Exercising Independently and Exercising Independence: A Phenomenological Study of Physical Activity and Choice among Adults with an Intellectual Disability

Sheila O'Sullivan
Department of Health and Leisure, Institute of Technology, Tralee, Co. Kerry, Ireland.

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Sheila O’Sullivan

Department of Health and Leisure Institute of Technology, Tralee 2016
Exercising Independently and Exercising Independence: A Phenomenological Study of Physical Activity and Choice among Adults with an Intellectual Disability

Sheila O’Sullivan BSW (Hons)
Department of Health and Leisure
Institute of Technology Tralee

A thesis presented to the Institute of Technology Tralee for the degree of Master of Science

December 2016

Supervisors:
Dr. Anna Marie Greaney, Department of Nursing
Mr. Pat Flanagan, Department of Health and Leisure
Declaration of Authorship

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Master of Science is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

Signed: ________________________________

Date: _________________________________
Acknowledgements

Without a research site and participants, who have unselfishly given their time and told their stories so beautifully, this research would not exist. I would like to give a heartfelt thanks to all of the participants and service directly involved in this study and hope that it impacts positively on their lives is some small way. While each of the nine participants remains anonymous on paper, they endure in my memory.

So too do the memory of my two supervisors Anna Marie Greaney and Pat Flanagan endure in memory. Their expert guidance and advice, constant feedback and time cannot be overestimated. Thank you and I would also like to extend my deep gratitude to my mentor supervisor Deirdre Corby, DCU.

I would like to thank the Research department in the Institute of Technology, Tralee and especially Tom Farrelly and Siobhán Mc Sweeney for their academic and practical support throughout.

I would like to express my deep gratitude to the library and staff that became an integral part of my life for the two years spent in the IT.

While research is largely depicted as a solitary pursuit, I can definitely say that there were days that I would not have survived without my fellow researchers, those who began the journey with me and those who came on board as time went on. Thank you: Miriam (especially), Thabo, Chrystal, Orla, Ciara, Kofi and Niamh.

Research is a very selfish pursuit as time and energy impacts on family life, something which I often forgot. I was fortunate that my partner JJ supported me practically, intellectually and emotionally throughout and I want to thank you JJ for that.

The joy that life gives us and the tragedies that we are faced with do not stop because of research. Therefore, I want to especially acknowledge the very painful loss of Pamela, a beloved daughter and dear friend, during this period. I would like our granddaughter Evalee to know that my doing this research would never have happened without the encouragement of her grandfather JJ and her mother Pamela.
Dedication

In memory of Pamela O’Donoghue-Schneeberger
(1981-2016)

For believing in what I could achieve
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<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ACMS</td>
<td>American College of Sports Medicine</td>
</tr>
<tr>
<td>APA</td>
<td>American Psychiatry Association</td>
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<tr>
<td>CARA</td>
<td>This is not an acronym but to avoid confusion a definition is provided. It is a national organisation aiming to enhance sport and physical activity opportunities for people with disabilities.</td>
</tr>
<tr>
<td>EFDS</td>
<td>English Federation for Disability Sport</td>
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<tr>
<td>HIQA</td>
<td>Health Information and Quality Authority</td>
</tr>
<tr>
<td>IASSID</td>
<td>International Association for the Scientific Study of Intellectual Disability</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning</td>
</tr>
<tr>
<td>ICIDH</td>
<td>International Classification of impairments, Disabilities and Handicaps</td>
</tr>
<tr>
<td>ID</td>
<td>Intellectual Disability</td>
</tr>
<tr>
<td>MVPA</td>
<td>Moderate to Vigorous Intensity Physical Activity</td>
</tr>
<tr>
<td>NDA</td>
<td>National Disability Authority</td>
</tr>
<tr>
<td>PA</td>
<td>Physical Activity</td>
</tr>
<tr>
<td>PCP</td>
<td>Personal Care Plan</td>
</tr>
<tr>
<td>Qol</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>SDS</td>
<td>Society for Disability Studies</td>
</tr>
<tr>
<td>TILDA</td>
<td>The Irish Longitudinal Study on Ageing</td>
</tr>
<tr>
<td>UDHR</td>
<td>United Nations</td>
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<tr>
<td>UNCRPD</td>
<td>United Nations Convention on the Rights of People with Disabilities</td>
</tr>
<tr>
<td>UNESCO</td>
<td>United Nations Educational Scientific and Cultural Organisation</td>
</tr>
<tr>
<td>UPIAS</td>
<td>Union of the Physically Impaired Against Segregation</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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Abstract

**Aim/Background:** This study examines how adults with intellectual disabilities choose the physical activities they engage in, inside and outside of the day service they attend. Of particular relevance are the benefits derived from physical activity which promotes wellbeing, inclusivity, new opportunities and social acceptance for people with intellectual disability. This is timely in light of current policy with regard to New Directions 2012-2016 which is directed towards moving people with ID from congregated to community settings and the enactment of the recent Assisted Decision Making (Capacity) Act (2015) which supports decision-making for all citizens.

**Methodology:** The study used phenomenological analysis (IPA) to elicit the participants’ experiences of choosing physical activity as an adult with an intellectual disability. IPA is concerned with the detailed examination of human lived experience. The use of phenomenology facilitates the meaningful participation of adults with an intellectual disability in research about their lives. Following ethical approval, immersion in the service commenced leading to the purposive sampling of nine core participants. Data collection adhered to the IPA format of asking overarching questions. Semi-structured Interviews with staff were conducted in order to illuminate the study and not replace the experiences of the core participants. The framework of analysis, as outlined by Smith, Flowers and Larkin (2009), traced the development of emerging themes that evolved into superordinate and related subordinate themes.

**Findings and Recommendations:** Three superordinate themes emerged from the research. They include, firstly, the less strong link between physical activity and health on behalf of the participants. Secondly, the important role the service plays as a facilitator of physical activity. Thirdly, choice and choice-making is not a concept readily understood or practiced by the core participants. These findings resonate with the extensive literature review that incorporates self-determination and antecedents to choice-making in its corpus. Findings suggest recommendations for service, policy and research, especially in light of the supports needed to facilitate the Assisted Decision-making Capacity Act (2015) and the current transition from segregated settings to community. It also recommends services linking into relevant, cost effective local programmes that support people with ID in physical activity. This study will contribute towards the current knowledge base regarding physical activity and choice among adults with ID.
1.1 Introduction to the Research
This research is about the lived experience of physical activity (PA) and choice among adults with an intellectual disability (ID). However, two separate concepts both have become significant in the disability discourse. Current policy around day care services, a notable interest of this research, as outlined under New Directions 2012-2016 (HSE 2012), proposes choice combined with leisure pursuits for people with ID in this setting. Physical activity (PA) has become increasingly important for people with ID as a means of improving their quality of life taking into account the phenomenon of increased longevity. The focus of this study therefore, is concerned with the holistic beneficial features of PA for people with ID, one that promotes psychosocial and emotional wellbeing, choice, inclusivity, new opportunities and social acceptance. It examines how adults with an ID, attending a day service are facilitated and supported in selecting a PA of choice. This is studied through the medium of phenomenology, or more specifically the methodology of interpretative phenomenological analysis (IPA). In essence, IPA is concerned with the lived experience of the person regarding a phenomenon (Smith, Flowers and Larkin 2009). The phenomena in this research are physical activity and choice.

1.2 Background and Rationale
The World Health Organisation (WHO 2008) issued The World Health Report focusing on concerns for the present and future predictions for physical health issues specifically targeting people with an ID. The increase in longevity, medical advancement and the rapid increase in overall population growth have resulted in overwhelming stressors on health systems. The WHO (2008) emphasised the need to address these forecasts and their management due to the escalating levels of chronic illnesses worldwide, especially among people with an ID. Chronic illnesses include heart disease, stroke, cancer, chronic respiratory diseases and diabetes (WHO 2008). Out of the 35 million people who died from chronic disease in 2005, half were under 70 and half were women (WHO 2008).
Researchers find that the endorsement of PA as an effective measure in promoting overall well-being of people with ID is significant (WHO, 2008; Moss, 2009; Carmeli et al., 2009; Carraro and Gobi, 2012). Greater physical activity for people with ID has been shown to improve cardiovascular health (Moss 2009), decrease anxiety levels (Carmeli et al. 2009) and positively impact on psychosocial outcomes (Lante et al. 2011). This research addresses the link between PA and health for people with ID and examines the opportunities and choices people have in accessing PA.

Approximately 15 per cent of the world’s population, 1 billion people have a disability (The World Bank 2016). They comprise the world’s largest minority. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, with various barriers, may exclude them from full and effective participation in society. More recently, the American disability activist, Keith Jones, contended that disability is the last frontier in the struggle for civil rights (Chicago Tribune 2008). In an Irish context this struggle was recently evidenced when the Assisted Decision Making Act (December 2015) was enacted to comply with the UN Convention, but it had taken eight years to do so. Ireland has yet to ratify the convention.

On June 9, 2011, the World Health Organisation (WHO) and World Bank launched the first ever World Report on Disability. Having gathered data on disability from best scientific information available it made recommendations for action at national and international levels to promote the "well-being, dignity, social inclusion and human rights of people with disabilities around the globe" (The World Report on Disability Editorial 2011, p. 495). Such was its exhaustive work that it took four years to complete, 370 experts and 74 countries (World Report on Disability 2011). The central theme of the report is that disability is fundamentally an issue of human rights. It concludes with nine broad policy and practice recommendations, including and chiefly for the focus of this research: enablement of access to all mainstream systems and services; involvement of people with disabilities; improvement of disability data collection to strengthen and support research on disability (World Report on Disability 2011). It set out to provide an important opportunity to raise the profile of research in ID and situate it in a human rights agenda forum (The World Report on Disability 2012). This phenomenological study on PA and choice among adults with ID similarly intends to
collect data from core participants in order to support disability research and highlight the human rights agenda.

1.3 Aims and Objectives of this Research
This research examines and contextualises the meaning of physical activity and choice for adults with an ID attending a day service. It explores the policy of New Directions 2012–2016 (HSE 2012) as adhered to by the service provider whose aim is to transition people from segregated services in largely congregated settings to community settings. It evaluates choice-making through the lens of PA in light of the qualitative data collected from the core participants. It gathers the perspectives of key workers and other workers in order to illuminate the experience of the participants but significantly not replace them. It aims to augment the current evidence base with regard to how people with ID make choices about PA they engage in. It aims to add to existing literature regarding the use of phenomenological research methodologies involving people with ID.

1.4 Context of this Research
This research is concerned with the lived experience of PA and choice among adults with an ID. Therefore, this research explores the meaningful participation and views of adults with ID regarding the physical activities they engage in arrived at through self-selection. The overarching design is IPA, which is concerned with 'detailed examination of human lived experience' (Smith, Flowers and Larkin 2009, p. 32). This is situated in Heideggerian philosophy which seeks to answer the meaning of 'being' and its belief that humans are hermeneutic or interpretative, capable of finding meaning and significance in their own lives (Wojnar and Swanson, 2007). For the individuals in this research, this means that they relate their experience of PA through the lens of choice. This research is mindful of the varying levels of communication skills held by the participants who contribute a unique and rich understanding of the phenomena of physical activity and choice. However, to get to this point, a definition setting out what ID is and how it is diagnosed is an important factor in setting the context for this research.
1.4.1 Definition and Diagnoses of People with an Intellectual Disability

Definition of ID today differs greatly from what is now considered highly offensive terminology such as ‘mental retardation’. The World Health Organisation’s (WHO) description of ID is as follows:

*Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.*

(WHO 2016)

The language used shows a change in emphasis from talking in terms of disease or impairment, to talking in terms of levels of health and functioning. The American Psychiatric Association (APA) diagnose and apply criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM 2000) to devise a four-level system that classifies learning disabilities as mild, moderate, severe and profound on the basis of IQ scores (Passer et al. 2009).

Historically, the identification of ID began in the early 1900s and contributed to institutionalisation. In 1905, Binet and Simon developed a test for children with special needs. For the purposes of war and admission into the US army Robert Yerkes developed IQ tests, marking it as the cornerstone for identifying moderately disabled people whose participation needed in wartime were nevertheless excluded if the test returned IQs consistent with ID. While this approach served a specific purpose, it did not take into account varying levels of ID and nowadays categorisation remains at the four-level range. According to Power (2010 p.8), ‘the meaning and interpretation of intellectual disability is negotiable and varies across time and place’. Divergent definitions also exist in organisations but the two most recognisable schools of thought regarding ID are the medical and social models of disability further discussed in this chapter.

There are three main models used to define ID namely, statistical, pathological and the social systems model. The statistical model is the most pragmatic and widely used and accepted model. A more traditional method of testing for ID has been underpinned by norm-based tests which yield an Intelligence Quotient (IQ) combined with an adaptive functioning test (Williams 2013). Its drawback is that it assumes a continuum of
cognitive abilities that places ID on a spectrum, which according to Harris (2006) does not follow a clear bell curve. More generalised categories such as mild, moderate, severe and profound degrees of ID are better indicators as inconsistencies in cognitive profiles makes assessment and categorisation complicated (Harris 2006). The IQ method states that a profound learning disability is notionally associated with an IQ of below 50 and a moderate learning disability of between 50 and 69 (Williams, 2013). The reliability of the IQ test has been called into question as the philosophy of a fixed general intelligence excludes individuals from having a unique profile and a valuable personal skill set.

Epidemiology provides a basis for understanding the distribution and dynamics of health disease and disorder for people with an ID (Harris 2005, p. 89). This is the foundation of public health practice as it comprises statistics, accurate data and clearer definitions. As a science, epidemiology requires knowledge of demography, social sciences, environmental science and clinical sciences. It allows us to learn about the nature and scope of ID and its associated general medical, behavioural, emotional and psychiatric features. Its significance lies in the fact that plans can be put in place for health and PA interventions, where appropriate, and national and international health budgets can be calculated.

Many individuals with ID are prone to secondary conditions. There is an increased risk of physical, psychological, social and emotional problems referred to as secondary conditions (Rimmer, Chen and Hsieh 2011). For this reason, the WHO is investigating ways of delaying or preventing these conditions from interfering with quality of life in increased longevity for people with ID. Improving or maintaining health can prove challenging for people with ID. Cross-sectional studies have shown that there are between four and thirteen secondary conditions in existence across the physically and cognitively impaired (Rimmer, Chen and Hsieh 2011). Ambiguity surrounds what comprises a secondary condition. On the one hand, it is described in medical terms as a disease stemming directly from the primary disability. On the other hand, it is considered that the person has difficulties and barriers regarding access which refers to physical and mental health conditions only (Rimmer, Chen and Hsieh 2011). Secondary conditions exist as a result of primary conditions which must exist for a person to be
diagnosed with an ID. For all disabilities, intervention and prevention strategies include rehabilitation, health promotion, assistive technology and policy. On a micro level, secondary conditions affect the person with ID’s quality of life, community participation and employment opportunities. Broader societal impacts include exchequer health costs and health disparities for people with ID. Modifiable risk factors are especially relevant to the participants in this study who may be at personal risk of environmental factors. While these risks include such features as sedentary lifestyles and poor diet, others include poor health promotion, access and little social support (Rimmer, Chen and Hsieh 2011). There are areas that can be addressed successfully but it requires political and organisational change in attitudes and interventions for this to become a reality. ‘Responsible policy change means facing squarely the challenge of re-engineering deeply embedded systems to change how they function’ (Quinn 2005, p.8). Therefore, despite the vision and mission statements that contribute to the disability discourse of inclusion, participation, choice and equality, the discourse remains aspirational at best and patronising at worst. This research addresses this by examining whether adults with ID are facilitated with choice-making opportunities and whether they have the tools necessary to make choices. The legislative and policy context is therefore a very necessary part of the disability dialogue.

1.4.2 The Historical Context of Intellectual Disability
So far, this chapter has introduced the topic of this research, a phenomenological study of choice and PA among adults with an ID. It has charted the social landscape of ID in a contemporary setting from its definition to policy context. The following section looks at the evolution and recognition of ID through the disability models that shaped it.

Time, place and context provide an important background in tracing the journey of disability. The earliest reference to ID is contained in the Egyptian papyrus of Thebes in 1552 BC (Harris 2006). The first known programme of intervention was developed in France in 1799 by Dr. Jean-Marc Itard who developed a skill-based programme for a feral child called Victor (Harris 2006). Eduard Seguin further developed Itard’s methods adopting a systemic programme which emphasised physiological and moral education employing individualised instruction and behaviour management. Guggenbuhl subsequently pioneered the concept of residential facilities creating a prototype for
institutional care (Beirne-Smith et al. 2006). Several reformers emerged in the US from the early to mid-1800s including Dorthea Dix, Samuel Howe and Hervey Wilbur. They operated from the perspective that rehabilitation and training would reintegrate people with ID into the mainstream, a notion that was aspirational when they found that the condition of ID was 'incurable' (Beirne-Smith et al. 2006). This constitutes the first recorded contribution towards advocating for people with disabilities even if that focus meant personal adjustment as opposed to societal adjustment, a subject disability activists would later heavily criticise.

As the US population became more urbanised in the second half of the eighteenth century, people with ID were less able to adapt to new types of employment. Family members, who had been carers, became part of this new industrial age removing them from the home. Normalcy became less attainable and the systemic programmes of Dix and her ilk dissipated and led to even more residential institutions being utilised for the 'problem' of disability (Harris 2006). Similarly, capitalism had a pronounced adverse effect on people with ID who were largely regarded as unemployable and reliant and therefore excluded from economic life. An alarmist attitude towards people with ID and their family members ensued and ID was deemed heritable (Harris 2006).

In 1869 Francis Galton, a cousin of Charles Darwin, published *Hereditary Genius*. This publication established a theoretical basis for the heritability of ID and provided the foundation for the eugenics movement (Beirne-Smith et al. 2006). Eugenics promulgated that nature, not nurture determined personality and intellect intimating that reproduction ought to be managed in order to prevent the degeneration of the human species (Bachrach 2004). Economic costs of maintaining and sustaining people with ID was a major factor in promoting the eugenics cause and many US states enacted sterilisation, segregation and institutionalisation laws and principles as a result (Joseph 2005; Radford 1991; Reilly 1987). This practice of sterilisation persisted in Canada until the 1970s and in some states in America remained until the 1960s (Reilly 1987). In the 1930s and 1940s non-genetic factors such as metabolic disturbances or phenylketonuria and environmental factors, such as infection, were recognised as being associated with ID. This meant that people born with an ID were proportionate and not consigned to the lower classes as eugenics had suggested (Reilly 1987). The late 20th century saw the
birth of models of disability discussed in the next section which still of bear relevance today.

1.4.3 Models of Disability
Synonymous with disability are the models of disability that evolved which reflected the attitudes to disability that existed at the time. They are very much a part of the history of the disability story and include elements of, tragedy, medical, social and biopsychosocial models. For the purposes of this research the latter three will be are discussed.

1.4.3.1 The Medical Model of Disability
The medical or individual model of disability is inextricably interwoven into the earlier history of disability. By the late nineteenth century, this approach to disability was located in medical knowledge, a widely accepted phenomenon in Western industrialised societies (Barnes and Mercer 2010). The medical model focused on bodily 'abnormality' disorder and how this 'causes' functional limitation or 'disability' (Barnes & Mercer 2010). It relies on professional diagnosis, treatment and the measurement of recovery (Barnes and Mercer 2010). The medical model, according to Oliver is a type of reality divorced from the direct experience of disabled people (Oliver 2009). The medical model overrides the opinions of the person concerned leaving experts to dictate how people should live their lives by making decisions for them. Oliver (2009, p. 43) states that he does not ‘deny the influence, some positive, some negative, of medicine’, in the lives of disabled people, but that it does not offer a sufficient foundation for building a distinctive model of disability.

1.4.3.2 The Social Model of Disability
The social model of disability is relatively recent and its idealistic roots can be legitimately traced back to that period in history where civil rights activism, feminism and black rights movements of the 1960s became synonymous with rights-based organising/organisations of marginalised people. While the model in itself was not directly established until 1976, it is of note that increasingly segregated and intolerant minority groups inspired the disability movement to look within itself. The 1970s and 1980s were decades when disabled people were emerging from the shadows, so to speak, partly due to increased access to education and the opening up of new initiatives
specifically for and by disabled people (Shakespeare 2006). The publication of the *Fundamental Principles of Disability* by the Union of the Physically Impaired Against Segregation (UPIAS 1975) turned the understanding of disability completely on its head (Oliver 2009). It stated that it was not impairment that was the main cause of the social exclusion of disabled people but the way society responded to people with impairments (Oliver 2009). Oliver, who at the time was lecturing social workers and occupational therapists at Leeds University, wanted to incorporate into teaching the notion of ‘applying the idea that it was society and not people with impairments that should be the target for professional intervention and practice’ (Oliver 2009, p.43). This approach was introduced to a wider audience in 1982 at a conference on disability and advanced in *Social Work with Disabled People* in 1983 (Oliver 2009). Tied into this theory is the cultural meaning of disability, which the sociologist Erving Goffman and anthropologist, Robert Edgerton, made evident in their research in the 1960s (Ferguson and Nusbaum 2012). They used the social construct of stigma to explore the phenomenological and cultural experience of disability. In the 1970s and 1980s Irving Zola illustrated how the study of disability could usefully employ methods and concepts of the social sciences to place the personal experience of physical disability within a social context (Ferguson and Nusbaum 2012).

1.4.3.3 The Role of the Social Model in Intellectual Disability

The social model of disability challenges the economic and social inequalities experienced by people with disabilities which arose in response to the diagnostic medical model. While people with physical disabilities rejected the imposition of medical authority on their personal autonomy, this liberating message was not being advanced in favour of people with ID (Dimopalos 2010). At the time UPIAS and other groups were shaping ideas which in time emerged as the social model of disability, ‘normalisation principles still held sway in relation to issues of ID’ (Dimopalos 2010, p. 24).

Disability as originally defined by UPIAS clearly excluded ID by specifically mentioning physical disability,

*Disability is the disadvantage or restriction of activity caused by contemporary organisations which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities*
It was only after the social model gained firm popularity that ID came under its scope but in consideration of its inaccessible terminology and language, the relevance of the social model of disability to ID is questionable. Jan Walmsley, a researcher and disability advocate who promotes inclusiveness in learning disability questioned its relevance in 1997 (Dimopalos 2010). She maintained that the social model is a theoretical approach developed by physically disabled people with the unique problems they face. She added that it ‘remained unclear whether people with ID will ever be able to engage on equal terms as normalisation does not have all the answers’ (Walmsley cited in Dimopalos 2010, p. 24). She continues, ‘this is an area where oppression and exclusion take a distinct form for people with learning difficulties’ (Dimopalos 2010, p. 24). Physical disability challenges physical barriers while the barriers within ID are legal, according to Walmsley, so the quest is how to interpret it in order that persons with ID may be become active bearers of human rights (Dimopalos 2010).

1.4.3.4 A Critique of the Social Model of Disability
The social model of disability has come in for much criticism even within its own ranks. Jenny Morris has said that the social model ‘denies the pain of impairment’ (Morris 2001). Oliver says political campaigning for rights have forced disabled people back into the role of tragic victims of their impairments setting it back more than 30 years (Oliver 2002). What it expresses for people with ID is questionable of their representation and understanding of what the social model implies. Authors with learning disabilities expressed their views on the social model of disability in The Disability Studies Reader (2010). In it, they say that it is not accessible as a model to ‘learning disabled’ people and point out that ‘we might want to study the social model ourselves but we can’t because it isn’t accessible’ and add that ‘it should be in pictures and large print’ (Docherty et al. 2010, p. 434). This contribution is also critical of the hierarchal nature of disability, the top echelon regarded as physical and sensory impairment while ‘we come with mental health right at the bottom, so we’re like the doormat of disability’ (Docherty et al. 2010, p. 438).
Both the medical and social models linger in the background of the disability discourse but periodically come to the forefront. Medical advancement and intervention enables individuals to gain longer life expectancy which is welcomed. Other interventions such as providing cosmetic surgery for people with Down Syndrome 'seem more designed to normalise' rather than tackle the underlying societal attitudes towards true inclusion (Shakespeare 2006). Similarly, pre-natal screening and the bio ethics of medical science questions whether society has made any significant move away from the notion of eugenics which promotes 'fixing', thus reviving the medical model. ‘In many ways, disability continues, by definition, to be a lesser state of being that justifies paternalism at best and extermination at worst’ (Ferguson and Nusbaum 2012, p. 73). Walmsley expresses this view with echoes of Jenny Morris in a more temperate manner when she questions whether people with ID even armed with time, technology and teaching can learn skills enabling them to represent themselves on equal terms,

_The dice are loaded against such a development, not just because of poor opportunities for learning, not just because we lack resources or have the wrong attitudes, but because it is ultimately a normalising agenda we are working to, an agenda which maintains that to take part in society on equal terms people with learning difficulties must heroically rise above the impairment and join in a conspiracy to deny that their intellectual limitations matter._

(Walmsley 1997, p. 73)

This highlights the inadequacies of the social model of disability in relation to its relevance and accessibility to people with ID. Significantly, people with ID have expressed their views on it as well as disability advocates and authors. The following and final model, for the purpose of this research, appears to be one of the more applicable models for people with ID.

1.4.3.5 The Bio-psychosocial Model
A new conceptual framework emerged in the mid-1980s, created to describe and facilitate a more holistic understanding of the experience of disability (Guscia et al. 2006). Rather than focusing on individual deficits as the chief determinant of disability, the new paradigm locates the experience of disability within a broader category where aspects of the social, physical and attitudinal environments are of equal importance (WHO 2011). This model materialised as a result of two events. In 1980 the WHO released the International Classification of Impairments, Disabilities, and Handicaps
(ICIDH) and in 1981, the International Year of the Disabled Person, facilitated calls for the universal rights of people with disabilities (Guscia et al. 2006). Both these events challenged the medical model which represented the phenomenon of disability. While the ICIDH attempted to capture the social element in the classification system its major weakness was that it continued to express impairments as factors that lead to disabilities by using the word handicap in its text. Due to criticism the ICIDH became the International Classification of Functioning, Disability and Health (WHO 2001). It was the first internationally recognised classification system to fully embrace both the social and medical models of disability in what is now known as the Biopsychosocial model. The model uses a holistic approach to the person by incorporating the biological, psychological and social elements of their being. The classification structure of the ICF is divided into two parts: Part 1 is the physiological and Part 2 is the environmental or contextual factors that frame disability. The types of services and policy are dependent on the model of disability that is being adhered to.

1.4.4 Legislative Context of Intellectual Disability
Persons with ID became explicitly recognised under International Law when the UN General assembly adopted the Declaration on the Rights of Mentally Retarded Persons 1971 and the Declaration on the rights of Disabled Persons 1975. The World Programme of Action Concerning Disabled Persons (WPA) was adopted by the UN in 1981 with the goal of creating equalisation opportunities for people with disabilities and is regarded as an antecedent of the UNCRPD (UNCRPD 2006). The creation of the UNCRPD reframed the needs and concerns of persons with disabilities into a human rights context existing ‘to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities while promoting respect for their inherent dignity’ (UN Convention 2006, Article 1). The Committee on the Rights of Persons with Disabilities (UNCRPD) consists of a body of independent experts who monitor implementation of the convention by the State Parties, Ireland being one of those States (UN Convention 2006). Though Ireland has signed up to the UNCRPD, it has not ratified the convention. It is a universally legally binding set of standards ensuring the rights of persons with disabilities are guaranteed everywhere (UN Convention 2006). It marks a shift in how society regards disability moving away from a social welfare concern to a human rights issue, while acknowledging that societal barriers and
prejudices are in themselves disabling (UN Convention 2006). The following three articles under the Convention of the Rights of People with Disabilities (UNCRPD) are directly related to this research insofar as they necessitate informed consent, are concerned with the health of people with ID and stipulate the right to equal access to leisure and sport for these purposes. Thus, Articles 12, 25 and 30 are concisely described below along with the reasons for their importance.

**Article 12** - The Assisted Decision-Making (Capacity) Act 2015 was signed into law under Article 12 of the UNCRPD. It provides a statutory framework for individuals to make legally-binding agreements to be assisted and supported in making decisions about their welfare and their property and affairs (Relate 2016). It moves away from the best interest’s approach towards the will and preferences model. This resonates with this research where people are being asked about the choices they make and the opportunities to do so along with their capabilities with regard to PA.

**Article 25** – Is concerned with health under the UNCRPD insofar as it promotes the right to the enjoyment of the highest attainable standard of health without discrimination (UNCRPD 2006). This research is concerned with the health and health disparities that exist for people with ID. People with mild ID in developed countries are reported to have a life expectancy close to that of the general population with the National Intellectual Disability Database documenting a sixty per cent growth from 1996 to 2010 in those over 55 years of age (McCallion and McCarron 2015). However, people with ID enter the ageing process earlier due to poverty in childhood and tend to lead unhealthy and sedentary lifestyles in comparison to the general population (McCallion and McCarron 2015, p. 220).

**Article 30** – Is concerned with access to participation in cultural life, recreation, leisure and sport for people with ID. The section of article 30 that has most relevance for this research is the section regarding the provision of the opportunity to participate on an equal basis as the general population.
1.4.5 Policy Context

A Social Portrait of Disability in Ireland published in 2011 indicates that between 16.8 per cent and 20.4 percent of the population have a long-term disability which equates to one in five/six people. Seventy thousand people approximately experience an intellectual and learning disability (Department of Social Protection 2011, p. 8). In Ireland, there are specialist services and supports funded by the Health Service Executive (HSE) for people with disabilities. In the case of ID, this is managed by the Social Care directorate (NDA, 2016). The National Disability Authority (NDA) conducts research into disability services and informs relevant parties on policy advice and the development of standards as they unfold. In the past number of years’ key policy developments directly leading to New Directions 2012-2016 (HSE 2012) include Value for Money and a Review of Services 2009-2011 (NDA 2016). Other organisations and bodies that work in the area of disability also exist. The National Federation of Voluntary Bodies (NFVB 2016) is an umbrella organisation for voluntary/non-statutory agencies providing direct services to 22,000 people with ID and their families. They employ 15,500 people in a wide range of roles and account for 85% of Ireland’s direct service provision to people with ID to this population (National Federation of Voluntary Bodies 2016). In their 2009 Discussion Paper, Exploring Disability Entering The 21st century, they raised issues of self-determination, meaningful and freely chosen friendships, inclusion, equity, mainstreaming, models of service and equal citizenship for people with ID (NFVB 2016). At the time long-awaited Assisted Decision Making Act had not been passed and was not done so until December 2015. Similarly, with the increasing move from segregated to community settings, policy was required to smoothen and enable the transition. Consequently, New Directions 2012-2016 (HSE 2012) came about under what was then New Steps because the majority of day services are segregated from mainstream community (Inclusion Ireland 2016).

1.4.5.1 Standards for Day Services

Day services for adults with ID are a network of support for over 18,000 people (Inclusion Ireland 2016). These adults have a wide range of abilities and ages, live in small communities, are often isolated in both rural and urban metropolitan areas. Day services for adults with ID have been unregulated and New Directions 2012-2016 proposes an approach to services that are person centred, feature community, inclusion
and aspire to active citizenship (HSE 2012). Person-centeredness is a key message of the previous policy *Value for Money* and *Policy Review of Disability Services* (Department of Health, 2012) migrating an approach that has been chiefly focused on group-based delivery towards the person-centred model. The policy review referred to was an evaluation of the efficiency and effectiveness of the HSE-funded statutory and non-statutory disability services in Ireland. The vision is to embed the individual in their natural support system and wider community (Department of Health 2012). This requires existing supports in the community but for now it appears that the service user will be heavily reliant on disability services until wider community supports become available. This is evident in this research where the transition to community for one group has meant a geographical transfer from a congregated setting to premises in the community. What *New Directions 2012-2016* as a policy hopes to achieve is considered under the next section.

1.4.5.2 *New Directions 2012-2016*
The growth of community living amongst people with an ID and the resultant demand for and reliance on adult day care services has prompted the policy of *New Directions 2012-2016*. The HSE reviewed funded adult day services in August 2007 in order to reconfigure and modernise day services for adults with ID while adhering to the principles of person-centeredness, access, accountability and quality (HSE 2015). The ethos behind *New Directions 2012-2016* incorporates ‘having choices, doing interesting and useful things with one’s time, learning new skills, meeting people and enjoying their company’ (HSE 2012, Foreword). While these are ordinary everyday experiences for most people, this report acknowledges the need to change direction in line with these principles for people with ID. It calls for a blurring of the boundaries between special and mainstream services (HSE 2012). *New Directions 2012-2016*, sets out six core recommendations. They include change management, turning policy into action, increasing person-centeredness, clarification of HSE role in work/employment, planning, monitoring and quality assurance and aligning funding. As a means of assessing whether a service is measuring up to the core values of New Directions, change management acts as a benchmarking tool to assist in this task. Seventy-five service providers adhere to this policy and have completed this benchmarking tool and results of these findings are to be published in 2016 (New Directions Bulletin 2015) which are not yet available. The vision is that *New Directions 2012-2016* will be a catalyst for community inclusion and self-determination for adults with ID and furthermore services will be provided with supports to achieve the stated objectives as outlined in *New*
Directions 2012-2016 and Value for Money Reports (HSE 2012, p.3). This approach is arguably more pragmatic in terms of actively and meaningfully including adults with ID in the community. These plans satisfy Article 30 of the UNCRPD which encourages and promotes participation of persons with ID in cultural, sporting, recreational and leisure activities (CRPD 1989). Personal Care Plans (PCPs) will feature heavily as a means of accessing relevant services in the community to achieve the goals set out.

1.4.5.3 Personal Care Plans (PCPs)

Personal Care Plans are the mechanics of how the service system works and are a requirement under the Health Information and Quality Authority (HIQA) standards (HSE 2012). A PCP constitutes a record of every possible detail about an individual attending a disability service, such as the one in this research, with a view to assessing their needs and making plans to fulfil their identified goals. Its format consists of a section on personal details such as age, name, and gender. This is followed by a section on the person’s goals and identifiable preferences. Goal setting involves the individual’s chosen activities and objectives and how they might realistically achieve them. This requires the formulation of a plan which is to be reviewed periodically in order to check on both progress and/or lack of progress. A section on the individual’s health and care is addressed alongside a risk assessment which determines the individual’s boundaries with regard to safety and welfare. Personal Care Plans are generally attended by a multidisciplinary team which consists of the individual concerned, their key worker, doctor, social worker, psychologist and speech and language therapist where applicable. It is unknown whether the attendance of a large range of professional personnel inhibits the individual from expressing their choices and opinions. This is wholly dependent on the individual’s personality and how comfortable they feel in group situations and around professionals. While the PCP is individualised and tailored this overly professional setting might not be conducive to a vulnerable person’s freedom of expression.

1.5 The Researcher

According to Harvey (2013), research is a two-way street insofar as researchers should acknowledge the impact they have on research while being aware of how their identities can be influenced by the process of carrying out research (Harvey 2013). Throughout my research I have included my own thoughts and experiences as this is one of the
requirements of a researcher when conducting research using IPA. These experiences come from both my professional life as an instructor in disability services and as a social worker. On a personal level, experiences of ID among family has encouraged me to be more reflective on how I view policy, practice and question my own value system.

Berger (2013) regards researcher reflexivity as impacting significantly on the experience and characteristics of research. He argues that it is a major strategy for quality control in qualitative research and understanding. There are three areas of reflexivity according to him; firstly, when the researcher shares the experience of study participants; secondly when the researcher moves from being an outsider to an insider in the course of the study; thirdly when the researcher has no personal experience of familiarity with what is being studied. I would argue that there are elements of all three during the entire process. In the first instance I would have shared the phenomenon of choice as being a complex and complicated phenomenon not unlike the experience of the participants. Secondly, during the process of immersion in the research site and with the participants, I moved from outsider to insider by forming a rapport, sharing information and sharing experiences with the participants. In the third instance I would agree that I did not have an in-depth knowledge of PA which while it didn’t detract from the experience necessitated my familiarisation with the subject. In consideration of the fact that there is an explicit recognition of the interpretative role of the researcher in IPA, the fact that this is chosen by the researcher as a method of data analysis implies “a tacit acceptance of this role” (Brocki and Wearden 2006, p. 98). The analysis is not inductive, i.e. not characterised by the inference of general laws thus bringing other perspectives to the analysis. This, combined with reflexivity, gave me the opportunity to move away from accepted beliefs I had on areas such as choice and become more open to considering other perspectives.

Equally important to this research is UNESCO, an acronym for the United Nations Educational, Scientific and Cultural Organisation. It was created over 50 years ago and developed UNITWIN/UNESCO Chairs Programme in 1992 to promote international inter-university cooperation and networking for the purpose of enhancing institutional capacities through knowledge sharing and collaborative work (UNITWIN/UNESCO, 2009). In 2013 the IT, Tralee became the first third level institution in the world to
receive a UNESCO Chair in Inclusive Physical Education, Sport, Fitness and Recreation. Its commitment is to “transform the lives of people with disabilities, their families and communities through enabling their inclusion in physical education, sport, recreation and fitness” (UNESCO, 2013, p. 1).

