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Master of Science by Research

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2018

**Towards a Psychosocial Theory of Ageing
with Lifelong Intellectual Disability**

University of Limerick

**Towards a Psychosocial Theory of Ageing with
Lifelong Intellectual Disability**

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***Submitted for the award of Master of Science by
Research***

University of Limerick

Supervised by Dr. Barry Coughlan

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Declaration

I declare that this submission is entirely my own work and has not been submitted in part or full to any other university for the award of degree.

Abstract

Background: In the context of ageing populations in the western world, people with lifelong disability are among the fastest growing groups of older people. The largest sub-group of these are older people with intellectual disability. Yet little is known about how men and women with lifelong intellectual disability experience their later years. The purpose of the study is to develop a better apprehension of what ageing implies for those with lifelong intellectual disability, through direct consultation about psychosocial aspects of their lives.

Method: This is a cross-sectional study carried out in a community based service for adults with moderate to severe intellectual disability in South West Ireland. It utilised a qualitative approach with a non-experimental, exploratory design. Participants (n=46) ranged in age from 36 to 76, with a mean age of 52. There were 24 males and 22 females. Participants lived in community residential houses (54%), with family (39%), in supported living (4%) and in a community hospital (2%). Fifty five interviews were undertaken. Data analysis drew on the principles of the Constructivist Grounded Theory Method.

Results: The findings point to a life course theory of ageing and show that outcomes in ageing with lifelong intellectual disability are a function of both the ageing process and how age-related changes interface with the lived environment. Ageing well is linked to the quality and timing of supports received across five areas (1) *self-determination* (2) *safety and security* (3) *social participation* (4) *loss and spirituality* (5) *coping patterns*. A planning tool is developed from the findings and is used to identify individualised supports required across these five areas (*Wellness in Ageing Tool – Intellectual Disability – WiAT-ID*).

Conclusions: (1) ageing experience cannot be set apart from whole of life experience (2) a five area support model, grounded in the experiential reality of actual lives, facilitates psychological and social wellness as men and women with lifelong intellectual disability grow old.

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Table of Contents

	<i>page</i>
<i>Declaration</i>	4
<i>Abstract</i>	5
<i>Acknowledgements</i>	6
<i>Table of Contents</i>	7
<i>List of Tables</i>	12
<i>List of Diagrams</i>	13
<i>Glossary</i>	14
<i>References</i>	217
<i>Bibliography</i>	236
<i>Resources</i>	236
<i>List of Appendices</i>	237

CHAPTER One: *Introduction to the Thesis* **page**

1.1 Background	16
1.2 Aim of the Study	16
1.3 Literature Search	17
1.4 Outline of the Thesis	18

CHAPTER Two: *Understanding Ageing with Intellectual Disability – the Need for Theory*

2.1 Overview	21
2.2 Gerontology – The Story So Far	21
2.3 Understanding Intellectual Disability	22
2.4 Demographics	24
2.5 The Need for Theory	25
2.6 Towards a Psychosocial Theory of Ageing with Lifelong Intellectual Disability	26
2.7 Psychosocial Theories of Ageing Outlined	27

2.8 Goodness of Fit	31
2.9 Going Forward	33
2.10 In Conclusion	33

CHAPTER Three: *Life Course*

3.1 Overview	34
3.2 Life Course and Ageing	34
3.3 Life Course Issues and Impact on Ageing with Intellectual Disability	35
3.4 Social Exclusion	36
3.5 Self Determination	38
3.6 The Role of the Family	41
3.7 Transitional Shifts	42
3.8 Work and Retirement	42
3.9 Loss and Bereavement	43
3.10 Health	44
3.11 In Conclusion	47

CHAPTER Four: *Successful Ageing – a More Inclusive Approach*

4.1 Overview	48
4.2 Successful Ageing	48
4.3 Subjective Opinion on Ageing Well	50
4.4 Supporting Successful Ageing for All	50
4.5 Contextual Issues Across the Lifespan	52
4.6 Bridging the Fields of Ageing and Disability	53
4.7 In Conclusion	54

CHAPTER Five: *Consulting with Research Participants with Intellectual Disability and Communication Difficulties*

5.1 Overview	56
5.2 Background	56
5.3 The Right to be Included and Consulted	56
5.4 Why Consult?	58
5.5 Respect	59

5.6 Establishing Individualised Communication	59
5.7 Data Collection Methods	61
5.8 In Conclusion	63

CHAPTER Six: *The Research Methodology*

6.1 Overview	65
6.2 Context of the Study	65
6.3 Choice of Methodology	66
6.4 Rationale for the Study	69
6.5 Defining Old Age in the Study Population	69
6.6 Ethical Approval	70
6.7 Participants	70
6.8 Ethical Considerations	74
6.9 Informed Consent	76
6.10 Eliciting Informed Consent	77
6.11 Creating an Effective Communication Environment	78
6.12 Data Collection and Management	82
6.13 Data Analysis	87
6.14 Reporting Results	92
6.15 Enhancing Credibility and Ensuring Validity of the Research Study	93
6.16 Summary of Study Design	96
6.17 Going Forward	97
6.18 In Conclusion	97

CHAPTER Seven: *Presentation of Findings*

7.1 Overview	98
7.2 Self Determination	99
7.2.1 Choice	100
7.2.2 Acceptance	104
7.2.3 Dependency	105
7.2.4 Disempowerment	108
7.2.5 Self determination: summary of analysis	115

7.3 Loss and Spirituality	115
7.3.1 Pervasive loss	116
7.3.2 Spiritual life	120
7.3.3 Death and dying	122
7.3.4 Loss and spirituality: summary of analysis	123
7.4 Social Participation	124
7.4.1 Social engagement	125
7.4.2 Relationships	130
7.4.3 Social roles	136
7.4.4 Self concept	138
7.4.5 Community	140
7.4.6 Social participation: summary of analysis	141
7.5 Safety and Security	142
7.5.1 Confidence	143
7.5.2 Adaptation	148
7.5.3 Stress	149
7.5.4 Safety and security: summary of analysis	152
7.6 Coping Patterns	153
7.6.1 Positive coping response	153
7.6.2 Minimising health-related decline	156
7.6.3 Focus on the present	157
7.6.4 Achievable goals	158
7.6.5 Positive outlook	159
7.6.6 Coping patterns: summary of analysis	163
7.7 In Conclusion	163

CHAPTER Eight: *Development of a Psychosocial Theory of Ageing with Lifelong Intellectual Disability*

8.1 Overview	165
8.2 Kate's Story	165
8.3 The Life Course Trajectory	167
8.4 Key Findings Informing Theory Development	168
8.5 A Theory of Ageing with Lifelong Intellectual Disability	171

8.6 Using the Theory	174
8.7 In Conclusion	175
CHAPTER Nine: <i>Successful Ageing Revisited</i>	
9.1 Overview	177
9.2 Supporting Competencies in Advancing Years	177
9.3 Supporting Competencies in Ageing – Qualitative Checklist (SCIA-20)	179
9.4 In Conclusion	181
CHAPTER Ten: <i>Discussion</i>	
10.1 Overview	182
10.2 Differences in Ageing Experience Relative to the General Population	182
10.3 Seeking Common Ground- an Inclusive Agenda in Research, Policy and Practice	185
10.4 Where does the Research Fit with The Wider Research on Intellectual Disability and Ageing?	187
10.5 Where does the Theory Fit with General Ageing Theory?	188
10.6 What does the New Theory Add to Ageing Theory?	191
10.7 How do Findings Fit with Current Intellectual Disability Practice and Policy?	192
10.7.1 Person centred planning	192
10.7.2 Generic integration	193
10.7.3 Rights and citizenship	194
10.7.4 Housing	196
10.7.5 Personal safety	197
10.8 Implications for Future Research	198
10.9 Contribution of the Study to the Field of Ageing and Intellectual Disability	202
10.10 In Conclusion	204

CHAPTER Eleven: *Guidelines for Practice*

11.1 Overview	205
11.2 Self Determination	206
11.3 Loss and Spirituality	209
11.4 Social Participation	210
11.5 Personal Safety	211
11.6 Coping	211
11.7 Overall Adaptation to Ageing	212
11.8 In Conclusion	213

CHAPTER Twelve: *Reflection*

12.1 Overview	214
12.2 Key Issues in Ageing Well	214
12.3 Ongoing Challenges	215
12.4 A Lifelong Approach	215
12.5 In Conclusion	215

List of Tables:

Table 1	Response to Participation by Target Group (pg.71)
Table 2	Male/Female Age Demographic (pg.73)
Table 3	Mean Age of Participants (pg.73)
Table 4	Adapted SOC Framework (pg.178)
Table 5	Supporting Competencies in Ageing with Lifelong Intellectual Disability using Selection, Optimization, Compensation(pg.180)
Table 6	Factors Specific to an Intellectual Disability Population in Adapting to Ageing (pg.184)

List of Diagrams:

- Diagram 1 Participant Age Profile – Overall (pg.72)
- Diagram 2 Participant Age Profile – Down Syndrome/Other (pg.72)
- Diagram 3 Living Arrangements of Participants (pg.73)
- Diagram 4 The Psychosocial World of the Older Person with Lifelong Intellectual Disability (pg.98)
- Diagram 5 Self Determination (pg.99)
- Diagram 6 Loss and Spirituality (pg.116)
- Diagram 7 Social Participation(pg.125)
- Diagram 8 Safety and Security (pg.143)
- Diagram 9 Coping Patterns(pg.153)

- Diagram 10 Lifespan Trajectory of Development (pg.168)
- Diagram 11 Five Area Support Model of Ageing Well with Lifelong Intellectual Disability (pg.172)
- Diagram 12 Differences in Ageing Experience Relative to General Ageing Population (pg. 183)
- Diagram 13 How Psychosocial Change is Experienced in Older Years(pg.205)

Glossary

Biopsychosocial: A term used to imply that biological, psychological, and social factors and their complex interactions all have a role in human functioning and in our understanding of health and illness (Engel 1977).

Gerontology: The scientific study of ageing as a physical, psychological, cultural and social process. Pioneers such as James E. Birren began organising gerontology as a separate field in the 1940's.

Key worker: People with intellectual disability attending services in Ireland can have a Key Worker to co-ordinate their care. The Key worker is responsible for co-ordinating a person-centred plan for an individual.

Life Story Book: This is a homemade book made to store memories about a person's life in a variety of ways such as photos, stories, documents, drawings. It might be used as a valuable resource for present and future carers or for the individual and family. The concept of life story books originates in social work where it is used in the adoption and fostering services and dates back to at least the 1960's.

Person Centred Planning (PCP): Person centred planning is a way of discovering how a person wants to live their life and what is required to make that possible (National Disability Authority 2005). The aim of person centred planning is “good planning leading to positive changes in people's lives and services” (Ritchie *et al* 2003). It has its roots in the normalization movement (Wolfensberger 1972) and is grounded in a social model of disability and a strengths-based approach.

Personal Communication Passport: A booklet created with and for a person with communication difficulties which contains important information about that person, presented in an accessible way and thereby supports ease of transition between services for that person. The first Personal Communication Passports were made by Sally Millar in 1991 as part of a CALL project, funded by the then Scottish Office Education Department.

Psychosocial: Relating to the combined influence of psychological factors and the surrounding social environment on physical and mental wellness and ability to function. It was first commonly used by psychologist Erik Erikson (1982) in his description of the stages of psychosocial development.

Total Communication: An approach which encompasses and values all forms of communication equally. Non verbal communication (body language, facial expression, gestures, pictures and written forms) is valued as much as spoken language (Hassiotis, Barron & Hall, 2013).

Chapter One – Introduction

1.1 Background to the study

While Hendricks and Achenbaum (1999) point out that earliest historical records indicate that populations throughout all times and places have tried to make sense of the way people age, the current growth in ageing populations across the globe has led to increased research interest in the area of ageing, and in particular, the idea of ageing successfully.

Prior to the 1990's ageing was viewed as an inevitable process of deteriorating health and function. In 1997 Rowe and Kahn redefined ageing by advancing the concept of successful ageing which entailed low risk of disease, good physical and cognitive function, and productive engagement in life. While their theoretical approach to ageing had a significant effect on how general ageing was subsequently viewed, men and women with intellectual disability were omitted from the analysis as they could not meet the criteria set out by the authors.

Growing old with a lifelong intellectual disability is now a common phenomenon in Ireland, as in the western world as a whole (World Health Organization 2001a). As such we are seeing the first substantial group of older adults with lifelong intellectual disability reach old age (Bigby 2004). Many are surviving to their mid-sixties, with some living well beyond this age (Buys *et al* 2008). It is time then to expand the discussion on experience of ageing beyond the typical population and to explore how those ageing with lifelong intellectual disability experience later life.

This is the context of the study presented in the following thesis and the researcher seeks to bring new voices to the research arena in order to begin a narrative and stimulate debate on experience of ageing in this minority group.

1.2 Aim of the study

The study aims to broaden understanding of ageing with intellectual disability through direct consultation with the research population around individual change in psychosocial aspects of functioning. Much of the research in the disability field has traditionally drawn from the perspectives of others, rather than including those of the people themselves (Buys *et al* 2008).

Morris (1999) describes attempts to construct a theory using the methods and perceptions of those without disability as ‘the original error’ of the investigation. Bogdashina (2003) suggests that to avoid ‘the original error’ personal accounts and communications of the target population should be regarded as the main source of information. The approach adopted in this study is to listen to those who are ageing with lifelong intellectual disability, to afford them an opportunity to explain how they experience the world, and challenged the assumptions that only the views of specialists and carers are relevant and correct. By adopting a consultative approach using individual interviews the study will provide first-hand insight into how this group experiences older age, as opposed to how others think they do. More specifically, the purpose of the study is to explore the psychosocial aspects of ageing with lifelong intellectual disability, and to be guided by the need to understand the values and purposes of those at the centre of the enquiry. The central research question is therefore:

How do men and women with lifelong intellectual disability experience ageing?

In particular:

- a. *How is the ageing process described and explained?*
- b. *How is the subjective experience of change due to ageing described and explained?*
- c. *How are the effects of change due to ageing described and explained?*

Psychosocial theories of ageing explain human development and ageing in terms of individual changes in ***cognitive functioning, behaviour, roles, relationships, coping ability,*** and ***social changes*** (Wadensten 2006). The research questions are therefore addressed in relation to these specific areas of life experience and individual functioning.

The study site: a community based service for adults with intellectual, physical, and sensory disabilities, in the South West of Ireland.

The researcher: a clinical psychologist working at the study site.

1.3 Literature Search

Electronic and print resources were screened in order to identify literature for inclusion in the study. The search strategy for reviewing the literature was mainly an electronic search of databases held in the University of Limerick Glucksman Library and search of print resources in the Social Sciences/Health Sciences sections of the library. Key academic and clinical text

books within the field were accessed and utilised as part of this search. Frequently accessed databases were Pubmed, Cochrane Library, PsycINFO, PsycARTICLES, and CINAHL Plus. These searches were first carried out in April 2011 covering all available years for each database. No date restrictions were applied at that time as the aim was to acquire an overview of all material relevant to the area. Search terms used initially were ‘ageing theory/psychosocial’, ‘ageing and intellectual disability’, and ‘psychosocial theory and intellectual disability’. This led to a broadening of the search to other areas that were of interest to the study. Additional search terms included ‘self-determination’, ‘social exclusion’, ‘family’, ‘loss’ and ‘retirement’, as well as ‘successful ageing’ and ‘life course theory of ageing’. Reference lists of included studies were searched for additional studies, print sources, and web searches. These reference lists also provided access information to relevant policy documents, guidelines, and both national and international conference papers. Electronic search and reference list reviews were followed up by manual searches of the books, journals, and policy documents available in the Glucksman Library (Social Sciences/Health Sciences sections). Electronic searches of databases were subsequently carried out periodically from 2011 to 2016 in order to find new studies or to follow up on additional areas of interest. Towards the final stage of the project, publications from 2013 to 2016 were of particular interest, as was bridging literature in respect of general ageing and ageing with intellectual disability.

1.4 Outline of the Thesis

The thesis is presented in twelve chapters. Following this introductory chapter, a review of the relevant literature is contained in Chapters Two, Three and Four. The aim of the literature review is to provide a broad understanding of the relevant issues impacting on people with intellectual disability as they go through life and as they age. As such they provide a contextual foundation for the thesis. While each chapter of the literature review has a distinct focus, they function as a whole in building understanding of ageing for this population.

Chapter Two draws on existing literature to outline trends in ageing and the current understanding of ageing in order to examine how generic psychosocial theories of ageing might apply to an intellectual disability population. An argument for the development of theory specific to those ageing with lifelong intellectual disability is also presented.

Chapter Three examines the literature on life course to evince an explanation of how dynamic factors throughout life impact on the ageing experience for people with intellectual disability. It is argued that psychosocial theories developed around normative ageing may not provide adequate explanations of their experience.

Chapter Four focuses on the literature of ‘successful ageing’. It examines how this phenomenon is understood and portrayed and whether it should be redefined in order to include people with lifelong intellectual disability.

Chapter Five lays the foundation for the methodology of the study by examining the core challenges in consulting with research participants with intellectual disability and associated communication difficulties. Evidence-based solutions and best practice guidelines are also outlined.

The methodology of the study is fully presented in Chapter Six and the rationale for choice of methodology is also provided.

The findings of the study are presented in Chapter Seven. The aim of this chapter is to provide insight into the ageing experience of participants. It therefore begins with a visual portrayal of their psychosocial world developed from thematic analysis of the collected data. Themes and subthemes are drawn out across five broad areas in order to illustrate the psychosocial experiences of participants as they age.

Chapter Eight presents the key findings contributing to theory development. A model of the new theory is demonstrated and the postulates of the theory are outlined. The chapter concludes by examining practical applications of the theory.

Chapter Nine revisits the idea of ‘successful ageing’ in order to explore how the findings can be used to optimise quality of life for the study population. A means of supporting ageing through timely planning and individualised supports is also set out.

Chapter Ten provides a discussion on the study in its entirety and positions it in relation to the wider research in the area, and in relation to practice and policy in the fields of both intellectual disability and ageing. The ways in which the new theory adds to ageing theories generally is explored and the contribution of the study to the field of ageing and intellectual disability is considered.

Guidelines for practice developed from the findings are presented in Chapter Eleven.

Chapter Twelve presents a short reflection on key issues that resonated for the researcher at the final stages of writing the thesis.

Chapter Two - Understanding Ageing with Lifelong Intellectual Disability: the Need for Theory

2.1 Overview

A broad context for the study, in terms of global trends on ageing and efforts to understand ageing generally, is presented in this chapter. It is argued that men and women with lifelong intellectual disability have lived atypical lives and thus a different psychosocial experience of ageing might be expected. Building on this premise, generic psychosocial theories of ageing are examined to consider how they include intellectual disability in their framework and whether they could be useful in explaining ageing with lifelong intellectual disability. The need for theory specific to those ageing with lifelong intellectual disability is discussed and the postulates of such a theory are outlined.

2.2 Gerontology: the story so far

The scientific study of ageing has been conducted for several decades. In fact, one of the first laboratories specifically dedicated to this field was established in 1927 within the psychology department of Stanford University. However, actually understanding and explaining the processes of ageing has proven complex and Birren (1996) contends that ageing may be one of the most difficult topics undertaken for research in the life sciences. Nevertheless, the field of gerontology is growing and expanding. The first large scale longitudinal study on ageing commenced in 1992 when the University of Michigan in the United States began the *Health and Retirement Study* (HRS). This sampled a representative sample of more than 26,000 Americans over the age of fifty, every two years. Interest in the area of ageing is also growing in Europe and a longitudinal study on ageing is currently underway. Following a call from the European Commission to establish a European longitudinal ageing survey, the *Survey of Health, Ageing and Retirement in Europe* (SHARE) commenced, with the first wave of data collection in 2005. SHARE is a multidisciplinary and cross-national database of micro-data on health, socio-economic status, and social and family networks, and involves more than 85,000 individuals aged fifty and over across 19 European countries. SHARE has now become a pillar of European research on ageing. In parallel to this, the *English Longitudinal Study on Ageing* (ELSA), which is modelled on the HRS in the United States, is

also underway and in Ireland a 10-year longitudinal study, named *The Irish Longitudinal Study on Ageing* (TILDA) (Kenny 2006) was launched in November 2006, using a sample of 8,500 people aged fifty and over. The Irish study has been expanded to include those ageing with intellectual disability and to this end an adjunct *Intellectual Disability Supplement (IDS)*, unique to Ireland, is also underway (McCarron and McCallion 2006; Burke, McCallion and McCarron 2014). The IDS/TILDA study is groundbreaking in that it is a step towards bridging the gap between ageing studies and intellectual disability studies at a time when such a partnership is seen as critical to meeting future demographic challenges (Bickenbach *et al* 2012). Overall it is clear that there is currently an international drive to understand the processes of ageing and what that means for people. This growth in interest is based on demographic data which confirms that both developing and developed societies include increasing numbers of older persons within the general population. This generates changing needs which impact on society in terms of economic and social policy and in service levels. As such, policymakers, economists, service providers, service users, and society in general are questioning standards and efficiencies and engaging with how such needs are met. This in turn has led to the need for a sound scientific foundation on which to base decisions across all interested sectors so that older populations may be served appropriately.

2.3 Understanding intellectual disability

In exploring the issue of ageing with lifelong intellectual disability it is important to outline how intellectual disability is defined and explained, in order to ground the inquiry in a clear epistemology. Historically, persons were categorized or identified as having intellectual disability if they failed to adapt socially to their environment (American Association of Intellectual and Developmental Disabilities, 2010). The emphasis on intelligence did not come until later. The current definition used by the AAIDD is as follows:

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

(AAIDD 2010, p.6)

According to this definition then, the three essential elements of intellectual disability are limitations in cognitive functioning, limitations in adaptive functioning, and early age of onset. However, the emergence of critical disability studies has helped broaden perspectives

and understanding beyond such narrow definitions and places the problems of disability within society. Goodley (2011) describes this as a major paradigm shift from disability as personal predicament to disability as social pathology. He argues that if we locate disability in the person we maintain the disabling status quo. However, by viewing disability as a cultural and political phenomenon, we can ask more searching questions about the social world which allows disability to be re-conceptualised as a social category that contributes to the exclusion of, and/or prejudice against, people with bodily or cognitive variations (Heller and Harris 2012). Conceptualizing disability as a social category that draws on the social model of disability (Oliver 1990) has been transformative in the lives of many people with disabilities by giving them both a shared identity as well as a political platform (Heller and Harris 2012).

Disability studies do not differentiate between types of disability and people with physical, sensory, mental health, and cognitive impairment, as well as those with age-related disability, are all included in the debate. The field of disability studies is diverse and interdisciplinary and emerged from the disability rights movement. In the United States, disability studies have identified disability as consisting of complex interactions between the biological reality of disability and the social structures which create disability (Mitchell and Snyder 2006). As such the social, emotional, psychological, and indeed, the practical impact of disability through the life course must be of interest to those seeking further understanding of living and ageing with disability. Heller and Harris (2012) point out that while there is little research to date on disability through the life course, core themes stemming from critical disability studies, such as the role of the family, the influence of policy and legislation, and the ability to enact self-determination, are significant factors in understanding disability across the life course. They argue that as disability studies is embodied in a critical theoretical approach which seeks to address a person's whole-of-life, it provides further awareness of the issues facing people with disabilities across their lives. In terms of seeking to understand and explain intellectual disability, a life course approach grounded in a critical disability studies paradigm is therefore useful. Furthermore researchers are now taking the first steps towards bringing ageing and later life directly into critical disability studies (Kahlin *et al* 2014).

2.4 Demographics

In many developed countries, the life expectancy of a person with an intellectual disability and no other significant health co-morbidities, now approximates that of the mainstream (Coppus, 2013), although UK statistics show that on average the life expectancy for men with intellectual disability is still 13 years less than the general population, and 20 years less for women (Public Health England, 2014b). Nevertheless, old age is now an important phase of the life course for many more individuals and as the first generation of people with intellectual disability to attain old age they have experiences of both institutional and community living (Kahlin *et al* 2014). This effectively means that the typical lived experience of this group differs significantly from the standard ageing population (Newberry *et al* 2015) as well as from earlier cohorts.

The World Report on Disability (2011) produced jointly by the World Health Organisation (WHO) and the World Bank, estimates that there are over one billion people with disabilities in the world today, of whom 200 million experience significant difficulties (Bickenbach *et al* 2012). At the same time, the Global Health and Aging Report (2011) released by WHO in partnership with US National Institute on Aging, revealed that in almost every country, the proportion of people aged over 60 years is growing faster than any other age group, and is forecast to reach 1.5 billion by 2050. Taken together, the dual phenomenon of global ageing and increased longevity for individuals with disabilities presents multiple economic, social, and political challenges for both developed and developing nations. However, in order to progress the advances made in public health and education in relation to both ageing and disability in the years ahead should also be welcomed as an opportunity for growth in knowledge, experience, and expertise.

In the context of ageing populations in Australia, Europe and the USA, people with lifelong disability are one of the fastest growing groups of older people, with the largest sub-group comprising those with intellectual disability (Bigby 2004). In Ireland, older people with lifelong intellectual disability represent a small but growing cohort of our ageing population. In 2013 the National Intellectual Disability Database (NIDD) showed that there were 16,000 men and 11,650 women registered as having an intellectual disability, of which 13% were 55 years or over (Kelly and O'Donoghue, 2014). Figures published by the Centre for Ageing Research and Development in Ireland (CARDI) in 2015 demonstrated the growth in numbers

of people ageing with intellectual disability in the last decades. Their figures show that in 1974 only 29% of people with an intellectual disability were aged 35 or over. By 2013 this figure had risen to 49%. CARDI also draws attention to the projected growth in numbers of people ageing with intellectual disability in the next two decades, as in 2013 the most populous age group was in the 35 to 54 range. Improved life expectancy means that policy makers, service providers, and carers, are facing new challenges and opportunities in terms of lifestyle support issues as adults with intellectual disability move through “the new ‘unknown’ phase of their lives” (Buys *et al* 2008).

2.5 The need for theory

The absence of a coherent theory by which to empirically assess whether the supports currently in place are appropriate to the needs of people ageing with intellectual disability is of major concern. It is clear that in order to progress further there is need for enhanced scientific enquiry and new theory. The development of a theoretical account of ageing with lifelong intellectual disability could utilize data to inform meaningful explanations about the process and consequences of ageing for this population. Over time a richer understanding could result in improved care and supports by ensuring a better match between interventions and individual need. In addition it is likely that theory could create the knowledge-based environment conducive to further study, meaning that the contribution of individual studies is likely to have greater impact.

The term theory can be defined in many ways, from a very formalised to a very broad sense. Wadensten (2006) argues that a theory is like a map, in that it highlights what is important for its given purpose. As such, no theory reflects all that is contained within the phenomenon. However, application to the ongoing development of theory is valuable as the use of theory offers structure and organisation of knowledge. Birren (1996) argues that gerontology is a field that is generally data rich and theory poor. Researchers in the field explain the value of theory. Schroots (1996, p.559) maintains that there is nothing so practical as a good theory because “a theoretical framework helps the scientist to accumulate and integrate data into a body of knowledge, as well as to provide directions for new research”. Hendricks and Achenbaum (1999, p.21) assert that “...theories have provided the perspectual eyeglasses that resolve how the so called facts of aging are seen and how they are explained”. Bengston *et al*, (1999, p.5) define theory as “the construction of explicit explanations in accounting for

empirical findings” and emphasise that the key process is “explanation”. These authors pose an important question that perhaps illustrates most clearly why development of theory is important; namely, “If you don’t understand the problem, how can you fix it?” (p.7), and advance the following justifications for continued theory development in the field of ageing: integration of knowledge; explanation of knowledge; predictions about what is not yet known or observed, and intervention to improve human conditions. The authors also suggest that researchers have a responsibility to act also as theorists, and to interpret and explain their findings within a broader context of inquiry. They go on to emphasise that applications of knowledge in gerontology demand good theory since it is on the basis of such explanations about problems that interventions should be made. This underscores the urgent need for theory development in the area of ageing with intellectual disability, as at the present time decision-making regarding interventions and supports take place in a theoretical void.

2.6 Towards a psychosocial theory of ageing with lifelong intellectual disability

Ageing can be viewed through different lenses, each bringing into focus a different perspective or a different aspect of the phenomenon. It can be examined from a biological perspective with a focus on decline of the physical functions of the body, viewed from a psychological angle which looks at aspects of change in mental functioning and emotional coping, or indeed from the social standpoint which takes account of changing roles, changing relationships, and the broader social structures which impact on the individual as he or she ages. However, it is possible to merge all three perspectives to constitute what is known as a biopsychosocial approach to ageing. This particular lens acknowledges the complex interactions between biological, psychological, and social factors which determine and modify the ageing experience (Minichiello, Browning and Aroni 1992). In the past, psychological and social aspects of living and ageing in relation to those with intellectual disability did not receive much research attention and the focus of interest and of care emphasized the biological aspects of their lives. To this end care was routinely structured around a medical model of support and intervention. It was not until the 1970’s when Wolf Wolfensberger proposed the idea of ‘normalisation’ and the later ‘social role valorization’ (Wolfensberger 1972, 1983) that the focus began to shift away from a medical model towards a social model of supports in relation to those with intellectual disability.

Subjective experience is core to developing a psychosocial theory of ageing, yet historically, those ageing with intellectual disability have not been asked about their lives, their experiences, or to voice their personal accounts of ageing. Planning of supports and interventions have been based on carer perspectives, expert views, or the assumption that people ageing with lifelong intellectual disability have the same needs and function similarly to the general ageing population. While it is possible that general theories of ageing may have some application to people ageing with intellectual disability, in the absence of any formal or empirical inquiry we cannot know this to be the case. We do know however, that psychosocial theory of ageing based on the general population does not address the cumulative effects of disability over the life course (Putnam 2002).

While it seems reasonable to assume that variations in the typical life pathway would be of interest to gerontologists and that people ageing with lifelong disability as a group would generate particular research interest, examinations of their ageing experience has been largely ignored by the research community. However, a study by Putnam (2002) on ageing with lifelong physical impairment poses some interesting questions relevant to those ageing with lifelong intellectual disability. She points out that research in her area of interest is in its infancy but asks whether current ageing theories provide a sufficient theoretical basis to predict and explain the experience of ageing with physical impairment or whether they could be made more robust and inclusive of the life experience of people ageing with physical disabilities. These questions are commensurate to those ageing with intellectual disability and it is therefore useful to outline examples of psychosocial theories of ageing applicable to the typical population. In order to be able to map experiences, make comparisons, and draw conclusions about ageing with lifelong intellectual disability, psychosocial theories which purport to explain ageing in the general population are now discussed.

2.7 Outline of psychosocial theories of ageing

Theorists began to explore psychosocial aspects of ageing in the late 1950's and developed three seminal theories over the next few decades. These were 'Disengagement Theory' (Cummings and Henry, 1961), 'Activity Theory' (Havighurst, 1961), and 'Continuity Theory' (Atchley, 1989). Life Span Development theories also emerged, the most popular of which being developed by Erikson (1982) and in which he proposed eight stages of

development from infancy to old age. Transcendence theories also appeared in the literature, with the theory of ‘Gerotranscendence’ being proposed by Tornstam in 1997.

Disengagement Theory:

This theory proposes that ageing entails a gradual withdrawal from personal relationships, previous roles or activities, and from society in general, and that this withdrawal begins to occur from middle age onwards. Cummings and Henry theorized that this primary mental process produces (a) a natural and normal withdrawal from social roles and activities, and (b) an increasing preoccupation with self and decreasing emotional involvement with others. The theory was criticised by subsequent researchers who found little evidence that older people disengage from their surroundings. Schroots (1996) argues that, although the theory professes to explain general psychological and social processes of ageing, it has no more to offer than a one-sided view of the aged, and in an address to the ‘National Council for the Elderly’ on ‘*Theories of Ageing and Attitudes to Ageing in Ireland*’ Davies (1994) suggests that where disengagement does occur, it may be due to factors such as disability, poverty, retirement or widowhood.

Activity Theory:

The unpopularity of disengagement theory prompted further research and encouraged the development of a directly opposing view of ageing called Activity theory. Its main proponent, Robert J. Havighurst, stated that in order to maintain a positive view of self the ageing person must substitute new roles for those lost. Ryan *et al* 2011 claim that Activity theory is a symbolic interactionist perspective on ageing which posits that those elderly individuals who remain most active will also be the best-adjusted. According to this theory continued productivity, group activities, informal social interaction, and even solitary activities, are all considered to be positive in terms of optimising quality of life. Wadensten (2006) reports that care plans in Swedish nursing homes are largely influenced by Activity theory with programmes for residents developed around activity and productivity. However Ryan *et al* (2011) reminds us that while Activity theory has been supported by anecdotal and empirical evidence, it does not take account of the need for reduced activity among some of the aged. Activity theory can therefore place unrealistic demands on ageing individuals and has been criticised for being overly optimistic and failing to recognise the heterogeneous nature of older age (Zrinscak and Lawrence 2014).

Gerotranscendence:

This theory was developed by Lars Tornstam and his colleagues at the Uppsala University in Sweden and is comprehensively explained in his 2005 book '*Gerotranscendence: A Developmental Theory of Positive Ageing*'. The theory is based on the theoretical concepts of psychologists such as Jung, Erikson and Peck, along with his own empirical studies. In it Tornstam hypothesizes that human development is a lifelong process which continues into old age and that Gerotranscendence, as the final stage in a possible natural progression towards maturation and wisdom, increases with advancing years. When optimised the process of Gerotranscendence leads to a new perspective, which is qualitatively different from those occurring earlier in life. Tornstam further suggests that there is a mismatch between theory and empirical data which has led to midlife values, activity patterns, and expectations, being projected onto old age, which has in turn given rise to these values, activities and expectations becoming defined as successful ageing. While positive solitude and meditation are key ideas within the theory, he insists that Gerotranscendence is not disengagement theory in a new disguise. Tornstam argues that the theory does not imply a state of withdrawal but rather a developmental pattern related to increased life satisfaction, a redefinition of self and of relationships to others, and an enriched understanding of existential questions. Follow-up research to critically review the theory carried out by Jonson and Magnusson (2001) concluded that Gerotranscendence theory has parallels in the New Age movement and romantic orientalism and can be understood as an attempt to re-enchant ageing. They also conclude that the theory itself is empirically weak. Nevertheless, through his work, Tornstam drew attention to what he regarded as a societal emphasis on productivity, effectiveness, and independence, and how this can result in mid-life values being unfairly foisted upon elderly people. This issue, in and of itself, represents a significant contribution to the ongoing exploration and understanding of gerontology.

Life Span Development Theory:

This theory seeks to explain ageing in terms of personality development over the life course and originated with Erik Erikson's 1950 publication of '*Childhood and Society*'. Developing his concepts over the following decades Erikson ultimately proposed that personality develops in stages over the whole of the life span and explains the impact of social experiences on outcome at each stage. He describes his theory as 'psychosocial' because he

sees development as a function of both the internal and external environment, in other words, in terms of factors specific to the person as well as social and cultural factors. The theory is based on the premise that eight stages of development exist and each stage must be successfully mastered in order to develop competence in that area. If a stage is not managed well the person will emerge with a sense of inferiority or inadequacy. The central idea in Erikson's theory is that each stage presents as a crisis which arises from two opposing tendencies. In explaining the theory Schroots (1996) says that the developmental task of each stage is to resolve the conflict, an aim which demands the integration of personal needs with societal demands. He provides an example of how this might play out in relation to old age:

...the last stage of life, Old Age, refers to the opposite tendencies of "Integrity versus Despair". At this point an individual's life either makes sense because of some cross-cultural, human principles or is marked by a sense of despair, because it seems meaningless. The successful achievement of Integrity might lead, eventually, to the virtue of Wisdom.

(Schroots 1996, p.561)

Erikson held the view that individuals either grow and develop or stagnate and wither throughout life and the manner in which this evolves is dependent on personality development through the life course. Of interest to this discussion is that according to the theory, important events are associated with developing a sense of mastery at each stage of development. For example, *Young Adulthood* is associated with the formation of intimate loving relationships. Failure to gain competence in this area leads to isolation. *Middle Adulthood* is linked with work and parenthood. Failure to gain competence in this area leads to stagnation. Many people with lifelong intellectual disability do not experience intimate relationships, do not marry, are not parents, and are not part of the paid workforce. This raises the question of whether the conflict linked to those later developmental stages can be resolved in any way that could yield developmental benefit in respect of adults with intellectual disability. The theory offers very little explanation of lifespan development in relation to this population.

Continuity Theory:

Continuity theory was formally proposed by Atchley in 1971. He continued to develop the theory over the following decades with a comprehensive account put forward in his book *Continuity and Adaptation in Aging: Creating Positive Experiences* published in 1999.

This theory also adopts a life course perspective which proposes continuous adult development and adaptation. It was developed in an attempt to amplify a research finding that showed that many older adults display consistency over time in activity patterns, social relationships, living arrangements, and thinking patterns. The theory is not deterministic and instead indicates a strong probabilistic relationship between past, present, and anticipated future patterns of behaviour, thinking, and social arrangements. Atchley was provoked to pursue this line of inquiry in relation to how people age when his research indicated that, rather than the conventional wisdom which held that people lose their occupational identity following retirement, that occupational identity was carried over to the retirement years. In fact, the theory claims that older adults maintain the same activities, relationships, personalities, and behaviours as they did in younger years, and sustain this continuity of lifestyle by adapting strategies which are connected to life experiences.

Bigby (2004) believes that Continuity Theory can offer some explanation of ageing with intellectual disability in that it stresses the significance of earlier life experiences to the ageing process and reinforces the idea that a person's quality of life and adequacy of support networks in their younger years will impact on their experience of ageing.

Overall, it is prudent to remain open minded to the applicability of general psychosocial theories of ageing, at least until proper research can support an alternative view. To this end, a closer look at goodness of fit with a population ageing with lifelong intellectual disability in relation to these theories is helpful.

2.8 Goodness of fit

The above brief outline of various psychosocial theories of ageing formulated in relation to the general population highlights many questions regarding their goodness of fit in respect of those ageing with lifelong intellectual disability. Differences in terms of life experience and trajectory of development between those ageing with lifelong intellectual disability and the general ageing population are evident throughout.

Erikson's stage theory, for example, assumes a high degree of environmental normalcy and general developmental trends. At no point does the theory take account of the adverse conditions which are integral to a life path problematized by intellectual disability in terms of:

- a. segregation in special schools which highlights difference
- b. protective home and social environments which impacts on the development of autonomy
- c. social exclusion which leads to feelings of inferiority
- d. lack of opportunity for intimate relationships which results in isolation and loneliness

Activity Theory is also predicated on assumptions of a mid-life experience of valued social roles, arising out of work, involvement in the community, parenthood and grandparenthood. Yet studies have repeatedly revealed that these are unlikely to be part of the life experience of those with lifelong intellectual disability. In relation to the cohort of 46 participants in this study, for instance, only one person is a parent, one person has ever enjoyed paid work, and no one has experience of planned retirement.

Gerotranscendence theory also appears to omit those ageing with lifelong intellectual disability. From Tornstam's own explanation of the theory it is clear that in order to achieve Gerotranscendence one must engage in a level of life review, reflection, and contemplation, beyond the ability of people with lifelong cognitive impairment. In addition, many of the current cohort of people ageing with intellectual disability have lived fragmented lives, and the personal histories of their lives may have died with parents or remain stored in files across their residential placements. With such gaps in information persons with lifelong intellectual disability would likely find it impossible to draw together the full account of their lives or to undertake a life review.

Finally, Continuity Theory (Atchley, 1999) is considered. Atchley suggests that a large proportion of older adults show consistency over time in their patterns of thinking, activity profiles, living arrangements and social relationships. This theory reinforces the significance of earlier life experiences to the ageing process in a way that can also take account of the experiences of people with lifelong intellectual disability. Continuity theory holds that a person's quality of life and adequacy of support networks in their younger years will positively or negatively impact on their experience of ageing. There may be some potential goodness of fit within this theory to explain the ageing experience of minority groups, including those ageing with lifelong intellectual disability.

Putnam (2002) began bridging the gap between ageing theory and disability models by linking the areas of ageing and physical disability in her research. She found that most social theories of ageing do not address ageing with physical impairment or the cumulative effect of

disability through the life course. Nevertheless, Grant (2010) proposes that while theories of ageing are yet to be formally tested on populations of older people with intellectual disabilities, they are worthy of consideration in attempting to formulate an explanation of ageing with lifelong intellectual disability. He argues that generic theories can sensitize thinking around the psychological and social processes of ageing and the ways in which these can interact with environmental and individual factors. Some potential may then exist for an application of generic psychosocial theories of ageing to an explanation of ageing with intellectual disability, with Continuity theory as the best fit.

2.9 Going forward

The above discussion sets out a rationale for development of a theory of ageing specific to the intellectual disability population. A satisfactory psychosocial theory of ageing for those ageing with lifelong intellectual disability should ideally aim to:

- a. explain the impact of life long experience of disability on the ageing experience
- b. anticipate areas of change and adaptation in terms of psychosocial aspects of living
- c. predict how this change and adaptation might be experienced

As a predictive mechanism the theory may be utilised to steer individual supports towards prevention or amelioration of the negative impact of change.

2.10 Conclusion

It may be argued that development of theory in relation to ageing populations is an attempt at scientific reductionism which ignores diversity and complexity. However, the absence of theory leaves a dangerous void in knowledge, particularly as the population in question is already a marginalized group whose voice is rarely heard in relation to their own experiences. In fact, without the guiding reference of a specific theory in this area, policy making, service supports, and care interventions are based on poor information, best guess, and the value systems of decision-makers. Wadensten (2006) found that the care and treatment of older people is highly influenced by the knowledge and views which staff and society hold about the implications of ageing. It is clear that the value of theory development based on direct consultation with target populations is in its agency to challenge current practices and to develop appropriate supports for the population concerned.

Chapter Three – Life Course

3.1 Overview

There is a growing body of evidence that all forms of ageing, whether pathological, normal, or successful, have their foundations in factors and events occurring at younger ages (Davidson *et al* 2004). To further elicit why a generic theory of ageing may not be a good fit for a population with lifelong intellectual disability it is useful to examine the psychosocial aspects of the life course and consider how whole of life experience is likely to impact on the experience of ageing for all populations.

3.2 Life course and ageing

The field of ageing theory has contested numerous theoretical perspectives and debates over the last ninety years. More recently there is an ever increasing interest in lifespan development theories of ageing. Life span development ideas hypothesize that behaviour and development are influenced by many factors and as such it is an approach that can better account for the variability in ageing between individuals commonly observed. This perspective casts a wide lens on the antecedents and consequences of development across the life course and challenges researchers to conceptualize the importance of the past, present, and future developmental status of an individual with intellectual disability (Esbensen *et al* 2012). To this end, theorists and researchers have become much more interested in the whole of the person's life and are moving from a focus on the middle to late years in isolation to consideration of whole life experience. Bigby (2004) observes that ageing occurs at a different rate with diverse manifestations for each individual and that health, lifestyle, and informal and formal supports from earlier years, in combination with genetic dispositions all influence the process of ageing. Marshall (1996) points out that the life-course perspective is the most broadly shared among social gerontologists. He asserts that despite frequently contrasting theoretical perspectives the following set of principles unifies life-course theorists:

- (i) aging is influenced by social processes and in turn influences these processes
- (ii) aging is a lifelong process and to understand people at a given age one must understand where they have come from and where they are going

(iii) the age structure changes over time and is experienced differentially by different cohorts

This way of thinking opens a gateway for including minority groups in an understanding of ageing. Thus a life course perspective may provide an effective framework for exploring the experience of ageing with lifelong intellectual disability. Indeed Ryan *et al* (2011) suggest that as a lifespan development approach broadly focuses on the challenges and changes which occur throughout adulthood, a number of general principles associated with this approach may well apply to those ageing with lifelong intellectual disability. Lifespan approaches acknowledge change and loss but also allow for growth and development through to the end of life. This viewpoint assists in a fruitful exploration of ageing with intellectual disability as there is acknowledgement that older adults deal with ageing in an individual manner and that responses to ageing may depend on personality and previous life experiences. Examining ageing with intellectual disability within the context of the life course emphasizes individual responses to ageing within this specific cohort and facilitates comparisons with the general ageing population.

3.3 Life course issues and impact on ageing with intellectual disability

People with lifelong intellectual disability experience a non-normative life course (Priestly 2003). For this reason many experiences common to the general population are absent in their lives. Life experiences such as going to college, beginning a career, buying a home, marriage, parenthood, retirement, are infrequent within the intellectual disability population. For example, in Ireland 99% of people with an intellectual disability are unmarried (CARDI 2015). In addition, as these experiences are life markers and associated with stages of growth and maturation, their absence is likely to impact not only on self-conceptualization, but also on how this cohort is perceived by the rest of society. Holland (2000) asserts that ageing is associated with significant social and economic change and suggests that there is a significant contrast between those with and without intellectual disability in this regard. He further explains that while for the mainstream population life is structured into infancy, childhood, working adult life, and retirement, many of the life expectations of people with intellectual disabilities are not open to actualization.

Seltzer (1993) speculates that although the tasks of ageing for people with intellectual disability may be similar to those of the general population, the challenges may be different in terms of the timing, problem-solving capacity, and the meaning of experiences. People

with intellectual disability may be severely disadvantaged in terms of the availability of internal and external resources to buffer stress, adapt to change, and support coping with loss. Seltzer posits that poor cognitive abilities, lack of informal social supports, low status in society, and disadvantaged or restrictive life experiences, mean that people ageing with intellectual disability may be poorly prepared or resourced to adapt to change. Rothman (2003) took the opposing view, arguing that having a lifelong disability may facilitate aging well, since these individuals have knowledge and experience with acquiring needed resources, which makes them better able to navigate disability systems. Jenkins (2010) supports this view, concluding that as people with intellectual disabilities face discrimination and barriers to relationships and opportunities throughout their lives, the impact of old age may be reduced. What we can say with certainty is that the typical life experience of this group differs from that of the general ageing population. In particular, given the level of disadvantage and challenge reported in the disability literature (Holland, 2000; Seltzer, 1993) the psychosocial aspects of ageing are likely to be particularly difficult.

A number of psychosocial factors relevant to this particular cohort in terms of how life course experience impacts on ageing may be:

- i. social exclusion
- ii. self determination
- iii. lifelong health issues
- iv. loss
- v. retirement
- vi. transitions
- vii. the role of the family

The following sections will explore each of these areas in order to better understand how the experience of ageing *with* disability might differ from the experience of ageing *into* disability. In addition, these key areas can provide a framework for contextualising intellectual disability across the life span.

3.4 Social exclusion

Priestley(2003) stresses that people with disabilities have historically had restricted opportunities to participate on an equal basis with others and that barriers such as

environments, attitudes, institutions, discourses, policies, and practices, have shaped the experiences of people with disabilities throughout the life course. As people age, Kahlin *et al* (2014) found that life course experiences, and specifically institutionalisation and stigmatization, are described as inhibitors by staff in relation to participation in everyday life by older people with intellectual disability. Their study revealed that physical, psychological, and social changes related to old age, combined with intellectual disability, affected participation in a negative way. A recent study by Wark *et al* (2014) also found that impediments to inclusion in the life of the community persist as people age with intellectual disability. Their study identified twenty five different impediments, and a thematic analysis of the items classified the three main themes of funding, training, and access to services. Under the issue of training the study found that lack of understanding of disability within mainstream aged-care services was a significant impediment as there was a focus on ‘weakness’ rather than the continuing strengths of the individual. This perpetuates the distorted view that ageing people with disabilities are more dependent and require a greater level of care than actually needed.

As more adults with intellectual disability are living to older ages, social inclusion is vital for the health, wellbeing and quality of life of this generational group as they age (CARDI 2015). However, adults with intellectual disability tend to have a restricted social network and Wilson (2012) found that they have more limited opportunity than the general population to make and maintain interpersonal relationships. In addition, because most people with intellectual disability do not marry or have children they often age without the family and social supports that other adults enjoy. In Ireland, for example, 65.9% of adults over the age of 65 have no family whatsoever (Burke *et al* 2014). Despite this, McCarron *et al* (2011) found that older adults with intellectual disability are heavily reliant on family for social participation, while Robertson *et al* (2001) found that adults with intellectual disability have few meaningful relationships with people who do not also have intellectual disability, are not relatives, and who are not paid to support them. Moreover, interaction within the community in which people with intellectual disability live is often regulated and controlled by professionals, making it difficult for them to break through a paternalistically protected life and experience natural community (Heller and Harris 2002). An Australian study by Ashman and Suttie (1996) revealed similar findings which demonstrated that older people with intellectual disability experience lack of opportunity in relation to community and social

engagement and that most participants (n = 446) in the study had limited use of community facilities and infrequent contact with family and friends. A 2015 review of research data carried out by CARDI to examine social inclusion of older adults with intellectual disability in Ireland shows it to be at a low level, with limited involvement in mainstream community organisations, retirement clubs, residents' associations, or basic engagement with neighbours or other community members.

