (2000, p.11) defines PCP as ‘a process of continual listening, and learning; focused on what is important to someone now, and for the future; and acting upon this in alliance with their family and friends.’

The Department of Health, United Kingdom, in its document ‘Independence, Well-being and Choice’ (2005, p.17) has written that ‘Services should be person-centred, seamless and proactive. They should support independence, not dependence and allow everyone to enjoy a good quality of life, including the ability to contribute fully to our communities. They should treat people with respect and dignity and support them in overcoming barriers to inclusion.’ (Emphasis author’s own)

Sanderson (2000) has also expressed that person-centred planning focuses on capacities and capabilities, on what people can do, who they are and what their gifts are. She further states that Person-centred planning is based on learning through shared action, about finding creative solutions rather than fitting people
into boxes and about problem solving and working together over time to create change in the person’s life, in the community and in organisations.

The West Virginia Developmental Disabilities Council (2010) reviewing Person Centred Planning has stated it has a number of features that distinguishes it from service planning:

- The focus is on the individual's whole life – not just services, not just a type of service.
- The plan is the person's plan – not an agency’s.
- The people involved in the planning are there at the person's invitation – no agency decides who should or must be involved.
- There is an emphasis on involving friends and family in the planning – professionals participate to advise, and not control.
- The focus is on a vision or a dream for the future, practical ways to get there, and building commitment – not starting from compromises based on what is.
- The emphasis is on the person's strengths, gifts and talents, building on them and supporting the person in areas of individual needs.
- The challenge is how the individual, family, friends, and services (not only services) can work together to achieve the vision.
- The person's plan may serve as a focus for discussions about what services should be provided. A service plan may then result.
Schwartz, Holburn et al. (2000) conducted research utilising an expert panel and consensus workshop in New York, which attempted to define the primary characteristics of person centred approaches in planning and providing services and supports to individuals with Intellectual disability. They began by convening a work group of 17 people including consumers, parents, advocates, providers, and agency staff to establish a working definition using a consensus process. This work identified eight hallmarks, and 23 indicators, of person-centred planning, regardless of the approach. Following the meeting of this workgroup there was a workshop held which drew nearly 50 attendees representing 17 American states and Canada. The workshop brought together a panel of experts who discussed methods of evaluating individual, team, and organisational outcomes of Person Centred Planning. The eight hallmarks of person-centred planning, as identified in this work are:

1. The person's activities, services, and supports are based on his or her dreams, interests, preferences, strengths, and capacities.

2. The person and people important to him or her are included in lifestyle planning and have the opportunity to exercise control and make informed decisions.

3. The person has meaningful choices with decisions based on his or her experiences.

4. The person uses, when possible, natural and community supports.
5. Activities, supports, and services foster skills to achieve personal relationships, community inclusion, dignity, and respect.

6. The person’s opportunities and experiences are maximised and flexibility is enhanced within existing regulatory and funding constraints.

7. Planning is collaborative and recurring and involves an ongoing commitment to the person.

8. The person is satisfied with his or her relationships, home, and daily routine.

The authors of the study acknowledged that hallmarks and indicators were developed from group processes involving a limited number of participants (17 and 50 respectively). However it can be seen that the hallmarks their work produced is consistent with other studies (Sanderson 2000).

Taking cognisance of these definitions, it is clear that they all have at their core the recognition of the importance of the individuals’ wishes, dreams and aspirations.

The definitions outlined display more commonalities than differences, and are spread geographically from Europe to Australia and the U.S.A.

2.7 Benefits of Person Centred Planning

Robertson, Emerson et al. (2005) conducted a study which aimed to evaluate the impact of the introduction of PCP on the life experiences of people with learning disabilities. The project was a longitudinal study of the impact and cost of the
Introduction of PCP for 93 people with intellectual disabilities living in four areas in England (of whom 65 had a plan developed within the timescale of the project.) PCP development work was undertaken with organizations in the four areas to provide support in the development of policies and procedures and good practices to implement PCP. Development work was undertaken with organizations in the four localities to provide additional support to help them develop robust policies, procedures and practices to implement PCP. Training and support took place over a period of 2 years from March 2001 to March 2003. Training was provided to both facilitators and managers; information was collected at approximately 3 month intervals for each participant following their recruitment into the study regardless of whether or not they had had a plan developed. However, it should be noted the information was garnered from ‘key informants’ who knew the participant well (e.g. the person’s key worker). The role of this key informant in relation to the participant’s life was not detailed as part of the study, and therefore it is not possible to link responses to informant’s role.

This study found that PCP was associated with benefits in the areas of:

- Community involvement
- Contact with friends
- Contact with family
- Choice.
The most common main benefit of PCP of increased activities and opportunities' reported for 57 % of participants. For 48 % of participants, a main benefit of PCP was that they felt better in themselves, in terms of happiness or self-esteem. Person Centred Planning resulted in: a 52% increase in the size of social networks; a 2.4 times increase in contact with a member of their family; 40% increase in the level of contact with friends; 30% increase in the number of community-based activities; 33% increase in hours per week of scheduled day activities; and 2.8 times more choice .PCP was found to build on the existing capacity of services and supports. In other words, PCP may be best considered an evolutionary step in the long-standing trend towards the increasing individualisation of supports and services.

Miner and Bates (1997) reported a study involving 22 students in special education services for persons with intellectual disability at a public high school and their families. The participants were divided into 11 pairs, and one member of each pair was randomly assigned to a treatment group of Person Centred Planning activities or to a control group. The study found that the parents or guardians who had been involved in Person Centred Planning attended and contributed significantly more in educational and transitional planning meetings than those in the control group, and reported high satisfaction levels with Person Centred Planning.

Robertson, Emerson et al. (2005) suggest five factors that lead to improved outcomes for people who are supported by services. These are:
1. A facilitator committed to Person Centred Planning: In their research this was found to be the most powerful predictor of successful outcomes for people.

2. A facilitator who had planning as part of their formal job role: Planning was more effective where people had dedicated time and an acknowledged planning role. Interestingly the research found that having a facilitator who was a member of support staff was associated with benefits in the area of the size of social networks however it had disadvantages in the areas of community activities, contact with friends and contact with families.

3. Personal involvement of the individual: The guidance for Person Centred Planning (Department of Health 2002) stressed the importance of people having an opportunity to lead planning. This was supported by the research findings as people who took an active role in Person Centred Planning (e.g. in directing their own meetings) had more positive change in their lives.

4. A person centred team: Sanderson (2002) found that where there was leadership, stability of staff and evidence of the prior existence of person centred approaches this was associated with improved outcomes for people.

5. Managers actively involved in planning: Several of the Person Centred Planning facilitators were first line managers and this was again associated with better outcomes.

Wigham et al. (2008) in a study presenting data from open-ended comments collected during research on the impact of PCP on the life experiences of 65
people with intellectual disabilities living in England, found that a number of the main benefits reported mirrored the findings of quantitative measures previously reported (Robertson et al. 2006) with benefits reported in the areas of activities, social networks, and choice.

However, it was noted in their research that’s several of the most frequently reported main benefits were in areas which could not be addressed by quantitative measures.

Firstly, Person Centred Planning was seen to bring about a fresh look at the person and their life for over half of participants. Secondly, PCP was reported to have led to nearly half of participants feeling better in themselves, in terms of improved confidence or self-esteem, or being happier. Third, PCP was seen to lead to ‘empowerment and control’ and ‘choice’ for over a third of participants.

2.8 **Barriers to Effective Person Centred Planning**

Kinsella (2000) writing in an Irish context, is of the opinion that despite progress in many places, frequently funding is still tied into particular services, agencies or buildings – often proving a critical and immovable barrier to implementing many of the things that people identify they want through Person Centred Planning. Funding and service planning is now being looked at in a different manner, from a political perspective.

The Summary of Key Proposals from The Review of Disability Policy (2010, p.11) states ‘An independent comprehensive assessment of need will shape the individual
support plan for each person. Individualised supports will be used to identify an individualised budget, which is used to provide the supports and services they need. The service user (and family as appropriate) will have an input into how budget is used and which providers will provide which supports.” (Emphasis author’s own)

However, the review of HSE Day Services & Implementation Plan 2012 -2016 (2012, p.67) reports that ‘the research points to the benefits of moving from ‘fee per item’ services to outcomes based payments for service providers. However, the research also cautions against a national rollout of such schemes and instead advises small scale pilots to create the right package of incentives for both service users and providers.”

Cumella (2009) argues that while many parts of the world are developing specialist services for people with intellectual disability, government policy in England favours a move in the opposite direction. This it could be argued is similar to Irish governmental policy in relation to mainstreaming of services. Cumella argues that quite specialised clinical skills are necessary in order to assess, treat and support people with intellectual disability, and that there should be no rush to accept policies that seek to impose a uniform or blanket set of services for all.