1.6 Dissertation Structure and Conclusion

Chapter One introduces the research, explains the rationale and outlines its aims and objectives. It sets the research in context from a participant, historical, legislative, policy and researcher perspective. This encompasses such topics as the definition of ID, its evolution through the models of disability and how policy has developed up to the present day and particularly in relation to adults with ID who attend a day service. It also describes the positionality of the researcher which further contextualises it. Chapter Two comprises the literature review. This chapter is extensive and examines where people with ID are positioned in disability research, considers the philosophy of choice and whether people with ID are facilitated and supported in this domain. It covers the substantial area of physical activity among people with ID and its associated facilitators and barriers. Chapter Three begins by looking at and defining qualitative methodologies and goes on to discuss and justify why interpretative phenomenological analysis (IPA) is chosen for the core participants in this research. Chapter Four presents the findings of the experiences of the core participants with regard to physical activity and choice. Chapter Five discusses the contribution this research makes to service and policy in light of existing literature revisiting Chapters Two and Four to support this. Chapter Six concludes with the implications this research has for practice and policy. It deliberates on its limitations and makes recommendations for research, service and policy going forward.
Chapter Two – Literature Review

Above all people have a deep rooted desire to belong, to be in a relationship, to live within the intimacy and security of their family and friends, to be included in the greater life around them with all its attendant possibilities for hope and fulfilment and to do so, to the greatest extent possible, on their own terms. The implications of this simple truth will determine our actions on behalf of all citizens with Intellectual Disabilities.

(National Federation of Voluntary Bodies 2009, p.3)

2.1 Introduction

The purpose of a literature review is to find out what already exists around a research topic. It also reviews methods applied in previous studies and decides which methodology is most appropriate to this research. In essence, it tells a story about how a research topic has emerged (Potter 2006). The theme of this research is to ask people with Intellectual Disabilities (ID) what physical activity (PA) means to them and how they choose or are facilitated in their choice of PA. An important facet of this research is that it involves people with ID in research firstly, and secondly it involves them in an area of research that directly impacts on their lives. Therefore, the research is interpretative in nature which means that it is designed to gain an insight of people’s understandings, thoughts and opinions on a given topic. While this research began as a broader concern around increasing longevity amongst people with ID, their quality of life and the health issues they are particularly prone to, the topic remains faithful to that concept. According to the World Health Organisation (WHO 2008) increased longevity amongst an already growing aging population, due to improved care of acute illness, is not necessarily associated with a longer period of good health or quality of life. They argue that this phenomenon could be as easily associated with illness, disability and dependency. This trend is mirrored in the particular context of adults with intellectual disability (Dixon-Ibarra et al. 2013). Greater physical activity for people with ID has been shown to improve cardiovascular health, decrease anxiety levels and positively impact on psychosocial outcomes (Moss 2009; Carmeli et al. 2009; Lante et al. 2011). This research aims to uncover the psychosocial benefits that promote wellbeing, inclusivity, new opportunities and social acceptance through PA and choice for adults with ID. To
capture this information interpretative phenomenological analysis (IPA) is the chosen methodology as it is concerned with the lived experience.

Research also has a role to play in gauging, assessing and measuring the current state of disability services and policy and whether they are being applied? The previous chapter has looked at ID from an historical and policy perspective. It examines whether people with ID are directly involved in decisions that affect their lives and examines the barriers and facilitators that might impede them from making choices or engaging in PA. Choice is considered under themes that matter to people with ID. These include friendships, the role of family and staff, social connectedness, cost and access. A notable feature of the context of this research is the current ongoing transition for people with ID from congregated to community settings and consequently this research also touches on that subject. More importantly, however, this research is interested in finding out what the participants think about their health, PA and choice. As it moves towards the philosophy of choice it explores the role of self-determination, for people who are unused to making choices, and the antecedents required to facilitate choice fully. This chapter concludes with a recap of its aims and objectives while signposting the chosen methodology which follows in Chapter Three.

2.2 Literature Sources
This chapter reviewed current literature around disability and was researched using the IT Tralee library both on and offline as its chief source. Literature used generally did not predate 2000 in order to keep the information current. The geographical spread of literature included Ireland, U.K, United States, Australia, The Netherlands, Canada and Scandinavia. A guide to how the literature was accessed and the most common websites are included in Appendix A.

2.3 Who is Included in Disability Studies?
'Twenty years ago there was no such thing as disability studies', (Barton and Oliver 1997, p.1). Prior to this, in the 1960s, sociologist Erving Goffman and anthropologist, Roger Edgerton, were using the social construct of stigma to explore the phenomenological and cultural experience of disability (Ferguson and Nusbaum 2012). At Syracuse University, Burton Blatt recruited social scientists and policy analysts to expose
institutional abuse of people with ID through scholarly rigor. Subsequently, four sociologists were instrumental in forming an organisation named the Society for Disability Studies (SDS) in 1986. Walmsley (1997, cited in Barton and Oliver 1997, p. 63) states that in 1984 only five British studies in the previous twenty years involved people with ID as “informants in research projects”. Walmsley argues, that this may now amount to thousands of studies, the situation remains that people with ID are “uniquely reliant on human intermediaries to gain access to the sort of complex ideas represented by academic and political debate” (1997, cited in Barton and Oliver 1997, p. 74). This is a valid reason for affording people with ID the opportunity to voice opinions and become part of the research process with regard to research that impacts on their lives. This has led to the whole notion of inclusive research as opposed to ‘research’ in the disability discourse.

Inclusive research is defined as “a range of research approaches that have traditionally been termed participatory, action or emancipatory” (Walmsley and Johnson, 2003, p. 10). The type of inclusive research chosen is dependent on what level of involvement is required in the research process or what the vision of the research is. Oliver maintains that research “must be located in the social model” meaning that both the disability and the disabled person must be “properly recognised” in social research studies which may include family, employment, sexuality, education’ (1990, cited in Barnes & Mercer 1997, p.5). The idea of inclusion in Australian research in ID is embedded as a principle in that country’s agenda as set out in Disability Policy & Research Working Group 2011 (Department of Human Services 2012). Emancipatory research in disability presents a radical alternative to mainstream research theory and methods suggesting that disability research “is about changing the world and not just describing it” (Barnes and Mercer 1997, p.5). This is relevant to this research topic which aims to present findings in an Easyread format for the core participants at a later date. Otherwise, research emerging from disability studies cannot have any special relevance to improving the lives of individuals with ID and their families. Atkinson and Walmsley (2010, p. 282), argue that in response to the challenge of “Nothing About Us, Without Us” position oral and biographical accounts should be included in order to augment histories told through official sources. They conclude that researchers alone should not be the only
contributors to research in ID. They promote the idea of creating an inclusive history of individual and shared stories contributed by the historian and insider perspective, rather than producing a grand narrative of intellectual disability. Pfeiffer (2003) contends that there has never been and nor is there now a statement of the disability perspective in disability studies which he believes excludes them from the disability discourse. Bigby, Frawley and Ramcharan (2014, p.3) support involvement from people with ID in research asserting that there are assumed benefits ‘that flow from their participation’.

According to Nind (2011), for the researcher, there is little conceptual clarity regarding the nature of inclusive research to guide them or judge the fidelity, impact, feasibility and rigour of the research. An Australian review on theoretical transparency accepts that while research funding requires the inclusion of people with disability, this alone does not provide the conceptual clarity required to understand and practice inclusion in research or how to judge its reliability (Bigby, Frawley and Ramcharan 2014). It concludes that there is more than one way to carry out inclusive research in ID. People with ID can inform the research, lead and control it, researcher and participant can work together in roles that suit their individual interests and skills. It is evident that research in ID is still in flux and that there is a tension between separating ID research from other research. Research in ID tends towards a grand narrative because the very people it is about have historically been excluded from it. It is only by loosening restrictive practices, such as relaxing ethical processes for consenting adults and allowing the researcher and researched to negotiate the process that this can change.

2.3.1 Listening to Service Users

Being supported to live one’s life on one’s terms is a very encouraging policy vision entailing risk and commitment to realise it. Yet, The Quality of Life of People with Disabilities in Ireland (2007), Outcomes for People Project, the National Intellectual Disability Database, the National Federation Research Strategy 2008 all point to the evidence that what many people with ID want in their lives is not addressed in today’s service models and supports. This is an indicator of the limited choice available to adults with ID on the one hand and on the other it points to the fact that people are, at least, being asked their opinions. Asking people their opinion is one of the requirements for
creating antecedents of choice within the disability discourse. Choice can be fostered and assessed through assessment of practice and satisfaction, e.g. asking people to rate their service as customers. Unfortunately, and too often these questions are asked after an ‘event’ in an organisation rather than as a matter of course as with any other consumer service. In support of this and following the broadcast of the RTÉ Prime investigation *Inside Bungalow 3* on the 9th December 2014, the HSE commissioned an independent review on the quality of care in particular care homes (HSE 2016). Ostensibly, the review intended to put safeguards in place to eliminate risk, a separate report on a self-advocacy focus group entitled *Start listening to us* brought up how some residents felt about being excluded from areas that directly affect their lives. It asked questions regarding what needed to be changed in order to make life better referring to law, policy, leaders, services, the culture of services and generally what would help people with ID to live well (HSE 2012). Residents when asked were forthcoming and contributed positively to aspects of practice that could be improved. Areas highlighted included personal autonomy and some of the contributions were very disturbing. For example, one person had never experienced control over their own money or how they chose to spend it stating, “I never bought anything for anybody in my life” (HSE 2016, p. 20). These are the questions that need to be asked as they are in this research which examines the level of independence and choice people with regard to choice and PA.

2.4 The Philosophy of Choice

This section deals specifically with choice, choice-making and how it is practiced among adults with ID. It includes the model of self-determination and antecedents of choice-making with referring to studies and theories on the experience of choice and choice-making for this group the participants in this research.

2.4.1 Changing Terminology in the Intellectual Disability Discourse: ‘Choice’

Periodically, emphasis in the disability discourse changes direction in relation to vision, terminology and policy. For some time ‘inclusion’ was the catchall for working towards fairness and equity in this discourse. Inclusion is an ongoing ambition and choice has now been added to the vision for disability services practice and policy. Choice is

perhaps seen to be a prerequisite for community transition and should logically precede inclusion. This research includes choice as an element of deciding on PA. How then choice is defined and is it defined differently depending on who is offering or making those choices? Choice is an integral part of the human rights agenda and is becoming common parlance in ID. Fyson and Cromby (2013) argue that choice is denying people with ID effective delivery of social care services. They argue that through the lens of the neo-liberal agenda increased choice is handing over responsibilities to vulnerable people who cannot make choices because there is a disconnect between the choice discourse and reality. The change in terminology becomes a distraction from the real issues in ID which while benefitting the politics of the day, detract from the real issues of instigating good policy for people with ID.

Under the Universal Declaration of Human Rights (UDHR), "All human beings are born free and equal in dignity and right. They are endowed with reason and conscience" (UN 1948). This social construction of rights, they argue, specifies a particular understanding of personhood which creates difficulties in relation to the human right of people with ID. Fyson and Cromby (2013) reason that human rights cannot be made effective until more inclusive concepts of personhood are adopted, for example, through employment and participation in society. Consequently, they add, there are tensions within law and welfare service flowing from the disjuncture between the kinds of persons that people with ID are actually able to be and the individual capacities of reason and conscience that talk of rights presumes (Fyson and Cromby 2013). This does not imply that people with ID are in any way less than people without ID. Neither does it say that every person is independent and free to make any choice they want to make because that is not true either. "Rather we are all fundamentally both relational and interdependent and this conceptualisation should be the starting point of the human condition" (Fyson and Cromby 2013, p. 1165). In contrast, it could be argued that choice is a Western philosophy and the constructed notion of personhood under the UNCRPD is based on personal autonomy (Young and Quibell 2000). Therefore, while there must be a realisation that choice-making might have to be monitored for the sake of safety, it is also a right to make choices good or bad, like the rest of the population.
2.4.2 Antecedents to Choice-making
The antecedents to making choice meaningful comprise of a set of elements. There must be an understanding of the full range of options available, a realisation of the personal consequences of making a certain choice, both immediately and in the longer term, and knowing that some choices can be reversed without causing permanent damage (Fyson and Cromby 2013, p. 1167). This is compromised for people with ID because they are more unlikely to meet these preconditions (Fyson and Cromby 2013, p. 1167). Being unused to practicing choice making may cause fearfulness and the availability of too much choice can appear overwhelming. Schwartz (2004) argues that too much choice is bad because in the general population it creates a fear of making the wrong decision. This is no less relevant or applicable for people with ID. Similarly, over-protectiveness inhibits choice making which denies people with ID the right to make choices.

2.4.2.1 Permissive versus Protective Rights
Arguably, the human rights discourse can delimit other rights some of which are protective and some of which are permissive. Permissive rights allow us to do and live in certain ways and to be free of certain restrictions. Protective rights involve the right to be protected from certain unwanted actions of others (Fyson and Cromby 2013). It also means that they act as a protection against the individual who might make a bad decision regarding their welfare but who has somebody to oversee that choice. An example in this research might be the person who does not want to engage in a particular PA i.e. walking whereas staffs believe that it would benefit the person’s wellbeing. The question is whether this constitutes a denial of permissive rights by imposing a protective right based on the individual capacity of reason and conscience, as outlined above. Extensions of permissive versus protective rights, which come under the umbrella of the social model of disability, are also evident in the medical model in the delivery of healthcare.

2.4.2.2 Logic of Care versus Logic of Choice
For those professionals, such as staff and key workers, there are another set of realities when working and caring for people with ID. It is an area often fraught with ambiguity where the organisational vision to promote individuality and choice may become
thwarted by staff responsibility for the day to day care of the safety and care of their clients.

According to Mol (2008) logic of care is about life with a disease, inclusive of all aspects of daily life which involves a range of people, i.e. the patient, family and professionals. Choice, which is framed in policy, suggests that patients are given options to choose a way of treating their illness. While it emphasises the right to choose, in her view the patient is held to account if they make an 'incorrect' decision. Should the power to make such decisions, or the right to choose, be taken away from the patient if it means safeguarding them against blame? Similarly, doing nothing, she adds, is the equivalent to not making a choice. The model of choice in this setting highlights the ambiguity and confusion surrounding the concept of choice. On the one hand, it is promoted as a right and entitlement and on the other it is recommended with stipulations attached, i.e. the imperative to make 'good choices'. With this in mind, choice must appear narrow and limited to people with ID considering they are protected against making what are regarded as 'bad choices'. Yet, in the process of allowing people to become self-determined, bad decisions and bad choices must be made in order to recognise the consequences and implications of making choices, good or bad. While there are health and safety concerns around vulnerable people, they simply do not get to make choices so readily available to the wider population.

Schelly (2008) provides an empirical example of this in an account of a year working with a man with mild/moderate ID. The man consistently made choices that were in opposition to his own self-interest. He would opt to spend his days indoors watching TV and drinking soda given 'free choice' though it made him unhappy. His key worker intervened against these expressed choices by actively promoting alternatives. Better outcomes were achieved and Schelly concluded that some people with ID "cannot think in the ways necessary to make choices that would improve (their) quality of life" (Schelly 2008, p.719). The methodology constituted a reflexive narrative recorded by the care worker underpinning Bourdieu's philosophy of improving the practice of theory rather than the theory of practice. Arguably, the study could have been given further depth if the voice of the person with ID had been included. While better outcomes were
achieved by providing alternatives it would have been interesting to discover what the individual felt about these and why he chose to follow them.

2.4.3 The Self-Determination Model
Other schools of thought believe the self-determination model is effective in teaching people how to make choices. In the disability discourse, self-determination is concerned with promoting skills that increase autonomy and making life choices. This is becoming more relevant as the move from institutional to community settings accelerates. Wehmeyer and Bolding (2001, p. 371) highlight the desired direction of adult day services for people with ID being steered towards ‘increased consumer control’ in an era where ‘the self-determination construct has received increased international visibility and utilisation in the field of ID’. They add that an important component in ensuring success in self-determination for people with ID is the environment. Wehmeyer and Bolding (2001) measured self-determination among adults with ID before and after a move from a more restrictive to a more open community-based setting. They found that the environment impacts greatly on how self-determinate people are. Their findings suggest that people with ID are less autonomous in more restrictive settings whereas community-based and normalised settings enhance self-determination amongst these individuals. Their study resonates with this current research where a move from a congregated setting into the community, in accordance with New Directions (2012-2016), is ongoing. While the aim of this research, unlike Wehmeyer and Bolding (2001), is not to evaluate the incidence of increased choice-making in this transition, it is relevant insofar as policy is concerned with the self-determination of people with ID and an awareness of all aspects of how this can be achieved and applied is significant.

A definitive description of Self-Determination Theory (SDT) is used by Farrell et al. (2004) to understand sport motivation in their study on the driving force and motivation in Special Olympians. This definition borrowed from Deci and Ryan, (1985, 1991 and 2000) defines it thus,

‘Motivation is self-determined when individuals perceive their behaviour to be autonomously controlled and relatively free from external constraints’ (Farrell et al. 2004, p. 154).
Their definition further suggests that SDT has a continuum of seven types of motivation of which individuals with ID can meaningfully identify and meaningfully differentiate with four. For the purpose of this research population, these four types include, amotivation (the absence of motivation), external regulation (rewards or sanctions for performing an activity), identified regulation (performing an activity because it is meaningful to the individual), and intrinsic motivation (performing an activity because it is perceived to be both important and pleasure is derived from it (Farrell et al. 2004). Additionally, motivation is promoted in social contexts that serve to support an individual’s sense of competence, autonomy and relatedness. The findings in their study based on SDT, supported the prediction that motivation and self-determination were fostered by environments that fulfilled needs for autonomy, competency and relatedness. Elements of support included coaching, choice and feedback, challenges, meeting friends, mentoring others and building relationships.

Much research has been carried out on self-determination in ID and all have found that it is linked to better quality of life when certain determinants are present (Nota et al. 2006). Stancliffe and Abery (1997, cited in Nota et al. 2006) did a comparison study on individuals with ID who moved from institutional care to community settings as opposed to those who remained in institutional care. This was a three year longitudinal and observational study based on the characteristics of two groups. It found that those who moved to community had significantly more opportunities. Significantly, it also revealed that the absolute level of choice-making available to both groups was very low. Duvdevany et al. (2002, cited in Nota et al., 2006) found opportunities to make choices significantly higher for people with ID who lived in family homes as opposed to those who lived in group homes. Duvdevany’s study was on lifestyle satisfaction of eighty adults with mild to moderate ID living in group homes or with their family. They were assessed through the choices they made in the domestic, financial, health, social and work domains but it is noteworthy that their opinions were not asked. Data relating to what makes some participants more self-determined than others is also limited.

Characteristics, or intraindividual factors, include intelligence level, age, gender and adaptive behaviour. The most significant and unintended finding was that older people were more likely to belong to a higher autonomy group (Wehmeyer and Garner, 2003).
This study examined the self-determination and autonomous functioning of 301 adults with ID and IDD. This is a noted point of interest for this research insofar as it assesses the level of choice among adults with ID in regard to how they select PA and whether in fact they make these choices or whether these choices are made for them. The study conducted by Nota et al. (2006) examined the relationship between personal characteristics, as noted, self-determination, social abilities and the daily living status of people with ID alongside Quality of Life (QoL). Participants in the research lived in residential, semi-residential (day centres) and assisted group housing. It involved 141 participants and used the Evaluation of Self-Determination Instrument to measure their findings (Nota et al, 2007). The setting was largely congregated and relatively isolated from the surrounding community (Nota et al. 2006). It found that those who lived in assisted group housing had higher self-determination, especially in expressing their emotions and opinions than those living in institutions, also attending day services. It concludes that higher autonomy leads to higher incidences of self-determination.

The self-determination model is a lifelong developmental process that intends:

"to act as the primary causal agent in one’s life, making choices and decisions regarding one’s quality of life free from undue external influence or interference" (Wehmeyer and Sands 1996, p.24).

For self-determination to be realisable it must satisfy the following four characteristics: autonomy, self-regulated behaviour, initiating behaviour in a psychologically empowered manner and being self-realising (Wehmeyer and Sands 1996). Autonomy implies making decisions on one’s own behalf without coercion. Self-regulated behaviour recommends that people evaluate their environment and respond appropriately to it. Psychological empowerment is the belief in personal control over matters that are important to the person and acquiring the skills to reach the desired outcomes. Self-realisation requires the person to know themselves sufficiently to reach their desired outcomes. The cycle of self-determination, involves individuals making a choice, acting on that choice, experiencing the results and then making new choices (Agran, Storey and Krupp 2010). It is a cyclical pattern of learning often denied to people with ID mainly due to overzealous gate-keeping and lack of time and training amongst staff.
The advancement of choice-making has become a significant component of disability services (Fyson and Cromby 2013). While literature indicates that people can be taught to make choices, the type of choices individuals make and how they are supported in doing so remains unclear (Agran, Storey and Krupp 2010). Traditionally, research has addressed questions regarding choice about people with ID to caregivers and staff rather than the people directly involved. According to Agran, Storey and Krupp (2010), choice making is recognised as being an adaptive skill and the more individuals experience active meaningful choice, the better their understanding of how to achieve self-selected goals. Being supported by staff in making choices is demonstrated in a study where employees with ID worked in a competitive, supported and sheltered employment program where their choices were taken seriously. It established that, apart from learning the skills of how to make a choice, organisational supports were also needed to realise meaningful choice (Agran, Storey and Krupp 2010). For this research, staff and key workers have an important, but not overarching, role to play as a necessary support for the client in facilitating choice and helping to process it. In Agrans, Storey and Krupp’s (2010) study, the individuals concerned were asked about their choice-making opportunities through surveys and whether their choices were supported and important. New Directions 2012-2016 (HSE 2012) recognises the importance of choice but its implementation is only feasible with support and knowledge. Outside of support from the key worker, the client also needs community supports to make effective and meaningful decisions. Similarly, when people with ID choose activities outside of dedicated services, supports are needed in the community to facilitate this.

2.4.3.1 A working model of Self-Determination in a Leisure Setting
In a phenomenological case study centred on two care homes consisting of all female residents with ID approaching retirement, self-determination was explored in the context of meaning and practice. Methodology included participant observation, artefacts and semi structured interviews carried out through the lens of self-determination. Five staff members were interviewed and one home facilitated self-determined leisure while the other did not, but all of the women experienced leisure with family, friends and the community. In the more successful sample, the women were the focal point of the home and the activities of staff, based on teaching skills, required people to be independent, spontaneous and self-selecting (Rossow-Kimball
and Goodwin 2009). According to Parker (1981, cited in Rossow Kimball and Goodwin, 2009) personal choice, decision making, autonomy and spontaneity are the tenets of leisure. Strategies that supported self-determination included: encouragement of choice; setting goals for autonomous leisure; commitment of staff members to independent leisure; determining individual preferences; creating opportunities to act on choices; and educating staff on self-determined behaviour. This resonates with Personal Care Plans (PCPs) that participants in this research are required to have as part of their care and goal setting strategies.

By contrast, the experiences in the other home differed for as many reasons. They included, staff underestimating ability of clients, perception of clients differed, staff were less educated, beliefs of the agency differed and policy impacted on staff's interpretation of what they were allowed do and how innovative they could be when working with clients (Rossow-Kimball and Goodwin, 2009). Over forty years ago, in 1972 Nirje (cited in Rossow-Kimball and Goodwin, 2009, p.17) argued “that for persons with ID to experience and freely choose leisure activities, they must develop self-confidence through authentic experiences within the community”. This is relevant to this research on choice and PA among adults with an ID who are transitioning to community on an ongoing basis. While the focus of this research is not to evaluate the transition it does take note of how interactive participants are with the wider community and whether they are welcomed into this space. Choice and decision making is valued, but it is not always easy to put systems in place in order to encourage and facilitate this. Support staff often face their own hard choices between facilitating those they support or focusing on health and safety instead in order to comply with their institutions’ service targets (Antaki, Finlay, Walton and Pate 2008). These are significant factors to consider when facilitating choice in ID.

2.4.3.2 Self-reflection - an Extension of Choice-Making

In becoming self-determined the act of reflection plays an important role in how people with ID consider how to make choices and what kind of choices they want to make. Staff plays a very important role in motivating and encouraging people with ID to reflect on their activities and in their expression of them. Antaki (2013) examined two practices where staff encouraged reflection with clients who initially gave unsatisfactory
responses. While both experiments began with open-ended questions they diverged in two ways. The first setting is residential and staff use conventional question-and-answer formats. The other is a horticultural setting where the end of day exercise is to reflect on the day's events. Follow up questions to inarticulate or unsatisfactory responses using interrogatory style methods and yes/no or closed questions fail to achieve any interational outcomes. The horticultural setting uses open-ended questions, which are more elaborate, pressing the client to elaborate thus escalating grammar and concepts (Antaki 2013). Antaki concludes that different practices might reflect contrasting institutional objectives. In the second scenario there is an invitation for the participant to reflect on their day's activities. Antaki (2013) makes a point in acknowledging that staff was at a disadvantage because they were not therapists. Rather, their days were more involved in concrete requirements of routine, food hygiene and perhaps health and safety training. The ambiguity is that the service that employs them may have personal empowerment enshrined abstractly in its mission statement but due to “lack of training, time and real commitment may not be able to invoke the ideology” (Antaki 2013, p. 587). This is noteworthy when asking people with ID their opinion and whether stock answers to open, over-arching questions about PA and choice offer total satisfaction for the participant within the service.

2.4.3.3 Fundamentals of Choice from the Perspectives of People with Intellectual Disability

In an attempt to understand how people with ID make choices, a study explored how people with ID make friends, where they make them and how they sustain these friendships. "For many people with ID friendships can be limited and restricted leading to loneliness but little attention has been given to exploring these issues with this population" (Mason, Timms, Hayburn and Watters 2013, p. 108). The study found that participants held similar conventional understandings to friendship as the mainstream population. They were aware of the psychological benefits of friendship and its value for wellbeing. It found that relationships with key staff were prioritised and different to other relationships. Support staffs were perceived to be the key holders to social activities, yielding power to influence important decisions in their lives and depended on for practical and sometimes emotional support (Mason, Timms, Hayburn and Watters 2013). This is of concern as it may then also hold true that staffs make the
ultimate decision when there is not enough time to explore group dynamics and how decisions are arrived at.

For those living relatively independent lives, friends and other networks are also important outside of the service as they provide a social connectedness. According to the National Federation of Voluntary Bodies (2009) policy should be directed towards the primacy of the family and other natural support networks such as friends and neighbours. They would like to see these natural networks at the heart of policy to counteract the loneliness that is especially felt by people with ID (National Federation of Voluntary Bodies 2009). They posit that the current system, albeit unintentionally, allows the only friendships for people with ID to make as those who are paid to know them (National Federation of Voluntary Bodies 2009). A study on what things make people with a learning disability happy, or as researchers refer to as subjective well-being, found that “relationships, choice and independence, activities and valuable social roles” were the leading elements that made them feel happy about their lives (Haigh et al. 2013, p. 26). Personal characteristics such as optimism and being able to handle difficult emotional states also featured and the study concluded that it is important for people with ID to have good things in their lives but that it is also important to be enabled to access these good things. Having no access to new experiences and new people further insulates this group of people with intellectual disabilities from forming new friendships and the skill it takes to make new friends and retain them as friends.

2.4.3.4 Inclusion and Participation as Drivers of Choice
The real meaning of inclusion is about connectedness to one’s wider community, not to be confused with location or service. It is about developing a sense of belonging through participation and reciprocity and building an identity (Simplican et al. 2015). Reciprocity, as defined under the systems theory, is the idea that if one part of a system changes, that change interacts with all the other parts (Payne 2005). It occurs in informal or natural systems such as family, formal systems such as community groups and societal systems such as leisure complexes. Many contemporary services are located in community settings but are not wholly effective in realising inclusion. “Inclusive leisure contexts are not always welcoming environments for people with intellectual
impairments” (Rossow-Kimball and Goodwin 2013, p.2). Disability services support people with ID while inside the service, but outside of the service this level of support is not as evident. However an individual might attend a gym with a group of peers from a service but be reluctant to go independently due to lack of community support and encouragement.

Independence and autonomy is also contingent on participation in society which becomes increasingly significant with the vision for transition to community. While transition to community is promoted as a means of enhancing opportunities for participation and engagement in daily life and promoting equality and inclusion, occupational therapists are concerned with the facilitation of these opportunities (King et al. 2016). They believe that engagement in meaningful occupation has a significant positive impact on well-being and quality of life but that older people with ID will be precluded from this type of engagement exacerbated by social norms of attitudes towards disability and age (King et al. 2016). This inevitably also has a negative impact on the availability and opportunity to make choices and is challenging for effective community transition.

2.4.3.5 The Leisure Context of Physical Activity for people with Intellectual Disability

New Directions 2012-2016, acknowledges that people with ID are entitled to pursue leisure activities in the same way as the wider population. A study regarding leisure contexts included four senior adults with ID, four mainstream senior adults and staff at a senior citizens centre. The themes that emerged concluded that both groups felt alone in some way and wanted fellowship and belonging by meeting new friends. Those with ID expressed the same feelings using less elaborate language and tended to give concrete examples, i.e. “spending time with friends”, “having coffee” and “going to dances” (Rossow-Kimball and Goodwin 2013, p. 8). In essence, what the study notably found was that self-determined leisure behaviours were possible within the inclusive leisure setting of the senior citizens centre (Rossow-Kimball and Goodwin 2013). However, the mainstream participants felt that the staff expected too much of them and felt pressurised to be more interactive with the ID participants, something they didn’t all feel comfortable with. Previous lack of exposure to people with ID also inhibited full social integration. This is significant for transitioning to community and it
is unknown how prepared the community is for this or in fact whether there is an awareness amongst policy makers of this. Equally, it is unknown how people with ID feel about moving from congregated settings into the community as they have not been asked. Another notable facet of the study found that naturally occurring phenomena such as cliques and closed groups within both groups had the effect of keeping them apart. Staff suggested that a skill development training programme would be beneficial but this was rejected as it would take away from the spontaneity of inclusive leisure activities (Kimball-Rossow and Goodwin 2013). This perhaps is indicative of an over-reliance on training programmes to fix rather than using their own resourcefulness and experience. Staff can be very inventive and proactive when introducing new activities and this is something that should be rewarded or certainly recognised. It also exemplifies how disability tends to be institutionalised even in a community setting which is worrying because it guarantees failure if not handled properly.

Inclusion in qualitative research is a relatively new concept. Non participation has been attributed to the researcher’s inability to communicate with people who are verbally challenged and difficulty in accessing people to participate because of a stringent ethics process (Hall 2013). “The ethical issue of involving people with ID in research challenges ethics committees, researchers and potential participants” (Iacono 2006, p. 178). Iacono concludes that researchers may play a role in educating ethics committees about the involvement of people with ID in research so as to reduce their potential for increasingly conservative decisions (Iacono 2006). People with ID would benefit from research that focuses on their strengths and abilities as it provides opportunities for them to learn about themselves and improve their lives. According to Hall (2013), when people understand their experiences and perspectives and realise their abilities, the potential exists for greater acceptance and inclusion in society. This view makes the methodology for this research a very valid reason for choosing phenomenology.

2.5 Definition and Features of Physical Activity

This next section discusses the phenomenon of physical activity, how it impacts on the overall wellbeing of people with ID, and why it is necessary to promote as an integral part of everyday living to ensure good quality of life for people with intellectual disabilities.
The World Health Organisation (WHO) defines PA as any bodily movement produced by skeletal muscles that requires energy expenditure (WHO 2011). It is estimated that physical inactivity is regarded as the fourth leading risk factor for global mortality (WHO 2011). Health care systems are suffering under the strain of increasingly sedentary behaviour which is an underlying factor in obesity. This has an adverse effect on health budgets, waiting lists and healthcare capacity, necessitating governments and policy makers to turn to preventative measure, i.e. increased levels of PA, to counteract this. These measures, as well as healthy eating, are supported by the WHO. Stanish (2006) articulates that it is an ongoing quest in free-living populations to define what PA is but that a true ‘gold-standard’ measure has as yet eluded researchers. Criticism is levelled at a lack of knowledge regarding an appropriate amount of PA for people with ID. Lloyd (2016) argues that more research is required to quantify the appropriate amount of PA necessary for health. This requires, she states, an accurate collection, analyses and interpretation of PA data for people with IDs. The International Association for the Scientific Study of Intellectual Disability (IASSID), has developed a consensus statement on the health of people with intellectual disabilities which recommends accessible health promotion programmes for people with an intellectual disability, as well as research into fitness, nutrition and common health problems associated with intellectual disability, to redress the longstanding disparities (Scheepers et al. 2005). Evidently this is an area of research that still requires a significant amount of work.

However, several methods have demonstrated acceptable validity such as self-reports, activity monitors, heart rate monitors, pedometers and direct observation (Dale et al. 2002, cited in Stanish, 2006). Guidelines on how PA is interpreted or what is regarded as sufficient to maintain wellbeing is advanced. Current recommendations state that individuals engage in at least thirty minutes of moderate exercise daily for at least five days a week in order to gain health protective benefits (British Heart Foundation, 2001). Caspersen, Powell and Christenson (1985) opine that PA in daily life varies and could be categorised into occupational, sports, conditioning, household and other activities. More recently Darker et al. (2007) argue that there has been a shift away from advocating structured formal exercise towards more lifestyle activities. These are activities that are performed as part of everyday life and include climbing stairs, walking
and cycling (Department of Health 2005 in Darker et al. 2007). PA may be further divided into light, moderate or heavy in intensity; voluntary or compulsory; weekday or weekend activities (Caspersen, Powell and Christenson 1985). For the general population this offers the individual options regarding type of activity by using self-efficacy, financial independence and personal autonomy. In Ireland the reported levels of inactivity amongst people with ID has been recorded under the IDS-TILDA study. Participants were asked how many days they had engaged in PA in the 7 days prior to interview categorising it into low, moderate or high and found that the majority engaged in low levels of activity. Even for those who engage in moderate levels (24.3%), it is still not sufficient for people with ID to accrue health benefits (Burke and McCallion 2014) though Lloyd (2016) argues that proper focused guidelines on PA for people with ID is under researched and simply doesn’t exist. Without proper guidelines, services and families will remain overprotective whereas if they were aware of the detrimental health consequences of under activity this would motivate them to be more proactive.

The American College of Sports Medicine (ACMS 2015), in a publication on adopting fitness for special populations, especially focusing on obesity levels amongst children and adults with disabilities, highlighted that much of the fitness and wellness industry does not recognise that health and disability can co-exist identifying barriers for people with ID. These included inaccessible facilities, lack of transportation and untrained staff in the relevant area (ACMS 2015). They, however, do not consider these factors as a drawback for people with disabilities, but regards it as a challenge for their association to be more creative in adapting ways to include people with ID. Similarly, their guidelines echo those of other organisations and they recommend 150 minutes of moderate intensity aerobic activity a week (ACMS 2015). Their recommendations include encouragement to engage core muscles, train the muscles most relied on for daily living and refer to the individual’s health care professional as a safeguard (ACMS 2015).

2.5.1 Physical Activity as a Health Determinant for people with Intellectual Disabilities

People with ID take part in activities in many settings classified as three structural categories: segregated, semi-segregated and integrated (Simplican et al. 2015). Exercise is actively encouraged for the general population but is seldom advocated as an
effective or real intervention for those with ID (Stanish et al. 2006). Yet, much of the literature attributes the myriad benefits of PA for people with an ID (Janicas, 2014; Stanish et al., 2006; Elinder et al., 2010; Moss, 2009). Besides the corporeal benefits of PA there are also mental health benefits. People with ID are at much greater risk of developing a psychiatric illness, with some estimates suggesting that they are three to four times more likely to do so in comparison with the general population (Cooper et al. 2007, cited in Janicas, 2014). Despite the indisputable health effects, most individuals with ID fall short of meeting recommended exercise guidelines. This questions how seriously these guidelines are taken and applied and whether or not the adult with ID is aware of the benefits of PA. For example, the National Guidelines on PA for Ireland (2009) includes eight (8) lines recommending people with disabilities to be as active as their ability allows while aiming to “meet adult guidelines of at least 30 minutes of moderate-intensity activity 5 days a week” (Department of Health and Children 2009, 13). It does not go into any depth, however, on how realistic and achievable this is, who facilitates it and at what cost (Department of Health and Children 2009). *New Directions 2012-2016* looks to the community as a new setting where everybody can live and exercise in harmony regardless of ability and capacity. This is still in transition and the mainstreaming of physical activities are not integrated, advertised or overtly promoted. It would appear then that physical activities and leisure pursuits for people with ID are still very much segregated and dependent on service providers at this point in time.

In academic literature, it is widely accepted that people with an ID experience poorer physical and mental health than the general population; they are also at a higher risk of morbidity and mortality than that of the general adult population (Heller & Sorensen, 2013; Peterson et al., 2009; Brooker et al., 2015; Jones et al. 2007). It increases the likelihood of the onset of chronic illnesses amongst people with ID, the most prevalent of these chronic illnesses being cardiovascular disease, Type 2 diabetes, stroke and hypertension (Moss, 2009; Elinder et al., 2010). Contemporaneously, evidence points to the fact that the lifespan of people with ID has increased substantially over the last century due to scientific, social and medical advancements However the ID cohort experience poorer health marked by the onset of premature ageing in comparison with the wider population (Heller and Sorensen, 2013). Therefore, understanding and
addressing the association between chronic disease and increased longevity and quality of life has become an important issue in the care of adults with an ID (Haveman et al. 2010). Current literature suggests that PA is a beneficial factor in contributing meaningfully towards an enduring and healthier way of life for adults with ID (Heller et al., 2013; Emerson, 2011). While we have some insight into what constitutes PA for adults with ID in residential settings, new and increasing patterns of community living are emerging. This increases the need for community to support people with ID in affording choice in PA along with participation in PA in the community.