The Pomona II study (Haveman *et al*, 2001), a European project on ageing and health status in adults with intellectual disability, found statistically significant differences between younger people and older adults with intellectual disability in terms of social inclusion, with the latter group more likely to live in bigger institutions and to be socially isolated. Martin and Cobigo (2011) assessed 1,341 adults with intellectual disability living in Canadian institutional and community-based settings to obtain a better understanding of the nature of social inclusion among this group. They propose that social inclusion should be understood in relation to relationships, leisure, productive activities, accommodation, and informal supports. The review by CARDI included an examination of social inclusion in terms of each of these five domains. Their findings revealed a poor degree of inclusiveness across all areas. However, ways to combat social exclusion for this cohort are being actively explored and identified by researchers. Duggan and Linehan (2013) found that policy and service strategies including circles of support, peer-based approaches, training programmes, and befriending schemes, can have a positive impact. Nonetheless, it is a matter of ongoing concern that despite aspirations for continuing inclusion, older people with intellectual disability continue to experience few opportunities to participate in meaningful activities of their choice (Bigby 2005) and social exclusion persists as they age.

3.5 Self determination

The construct of self-determination can be described as “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer 2005, p.117). The dictionary definition of self-determination is ‘the power or ability to make a decision for oneself without influence from outside’ (<http://www.collinsdictionary.com/>). While research shows that adults with disabilities value self-determination and feel it contributes significantly to their quality of life, they experience many barriers in exercising it (Nota *et al* 2007; Lachappelle *et al*, 2005). Due perhaps

primarily to restrictive settings, poor accessibility, and low income, adults with intellectual disability have little opportunity for autonomy and decision-making throughout their adult lives. The role of choice opportunity has been identified by multiple researchers as a key element in enhanced self-determination and enhanced quality of life (Nota *et al* 2007). Unlike most adults, those with intellectual disability often continue to live with family carers through adulthood (Braddock *et al* 2008) or they may live in congregate settings with rules which restrict choices, and staff who may not honour or know their desires (Heller *et al*, 2002; Stancliffe, 2001). For example, Wehmeyer *et al* (2007) found that persons who support adults with disabilities tend to view self-determination as less important than do individuals with disability themselves. It is not then surprising that adults with disabilities are found to be less self-determined than their able-bodied peers (Chambers *et al*, 2007). Studies carried out specifically with older adults with intellectual disability support this view and confirm that they typically have had few opportunities to exercise self-determination in their lives (Heller *et al*, 1996). It follows that they often have little understanding of, and few skills, to actually express their desires. Kahlin (2014) suggests that older people with intellectual disability living in community residences have life course experiences which render them unprepared to speak up for themselves. Similarly, McDermott and Edwards (2012) found that in relation to transitioning into retirement older people with intellectual disability were unprepared for making self-directed choices. Yet these older adults, just like their non-disabled peers, have a right to personal growth, and integral to this is the exercise of choice and self-determination (Nowak, 1999).

While, the process of becoming self-determined begins in early childhood through exposure to and the experience of choice-making, problem-solving, and so on, it continues across the life course (Heller and Harris 2012). Such a lifespan perspective is essential as it takes account of the social and physical environment, the role of the family and community, and the role of services and public policy, in supporting or inhibiting opportunity for autonomy, choice, and personal decision-making in the lives of people with intellectual disability throughout the whole of their lives. Furthermore, by drawing attention to the ongoing dynamic and complex relationship which exists between the person and his or her environment through the life span, a life course perspective also facilitates an understanding of the impact of these factors on self-determination over time.

Although people with lifelong intellectual disability may require lifelong support this should not have a bearing on the right to a self-determined life and the access and opportunity to acquire capacity in essential skills such as choice-making and planning. As the acquisition of skills to support self-determination continues throughout life, it is never too late to support people to enhance self-determination. In particular, for older people with intellectual disability, interventions and instructional strategies to facilitate the development of planning skills can greatly enhance quality of life as they age. Heller and Harris (2012) underline the importance of informed choice and planning for those ageing with lifelong disabilities as it can create a timely focus on skills acquisition, independent self-care, rewarding use of leisure time, and sustaining current skills.

Recent trends have helped to foster self-determination and greater autonomy in people with intellectual disability, including the ageing disability population. These include deinstitutionalisation and the move to community-based residences, the growth of the self-advocacy movement, and person-centred planning. In the United States figures show a significant drop in the numbers of people with intellectual disability living in congregate settings, from 500,000 in 1960 to 100,000 by 2006 (Braddock *et al* 2008). In Ireland, the Health Service Executive report entitled *Time to Move on from Congregate Settings* (2011) has been adopted as the agreed national policy aimed at supporting people with disabilities to live ordinary lives in ordinary places. It is envisaged that this new model of residential support will enhance community participation and choice-making for people with lifelong intellectual disability. Self-determination has been conceptually and correlationally linked to a more positive quality of life (Nota *et al*, 2007), while promoting self-determination has emerged as a valued goal for people with disabilities over the last two decades and underpins much of the legislation and many of the practices in the field (Heller and Harris, 2012). Planning for later years interventions have also been developed to provide individuals with intellectual disabilities increased knowledge and opportunities to make choices as they age (Heller and Caldwell, 2006). Studies are now beginning to assess the effectiveness of various training programmes and planning interventions designed to promote the development of self-determination skills in adulthood, such as self-advocacy, person-centred planning, and methods of directing one's personal supports. For example, the effectiveness of a person-centred later-life planning training programme designed to teach older adults with intellectual disability about later-life planning issues and increase their participation in choice-making

was examined by Heller *et al* (2000). The results showed that participants in the training programme gained more knowledge of later-life issues and options and developed more autonomy in choice-making than did a control group. The researchers concluded that with adequate support, people with intellectual disability can continue to develop skills around self-determination as they go through adulthood and thereby have a greater voice in directing the course of their lives.

3.6 The role of the family

The family environment is one of the most durable influences on the development and quality of life of persons with intellectual disability (Esbensen *et al*, 2012). Family care provision is the norm for adults with intellectual disability and the role of primary carer frequently transitions from the parent to a sibling as ageing parents die or themselves become too old to provide continued support (Coyle *et al*, 2014). In the United States, for example, approximately 75% of adults with intellectual disability live with a family member and 25% of these carers are over 60 years of age (Fujiura, 2003). The role of the family in supporting a family member with intellectual disability to live a person-centred and goal-driven life is problematic as life goals are often contextualized by family within parameters of protection. This can continue through the life course with perhaps different family members adopting the caring role at different stages of the persons' life. Bigby (1997) found that nearly half the siblings in her study (n=62) replaced parents as the primary carer of older people with intellectual disability. Heller (2000) affirms the important role of families in providing supports to adults with intellectual disability in meeting their preferred life goals. However, lifelong dependency on a family care system which has its own tensions and transitions can result in poor flexibility for persons with intellectual disability to live lives of their own which are congruent with personal interests and wishes. A family has a life course of its own, in addition to the life course of each family member (Ferguson *et al*, 2000). It follows that interventions in the lives of persons with intellectual disability and their families change over time, motivations to provide family-based care, and expectations for themselves as a family unit and for each individual member (Esbensen *et al*, 2012). A life course approach offers a useful means for understanding such complexities.

3.7 Transitional shifts

The concept of transitions is critical within life course research and refers to disruptions in individuals' day-to-day lives, which include both proximal (daily irritants and stressors) and distal (major events) changes (Elder 1985). Transition due to a change in family circumstance can often lead to unwanted change for the person with disability. Major life changes such as the death of a parent and the subsequent renegotiation of family relationships may cause a great deal of stress in individuals' lives, which lead to transitions between life stages (Almeida and Wong, 2009). People with disabilities may experience greater obstacles to navigating transitions due to age-related change and change in their supports (Heller and Harris, 2012) along with the fact that transitions may not be planned or wanted by the person themselves, but rather imposed due to change in circumstance or resources. People with intellectual disability tend to rely heavily on routines and need time and support to plan for change (McDermott and Edwards 2012). Unplanned transitions can be experienced as very stressful.

3.8 Work and retirement

Modern societies continue to define adulthood through highly gendered and idealized expectations of productivity in the workforce which may preclude many individuals with disabilities (Priestley, 2003). Much of adult identity is built around the socially valued roles related to being part of the workforce. The barriers to participating in employment are substantial for adults with disabilities and the majority of adults with intellectual disability do not engage in paid work (Verdonschot *et al*, 2009). A national Australian study of people with intellectual disability aged 55 years and over carried out by Ashman *et al* (1995) found that the majority had never worked despite having a desire to do so. Nevertheless, being gainfully employed remains a primary signifier of adulthood roles in modern societies (Priestley, 2003) and therefore people ageing with intellectual disability are set apart in terms of typical life experiences and valued roles.

Rather than paid work, attendance at sheltered workshops and day centres is the norm for adults with intellectual disability in Ireland. Retirement from day services to spend more time in community residences is not often possible as many houses are not staffed during the day. Therefore going to the workshops four or five days a week can continue throughout life, with no hope of retirement. In any event, most will not have planned financially or have

savings for retirement having perhaps spent the majority of their lifetime in receipt of social welfare (McDermott and Edwards, 2012). Barriers to retirement such as insufficient staffing and financial constraints have been identified as issues for older adults with intellectual disability and can result in feelings of powerlessness (Newberry *et al*, 2015; Strnadova and Evans, 2012).

Even when retirement is financially possible McDermott and Edwards (2012) found that older adults with intellectual disability are unprepared for making self-directed choices about the transition to retirement. To address this they suggest there ought to be more flexible services, better information about retirement, exposure to real experience, and assistance to express preferences and participate in problem-solving throughout the lifespan. In order to properly address retirement issues and plan for ageing in a supportive and enabling manner then, the ground work must be in place for proper exposure to decision-making, practice of choice-making, and knowledge and experience of the options available. Bigby and Knox (2009) found that neither service providers nor family take responsibility for assisting older people to plan in this way. Lack of planning and poor information around retirement has resulted in older people with intellectual disability resisting retirement because of fears for the implications of poor health, and loss of meaningful activities or friendships (McDermott and Edwards, 2012). There is clearly a responsibility on service providers to enable people to express preferences, conduct person-centred planning, and provide information through communication strategies that can assist in the transition to retirement (Storey, 2005; Wehmeyer, 2005) and to provide this support in a timely manner. This approach is in keeping with the World Health Organization (WHO) recommendations supporting retirement for this population. In fact, the WHO called for age-appropriate, fulfilling activities based on personal choice to be made available to retirees with intellectual disability and for pre-retirement preparation to be conducted to the standard deemed appropriate for the wider population of retirees (Hogg *et al*, 2000).

3.9 Loss and bereavement

Issues around the impact of bereavement on people ageing with intellectual disability are crucial to considerations of a number of the specific psychosocial aspects of their life journey. In particular, the impact in terms of psychiatric and behavioural morbidity of the loss of a parent and its concomitant life events, in adults with intellectual disabilities has been

underestimated (Hollins and Esterhuyzen, 1997). Bereavement is usually a time of general disruption and emotional distress. For people with intellectual disability, a limited understanding of the concept of death may exacerbate this distress (McEvoy *et al*, 2012). Confusion around the abstract concept of death may play a significant role in intensifying or prolonging grief for many adults with intellectual disability (Clute, 2010; Blackman, 2008; Brickell and Munir, 2008). Left unresolved these bereaved individuals may experience feelings of confusion, insecurity, and guilt, which both impedes adjustment to the loss and complicates attempts to provide support (McEvoy *et al*, 2012).

The death of a parent for this population often leads to devastating change, such as loss of the family home and a move away from a familiar community. In addition, the intimate social support system available to most adults, such as a partner, children, or grandchildren is usually absent and the usual supports and interventions which help people manage their loss may be inappropriate or lacking. Grief can present atypically in this population and symptoms can be missed or misunderstood. Dowling *et al* (2006) claims that bereaved adults with intellectual disability are known to experience prolonged and atypical grief which often goes unrecognised. When this happens supports and interventions are likely to focus on overt challenging behaviour rather than the underlying cause of distress. Behavioural support alone ignores the emotional aspects of their lives.

3.10 Health

The World Health Organization Fact Sheet on Disability and Health (2015) shows that, due in part to population ageing, about 15% of the world's population have some form of disability and that this cohort have less access to health care services and experience unmet health care needs. Lifelong health issues associated with disability have psychological and social implications which impact on the ageing process and the ageing experience. Nevertheless, life expectancy for individuals who have had lifelong disabilities or disabilities acquired in early age has increased with medical advances (Kemp and Mosqueda, 2004). As they age, it is evident that they have needs that both align with and diverge from their peers in the general population (Judge *et al*, 2010). Similar to same age peers they are likely to develop dementia (Cooper and Van der Speck, 2009; Strydom *et al*, 2005), sensory impairments (Lifshitz and Merrick, 2004), and difficulties with mobility (Cleaver *et al*, 2009). However, because of their different life course experiences, their psychosocial needs

may be very different. Exposure to adverse life events and environmental stressors such as violence, poverty, sexual abuse, has been found to be high in intellectual disability populations when compared to their non-disabled peers (Wigham and Emerson, 2015). While these authors caution against over-pathologising life experience for this population, at the same time they maintain that they are at higher risk of having their resilience compromised and developing mental and physical health problems.

Many people ageing with long-term disability experience secondary health conditions related to the effects of ageing (Sheets, 2005). These conditions have been described as “premature ageing” because they occur fifteen to twenty years earlier than would be the case with normal ageing (Kemp and Mosqueda, 2004). Physical disability can add complications to the ageing process, including the development of additional impairments, and experiencing changes in function earlier than non-disabled peers due to a lower level of reserves and limited economic means (Kemp and Mosqueda, 2004). Evenhuis (2011) found that people with intellectual disability at 50 years of age are comparably vulnerable to people aged 65 in the general population.

Evidence from the Pomona II study (n=1253) also confirmed health disparities between people with intellectual disability and the general population, particularly in terms of under-diagnosed or inadequately managed preventable health conditions. Specific health disparities noted relate to communication, mobility, oral health, vision, hearing, neurological disorders, pain, osteoporosis, and gastro-intestinal problems. Evenhuis *et al* (2001) found that undiagnosed mental health and medical conditions can have atypical presentations in adults with limited language capabilities. They further noted that older-age onset medical conditions are common in this population and may require a high index of suspicion for clinical diagnosis. The authors assert that while in theory people with intellectual disability living in industrialised countries have equal access to essential healthcare services, in practice access varies depending on service delivery models, and that general barriers exist. They conclude that healthcare providers and policy makers must acknowledge that many people with intellectual disability have special needs which necessitate a modification of standard healthcare practices and service models.

The findings of a study by Baxter *et al* (2006) reflects a concern that current care delivery leaves adults with an intellectual disability at risk of both severe and milder illness going

unrecognised. They suggest that health checks present one mechanism for identifying and treating such illnesses within primary care. A pro-active approach was also advocated by the Pomona II study where the authors suggest that a more active, systemic and regular approach to monitor and measure preventable and common medical problems would be beneficial for this group of people.

The *Tampa Scientific Conference on Intellectual Disabilities, Ageing and Health*, held in 2002 to examine health issues germane to older adults with intellectual disability recognised health disparities between people ageing with intellectual disability and the general ageing population and made recommendations for age-related medical and health surveillance practices that would improve their overall health status. A report prepared by the International Association for the Scientific Study of Intellectual Disabilities (IASSID) for the World Health Organisation (WHO) (Evenhuis, 2011) recommends that people with intellectual disability should receive the same array of life-span preventative health practices as those offered to the general population.

Yet just as Wigham and Emerson (2015) have cautioned against pathologising this cohort of people, it must be acknowledged that research is also showing positive experiences of ageing. Lehmann *et al* (2012) examined longitudinal survey data on 667 people with mild to moderate intellectual disability in the Netherlands. They found that while age is associated with poorer physical and mental health in this population it is also related to more satisfaction with life, greater satisfaction with the social contacts one has, and less loneliness. They concluded that older people with intellectual disability have relatively high levels of well-being, a finding that they did not expect, although the researchers acknowledge that the finding is in line with previous research on ageing among the general population (Zantinge *et al*, 2011; Smith *et al*, 2002). Possible explanations for this are (1) change in needs and expectations (Zantinge *et al*, 2011) and (2) the use of downward social comparison to adjust criteria for determining life satisfaction (Frieswijk *et al*, 2004). Both of these explanations could apply to those ageing with intellectual disability. Lehmann *et al* (2012) did not collect data on coping strategies used by people with intellectual disability to deal with advancing age but advised that this would be a useful avenue of research in the future.

3.11 Conclusion

Much can be learned about disability debates by examining them within the context of the life course as using the life course as a conceptual framework forces considerations of a wider range of issues affecting people at all points of life (Priestley, 2003). While traditional approaches to researching human life within the social sciences often focus on discrete life stages, Settersten (2003) warns that this may lead to a reductionist and limited view of humanity. Esbensen *et al* (2012) asserts that the study of life course is focused on patterns of individual development, with an emphasis on the effect of specific contextual phenomena on life outcomes and that one of its central tenets is that no single period of life dominates the continuous process of human development. Recognising that ageing is a continuous dynamic process that occurs throughout life (Elder and Giele, 2009) reconceptualises human lives and acknowledges that individual life trajectories are the result of a complex interplay between human agency and generational and social forces (Elder 2003; Bryman *et al*, 1987). It therefore follows that while the life trajectory of each person is individual to their experience, period and cohort effects occur due to a sharing of historic time and place and the commensurate social, cultural and political influences. Life course experience for adults with intellectual disability who are currently ageing is presented in this discussion as significantly different from that of the general population and existing psychosocial theories of ageing developed around normative ageing may not provide adequate explanation of their experience. However, it is likely that future cohorts will experience very different influences through their lifespan, and as such theory development must be conceptualised as perpetual. Future researchers must respond dynamically in order to continue to provide explanations of ageing that are responsive and beneficial.

Chapter Four – Successful Ageing: a More Inclusive Approach

4.1 Overview

As increasingly more people experience old age as a time of growth and productivity, theoretical attention to successful ageing is needed (Baltes and Carnesten 1996). This chapter examines how successful ageing is currently understood and how it might be understood in the future in order to take account of people ageing with disabilities.

4.2 Successful ageing

While traditionally, gerontology literature has been dominated by an emphasis on ageing as a period of decline and loss of function (Achenbaum 2005), the word ‘successful’ in relation to ageing has permeated the ageing literature in recent decades. The concept of successful ageing was particularly popularised in the 1980’s, but a number theories of successful ageing do not take account of day to day life experience of older people with disabilities. Baltes and Baltes (1990) defined the criteria for successful ageing as good physical and mental health, cognitive efficacy, social competence and productivity, personal control, and subjective life satisfaction. Rowe and Kahn (1997) delineated successful ageing in a similar fashion, stressing cognitive and productive abilities and good health. This paradigm is problematic for individuals with disabilities however, as it compounds the marginalization and stigmatization they have experienced throughout the life course (Minkler and Fadem 2002). Tornstam (2005) argues scratching the surface of the concept of ‘successful ageing’ reveals that the it is understood as continuing to be a western-cultured, white, middle-aged, middle-class successful person, with the emphasis on activity, productivity, efficiency, individuality, independence, wealth, health, and sociability. Such conceptualisations of successful ageing are predominantly based on criteria that reflect dominant norms and values and emphasise absence of physical and cognitive impairment, and thereby automatically preclude people with disability from the possibility of ageing successfully. Coleman (1997) argues that an emphasis on successful ageing may lead to issues of impairment and experiences of chronic illness being overlooked and further points out that restriction and decline in some areas of life does not rule out the possibility of growth and development in others. Janicki (1994),

clearly cognisant of the heterogeneity of the ageing population and taking account of people ageing with disability, took a broader view in his definition of successful ageing:

“..an individual retaining his or her capacities to function as independently as possible into old age and promoting the belief that persons who age successfully are able to remain out of institutions, maintain their autonomy and competence in all activities of daily living, and continue to engage in productive endeavours of their own choosing.”

(Janicki 1994, p. 146)

This definition allows for the possibility of including people with disability in objective categorisation of successful ageing because it takes account of the fact that individuals may have different pre-existing levels of functioning, and as such, the pursuit of meaningful goals will be unique to each person.

Baltes and Baltes (1990) also considered individual difference in their broader conceptualization of successful ageing. Based on lifespan development psychology they describe a psychological theory of ageing called ‘Selection, Optimization and Compensation’ (SOC) to elucidate how people behave as they age so that their functioning is optimised. The SOC model attempts to represent scientific knowledge about the nature of development and ageing with the focus on successful adaptation. SOC theorizes that people who age successfully employ three basic strategies:

- i. they select the activities most valuable to them
- ii. they optimise their ability to participate in these activities by making the most of personal reserve
- iii. they compensate for functional losses by using alternative means to achieve goals. i.e. environmental alterations

The model takes both gains and losses into account and is cognizant of the great heterogeneity in ageing and successful ageing (Baltes and Carnesten 1996). Investigations with older adults indicate that employing SOC strategies is moderately correlated with "subjective aging well" (Freund and Baltes, 1999). People ageing with lifelong intellectual disability could be included in this configuration of how people behave in order to age successfully. The process outlined also fits well with the social model of disability as compensation for compromised or lost skills often occurs through adaptation of the social or physical environment. One criticism of the SOC model is that it is less salient for older adults who have profound limitations since they have fewer opportunities to make selections and diminished capacity to re-allocate resources (Baltes, 2003; Freund and Baltes, 1998), but it

may also be argued that with sufficient and appropriate supports, barriers to using the model to plan desired goals and to maximise engagement and satisfaction can be overcome.

4.3 Subjective opinion on ageing well

Measures of successful ageing are increasingly taking subjective opinion into account. Recent studies suggest that for many older people subjective quality of life is more important than the absence of disease and other objective measures related to physical health and mental health. Studies carried out by Depp *et al* (2010) and Montross *et al* (2006) show that the vast majority of senior citizens rated themselves as ageing successfully, even though many did not meet objective physical and mental criteria for successful ageing. Findings from the IDS-TILDA study (Burke *et al* 2014) reveal that 46% of adults ageing with intellectual disability rate their health as excellent or very good. Interestingly then, studies such as Jeste *et al* (2010), Reichstadt *et al* (2010), Depp *et al* (2009), Lamond *et al* (2008), and Depp *et al* (2007), which all took account of the views of older adults themselves, arrive at models of successful ageing which indicate that optimism, effective coping styles, and social interaction, are more central to ageing successfully than objective measures of health and wellbeing. These studies also show that subjective quality of life is linked to psychosocial protective traits such as resilience, optimism, and emotional status.

It is now widely acknowledged that consensus regarding either an agreed definition or agreed determinants of successful ageing does not exist (Franklin and Tate, 2009) due to the complexity inherent in such a construct and the multiplicity of psychosocial and biological factors at play. The debate has therefore opened up and there is now more recognition that people with disabilities may age ‘successfully’.

4.4 Supporting successful ageing for all

Individualized supports:

Heller and Harris (2012) suggest that it is time to change the narrative around ageing from *successful ageing* to *ageing well*. They suggest a Supports Outcome Model of Ageing Well and say that positive outcomes of ageing well are (1) to maintain health and function, and (2) an active engagement with life. This model of ‘ageing well’ differs from the model of ‘successful ageing’ in that it emphasises the importance of the environment and

individualized supports throughout life in effecting outcomes in later life. As such, this model demonstrates the value of lifelong supports and seeks to shift the responsibility for successful ageing, or ageing well, to the social world. The role of supports is particularly important in relation to people ageing with moderate to severe intellectual disability, and individualized supports are essential to ageing well. Those ageing with significant cognitive impairments are unlikely to be personally resourced to maintain health and function, or to initiate a process of active engagement with life, without considerable support. Much more attention should therefore be applied to understanding the role of individualized supports and to developing a comprehensive support model of ageing well for this population.

Structural supports:

Two important pillars of support for people with intellectual disability are government policy and service systems and both must work together to deliver responsive, appropriate, and timely action. In Ireland, government policy and commitment in relation to people ageing with intellectual disability can be summarised as follows:

- The Graz Declaration (2006) - which holds that ageing and the associated development of skill, wisdom, experience and respect is central to people with disability that are ageing
- The Council of Europe (2009) - recommendations on disability and ageing
- National Disability Strategy Implementation Plan, 2013-2015.
- Positive Ageing Starts Now! – The National Positive Ageing Strategy, 2013
- Ireland was amongst the first signatories of The Convention on the Rights of Persons with Disabilities (2006).
- Time to Move on from Congregate Settings, 2011
- New Directions (2012) - Personal Support Services for Adults with Disabilities
- Assisted Decision-Making (Capacity) Act, 2015
- Safeguarding Vulnerable Persons at Risk of Abuse, National Policy and Procedures, 2014
- Setting up of Health Information and Quality Authority and the development of regulation and standards for residential settings.

However, despite this comprehensive package of nominal support the reality on the ground is somewhat different. In recommendations for the *National Ageing Strategy* McCarron (2010) stated that although Ireland is a country where people with intellectual disability are

increasingly getting older, there is insufficient preparation to meet changing need. She points to gaps and inequities due to lack of planning and lack of data on which to base policy and resource allocation decisions.

Service systems are also struggling to adapt to a changed demographic with associated changing needs. Bigby (2004) emphasizes that responding effectively to ageing with lifelong disability is uncharted territory for human services, and an enquiry carried out by Hogg and Lambe (1997) concludes that intellectual disability services in the UK were unprepared for the changing needs of older people with intellectual disability, and that this the generic services for the elderly were not easily accessible for this population. Holland (2000) argues that with increasing age there is a convergence in terms of health and social care needs between those with and without intellectual disability. Nevertheless service systems remain separate, and ageing care and disability services have not risen to the challenge of developing an appropriate and integrated response to support the first sizable cohort of individuals ageing with intellectual disability. In order for this to happen, professionals within these services must be open to new learning and be willing to adapt and innovate as they navigate different aspects of service systems and manage new demands. In speaking about the extended life expectancy of people with disabilities in developed countries Grant (2004) emphasises that this puts a premium on supports being available to help people to anticipate and plan in order to realize their hopes and dreams throughout the life span.

One difficulty at the present time is that any response by service systems to meet this changing demand would be rolled out unsupported by empirical data and within an information and research vacuum. Policymakers and government bodies are attempting to meet legal and moral obligations towards citizens ageing with intellectual disability within the same data vacuum. Research into how people with lifelong intellectual disability experience ageing is crucial at this time, so that they may be supported to age well with confidence.

4.5 Contextual issues across the lifespan

Elder and Giele (2009) assert that historical and geographic location, social ties, human agency, and variations in the timing of events and social roles, all assist in putting the life of individuals and cohorts into a meaningful context. Thus, contextual factors are central to experience of living and of ageing. People age in social, political, economic, historical, and

cultural contexts which impact on attitudes, values, ideologies, service supports, funding, care paradigms, rights issues, and ultimately on the psychological wellness of each ageing individual. Period and cohort effects are inevitable as over the life course contextual factors impact on overall development, opportunities for growth and learning, relationship building, development of social roles, and opportunities for valued experiences. Hagestad and Dannefer (2001, p.7) state that “old age is part of lifelong journey, of individual lives embedded in changing social contexts hence of complex interplay between biographic time and historic time”.

Future cohorts of people with lifelong intellectual disability will come to old age with different lived experiences, needs and expectations. Therefore Settersten (2007) advises anticipatory thinking and dynamic policy-making as it remains unclear whether any of our current knowledge will be pertinent to future cohorts. Meanwhile the lives of those currently ageing with intellectual disability are embedded in their own time and place and policy-makers must be ready to rebuild policies and institutions which are sensitive to contemporary changes. Successful ageing for future generations of people with intellectual disability depends upon a high degree of openness, preparedness, and timely responsiveness from policymakers, service systems, and the wider community.

4.6 Bridging the fields of ageing and disability

Naidoo *et al* (2012) highlight the case for bridge-building between concepts of ageing and disability in order to support older adults ageing into or with disabilities. As such, there is awareness of the need to facilitate knowledge development across the areas of ageing and disability and to transfer and translate this knowledge between both fields. This recognition was brought to an international forum in 2011 with the Growing Old with Disability Conference in Toronto, Canada. *The Toronto Declaration on Bridging Knowledge, Policy and Practice in Ageing and Disability* emerged from this conference along with calls to support implementation of an action plan (Bichenbach *et al* 2011). The authors state that “the experience of growing older with a disability and growing older into disability may differ – in part because of the different dynamics of ageism and ableism and the differences in economic and social conditions that result – but these life course trajectories present similar challenges and opportunities“. They contend that the time has come to accentuate the similarities in experiences and needed supports, services, and policies, rather than focusing on differences.

Lightfoot (2007) similarly acknowledged the overlap and shared goals in the fields of ageing and the fields of disability, stating that both fields have experienced a co-occurring trend toward community-based services and consumer-direction in service delivery, and share similar goals in regard to accessible transportation, family care-giving, and residential options (Lightfoot 2007).

The development of the National Positive Ageing Strategy in Ireland then is a step in the right direction, wherein all ageing adults are the focus of government policy and all can benefit from strides forward. In the United States the Administration on Aging and the Centres for Medicare and Medicaid jointly developed the Aging and Disabilities Resource Centers (ADRCs). This network of one-stop-shops is designed to streamline access to the full range of long-term supports and services regardless of whether disability is lifelong condition or later-life onset. To date, nearly every US state has an active ADRC (Heller and Harris 2012). As the size and population of the Ireland is similar to a number of US states the efficacy of a model which integrates ageing and disability services could be usefully explored in relation to Ireland, and perhaps even piloted here for other European countries. By so doing, the model could be transferred efficiently and monitored accordingly, with a view to application to service systems here in Ireland and across the European Union.

4.7 Conclusion

The roundtable discussion held by ‘The National Council for the Elderly on Theories of Ageing and Attitudes to Ageing in Ireland’ (Davis 1994) concluded that there is an emphasis on able-bodied and active older people and a corresponding lack of focus on the needs of less active older people. It was judged that the assumption that independence is paramount should be challenged and more thought given to the promotion of positive attitudes towards more vulnerable older adults. Since then however, there has been little real change in terms of attitudes or practices, and conceptualisations of successful ageing are still predominantly based on criteria which reflect dominant norms and values and reinforce the absence of physical and cognitive impairment. There is a need to address the challenges involved in understanding what it means to be old for individuals who have lived with intellectual disability their whole life (Perkins and Moran, 2010). The findings of Thorpe *et al* (2001) are a welcome contribution to the knowledge base. The authors highlight the importance of psychosocial factors as well as biological factors in determining functional outcomes and

conclude that in spite of gradual declines in various domains those getting older with intellectual disability may still maintain active and varied lifestyles and an excellent quality of life. Romo *et al* (2012) also concluded that disability does not preclude the possibility of successful ageing and reported that many individuals ageing with disability enjoy their lives and assess themselves as ageing successfully.

The emergence of critical disability studies and the social model of disability has meant that researchers have become interested in variations in what is considered the typical life pathway, along with the dynamic factors which influence the life course. A growing body of research is emerging which may help to redefine successful ageing in the years ahead.

Goodley (pp.154-155, 2014) states that “when achievement and progression are narrowly defined and held up as the main qualities that we value in others and ourselves, then we are in trouble”. Therefore, it is clear that successful ageing must be understood differently going forward and take into account the meaning that individuals and cohorts place on their own lives. Such a new understanding can come about by timely research, sensitive policy-making, and ultimately, in changes in societal awareness and response.

Chapter Five – Consulting with Research Participants with Intellectual Disability and Communication Difficulties

5.1 Overview

This chapter focuses on the core challenges involved in consulting with research participants with intellectual disability and communication difficulties and lays a foundation for the methodology of the study. It identifies a number of the barriers and obstacles to effective communication, and delineates best practice guidance as well as evidence-based support strategies and solutions. The discussion is framed around a rights-based paradigm and thus the legislation supporting the right to be included is briefly explored.

5.2 Background

The Foundation for People with Learning Disabilities (2000) notes that between 50% and 90% of people with an intellectual disability experience varying degrees of communication difficulties. Gray and McAnespie (2004) elucidate what this means for people, explaining that “they might have difficulty in both understanding and using spoken language, resulting in mild to severe communication breakdown for both the individual and the person with whom they are communicating”. As such, in order to be heard the person with intellectual disability will most likely require both opportunity and effective supports. This is the challenge faced by researchers who aim to support people ageing with intellectual disability to tell the story of their experience and to ensure that opportunity for engagement and inclusion is maximised. However, it is important to preface this discussion on the practical aspects of supporting communication with a clear understanding of the research community’s moral and legal obligation to design studies that support inclusion.

5.3 The right to be included and consulted

The Graz Declaration on Disability and Ageing, June 2006, contains a re-affirmation of the principle of “nothing about us without us”. This principle strives to ensure that policies and measures affecting people with disabilities cannot be decided without their involvement and consultation. In addition, the importance of conducting research related to disability has been

underscored in both ‘A Strategy for Equality: Report of the Commission on the Status of People with Disabilities’ (1996) and in the United Nation’s ‘Convention on the Rights of Persons with Disability’ (UNCRPD), which was formally adopted in December 2006. The core principles contained in Article 3 of the UNCRPD and central to participation in research are:

- respect for inherent dignity
- individual autonomy, including the freedom to make one’s own choices
- non-discrimination
- full and effective participation and inclusion in society
- equality of opportunity
- accessibility

In effect, it is clear that a range of mechanisms currently exist which support the inclusion of people with intellectual and communication challenges in research studies.

Taking a rights based approach, Iacano (2006), explored whether the increasingly conservatism of the decisions and approaches of ethics committees has the potential to exclude certain categories of people with intellectual disability from research. While a central tenet of ethical research considerations is sheltering vulnerable groups from exploitation and harm (Dalton and McVilley, 2004), Iacano argues for better balance, stating that the very notion of shelter evokes paternalistic protectionism, with a concomitant risk of non-inclusiveness and discrimination. She believes that ethics committees must reframe their approach to decision-making in relation to people with intellectual disability and respectfully consider the rights and perspectives of potential participants and the group they represent. A move towards better balance between conservatism and exploitation develops a mindset open to recognising competence in relation to people with intellectual disability and brings researchers and ethics committees more in line with contemporary rights-based legislation. For example, this approach fits with the new Assisted Decision-Making (Capacity) Act, 2015, here in Ireland. The Act provides for consent to be obtained through a supported decision-making process, which may take place as a result of a presumption of competence and the provision of support by a trusted individual to evaluate risks and benefits of participation in research. As such it appears that the tide of opinion as well as legislative support is moving towards inclusiveness rather than protectionism. Going forward it is the

responsibility of the research community to ensure that people with intellectual disability can have meaningful engagement in research studies and to find the means of ensuring that this can take place in a supportive and safe way.

5.4 Why consult?

Consultation around subjective experience is key to developing theory around psychosocial aspects of peoples' lives. It follows that in order to progress knowledge, researchers must develop valid and replicable ways to elicit information from populations who may find themselves excluded due to communication difficulties as excluding those with communication difficulties from such studies raises the issue of validity in relation to outcome data which is likely to be unrepresentative. In the last decade there has been a distinct move towards an inclusive research model. For example, in relation to service developments in the intellectual disability services Dukes and Sweeney (2009) argue that the opinions of those whose lives are most affected must be sought and valued, while Stickley (2006) reveals that such consultation is now widely expected in respect of the UK healthcare agenda. Given the diversity in levels and the range of communication supports which individuals might require in order to participate in research, the reproduction and transparency in data collection method is a considerable challenge, but one that must be overcome nonetheless.

Stalker *et al* (1999) assert that people with intellectual disability are being increasingly acknowledged as the experts on their own lives, and as such, are more than able to offer views and insights from their own unique perspectives. It is therefore essential to begin to hear more clearly what people with intellectual disability say they want and need as opposed to merely providing what has been deemed best for them. Sensitive study design can play a critical part in facilitating the elicitation of these unique views, opinions and experiences.

A further concern is the selection of research areas. For far too long areas to be considered in research studies have been pre-determined by the researcher. This affords little opportunity for participants, and particularly those with communication difficulties, to put forward their areas of concern. For the most part the focus of studies has reflected normative views held by professionals, carers, or society in general, and may not reflect important areas of life for people with intellectual disability. Therefore, it is clear that two key areas that researchers must consider are: firstly, how to ensure meaningful engagement through supporting

communication; and secondly, how to allow scope for individual concerns to be brought forward.

5.5 Respect

Key to whatever approach is selected to engage with research participants is the central issue of respect. Iacano (2006) touched on this in relation to respect for people and groups and their right to be consulted and included. Ideally however, respect should permeate the entire research study, and in particular, should be experienced by participants in all face to face interactions. For example, during individual interviews the researcher must remain mindful of mutuality and reciprocity, while compensating for the inevitable power imbalance. Only when the person can experience this sense of being respected and valued will the researcher be in a position to elicit clear and accurate information, given freely without fear or stress. Respect can be imbedded in research design when the researcher moves away from the idea that potential difficulty in eliciting information arises from deficits attributable to the participant. Instead he or she must look to research methodologies, so that the responsibility to find a common communication pathway shifts to the researcher who should strive to be creative and skilful in how the study is designed and carried out.

5.6 Establishing individualised communication

Guidelines published by the National Disability Authority (2002) and the National Federation for Voluntary Bodies (2005) on supporting adults with intellectual disability to participate in research outline individualised communication strategies. The value of individualised communication strategies in enhancing communication and improving engagement is supported by empirical studies. Cambridge and Forrester-Jones (2003) demonstrated the benefits of individualised communication in research which utilises established individual vocabularies through a range of signs, drawings, graphic symbols, and photographs, to supplement spoken English. Their research shows that good communication outcomes can be achieved for both researcher and participant through the use of core and individualised vocabularies within a 'total communication' framework. Total communication relies on a whole range of objects and cues, as well as facial expression, gesture, body language, and electronic devices; in effect, not just speech, but the use of all possible ways to communicate. They concluded that the use of individualised communication for interviewing people with intellectual disability facilitates participation and involvement and improves the quality of

data collected. Individualised communication happens when the person's communication support needs are determined within a total communication framework and specific supports identified and put in place for that particular individual.

Gray and McAnespie (2004) undertook a consultation process with people with intellectual disability regarding the services they use by adopting an inclusive communication approach. They define inclusive communication as "an approach to create a supportive and effective communication environment between people, thereby promoting social inclusion". The authors found that with appropriate communication supports, many people with intellectual disability can be consulted and included in a meaningful way. Both staff and those who participated agreed that the provision of supported communication had enabled them to participate meaningfully.

Dukes (2009) carried out an exploratory study to elicit views and opinions about experiences of using a day and residential service within an intellectual disability population. An individualised communication approach was used with each participant's communication support needs considered in advance through consultation with key staff. Focus groups were conducted in line with a protocol that was designed to take account of factors that support communication, such as allowing sufficient time for response, repeating what was said to ensure meaning was understood, and helping people to maintain focus by inviting individuals by name to respond. The structure and presentation of questions used was also considered in terms of how best to elicit valid responses. Open-ended questions were employed with prompts being used sparingly and only to draw further exploration of views on certain aspects of the service. Using this study design, findings showed that all participants were able to engage meaningfully in the study and to have their 'voices' heard.

A range of studies then support the view that an individualised communication strategy is likely to be the most effective way of opening up research participation to those with intellectual disability and communication difficulties. However, as each research participant must have communication needs identified and individualised supports put in place to maximise communication, this approach has significant resource implications. In particular, it requires a commitment to working with individuals over a long period of time. As such resource considerations may prove a barrier to its widespread use but increasingly flexible

approaches are being used in data collection in order to ensure that all those who wish to participate in research are supported to do so.

Identifying individual communication support needs is a challenge for researchers and it may be necessary to enlist the help of other professionals and specialists to assist with assessment. For example, Cambridge and Forrester-Jones (2003) developed individual communication strategies based on assessment of each person's communication skills through consultations with local managers and others that knew the person well. Gray and McAnespie (2004) showed that speech and language therapists can have a key role in enabling and supporting communication in order to maximise an individual's potential for inclusion and participation. In their study they employed speech and language therapists to act as facilitators in focus groups to provide communication strategies and direct support to participants.

However, there is probably no substitute for the researcher spending time with potential research participants, getting to know them through observation and interaction, engaging with them over photograph albums and life story books, and consulting closely with those who know the person well (Dukes 2009). This level of engagement not only assists the researcher in identifying the individualised communication supports required but also assists the person in getting to know the researcher and in making a more informed decision in relation to giving or withholding consent to participate in the study.

5.7 Data collection methods

Myers *et al* (1998) note that face-to-face interviewing is the technique most frequently employed to elicit the perspectives of people with intellectual disability. They purport that the advantages of this approach include the opportunity to communicate directly with the participant, to establish rapport, to clarify any areas of confusion on the interviewer's or participant's side, and, when using semi-structured schedules, to be flexible in terms of adapting the questions or prompts to suit each person's priorities and communication style. The following guidelines for semi-structured interviews, taken from Azmi *et al* (1997) and Flynn (1986) make some important practical suggestions to support engagement:

- wherever possible audio record interviews to avoid discomfort and anxiety
- begin with relatively straightforward questions

- use the interview schedule flexibly, modifying the order and content of questions as appropriate
- avoid abstract notions and questions relating to time and frequency

To support people with intellectual disability to participate in research Cameron and Murphy (2006) further recommend that the researcher should:

- allow more time
- be good at communicating and getting to know people
- use different ways to communicate, not just speech

Studies also show that rigorous adherence to an interview schedule can stifle communication in this study population. Cattermole *et al* (1990) used an ethnographic approach in their study of individuals moving into staffed community homes in order to explore users' perceptions of changes in their quality of life over time. The researchers met with each participant on two to three occasions before formal data collection began. They approached the interviews with a list of topics they wished to cover but encouraged the participant to talk freely, thus opening up the scope of the inquiry. This approach fits with the findings of Jahoda (1988) who suggests that researchers should "open a mindset" in the participants, whereby they are drawn to talk about the particular aspects of their lives that are important to them and pertinent to the research topic. He observed that when applying more flexibility around how interview schedules are used, participants' communication and cognitive difficulties were rarely found to be limiting factors. It may therefore be more fruitful to follow the person's lead (Kitwood, 1997) and to use verbal and non-verbal prompts (Jahoda 1988) as well as a variety of stimulus material to encourage response.

Stalker *et al* (1999) contend that in attempting to elicit views and opinions from research participants with cognitive impairment, methodological eclecticism is a strength rather than a weakness, and that non-verbal methods of collecting self-report data are valid and reliable. The authors report that a variety of non-verbal methods have been developed to accompany or replace more conventional approaches, and they make specific mention of the use of photographs. It is evident that photo-elicitation interviews can be an appropriate means of obtaining information from research participants with intellectual disability and communication difficulties. Photo-elicitation involves an interview stimulated and guided by

photographic images. This procedure has been welcomed as a method which can break down barriers between researchers and study participants and promote more collaborative discussion (Harper 2001). Photo-elicitation can be used with the photos that participants have in their own homes to provide stimulus for discussion, and as such are a very accessible way to generate responses.

Useful guidelines to aid understanding of communication by people with severe and profound intellectual disabilities were published by the British Institute of Learning Disabilities in 2000. The authors, Grove *et al.* state:

People who have limited language skills must have the means to answer open-ended questions available to them, ideally in the form of pictures, symbols, real objects or people. Even people who appear to speak or sign well may benefit from a collection of photographs or symbols relevant to the discussion topic, since this will help their memory for what they want to tell you.

(Grove *et al* 2000, p.21)

One useful resource listed in the publication is ‘Talking Mats’.* This is a communication framework designed to allow people to express their feelings, make decisions, and think and communicate about relevant issues. A specific Talking Mats pack is available for use with people with intellectual disability and provides a means for those with communication support needs to engage in research, whilst in the past this opportunity may have been denied them.

Finally, it is important to be mindful that as people age additional problems can arise to impede communication including a decline in vision or hearing. These may prove exceptionally debilitating for people with prior intellectual disability and existing communication difficulties, and to this end researchers should ensure that participants are appropriately equipped with their eye glasses and/or hearing aids during the interview.

5.8 Conclusion

Sensitivity to preferred style of communication and flexibility around the manner in which interviews are conducted are key factors in any study design of research which aims to broaden its scope to facilitate a discussion of issues which are deemed most important to the individual participants. Additionally, the data collection method must permit a degree of latitude for participants to take the content in his or her own direction to reveal areas of

experience important to the individual. Due to the various legislative and policy instruments now in place to support a rights-based approach to inclusion in research, the discourse has shifted from *if* certain populations ought to be included, to *how* they can be supported to do so in a meaningful way.

* **Talking Mats** is a communication tool designed by Speech and Language Therapists to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about things that matter to them. It uses specially designed picture communication symbols and is used by clinical practitioners, carers, and support workers across a wide range of health, social care and educational settings. Available from AAC Research Team, Department of Psychology, University of Stirling, FK9 4LA, Scotland.

Chapter Six – The Research Methodology

6.1 Overview

This chapter sets out the methodology of the study and begins by contextualising the study and how the researcher is situated within it. Rationale for the choice of methodology is also presented. The chapter outlines the study design in detail, with particular attention to the ethical and practical complexities of including people with intellectual disability and communication difficulties as participants in research.

6.2 Context of the study

The demographic information outlined in Chapter Two shows that over the past few decades there has been a steady increase in the life expectancy of people with intellectual disability. In Ireland the National Intellectual Disability Database (NIID) shows this trend continuing year on year. Planning for ageing then is a new challenge for service providers. In response to this the service at the study site set up a *Planning for Ageing Steering Group* to explore and report on how best to structure and deliver a person-centred service to people as they age. This steering group comprised a broad skill mix, including clinical, managerial, and administrative staff. The researcher was a participant in the group. The group set about this task in the autumn of 2009 and in June of 2010 produced a report of their findings, entitled “*Responding to the Challenge of Ageing with Intellectual Disability*”. One outcome of the work undertaken by the group was the identification of a gap in information in relation to personal accounts of ageing within this population. A review of empirical studies carried out to complete the report confirmed that very little is known about how people with intellectual disability experience ageing. This observed gap in information provided the impetus for the researcher to carry out the present study. As a clinical psychologist in the service, practice-based and service-based research is an aspect of the role of the researcher. Service-based research carried out to date demonstrates that the service has a culture of consulting with those using the service in order to inform the direction of change. As such, when the researcher proposed to the steering group that a thorough consultation process was needed with those ageing within the service in order to appropriately inform future planning, agreement regarding the benefits of such a project was readily forthcoming. The researcher submitted a research proposal to the Director of Services and requested permission for the

study to be carried out on site. It was suggested that the project be funded independently in order to ensure impartiality and minimize the risks of interference with presentations of the outcome data. This was accepted by the Director of the Service and as such practical support for the study was assured.

Positioning the service (study site) in relation to the study:

The service was first developed in 1975 and grew from volunteerism and community good will. It currently thrives on a person-centred ethos and a willingness and openness to new learning in order to improve the lives of those using the service. The service strives for high standards and ‘excellence in ageing’ is a stated objective in the Strategic Plan, 2016 - 2020. A willingness to work towards positive change, informed by those using the service has been demonstrated repeatedly by the service. For example, prior to the introduction of a person-centred planning model, people using the service were invited to participate in focus groups. The data collected highlighted both desired and undesired changes and subsequently informed a new planning system. Similarly, focus groups were convened and one-to-one interviews held to enable service-users to express their opinion in the matter of the appointment of a new Chief Executive Officer for the service. As such, the service in question has a proven track record as a learning organisation, open to planning for change through consultation with those that use the service.

6.3 Choice of methodology

Chamberlain-Salun *et al* (2013) maintain that researchers approach the world with a set of beliefs and ideas about the nature of being (ontology) which raise questions about the relationship of the knower to the known (epistemology). It is therefore imperative that the philosophical foundations of a research study are clearly set out at an early stage of the project. Indeed, Mills *et al* (2006) argue that in order to ensure a strong research design, researchers must choose a research paradigm which is congruent with their beliefs about the nature of reality. The choice of methodology for this study then was informed by the goodness of fit with theoretical underpinnings associated with contemporary clinical psychology practice, and more specifically with relativism and subjectivism.