The review of HSE Day Services & Implementation Plan 2012 -2016 (2012, p. 4) would appear to concur with that partially, stating that “It recognises that people with severe and profound disabilities may need specialised support throughout their lives. The guiding principle for the future is that supports will be tailored to individual need and will be flexible, responsive and person-centred.”
Dowling, Manthorpe et al. (2006) writing in relation to barriers find similarities with those barriers identified by Kinsella (2000), such as a lack of evidence for Person Centred Planning, the perceived complexity of the process, the risk of the process becoming tokenistic, the search for the ‘best’ type of plan, the reliance on the very staff and services to implement a plan that may make them redundant, and a lack of support among some key stakeholders, such as advocacy organisations and some families.

Many people who use residential and day services end up spending their time largely with people who are paid to work with them (Sanderson, 2000). Therefore, the development of a network of informal support or a circle of support may be harder to instigate. Consequently, people frequently have restricted social networks. This can often result in barriers to increased engagement in the community at large or in the development of a circle of support to help facilitate person-centred planning (Cambridge et al., 2001, Mansell & Beadle-Brown, 2004). Robertson et al. (2007) noted the reluctance of people other than paid support staff to engage in the PCP process.

Williams (1993, p9) writing in regard to staff / service user relations states the need “to recognise clients’ experiential knowledge as the foundation for learning, with ‘the professional’s expert knowledge at the service of the client … It removes power from them and hands it over to the client; and locates their base of power with their clients rather than with the professional body”.

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Hagner et al. (1996) in an American study, based in New York reported the results of a qualitative study of the outcomes of PCP for 6 young people. Participant observation and in-depth interviews were conducted to determine processes involved in person-centred planning. Initial planning meetings of 6 individuals were studied in connection with a project to assist young adults in transition from school to adult life. Their results found that, after 6 months of PCP, only a few planned outcomes had been achieved and several participants felt that “not much had happened” Similarly, Dumas et al. (2002) interviewed 13 people with intellectual disabilities and their families who had participated in PCP, reporting that, although needs and desires were identified, in many instances plans were not implemented because of a lack of viable service or support solutions. Further, they reported that most participants seemed to believe that they were limited to existing models of service delivery rather than being able to gain access to individualised services and supports.

John O’Brien (2011, p.19) sums up the problem of trying to deliver person centeredness through formal service systems that have a very different culture as follows: “Many human service settings are zones of compliance in which relationships are subordinated to and constrained by complex and detailed rules. In those environments, unless staff commit themselves to be people’s allies and treat the rules and boundaries and structures as constraints to be creatively engaged as opposed to simply conforming, person centred work will be limited to improving the conditions of people’s confinement in services.”
Duffy (2004) also discusses the tension that exists between organisational planning and individual planning. Duffy sees PCP and system planning as revealing tensions that can be managed because each type of planning needs and impacts on the other. In order for the service to develop in a responsive manner it needs to know the individual needs and wants of service users; and in order to plan for the person, people need to know what organisational constraints exist in order to overcome them. This will continue to be a challenge for service providers in the difficult financial times ahead. However it could reasonably be argued that it also provides an opportunity for services to work more creatively, by acknowledging that they may not be the best and only source of providing all supports that people may require.

2.9 The Future

Mansell & Beadle-Brown (2004) wrote that there are a number of main factors required to ensure that Person Centred Planning is successful. These factors include the following.

That Person Centred Planning is given a legal status, based on a human rights agenda. This would allow people to challenge failure to provide services to help them achieve what they want. It would also allow them to test the decisions of public agencies in terms of reasonableness.

That more funding is service user controlled, as mentioned earlier this is now part of Governmental policy in Ireland, however we have yet to see a concerted
programme taking place, even though a number of service providers do operate a grant system for service users. Mansell & Beadle -Brown (2004) also write that there is a need to develop policy and practice to ensure that as many people as possible gain access to the types of benefits that appear to be associated with PCP. This must involve directly addressing inequalities in both access and efficacy. There is also a need to learn more about the conditions under which PCP may have an impact on a broader range of outcomes. This would appear to be particularly important with regard to outcomes central to the social exclusion (e.g., employment, inclusive social networks) and positive health; outcomes that are central to the broader sweep of health and social care policy for adults.

These tasks will require action on a number of fronts. Specifically, they will require that services maintain and enhance investment in PCP as an important component of service improvement.

Emerson et al. (2005) in their research demonstrated that a person centred team where there was ‘leadership, stability of staff and evidence of person centred approaches’ was a key factor in the success of person-centred planning. Emerson et al. (2005) in their research demonstrated that a person centred team where there was ‘leadership, stability of staff and evidence of person centred approaches’ was a key factor in the success of person-centred planning. Emerson et al. (2005) in their research demonstrated that a person centred team where there was ‘leadership, stability of staff and evidence of person centred approaches’ was a key factor in the success of person-centred planning. Emerson et al. (2005) in their research demonstrated that a person centred team where there was ‘leadership, stability of staff and evidence of person centred approaches’ was a key factor in the success of person-centred planning. Emerson et al. (2005) in their research demonstrated that a person centred team where there was ‘leadership, stability of staff and evidence of person centred approaches’ was a key factor in the success of person-centred planning. Emerson et al. (2005) in their research demonstrated that a person centred team where there was ‘leadership, stability of staff and evidence of person centred approaches’ was a key factor in the success of person-centred planning. Emerson et al. (2005) in their research demonstrated that a person centred team where there was ‘leadership, stability of staff and evidence of person centred approaches’ was a key factor in the success of person-centred planning.

Robertson et al. (2007) write of the importance of ensuring there is ongoing training and support of facilitators, as well as the need for the development of robust procedures for ensuring access to and the monitoring of the impact of PCP. Services should continue learning about the conditions under which PCP delivers the maximum benefits for people with learning disabilities.
Kinsella (2012) writing in the foreword of The Review of HSE Day Services & Implementation Plan 2012-2016 envisages that the supports available in communities will be mobilised so that people have the widest possible choices and options about how they live their lives and how they spend their time. The guiding principle for the future in terms of day service provision is that supports will be tailored to individual need and will be flexible, responsive and person-centred.

The foreword also states that “One of the basic principles of person centeredness is the focus on the individual and their life plan as distinct from a focus on the service. The service must be responsive to individual needs and individual aspirations throughout the different stages of the life cycle.”

Emerson & Stancliffe (2004, p.27), commenting on Mansell & Beadle-Brown (2004) write that “without sufficient attention to the difficulties and without the necessary changes to system architecture to ensure that those involved in PCP have the authority or resources to achieve the plan's goals. If so, PCP will become another fad, and service users, and their families will become even more discouraged, disheartened and alienated by a system characterised by rhetoric rather than meaningful action.”

While as can be seen from the literature reviewed there is an increasing volume of research into the area of Person Centred Planning in the field of Intellectual Disability, there remains a scarcity of research undertaken ascertaining the perspective of the Person with Intellectual disability. However, service user involvement in service development in health care is now common. Stickley
(2006) says that service user participation in the healthcare arena is now commonly expected. Bradshaw (2008) argues that the principal features of user involvement are a more personalised service and recognition that users have a rightful role in determining the design of service development and delivery. Eales et al (2006) would also recommend service user consultations as an important planning tool. They identify three reasons why the opinions of service users are useful:

1. for evaluation.

2. as an outcome variable.

3. as an indicator for change or improvement.

Miller et al. (2008) undertook a project that sought to identify the outcomes that are important to people with intellectual difficulties. They concluded that if agencies are to deliver good outcomes they should accurately reflect what users themselves define as important. Stalker et al. (1999) pointed out that those with learning difficulties or mental health problems, and people with physical and sensory impairments, have increasingly been recognised as the experts on their own lives. It will be incumbent on service users and their families, service providers, and governmental and non-governmental agencies to be cognisant of this when planning for the needs of persons with intellectual disability. This planning will have to be done in the context of a much changed financial
situation, allied to the potential changes in funding arrangements being proposed.

Organisations in Ireland will also have to be cognisant of, and compliant with, the Health Information and Quality Authority (HIQA) standards: National Quality Standards: Residential Services for People with Disabilities, which include areas specifically related to person centredness. The standards are organised into seven sections to reflect the dimensions of a quality service. They are based on seven fundamental principles: quality of life, safety, rights, anti-discrimination, person-centredness, community integration and responsive services.

The Authority is responsible for the registration and inspection of “designated centres”, that is, residential services for children, older people and people with disabilities.

The following HIQA standards are related to person centredness

**Standard 1: Autonomy and Participation:**

Each individual exercises choice and control over his/her life and over his/her contribution to his/her community.

**Standard 8: Personal Plan**

Each individual has a personal plan to maximise his/her personal development in accordance with his/her wishes.