McCallion and McCarron (2015) argue that there is a tendency to obscure old age amongst people with ID resulting in 40-50 year old people being regarded as old and resultantly disregarding middle-age. This, in effect, dismisses an entire generation of people with ID. People with ID also age with disadvantages due to lack of preventative health screening and other health promotions (McCallion and McCarron 2015). On a global scale the WHO (2011) report that many people with disabilities experience worse socioeconomic outcomes than people without disabilities. The preamble to this is that good and equitable health depends on a wide range of factors including, employment, and access to healthcare, a healthy environment and the cultural status of the individual (WHO 2011).

2.5.2 Leisure Time Pursuits for people with an Intellectual Disability
From a public health viewpoint, increasingly national and international health policies endorse PA as a prerequisite to maintaining a healthy existence. The definition of health has remained relatively static since 1948 when it was introduced in the preamble of the WHO’s constitution as “A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO 2011, p. 100). Article 30 of the UN Convention encourages and promotes participation of persons with ID in cultural, sporting, recreational and leisure activities (CRPD 1989). This is reflected in organisations such as the English Federation of Sport (EFDS) and Disability Sport Wales. The EFDS supports and advocates the involvement of disabled people participating in activities by linking in with their disability organisations/services. Disability Sport Wales promotes play, performance and learning in order to encourage diversity and equity in disability specific inclusive sport opportunities.
The WHO recognises PA as being a preventative measure to ill-health and in their report outlines and recommends preferable activity levels which are age-related (WHO 2009). While there is no specific section dedicated to ID it does state that the recommendations made can be applied to adults with disabilities. It also recognises that they may need to be adjusted for each individual based on exercise capacity and specific health risks or limitations of the individual (WHO 2009). It defines physical activity as including leisure time, transportation (e.g. walking or cycling), occupational, household chores, play, games, sports or planned exercise in the context of daily, family and community activities recognising the gap in research in this area (WHO 2009). There are studies on what constitutes leisure time and how it is expressed in group settings. Historically, according to Nirje (1972, cited in Rossow-Kimball and Goodwin, 2009, p.1), leisure for people with intellectual impairment has been described as “grey, monotonous, and confined without much sense of freedom”. This is contextual as well as historical and people in group homes have had no opportunity to experience leisure time without their peers or without being under the supervision of staff personnel (Rossow-Kimball and Goodwin, 2009). Inclusive leisure contexts have not always been welcoming of people with ID, yet Devine (2004) reports that this type of leisure creates an environment where people connect to each other and their communities bringing people with and without impairments together ultimately leading to social acceptance.

2.5.3 Involvement in Sport for people with Intellectual Disabilities

Sport for people with ID has also been identified as an essential element for health and well-being (WHO 2003). It has been linked to a range of physical, social and mental health benefits but factors associated with participation are of concern. Robertson and Emerson (2010) found that participation was strongly linked with socioeconomic status and safety. For example, people in more deprived neighbourhoods feared for their personal safety which lowered participation rates. Furthermore, the study established that there is a need to move away from the more prescriptive and authoritarian benefits of PA and to focus instead on the “social relationships and fun elements” as motivators of participation (Robertson and Emerson 2010, p. 621). This emphasises the importance of being able to choose one’s own activity. It allows the individual to decide what and why they want to be involved in an activity whether it is for sport, competition, fun,
physical fitness, friendship and socialisation or a combination thereof. This makes the personal experience more meaningful increasing the likelihood of their continued participation.

The 1993 United Nations' Standard Rules on the Equalization of Opportunities for Persons with Disabilities declares that member states should take measures to ensure that persons with disabilities have equal opportunities for recreation and sports. While this is true, it needs to be carefully balanced with choice, satisfaction, suitability and enjoyment. The National Disability Association's (NDA) report, *Promoting the Participation of People with Disabilities in Physical Activity and Sport in Ireland* leans towards this (NDA 2005). It emphasises the need for physical literacy or developing the fundamentals of movement through appropriate opportunities and environments for learning and attainment (NDA 2005). Physical literacy is something that needs to be taught and is not a naturally occurring element in the human condition (NDA 2005). The report is perhaps over-reliant on the idea of sport as a means of inclusion and is less emphatic on the importance of everyday physical activity as a means of staying healthy. Sport is not always readily available, requires many people to support it and is generally competitive which can deter some people from participating.

The SOPHIE study, which reported on the Special Olympics, evaluated the impact of PA on health and found that participants had a higher self-reported health status and a better quality of life than those who do not take part in Special Olympics programmes (Bowser et al., 2015). It found that participants in Special Olympics clubs throughout Ireland are more active, physically fitter and have a greater sense of well-being. Their families found it increased social connectedness but barriers to participation included transport or elderly carers who could not actively support them (Bowers et al. 2015 p. 1).

2.6 The Role of Research in Physical Activity and Intellectual Disability

The literature suggests that PA amongst people with ID is chiefly studied as a result of a focused intervention, for the purposes of research, rather than on lifestyle choice, health awareness, corporeal concept or an everyday way of being. A study in Australia found that an international review of obesity research found that 8-16 per cent of adults
with ID met activity guidelines compared with 30-47 per cent of the mainstream population (Brooker et al. 2015). Another study found that the determinants and benefits of engaging in less strenuous activity includes balance, mobility and strengths (Schijndel-Speet 2015).

Health research is aware that intervention research is needed to investigate effective programmes that increase PA (Peterson et al. 2009). A shared emergent theme is the proportion of individuals with ID who actually achieve 30-minutes of continuous moderate activity, as recommended, being unmet (Temple and Stanish, 2008; Brooker et al., 2015; Peterson et al. 2009). Much research provides well-documented accounts of the rate of exercise for people with ID with the perception that physical health is significant to well-being (Heller et al., 2013; and Elinder 2010). Nevertheless, there is little research about how frequency of exercise affects quality of life (Blick et al. 2014). Blick advances that quality of life indicators include satisfaction with services received, amount of dignity, rights and respect received from others, choice and control over daily activities, employment, quality of relationships and inclusion in community activities. The National Disability Authority (NDA 2009) indicated that a shift in practice could improve attitudes towards PA amongst people with ID beginning at an early age and for older adults alternative interventions need to be applied. This might appear burdensome for overstretched and under resourced services where the age range of clients differ but to take PA seriously as a health benefit this needs to be addressed whether inside or outside the parameters of the day service.

2.7 Inhibitors and Facilitators to PA for people with ID

Many studies acknowledge a higher prevalence of sedentary lifestyles amongst adults with ID and tend to focus on assessing PA levels and evaluating PA programmes. This study differs insofar as it is concerned with the lived experience of those who participate in PA and exercise choice in this regard. Evidence suggests that PA levels in people with ID is low and associates it with a more sedentary lifestyle which increases health risks (Emerson, 2005; Moss, 2009; Temple and Stanish, 2009). In effect lack of regular PA is a significant adverse risk factor to health (Finlayson et al. 2011). The health disparities that exist among people with ID in comparison to the rest of the population is also a
very recognisable adverse feature which can lead to a greater risk of obesity and chronic disease (Prasher and Janicki, 2002; Havercamp et al. 2004). There are relatively few studies addressing barriers to PA for people with an ID (Bodde and Seo 2009). Studies are very much based on short-term intervention type programmes (Moss 2009). These generally preclude the views of participants as the studies are specifically focused but themes to barriers do emerge. Others state that people with ID face the same barriers to participation as the general population with regard to cost, transport and access (Brooker et al. 2015). There are many other real barriers to participation and opportunity outside of general societal barriers, such as overly-protective caregivers and medical professionals who may inadvertently reinforce sedentary behaviour because of safety fears (Brooker et al. 2015). Bodde and Seo (2009) and Temple and Walkley (2007) identify transportation costs, financial constraints, a lack of awareness with regard to what is available, negativity of gatekeepers and unclear policy as very real barriers for people with ID. Cost isn’t always a constraint as Lante, Walkley, Gamble and Vassos (2011) conclude in their study on community-based PA. They maintain that long-term sustainable, low cost PA programs can minimise barriers to PA for people with ID. Their study of a community programme earned enthusiasm and praise from the support staff who acknowledged their own satisfaction in supporting people with ID to participate, seeing the participants enjoying themselves and making social connections while gaining social skills (Lante, Walkley, Gamble and Vassos 2011). They used accelerometry to collect PA data during the program and for 7-day periods outside of the program in order to explore the psychosocial outcomes gained from participation. Both participants and caregivers were interviewed regarding their experiences.

Staff were found to be a key to the Quality of life (Qol) in community transitioning study in Ireland, key to implementing change, facilitating independence and knowing the likes and dislikes of individuals (Kilroy et al. 2015). Provision of permanent staff also made a” huge difference in facilitating individual’s choice” because they were sufficiently in tune with the individual to interpret their wishes (Kilroy et al. 2015, p. 73). Services generally justify lack of supports through underfunding or under-resourcing. According to Power (2008), this is not just symptomatic of a lack of resources but is of the system working
for the system and not for the user. It also has to do with supportive attitudes and flexibility which are crucial in meeting user requirements at delivery level (Power 2008).

According to Lante, evidence exists that PA programs benefit adults with ID in the short term; however no research has been reported on the effect of long-term engagement (Lante et al. 2011). Cognisant of the gap in research, Lante (2011) explored the physical and psychosocial benefits gained by two individuals with mild ID who participated in a long-term PA program of fifteen months duration. The Australian study called Creating a Sporting Chance Program, (CASC), is a low cost program available 40 weeks of the year. It was designed to give people with ID the opportunity to participate in sport, exercise and active recreation within a community-based setting and funded by three different local organisations (Lante et al. 2011). Physical benefits were measured and the psychosocial outcomes recorded by interviewing participants and caregivers about their experiences. While the physical benefits are somewhat noteworthy the psychosocial elements are equally important. Participants valued the experience of engaging in and learning a new activity, appreciated the opportunity to meet a wider range of people and more people, gained social praise and acknowledgement (Lante et al. 2011). There was some increase, though small, in weekend activity which showed that participants had the ability to build on their capacity even when not constrained by routine (Lante et al. 2011). Duration, low costs were resounding positives of the program in the study’s discussion. Conversely, others say the financial cost of training staff, providing access to community sports facilities and the lack of availability of appropriate resources is particularly synonymous with ID (Jones et al. 2007). Training people or professionals who provide PA opportunities in the community or in residential settings is a determinant to making PA more accessible and safer. Generic gyms and fitness instructors do not always have the necessary skills that would enable people with ID into gym programmes (Jones et al. 2007). This becomes a concern as policy is directed towards people with ID to live in the community as a matter of course and yet the supports are not always there to make this transition effective.
2.8 Health Promotion in Eliminating Health Disparities

Research points to the fact that PA on its own is not enough. Heller and Sorenson (2013) conducted a mixed methods study in health promotion combining health education, screening services and PA. The rationale was that each intervention is necessary in order to reduce health disparities amongst individuals with an ID (Heller and Sorenson 2013). Studies that focus only on PA show improved fitness, some success in reducing obesity, reducing maladaptive behaviour and improving alertness but find no longer term health benefits (Heller and Sorenson 2013). Any singular program that targets a specific area will garner results to the detriment and exclusion of longer term benefits. Studies that take a more holistic approach by combining exercise and health nutrition tend to show not only physical health benefits but also changes in health behaviour attitudes and exercise self-efficacy (Heller and Sorenson 2013).

Lante’s triangulated study involved participants, staff and caregivers. The views of staff were consistent with those of the participants regarding psychosocial benefits of PA. Nonetheless it was noted that the participants having expended higher levels of energy in their PA resulted in low levels of activity for the remainder of the day. It is evident that the need for balance and common sense while remaining aware of context is essential. One of the recommendations in Lante’s study suggested education of participants and carers around PA and health alongside opportunities to be physically active (Lante et al. 2011). This theme also emerges in Elinder’s 2010 Swedish study of an evaluation in a community health intervention program aiming to improve diet and PA. This was the first study that targeted both the participants with ID and the staff who cared for them. Part of the rationale for the study was that often staff in these settings has insufficient education regarding the special health needs of residents (Elinder et al. 2010).

Notably, in many of these qualitative studies the voice of the participant is not included. To gain a true experience on a topic that directly affects the life of an individual, the source of information should be that person. To reiterate, research in the past has relied heavily on observation alongside the opinions of staff and significant others to arrive at a conclusion. This detracts from the depth of research as it tends towards being narrow and one-dimensional and at worst biased as it is viewed from one side only. A case in
point is the TILDA study where one-third respondents reported having no PA itinerary while one fifth reported that they “did not like exercise” (IDS-TILDA 2011, p. 90). 37.3 percent reported health considerations as a factor (IDS-TILDA 2011). The barriers posited by this group diverged from traditional reasons put forward by researchers such as lack of money, self-consciousness, inaccessible facilities, not being allowed to go, lack of transport, negative or unfriendly attitudes (ID-TILDA 2011). This gives a very different view of what people with ID perceive and understand as determinants such as bad health that inhibits activity and the other reality where people do not like to exercise thus exhibiting preferences.

In another study on walking behaviour participants did not regard walking as “proper exercise” though the researchers believed differently and provided a list of health benefits including the psychological meaning and value it imparts (Darker, Larkin and French 2007, p. 2172). All of this research contributes valuable opinions from participants regardless of whether the results are less positive than others. It indicates that by supporting inclusion in research for adults with ID that is relevant to them the “subsequent discussion in the literature becomes more complete” (Hall 2013, p. 138). Qualitative methodology is varied and finding the one that best fits the research question and participant is directly related to the overall project.

2.9 General Conclusion on Literature Reviewed

The purpose of this review was to research studies conducted in PA and choice for adults with ID in order to examine whether the discourse on it had changed and is still changing. The studies referred to span a period of twenty years approximately. It is clear from the research reviewed that the type of research being conducted in ID has only relatively recently begun to move away from more evaluative type towards a more inclusive approach. However, questions remain about the nature and conceptual clarity of inclusive research (Nind 2011) which makes it difficult for inclusive research to flourish considering the lack of guidelines there are for researchers. This is symptomatic of the difficulty in accessing people with ID to participate in research due to the stringent ethics process. This is also a frustration for the person with ID who wants to participate in research that directly impacts on their lives. While people with ID are being asked their opinion increasingly it is often as a result of making repartitions for institutional
abuse as in the case of Áras Attracta (2016). It would appear that adults with ID remain sitting on the periphery of research.

2.9.1 Literature around Physical Activity and Choice

More specifically, the literature review reveals that research around the phenomenon of choice and physical activity exist separately and not in combination with each other. Research carried out on physical activity tends towards evaluating short-term programmes which are graded on their success or marginal success and notably the participants are rarely asked to give their feedback on the programme. Debate continues around the usefulness of short-term or long-term interventions in PA but there is no conclusive answer.

Research around choice for people with ID is often researched and argued quite academically through the lens of the human rights agenda or neo-liberalism. This is done without asking people with ID what they perceive choice to be, whether it is important to them and whether they have access to it. This is further exacerbated when the researcher promotes inclusion and choice but continues the research without asking the core person their opinion. Much research remains observational and based on characteristics of people such as age and gender as opposed to exploring personality which tends to label ID. While all research is not observational, other research tends to ask staff their opinions about the experiences of people with ID. While it is appropriate to sometimes include those closest to people with ID, it is dependent on what the research wants to find out. For example, staff is included in this research for the purpose of illuminating the experiences of the core participants and significantly not replacing them. Notably the methods of collecting data indicate how inclusive research is and this is discussed in the next section, methodological process.

2.10 Methodological Process

Inevitably, there are challenges involved in collecting data from participants with ID. Considering the studies looked at in this review, it is notable that many of them rarely ask the people who matter, their opinions. Elinder et al. (2010) recognise the challenges and reasons for not recruiting and working with a client group whose communication levels make it difficult for them to understand the intervention and the consequences
of participation. They found it difficult to assess people with ID's quality of life due to the cognitive limitations that interviews and questionnaires yielded for these participants. Neither could they find any suitable scale in literature for conducting this type of research (Elinder et al. 2010). It could be argued that rather than finding a scale to measure the participants input, a narrative or interview could prove appropriate. It engages people with ID in a subject new to them and it encourages them to communicate with different people at varying levels. Elinder found this to be worthwhile and developed a scale by using relevant questions from different quality of life questionnaires. It referred to the challenge of collecting data from the target group with regard to the individual's interest and ability to participate in each specific measurement as well as the motivation among the caregivers to give support (Elinder et al. 2013). They concluded that seasonal differences might have affected the level of PA and were critical of self-assessment of work routines which they felt was a weakness due to its inaccuracies (Elinder et al. 2013). Studies like this at least encourage and actively pursue participation from a client group who would otherwise be excluded from research. This is supported by Hall who believes the inclusion of people with ID in research strengthens it (Hall 2013).

The next challenge is to locate a methodology that fully engages the participant with ID. In a phenomenological study on how people with ID make sense of friendships, objectives focused on gaining access to individual perspectives while exploring detailed personal experiences and the meanings attributed to them (Mason et al. 2013). IPA is a data driven method with regard to facilitating understanding and interpretative in that it requires the researcher to engage in the 'double hermeneutic' (Mason et al. 2013). This is the researcher's attempt to make sense of the participants experiences (Smith 2009). Their participants were purposively sampled from a self-advocacy group and the data collection technique used was the semi-structured interviews. The interviews focused on three key areas: perspectives on friendship, experiences of friendship and friendship desires. The researchers felt that IPA was the best approach as "it is committed to exploring experience in its own terms" (Mason et al 2012, p. 110). While the language is simply expressed by the participants what emerges are underlying complex concepts such as power dynamics and autonomy.
Similarly, a study on the exploration of walking behaviour provided a rich and detailed account of participants' experience of walking using the qualitative method of IPA. Factors cited for making the activity easier included the "functionality of walking for transport, contextual factors of social support and psychological benefits" (Darker, Larkin and French 2007, p. 2172). This would not have been as rich in detail if the participants were observed performing the activity only as their personal experience of walking would not have been recorded.

2.11 Research Question
This research looks at the phenomenon of PA and choice among adults with an ID from their point of view. With that in mind, IPA allows the participants to recall the experience and tell it in their own words. It would appear that IPA is especially beneficial for collecting psychosocial outcomes as is further endorsed by Lante, Walkley, Gamble and Vassos (2011). In their community-based PA initial evaluation study, they combined observational research by using accelerometers and IPA interviewing techniques to evaluate the success of the exercise which included meeting new people and gaining social acknowledgement (Lante, Walkley, Gamble and Vassos 2007).

Another study on the exploration of how people with ID might make sense of friendship and their own friendship experiences (Mason et al. 2013) employed innovative and adaptive methods of collecting data from the participants. Notably, the study suggested that future studies using IPA would benefit from collecting data with more flexibility, for example, through the use of art and photography. It also highly recommended that researcher/s develop a rapport with participants, thus reducing the formality of researcher-participant interactions and using visual materials to aid discussions (Mason et al. 2013).

2.12 Conclusion and Summary of Chapter
This review began by outlining the range and breadth of relevant sources; highlighted the different elements of the disability discourse landscape and made the case as to why disability research needs to include the voice of the participant. One of the most striking aspects of this topic to emerge from the review was the phenomenon of choice. What was particularly noteworthy was the extent to which the antecedents of choice impact on the decision making process; noting the need to balance choice against the
need to protect people against making detrimental choices. This examination of choice was explored through the various models of choice such as self-determination and self-reflection and ends with how people with ID make choices and what facilitates and inhibits them in this regard. Given that the central theme of the research study is physical activity (PA) it was important for the review to examine how physical activity is defined; the manner in which people with intellectual disability engage with it and to look at how physical activity and intellectual disability has been conducted. This section highlighted the different elements that impact on engagement with PA by people with an intellectual disability, identifying friendships, service facilitation, role of family, social connectedness, barriers and facilitators through the lens of PA and choice. In analysing previous studies particular attention was placed on exploring the various methodologies employed and by extension making the case for the approach used in this study, namely, interpretative phenomenological analysis.

To recap, this research examines and contextualises the meaning of physical activity and choice for adults with an ID who are transitioning from segregated services into the community. It evaluates choice-making through the lens of PA in light of the qualitative data collected from the core participants. It gathers the perspectives of key workers and other workers in order to illuminate the experience of the participants but significantly not replace them. It aims to augment the current evidence base with regard to how people with ID make choices about PA they engage in. It aims to add to existing literature regarding the use of phenomenological research methodologies involving people with ID. It aims to do this by using IPA. The next chapter Three will look at these aims and objectives through IPA.
Chapter Three – Methodology

Phenomenological research does not start or continue in a disembodied fashion. It is always a project of some one: a real person, who in the context of particular, individual, social and historical life circumstances, set out to make sense of human existence

(Max van Manen 2006, p. 31)

3.1 Introduction

This chapter provides the rationale for choosing interpretative phenomenological analysis (IPA) in order to investigate the experience of physical activity and choice among adults with an intellectual disability. This has already been referred to in Chapter two but is discussed in more depth in this chapter. It explores other qualitative frameworks, gives an outline of qualitative research and goes on to discuss the more recent history of interpretative research and phenomenology. Specific to this study, and a major constituent of this chapter, is interpretative phenomenological analysis (IPA), described in terms of people’s lived experience of a phenomena. Its application here is through its core participants, adults with an intellectual disability (ID), the phenomena being physical activity (PA) and choice. What follows is an account of why IPA was chosen as the preferred method above other qualitative methods. It continues with the purposive sampling of the participants on completion of obligatory and rigorous ethical approval. A description is given of the data collection process which includes immersion in the service in order to get to know the potential participants, pilot studies, and preparation of the interview guide. Conducting semi-structured interviews with staff as a means of illuminating the research and significantly not replacing the experience of the core participants is also included. Towards the end of this chapter the analysis process, necessary to establish rigor in research, is discussed in detail. This is represented through a framework of analysis describing how superordinate and subordinate themes are arrived at, a feature of IPA, and how findings are expressed through the transcripts of core participant experiences of the phenomenon.
3.2 A Qualitative Approach in Research

Selecting a suitable research methodology is dependent on the nature of the research question. It must address the aims and objectives of the study and in particular the relevance of the core participants to the overall study. While it has been recognised that individuals with ID are experts in their own lives they have as a group been largely omitted from the disability discourse (Kelly and Watson 2013). Historically, research has relied heavily on observational type fieldwork where studies have "typically been done on individuals with disabilities rather than with the, disempowering this already vulnerable population" (Kelly and Watson 2013, p. 14). The social model of disability has been the catalyst for attitudinal change towards disability leading to aspirations of integration and inclusion for these individuals. The emergence of the bio psychosocial model and human rights agenda has become particularly relevant to ID and these are models that sit well with phenomenology, a point that emerges as the chapter progresses.

3.2.1 Qualitative Methodology Frameworks

Qualitative methods have gained greater legitimacy in recent years in the social sciences and as a result more researchers have turned to phenomenology to inform their work (Cosgrove and McHugh 2008). Psychology in particular removed itself from experimental research adopting its own terminology including IPA (Barbour 2008). A comprehensive definition of qualitative research asserts that it,

"Allows for the detailed investigation of individual experiences, where researchers seek to understand the perspective of participants and the influence of the context in which an experience occurs"


Academics in disability studies and research believe that the voice of individuals with ID is necessary in the production of research that is central to the epistemology of disability (Ferguson and Nusbaum 2012). An example of epistemological developments in postmodernism includes the qualitative method of phenomenology. Postmodern research is a radical rethinking and deviation from the empirical positivist approach
because it “questions some of our most taken-for granted assumptions about the nature of reality truth, and knowledge” (Cosgrove and McHugh 2008, p.74).

According to Dowse (2009) positivist research, such as research conducted in the medical field, has often “diminished and silenced the voices of people with ID” (Dowse (2009, cited in Coons and Watson, 2013, p. 14). This makes research in the area of disability all the more important and the goal of this study is to address that by capturing the individual’s experience of self-selection in PA. Meaning is central in IPA and the aim is to attempt to understand the content and complexity of those meanings rather than measure their frequency. This differs from previous research in ID which involved testing theories and hypotheses by conducting experiments through observation (Pietkiewicz and Smith, 2014). A growing body of qualitative research methodologies have emerged that measure results in a qualitative manner. Measurement consists of evaluating programmes, recording stories and analysing them and in the case of IPA finding emerging themes. “The essence of qualitative research is to make sense of and recognise patterns among words in order to build up a meaningful picture without compromising its richness and dimensionality” (Leung 2015, p. 325).

3.3 Historical Outline of Qualitative Research

Up to the late 1970s qualitative research was the preserve of consenting academics in the fields of sociology and anthropology (Barbour 2008). The mid-1990s witnessed a sea of change and qualitative research emerged as a viable alternative to quantitative research and significantly not just an extension of it (Willis 2007). It is based on a different paradigm employing different reasons and methods as well as having additional data collection and analysis methods. It is now used in a broad range of disciplines, including health, psychology and education. Testament to the enthusiasm for qualitative methods are the emergence of numerous journals on the subject including Qualitative Social Work, Irish Journal of Qualitative methods, and the International Journal of Qualitative Methods to name but a few.

Creswell (1997, cited in Willis 2007) states that qualitative research is ethnographic, interpretative, critical or postmodern. Quantitative research on the other hand according to Henrickson and McKelvey (2002, cited in Willis, 2007) is empirical,
positivist, post positivist and objectivist. The distinction of human science versus natural science is often attributed to Wilhelm Dilthey (Van Manen 2006). Dilthey regarded the proper subject matter for human sciences as inclusionary “thoughts, consciousness, values, feelings, emotions, actions and purposes, which find their objectifications in languages, beliefs, arts, and institutions” (Van Manen 2006, p.3). Phenomenology comes from the same stable as symbolic interactionism and ethnomethodology. The traditions of symbolic interactionism emerged from the second wave of the Chicago School of sociology which concentrated on studying the social and interactional process of specific cultures or occupational groups (Barbour 2004). Phenomenology shares many of the assumptions and underpinnings of social interactionism as they both focus on the process of interaction and the active construction of meaning. This is very much reflected in how phenomenology is presented in its written format. Van Manen (2006 p. 113) refers to this.

Sometimes the other person is a member of a group that has access to certain experiences which are unique for reasons that are cultural, generational, social professional, or gender specific, such as children, the sick, the poor, prostitutes, athletes, women, gays, fathers and so on.

This by definition can be extended to any group regarded as different or unconventional. As a group, people with ID share difference and unique experiences outside of the majority. Phenomenology therefore serves the purpose of allowing us into an otherwise obscure world by giving a voice to the historically unheard person with ID.

3.4 Phenomenology

Phenomenology focuses on the subjectivity and relativity of reality, pointing out the need to understand how humans view themselves and the world around them. In the early days and following Kant, phenomenologists distinguished “phenomena - perceptions or appearances from the point of view of a human - from noumena - what things really are” (Willis 2007, p.53). Van Manen, states that

consciousness is the only access human beings have to the world and that anything that presents itself to consciousness is potentially of interest to phenomenology, whether the object is real or imagined, measurable or subjectively felt (2009, p.9).

To be conscious means one has to be aware of some aspect of the world and phenomenology is interested in exploring the significant aspects of the human being’s world. Consciousness in this research refers to the concept of choice and PA among people with an ID.
3.4.1 The Modern Architects of Phenomenology

Phenomenology is not only a methodology but it is also a philosophy. There are many styles and schools of phenomenology and though they all have some commonalities they also have distinct features (Dowling 2007). The philosophy of phenomenology goes back to biblical times and interest grew in it again in the mid to late 1800s. The following section traces its history.

3.4.1.1 Husserl and Heidegger – Descriptive versus Interpretative

Though he was not the first to coin the term, Edmund Husserl (1859-1938) is regarded as the father of the philosophical movement known as phenomenology in response to what he saw as a crisis in science. He believed science was losing its philosophical underpinning which meant that the “focus was shifting from description to causality” arguing that returning to descriptive methods was necessary to capture the “experiential nature of human phenomena” (Cosgrove and McHugh 2008, p. 76). Husserl’s approach to enquiry was descriptive or eidetic and his central insight was that consciousness was a universal condition of all human experience (Wojnar and Swanson, 2007). Having begun his career as a mathematician he coined the term bracketing in phenomenological research as a means of taking hold of a phenomenon and placing it outside of one’s knowledge of the phenomenon (Van Manen, 2006). Husserl’s primordial phenomenology requires us to cast aside the existing understanding we have of the world or bracket it so that the phenomenon speaks to us at first hand (Crotty 2005). Bracketing developed when Husserl attempted to evaluate the human experience by applying a mathematical formula to it. He believed that bracketing enabled the researcher to gain insight into the common features of any lived experience or universal essences (Wojnar and Swanson, 2007). Husserl’s phenomenology attracted criticism because of its strict adherence to being purely descriptive in the main.

Martin Heidegger (1889-1976), a one-time student, and work colleague of Husserl, was a critic of bracketing. Heidegger sought to answer the meaning of ‘being’ and believed that humans are hermeneutic or interpretative, capable of finding meaning and significance in their own lives (Wojnar and Swanson, 2007). He attempted to access ‘being’ by means of phenomenological analysis of human existence known as Dasein. Heidegger referred to Dasein as that entity “of our humanness which is capable of
wondering about its own existence and inquiring into its own being” (1962, cited in Van Manen 2006, p.176). More simply put Dasein is the concept of the human way of being in the world. In light of the research question, IPA gives the participants the opportunity to interpret the meaning of choice and PA by reflecting on its significance in their lives. Unlike Husserl, Heidegger believed in the concept of situatedness or context which is significant in light of the participants selected for this research, the particular time chosen as well as the experience. For example, this research which explores the experience of PA and choice among adults with an ID would differ greatly if it occurred at a different time and place. All contextual dimensions are equally important and situate the phenomenon in a time and place. IPA “gives voice” to a phenomenon and makes sense of that initial description relative to a wider social, cultural and theoretical context (Larkin, Watts and Clifton 2006, p. 102). It allows the researcher to look at the phenomenon of choice among adults with ID in the above settings through the lens of PA. The setting is an important aspect of IPA as context allows us to look at a phenomenon at a given time in a given place.

3.4.2 Justification for Choosing IPA for this research
Phenomenology seeks to understand what a particular experience is like and what meaning it has for an individual. Descriptive phenomenology “attempts to describe the essential qualities of an experience” while interpretative or hermeneutic phenomenology “seeks meanings and understandings in what people experience” (Corby, Taggart and Cousins 2015, p. 453). Choosing the research method is the initial task for the researcher based on the research interest/problem and not tradition or norms (Englander, 2012). An overriding and deciding factor for choosing IPA is that its theoretical orientation and primary goal is to place the individual’s sense-making of their experiences at its core. The aim of IPA is to explore in detail how participants are making sense of their personal and social world, using the meanings of particular experiences and events to do so (Smith and Osborn 2007).

The significance of IPA, and its underlying philosophy, is that it is understood as drawing “upon the fundamental principles of phenomenology, hermeneutics and idiography” (Pietkiewicz and Smith 2014, p. 361). This is best explained through its three components. Firstly, phenomenology is a philosophical approach to the study of
experience (Smith, Flowers and Larkin, 2009). Secondly, hermeneutics, an important part of IPA and “explicit to Heidegger's ascription of phenomenology, examines how a phenomenon appears, and how the analyst is implicated in facilitating and making sense of this appearance” (Smith, Flowers and Larkin 2009, p.28). Thirdly, idiography is concerned with particular/individual detail on the one hand and on the other hand the general, without making generalities. With regard to this research this means gathering the perspectives of the core participants and interpreting their experiences as a researcher. This requires consideration of the unique quality of each case being mindful not to formulate a theory despite an awareness that emergent themes are constantly evolving during the entire process.

In support of IPA it is a movement in research that “attempts to understand the local context rather than find universals or laws of human behaviour” (Willis 2007, p.108). This is an important consideration when recruiting participants. While all participants experience choosing PA in this sense, IPA focuses on how each person responds to and relates to the experience. It allows respondents to perceive their experiences uniquely though they might share a common space, and it presumes that the individual experiences of the phenomenon will be experienced differently. A phenomenon is defined as something that is seen, heard, touched, smelled and tasted implying that it is experienced directly rather than constituting some abstract concept (Denscombe 2004). The relevance for these participants with ID is that it makes it easier to describe the phenomenon that is seen in real terms and not as an abstract concept. This research attempts to understand what it is like for people with ID to experience choice and PA, and how it is understood and interpreted by the individual. It does not attempt to measure or explain that experience as this is not at the heart of phenomenological research.

3.4.3 How IPA addresses the Aims and Objectives of this Research

Phenomenology has been used mainly in psychology and nursing: the former because many of its proponents had a psychology background; the latter because it is a fundamental component of holistic nursing which captures the “bio-psychosocial and spiritual well-being of individuals, families and communities” (Wojnar and Swanson 2007, p. 172). This overarching approach resonates with the stakeholders involved in
this research. According to Finlay (2009) phenomenological research begins with concrete descriptions of first-person accounts of lived situations, written in everyday language without any abstract intellectual generalisations. In reflecting and analysing these descriptions the researcher wants to go “beyond the surface or explicit meanings to read between the lines so as to access implicit dimensions and intuitions” (Finlay, 2009, p. 4). Heidegger (2001) maintains that interpretation is not an additional procedure; rather it is an inevitable and basic structure of our being in the world because when we experience something it has already been interpreted. IPA leans towards using language and social relationships “and the inescapable historicity of all understanding” (Finlay 2009, p.4). IPA for example contextualises disability and has an idiographic focus and aims to offer insights into how a given person, in a given context makes sense of a given phenomenon. Heidegger believed that our environment impacts on our being which is a very strong argument for this research, because arguably, disability is a social construct impacted on by context and the ever changing environment in which it is located. Notably, the phenomenological oriented researcher does not merely narrate and summarise the participant’s experience. Rather he/she commits to the articulation of the individual’s lived experiences and commits to analysing the socio-political context in which experience is always embedded (Cosgrove and McHugh, 2008). The background context given in Chapter One is therefore very necessary in our understanding of where the core participants in this research are politically and socially situated in their world.

3.4.4 Strengths and Weaknesses of Interpretative Phenomenological Analysis

Every methodology has its merits and shortcomings but IPA does offer the prospect of authentic accounts of complex phenomena which suits this research. As the social world is never straightforward IPA allows the researcher to explore this complexity. A perceived strength of IPA,

*Is the creation of a richly interpreted, phenomenological account of participant data, arising from the meticulous engagement between the researcher and a small number of participants*

(Wagstaff et al. 2014, p. 10).
A critique of it suggests that the "reading between the lines" in its interpretation has generated uncertainty because as Finlay (2009) points out to what extent does this approach go beyond what the person has actually said and the researcher’s interpretation of it. As a counter argument, the framework of analysis that it uses and its strict adherence to it, traces each interpretation and thought back to the original transcript. Therefore, misinterpretation or exaggeration is not a feature of IPA studies because of this accountability process. IPA is also criticised for its lack of generalisations which occur in other qualitative research but this is what makes IPA unique. Rather than levelling criticism at it for this, it should be regarded as an inclusive methodology with humans and the human condition at its heart.

Furthermore, its humanistic approach has an “inbuilt respect for people” (Denscombe 2004, p. 105). As a result it does not treat participants as inanimate objects whose outcomes can be measured. It meaningfully engages the individual with the phenomenon in question and opens the discourse for people to get involved in areas of research that directly affect their lives. It is suited to the participants with ID in this small-scale research of nine core people. Their inclusion allows for their contributions and rich descriptions of their experiences of the phenomenon of choice and PA under consideration.

3.5 Meaningful Inclusion of Participants with ID in Research

The core participants in this research are adults with ID who engage in PA. It is good practice to reflect on how people with ID are regarded and treated by society prior to conducting research. It is important to know that, People with intellectual disabilities are disproportionately vulnerable to social exclusion, poverty and abuse (Corbett, 2011). It is no longer appropriate and loses relevance if research is conducted in an observational manner from an ‘asking others’ perspective. Core participants are the primary stakeholders in research concerning issues that directly affect their lives and IPA supports this. Research is therefore obliged to actively include people with ID and not to exclude these people because of methodological challenges. In an informed synthesis review and in reference to people with intellectual disabilities, the Social Research Council (ESRC 2008 p. 4) found that ‘qualitative research with this group is particularly rare and difficult’. The aim of the review undertaken by the ESRC was to,
take stock of, and gather methodological guidance to inform continued development of qualitative research methods for people with ID. It found direct participation uncommon for these very reasons. To effectively support a vision of inclusion in research, it is crucial that researchers acquire alternative ways of gathering information from people with varying communication levels. This helps to fulfil the goal of qualitative research which is quite explicitly to “ground studies in the experience and views of respondents” (Kiernan 1999, p.43). The participants in this study are not bystanders to be merely observed, but meaningfully contribute to research by giving their time, drawn from the expertise in their experiential lives. Although the levels of communication skills are diverse and challenging, this should not preclude people from being given the freedom to express themselves. In order to make research meaningful effort must be put into learning new and alternative ways of communication and inclusion.

3.5.1 Unequal Power Relations between Researcher and Researched

Wagstaff et al. (2014) points to the potential risk of abuse of power between participant and researcher. The difficulty of responsiveness and acquiescence are common, as are memory problems, and comprehension (Corby, Taggart and Cousins 2015). A clear definition of acquiescence suggests that the power dynamic might lead the participant to respond positively and appear agreeable to the interviewer (Corby, Taggart and Cousins 2015). These issues can be partly addressed through immersion, the interview guide and pilot studies. Acquiescence towards staff is a feature of ID and the researcher must be mindful that this can as easily be transferred to the researcher. It is important for the researcher to normalise the relationship as much as possible by building a rapport with service users for a suitable period of time prior to interviewing. It also yields richer and more authentic results from the data collected as the participant, at this point, feels comfortable in conversing with the researcher. For the purpose of immersion in this research, I attended the service twice weekly for whole days and participated in the same physical activities that the clients did and other activities besides. These ranged from aerobics, Weightwatchers, cookery and diet information classes, to attending the gym. My presence became normalised and my attendance
expected on those days and so the element of consistency by attending regularly also became significant for the clients.