In this study the researcher aims to generate data and develop an understanding of the meaning people with lifelong intellectual disability attach to their lives and their experiences

as they age. Grounded theory is a methodology that seeks to construct theory about issues of importance in people's lives (Glaser, 1978; Glaser and Strauss, 1967; Strauss and Corbin, 1998) and is a good fit with the aims of the study. However, over the past five decades this methodology has broken into three discernible schools of thought, each with some variation in ontological and epistemological positions. They are; classic grounded theory associated with Barney Glaser; evolved grounded theory associated with Anselm Strauss and Juliette Corbin; and constructive grounded theory associated with Kathy Charmaz. For this reason individual researchers must identify their own ontological and epistemological position in order to best choose the point on the methodological spiral of grounded theory where they feel theoretically comfortable (Mills *et al*, 2005).

In acknowledging the author's subjective position relative to the study population, a grounded theory methodology, epistemologically derived from social constructivism was considered an appropriate approach to meeting the aims of this study. As an epistemological stance, constructivism asserts that reality is constructed by individuals as they assign meaning to the world around them (Appleton and King, 2002) and as such has its foundations in symbolic interactionism. In contrast to classic grounded theory which aims for a conceptual understanding of social behaviour, constructivists focus on interpretive understandings of participants' meanings (Breckenridge *et al*, 2012).

Ontologically relativist and epistemologically subjectivist, a constructivist grounded theory approach is a good fit with the beliefs and working practices of the researcher. The clinical psychologist and the constructivist researcher seek to:

- (i) work with another person's perspective in order to co-construct meaning through mutual understanding
- (ii) focus on the central role of the relationship in the creation of meaning
- (iii) acknowledge that meaning is an interpretation of reality

Constructivist researchers and clinical psychologists are concerned with building a respectful and reciprocal relationship with another individual and both recognise the person as the expert in their own lives. In addition, both disciplines are cognizant of the power differential which inevitably exists in the relationship, a differential which requires even greater consideration when working with individuals with additional vulnerabilities, such as intellectual disability. Only when these areas are effectively managed can the constructivist

researcher and the clinical psychologist begin to develop an understanding of the person's experiences and how they interpret their social and psychological worlds. Developing mutual understanding is consistent with the therapeutic work of clinical psychology and the interpretive nature of constructivism.

Kathy Charmaz is one of the most important thinkers in constructivist grounded theory today (Charmaz and Keller, 2016). In proposing a version of grounded theory based on constructivism she asserts that we can only understand reality, society, and the self, within a broader framework which is contextually positioned within a certain time, place, and culture (Charmaz, 2006). As methodologically constructivist grounded theory is interpretivist in nature, the relativism of multiple social realities is acknowledged. A key principle of this version of grounded theory is that data and analysis are co-constructed in the interaction between the researcher and participant. A core understanding in the constructivist grounded theory method then is that the researcher cannot be completely objective. The existence of an interrelationship between the researcher and the participant is acknowledged (Mills *et al*, 2006). From a constructivist perspective the author's dual position of researcher and clinician in this study can be viewed as facilitating both rich data collection and sensitive, interpretative understanding. Gardner *et al* (2015) assert that using a constructivist approach fosters reflexivity on the part of the researcher and leads to a co-construction of theory which is a combination of the researcher and the participants' stories and views. In addition, Charmaz (2006) underscores the importance of using a broader definition of the concept of 'theory' when considering the development of a grounded theory by emphasising that interpretive theory relies on the researcher's interpretation and analysis of the data and seeks an understanding of the social phenomena rather than an explanation.

Constructivist grounded theory assumes that reality is socially constructed, that no objective reality exists, and that individuals make sense of the world through social interaction and shared understanding. In signing her book for the author, Kathy Charmaz wrote 'with hope that you construct many grounded theories' a sentiment which positions the researcher as an active participant in the social phenomena under study. Constructivist grounded theory then was deemed an appropriate methodological approach to adopt for this study, specifically in relation to the views of the author, the author's dual role at the study site, and the author's long-established relationship with the participant population.

6.4 Rationale for the study

In order to provide appropriate and valued supports it is important to have a clear understanding of how ageing is conceptualised for older people with an intellectual disability. To this end, there is a need to gather information on the knowledge, the experiences, and the opinions of this population, in order to inform and structure an ageing theory which is grounded in the voices of those with lifelong intellectual disability who are currently ageing. Going forward it may be possible to use the findings of the study to begin to develop a relevant lifestyle support model appropriate to this population. As such the study aims to fill a gap in the Irish context for an in-depth qualitative study of ageing in respect of this population. While the IDS to TILDA study is ground-breaking in Ireland and across Europe, the necessity for studies using different methodologies to access the voice of this population nevertheless remains. The IDS to TILDA study involves a random sample of participants from the National Intellectual Disability Database (NIDD) 2008, with each participant completing a pre-interview questionnaire, and taking part in a face-to-face interview with a researcher who they meet for the first time on the day of interview. A qualitative study using a constructivist methodology and individually tailored interviews with sensitive communication supports can provide another perspective, enriched insights, and add to the knowledge base in respect of those ageing with intellectual disability in Ireland.

6.5 Defining old age in the study population

Head *et al.* (2012) observe that within the empirical literature it is strongly argued that the ageing process commences at the younger age of approximately 40-50 years in people with intellectual disability. Dodd (2003) asserts that adults with Down's syndrome tend to develop dementia in their late 30's and early 40's and are more likely to die younger as a consequence. A joint report by the Royal College of Psychiatrists and the British Psychological Society (2009, p. 9) states that case reports, cross-sectional, and longitudinal studies have all confirmed an increase in the prevalence rates of clinically diagnosed dementia with increasing age, which starts when people with Down syndrome are in their 30's. In the Irish context, Lavin *et al* (2006) reviewed the age of death from statistics from the National Intellectual Disability Database (NIDD) from 1996 to 2001, and found that of a sample of 1,120 persons with intellectual disability comprising of 590 (52.7%) men and 530 (47.3%) women, the average age of death calculated per group was 48.88 for mild intellectual

disability, 51.16 for moderate intellectual disability, 44.53 for severe intellectual disability and 29.37 for profound intellectual disability, giving an average of 45.68 years for the total intellectual disability population. For people with intellectual disability then, it is widely accepted that ageing-related problems manifest earlier when compared to the general population. Based on the information currently available and given that ageing-related change is the focus of this enquiry, the inclusion criteria selected in relation to age for participation in the study is therefore as follows:

- i. People with intellectual disability and Down syndrome age 35 and over
- ii. People with intellectual disability without Down syndrome age 50 years and over

6.6 Ethical Approval

A detailed research proposal was submitted to the Director of Services of the community based Intellectual Disability Service and reviewed by the Chief Executive Officer. The researcher subsequently met with senior management so that any ethical considerations could be identified and addressed. The service provider (CEO and senior management team) approved the undertaking of the study and approval was duly signed by the Director of Services.

The research proposal was also forwarded to the University of Limerick, Faculty of Education and Health Sciences Research Ethics Committee and the Research Ethics Application Form was completed. Ethical approval for the study was granted by the Ethics Committee until February 2016. The University of Limerick assessed progression in December 2015 and the researcher was notified of a successful outcome. The study was allowed to continue beyond the original date.

6.7 Participants

Participants are people ageing with lifelong intellectual disability availing of a service from the research site. While an assessment of the cognitive functioning of individual participants was not carried out, eligibility for participation in the study was determined through a 'social system' perspective (Mercer, 1973; Budd and Greenspan, 1984, Booth and Booth, 1993), which is to say, people who are in receipt of a service specifically devised for people with intellectual disability. Determination of 'old age' in relation to inclusion criteria for the study was based on a review of the empirical literature (Lavin *et al*, 2006; Royal College of

Psychiatrists and British Psychological Society, 2009; Ryan *et al*, 2013), as outlined above. According to the service provider database (12/5/2011) the age profile of people availing of a service from the study site was as follows:

- Total number on database = **242**
- Number of people with Down syndrome and over 35 years of age = **47**
- Number of people over 50 years of age and without Down syndrome = **50**
- Total number of people in ‘old-age’ category = **97**

These 97 people made up the study population and all were considered for inclusion in the study. However, some exclusionary criteria were applied as follows:

- those with advanced dementia
- those with mid-stage dementia where main carers were satisfied that attaining informed consent to participation would not be possible
- those whose severity of cognitive impairment would deem consent to participation unreliable

Table 1: Response to Participation by Target Group

Gave consent and participated	46
Withheld consent and did not participate	6
Consent could not be relied upon	12
Advanced dementia	4
Deceased by commencement of study	3
No response	26

Three people died between the time the database was originally accessed and the time that consent was sought. The centre managers and staff of each unit were also consulted to identify individuals with advanced dementia and those whose consent could not be relied upon. These amounted to 16 people in total. Therefore 78 people were initially invited to take part in the study. Of those, 46 gave consent and participated, 6 withheld consent, and 26 did not respond. The final sample consisted of 22 female and 24 male participants with an age

range from 36 years to 76 years, and a mean age of 52 years. Participants had a range of intellectual, physical and sensory disabilities.

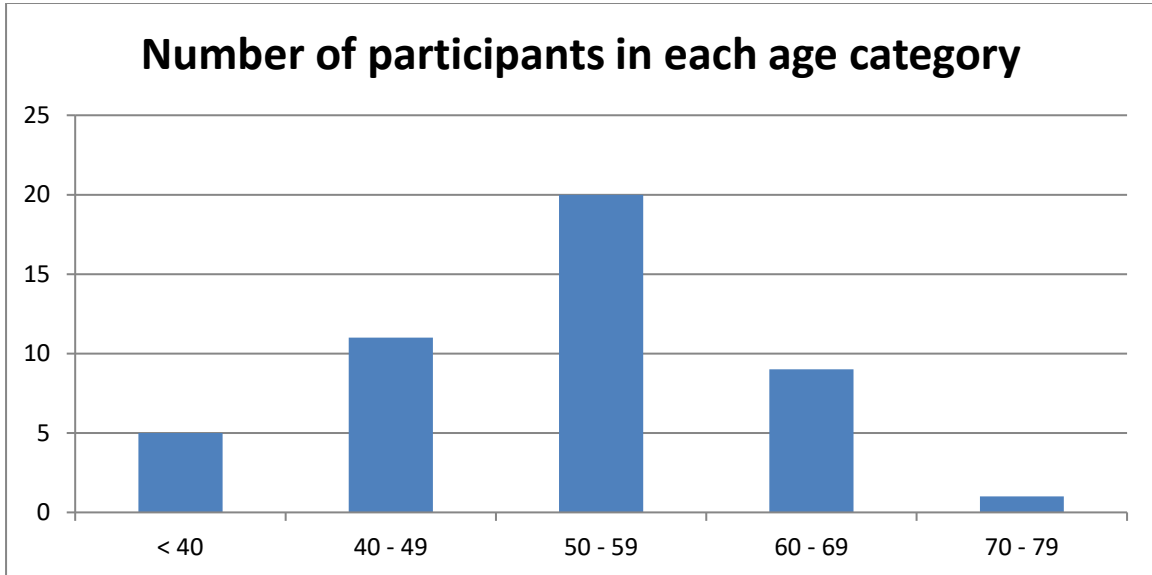


Diagram 1: Participant age profile – Overall

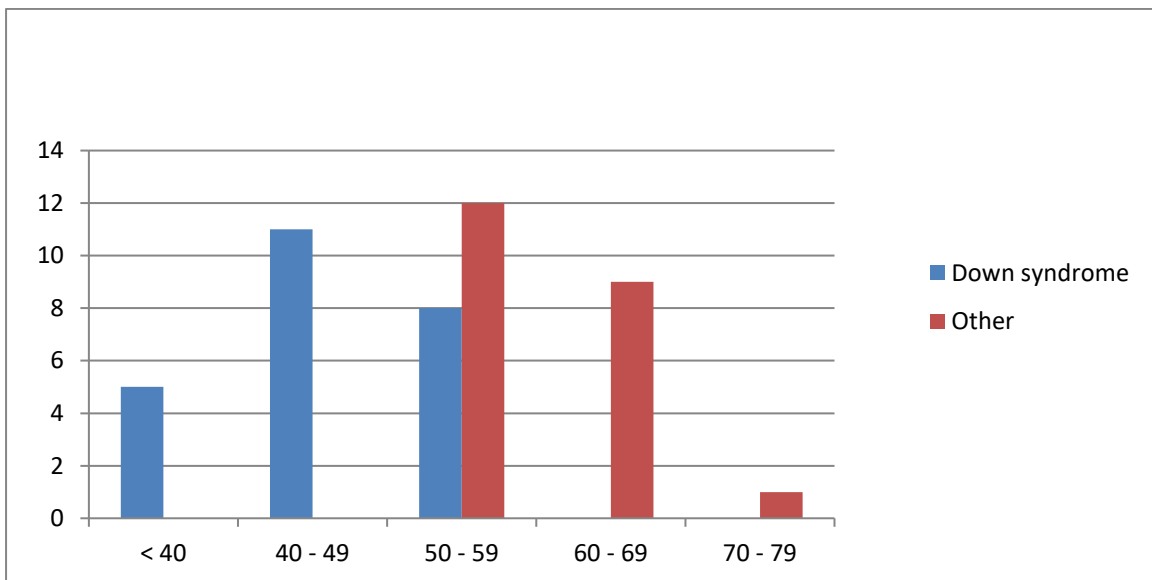


Diagram 2: Participant age profile – Down syndrome/Other

Table 2. male/female age demographic

male	female	age range
4	2	36 -39
5	4	40 – 49
8	12	50 - 59
4	5	60 - 69
0	2	70 - 79

Table 3. Mean Age of Participants

<i>Mean age across all participants</i>	52
<i>Mean age of participants – Down syndrome</i>	46
<i>Mean age of participants – Other</i>	63

Living arrangements:

Participants had a range of living arrangements. The majority lived in residential care in the community, while others lived with family members, of whom several availed of respite care. Two participants lived in their own homes with some support, and one further participant lived in a community hospital. The following diagram is a visual representation of this demographic data:

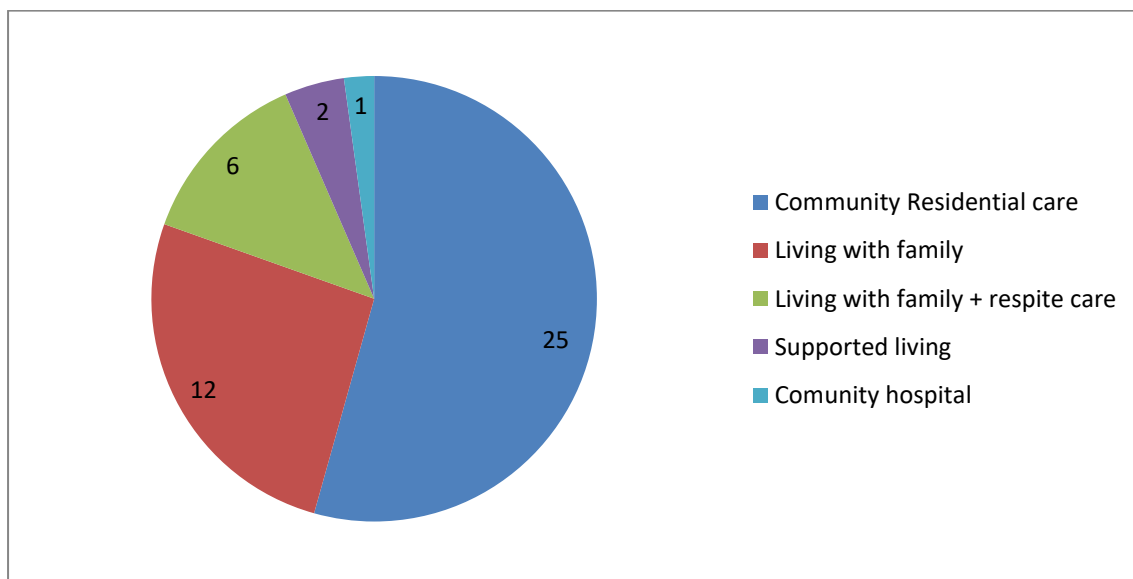


Diagram 3: Living arrangements of participants

6.8 Ethical considerations

The National Disability Authority (2009) point out that the extent to which research and ethical values are embraced in a research study influences the quality of research and its outcomes. Core research values for the author are the quest for new knowledge, applying an appropriate methodology to obtain valid results, and to report results in a way which represents the participant population with honesty and sensitivity. To this end, every effort has been made to ensure the integrity and independence of the study and to manage any ethical tensions in relation to the researcher's dual role at the study site. For example (i) while the service approved the study, it was not commissioned by the service and all funding costs were incurred exclusively by the researcher (ii) the goal of the study was to arrive at new knowledge and there was no expectation that the researcher would necessarily represent the service positively (iii) as service managers did not have access to the raw data they could not influence data collection and analysis and were not in a position to censor any potentially uncomfortable findings. However, at the request of the researcher, members of the original steering group on ageing were asked to monitor the welfare of participants throughout the study to ensure that they were 'treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being (Belmont Report, 1978). This was done by service managers overseeing how the research process was impacting on individual participants and giving direction to the researcher should such concerns arise. For example, if a participant was in poor health or had a change in circumstance, the researcher was advised that interviews would need to be postponed or cancelled. Changes in circumstances occasionally arose when participants were bereaved or were managing some other significant change. In effect the researcher sought to apply the 'ethics as process' model proposed by Ramcharan and Cutcliffe (2001) which is deemed particularly suitable for qualitative research where ethical considerations emerge as the research proceeds.

Ethics and response bias:

Perry and Felce (2004) assert that response bias such as acquiescence, naysaying, and recency bias, can occur in any interview. However, there is evidence that people with an intellectual disability are particularly prone to response bias and can have low levels of responsiveness (Harner, 1991; Heal and Rubin, 1993; Novak *et al*, 1989; Perry and Felce, 2002). Grove *et al* (2000) explain that acquiescence refers to the tendency of people with

intellectual disabilities to agree with what is proposed to them and that on the whole they are more likely to say *yes* than *no* to a proposed course of action. Heal and Sigelman (1995) suggest that people may acquiesce in order to be agreeable and may say 'no' to questions that mention socially undesirable behaviours to deny association with these taboos. Of course, the issue of power relationships is also significant in examining this phenomenon as social desirability may be a consequence of a perceived imbalance in the status of interviewer and interviewee. Evidence for this view is provided by Richman *et al* (1999) who reported that there was less social desirability distortion in studies which used computerised versions of interviews than in those in which face-to-face interviews were conducted. They concluded that levels of response bias and responsiveness might vary as a consequence of the characteristics of the interviewer. Results of the study by Perry and Felce (2004) however, did not support this view. Instead they found that levels of responsiveness and response bias may rather be attributed to interviewee characteristics, such as ability level. Irrespective of the reasons for response bias, the fact that this is a commonly observed occurrence in relation to interviews with an intellectual disability population means that researchers must be alert to it and incorporate measures to manage it into the study design. The author was keenly aware of the possibility that those invited to participate in the study might act in a way that they believed the manager, keyworker, or support staff, wanted them to act (such as, agree to participate). While the author realizes that this issue cannot ever be fully avoided, every reasonable effort was made to ensure participant understanding of the voluntary nature of their involvement, including information letters to participants and to support persons, consultation with centre managers, accessible formats, reminders at the beginning of interviews, monitoring throughout interviews, and offers to terminate interviews if any unease was observed.

It is also notable that of the 78 people invited onto the study, 26 did not respond, and a further 6 withheld consent. This demonstrates that 41% of those receiving letters of invitation did not respond in an acquiescent manner.

The structuring of interviews and precise wording of questionnaires is also key to managing and/or avoiding acquiescence. These considerations will be addressed in more detail by outlining the methods by which communication was supported throughout the study.

6.9 Informed consent

The researcher was guided by the ‘Psychological Society of Ireland - Code of Professional Ethics’ throughout the process of attaining informed consent from would-be participants, with particular reference to Articles 1.3.4. and 1.3.5. Article 1.3.4 pertains to the provision of information necessary for a person to make the decision to either give or withhold consent. It states that this information must be provided “in language which the persons understand” and charges the psychologist to “take whatever reasonable steps are necessary to ensure that the information is, in fact, understood”. Article 1.3.5. holds to the precept that in the process of obtaining informed consent, the psychologist must ensure that key points are understood, including the purpose and nature of the activity, the likely benefits and risks, and the option to refuse or withdraw at any time, without prejudice. The author was further guided by the *Disability Research Series 13* (NDA, 2009) which is grounded in recommendations of the Belmont Report (1978):

Researchers need to invest time and effort in securing actual informed consent, which entails not only ensuring that potential research participants are fully informed about the research but that they understand 1) its implications; 2) their freedom to choose to participate in the research or not; and 3) their freedom to withdraw from participation in the research at any time (p. 36).

These core principles were adopted by the author as central components in the process of attaining consent from participants of the study.

6.10 Eliciting informed consent

In the first instance, potential participants were supported in their decision-making by the development of easy-read information on the purpose and scope of the research. This which was distributed to those key support workers best placed to decide how to help individuals to understand the content. In consultation with local managers a key support person was identified for each individual who was invited onto the study. For the most part, this was the person’s keyworker. Letters of information were hand delivered to each day centre and residential house and addressed to the identified support persons (see Appendix A).

Residential and day centre managers were also provided with a copy of the letter to ensure they were fully informed about the study. Managers were asked to display the letter on notice boards so that all staff, carers and family members were aware of the study and in a position to support potential participants around any questions they may have. The letter explained the aims of the study and that the people they supported would soon be getting letters of

invitation to participate. They were asked to support the person to understand the content of the letter and to assist them around indicating whether they wished to give consent or to withhold consent, where such assistance was required. All the support people were trained in working with people with intellectual disability and skilled both in effective information communication with those in their care and in understanding and interpreting the responses of those with communication difficulties.

All potential participants were subsequently invited to take part in the study by hand-delivered letter (see Appendix B). Letters were delivered in person to each house or day centre by the researcher. These were addressed to potential participants but given to the relevant manager who decided how each person would be supported to read and understand the content and to give or withhold consent to participation. Typically the support person already identified by the centre manager was assigned that responsibility. Potential participants were asked to mark the word YES or NO on the letter of invitation to indicate their preference to participate or not to participate. The voluntary nature of participation was stressed in the letter and also the fact that the findings from interviews would be part of an academic study. Letters of invitation, with or without consent, were to be returned to the manager and were collected by the researcher in advance of interviews happening. The Booth and Booth (1994) “golden rule” was applied to all aspects of the study including the attainment of consent. In other words the axiom that “where the interests of individual participants conflict with the demands of the research, the former must take precedence” was consistently observed. No attempt was made to follow up on any unreturned letters of invitation as the researcher was wary of any actual or perceived pressure being felt by those invited onto the study.

Ongoing consent:

The NDA (2009) advises that upon attaining consent from participants the researcher must ensure that consent issues are reviewed throughout the research process. This is a good fit with the ‘ethics as process’ principle employed by the researcher. Wiles *et al* (2004) outline practices to help researchers check that they have the ongoing consent of research participants. This might include reiterating the opt-out clause to participants. The researcher continuously monitored consent by re-establishing that the participant understood what the interview concerned at the beginning of each interview with the question, “Why are we

meeting today?” Depending on the response the researcher went through the initial information provided to the participant again and once again enquired whether they wished to participate or not to participate. At the beginning of each interview the researcher always reiterated that the participant was free to participate or not to participate and their choice-making was supported by offering to talk for a while, if they wished, regardless of whatever the person ultimately decided. In addition the researcher was alert to any signs that the participant may wish to leave during interview and frequently offered this option. For example, if a participant did not sit down on entering the room, or stood up during interview, the researcher gave them the option to leave or to postpone the interview as they wished.

6.11 Creating an effective communication environment

One crucial aspect of the study was to establish an inclusive design so that anyone that wished to participate in the study would be supported to do so. As such, a key aim was to ensure that as far as possible, communication deficits were not a barrier to participation. A *total communication* approach was therefore adopted, meaning that all possible ways to communicate were utilised as appropriate to individuals (Cambridge and Forrester-Jones, 2003) in order to create an effective communication environment. Total communication is demonstrated throughout the study and the range of supports and strategies utilised include:

- (a) the BILD Guidelines (Grove *et al*, 2000)
- (b) consideration of communication support needs
- (c) flexible use of the interview schedule
- (d) use of a variety of stimulus materials
- (e) sensitive responding

The BILD guidelines:

The guidelines published by BILD in 2000 assist researchers in understanding communication by participants with intellectual disabilities. The guidelines comprise a set of procedures for gathering information, considering preferences, discovering the persons’ wishes, along with procedures for checking interpretation. The publication provides also useful interviewing direction in terms of time, place, setting and recording. These guidelines were integrated into all areas of the study which involved either direct or indirect communication with participants.

Consideration of individual communication support needs:

The researcher liaised with key people who knew the person well in order to assist with understanding individual vocabularies and general communication styles and methods. The information gathered ranged from acquiring certain pronunciations utilized by participants, names for objects and people, names of key items and places of importance to this person, and words, sounds, and gestures commonly used to communicate a meaning unique to him or her. One example that arose was an individual who used the word 'now' to indicate 'finish'. Another example was of a man who used the word 'bopeen' to indicate that he wanted a cup of tea. Having worked with many of the participants over a long period and being familiar with individual communication styles and content, the researcher had the advantage of understanding a great deal of the participants' idiosyncratic communication. In addition this prolonged engagement with the study population meant that the researcher was familiar with the names of people and places of importance for a great number of the participants and this greatly assisted rapport. Consultation with staff also involved obtaining information to help the researcher to ensure that interviews would go well and the person would be at their ease, such as, the person's favourite place to sit, favourite objects that might be required, use of hearing aids or eye glasses, and how to recognise onset of seizures. Information gained from this process was utilized to support and enhance communication at the time of individual interviews.

Further familiarization with individualised communication support needs happened through meeting with each participant prior to data collection interview. Meetings took place at a time and place decided by the participant. At this meeting the researcher assisted the participant in developing a personal communication passport using a modified version of the CALL Centre Passport Starter 2003* (see Appendix C). In addition, personal photograph albums were used to establish rapport and to determine speech patterns, abbreviations, and pronunciations. These worked well as people were very familiar with their photographs, liked to show them, and were comfortable and relaxed using photographs to assist communication. Some individuals had completed *Life Story* books and browsed through these with the researcher. This meeting was also used to establish all other means of communication such as use of gestures, eye movement, and sounds. The researcher liaised with support staff to confirm that non-verbal communication had been correctly interpreted. The purpose of the meeting then was threefold:

- a. to become familiar with communication styles and patterns
- b. to develop a personal passport which would allow the researcher to get to know the participant better
- c. to develop rapport

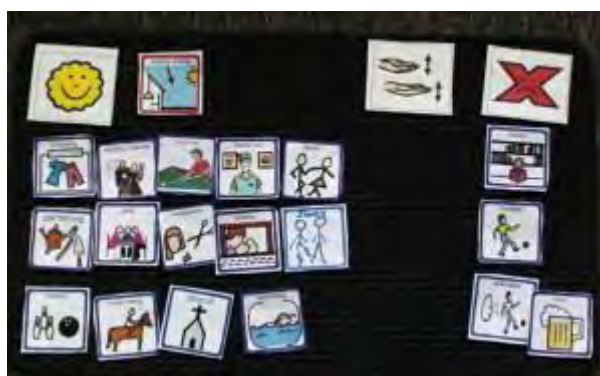
All information gained throughout the process was used by the researcher to determine how the data collection interview would proceed in terms of supporting the person as fully as possible to communicate.

The Interview schedule:

Framing an interview schedule around terms such as ‘old’ and ‘young’ may not yield meaningful data as these terms are relative and are best understood in context. The interview schedule was therefore constructed with this in mind with questions contextualized for participants and presented in relation to ‘change over time’. The schedule itself was used flexibly and the order and content of questions modified as appropriate, with the participant always guiding the direction of the interview. This was to ensure that areas pertinent to the lives of individuals were captured in the data as opposed to what the interviewer might feel is relevant. The conventional approach to conducting semi-structured interviews, as suggested by Kitwood (1997) was thus adapted, in that the interviewer followed the interviewee’s lead rather than imposing structure on the conversation from without.

Use of stimulus material at interview:

Personal photographs, *Life story* books, objects, pen and paper for writing, symbols, and pictures were utilised to support communication as appropriate. * *Talking Mats* – a low-tech framework to help people with communication difficulties express their views was also utilised. See below in which *Sunshine* indicates ‘likes’ and *X* indicates ‘dislikes’:



In addition a booklet was designed specifically for data collection and entitled “*Let’s Talk About Getting Older*” (see Appendix D). As the process of completing the personal communication passport was helpful in developing rapport at first interview, this document was also occasionally used to prompt discussion on certain topics and issues at data collection interviews.

Sensitive responding:

Regardless of the amount and level of advance preparation to support the flow and depth of communication at interview, the researcher also had to remain alert to all communication attempts once the interview began and to respond sensitively and respectfully to all efforts on the part of participants. Sometimes the interviewee responded only mono-syllabically, but if the person seemed comfortable to stay at the interview, albeit saying little, this was respected. For this reason interviews were often slow but invariably fruitful. Even participants with little verbal communication were observed to convey meaning through facial expression; a smile, tearfulness or an animated look, when discussing certain topics, or a disinterested expression when discussing other areas. Spontaneous efforts to communicate meaning were often unexpected and always creative.

*CALL Centre Passport Starter, Callcentre.education.ed.ac.uk.

Summary of communication supports used throughout the study

- **The British Institute of Learning Disabilities (BILD) guidelines** (Grove *et al.*, 2000) outlined in “*See What I Mean*” were used in relation to all aspects of communication, including considerations regarding time, place and setting.
- **Familiarization with communication style and patterns** to establish individualised communication and support needs as recommended in the literature (National Disability Authority, 2002, 2009; Cambridge and Forrester-Jones, 2003; Gray and McAnespie, 2004; National Federation of Voluntary Bodies, 2005; Dukes, 2009.)
- **Flexible use of an interview schedule** was used as advised in the relevant research (Cattermole *et al.*, 1990; Kitwood, 1997; Myers *et al.*, 1998).
- Use of a variety of **stimulus materials** was used to encourage and support response.
- **Remaining alert** to all communication attempts and **responding sensitively**.

6.12 Data collection and management

Setting:

Interviews took place in locations familiar to each individual participant and in rooms with appropriate heating, lighting, and seating. Rooms were also located in areas private enough to allow participants to communicate in whatever way they wished without either being overheard or the likelihood of interruptions. The participant was invited to select the space to be used from a choice of two to three possible options.

Rationale for data collection method chosen:

As discussed earlier, Myers *et al.* (1998) outlined the benefits of face-to-face interviews to elicit the perspectives of people with intellectual disability. In particular this technique allows for flexibility to adapt questions and prompts to support individualised communication. This was of core importance and relevance to the study. In addition, as the comfort of participants was paramount, this method of data collection maximised the possibility of early detection of discomfort and timely and appropriate responses by the researcher. In all, individual face-to-face interviews with the researcher using a semi-structured interview schedule was deemed the most appropriate way of eliciting the views, opinions, and details of life experience from the population under study and this approach was undertaken for data collection.

How data was collected:

Data was collected for the study by way of responses given during interviews. These were audio recorded and subsequently transcribed verbatim. The researcher collected all data in person. This was an integral part of the design of the study as the researcher alone had full information on communication supports required by each participant. Interviews were arranged to suit individual participants in terms of their preferences of time and location. Suitable times were communicated to the researcher through key workers. The duration of interviews varied considerably, from approximately 5 minutes to 70 minutes. A small number of the participants could only engage for short periods at any one time, but if they wished to have a further interview, this was facilitated.

Interviews generally took place in a room in the person's day centre or residential house. The format was relaxed and a beverage was often taken by both participant and interviewer. Participants were welcomed, (or thanked for allowing the researcher to visit if it was in the participant's home), invited to sit wherever they wished, and thanked for agreeing to the interview. The researcher also often asked a participant where they would prefer her to sit.

Ongoing consent was confirmed by asking participants prior to commencement of interview if they still wished to proceed. All participants chose to proceed with the interview. The purpose of the meeting and what would happen during interview was then explained. The interviewer also reiterated what was said in the information letter in relation to confidentiality. Participants were reminded of the voluntary nature of participation and their right to leave at any time. Questions were invited from participants to clarify any issues regarding the nature of the interview.

At this point it was usually necessary to contextualize the interview by alluding to the age of someone the person knew well and the participant's own age by comparison. For example, the researcher might state, "I am fifty two now and you are nearly as old as me. You are fifty", or perhaps refer to the age of a sibling or a member of staff to which the person relates well. The interview then moved on to considering how people in general change over time before discussion began on how the participant has experienced change. Overall the interviewer had to spend some time facilitating an understanding of the research topic by contextualising and referencing in relation to the person's own lived experience.

Photographs worked very well in contextualizing change and most participants had photograph albums with them or could access them readily.

The interview schedule designed for the study was flexible and used only to guide the interview (see Appendix E). Questions were posed in a natural way and in a varying order so as not to interrupt the flow of an interview. In this way the interviewer allowed the participants to take the lead and to talk about whatever was important in their lives. Prompts were offered if they got stuck and these were used to steer responses towards a pertinent area or to encourage further response on a particular area. A range of stimulus material was used to contextualize interviews and support communication. Using a *total communication* approach the researcher drew on all information gained from familiarization with each person's communication support needs to keep stress to a minimum and enhance the quality of data collected. One strategy which worked well across a large number of participants was repeating back what the person said. There was often a reluctance to move forward until the person was certain that he/she had been fully understood. The researcher did not always get it right and participants would usually try again, but would move on if the researcher continued to fail to understand the communication. Individual creativity and persistence in attempts to be understood was one remarkable aspect of this stage of the study. For example, on two occasions participants sang a relevant song to enable the researcher to grasp what was being communicated.

The researcher took a proactive approach to monitoring the need to terminate an interview. She watched for signs of tiredness, unease (such as a person looking towards the door, looking at their watch, standing up), perhaps rubbing of head or stomach (indicating pain or hunger), and offered termination or postponement throughout interviews if any signs of discomfort were observed. This was considered a more appropriate response to support this particular study population as the vast majority had little or no experience of using mechanisms to indicate "finish" such as raising the hand or pointing to a STOP card.

Recording information:

The researcher audio recorded interviews using a Sony IC Voice Recorder (2GB) and these interviews were later transcribed verbatim. This allowed for detail to be preserved for later data analysis and direct quotes used in the report of findings. The researcher also made a written record of observations of body language and the tone or emotion attached to

particular responses, as this can add greatly to the quality of data for analysis. These observations were recorded in a notebook immediately after completion of interview. Three participants did not wish to have interviews audio recorded and this was respected. A written transcript was taken in vivo for these individuals. To protect anonymity, individual participants were not identified during the recording or reporting of responses, although first names were used when the interviewer addressed interviewees. One interesting aspect which emerged in relation to audio recordings was that when the researcher asked participants if they wished to hear their recording, those who chose to listen to the playback appeared very pleased at hearing their own voice. Arguably the playback provided tangible evidence for the person that he or she has a voice and that it was important enough to be heard.

Concluding information:

Efforts were made to elicit responses across all questions and once this was done the researcher thanked the participant for their involvement, and reiterated the issues of confidentiality, how information gathered would be used, how information would be disseminated to them and others, and how they will be able to access it. The offer of further support was made to participants by means of an identified staff members (usually a key worker or manager). However, on a few occasions participants asked if they could meet the researcher again in relation to a specific issue which had arisen for them at interview. As a clinician attached to the study site, these requests were always accommodated by the researcher.

Confidentiality and data protection:

To protect confidentiality interviews were held in settings where the discussion could not be overheard by anyone outside the interview room. Recorded data was held by the researcher only and transported directly to a secure location after each interview where it was stored in a locked filing cabinet. Transcribed data was held on the researcher's personal computer which has a secure password known only to the researcher. No information pertaining to the identity of participants was written or reported. Each participant was given an identifying code which was used at all times for any written records, such as memos, transcript, and so on.

Care of research participants:

The researcher was aware of the possibility that participants could develop expectations that wishes expressed at interview would be implemented by the service, whereas there is no guarantee that this will happen. Therefore, participants were reminded of this at the start and end of each interview. Interviews were presented to participants as an opportunity to express opinion and share personal experience, as opposed to any guarantee of an outcome. As all staff within the service and family care-givers were made aware of the study and what it involved for participants, they were in a position to address questions or specific concerns that participants may have in relation to their involvement in the study.

Concerns that participants would worry that the interviewer was implying that they were old when they may not have seen themselves as such was managed by contextualizing age in relation to change and referencing others they may know of similar age whom they think of in a positive light, such as the CEO, the interviewer, or a sibling.

Data management:

Audio recordings of interviews were not suitable for use with voice recognition software because of speech and pronunciation difficulties of many participants and therefore all interviews were manually transcribed verbatim, with a new line for each speaker. This was time intensive but had value in that it allowed the researcher to become intimately familiar with the data. Each interview was assigned an identification number. Nine volumes of data were transcribed each containing from 4 to 7 interviews. Volumes ranged from 92 to 125 pages in length. In all 1042 pages of data were transcribed.

Memo-writing was an integral part of the research process and assisted in developing inductive theoretical analysis from the data collected as well as guiding the collection of further data to check these analysis. Memo writing also functioned as an audit trail which enabled the researcher track the analytic process. Charmaz (2006) tells us that memos form the core of grounded theory because they capture the researcher's thoughts and how ideas and insights emerged (see Appendix G). Memos were captured in hand-written format and were also included in a separate column of the WORD document during transcription of interviews.

A notebook was used to record field notes and the researcher's personal response to interviews as well as any key ideas that arose. The recordings in this notebook thereby facilitated reflection on not only what was said at interview, but also on context and meaning. Field notes were integrated into the data by way of guiding the analytic process and steering the researcher in certain directions in order to explore whether hunches and observations could be sufficiently fleshed out to inform category development. In addition, written and diagrammatic representation of thought processes in developing themes and categories were represented in an A3 sketch pad.

During the transcription phase of the study the researcher was therefore able to conduct open coding and begin to identify themes, concepts, experiences, and ideas, to explore further at subsequent interviews. Thus, through the process of integrating transcripts, memos, and field notes, themes and patterns emerged that could then be followed up in a more focussed way in subsequent interviews enabling the constant comparative method central to grounded theory.

6.13 Data analysis

Analysis of the collected data (transcripts, memos, and field notes) involved a process of coding, developing categories, and an ongoing comparison and regrouping of these categories to explore the meaning of ageing for this group. Microsoft Office Word (2007) (MS Word) was used to manage the data. Other software tools were explored as possible mechanisms for managing the data. More specifically the researcher attended a workshop at the University of Limerick on the use of INVIVO software. The decision to use MS Word was ultimately determined by a strong preference of the researcher to remain in full control of all manipulation of the data. The researcher wished to only move data manually and to always preserve the original transcript so that an audit trail was facilitated and data could always be traced back to its original source. The researcher acknowledges that the decision was primarily based on trust in the software and her own comfort and familiarity with MS Word. The rationale for using MS Word was that it enabled the researcher to engage intimately with the data and over a long period of time. Although this was labour and time intensive, overall this was considered a strength given the phenomenon under study. All manipulation of data could only happen with the researcher's full control and this was regarded as a strength in managing the data.

Coding is the pivotal link between collecting data and developing an emergent theory to explain these data (Charmaz, 2006, p.46). Therefore data analysis involved the three steps of open coding, axial coding, and selective coding. Bryman (2008) explains that while *open coding* is the process of breaking down data in order to yield concepts which are later grouped into categories, *axial coding* brings data back together in new ways by making connections between categories. *Selective coding* is the procedure of selecting the core category, the focus around which all other categories are integrated. While the three types of coding reflect different levels of coding, not all grounded theorists use a three-fold approach. Charmaz (2004) prefers to distinguish between two forms of coding phases; initial open coding, and focused or selective coding. Whichever approach is used, it is essential to remain open to generating as many ideas as required in order to encapsulate the data at the early coding stage. Thus the researcher must remain open to the data throughout and resist any temptation to force it in the pursuit of theory. Bryman (2008) explains that axial coding is sometimes criticised for closing off the exploratory and open-ended character of coding in qualitative research too hastily. As such the data analysis is explained below in terms of a threefold distinction for ease of description, but in practice the researcher was engaged in a process of ongoing examination, comparison, conceptualization, grouping and re-grouping of data throughout the project; and re-visiting and re-categorization, even at the latest stages of the project.

Corbin and Strauss (2008) underscore the importance of the early data in guiding the collection of subsequent data and therefore, following the iterative nature of grounded theory, the researcher moved back and forth between data collection, data analysis, and development of theory. This approach also facilitated the examination of outlier cases as an exploration of variation could take place by introducing questions pertaining to this variation into subsequent interviews. As such, coding was not a linear process. Through the ongoing scrutiny of the transcripts, memos and field notes, the researcher periodically revisited established topics with fresh inquisitiveness, and occasionally returned to interviewees for further inquiry.

Open coding

This entailed reading through the data several times and creating tentative labels that can begin to provide explanation of what is happening in the data (see Appendix H). Open coding

from an early stage informed the direction of subsequent interviews in relation to areas to be followed up, as well as identifying areas where little of relevance was emerging. While engaging in early coding the researcher selected what was deemed to be the most useful labels to begin the process of thematic development and these were subsequently tested against further data as interviews were being transcribed. Early themes and categories were identified, explored further, refined, or in some cases, set aside, as analysis progressed. An identifier was assigned to each piece of text coded in order to be able to track back to the original source. For example, the identifier JB6 indicated a person's initials and where the original transcript on that person's interview is held; i.e. *Joe Bloggs -Volume 6*. An electronic file was created and each page on MS Word utilised 4 columns: Identifier; Text; Memo; Label/Code. This process generated an extensive list of codes that had to be separated, sorted, and synthesized, in order to form categories and progress to a higher level of conceptual abstraction.

Axial coding

This consisted of identifying relationships among categories and grouping them thus (see Appendix I). The initial categories were further refined and organised into coherent themes in an effort to summarise and give meaning to the text. The first broad theme identified was *Low Expectations* and assigned the number 1. All categories identified at open coding stage that were deemed to fit with this broad theme were assigned a number prefixed with 1. , i.e. 11, 12, 13. Broad theme 2 was *No Blaming* and categories were assigned numbers prefixed with 2. , i.e. 21, 22, 23. Assigning numerical codes in this way facilitated sorting of data in MS Word later. As such each MS Word page was extended to five columns: Identifier; Text; Memo; Category; Numerical code. All data were examined in order to carry out axial coding and assign numerical codes. Using an iterative process the themes, categories and sub-categories evolved as the researcher worked through the data. The researcher continued to engage with the data to reflect all the nuances within it until no new themes, categories, or sub-categories could be identified.

Selective coding consisted of firming up the core themes to accurately reflect all of the data (see Appendix J). This was done by re-reading the transcripts and selectively coding data that relates to the core themes identified. This process was a difficult one as selective coding involves the selection of core themes and correlating all other categories or sub- themes to

them. Over the duration of the study the researcher came to see data differently. Corbin and Strauss (2008) acknowledge that new insights can develop through to the final stages of the study. Through prolonged immersion in the data the researcher began to apprehend meaning in different ways and understanding grew. At the end of the process a number of broad themes, categories, and sub-categories were established which formed a framework for explanation of the data. All coded categories under each of the broad themes were grouped in MS Word using the numerical sort function. While the researcher attempted to create separate and discrete categories it sometimes happened that sections of text could apply to more than one category/sub-category. In this event a decision was made to place the text in the most appropriate category while a manual note was recorded for cross indexation purposes. This method was used in order to ring-fence the data and make it more manageable. Further re-conceptualization and synthesization of the data continued over a long period with theoretical possibilities emerging and losing importance as the theoretical framework was developed. The journey from early coding to theoretical insight was therefore a long and arduous one. In the final year of the project, and following a viva voce examination at the University of Limerick, data was further analysed and themes and categories were refined resulting in a better understanding of the data in the final presentation. Two of the original themes were understood differently and subsequently combined and renamed leading to a more comprehensive and transparent presentation of findings.

Reflexivity: a key component in data analysis

Reflexivity can be understood as the ‘disciplined self-reflection’ (Wilkinson 1988) which is integral to the constructivist method of grounded theory. Reflexivity is only an awareness of self-reflection, but an active engagement in the process. Reflexivity and memo writing together provided clarity around the decisions of the researcher as data analysis progressed. In particular short memos captured in a ‘note to self’ style, later acted as prompts for prolonged reflexive experiences. For example:

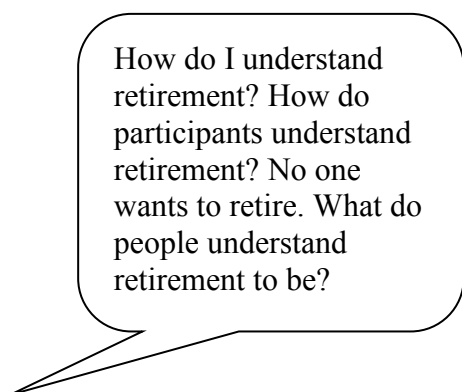
Short memo 1/3/13

Planning is crucial to how I manage my day/week/life. But, why would you plan if your experience has been repeat disappointed. Isn't 'not planning' a protective strategy then? – a way of coping? How would I cope with not planning?

However, reflexivity in constructivist grounded theory goes beyond memo-writing to permeate all of the data collection and analysis, and indeed the project as a whole. Finlay (1998) states that being reflexive requires constant reflection, interrogation, and evaluation of the research in order to understand the influence of subjectivity on data collection and analysis. The researcher fully utilised the process by constant self-dialogue and ensuring that there was always a way of capturing reflexive experiences as they happened (audio or written). Over time, it became possible to link decision-making to reflexive periods. The following are snapshots of ideas that led to reflexive experiences, and in turn, influenced decision-making:

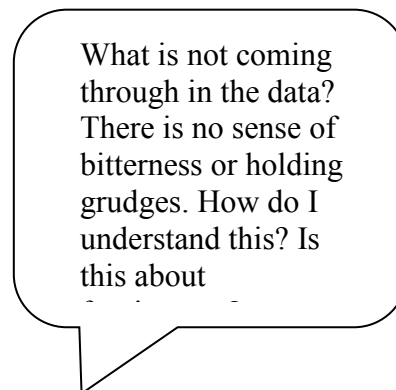
Reflexivity and self-dialogue:

27/2/2013



How do I understand retirement? How do participants understand retirement? No one wants to retire. What do people understand retirement to be?

28/3/2013



What is not coming through in the data? There is no sense of bitterness or holding grudges. How do I understand this? Is this about

Etherington (2004) asserts that reflexivity can lead to rigour in qualitative research as the researcher acknowledges and reflects on how his or her own context and experience inform the inquiry. This kind of self awareness is therefore key to establishing the integrity and authenticity of the research project as the researcher is held to account by naming from the outset, and as the study progresses, how thoughts, feelings, values, and personal history, inform and influence the study. Much about the author's dual role, qualifications, and personal history has already been discussed and made transparent, but a key area of reflexivity for the author was closeness in age with the participants and a resulting empathy and sense of closeness to the phenomenon under study and the study population. This is regarded as neither a positive nor a negative aspect of the study but rather helps to illustrate an area that warranted self-reflection so that any affirmative aspects of the empathic

relationship could remain a positive and safeguard against any adverse impacts in the dialogue, transcription, or representation of the work.

Theoretical sampling:

To reinforce the credibility of the data and support the integrity of the study a mechanism called theoretical sampling was used. Charmaz and Bryant (2011, p.304) explain that a major strength, and largely untapped potential of grounded theory, resides in theoretical sampling. Researchers use this form of later sampling to check and fill out the properties of their tentative categories and thereby increase the depth and precision of categories and overall credibility in the data. Charmaz (2006) states that while few grounded theorists use theoretical sampling in a systematic way such a strategy can help researchers to render their work distinctive and theoretically sophisticated and thus increase its credibility. As many participants agreed to further interviews should be considered useful, the mechanism for theoretical sampling was assured and utilized to good effect (see Appendix K). In applying theoretical sampling the researcher checked back with participants from time to time as data analysis progressed in order to establish that meaning was correctly understood, or to clarify meaning if the researcher was not sure. The process often led to areas of initial interest becoming less important when new information was applied. For example, the idea that a keen interest in soap opera families may be related to a need for a replacement family was discarded as new information indicated this phenomenon was a result of a restricted range of leisure opportunities. Charmaz (2006, p. 102) explains that theoretical sampling involves starting with data, then constructing tentative ideas about the data, and finally examining these ideas through further empirical inquiry. As such theoretical sampling is strategic but also systematic and ultimately leads to elaboration and refinement of theoretical categories.