**Standard 11: Informed Decision Making & Consent**
The right of each individual to make decisions is respected and his/her informed consent is obtained in accordance with legislation and current best practice guidelines.

This chapter has reviewed the literature in relation to Person Centred Planning, its historical underpinnings, international perspectives and the Irish context. The literature has pointed out that there are benefits to be gained from involvement in Person Centred Planning for the person with intellectual disability, (Robertson et al. 2005) however the success of PCP would appear to be contingent on a number of factors, including the commitment of the service providers involved to promote person centredness in terms of providing training and ongoing support for staff as facilitators (Robertson et al. 2005, Sanderson et al. 2007).

The literature has outlined Governmental policy in relation to Disability, and the importance placed on Person Centred Planning.

The literature review has highlighted to the researcher that whilst there is a growing volume of mixed methodology based research into the efficacy and cost to services of PCP (Robertson et al. 2005), there is little available literature that ascertains solely the perspective of the person with intellectual disability in relation to the process of Person Centred Planning. The majority of the available qualitative literature is based on information garnered from service users and carers through interviews and focus group work, (Wigham et al. 2008, Schwartz et al. 2000). The evidence from the literature suggests that further research is
required to explore service user’s perceptions of the Person Centred Planning process.

The author thus aims to carry out research based solely on the opinions of the participants who have agreed to take part in the study. This will be a qualitative descriptive study, and the following chapter will outline the research methodology used to conduct the study.
Chapter 3

Theoretical Perspective, Methodology and Methods
3.1 **Introduction**

This chapter outlines the sequence taken to carry out the research. It begins by outlining the rationale and aims of the research, followed by the research design. Subsequently it looks at participants chosen, along with the sampling and research methods used, and justifies why semi structured interviews were favoured as the primary method for data collection.

3.2 **Aims and Research Questions**

The research question seeks the opinions of persons with a mild/moderate intellectual disability regarding the utility of the Person Centred Planning Process as carried out in their service.

The research aims to gather knowledge from the lives and experiences of people with intellectual disabilities, to ascertain the utility of the PCP process in their service. The expected outcomes of the research are that the researcher will gain first-hand knowledge of the PCP process from persons with an intellectual disability, and utilising this information recommend any changes, if required, in the delivery of PCP within the service.

The theoretical perspective of this research project is from a social model epistemology standpoint.

In relation to disability research, Barnes (2003) suggests that rather than being accountable to colleagues and the academy, researchers working within an emancipatory research paradigm should be accountable to disabled people and
their organisations. Finlay et al. (2008) contend that people with learning disabilities continue to be a group of people who are the most excluded, least independent and most likely to lack control in everyday life. Barnes (2003) writes that the one of the main integrative themes running concurrently through social model thinking and emancipatory disability research is its aim for transformation: the removal of barriers and the promotion of disabled people’s individual and collective empowerment. Looked at from this perspective the role of the researcher is to help facilitate these goals through the research process.

The objective of the study was that following on from this the researcher aims to inform the development of an efficient model that takes into consideration any emergent strengths and/or deficiencies in the current Person Centred Planning process based on the findings of the study.

The Person Centred Planning process includes information gathering, choosing goals, development of circles of support and ongoing meetings. The researcher seeks the opinions of the participants on the effectiveness of the overall process.

3.3 Research Design

Manstean & Semin (1988) propose that the approach and method used to carry out a piece of research should depend on the objectives and type of questions that one hopes to be answered. The researcher when designing this study chose a qualitative descriptive methodology.
Qualitative descriptive studies have been described by Sandelowski (2000) as offering a comprehensive summary of an event in the everyday terms of those events. She further states that “Researchers conducting such studies seek descriptive validity, or an accurate accounting of events that most people (including researchers and participants) observing the same event would agree is accurate”. (p 335)

As outlined in the conclusion to the literature review, there exists a gap in the qualitative research related to the direct experience of participants in PCP. The research aims to gather knowledge from the lives and experiences of people with intellectual disabilities, to ascertain the utility of the Person Centred Planning process in their service. Taking this aim on board, the author argues that a qualitative descriptive methodology is the most suitable for this study.

3.4 Population and Sample

Background to the Organisation

The organisation where the participants attend is located in the west of Ireland. Its stated aim to provide a comprehensive, efficient and innovative range of personal, high quality, community based services to over 500 people listed on their database people comprising of over 100 children and more than 400 adults with intellectual disability.

Person Centred Planning as an organisational ‘must’ began rolling out in spring 2010. A core group was formed to oversee the training process, and to evaluate
the work being completed. The group consisted of the Director of Client Services, an Area Manager, Service Quality Manager, Two Unit Directors and five frontline staff, based in day and residential services. Training was arranged in monthly cycles of fifteen staff being trained. Training took place over two days eight weeks apart. This means that approximately 150 staff had been trained in facilitating the PCP process. It also meant that a Person Centred Plan was commenced by each of these staff members.

Day 1 of training focused on the principles of PCP, the information gathering process, and ‘rediscovering ‘the person.

Day 2 training looked at the importance of the circle of support meetings for the individual.

At all times during the training the emphasis was on the importance of the service user’s contribution, their wishes, desires and goals being expressed, regardless of perception of attainability. As well as the two days training, all staff working as facilitators were given 30 hours dedicated time to work with the service user to gather information prior to initial Circle of Support meeting. A dedicated web based support portal is available for all facilitators

At the time of writing this report, over 180 adults are participating in Person Centred Planning in this service, with over 150 staff that have been trained and supported as facilitators.
Sampling

Sampling is a method described by Robson (2002) as identifying the population of interest. The researcher for the purpose of this research chose a purposive non-probability sampling method. The researcher in conjunction with the managers and keyworkers selected participants who offered a high probability of participation and engagement in the process, required to meet the rationale and objectives of the research. This is due to the staff having insider knowledge of all the participants in question, and also this group would be described as being generally purposive having a mild/moderate intellectual disability and partaking in the Person Centred Planning process.

Inclusion/Exclusion Criteria

The criteria for inclusion/exclusion in the study were as follows,

- Participants had to be over 18 years of age for inclusion.

- Only participants in mild/moderate range of intellectual disability were considered.

- The participants had to be able to communicate verbally.

- Participants had to be undertaking the PCP process at the time of the study.
Exclusion Criteria

- Services users who had worked directly with the researcher were excluded.

- Service users who had not commenced PCP were excluded.

Participants were recruited with the help of individuals who work closely with the service users. Service users were initially approached by their keyworkers, and the detail of the research was explained. When the service users expressed an interest in taking part, each of the potential research participants was given an information sheet and consent form in a language friendly format. If required, keyworkers explained the context and background of the study. All potential participants were given up to two weeks to decide if they wished to participate, and contact details of the researcher were given. The opportunity to withdraw from the research at any stage was offered.

A total of 12 service users agreed to participate in the study, there were 6 female and 6 male participants, ages ranged from 28 to 60. 5 of the participants live in residential services supported by staff, the remainder live with their families, and all attend a day service on a 5 day basis.
11 interviews took place, one participant declined to take part on the day of the proposed interview.

**Participant Vignettes**

Interviewee A is aged 43, and lives at home with her parents and one brother. She attends on a 5 day placement in an Adult Day Service setting. She is quite independent and goes down town to the local pub or restaurants for lunch daily. Enjoys reading the local papers and has a keen interest in local news.

Interviewee B is aged 28, B attends his day service in dual locations, one rural one urban. He is a big music lover and regularly DJs for parties locally. B lives full time in a low support apartment, and has regular visits home and holidays abroad with his family.

Interviewee C is a man aged 38; he attends a day service in a rural area, but comes from the city on transport daily to and from this service. He lives at home, and appears to have a strong committed family support network.

Interviewee D is a man aged 32, originally from a rural background; D currently lives with his brother while awaiting access to a minimally supported accommodation model with a number of other service users. D has strong links to his local community, and visits regularly. He is a very keen supporter of GAA, Particularly Hurling.
Interviewee E is a 30 year old woman, who attends a day service 5 days per week, she currently lives at home, and does not access any respite supports. She is a big animal lover, with a particular affection for Ponies and Horses.

Interviewee F is a man aged 50 who attends day services for 5 days in two locations, 1 rural, one town based. He lives with his brother and sister in law. Originally from the United Kingdom, he has been resident in Ireland for 12 years.

Interviewee G is a woman aged 31, who attends a day service 5 days a week and lives in full time residential setting with staff support. She is very fashion conscious. G has a very strong family support network, who advocate strongly on her behalf.

Interviewee H is a man aged 45; he attends day service 5 days per week and lives full time in a residential service with staff support. H has a number of physical needs, but is fiercely independent and a strong advocate for his own and other’s needs.