3.6 Ethics

In a systemic review of IPA studies in ID it was found that consent was the most significant issue raised throughout all those reviewed (Corby, Taggart and Cousins 2015). The need for consent fulfils the ethical and legal requirements in order to protect humans involved in research. It also supports the researcher and promotes responsible and quality research. The development of ethical guidelines begun after the Second World War, under the Nuremberg Code 1947, in response to the investigation of experiences in concentration camps. It set out directives for human experimentation and emphasised the need for voluntary consent from the research subject. The Declaration of Helsinki, World Medical Assembly (1964) protects subjects in medical research and puts their well-being above that of the research. The Belmont Report 1979 ruled that the three ethical principles of respect for persons, beneficence and justice be applied to guide clinical research. In fact most organisations have a code of ethics, for example the college has a code of ethics as does the service in this research and they are guided by their own ethics, national and international ethics including the National Disability Authority (NDA).

Locating a research site, positing a proposal to an organisation, seeking and obtaining approval, documentation and putting the proposal to an ethics committee is a lengthy and stringent process. While ethical approval had been processed in the college, the ethical process for the service took seven months to complete. Considering that the ethics approval is for a day service where people with profound disabilities are exempt, the process appears outdated and overly protective. The ethics form in itself covers all medical eventualities and while this is the practice of the organisation which must be adhered, it is not conducive to welcoming research. The internal workings and ethics for researchers who work with the service is much more straightforward but there is also a need for researchers outside the service to get involved. This ensures that new ideas and research topics are introduced and considered. Ethics rarely gets approved without some amendments; therefore it is important to ensure rigour from the outset. Delays in ethics approval can significantly impede the progress of the research. It would be
unethical to include documentation with regard to ethics in the appendices of this thesis and therefore it is omitted for the protection of the participants who remain anonymised throughout. Ethics do not end at this stage as it is ongoing during the entire process of the research. Participants are informed at the beginning of the interview of their right to withdraw at any point even if the consent form is signed. It is especially important for the individual with ID to understand that ethics are there for their protection and that research is not a coercive process even when the individual is in the midst of it. It is important to be mindful that the participant’s informed consent cannot be taken for granted and must only be seen as part of a process rather than an initial agreement (Hall 2009). This safeguards the participant and by pointing out that the option to leave the research reinforces the meaning of choice for people with ID who might not experience it in their everyday lives. On an ongoing basis it became more evident why it is necessary to return to the issue of consent. The consent form for this research was produced and spoken through early in the process and also before each interview and signed at the end. Participants were given the option to withdraw from the interview at any time. See Informed Consent Form Appendix B.

3.6.1 Ethical Considerations for This Research
It is worth considering some of the ethical considerations that precede research, in particular issues of consent and capacity. The service involved did not wish to have any participants with profound disabilities involved in this research. They also requested that staff be approached at the outset in order to gain access to suitable participants. This raises the question as to how much real autonomy is exercised and how much choice people with ID are given in their own lives (Dysch, Chung and Fox 2012). People with ID are often seen as vulnerable individuals who need to be protected and safeguarded but the extent to which it is performed may significantly curtail their independence and control (Dysch, Chung and Fox 2012). This is especially true in day services where people are allowed generally to come and go as they please. Yet determining capacity to consent is generally assessed by involving others who know the individual best such as family members or paid caregivers (Coons and Watson 2013, p. 17). This is an area that has grown more important since the enactment of the Assisted Decision Making (Capacity) Act 2015. If people are denied or curtailed from making decisions and exercising choice around what they would like to do, it would appear that
the Act will remain irrelevant. Organisational constraints discourage people with ID from participating in research easily as it is difficult to access. Watson argues that this is especially true if the notion surrounding research in ID is not merely about seeking information but also about involving a component that aims to promote social change (2009, cited in Coons and Watson 2013, p. 15). Dye (2007) suggests that research regarding consent in research participation amongst people with ID has rarely been studied empirically amongst people with ID (2007, cited in Coons and Watson 2013, p. 14). There are several arguments raised with regard to research and how difficult it is for people with ID to become involved in research and whether indeed they would like to or not. This needs to be highlighted within services and especially those services now transitioning to community where greater autonomy ought to feature prominently.

3.7 The Process of Rigor in Qualitative Research

Rigor or trustworthiness in all research is necessary and indeed qualitative research has been especially scrutinised with regard to methodological rigor. There is a broad range of criteria for judging rigor in IPA and include balanced integration, openness, concreteness, resonance and actualisation (De Witt and Ploeg 2006). They add that balanced integration is the intertwining of philosophical concepts in the methods and findings as well as a balance between the voices of the participants and the philosophical explanation. Openness refers to the explicit process of accounting for each decision made throughout the study. Concreteness refers to how useful and applicable the study findings are to practice. Resonance gives the reader the experiential effect on reading the findings. Actualisation relates to the future realisation of the resonance of the findings. The best way to achieve this is to be meticulous at each step of the research process as outlined below.

The tools used to collect data and how that data is interpreted must be accountable. The tools should maximise the opportunity to identify the full range of phenomenon of interest. Collection techniques must be adequate to generate the level of detail needed and the analytical techniques should ensure the discovery of the full range of relevant themes and topics. Conflict and doubt especially exists for the novice researcher when using phenomenological research methods in analysis (Pereira 2012). Due to the diverse
theoretical and methodological approaches in research, a single set of criteria may not always be appropriate for all types of research.

This section will refer to an appendices section which will include the full rigor of research process from beginning to end for an anonymised participant.

3.7.1 Sampling
Interpretative phenomenological Analysis (IPA) is committed to understanding how a particular event, process or relationship has been understood from the perspective of particular people in a particular context (Smith, Flowers and Larkin, 2009). Consequently “IPA uses small, purposively-selected and carefully-situated samples” (Smith, Flowers and Larkin 2009, p.29). According to Smith, Larkin and Flowers (2009) there is no right answer to the question of the sample size and that it altogether depends on the level of commitment given to the analysis, the richness of the individual cases and organisational constraints that one may be operating from. For example, the participants in this research had mild to moderate ID as I could not gain access to persons with profound ID. Depending on the parameters of the study generally the number involved in an IPA study ranges from two to ten. As an idiographic method, small sample sizes are the norm in IPA as the analysis of large data sets may result in the loss of subtle inflections of meaning (Darker, Larkin and French 2007). The researcher can decide whether the study enables a detailed and very time consuming case-by-case analysis on a particular participant’s experience or whether to present a more general account on a group or specific population (Pietkiewicz and Smith 2014).

3.7.1.1 Purposive Sampling
The participants were selected in a purposeful sample and so they needed to fulfil certain criteria, i.e. being an adult and involvement in PA. The participants were recruited by accessing organisational information sharing, judgement, interaction with the organisation and snowballing initiated by the participants themselves. This proved to be interesting as those who engaged in the pilot study were eager to share the interview experience with their peers and actively encouraged more reserved people to participate in the research. It became apparent that one of the pilot study interviewees was influential and held in high esteem and trust by all of the groups.
The sample consisted of 7 women and 2 men with ID (mild to moderate as defined by the DVSM), aged between 23 and 58 residing in community housing and family homes or con-joined to family homes in independent living quarters. While the temptation was there to intentionally select 'rich' cases for the nature of the study, this was avoided in order to portray the reality of the varying communication levels of people with ID. This varied as some participants were very informative and forthcoming, some had less to say, and others needed to be prompted or probed at times. One participant was non-verbal and her sister agreed in advance to attend the interview with her. The participants had varying levels of communication. They cooperated voluntarily and expressed a genuine interest in the study and looked forward to the presentation of the findings at a later date. The overall experience of the researcher and participants was very positive insofar as they expressed feelings of accomplishment and asked for feedback regarding their performance at the end of their respective interviews.

3.7.2 The Data Collection Method
The preferred method of collecting data in IPA is through one-to-one interviews (Smith, Flowers and Larkin, 2009). This type of qualitative research interview is referred to as "a conversation with a purpose" and aims to facilitate interaction between the researcher and participant while giving the participant the opportunity to tell their story in their own words (Smith, Flowers and Larkin 2009, p.110). The researcher should come at the questions 'sideways' which means the interview is set up as an event which allows for the discussion of relevant topics, which allows the research question to be answered (Smith, Flowers and Larkin, 2009).

It is advised to have an interview schedule in order to be prepared as it allows the researcher to set a loose agenda. The interview schedule in the appendices does not truly reflect the sample interview from the anonymised person named Eileen for the purposes of this research (Appendix D). The reason for this is that while it serves as a general guide, it is not meant to strictly adhere to the script. This reinforces the idea that IPA interviewing is a conversation with a purpose and the interaction becomes organic with time and experience. This conversational style interaction is honed and perfected through the use of pilot studies. Pilot studies are used in many papers involving ID as it enables the researcher to refine the schedule over the course of the
interview process (Darker, Larkin and French, 2007). A schedule enables the researcher to plan for difficulties that might arise such as the breakdown and rephrasing of over-complex questions which changes the pitch and tone of the interview. Complex questions involving a concept like choice can be broken down into manageable steps that invite people to tell a story as opposed to defining a concept. According to Smith, Larkin and Flowers (2009) it is generally assumed that both the researcher and participant are active players within the research process and that the interview should in part be participant-led as he/she is the experiential expert on the topic. The participant should be “encouraged to talk at length” and invitations for more depth of thought and analytical discussion can be introduced as the participant “eases into the interview” (Smith, Flowers and Larkin, p. 59). Likewise, constructing the schedule is a useful way to think qualitatively and can be practiced on supervisors, peers or tested on a pilot group which is good practice. This results in either changing the interview guide significantly or simply using it as a reminder of what the researcher wants to find out and use appropriate level of communication to achieve this.

3.7.2.1 The Interview Guide
Questions should be prepared so that they are open and expansive and not over-empathic, manipulative, leading or closed (Smith, Flowers and Larkin, 2009). The opening question “should allow the participant to recount a fairly descriptive episode or experience” (Smith, Flowers and Larkin 2009, p. 56). “A schedule of between six and ten open questions, with possible prompts are ideal for articulate adults, with interview time occupying between forty-five and ninety minutes” (Smith, Flowers and Larkin 2009, p. 56). For those with varying levels of communication and those individual who are less conversational, language was kept simple. The sample interview (Appendix G) portrays what is meant by this. Open-ended questions and unstructured interviews are a feature of IPA as it ensures the subjective character of the experience is not prejudiced and themes emerge organically rather having them imposed through targeted questioning (Crotty 1998). Questions suitable for IPA may concentrate on sensory perceptions or mental phenomena such as thoughts, memories, associations and in particular individual interpretations (Pietkiewicz and Smith 2014). It is recommended that during the interview the researcher should feel comfortable with moments of silence so that both researcher and participant can take time to reflect on what has been discussed.
Silence was an issue during the pilot interview stage but the value of silence became much more apparent and appreciated as time went on.

Most qualitative methodologies do not formulate hypotheses prior to research being conducted (Pietkiewicz and Smith 2014). Themes must genuinely arise out of the data and not be imposed on it. Because IPA emphasises studying people idiographically this helps define the type of question which is suitable for an IPA study. The focus is on understanding from the perspective of the person being studied (Willis 2007, p.107). The types of questions included in an IPA interview/conversation will include some or perhaps all of what Smith, Flowers and Larkin describe as; descriptive, narrative, structural, contrast, evaluative, circular, comparative, prompts and probes. Ideas may develop and change after a pilot study. Consequently, questions changed as interviews progressed. Questions such as, ‘can you tell me what type of PA you are involved in’ tended to evoke more descriptive answers whereas conversational type questions such as ‘tell me about a day in your life ...’ evoked a richer narrative and provided more detail about the person’s life. Significantly, it is important not to simply ask participants the research question. Instead the research question needs to be looked at as a set of interview questions which when answered by the participants will provide the researcher with an opportunity to answer their research question (Smith, Flowers and Larkin, 2014).

The interview guide also takes into account that people with ID tend to give answers that aim to please the interviewer. Consequently, pilot studies were of immense use in this research. It allowed for the refining of questions which allowed the participant to speak freely, awareness of body language that might indicate approval and appreciation of silences. The following section deals specifically with pilot studies.

3.7.3 Pilot Studies
A pilot study is used in two different ways in social science research, as a small scale version of the main research or as a pre-testing of a particular research instrument (Van Teijlingen and Hundley, 2001). One of the main advantages of a pilot study is that it gives an accurate indication of whether a research project could fail due to using incorrect tools for gathering information or using inappropriate and complicated ones. This is especially true when conducting research in ID as levels and methods of communication
vary. Pilot studies have a myriad of uses. They test the adequacy of research instruments, design a research protocol and assess its practicality, assesses the frame and the likely success of proposed recruitment approaches. It can also be used as a resource for collecting preliminary data and is a good indicator of the proposed data analysis techniques that can be used. In order to strengthen the validity a questionnaire/interview, the researcher can ask the participants for feedback to identify ambiguities and difficult questions and to discard these where appropriate (Teijlingen and Hundley, 2001). It is also a check that everything the researcher wants answered is covered.

Nevertheless, pilot studies are not a guarantee of the overall success of the research because they are usually conducted on a small-scale basis. Pilot study results are not included in the main study, nor are the participants who engaged in the pilot study used again for the main study. Full reports of pilot studies are rarely reported in the research literature usually only stating that it was used. This is a criticism levelled at researchers who should be made ethically accountable by including pilot studies in their research reports (Teijlingen and Hundley, 2001).

The pilot study for this research was carried out with three people and proved very worthwhile. The results of the first pilot interview yielded thought-provoking results. While the interview read well as a text it did not address the phenomenon of choice until nearing the end of the interview. This was an indication that the research question was not being addressed. The other two interviews were similar and it was difficult to steer one person towards the question at hand as they tended to talk about their dissatisfaction with the service while ignoring the questions. It was revealed at the third interview that the pilot participant had no involvement in PA. As the interviews went on confidence and skill grew and it became a more enjoyable experience for the interviewer. This became apparent in the way the participants responded and how relaxed they looked. One of the most important lessons learned from the pilot study for this research was learning how to appreciate silence and the role silence plays in IPA. While typing the transcripts, silences became more meaningful and were could be associated with the particular participant readily. The depth of the experience and value
of pilot studies cannot be expressed in this section but a reflective journal was maintained throughout. An abstract from that reflection is included in (Appendix C).

3.7.4 Interviewing People with Intellectual Disabilities

To reiterate, IPA is best suited to a data collection style that asks participants to give a first person account of their experiences which gives them the opportunity to express themselves and reflect (Smith, Flowers and Larkin, 2009). Reflection in action became evident throughout the interview process and practically occurred in all interviews. Often the uncomfortable silences at the beginning became pronounced periods of reflection for the participant.

The researcher wants to facilitate the elicitation of stories that are not merely descriptive but must also elicit feelings and thoughts about the target phenomenon (Smith, Flowers and Larkin, 2009). This became more difficult with some participants who were used to speaking literally at all times. This rarely allows for evoking any real sense of emotion but as I had immersed myself in the service I came to know how individuals uniquely responded to questions and how they interacted with their peers and staff. This is reflective of a study conducted on the experience of people with ID and diabetes. Participants tended to describe the impact of some of the physical experiences as a result of not taking medication and not the emotional consequences (Dysch, Chung and Fox, 2012). The authors found that this was directly linked to the difficulty they had in articulating or making sense of their emotional responses. Additionally, they reported that the experience of many people with ID is that their emotional needs are not prioritised by others (Reed, 1997; Arthur, 2003, cited in Dysch, Chung and Fox, 2012). Careful questioning, building a rapport, regular interaction is important in order to alleviate such anxieties. When preparing for the interview and planning the interview schedule it is essential to anticipate these types of closed answers so that prompts and probes are prepared to continue with the conversation.

Depending on the nature of the research, many IPA studies explore very personal experiences. IPA studies are often concerned with significant existential issues so it is crucial that the interviewer monitor how the interview is affecting the participant. For example, if the participant avoids talking about certain issues or starts to feel awkward, ashamed or emotional, an experienced professional will pick up on this and follow
specific organisational procedures (Pietkiewicz and Smith, 2014). Personal issues unrelated to the research question may be divulged by the participant and may need relaying to the organisation. Support and protocol provided by the service pre-immersion and interview was provided in a structured manner and required a training and familiarisation period. Otherwise, if the participant has anxieties, it is recommended to end the interview and report it to staff. While none of these issues arose during the research period, supports were in place to manage them.

3.7.4.1 Interviewing the Core Participants
The logistics of location, time, surroundings and bathroom facilities are an important element of conducting a good interview. It cannot be underestimated how the interview environment impacts on the quality of data collected. This is especially true when participants might feel nervous and vulnerable, despite researcher immersion, when the interview day arrives. For all participants this was their first time being interviewed for research and they were both excited and concerned about their performance, i.e. 'saying the right thing'. This is something that needs to be taken into consideration when interviewing people with ID and is addressed under the Interview Guide in 3.7.2.1. Prior to interview other arrangements were considered, i.e. booking the interview room in advance, organising a mutually suitable time and minimising the risk of interruptions during the interview.

Interviews were conducted either in the reflection room or the conference room in the organisation. Generally, two interviews were conducted in a day, one in the morning and one in the evening. Prior to interview we met in the service canteen and had tea and a 'chat'. The interviews were conducted using a recording device which the participant already knew but it was evident that for some participants the recording device, though small, inhibited them for the first five minutes approximately. Interviews generally lasted up to and sometimes over an hour. The seating arrangement during the interview consisted of sitting opposite each other on two armchairs which contributed to the relaxed atmosphere. The beginning and the end of interviews proved to be where the participants spoke most freely, especially the end. I would say, we have been here for this amount of time now so is there anything you would like to add? At this point, and especially for the more non-communicative participant, the person became more
Each transcript was analysed separately and is discussed in the following section.

3.7.4.2 Semi-structured Interviews with Staff
This research is concerned with the core participants' experiences and views on choice and PA. On a daily basis within the service, participants are supported by key workers and other organisational and contract staff. For this reason, four people which include three key workers and one aerobics instructor have been selected for interview in order to illuminate the experience of the participants and significantly not replace them. These are semi-structured interviews and the informed consent and interview guide is attached (Appendices E and F). The purpose of these set of interviews is not to triangulate the data, but rather to illuminate the experience of the core participants.

3.8 Analysing the Data
In IPA the assumption is that the analyst is interested in learning something about the respondent's psychological world (Smith and Osborne, 2007). Meaning is central and the aim is to understand the content and complexity of those meanings rather than measure their frequency. It involves the researcher engaging in an interpretative relationship with the transcript (Smith and Osborne, 2007). Descriptive phenomenology seeks to throw light on the essential and general structures whereas IPA purists employ an idiographic analysis in an attempt to understand the individual which may not offer general insights. Halling (2008) suggests a middle position by including the particular and general because idiographic research has the capacity to be general in the way it identifies structures of experience. Halling further suggests that phenomenologists engage in three levels of analysis: firstly, they look at the particular experience, secondly, they identify themes common to the phenomenon and thirdly they look at
philosophical and universal aspects of being human (Halling, 2008). In this research and in response to the transcript, the participant and their experience are central. Common themes subsequently begin to emerge and finally, but much later when all of the transcripts are merged and superordinate themes identified, theoretical underpinnings become evident.

In their systemic review of phenomenological studies using interviews for data collection in ID, Corby, Taggart and Cousins (2015) refer to the management of data and the method of analysis as being an important part of maintaining rigour in research. While acknowledging that the number of participants may be low the amount of data collected is significant and requires the use of management tools. The number of participants does not however reflect the volume of data. The majority of studies were guided by the approach developed by Smith and the stages applied as he recommended (Corby, Taggart and Cousins, 2015). This is because it is a more definitive guide to analysis, flexible in its steps and can be personalised to adapt to the research without losing its meaning.

Referred to briefly, in the introduction to this section, is the conflict that exists for the novice researcher in IPA with regard to rigor and validity. Pereira (2012) asks whether the validity of a phenomenological study is better ensured if the researcher scrupulously follows a set of pre-established rules and techniques or whether an experiential approach which allows for flexibility and creativity is best. This argument is arguably applicable to any qualitative study. Some authors argue for an overarching framework that incorporates rigor, subjectivity and creativity (Whittemore 2001). Others maintain that reliability and validity remain pertinent and that the introduction of alternative criteria undermines rigor and is addressed by Pereira (2012). He refers to it as ‘a preoccupation with selecting and defending methods to the exclusion of the actual substance of the story being told’ (Pereira 2012, p. 18). As a novice researcher, I have chosen to follow the Framework of Analysis as set out by Smith, Flowers and Larkin (2009) as it gives a step-by-step set of guidelines. However, I am also aware of the importance of context in interpretation and the role of the research has of understanding at analysis stage. Consequently, constant reflexivity is essential which is maintained in the in the form of a written journal. The ultimate goal of this
phenomenological piece of research, and indeed all research, is to balance philosophical principles without losing the voice of the participant, openness, concreteness of phenomenon to context, resonance and actualisation of the research findings, discussed earlier in this chapter.

3.8.1 Framework of Analysis
A framework of analysis is required to navigate the process accurately and to keep order of emerging themes. There are no definitive and prescriptive methods of how to carry out an IPA. It is a decision made early on as to what works for the researcher while remaining faithful to the participant’s description of the data. The framework used in this research is that recommended by Smith, Larkin and Flowers (2009). Similarly, I have decided not to use computer generated programmes to analyse data such as Nvivo though some IPA researchers do. A systemic review of phenomenological studies in the area of ID found that qualitative data analysis through software packages was not identified as a feature in the majority of the studies (Corby, Taggart and Cousins 2015).

For ease of reference, while reading through the process of analysis, a sample that traces developing emerging themes is included (Appendix I). When there are a number of participants, it is then best to take an idiographic approach to analysis by reading each transcript in detail before moving onto the next one, “slowly working up to more general categorisations or claims” (Smith and Osborne 2007, p. 67). Similarly, listening to the recordings of the interviews at least three times sets the tone of the interview and interprets silences well. The first reading of the transcript with the recording in mind is good practice. The transcript is read a number of times and the left hand margin is used to annotate interesting or significant points about what the participant says. It is important to read and reread the transcript closely in order to become familiar with the account intimately, as each reading has the potential to throw up new insights. Richer data will attract more comments and some of the comments are used to summarise and paraphrase. Commentary on the use of language, similarities and differences and contradictions within the text transcript is worth noting.

The right hand margin of the transcript is used to document emerging theme titles (Appendix H). Themes move the data to a slightly higher or more abstract level evoking psychological terminology. It is advised to read the text backwards at this stage in order
to identify significant language, words or phrases (Smith, Flowers and Larkin, 2009). While this might seem peculiar it does raise some unexpected results especially in reference to how people express themselves and the type of language they use. Notably, the palindromic characteristics associated with this technique highlights repetition of words and phrases which is very useful. Initial notes are now transformed into themes and these themes may be repeated within the transcript where a similar is repeated. There is a tendency to call some of these themes by another name and is entirely dependent on the transcript the interpreter is working from as it identifies the uniqueness of language as a medium of expression. For example, more elaborate language evokes a more elaborate and higher level title, i.e. ‘defer to staff’ in narrower language might equate to ‘acquiescence’ in more elaborate language. The entire transcript is now treated as data and no attempt is made to omit or select particular passages for special attention as this contradicts IPA. The process is iterative and when all transcripts are completed and analysed, superordinate themes emerge with several subordinate themes.

3.8.1.1 Identifying Emergent Themes

Emergent themes are listed on paper and connections sought to make a link between them. In the initial list the order is chronological, i.e. the sequence in which the themes arise in the transcript. The researcher tries to make sense of the connections between themes which are emerging and some of these will cluster and others may emerge as subordinate themes (Smith and Osborne, 2007). Because the researcher is going back to the text in an iterative process frequently Smith suggests that the compilation of a directory of phrases that support related themes is helpful to compile. For example, words and phrases frequently used include: choice; self-selection; PA; health; and well-being in this research. Locating them through the ‘Find’ button on the toolbar indicates how often and in what context these are used. This helps to cluster them under relevant subordinate headings when writing up the findings chapter. All the while there is a need to be mindful of the fact that IPA is not concerned with generalisations. However, the data must be organised in order to make sense of it so that it can be interpreted.

While a single participant’s transcript can be written up individually it can also be done in combination with others. It is important to discern repeating patterns and
acknowledge new themes which will acknowledge similarities and divergences in the
data. Having analysed each transcript a final table of superordinate themes are
compiled and the analyst then decides which themes to focus on by prioritising data and
reducing it.

As the data emerges and counting begins it becomes evident that some headings or
superordinate themes are similar to the point that they can be subsumed into a larger
one. Superordinate themes come about when people express their experiences which
are unique to them through subordinate themes. People may speak of outings, food,
friendships and walking in a manner that suggests socialisation as indicated below.

Socialisation
- Outings
- Food
- Friendships
- Walking
- Holidays

Across the group some of these subordinate themes might come under the
superordinate theme of routine for example:

Routine
- Outings
- Food
- Walking

It is dependent on the experience and the context and so subordinate themes might be
replicated under varying superordinate themes. In order to illustrate process an
example of it can be found in the appendices (Appendix J). When writing up the research
findings and in the interests of rigor, the transcript of super-ordinate themes for each
person is allotted a line number (Appendix I). Therefore, when the reader wants to verify
a quote from the transcript, they can refer to the super-ordinate theme page. This
research gave rise to three superordinate themes, perceptions of health and PA, the
service as a facilitator and the concept of choice among adults with ID. Writing up the
data concludes the process as it outlines the meanings within the participant’s
experiences. It translates themes into a narrative account or argument interspersed
with verbatim extracts from the transcripts to support what is being said. The discussion
chapter is a mirror image of the findings chapter but rather than being descriptive it
engages with theories and philosophies with regard to the issues raised by the core
participants. This is interspersed with the recorded semi-structured interviews from the
staff and key workers. They are excluded from the IPA analysis process as their interviews serve to illuminate the experiences of the core participants and not replace them.

3.9 Conclusion
This chapter has given a comprehensive account of how this research has been methodologically conducted from beginning to end. In its introduction it has considered the qualitative approaches used in research, defining phenomenology and specifically choosing interpretative phenomenological analysis (IPA) as the method of choice. It offers an in-depth analysis of the justification for using this method moving on to the actual process of data collection and analysis. It considers the ethical considerations and implications of conducting research in ID asking whether this might contribute to the discouragement of research in this area and excluding people with ID. It describes how participants are selected for the research through sampling and the steps required before interviewing commences. This involves, immersion, a pilot study, the preparation of an interview schedule and the formulation of questions. The interview period or data collection period involving the core participants is described and this is followed by the method used for recording and analysing the data. This entire procedure is explained through the framework of analysis, and connecting the themes. This entire section is described under the rigor that is required in research. The following chapter Four presents the findings weaving the narrative of the core participants into this thesis.
Like, there's choices like, if I was told tomorrow to go for a walk, I'd go for a walk, for here if Elizabeth or Jane tells me to go for a walk, I go for a walk. And if we're going swimming, we go swimming, and if you go to the gym, we go to the gym. So that's my choice. I make a choice and I do all them things

(Eileen 2016).

Chapter 4 – Findings

4.1 Introduction
This chapter presents the main features, superordinate themes, of the participant experiences regarding the self-selection of physical activities (PA). It is narrated through the medium and methodology of Interpretative Phenomenological Analysis (IPA). This methodology encompasses superordinate and subordinate themes illustrating how individuals make sense of their experiences in relation to a phenomenon. This is arrived at through a framework of analysis whose process is comprehensively outlined in chapter Three. There are three superordinate themes: Perceptions of Health and Physical Activity (PA): The Service as Facilitator: and the Concept of Choice all considered through the lens of PA. By way of explanation, while health may appear to be tangential to the first superordinate theme, it is initially used as a 'hook' to get participants to expand on the subject of PA. After the pilot study it becomes apparent that participants themselves direct the notion of health as being a significant part of their experiences of PA.

Each superordinate theme has variations, or subordinate themes, which provide more in-depth and more specific detail of the theme being discussed. Under the superordinate theme Perceptions of Health and PA are, diet, weight control, definition of PA, activities organised by the service and the perceived benefits of PA. Under the superordinate theme Service as Facilitator are, Personal Care Plans (PCPs), the policy of New Directions, reliance on staff, role models in the form of staff and family and social connectors. The final superordinate theme Choice includes subordinate themes of, terminology, contextualisation of choice, settings that promote choice, expectations, independence and the inhibitors and enablers of choice. Themes are illustrated and supported, for the purpose of rigor, with direct quotations from the original transcripts
contributed by the core participants. Additional data collection from three members of staff and one aerobics instructor are included in order to illuminate the experiences of the core participants in this research but pointedly not to replace them. To illuminate is to provide an interpretation that removes obstacles to understanding but not an understanding of the participant's experiences. Rather it serves to illuminate the workings of the service, to discuss the application of policy and to understand the day-to-day challenges of service delivery to people with ID.

For the purpose of anonymity all references to locale and personal information that might disclose personal identity is either excluded or changed sufficiently where necessary. Each participant is assigned a pseudonym rather than a number, in line with the principles of IPA which is concerned with the personal. Van Manen (2007) argues that a phenomenological text is most successful when readers feel directly addressed by it. Hence, by naming participants in relation to their experiences reads like a story that the reader can easily follow. Names are assigned alphabetically but bear no significance or relation to the participant's true name. However, names are gender assigned and of the seven females and two males, the nine pseudonyms include Aisling, Barry, Catherine, Deirdre, Eileen, Fintan, Gemma, Helen and Isolde. Similarly, and for the purpose of anonymity staff are referred to as Keyworker 1, Keyworker 2, Keyworker 3 and Aerobics Instructor (AI). Notably they have not been ascribed first names in line with the requirements of interpretative phenomenological analysis (IPA) whose purpose is to place the core participant at the centre of research. The following table (1) provides a list of the nine core participants with some detail added in order to give an overall profile of the individuals concerned.
Table 1 Profile of Participants

<table>
<thead>
<tr>
<th>Participant Pseudonyms</th>
<th>Age</th>
<th>Living Arrangements</th>
<th>Length of Time in Service</th>
<th>Frequency of Attending Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aisling</td>
<td>30</td>
<td>Independent Community</td>
<td>13 years</td>
<td>Once Weekly</td>
</tr>
<tr>
<td>Barry</td>
<td>27</td>
<td>Home with parents</td>
<td>9 years</td>
<td>3 days per week</td>
</tr>
<tr>
<td>Catherine</td>
<td>52</td>
<td>Supported living</td>
<td>Over 30 years – Worked in Sheltered Workshops</td>
<td>3 days per week</td>
</tr>
<tr>
<td>Deirdre</td>
<td>59</td>
<td>Lives with siblings</td>
<td>30 years – Worked in Sheltered Workshops</td>
<td>5 days per week</td>
</tr>
<tr>
<td>Eileen</td>
<td>52</td>
<td>Cares for her elderly parent at home</td>
<td>30 years – Worked in Sheltered Workshops</td>
<td>3 days per week</td>
</tr>
<tr>
<td>Fintan</td>
<td>45</td>
<td>Lives at home on the farm with a purpose built flat beside his elderly parent</td>
<td>28 years</td>
<td>3-5 days per week</td>
</tr>
<tr>
<td>Gemma</td>
<td>43</td>
<td>Home with parents</td>
<td>20 years – Worked in Sheltered Workshops</td>
<td>5 days per week</td>
</tr>
<tr>
<td>Helen</td>
<td>23</td>
<td>Lives with parents and siblings</td>
<td>5 years</td>
<td>5 days per week</td>
</tr>
<tr>
<td>Isolde</td>
<td>39</td>
<td>Lives with recently widowed parent</td>
<td>20 years</td>
<td>5 days per week</td>
</tr>
</tbody>
</table>

This table gives information on the core participants in tabular format for ease of reference. It provides a comprehensive list of details including, age, living arrangements, length of time attending the service and the number of days a week they attend the day service.
4.2 Types of Physical Activity

The menu of physical activities available to the participants is varied. For ease of reference, a list of physical activities engaged in by the participants inside and outside of the service is illustrated in the following table (2):

<table>
<thead>
<tr>
<th>Physical Activity</th>
<th>Facilitated by Service</th>
<th>Outside of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking</td>
<td>Organised Outings</td>
<td>Functional</td>
</tr>
<tr>
<td>Swimming</td>
<td>Organised</td>
<td>Less Often</td>
</tr>
<tr>
<td>Gym</td>
<td>6-8 Week Programme</td>
<td>None</td>
</tr>
<tr>
<td>Basketball</td>
<td>Organised and played in Community setting</td>
<td>None</td>
</tr>
<tr>
<td>Soccer</td>
<td>Organised and played in community</td>
<td>None</td>
</tr>
<tr>
<td>Dance and Stage</td>
<td>Organised. Generally a bi-yearly event with a stage production as an endpoint</td>
<td>None</td>
</tr>
<tr>
<td>Aerobics</td>
<td>Weekly. Segregated.</td>
<td>None</td>
</tr>
<tr>
<td>Weight Watchers</td>
<td>Weekly – Semi Segregated</td>
<td>Other weight watch programmes such asSlimming World</td>
</tr>
<tr>
<td>Cycling</td>
<td>Not an organised activity</td>
<td>Functional</td>
</tr>
<tr>
<td>Farming</td>
<td>Skills and Community integration</td>
<td>Vocational</td>
</tr>
<tr>
<td>Personal Exercise</td>
<td></td>
<td>Two participants and special footpath designed for partially sighted participant</td>
</tr>
<tr>
<td>Equipment in own home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Horse-riding</td>
<td>Yes</td>
<td>None</td>
</tr>
<tr>
<td>Golf</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Boxing</td>
<td>Yes</td>
<td>None</td>
</tr>
</tbody>
</table>

This table indicates the activities that are organised within the service and whether these are further engaged outside of the service. It concludes that activities outside of the service are minimal and functional.
4.3 Personal Care Plans (PCPs)

The service follows the policy of New Directions 2012-2016 (HSE 2012) which requires, under HIQA standards (HSE 2012), that every individual attending the day service has a Personal Care Plan (PCP) drawn up. This is prepared at the time of the client's induction to the day and PCPs provide the mechanisms for how day services operate. The PCP has replaced the Personal Outcome Measures (POMs) but the principles remain the same. The PCP form begins with personal details about the individual such as age, name, and gender. This is followed by a section on the person's goals and this goal setting involves the person's chosen activities and aspirations and how they might achieve them within a specified period of time. A progress section follows this and requires frequent updating by the appointed key worker. The final section is on health and risk assessment as one area impacts on the other. PCP meetings are attended by a multidisciplinary team which consists of the client, key worker and social worker but other professionals that might attend are the psychologist, doctor and language therapist, where applicable. Items up for discussion besides goals include interests, activities, health and finance. This has the potential to link clients into other services in the community, for example the 'Men's Shed'. (To clarify, the Men's Shed is a grassroots organisation set up in Ireland in 2011 based on the original Australian model of 2007 (Men's Shed Ireland 2016). It works towards engaging all men in improving and maintaining their health and wellbeing by participating in a community Shed.

Individuals pay a nominal fee for activities. Some facilities in the community are subsidised as a gesture of goodwill, e.g. the use of a basketball court. Staff are mindful of the budget limitations of the individual which might sometimes override individual preferences. Similarly, if the participant or client has difficulty managing their weekly disability benefit they are referred to the Money and Budgeting Service (MABS) a financial advisory organisation independent of the service and another link into the community.

Organised activities feature heavily within the service, a necessity when managing groups. Indicative of this is the annual six-to-eight week gym community programme
involving participant engagement in various gym and swimming activities. Participants use exercise bikes, rowing machines, treadmills, swimming pool, sauna and Jacuzzi. Staff are aware of the need for rotating activities in order to avoid ennui and generally keep good seasonal weather free for more outdoor pursuits. These activities are less formal allowing for more spontaneity; according to staff who add that they are also more cost effective for the client. They include walking excursions to the beach, woods and Town Park. The frequency with which the participant attends the day service is a matter of choice and range between two and five days a week giving clients time for other activities and family commitments. The day service does not operate at weekends.

By way of explanation for the reader, transcripts from the core participants are referenced throughout by using the assigned participant name with the line taken from the original transcript in brackets. For example Aisling line 5 will read Aisling (5).

Reference therefore to a superordinate or subordinate theme will read:

Choice: **Because I love taking part in dancing** (Isolde, 14)

This does not apply when quoting from staff as their contributions are not being analysed phenomenologically but the page number that the quote has been taken from will read as (Keyworker 1, p. 5) by way of example.

### 4.4 Perceptions of Physical Activity and Health

It became obvious from the pilot study that people found diet and health an intrinsic part of their experience of physical activity (PA). The in-house Weightwatcher's programme was very current and set the notion of diet and health on course and in context with this research. It also became apparent during the pilot interviews, but more especially during the immersion process, that people liked to talk about their health and were intimate with this subject. This was notable in older participants initially but became more apparent when talking to younger participants who also enthusiastically offered their medical health history.