6.14 Reporting Results

Findings of the study are presented in the form of an academic thesis to the University of Limerick, Ireland. The findings will also inform a strategic plan to be developed at the study site in relation to supporting ageing 2016-2020. The strategic plan will be made available to those using the service, their staff, and their families.

The findings of the study will also be presented in a more accessible format for people with intellectual disabilities and communication difficulties, using appropriate language,

formatting, font size and style, and symbols/ illustrations to supplement written information. A video/audio version of the report based on the accessible written format will also be developed.

It is anticipated that the findings will also be disseminated to the broader community of intellectual disability services through journal publications and conference presentations. Early findings were presented at the Psychological Society of Ireland Annual Conference 2015, in Galway, Ireland. A poster presentation of the study was shown at the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) conference in Belfast, Northern Ireland, in June 2017.

6.15 Enhancing credibility and ensuring validity of the research study

Polit and Beck (2004 p. 430) state that the criteria currently considered the gold standard for qualitative researchers are those out-lined by Lincoln and Guba (1985) and that credibility is viewed by these researchers as the overriding goal of qualitative research. Lincoln and Guba suggest a variety of techniques for improving and documenting the credibility of qualitative research including, prolonged engagement, peer debriefing, triangulation, member-checking, searching for disconfirming evidence, and researcher credibility. The following points demonstrate how factors contributing to analytic rigour were applied to the research study.

Peer-debriefing:

External validation was utilised to offset any potential bias in relation to how interviews were conducted and data analysed. Peer debriefing requires the researcher to work with peers who hold impartial views on the study. Three separate independent reviewers, experienced in the method of inquiry and the phenomenon under study, read transcripts of sample interviews and applied open codes in order to extract initial understanding of the data. Two reviewers were from outside the service. Following this, they reviewed the researcher's analysis of findings and the questions and techniques used, for the purpose of comparison. Feedback was provided to the researcher by way of face-to-face meetings as well as the return of transcripts with feedback annotations. This feedback was integrated into the methodology and guided ongoing data analysis. This process was particularly valuable at the early stages of data management when data analysis seemed to be showing a weighting towards a positive experience of ageing, which the researcher had not expected. However, analysis by peers in

relation to these transcripts supported the researcher's findings and provided re-assurance around utilising the inductive process for further data collection. Peer-debriefing continued throughout the data analysis stage of the study.

Triangulation:

Themes and ideas drawn from the data were tendered by the researcher for consideration by the project supervisor. The utilisation of peer debriefing, combined with supervision from the lead investigator enabled the process of triangulation to verify the authenticity of the findings being reported.

Member checking:

In vivo member checking was carried out routinely through the data collection stage of the study with the researcher checking at opportune times throughout interviews that she had understood the person correctly. This was done by summing up or repeating back and asking the question "Is this what you are telling me"? This was a very fruitful way of working as not only did it provide the researcher with confirmation that data was being correctly understood but it allowed the interviewee to know that he or she had been heard. Playing back of interviews to interviewees provided a further opportunity to confirm proper understanding of the communication.

Prolonged engagement:

The researcher began engaging with participants prior to the data collection phase of the study for the purposes of rapport building, getting to know individual vocabularies, and evaluating communication support needs. This engagement phase took place over a 6 month period. The data collection phase happened over a prolonged period with interviews conducted for 18 months, and theoretical sampling continuing for a further 12 months. In total, engagement with the participants continued for a 3 year period, providing the investigator with an extended period of time to engage with the data and the participants as well as opportunity to check confirming and disconfirming evidence as data analysis proceeded.

Credibility of the data was further assured as the researcher underwent intensive engagement with the data through repeatedly listening to audio recordings, writing up of interview

transcripts, reading and re-reading of interview transcripts, and writing up all versions of the data as the analysis progressed through the coding stages. As coding and identification of themes and patterns was carried out with little supporting software, engagement with the data continued over a prolonged period of time. For example, five different coding documents existed of each interview, demonstrating the intense commitment to the task of developing theory from the data.

Searching for disconfirming evidence:

The search for disconfirming evidence was facilitated through processes already described such as prolonged engagement, peer debriefings, theoretical sampling, and an ongoing comparative method.

Researcher credibility:

The researcher's qualifications and experience are important in establishing confidence in the data. It is of note that the researcher has many years experience in working with adults with intellectual disability, is a member of a relevant professional body and bound by a code of ethics which includes ethical considerations pertinent to conducting research.

Respect:

In addition to the above measures the investigator sought to enhance credibility and validity by continually endeavouring to respect the authenticity of the interview data. A key part of analysis was to afford due respect to the individuals participating in the study, and therefore to the authenticity of what was said at interview. In other words, the researcher sought at all times to trust the data. Charmaz offers excellent guidance in this area:

Try to avoid assuming that respondents, for example, repress or deny significant 'facts' about their lives. Instead, look for how they understand their situations before you judge their attitudes and actions through your own assumptions. Seeing the world through their eyes and understanding the logic of their experience brings you fresh insights.

(Charmaz 2006, p. 54)

This proved to be sound guidance as early in the data analysis process the researcher identified a tendency towards doing exactly what Charmaz had cautioned against; that is, trying to go deeper into the data and analyze it through a clinician's lens. This provided an opportunity for reflexivity at an early stage of data management in order to enhance the quality of the analytic process. Early insight and corrective action avoided the risk of the

researcher undermining the authenticity of the communication by trying to find alternative meaning. As such, respect was afforded to the meaning individuals applied to their lives and experiences, albeit from an interpretative perspective.

6.16 Summary of study design

- This is an exploratory cross-sectional study to develop an explanation of ageing in an intellectual disability population. The setting is a community-based voluntary organization for adults with an intellectual disability in South West Ireland.
- The objective of the study is to establish participants' understanding of old age, experiences of age-related change, and their views on the personal impact of age-related change and hopes, and expectations for the future.
- The aim of the study is to develop an explanation of what ageing implies for those with lifelong intellectual disability, through in-depth consultation around the psychosocial aspects of their lives.
- The study uses a qualitative approach with a non-experimental, exploratory design. It represents formative research with the aim of informing future service development.
- The study employs an interview method that encourages the elicitation of personal views and opinions in areas important to each individual. Through in-depth face-to-face semi-structured interviews the researcher collected data from people with varying levels of intellectual disability who are ageing. Fifty five interviews were conducted in total with forty six individuals. An interview schedule was developed that set out the broad topics to be explored. The purpose of the interview schedule was to generate and guide discussion but it was used flexibly and participants were encouraged to raise issues that are important to them, including their hopes and expectations for the future. Questions were open-ended and followed up with probes as necessary. This format enabled the phrasing of initial and follow-up questions to be adapted by the interviewer and ensured that participants had the opportunity to express their understanding and experience of ageing and their future aspirations in their own way. Interviews were conducted in line with a protocol designed specifically for the study (see Appendix F).

- Individual communication support needs were determined in advance of interviews and a *total communication* approach (the use of all possible ways to communicate) was adopted to optimise the quantity and quality of data collected.
- The study is part of a broad approach taken by the service provider at the study site to improve goodness of fit between supports provided to people ageing in the service and individual support needs.
- Data analysis draws on the principles of Constructivist Grounded Theory Method (Charmaz, 2006) and follows an inductive process, using constant comparative method. Reflexivity and memo writing are key components of data analysis.
- Credibility and validity of the study is assured through use of mechanisms such as peer debriefing, triangulation, member checking, prolonged engagement, and searching for disconfirming evidence.

6.17 Going forward

Participants of the study are expected to benefit from its findings by means of service developments in relation to ageing that are based on the information they provided. This outcome will affect all those using the service, going beyond those who actually participated in the study, and including those who declined to participate thereby generalising the benefit to the full population using the service.

As it is planned to disseminate findings of the research to the broader community of disability services it is hoped that other service providers may use the information to benefit their own population, thereby generalising the effects of the study to even greater numbers.

6.18 Conclusion

This chapter outlines the lengthy and mindful research deliberations pertaining to the study design, choice of methodology, ‘ethics as process’ and the researcher’s position in relation to the study. In particular, the importance of choosing a methodology which is a good fit with the values of the study is highlighted. A core value of the study is that the meaning participants attach to their lives and their experiences as they age is central to the inquiry. The methodological approach chosen for the study facilitates this and ensures that participants’ voices are heard in the presentation of findings. The following chapter outlines those findings and provides a thematic understanding of the psychosocial world of men and women ageing with lifelong intellectual disability.

Chapter Seven– Presentation of Findings

7.1 Overview

This chapter provides an analysis of the collected data. It illustrates the development of key themes, sub-themes and associated categories in the exploration of psychosocial aspects of participants' lives. The findings are drawn from the researcher's interpretation of all collected data. The chapter aims to develop insight on ageing with lifelong intellectual disability and therefore begins with a diagrammatic framework of the psychosocial world of this older age population based on the findings:

Diagram 4:

THE PSYCHOSOCIAL WORLD OF THE OLDER PERSON WITH LIFELONG INTELLECTUAL DISABILITY (thematic analysis)



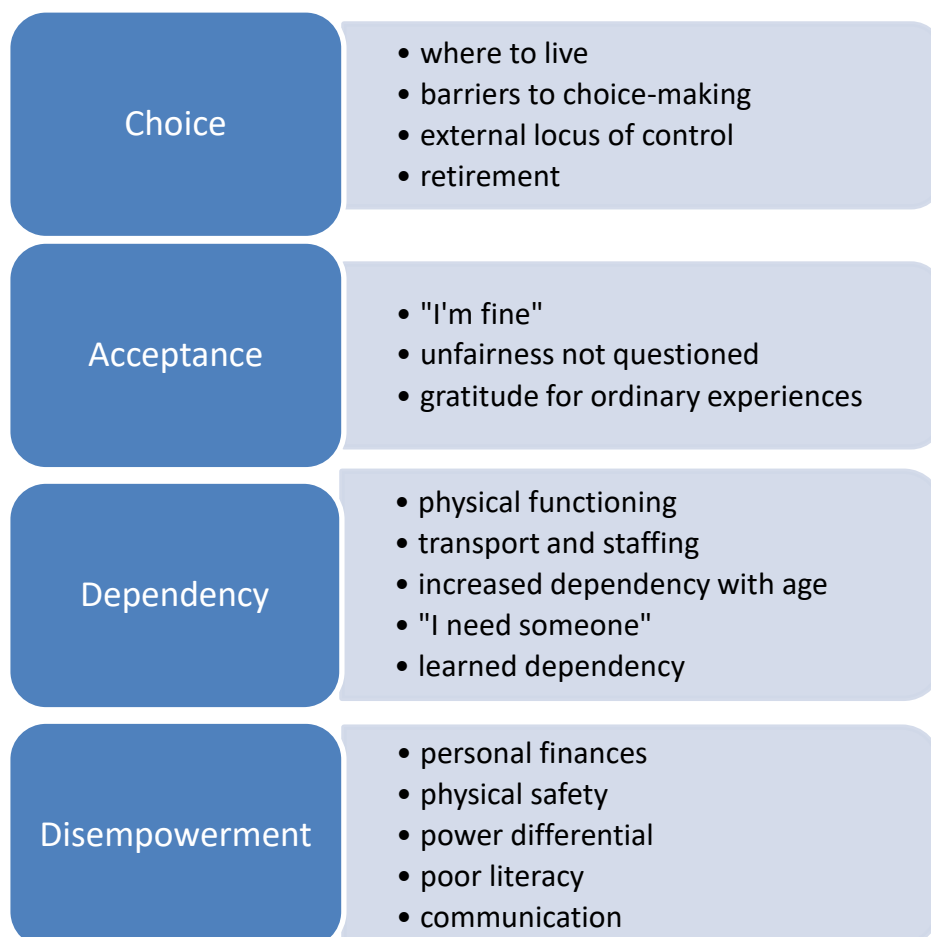
The diagram shows the broad thematic areas emerging from the findings as well as associated sub-themes. Each psychosocial area is discussed in the following sections of the chapter in

order to further elucidate the thematic analysis. The chapter concludes with a summary of key findings which provide the foundation for development of theory.

7.2 Self Determination

Due to lifelong experience of choice limitation, dependency on others, disempowerment, and difference, the participants' accounts of ageing portrayed both poor opportunity and often poor ability to enact self-determination. Areas addressed by participants were categorised as follows:

Diagram 5: Self Determination



7.2.1 Choice

The findings show that this group of people have little or no choice in relation to **where to live** and that this has been a feature of life throughout their lives. Many participants reported being placed in residential care from three to four years of age, and only going home to family at holiday times and for occasional weekends. This pattern has continued for many, leading to multiple placements and fragmented lives. When asked about decision-making around where they were to live participants reported that *'they'* said I was to go. Consultation with individuals themselves about where to live was absent for the most part and many participants said that if they had been given a choice they would have wished to remain in the family home. Participants sometimes exhibited strong emotion about being placed in residential settings:

P1. *Who put Mary (herself) in (residential care)?*

R. *Are you saying you didn't want to be there?*

P1. (Shouts) *Not that place* (appears upset)

The family home and communities of origin are held very dear by most participants. Even individuals who had not lived in their original home for forty or fifty years still related to it as home and indicated that they would like to live there again if given a choice. One participant's words highlight this and stand out because of the poignancy of what followed. His interview happened on the day the day-centre was closing for summer break and he was staying on in the residential house:

R. *How are you today?*

P2. *Home.*

R. *You want to go home?*

P2. *Home, home.* (distressed)

R. *When you were younger did you always go home for the holidays?*

P2. (nods to indicate 'yes')

This man died unexpectedly a few months after this interview. He had lived in residential care throughout his entire life, having attended a residential school as a child and been moved to a group home in the community at the age of twenty. He remained in the same group home

until he died there at age fifty eight. Yet the family home in his community of origin was where he wished to be, right through to end of life.

For those that continued to live at home into adulthood, critical life events, usually the death of a parent, led to unwanted change over which participants indicated that they had no choice. This change generally involved a move away from communities and into residential houses, a long way from family, friends and neighbours:

R. *What happened after Mom died?*

P3. *I had to make a lot of changes in about 24 hours or 48 hours.*

This individual said that she never thought she would “*end up*” in residential care, but she is lucky to have it. This sense of gratitude, or at least being ‘glad to have it’, was common to all participants in relation to where they live, even though most did not choose their current home. A few people were able to express what they would have liked to see happen in relation to where to live following the death of a main carer:

P4. *If I had anyone to come in to get me up in the morning and help me to go to bed at night, I don't think, if I had a choice at the time, I don't think that I'd ever go there. (group home)*

This woman said that while she is glad to have somewhere to live she would have preferred to have been supported to remain in her own home. This view was echoed by four other participants who found that they were not given the choice of home support, and in some cases, the reason given for this was that the family home was being sold.

Some participants indicated that home for them is being with family as opposed to any particular house or location and many said they would like to live with a sibling if given a choice. Those that were already living with a sibling indicated that they are happy with this. While the vast majority of participants indicated that they are happy with their living arrangements very few living in group homes said that they chose this or would choose it if given options. Two people said they would like a home of their own and hoped that this would happen in the future. However, a number of others said they would be lonely living in a home of their own. Participants mainly painted a picture of fragmented lives with numerous unwanted residential moves. One woman spoke of being in four separate institutions as an adult, three of which were very controlling environments with little stimulation and low exposure to pleasurable activities. She stated she never wanted to be in any of those places

but that she was given no choice. When asked why she thought no one had asked her where she wanted to live she replied it was because “*they thought I was mental handicap*”.

There were also instances where people moved (as adults) to Ireland from abroad and were not consulted about the move. Invariably it was other family members that wished to move and the person was left with no other choice. When asked about who made the decision participants responded with comments such as, “*You see, my Mum wanted to come here*”.

One woman was asked how she felt about the family’s decision to move to Ireland:

P4. *Why, didn’t they ask me, ask me properly. Why didn’t they ask me?*

R. *So do you feel that you weren’t consulted about it?*

P4. *I felt, no, I wasn’t given the chance to say go or not.*

When the same woman was asked how she felt generally about not having choice in relation to where she lives she explained:

P4. *I’ve been used to that since I was a very small baby. I’m used to things like that happening.*

It seems she now has little expectation that she will ever be consulted on important matters in her own life.

For many participants **barriers to choice-making** throughout life was evident and this issue was alluded to by one woman:

R. *Do you think that you had restricted choices in your life because of your disability?*

P4. *Definitely.*

R. *Tell me more about this.*

P4. *Well, I wanted to do other things that I was never able to do before. I wanted to do lots of things but through my disability I felt that I couldn’t do it. So...*

R. *Do you think other people stopped you doing it?*

P4. *Not other people, but I couldn’t go places that I really wanted to go.*

R. *Like what?*

P4. *Well my dream....my dream really was....that if I could, I’d really love to go to....but that’s only a dream....I’d love to go to New York.*

R. *Do you think that will happen for you?*

P4. *Ammm.....I don't think so.*

There was some evidence that as people are getting older family members are making more decisions for them, pointing to a double stigma in relation to perceived capacity to make choices, in other words intellectual disability plus ageing. One woman was quite annoyed that her sisters are interfering more in her life now since they have raised their own families and, as she saw it, they now have more time on their hands. Another man also feels he had more independence when he was younger, but that his brothers are controlling his life now that he is getting older.

Many comments indicated that participants feel that the **locus of control** around choice-making is often outside themselves. For example, when asked if it was his own choice to have all his teeth extracted, one man replied, '*they* took them all out'. Similarly, in relation to whether the person wished to take up a day placement, he explained, '*they* told me to go there' and '*they* decided that I could go to respite once every second week'. One woman who lives in a nursing home was asked if she would like to be involved in more activities. She replied:

P5. *Ah, I would, but they wouldn't allow you there, sure.*

In relation to day services a number of participants indicated that they would not choose to attend but that a family member, community nurse, or GP had "*told*" them to. One man said that given a choice he would stay at home and listen to Abba all day but that his brother "*makes*" him go to the day centre. However, the vast majority of participants indicated that they enjoy the day service, usually because of the social aspect of it.

The concept of **retirement** seemed unfamiliar to many participants. When the subject was introduced by the researcher one participant asking "*what's that?*", and another asked "*what would that be now?*" Once the concept of retirement was explained, the idea of having choice around whether or not to go out to a workshop each morning seemed very attractive to a number of participants.

Most participants indicated that they can make day to day choices in relation to what to eat, what to wear, and their recreational activities. However, further exploration revealed that choice was limited and dependent on such considerations as staffing levels, pre-agreed

programmes, and pre-agreed menus. One source of disappointment for people was not having choice around attending certain events or activities which are important to them, such as, attending weekly mass. The reason this choice is not available, according to participants, is that there is no one to provide transport or to accompany them.

7.2.2 Acceptance

It is clear that over time many study participants came to accept that they are different from siblings and same age peers in the community. Although at interview they gave accounts of segregation, inequality, and oppression, no one questioned the fairness of their treatment through their formative year into adulthood, and now into older age. The phrases, “*I’m fine*”, “*I’m grand*”, “*I’m ok*“, are heavily repeated throughout the interviews. When asked directly if the person would like more for themselves or whether they wished anything to be different, the usual response was, “*I’m alright*”. While some participants reported that they had attended their local primary schools with their sisters and brothers, most reported being segregated in special schools. At school leaving age a number of participants gave accounts of being placed in institutional care. **Unfairness** was not mentioned by any participant. Two accounts of poor treatment stand out particularly because of the way participants reported them as being a normal part of life.

R. *Did you play football with (local team)?*

P6. *Yeah, yeah, yeah. I scored a goal and a point against (local rivals).....The point went just over the cross bar.....they were only laughing at me. They were only laughing at me. They usen’t put me on the team at all. They said I was no good.*

This man was seventeen the day he scored for his local team and while he told of how people laughed at him he appeared to accept that this was no more than what he had come to expect given his life experience at the time. Another participant gave the following example to describe how “good” the neighbours were to her:

P5. *Always at Christmas MB give me a good piece of turkey after their own dinner that’d be left over.*

R. *So she’d give you a bit of turkey. That was your Christmas dinner was it?*

P5. *That was my Christmas dinner. (said in an appreciative tone)*

Again this woman reported this in a way that indicated she was **grateful** for the ‘bit of turkey’ and did not appear to think that she might have been treated more kindly on Christmas Day. Such examples were common across interviews and pointed to poor skills, poor support, and poor opportunity, to enact self-determination and a growing acceptance as years advanced that nothing was likely to change. This, in turn, appeared to result in lowered expectations of life and exaggerated gratitude for ordinary experiences. One 71 year old woman had this to say:

P7. *I suppose when you be getting old you kind of feel it and things like that. Still, I’m able to go around. I often said.....if you get up in the morning, dress yourself, and come down and have your breakfast, that’s a big thing. If you were inside in bed for good, and couldn’t get up, that’d be a lot worse.*

7.2.3 Dependency

Examples of dependency and self-sufficiency were reported on a continuum ranging from relatively high dependency throughout life to some valiant individual examples of self-sufficiency. Level of **physical functioning** was a significant factor in how much people could do for themselves and deteriorating physical function with age led to greater dependency. Examples of self sufficiency were illustrated in how people talked about managing everyday activities and many participants reported making their own breakfast (usually cereal), tidying their bedrooms, dressing, and shaving and showering. The participants appear to have very clear insights of how much help is needed and areas where they are more independent. One woman was very clear about her needs:

P8. *I make my bed and everything in the morning when I get up.....Getting dressed is the problem.*

Transport was observed to be a major issue for everyone. Only two participants use public transport. All others are dependent on family, neighbours, and service transport. Some use taxis but as the cost was flagged as very prohibitive they are only used occasionally. One participant actually owns a car but is dependent on others to drive it. She explained:

P3. *Somebody else has to drive it and there’s an issue there too, because P. can’t do only every second weekend.*

When asked how she felt about having to depend on others to drive her car she said:

P3. *I feel angry over it because...there are plenty of people out there that could do it, but....I can't approach them because I have no way of getting in touch with them.*

It is evident that this woman feels doubly disempowered due to dependency and poor social networking. In fact, a number of participants have had to give up much loved activities due to lack of suitable or affordable transport. Even when suitable transport is available low **staffing levels** in residential houses and day services often means that people do not get to attend planned events or go on outings. As one person explained:

P10. *They don't have no staff now to go, unfortunately. They have only one staff on, and then you have no cover for the other staff then, like.*

Dependency was found to **increase with age** as health concerns arose such as onset of diabetes, falls, and broken hips. Participants' accounts showed that family members were often no longer able to manage when support needs increased. This meant that those who used to go home regularly were doing so much less often, and this was a source of sadness for people. Sometimes increased dependency led to a move into full time residential care, especially when the main carer was an elderly parent. A number of participants became wheelchair users as the years advanced and as such independence was further compromised because adapted buses and adapted taxis were not always available for outings.

Dependence on others was also evident by repeated comments such as "*if someone can take me*" in relation to so many things people wanted to do or places they wished to go. One man was asked if he could access the community on his own. He said:

P12. *Ahh.....can't do that.*

R. *Why can't you do that?*

P12. *I need someone.*

This statement, "***I need someone***" summarizes what all participants said in terms of their level of dependency/self-sufficiency and no participant reported being completely independent. To a greater or lesser extent every participant reported that they need someone to manage daily life and to access the community. They particularly require help to organize and facilitate a social life.

There were many examples of increased dependency with age but this was not always because of change within the person. Rather, increased dependency occurred over time for some people on moving from home into residential care and there was evidence of people doing much more for themselves while living at home. One such woman, who had done most of the housekeeping while living at home and was well into her fifties when she moved to a residential house, was asked if she still washes her own clothes. She replied:

P7. *Staff do that. That's what they're there for, and I let them do it.*

This type of **learned dependency** was noted in relation to a number of participants with one woman saying she does not retain information, such as her age, in her head, because she can always check with staff if she wants to know. When this was explored with her she revealed that since childhood she had become accustomed to always having to check everything with someone else, and as such a degree of learned helplessness had emerged and prevailed over time.

On the other hand, an intrepid example of enhancing skills of independence was demonstrated by a man who likes to go on pilgrimage but was dependent on someone to accompany him. Having travelled to Lourdes and Medjugorje with relatives a number of times he came to realize that he is competent to find his way around in Medjugorje because the church and the restaurants are close to the hotels. Having gained confidence over time while supported by his family, he now goes to Medjugorje without a family member, and has decided to forego trips to Lourdes. As such, he is no longer dependent on family to accompany him on pilgrimage.

This example is in stark contrast to the woman whose dream it is to go to New York. As she believes she cannot go there on her own, someone else would need to share her dream if it is ever going to come true. At interview the woman revealed that this level of dependency makes her feel that she has no control over her life. However, the other man is supported by his family to fulfil his desire for regular pilgrimage abroad and subsequently was better able to direct a big part of his life. Others also found ways to hold on to a level of self-sufficiency when faced with change. One man arranged to bring a dinner home from his day service each day when he could no longer cook for himself due to ill health. Another woman said that her favourite meal had always been bacon and cabbage. When her mother passed away she still wanted this meal, but while she had no difficulty putting the bacon on to boil she was unable

to cut up the cabbage. She was supported by her brother in solving this problem and they decided to buy pre-packed cut cabbage in the supermarket during the weekly shopping.

When she was asked if she thought older age was a good thing or a bad thing, one woman summed up how most participants feel about dependency and older age. She said:

P4. *Older age is a good thing if you could do the things you really wanted to do...like get out more and not depend on (siblings).....to be able to try to get things done myself.*

A willingness 'to be able to try to get things done myself' was evident across the findings indicating that, despite older age, participants welcome opportunities for greater independence.

7.2.4 Disempowerment

As with other areas of the findings this issue can also be understood in terms of a continuum. There were a small number of examples of participants pushing the boundaries towards empowerment but many more examples of disempowerment in relation to one's own life. Examples of disempowerment were notable from early adulthood and persisted throughout life. The area where disempowerment was most frequently reported was in relation to **personal finances** and no one reported having control over their own money. A number of people said that they could spend their money as they wish but on further exploration it emerged that they were referring to small sums of money given to them by family members, perhaps five euro at a time. Two participants reported winning money prizes. One had won a large sum of money but reported that while he does not know what happened to it, he does know that he did not invest it and he did not spend it.

There were examples of personal money being withheld by others and this prevented the person engaging in an activity. One man said he enjoyed going on respite weekends but an increase in fees meant that his mother will not give him any more of his social welfare money.

R. *I know you were trying to arrange to go into respite....did that happen?*

P14. *My mum gave me seven euro respite money and she put it in a brown envelope. I put it in the white pillar box and.....respite money gone up....to do with the budget.*

R. *So you haven't gone to respite at all. Are you disappointed about that?*

P14. *Just a bit. My Mum put a stop to it.*

However, when asked if money is a problem or a worry for him he says it is not. Another woman spoke of how upset she is that all her siblings have their own post office account but that she does not.

P4. *They own post office books. They got their own private post office books.*

She said that she wanted her own account and her own book for “*money out*” but that her mother said that she would not be able to manage it. This upsets her and she says that she could manage her own money and that she is able to sign her name. However, she does not have bad feelings towards her family and does not blame them for disempowering her in relation to her finances. She says:

P4. *They’re looking out for me, looking out for me, what’s best for me I think.....like they know best.....but, I know. I’m clever enough to know.*
(what is best)

She goes on to say that her family are bringing her down and that although she is a “*woman with special needs*” she has got “*the sense*” to know what she wants to do.

Another participant reported being in a similar situation, with his brother collecting his social welfare payment each week and giving him “*a fiver*” for certain things. He says he has no issue with this. Further discussion however, revealed that because he does not have access to his money, he cannot do many things he enjoys.

P10. *It’s not easy have fivers if you’re stuck for fivers. (brother)....mightn’t give you any fivers if you’re stuck then, you see.*

This participant no longer goes on a regular social outing because his brother will not give him the money from his social welfare. He accepts this saying that his brother “*minds*” the money.

Physical safety was an issue for a number of people and their experiences are very distressing. One account of physical abuse in the community is as follows. The man in question told of his experience in a matter of fact way:

P16. *I was coming up by the sports field one evening. I don't know. He was drunk. Then he started belting me to the legs and everything.*

He rationalized this unprovoked attack by saying the man was drunk. When asked if people had “picked” on him like this growing up he replied:

P16. *They used. Some of them.*

Lack of power in relation to physical safety was also evident when participants spoke of living with people with challenging behaviour. This area will be discussed again later in relation to safety and security, but is also relevant to experiences of disempowerment. Some participants were able to report that they are afraid of another resident. One man spoke of being hit and kicked by a resident and said, “*No happy at all*” about this situation. He said that he has told the staff and when asked if the staff are doing something about it, he replied,

P.18. *No. Me all alone. Me all alone.*

(This situation was subsequently resolved when the resident with challenging behaviour was moved to another house more suited to his increased support needs which had arisen due to onset of dementia).

Another woman, a wheelchair-user, reported being afraid of a man in her residential service. Even though she has her own private apartment she explained:

P3. *One night he was so bad they were going to call the guards.*

She says she fears getting hurt and that “*I might end up somewhere I don't want to end up*”. She is feeling very vulnerable in her apartment and feels powerless to change her situation.

In relation to **power differential** generally, participants regularly talked about who is “*in charge*” in the residential house, in the family home, in relation to their health, etc. Those in charge were generally reported to be a member of staff, a parent, a GP, etc. Even such ordinary experiences such as speaking to a professional about personal issues and concerns were often denied people:

R. *Do you speak yourself? (to GP)*

P8. *My mother talks to the doctor.*

R. *Would you like to speak for yourself?*

P8. *Yeah. (begins to cry)*

There were many such accounts of people being disempowered in relation to their own health and well-being and repeated experiences of other people managing their healthcare seems to have led to an acceptance of this over time.

A few participants talked about not wanting to attend the day service but feeling they did not have the power to withdraw as family members made those decisions.

P4. *My family want me to carry on here. That's the hardest bit.*

This participant says that it makes her feel “*very sad*” that she cannot control her own life and says “*I'm old enough now*”. Another participant gives a similar account of disempowerment and how his family are “*forcing*” him to go to day services.

P20. *Me know in my soul deep down me not want here at all.....Me know B force me to come in.*

This participant said he would like to retire and when asked what he would do if he retired he replied:

P20. *Me go back to bed. That's all.....that's all me want.*

One example of disempowerment that can be attributed to how society was structured in the past was reported as follows:

R. *What age were you when you married?*

P5. *I was only about 22 or something.*

R. *And how did you meet your husband?*

P5. *Well sure, a match that was made for us.*

While this woman did not indicate that she felt she should have had a say in choosing a life partner she did try to manage her situation in the years that followed by taking breaks from her husband.

P5. *I often left him but I used come back again to him.....for a day off like.*

Perhaps this was an example of empowering herself by taking a “day off” every now and again. However, the power structures of the state were more difficult for her to manage and

her four children were taken into care over time. She reports that she does not know why they were taken from her and that she was “*lonesome*” after them. She says that people have told her what to do for her entire life. She says she has had a hard life and when help was provided she did not find it supportive.

P5. *Well, I had a home help, and she wasn't too nice to me.*

It annoyed her that the home help would repeatedly tell her that she would “*end up*” in a nursing home. She now lives in a nursing home and can describe very well the power structure that exists there and how little influence she feels she has on decisions being made that are important to her. She is unhappy with having to share a room with someone who talks all night in her sleep and having to get up at 8 o'clock in the morning while others are allowed to lie in bed until 11 o'clock. She does not see any point in complaining and says that when she complained to a nurse in the past “*God knows she didn't do anything about it*”. She describes some of the nurses as being “*saucy*” and always telling her what to do.

Another area which resulted in disempowerment in the lives of participants is the area of literacy. Poor literacy skills, and in many cases actual illiteracy, accounted for some examples of disempowerment reported.

R. *When you left school, did you read then?*

P16. *No.*

R. *And what about writing?*

P16. *Well, I do, but bad.*

This man reported that his **poor literacy** means he cannot read the newspaper and he does not know what is written about him, even in his Life Story book. He said that staff put the book together and he does not know what it says.

Poor knowledge regarding medication was found to be partly due to poor literacy and was another example of disempowerment. One woman reports that she has suffered lifelong depression. The hardest thing for her she says is getting up in the morning. The researcher asked her about her depression.

R. *Are you on any medication for that?*

P22. *I am, I'd say.*

R. *And does it help?*

P22. *I don't know.*

R. *Do you know what you're on?*

P22. *No.*

This woman has very poor literacy skills which is likely a factor in her not knowing what medication she is taking or why she is taking it. This indicates that she has little power in relation to managing her own health. However, another woman showed how she tries to cope with illiteracy. She spoke of how her inability to read means she has to use other abilities to gain knowledge and information. She says she listens carefully instead. In particular, she listens to the local radio for information about her community.

Finally, it was observed that a core issue in participants' experience of disempowerment is an ongoing struggle with **communication** and insufficient support around this. The issue of familiarity in supporting communication was discussed by a few participants with people indicating that they are better supported to communicate when they are interacting with people that know them well. For example, people preferred to see their own GP rather than a doctor that did not know them. Being understood was observed to require a great deal of focus, energy, and patience, from participants. An example from interviews is as follows. This woman was asked what she would buy if she won the lotto:

P24. *Banana.*

R. *I'm not getting that now.*

P24. *Banana.*

R. *Is there anything else you would buy? (researcher attempting to move on)*

P24. *Banana. (participant persists)*

R. *I'm not getting what that is.*

P24. *Is food.*

R. *It's food, is it?*

P24. *Food. A banana.*

R. *Banana is it?*

P24. *Yes.*

R. *Ah, I got it.*

P24. (laughs and claps)

Extraordinarily she maintained her sense of humour in her attempt to be understood. However, in an everyday situation she may not be given the time to get her meaning across. The effort to communicate and to be understood is a central struggle in peoples' daily lives and this was evident throughout interviews with the researcher not understanding words or sentences and participants remaining calm and persistent. One man attempted to converse about Michael Jackson giving the researcher many clues, such as saying "*He's dead now*" and pointing to a concert T-shirt. The researcher failed to understand the communication at the time and only understood when the interview was played back later.

Strategies that participants were observed to utilize to help the flow of communication were included:

- a. reliance on topics of conversation that were commonly in the media (usually television and radio) such as sport
- b. connecting certain people with certain jobs in order to give clues as to the context of what was being said, i.e. Brian/Chef/Food
- c. listing
- d. using picture cards (Talking Mats)
- e. demonstration, i.e. miming playing the fiddle to indicate a liking for listening to music or rubbing the tips of the fingers together to demonstrate baking a cake.

In fact, the participants were observed to be keen communicators and to use whatever they could to be understood. Photographs in particular proved to be invaluable. For example:

R. *How many sisters have you?*

P26. *I show (gets his photograph album)*

One woman found that picture cards had helped her so much in indicating to the researcher her likes and dislikes, that at the end of the interview she put all her "likes" in a pile, handed them to the researcher, and said "*copy it*". She wanted to have a set of her "like" cards for future use. Thus it was observed that in a controlled situation such as the interview, with ample time available and communication supports such as photographs and Talking Mats at hand, participants were able to communicate effectively. In terms of empowering participants

to make decisions to live lives of their choosing, supporting communication was observed to be a core issue.

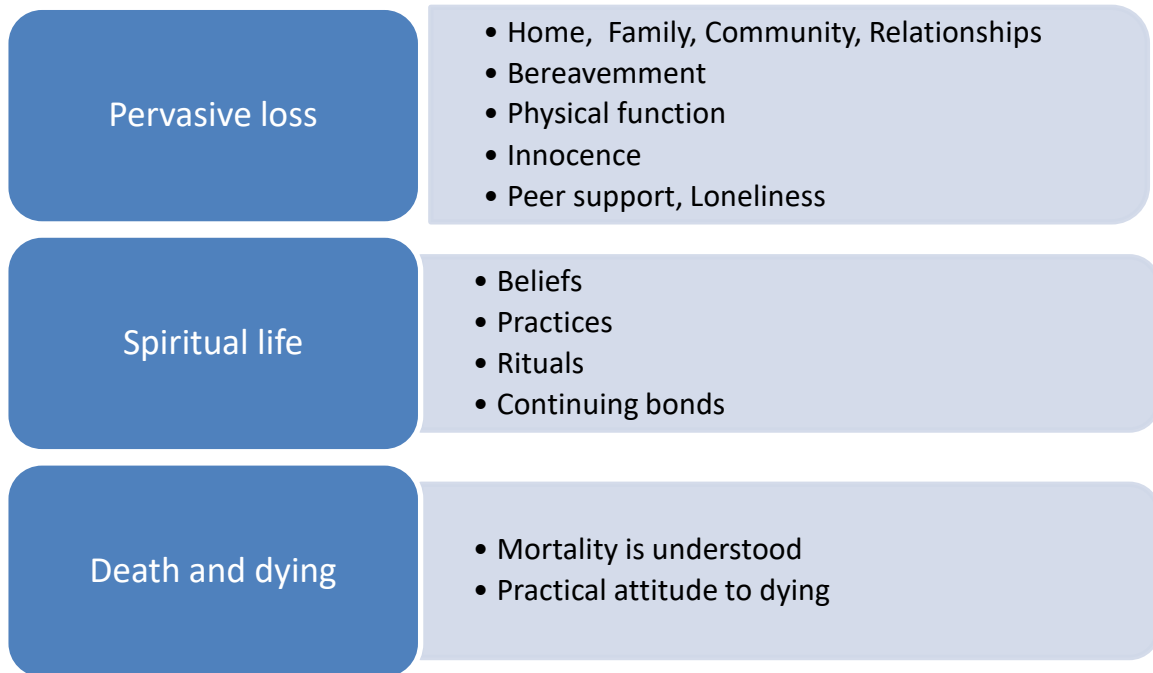
7.2.5 Self Determination: summary of analysis

Ability and opportunity to enact self-determination were found to be severely limited throughout life for participants and this continues as they age, with negative impact on day-to-day living as well as quality and quantity of meaningful experiences. This supports the findings of Chambers *et al.* (2007) and Heller *et al.* (1996) which show that adults with disability are less self-determined than their able-bodied peers. Acquisition of skills around decision-making and planning was found to be poorly supported in family-based and service-based care settings, and for this reason, participants have not lived self-directed lives. However, there were also more hopeful findings with examples of participants making life enhancing decisions once appropriately supported. Also demonstrated by Heller *et al.* (2000) this illustrates that older people with intellectual disability can develop skills in order to become more self-determined, and underscores the value of a support model to facilitate decision-making as people age. While lifelong experience of barriers to choice-making, dependency, and disempowerment, has led to an acceptance of an external locus of control among participants, the findings show that there is willingness and an ability to change, with the right supports. Participants indicated that as they get older they want to make decisions, to be able to engage in activities of their choosing, and to be able to have more control over how to spend their money. The findings reveal that family, community, and services, each have a role in supporting opportunities for autonomy, choice, and personal decision-making, in the lives of older people with intellectual disability.

7.3 Loss and Spirituality

Loss was found to be pervasive in the lives of participant and impacted on all aspects of their existence from a young age. In addition, experiences common to the general population were absent in their lives. For example, just one participant had married and parented children. No one had attended college, drove a car, had a paid job, or owned a home of their own. However, there was very high on-going exposure to loss through bereavement, and the impact of certain losses (usually the death of a parent) was found to be devastating as such key relationships were never replaced. Spiritual beliefs and a spiritual life were found to mitigate stress caused by loss.

Diagram 6: Loss and Spirituality



7.3.1 Pervasive Loss

It is evident that experiences of loss began from a very early age for participants, with some reporting placement in residential schools from school age with the attendant loss of **home**, **family** contact, **community**, and contact with family pets. One woman spoke of her sadness at not being able to attend the local school with her twin sibling, explaining that “*I was a slow learner you see*”. For this reason she attended a residential school two hundred miles from home. For those people who did attend local schools a pattern of frequent change began in early adulthood, with movement to day and residential services. Over time leaving friends and valued staff to move to new placements became the norm. Loss of close **relationships** through co-residents moving to other housing was common and all too often once a person moved, contact was minimal, if indeed it took place at all. The vast majority of participants reported that they had not stayed in touch with people they had known when they were younger, such as school friends or neighbours. In fact, losing touch with people was a lifelong pattern reported by most. Some participants even lost touch with siblings. When asked what difference it made to her life when her sisters emigrated to England one woman simply said:

P28. *I don't know. When I was young they were there.*

She reported that she misses them now. Looking at an old photograph of the family together she observed “*We were happy there*”. This woman experienced a traumatic loss as a result of the death of a close sibling and lifelong companion. Soon afterwards her mother also passed away and she moved into residential care, far from her home community. This is a great source of sadness for her.

The most profound loss for all participants was **bereavement** following the death of one or both parents and many reported that they had never really recovered from the loss of this closest of relationships. One man said of the loss of his father:

P6. *He’s dead twenty-six years and I still miss him.*

One participant opened his interview with the words:

P30. *My mother passed away.*

This was the most significant piece of information he needed to share in order for the researcher to understand his experience of ageing. His Life Story book revealed that when his mother developed mental health problems she was institutionalised and with no one to care for him he was placed with her. He was a teenager at the time. He remained there until his mother died, at which time he was a man in his fifties. Although this man’s interview only lasted five minutes he managed to share his most significant information in that short period of time; namely, that his mother had passed away. Sadly, he too passed away some months after his interview (RIP).

Participant exposure to death and dying was far beyond the typical experience of the general population with frequent loss of close friends (co-residents) and favourite staff. One forty year old man named four people he had lived with over the past few years and a member of staff who had been his key worker that had all died.

The impact of loss following death of a parent is described by this participant.

P7. *Well, when Dad was gone, and Mom was gone, I had no more to do but to come in to (the service).....I had to leave my home. That was it. A hard thing to do. But we had to do it. I’ll get over it...I’m fine now.....leaving my community and my place behind me...where I was reared, like.....but things is worked out very well (appears sad, lowers voice).....I got alright after it, but of*

course, as you know, I was very lonesome after my parents because I was with my parents for a long time.....but these things happen, sure.....I left a lot behind. My neighbours was very good to me – but 'tis nothing I can do with it. I'm here now and I'm happy. I left home and now the family home is gone. Ah, but sure, I couldn't be left alone in the house. No.

This woman stated that she has since lost contact with her neighbours and this is a source of regret for her. She says that the manager in the residential house had told her that she could phone her neighbour any time, but she says there is no point because “*P is stone deaf. She can't hear*”.

One man explained how much he has lost because of the death of his brother. They both lived in the family home and had a full life. They had a dairy farm and both men worked together on the farm by day and often went for a pint to the local pub in the evening. They also enjoyed walking together. Then, without warning, his brother died. In a sad voice he explained that after his brother's death the cows were brought to the mart and sold, the house was locked up, and he himself placed in residential care. When asked if he has returned home since then he said:

P34. *The house is locked. No one there. I look in a window. No key on it. The dog is gone. The dog is dead (long pause, head down)*

Loss of **physical function** and its impact was an issue raised by one woman.

P28. *I could walk when I was young. I can't walk now.*

R. *What was different back then when you were young?*

P28. *I could walk. I'd like to walk again.*

R. *Did things change a lot when you couldn't walk?*

P28. *Yeah.*

R. *And how did that make you feel?*

P28. *Sadder.*

This woman finds it very difficult to come to terms with losses related to her disabilities and says she will never be able to accept the loss of a typical life. She particularly wants to marry and to have a baby. She says she does not think this will ever happen for her now as she is in

her fifties. Another woman also said she experiences her physical disability as a loss of a normal life which a source of great sadness to her:

- P3. *I'd have liked to be born normal so that I could walk on my own and go places that I was never at, but that never materialized.*
- R. *Had you hoped, when you were a child, had you hoped that you would walk some day?*
- P3. *Yeah, I did, yeah.....into my teens, yeah. And then I had my hip done and the surgeon said you might never again get back walking, you might be in a wheelchair....and I didn't want that. He said you might never again walk, so I'm lucky to be as good as I am, I suppose.*

This woman explained that she was only sixteen at the time and that she felt terrible when she first realized that she would be in a wheelchair. She said that “*terrible*” things went through her head like “*what I wouldn't be able to do, worried that I might end up somewhere*”. She seemed to be aware of the impact of double disability in relation to her cognitive impairment and now physical impairment, and claimed that the risk of ending up in residential care is always there because of the “*background of my disability*”. She said this was her greatest fear as she got older.

There were some harrowing accounts also of what might be termed **loss of innocence**.

Participants spoke of being exposed to institutional life at a young age and for some people this also resulted in a loss of large parts of their childhood. One man was able to give a all too clear account of his experience:

- P6. *I was above in the hospital (adult psychiatric facility) long ago, 1967, I gave two months there. Something happened my speech, something happened my speech. I gave two months above before Christmas and into the month of January for two months above.I was only 14 or 15. You're not supposed to go till 16.....because the doctor came....he sent me there.*
- R. *What was that like?*
- P6. *It wasn't too bad. It wasn't too bad. 'Twasn't too good either. They used to give them shock treatment for the patients, and some of the people, when they come out of shock treatment, they be up in the wall there then, craving up in the wall and everything.....I didn't like it at all.*

This was not the end of this man's traumatic experiences in institutional care. He went on to say:

- P6. *I was in Galway in 1968, for six weeks up in Galway. I got homesick and everything.....if you done anything out of the way they put you to bed and everything.....I didn't go there no more cos my Dad wouldn't leave me go back there no more.*

Peer support in relation to grief and loss was in evidence from interviews. When talking of a personal loss a participant was able to accept what was happening better because of a sense of shared experience:

- P36. *Joe's Mom, she's sick as well.*

Due to frequent exposure to loss across participants the sharing of experiences and related emotions was experienced as supportive by participants and perhaps normalized loss experiences in some way. For example one woman has lost contact with all of her family but rather than dwell on this she focuses on the people she is with every day. She says:

- P7. *I have a couple of old people I does things for sometimes.....they look after me and I do it for them. I mind them.*

Loneliness was reported generally in relation to missing a loved one or missing the family home and community of origin. However one participant talked about the loneliness that comes just from being alone.

- P10. *I'd like to meet other people that I don't normally meet.....maybe go for coffee or something. Maybe would be alright. I could meet people for coffee and might have a chat or something.*

- R. *What kind of people would you like to meet?*

- P10. *I don't mind whose there anyway once I knew who it was. Someone is there, I can chat away. Whether it's a man or a woman.....any kind. It doesn't make a difference who I meet anyway. Once you get to know someone, they get to know you, and if you said your name is Pat, and they said their name was Mary. or what name comes up anyway...I like company.*

He went on to say that he prefers to be with people than to be on his own and that he often feels lonely at home.

7.3.2 Spiritual life

Whether through **beliefs** and **practices, rituals** or behaviours demonstrating a **continuation of bonds** with deceased loved ones or attitudes to death and dying, participants generally portrayed themselves as spiritual and as leading spiritual lives. In many cases it was observed

that a spiritual life and specifically, belief in an afterlife mitigated the potential stress of loss. This was most evident in relation to loss due to death of a parent or sibling. Some participants were invested in belief systems which included attending Mass and devotion to the Virgin Mary. A number of participants were saddened by the fact that they could not attend Mass as frequently as they would like and this was invariably because of having to depend on others for transport and someone to accompany them. There was a common belief among participants who had lost close relatives that their loved ones are in “*heaven*” and that heaven is a place somewhere in the sky.

P38. *Michael gone up to the sky. Gone to heaven. A nice happy place and cake. There's cake and all. I miss him.*

The belief that loved ones are in heaven was experienced positively by participants and many said that they pray to their loved ones regularly. Most also said that they believe their loved ones can hear their prayers and this was experienced as a source comfort. Visiting graves of deceased loved ones was generally experienced as comforting as well, although some people said they prefer to go to church to light candles to remember loved ones rather than visiting the grave.