Interviewee I is a woman aged 30, who lives at home with her mother, she does not avail of any respite or community supports. She attends an urban day service 5 days per week. She is originally from the United Kingdom and has been living in Ireland for the last 3 years. She enjoys Dance and Art especially.

Interviewee J is a woman aged 35, who lives at home with her family; she attends a day service 5 days per week. She loves cooking and drama.
Interviewee K is a woman aged 60, she attends day service 5 days per week, and lives in a residential group home setting with staff support. She is a member of the service user’s council in the organisation, and is a strong advocate for her peers, and herself.

One putative participant turned down the opportunity to participate on the day we were due to meet.

3.5 Research Methodology

The researcher proposed that Qualitative research would be carried out using 12 semi-structured interviews. Bryman (2008) describes semi structured interviews as a form where the interviewer has a series of questions in the form of an interview guide. (See appendix 1) The questions have been framed taking into account the researchers experience, and review of relevant literature. The semi structured nature of the interview allows the interviewer to vary the order of the questions and it allows some latitude for further questions if what are seen as significant replies emerge. Brown & Dowling (1998) propose that semi structured interviewing allows for clarity, probing and prompting as required.

The author conducted a pilot Interview, following which the author made a number of small changes in relation to the questions being asked.

Materials used in the interviews included a Dictaphone for the sole convenience of the interviewer. The interviews were all recorded on audio tape. This allowed total concentration throughout the interview. However on occasion the
interviewer did take brief notes regarding body language to assist in the analysis of the data. Following the completion of the interviews process the interviews were transcribed verbatim by this researcher.

3.6 **Rigor**

Lincoln & Guba (1985) described four general types of trustworthiness in qualitative research: credibility, transferability, dependability, and confirmability.

Credibility - confidence in the 'truth' of the findings. The researcher interviewed 11 participants from a diverse age, and service type. Ages ranged from 28 – 60, participants lived in semi-independent settings, group home settings and at home. This is one way of triangulating via data sources. Here individual viewpoints and experiences can be verified against others and, ultimately, a rich picture of the attitudes, needs or behaviour of those under scrutiny maybe constructed based on the contributions of a range of people. Member checking was carried out as the participants were given the opportunity to review and amend as necessary their interview notes. No one had any changes to make.

Transferability - showing that the findings have applicability in other contexts. Generalisability or transferability, in terms of qualitative research is based on the assumption that it is useful to begin to understand similar situations or people, rather than being representative of the target population (Maxwell, 1997). Bassey (1981) proposes that, if practitioners believe their situations to be similar to that
described in the study, they may relate the findings to their own positions. However this researcher would argue that the findings of a qualitative project such as this are specific to a small number of particular environments and individuals, it is impossible to demonstrate that the findings and conclusions are applicable to other situations and populations. This study however does highlight the feelings and thoughts of the 11 service users involved in this particular piece of research with regards to Person Centred Planning.

Dependability - showing that the findings are consistent and could be repeated. Whilst this is a qualitative descriptive study, there are comparable studies that have utilised mixed methodologies, (Robertson et al. 2005, Wigham et al. 2008). An audit trail was compiled, detailing each step of the research process. This included research design and data collection decisions and the steps taken to manage, analyse and report the data. The audit trail enables the research process to be closely followed and replicated.

Confirmability and audit of the research process was established by maintaining accurate documentation retention of audiotapes, and transcription of interviews.

3.7 Data Analysis

Data collection according to Bell (2005) requires the researcher to allow the interviewee to structure the conversation with the researcher/interviewer asking follow up questions if necessary.
The author decided to utilise a general inductive approach to analysing the data produced by the interview process. The primary purpose of the general inductive approach to research is to allow findings to emerge from any regular, dominant or significant themes present in raw data.

Thomas (2003) states that key themes can frequently be left obscured framed incorrectly or left invisible because of the preconceptions in the data collection and data analysis procedures imposed by deductive data analysis. The following are some of the purposes overarching the development of the general inductive approach.

1. It allows for large amounts and varied content of raw text data to be condensed into a summary.

2. To establish if there are clear links between the research objectives and the summary findings derived from the raw data. It assesses if these links are both transparent to others, and defensible or justifiable given the stated objectives of the research.

3. The development of a model or theory about the underlying structure of experiences or processes which become evident in the text.

It is important that the researchers to be cognisant that their findings may be shaped by their assumptions and experiences. In order for the findings to be usable, the researcher is required to make decisions about what is more and less important in the data. For this reason it is likely that different researchers will be
unlikely to produce findings that are not identical and will have non-overlapping components. Thomas (2003) also discusses a number of underlying assumptions which are made in the use of a general inductive approach. Data analysis is determined by the research objectives and there is a requirement for multiple readings and interpretations of the raw data.

This researcher utilising a general inductive approach, as outlined by Thomas (2003) to analyse the data, started the coding of the interviews by reviewing the data for themes, ideas and categories in the answers given to the interview questions (see appendix 1). Initial themes were based on the interview questions. Reading of the text allowed categories under these themes to emerge. Similar passages of text were then marked with a category for comparison and analysis as the study continued. This researcher then compared the passages of text with those already in that category. This was to ensure that the categorising was consistent and allowed consideration of the possibility that, either some of the passages categorised that way did not fit as well and might therefore be better categorised as something else, or, the initial categorisation was correct. Through analysis of the data, a necessity to modify the emergent key themes developed resulting in some categories becoming themes. The study as it comprised of 11 interviews with participants generated a significant amount of text to be analysed. The findings of the analysis will be discussed in the next chapter.

3.8 Limitations of the Research Methodology
The researcher has found throughout the interview process, that even though the participants were all able to be involved in the study, it was quite difficult at times to delve deeply into the interviews, that responses given were quite short on occasion, however Booth & Booth (1996) suggested that participants with intellectual disabilities have restricted language skills overlaid by a lack of self-esteem, which produces an apparent unresponsiveness.

Booth & Booth (1996) advise avoiding open-ended questions and the adoption of a more direct style. They observed the importance of the participant's body language in suggesting to interviewers that they can proceed with a line of questioning, or that they should hold back. The researcher was conscious of not trying to lead the participants’ responses, and looking reflectively at the interviews found an improvement the more interviews were completed. The author notes the expectations he had with regard to the participant's abilities to express their feelings, may not have been consistent with his experience working in the area for a number of years, Harris & Roberts (2003, p.2) write that ‘Rarer yet is any acknowledgement of the difficulties, or barriers, that need to be overcome to enable both potential interviewer and potential respondent to participate in the qualitative research process”. Finally as noted in section 3.6 the small sample limits the possibility to generalise on the basis of the results of this study.

3.9 Insider Research

Work based research is regularly carried out, particularly in circumstances where the research and opportunity to study has been partly funded by a service
provider and where a decision to choose a topic that could benefit the organisation and have practice implications is made.

The aim of this research was to explore Person Centred Planning process from the perspective of the person with intellectual disability, whose plan is being worked on. The researcher has worked within this organisation for almost 12 years and in the field of Intellectual Disability for more than 17 years. The researcher had a daughter who lived with Edwards Syndrome (Trisomy 18) to 11 years of age, and thus has also a familial perspective in relation to intellectual disability.

The advantages of insider research are; primarily the researcher is known to service users and professional staff who work with them. The researcher has a detailed knowledge of the context of the study, along with historical, current and future perspective of the service provider involved. However this type of research also presents challenges and inherits ethical considerations. Grady and Wallston (1998) write that the participant may be of the view that if they are forthcoming with the truth their service may be affected negatively as a result.

The researcher was cognisant that information collected may include that which for good practice needs to be passed on, and so depending on its nature the researcher may be in a position where the assurance of confidentiality may be compromised.
Familiarity between the researcher and participants carries a risk that results may be compromised. (For this reason the participants in this research have never worked directly with the researcher or vice versa).

To allow for these occurrences, Grady & Wallston (1988) offer the following principles:

- Try to foresee likely conflicts, for example if whilst undertaking the research, it emerges that there are deficiencies in a work colleagues work practice.
- Responses should be recorded, thus ensuring all comments are logged and dated allowing for use if required subsequent to the interview.
- Where possible, access collaboration of research colleagues from outside the situation. This will ensure that as a researcher, one stays in the appropriate role whilst undertaking the research.
- A pilot interview prior to the interviews taking place allows for positive criticism and amendments to techniques to be used. The Author undertook one pilot interview which allowed for amendments to the interview questions to be made where desired.

3.10 **Ethical Considerations**
This researcher was cognisant of ethical considerations in relation to carrying out research involving adults with intellectual disabilities and the following measures were taken.

- The researcher was cognisant of the potential issues in relation to capacity to consent and thus ensured that documentation was available and given to potential participants in plain text and language friendly versions. If required, keyworkers explained the context and background of the study.