This superordinate theme therefore emerged as a result of the refined overarching question, 'tell me what health and physical activity means to you'. The following
subordinate themes developed from the superordinate themes included diet, weight, healthcare, moderation and education. While they are given a subordinate theme, they are woven into other themes. The most spontaneous response to the question suggests that diet contributes greatly to perceptions of health. It illustrates the attributes participants ascribe to 'good' food and 'bad' food. Notably, the service asks clients to bring a packed lunch every day as nowadays there is no fully working canteen operating in the facility. When sheltered workshops existed, the service had a fully operational kitchen serving lunch to clients, staff and members of the general public who visited. Currently there is a policy of no chocolate or biscuits on sale and from observation, the lunch boxes follow the healthy eating policy that the service promotes.

4.4.1 Healthy Eating
Diet is a prominent feature of the health plan that participants practice both inside and outside of the service. The promotion of water intake is as notable as the downgrading of 'fizzy drinks'.

 *Drink loads of water* (Helen, 2)

Gemma recommends the avoidance of certain foods.

 *Yeah, stay away from sugar and bread.* (Gemma, 13)

Barry is equally emphatic about what foods should be avoided and significantly is not the only participant to point out that moderation is also a feature of healthy eating. This brings a sense of reality and common sense to the notion of food intake.

 *Eat healthy, eat veg, maybe only eat chocolate and ‘taytos’ at the weekend and just stay healthy* (Barry, 7)

(Note: To the non-Irish reader, Taytos are a brand of crisps or potato chips in Ireland)

Eileen recognises why she must watch her diet,

 *I always exercised but the eating was a problem, the eating, the eating, you know, small portions. I go to weight-watchers* (Eileen, 17)

She is very aware of where her past problems have stemmed from and repeats the word ‘eating’ three times in order to stress her experience of it.
4.4.2 The Role of Dieticians

These are personal concepts of health-related links to diet but there are other more formal approaches that people are required to incorporate into their lives. Consequently, many participants mention that they have or have had a dietician in their lives.

*I go to a dietician. She talks to me about my diet and things* (Gemma, 14)

Catherine attends a dietician in the hospital periodically and keeps a food diary. She recites a list of foods to be avoided including fizzy drinks. When asked if she adheres to it she replies,

*I do, she'd say (the dietician) you can have a treat now and then you know. I watches it alright* (Catherine, 11).

She openly dislikes attending the dietician

*I don't like going over there because I don't know. When you go over there to the hospital and you weigh in I don't really like... well I have to go over like but at the same time* (Catherine, 11)

There are more attractive health programmes available within the service such as Weight Watchers which Catherine doesn’t attend. Attending the hospital appears to be an ordeal rather than a positive experience for her. Her reason for attending, it would appear, is linked to an existing health condition she may have,

*If you don’t keep healthy and you don’t watch your weight you could get a heart attack* (Catherine, 9)

Individuals are aware of their physical health conditions and this does entail some people attending the hospital weekly or fortnightly to be monitored. There is also a duty of care attached to the ethos of any service working with vulnerable people. Therefore, while the dietician might not be the most popular choice, it does highlight the health conditions that people with ID need to have addressed and cared for. It also resonates with the medical model of disability which is concerned with diagnoses and cure in a medicalised rather than biopsychosocial manner.
4.4.3 Personal Awareness of Weight and Weight Control

Watching one's diet impacts positively on weight and participants are aware of this. Some participants consistently associate weight with diet and are innovative in the manner they self-regulate their weight.

_I know if something is too tight. My weight would be gone up but it hasn't_ (Catherine, 12)

Similarly Deirdre who is non-verbal has her way of acknowledging weight gain by communicating it through her sister,

_If you show her your belly she'll go push it in with her finger_ (Deirdre, 6)

Deirdre's family are supportive in the maintenance of healthy weight and besides diet look to activity in order to control it.

_A few years ago there the doctor said to my mother that she'd want to lose weight so she bought her an exercise bike for home and she used to be obsessed with it_ (Deirdre, 6).

A recent and major addition to the service is the Weight-Watcher's programme. Weight-Watchers attend the service weekly and the mainstream community are invited to attend. This came about when Key worker 2 suggested it as an option to the service and to the Weight-Watcher co-ordinator who was seeking a suitable venue. Keyworker 3 says,

_It works well in the sense that for some people it has motivated them. ....Again its choice for them....they can stay or they can go and some people have been given that choice_ (Key worker 2, p.6)

This approach is new to the service as it provides a Weight Watcher's programme for people with ID on their premises and invites the wider community to enrol, which they do. A period was given to familiarise the participants into this new way of operating. The key worker explains,

_For the first three weeks we would have only had the service users because we just wanted them to get used to the routine of weighing, sitting down, having_
It brings men and women of all ages into the centre, some with young pre-school children. It doesn't stand out as anything other than what it is, a Weight Watchers programme. Having personally attended on several occasions it is evident that people swap information on weight loss or gain and congratulate or commiserate while offering mutual support. Information and recipes are shared and some staff also attend, not ostensibly as workers but as members of Weight Watchers also. For a programme that evolved more by accident than design, it has proved to be very successful. In addition it inadvertently acts as a facilitator for community transition for people with ID by reversing the normal strategy and asking the community to share in this effort.

As a point of information, all of the participants that attend Weight Watcher's in the service mention it in general conversation but do not add anything specific about it in the interview. Any information I have around the Weight Watchers programme results from my attendance at these weekly sessions for a month as a means of immersion.

4.5 Definition of Physical Activity

4.5.1 'There's dusting and polishing and making the dinner'

Having not associated PA readily with health it was necessary to define it. While there is recognition that PA is something that is good, this section finds that there is some lateral thinking around what PA is. It is not always automatically linked to sport or leisure and many initial responses related PA to everyday life in its most purposeful and functional form. The most active of all the participants contributed,

*Do you know say if you were at home and you were doing the housework you know you're hoovering and stuff and cleaning? That's actually physical activity as well* (Aisling, 18).

This view on what exercise is shared by many women while men will refer to farming and outdoor work which is interesting in light of how gender oriented people are across populations. Eileen, who lives with her elderly mother, outlines how her day begins.
And I take out the ashes and cleans the fire and there's dusting and polishing and making the dinner. And that's all activity you know (Eileen, 4)

While Eileen recognises this as an activity it also demonstrates how much of Eileen's time is taken up with caring for her mother and the extra responsibility she has.

Key worker 1 notes,

And then we have people going home to very, very elderly parents. Some of our clients would literally be carers for their parents. We have one girl there who cooks and everything for her mom though there are other family member (Key worker 1, p.8)

Activities organised by the service are recognised more easily than more strenuous one. Fintan goes home to help on the family farm charting the activity of feeding animals and doing yard work.

I puts out slurry and things for a friend of mine. I puts it out for him and he puts it out for me (Fintan, 6),

This act of reciprocation is synonymous with farming communities and Fintan regards his neighbours highly. Key worker 3 describes a programme that his group are involved in with a similar theme. He acknowledges that many people do not always have access to certain types of physical activities due to health and protection concerns from care workers and family. With this in mind he has organised a weekly visit to a local farm.

We go farming every Monday evening so we’re actively working and tipping around doing jobs. So we could be feeding the animals, pigs, helping bring in the cattle, picking carrots, potatoes, sorting potatoes for the winter, cleaning out the outhouses, the sheds, stacking turf. The reward is the activity, doing it (Key worker 3, p.5)

Later, this key worker and participants in this activity sit down with the farmer and his family and have a meal and chat as any group would. There are several layers to this activity. It teaches new skills regarding more specialised farm work and gets groups to work in a co-operative manner. It also allows people to participate in activities normally closed to them due to being over-protected as this key worker points out. It introduces
people with ID into the community in a manner that regards them as being productive, capable human beings. These types of activities indicate that some people are more involved in PA than heretofore thought and highlights aspects of the service as being proactive and progressive in seeking out new ways to motivate people to get interested and more active in their everyday lives outside of sport.

Other people while going about their daily lives such as shopping and visiting friends or family are self-reliant as a means of transport. This requires walking or cycling considerable distances. Helen recognises the social aspect of PA when she walks into town visiting shops and cafes. Therefore, it is leisurely as opposed to functional for the participant.

_We might walk, maybe into town_ (Helen, 3)

Key worker 3 acknowledges the functionality of this exercise

_Some people are unable to cross the road safely without instruction and this is a skill that is taught on these occasions_ (Key worker 3, p.3)

While these activities might appear to be unplanned, they are very much planned by staff to address practical issues in order to train and educate.

### 4.6 Organised Activities

#### 4.6.1 Activities the Service Facilitates

The most common activity both inside and outside of the service is walking. This is an activity that doesn’t ostensibly require money, special equipment or trained personnel. Eileen doesn’t always like these organised walks according to Key worker 1. She objects to them if she has already been to the post office or ran some other errands. This key worker regards this as purposeful walking constituting PA and does not feel Eileen needs to be forced into additional walking. However, she encourages her in other activities. This serves to protect her health in a caring way as opposed to denying choice or making a bad decision regarding her well-being.

The weekly aerobics class is an activity which approximately 25 to 30 people from the service attend in a very large gym room on site. It is regarded as a segregated setting as it is only attended by clients of the service and on their premises. Unlike Weight
Watchers it is not open to the community. It is an activity that is eagerly anticipated and most people attend consistently.

*My favourite thing is going to the gym, go to basketball and go to aerobics*  
(Gemma, 13)

Others may wander in and out during the hour long class and this is very much dependent on endurance and interest.

Nevertheless, there is a structure to the class and each individual is given dedicated one-to-one time in the group setting. The Aerobics Instructor (Al), who leads the class, has been working in this capacity for many years. Her set formula involves a series of exercises and interactive play with the group. This takes the form of asking each person separately to perform an activity to music in the centre of the group circle. There is an excitement and willingness shown by the participants in their engagement of this feature of the activity and no one is forced to do this. The programme is the same every week and is designed as a means of memory recall for the participants who often shout out what comes next.

The aerobics instructor believes,

*Everybody has the ability regardless of their disability and it's about participation rather than the activity* (Al, p.1)

It is obvious that the participants regard it as fun and it is also an occasion where groups from other parts of the service have the opportunity to meet up and have lunch together afterwards.

The participants interact very well with the aerobics instructor, who says of her role,

*My job is to nurture and bring everyone in their lives to the best that they can do and be and have their dreams* (Al, p.2)

Key worker 3 echoes this philosophy in their role also.

4.6.2 Popularity of the Gym

The gym programme is a notable popular activity organised by the service. The gym itself is located geographically in the community but acts as a semi-segregated setting
for the participants as they exercise as a group, though independent of each other. It is a six-to-eight week programme and participants follow a gym programme facilitated by staff from the service and specifically trained gym staff such as students from the local college. It allows participants to self-select various exercise machines through sampling.

A gym is a very pre-defined area in dimension and activity base. Yet it offers much choice, independence and variety to the participant. This subject of this programme is raised in all interviews. It is an area that does not require prompting to expand on or indeed introduce.

I love the gym alright (Catherine, 7)

And

My favourite thing is going to the gym (Gemma, 13)

Many participants raise the subject of the 6-8 week gym programme being too short at interview stage but as a group tend not to challenge this with staff. It appears not to be as important for everybody and participants tend not to want to challenge authority. Alternatively, they may not know how to voice dissatisfaction or fear that it may put them out of favour with staff and service.

Barry refers to past requests to have the programme extended without being overly concerned with it himself,

But some of the lads might want to do that and we don’t mind (Barry, 9)

These testaments strongly indicate the popularity of the gym. The gym programme lasts for 6-8 weeks during the winter months. This relatively short duration leaves some participants wondering why this is so but generally there is an overall acceptance that ‘other’ people make decisions that the participants have no control over. The responsibility for this action is placed firmly at the feet of ‘they’, nameless figures. The reasons for the short duration of the gym programme as outlined by staff indicate money issues for participants, resources and staff say they like to rotate activities,

We’ve learned down through the years that it’s good to do stints of eight-to-ten weeks and then change to something else. It keeps the interest up. (Key worker 3, p.1)
These do not appear to translate well into how the participant understands the cessation of something they clearly enjoy,

*Then they stops it, I don’t know why they stops it* (Catherine, 6)

Ultimately, there is an ambiguity between advancing sampling as a method of discerning preferred activity of clients and then stopping the activity because there is a need to rotate activities for the sake of variety.

4.6.3 Involvement in the Arts

Dance is another particular favourite especially amongst younger members of the groups. To date, many of the participants have been involved in the staging of two musicals in the local theatre. This event not only involves the actors on stage but also includes other sectors of the service in their whole service approach. One workshop in the men’s group produces the stage scenery for productions which are attended by the general public. An externally trained coach/choreographer is brought in to manage the training and rehearsals. Participants appear to enjoy the weekly rehearsals as much as the performance element.

*Yeah, because I do, I do love doncing....because I love taking part in doncing* (Isolde, 14)

It is regularly and eagerly discussed amongst the participants and is ardently supported by key worker 3.

Without prompting she says ‘they love dancing’. Keyworker 2 adds,

*If we were doing dancing and a drama class and that kind of activity seven days a week a lot of our lads would partake in it* (Key worker 2, p.2)

This negates the previous comment made by Key worker 3 who promotes the idea of rotating activities in order to keep interest alive. Dance classes in themselves, and not just for the specific purpose of staging a performance, could prove to be a worthwhile and effective activity during the year. The choreographer who teaches dance is not interviewed for this research but he is clearly highly regarded by the participants.

*And I love taking part with Michael (choreographer) because Michael is the fantastic dancer* (Isolde, 15)
It is also an activity that imparts confidence, improves mobility and balance and showcases the many abilities of the participants.

4.7 Perceived Benefits of Physical Activity

Physical activity (PA) for every population has a wide range of holistic benefits. Besides bestowing corporeal benefits it is also recommended as a therapy for good mental health, improved mood and overall well-being, criteria that fulfil the biopsychosocial model. The participants in this research give their varying experiences of PA, none of which are negative.

4.7.1 The Expressed Holistic benefits of Physical Activity

The overarching question, ‘can you tell me how PA makes you feel and what benefits you get from it’ made participants stop and think. It appeared that they had not thought about this before or perhaps may not have been asked about this part of their lives previously. Many of the responses referred to a sense of holistic wellbeing rather than any one specific benefit.

_I feel a lot better, better and refreshed_ (Aisling, 9)

And

_I feel relaxed and chilled down_ (Isolde, 10)

Deirdre’s sister explains,

_Oh she’d be on a high before she gets into the pool and she’d be calmer after_ (Deirdre, 5)

As Fintan walks a lot for functionality, it was interesting to ask him to describe his thoughts during these periods,

_Ah, I do be thinking about the views and the scenery_ (Fintan, 10)

Less elaborate but equally rich, Gemma says,

_I feel I like it. I feel comfortable in it. Yes. It affects me OK_ Gemma (9)
Catherine is very well able to explain her feelings when the question is turned around so that she has a better understanding of what is being asked of her. The question becomes, ‘tell me how you would feel if PA was taken away from you’?

I’d feel very sad about it. I’d feel hurt and sad about it. I’d crack up about it
(Catherine, 13)

PA is very important to her and not just for the activity itself but for the other social benefits it bestows, such as friendships and being with people, which is evident when she speaks of socialising later on in the chapter.

Another emergent theme suggests that PA alleviates boredom by getting people out of their home environment. Though Aisling's contact with her family is not as frequent as she lives independently she also recognises the importance of getting out of her own familiar surroundings.

I suppose it makes me feel happy. I suppose and it gets me out of the house
(Aisling, 14)

Barry takes the holistic approach to the benefits of PA referring to mental health in the first section,

Keeps it good, keeps you occupied and keeps you fit  (Barry, 8)

Other factors included in the benefits of PA were the fun that the activity brought and meeting friends was another important benefit.

4.7.2 Friendship and Networking

Equally important to the activity is its social aspect which many participants speak of. Food and refreshments feature heavily in this process and it would appear is as much looked forward to as the activity itself. This is despite the heightened awareness of diet, Weight-Watchers and the presence of dieticians in participant's lives. It is of course also an opportunity for a change of scenery going to a restaurant.

Post activity outside of the centre lunch is looked forward to and treated as a social occasion.

We might come back here for lunch then (Helen, 4)
Socialisation stemming from these friendships facilitated by the service is a very important part of the participant's lives. They value and look forward to occasions when they go outside of the service to engage in various activities, have a meal, go to the theatre or cinema, and go to the pub or bowling. Once a week, a night is allocated to a social outing.

_We all, the helpers and us get together and we do bowling one night, have a drink the second night._ (Catherine, 13)

This is eagerly anticipated,

_I get my dinner eaten and then I have then I'll get my coat and get my tops and clothes, nice clothes, to put on me to go out._ (Catherine, 16)

The process of and the skills required to foster friendship is succinctly described by Eileen,

_And you talk to people and you get to know people and mix in and make friends that way._ (Eileen, 7)

Equally, the cancellation of an activity which results in not getting the opportunity to meet friends is disappointing for some people,

_Well I missed the soccer this morning and I like meeting people._ (Fintan, 2)

Fintan repeats this many times throughout the interview.

Friendships are very personal and unique and encourage people to engage in activities. Some people like to get to know people through their groups or may have known them for a number of years through the school and service system.

_I have one very good friend and he's here. There's one or two of them here from school._ (Barry, 6)

It may also be the proximity in which they live

_I go out with my friend Sandy Shaw. She lives, she has a flat next door to me, across the way from my flat. We do our own things together._ (Catherine, 15)
Usually the stronger friendships are within the service with a combination of friendships and social connectedness through community, neighbours and family outside. It is also very dependent on how sociable the individual is.

_There'd be a game on there now and a friend would ring me and say 'are you going to the game' and I'd say yeah_ (Fintan, 8)

He is also a member of the GAA club,

_A few of the lads there now in the club, in my local GAA club_ (Fintan, 9)

There is also the reward of friendship attached to participating in a PA.

_With your friends. Meeting up with them_ (Helen, 9)

For others it may be an activity or shared interest that brings people together to be active.

_I go walking with my friends. It's the four girls or the three girls I walk with_ (Aisling, 1)

Though the memory of why an activity started might be vague it is significant enough for Aisling to continue on with it and sustain long-lasting friendships as a result.

This section on the participant's experiences of health and PA has looked at types and definition of activities. It has regarded health through the medium of diet and weight. It discovers that participants do not readily associate PA with health. The activities are described as organised within the service and as functional, purposeful and vocational outside of it. The next superordinate theme looks at the service as a facilitator and support for the participant. This is expressed through the experiences of the individual. It can be said that this section has reflected on how the service has educated people towards healthy lifestyles though diet and that there is room to translate the same spirit into the notion that PA is as important.

4.8 The Service as Facilitator

The service carries out many functions for the client. Besides organising activities and outings it provides a safe place for people to carry on with their daily lives in a day
centre. The service adheres to *New Directions 2012 -2016* and it is currently involved with the transition from service setting to community.

Where possible the service attempts to link clients in with services in the community. While care plans are individualised it is not always possible to satisfy every preference on all occasions due to under-resourcing, managing larger groups and the everyday challenges that arise when running a large and diverse organisation. Some participants attend the service on a daily basis while others attend from two days upwards and less than five per week (Table 1). Higher functioning younger participants appear to rely on the service less than lower functioning and older participants. The attraction of what is on offer is also a reason for people to attend more often.

The service has a wide range of activities available created and added to over the years (Table 2). Individuals pay a nominal fee for each activity some of which are subsidised by the community, for example, the hiring of a basketball court or a community centre. Staff are mindful of the budget limitations of the individual and this may sometimes result in leaning towards majority preferences instead of individual ones. However staff, as far as possible, set out to focus on individual requirements and are also aware of age appropriate activities and changing needs and trends.

It is evident having spoken to staff that they are very proactive in seeking out new opportunities to engage in activities. While some activities such as basketball, swimming, walking and soccer remain stalwarts, staff are conscious of introducing fresh activities in order to hold the interest of younger members.

4.8.1 ‘I’ll have to ask my keyworker’

Connection to staff is a common feature of the service though it is not true of all participants. There is a tendency for participants, who have a lower level of capacity for independence; to be very dependent on staff is obvious. All staff has a policy of encouraging and promoting independence. Helen was in the process of leaving her group and the centre during the research period to move to a branch closer to her home.

When asked about this Helen describes the move as,

> *It’s a new group* (Helen, 1)
It doesn’t appear to weigh heavily on her mind that she is leaving one group to be with another and refers to missing her key worker more than her peers.

While staff are very much in favour of people moving on they also recognise that it is not for everybody. As Key worker 1 says ‘they like coming here too’ (Key worker 1, p1). Participants also give views on how they exercise their independence within the service.

*We mix with other people* (Barry, 10)

Keyworker 2 believes that a level of segregation is required in order to acknowledge difference that might require specialist services. She refers to the mainstreaming of children with ID in schools who are facilitated well in the classroom but may not have the same support when going to the local pool to swim with their peers. While she is not directly referring to anybody in the service, rather to a situation she knows outside of the service, she feels strongly about this. Key worker 1 supports her and feels there is a need for more trained staff in gyms and pools to work with people with ID.

4.8.2 Connecting Outside of the Service

As part of *New Directions* policy, facilitating links to other services in the community not only depends on the service but on the participant’s social networks also. For the participant who is now an enthusiastic member of the Men’s Shed he describes how it came about.

*Well one of my neighbours living down the road from me, Joe Bloggs, and I was actually down the mart one day and I joined up and became a member. I joined up* (Fintan, 11).

He is very proud of this achievement which becomes apparent through his tone and demeanour. The service has a role in this and encourages other members to join the Men’s Shed also. There is a weekly meeting where men in the service convene in the centre, play soccer, have lunch and then have a closed shop on men’s health. For Fintan being a member of the Men’s Shed also means that he is recognised and included in their activities outside of the Shed as a peer,

*We go on day trips* (Fintan, 11)

The encouragement of this type of social connectedness is very important as a method of linking people with ID into community life.
4.8.3 'I go by the staff'
Staff in the service recognise their pivotal role in people's lives. Key worker 1 says of it,

"I would think so because the two days that the people would meet us it's the only source for them actually getting out of the home for those two days" (Key worker 1, p.3).

At times reliance on staff almost transforms into acquiescence to the detriment of the group. To acquiesce is to comply or agree in order to maintain stability and harmony. That harmony exists between client and staff or client and group and between staff and organisation. At times one may be at odds with the other and the client might acquiesce to the staff member while ignoring the group. This is especially evident when participants give ownership of the group that they are a member of over to the tutor or instructor. Helen assigns ownership of the group to her key worker,

"John's group" (Helen, 1)
(Key worker anonymised but first name included in order to relay message)

Staff and people like the aerobics instructor play an important role on a personal level to the individual as contact between them is a constant. When referring to the organisation or staff the language that the service user uses has an impersonal, distant tone at times. The notion of organisation is again a difficult concept to comprehend in the client's eye and is generally referred to as 'them' or 'they'. This objectivity allows the individual to air their dissatisfaction with aspects of the service rather than being critical of staff.

Similar type acquiescent behaviour is evident when a decision needs to be made where a walk is to take place Eileen perceives it as,

"They choose where we go, they choose. I go by the staff, what they tell us to do, yeah" (Eileen, 6)

Besides acquiescence, this statement also implies that staff knows best and that it might be easier to hand over the responsibility of making a decision to somebody else. Clients may be capable of making an individual decision but incapable of making a decision as a group as they might be unused to the process. Yet there is no animosity on the face of
it for handing over decisions but this might play out differently in reality. All staff has referred to the member who is in every group, ‘the one that shouts the loudest’ but who cannot get their preferences heard every time.

Reliance on staff also depends on the ability and capacity of the participant. Helen is asked what she is doing that afternoon. She stands up to leave and says,

*Do today? I'll go an ask Joe* (Gemma, 9)

The level of reliance placed on staff is dependent on the level of functioning of the individual. This demonstrates the important role that the trusted staff member plays in the life of the more vulnerable participant. While staff encourages and welcome independence they are also aware that for some people it may not be as possible. Gemma’s short-term memory is significantly low which creates that vulnerability.

Key workers and staff are seen in a positive light and play an important role in the life of the participant. They are often mentioned in conversation and for some act as guardians and protectors during the participant’s time in the service. They are regarded as role models, protectors, friend and trusted person depending on the participant and experience. When asked why she talks about her key worker so much, Helen replies,

*Minds us. In case we get bullied and he minds us* (Helen, 1)

She doesn’t explain what type of bullying when asked but she trusts her key worker to protect.

The aerobics instructor is highly regarded and mentioned in many of the participant interviews in a very positive manner. By the instructor’s own admission this is easy because she is not a staff member

*I don't have to get involved in the politics. I just do the fun stuff* (Al, p.)

She emphasises the importance of rapport and the success of her aerobics class is apparent by its large attendance. Why there are not more classes is explained by her. Limited finances for clients are the main reason given. Though the aerobics instructor keeps charges to a minimum she points out that the client have other activities to pay for and therefore does not force the issue.
Neither can it be ignored that her role is as she says ‘fun’. For staff service members the role may not translate to the participant as being as much ‘fun’ because staff have obligations and need to tend to the everyday logistics of running a service efficiently. The staff member takes on many roles including, guardian, organiser, negotiator and peacemaker with associated attributes of patience, listening ear and advisor.

Role models also exist outside of the service and for Aisling who works part-time in the community her role models also include her co-workers.

> I would find it different that I’m working that I can make my own choices and I suppose I’m learning from other people too and I’m picking up you know I suppose Aisling(20).

Aisling recognises the fact that because she is working and earning money she has more options to make choices as opposed to only selecting from the service menu. She is aware of other people around her, work colleagues, and realises the subtle impact they are having on her life actively reflecting on it.

4.9 The Role of Family

In relation to PA, family play an important part as role models and support systems. Fintan plays golf, albeit nowadays, in a field near his home practising shots. When asked how this interest came about he explains,

> Through my grandfather (Fintan, 8)

He reminisces on past role models in his life, especially his late male relatives, father and uncles. He is very much involved in the local Men’s Shed through the service and regards both his service key worker and Men’s Shed co-ordinator as other role models

> Yeah my key worker. Yeah. And then my other boss Mike down in the Men’s Shed (Fintan, 11)

He treats both the service and the link to the Men’s Shed as workplaces demonstrating the status symbol attached to being employed. He describes the camaraderie of the Shed referring to the daily cigarette break with the lads.

Deirdre’s late mother is her role model. She carries a picture of her on her person. Her sister supports this view and believes her level of independence is due to her mother.
People would always say, it’s my mother. My mother and herself you know... they just had this thing. They just knew exactly what they wanted, the two of them (Deirdre, 12)

Catherine, who is partially sighted, is supported by her family referring to her brother who specially laid a footpath around her house so that she can exercise independently of family and friends.

And we have a footpath all around our house and I goes out walking all around that, three or four times (Catherine, 3).

Gemma’s sister wants her to stay healthy and buys her equipment to help maintain her health,

I have the steps as well at home. Yeah I use it often. I often use it every week (Gemma, 14)

4.9.1 ‘My sister and my two brothers live near me, and my niece’

Family can act as agents of social connectedness. Barry lives with his parents and has an extended family of siblings, uncles and young nephews and nieces. He appreciates family time and the opportunities it gives him to connect with people.

It gets you places like to get out and to meet people, have a chat and a laugh (Barry, 3)

Such outings include a trip to the local pool with his family describing the experience,

I wouldn’t call it swimming but we have great fun (Barry, 8)

Most participants live independently but perhaps annexed to the family home in bespoke living quarters. The experiences of these living arrangements are conveyed positively with a sense of heightened belonging.

My sister and my two brothers live near me and my niece (Catherine, 4)

Some aspects of family life nurture new traditions for that family. Deirdre, who learned to swim later in life, loves to fly and has an annual holiday with her siblings and extended family.
We've been doing it maybe twenty years now. Every year we go somewhere. We have to fly. Always have to fly. Even if it's only up to Dublin from Kerry. We have to fly (Deirdre, 8)

Staff appreciates the family as social connectors. Key worker 2 responds to a question on the role of families at weekends.

A lot of them are rural and living with their parents, are reliant on transport and they tend to have more family oriented activities (Key worker 3, p.2)

Key worker 3 describes the role of family in the life of the client and the service as being highly important. Key worker 1 agrees adding,

A lot depends too on the age profile of the client that you're dealing with and the age profile of the parents that you have (Key worker 1, p.2).

She believes that the rapport built up between service and family is affected by continuity and transience of staff that often move on fracturing that important link.

In conclusion this superordinate theme has looked at the service as a place of safety, facilitation and support in transitioning to community. These are considered through the subordinate themes of PCPS, New Directions, ongoing transition to community, exploring the role of staff as role models and trusted other and the important role of the family. Examining the role of the service is the lynchpin between perception of health and PA. The third and final superordinate theme examines choice and self-selection through the lens of PA among adults with an ID.

4.10 Contextualising Choice

This theme covers choice and how people with ID select PA, what choice means, the terminology used to describe choice and how choice is practiced. The concept of choice is difficult for the participants to express readily. It becomes evident that participants find it easier to manage preferences and base their choice-making around that concept. A preference is the selection of one thing over others while choice is an option; a decision; an opportunity to choose or select something. Choice suggests assortment and range and is broader than preference. In direct relation to the research question participants are asked to relate their experience and understanding of choice. Subordinate themes categorised under this main theme have emerged and are dependent on how the participants responded. The expression of choice indicates
participant self-concept and examines whether the participants have control over meaningful choice in their lives with regard to PA. The transcripts reveal that the easier the notion of choice is for the participant to discuss, the more understanding they have of the concept and practice of choice.

4.10.1 'I make a choice and I do all them things'

The terminology used to express choice varies with regard to PA. Catherine opines,

\[ \text{We should pick what we want} \quad (\text{Catherine, 8}) \]

There is an unambiguous understanding here that choice is an entitlement and that the availability of choice ought to exist as indicated by the word 'should'.

Eileen's initial view on what choice means to her is both vaguely impassive and profound.

\[ \text{Like there's choices like. If I was told tomorrow to go for a walk, I'd go for a walk. For here if Mary or Joan tells me to go for a walk, I go for a walk. And if we're going swimming we go swimming and if you go to the gym we go the gym. So that's my choice. I make a choice and I do all them things.} \quad (\text{Eileen, 15}) \]

The tone is indignant and the language defiant. It suggests that this is a question that should not be asked because everybody knows what choice is. Similarly she might realise that she is not proactive in how she makes choices. While it illustrates the menu of options available to Eileen, it does not translate that she understands that choice-making is not equivalent to being told what to do. 'I make a choice and I do all them things' is illuminates her narrow understanding of choice. 'I make a choice' using the indefinite article as opposed to being more definite with 'my' choice or 'the' choice. 'I do all of them things' indicates that there are several options and rather than choosing one above the other, Eileen chooses 'all' of them. Implicit in this statement is that she self-selects several things in the menu of options provided by the service while practicing obedience.

Eileen's experience of choice is further illuminated by key worker 1. She explains that Eileen's attendance at the service alone is a major decision as she cares for an elderly mother. At times, when a social event is arranged, Eileen needs to check at home first
to see if she is free to go though she is a lady in her fifties. Another explanation for this is that Eileen is an adult with responsibilities towards her elderly mother. Eileen is very aware of what she doesn't like as opposed to what she does. A process of negotiation ensues when Eileen refuses to do what might be good for her health. While key worker 1 accepts Eileen's reasons she also gives her alternatives. Staff face their own hard choices between accommodating choice to those they support and taking responsibilities for health and safety in order to comply with service targets (Antaki, Finlay, Walton and Pate 2008)

In another example, which highlights the significance of terminology, Eileen uses second-person language when expressing her experience of choice.

Well what kind of things would you like (Eileen, 5)

This second-person language of things would you like is resonant of a person unused to being asked questions or answering questions about themselves. This is a concept that reverts to the notion that people with ID are rarely asked about their lives, experiences and opinions. This bolsters this research where people with ID are being asked about their experiences. Ordinarily, the experience is that people with ID are generally excluded from the disability discourse (Kelly and Watson, 2013). Offering people the choice to describe what choice means to them yields a hesitance in the description of choice but also garners rich data. This reply echoes of what a member of staff might ask Eileen, what kind of things would you like, signposting that staff do ask people these questions but that clients have difficulty internalising their meaning. Staff in this research have said that they get frustrated several times a day when participants do not volunteer opinions or make suggestions stating,

This is a constant thing. This is daily, not just once in a while (Keyworker 3, p.4)

Learning how to self-determine would provide the individual with the necessary skills to make choices, therefore encouraging them to avail of opportunities to make choices.

Despite any frustrations, all staff agree that,

You don’t push anybody into things that they don’t want to do or they’re very resistant (Keyworker 3, p.4)
While the research question relates to choice regarding PA, some participants relate it to other areas of their lives which is helpful when factoring in how the participants regard choice. Keyworker 1 contends that choice and choice-making is impacted by social and cultural elements. She continues,

*When I came here over thirty years ago the lads had very few choices. They came to work went home to the group homes. I don't think they were asked for their opinions too often* (Key worker 1, p.3)

As a backdrop, the service at one time was a place of work with sheltered workshops and clients attended as a place of employment where lifestyle activities weren’t featured. Catherine recalls,

*We used to do no activities below in (service) cos we were working in the kitchen. We used to go walking alright but we used to go walking home I think* (Catherine, 5)

She reflects in action and recognises how her life in the service has changed from being an employee to a place where she can avail of choice. This reflection is especially thoughtful with the addition of *I think*. The realisation sets in that life has changed for this woman now in her early fifties.

Choice can prove to be overwhelming, especially for those who are unused to being asked a question like this,

*Choice, Jeez, I wasn’t asked that question for years and years* (Barry, 10)

Once Barry feels comfortable that this is not a test, he visibly reflects and continues,

*I goes down town. I meets up with my friends. We go to the beach for a walk* (Barry, 4).

This is his definition of making and having choices, while another variation on the definition of choice indicates that it’s about rights and entitlements under the law.

*To talk about rights* (Isolde, 9)

In other ways participants allow staff to make decisions for them for events such as the annual day trip.
Last year we went to ******* but they’re not sure where we’re going this year yet
(Catherine, 14)

The use of the word *they’re* in this statement suggests that participants do not have any
input as to where they go. It could also mean that staff are awaiting feedback from the
clients but this was not clarified.

Eileen has a desire to go to ******* but it is unknown whether she informs staff of this.
Rather, the situation remains,

We go to Dublin or Cork maybe (Helen, 11)

This either/or scenario hails the creative process of making choices individually and in
group settings. While the agenda may be already set on the basis of cost and staff
availability, good practice would be to invoke a new process of learning. Barry similarly
relays this either/or scenario

We all had a choice to pick Cork or Dublin and we all picked our own place (Barry, 5)

Barry does not realise that this is not choice in the conventional sense. Participants can
only pick one and adding *we all picked our own places* is an exaggeration of the
opportunities for choice offered.

4.10.2 Isolating Best Practice in the Facilitation of Choice

Optimal settings for choice or places where people can comfortably make choices with
spontaneity are worth noting. The gym, set in the community educes enthusiastic
replies with regard to self-selection.

I do, I do the bike, the rowing machine and I do the weights (Helen, 3)

Catherine describes what she selects and how much she likes what she selects.

I does the rowing machine and I does the exercise bike and love it(Catherine, 2)

Keyworker 3 states that while people’s right to make their own decisions is encouraged,
it is not always the service’s experience that this happens or that people are eager about
trying out stuff. Therefore, rather than imposing pressure on people to make decisions
regarding PA they employ a method of sampling as it is another way to discover what people's preferences are. This is evident in the gym where people can decide for themselves what they like once they establish whether they enjoy the gym environment. Other activities such as specific team sports like basketball or soccer will not afford the individual the same ambit for self-selection as it requires that the individual to like the game and be a team player. This is not always the case so even though the gym is a narrow setting it has the dimensions to afford wider choice.

In the setting of the gym, participants also choose the other facilities on offer post-exercise such as the sauna and Jacuzzi and look forward to certain aspects of this.

_I go to the steam room_ (Gemma, 6)

And

_I like the Jacuzzi all right though_ (Catherine, 3)

This proves that people have the interest and proficiency to explore and discover other enjoyable elements PA settings might yield. While this self-selection process is set in the narrow environment of the gym, it is nevertheless a valid expression of choice through sampling and exploration. Individuals select for themselves without being led by staff, friends or peers. This fits well into the IPA ideology of how differently people experience the same phenomenon. Similarly, it is a good example of a setting where people with ID make optimal choices and could act as a template for self-determination in practice.

This rich data gives a varied picture of what the participants in this research think when asked about choice and how they explain it in abstract and real terms.

4.10.3 ‘No, I don’t mind, I don’t mind at all’

While this research wants to avoid quantification, a feature of many of the interviews is acquiescence which ultimately translates into low expectations. Group dynamics is an example one person in the group decides for everybody else, which can happen if staff are not vigilant. What is absent but can be interpreted from this however, is the fact that there is no input either way from the individual as to what they might like or indeed if they have a preference at all. Common terms when asked if they would like to exercise authority within their group includes,
No, I don’t mind, I don’t mind at all (Aisling, 15)

Or

I’m happy, I’m happy with everything (Barry, 6)

Both Aisling and Barry repeat their views in these sentences as if to confirm and convince themselves and the researcher.

Key workers illuminate the experience of unquestioning consent amongst group members which does not necessarily give a balanced picture of the dynamics in operation within a group. Keyworker 1 says a lot of clients are free and easy and couldn’t care less. However, she adds that there are

Always one or two in the group’ that voices what they want and we just say to the others are ye happy with this and they generally are, you know (Key worker 1, p.1)

The word generally needs interrogation as it suggests that a very small minority of the group sway the decision in their own favour based on the inability of the rest of the group to practice self-determination.