Continuing bonds with deceased loved ones was reported to occur by celebrating yearly anniversary masses, bringing flowers to graves, lighting candles in church, and praying. Continuing bonds was also evident in reminiscences offered by participants, such as, remembering how a mother made currant bread and how currant bread is now a favourite food of the person. Such memories brought joy to participants, and even laughter. Some participants talked about continuing an interest or an activity important to a deceased relative after they had passed away and how this now brings them joy. One participant declared that he had been an Arsenal FC supporter but his friend who had passed away supported Liverpool FC. He recalled that on the day his friend left home for the last time, he accompanied him to the ambulance bringing a CD player with him and played “*You'll Never Walk Alone*” (Liverpool FC anthem) for him as they said their final goodbyes. His friend died a few days later and ever since then, this man is supporting Liverpool FC in order to remember him. Another participant had a similar story and explained that he now supports his deceased friend's favourite football club in order to keep his memory alive. A further participant is keeping up the charity work that her father was involved in and she says she is

doing this for her Dad. She reports that this helps her cope with his loss and to remember her father fondly. She says that her father is helping her now:

P4. *Now he's helping me. I got free time to raise money for different charities. I got that from Dad really.....because he loved raising money and things like that.... (I'm) taking over from him. I'm doing his job. Feel I'm taking over from him doing that.*

Another woman explained that she carries memories of her mother with her all the time and talks to her every day:

P40. *She's always in my dreams..... I tells her, 'I love you, Mam'. She says, 'I love you too, honey'. She's always in my heart.*

Others also reported continuing bonds with deceased parents through dreams:

P10. *The other night I dreamt my mother was talking to me in person....she appeared in front of me.*

R. *What did it feel like?*

P10. *It felt good.*

R. *When you woke up, how did you feel?*

P10. *I felt happy and great. She's probably looking down on us anyway....see how we're doing and how we're coping. She wants us to keep doing what we're always doing.*

R. *Do you feel that's a support for you?*

P10. *Yes, she's around. In fact she's in this room now while we're talking.*

R. *Do you feel that?*

P10. *I do, cos I can feel her.*

R. *And is that a good feeling?*

P. *'Tis.*

Some participants had memoriam cards of deceased parents and carried them with them every day.

7.3.3 Death and dying

An **understanding of mortality** and a foreshortened future due to advancing years was evident but participants were not morbid about death and dying.

R. *Why is it so important to you, this (birthday) party?*

P7. *Because I'll be 70 and I won't be 70 no more. I could be gone for the next one.*

This woman said that even though she feels healthy, she is also aware that any birthday could be her last one and so she must make the most of each one. Participants portrayed a **practicality** about how they understood death and dying. One man named ten people that had died and was asked how he felt about that:

P42. *They went down in ground.*

R. *Were you sad when that happened?*

P42. *They're gone. Said goodbye. No ten boys. Ten boys gone. They're dead. (joins hands to indicate that he prays for them.*

Another man was very forthright in his attitude to dying:

R. *Would you ever worry about dying? Would that worry you?*

P6. *I don't take any notice of it. If you're going to die, you're going to die. You'll die when your day will come.*

Others were equally dismissive of the need to ponder death:

R. *How long would you like to live?*

P44. *I don't really know.*

This woman indicated that she has never thought about death and dying. Another woman who was asked the same question replied:

P5. *If I was 80 (laughs)*

She seemed bemused at the thought of living until she is 80. She is currently 74 but she thought 80 would probably be long enough. Another participant also indicated that he does not engage with thoughts on death:

R. *Do you ever think about dying or death?*

P10. *Not at the moment anyway, no, no. No. We won't worry. We'll stay healthy as long as possible anyway.*

7.4.4 Loss and Spirituality: summary of analysis

The findings show that participant experiences of loss have been lifelong and impact all aspects of life. In addition, transitional shifts in families usually resulted in unwanted change

for participants and further experiences of loss. As such adaptation in advancing years to changing accommodation, changing relationships, and changing health appears to be managed by participants as change and adaptation have been integral to whole-life experience. This management largely takes place through acceptance of loss as a normal part of living, peer support, and belief in a better life after this one. However, some losses, such as not having children and not being able to walk, were found to be very difficult for some individuals and there were indications that such losses will always be experienced as painful. Loneliness was evident from reports of loss of key persons, usually parents, and a poor support system to buffer such losses, such as an absence of spouses, children or grand children. As such, close bonds were not replaced by further close relationships. Perhaps because of this, death and dying in relation to oneself did not seem to be a concern for participants. They did not appear to be strongly attached to this life. No one raised any concerns about dying or what would happen after they are gone. The findings support a view that people with intellectual disability are in some ways better prepared for ageing (Rothman 2003; Jenkins 2010) and that adaptation to ageing can happen seamlessly for participants.

7.4 Social Participation

The findings reveal that participants generally seek to continue lifelong social participation patterns as they age. Patterns of social engagement, relationships, social roles, and community involvement, all influence how participants respond to age-related change and how they experience life. A further significant area in adaptation to ageing was found to be participants' existing self-concept.

Diagram 7: Social Participation.



7.4.1 Social engagement

A universal response by participants is that they love to socialize, be it at weddings, parties, football games, card games, or out for a meal or a drink. Older age or increased support needs were not generally advanced as a reason to withdraw from social engagement or to lead a quiet life, although individuals did report losing confidence around some activities. A family get-together, especially **weddings**, brought people great joy and photographs from these occasions were treasured and shown with pride. The person's own birthday party was probably the next most talked about social event at interview, especially the "big" birthdays where family were more likely to arrange a party and make an effort to attend. **Parties** of all kinds are enjoyed and people particularly look forward to Christmas time when there are plenty of parties.

With the exceptions of special occasions however, it seems that those participants living at home, especially those living with elderly parents, do not go out very much in the evening time or at weekends. Those living in residential houses often go out for a meal or a drink at the weekend although more often this happens during the day time. A few men have a regular night out on a Monday with a local men's club and this has been the custom for twenty years

or more. They have a light meal and a few drinks in a local pub and are home by 10 o'clock. This outing is valued by those who avail of it.

Football matches are also experienced as an opportunity to socialize but people are dependent on relatives to accompany them to games and to provide transport. Some participants have attended games on big occasions such as the All Ireland Football Final, accompanied by either family members or staff. Individual participants also have their own favourite premiership soccer team and some people enjoy going to the pub to watch matches. This only happens if a family member facilitates it. Typically those who follow a team consider themselves to be very loyal supporters.

R. *Who do you support?*

P34. *United. Number 10. Rooney.*

R. *Did you always support United?*

P34. *Yeah.*

R. *Have you the jersey?*

P34. *Yeah. Four. Get more – birthday.*

One woman prides herself on being a loyal Arsenal supporter, saying, "*I'm with them 27 years now*". She talked of her trip to the Emirate Stadium arranged and facilitated by her key worker. This was reported as a significant event in terms of her whole life experiences.

People generally said they like to go out for a drink, with Guinness being the most mentioned preferred drink, while others said they like a glass of wine. Participants also said they like to **dance**. A small number go to a bi-monthly disco arranged by families for people in the service. One woman says she enjoys going to bingo while others like playing radio bingo every week. Another participant said he goes to the community centre to play cards twice a week and he likes the mix of people he meets there, commenting, "*They're from everywhere.*"

Some participants mentioned attending music **concerts** and those that did seem passionate about music. One woman goes to see Sharon Shannon each time she plays locally. Another woman is a Daniel O' Donnell fan and likes to show the photograph she had taken with him (reported by her as "*best thing that ever happened*"). Many participants indicated that they use the day service simply as a means of social engagement and enjoy coming to meet friends

and staff, having a cup of tea and a chat. A few people mentioned going to **Special Olympics** and enjoy competing in various sports, but mostly they seem to use the club as a social outing.

Overall however, the range of activities people engage in remains limited. **Travel** also appears to be confined to organized pilgrimages, visits to the UK to spend time with family or to attend a soccer game, and trips with Special Olympics. Sunshine holidays are very rare. Travel around Ireland is more frequent. One woman reported that she was never away on holiday, at least not as an adult anyway:

- R. *Have you ever travelled?*
- P8. *No, I don't.....no, no.*
- R. *When you were younger, did you travel?*
- P8. *I think I did, yeah.*
- R. *Did you ever go on an airplane?*
- P8. *No.*
- R. *You've only travelled in Ireland, is it?*
- P8. *Yeah. I like to stay home with my mother, like.*

Another participant said that staff took her to the seaside once for a holiday but other than that she has not travelled. She said she would like to go to Lourdes. One person who is deteriorating physically said that, although she was in Lourdes and England in the past, she is losing confidence in relation to travel now.

- R. *So you got to travel.*
- P28. *Yeah. I can't travel now...I'd be nervous.*

A number of participants reported that they no longer attend previously enjoyed activities. One participant who had won gold medals in swimming in the Special Olympics said she swims very little now. She said her sister has no time to bring her to the pool but indicated that she would like to swim more often. Another man recalled he used to ride horses with his sisters when he was at home, but never does this now. He indicated that he would like to ride horses again. Some current activities have followed through from childhood, such as colouring, making jigsaws and **art and craft**:

R. *Do you enjoy doing art?*

P10. *I do yes.*

R. *Is that something you always liked to do?*

P10. *Yes, cos I have done art before anyway when I was behind (in school)*

Participants reported that they enjoy many aspects of **cooking**. This ranges from mixing and baking, to looking through cook books or watching cooking programmes on television. Some people enjoy doing housework or as one woman put it, “*helping out*”. Looking at **photographs** is enjoyed by many participants, and one man has photography as a hobby. **Walking** is reportedly a rewarding activity but some participants said that they walk less now than when they were younger. **Listening to music** and watching DVDs are popular activities for participants. **Cinema, bowling, gardening** and **shopping** were also mentioned as pleasurable activities. Participants also avail of body-based therapies such as **reflexology**, head or hand massage, and **beauty therapies** such as manicures.

One man enjoys reading and is particularly interested in history, politics, and sports. He says these have been lifelong interests for him. Another likes to bet on horses. **Television programmes** favoured by participants are programmes that they have watched for a large part of their adult lives such as The Sunday Game and the Late, Late Show. **Local radio** is very important to participants. One woman articulated why listening to the news on the local radio station is important to her:

R. *Why do you like listening to the news?*

P44. *In case I hear of someone from home – dead or something.*

One woman who said she likes to watch television was unhappy with some programming, indicating a strong sense of her own values:

P7. *I don't like Emmerdale and I don't like Coronation Street – Not my cup of tea.....there was one last night after the news but I turned it off. It wasn't suitable for anyone. I went up to bed.*

Passing the time was mentioned by a few participants with one person saying that although she is not bored she finds the day long. Another person said that he would be bored if he did not attend day programmes:

R. *What do you do now to pass your time?*

P6. *I come in here and I be at home....I goes to the day centre every Tuesday. I comes here Monday, Wednesday, Thursday, Friday. I be at the day centre insideevery Tuesday. We do have lunch about 1 o'clock. We do have bingo and arts and quizzes. Different things...and question time.*

R. *If you weren't coming here what would you be doing?*

P6. *I'd be doing nothing. I suppose I'd be at home.....They'd be nothing on the box. You'd get bored at home all day doing nothing.*

R. *Do you like being occupied?*

P6. *Yeah, yeah.*

One participant had been due to move to a higher support unit because she had broken her hip. At interview she said that she spoke up to say that she wanted to stay in her original house as she enjoys sitting on the porch and seeing everything. This house is opposite the church and very much in the centre of everything happening in the village. So '**people watching**' is an important activity for her and she is fortunate in being able to speak up for herself in order to hold on to her preferred residential place.

Sometimes participants choose to partake in an activity in order to spend time with specific people rather than having an interest in the activity itself. One man said he would like to make another rug because he likes the arts and crafts instructor. When asked what she likes to do another person said, "*anything, anything*" and on further exploration it was found that she meant she does not mind what she is doing as long as she is in preferred company. Even the bus drive to the centre is an enjoyed activity as she likes the bus driver. A woman who lives in a community hospital likes to attend her day service just for the company.

R. *If you were above in the hospital now what would you be doing?*

P5. *I could listen to the radio there or watch the television.*

R. *Do you get bored with that?*

P5. *Oh, I would sometimes.*

This woman particularly likes to go for **drives** on the day service bus, especially if the drive is around her home locality. When asked what she likes about going out for a drive she replied, "*the 7 Up and chat away*" explaining that the group would often stop off at a pub for a drink while on the bus outing and they would have an opportunity to socialize.

Generally though there is sameness in terms of activities participants engage in and the diversity one might expect across a group of 46 males and females aged between 36 and 76 was absent. This **lack of diversity** was most notable in the music that people said they like. The range was limited mainly to a very small number of artists with Daniel O' Donnell being very popular with participants.

Few new activities commenced for participants as they got older. However three men have started drumming lessons which were arranged by the managers of their respective day services. Another new activity that people identified as something they have come to later in life is drama, with participants saying they have appeared on stage for the first time over the past few years. Those that took part in drama reported enjoying this with one man travelling to Cork City to perform. Some participants engage with computers and use them for a variety of activities such as typing (transcribing usually), playing games, watching You Tube, although no one reported using computers to Skype or to email. Participation in generic **eldercare programmes** in the community is being availed of by some people and this is reported as a very positive experience by those who attend. Participants say that they really look forward to meeting people there.

7.4.2 Relationships

The importance of **family relationships** was reiterated across interviews with only a very small number of participants reporting negative aspects of their relationships with family. All but one participant would choose to spend time with a member of their family than with anyone else. Relationships with parents are universally reported as positive and the loss of a parent at any age remains a great source of sadness. Relationships with siblings were reported as very positive during childhood with many participants enjoying showing photographs of all siblings together as children. As siblings grew into adulthood the pattern reported was that they left home to set up lives of their own elsewhere. Participants spoke of siblings going to college, moving abroad, getting married, having children, and as a result participants had reduced contact with them during adult years, with a small number reporting having no contact with siblings anymore. One man had not seen his sister in five years although there was some telephone contact (initiated by staff). Another man had not seen his brother since their mother's funeral ten years previous. However, for some participants sibling relationships increased in importance after the death of a parent, especially when the parent

was the main carer for that person. In many cases one particular sibling became more involved in their lives and some participants reported going to live with a sibling after the death of a parent. Participants who are now living with a sibling reported this as very positive and their relationship with this sibling as supportive and fond.

Participants living in residential care generally want more contact with family and those that go home to parents or siblings for weekends and holidays look forward to spending time with their family members. One participant says she has her bag packed days in advance of her trip home to her sister's house, such is her excitement about the visit. Most participants seem to enjoy talking about their siblings and from what was reported it seems that very often siblings are facilitating a social life and community integration for their family member. Participants who have little or insufficient (from their perspective) contact with siblings did not blame the sibling for this, but excuse them by saying things like "*He's very busy*", and when contact happens it is appreciated. In general, siblings are admired and valued.

However, one woman reported that she feels bullied by her family and she does not want to have contact with them. She is having unwanted visits from them and feels powerless to stop this. She said "*it will be worse for me if I do*", feeling they could punish her in some way. Two other participants reported a difficult relationship with siblings because of unwanted interference in their lives but both of these participants feel that siblings are interfering out of concern.

Relationships with nieces and nephews are very important to participants and photographs of christenings, communions, graduations, and weddings, were proudly shown at interview. Contact with children generally is valued by participants and some participants enjoy contact with or knowing details about the children of members of staff. Only one participant has children of her own. Of her four children, one has recently died, and of the three remaining children, only one visits her and these visits are irregular. She also said she has two grandsons that she has never seen. Some people said they are very fond of children and would like more contact with them.

R. *So, you don't have much contact with children.*

P7. *No and I love them, you know. I love them. I do.*

R. *Would you like to have contact with children?*

P7. *I would, faith, I would. I love babies. I love children.*

No participant specifically said they want an **intimate (sexual) relationship** although three males did say that they would like to get married. One of these men said that the reason he wants a wife is so that he would have someone who could take care of him. Another said he would like to get married and named the men in his family that have already married. He indicated that he has some understanding that he is different from the other men in his family:

R. *Why did you not ever get married?*

P32. *I'm not tall.*

No one reported that they have a current partner and only the woman who had been married reported ever having had a sexual partner. A small number of females said they would have liked to have had a boyfriend or a husband but only one female says that she still wants this. Generally participants reported that they are not seeking an intimate relationship at this time in their lives:

R. *Was that something you were ever interested in.....having a boyfriend or a husband?*

P40. *No boyfriend. They're bad luck.*

R. *That's not something you are interested in?*

P40. *No.*

R. *Were you ever, when you were younger?*

P40. *No. No. I'm happy without them.....I have my family around me.....I look after my nieces and nephews.*

Friendships with people outside of family or service settings are conspicuously absent with no one saying that they have a friend in the community. Some people named a brother or a sister as a friend:

R. *Who are your friends now?*

P46. *Helen.*

R. *Helen your sister. Anybody else?*

P46. *That's all.*

Another participant echoed this:

R. *Who is your closest friend?*

- P34. *Dee. Dee my brother.*
- R. *Have you any other close friends?*
- P34. *P and Mand the three girls.*
- R. *That's your family, isn't it?*
- P34. *Yeah.*

Many named the people they live with or the people in the day service as friends, but overwhelmingly participants named staff as friends. A few participants said they had no friends. In some cases relationships between participants and others that use the service have endured for a very long time as they have shared services since school age. Sometimes this was reported as positive and participants might name these people as friends. In other cases participants indicated that a particular person they have known all their lives annoys them and they would not choose to spend time with them if the option was there. So while there has been continuity over time in terms of some relationships, not all of these relationships are enduring by choice.

Some participants reported forming a strong bond with a fellow resident based on companionship and a symbiotic relationship that emerges over time from sharing the same social space.

- R. *Who is your friend here?*
- P16. *G.*
- R. *So yourself and G. would get along. Ye both smoke, do ye?*
- P16. *Yeah, he smokes as well.*
- R. *So, ye sit down there in the smoking area and have your smoke.*
- P16. *Yeah, yeah.*
- R. *Does he talk to you?*
- P16. *He don't talk much.*
- R. *And do you mind that he doesn't talk much?*
- P16. *You wouldn't know what he be saying anyway.*
- R. *Do you like his company though? Do you like sitting with him?*
- P16. *Yeah.*

G. died a short time after this interview causing great distress to the participant, even though the two men never really spoke to each other. He had clearly derived comfort from the companionship and having a cigarette together. Similarly, another woman had always sat beside a particular resident but he had recently passed away. At interview she showed the researcher his photograph:

P38. *He's beautiful. That's my friend. (Kisses photograph). He's gone now....up there (heaven).*

Relationships with staff are experienced very positively, and in particular people like to talk about their key worker. In some cases participants had known members of staff for over 20 years. Participants indicated that they like to see photos of staff and their families and to know how everyone is doing. Staff were sometimes named as girlfriends:.

R. *Did you ever have a girlfriend?*

P12. *I have.*

R. *Who's that?*

P12. *Catherine (Community Nurse)*

Staff moving on was often a source of sadness for participants:

P34. *MJ gone ...Australia.....she gone last Monday.*

R. *How do you feel about that?*

P34. *A small bit sad.*

However, the same man demonstrated an ability to cope with the impermanence of some relationships and went on to say:

P34. *MS is on tonight.*

R. *Is that ok with you?*

P34. *Yeah, happy. Grand.*

Extended family in a key relationship role is rare but when it happens it is greatly valued. One man's main link with the community is a male cousin. They go out every Wednesday and this arrangement began when the participant's parents passed away. He is an only child. Another man, also an only child, has a very positive relationship with two separate but distant

relatives. Both of these relationships are meaningful to the person and he shares his leisure time between them. He spoke fondly of them both at interview.

Participants talked about former **neighbours** (from communities of origin) in a positive way and it is clear that neighbours have been important to them in the past. Most relationships had not endured once people came into residential care. One woman named three females who had lived next door to her as her close friends. But then explained:

P28. *But they're married now and live in England somewhere.*

R *Have you lost contact with them?*

P28. *Yeah.*

A further observation from findings in the area of relationships is that **male companionship** is sought and valued by male participants and experienced as positive. One man who had three sisters chose his brother-in-law as his favourite member of the family.

A final area brought out in the findings in terms of relationships is **family pets**. Many participants had warm relationships with house pets throughout their childhood, teenage years, and young adult lives. For those who remain living with family members, pets still are a significant part of their social and emotional lives. Those participants now living in residential care who had exposure to family pets in their earlier lives, report that they still have a fondness for a variety of pets, mainly dogs and cats, but horses were also mentioned. Residential houses in the service allow no pets and one participant spoke of her distress at having to leave her dog on coming into care:

P7. *I gave the dog when I was coming in here to a fella.....I gave him my dog. Max was his name.....I would miss him but I couldn't bring him in....J. is afraid of dogs.*

Another participant said:

P28. *I feel lonely after Prince. He was nice. He was a Jack Russell.*

A few participants hold out hope of having a dog again, even planning what kind of dog it will be and what to call it. One man said he would like a white terrier and that if he had one he would keep it in his room. A woman said she would like to have a dog of her own and that she would call him *Small Bob*. Those participants living with family that have exposure to pets reported on the value of this experience:

- P9. *There's a dog called Sheba at home, and do you know, when I comes home s he be mad about me.*
- P40. *When I come in every evening the two of them (dogs) out at the gate waiting f or me to come in...so I adore them.*

This woman explained that the dogs are her responsibility and that she enjoys looking after them. Taking responsibility to care for a pet is important to other participants as well.

- P11. *Sam (dog) is lovely. He's very good. I feed him every day.*

Of course participants who had pets also experienced the loss of pets through accidents, illness, or natural death due to age. Participants reported feeling *lonely* or *sad* at the death of a pet, but memories remain fond and in most cases dogs in particular were replaced by other dogs, and some participants had stories to tell of a number of pets going back years.

7.4.3 Social roles

For some participants an expansion of roles was evident as individuals got older and services for people with intellectual disability advanced. Some participants had become involved in advocacy in their later years with very positive outcomes. More participants however, experienced a diminution of social roles on leaving their homes and communities and taking up residence in a care setting. One participant gave an account of **social roles disappearing** over time with a changing social environment. He was also able to describe how his day to day life has changed over the years. Although he had gained a level of competence in the area of work as a young man, this work is no longer available for him to do:

- P6. *I'd work at home (as a young man), maybe cut the turf. I used to go up to my uncle over the road, making the hay and footing the turf...with my uncle I used be at the hay, saving the hay, making the oats, bringing in the oats and all.*
- R. *Do you do any of that now?*
- P6. *No, no. My uncle has no hay now. There's no cut turf now. The turf is cut now by machine, by machine now.*
- R. *Would you still be able to do that work?*
- P6. *I would if it was there. They used cut it by the slean, you must remember they used cut it by the slean. They used be mad cutting it by the slean and then spreading it around the bog...to dry out. Now they cuts it by machines. They used to make it up in forts, they used to make it up in small reeks for to dry it long ago.*

R. *So things have changed around (your area).*

P6. *They have, they have.*

There are many examples of **loss of social roles** once people moved away from their communities and into residential houses. One man said he used to walk greyhounds for a neighbour during his young adult years but lost this role on leaving his community. Another woman was sole carer for her elderly parents and came into residential care when her mother passed away:

R. *You talked to me a little bit about roles when you were growing up. Were you the person who looked after your parents?*

P7 *Yes, yes, yes.*

R. *That was your job.*

P7. *That was my job and I stayed with them....till she died in her own bed, the poor woman.*

This same woman lost many roles on leaving her home, including the role she had in caring for the farm animals, especially the hens:

R. (looking at photo) *Did you have hens?*

P7. *Yes I had hens, I had.*

R. *Used you look after the hens?*

P.7. *Yes and they used come up to the back door and start pecking the back door when they were hungry. Oh, they would, faith.*

R. *Was it your job to look after them?*

P7. *Yes. They were mine.*

In terms of role expansion with age, three men were recently part of a committee established through an **advocacy** network to lobby the local council to have a footpath laid from their residential house into the nearby town so that people in wheelchairs, and indeed all pedestrians could safely go into town. One man said he was chairperson of this committee. The work on the footpath is now complete and all three participants reported that they are proud of their achievement and pleased to have made such an important contribution to their community.

Participants reported getting great joy from becoming **aunts and uncles** and sometimes **godparents** as well:

P13. *I love my own niece. She's my godchild.*

R. *That's a positive thing for you.*

P13. *Yeah. I've become an aunt and I'm a godmother again.....*

Some participants have roles within their day centres such as helping in the kitchen. This was invariably reported as a positive experience and people seem to enjoy **helping out** and feeling that they are **contributing**. Three participants living in a rural setting have opportunities to do work caring for hens, donkeys, and doves. They also do gardening and reported that they experience satisfaction from the work, with one man saying he just likes to keep busy. They also had opportunity to sell eggs from the hens to their local community thus expanding social roles and the contribution made to the community.

Only one man reported ever having had a paid job having worked for a few years as a labourer for a local farmer on leaving school. Eight participants reported currently having jobs in the community but all of these are **work experience** roles and are not paid jobs. Others had work experience roles in the past. Areas of work mentioned were hairdressers, supermarkets, nursing homes, coffee shops, stables, and community centres.

Two women were involved in **fundraising** for charities and said that they enjoy making this contribution to their communities and wider population. Those living at home with their families report that they have roles within the household helping with **housekeeping** and one man helps in the family pub collecting the glasses.

7.4.4 Self concept

Participants overwhelmingly reported interest in their appearance and **looking well**. For the males this might mean always wearing a shirt and tie and for some of the female participants it might mean an interest in collecting and wearing jewellery or having brightly painted nails. For both sexes interest in good personal grooming was evident:

P24. *I nice.....Lovely clothes and bag....hand bags.....and new boots.*

Having nice clothes and choosing one's own clothes are important factors for most participants. In fact, in one way or another all participants indicated that how they look and

how they present themselves each day is important to them. Many people said they like to have their clothes, jewellery, hairstyle, etc, to be admired by others. Each person has individual aspects of appearance that are particularly important to them. For one man it is his glasses. He likes to have a selection of glasses and his greeting on meeting people is “*Do you like my glasses.*” One woman explained she is not too interested in clothes but her hair is ‘very’ important to her.

Birthdays are important to the vast majority of participants and people reported looking forward to their special day. Participants generally have a recognition that they have changed with age, on comparing birthday photographs across the years. One woman was looking forward to her 70th birthday and planning with staff to have a party in a local hotel.

R. *What would that mean to you, if a lot of people come?*

P7. *It would make my day.....a big day for me.*

Some participants commented that they are good at a particular **skill**. One person said he is a good singer, another said she is good at rug making, while another said she is good at art. One very softly spoken woman (barely audible) asked to sing once she understood her interview was being recorded. She sang clearly and loudly as if realizing that this is her strength and talent. A 60 year old man is proud of his ability to still run and of the fact that he is nicknamed “the greyhound”:

P6. *I could nearly beat D and E and all and I sixty year. I could nearly beat the best of them yet. I could beat people that’s half my age.*

He went on to clarify why it is important to him to still be able to run:

P6. *You have to keep going ‘til you give up. Keep going while you can.*

This man and some other participants did not think that they are changing in any negative way with age. One man stated that he feels the same now as when he was younger. Another man feels he has changed for the better with age:

P10. *I’m more capable handling the money now than years ago.*

One woman commented that she has noticed her own **self confidence** and that of her peers growing over the years:

- P7. *I think people is more up than long ago.....more up in their self. People can talk up now like I can talk If I want my opinion. I'll talk my opinion to you like.*
- R. *When you were younger did you find that you weren't able to give your opinion?*
- P7. *When I was at home with my Mom and Dad I couldn't have no opinion with them, like. They were fine to me and everything, like.....I'm speaking up now for myself.*

7.4.5 Community

Access to the community is a significant difficulty for most participants with many people indicating that they would like to get out more but that issues such as staffing levels, availability of suitable transport, cost of transport, and availability of a companion, all being described as barriers to desired level of community access and engagement.

Interest in what is happening in the local and the wider community is evident from interviews and a primary source of information in this regard is **local radio**. Radio Kerry is a source of information and of entertainment for many people with four people playing radio bingo every day. Many people listen to Radio Kerry to hear news about their communities of origin, especially news of deaths, or sports results from local teams.

Participants reported that going out to **local pubs, hotels and restaurants** for meals is something they enjoy but few go out on a regular basis. **Community centres** are utilized by some participants for eldercare day programmes, indoor games, or to participate in drama or art groups. One man goes to play cards in his local community hall once a week. Three participants have a regular Thursday night slot booked in a local community hall for indoor soccer. One woman accesses her community to do grocery shopping but incurs the expense of a taxi in order to do this. The expense of taxis, as well as lack of availability of suitable transport (wheelchair taxis), was reported as a major **barrier to community involvement** with one woman saying it costs her 50 euro (all her disposable income for the week) just for one return trip in a wheelchair taxi to a desired weekly activity. Two women were supported by the Irish Wheelchair Association to access the community. Nevertheless community involvement was reported as rewarding and desirable, with one person explaining why this was so:

- P40. *Love meeting the people.*

Community awareness is evident from interviews, with one man reporting on road works and what is planned in terms of a bypass into the future, while another woman demonstrated a keen awareness of the needs of community charity groups by raising money for a range of needy causes, such as Multiple Sclerosis. Community support was also demonstrated by one woman who talked about supporting a neighbour by giving him a mass card when his wife died.

Other community facilities utilized by participants are the church, swimming pool, hairdressers, beautician, shops, library, but all planned outings are **dependent on the support** of other people. Only two participants indicated any level of independence with regard to accessing the community.

7.4.6 Social Participation: summary of analysis

The findings show the key role of relationships and social experiences in ageing well, but changes in how these are experienced as the person gets older was also observed. Participants typically have fewer relationships as they age and family and peers die, supporting findings by Burke *et al* (2014). Quality relationships become key as quantity diminishes. In fact, one or two meaningful relationship can be sufficient for a person to feel engaged and valued. Family relationships remain crucial in older years and, as concluded in the study by Robertson *et al* 2001, few people have highly valued relationships outside of family. As parents age and die it seems that one or two siblings become essential to the person's life and that participants prefer to spend time with family than with anyone else. In addition, participants were found to be heavily reliant on family for social participation, supporting findings by McCarron *et al* (2011). Cross generational contact is highly valued. An intimate sexual relationship was not part of participants' life experience and is not specifically sought by participants at this time, although four men would like to marry in the future. Participants reported social and emotional wellness from contact with pets but only those living with family currently have pets of their own.

Participants tend to engage in a relatively (relative to the general retired population) small number of activities, enjoy a limited range of music, and travel little as years advance. Boredom is an issue for a number of participants. However, participants show openness for growth, development, and new learning, with examples of people getting involved in drama, playing the drums, and using computers for the first time in their older years. Participants

also show interest in what is going on in the community and an eagerness to get involved. Community participation and access are valued as people age but barriers to access limit possibilities. Specifically, transport and a supportive companion are often not available or prohibitively expensive. As such, empirical findings across a number of studies (CARDI 2015; Wark *et al.* 2014; Heller and Harris 2012; Bigby 2005), highlighting impediments to inclusion in the life of the community, are supported by the findings, showing that these impediments persist as people with intellectual disability age.

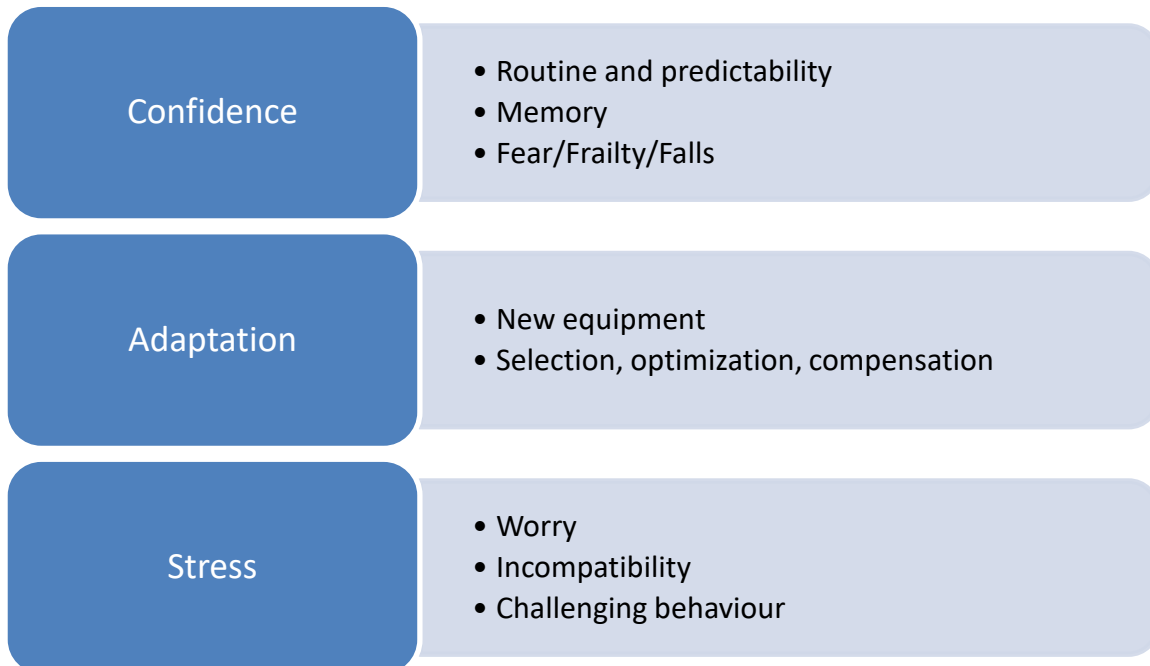
In the area of relationships and social experiences then, change with age comes about mainly, not from change within the person, but in limitations in social and support networks.

Participants are keen to engage in quality social relationships and to participate in activities that are meaningful. They need support to broaden their experiences and additional resources to facilitate access. The findings show that adaptation to change in relationships and social experiences can be managed effectively by the ageing person as long as key supports are in place. If this happens, the evidence points to ageing as a time of growth and development for people with intellectual disability.

7.5 Safety and Security

Both physical and emotional safety and security are of great importance to participants as they manage age-related change and the research found that these are key areas in determining how well people age. Feeling safe and secure was found to be associated with personal confidence and how well people can adapt to their physical and social environment. The findings demonstrated that people rely on routines and continuity to create predictability in their environment. Safety behaviours were in evidence as people spoke of withdrawing from some activities or reducing the level or frequency of engagement in activities, usually due to fear for personal safety or fear of falls. Participants also demonstrated how they have adapted to developing physical and sensory challenges through using environmental supports to enhance safety. Adaptation was not always easy for participants and many reported worry and associated stress due to change and changing needs. Environmental stress such as challenging behaviour and incompatibility with peers sharing day and/or residential services was found to be an issue for participants, causing some individuals to feel unsafe and powerless to change their situation.

Diagram 8: Safety and Security



7.5.1 Confidence

Reliance on **routines** was found to create **predictability** around a person's day, and as such confidence around managing the day is increased. Participants indicated that they do not like change and that routine, even in little things, is more comfortable.

R. *You like doing the jobs in the kitchen?*

P42. *Yeah.*

R. *And you don't like anyone else to do it?*

P42. *Nooooo* (laughs as if the idea was ridiculous)

This man later stated *"Don't like change"* and that he wants to stay in his residential house *"for always"*. Participants indicated that they would be annoyed if anyone did their particular house chores and people take ownership of personal jobs and work areas. Daily and weekly routines, such as getting the RTE Guide on the same day each week, or playing Radio Bingo or watching particular television programmes on certain days, are considered important. According to participants changes to such routines would not be welcome. Predictability about weekend trips home or respite, holiday times, staff rosters, and individual day programmes/activities, make positive contributions to peoples' lives by creating a more predictable environment which reduces stress. For example, one woman was talking about

going to respite for the weekend and she felt it important to know who would pack her bag, who would be driving the bus etc. Routines appear to create the comfort of familiarity and predictability is experienced as empowering. However, in some cases, familiar routines may not necessarily have come about through agreement. For example, bedtimes are strictly adhered to, but participants did not indicate that they had choice in this matter. More often routines appeared to be service driven, and patterns around the time people go to bed or get up in residential houses were evidently dictated by other considerations, such as bus collection times, staff rosters, meal times, and so on. Nonetheless, these patterns provided a level of predictability and participants expressed annoyance with residents who refuse to keep to the “rules”. For instance, one man complained that a fellow resident was still up at 10.45 pm although bedtime is 9.30 pm. Participants living in residential houses are able to relate routines for entire days and even the week. One participant summarized:

P34. *Chips on Friday.....chicken stir fry on Thursday....yogurts after.....the centre will be closing at 5....David (staff) going home at half 3fry for supper....Coronation Street tonight....9 o'clock bed time, and get up at 8.*

Many such routines were reported, usually around activities, chores, respite weekends, and staff rosters. Staff changes are experienced as particularly unsettling and participants indicated that they prefer familiar staff. Participants have a good grasp of many day-to-day routines and this competence appears to increase confidence. As such, individual events and outings which routinely take place on a given day are expected to continue occurring on that day. One woman enjoys going out for a sandwich on a Friday.

R. *That's a nice treat, on a Friday, is it?*

P1. *Yeah, Friday afternoon.*

R. *Not Monday?*

P1. *No way.*

Calendar events are also used as a guide to what is happening and this is supportive to individuals. For example, the annual Rose of Tralee Festival always takes place in the third week in August. Participants use such events as a way of following the progress of time as opposed to using the months of the year.

Participants mainly attested that their **memory** is as good as ever, but there were some reports of declining memory. One man stated that he may be a little more forgetful now and therefore uses memory aids such as lists.

R. *Do you think there is any change in how well you remember things?*

P10. *There were one or two changes alright. One, I might probably forget what I wanted to do and maybe sometimes (say) "Did I tell you this"; "maybe I forgot to tell you this". That happens sometimes anyway.*

He reported that he sometimes writes things down in order to remember. Long-term memory was reported to be good by participants, and also observed to be so using the aid of photographs. For instance, people remembered school friends that they have not seen for many years. One man was particularly interested in history and he could remember back to when the landscape was very different in his old community. Speaking of a recent visit to his old home he observed:

P15. *We went down there the other day. The house has changed a bit now. Do you know what's gone now too?...the old railway line. It's all changed.....there was a railway line....and it's knocked down now....the whole thing gone.*

R. *Can you remember things as well as ever you did?*

P15. *Yeah.*

R. *Do you think you have a good memory?*

P15. *Yeah, I have*

One woman now in her seventies was proud of her good memory:.

R. *Can you remember things as well as ever you did?*

P7. *I can, faith, I can. I have a great memory.*

Another man was equally proud of his good memory:

R. *Are you getting forgetful in any way?*

P6. *No, no, no, no. I can think of things a way back. I can go back to when I made my confirmation and everything. I remember long ago in 1963, the time that President Kennedy was assassinated... I remember there was no television there that time. I was coming down from my uncle and some friends told me about President Kennedy being assassinated. There was a lad up in a building that shot him.....Jack Ruby that killed the man that shot him.*

Pride in having a good memory was also reiterated by a further participant:

R. *How is your memory?*

P4. *Very good. I got better memory than my Mum. I got good memory. Better than my sisters and brothers. Much better.*

Many participants did not know their age or their date of birth but they generally knew the month of their birthday and age was reported usually as the last milestone birthday (50, 60, 70). A small number reported their age as in their teens.

However, for some participants, particularly those that remained at home for a large part of their adult years before availing of day or residential services, the years following school age appear to be somewhat blurred:

R. *Can you remember what you did after school? When you finished school?*

P17. *I don't know.*

R. *Did you stay at home with Mom?*

P17. *I did.*

R. *And what did you do at home all day, you and Mom?*

P17. *What's it I done at home? What did I do with Mom? What did I do? (thinking)*

Still more prompting could not help this participant to recollect what she did for the three decades she spent at home before she began to attend a day service. However, the use of photographs helped her to recall some important family occasions. This exemplifies the benefit of life story work for those ageing with intellectual disability, as when there are few significant events to anchor memories in time and place, the story of one's life can be difficult to recall.

Participants then do not generally report poor memory and findings indicate that adhering to the routines and structure associated with service-based residential and day supports boosts confidence in day-to-day remembering. In addition, it is observed that participants do not need to rely heavily on memory to manage their day while in services, as the care culture of the service means that there is most often a member of staff to provide reminders about what is happening next, or recalling what happened already. In fact, the researcher was often advised by a participant to 'ask the manager' when asking about one's age or birthday. In relation to those living with family, the family care structure and culture was found to provide

support in respect of remembering. As such, in relation to this group of participants, memory is not reported as a factor which impacts negatively on ageing with confidence.

Participants indicated that increasing **frailty** and **fear of falls** can be a factor in curtailing their level of engagement in the community. A number of participants had withdrawn from previously enjoyed activities, specifically swimming, travel, and sailing. Three people said they had given up attending Mass and others said they like to stay indoors more now than they used to. While some participants said that they do not know why they have given up activities, some recognized that they have become more fearful in terms of personal safety:

R. *Why don't you go out in the boat now?*

P19. *No more now – only (home)*

R. *You only stay (home) now. You don't like going out in boats anymore.*

P19. *No.*

This man admitted he is afraid to go sailing now. He also said that he does not dance anymore and that he prefers to stay indoors. He said while he still likes to go shopping he feels safer at home. A woman participant said “*I stay inside*” when asked whether she likes to go out or stay at home. Explaining why she does not go out as much now, one woman explained:

P44. *The showers be so heavy, you know, and the gale, do you know. And some of the cars would knock you down.*

But she maintained she still goes out “*when I feel like going*” Another man recalled his experience of a fall thus:

P16. *One night I was coming up and it was raining and the path was wet and I fell and put a good gash in the back of my pole (head)....when I went down, there was old rough cement there.*

R. *Did you get a fright?*

P16. *I did.*

One woman explained her fear of falls prior to getting a wheelchair:

P8. *When I stand up, like, if I took one step I might fall you see. So it's easier in the wheelchair.*

Fear and falls, and more specifically, fear of falls, was observed as a significant factor impacting on confidence to stay engaged with community activities as participants grow older. Activities that were previously enjoyed were sometimes foregone as participants began to feel unsafe. However, when participants were supported to adapt to frailty and changing need, feelings of safety improved and community access was better managed.

7.5.2 Adaptation

Participants reported on how they have adapted to change as years advanced in order to feel safer and more secure. They spoke of using **new equipment** to cope with physical change. A woman who had developed sight loss is delighted with her new talking watch and her new folding cane. She never had a talking watch before and was very excited about demonstrating how it works at interview. She feels that her new equipment provides her with increased independence. Others spoke of using equipment for mobility, but only at the level required. One man said that while he can manage with a walking frame indoors, he uses a wheelchair while out in the community for safety reasons. Another man also said that he only uses a wheelchair when he needs it (on rough ground) and uses the walking frame to get around otherwise. A woman who had become nervous of falling says she uses the wheelchair now because *“It’s safer”*. Other adaptations which participants spoke of were around practical solutions to developing difficulties such as using pre-packed cut vegetables when arthritis made using a vegetable knife difficult or impossible. Sensory impairments that developed over the years are managed by use of hearing aids and eye glasses.

Examples of practical changes leading to adaptability involved changing exercise routines to adjust to physical changes. For example, one woman explained that she had to give up walking because this form of exercise was putting too much of a strain on her ankles but that she now uses an exercise bicycle instead. Some participant said that while they do not wish to completely relinquish a specific activity they have reduced the frequency or intensity of engagement. For example, participants said they still like to walk but not as far or often as previously. Participants had also reduced the number of days they attend day services and the main reason cited for this was energy conservation. Participants find that they enjoy the service more if they have rest days during the week. A **‘selection, optimization and compensation’** (Baltes and Baltes, 1990) approach was therefore evident in how people adapted to age related change. For example, selecting an activity that one wants to continue

doing (attend the day service), optimizing ability to engage (additional rest), and compensating in relation to the activity itself in order to be able to engage well (reduce the number of days to attend).

7.5.3 Stress

Although many spoke of adapting well to age related change, others experience change as stressful. Change, changing needs, and associated **worry** were all raised as sources of stress during interviews. Experience of change was evident from participants' accounts of physical change, social change, and change related to family. Due to changing need, usually involving increased dependency, participants visit home less often as years go by, and many are now going to family for day visits only, with no overnight stays. Sometimes this occurs because parents and carers are themselves in their declining years. Also participants spoke of moving to different houses due to changing need. For example, when participants could no longer manage the stairs they often moved to bungalow residences. Reduced energy levels and need for more rest also resulted in change for participants. A small number have moved to eldercare facilities and no longer attend day programmes outside of their residence. Social activities were often lost as a result of this move and distance from main centres led to greater isolation for participants. For example, one man explained that he used to live in a house in a busy town near to the day service where he also enjoyed the support of other agencies for social activities. On moving to an eldercare house in a rural setting much changed for him and social isolation is evident from his account of life now. Some participants however, reported giving up activities because of some physical change in themselves, as in one participant who said she does not write so much anymore because she gets pins and needles in her hands. Another man has given up his Special Olympic activities. He said:

P11. *"It was too much. I kept falling.... I get dizzy"*

Change due to physical deterioration was reported to have resulted in loss of independence for participants, with family members becoming more cautious about the safety of the person in certain situations. One man who had been independent in terms of public transport no longer uses this method of travel as his family are worried that he will fall. In another situation it was the person himself who became worried about his own safety as he got older and he no longer travels unaccompanied. He said he would be *"afraid"* on his own. Another

man worries about physical deterioration and recognizes some change within himself which he attributes to age.

P10. *Sometimes you might feel you're getting older. Sometimes it might be bad and more times it can be good.*

He qualified the bad bit as *"feeling old and feeling cold at night."* While reporting that he is doing very well at the moment he also said that he does wonder what the future holds. He says the bad parts of getting older cause him worry and identified these as:

P10. *Probably not being able to get around. If you weren't able to use your hands or your legs, if your body wasn't doing the normal things that you're supposed to be doing, like.*

R. *That hasn't happened to you though.*

P10. *Not yet anyway. No. It will happen sometime anyway. At a later stage anyway.*

Participants regarded physical changes as being unwanted. For instance, they reported *"I can't walk"*, *"I'm losing my balance"*, and *"me cannot stand here"*. These changes were sometimes accompanied by fear and a reluctance to engage in certain things.

Two women spoke of how menopause is impacting on them. This change was not welcomed by either of them due to unpleasant symptoms such as *"hot flashes"*. One woman who experiences lifelong depression feels that her advancing age is making her condition more difficult to manage. For example, getting up in the morning was always a challenge for her, but now it seems even harder to do. While she can never remember a time when she was happy, she feels that getting old is harder on her, and bouncing back from low mood is not easy. Change in ageing parents was reported as impacting on participants with one woman explaining that she worries about her mother who is eighty. She says she does not like to see her in pain, and that she now must look after her mother who is becoming forgetful. However, complaints about change were relatively rare, with most people saying, *"I'm alright"*, *"I'm fine"*, and *"I be OK"*.

Participants reported specific stressful experiences causing them to feel unsafe. Stress was associated with **incompatibility** with peers, which is to say, having to live with people that they do not get on with, or that exhibit **challenging behaviour**, and the experience of living in this situation over a long period with no change in sight. One man was picking at his skin at interview and recognized that his distress was related to his fear of a fellow resident who

kept hitting out at him. Another man also reported a long standing poor relationship with a man in his day centre saying:

P12. *And he was calling me names every day at the centre.....and the bus as well. That's a problem.*

R. *And how do you cope with that?*

P12. *I don't like it no more.*

R. *Did it always bother you?*

P12. *Yeah.*

R. *And still bothers you.*

P12. *That's right.*

For another participant stress was caused by a poor home experience where the family did not appear to get along. She said:

P4. *.....sisters shouting at Mam....shouting.....I had to walk out of the room on it....I want this to be stopped. I want it to be stopped now....It's not good for me to see them going like that.*

Another participant was experiencing a great deal of stress due to fear of what might happen with a fellow resident:

P3. *The hardest thing is I'm having terrible difficulties with P.....he lashed out at the staff and they have to lock the door now at night. He threatened one of the staff with a knife one night.*

R. *How does that make you feel?*

P3. *Scared.*

A further participant reported being afraid for her own safety as she uses a walking aid to get around:

P44. *You'd get afraid of him too when you walk with the walker. Him punch the door and kick the door. He wouldn't let me out of the bathroom door. And I want to stay here.*

She said she would like to “get rid” of this man from the house as he is getting “very dangerous”. When asked what she wants to see done about this she said she wants him to move out. A male participant was also experiencing stress due to his family situation and worried about his own health and that of his family into the future.