- All potential participants were given up to two weeks to decide if they wished to participate, and contact details of the researcher were given. There was no contact from the participants with any queries prior to the interviews.

- Participants were also free to withdraw at any stage and to refuse use of their interview in study. There were no changes made to the interview notes following review by the participants.

- The participants were assured that all interview transcripts would be anonymised, and that taking part would not have a detrimental effect on their service provision. They were further informed that it would be the researcher who would complete the transcribing.

- The participants were informed they could bring an advocate to the interviews if they wished, however confidentiality and anonymity would be maintained.
The beneficence of the study was outlined to participants also, that the findings of the study would inform future and current practice in relation to Person Centred Planning, thus benefiting themselves, their peers and the staff working with them. Other potential benefits were that the service provider, upon reviewing the study would continue to support the PCP process to the current level, and implement any requisite changes to improve the process. The dissemination of the findings may impact the quality of service provided to people with intellectual disability in other service providers in Ireland and elsewhere.

The venue for interview would be at a place and time of the interviewees choosing. The interviewees were given the opportunity to ask any questions they may have had related to the study, including any of the ethical considerations mentioned above.

The participants were given the opportunity to review transcript of interview, edit the transcript and make additional comments.

Transcripts, consent forms, audio tapes, and all other written work produce of this study was stored in a locked cupboard, accessible only by the researcher. The researcher has stored information on his laptop, which is a secure, encrypted, password protected machine. The researcher adhered to the Data Protection Act (1998) and Data Protection (Amendment) Act 2003 in relation to storage and disposal of data.
• The participants were assured that confidentiality would be maintained at all times throughout the study. The service provider was also assured that anonymity would be maintained. Permission would be sought from the person involved and their service provider to access notes as required.

3.11 Conclusion

Fielding (1993, p115) contends that “good qualitative analysis is able to document its claim to reflect some of the truth of a phenomenon by reference to systematically gathered data;” in contrast, “poor qualitative analysis is anecdotal, unreflective, and descriptive without being focused on a coherent line of inquiry.”

The general inductive approach presents a vigorous and efficient way of analysing qualitative data for many research purposes, and fits well with this particular piece of research.

Some researchers are likely to find using a general inductive approach more straightforward than some of the traditional approaches to qualitative data analysis. The author has found the interview process, transcription, multiple readings, coding and analysis to be a time consuming but rewarding experience. The readings of the interviews did require a number of visits to ensure that emergent themes were captured correctly.
CHAPTER 4

Findings
This chapter presents findings from the primary data collected through the interview process in this study.

4.1 **Emerging Themes**

Utilising a general inductive methodology as outlined in Chapter 3, a number of initial themes emerged from the interview data. The initial emergent themes were the following,

Participation, Gaining Knowledge, Circle of Support, Independence, Opportunities, Goals and Choices, Changes required? There also emerged a number of subcategories, 23 in total.

These themes were linked to the initial questions asked (see Appendix 1), however the subcategories emerged through thorough readings of the interview transcripts. The researcher read each of the interviews on multiple occasions and utilising a spreadsheet system began coding responses based on the interview questions. Multiple readings and Coding allowed the emergence of significant themes in the interview answers, as well as subcategories within these themes. Utilising the spreadsheet the author was able to ascertain how many times and in what context the subcategories were emerging. On further review of the interviews and the initial themes in this study by this researcher, looking at the answers given and their significance, the researcher clustered the 23 categories together into 6 key themes. Each of the key themes reflected the meaning of the
categories that were grouped under that them, which will be outlined below, as well as the subcategories where appropriate that emerged in the data analysis. A number of subcategories could be linked to more than one of the key themes.

4.2 Key Themes

These 6 key themes were the following.

1. *The feeling of greater independence, and the emergence of one’s own voice*

   **Subcategories**

   Service user involvement

   Your input/contribution

   Content

   Perception of independence

   Changes in lifestyle, people treating differently.

2. *Opportunity to pick Goals and make Choices*

   **Subcategories**
Who chooses members?

Goals, who sets them?

Choices.

New opportunities

Returning to old favourites.

3. *Enjoyment of the Process*

Subcategories

Choices

Taking part in the process

Time spent

Information gathering

Staff involvement

4. *The lack of any emergent difficulties in the process, from the service user perspective*
Subcategory

Changes needed

Difficulties?

There were very few negative comments made in relation to the process itself, the only query being in relation to the number of questions required to be answered as part of the process.

5. *Family and Peer participation*

   - Family
     - Changes in lifestyle
     - Who chooses members?
     - Information gathering

6. *Services users would recommend PCP to their peers.*

   - Being treated differently as a result of PCP
4.3 The feeling of Greater Independence, and Emergence of One’s Own Voice

Of the 11 interviewees, including the pilot interviewee, there was a strong indication of participants feeling more independent, vocal and empowered following participation in Person Centred Planning.

Responses from participants included the following:

Interviewee H

“I’m happy with the way things are, and I’m happy with the way people ask you first. I don’t like people going behind my back saying this now or not it’s it worth when I wasn’t asked about it first, do you know what I mean?”

The following from subcategory – perception of independence

“Yeah I have, yes I have more independence now, ammmm even though I didn’t lose my independence, I have more independence now.”
Interviewee J “Person, it’s about yourself, about myself, and it’s all about, it’s all around me. Say if I wanted to go, if I wanted to go anywhere, or (indistinct). It’s all about the person.”

Interviewee K “Helping me to talk to people, looking at people.”

One interviewee spoke about self-knowledge stating that the process had helped him think about what he wanted:

Interviewee B ‘doing all the bits, learning bits about myself’

The following responses come from the subcategory – your input / contribution

Interviewee K - “Now the first day I went there I was kinda nervous, well not nervous, but I didn’t know what they were going to come out with, do you know, when you wouldn’t be having that kind before. And that it made me more confident to be able to speak up for myself and be able to express what I want, and how I felt, and it did great for me now, I cannot fault it.”

Interviewee B - “Yeah, yeah, I do speak up for myself … mmmm and I have talk up for myself more and have learnt a bit , .. a bit about talking up a bit more”

Interviewer –”Do you feel any different yourself?

Interviewee J – I see myself improving every day…”
Interviewee H - 'so that’s where I be happy, like doing things do you know, independent for myself I like doing things you know.'

Interviewee D - "Help me to do (indistinct) make more, more choices, doing what I want to do.”…

A number of participants mentioned that the situation for them in terms of people listening to them had changed over time, it could be argued that when individuals are given the opportunity to express their choices and goals for the future, within a setting that is primarily set up to facilitate the achievement of those goals and choices then they could feel more empowered. This is demonstrated in responses that follow.

From the subcategory- People treating differently- the following responses emerged

Interviewee H - "Yeah they listen to me more now than, than, than years ago, and I have more of a choice now, than years ago, they wouldn’t listen to you at all years ago.”

"I was able to talk up for myself, and nobody disturbed me, and and I found it very good.”

Interviewee J - "perfect, I, I, if a person tries to talk for me, I say excuse me, let me talk. (Interviewer – That’s very good) I do, I like say, let me talk. No names
mentioned, cause a person did try to talk for me, and I went uh uh (shaking head) let me talk for myself.’

This interviewee also stated the following during the interview:

Interviewer– And do you think the people listen to you at the meetings?
Interviewee– Yeah they would, ‘cause id make them listen.

Interviewer– (Laughs) how would you do that?
Interviewee – I just tell them…..”

Interviewer – What do you tell them?
Interviewee – I just say you have to listen now…. And if they don’t do the job then I just say sorry now, you’re put out unless you pull up your socks or I’m going putting you out. One of the two.”

This was in stark contrast to her perception prior to Person Centred Planning

Interviewee - no… I was quiet… very quiet

Interviewer - What about Person Centred Planning made that change?

Interviewee – What made the change? Kept me (indistinct) I kept talking then, and people knew then I was able to talk

Interestingly one of the participants mentioned Person Centred Planning giving her confidence in helping her advocate for others. Dearden-Phillips & Fountain
(2005) observe the role of collective power in enabling people with learning disabilities to gain more control over their lives.

Interviewee K - “one of my goals is here and helping out other ones and speaking up for them that isn’t able to speak up for themselves”

“We’ll start the same thing over again like the advocacy meeting, so that has helped me…so speaking up for them and like if there’s anything going on that would want to know about”

4.4 **Opportunity to pick Goals and make Choices**

A strong pattern emerged in the data that participants were availing of the opportunity to choose their own goals throughout the process. Of the 11 participants in this study, 8 picked their goals themselves, 2 picked goals in collaboration with their facilitator. 1 participant was unsure in relation to this area.

B - ‘I did, I picked my goals, I get to pick my goals,’

E - ‘I decided what I wanted to do.’