In group dynamics the observation is that the participant tends to go with the flow rather than upsetting the status quo as the preferred option. Similarly, participants are non-confrontational when something is cancelled or ends. In conversation with Catherine with regard to the gym programme ending, which she clearly likes, whether she will miss it,

I will but they’ll be walking sure (Catherine, 7)

Adding

I don’t mind, sure weren’t we out yesterday? (Catherine, 8)

This gives a sense of the gratitude and low expectations people with ID have got used to. Whether there is an undercurrent of resentment is unclear but the attitude is one of being happy with one’s lot and disliking confrontation. On the one hand, Catherine can identify what she likes and she actively pursues it. On the other, when it is removed she is grateful for having had the opportunity to experience it rather than seeking out why
it ended. Illuminating this experience, Keyworker 2 adds that this year another two or three classes were added because

That's what the lads wanted to do but not everybody wants that so when you're in a group of ten to twelve people you can't suit five or six who really want it and you have to accommodate the other people as well (Key worker 2, p.2).

While the complexities of managing a group are understandable and may be symptomatic of under resourcing, what is most striking about this statement is that five or six out of a group of ten to twelve comprises fifty percent of that group. The split decision has to be decided by someone but we don't know who. It is indicative of what people with ID have come to accept and/or indicates the lack of self-determined skills this population enjoys (Wehmeyer and Sands 1996).

4.10.4 Exercising Independently and Exercising Independence

An essence of this IPA study is to get a sense of whether ‘Exercising Independently and Exercising Independence’, amongst adults with ID attending a day service, is real or aspirational. The centre itself acts chiefly as a segregated setting for the homogeneous groups. As a space belonging to the service, cost is contained for the organisation and the service users. It eliminates any unnecessary transportation costs and is set in a familiar location. Peer groups from outlying areas of the service travel to avail of their chosen activities. This allows for difference and is a good starting point with which to give the individual the opportunity to make personal choices and identify preferences. It gives people the opportunity to choose what they want to do outside of their normal group. Keyworker 3 explains,

You'd see sometimes during lunchtime a group could go into a restaurant and all split up into different tables. That they want their own space. It's been a case that they've been in a service like ours for quite a few years and they get fed up with people as well and they get tired of them. They just want to exercise their own individuality (Key worker 3, p.4).

The participants themselves do not express these feelings in the interviews, but from observation, tensions do exist between people within groups who know each other a long time. The opportunity to meet new people is limited when people remain in the same environment. This points positively towards transition to community where
people are afforded the opportunity to network outside of this cloistered setting. Not everybody remains at the same point in their lives with regard to friends and people begin to move in different directions as they learn from new experiences and get older.

Some participants refuse outright to follow group activity due to personal dislike of the activity and sometimes the group. This is not a negative however in light of the research question as it establishes how people want to live their lives through PA and choice. Deirdre chooses not to be a group member for any activity. She is a non-verbal participant who communicates her choices through a unique form of language only known to her late mother and some staff in the service. Despite being non-vocal she has the ability to identify and ensure that her choices are carried through. She carries a timetable around her neck at all times as a reminder. Her activities of choice are swimming and basketball. Interviewed through her sister and key worker she brings photographs to the interview to indicate what she likes.

*Those pictures relate to her activities in the week so she can plan it out* (Deirdre, 9)

She uses her arms to describe swimming strokes indicating her love of swimming. She has high personal autonomy and communicates it well. According to her sister, Deirdre regards herself differently and as a result distances herself from her group and other groups.

*She gets on a lot better with us then she would with other people. She thinks she’s smarter than the rest* (Deirdre, 11).

The latter part of this is difficult to corroborate. It may be the way her family reflect on her abilities or what she herself conveys to them. As there were four people attending this interview I did not get the opportunity to pursue this further but included it as a point of interest.

Whether people engage in PA outside of the service or pursue other interests is worthy of note.

Aisling goes walking explaining,

*It’s nice to do things by yourself as well* (Aisling, 10).
Fintan doesn't need to go to a golf course to practice his shots,

And if I was at home and I had a club at home I'd hit a few balls in the field (Fintan, 8).

Key worker 3 says that while the service encourages people to engage in activities outside of the service,

I suppose sometimes we find as well that people have been so busy throughout the week they might like a quiet weekend like ourselves (Key worker 3, p.1)

The service makes it easy for people to participate in activities during the week because everything is organised for them. This is not a skill that they can transfer to their outside lives as it is not one that they possess which is a criticism of over organisation insofar as it prohibits people from learning new skills which nurtures confidence and independence.

Eileen manages to cycle a long distance every day to meet her friend John in town for tea somebody she knew from the service going back in time,

Every day I meet John. I cycle into town to meet him (Eileen, 4)

She doesn’t consider this to be a PA. Rather, it is an occasion to meet her friend and her means of getting there is immaterial to her. Having explored the distance and effort required to cycle this distance, it is a considerable measure of PA. She chooses to do this because this is something that she enjoys and the friendship must be important to her.

Catherine describes a day out with her friend, Nora, when they visit another town for pleasure and shopping which requires a substantial journey on foot to the bus station,

We do our own things (Catherine, 16)

This description removes itself from the abstract and describes choice in action. It requires commitment and planning to execute that choice while also incorporating PA into the overall decision providing an opportunity to nurture friendship. People with ID are able to make choices in many contextual settings Reid, Reynolds, and Bumgarner (1990, cited in Rossow-Kimball and Goodwin 2009).
Nevertheless, despite the popularity of the gym, participants do not attend independently. Neither is it something introduced or considered by the service. More independent individuals do not attend for varying reasons. Aisling explains,

_The only thing alright is I'd have to have my own transport you know if I was to join the gym_ (Aisling, 16).

For other participants the venue is outside of the main town. Yet Key workers 1 and 2 state that one of the reasons for using this particular gym is because, _many of the lads are from around there_. Despite this none of the participants interviewed indicated that they would attend independently of the service when the question was raised during the interviews. Neither did they show any appetite to attend there or any other gym. Rossow-Kimball and Goodwin (2013, p. 2) argue that “inclusive leisure contexts are not always welcoming environments for people with intellectual impairments”. Participants might have a fear of this along with not being supported by a familiar person or have trained staff to support and facilitate them.

4.10.5 Cost as a Limiting Factor to Choice

Interestingly, cost is not a subject the participants raise but it is something that staff are aware of in all interviews and is therefore included in this section. This subordinate theme illustrates the purpose of including staff in this study a means of illuminating an important area that would otherwise be overlooked. Including cost serves to illuminate what is available to the participant, why popular and beneficial programmes are short-term and whether cost actually restricts choice with regard to PA in the eyes of the service.

Staff are keenly aware that costs must be kept to a minimum for clients while recognising the need to provide good quality programmes. They are, for example, very aware of the cost of gym membership and give this as one of the many reasons for the relatively short-term six-to-eight week programme. Traditionally, they explain, summer months are flexible so that outdoor activities denied to people in more unseasonal months can be availed of at lower cost to clients. Trips to the Town Park, shops, local woods and the beach, are a good use of natural resources and also bring visibility of people with ID into the community which staff regards as quite important. Likewise
good weather means that people can get to and from their home and shop on foot. Key worker 1 suggests that these everyday activities are also weather dependent mentioning the cost of taxis as an added expense which people cannot afford out of their budget. Key worker 2 puts it in context,

So for us to do an added thing of them going to the gym is costing them maybe six or eight Euros a week and that’s at a special price. And if you take from someone who is only earning 188 Euros a week, 10 Euros of that is huge (Key worker 2, p.2)

This is a significant amount of monies taken out of the set weekly payment coincidentally similar in amount for an unemployed person. Rent, utility bills and food costs are deducted from this and key worker 1 estimates that having paid everything the person is left with fifty Euros a week for themselves.

Cost is an issue regardless of the 'goodwill of the community' as Key worker 3 points out. Goodwill cannot always be relied on and does not make for structured planning if it is applied in an ad hoc manner. This same key worker relates that on one occasion he asked a community based computer training programme to facilitate service users. The organisation were under the impression that ye do that kind of thing yourselves, don't you? He adds that this is the type of reality you are dealing with in the community. This is an indicator of how prepared the community is for the transition of people with ID from congregated settings.

Besides cost, other reasons given for short gym programmes is the consideration that shorter programmes sustain interest and the need to rotate activities is important. Keyworker 3 is cognisant of the fact that there are young people in the service who have different needs and tastes to the older members and consequently he constantly looks for fresh ideas. Mary and Joan add that because they are always in the community they too are constantly looking for fresh ideas.

4.11 Conclusion
This chapter has considered the findings from the data collected from the core participants for this research and the semi-structured interviews from key workers who
contribute towards illuminating the experiences of the core participants. It has identified three superordinate themes, namely perceptions of health and PA, the service as facilitator and the concept of choice. Many subordinate themes have been developed from each of these main headings indicating the scope of the study but more especially the richness of the text. The research illustrates the menu of activities developed by the service for and because of participant input. While there are many positive findings there are also findings that suggest choice largely goes unpractised. This chapter is chiefly descriptive rather than being critical or interrogatory. The next chapter, the discussion chapter, explores these findings under the same superordinate and subordinate themes already identified in light of the literature and this research.
Chapter 5 Discussion

People live in communities, not in services

(Liz Weintraub, self-advocate)

5.1 Introduction

This chapter discusses the findings, looks at existing literature and revisits the objectives of this research entitled a phenomenological study of physical activity (PA) and choice among adults with an intellectual disability. In summary, three superordinate themes emerged during the process of this research. The first theme considered the participants’ perception of health and well-being. This revealed that the link between PA and health and well-being was less evident than the link between diet and weight control. The third theme examined how the participants made choices, the terminology used, where they made choices best, in consideration of the many subordinate themes that contributed to this outcome. The second theme looked at the pivotal role the service played in the lives of the participants with regard to the provision and facilitation of PA. This chapter discusses these themes in light of existing literature while identifying areas that need attention in future research.

At this point, it is important to highlight the methodology used in this research in order to set the findings in the context of how they are reported. Interpretative Phenomenological Analysis (IPA) does not present findings in general terms as IPA does not strive to make universal claims, but rather cautious general claims about the particular group studied (Smith and Osborn 2008). It situates the researcher at the core of the research process. As IPA is both phenomenological and interpretative, it necessitates reflexivity throughout. Consequently, a journal was maintained throughout the research process and was used as an aid for reflection in the writing of this chapter.
5.2 Participants Understanding of Physical Activity

A perquisite to participation in this research required that the adult with ID being engaged in PA. This section therefore looks at how the participants in this study regard PA and what part it plays in their lives. It began with their definition of PA which was broad, made evident in how they replied to the overarching question about their understanding of PA. Rather than just referring to the types of PA that the service offers, the participants associated PA with purposeful and vocational activities as part of their everyday lives. The World Health Organisation (WHO) describes PA as any bodily movement produced by skeletal muscles that requires energy expenditure (WHO 2011). Caspersen, Powell and Christenson (1985), state that PA in daily life varies and can be placed in the categories of occupation, sport, conditioning, household and other activities. Indicative of purposeful PA outside of the service especially, some participants give an insight into their daily responsibilities such as caring for an elderly parent. Physical activity therefore, is not recognisable as something that happens in the service alone but is represented as part of daily living.

5.2.1 The Physical Activity Programme

Participants are not disposed to give an overview of what the service offers so it is left very much up to the staff to illuminate this area of the research. Participants know what they like and engage in their specifically chosen activities as well as the more structured group activities. The service has built up a limited but varied menu of PA over the years which they tend to rotate to ‘keep interest alive’ (Keyworker 3, p. 1). Traditional activities include walking, swimming, football and basketball, while newer ones include the six-to-eight week gym programme, the weekly aerobics classes and the Weight Watcher’s programme. The take-up for these are high amongst the participants and they enjoy and look forward to them. The gym programme is quite short at six-to eight weeks, considering gym membership in the general population ranges from three months to a year allowing the member to attend as many times as they wish during the week. Outside of the service however, people are reluctant to attend the gym independently.
Besides distance and transport, people don’t like doing things by themselves especially when it is something new and there is no obvious support available to facilitate it. Linked into this perception is that people like to go to familiar places and may lack the confidence to go to a new place on their own.

These are very valid reasons, not removed from how people in the general population feel about going to new places on their own. Furthermore, generic gyms and fitness instructors do not always have the necessary skills that would enable people with ID enter into gym programmes (Jones et al. 2007). The popularity of the gym programme cannot be underestimated in this research and the value the participants place on it is evident. The interest shown could be nurtured and encouraged by extending the gym programme, thus making it a long term PA commitment as a means of extending the knowledge base in this area. According to Lante et al. (2011) evidence exists that PA programs benefit adults with ID in the short term, however no research has been reported on the effect of long-term engagement. This, however, does not mean that short-term engagement is better, it means that research interventions are generally limited and constrained by time. This research has shown that the benefits of gym activity extend beyond the physical to areas such as confidence building, increased independence and social connectedness. This is evidenced by Barry who says that his keyworker who attends the community gym with his group does not discourage him from interacting with other people outside of the group while in the gym. Lante (2011) found that programmes that exist in the community for people with ID allows them to value the experience of engaging in and learning a new activity, the opportunity to meet a wider range of people, meet more people and gain social praise and acknowledgement. He also noted that as a result of this there was a slight increase in weekend activity for the participants.

5.2.2 Functional Physical Activity
Walking is a traditional and cost effective way of getting exercising, socialising with friends and becoming a visible part of the community. For Fintan it serves as both a function and leisure. However, it is not favoured by all participants. If the participant spends a lot of their time walking as a means of transport and purpose, they do not necessarily want to engage in it as a leisure activity. Therefore, Eileen might sit on the
beach, during the beach walk, and refuse to go any further at which point Keyworker 1 might coax her or agree that she has enough walking for now. Keyworker 3 also experiences this with his clients and describes a participant who had for some time remained reluctant to participate in walking due to his low mood.

_We have learned that this particular person has benefitted greatly from a walk, the exercise, seeing new things in the town park, flowers, it brings around conversation and the next thing they forget about their problem_  
(Keyworker 3, p. 4)

Consequently, encouragement, motivation, concern for well-being and finding and tailoring solutions to difficulties all serve to change the experience for the client. This is supported by Schijndel-Speet, Evenhuis and Wijck (2014) who have found that motivation to participate in activities can be difficult but research has found that demonstration of behaviours, tailoring and positive encouragement are thought to be effective strategies. Thus, while staff are aware of the multi-functional benefits of PA, participants are largely unaware of these benefits in comparison to their wider knowledge of diet and weight control which is much more evident.

5.2.3 Linking Health to Physical Activity for the Participants

Participants did not link PA to health and wellbeing as strongly as they did to diet and weight control and certainly not without prompting. Diet and weight preoccupied much of their time speaking about health in general.

_If you don’t watch your diet, you could get a heart attack_ (Catherine, 9)

Yet, prevailing evidence and recommendations shows that PA contributes meaningfully towards an enduring and healthier way of life for adults with ID (Heller et al. 2013 and Emerson 2011). Similarly the World Health Organisation (WHO) estimates that physical inactivity is the fourth leading risk factor for global mortality (WHO 2011). This pertains to the entire population but there is evidence that PA levels in people with ID are low. Consequently, a more sedentary lifestyle associated with ID, increases health risks (Emerson 2005; Moss 2009; Temple and Stanish 2009). The reality for all populations is that lack of regular PA is a significant adverse risk factor to health (Finlayson et al 2011).

The service in this research designs the provision of its activities around the Personal Care Plans (PCPs) that every member is entitled to under HIQA standards as outlined in
New Directions 2012-2016 (HSE 2012). A full description of Personal Care Plans (PCPs) and their remit is described in Chapter One, Section 1.8.3. PCPs set goals for the individual factoring in relevant activities that facilitate the needs and further development of the individual's identified goals. For many, and from observation, being overweight is an issue for participants that may incur secondary conditions that the organisation is aware of. Therefore, participants had or have dieticians factored into their care plans. This inevitably makes the participant more aware of diet and weight.

It is not that the service discourages PA, in fact the opposite is true, but the health agenda appears to be more successfully focused on weight control and diet. It also resonates with the medical model of disability which the service adheres to with regard to the health cares of individuals. Employing the psychosocial model would veer the focus away from medical intervention towards a more holistic approach to well-being. Exercise is actively encouraged for the general population but is seldom advocated as an effective or real intervention for those with ID (Stanish et al. 2006). Similarly, the health disparities that exist among people with ID in comparison to the rest of the population is also a very recognisable feature which can lead to a greater risk of obesity and chronic disease (Prasher and Janicki, 2002; Havercamp et al. 2004). These are all notable reasons for participants being largely unaware of the correspondingly enormous benefits of PA.

The information gleaned from this research highlights the type of research questions appropriate to the ID population. According to Knox and Hickson (2001) participatory research, involving people with ID, has provided a means of gaining access to and an understanding of relevant people's perspectives. It allows for the emergence of issues significant to the participants themselves rather than the researcher. This research is a contributing factor towards adding to literature in this regard and acknowledges the information gap with regard to participant understanding of the benefits of PA to their health and wellbeing. It is noteworthy that, when asked, the participant's view on health and wellbeing is given from how they regard it and not how professionals do. Ordinarily, as Moss (2009) points out much of the research in ID involves short-term interventions that evaluate programmes. What is lacking from this type of research is feedback from the participants who have engaged in it in order to learn more about the effectiveness.
and relevance of the intervention to the people it concerns. This would serve to inform policy well. The participants interviewed for this research all engaged in more than one activity on a weekly basis during their time in the service.

From personal observation, the participants did not appear to reach a moderate level of aerobic level of activity. Current recommendations state that individuals engage in at least 30 minutes of moderate exercise daily for at least five days a week in order to gain health protective benefits (British Heart Foundation, 2001; ACMS 2016). Despite this, many adults with ID do not engage in sufficient moderate to vigorous intensity physical activity (MVPA) to accrue health benefits (Lante, Walkley, Gamble and Vassos, 2011). Neither is there an extensive understanding or knowledge of the health behaviours of older adults with ID (Dixon-Ibarra, Lee and Dugala, 2013). Lloyd (2016) argues that more research is required to quantify the appropriate amount of PA necessary for health. This requires, she states, an accurate collection, analyses and interpretation of PA data on people with IDs. None of the participants in this research indicated that they felt they were not doing enough PA to maintain their health but neither was this used as a probe or prompt during the interview process. Yet, the popularity of the aerobics class and gym programmes are good indicators of how guidelines, if given, could be met. Evidently the length of the gym programme cannot convey this information at present. There is a need to have intervention research to investigate effective programmes that increase PA (Peterson et al. 2009), but there is little research about how frequency of exercise affects quality of life (Blick et al. 2014).

Though, the World Health Organisation (WHO) is concerned with the levels of activity amongst people with ID. Robertson and Emerson (2010) argue that there is a need to move away from the more prescriptive and authoritarian benefits of PA and to focus instead on social relationships and fun elements. All participants enjoy the activities they choose and, as with the general population, their focus is not always on health and in this research many also refer to the ‘fun’ element of PA.

Having fun also lifts the mood but probes and prompts had to be invoked regarding the effect PA has on personal mental health. It is unknown, from this research, whether people do not readily associate mental health with PA or whether they dislike talking about their mental health. Posing the question therefore evokes descriptive nouns such
as happiness and participants allude to *getting out of the house* as being particularly significant as a contributory factor for good mental health. People with ID are at much greater risk of developing a psychiatric illness, with some estimates suggesting that they are three to four times more likely to do so in comparison with the general population (Cooper et al. 2007). A recent report on the health impact of Special Olympics programmes on wellbeing cited that people who participated in these programmes were happier than those who didn’t (The SOPHIE Study 2016). In this research a good example of the impact PA has on maintaining overall health is illustrated by Aisling.

*I think it’s healthy to keep my weight down maybe and to keep active* Aisling (13)

5.3 The Nature of Choice

The third superordinate theme, choice, has proven to be the most problematic and complex phenomenon in this research. Consequently there was much reflection on the concept of choice throughout the research process. A personal reflection concluded that there are minor choices such as what to have for lunch and there are more life-changing choices that dictate the path taken in life. Choice is ultimately selecting from alternatives. The danger of approaching a concept such as choice is that there are preconceived notions in the general population as to the definition and exercise of choice. Knox and Hickson (2001) signpost this in their study on friendship among people with ID. They state that friendship is generally measured in terms of what the researcher considers as important relationship attributes rather than what the person with ID considers as important. For the purpose of this research, therefore, choice refers to the act of “selecting an item or activity from an array of options at a particular moment in time ”Romaniuk and Miltenberger (2001, cited in Cannella, O’Reilly and Lancioni 2005, p. 2).

5.3.1 Optimal Settings for Choice

This research concluded that participants were more accomplished and more comfortable at making choices in narrower settings than in the wider group context. For example, the gym is found to be a successful facilitator of choice at two levels. Firstly, people have no issues in picking their favourite piece of equipment and secondly they achieve this through sampling which affords them the opportunity to identify preferences. The language however does not suggest that this person makes choices
easily. Catherine speaks for everybody when she uses the word ‘we’ and ‘should pick’ implies that this is the theory of choice but not necessarily the practice of choice. *New Directions 2012-2016* (HSE 2012) advocates that people with ID who attend day services must be facilitated in having choices, doing interesting and useful things with one’s time, learning new skills, meeting people and enjoying their company (HSE 2012). The ability to make choices will soon be tested under The Assisted Decision Making Act (2015) whose tenet is to allow people with ID to make decisions concerning their legal affairs and is dependent on their capacity to do so. By definition, a person lacks capacity if they are unable to understand the information relevant to the decision, to retain that information, to weigh the information as part of the process of making the decision or to communicate their decision (ADMB 2015). This is a very large demand if the participants in this research are representative of people with ID who attend day services with regard to the understanding and practice of choice.

Choice features more and more in the disability discourse and one argument against it is that increased choice is handing over responsibilities to vulnerable people who cannot make choices because of the disconnect between the choice discourse and reality (Fyson and Cromby 2013). The authors support this by explaining that the notion of personhood requires people to work and participate in community life, something people with ID are largely excluded from. Only one participant in this research works part time and she refers to what this means to her life and how it differs from that of her peers who rely heavily on the service to fulfil and validate them.

This queries how the transition for people with ID to the community will transpire. Initial findings from the IDS-TILDA longitudinal study on aging with a disability in Ireland, indicate that the social and cultural environment influence opportunities to engage in activities of daily life but without the right supports the transition will be challenging (King et al. 2016). Employment is something that many of the older clients miss since the sheltered workshops that operated in the service were closed several years ago. Lack of employment impacts on the amount of money clients have to spend on their leisure pursuits and this is something that New Directions 2012 -2016 (HSE 2012) omits to address. There are however, other links into the community which Fintan avails of.
and clearly enjoys so much so that he considers it as a place of employment due to the nature of the work.

Yeah. And then my other boss Mike down in the Men’s Shed (Fintan, 11)

This provides him with a status and social standing and gives him the opportunity to be part of something larger than the service. On a global scale the WHO (2011) report that many people with disabilities experience worse socioeconomic outcomes than people without disabilities. This is largely because they are excluded from employment which in turn denies the individual of an additional avenue of choice.

Generally for people with ID choice is contingent on access, availability, family and service provision. Contributing reasons for not being proficient in choice-making includes the ability to choose, not being privy to choice, unused to making choices, used to having other make choices for them or not wanting to take responsibility for choosing. Individuals with ID have not been provided opportunities to make choices and decisions based on their own preferences (Agran, Storey and Krupps 2010). Eileen’s perspective on choice brings all of these elements together.

Like there’s choices like. If I was told tomorrow to go for a walk, I’d go for a walk. For here if Mary or Joan tells me to go for a walk, I go for a walk. And if we’re going swimming we go swimming and if you go to the gym we go the gym. So that’s my choice. I make a choice and I do all them things. (Eileen, 15)

Therefore, a dedicated guide that supports people with ID to make their own decisions is of paramount importance. A view advanced by Schelly (2008, p. 719) is that some people with ID “cannot think in the ways necessary to make choices that would improve (their) quality of life”. The freedom to make decisions which affect our lives is a fundamental right that each of us should enjoy (Department of Human Services Australia 2012). A guide to supporting people with an ID in this regard has been published in Australia (2012) and is all-encompassing with regard to capacity, decision-making, disability supports, dignity of risk, duty of care and substituted and supported decision making (Chapter Two). It sets out the antecedents required for good choice making for people with disabilities because, as this research reveals, the notion of choice
for the participants does not convey a wholly positive image of how they have grown to understand and practice choice.

Otherwise, choices are often made by staff if they believe it is in the interest of the individual's welfare. Catherine attends a local hospital to keep an appointment with a dietician and openly dislikes the experience but appears to have no choice in whether she wants to attend or not.

There are many other real barriers to participation and opportunity outside of general societal barriers for example overly-protective caregivers and medical professionals who may inadvertently reinforce sedentary behaviour because of safety fears (Brooker et al. 2015). On the other hand, staff are also faced with dilemmas such as concern for care over the right to choose. Choice, which is framed in health policy, assumes that patients are given options on how to be treated (Mol 2008). Whether this translates to people with ID is doubtful considering Catherine does not appear to be overtly approached with given alternatives by staff or medical personnel. This echoes the ethos of the medical model of disability, discussed in chapter Two, which medicalises disability, demonstrating the "dominance of medical approaches and of medical experts" (Shakespeare 2006, p.15). Modern alternatives involve carrying out a risk assessment in the interests of supporting people's autonomy (HIQA 2016). One of the suggestions for setting the tone for respect for autonomy involves "including people in communication regardless of cognitive ability and operating restraint-free environments wherever possible" (HSE 2016, p. 18).

5.3.2 Exercising Choice
Many of the participants exercise choice by stating what they don't do which is another approach to making a decision. Helen doesn't go swimming when she goes with the group. This limits choice and the act of making choices because it doesn't require a skill set to say 'I don't' without being offered alternatives. Considering the group goes swimming weekly, Helen is not learning anything new. The implementation of a strategy to self-determine could resolve this. Strategies that support self-determination include encouragement of choice, setting goals for autonomous leisure, commitment of staff members to independent leisure, determining individual preferences, creating
opportunities to act on choices and educating staff on self-determined behaviour (Rossow-Kimball and Goodwin 2009). Because group activities are a feature of the service due to understaffing, impromptu outings arise, such as going for a walk or to the pool which are relatively cost effective. Not everybody wants to go for a walk or, like Helen, don’t want to swim but cannot be left behind either. This is representative of the limitations of choice and the lack of availability for alternatives where the only option is to ‘do nothing’. The type of choices individuals make, if they are taken seriously and how they are supported in doing so remains unclear (Agran, Storey and Krupp 2010). This constitutes the missing link where the breakdown occurs between the choice of the individual and the ability of the service to provide other services and supports. This occurs most often in the group context and an example of how it is dealt with and how participants react is demonstrated in what Barry says,

*But some of the lads might want to do that and we don’t mind* (Barry, 9)

This is further illuminated by what Keyworker 2 says,

*That’s what the lads wanted to do but not everybody wants that so when you’re in a group of ten to twelve people you can’t suit five or six who really want it and you have to accommodate the other people as well* (Keyworker 2, p.2).

*New Directions 2012-2016* (HSE 2012) promotes choice amongst people with ID but it is unclear as to how it aims to achieve this effectively when staff are constrained by time and under resourcing. Staff are faced with difficult challenges in their work where the reluctance to offer choices may conflict with their responsibilities for health and safety reasons or the need to meet institutional targets or being constrained by time (Antaki 2008). Staff often circumvent this by giving the client limited choice in the form of either/or, which technically constitutes choice, however limited.

The either/or scenario arises in this research predominantly around day trips. Agendas may be already set on the basis of cost and staff availability but the how choice is understood and made remains ambivalent.

*We all had a choice to pick Cork or Dublin and we all picked our own place* (Barry, 5)
Offering a list of more than two alternatives can lead to confusion leading to the institutional imperative of having an acceptable working answer to a question is what wins out (Antaki et al. 2008). There may be more importance attached to the day-to-day running of the service over and above the interests of its members. For example in reference to a walk that staff takes the clients on, issues of time is raised.

*We'd have maybe a set time and it's up to people themselves to walk 20 minutes or 25 minutes there and 20 minutes back* (Keyworker 2, p. 5)

*And*

*We can certainly keep a better focus on our timetable* (Keyworker 3, p. 3)

The ambiguity is that the service that employs staff may have personal empowerment enshrined in its mission statement but due to lack of training, time and real commitment may not be able to invoke the ideology (Antaki 2013). The mission statement for the service in this research is to identify, respond to and support the needs of individuals in the manner of the organisation and the vision they aspire to strive to actualise the potential of each individual. The needs are identified through PCPs but may not always be carried out in a group context or time spent on an individual basis may be constrained by resources and time.

Keyworker 2 in her description of what choices are offered compels the notion of either/or,

*Like yesterday was a really warm day and they got a choice for their dinner, whether they wanted a cooked meal or they wanted to do a cold salad* (Keyworker 2, p. 4)

Embedded practice also explains why decisions are made in this way. Wong and Wong (2008) find that people who are close to individuals with ID such as support staff might consciously or unconsciously provide fewer opportunities for personal control to individuals with ID. This is due to a combination of factors such as ingrained practice, time constraints, organisational goal-setting, attitudes and lack of specialised training in offering choices.
This research found that some participants acquiesced to group or staff decisions due to the lifelong experience of low expectations. There is a sense of gratefulness expressed by Catherine, who misses the gym but is accepting of what it is replaced with,

I don’t mind, sure weren’t we out yesterday? (Catherine, 8)

It is indicative of what people with ID have come to accept and/or indicates the lack of self-determined skills this population enjoys (Wehmeyer and Sands 1996). Low expectations for people with ID are widely felt to be a significant barrier (WALK 2007-2013, P. 6). This begins for many in the education system where people with ID are generally excluded from the higher expectations of their mainstream peers who are being trained for employment. The individual with ID begins to accept and adopt this attitude for themselves and regards it as the norm. Staff, family and the general public are also responsible for this attitude because the person with ID occupies a place in society which remains on the margins. As a group, what people with ID have in common is that their voices have traditionally been marginalized – both within the research process and as part of a wider experience of oppression (Northway, 2009, p. 175).

5.4 The Service as Facilitator
The role of the service as a facilitator of PA and choice is the final third and final part of this discussion chapter. In effect much of this has been interwoven into the first two sections on the concepts of PA and choice amongst adults with an ID. To reiterate and as illustrated in chapter Four Table 1, the service provides a menu of activities added to over the years as the needs of the clients change. While the more traditional activities of walking, soccer, basketball and swimming remain constants, other activities such as the gym and the Weight Watcher’s programme are more recent. Aerobics falls somewhere in between these two and proves to be a popular activity where a large group congregate to exercise weekly.

Most pertinent, and what this research has found, is the pivotal role the service plays in the lives of the participants with regard to the provision and facilitation of PA. Otherwise, clients would not have the same access to these types of activates, tailored especially for this heterogeneous group. The service also recognises that the transition to community is ongoing and requires a strategy to implement it effectively. The service
links individuals into community services such as the Men’s Shed and keeps costs to the minimum for the client. To access the variety of these activities in the community would be largely unaffordable for a group that relies on disability payments for basic needs such as shelter, food, utility bills before they can consider leisure activities. The National Disability Authority (NDA) promotes equal opportunities for recreation and sport but adds that physical literacy is lacking and needs to be taught to people with ID (NDA 2005). While promoting equal opportunity is commendable it could be argued that there are few opportunities in the community for people with ID. This is a contributing factor towards the heavy reliance on the service as a facilitator of PA. It also means that while the service provides these activities it is the place where participants spend most of their disposable income. In a report on self-advocacy Start listening to us on foot of an Áras Attracta investigation (HSE 2016) residents spoke about areas of their lives they felt they had little personal autonomy. Areas of significance for the participants included personal autonomy for example in how they chose to spend their money (HSE 2016). While this is not a feature of this service that participants raise, they may not have an understanding of it. It does meant that participants spend a large part of their income in the service and consequently have little disposable income to spend on activities outside of the service should they wish?

5.4.1 Connection to Staff
For those participants who attend the service daily, there is an inevitable rapport between participant and staff member. Participants often regard keyworkers as protectors and guardians. Helen is asked what her instructor/keyworker does with her and her group she replies,

_Minds us. In case we get bullied and he minds us_ (Helen, 1)

This is a thought-provoking choice of words and it gives an insight into the trust that clients place in staff. Support staff are perceived to be the “key holders to social activities, yielding power to influence important decisions in their lives and depended on for practical and sometimes emotional support” (Mason, Timms, Hayburn and Watters 2013, p. 116). Participants validate this view by handing over any decision-making skills they have to those they regard as having the ultimate power over their lives. While staff may be unconscious of this they nevertheless recognise the important
role they play in the lives of the clients. When this is alluded to in the interview, Keyworker 1 agrees that staff are important.

*I would think so because the two days that the people would meet us it's the only source for them actually getting out of the home for those two days* (Keyworker 1, p2)

This gives an insight into the power imbalance that exists between people with ID and others and it contributes towards the notion of low expectations that people with ID have come to live with.

The level of reliance placed on staff is dependent on the level of functioning of the individual. This demonstrates the important role that the trusted staff member plays in the life of the more vulnerable participant. While staff encourage and welcome independence they are aware of limitations of some participants and realise their need to adjust and innovate when managing group activity. This type of reliance manifests itself, during the interview, when Gemma when asked what your plans are for today says,

*Do today? I must ask John* (Keyworker 3) (Gemma, 9)

While activities within the service are very structured what happens outside of the service differs.

5.4.2 Participant Experiences of PA Outside of the Service
The research found that participants were less likely to get involved in structured physical activities outside of the service. None of them were involved in a sport or had a hobby to fill their leisure time from home. Only one participant was in part-time employment. However, this did not preclude everybody from engaging in PA of some description and the most popular form of PA was found to be walking,

*I try to walk as much as I can if the weather is nice I go out walking* (Aisling, 10)

Others speak of home life which is ordinary but most notable is that there is no mention of having friends visit or the participant visiting with friends. An exception is Catherine and her friend Sandie who live opposite each other who might go somewhere together. Additionally, Catherine cannot go out on her own as she is partially sighted and is
therefore dependent on other people for support. Engagement in activities is either solitary or involves friendships from the service.

For many people with ID “friendships can be limited and restricted leading to loneliness” but little attention has been given to exploring these issues with people with ID (Mason, Timms, Hayburn and Watters 2013, p. 108). People with ID tend to rely on friendships made through the service simply because they do not have the same opportunities as the general population to nurture friendships through work, social life, networking and dating. For example, the participants interviewed who were in relationships met their partners through the service and saw them every day in the service. Keyworker 3 acknowledges the participant’s view on the restricted nature of fostering friendships,

_It’s been a case that they’ve been in a service like ours for quite a few years and they get fed up with people as well and they get tired of them._ (Keyworker 3, p. 4).

Keyworker 1, adds another dimension to participants who may not be able to foster friendships because people are in effect carers for their elderly parents. The TILDA study recognises that people with ID are living longer than before and in many cases outliving their parents who are often their primary caregivers (IDS -TILDA 2016). Currently there is a deficit of research exploring family care giving capacity in Ireland especially in the ID sector. Trinity College Dublin’s School of Nursing and Midwifery, funded by the National Disability Authority (NDA) aims to research this area (IDS TILDA, 2016).

This is one of the barriers that restrict participation in community settings. When the individual is confined to one set of friendships within the service, there is less opportunity to participate in PA in the community due to the lack of more extensive networks. According to Corby (2012), people with ID appreciate being given opportunities to network. The subjective well-being of people with ID depends on “relationships, choice and independence, activities and valuable social roles” and are the leading elements that make them feel happy about their lives (Haigh et al. 2013, p. 26). It is therefore important for people with ID to have good things in their lives but it is equally important to be enabled to access these good things. Having no access to new
experiences and people further insulates people with ID from forming new friendships and indeed the skill it takes to make new friends.

Otherwise, participants need more community supports and more initiatives to participate in activities. However, Inclusive leisure contexts have not always been welcoming of people with ID (Rossow-Kimball and Goodwin 2009). This prevents people with ID, who might like to participate in these activities in the community, from attending these venues. Self-determined leisure behaviours are possible if the nature of the leisure setting is inclusive but previous lack of exposure to people with ID among the general population inhibits full social integration (Rossow-Kimball and Goodwin 2013). Therefore, the transition period to community important not just as a means of moving geographically from one premises to another but to be seen in the community. Staff were found to be a key to the Quality of Life (Qol) in community transitioning in Ireland were key to implementing change, facilitating independence and knowing the likes and dislikes of individuals (Kilroy et al. 2015).

Staff in this research raised their concerns about the turnover of staff which affects both the participant and their family.

It also depends on continuity of staff and staff building up a rapport with these people (Keyworker 2, pp. 2 and 3)

Provision of permanent staff also made a huge difference in facilitating individual’s choice because they were sufficiently in tune with the individual to interpret their wishes (Kilroy et al. 2015).