7.5.4 Safety and Security: summary of analysis

Participants spoke of various issues which impact on their sense of safety and feelings of security as they age. Adherence to routines can create predictability for participants and as such confidence is boosted. Memory is generally reported as good and memory problems were not reported as impacting on safety and security. Frailty and the associated fear and fear of falling was reported as impacting on participants as they age and people said they do not feel safe. Many participants embraced the use of mobility aids and other environmental supports, and as such adaptation to changing physical need was demonstrated.

However, adaptation was found to be difficult for a number of participants. Stress due to change, changing need, and associated worry, was found to be a factor impacting on ageing with confidence and it was clear that this could be overlooked as participants were unlikely to verbalize stress or worry. There were many examples of people experiencing physical decline and responding by withdrawing from activities and community engagement due to fear or worry. They did not report that they were supported to understand what was happening or that they were assisted to explore better solutions. In addition, the findings point to a need to be vigilant around indicators of stress associated with worry in this population, and withdrawing may be a key indicator of this type of stress.

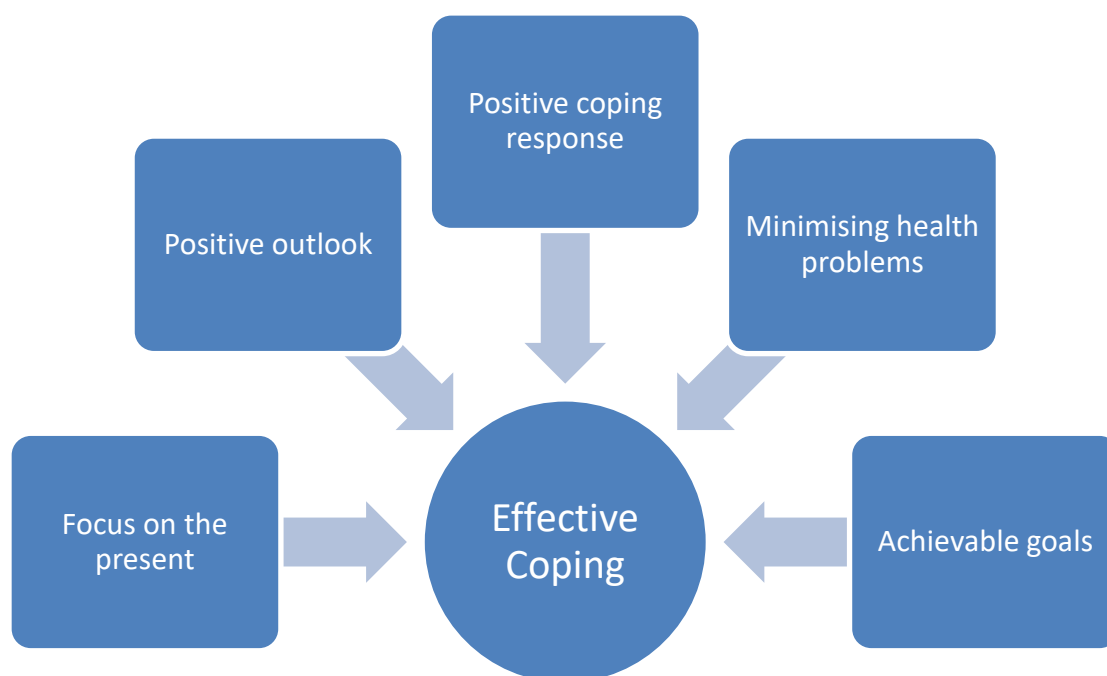
Stress due to peer-to-peer abuse resulted in the experience of feeling unsafe. Challenging behaviour was experienced by participants when (i) age-related change and additional frailty meant that the person became more vulnerable in a mixed ability setting, and (ii) when another resident developed dementia with its associated challenging behaviour. Five participants spoke of feeling unsafe in this way, representing almost 11% of the population studied. If these figures are transposed to the wider intellectual disability population in Ireland, then the implications for people ageing with intellectual disability within services is very worrying.

Overall, while the common vulnerabilities in relation to ageing, such as frailty, worry, fear of falls, and abuse are in evidence in the findings, it is shown that those ageing with intellectual disability are additionally vulnerable. Legislation and national policy are beginning to acknowledge this and to respond appropriately. A core finding of the study indicates that managing safety and security as people with intellectual disability get older is key to physical and emotional well-being and ageing well.

7.6 Coping Patterns

For the most part participants were focused on present day living and making the best of every day. This section presents the findings in relation to ways of coping with ageing and age-related change. Specifically, positive coping responses, minimising health concerns, setting achievable goals, focusing on the present time, and a positive outlook on life and living were observed.

Diagram 9: Coping Patterns



7.6.1 Positive Coping Response

Participants discussed coping and adapting as they age and in particular, gave accounts of strategies learned for emotional coping along with how physical adaptations have been used to manage age-related change. Participants generally feel that with age comes better coping ability, with one woman saying that she has mellowed with age and can control her temper better now. She says she has learned over the years that it is best to walk away when she feels anger coming over her:

- R. *You think you manage your temper a bit better?*
- P7. *Oh I am, I am. Out the door I go...I walk away now and just say no more.*
- R. *In the past would you react?*
- P7. *Oh, then I would. If they're at me they'll get it - a bit of the tongue – but not now.*

Another participant reported a similar experience of coping better with angry feelings as he is ageing:

- R. *How do you cope now when you are feeling upset or angry?*
- P10. *I'm coping fine and well now. I'm using my relaxation now, and also I'm remembering to walk away. Sinead (therapist) wrote that down for me. I'm used to that now. I walk away from something if somebody upsets me. I walk away. I feel I'm coping more better now than I was.*

Coping with feelings and emotions as one ages was an issues raised by many participants.

- R. *How are you coping?*
- P3. *Bad some days.*
- R. *And on those bad days, how do you get through the day?*
- P3. *I go up to the room above and I lock the door and I just turn on the television..... I'm taking every day at a time.*

Another man reported day by day coping in a similar way.

- R. *Are you coping?*
- P10. *Yes, I am, yes. Sometimes it can be difficult. More times it might be alright. It'll always happen you'll have good days and bad days anyway. Not all the time. Good days and bad days anyway.*

Another woman said that with the passing years some worries have left her:

- P13. *I haven't got them anymore now. They're gone away from me. I'm not sad or lonely anymore.*

Three participants spoke of using **relaxation techniques** that they have learned over the past few years to help them cope and to reduce stress. All found that these techniques are beneficial to them.

Many also deemed **social support** helpful to enhance coping, and especially in coping with loss. One woman said she would never have coped with the death of her mother without the support of her brother:

P40. *I couldn't cope with what happened to my mother.*

R. *What helped you get through that hard time?*

P40. *My brother.*

She explained that following the death of both her parents she went to live with her brother and is very grateful to him for giving her a home. Although admitting she finds it hard to cope, her brother's support has helped her to remain in good spirits. Another man said that talking with people and enjoying nice food, especially coffee and dessert, are the things that help him cope as he gets older. He went on to say there are people that he trusts and can talk to, and this helps him to cope and to manage the feelings of sadness that he has been experiencing since the death of his father some years ago. Social support was also highlighted by another participant as the most important factor in helping her cope through the loss of a parent. She explained that following the death of her mother she began to avail of weekend respite and to socialize with the group of people in the respite house. She experienced this increased socialization as very positive and as helping her through a difficult time.

There was varying levels of insight evident from interviews in relation to understanding of one's own advancing years and foreshortened future but in the main, **age was not an issue** for people. Some participants recognized change within themselves due to advancing years, with one participant stating "*I old*". Comparing a current photograph of herself to one when she was younger she was able to observe, "*Different now*". One woman had interesting insights into her ageing experience and change:

P4. *I feel my age. I feel I'm getting too old.*

R. *What does that feel like?*

P4. *Fighting it.....very, very....fighting it..... Really don't want to get old. I wish that I wasn't getting old. A lot of us would, wouldn't we?*

She did not welcome getting old but she had adopted the positive stance of '**fighting it**'.

7.6.2 Minimising health-related decline

Minimizing was evident in coping with change due to ageing and this was particularly so in relation to deteriorating health. Participants generally reported that their health is good and tended to minimize obvious deterioration with many saying phrases such as, “*I’m fine*” or “*I’m alright*”, when asked about their health. Even participants with serious illnesses seemed to want to **give a positive account** of their health. When asked about his serious illness, one man replied “*better now*”. Many participants acknowledged that they are slowing down with age.

P20. *I notice I used to walk very good, but I can’t now.*

However, the fact of slowing down was also minimized with participants saying they are only slowing “*a small bit*”. Tiredness and reduced energy was reported by many participants, and in particular, a wish to stay in bed until later in the morning. Interestingly, participants reporting tiredness occasionally insisted they can still do as much now as when they were younger and reduced energy would be explained away as temporary:

P3. *I have less energy but I think myself that the blood has gone down.*

Participants who had experienced falls and broken bones (especially hip fractures) in recent years did acknowledge that they are slower now. But even then participants were slow to acknowledge deteriorations and frequently blamed mobility aids as a factor in slower movement:

R. *Do you find it hard to get around?*

P16. *Sometimes the walker goes sideways.*

One sixty year old man stated that he still competes in Special Olympics but is now prone to injury. However, this was also minimized:

P. *At times I get a bit injured. I get hurt. I gets a bit hurt. Small bit. Not much.*

The researcher asked this man if he was slowing down with age:

P6. *Small bit, small bit. I can’t keep going till I be 100. I can’t keep going like a hare. The hare must stop sometime. I can’t keep going all the time.....My legs won’t be able to carry me.*

R. *Are they slowing down any bit?*

- P6. *A small bit, now. A small bit anyway.*
- R. *But you still want to run?*
- P6. *I do, I do.*
- R. *So you do as much as you can do?.*
- P6. *That's all I can do, Yeah. You can only do your best. That's all you can do. Do your best.*

Some participants reported onset of seizures with age, or an increased number of seizures in the case of lifelong epileptics. Onset of diabetes in recent years was reported by one man but he insists that this is not a problem for him and that his daily injections are “*not sore*”. In fact, no matter what condition was reported, no participant reported associated pain.

Participants generally reported sleeping well and enjoying a good appetite.

In relation to mental health one woman admitted that as she got older her head became “*more mixed up*”. She reported feeling stress as she got older and requiring strategies to help her with this. This stress she referred to is experienced as both nervousness in her stomach and confusion in her head. She said she uses a relaxation CD which works well for her and she spoke very positively about the benefits of a variety of therapies of which she avails. Another participant reported experiencing more “*worry*” with age, but managing this with medication. One woman spoke of her improved mental health over the past few years and explained that she feels that the best way for her to cope is to stay occupied:

- P22. *Keeping busy helps. I'm helping now with the garden fete. Being out there helps me to relax.*

7.6.3 Focus on the present

There was evidence across interviews that participants tend to focus on the present with numerous examples of here and now concerns. When participants were asked about being happy/unhappy participants often focused on what was happening at the present time in their response. For example, feelings of unhappiness were attributed to “*the internet is playing up*” or “*I cut my finger*”. There were many examples of present moment living and enjoyment of everyday pleasures. When asked what he is looking forward to in the future one man replied that he was looking forward to his supper. In fact, there were numerous examples of participants reporting that they were looking forward to the pleasure of the next meal or favourite treat, and one man was looking forward to enjoying his next cigarette:

R. *Would you like to travel some place again?*

P21. *I like to go down town for a cup of coffee and for my dinner.*

Another man indicated that tea and coffee are his main pleasures in life now, especially as he has no appetite for dinners. Participants mostly indicated that they only plan **one day at a time**:

R. *Do you ever plan what you are going to do next week or next month?*

P36. *No, no, no. I don't plan ahead.*

One participant explained why he does not plan:

P6. *'Tis no good planning ahead cos you might never make it. I remember a lad, he died there about four or five years ago. He got killed in a car crash. He wasn't twenty-one. He was going into town and he after drinking. He had a car crash on the Sunday, died on the Thursday. Wasn't he planning ahead for his 21st birthday, and never made it.*

While he says that he does not see the point in planning ahead because he may not “*make it*” he also says that he does not worry about the future and what it may hold. One man reported not looking forward to anything and that he has no future plans but that he is happy for his life to continue as it is.

7.6.4 Achievable goals

For the most part goal setting and looking forward centred around **immediate goals** over a relatively short time. In addition participants tended to set **goals around familiar experiences** with very few saying that they want to do something that they have never tried before. However, one woman dreams of visiting New York which would be a new experience, for her while another woman wishes to go to France or Spain, as she has never been on a sunshine holiday. Participants were generally confident that goals and plans would be achieved and only one participant said that she did not think her future dreams would be realized. She is a wheelchair user and feels that her support needs are too great for her goals to be achieved. Most participants' goals tended to be very **modest** and achievable. One woman who seemed content with her lot and was not seeking any change was prompted to think about goal setting by being asked what she would do if she won a lot of money. She responded that she would buy sweets, a book, a rose, and a banana. She also said she would like a dog and a cat and would like to travel on a train to Cork or Dublin. A number of

participants struggled with the abstraction of future planning and sought clarification, such as, “*Like what now?*”, or relying on the researcher to prompt them with ideas. In general, participants looked forward to more of what they already enjoy; more concerts and outings, more travel and shopping, more CDs, and more football matches. One woman said that all she wants for her future is:

P21. *To go out, and go often....doing as much, eating as much, and you're happy.*

Many participants were looking forward to their next birthday and some people approaching milestone birthdays were planning celebrations. One man had a very simple but clear goal for the future:

P20. *Me want to sing songs...Abba, Neil Diamond, Joe Dolan. That's it.*

Only one woman reported what has been a long-term dream for her. She wants to meet the captain of Arsenal Football Club:

P40. *The only player I love is Van Persie. He's my favourite. Always my favourite. I'd love to meet him. See what he looks like. Love it to happen.*

Three female participants had goals around their accommodation. One woman hoped that her self-contained apartment would be renovated, while another woman currently living in residential care hoped to move to a home of her own in time. A third woman living in a nursing home hoped for a room of her own. Generally though, participants reported that they would like things to stay the same. They want more of the good things that they currently enjoy and they hope that negative change does not impact on current enjoyable experiences.

7.6.5 Positive outlook

Participants were mostly positive in relation to their lives, the past, present and future, perhaps demonstrating what has been termed the ‘positivity effect’ (Mather and Carstensen, 2005) in respect to ageing. This term was used to describe a phenomenon whereby older people tend to take a positive view. The vast majority of participants said that they are currently happy and most also confirmed that they have always been happy. Asked exactly what makes participants happy elicited a variety of responses. One woman said “*coke*” (*Coca-Cola*) makes her happy. Others identified watching television, talking to people, going to bingo, gardening, family visits, and trips away, as sources of happiness:

P40. *I'm always happy. At least I have my family around me.*

P18. *Happy now, happy now, thanks be to God.*

Participants struggled to identify what makes them sad. Again a common response was “*I'm fine*”. In fact, many said they never feel down. Participants tended to identify someone or something that annoyed them as a source of sadness, or a current annoyance, such as another resident spitting. A few participants deflected questions on sadness by changing the subject entirely. One woman said she does not like to talk about sad things. She prefers to smile a lot but admitted that being happy all the time is difficult. Many participants also state that they never cry. Only one admitted to crying, although six participants shed tears during the course of their interview.

R. *Does anything make you cry?*

P23. *No, never.*

R. *Does anything make you sad?*

P23. *Never.*

In general, participants were also reluctant to admit feeling angry although this emotion was sometimes evident in relation to certain circumstance or conditions. Most people said that they could talk to someone when upset, and usually named their support staff or occasionally a sibling or parent as that person. As such, a general positive outlook was evident from interviews and almost all participants reported being happy at the present time.

Positive change with advancing years was reported, including social changes due to service developments and changes due to the development of improved paradigms of support.

Participants generally indicated that changes have been good:

R. *Lots of things have changed for you?*

P10. *They did – change for the better.*

People who now utilize a respite service experience this as a positive change and indicated that they would have liked to have had respite earlier in life:

R. *Is it better now that you go to (respite house) or before when you were at home?*

P23. *Better now. I love the house. Better than being at home with Dad.*

R. *What do you do now, that you didn't do before?*

P23. *Shopping, buy clothes, jumper, socks, shoes.*

R. *Are things better now or worse?*

P23. *Better.*

A number of participants are engaging in more activities now than they did when they were younger, and there were examples of people getting their first exposure to work experience in their fifties. A number of people reported they had recently got a computer. One woman who had lived at home with elderly parents throughout her adult life recently started attending day services and was delighted at how this has expanded her life, saying “*All my friends be here*”. Another woman in a similar position discussed about getting involved in fundraising and other activities since coming into services for the first time as an older adult. Reflecting on how she was at home compared to now she observed, “*I got good since I came*”. Another woman also reported getting involved in charity work and fundraising in recent years, something she had not done when she was younger. One man said that a positive change for him with advancing years is that he now has a hot whiskey every night before he goes to bed.

Participants spoke of **the past** with many positive and occasional negative recollections, but again positivity was the general theme in the stories, events, and experiences recalled. Christmases, First Holy Communion Day and Confirmation Day were all remembered with pleasure, and in fact, most participants seemed to remember their childhood fondly with some people describing this time as the best of their lives. Tiny details were held in memory and remembered as giving joy and happiness.

R. *Was your childhood happy?*

P7. *I was, faith, I was. Do you know what I used like long ago? When the people made currant bread.*

For participants who became more incapacitated as years past, childhood and early adulthood were remembered as a time of higher functioning and greater engagement with life. One man who now uses a wheelchair, remembers being happier when he could go independently to football matches. A participant with speech problems also remembers childhood as a good time for him when his impediment impacted less upon him.:

P6. *When I was thirteen I could talk. Nothing wrong with my speech that time.*

This man's overall impression is that people were happier in the past:

P6. *I'd say times long ago were away better. Better than what they are now. The people long ago they used to be happy out. The neighboursthey'd work for no money. If you ask a person now to do a job, they won't do it unless you give them money.*

This view was reiterated by another participant:

P25. *'Tis an awful world. The people were away nicer before.*

However, she says that although she feels the world is "getting worse" she does not allow this bother her or get her down. Participants reporting that the world was better in times past appear to derive comfort from their fond memories, rather than wishing that life had remained the same. Some participants, who had lived in residential schools in childhood however, remembered these years as unhappy. One woman would not even discuss her early years, protesting, "I can't think now, don't ask me". She does remember being unhappy as an adult living with her sister and welcomed the opportunity to come into residential care. She says she is happy now.

Photographs usually provided the prompt and the context for discussions of the past and participants mostly spoke favourably of neighbours, neighbourhoods, family and events, while using photographs as an aid for recall. Many participants recalled the past as being happy for them because of associations with their parents and experiences they had as a family:

P7. *We used to go to churches and go shopping and everything with my Mom.*

R. *Were you happy then?*

P7. *Yeah.*

Participants generally indicated satisfaction with **the present** and their current lives and circumstances. However, few could be specific. When prompts were provided, such as "are you happy with where you live?" or "are you happy with your room?" responses were generally positive. However, expressions of satisfaction with the present appear to be grounded in a desire for stability with people insisting, "I'm here for good now, they can't move me again". Once again, the phrase "I'm fine" was frequently used when people spoke about the present. When participants were asked for an opinion on something from the past compared to the current situation the tendency was to remain with the present:

R. *Do you think you were happier when you were younger or are you happier now?*

P27. *I'm happy now.*

This participant reflected on her life across the years and concluded that “*Everything has changed*”. However, she says that these changes have mostly been for the better. In particular, she was lonely during the years that she lived with her mother and enjoys more company now. While many participants were unable to give a reason why the present time seems good to them, one woman was very clear as to why she is happy.

P13. *Getting older is a great thing. Life gets a lot easier.*

While many participants indicated that they feel positive about some changes and no one welcomed onset of physical deficits, many more were neither positive nor negative towards change, but rather accepted it as an inevitable part of life. One man said he has no regrets, is happy with his life, and although not looking forward to anything in particular, is content to just take each day as it comes. One woman said that although she knows and feels she is getting older, she never thought she would live this long and so welcomes these changes.

7.6.6 Coping Patterns: summary of analysis

Effective coping which facilitated the management of change due to ageing was demonstrated by participants. Specifically, participants gave clear examples of positive coping responses and a general optimism was evident from interviews in relation to personal health, goal setting, and future plans. In relation to health, participants sought to minimize deficits and any deterioration and portray normalcy rather than pathology. It is possible they have done this throughout their lives in order to generate a positive response from others (Cummins, 1997). Participants spoke of using coping strategies such as using social support, ‘fighting’ advancing years, and using relaxation, in order to live well and to age well. Participants demonstrated the ‘positivity effect’ in respect of their past, present and future lives. A particular focus on the present time was demonstrated by participants and helped to facilitate day-to-day coping and management of more enduring change.

7.7 Conclusion

Thematic analysis of the data as presented in this chapter is central to a theoretical model of understanding ageing in this population. The findings show that in order to understand how

participants change and adapt as they get older, life course experience must be taken into account. The findings therefore support a lifespan theory of ageing for men and women with lifelong intellectual disability and confirm that it is not possible to separate whole of life experience from ageing experience. Specifically, the importance of five psychosocial areas and how these are experienced as the person grows older is highlighted:

1. the ability and opportunity to enact self-determination
2. meaningful social relationships and quality social experiences
3. physical and emotional safety and security
4. the pervasiveness of loss and how this is managed
5. coping patterns.

In addition, links between these psychosocial areas are in evidence. For example, lack of support around enacting self-determination is found to impact on the experience of safety and security, coping patterns influence the management of change and loss, and feeling unsafe often leads to the curtailment of social participation. Thus a theory of ageing for this population must take account of the dynamic nature of their psychosocial world. Central to an explanation of ageing in people with lifelong intellectual disability is an understanding of the role of appropriately timed and individualised supports. A support model offers the best understanding of how ageing is experienced in this population, as it takes account of individual difference and accommodates minority ‘voices’. For example, only 11% of the study population report abuse, but this finding is of major interest to the wider disability community in understanding ageing in this population. Similarly, while many participants demonstrate effective coping patterns, it is crucial to explore the experiences of those who live with fear and worry, so that they may be appropriately supported to adjust better to their ageing experience. The following chapter will build on these findings to develop a theory of ageing for this population. Practical applications of the theory will also be proposed.

Chapter Eight – Development of a Psychosocial Theory of Ageing with Lifelong Intellectual Disability

8.1 Overview

A life course understanding of ageing with lifelong intellectual disability emphasises the connection between individual lives and the historical, social, cultural, and economic, contexts within which lives unfold. In order to hypothesize a theory of ageing for this population this chapter will begin with a case history of the life of one specific participant. The chapter will then provide a short discussion on life course in relation to participants generally, before presenting the key findings that contribute to theory development. A model of the new theory will then be demonstrated and the postulates of the theory outlined. The chapter will conclude by examining practical applications of the theory.

8.2 Kate's Story

Kate is seventy years old, and by her own account, she has had a difficult life. As the eldest of a large family of girls she recalls being teased by her sisters in their youth, and feeling that she was different as result. She attended the local school for a short time but found reading and writing difficult. She was withdrawn from school at a very young age and she still feels sad about this. She would have liked to have learned to write her name. However, she copes with illiteracy by listening very well. It seems that she began to develop this skill early in life and can repeat conversations between her family members from sixty years ago.

When Kate left school she continued to live at home with her parents. Over time her sisters left the family home and each of them got married. Kate's life however, stagnated. She had no money of her own. She did not go out socially, except to Sunday Mass. Her mother bought her clothes. As Kate's mother got older Sunday mass was curtailed until they stopped going altogether. By the time Kate was in her forties she did not go out socially at all, but passed her time looking after hens. She also had two donkeys and a dog to care for. This was not the life that Kate wanted but she does not complain. However she did mention that, "*when I was*

at home with Mom and Dad I couldn't have no opinion", recognising that she had no real voice at that time. It seems that Kate had little contact with her sisters during their middle adult years but she speaks well of them and is grateful for any attention she receives from them.

Kate's life changed when she was in her fifties and her mother passed away. She developed serious mental health problems and was admitted to the acute mental health unit of the local hospital. In the meantime her father also became unwell and he was admitted to the eldercare unit of a local community hospital. On discharge from the acute unit Kate joined her father in the same long stay eldercare facility. When Kate's father died a few years later her situation was referred to the local intellectual disability services. Kate's life began to improve after that. Sadly however, she could not return to her home and her community as the family home had been sold. Kate was not consulted in this matter and still grieves the loss of her home and contact with former neighbours.

Kate now lives in a residential house with three others and strongly affirms feelings of gratitude for her life as it is now. She embraced positive change from the time she came into services, and with individualised supports, soon began to speak up for herself. *"If I want my opinion, I'll talk my opinion"* she now says. Her special interest is clothes and she says she loves *"style"*. She laughs at how she used to look when she was younger and dislikes photographs of herself taken before she came into services. She says she is *"swanky"* now. She has a strong sense of herself, who she is, and what she wants. Going forward she wants to buy more clothes. She is very grateful for everything she has, and although she has little contact with family, looks to those around her for companionship. She has done her best to continue relationships with family after coming into services by spending all of her disposable income buying gifts for young grand-nieces and grand-nephews, but as the children grew up and years went by, family contact faded. She misses having contact with children and takes interest in the lives of staff, and their children and grandchildren. When asked what it is like to have little contact with her family she admits, *"Well I feels it sometimes, but the only thing is, I'm fine"*.

Kate has had a very difficult life but remains positive. Despite recounting many experiences of poor control, disappointment, and loss throughout her life, she maintains that *things is worked out very well*". She seems determined not to dwell on the past and has nothing but

praise for those supporting her at the moment. Referring to upsetting experiences of the past she reiterates phrases, such as *“’Tis nothing I can do about it”*. When asked about the future Kate merely states that she does not want any more change. She says: *“I have a good garden outside and what more do I want, like?..I’m happy the way I am. I’m grand the way I am.”* Kate says she sometimes feels *“lonesome”* since her parents died, but she will get *“a big stone”* made for their grave. She remembers them often and always has Mass said for them on the anniversaries of their death.

Kate did not prepare for retirement. While she used to help the chef in the kitchen of her day service she says she has now cut back on this as she was finding it too tiring. She rests each morning to manage the tiredness that has come with age. She realizes she is getting on in years but she does not dwell on this. She observes that her birthday is coming up and that she could be *“gone for the next one”*. She lives for the present. She attends the local community programme for the elderly each afternoon. Everyone remarks how well she fits in there.

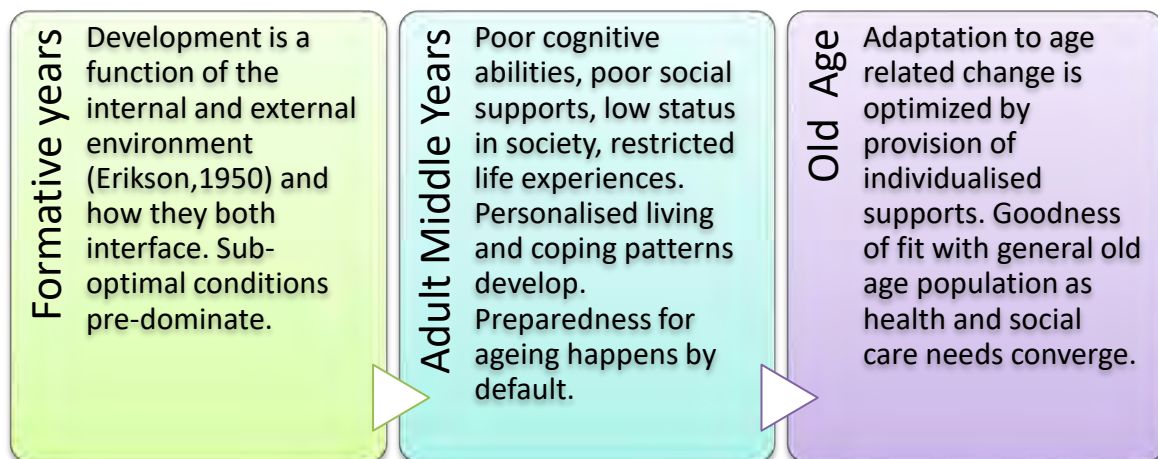
8.3 The life course trajectory

Kate’s story and the accounts of other participants of their experiences of living and ageing show that from early life through to the present day this cohort of people have had to cope with adversity. Accounts of early separation from family and community, of segregation and difference, and of teasing and bullying, all illustrate exposure to adverse conditions in childhood. Through the middle years of life people spoke of being different from siblings and peers and the lack of opportunity to experience further education, intimate relationships, paid work, marriage and having children, driving a car. Advancing years brought poor health and considerable unwanted change, such as loss of key support people or changes in residential placements. Communication difficulties, loss, lack of choice, disempowerment, and poor control over personal finances, were common features throughout their lives. Many such factors were compounded by advancing years and resulting changing need.

Sadly, it is all too clear that participants have lived their whole lives in challenging circumstances. Yet the development of coping strategies to navigate life and optimize survival is also evident from interviews. In addition, it was found that with individualized supports growth is possible as the person ages. In instances where those availing of services for the first time in their later years, they demonstrated a rapid period of development consistent with rights-based supports, until parity with others using the service was attained.

Finally, as in a study by Holland (2000), some goodness of fit with the general ageing population was observed as health and social care needs of those ageing with and into disability converge as years advance. Kate and other participants attending community based elder care programmes appear to enjoy this experience and to fit in well.

Diagram 10: Lifespan trajectory of development:



8.4 Key findings informing theory development

- Ability and opportunity to enact self-determination are found to be limited throughout life with negative impact on quality of life as years advance. Lifelong experience of barriers to choice-making, dependency and disempowerment with concomitant vulnerability has led to an acceptance of an external locus of control. However, willingness and ability to change and develop with the right supports, is also observed. Participants indicate that as they get older they want to live lives of their choosing and to be able to have more control over how to spend their money.

Key Finding: Supporting self-determination can bring about positive change as people age.

- Experiences of loss permeate and impact all aspects of life. It is found that adaptation to loss as years advance, due to change in accommodation, lost relationships, decline in health, can take place seamlessly as change and adaptation are integral to whole-

life experience. Loss is managed better in the context of a spiritual belief system and specifically a belief in an afterlife. Loneliness is evident from accounts of loss of key persons and a poor support system to buffer such losses. Close bonds are not replaced by further close relationships. Death and dying in relation to oneself does not seem to be a significant concern for participants.

Key Finding: Spiritual beliefs mediate potential stress of multiple and ongoing losses.

- Social participation has a key role in ageing well but change in how social relationships and social engagement is experienced as the person gets older is observed. As family and peers die, participants typically have fewer relationships as they age. Quality relationships become key as quantity diminishes. Family relationships remain crucial and few people have highly valued relationships outside of family. Cross-generational contact is highly valued. Participants report social and emotional wellness from contact with pets.

Key Finding: Quality social relationships are valued and must be fostered and facilitated as important support persons die.

- When compared with the general ageing population where retirement is often a time for new experiences, participants tend to engage in a relatively small number of activities as years advance. Boredom is an issue for a number of participants. However, participants demonstrate openness to growth, development, and new learning, along with an eagerness to keep up to date with and be involved in community affairs. Community participation and access are valued as people age, but certain barriers to access limit possibilities. Specifically, transport and a supportive companion are often not available or prohibitively expensive.

Key Finding: Older age can be a time for growth and development when meaningful social participation is encouraged and supported.

- Experiencing safety and security are key to ageing with confidence. Daily routines create predictability, which in turn, boost confidence. Frailty, and associated fear and falls, impact on people as they age causing them to feel unsafe. Many participants embrace the use of mobility aids and other environmental supports and in such cases

adaptation to changing physical need is evident. Adaptation is found to be more difficult for other participants. Stress due to change, changing need, and associated worries, is found to be a factor impacting on ageing with confidence. People experiencing physical decline may respond by withdrawing from activities and community engagement due to fear or worry.

Key Finding: Support is required to adapt to changing need in order to age with confidence.

- Stress due to peer-to-peer abuse results in people feeling unsafe. Abuse is experienced by participants in situations when (1) age-related change and additional frailty meant that the person becomes more vulnerable in a mixed ability setting, and (2) when another resident developed dementia with associated challenging behaviour.

Key Finding: Managing personal safety as people with intellectual disability get older is key to physical and emotional well-being and ageing well.

- Participants are generally focused on present day living and make efforts to make the best of every day. In addition, positive coping responses, minimization of health problems, setting achievable goals, and a positive outlook on life and living, are all observed. A general sense of optimism is evident from interviews in relation to personal health, goal setting, and future plans. Participants exhibit the ‘positivity effect’ in respect of their past, present, and future lives. These coping patterns are observed to be effective in navigating age-related change.

Key Finding: Coping patterns are individual but generally positive and help navigate change due to ageing.

Summary of findings informing development of a psychosocial theory of ageing with lifelong intellectual disability:

General:	<ol style="list-style-type: none"> 1. Ageing experience cannot be set apart from life course experience. 2. Appropriately timed and individualised supports are required to adapt to changing need in order to age with confidence.
Specific:	<ol style="list-style-type: none"> 3. Supporting self-determination brings about positive change as people age. 4. Spiritual beliefs mediate potential stress of multiple and ongoing losses. 5. Quality social relationships are valued and must be fostered and facilitated as important support persons die. 6. Older age is a time for growth and development when meaningful social participation is encouraged and supported. 7. Managing personal safety as people with intellectual disability get older is key to physical and emotional well-being and ageing well. 8. Coping patterns are individual but generally positive and help navigate change due to ageing.

8.5 A theory of ageing with lifelong intellectual disability

When overall findings are synthesised a life course theory of individual development and adaptation emerges which offers an explanation of ageing in men and women with lifelong intellectual disability. Specifically, the findings support a theory based on an understanding of five psychosocial areas and how these are experienced as the person grows older. A support model is central to understanding the theory as each of these areas must be sustained in order to bring about positive change and functional adaptation.

A PSYCHOSOCIAL THEORY OF AGEING WITH LIFELONG INTELLECTUAL DISABILITY

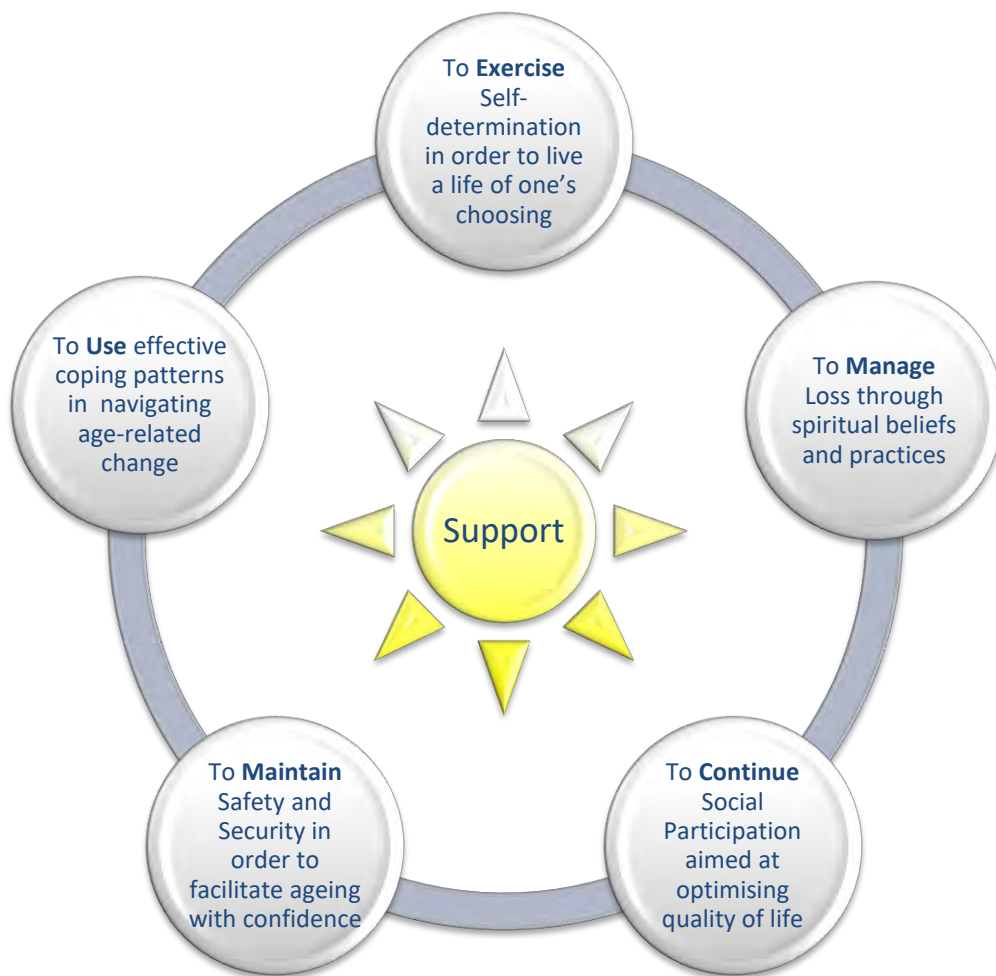


Diagram 11: Five area support model of ageing well with lifelong intellectual disability

Summary of a psychosocial theory of ageing with lifelong intellectual disability:

The key psychosocial factors impacting on ageing with lifelong intellectual disability are:

- *exercising* Self-determination to live a life of one's choosing
- *maintaining* Safety and Security to support ageing with confidence
- *continuing* Social Participation to enhance quality of life
- *managing* Loss through spiritual beliefs
- *using* Effective Coping Patterns to navigate ageing

If each of these actions is on a continuum from 'poorly achieved' to 'well achieved' the ageing experience is optimized as the person is supported to move towards the 'well achieved' end of the continuum. Individualised supports are required to progress actions and movement in one psychosocial area can impact positively on other areas.

Key postulates of the theory are:

- Psychosocial wellness in ageing is associated with *exercising* Self-determination; *maintaining* Safety and Security; *continuing* Social Participation; *managing* Loss; *using* Effective Coping Patterns.
- Wellness is enhanced when these actions are supported in an individualised and timely way.

- The theory is dynamic and conceptualizes a continuum of psychosocial wellness in which an increase in support in any of the five areas can bring about positive outcomes in other areas.

8.6 Using the theory

The theory is understood in terms of change and progress, and a developmental framework also explains how it can be used in practice. The theory can be used to:

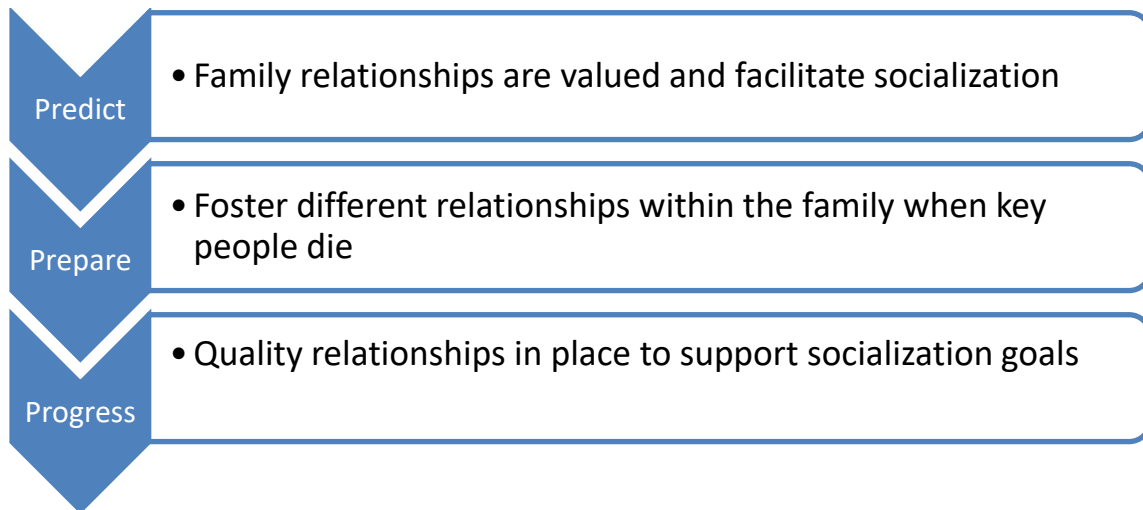
- a. **predict** psychosocial change for an ageing intellectual disability population
- b. **prepare** for these changes in a timely and supportive way
- c. help **progress** to a successful aging experience through person-centred planning and having resources in place to meet changing need

Core predictions in relation to how this population change and adapt as the years advance are as follows:

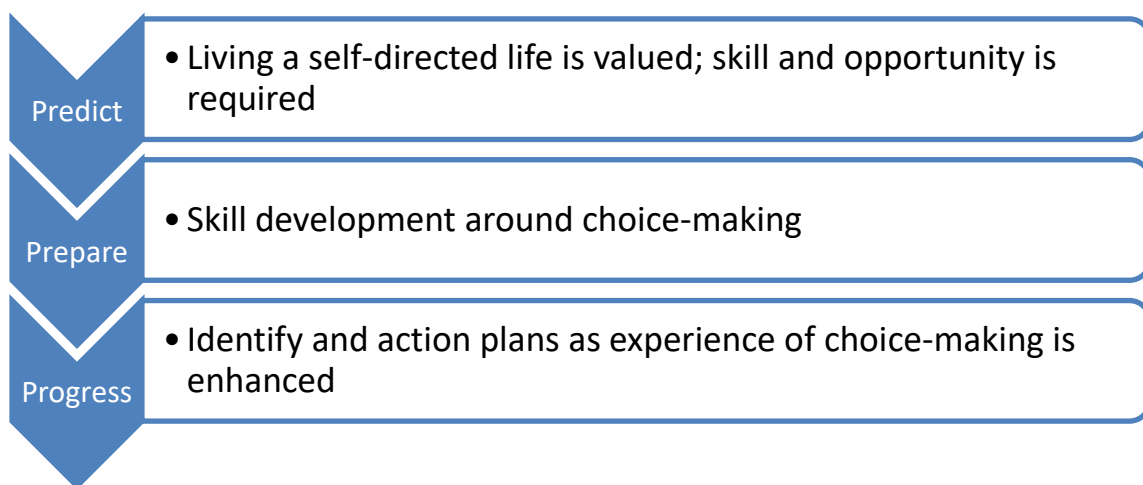
- People want lives of their choosing as years advance and need supports to facilitate this
- People value social participation with quality relationships and meaningful experiences
- A spiritual life mediates stress due to loss as people age
- Safety and security are the cornerstones of ageing with confidence
- Positive coping patterns are adopted to manage age-related change

These predictions can be further broken down and developed under each core prediction such as the desire to have more control over finances, need to live without fear of abuse, and how contact with pets engenders wellness. Predictions can be used to prepare for ageing through goal setting, skill development, person-centred planning, and resource planning. For example, preparation through enhancing skills in choice-making means people are better equipped to enact plans and lead more self-directed lives. Preparation can involve maintaining or fostering social relationships in middle years as key relationships are lost. It can entail facilitation of spiritual practices through continued involvement with local places of worship. As ageing is an ongoing process, appropriate preparation for ageing must be continually supported so that progression to good outcomes as years go by is more likely to take place. The following demonstrate how the new theory can be used in practice:

Example 1:



Example 2:



8.7 Conclusion

The study set out to develop a theory of ageing. The data from the findings has been used to generate a life course theory of ageing specific to men and women with lifelong intellectual disability. The theory offers an explanation of the ongoing impact of life experiences on adaptation to ageing. It purports that ageing well is a function of internal and external factors relative to the person and the appropriateness and timing of supports they receive. The next chapter will revisit the idea of successful ageing and will explore how these findings can be

used to optimise quality of life for this population. A way of supporting ageing through timely planning and individualised supports will also be presented.

Chapter Nine – Successful Ageing Revisited

9.1 Overview

The literature review elicited the important question: can men and women with intellectual disability age successfully? The findings show that people with lifelong intellectual disability can age with better outcomes when key psychosocial areas are supported through the life course, and with more focused supports as years advance. As such successful ageing in this population is dependent upon the availability and implementation of individualised, timely supports commensurate with changing need. While the previous chapter presented a theory of ageing which can guide good outcomes in ageing with lifelong intellectual disability, this chapter focuses more closely on how to bring this about. Specifically it looks at how the new theory can be used in tandem with the empirically-based model of adult development and ageing of Selection, Optimization and Compensation (Baltes and Baltes, 1990). It is suggested that data generated from use of a planning tool developed from the findings can inform the selection, optimisation and compensation process in order to drive self-efficacy and growth as years advance.

9.2 Supporting competencies in advancing years

Individualised supports at the right time can have a marked bearing on continued or even improved quality of life as people age. If, for example, support needs respecting ambulation are not identified and the person falls, the result can be fear, withdrawal, or even worse if enduring physical disability follows. While studies show that there is a need to support older people with intellectual disability to adapt to changing need as years advance (Newberry *et al.*, 2015; Heller and Harris, 2012) it is clear that neither family nor service providers are assuming responsibilities to assist this population to plan in this way (Bigby and Knox, 2009). The reasons for this may be twofold: (1) the newness of this particular ageing population and a poor understanding of their ageing experience; and (2) the lack of appropriate planning tools for goal-setting around growth and development in the context of functional decline. Nevertheless, many participants in the current study demonstrate that they already utilize strategies to optimise functioning. These strategies, as described by participants, appear to have a goodness of fit with the model of selection, optimization and

compensation (SOC). It is proposed then that the SOC model is an appropriate basis for development of a planning tool for ageing in the intellectual disability population.

While Baltes (2003) and Freund and Baltes (1998) questioned the usefulness of the model for those with more profound limitations, an adaptation of the model to include individualised personal support can be used to good effect to maintain competencies and age well. An adapted SOC model can be used as a practical framework to demarcate psychosocial changes and plan appropriate supports. Aligning the findings of the study with a SOC evaluation is useful as it embeds outcomes in the social model of disability and critical disability studies and explains the effects of ageing in terms of a bi-directional engagement with the wider physical and social environment. It is proposed to adapt the model by using the term ‘supported’ in relation to each of the three elements of the model: *supported* selection (selecting an area of age-related change); *supported* optimization (supporting the person to maximise competence in this area); *supported* compensation (install modifications to compensate for losses).

Table 4: Adapted SOC Framework

SUPPORTED SELECTION		SUPPORTED OPTIMIZATION		SUPPORTED COMPENSATION	
What age-related change is identified?	What is being selected for attention?	How to optimize the person’s competence or gains?	What supports are required to optimize competence or gains?	How to compensate for functional change?	How will compensation happen? Who is responsible?

This adapted SOC model can be used by carers and frontline staff to support the person to maintain competencies and to continue valued engagement with life as years advance. It can accommodate psychological and social change factors and help illustrate the impact of ageing. Issues related to self-determination, safety, loss and spirituality, socialization, and coping, can be explored within this model in order to arrive at best outcomes for the person and ongoing development into older years.

9.3 Wellness in Ageing Tool – Intellectual Disability (WiAT-ID)

In order to be able to identify age-related change across psychosocial areas in a timely way the findings of the study have been used to develop a planning tool comprising of twenty questions which can generate data required to commence the adapted SOC process. The *Wellness in Ageing Tool-Intellectual Disability (WiAT-ID)* is included in the appendices (See Appendix L). The data generated from completion of the twenty item instrument identify areas of age-related change. The impact of change on the person is examined in order to *select* areas for attention. For example, if it emerges from the data that the person no longer visits home for weekends, then ‘valued relationships’ may be selected for attention and the adapted SOC framework can be used to develop areas such as “maintaining contact with home community” or “facilitating sibling relationships”.

The example below demonstrates how the model can be used by carers and frontline staff to support the person in maintaining competencies and to get the most from life. The model is dependent on the provision of personal support by key individuals and the use of a variety of mechanisms to identify age-related change (in addition to the WiAT-ID). This approach is consistent with the Health Information and Quality Authority (HIQA) requirements in relation to older adults with intellectual disability living in residential services. Inspection Reports by the Authority (available online at www.hiqa.ie/social-care/find-a-centre/inspection-reports) enunciate the full expectation that age-related change is formally recorded in service settings, using suitable monitoring and measuring instruments, and that when change is identified a response pathway made available.