F - ‘I do yeah, I make my choices’
H - ‘I picked them myself, picked them myself, you know I picked out all the stuff you know’

K – ‘myself that picked them. Myself that picked them out yeah.’

Two of the participants stated that the goals were jointly set.

A - ‘Me and (keyworker) set them, set them up.’

A number of participants mentioned the goals that had not been met as of yet.

Interviewee H - “Good things that came out of it, physiotherapist, (Interviewer – Aha) Physio and swimming, ammmm they well, ah, they would be the two things at the moment, but we’re working on the other things.”

Interviewee K– well I’m happy with everything I do, now as I said I know that I can’t do everything in one day, like , but I’ll get there at some stage of my life, However, none of the service users whose goals had not yet been met raised any concerns in relation to this.

4.5 Enjoyment of the Process

The participants responded mainly positively about the process itself, many mentioned the making of plans, and the opportunity for talking as the positives.
Interviewee D— I thought it was very good, 'cause it give you a chance to talk to the... About it, and they talk to you about being an idea, what you know, what we wanted to set up. You know?''

Interviewee F - ‘’ - Yes, yes, I do like it, I’m, and I’m enjoying it.

Interviewer– And what are you enjoying about it?

Interviewee– My age, and making, making, making plans’’

There were a number of general positive responses where participants could not elaborate on the response. They had a positive experience but could not pin down a precise reason, or area of the process that stood out.

Interviewee B - “what'll I say , I have gotten good pcp and I like it a lot, and I keep at it , and I keep at it when I go to my meetings.”

Interviewee A -“Yeah, yeah, I’ve enjoyed it; it was fun, doing it? (Indistinct) doing all the bits, learning bits about myself and ….”

One interviewee when asked was he enjoying the process replied "yeah" and when asked for more detail replied as follows, from subcategory - staff involvement.

Interviewee C - “The plan, bring me out dinner, snooker
Interviewee E - “… I liked doing the folder- … doing sorting the goals out.”

Interviewee G – “Do I enjoy it? Yeah!

Interviewer – can you tell me why?

Interviewee – Don’t know, just do.

Interviewee A – Ahhhhhh. Speaking up for yourself.

Interviewer – You didn’t enjoy that?

Interviewee A – No I did enjoy it (emphatic)”

4.6 The Lack of Any Difficulties in the Process, No Requirement for Changes to the Process at this time

The researcher found that the majority of interviewees expressed satisfaction with the process itself and the progress being made in their own lives as a result of Person Centred Planning.

The researcher asked if any changes were required, or any difficulties encountered in the process.

From subcategory – changes required?
interviewee A - ”Ehhhhhh. No, not really, I’m happy with it as it is”

Interviewee B - ”At the minute I have nothing to change yet, but if I have I change them, and I will talk about at Meeting.”

Interviewee C - ”No it was good fun.”

Interviewee F”– I can’t think of one”

‘Interviewee K -　”Not at the moment anyway…… No, I wouldn’t think so, no. Do you know, not off the top of my head at the moment”

Interviewee J - “no I think it’s all ok”

‘Interviewee G -‘– I think everything is ok.”

There was however one negative comment in relation to the process, which follows, the participant was asked what if any things he did not like about the process.

Subcategory - difficulties

Interviewee B - ”ahhhhhh, like questions, so many questions”
4.7 Family and Peer Participation

Of the 11 service users interviewed, all had family involvement at the circle of support stage, as well as there being an involvement for most at the information gathering stage also. Comments made by interviewees with regards to family participation in Circle of support included:

Interviewee A -“there’s me and (names keyworker), (names brother) and (names brother) my brother. My two brothers, and my sister in law.”

In relation to having family present at the circle of support meeting this participant also stated the following,

“Interviewee – But it was a bit shy at first, hard to talk to people in a big room.

Interviewer – Ok, and who would have been in that room?

Interviewee – Well, All my family.

Interviewer – You were with your family. Why were you shy, why was that?

Interviewee – Cause they never usually hear me talking about things.

Interviewer – They never used to hear you talking, I find that hard to believe.

Interviewee – No I mean in front of other people.”
Interviewee H - “(Named person, repeated) you know him, you don’t? My sister is on it, (names facilitator) be on it, ammmm who else, there’s a few more on it. …can’t remember now.”

Interviewee C - “Well, my sister... My brother in law, my two nieces.”

“Interviewee F –Yes my brother yeah.

Interviewer– Your brother will be on it will he?

Interviewee - My brother and my sister. My sister looks after me very well actually; she is very good to me.”

A number of service users have also included peers and people outside of the organisation as part of their support group.

Interviewee J - “interviewee– (Named person), and myself and my mum, and (names two individuals) … (Person) is my sister in law; (other named individual) is my volunteer. (Then names two more individuals)……

Interviewee – Cousins of mine. And a friend of mine (names person), a friend of mine (repeats name)….She just lives down here near the shop, and the other named person works in (names business where J attends for work experience one day per week)
Interviewer – And you asked all those people did you?

Interviewee – I did’’

Interviewee B - “Myself, Brother, My mother, (names facilitator) ahhhhhh, my girlfriend (girlfriends name) mmmm. (Then names 3 day services staff)”

Interviewee A -”So I have chosen (names friend), because she’s a friend of mine.”

One interviewee when asked about family participation stated the following,

Interviewee I - “don’t know who’s on it, I and (names facilitator) didn’t talk about it yet.”

However she later states the following in relation to facilitator meeting her mother in relation to information gathering and circles of support:

” yes she has, but not yet. She’s talking to (names facilitator) as well. ’’

In the context of participation it is worth noting that every participant had a staff member working with them to facilitate the process.

Of the 11 participants, 10 had their keyworker as facilitator, only 2 participants requested who they wished to facilitate.
4.8 **Recommending PCP to Others**

The participants were asked if they would recommend Person Centred Planning to their peers who attend services. The responses were overwhelmingly positive, when the question was answered, and included the following:

**Interviewee H** - “I would, I would, and I think it’s very good… I think it’s the best idea they came up with in (Organisation Name) for years.

**Interviewer** – Why is that?

**Interviewee** – Because you get to make your own decisions and all that, and you get, you get to know other people like, that you didn’t know before.”

**Interviewee D** - “Making choices, worth doing? Yeah, doing well,”

**Interviewee J** - “Yeah, definitely…”

**Interviewer** – Why?

**Interviewee** - Because they’ll have to do what I did… They’ll have to do PCP and planning and what they want”

**Interviewee B** - “I’d say it is, it is worth doing, to learn a bit about yourself, and to talk a bit about PCP”
Interviewee K - "I think more should do it...— yeah, now because it’s very handy to know where a person is or what they’re doing in their life, do you know."
CHAPTER 5

Discussion
5.1 The Feeling of Greater Independence, and Emergence of One’s Own Voice

Edwards & Staniszewska (2000) argue that giving voice to largely unheard service users empowers them, through the expression of their own needs, and that their involvement is essential to delivering high-quality services, as well as in developing more appropriate supports. A number of the benefits of Person Centred Planning have been outlined in the literature such as Robertson et al. (2005) and Wigham et al. (2008). These include the findings that almost half of service users who have been involved in Person Centred Planning reported feeling better in themselves, in terms of improved confidence or self-esteem, or being happier.

The findings of this research study would be in broad agreement with their findings. 8 of the 11 participants in this study made positive statements regarding independence or general wellbeing as a result of being involved in Person Centred Planning.

The author would argue that another important consideration going forward, in terms of independence gained from Person Centred Planning is the potential impact of individualised budgets. It is worth noting that though funding may be made available for individuals on a needs based model, (the National Intellectual Disability Database, NIDD.) the choice of how that money is spent is not currently in the power of the individual, rather the local service provider. This powerlessness continues to perpetuate the hold that professionals have on the
lives of people with intellectual disability. As Toolan (2003) has described a culture of care pervades the funding system in Ireland. It could be argued that it is very difficult to describe services as being person centred and based on the Social Model when the funding for service provision and supports remains within the grasp and control of the service providers, and the professionals employed therein. However, parents have long played significant roles as initiators, managers and administrators of direct payments for their adult disabled sons or daughters (Williams et al. 2003). In terms of outcomes, Williams et al. (2003) reported that direct payments facilitated arrangements that were felt to be generally better and that carers were able to take more breaks from direct caregiving. Crehan–Roche (2011, p12) writes ‘The future will see a paradigm shift to individualised assessment of need and support with ring-fenced individualised funding, thereby transferring the balance of power from the service provider to the person with intellectual disability and their families.’ The findings of this study have shown that service users when given the opportunity to express their choices in Person Centred Planning Process feel more independent and confidence. The introduction of individualised funding packages is potentially a very powerful opportunity for service users to voice their wishes in a tangible fashion, insofar as their ability to choose the service type they would find most appropriate.