5.4.3 Family as social connectors
The service considers the role of family in the lives of the clients as being very important. Similarly, for the participant themselves, family play an important role in their lives. Many live in rural communities and are transported to the service by a family member daily. Fintan has strong neighbourhood bonds sustained through the farming community. Besides meeting his neighbours on a regular basis he refers to them as friends,

I puts out slurry for a friend of mine. I puts it out for him and he puts it out for me
This act of reciprocity depicts community life and participation. Policy should be directed towards the primacy of the family and other natural support networks such as friends and neighbours (NVFED 2009). They add that these natural networks would serve to counteract the loneliness that is especially felt by the ID population. Barry has an extended family network and spends a lot of time with them. In reference to this he says,

*We all go together and we do stuff together* (Barry, 8)

"Forty-seven per cent (47%) of people with ID in Ireland live in the family home supported by parents and relatives" according to 2006 figures (Felce, Perry and Kerr, 2011, p. 421). These authors also found that little research has been conducted about the quality of life (Qol) of adults who live at home with their families. McConkey et al. (2010) conducted two studies into community contacts and leisure pursuits of adults with ID finding that few had diverse contact with other citizens. Their leisure activities were found to be passive or solitary as clients are generally dependent on the habits of their parents and extended family. Staff address the fact that some participants are carers for elderly parents which was a surprising discovery, and this further constrains them from getting involved in activity outside of the home.

Results from wave one of IDS TILDA shows that community dwelling people with ID have greater contact than those living in institutions but that levels are below those for the general public (IDS TILDA 2016). It adds that while community settings offer more opportunities for people with ID they still have low levels of connectedness with family and friends and have small social networks outside of staff and other people with ID (IDS TILDA 2016). Contact with family in this research was very evident and friendships were found to be mainly with other people who had an ID because of the length of time they knew each other as a result of going through the school and service systems together.

Community capacity building and the involvement of community are recommended as prerequisites to improving equitable access to prevention and health promotion (Brand et al. 2016). In recognition of the benefits of PA for people with ID, this study found that physically active people play more active roles in their respective communities than
those with less engagement (Lavesseur, Desrosiers and Tribble, 2008). A systemic review conducted by Stith et al. (2006) concludes that a community should fulfil four conditions before a preventative health intervention can be successfully implemented. Firstly, community capacity must exist, secondly there must be a recognition that existing programs cannot solve the problems sufficiently, thirdly a key person or organisation should be identified and fourthly stakeholders must benefit from participation without drawbacks such as high cost. While this is not strictly a health preventative intervention, it does explain what is needed to make transition smoother while recognising its complexity.

5.5 Conclusion

In conclusion this chapter has discussed the findings in light of what it adds to the disability discourse through three superordinate themes. These include perceptions of PA for adults with ID, the nature of choice within ID and how reliant the participants are on the service to avail of PA. It suggests that research is not asking relevant questions of relevant people and so it is illuminating to discover how people regard their health and on probing how PA impacts on their corporeal, psychological and social well-being. It determines that choice-making amongst the participants is limited to narrower settings and that group dynamics deter people from making choices. Rather, they hand the choice-making over to the 'experts' or staff. Finally the role of the service and family as social connectors and supports are a significant part of the participant's life. While this is a time of transitioning to the community it appears that the service will remain an integral part of the lives of the participants for some time to come. The following and final Chapter Six concludes and proposes recommendations arrived at as a result of this research.
Chapter 6: Conclusions and Recommendations

*Phenomenology involves detailed examination of the participant’s lifeworld; it attempts to explore personal experience and is concerned with an individual’s personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself*

(Smith and Osborn 2007, p. 53)

6.1 Introduction

This chapter concludes this research by providing a summary of the findings with reference to: ‘Exercising Independence and Exercising Independently: A phenomenological study of physical activity and choice among adults with an intellectual disability’. It identifies superordinate and subordinate themes, arrived at through interpretative phenomenological analysis (IPA), and discuss the implications of these findings for practice, policy and research going forward. While conducting the research a reflective journal was maintained with suggestions for future recommendations. It was used to guide this chapter which concludes with recommendations for future research.

Smith, Flowers and Larkin (2009), caution against moving toward general claims in IPA. IPA research does not attempt to produce an objective or definitive account of a phenomenon and only claims to access a version of the experience as the participant makes sense of it through their narrative account (Smith and Osborn 2008). Findings lend themselves to being transferable rather than being generalisible because a phenomenon is experienced by an individual in a unique way but may be lived in a shared context. Green and Britten (1998, cited in Cassidy et al. 2011 p. 267) suggest that for the practitioner, findings are ‘attuned to issues that could be usefully explored in practice’. IPA, as an approach to research challenges conventional discourse and ways of thinking. Care has to be taken to avoid trying to fit data into frameworks that fit current discourse as it tends to obscure the reality of the experience while simultaneously arriving at false assumptions. Smith, Flowers and Larkin (2009) think in terms of theoretical transferability rather than empirical generalisability. In simpler terms this means, that the reader can make a connection between the analysis in an IPA
study, their own personal and professional experience (resonance) and claims made by the literature. Rigorous analysis, therefore, allows us to evaluate its transferability to people in contexts more or less similar while simultaneously further illuminating the broader context.

The quote at the beginning of this chapter signifies the importance of the use of IPA for people with ID and for this research. The subjectivity of experience is evident in this research and the richness of the data evidenced in extracts from the transcripts. The research questions were designed to look at how people with ID regard physical activity (PA) and how they selected their activities captured through the lived experiences of the participants. The study of the literature focused on the holistic and biopsychosocial benefits of PA for people with ID; the meaning of meaningful choice-making and the range of choices available to adults with ID through the lens of PA. Pivotal to the study is the personal experience of choice and PA among the core participants which led to the selection of IPA as the most appropriate methodology. The perspectives of keyworkers were also gathered as a means of illuminating the experience of the core participants and significantly not replacing them. The activity of choice and choice-making took into account the ongoing transition from segregated settings to community as outlined in the policy New Directions2012-2016, and adopted by the day service. Finally the study sought to add to existing literature and augment the current evidence base with regard to PA and choice among adults with an ID.

A summary of the findings for this research uncovered three superordinate themes. Firstly, adults with ID in this study do not readily link PA with health or well-being. Secondly, the service plays a pivotal role in the lives of the participants as a facilitator and motivating factor in their involvement in PA. Thirdly, the participant’s concept of choice is vague and appears unpractised. The following part of this chapter explores the conclusions and implications arrived at under these superordinate themes and what it means for people with ID, through services, policy research going forward.
6.2 Conclusions

The conclusions echo the superordinate themes that emerged from the findings. These three themes, already outlined in the previous section, are discussed in the following sections.

6.2.1 Perceptions of Physical Activity and Health

The first finding regarding perceptions of PA and health conclude that the link between them is not as evident as that of diet and weight control. In fact, for the majority of participants, health is inextricably linked to diet and weight. This is mainly due to the fact that many participants attend dieticians in the local hospital, which resonates with the medical model of disability. The extent of the health status of people with ID and the importance of PA to their well-being is discussed extensively in research literature. It is widely acknowledged that people with ID experience poorer physical and mental health than the general population and are at a higher risk of morbidity and mortality in this regard (Heller and Sorensen, 2013; Peterson et al. 2009). Greater PA for people with ID has been shown to improve cardiovascular health (Moss 2009) decrease anxiety levels (Carmeli et al. 2009) and positively impact on psychosocial outcomes (Lante et al. 2011). This focus on diet and weight is one of the features of the service insofar as there are cookery classes, budgeting and information on diet on a regular basis. Additionally, Weight Watcher’s attends the service once a week and this further emphasises diet and weight control as drivers of good health. While the service does not discourage PA, it often requires less effort and resources to conduct classes on diet and weight than organising a physical activity due to untrained staff and not enough staff. Significantly, however, the participants are largely unaware of the health implications of not being more active and the negative impact of sedentary behaviour which is high in people with ID.

However, participants are aware that PA is not confined to service provision and are knowledgeable in their understanding of PA. They do not automatically refer to sporting or leisure activities to explain PA. For many, the routine of housework or farming is incorporated into their understanding of PA. The activities they are involved with in the service largely remains there, and their activity levels outside of the service, as self-reported, are much less.
6.2.2 The Central Role of Disability Services

The second finding concludes that day services, such as the one in this research, acts as a facilitator and a motivator for clients to get involved in PA. The service arrives at its programme of activities or PA through Personal Care Plans (PCPs). Within the service it offers activities that are not accessed or accessible by these adults in the community. Outside of the service PA is less structured and is either designed as a leisure pursuit to be enjoyed with family, alone, or as functional and purposeful in the form of walking or cycling for transportation. However, New Directions 2012-2016 whose vision is transition to community, places leisure time in a pivotal position for people with ID, without facilitating access or suggestions as to how this leisure time can be facilitated in the community.

Participants did recognise PA as being something they performed outside of the service in the guise of housework, mainly functional walking and some periodic swimming. However, there were no sporting activities or meetings organised with friends involved except for a shopping expedition in one case. In its definition of PA the WHO (2009) states that it includes leisure time, transportation, occupational household chores, play games, sports or planned exercise in the context of daily, family and community activities. Therefore, participant accounts of what PA is largely concurs with the WHO's definition of activity. The argument could be advanced that people with ID are used to having activities organised for them within the service which results in an inability to do so for themselves because, like choice, they are unused to the practice of being 'allowed' to organise their own leisure time and physical activities.

Notably, much of the activity outside of the service for participants is solitary in nature. Family do provide opportunities for people to be active and there are instances where family provide exercise machines or build a safe walkway for their partially sighted sibling. This reinforces the notion of solitary activity however, despite the well-meaning intention of family and friends. It emphasises and highlights the solitariness of ID even when surrounded by family.

While the service facilitates Personal Care Plans (PCPs) which are very individual, they do in all instances ideally require one-to-one attention. Under-resourcing and a lack of specifically trained staff in PA for people with ID curtails how broad and choice driven
the PCP can be. Yet, without the service and PCPs, options to partake in PA would prove to be limited.

6.2.3 Choice
The third finding concerns choice as experienced in the lives of adults with ID in this research though the lens of PA. In this regard, the findings conclude that choice and choice-making is not a concept readily understood or practiced by the core participants. This was observed under four subordinate themes which included ambiguity, terminology around choice, low expectations around opportunities to choose and the either/or scenario. The latter was the preferred and most popular way of making choices for the participants in this study.

Ambiguity around choice strongly suggests that choice sounds like something you might like to do but in reality it is about what somebody else wants you to do. Therefore, the participant gets confused because its definition does not match the activity of choice and choice-making. The terminology around choice is reflected because of its ambiguity. For some participants who state that it is what ‘you’ would like, there is almost a sense of trepidation about personally owning or being entitled to choice. It is also reflective of how people with ID are spoken to, often with paternalistic language suggesting that it is the only way the individual with ID will possibly understand. Consequently, low expectations are a direct result of ambiguity, terminology and practice because there is confusion around choice and meaningful choice. Therefore, the participants in this research default to the either/or scenario of choice because it is the one most accessible to them and it is the least disturbing solution for everybody concerned.

A further understanding of choice in this research arrives at the conclusion that the most autonomous choices participants make were most evident and realisable in narrower settings. This is particularly noticeable in the gym where preferences are easily identifiable. Participants are allowed to sample a range of exercise machines such as the treadmill, rowing machine and exercise bike independently. In this regard they are exercising independently and exercising independence. This has the very real potential of teaching participants what choice is, what it entails and how to choose based on an identified preference. Additionally, the participant is further benefited by being able to
choose in a semi-segregated setting with peers and staff there to support him/her, if required.

This type of environment can be strongly recommended for people with ID to learn about choice and how to make choices based on their experiences of sampling. In light of the Assisted Decision Making Act (2015) (Chapter Two), teaching people with ID about good choice-making that needs to be factored into policy and service provision. People with ID are more unused to making choices about their lives than the mainstream population. Research can also contribute by including the voices of people with ID in matters that affect their lives and as experts in their own lives.

With regard to implications for policy and services, strongly supported by the literature, is the need for more research to be carried out on more defined PA guidelines for adults with ID attending day services, i.e. how much is enough and what are the most suitable PA programmes for people with ID. The current recommendation with regard to PA for people with ID is similar to that of the general public, i.e. 30 minutes a day, 5 days a week (Department of Health and Children, HSE, 2009). Similarly the American College of Sports Medicine (ACSM) advocate PA in ID and joined forces with the National Centre on Health, Physical Activity and Disability (NCHPAD) in 2007 to launch the Certified Inclusive Fitness Trainer (CIFT) in order to increase access and train staff to work with people with disabilities (ACMS 2015). They similarly recommend the same amount of exercise as outlined for the general population, 150 minutes a week of moderate intensity, aerobic activity a week (ACMS 2015, p. 5).

A criticism of research in the past is that studies are based on short-term intervention type programmes (Moss, 2009). Yet, health research is aware that intervention research is needed to investigate effective programmes that increase PA (Peterson et al. 2009). Furthermore, exercise is actively encouraged for the general population but is seldom advocated as an effective or real intervention for those with ID (Stanish et al. 2006). In Ireland the Get Ireland Active programme (2015), which targets the entire population, is addressing this phenomenon. It recognises the important role of promoting an awareness programme regarding the benefits of PA as a lifestyle option and also as part of a treatment programme for illnesses in their early stages and to encourage social interaction through participation (Healthy Ireland 2015). This is a
positive step as it ensures that people with ID will be informed about their health issues and how to address them through early intervention. Denying personal information is in contravention of human rights and disregards people with ID as not being capable of being involved in decisions regarding their personal health and well-being. Similarly, there is a need to know what people with ID consider important in their lives and what their perspectives are on their health and wellbeing. This can be achieved by including the voice of people with ID in research that concerns them. Similarly, CARA a national organisation which provides a collaborative and partnership platform throughout Ireland to impact on enhancing sport and PA opportunities for people with disabilities had launched a Me Too campaign. The Me Too campaign is about listening to people about the importance of sport and physical activity in their lives (CARA 2016). As a positive, the message conveyed in the health promotion of diet and weight control has been successfully conveyed insofar as it is understood and adhered to, as much as possible, by the participants in this research. There is a call for well designed, theory driven and evidence based health promotion programmes for the target population (Schijndel-Speet 2013).

Though none of the participants referred to cost at any point during the interviews, keyworkers and staff were very aware throughout of cost as a limiting factor to choice and physical activity. They were all very aware of how much disposable income participants had remaining, having covered their living costs, and saw this as an impediment to extending activities. Some staff were conscious that if the service provided too many PA programmes the participants would not have any income remaining to spend on themselves for socialising.

6.3 Limitations of the Study

Limitations to this study have been identified and should be considered in interpreting findings and considering directions for future research. Participants for this research were selected using purposive sampling and snowballing. Snowball sampling is very unlikely to be representative of the population (Bryman 2004, p.102) because it lessens the diversity of participant as people tend to recommend friends who are usually in the same age bracket and have similar interests. Similarly, IPA is unconcerned with generalisability and focuses on the experience of core participants. This tends to make
the research subjective in comparison to other methods. On the other hand, it focuses attention on a group that would otherwise not be included in an area of research that directly affects them. The literature review found that the majority of studies concerning PA and choice concerning people with ID did have their input. It also found that when asked, people with ID had different perspectives on areas such as friendship. It cannot be assumed that all people or groups have similar experiences with regard to a phenomenon and this is one of the strong features of IPA as it allows for those experiences to be expressed uniquely.

A feature of IPA is its intended low level of participation, i.e. small-scale studies. This alongside the criteria set out for sampling which could only include people involved in PA, meant that a number of service users were exempt from the research. It is therefore unknown as to how these service users utilise their leisure time, a concern of New Directions 2012-2016, or if they are not involved in PA, how this is affecting their physical and psychosocial wellbeing. These are significant factors as it is unknown whether the only choice for leisure time only involves PA and whether PA would significantly improve the lives of those people not involved in it if given the opportunity. Similarly, the small number of participants, as required by IPA, makes this a relatively small sample size for the purpose of gathering all information regarding choice and PA. The purposive sampling of this homogenous group represents a “perspective rather than a population” (Smith, Larkin and Flowers 2009, p. 49). However, it is a very important perspective.

It can be argued that how one researcher interprets data differs from how another researcher might do so. Any inferences drawn from the data are done so with an awareness of the context and culture within which the research is situated. The results therefore cannot be generalised and applied to all people with ID who experience PA and choice due to the unique nature of how people experience a phenomenon. Therefore, while this research portrays the essence of how participants in this research experience PA and choice in their lives, it is not designed to be universally transferable.

A limitation imposed by the service research and ethics committee is that people with profound ID were not to be included in this research. Iacono (2006) draws attention to the conservative decisions organisational ethics committees make which exclude people from research because of the type of disability they have. Iacono argues that
while the service knows the client best, a better approach would be to report to ethics committees on inclusive research regarding people with more profound disabilities to highlight its benefits for people with ID (Iacono 2006).

6.4 Summary of Conclusions
This study has concluded that by recording the experiences of people with ID, this research has given the insight necessary to look at how necessary it is to make changes in the areas of practice, policy and research going forward. The three superordinate themes with regard to how people with ID interpret health, how reliant they are on services in order to access PA and how their notion of choice is vague and unpractised significantly contributes to the disability discourse.

6.5 Recommendations
On foot of the results and conclusions drawn from this research, the following recommendations are put forward for practice, policy and research and in that order.

6.5.1 Practice
Recommendation: Acknowledge innovation and share Information with regard in this regard across services

Extending the knowledge base across services by sharing information on what works well within organisations. The Weight-Watchers programme, for example, has gone some way in reversing the notion that people with ID must always go to the wider community to access services. Success stories like these could be shared on an online forum that staff and clients could access with their experiences and suggestions. Extending this to the aerobics programme, which has proved very popular, could also be extended to the community.

Recommendation: Extend programmes that are already successful.

Extending existing PA Programmes and Participation: Those programmes that have proved popular, effective and successful such as aerobics and the gym, to be extended. Similarly a dance programme could be introduced as an activity on a long-term basis for its aerobic fitness benefits rather than a once off activity. Both participants and staff have acknowledged these activities as being popular and beneficial. Activities such as
using local gyms provide a range of fitness activities which increase fitness but also assist decision-making that facilitate choice.

**Recommendation:** Services to utilise local resources and engage with their Local Sports Partnership by linking clients in to them. It promotes community integration and provides specialised and professional training.

Cara, which is a national collaborative platform in the local area, to enhance sport and PA opportunities for people with disabilities. It works with Sport Ireland to deliver the Sports Inclusion Disabilities Programme (SIDP) through a network of Sports Inclusion Officers based in the Local Sports Partnership. Its ethos echoes that of the English Federation of Sport (EFDS) and Disability Sport Wales. The EFDS supports, engages, aims to improve and advocates for the involvement of disabled people participating in activities by linking in with their disability organisations/services. Similarly, Disability Sport Wales promotes play, performance and learning in order to encourage diversity and equity in disability specific inclusive sport opportunities. Additionally, for the more independent individual, a follow-up programme where people are supported to attend activities independently of the service could be considered in the move towards community transition.

6.5.2 Policy

**Recommendation:** Recognise that people with ID need to learn how to make decisions.

**Self-determination Training Programme:** Training for key staff in the development and delivery of a self-determination programme for the purpose of facilitating the participant to make decisions and understand the concept of choice. New Directions 2012-2016 (HSE 2012), has a policy of offering choice but information around accessing and delivering choice is firmly rooted in PCPs which are very individualised. This does not allow for the reality of everyday services which due to under resourcing need to have more group activities which can curtail choice. How people make choices within services is largely undocumented outside of PCPs. This is especially germane to community transition and the Assisted Decision-making Capacity Act (2015) which requires people with ID to make informed decisions about more serious aspects of their lives. The following two suggestions are worth considering:
Invoke a programme as outlined by the Australian Disability Services supporting Decision-Making which incorporates a seven point plan:

1. Everyone has the right to make a decision
2. Capacity to make decisions must be assumed
3. Every effort should be made to support people to make their decisions
4. Capacity is decision specific
5. People have the right to learn from experience
6. People have the right to change their minds
7. People have the right to make decisions others may not agree with

Similarly a programme developed by Downs Syndrome Irelandentitled My Opinion, My Vote (MOTE) a European Project which aims to empower people with learning disabilities through active citizenship and participation in political elections.

**Recommendation:** Promote Awareness among people with ID to the negative effects of sedentary behaviour

Policy makers need to implement health promotion programmes for people with ID in recognition of longevity, an older demographic, quality of life and to avoid the inevitable financial burden on health services in the future. Ideally the promotions would include an education, educational package incorporating diet, leisure, PA and long-term health care plans as outlined in Get Ireland Active (2015). This may be implemented through Me Too in conjunction with the Local Sports Partnerships.

6.5.3 Research

**Recommendation:** Include people with ID in research about them

**Inclusive Research:** Including people with ID in research about them. This became increasingly significant as the research progressed and at analysis stage it became evident that the participants had diverse opinions on PA. The research concluded that what is being researched is not necessarily how people with ID understand a phenomenon. Without the voice and opinions of people with ID and their understanding of choice and PA, these phenomena cannot be supported effectively or to the satisfaction of the client. IPA is being used more frequently in researching ID (Corby, Taggart and Cousins 2015) because it allows people to interpret their world by formulating their own biographies (Brocki and Wearden 2006).
**Recommendation:** To protect the rights of people with ID to be included in research and to participate in that decision-making process, while guarding against exploitation or potential harm.

**Review the Ethics Process for Day Services:** The ethics process took seven months to complete in its entirety. This is a significant time factor for researchers who want to put participants at the core of research. The participants in this research attend a day service and otherwise live independently of the service. Perhaps a review of what Iacono (2006) refers to the protective practices of ethics committees within services towards research participation. A review of the ethics process for day services, in line with the review of day services generally as outlined in *New Directions 2012 -2016* (HSE 2012), should be addressed in order to make participation easier to access while respecting the vulnerability and privacy of clients. Heightened restrictions to access pose as a deterrent to include people with ID in research ensuring that research going forward will lose the voice of the participant.
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Appendix A – Sources of Information for Research


Policy documents used for this research are both national and international and include the World Health Organisation (WHO), The UN Convention on the Rights of People with Disabilities (UNCRPD), and the Disability Act 2005. Other Special Reports, Organisations, Government Departments and studies include the TILDA Report on people Aging in Ireland with an Intellectual Disability, the Special Olympics (SOPHIE) study, the Áras Attracta Report, American Psychology Association (APA), American Psychiatric
Association (APA), Department of Health (HSE), Department of Health and Children, Department of Health, Transport, Tourism and Sport, Department of Justice and Equality, Department of Social Protection, Health Information and Quality Authority (HIQA), Inclusion Ireland, National Disability Authority (NDA) and the UN General Assembly. Other literary references included books borrowed from the IT library and online databases accessed through Google Scholar. Other sources of information and professional learning included attending and presenting at conferences such as ‘The European Congress of Adapted Physical Activity 2016 “APA ROAD” at the University of Olomouc in the Czech Republic and “The 17th Healthcare Interdisciplinary Research Conference (HIRC2016): Contemplating the Past Present and Future” at Trinity College Dublin.

For the purposes of the methodology I used, Interpretative Phenomenological Analysis (IPA), I became a member of an online forum [IPANALYSIS], which shares information and answers questions on the entire IPA process as they arise. Michael Larkin, an expert in IPA, is a contributing member. I also enrolled in the National Health Service (NHS) website to gain access to current information on ID and the British Medical Journal (BMJ) who sent links on recently published articles in health and disability services regularly.
Hello, My name is Sheila and I am doing some research.
It is about the part Physical Activity plays in your lives.

I am studying this Very Important subject in the Institute of Technology in Tralee.

The Questions I want to ask you are about the types of physical activities you do.
How You Feel About Them.
I need your help to gather this important information.
You can talk to me.
You can draw a picture
Or....Maybe you have other ways of letting me know how you feel
You are the most important person in this research
But I would like to ask your permission if I could also speak to a member of your family
You can choose which one if that’s what you want
If you want to be part of this Research You Can
But You Don’t Have to if You Don’t Wish to
You can also say No at any time
We Will Publish the Results of the Findings
You will Not Be Named in these Publications
At the End I will present the Findings to You. I am Not going to Make a Decision Yet as to How we will do that

Signed (using signature, handprint, writing or drawing done by the participant)
Appendix C - Reflection on 3 Pilot Interviews using Gibbs Reflective Cycle

Description
In the process of conducting my pilot interviews, I believed that they were perfect material for my findings chapter. I believed the information to be rich, that I could extract themes, as related in the literature review to them very easily and relevantly. I also believed that my background, having worked with people with ID, being a social worker entitled me to skip the pilot study part. However the approach the researcher takes, while it may not be very different, is meant to focus on the aims and objectives of the study, which I believe I omitted. This is, despite the fact that I had an interview guide with me during all of the interviews. A meeting with my supervisors outlined for me the huge gaps the interviews left as did subsequent transcriptions.

Feelings
My feelings during the first interview were very positive towards the whole process. I thought that if the remainder of the interviews went this well, my data collection would be completed ahead of time. I also believed, at this point, that I did not need to make this a pilot interview as it was too good to waste the material. I put this down to my communication with the person, the non-leading questions, and the ability to let the person speak and to appreciate silences, of which there were few notably. I also felt that having studied social work and having worked in the area of intellectual disability for some years that I had acquired and utilised all the skills necessary for collecting data from a challenging audience entitling me to bypass the pilot stage. Added to this, I felt that in order to reach the submission deadline I needed to work at this pace regardless of quality.

Evaluation – What was good and what was bad
The first interview was with a higher functioning and very communicative participant. The content on transcription read very well and as the interview progressed, themes began emerging readily. I had alerted my supervisors in an email to the two interviews posing as more challenging. That next interview was with a younger female who gave very clipped answers and was less inclined to expand. On transcription I noted that my silences lasted 3 seconds on average, I overused some words and expressions. I was more inclined to ask leading questions on occasion though I checked myself each time. I also posed either/or questions a few times which is not good practice. The major concern, and this is something I did not observe myself, is that I left the question of voice as add on rather than making it the central theme of the interview. This is why supervision is absolutely vital for guidance and observation. I felt that the last interview was rushed as I was constantly aware of gathering as much data as possible in as little
time as possible. Conducting 2/3 interviews per day, I found to be exhausting and unproductive.

To balance this there were positive experiences also. I did establish a good rapport with each participant. There was a sense of ease about the conversational interview and the technique of probing was generally good and leading questions were minimal. This view is supported by my supervisor.

Analysis

Being a novice at interviewing I am now aware of the major pitfalls that have been encountered. I am aware of the varying and unique personalities that present. While the person with an ID may communicate differently, it does not take a vast amount of time and effort to adapt to this. However, this would not be successful without having immersed myself in the experiences and activities that the participants live out in their daily lives at the day centre. People with ID are very friendly generally and tend to gravitate towards a new person relatively quickly. As acquiescence is a common trait, it is important to be aware of this and to question and challenge the over willing individual outside of the interview forum to get them used to being themselves and to, along with the staff, actively encourage independence. It is very useful to engage in this manner as it removes any fear factor, apprehension or uneasiness regarding me being a stranger in their midst. It also removes the mystery of research and I have found that people already interviewed encourage their peers to do the same saying ‘it is very easy’ and ‘just be yourself’. This is to an extent snowballing.

Action Plan – If it arose again what would you do?

I have updated the interview guide to reflect the importance of putting choice as the central theme and looking at it through the lens of physical activity. I reflect after each interview in a note book chosen for that purpose and amend my questioning accordingly. On advice of Deirdre Corby my supervisor mentor in DCU and an expert in this field of research, I have returned to my Information Leaflet and posed my questions using that guide. I have also returned to Van Manen’s and Larkin, Smith and Flowers on chapters regarding interviewing as they make even more sense while actually practically conducting the research. I have also returned to the methodology chapter to explore how much emphasis and explanation I have placed on the interview process as it is, as I have discovered, crucial to the last three chapters of this research.

Be aware not to ask or over emphasise length of time or distance in questioning as I have found so far that people with ID find these dimensions difficult to comprehend and assess. When transcribing I have counted the seconds of silence. Up to now the longest is 4 seconds. I am getting used to letting this occur for much longer and can now go from 6 to 8 seconds. This length of time, which hangs heavily on both of us, encourages the other person to begin speaking again.
Appendix D- Interview Schedule for Core Participants

Over-arching Question – Descriptive

A. The Activity

1) Could you give me a short description of the physical activity that you take part in from when you started?

2) If I was to ask you to describe one day in your life where you do this activity how would you describe it to me?
   Prompt: Would you prefer to draw it?

3) How do you feel when you are exercising?
   Prompt: physical, emotionally, mentally

4) How does this activity affect your life?
   Prompt: everyday life, health, interests, relationships (any other)

5) If you were to describe what the physical activity means to you, what would you say?
   Prompt: What words, images come to mind? Maybe you have a particular name for it. Or may you would like to draw it for me?

B. Identity

6) How would you describe yourself as a person?
   Prompt: characteristics: happy, adventurous, shy, quiet, fun-loving, moody?

7) Does this activity make you see yourself differently?
   Prompt: Have you changed since taking it up? In what way?

8) What about the way other people see you?
   Prompt: family members, friends, and keyworkers, outside the centre?
C. **Self-Concept** -

9) What does the term health mean to you or how would you describe it?

10) Do you think you look after your own health well?  
Prompt: physical, emotional, mental

11) Do you see yourself as being healthy?  
Prompt: always, sometimes?

D. **Funnelling**

12) What do you think of SJOG allowing people to make their own choices regarding physical activity?

13) What does it personally feel like to be given a choice to choose your own activity?  
Prompt: difficult, easy, stressful, liberating, meaningful?

14) Do you always get to choose on your own or do you get help?

15) How does that make you feel?
Appendix E - Informed consent for Keyworker

I ____________________________ consent to ___________________________,
of whom I am the keyworker, to participate in the research titled ‘The Experiences of a Self-Selected Approach to Physical Activity among adults with an Intellectual Disability: A Phenomenological Study’ which is being conducted by Sheila O’Sullivan a postgraduate student in the Institute of Technology Tralee who is studying this subject.

I have been provided with the relevant information (aim of research, steps involved in the research and any risks) thus facilitating my ability to provide informed consent for __________ participation.

I understand that ______________ will be interviewed for the data collection phase of the research as will his/her (mother/father/brother/sister – relative) of which ______ has approved.

I understand that the service will be cited in any publication regarding this study but that the local service will not be identified or identifiable. Nor will any of the interview participants who will at all times be anonymised/psuedomised in any such publication.

I understand that when the research is finalised, the researcher will present her findings in one of our centres for the benefit of the participants and that this will be delivered in a comprehensible manner.

I understand the information provided and I understand that ____________ can withdraw at any time without any consequences.

I understand that the information provided by the participant will remain confidential.

Signature: ____________________________
Date: ____________________________

Print Name: ____________________________
Appendix F - Semi-Structured Interviews for Keyworkers

Group appears to be important. Why do you think this is?

Are you aware of the significance of your role in the client’s lives?

There are a large range of activities. Who decides on these?

On what basis is the program decided on? (Note to self: Frequency, intensity, time, type, person-centred planning)

Would you have a policy of doing something different because it is a fine day?

Who pays for the programs?

Is there a policy to encourage physical activities in the service?

Do you think the 6-week program in the gym in Banna is enough to maintain well-being?

Why is (Place Name) the gym of choice when there are other gyms nearer to Tralee? And is there a significant dropout rate?

Participants have mentioned that there are less activities during the summer. What do you think the reason for this is?

Is there a difference between the individual supported by family and those who are not?

People appear to foster friendships in the service. In your experience do you think this helps them to foster friendships outside or does this happen?
Appendix G - Sample Interview/Transcript

Interview - 16th February at Location 12pm : Eileen (Anonymised)

I turn on the tape recorder during the process of going through the informed consent form in order to ensure continuity of the prior warm-up conversation.

Me: So, the informed consent is, I'm saying to you, giving you my name...
E: It's Sheila, yeah
Me: So, it's about what physical activity means to you...
E: Well, it means walking, cycling, exercise, swimming...and I was swimming now yesterday in Banna Leisure Centre...and it's very good for you to get down weight and to keep back from the food as well, yeah
Me: So, the next part of this is, its being done for the organisation, SJOG, so basically what happens there is, we do research to see what you as a service user, what you find good about it, what you don't find good about it, what would you like to see...would you like to see a change, would you like to see something new. That's another reason for research. So, I'm studying this very important subject up in the Institute of Technology, do you know it, up in the
E: Yes, Yes
Me: North Campus and the questions I want to ask you are about the types of physical activity you do and also...
E: And then housework because you're walking, you're bending down, you're taking out ashes, you're dusting and you're physical and you're using the wheelbarrow. You know your weeding around the house and cutting lawns in the summer...you're moving around and things like that...yeah
Me: So, I need your help
E: Yes, yes
Me: Like what you're doing now, to help me to gather information
E: Yes
Me: So, you can talk to me or as I say you can draw a picture, right?
E: Yes
Me: We'll talk more about that later, and you're the most important person here today
E: Yeah
Me: You, because this is about you. Is there anybody else then you would like me to speak to, for example do you have a keyworker..

E: I do but she's out having a baby, (Name), but she's out at the moment, she's out

Me: Ok and is there anyone else

E: No, I have no one else at the moment

Me: And do you have family living here?

E: I do, they're all in (Town)

Me: Ok, and do you see much of them

E: I do, a lot of them

Me: Is there any chance that you would like one of them to talk to me

E: Oh, they would, they would of course yeah

Me: But we can talk about that later anyway but I'll leave you think about that. It's just to get their opinion as well. Your opinion is most important

E: Yes

Me: This will be published, but I won't publish your name so you can say what you like here to me today.

**Eileen's Background**

Me: You have already given me details of what you do regarding physical activity. Could you now describe to me a day where you get up in the morning..just give me your day

E: I get up in the morning and I work around the house, I hoover, I brush the floor and, take out the ashes and, put on the fire and then go for my walk down the road and things .. yeah.. and the dog don't go like, the dog don't go. He doesn't go. He's lazy, the dog. He won't move. He goes up to the field alright. He doesn't walk like. Yeah

Me: And how old is the dog

E: Ten years

Me: He's your own dog is he (Animals can be a good way of getting people out to exercise)

E: Hes my own dog, yearh

Me: Where do you live Eileen

E: The (place name) Yeah, its out the (place name) alright

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Me: Do you live with other people?
E: My mother. My mother and myself live together, you know
Me: And what age are you Eileen?
E: 51
Me: So you had the big birthday there
E: A year ago yeah
Me: Did you have a celebration
E: I had, in (place name) with the family and nieces and nephews

INTERVIEW – Activity during the Day

Me: So, you get up in the morning, you live with your mother. How do you get in here then?
E: Oh, Cycle. Cycle to town, cycle home, cycle into the centre and you know, that’s the way now. I don’t drive but I’d love to learn but, the cycling I do a lot like, the cycling
Me: How long would it take you then to get from home into town, on the bike?
E: Not very long. It’s very near. About a mile, about a mile.. Yeah about that
Me: And how often would you do that?
E: Everyday. I meet (male friend), (male friend) for tea, a friend of mine. I meet him for tea (Introduces new person into the conversation)
Me: And (male friend), does he come here as well?
E: No, not anymore. He’s in (place name). He lives with his mother and father
Me: And so you meet him. And where would you go for coffee
E: (Name of Cafe). I go to the (can’t catch it) (Social aspect and independently social part of Rita’s life)

CHOICE

Me: Eileen, what I really want to talk to you about is choice, you know what choices you have in your life. What do you understand by the word choice?
E: Well, what kind of things would you like and things like that yeah....yeah
Me: Could you give me an example?
E: Like, see there's no other choices, like **there's no work around now**, the work is gone, see with the recession like... yeah (Immediate association with work and the loss of work)

Me: But, would there be choice in other areas of your life do you think

E: Do you know **its hard to get work now**, its hard

**RETURNING TO PHYSICAL ACTIVITY**

Me: Say, if we brought it back to physical activity and exercises, what choices do you think you have

E: Ah... **swimming, cycling and walking**... I'm in a walking club as well in (the service), I'm in a walking club...and we do it every month. We go to (place names) and different places, yeah. We go about 10 miles or 8 miles... yeah. A walking club they call it

Me: And would you walk the whole time

E: Oh the whole time and then we stop then for **lunch** and we keep... continue then until we're finished (Social aspect of the walk)

Me: And how many would be in that group

E: Oh, about twelve of us, thirteen. Yeah, there's a lot of us there like, involved in it, yeah

Me: **So going back to choice now again** who decides where ye go for the walk

E: (Keyworker), **she's the leader**. She decides where we go......

Me: And are you asked where you would like to go

E: Yes I **don't mind, they choose where we go**, they choose

Me: And do you always like where they choose

E: I do, I **don't mind** (very matter of factly) I don't mind at all

Me: Would you ever feel that maybe you'd like to choose for that day

E: No, no (very emphatic). I **go by the staff, what they tell us to do**..yeah

Me: Why do you, why do you do that?

E: I don't know because I prefer..I don't know.. I **accept** the way I go, the way I go like, yeah

Me: Would you like to make a decision on your own

E: I **like to be with the group**. And you talk to people and, you get to know people and mix in and make friends that way, yeah (enthusiastic)
Me: Do you always then get to do what you want to do or was there ever a time you didn’t get to do what you wanted to do?

E: No, never, never did, no, Never happened. That never happened no Ok. No, and I enjoy it. When the walk is over then, we go for a cup of tea somewhere, yeah, yeah (social aspect again of the activity important)

Me: So, what do you think choosing means in physical activity?

E: I make the swimming and the walking and the gym and everything, you know. Well I go to the gym now every Tuesday with the Program. I go to the (place name). I go there every Tuesday so I choose that for me because it’s good for me, to get out, you know...yeah

Me: Let’s, say you wanted to go on a Wednesday

E: Yeah but I go on a Tuesday. That’s the day that was choosed. I choosed the Tuesday anyway, yeah (Routine appears to be important)

Me: Do you ever feel that you’d like to go another time?