Table 5: Supporting Competencies in Ageing with Lifelong Intellectual Disability Using Selection, Optimization, Compensation (SOC)

SUPPORTED SELECTION		SUPPORTED OPTIMIZATION		SUPPORTED COMPENSATION	
What age-related change is identified?	What is being selected for attention?	How to optimize competence or gains?	What supports are required to optimize competence or gains?	How to compensate for functional change?	How will compensation happen?
Reduced contact with family as person can no longer go home due to difficulty with mobility	Valued relationships	Actively foster valued relationships with family members	Arrange home visits with 1:1 support from staff	Physical aids are required i.e. walking frame	Staff take responsibility to arrange physical aids are in place for home visits
No longer attends active ageing group due to decrease in energy levels	Social engagement	Attend one day instead of three days	Ensure adequate rest the day/night beforehand	Individual transport instead of public bus	Staff arrange for taxi pick up and drop off
Person no longer attends Sunday Mass due to hearing deficits	Spiritual practice	Sunday Mass to be streamed to residential house	Assist person to contact local church for information on live streaming i.e. mass times	Hearing aid required and quiet environment during Mass times	Staff ensure hearing aid is in place and person has individual use of TV during Mass times
Withdrawal from activation due to agitation in large groups	Coping skills	Choose small-group activities	Attend for short period	Sit by the door and ensure easy exit route	Group facilitator remains alert to the person's need to exit

The model allows for continual change and adaptation. Areas can be re-examined as change occurs and supports adapted or increased to provide best fit with changing need. The model requires a proactive approach on the part of carers in order to support the person in identifying change. In addition to the *WiAT-ID*, community supports such as physiotherapy, occupational therapy, and speech and language therapy, as well as person-centred plans and a range of care plan checklists documenting such matters as falls, continence, epilepsy, dementia, and so on,

are integral to assessing and responding to age-related change. This competency approach to ageing well focuses on maintained abilities and on what the person can still do. Competencies are therefore supported and functional decline is managed.

Although Baltes and Baltes describe SOC as a psychological model of successful ageing, the adaptation of the model proposed here involves a social component as each element of the model must be supported by others. Thus in relation to the intellectual disability population the model can be understood from a psychological and a social perspective. The fact that the model is embedded in how the person interacts with the environment, and vice versa, further strengthens a social understanding of the model. In developing the model Baltes (1987) emphasised that investing resources into specialized areas in order to enhance efficiency and improve performance demands time, effort, and motivation. In the adapted version of the model, the support system around the person, and in particular frontline staff and close family members, must prioritise the required time, effort, and motivation in order to drive change.

9.4 Conclusion

While the wider research shows that disability does not necessarily preclude the possibility of successful ageing (Newberry, 2015; Romo *et al.*, 2012) people with intellectual disability need more support to transition to successful older adult years (Bigby, 2011). The support framework of the adapted SOC model, together with the WiAT-ID can be utilised to steer continuous growth and development and to ensure that valued activities are not dropped as soon as difficulties arise. The framework allows for continuous change and planned adaptation as change happens, and provides a way of working through and finding solutions. In this way, as needs continue to change, supports also change.

Objective categorization of successful ageing is difficult to determine or to define in relation to atypical groups, particularly when there is pre-existing compromise across many constructs of ageing, especially in terms of health and dependency. In his explanation of successful ageing Janicki (1994) took account of the fact that individuals had varying starting points in terms of pre-existing levels of functioning. This of course means that individual aspirations will also differ, and therefore objective measures should also be differently calibrated for those with lifelong challenges. The support framework outlined in this chapter is designed as a way to action those individual aspirations so that we are not simply witnessing merely additional years of existence for the intellectual disability population, but also a good quality of life.

Chapter Ten – Discussion

10.1 Overview

This study focuses on the gap in empirical research with regard to the subject of ageing with lifelong intellectual disability and aims to redress the current absence of specific theorization in this field. The literature review outlined why a psychosocial theory of ageing with lifelong intellectual disability is merited and offers a rationale for the study. The findings aim to transpose the data collected into a meaningful elucidation of ageing in this particular group and provide the foundational baseline of information and knowledge for further research.

This chapter examines how the findings and the new theory align with current theories of ageing developed around the general ageing population and how this study is positioned relative to the extant research, practice and policy within the fields of intellectual disability and ageing. Ways in which the new theory may complement general ageing theories are presented, and the implications for future research, practice, and policy, arising from the findings fully addressed. Finally, the contribution of the study to the field of ageing and intellectual disability is evaluated.

The areas of the findings that highlight divergence and convergence relative to the general ageing population are discussed firstly, in order to contextualize the research in terms of the broad study of gerontology. Areas of divergence underline the additional vulnerabilities experienced by the intellectual disability population and the need for additional supports to manage age-related change, while areas of convergence show some goodness of fit with men and women ageing into disability as years advance, especially around health and social care needs. The benefits of accenting similarities in experience and needed supports rather than focusing on differences are therefore discussed.

10.2 Differences in ageing experience relative to the general population

The findings support extant research which shows that the typical life experience of people with lifelong intellectual disability differs in significant ways from that of the general population (Foundation for People with Learning Disabilities, 2002; Bigby 2004; Mencap 2003; Bigby *et al.*, 2011; Newberry *et al.*, 2015). As a sub-group of the community Wark *et al.* (2015) found that those ageing with intellectual disability are substantially disadvantaged,

while studies also revealed that potential vulnerability is further exacerbated in this population if they reside in a rural location (Dew *et al.*, 2013; Eley *et al.*, 2009). Heller and van Heumen (2013) contend that many persons with disabilities experience an accumulation of restricted opportunities and major inequalities throughout their life course which affects their ageing process in different ways from their non-disabled peers. The following diagram provides a snapshot of main areas of divergence between the findings of the current study and the general ageing population:

Diagram 12: Differences in ageing experience relative to general ageing population:

Self Determination	Loss/Spirituality	Social Participation	Personal Safety	Coping Patterns
<ul style="list-style-type: none"> • Experience and opportunity to enact self-determination throughout life is limited. Greater vulnerability in later years due to skills deficits. • Lifelong dependence impacts on self-efficacy and locus of control in ageing. • Limited control over personal finances and lifelong social welfare dependence leads to poorly resourced later years. 	<ul style="list-style-type: none"> • Exposure to loss is lifelong and pervasive so age related loss is managed as a normal part of living. • Emotional impact of loss of important others, i.e. a parent, is high as significant relationships are not replaced 	<ul style="list-style-type: none"> • No Spouse, children, grand children means small support network in old age. • Lifelong barriers to making and maintaining friendships means no friendships outside of family and paid carers. • No experience of paid work and social value attached to this. • Limited social roles. • Barriers to community access: no one can drive a car; few can access the community unaccompanied. 	<ul style="list-style-type: none"> • Lifelong physical and health challenges and atypical living arrangements leads to additional vulnerability. • Service based lives leading to exposure to challenging behaviour, stress and worry with additional vulnerability as years advance. 	<ul style="list-style-type: none"> • Acquiescence may lead to portraying "I'm fine" to carers. Higher index of suspicion required around health concerns, and more support needed to express needs and wants. • Coping with age-related challenges (health concerns, disempowerment, restricted community access) for the whole of life, so old age may not be a qualitatively different time of life. Transition to older age may happen seamlessly.

The above table shows that the psychological and social experiences associated with ageing are imbedded in the life course. One significant area of divergence from non-disabled peers is self-determination. The general ageing population will typically have lived their lives in different economic and social conditions (Bickenbach, 2012), in control of personal decision-making, and managing personal finances. People with intellectual disability age with little experience or opportunity to enact a self-directed life and are therefore less likely to have a life of their own choosing in later years. In addition, personal safety and security is a real concern for participants and is an area of high vulnerability due to life-long disadvantage. Exposure to adverse life events and environmental stressors such as violence, poverty, and sexual abuse, is found to be higher in this population than their non-disabled peers (Wigham and Emerson, 2015). While the findings of this study did not reveal sexual abuse, exposure

to a broad range of adverse experiences throughout life and into old age is nonetheless reported.

A weak social system in later years is also observed as participants (with one exception) had no spouses or children and generally relied on a more fluid network of support such as siblings or paid carers. Experience of poor social value, living on social welfare, health concerns, loss, and powerlessness are integral to their whole of life experience. Paradoxically, this means that the participant population may be better prepared for ageing than the general population as transition to later years may happen seamlessly. This aligns with findings by Jenkins (2010) who demonstrated that having faced discrimination and barriers to relationships and opportunities throughout life, the impact of old age on people with intellectual disabilities may be reduced. In addition Kahlin *et al.* (2014) found that age-related physical change may not be an issue for people ageing with intellectual disabilities as they have always been involved with services for the disabled. The participant population presented with a degree of resilience in their adaptation to ageing with coping strategies in evidence such as minimization of difficulties, as was found also in a study by Lloyd *et al.* (2007), and the normalisation of experiences of loss. As such, a degree of positive adaptation to ageing as a direct result of life course conditions and experience was observed. The following is a table drawn from the findings illustrating positive adaptation to ageing:

Table 6: Factors specific to an intellectual disability population in adapting to ageing

Participants may transition seamlessly to older age, having had lifelong experience of psychosocial factors associated with ageing such as, poor control, managing deficits, disempowerment, dependency, and often ill health.
Old age is a time when participants find a better fit with peers in the general population. Comparison with same age peers in other periods of life; pre-school, school age, teenage years, and young adulthood show greater disparities and poor acceptance. Disparities in functioning are not as great in older age when health and social care needs can converge.
The impact of age-related decline in health and slowing down is ameliorated by the fact that complete independence was never attained and participants have lifelong links with necessary support services.
Participants appear to come to old age with a degree of resilience and acceptance having experienced multiple and pervasive hardships and losses throughout life.

10.3 Seeking common ground - an inclusive agenda in research, policy and practice

While life experience for the intellectual disability population diverges from the general population across a range of areas, as the years advance these life course trajectories present similar challenges and opportunities (Bickenbach *et al.*, 2012). Changes related to physical ageing such as reduced mobility, decreased cognitive ability, and changed health status, are factors which impact both those ageing with disability and the general ageing population alike (Ellison *et al.*, 2011). There are now calls for greater collaboration between these two populations as the overlap and shared goals are acknowledged (Lightfoot, 2007). In Ireland the *National Positive Ageing Strategy* (NPAS), 2013, identifies the key psychosocial factors impacting on ageing as cultural and social participation, health, retirement, transport, housing, safety and security, elder abuse, financial security, and the built environment. Evidence from the study confirms that these same factors impact on those ageing with lifelong intellectual disability. Some positive news for all ageing populations in Ireland is that the NPAS aims to prioritise these areas going forward (pg.11). However, the disability sector must be positioned alongside all other ageing groups in order to benefit from such a policy development and as such the ground work in terms of working co-operatively with the wider ageing sector through dissemination of knowledge, sharing of resources, cross service training for staff, and cross sector research initiatives need to get under way immediately. The disability sector must aim to ensure that those ageing with disability are on the map as a visible sub-group within the ageing care system. This is also a core principle of the current research study. Bigby (2002) argues for this type of cohesive thinking and for developing partnerships and joint-planning which eliminates cross and intra-sector obstacles to accessing appropriate services.

The concept of cross-sector collaboration and shared services is gaining momentum and there are increasingly more voices from the fields of research and policy, calling for more attention to the intersection of ageing and lifelong intellectual disability (Kahlin *et al.*, 2013; Bickenbach *et al.*, 2012; Davidson *et al.*, 2004) and a focus on commonalities rather than differences for the benefit of all. Specifically in the area of research, Davidson *et al.* (2004) argues that the scientific fields of geriatrics and gerontology are developing a body of information of which data on ageing in persons with intellectual disability should be a subset. They state that “It would be theoretically counterproductive and fiscally inefficient to establish and expand scientific inquiry on ageing and ID independent of this substantial body

of scientific information” (p.4). However, there have been a number of missed opportunities, specifically in relation to the English Longitudinal Study on Ageing (ELSA). This study is currently on its fifth wave of data collection, and while it does provide a rich source of data on older people it does not adequately address the sub-set of older people with intellectual disabilities (Walker 2015). When the research community in Ireland commenced the Irish Longitudinal Study on Ageing (TILDA), an Intellectual Disability Supplement (IDS) was included and is currently disseminating findings from Wave 2 of data collection. As such, the project as a whole is bridging the information gap between the two sectors, and providing rich and up-to-date information to inform policy and practice across all ageing populations in Ireland.

An inclusive policy-making agenda can also benefit both sectors and European Union policy is beginning to reflect this. The Graz Declaration on Disability and Ageing was produced as part of the June 2006 European Conference on Ageing and Disability to amalgamate matters of concern across both the ageing and the disability sectors. The Declaration aimed to establish a bridge between ‘ageing people with disabilities’ and ‘older people with disabilities’ by addressing such principles as equal opportunities, non-discrimination, and self-determination, in respect of both groups. While the Graz Declaration was a first attempt at developing an integrated European document on disability and ageing, it was soon followed by the Barcelona Declaration on Bridging Knowledge in Long-Term Care and Support (2009). Internationally too there is recognition of the value of common policies across ageing sectors. The Toronto Declaration on Bridging Knowledge, Policy and Practice in Ageing and Disability (Bickenbach *et al.*, 2012) was one outcome of the Growing Older with a Disability Conference held in Toronto in June 2011. The Declaration invites stakeholders across the globe to support and implement an action plan aimed at promoting ageing and disability knowledge, policy, and practice. At the core of these relatively recent policy initiatives and European and international directives is increased recognition of a biopsychosocial approach to disability and support of individual human rights. The findings of this study contribute to the knowledge in this area, specifically in terms of what is known about psychological and social factors in ageing with intellectual disability. While Turner (2015) alerts the intellectual disability community to the value of keeping abreast of policy for all older people so that people with disability may benefit from policy and practice aimed at improving the lives of older people generally, many others are now advocating for a

proactive and far-reaching bridge-building approach which is likely to change the landscape of ageing services more significantly. Bridge-building requires developing a common terminology and knowledge base (Bichenbach *et al.*, 2012) among stakeholders and merging knowledge and expertise in respect of those ageing with and ageing into disability for effective and efficient practices across both sectors and better lives for all. This study advances the concept of bridge-building by ring-fencing the commonalties and differences in the ageing experiences of those with and without lifelong intellectual disabilities. The study also sheds light on what the intellectual disability sector can contribute to the ageing care sector generally. While the ageing care sector has traditionally been concerned with managing deficits, the disability sector has spent the last two decades developing practice and policy based on competencies, individualised supports, and individualised planning. As such, a substantial body of knowledge and expertise has developed within community care services for those with intellectual disability which could make a valuable contribution to the ongoing development of research, policy, and practice, in respect of the general ageing population. This is particularly the case in relation to dementia services as supporting cognitive impairment is core to service provision in the intellectual disability sector.

10.4 Where does the research fit with the wider research on intellectual disability and ageing?

The findings are situated within a social model of disability and demonstrate that outcomes in ageing are a function of both the ageing process and how these changes interface with the environment. From the theoretical standpoint of social models of disability both the person and the environment have adaptive capabilities (Putnam, 2002) and findings concur that an unsupportive environment compounds, and indeed at times creates, difficulty for the ageing person. Restoration of balance then entails a shared responsibility between the environment and the person which ultimately stresses the need for individualised supports to accommodate adaptation. The idea of a support model of ageing well was also delineated by Heller and Harris (2012) who contend that it is essential to identify the gaps in support needs as people with intellectual disability age. The findings illuminate the most significant gaps in support for participants through accounts of their ageing experiences. They also build on the selection, optimisation, and compensation, approach developed by Baltes and Baltes (1990) in the general literature on gerontology where the notion of successful ageing arose. While the Heller and Harris model stresses the role of supports in influencing outcomes in ageing,

the findings of this study draws attention to the specific psychosocial areas that people ageing with intellectual disability have themselves identified as important to them, and where supports are most valued. As such, the findings address a gap in research between what is known about broad supports and specific areas important to the population under study. In a time of scarce resources such information is invaluable in terms of policy initiatives and service development. The findings identify areas where additional resources would be welcomed by the individuals themselves.

The findings augment specific areas identified in the IDS to TILDA study. Of particular interest are trends across Wave 1 and Wave 2 of the published data, such as reduced rates of family contact from Time 1 to Time 2, and a decline in rates of social participation generally. These results add weight to specific elements of the new theory, in particular, that family contact must be supported as key family members die, and that preparation and planning is required to support continuation of patterns of social engagement as people age.

10.5 Where does the new theory fit within general ageing theory?

Developing a core discourse in how people with lifelong intellectual disability experience ageing is fundamental to understanding an ageing theory in relation to this population. The literature review explored whether general ageing theories might help to explain ageing in a population who have had disability for the whole of life and in doing so identified a gap in knowledge in relation to how this population experience the ageing process. The findings of the study have attempted to breach this gap and facilitate a more informed analysis. The ageing theories introduced in the literature review of therefore are now revisited.

- *Disengagement Theory:*

This theory is characterized as a withdrawal from social roles and activities concurrent with an increasing preoccupation with self and decreased emotional involvement with others. This is not evident in participants' accounts of their lives. Participants are found to be very social and indicate that continued social experience is a high priority. Where withdrawal from social activities occurs this is usually as a result of failing health with associated reduction in energy. In some cases withdrawal is merely a practical safety tactic, i.e. the woman who no longer goes out in bad weather because "*the wind could knock you*". As such, the views of Davis (1994) are

somewhat supported in that where disengagement is observed it is not so much an inevitable consequence of ageing but a natural consequence of other factors, such as increased frailty. Therefore, *positive* withdrawal may be a better description of what is observed rather than disengagement. The word *positive* refers to the fact that where withdrawal is observed or reported, the impact of this may actually improve overall quality of life as people conserve energy for key activities and feel safer in their environment.

- *Activity Theory:*

This ideology, normatively prevalent in society (Council of European Union 2012; World Health Organisation 2002) presupposes that an active lifestyle is best and desirable for all older people. Kahlin *et al.* (2015) point out that this contradicts disability policy in Sweden which advocates for personal choice and independent decision-making in everyday life. In Ireland also, person centred decision-making is a central idea in policy and practice in the disability sector. Proponents of Activity theory emphasise the value of productivity in optimising quality of life. While the findings indicate that participants generally wish to remain active there is a change in the level and the frequency of activity for many people as the years advance. Tiredness and a general slowing down are the explanations given for this. The findings indicate that account must be taken of decreased energy reserves and how these are utilised to best effect when supporting people ageing with lifelong intellectual disability. As such, the views of Ryan *et al.* (2011) are supported by the findings in that the authors point out that Activity theory does not take account of the need for reduced activity among some of the aged. Wadensten (2006) alerts us to the influence of Activity theory in programmes for the elderly and Kahlin *et al.* (2014) warn that participation can be considered a mandatory requirement for an experience of active ageing in people with intellectual disability. Hence, the findings of this study align with that of other researchers in the field who caution against a one-size-fits-all approach to supporting active ageing. The study demonstrates that people have different starting points and active engagement is thus relative and individual. In fact, activity is described by participants as anything from being able to get out of bed, to running in an event in the Special Olympics. The findings therefore indicate that Activity theory as an explanation of ageing in the intellectual disability population is

flawed as it fails to take account of individual differences in ability and in desires. Activity theory poorly explains psychosocial aspects of ageing with lifelong intellectual disability and does not provide adequate guidance for practice in the area.

- *Gerotranscendence:*

This elucidation of ageing for men and women with intellectual disability is not supported by the findings. Although the self-concept appears to become more stable and death is generally accepted as the final phase of living, there is no indication that this represents a new understanding of existential questions. On the contrary, there is no empirical evidence that old age is a qualitatively different time of life for this population and, as noted earlier, for many, transition to old age is seamless. However, Tornstam's observation (2005) which emphasizes that mid-life values of productivity, effectiveness, and independence, are unfairly foisted upon the elderly has some validity in relation to the findings, especially in relation to siblings insisting on an 'activity and engagement' agenda for some of the participants. This is experienced as very stressful for a number of people who report being '*forced*' into certain activities by family members. However, the belief that family members are doing so with the best of intentions is also clear from the findings. As such, the urgent need for dissemination of the findings of the study to front line workers, carers, and family members is marked.

- *In Lifespan Development Theory:*

Erikson described his theory as psychosocial because he saw development as a function of both the internal and the external environment. This idea is demonstrated in the findings in relation to the core principle of the social model of disability and the interface between the person and his or her environment. However Erikson's lifespan development theory is deterministic and holds that each developmental stage must be successfully mastered in order to develop competence and avoid stagnation. The findings of this study are more optimistic, and it is found that people can adapt when conditions are not optimal, and that resilience can develop even in the most adverse conditions. Therefore growth and development are found to continue throughout the lifespan but not necessarily in the pre-set linear pattern outlined in Erikson's theory.

The trajectory of development for persons with lifelong intellectual disability is quite different.

- *Continuity Theory:*

This adopts a life course perspective which fits well with the findings of the study. Continuity and stability are found to be key constructs in the lives of participants, although this does not rule out ongoing adaptation, change and development.

Similarly, Continuity theory proposes continuous development and adaptation as people advance through adult years. Atchley (1999) delineated a cycle of learning both orientation and behaviour from life experience, and through this developing a personalized and resilient way of living and coping effectively. This process is evident also in the lives of participants, indicating that Continuity theory can offer a partial explanation of ageing with lifelong intellectual disability.

10.6 What does the new theory add to ageing theory?

The new theory is a first step in understanding ageing in the intellectual disability population and has some goodness of fit with Continuity theory. The new theory attempts to explain how people with lifelong intellectual disability evolve psychologically and socially in response to age-related change. It presumes that people continue to develop psychologically and socially as they age and this is optimised when they feel physically and emotionally safe. People continue to want self-determined lives, quality social experiences, and valued relationships, while also needing to feel safe and secure as they age. As with Continuity theory, the new theory holds that continuity of life patterns assist with coping and adjustment as years advance.

The main divergence from Continuity theory is that continuation of life patterns cannot occur without the provision of focused and appropriately timed interventions from external support networks. As self-determination is compromised throughout life, the ability and opportunity to enact self-determination remains an issue in later years. Therefore individualised support is key to being able to maintain preferred living, social, and coping patterns, in later years.

The new theory provides sign posts for service providers, policy-makers, and carers, in efforts to meet the needs of this ageing population. It contends that people do not stagnate psychologically or socially with age, even though age-related change may bring about further

challenges and increasing deficits. Rather, with appropriately timed supports change is managed and people can continue preferred patterns of engagement with life. However, the theory also shows that when important psychological and social areas are poorly resourced, continuity is adversely impacted.

Bengston *et al.* (1999) remind us that theory is a living process, and as such the findings of the study are just the beginning of theory development in the area. Further research may shed light on whether the findings represent a cohort effect, a cultural effect, a period effect, or perhaps some combination of all three, and so test the generalizability of the findings.

10.7 How do findings fit with current intellectual disability practice and policy?

A positive outcome of the study is that the findings and new theory provide a basis for critical evaluation of current practices and policy in the sector. Five areas pertinent to practice and policy emerged as being of particular significance and worthy of discussion. These are:

1. Person-centred planning
2. Generic Integration
3. Rights and Citizenship
4. Housing
5. Personal Safety

10.7.1 *Person centred planning*

Since the introduction of *Valuing People* (2001) a person-centred approach to planning is central to how services for people with intellectual disability are delivered in the UK. Many US states have also mandated the use of person-centred planning (Robertson *et al.* 2007). In Ireland over the past decade person-centred planning has also been rolled out as the planning mechanism of choice in relation to service delivery in the disability sector. The findings of this study contribute to the body of knowledge informing person centred approaches to supporting older people with intellectual disability by identifying key areas where supports are valued, and by devising mechanisms which enable planning and sensitive response on a person-by-person basis. The findings are timely as individualised planning is now further supported in this jurisdiction by the long awaited Assisted-Decision-making (Capacity) Act, which came into being December 2015, although it has not yet been implemented. The Act has been framed to meet Ireland's obligations under Article 12 of the Convention on the

Rights of Persons with Disabilities (2006). A core principle of the Act is that a person shall not be considered as unable to make a decision in respect of a specific matter unless all practicable steps have been taken, without success, to help the person to do so. As such, the legislation takes a functional approach to decision-making and is situation-specific. This puts the responsibility on services and those supporting individuals with disability to take all reasonable steps to ensure that the person is an active participant in decision-making relevant to important areas of his or her life. Over time, should cognitive or functional decline lead to impairment of decision-making capacity, the Act provides that effect should be given to past will and preference, and beliefs, and values are to be taken into account. The theory of ageing put forward by this study makes it possible to predict future need and to respond with timely and appropriate preparation and planning. As such, the process of carrying out more sensitive person-centred planning based on key psychosocial areas facilitates the amalgamation of solid information over time. Such information can be then used as the person ages to indicate a pattern of will and preference, beliefs and values, should this need arise.

10.7.2 *Generic Integration*

As discussed earlier, research shows that with increasing age, a convergence in terms of health and social care needs is evident between people with and without lifelong intellectual disability (Holland 2000), but in Ireland, both sectors remain largely apart. This shows a regrettable lack of forward thinking as in the accounts given at interview there was evidence of some local shared service arrangements which appear to work very well. To date it seems that few studies have examined people with intellectual disability's use of mainstream older people day-care facilities (Ryan *et al.*, 2013) but Bigby and Balandin (2005) propose that continued planning and collaboration between intellectual disability services and older people services would benefit all older people. There is some evidence that staff in general ageing-care residential services are less attuned to the needs of people with intellectual disabilities (Newberry, 2012). However, this claim does not appear justified in respect of community-based aged-care services. A study by Ellison *et al.* (2011) found that individuals with disability (N=60) using aged-care services in the community reported benefits including opportunities to develop relationship, maintain daily living skills, and participate in community activities. Similar benefits were reported by participants in the current study. So, while the up-skilling of staff would be a requirement across both service areas (in line with recommendations of World Health Organisation, 2001) a fusion of aged-care services and

intellectual disability services could well produce overall positive outcomes. A reluctance to move forward with merging of services to date may in part be attributed to a lack of empirical information on how people with lifelong intellectual disability experience ageing. This information gap has now narrowed and the findings of this study form a starting point on which to build new knowledge and to move services in a different and more person-centred and client-led direction.

10.7.3 *Rights and citizenship*

The findings of the study show that some participants are experiencing later years as a time to shake off constraints of the past, such as parental control, and to experience new freedoms consistent with rights-based services. This corresponds with the findings of other studies within this research such as Kahlin *et al.* (2013) and Judge *et al.* (2010). Service development and the paradigm shift over the past decade to a rights-based model of service for people with intellectual disabilities has meant that some participants are arriving at later years having only recently experienced positive change. Many are energised by this change. For those people, the present life phase is experienced as a time for continued development, and compensating for the missed opportunities and poor self-efficacy of the past. For those availing of services for the first time in later life a whole new world of opportunity can open up. Many participants indicated that life is better now than when they were younger as they have more opportunities, more socializing, and more choice. Some are only now finding a voice through focused person-centred systems. Going forward an emphasis on rights must drive continuous improvement in the intellectual disability sector.

The principles of citizenship, respect for the individual, and equal rights contained in The United Nations Convention on Rights of People with Disabilities (UNCRPD, 2006) must be at the core of practice development and policy development so that in future, the difficult experiences so bravely articulated by participants of the study are not the experiences of the coming generations. Unless the findings are viewed through a rights-based lens and ensure that people with disabilities are visible as citizens there is no guarantee that the conditions and experiences described by participants will not be repeated. While Article 1 of the Universal Declaration of Human Rights (1948) states that ‘all human beings are born free and equal in dignity and rights’ the moral obligations inherent in the declaration have been ignored by successive Irish governments. The individual accounts given by participants

cataloguing violations of their human rights and individual rights as citizens are worrying, and at times, disturbing. There were numerous incidents reported of injustice and unfairness. For example, P6 was admitted to an adult psychiatric hospital at the age of thirteen, and P30 was similarly admitted to an adult psychiatric hospital as a boy along with his mother, and was not released until her death some four decades later. P5 had endured an arranged marriage, and her four children were subsequently taken into care and further contact with them was not facilitated. P4 was not permitted to open a post office account as her siblings had done and P28 was not allowed to attend the same school as her twin. P16 was kicked and beaten by a drunken neighbour and was not supported by the criminal justice system. A number of participants spoke of the family home being sold against their wishes and it would appear, without being consulted. The findings reveal that such social inequities may be a function of how people with intellectual disability are viewed by the community, and even by their own family members. This alone points to an urgent need to change mindsets and the onus is on the government to lead the way. Ireland is a signatory of the UNCRPD but ratification is still outstanding. The absence of capacity legislation has been cited as a reason for this. There is now a pressing need to commence the capacity legislation in order to begin an honest and serious discourse on equality for our citizens with disability.

Possibly the most worrying aspect of the findings in terms of participants' lack of equality with fellow citizens is the fact that the study population comprised of a group of people who have never been in paid work and have spent a lifetime in the social welfare system. Setterson (2007) talks about the disparities in financial, social, and other resource, by the time people with intellectual disabilities reach old age and says the chasm between those who do and do not have resources create experiences in old age that are worlds apart. This is a stark message and policy-making must remain sensitive to this reality which is unlikely to change for many people. Those with moderate to severe intellectual disability (the study population) are unlikely to be in a position to avail of well-paid work into the future. Other instruments which can drive opportunity for people with disability to accumulate resources must be explored so that their experiences in old age can move closer to those of the general ageing population.

10.7.4 Housing

As an integral human right The UNCRPD avers that people with disabilities should be able to live in their communities and be part of those communities. The findings of the study support the steering of resources in this direction and present the argument for supporting people to make choices and to have self-directed lives. In addition to the directives of the Convention, national policy in Ireland reflects this trend towards community living. The government policy document *Time to Move on from Congregate Settings* (2011) proposes a seven year time frame (2013-2019) to move people out of residential arrangements comprising 10 or more people, and to support people to make choices about where and with whom they wish to live. Hence the findings fit with policies supporting self-determination, and especially choice-making, regarding where to live and with whom to share a home.

Grant (2010) discusses the importance of personal continuity in understanding how people age successfully and argues that there is need to manage factors which give rise to discontinuities across the lifespan. Housing is clearly the factor that led to the greatest level of personal discontinuity for participants of the study, right through their lives, and even now as they age. One policy change that could have a major positive impact on how people with lifelong intellectual disability experience living and ageing would be to put measures in place so that on reaching adulthood those with intellectual disability are provided with opportunity to have a home of their own, with inbuilt choice around this. This may mean different things for different people as many may wish to remain in the family home or very close to their support network. The idea of a home for life with opportunity to have input into what this may look like over the lifespan would eliminate a great deal of repeat stress and ongoing loss revealed in the findings. It would ensure that people would no longer have to live with fellow residents that frighten them and that they would not have to endure moves through different placements with loss of familiar people and environments each time circumstances change. In particular, the heartbreak revealed by a number of participants when the family home was sold by siblings, leaving them with no choice but to move out, would be avoided. Quality of life, particularly quality of one's later years, would be greatly enhanced by this one change. Allied to this, is the issue of biographical lacunae in people's lives. Having one home for life would also serve to ameliorate this issue which is still current in the lives of many.

The findings underscore the need for a more flexible approach to how housing is provided and while there are some local initiatives around supported living, this housing model is in its infancy for people with intellectual disability in Ireland. The findings strongly support a change in the direction of policy, away from residential houses for four and five residents (the only model available at the study site) and towards greater flexibility and options which include individual apartments or sharing a home with just one or two others.

10.7.5 Personal Safety

Safety and security were found to be key to ageing well and reports of feeling unsafe in the home environment were difficult to hear. The National Standards for Residential Services for Children and Adults with Disabilities were published by the Health Information and Quality Authority (HIQA)* in 2013. HIQA has statutory responsibility under The Health Act (2007), to monitor these standards in residential settings and to drive continuous improvement. Nonetheless, abuse in residential settings persists. In recent times the intellectual disability sector and the general public have been shocked by ongoing revelations of abuse in residential settings for adults with intellectual disability in Ireland. As an immediate response to these revelations the ‘Safeguarding Vulnerable Persons at Risk of Abuse, National Policy and Procedures’ was introduced in 2015, with local and regional supports such as Safeguarding and Protection Teams and the appointment of a Confidential Recipient to facilitate day-to-day working of the policy. In addition the Protected Disclosures Act (2014) was instantiated for the protection of whistleblowers across the public sector so that individuals will be supported by legislation if they come forward with a concern. The findings of this study provide further evidence that abuse continues to take place and that it has a detrimental impact on people’s lives as they grow older. The findings endorse the necessity for robust policy as well as extensive training of front line staff in order to sensitize people to abuse, what it looks like, how it is experienced, and more particularly, to set mechanisms in place which effectively manage risk of abuse in order to eliminate it from services going forward.

In summary:

The implications of the findings for future policy and service development advocate:

1. person centred-services throughout the lifespan

2. merging of community elder care and intellectual disability services with up-skilling of staff
3. equal citizenship and protection of human rights
4. a home for life in order to address issues relating to stress, discontinuities and biographical gaps
5. Robust policies and extensive staff training to eliminate abuse

However, while a life-course perspective forces anticipatory thinking and dynamic policy making (Setterson 2007), future cohorts will reach old age with special characteristics, experiences, resources, expectations, and needs. As such, although the findings of the study support certain policy and practice areas, in the future, new cohorts will require policy-makers and services to remain flexible and open to re-building and re-thinking in ways commensurate with a changing environment for ageing populations.

10.8 Implications for future research

There is a rich agenda for future research in the area of ageing with lifelong intellectual disability given that theory development in the area is in its infancy. The findings of the study, as well as points of interest arising from the process of carrying out the study, illuminate many areas in the field which could benefit from additional researchers.

Testing the theory:

- Research must now endeavour to further develop an understanding of the psychosocial aspects of ageing with lifelong intellectual disability by testing the tenets of the theory across further cohorts. The next step is to broaden the study population in terms of greater numbers and a wider range of intellectual disabilities in order to assess whether the theory can be generalised more widely. The majority of participants had a moderate intellectual disability, but whether those with mild cognitive impairment have similar psychosocial experiences as they age is not presently known. The views of carers may also be relevant in this case, in order to assess whether they match the participant narratives of experiences.
- Research designed to test components of the theory could look at the five psychosocial areas which have been identified one by one to further evaluate how

each contributes to the process of development in later life and to determine whether some areas are more important than others. If so it may be possible to rank areas in terms of impact on ageing when well resourced and when poorly resourced.

Additionally, it may be possible to identify areas which, if left unsupported, would lead to significantly poor adaptation to ageing. As such, the relationships between psychosocial areas may be relevant and worth exploring.

- Further research may contribute to expanding the theory or to give more weight to certain areas. Longitudinal research is also necessary in order to examine how people continue to adapt to age-related change over a longer period of time and to examine whether areas other than those identified in this study play an important role. This is only at the beginning in terms of investigating this phenomenon and much more needs to be done by the research community.

Using the theory:

- Research should be carried out on the use of the *Wellness in Ageing Tool (WiAT-ID)* and the adapted Selection, Optimisation and Compensation approach to supporting age related change, in order to ascertain their usefulness in collating and applying information aimed at improving the ageing experience. Both of these areas are an immediate follow-on from the study and outcomes will assist in fine-tuning the theory over time.

Retirement:

- In terms of psychosocial indicators of change, transition to older age for participants appears seamless. In the absence of any culture of retirement there is obviously no pre/post retirement marker to act as an indicator of moving towards a new phase of life. Moreover, there is no evidence that late adulthood is associated with an increase in positive experiences, such as a time to try new things or to spend quality hours with family. An interesting area of research may be to include people with lifelong intellectual disability in pre-retirement planning, similar to that available to the typical ageing population and to assess longitudinally the impact on quality of life. The World Health Organisation (Hogg *et al*, 2000) has already called for such an approach but it appears that little has changed in the area of retirement planning for this

population, now nearly two decades later. None of the participants of the study had engaged in any formal pre- retirement planning. In fact, many participants indicated that they did not even understand what retirement means or what it involves. This approach also fits with the person-centred paradigm currently driving intellectual disability services both here in Ireland and further afield. Research into retirement planning and its impact on ageing would add greatly to current knowledge of ageing in this population. Bigby (2010) argues that forced retirement could create an arbitrary way of excluding people from formal programmes, and claims that the matter is subject to much debate. Only further research can shed light on best supports for those ageing with intellectual disability in terms of retirement and retirement planning. Bigby also notes that issues of retirement and its impact on older people with intellectual disability have been ignored by governments in both the UK and Australia. Perhaps it is up to the research community to drive this particular agenda in term of providing the knowledge to inform the debate.

Emotional Coping:

- The scope of the study did not allow for an in-depth analysis of emotional coping. However, it was observed that participants were very reluctant to expose themselves emotionally and generally tried to take a positive view. Some participants deflected all questions around feelings and emotions. The researcher speculated that participants were using this as a coping strategy in order to protect themselves from hurt and disappointment, or whether this had arisen from a lifetime of acquiescent behaviour and efforts to please others. More in- depth research into the emotional content of peoples' lives as they age may prove fruitful but would need to be carried out sensitively and by skilled clinicians. It would be ill-advised to re-open potentially severe wounds without adequate support and therapeutic input.

Behavioural genetics:

- At the broadest level one might consider the influence of behavioural genetics and how this might shed light on the extent to which hereditary factors influence age-related change. A further related area for future research is to look at any differences in ageing related to the aetiology of one's intellectual disability. The high incidence of Alzheimers- type dementia in person's with Down's syndrome is already well

documented and investigations into amyloid depositions in persons with Down's syndrome continues to expand our understanding (McCallion and McCarron, 2004). While research in behavioural genetics is likely to contribute more to our understanding of the biological aspects of ageing with intellectual disability, new knowledge can only enhance the care and support aimed at the psychosocial aspects of ageing and quality of life more generally.

Communication:

- Emergent from the findings, although not specifically part of the analysis, was the impact that communication difficulties have on participants and their capacity to orient to the wider social and physical environment. The researcher became acutely aware of the amount of effort that many participants had to invest in making themselves understood and was left to speculate on the knock-on effects of this on all other aspects of life, such as the level of energy invested in communication alone. The researcher reflected that factors such as forward planning and reflection on the past may lose importance when one must place so much effort into just surviving the present. This is a potentially fruitful area for future research.

Resilience:

- Building on the point above is whether observed findings in relation to coping could or should be framed in a resilience context, or whether this would be placing a disproportionately positive connotation on the findings. Goward and Gething (2005, p. 282) state "a resilient person can be conceptualized as someone who has experienced adversity and not only survived but become more hardy in the process". While certain aspects of resilience such as adaptation to change, the ability to see positivity in the face of ongoing challenge, and so on, are clearly in evidence, resilience also ought to reveal emotional coping. The findings show that emotional congruence was inconsistent and that perhaps feelings and emotions are suppressed in order to preserve emotional safety. This area merits further enquiry.

Sense of self:

- The value of the interview itself, and specifically the recording of voices, could be usefully explored in terms of impact on sense of self. Audio recordings were

experienced by participants as tangible acknowledgement that their voices were heard and that voices mattered. Participants were keen to have recordings played back to them at the end of interview and often smiled broadly on hearing their own voice. One man expressed an interest in having his words printed in a book. An exploration of how tangible evidence of the self in terms of voice, person, words (i.e. audio recordings, video recordings, reading back words) can impact positively on sense of self in people with intellectual disability could usefully be studied.

Ageing as a social construct:

- Ageing as a social construct was not explored to any great extent in the study but at times the notion that an idea was being put forward to which participants did not consistently relate was observed by the researcher. As such, alternative ways of helping people understand what was being asked were explored and utilised in conducting the study itself; for example, using photographs to depict change over time, anchoring questions around events such as “before your mother died”. Ageing with intellectual disability may be too complex a construct to be able to map by chronological age alone. Life expectancy however, must be taken into account and as such it may be valid to talk about later years, if not old age. McConkey *et al.* (2004) state that it may be more informative and meaningful to identify how this group is affected by ageing rather than dwelling on how old age is defined. Further study in this area is warranted.

10.9 Contribution of the study to the field of ageing and intellectual disability

Men and women with moderate intellectual disabilities are seldom represented in research, largely because of their reduced skills in communication (Umb-Carlsson 2007). Although a recent small scale study (n=7) was carried out in the UK examining how people with mild intellectual disability experience and make sense of ageing (Newberry et al, 2015) no such study has been undertaken with an Irish population, nor with those with significant cognitive and communication challenges. The psychosocial theory of ageing outlined in the findings is a general theory of individual development and adaptation to ageing arising from the lived experiences of this largely invisible group of people. The study bridges a gap in that it brings the voice of people with moderate to severe cognitive impairment to the research arena and to the discussion on ageing. The study responds to calls by Bigby (2002) and others who

advocate for supporting inclusion and ensuring that older people with lifelong intellectual disability are visible within the aged care system. The study provides an opportunity for this group of people to be directly heard, in terms of their specific concerns, their strengths, and their challenges.

The study contributes to the national and international disability literature in the following ways:

- a. this is the first effort towards building a psychosocial theory of ageing with respect to men and women with lifelong intellectual disability
- b. all participants have moderate to severe intellectual disabilities with communication difficulties, and this population has not previously been supported to engage in face-to-face qualitative interviews on their experience of ageing
- c. methodological eclecticism was utilised, with flexibility in matching individual communication style and abilities to how data was collected

While the findings highlight five psychosocial areas important in the lives of those ageing with lifelong intellectual disabilities, the researcher is of the opinion that the areas of ‘self-determination’ and ‘safety and security’ merit particular attention because of the observed impact on the lives of participants when these areas are inadequately resourced. Specifically, people expressed a powerlessness to change their situation, even when they believed their personal safety was under threat. The findings are timely then in that recent Irish legislation and policy also reflect support needs in these areas; namely, Assisted Decision Making (Capacity) Act (2015) and The Safeguarding Vulnerable Persons at Risk of Abuse – National Policy and Procedures (2014). Services need to engage robustly with these developments and the findings of the research support this.

The study argues for a support model of ageing with intellectual disabilities. The value of this approach was also outlined by Heller and Harris (2011). However, the current study has made a further contribution to understanding how such a model can be used as an effective mechanism as it identifies specific psychosocial areas where support is most valued. It is clear that with timely planning and individualised supports a new landscape can emerge that offers the necessary flexibility for people with lifelong intellectual disability to live lives which are congruent with individual interests, hopes, and wishes.

10.10 Conclusion

The thesis presents evidence for a conceptual framework on ageing for this population by bringing together and analysing the accounts people gave of their lives. Given the lack of theory to date it is too early to determine whether this can be an over-arching framework for understanding individual development and adaptation to ageing in this population. (Strengths and weaknesses of the study are presented in Appendix M). It is possible that some areas need to be broken down further in order for their contribution to be more fully understood, and there may be areas that have yet to be taken into account. The strength of the theory as it is currently presented is that it has been developed from direct accounts of people's own experiences. As such, it is grounded in the experiential reality of actual lives.

This discussion has considered where the research findings fit in relation to many aspects of living and ageing with lifelong intellectual disability. An application to frontline practice will be explored in the next chapter. The focus will therefore shift to show how the research finding may inform more effective support to people ageing with intellectual disability and enhance their quality of life and quality of care on an ongoing day-to-day basis.

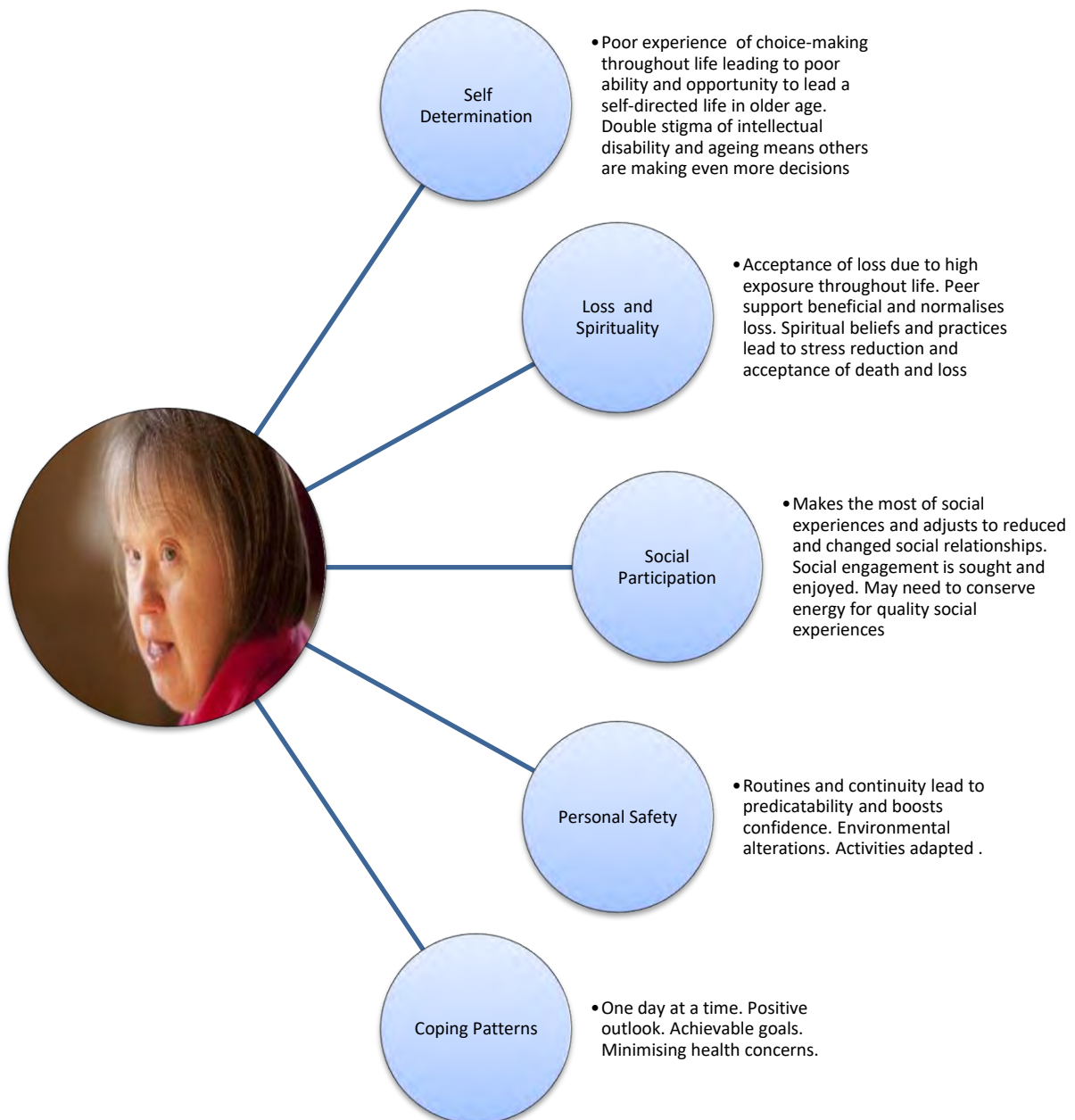
*The Health Information and Quality Authority (HIQA) is the independent Authority established to drive continuous improvement in Ireland's health and personal social care services, monitor the safety and quality of these services and promote person-centred care for the benefit of the public.

Chapter Eleven – Guidelines For Practice

11.1 Overview

Is there a mismatch between the delivery of frontline care and what the findings of the study reveal? This chapter brings together learning points from the research and outlines supports that are appropriate, person-centred and facilitative.

Diagram 13: How psychosocial change is experienced in older years:



11.2 Self-determination

Individualised supports:

Findings demonstrate the heterogeneous nature of the group of participants with each person having individual experiences, coping patterns, needs, and future plans. As such, any package of supports around ageing necessarily varies from person to person. The importance of individualised supports for people with intellectual disability is well-documented, and Mansell and Beadle-Brown (2004) emphasize that there is now no serious alternative to the principle that services should be tailored to individual needs, circumstances, and wants. However, it is worth reiterating the need for person-centred intervention in relation to how supports are provided in frontline care for those ageing with intellectual disability lest there be any tendency towards group thinking in respect of this relatively new demographic. Commonalities across the group of participants are far outweighed by diversity in terms of all aspects of living and of ageing.

Recommendation: Supports must be person-centred and individualised.

Recognising and nurturing strengths:

Grant (2010) asserts that resourcefulness and resilience do not ebb away when people age. Lifelong strengths and abilities should be respected and nurtured in each ageing person so that they can continue to flourish. In particular carers should aim to continue to enhance skills around personal agency in order to combat tendencies towards learned helplessness. The study showed examples of people becoming deskilled on coming into services, as staff and carers took over tasks that the person had previously done for themselves.

Recommendation: Lifelong positive qualities must be respected and nurtured so that personhood can flourish.