Currently funding is provided from grant funding through the Health Service Executive Areas.
Whilst it has been argued that staff participation and ‘buy in’ is key to successful outcomes in relation to Person Centred Planning, how then will this proceed if the very services that staff work in will be coming under increasing pressure to provide a value for money service, in what will potentially be an open market for service provision? It is to be hoped that the Irish experience will correspond with the findings of Timonen et al. (2006) who in comparing schemes operating in England, Finland and the Netherlands indicated the following as similar goals:

- Increasing freedom of choice, independence and autonomy for care recipients.
- Compensation for gaps in existing services.
- The creation of jobs in personal care services.
- Efficiency gains or cost savings through reduced overheads and increased competition between providers.

A report prepared by the Individual Budgets Evaluation Network (IBSEN) on behalf of the Department of Health in the UK in 2008 highlighted a number of issues with a pilot programme of individual budgets. The IBSEN’s evaluation report noted that one of the most significant challenges in implementing the pilot system was to ensure that each local authority was willing to support creativity and flexibility to allow the client to determine how each individual budget would be spent. Effectively combining disability funding streams along with resources
from adult social care also proved extremely challenging in the UK and similar problems could arise here in Ireland.

5.2 **Recommending Person Centred Planning to Others**

The author would argue that it is reasonable to link this finding to that of - The feeling of greater independence, and emergence of one’s own voice. The perceived benefits of greater independence and more choice translated into a number of participants wishing the same for others

This researcher has found no direct reference elsewhere in relation to this finding in undertaking his literature search for this study.
5.3 **Family and Peer Participation**

Family involvement came across as a very strong component of the findings in this research. The participants in this research study all had family involvement in their circle of supports. This would be at variance with Robertson *et al.* (2007) who noted the reluctance of people other than paid support staff to engage in the PCP process. This may be due to a number of factors, including that the research took place in a predominantly rural setting, and that a number of the service users live in small close knit communities. LeRoy *et al.* (2007) found that the presence of family, friends or advocates at planning meetings is an important ingredient in developing creative problem solving and strategies in the planning process.

Dunst *et al.* (1986) writing with regard to social support and social network theory emphasises the importance of relationships among social units, and how different relationships promote or stymy the flow and exchange of resources and social support. It is possible to define social support networks in terms of certain characteristics, such as their size, membership, nearness, frequency of contact and influence of contact. Grant (1993) found that support networks can be far from stable in a study of people with Intellectual Disability and their families, and may undergo quite major transitions in relatively short periods of time. However, Dunst *et al.* (1986) found that more supportive social networks are usually associated with better personal (carer) well-being, family cohesion, and improved child behaviour and development. A study by Williams *et al.* (2003) based on
interviews with 29 family carers of people with intellectual disabilities; found that parents played significant roles as initiators, managers and supporters of direct payments for their disabled son or daughter. They found that any additional responsibilities that parents undertook in helping their child get a direct payment, was counterbalanced by the benefits of greater independence for their son or daughter and a corresponding opportunity for parents to relinquish some of their own care-giving responsibilities. As stated earlier in this study, all participants had family involvement in their PCP process, which is significant considering that almost half of those interviewed attended residential services on a full time basis. This indicates a significant level of commitment from the families involved.

The importance of family involvement can be also be considered in the context of 65% per cent (or 17,112 individuals,) of those registered on the NIDD were living at home with parents, siblings, relatives or foster parents in 2010. Taking into account the numbers of persons with Intellectual Disability who attend services, and the proposed shift to individualised packages of care, this will present potential difficulties for both service providers and organisations, and the role of families will become even more central to ensuring delivery of services in a person centred manner.

Robertson, Emerson et al. (2005), found that Person Centred Planning had positive benefits in a number of area including community involvement and inclusion. Schleien, Green et al. (1999) show three characteristics of inclusion which distinctions between definitions in use. They argue that ‘the concept of
inclusion may best be viewed as a continuum that includes three levels of acceptance’ they define these levels as:

1. Physical integration, being the right to and actuality of physical accessibility.

2. Functional inclusion as the ‘ability to function successfully’ in given environments.

3. Social inclusion as social acceptance and participation in ‘positive interactions’ with other.

Smull & Sanderson (2001) similarly make this distinction for the success of outcomes in person centred approaches. They discuss the continuum of inclusion utilising the notion of an individual ‘being present’ in an event or community, ‘having presence’, and ‘actively participating’.

A number of the participants mentioned community activities as part of the goals and choices they partake in, including the following examples;

Interviewee E – “starting Special Olympics – horse riding, very good, going to a roller-coaster park, making new friends and going to a concert. .. going to a concert with Neil Diamond...”

Interviewee D – “Actually I go to Salthill on my break actually “
5.4 **Enjoyment of the Process**

As stated in the findings the majority of service users when asked expressed that they were enjoying the process, some of the responses in the study are as follows;

Interviewee K – “I found it great, wonderful, it’s a great, I should have done that from the first day I started, and in (names service) do you know? …Oh my feelings are great …, as I said to you; I have no regrets from the day I started”

A number of participants mentioned that they enjoyed talking to their facilitator as part of the process, subcategory – staff involvement;

Interviewee H - ‘you know (names facilitator) I had mighty crack with him, ya know.

The author notes that every participant in this research study had a staff member as facilitator, (not necessarily their keyworker). Each staff member would have attended training in Person Centre Planning as outlined earlier. One of the important elements of the training provided to staff in the service involves ensuring that staff utilise all available resources, including families, to maximise the potential of the Person Centred Plan. The importance of staff participation and ‘buy in’ to the process of Person Centred Planning is well documented (Robertson *et al.* 2005, Sanderson 2002, O’Brien 2000). The service provider in this research has shown commitment to the principle of ensuring staff involved are well trained prior to commencing Person Centred Planning with service
users. All staff working as facilitators are allocated 30 hours dedicated time to work with the service user, to gather information from the person themselves, their families, and services they attend. As outlined earlier there is a managerial commitment to the PCP core group including the Director of Client Services, an Area Services Manager and a number of front line directors. The responses overall were positive in terms of interaction and time spent with the staff members involved. In a number of cases participants mentioned staff calling to their homes to meet their families when gathering information.

Interviewee D – “Yeah, went to church and graveyard, pitch and pub and school”.

Interviewee E – “Yeah, she was at the house”

5.5 The Lack of Any Emergent Difficulties in the Process, from the Service User Perspective

As stated in the findings, there was a very positive response in relation to the process itself, with very few participants expressing any concerns about the process. Indeed one of the few negative comments related to the number of questions asked.

Typical responses included the following;
The author would argue that it is reasonable to link this lack of negative response to the positivity that emerged in terms of independence and setting of goals. The participants in general expressed a high level of enjoyment and satisfaction with the process, and that being the case, it is reasonable to expect a limited amount of negativity in relation to the process of PCP, the research findings bore out this correlation.

5.6 Opportunity to Make Choices (allied to perception that even if goals had not been met yet, they would be worked on)

Of the 11 service users who participated in this research, 8 stated that they picked their goals themselves, 2 picked theirs in consultation with their facilitator. The other participant was unable to answer in relation to who chose the goals.

Service user participation in service planning, development, and delivery is seen as a benefit to all who participate in terms of skills, experience, and fulfilment (McGlaughlin et al. 2004).

A survey was designed to assess Quality of Life of 256 adults with intellectual disabilities and was conducted across a range of 22 service providers in the Republic of Ireland using Personal Outcome Measures. The study carried out by McCormack & O’Brien (2009) aimed to gauge whether organisational processes are in place to support the achievement of personal outcomes of people with
intellectual disabilities and to identify people’s unmet priority outcomes. Results reveal that, on average, participants had less than half their personal outcomes fully present at the time of the survey.

The research carried out in this study does not deal with the number of goals being met as a result of Person Centred Planning, but the results would indicate that not all goals are being met at this time. However the participants did not have any discernible issue with this, the view being that even if the goals were not met at the time of the interview they would be worked towards in the future.

Examples included:

Interviewer-" And are you working towards doing those things?
– Interviewee J - Not quite yet, I’m going to start up again.”

Interviewee H – “Well, yeah, a few of them has been met yeah………

Interviewer – And what about the goals that haven’t been met yet?

Interviewee H – Not yet, ammmm, we have to go through that yet, yeah I have a few goals, like driving a car and all that. Have to go through all that yet.

Interviewer – Ok and will they take more work?

Participant– Yeah, more, more work. Harder to do.”
However the author would also argue that even if progress in achieving goals is slow, engagement on a meaningful basis with the person with Intellectual disability is itself a positive.