E: Yeah, but I have to do what I’m told to go by the orders you see. I don’t mind. I do what I’m told and I feel happy, do you know, yeah (Eileen is very upbeat and happy)

Silence

E: I like the gym and I like the treadmill and all the machines. I like all the machines

Me: What plans do you have for this afternoon?

E: Oh I go down meet them and have tea below (Eileen’s group who are in one of the kitchens in the building). I’m in Social Network group and I go down and I mix in with people, eat with them and get on with them and talk to them. And I clean up after me and I feel better that way, you know.. (Social group aspect)

Me: You enjoy that..

E: Because it gets me out of the house at home... not to be inside in the house all the time. You’d be bored at home like you know, find the day long and it gets you out of the house...yeah (importance for Eileen to have a life outside her home and family)

Eileen’s History

Me: And how long have you been coming to the service

E: Well, you see what happened at the beginning is I was coming 20 years but then the work did away, they did away with the work here then (Referring to the closure of the centre as an employment base for the clients)

Me: What work was that?
E: The garden centre and the kitchen you know
Me: And what did you work at here
E: Oh I worked in the garden centre and I did the potting and all that and the tunnels (Refers to it with nostalgia and happy memories)
Me: And did you get paid for that
E: No, it used to be... I think it used to be the Social Welfare used to pay. (The service) used never pay at all, no, no

Silence
Me: If you had a day where you could do whatever you wanted to do, could you describe that day to me?
E: Like I like.. you see then Thursday morning, I do the shopping with my mother, I, we go down in the car, do the shopping... I go round with the trolley, yeah, yeah (Eileen seems to enjoy routine)
Me: But could you imagine a day.. do you ever daydream or have a dream...
E: I do, I do, yeah. Thinking about things you know, thinking..................(silence) like thinking. I do be dreaming in my sleep alright..............I be dreaming...............but I don't dream anymore now like, no, I don't dream anymore...................but see like, you have to get up and get on with it like. I get up and get on with it................... (The practicality of living is much more important to Eileen)
Me: Is there anything you want to do next or, you know anything you would love to do in your lifetime
E: But, you see I have no one to go on holidays with. I have no one to go on trips with or anything....
Me: Could you talk a bit more about that to me
E: I'd like to have someone to go with but I have no one to go with like, for trips like, you know on holidays and things you know (Seeking out like-minded people)
Me: Where would you like to go?
E: Well I used to go to Lourdes. It's very expensive you know........silence...............very dear like....yeah
Me: And who used you go with
E: I used to go with the group like, I used to go with the group always
Me: And what would you do in Lourdes, describe that holiday to me
E: Oh, the praying all the time and you have the torchlight procession, all the walking around, mass every day and everything.

Me: What would you do in the evening then when you were finished with that?

E: You go down to the grotto like and things like that.

Me: Would you do other things, would you go for food?

E: A drink of tea like, a cup of tea, yeah...yeah.

Me: And is there anywhere else that you'd like to go on a trip?

E: I don't know, I don't know. I'd like to have a couple of nights away but I have no one to go with then like you know.

Me: Have you ever asked or suggested it here maybe to any of the staff that you'd like to go on a trip?

E: Yeah, but there's no money there, there's no money...yeah (Reality of funding cuts).

Me: Is that ok with you?

E: Well there's only one night away that's all..you never go way for anything like a week you know...yeah (Referring to the past).

Me: And where would you go for the night?

E: We go to Dublin or we go to Cork maybe. We went to Cork last year...

Me: And you stayed...

E: In a hotel. I forget the name of it now. T'was nice t'was.

Me: You'd like more of that?

E: Yeah, yeah (wistful expression).

Me: If I was to ask you know what do you want to do....Rita do you find that a hard question or an easy question?

E: I don't know. I like to do different things, you know you see. I go out then of a Wednesday night with (Mentoring group). I go Wednesday night. It was (another name) at the start but now it's (Mentoring group)...yeah (Variety is important).

Me: And what's that?

E: It's a club. They get together and they socialise. One night they go for a drink, one night they go bowling, they play bingo and dancing...and disco one night and different things you know.

Me: What do you think goes into making a choice.
E: It’s a hard question alright

Me: Could you think about that for a little while

E: Yeah, I could, yeah

Me: Would you draw me maybe something that you think might go into choice

E: What will I draw.. What would be nice?

Me: Well, well that’s for you to decide

(Introduce Eileen to paper and colouring pencils)

E: I don’t know, I’m not very good at drawing really. I’m not very good at it

Me: I’ll tell you what we’ll do. You draw and I’ll draw

E: Right ok (Eileen is happy with that)

Me: We’ll draw together

E: Yeah, I’ll draw a house anyway..........longer period of silence as we settle into drawing

She recalls another random place she knows

Me: What’s in that place?

E: There’s shops there, there’s houses there as well

Me: Is that somewhere you’d like to live

E: Oh no. I’m living in (place name), Sure (place name) is my town, (Place name) is my town sure (Pride in her homeplace)

E: Like, to go on holidays, do you know have more trips out you know. Holidays I’d like you see because I never went on a plane holiday. I went on a plane to Lourdes but I’d like to go on a foreign holiday do you know, do you know

Me: Where, what country... what would it look like, what would the weather be like

E: Too hot then some countries, very hot

Me: Have you made choices in the past

E: Never, no, no...for you see choices are hard. I don’t know it’s hard to know choices...very little choices

Me: Why do you say that?

E: I don’t know. I have very little choices
Me: You feel you have very little choices
E: Yeah, very little, yeah
Me: How does that make you feel?
E: Nothing, nothing at all like

Me: You’re saying there about making choices. Is it something you think you do or you don’t do?
E: Sometimes I make no choices, sometimes.............

Me: So you know life, everyday life, there’s choices made every single day of your life...
E: Like, there’s choices like, if I was told tomorrow to go for a walk, I’d go for a walk, for here if (keyworker 1) or (keyworker 2) tells me to go for a walk, I go for a walk. And if we’re going swimming, we go swimming, and if you go to the gym, we go to the gym. So that’s my choice. I make a choice and I do all them things

Me: If you said no, (Keyworker), I’m not going for a walk...
E: But then they want you to get down weight... so you know

Me: But what would happen if you said no
E: They’d say like, what’s wrong with your legs like

Me: And would you always feel like going for a walk?
E: I do, not all the time. I do be breathless. I have asthma, I do be breathless then sometimes

Me: And has it ever happened that you have said no
E: No, I never said no, no

Me: And how does that make you feel
E: I feel sometimes guilty you know, sometimes. But we have to look after our figure like

HEALTH
Me: So, you’re aware of your health I suppose, is it
E: Health, yeah, exactly. And keep back from the food

Me: What kind of foods would you have to keep back from?
E: Biscuits and cakes and all them things
Me: So, how do you choose that? How do you make those decisions?

E: I make an effort and have willpower

Me: Do you ever disobey that

E: I do sometimes yeah. Not often, not often, no

Me: But that’s a choice, that’s making...do you understand that as a choice

E: Yeah, tis, tis indeed a choice

Me: So when you make that choice, how do you feel then?

E: You feel better, you feel better then

Me: Would you feel better after having the biscuit

E: No, no, you shouldn’t eat it, no...you feel you have willpower then ....silence

Me: So, I suppose we’ve talked about the physical activities and the choices you make

E: We have yeah

Me: How does exercise make you feel

E: Great, (very enthusiastic). And you feel in much good form and you feel fitter you know. More energy and everything, yeah

Me: Do you remember when you didn’t exercise

E: I always exercised but the eating was a problem, the eating, the eating.... You know, small portions. I go to weightwatchers then Wednesday morning, here, I go to weightwatchers

Me: I think I’ve kept you long enough at this stage Eileen (It’s getting near lunchtime)

E: We have, we have. Are you happy with that?

Me: I’m very happy Eileen, and if I need to can I speak to you again?

E: You can, you can. Thanks very much

Me: Thank you Eileen.
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<tr>
<th>Original Transcript</th>
<th>Exploratory comments</th>
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<tbody>
<tr>
<td>INTERVIEW 16th February</td>
<td>Naming the activities attaching a story to the swimming. <strong>Understanding that activities are good for keeping your weight under control.</strong> <em>Keep back from the food – type of language used</em></td>
</tr>
<tr>
<td>Me: So, it’s about what physical activity means to you...</td>
<td>Reading from info leaflet</td>
</tr>
<tr>
<td>E: <em>Well,</em> it means walking, cycling, exercise, swimming... and I was swimming now yesterday in Banna Leisure Centre... and it’s very good for you to get down weight and to keep back from the food as well, yeah</td>
<td><em>Double ‘Yes’</em> – one of Eileen’s idioms</td>
</tr>
<tr>
<td>Me: So, the next part of this is, ..................</td>
<td>And continuation of previous sentence. Her mind is racing with information. This is well thought out and she is reliving the activity.</td>
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<tr>
<td>E: <em>Yes, Yes</em></td>
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<td>Me: I want to ask you are about the types of physical activity you do and also...</td>
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<td>E: <em>And</em> then housework <em>because you’re walking,</em> you’re bending down, you’re taking out ashes, you’re dusting and <em>you’re physical</em> and you’re using the wheelbarrow. <em>You know</em></td>
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your weeding around the house and cutting lawns in the summer..you’re moving around and things like that...yeah

Me: So, I need your help

E: Yes, yes

Me: Like what you’re doing now, to help me to gather information

E: Yes

Me: This is about you but is there anybody else then you would like me to speak to, for example do you have a keyworker..(referring to participants for future semi structured interviews)

E: I do but she’s out having a baby, ****, but she’s out at the moment, she’s out

Me: Ok and is there anyone else

E: No, I have no one else at the moment

Me: And do you have family living here?
<table>
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<tr>
<th>E:</th>
<th>I do, they're all in *****</th>
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<tr>
<td>Me:</td>
<td>Ok, and do you see much of them</td>
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<td>Me:</td>
<td>Is there any chance that you would like one of them to talk to me</td>
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<td>E:</td>
<td>Oh, they would, they would of course yeah (flat tone)</td>
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</table>

**INTERVIEW**

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<tr>
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<tr>
<td>E:</td>
<td>I get up in the morning and I work around the house, I hoover, I brush the floor and, take out the ashes and, put on the fire and then go for my walk down the road and things.. yeah.. and the dog don't go like, the dog don't go. He doesn't go. He's lazy, the dog. He won't move. He goes up to the field alright. He doesn't walk like. Yeah</td>
</tr>
<tr>
<td>Me:</td>
<td>Where do you live Eileen</td>
</tr>
</tbody>
</table>

No expansion on this

No especial link to anyone in particular in the family

Giving nothing away. Would perhaps like to keep family life and life in the centre separate

Overarching question. Tell me your story

Only hears last part of question

Explains why the dog won't walk. Considers him lazy. Is there a connection between not exercising and laziness? **He won't move. Movement equals walking**

Idiom of repeating words. Affirmation

Family Support

Independent. Two lives. Working and Home life. Doesn’t want them compromised

Importance of exercise. Routine prior to the rest of her day.
<table>
<thead>
<tr>
<th>Practical attitude to life</th>
<th>E: The ******. Yeah, its out the ***** alright</th>
</tr>
</thead>
<tbody>
<tr>
<td>Me: Do you live with other people?</td>
<td></td>
</tr>
<tr>
<td>E: My mother. My mother and myself live together, you know</td>
<td></td>
</tr>
<tr>
<td>Me: And what age are you Eileen</td>
<td></td>
</tr>
<tr>
<td>E: 51</td>
<td></td>
</tr>
<tr>
<td>Me: So, you get up in the morning, you live with your mother. How do you get in here then.</td>
<td></td>
</tr>
<tr>
<td>E: Oh, Cycle. Cycle to town, cycle home, cycle into the centre and you know, that's the way now. I don't drive but I'd love to learn but, the cycling I do a lot like, the cycling</td>
<td></td>
</tr>
<tr>
<td>Me: And how often would you do that</td>
<td></td>
</tr>
<tr>
<td>E: Every day. I meet Donal, Donal for tea, a friend of mine. I meet him for tea (Introduces new person into the conversation)</td>
<td></td>
</tr>
</tbody>
</table>

**Should I know this or is it another idiom. Practical description of living together**

No hesitation. That’s me and that’s my age

Rekap for Eileen.

*Language reflects the cycle of cycling and the cycle of her life. (Cycle/cycling mentioned 6 times in this sentence). In the midst of all this Eileen expresses the wish to learn to drive. There are easier means of transport. Is cycling getting too much and would driving make it easier*

Introduction to a new person outside of home and daily life. This is something she does on her own independent of her mother or group. This is a huge commitment meeting the same person every day, having to get there and back. Goes out in public with him.
<table>
<thead>
<tr>
<th>Independence</th>
<th>Routine</th>
<th>Socialisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition of Choice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work is the only choice</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Me: And Donal, does he come here as well</th>
<th>E: No, not anymore. He’s in (Home place). He lives with his mother and father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Me: And so you meet him. And where would you go for coffee</td>
<td>E: Local Café. I go to the (can’t catch it)</td>
</tr>
<tr>
<td>Me: Eileen, what I really want to talk to you about is choice, you know what choices you have in your life. What do you understand by the word choice?</td>
<td>E: Well, what kind of things would you like and things like that yeah....yeah</td>
</tr>
<tr>
<td>Me: Could you give me an example?</td>
<td>E: Like, see there’s no other choices, like there’s no work around now, the work is gone, see with the recession like... yeah</td>
</tr>
<tr>
<td>Me: But, would there be choice in other areas of your life do you</td>
<td></td>
</tr>
</tbody>
</table>

Probing. Who is he? Love interest? Friend?

Closed conversation. That’s all I choose to tell you

Socially independent and they go out in public together to the coffee shop

Childlike, simplified, understandable definition of choice. Saying it twice. Not elaborating, unsure of what those things are. Uses the word you. Not taking ownership of choice

Where is the choice in your life? How do you exercise it practically?

Immediately equates choice to work. There are no other choices in Eileen’s mind. Elaborates on lack of work due to recession.
<table>
<thead>
<tr>
<th>Work, Loss, Bereavement</th>
<th>Think</th>
</tr>
</thead>
<tbody>
<tr>
<td>Club/Group</td>
<td></td>
</tr>
<tr>
<td>Social aspect</td>
<td></td>
</tr>
<tr>
<td>Food</td>
<td></td>
</tr>
<tr>
<td>Part of a group</td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td></td>
</tr>
<tr>
<td>Sense of Belonging</td>
<td></td>
</tr>
</tbody>
</table>

**Me:** Say, if we brought it back to physical activity and exercises, what choices do you think you have

**E:** Ah.. swimming, cycling and walking... I'm in a walking club as well in SIOG, I'm in a walking club...and we do it every month. We go to ************ and different places, yeah. We go about 10 miles or 8 miles... yeah. A walking club *they* call it

**Me:** And would you walk the whole time

**E:** Oh the whole time and then we stop then for lunch and we keep... continue then **until we're finished**

**Me:** And how many would be in that group

**E:** Oh, about twelve of *us*, thirteen. Yeah, there's a lot of us like, involved in it, yeah

**Me:** So going back to choice now again who decides where ye go

**I don't expect this reaction/answer**

Cannot get away from the subject of work. Loss of identity, **finds it hard to get over this**

Refocusing the interview

Recaps on activities but moves from the general to the specific re walking. Naming of places all familiar to her. Significant long walks

**Who are they call it?**

Tell me more

Socialisation and enduring exercise

This group is important to her
Acquiescence. Handing responsibility over to someone else

| Me: And are you asked where you would like to go |
| E: Yes I don’t mind, they choose where we go, *they choose* |
| Me: And do you always like where they choose |
| E: I do, I don’t mind (very matter of factly) I don’t mind at all |
| Me: Would you ever feel that maybe you’d like to choose for that day |
| E: No, no (very emphatic). I go by the staff, what *they tell* us to do...yeah |
| Me: Why do you, why do you do that? |
| E: I don’t know because I prefer...I don’t know... I *accept* the way I go, the way I go like, yeah |

No hesitation. Vera’s the ‘leader’ and she’s given the title.

Doesn’t answer the question directly. ‘They’ choose. It’s out of my hands. Let them at it

This arrangement suits Eileen but I do and I don’t creates a contradiction

Reflective

*Double ‘no’.Uses the word us and they*

I emphasise you and mirror her idiom by repeating it

Language, stumbling, can’t answer readily

Group is important. Safety in numbers? Back to socialisation

One last question on this. Did you ever...
<table>
<thead>
<tr>
<th><strong>Friendships</strong></th>
<th><strong>Feeling of Safety and Protection when she doesn't have to choose or make the decisions</strong></th>
<th><strong>Making good choices</strong></th>
<th><strong>Routine Acceptance of the Status Quo</strong></th>
<th><strong>Is choice an option or does Eileen opt not to make a choice</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Me:</strong> Would you like to make a decision on your own <strong>E:</strong> I like to be with the group. And you talk to people and, you get to know people and mix in and make friends that way, yeah <strong>Me:</strong> Do you always then get to do what you want to do or was there ever a time you didn’t get to do what you wanted to do? <strong>E:</strong> No, never, never did, no. Never happened. That never happened no Ok. No, and I enjoy it. When the walk is over then, we go for a cup of tea somewhere, yeah, yeah (social aspect again of the activity important)</td>
<td><strong>Me:</strong> So, what do you think choosing means in physical activity? <strong>E:</strong> I make the swimming and the walking and the gym and everything, you know. Well I go to the gym now every Tuesday with the Program. I go to the IT up in Clash. I go there every Tuesday so I choose that for me because it’s good for me, to get out, you know...yeah <strong>Me:</strong> Let’s, say you wanted to go on a Wednesday <strong>E:</strong> Yeah but I go on a Tuesday. That’s the day that was chooser. I choosed the Tuesday anyway, yeah</td>
<td><strong>‘Never happened’. I don’t want to talk about this anymore. Changes the subject to avoid the question about decision and back to safety of the group</strong></td>
<td></td>
<td><strong>Understanding of Physical Activity</strong></td>
</tr>
<tr>
<td>Preferences</td>
<td><strong>Me:</strong> Do you ever feel that you'd like to go another time?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------</td>
<td>-------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Routine</td>
<td><strong>E:</strong> Yeah, <em>but I have to do what I'm told to go by the orders you see.</em> I don't mind. I do what I'm told and I feel happy, do you know, yeah (Eileen is very upbeat and happy)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socialising</td>
<td><strong>Me:</strong> What plans do you have for this afternoon?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colleagues</td>
<td><strong>E:</strong> I like the gym and I like the treadmill and all the machines. I like all the machines</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Silence</strong></td>
<td><strong>E:</strong> Oh I go down meet them and have tea below (Eileen's group who are In one of the kitchens in the building). I'm in Social Network group and I go down and I mix in with people, eat with them and get on with them and talk to them. And I clean up after me and I feel better that way, you know..</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chores</td>
<td><strong>Me:</strong> You enjoy that..</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Freedom</td>
<td><strong>E:</strong> Because it gets me out of the house at home... not to be inside in the house all the time. You'd be bored at home like you know, find the day long and it gets you out of the house...yeah</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>from boredom, being with the same person. Idle</td>
<td><strong>Me:</strong> And how long have you been coming to the service</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td><strong>E:</strong> Story-telling. 'They' did away with. Refers to work again. I wanted to work but 'they' did away with it</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Justifies why she likes physical activity
Socialising important as is 'cleaning up after me'
A set plan to be followed
Getting away from home. Freedom. Alleviate boredom. Likes to be busy

190
<table>
<thead>
<tr>
<th>E:</th>
<th>Well, you see what happened at the beginning is I was coming 20 years <strong>but then the work did away, they did away with the work here then</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Me:</td>
<td>What work was that</td>
</tr>
<tr>
<td>E:</td>
<td>The garden centre and the kitchen <strong>you know</strong></td>
</tr>
<tr>
<td>Me:</td>
<td>And what did you work at here</td>
</tr>
<tr>
<td>E:</td>
<td><strong>Oh I worked in the garden centre and I did the potting and all that and the tunnels (Refers to it with nostalgia and happy memories)</strong></td>
</tr>
<tr>
<td>Me:</td>
<td>And did you get paid for that</td>
</tr>
<tr>
<td>E:</td>
<td>No, it used to be... I think it used to be the Social Welfare used to pay. SJOG used never pay at all, no, no</td>
</tr>
<tr>
<td>Silence</td>
<td></td>
</tr>
<tr>
<td>Me:</td>
<td>If you had a day where you could do whatever you wanted to do, could you describe that day to me?</td>
</tr>
<tr>
<td>E:</td>
<td>Like I like.. you see then Thursday morning, I do the shopping with my mother, I, we go down in the car, do the shopping... I go round with the trolley, <strong>yeah, yeah</strong></td>
</tr>
</tbody>
</table>

Tell me about that because that is important to you I can tell

‘You know’

Wants to tell her story about her working life. Describes her role

Were you valued as a worker?

Understanding of payment system

Silence reflects how pensive she is

Bringing this feeling to a higher level

Only hears ‘day’. Describes the routine of shopping. The car is brought back into the story but in the context of transport for shopping rather than wanting to drive. Describes her role when shopping with the trolley
<table>
<thead>
<tr>
<th>Me:</th>
<th>Is there anything you want to do next or, you know anything you would love to do in your lifetime</th>
</tr>
</thead>
<tbody>
<tr>
<td>E:</td>
<td>But, you see I have no one to go on holidays with. I have no one to go on trips with or anything....</td>
</tr>
<tr>
<td>Me:</td>
<td>Could you talk a bit more about that to me</td>
</tr>
<tr>
<td>E:</td>
<td>I'd like to have someone to go with but I have no one to go with like, for trips like, you know on holidays and things you know</td>
</tr>
<tr>
<td>Me:</td>
<td>Where would you like to go</td>
</tr>
<tr>
<td>E:</td>
<td>Well I used to go to Lourdes. It's very expensive you know.........silence..............very dear like....yeah</td>
</tr>
<tr>
<td>Me:</td>
<td>And who used you go with</td>
</tr>
<tr>
<td>E:</td>
<td>I used to go with the group like, I used to go with the group always</td>
</tr>
<tr>
<td>Me:</td>
<td>And what would you do in Lourdes, describe that holiday to me</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E:</th>
<th>Oh, the praying all the time and you have the torchlight procession, all the walking around, mass every day and everything</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frustration of not being able to go on holidays and having no one to go with</td>
<td></td>
</tr>
<tr>
<td>Tell me how you feel about that</td>
<td></td>
</tr>
<tr>
<td>Holidays possible if I had somebody</td>
<td></td>
</tr>
<tr>
<td>Are there other things you would like to do with somebody else</td>
<td></td>
</tr>
<tr>
<td>Speaks of past trips</td>
<td></td>
</tr>
<tr>
<td>There were trips and people to go with</td>
<td></td>
</tr>
<tr>
<td>Remembering as if it was an endurance test</td>
<td></td>
</tr>
<tr>
<td>Was there a holiday feel to this</td>
<td></td>
</tr>
<tr>
<td>Wish for like-minded people. Can’t do this on her own Loneliness</td>
<td>Resources an issue</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>Me:</strong> What would you do in the evening then when you were finished with that..</td>
<td>Doesn’t expand. Activities may have been narrow</td>
</tr>
<tr>
<td><strong>E:</strong> You go down to the grotto like and things like that</td>
<td>What was the social aspect of this</td>
</tr>
<tr>
<td><strong>Me:</strong> Would you do other things, would you go for food</td>
<td>Not very exciting</td>
</tr>
<tr>
<td><strong>E:</strong> A drink of tea like, a cup of tea, yeah...yeah (flat tone)</td>
<td>I’d settle for a couple of nights. Frustration</td>
</tr>
<tr>
<td><strong>Me:</strong> And is there anywhere else that you’d like to go on a trip</td>
<td>Choice because this is where you can express what you would like</td>
</tr>
<tr>
<td><strong>E:</strong> I don’t know, I don’t know. I’d like to have a couple of nights away but I have no one to go with then like you know</td>
<td>Funding</td>
</tr>
<tr>
<td><strong>Me:</strong> Have you ever asked or suggested it here maybe to any of the staff that you’d like to go on a trip</td>
<td>Disappointment. This is not enough, one night</td>
</tr>
<tr>
<td><strong>E:</strong> Yeah, but there’s no money there, there’s no money...yeah</td>
<td>Choice (Either or?)</td>
</tr>
<tr>
<td><strong>Me:</strong> Is that ok with you?</td>
<td></td>
</tr>
<tr>
<td><strong>E:</strong> Well there’s only one night away that’s all...you never go way for anything like a week you know...yeah</td>
<td></td>
</tr>
<tr>
<td><strong>Me:</strong> And where would you go for the night</td>
<td></td>
</tr>
<tr>
<td><strong>E:</strong> We go to Dublin or we go to *** maybe. We went to *** last year...</td>
<td></td>
</tr>
</tbody>
</table>
Me: And you stayed...
E: In a hotel. I forget the name of it now. T’was nice t’was
Me: You’d like more of that?
E: Yeah, yeah (wistful expression)
Me: If I was to ask you know what do you want to do....Eileen do you find that a hard question or an easy question
E: I don’t know. I like to do different things, you know you see. I go out then of a Wednesday night with Solas. I go Wednesday night. It was *** at the start but now its ***s...yeah
Me: And what’s that
E: It’s a club. They get together and they socialise. One night they go for a drink, one night they go bowling, they play bingo and dancing...and disco one night and different things you know
Me: What do you think goes into making a choice
E: It’s a hard question alright
Me: Could you think about that for a little while
E: Yeah, I could, yeah
Me: Would you draw me maybe something that you think might go into choice

Really misses the trips
I do know. I like variety
‘They’ no sense of belonging? Perhaps not her usual group.
Difficult for her to conceptualise choice
Asking rather than making her own mind up
Wants to draw something nice
<table>
<thead>
<tr>
<th>E:</th>
<th>What will I draw... <strong>What would be nice?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Me:</td>
<td>Well, well that's for you to decide</td>
</tr>
</tbody>
</table>

(*Introduce Eileen to paper and colouring pencils*)

<table>
<thead>
<tr>
<th>E:</th>
<th>I don't know, I'm not very good at drawing really. I'm not very good at it</th>
</tr>
</thead>
<tbody>
<tr>
<td>Me:</td>
<td>I'll tell you what we'll do. You draw and I'll draw</td>
</tr>
<tr>
<td>E:</td>
<td>Right ok (Eileen is happy with that)</td>
</tr>
<tr>
<td>Me:</td>
<td>We'll draw together</td>
</tr>
</tbody>
</table>
| E: | Yeah, I'll draw a house anyway.................
*longer period of silence as we settle into drawing*
And Ballincollig is in Cork as well, Ballincollig |

| E: | Oh no. I'm living in "**". Sure Tralee is my town, *** is my town*
sure (Pride in her homeplace) |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>E:</td>
<td>Like, to go on holidays, do you know have more trips out you know. Holidays I'd like you see because I never went on a plane holiday. I went on a plane to Lourdes but I'd like to go on a foreign holiday do you know, do you know</td>
</tr>
<tr>
<td>Me:</td>
<td>Have you made choices in the past</td>
</tr>
<tr>
<td>E:</td>
<td>Never, no, no....for you see choices are hard. <em>I don't know</em> it's hard to know choices...very little choices</td>
</tr>
</tbody>
</table>

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Afraid of being judged

Still talking about other places

Sense of Identity

Back to the importance of trips and holidays
<table>
<thead>
<tr>
<th>Me:</th>
<th>Why do you say that?</th>
</tr>
</thead>
<tbody>
<tr>
<td>E:</td>
<td>I don’t know. I have very little choices</td>
</tr>
<tr>
<td>Me:</td>
<td>You feel you have very little choices</td>
</tr>
<tr>
<td>E:</td>
<td>Yeah, very little, yeah</td>
</tr>
<tr>
<td>Me:</td>
<td>How does that make you feel?</td>
</tr>
<tr>
<td>E:</td>
<td>Nothing, nothing at all like</td>
</tr>
</tbody>
</table>

**Silence**

| E:  | Oh, I do sometimes make mistakes, yeah. Yerrah, you know I had a change of jobs like and I often made mistakes too like. You know I was in the ******* I was in the Rehab in Clash and I left it.... You know I should have stayed in the one job you know, I should have stayed...yeah |
| Me: | And why did you leave |
| E:  | I don’t know. They did away with the work then in the Rehab, they did away with the sewing that time...yeah |
| Me: | But, I suppose there, there wasn’t a choice, was there |
| E:  | No. it closed |
| Me: | So that’s not a choice, a choice that you had no control over |
| E:  | No, no no |
| Me: | But let’s say a choice that you have control over |

**Denial. Contradictory. Uncertainty. Or it could be linking back to work again**

<table>
<thead>
<tr>
<th>Work?</th>
</tr>
</thead>
</table>

**Emptiness**

| Refers to earlier times. Work is important Difficulty of losing the opportunity to work |

<table>
<thead>
<tr>
<th>‘They’</th>
</tr>
</thead>
</table>

**Difficulty in understanding the concept of choice**
<table>
<thead>
<tr>
<th>E:</th>
<th>Yeah. Be happy, make a choice and be happy. But I’m happy now. That’s the main thing Yeah...</th>
</tr>
</thead>
<tbody>
<tr>
<td>E:</td>
<td>Sometimes I make no choices, sometimes..................</td>
</tr>
<tr>
<td>Me:</td>
<td>So you know life, everyday life, there’s choices made every single day of your life...</td>
</tr>
<tr>
<td>E:</td>
<td>Like, there’s choices like, if I was told tomorrow to go for a walk, I’d go for a walk, for here if Susan or Mary tells me to go for a walk, I go for a walk. And if we’re going swimming, we go swimming, and if you go to the gym, we go to the gym. So that’s my choice. I make a choice and I do all them things</td>
</tr>
<tr>
<td>Me:</td>
<td>If you said no, Mary, I’m not going for a walk..</td>
</tr>
<tr>
<td>E:</td>
<td>But then they want you to get down weight.. so you know</td>
</tr>
<tr>
<td>Me:</td>
<td>But what would happen if you said no</td>
</tr>
<tr>
<td>E:</td>
<td>They’d say like, what’s wrong with your legs like</td>
</tr>
<tr>
<td>Me:</td>
<td>And would you always feel like going for a walk?</td>
</tr>
<tr>
<td>E:</td>
<td>I do, not all the time. I do be breathless. I have asthma, I do be breathless then sometimes</td>
</tr>
<tr>
<td>Me:</td>
<td>And has it ever happened that you have said no</td>
</tr>
<tr>
<td>E:</td>
<td>No, I never said no, no</td>
</tr>
</tbody>
</table>

Definition of choice as something unique to everyone and this is Eileen’s take on it

That was out of your hands

Unsure

Moving past loss of job back to the present

This is a very definite statement. Eileen is saying that she does make choice and here they are laid out in front of me.

Conscious that this could lead to weight gain

Understanding of sarcasm
<table>
<thead>
<tr>
<th>Health condition</th>
<th>Me: And how does that make you feel</th>
<th>E: I feel sometimes guilty you know, sometimes. But we have to look after our figure like</th>
<th>Doesn’t not want to go walking because of choice but due to health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reluctance to say no</td>
<td>Me: So, you’re aware of your health I suppose, is it</td>
<td>E: Health, yeah, exactly. And keep back from the food</td>
<td>Never said no</td>
</tr>
<tr>
<td>Weight watching</td>
<td>Me: What kind of foods would you have to keep back from?</td>
<td>E: Biscuits and cakes and all them things</td>
<td>Guilt versus health</td>
</tr>
<tr>
<td>Health and Food</td>
<td>Me: So, how do you choose that? How do you make those decisions?</td>
<td>E: I make an effort and have willpower</td>
<td>Health equals diet</td>
</tr>
<tr>
<td>Bad Foods</td>
<td>Me: Do you ever disobey that</td>
<td>E: I do sometimes yeah. Not often, not often, no</td>
<td>The bad foods</td>
</tr>
<tr>
<td>Staying healthy means having willpower</td>
<td>Me: But that’s a choice, that’s making...do you understand that as a choice</td>
<td>E: Yeah, tis, tis indeed a choice</td>
<td>Willpower</td>
</tr>
<tr>
<td></td>
<td>Me: So when you make that choice, how do you feel then?</td>
<td>E: You feel better, you feel better then</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Me: Would you feel better after having the biscuit</td>
<td>E: No, no, you shouldn’t eat it, no...you feel you have willpower</td>
<td></td>
</tr>
</tbody>
</table>
then ....silence

Me: So, I suppose we’ve talked about the physical activities and the choices you make

E: We have yeah

Me: How would you say describe yourself as a person

E: Mmmmm, I don’t know really. Like I’m a person like. I’m my own person like, yeah (silence)

Me: How does exercise make you feel

E: Great, (very enthusiastic). And you feel in much good form and you feel fitter you know. More energy and everything, yeah

Me: Do you remember when you didn’t exercise

E: I always exercised but the eating was a problem, the eating, the eating... You know, small portions. I go to weightwatchers then Wednesday morning, here, I go to weightwatchers

Me: I think I’ve kept you long enough at this stage Eileen (It’s getting near lunchtime)

E: We have, we have. Are you happy with that

Me: I’m very happy Eileen, and if I need to can I speak to you again?

E: You can, you can. Thanks very much

Health awareness

Independent Self-Assertion

Good feeling exercise brings

Strong statement of Identity

Very real effects of exercise
<table>
<thead>
<tr>
<th>Battle with food</th>
<th>Me: Thank you Eileen.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Note to self: Yeah at end of every sentence means that Eileen was finished and did not want to add anything else</td>
</tr>
<tr>
<td></td>
<td>I didn't understand eating before</td>
</tr>
</tbody>
</table>
Appendix I- Super-Ordinate Themes

Eileen

<table>
<thead>
<tr>
<th>Themes</th>
<th>Page/Line</th>
<th>Key Words</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquiescence</td>
<td>6</td>
<td>They choose where we go, they choose</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>I go by the staff, what they tell us to do, yeah</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>I accept the way I go, the way I go like</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>That's the day that was chosen</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>But then they want you to get down the weight</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>No, I never said no, no</td>
</tr>
<tr>
<td>Independence</td>
<td>3</td>
<td>Oh they would</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Every day I meet Jack (anonymised)</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>I cycle. I can't drive. I cycle</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>Like I'm a person</td>
</tr>
<tr>
<td>Choice</td>
<td>5</td>
<td>Well what kind of things would you like</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>See there's no other choices (work)</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>They choose where we go, they choose</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>So I choose that for me</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>So I choose that because it's good for me</td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>I don't know. I have very little choices</td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>Never, no, no, for you see choices are hard</td>
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<tr>
<td></td>
<td>15</td>
<td>Like there's choices like. If I was told tomorrow to go</td>
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<td></td>
<td></td>
<td>for a walk, I'd go for a walk. For here if (keyworker 1) or</td>
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<td></td>
<td></td>
<td>(keyworker 2) tells me to go for a walk, I go for a walk. And if were going</td>
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<td></td>
<td></td>
<td>swimming, we go swimming and if you go to the gym we go to the gym.</td>
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<td></td>
<td></td>
<td>So that's my choice. I make a choice and I do all them</td>
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<td></td>
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<td>things</td>
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<tr>
<td>Health Benefits</td>
<td>7</td>
<td>So I choose that because it's good for me</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>But then they want you to get down the weight</td>
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<tr>
<td></td>
<td>15</td>
<td>And keep back from the food</td>
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<td></td>
<td>16</td>
<td>Biscuits and cakes and all them things</td>
</tr>
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<td></td>
<td>16</td>
<td>No, no you shouldn't eat it</td>
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<td>17</td>
<td>I always exercised but the eating was a problem, the</td>
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<td></td>
<td>the eating.. you know, small portions. I go to</td>
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</tbody>
</table>

201
<table>
<thead>
<tr>
<th>weightwatchers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Routine</strong></td>
</tr>
<tr>
<td>3</td>
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<td>4</td>
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<td>8</td>
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<td>8</td>
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<td>9</td>
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<tr>
<td><strong>Socialisation</strong></td>
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<td>7</td>
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<td>12</td>
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<td>12</td>
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<td>12</td>
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<tr>
<td><strong>Group</strong></td>
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<td>6</td>
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<td>11</td>
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<tr>
<td>12</td>
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<tr>
<td><strong>Group Think</strong></td>
</tr>
<tr>
<td>7</td>
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<tr>
<td>12</td>
</tr>
</tbody>
</table>
Appendix J Abstraction of Themes

What has emerged from the Transcripts for Eileen

How self-selection impacts on adult with ID
Independence
Choice
Routine
Socialisation
Group-think
Acquiesce
Health
Independence

Subsumption leading to the development of a superordinate theme

Choice
Associated with loss of work
Obeying orders
Handing responsibility over to somebody else/ Leader
Preference
Independent means of Transport (Cycling)

Group
Sense of belonging
Responsibility to group
Consensus
Acquiescence
I don’t mind at all
Socialisation
- Outings
- Food
- Friendships
- Walking

Routine
- Freedom from being at home
- Meeting good friend everyday
- Weightwatchers

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- Weekly shopping with mother

**Health**

- Good food versus Bad food
- Weightwatchers (Group activity)
- Awareness of health
- ‘Battle with Food’

**Exercise**

- What I like
- Description of
- Good feeling after exercise
- Getting out of the house
- Service

Having gone through the transcript line by line, the emergent themes can be placed under the above headings. These are merged with all of the participant analysis in one document.