5.7 **Recommendations and Conclusion**

On February 29th 2012 in a HSE press release to mark the launch of three new reports including •“New Directions – Personal Support Services for Adults with Disabilities” •“National Review of Autism Services” and •“Respite/Residential Care with Host Families in Community Settings”. The Press release gave a succinct message in relation to the direction in which the HSE views service provision heading. The following was stated;

‘’…disability service provision has been moving towards a community based and inclusive model rather than being institutional and segregated. The key learning from these reports…will provide a catalyst for achieving a more effective, person centred disability service provision, in line with international best practice…The radical change is not the sole responsibility of the Health Service Executive but rather, a collaborative responsibility shared between the person, their families and carers, a multiplicity of agencies, Government and society as a whole.”

Taking this statement into account it can be argued that there continues to be a shift to the Social Model of disability in the Irish context, linked to an expectation of person centred not service driven planning.

**Recommendations**
This researcher is cognisant that this is a small study group of 11 participants, with a mild intellectual disability and relatively good verbal communication skills. The researcher would recommend that further study take place ascertaining the views of service users with more complex needs, and those with non-verbal communication methods. What has been apparent in the findings of this study is that while most service users do enjoy the process of Person Centred Planning, it can be argued that this is due in part to a high level of commitment shown by facilitators, allied to family involvement. The researcher would recommend that the service provider continue to allocate specific hours to staff involved in Person Centred Planning. The author would argue that this level of commitment to staff involved has had a positive outcome, allowing sufficient opportunity to give the process and the service user the time required for comprehensive and meaningful work. The positive outcomes of which can be attested to by the findings from participants in relation to independence, enjoyment and goals.
**REFLECTION**

This researcher has found the completion of this study to be a most rewarding, if at times frustrating experience. The interaction with the participants has been enlightening and fulfilling for me.

This process has very much advanced my knowledge and understanding with regards to Intellectual disability and I would hope to utilise skills, experience and knowledge gained in completing this study in my professional life.
References


Finlay W.M.L., Antaki C., Walton C. & Stribling P. (2008). The dilemma for staff in ‘playing a game’ with a person with profound intellectual disabilities:


Methods, 2 (2). Article 2 Retrieved at


Nirje B. (1982) Keynote Speech *The basis and logic of the normalisation principle*
Sixth International Congress of IASSMD, Toronto.


Appendices
Appendix 1

Interview Guide for Questioning

**Question 1:** How have you found being involved in Person Centred Planning?

**Question 2:** Were you offered a choice about taking part in the PCP process?

**Question 3:** Who chose your facilitator?

**Question 4:** What parts of the process (if any) do you find worked well for you?

**Question 5:** What parts of the process (if any) did not work well for you?

**Question 6:** How were the goals picked?

**Question 7:** How were the people on the Circle of Support chosen?

**Question 8:** What positives have you experienced from partaking in PCP process?
Appendix 2

Information Sheet for Participants and Staff

Dear,

My name is Gerry Haslam; I am currently undertaking a Masters degree in Disability Studies at Trinity College, Dublin. As part of this course I am proposing to carry out a research study. The study will be looking at Person Centred Planning from the point of view of the person whose plan is being completed.

I respectfully invite you to take part in the study.
I hope that the study will find out what things are good about Person Centred Planning and what things are not so good. I also hope to find out if people think their lives have improved after having a Person Centred Plan.

If you are interested in taking part in the proposed study, your informed consent is required.
You may then be invited to an interview which can take place at a venue of your choice or within your service if you wish.
The interview will be taped for data collection purposes and a written record of the conversation will be made after this.

In the event of any information coming up in the interview that may place you or someone else in danger, the Designated Person in your service will have to be informed.
Your name and details will not be in the document and all data from the interview will be managed, stored and disposed of as the Data Protection Acts of 1988 and 2003 and Trinity College Data Protection Compliance.
You will get a chance to look at the written work to make sure you are happy with its content.

You are free to withdraw from the study at any stage. You will get to see the report before I submit it to the College, and I am happy to discuss the findings of the study with you.

Taking part in the study will not have a negative impact on your service provision. If you have any questions about the study, please don’t hesitate to contact me.

My Phone number is 087 7993545
My Email address is haslamg@tcd.ie

If you would like to participate in the study, please return the attached consent form in the stamped addressed envelope.

Thank you for your consideration.

Gerry Haslam
My name is Gerry; I am completing a college degree, part of which is a study about Person Centred Planning. I hope to meet 12 people to talk about PCP.

I would like you to share the story of YOUR PCP with me.

I need your consent to take part in the study.

We will have a conversation about your story.

With your permission I will record this conversation.
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<thead>
<tr>
<th>Image</th>
<th>Text</th>
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<tbody>
<tr>
<td><img src="image1.png" alt="Person" /></td>
<td>This is all about YOUR experience of Person Centred Planning.</td>
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<tr>
<td><img src="image2.png" alt="Clock" /></td>
<td>The interview will take up to 1 hour.</td>
</tr>
<tr>
<td><img src="image3.png" alt="Hand" /></td>
<td>You can LEAVE the study at any stage.</td>
</tr>
<tr>
<td><img src="image4.png" alt="Reader" /></td>
<td>You will get the chance to read your interview, and make changes if you wish.</td>
</tr>
<tr>
<td><img src="image5.png" alt="Lock" /></td>
<td>Your name will not be mentioned in the study, and all information will be kept safely.</td>
</tr>
<tr>
<td>![Image 1](115x585 to 230x683) ![Image 2](115x464 to 236x562) <img src="297x78" alt="Image 3" /></td>
<td>When I have completed the study, I hope to present it at conferences, and get it printed in magazines.</td>
</tr>
<tr>
<td><img src="297x78" alt="Image 4" /> <img src="230x667" alt="Image 5" /></td>
<td>You can talk to me at any stage about the study.</td>
</tr>
<tr>
<td><img src="236x366" alt="Image 6" /></td>
<td>My phone number is 087 7993545</td>
</tr>
<tr>
<td><img src="236x366" alt="Image 7" /></td>
<td>my email address is <a href="mailto:haslamq@tcd.ie">haslamq@tcd.ie</a></td>
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<tr>
<td><img src="236x366" alt="Image 8" /></td>
<td>Thanks for taking the time to read this.</td>
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Appendix 3

Consent Letter for Participants and Language Friendly version

Lead Researcher: Gerry Haslam

Background of research: The researcher aims to look at Person Centred Planning from the viewpoint of the person who is at the centre of the plan.

A lot of studies have been done that look at what staff members have felt, or the service provider.

This study will be giving the people who are supposed to be the most important the chance to give their opinions.

Procedures of this study: In this study, you will be asked to take part in a semi structured interview within your service, or at a venue of your choice, with the researcher. This type of interview includes a small number of questions, related to Person Centred Planning.

The researcher will use an interview guide and the interview will be recorded on tape and later written out. The interview may be between thirty to sixty minutes long and you have the right to withdraw at any stage.
Once the interview has been put into writing, you will have the chance to review what you said during your interview, and change anything you are unhappy with. Your confidentiality will be upheld as no real names will be used. The name of your service will also be kept confidential. Taking part in the study will have no negative impact on the service you receive.

Publication: The results of this study will be published in a professional journal and the researcher may also present the findings of this study at conferences, locally, nationally and internationally.

Declaration:
I am over 18 years of age and am competent to provide consent.
I have read, or had read to me, this consent form.
The opportunity for me to ask questions and to have them answered has been offered to me.
I understand the description of the research that I have been provided with.
I understand that in the event of any information coming up in the interview that may place me or someone else in danger, the Designated Person in my service will have to be informed.

I do not object to data collected from me being published in magazines in a way that does not reveal my identity.

I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.

I understand that I may refuse to answer any question and that I may withdraw at any time.

I am aware that taking part in the study will have no negative impact on the service I receive.

I understand that my participation is fully anonymous and that no personal details about me will be recorded, including the service I attend.

I have received a copy of this agreement.

Signature of Participant: _______________
Date: ____________________
Statement of investigator’s responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

Contact Details of Researcher: ________________

Signature of Researcher: ________________

Date: ________________
My name is Gerry; I am completing a college degree, part of which is a study about Person Centred Planning. I hope to meet 12 people to talk about PCP.

I would like you to share the story of YOUR PCP with me.

We will have a conversation about your story.

With your permission I will record this conversation.
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<td>The interview will take up to 1 hour.</td>
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<td>You can stop the interview at any stage. You can also leave the study at any time.</td>
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<td></td>
<td>You will get the chance to read your interview, and make changes if you wish.</td>
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<td>Your name will not be mentioned in the study, and all information will be kept safely.</td>
</tr>
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When I have completed the study, I hope to present it at conferences, and get it printed in magazines.

You can talk to me at any stage about the study.

My phone number is 087 7993545

my email address is haslamg@tcd.ie

I do not wish to take part in the study.

Please sign here

I am happy to take part in the study.

Please sign here

Thanks for taking the time to read this.