Choice:

Carers and families may project their own values, expectations, and activity patterns, onto the person ageing with intellectual disability and thereby disregard the person's stated or indicated choices. The research findings indicate that this generally happens, albeit with the best of intentions, as many care givers strongly feel that they know what is best for the person

they are supporting. Many participants indicated that pleasing others in certain ways, such as attending events and services because carers want them to do so, is experienced as stressful. This stress is likely arising from the poor sense of control people feel they have over their daily lives while others exert such a strong influence over what happens. An approach that can respect the individual's need for some measure of control over what happens in his or her day while acknowledging some fundamental necessities (i.e. physical exercise to enhance health and mobility; a carer's need for breaks) is required.

Recommendation: Respect the individual's need for control over what happens in their day.

Experiential enhancement

Increased dependency due to ageing coupled with lifelong intellectual disability can mean that people's lives diminish as they age in terms of range of experiences and number and range of relationships. As such experiential enhancement is vital as the years progress. It was clear from interviews that for the most part participants were living in the 'here and now' and the next meal was often what people said they were looking forward to on any given day. When people's lives become smaller due to failing health or reduced energy, day-to-day experiences ought to be made bigger. As such, an aim of care should be to enhance the ordinary experiences that make up the person's day. In addition, carers need to consider quality of engagement with daily activities as opposed to quantity of outings and activities. Positive psychology (Seligman, 2002) holds that happiness is not necessarily achieved by having a busy social life or a full activity schedule. Rather, people are most happy when they are fully engaged, and doing something fulfilling. As such experiential enhancement is more likely to bring about happiness than a multiplicity of activities where the person is poorly engaged.

Recommendation: Aim to enhance ordinary experiences that make up the person's day.

Conservation of Energy:

Butler (1975), who coined the word ‘ageism’, had this to say about the ageing population generally:

...they must conserve strength and resources where necessary and adjust creatively to those changes and losses that occur as part of the ageing experience.

Butler (1975).

This is also true of the cohort of participants in this study. They have demonstrated creative adaptation to change but they have also indicated a desire to conserve energy in the face of ongoing challenges and changing need. The research found that when participants indicated withdrawal from certain activities or a reduction in frequency of engagement in activities it was often merely as a way of managing energy reserves. As such, a refusal to go to the day centre one day did not necessarily indicate a cessation of this activity for ever.

Recommendation: Be mindful of the person’s need to conserve energy in order to adjust to changes that occur as part of the ageing process.

Communication supports:

The study shows that in the aim for good and meaningful communication there is no substitute for spending time with a person, and becoming familiar with individual vocabularies and idiosyncratic ways of communicating. Supporting people to communicate takes time, but it may be the most significant support that caregivers can provide. By sensitively seeking out ways to communicate, and slowing down to follow the persons’ lead carers can contribute and be part of each persons’ communication system.

Recommendation: Take time and tune in to all communication.

Pre-retirement planning:

While retirement culture was notably absent in the study population primarily because paid work was absent, The World Health Organisation (Hogg *et al.* 2000) called for pre-retirement planning similar to that available to the general population to be part of service provision for older adults with intellectual disability. Broadening person centred-planning to include pre-retirement planning is beneficial as needs can be assessed on an individualised and

personalised way, leading to goal setting and planning driven by individual circumstance and desires.

Recommendation: Pre-retirement planning must be part of person-centred planning and goal setting.

11.3 Loss and Spirituality

Life Story Work:

In order to inform the planning and provision of person-centred supports an individual's life story must be held securely over time, especially if they are unable or unwilling (perhaps due to traumatic events) to hold it or to retell it themselves. It is essential to know:

- a. the struggles, challenges, difficulties, and losses that this person has experienced through the lifespan
- b. how this person copes, adapts, acts, to make sense of the environment
- c. how this person can adapt and grow into the future while continuing to feel safe and secure

For this reason life story work should be an integral component in care and support of people with intellectual disability throughout the lifespan. To that end, a method of doing this comprehensively and storing the information safely so that it is available for life planning, through to end of life, must be in place.

Recommendation: Life story work is essential to care and support throughout the life span.

Spiritual life:

Snowdon (2001) observes that deep spirituality and profound faith buffer the sorrows and tragedies of experience. The findings revealed that spiritual beliefs and behaviours are protective factors in helping people with lifelong intellectual disability to cope with bereavement, especially in the case of repeat losses and the loss of key attachment figures such as parents or siblings. Participants demonstrated a strong belief that loved ones are in a better place, (P38 - *a nice happy place and cake, there's cake and all*), or in a place where they are always accessible, (P10 - *she's around. In fact she's in this room now while we're*

talking; P40 - I tells her 'I love you Mam'. She says, 'I love you too honey'). The belief in an afterlife appears to be a key support in managing the stress of bereavement and coping with repeat losses. As such, opportunity to express their spiritual beliefs and follow through on desired spiritual practices was found to help participants to integrate experiences of loss into their overall understanding of living, dying, and the afterlife.

Recommendation: Support individuals to express spiritual beliefs and to follow spiritual practices.

11.4 Social participation

Socialization:

While life story work is necessary so that carers can engage with the person about their past, it is also essential that people enjoy current stories and new experiences. To support people to stay engaged with everyday conversation carers must find ways to make current news and events accessible. People ageing with intellectual disability must be able to partake in ordinary experiences enjoyed by others in the community so that they continue to have new stories to tell.

Recommendation: Support individuals to have new experiences and new stories so that they are included in everyday conversation.

Pets:

It is impossible to ignore the issue of the therapeutic value of pets as the topic was raised by a sizeable number of participants in the study. It was clear that participants had an emotional bond with their pets through their formative years, through adulthood, and those still living in a family home reported still deriving great enjoyment from having a pet. Sadly, no person in residential care had a pet and some participants spoke of the heartbreak of leaving pets behind on coming into care. Access to animals needs to continue throughout life for those that wish this to happen, as the therapeutic value of this cannot be underestimated. As a dog owner, for example, a person has a social role. They can go to the park and meet other dog owners, be part of a conversation that many others participate in, and of course benefit from the sense of wellbeing that arises from having an emotional attachment to a pet. As such,

having a pet, caring for a pet, or having regular access to pets, was found to have great value for people as they age.

Recommendation: Consider the therapeutic value of pets and support individuals to have access to animals throughout life if they so wish.

11.5 Personal safety

Safety and security:

Safety behaviours were reflected in participant conduct and for the most part these behaviours contributed positively to quality of life and afforded individuals more control over their lives. For example, taking appropriate precautions due to past experience of falls or adhering to routines to provide predictability. Security however went beyond this and was found to mean a lot more to participants than just feeling safe. The researcher understood from interviews that safety could be specific and temporary, such as “I’m safe to cross the road” but to feel secure conditions needed to be more enduring. The main area where participants indicated feeling insecure and unsafe was where people shared accommodation with others that frighten or cause them stress. The importance of compatibility of residents and choice around who to live with were found to be key factors in feeling safe and secure as people age.

Recommendation: Compatibility of residents and choice around who to live with must be key considerations in order for people to feel safe and secure as they age.

11.6 Coping

Positive withdrawal:

Allied to the earlier point on energy conservation is the notion of positive withdrawal. While the core assumptions of Disengagement theory were not supported by the findings of the study, it was found that some level of positive withdrawal can lead to improved overall quality of life as energy is conserved for key activities and much anticipated events. Positive withdrawal is observed when people reduce the number of activities or the frequency of activities or the time spent on an activity.

Recommendation: Support positive withdrawal so that key activities are still enjoyed.

Mindfulness:

The findings point to the value of a ‘here and now’ approach to care and as such support the use of mindfulness-based ideas and strategies to guide practice, specifically, accepting the person as he or she is right now, without trying to change him or her and without striving for fit with the views and perspectives of carers, services, or policy. A mindfulness-based approach is envisaged in the very broadest sense of acceptance of the person, living in the here and now, enhancing everyday experiences, and allowing for growth and change to come about as a possible outcome. Mindful caring can lead to an increase in meaningful interactions between the carer and the person supported and lower levels of stress (Beer *et al.*, 2013). In addition research has underlined the value of mindfulness procedures in assisting carers to enhance quality of life of individuals with intellectual disability (Noone, 2013; Russell, 2011). Studies also indicate that individuals with mild to moderate intellectual disability may benefit from learning mindfulness-based techniques (Chapman *et al.* 2013; Robertson, 2011). As such, increasingly evidence is indicating that the use of mindfulness procedures and the practice of mindfulness techniques in frontline care can be of benefit to both the carer and to the person supported.

<p><i>Recommendation: Apply mindful caring techniques to increase meaningful interactions between the carer and person supported and to enhance experiences for all.</i></p>

11.7 Overall adaptation to ageing

Selection, Optimization and Compensation:

This useful model of support in responding to the needs of people ageing with intellectual disability is rooted in the theory of ‘selection, optimization and compensation’ (Baltes and Baltes, 1990) as discussed in earlier chapters. This explanation of successful ageing was reflected in the specific examples discussed above in relation to nurturing strengths, conserving energy, safety and security, and positive withdrawal. Throughout the findings there were further examples of participants selecting the most valued activities while setting aside others, thereby optimising ability to participate by conserving energy and making the most of personal strengths and compensating for losses by using aids and supports or altering the environment. The findings of this study strongly favour a model of frontline care that supports exploration and application of the three components of selection, optimization and

compensation as this approach focuses on the person's strengths and minimising deficits which leads to better adaptation to ageing.

Recommendation: Support individuals to select valued activities, to optimise their ability to participate, and to compensate for losses by adapting the environment.

11.8 Conclusion

While the explanation of a psychosocial theory of ageing with intellectual disability arising from the research did not explicitly determine how this cohort of older people ought to be supported or what is important in their care, analysis of the findings show what ageing implies for the study population. This allows for identification of factors appropriate to planning and applying interventions and supports in frontline care, as follows:

- Supports must be person-centred and individualised.
- Lifelong positive qualities are to be respected and nurtured so that personhood can flourish.
- Respect the individual's need for control over what happens in their day.
- Be mindful of the person's need to conserve energy in order to adjust to changes that occur as part of the ageing experience.
- Take time and tune in to all communication.
- Retirement planning ought to be an integral part of person-centred planning and goal setting.
- Life story work is essential to care and support throughout the life span.
- Support individuals to express spiritual beliefs and to follow spiritual practices.
- Support individuals to have new experiences and new stories so that they are included in everyday conversation.
- Consider the therapeutic value of pets and support individuals to have access to animals throughout life if they so wish.
- Compatibility of residents and choice around who to live with must be key considerations in order for people to feel safe and secure as they age.
- Support positive withdrawal so that key activities are still enjoyed.
- Apply mindful caring techniques to increase meaningful interactions between the carer and the person supported and to enhance experiences for all.
- Support individuals to select valued activities, to optimise their ability to participate and to compensate for losses by adapting the environment.

Chapter Twelve – Reflection

12.1 Overview

Reflection on the study focuses on aspects of the shared communication that resonated strongly with the researcher. Ongoing challenges are addressed and opinion is offered on what is needed in order to create an environment of positive change so that people with intellectual disability can look forward to later years.

12.2 Key issues in ageing well

Two areas stood out for the researcher because they were found to be intrinsically linked to the quality of participants' lives. Firstly, **self-determination**; people want self directed lives and control over personal finances as they age. Secondly, **personal safety**; people who are living in fear cannot experience a good life.

The need for change in how we support people with lifelong intellectual disability to live and to age was repeatedly emphasized during the course of the data collection and analysis stages of the study, as the researcher noted the frequency of the phrase "*I'm fine*". The phrase was common across interviews but the researcher came to realize that these words indicated feelings of powerlessness and resignation by participants who were not 'fine' at all.

Therefore, while the findings demonstrated that key areas where supports are needed are personal agency and personal safety, the study in its entirety also showed that participants require focused and extensive support around communication. As such, the experience of carrying out this study and spending many quality hours with participants has led the researcher to conclude that:

To live a good life as years advance people with lifelong intellectual disability must be able to: communicate their wants and needs, to action those wants and needs, and; to feel safe in doing so.

12.3 Ongoing challenges

This study has yielded findings linked to the socio-economic and historical context of how the lives of participants unfolded. As such it is possible that a similar study carried out in future decades may produce somewhat different findings. It is hoped that the paradigm shift to rights-based models of supports, recent policy and legislative developments, increased awareness, and more action around inclusion, will ultimately result in a better convergence in quality of life between those ageing with disability and the general ageing population.

However, some aspects of life for people with intellectual disability will continue to be a challenge. People with intellectual disability will continue to face a lifetime of exposure to certain adverse conditions, not typical in the lives of their economically independent and socially valued peers. Communication difficulties, limited finances, diminished personal agency due to some level of dependence, and even physical frailty, will all persist. The challenge for policy-makers, service providers, and society in general, is to find ways to properly resource individuals and their families from early years to ensure that those who may not be in a position to accumulate wealth or to be economically independent can live on level parity with the rest of the population, throughout life and into old age.

12.4 A lifelong approach

The findings shed much-needed light on how people with lifelong intellectual disability experience ageing, but this is only the beginning of understanding. The ultimate aim is to develop a widespread expertise so that conditions of living and of ageing, and in particular psychosocial aspects of ageing, can improve for this population. Better information will lead to more appropriate supports and better outcomes.

The need to adopt a lifelong approach to ageing, to optimise opportunities for health, participation and security (WHO, 2002 p.12) is supported by the research. The study shows that participants' ageing experience cannot be set apart from whole of life experience. This aligns with recent developments in social policy in Ireland and specifically the National Positive Ageing Strategy. In delivering the policy document the Minister of the day had this to say:

...it would be a mistake to think that this Strategy is only aimed at older people. Positive ageing starts from birth – the way we care for our children, educate our population and provide for a society in which all stages of the lifecycle can be supported to live well. An ageing Ireland is an issue in which we all have a stake.”

(Ms. Kathleen Lynch T.D Minister for Disability, Equality, Mental Health and Older People
April 2013, Forward of NPAS, p.4).

This statement highlights the absolute necessity to ensure that the intellectual disability community is visible in our communities generally, from birth through to end of life, so that there can be no doubt that when the Minister refers to “our children” and “our population” people with intellectual disability are firmly included.

12.5 Conclusion

This study aims to bring the voices of those ageing with lifelong intellectual disability to the research community and the wider intellectual disability community. The onus is now on us to listen and to act upon what they are telling us so that they can experience good quality years in later life and not just additional years of existence.

The study is historically positioned at a time of a changing worldwide demographic in relation to ageing populations. While the study focuses on developing theory for men and women ageing with intellectual disability, it is crucial to place the findings amid the wider changes taking place, so that this ageing population is never overlooked or left behind.

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Resources:

- 1) Talking Mats – A low-tech framework to help people with severe communication difficulties express their views.

AAC Research Team, Department of Psychology

University of Stirling, Stirling, FK9 4LA Scotland.

- (2) CALL Centre Passport Starter

Callcentre.education.ed.ac.uk.

List of Appendices

	page
A Letter of information for staff and carers	238
B Letter of information with consent form	240
C Call Centre Passport Starter 2003	241
D Let's Talk About Getting Older	258
E Interview Schedule	267
F Interview Protocol	268
G Memo Writing Sample	271
H Open Coding Sample	272
I Axial Coding Sample	291
J Selective Coding Sample	304
K Theoretical Sampling	307
L Wellness in Ageing Tool-Intellectual Disability (WiAT-ID)	308
M Strengths and weaknesses of the study	315

Appendix A

Letter of information for staff and carers

To Staff of the Old Monastery,

I am writing to let you know that over the next year I will be inviting many of the older people we support to take part in a service based study on ageing. It will involve meeting with me on at least two occasions. The number of meetings depends on concentration and fatigue levels. Some people may only want to meet for 10 or 15 minutes at a time and that will be fine. Others may be able to engage for an hour. Each meeting will take the form of an interview. I have a list of questions prepared and I will be seeking opinions on them. These questions are very flexible and will be put to each person in accordance with their individual communication abilities. As such, the first meeting will be a communication assessment meeting and an opportunity to develop rapport. Meetings will be on a one-to-one basis, unless a person wants someone to accompany them. Each person can decide where meetings are to happen and how long they will last.

The purpose of the interviews is to gather information on how people with lifelong intellectual disability experience ageing. My aim is to develop an explanation of what ageing implies for those with life-long intellectual disability. I hope to write the findings in a report for Kerry Parents and Friends. I will also be using the findings to write a doctorate thesis which will be submitted to the University of Limerick.

Older people in the service will be getting a letter of information about this study shortly. I would greatly appreciate it if individual keyworkers would help the person they support to understand the contents of the letter and what it would mean for him or her to participate in the study. It is important that people understand that they have a choice – they do not have to participate. The letter explains that consent to participate or not to participate must be indicated with a mark on the appropriate word **Yes** or **No**. Some people will need help with this.

If you need any further information contact me at 086 0714475. If you become worried at any time that any individual participating in the study is becoming distressed or adversely affected in any way through their participation please contact me.

If you have any concerns about this study and wish to contact someone independent you may contact:

Chairman Education and Health Sciences Research Ethics Committee

EHS Faculty Office

University of Limerick

Tel (061) 234101

Email : ehsresearchethics@ul.ie

Yours sincerely,

Eileen Dukes,

Senior Clinical Psychologist.

Appendix B

Letter of invitation with consent form

Dear

My name is Eileen Dukes. I am hoping to find out what you think about getting older and what life is like for you now. I am inviting you to meet with me to talk about getting older. We would need to meet twice, maybe more. A meeting could take one hour but you can choose when to stop the meeting. You can choose where the meetings will happen. At our first meeting I will learn how you communicate – that means how you let people know things. At other meetings I will ask you about how your life is now. I will ask about changes in your life as you have got older. I will ask about your hopes for the future. I will be putting your answers in a report. I will not put your name in the report. This report will be used by the managers to help plan for the future.

There is one more thing I want to tell you. I am doing a course in the University of Limerick because I want to learn more about people with Intellectual Disability who are getting older. I will be writing about what people say at the meetings as part of my course. It will be read by some of the teaching staff in the University. Your name will not be used in any report.

You do not have to go to the meetings. It is your choice.

If you want to go, use a biro to mark the word

YES

If you do not want to go use a biro to mark the word

NO

If you need some help to do this the staff in your unit will help you. Phone me at 086 0714474 if you want to know more or ask staff to phone for you.

Yours sincerely

Eileen Dukes

My communication passport

This book is about me!

My name is

Please read!

**This book will help you to get to
know me and how I communicate**

PAGE INDEX

1. All about me.
2. You need to know
3. My family
4. Important people in my life
5. Important things to me
6. Things I like to talk about
7. How I communicate
8. How I communicate (2)
9. You can help me communicate
10. Fun things I like to do
11. Places I like going
12. Things I don't like
13. I'm working on this....
14. Help!
15. Eating and drinking
16. What's my eyesight and hearing like?

All About Me



"You need to know"

1.

2.

3.

4.

5.

6.

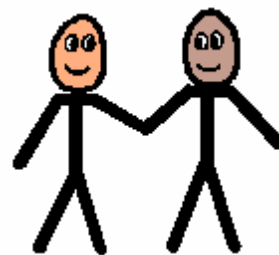
7.

8.

9.

My Family

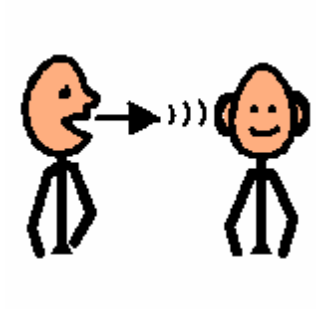
Important people in my life



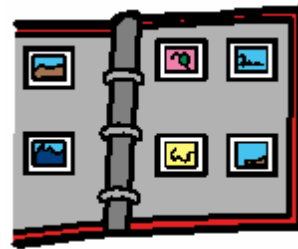
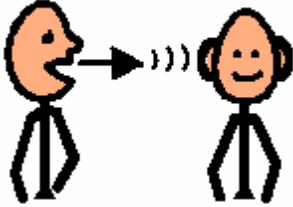
Important things to me



Things I like to talk about



How I communicate



You can help me to communicate

PLEASE DO	PLEASE DON'T

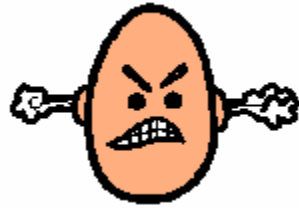


I like

Fun Things!

I like going to...

I can't stand it!



**So don't say you haven't been
warned...**

I'm working on this



HELP

I need help with

Eating and Drinking



What's my sight and hearing like?



Appendix D

LET'S TALK ABOUT
GETTING OLDER

Eileen Dukes talking with:

photo
Of you
Younger

Photo
of you
now

How have you **changed**?

Tell me about -

Things you like to do

Did you always do these things?

Are there things you used to do but don't do anymore?

Why? What has changed?

Tell me about -

People that are important
to you now.

People that were important
to you in the past.

People that will always be
important to you.

Tell me about-

Places that are important
to you

Are there places you like
that you don't visit
anymore?

Why? What has changed?

Tell me about-

Things that are important
to you

Tell me about-

What you need help with?

Did you always need this help?

What has changed?

Tell me about –
the **best** time in your life
– the time when you were
most happy.

How have things **changed**
since then?

Are you happy now?

Tell me about –

Your plans for the future

Have you hopes and dreams?

Appendix E

Interview Schedule

The questions are:

1. What does getting older mean to you?
2. How have you changed?
3. How has your life changed?
4. What has change meant for your life?

Prompts for each of these questions focus on individual change in the following areas:

- *cognitive functioning*
- *behaviour*
- *roles*
- *relationships*
- *coping ability*
- *social changes*

These six areas will be used as a framework to guide the interview, and the research questions will be addressed in relation to these areas of life experience and individual functioning

Appendix F

Interview Protocol

This document outlines how interviews are to be executed for the purposes of obtaining data for the study.

Setting

Interviews will take place in a location familiar to participants, in a room that has adequate heating, lighting, and seating arrangements. Rooms will be private enough to allow participants to engage in discussion without being overheard by anyone outside the room in order to protect their confidentiality. Participants will be in close enough proximity to the interviewer to be able to hear what is said. A table will be used to lay out the range of communication supports required by each participant.

Facilitation

Each interview will be conducted by the researcher and audio-taped. A member of the Ageing Committee Steering Group will attend a sample number of interviews for the purpose of monitoring (a) that the protocol is adhered to as set out and (b) the reliability and validity of data analysis.

Introductory Information

Participants will be welcomed and thanked at the beginning of interview. The researcher will explain the purpose of the meeting and what will happen during the interview. She will expand on information given in the Information Letter about the issue of confidentiality. Participants will be reminded of the voluntary nature of participation in the interview and their right to leave at any time. Questions will be invited from the participants to clarify any issues regarding what the meeting is about.

Content

Questions will be posed to participants in the order below. After each question is posed, time will be allowed for participants to consider their responses. Prompts will be offered to steer responses towards different pertinent areas of participants' lives. A range of stimulus material will be used to contextualize interviews and support communication. When responses are put

forward, the researcher will check that she understands the response clearly (perhaps by repeating it back to the participant or re-phrasing). The researcher will check with the participant if he/she has any more responses before changing topic and moving to another question.

The questions are:

1. What does getting older mean to you?
2. How have you changed?
3. How has your life changed?
4. What has change meant for your life?

Prompts for each of these questions focus on individual change in the following areas:

0. *cognitive functioning*
1. *behaviour*
2. *roles*
3. *relationships*
4. *coping ability*
5. *social changes*

These six areas will be used as a framework to guide the interview and the research questions will be addressed in relation to these areas of life experience and individual functioning.

Recording Information

The researcher will audio record interviews so that detail can be preserved for later data analysis and direct quotes used in the report of findings. The researcher will also make a written record of observations of body language and tone/emotion attached to particular responses, as this can add greatly to the quality of data for analysis. Written information will be recorded immediately after completion of interview.

Termination of Interview

Interviews will continue until participants have had the opportunity to offer responses to each of the questions, covering each of the prompt areas. The exception to this will be in the case where participants ask for the interview to stop, express their dissatisfaction with how it is

executed (including fatigue if the process feels too long), or dissatisfaction with the nature of questions asked. An agreed mechanism to indicate a participant wishes to stop an interview or to refrain from answering a question will be put in place in advance of each interview, i.e. pointing to a STOP card. The researcher will remain vigilant throughout the process for verbal and non-verbal signs of dissatisfaction or distress. When an interview is stopped without completion of the interview schedule, further interview(s) will be offered. (Being mindful of concentration and fatigue levels it is likely that some participants will engage in a number of short interviews).

Concluding Information

Once responses to each question are drawn out, the researcher will thank participants for their involvement, reiterate issue of confidentiality and how information gathered will be used, how information will be disseminated to them and others, and how they can access it. The offer of further support will be made to participants, by means of talking to identified staff members (i.e. centre managers or keyworkers).

Appendix G

Sample of Memo Writing

Memo On Unfairness - 14/3/2013

Many incidents of unfairness, injustice etc. reported. For example JJ - speech impediment developed aged 13 resulting in admission to an adult psychiatric unit. BM8 – an arranged marriage and children that followed placed in care. DR not allowed to open a post office account like the rest of her siblings. Yet no bitterness or anger is reported. Others who have experienced injustice i.e. Magdalene Laundries survivors, are expressing huge anger at the injustice they have experienced. Why are we not seeing this in the intellectual disability population? Is it because they feel they deserve no better? Do they feel that the same rights to do apply to them as to other citizens? Nihilistic beliefs? (I should never have lived). Ninety percent of Down syndrome pregnancies now aborted in the UK. Societal psyche-- ‘these babies should not be born’ – impacting in some vicarious way on adults with intellectual disability. It is important to place the research within a human rights paradigm, specifically UNCRPD. Lessons must be learned and so stories must be told. Simplistic to report the words used alone, must be put in context of fuller interview. For example, BM8 describes a lot of unfairness and yet when asked if she has had a good life, she replies that she has. This cannot be taken at face value. Consider ‘whole life’ experience. No experience of speaking up or of complaining. No sense that she deserved better.

Appendix H -

Open Coding - sample

	KS/F/69			
	R. What's it like getting older?			
KS1	V. It's ok. I don't feel it a bit. I am happy about it like.	Happy about getting older	Positive towards ageing	
	R. Are you?			
	V. I am.			
	R. Have things changed for you?			
	V. Well they have really. They have. But not much.	Acknowledges change with age	Change with age	
	R. Tell me how they have changed.			
	V. ammm, ammm, what way will I describe it to you? I like going, doing...ammm... I don't mind getting older. I'm happy here – don't you know... I gets out and go to bingo and what more do I want.	Gets out and goes to bingo and happy where she lives	<i>Should</i> be satisfied	
	R. Is there more you want?			
	V. Well no, not really but I goes down to agriculture (horticulture) and I goes down to arts and crafts now for a while and I have my garden out the back and I'm happy with that – I'm happy – oh faith – I'm very happy – I am. I'm very happy with Kerry parents and friends now – there is no fear about that Eileen.	Names all her activities – horticulture, arts and crafts, gardening and reiterates that she is happy with the service	Indicates satisfaction with service (maybe trying to please)	
	R. Ok. And have things changed since you were younger?			
	V. oh big time, big time. Oh they have big time. They have indeed.	Big changes since younger years	Change over time	
	R. Ok. In what way have things changed?			
KS1	V. Well i think that... I don't know what to say to you about it. Well I think people is more up than long go....more up in their self.	Indicates people are more confident now	Confidence with age	
	R. People are more cheerful now is it?			

KS1	V. Yes. People can talk up now like I can talk – if I want my opinion I’ll talk my opinion to you like.	Can express her opinion now	Feels more empowered	
	R. Oh right – ok. So when you were younger did you find that you weren’t able to give your opinion?			
KS1	V. Yeah, I was younger but like when I was at home with Mom and dad I couldn’t have no opinion with them like – they were fine to me and everything.	Could not express opinion with parents		
	R. Oh right, so now that you are older and you are with the service, you are getting an opportunity to speak up for yourself?			
KS1	V. Yes, I’m speaking up now for myself. Yes.		Self advocacy opportunity within services	
	R. And when you were living at home you found....			
KS1	V. No, because i had to do things for Mom and dad, the creatures , the lord have mercy on them.		Duty to parents while they were alive	
	Rbecause they needed to be taken care of..?			
KS1	V. emmm.. they needed to be taken care of.	Took care of parents		
	R. Ok.			
	V. You see, the creatures.			
	R. Do you find that you are in any way more forgetful now? Can you remember things as well as you ever did?			
KS1	V . I can, faith, I can.	Claims not to be forgetful		
	R. I notice that you have a good memory.			
KS1	V. I have a great memory.			
	R. You have indeed, Yeah, Yeah. Do you find that you are slowing down in any way?			
	V. Well I think I am a small.... well I think I am....not yet... I don’t think so.	Unsure whether she is slowing down	Slowing down	
	R. You’re doing as much as ever?			

KS1	V. Doing as much as ever. I goes for a walk and I goes to bingo – which I’ll be there today again – tis lovely - 4 days a week.	Bingo and walking for recreation	recreation	
	R. have you changed K. Over the years, do you think?			
	V. Changed...in what way like?			
	R. Any way at all that you can think of.			
KS1	V. I’ve changed a bit alright – a small bit – not much.	Unsure if she has changed over the years		
	R. In what way?			
KS1	V. I suppose when you be getting old you kind of feel it and things like that. Still, I’m able to go around. I often said inside to Margaret (manager), if you get up in the morning, dress yourself and come down and have your breakfast , that’s a big thing. If you were inside in bed for good and couldn’t get up that’d be a lot worse.	“feels” getting old but grateful for what she can still do	Gratitude for what she can still do	
	R. So, are you grateful for the things you can do ?			
KS1	V. Yes and I’m able to make bread and things like that and I’m able to go to the shop, which is a good thing – I can walk out. I like walking.	Can bake and can go walking		
	R. Have your relationships changed over the years? The people that were important to you, the people you spent time with, has that changed?			
KS1	V. No, I talk away to people.			
	R. But, think back the years now.			
KS1	V. Oh, my family, like.			
	R. Yeah. Think back even when you were quite young – who were the people that were important to you and are they still in your life now?			
KS1	V. well, ‘tis my family but as you know, the ones in Listowel don’t talk – well, I sent them a card (invitation) for my birthday anyway.		Family rift	
	R. So, you don’t have as much contact with your family.			
KS1	V. No (very firmly). Well, I can ring Marina and Anne alright – things like that.	Little contact with family		

	R. so, do you put other people in your life now cos your family aren't ...			
	V. I do. I have a couple of old people I does things for sometimes. I went out yesterday and brought in C. (in a wheelchair) to EC.	Helping others less fortunate	altruistic	
	R. So, you like to look after people yourself now?			
KS1	V. I do. They looks after me and I do it for them. I minds 'em. Poor old F. Is very bad. He came back in a wheelchair from the doctor. He did the creature, he's very bad. The creature. And he's very fond of me. He puts his two hands around me and kisses me.		Bonding with housemate	
	R. So, do you feel sorry for people who can't do as much as you can?			
KS1	V. Yes. I do.		Sympathy towards less fortunate	
	R. Your mom and Dad have passed away of course.			
	V. Oh, they did.			
	R. Did that change your life?			
KS1	V. Well, em..., I suppose a small bit, yes.			
	R. In what way did it change your life?			
KS1	V. Well when Mom was gone and Dad was gone I had no more to do but to come in to Kerry Parents and Friends and I'm fond out of 'em.	Had to leave the family home once parents died	Involuntary house move	
	R. Ok. So it made a big change to your life because you had to leave the family home.			
	V. Oh Yeah. I know that. Yes. I had to leave my home. That was it. A hard thing to do. But we had to do it. I'll come (get) over it. I'll come out of it. I'm fine now.	Struggling to come to terms with having to leave the family home but determined to get over it	Disappointm ent and loss	
	R. So, was that a hard thing to do?			
	V. Oh God, it was.			
	R. Leaving your community, was that hard?			

KS1	V. Yes, leaving my community and my place behind me – where I was reared like – but things is worked out very well (appears sad.....voice lowered).	Sounds sad talking about this	Loss of community and place	
	R. Things have worked out?			
	V. Oh Yeah.			
	R. Do you have regrets? Do you wish you were still living back in...?			
KS1	V. Wisha no, Eileen. I don't, to tell you the truth. I'd rather be here. I'd rather be with Kerry parents and friends to tell you the honest truth. I'm mad about it.	Seems to have accepted move and feels she is better off where she is now	acceptance	
	R. So, good things happened after you left?			
KS1	V. Yes, the good things and Tony (CEO) – Tony brought me in and kept me here. He was good to me. Ye're always good to me here.	Expresses gratitude towards those who helped her	Dependence on others but grateful for help	
	R. But it wasn't your choice at the time, was it?			
KS1	V. No, but I got alright after it, but, of course, as you know, I was very lonesome after my parents because I was with my parents for a long time – but these things happen sure Eileen.	Expresses lonesomeness after loss of parents	lonely	
	R. You were at home with your parents for about 55 years.	55 years at home		
	V. I'd say so. I had. I was, I was I was (pensive).			
	R. It's a big change. You left a lot behind.			
	V. I left a lot behind me – a good lot of it, I did but.....		loss	
	R. What about neighbours?			
KS1	V. My neighbours was very good to me – but 'tis nothing I can do with it. I'm here and I'm happy. Margaret (manager) says I can ring my neighbours if I want.		Loss of regular contact with neighbours	
	R. Oh, did she?			
	V. She said ring your sister if you want.			
	R. So, you talked to me a little bit about roles when you were growing up. Were you the person who looked after your parents?	Looked after parents growing up	responsibility	

KS1	V. Yes, yes, yes.			
	R. That was your job?			
	V. That was my job and I stayed with them. Ah, the creature, 'til she died in her own bed the poor woman.			
	R. What did you do at home?			
	V. I used to bake. When my Mom couldn't bake, I baked and everything, get the dinner and everything. Sent my father up one day for the bacon for the dinner. The Lord have mercy on him. He came in the door – that's the time he thought of the bacon.	Baked at home, cooked dinner. Remembers funny story re Dad.	roles	
	R. Oh really. He forgot all about it is it?			
	V (laughs) he forgot it. Jesus, said he, she's going to kill me, she's going to kill me.	Enjoyed recalling funny story		
	R. So, you did the baking. What else did you do?			
	V. I used to wash the clothes, go to the machine and put them out on the line.	Cared for laundry		
	R. Do you do any of those things now?			
KS1	V. I do, God. I put clothes on the line and bring them in. If I can at all, I bring them in for 'em.	Still can do these chores		
	R. Do you wash your own clothes now?			
	V. No, they wash them in the machine for me.	Staff taking over some roles		
	R. Staff do that?			
	V. Staff do that. That's what they're there for and I leave them do it (laughs).		disempowerment	
	R. So do you think you could, or would you like to, do more for yourself now?			
KS1	V. Yera, I'm alright the way I am. God, as long as I have my health, I don't mind.	Happy to let others do the work	Acquired helplessness	
	R. So, when you were at home you had a lot more....?			
KS1	V. responsibility....with my Mom and Dad you see.			
	R. Yes, you had responsibility. Do you feel you don't have as much responsibility now?			

KS1	V. No, no.	Less responsibility now		
	R. You just have yourself to think about?			
	V. Yeah, Yeah.			
	R. Is that a good thing or a bad thing?			
KS1	V. A good thing, oh God 'tis. Ahhh, 'tis now Eileen.			
	R. So can you do as much now as you used to be able to do in the past when you were younger?			
	V. I can.			
	R. Is there anything that you feel that you can't do anymore now because you are getting older?			
	V. Well, I was in the kitchen for a long time and I gave up the kitchen because I was tired of the kitchen.	Gave up kitchen duties		
	(Looking through personal photographs)			
	R. When I met you first you wore those bibs, do you remember?			
	V. I brought them in with me I think.			
	R. You did, Yeah.			
	R. Did you like wearing those kind of clothes?			
KS1	V. Not at all (in disgust). I'm swanky now. (laughs).	Prefers how she looks now. Disgusted with clothes she wore before	Pride in appearance	
	R. Why did you wear those kind of clothes. Who made the decisions about your clothes?		Mom making decisions for her	
	V. Mom,mom,mom.			
	R. Did she buy clothes for you?			
	V. She used to and we used to go to town in the car. Yeah.			
	R. So now you buy your own clothes?			
	V. Yeah.			
	R. You choose your own clothes?			
KS1	V. I choose them.		Asserting herself now and making choices	

	R. And you choose very different things to those clothes. (pointing to photograph).			
	V. Oh, you may be sure of it.			
	R. As you say , you are very swanky now.			
KS1	V. I'm very swanky now, my head up in the air.		Improved self concept	
	R. Are you proud of yourself?			
	V. I am very proud of myself. (Looks at photo). That's the devil in Dublin that walked out the door. Left Anne.	Expresses pride in herself		
	R. So some people die, like your Mom and Dad, and some people left.			
	V. Yes, yes. Broke up.		loss	
	R. What is it like for you not to have contact with that you used to have contact with in the past?			
KS1	V. Well, I feels it sometimes but the only thing is, I'm fine.	Feels the loss but says she is fine	resilience	
	R. (Looking at photo) Look at this picture here. Did you have hens?			
	V. Yes I had hens. I had.			
	R. Used you look after the hens?			
KS1	V. Yes and they used to come up to the back door and start pecking the back door when they're hungry. Oh they would faith.	Used to look after hens	Loss of social role and contact with farm animals	
	R. Was it your job to look after them?			
	V. Yes, they were mine.	Ownership of role	Loss of valued role	
	R. Did you have other animals to look after.			
KS1	V. Well, I had a dog and I gave the dog when I was coming in here to a fella. A dog died and he was crying after the dog day and night and I gave him my dog. Max was his name. He has him all the time I believe.	Move to services meant the dog had to be given away	Loss of valued pet	
	R. So you gave away your dog when you came in here?			
	V. I gave him to the man because he was crying after his dog. I gave it to him.			
	R. Did you miss the dog once you gave him away?			

	V. I would miss him but I couldn't bring him in.	Missing her dog but accepts she had to give him up		
	R. No I suppose not – going into a house where people were afraid of dogs.			
KS1	V. JS is afraid of dogs and as you know, H O'C is in hospital.	Other residents afraid of dogs.	Choice re who to live with not given	
	R. So if you could have brought Max with you, would you have brought him?			
KS1	V. I would, faith. Faith, then I would. I'd love him. He's the only dog. He was a nice little dog. I had a big black dog before Max. He died at the back door. Will I ever forget it? And if you.... he'd bring in the bread in his mouth inside in a paper bag and put it up on the table to you. I trained him.	Would have liked to bring the dog with her. Remembers another dog and speaks fondly of him. Proud that she trained him	Loss of other dogs leading to better ability to cope with this loss	
	R. You had him trained?			
KS1	V. And he wouldn't touch the bread. He wouldn't touch it – No- and he would come to me then and sit down. If a dog knows that there is thunder and lightning coming they go under the table and you will not get them out. E. Is afraid of thunder, you know.	Shares knowledge of dog behaviour	Willingness to share knowledge and experience	
	R. (Looking at photo) This is a very old picture – 1960.			
	V. How many years ago is that?			
	R. I was born in 1960 so it's 51 years. Have you any recollection of when you were a child?			
	V. I used to get plenty of money and everything.			
	R. Do you remember when you believed in santie?	Contextualising timeframe		
	V. I do, I do, I do.			
	R. Were they good times?			
	V. They were good times.			
	R. Was your childhood happy?			
	V. I was, faith, I was. Do you know what I used like long go when the people makes currant bread.	Expresses happy memories of childhood		

	R. You used to like your currant bread?			
	V. I do. That was it. I'm mad for it.			
	R. Who used to make currant bread?			
KS1	V. Mom. She was great. She was great. My sister moved to Limerick then – and she made a big cake. What did I do only throw a bottle of whiskey on top of it – for bla'guarding I done it.	Recalls happy memories of childhood	reminiscing	
	R. That was a Christmas cake?			
	V. Yes – a big cake – they were eating it – they weren't eating much of it. The devil mend ye now. Ye'll leave me alone the next time. A big bottle of it I threw in.			
	R. Were you just having fun?			
KS1	V. Well I did it. Well I was only having fun with them but I said they'd leave me alone. They were teasing me about something. They won't be teasing me now.	Recalls taking control to keep herself safe from teasing		
	R. Were people mean to you before?			
KS1	V. Ah no, they weren't mean. Ah no. I had good neighbours. Good neighbours, since the night Mom died. TS living along side me – inside in one of the new houses. He came out of his bed. He had a kind of flu or something and he came out the night Mom was dead. He brought us cakes in and everything. Poor mom. She'll be dead 18 years in June. She died before my Dad. My Dad died in Columbanus's, you remember?	Tells of support of neighbours around her mother's death	Importance of good neighbours	
	R. It's a very different life for you now.			
KS1	V. 'Tis, but I don't care. I don't mind.		Life changed after death of mother – loss of neighbours	
	R. Is there anything you miss that you would still want in your life?			
	V. No.			
	R. Is there anything you want for your future?			

KS1	V. Just to be going around – tipping around. I'm fine.	Maintain current health is a goal	Future goal is to maintain current level of functioning	
	R. If you had a vision for your future what would it be like?			
	V. I don't know really... (long pause). I don't know really Eileen... I don't know.	Can't envisage the future		
	R. Would you like things to be the same as they are now?			
	V. I'd like to be able to get up and make my bed and get out and wash myself and go out around.	Goal is to keep doing what she is doing		
	R. So, just for things to remain the same as they are.			
	V. Yes, yes. I have a good garden outside now and what more do I want like.		Grateful for what she has	
	R. Is there anything you would change?			
	V. No, no. I'm happy the way I am. I'm grand, the way I am.			
	R. That's good. Were you always happy? Were you always a happy person?			
	V. Yes, I was. I was a very happy person and always will be.	Reports happiness she has always been happy	Happiness as a trait	
	R. Were there times when you were not happy?			
KS1	V. Yeah. Of course I flew off the handle below one day, Leaside, you remember. Someone was after doing something to me. I forget.	Recalls losing her temper on one occasion		
	R. So, you had a tendency to get angry?			
	V. Yeah.		Gets angry with others	
	R. Does that still happen to you?			
KS1	V. Sometimes I do. If I get into a tear I would.			
	R. If you get in a temper?			
KS1	V. A temper – I got into a bit of a temper the other day with Margaret,	Reports getting in a temper with	Does not want to be	

	on Friday. I went up to put on this cardigan and she said that it wasn't nice on you and this isn't nice on you. I came down stairs and said "will you leave me alone". Margaret said "I'm sorry". She gave me a big kiss before I went down for dinner. I went down for my dinner on Friday because TB is gone now from me and I was lonesome after her. She was very good. I have a few asked to my party.	management telling her what to do	told what to wear	
	R. Don't you know the way you say that you sometimes lose your temper – do you think that is happening more often now?			
KS1	V. I walk out the door. I did the other evening.	Walks out to cope with feelings of anger	Coping with anger	
	R. As you are getting older do you think you are getting cranky more often or less often?			
KS1	V. Less often now. Yes – oh yes Eileen.		Mellow with age	
	R. Do you think you manage your temper a bit better?			
KS1	V. Oh I am, I am. Out the door I go.	Manages temper by walking away		
	R. So you have learned to just walk away.			
KS1	V. I walk away now and say no more. I say go away now and say no more.		Coping strategies to manage temper learned over time	
	R. In the past would you react and say nasty things?			
KS1	V. Oh, faith, then I would. If they're at me they'll get it – a bit of the tongue – but not now. I like them now.		Change in emotion regulation with age	
	R. Not as much now.			
	V. No. I'm very fond of E. Sure E. puts the two hands around me and gives me a kiss, God help us.	Bond with fellow residents and affection is welcome	Substitute family	

	R. I suppose you are somebody K, that has left home at such a late time in your life.			
KS1	V. Yeah, I left home and now the family home is gone. The neighbours was lonesome after me – Oh Jesus they was, girl. They was very lonely and I was lonely. Ah, but sure I couldn't be left alone in the house – No.	Sadness at loss of family home, loss of neighbours, lonesome, but acceptance that she couldn't manage on her own	Unwanted change leads to sadness and loss. Acceptance re need for support – leading to reduced choice	
	R. What would it have been like to have been left alone in the house?			
KS1	V. I wouldn't stay in the house alone at all – oh, no, no, no.	Not wanting to be alone		
	R. You wouldn't have been happy to do that?			
	V. Oh, no.			
	R. so, what do you miss about those times?			
KS1	V. I miss not going out to see them more often. I can't go out because there is no one that will take me out, you see. The staff here can't be taking me out. No.	Misses not seeing neighbours. Problem with unavailability of transport	Dependence on others for transport leading to reduced QoL because cannot visit valued friends	
	R. So you would like to have kept in contact with those neighbours?			
	V. I can ring them if I want.			
	R. But, do you ring them?			
KS1	V. P.S. is stone deaf. She can't hear.	Everyday means of communication may not work for those ageing	Obstacles to keeping in contact with valued others	
	R. So the phone wouldn't be any good?			
	V. No. If Tony was there it would be different. He works here in town.			
	R. A lot happened since you moved hasn't it. Some for the good, as you said, because you can make more decisions for yourself.			

	V. I do and I will.			
	R. In some ways.			
	V. In some ways.			
	R. In other ways I suppose you are not making as many decisions.			
	V. I'm happy now...mmm .. (appears pensive)	Resigned to poor control over life decisions	Resignation -	
	R. do you feel that you make enough decisions? Do you feel you have full choice about how you live your life?			
KS1	V. I am taken out for dinner and everything with them. I am being taken over to Debenhams on Saturday with Breda and Eleanor for my birthday clothes.	Outings – dinner out and shopping. “with them” seems to imply she is going along – not the focus of the outing	Focus on the positive-planned outings but strong sense of resignation to “as good as it gets” given where she finds herself	
	R. And when you were at home, you didn't go shopping for clothes, you told me.			
KS1	V. Oh no. I couldn't. My mother was too old.			
	R. But even when you were younger she used to shop for your clothes.			
KS1	V. The poor woman, she used to. The creature.	Did not choose own clothes throughout life	Others making choices – lifelong experience	
	R. Did you go out socially at all when you were living at home?			
KS1	V. No, not much.		Little opportunity to socialise - lifelong	
	R. Where did you go? Did you go to mass?			
KS1	V. Sometimes I do go to mass but my Mom couldn't walk it when she got older – the creature, she couldn't.	Went to mass sometimes but depended on mother	Outings depended on ability of others to go - lifelong	

	R. So did you get out at all when you were at home?			
	V. Not much, no.			
	R. Did you ever go to parties or anything?			
KS1	V. Oh no, no, no.	No parties or social events while at home		
	R. Did you ever walk to the shop?			
KS1	V. Oh, the shop is far away. There is no shop around us.	Rural living leading to inability to go to shop	Isolation due to rural living throughout life leading to reduced access to community	
	R. so, did you get out at all?			
KS1	V. Not.... No...not much....no.			
	R. So, you have a better social life now.			
KS1	V. I'm going down to my bingo 3 days a week – there's no fear of me.	Bingo 3 days a week	Social life and access to activities in community greatly improved since coming to services	
	R. so, lots of things have changed for you?			
KS1	V. They did - change for the better.		Some change is for the better	
	R. And the one thing I am picking up from you that was not for the better is that you lost so many relationships along the way?			
KS1	V. Yes, that's it.		But sadness due to losses persists	
	R. That makes you sad, is it?			
KS1	V. At times it does – but I will go out now to my Mom's grave and I have a big stone made but I'll have to put a wheelbarrow into the car and wheel it into the grave. The stone is too big.		Coping with loss through remembrance rituals	
	R. So, the next big thing is the party.			

	V. Oh yes it is.			
	R. Why is it so important to you – this party?			
KS1	V. Because I'll be 70 and I won't be 70 no more. I could be gone for my next one. God forbid – God forbid.		Awareness of fore-shortened future	
	R. Are you in good health?			
	V. I am alright.			
	R. Yeah, do you feel healthy?			
KS1	V. I do.	Reports good health		
	R. Do you feel as healthy now asI remember your 65 th birthday...do you feel as healthy now?			
	V. I feel ok. I'm alright.			
	R. So this birthday is important – do you feel it could be your last one?			
KS1	V. Yeah.			
	R. Even though you are very healthy?	Current health no guarantee that illness could be around the corner		
	V. I am.			
	R. What about people coming (to the party). Is that important to you?			
	V. It is.			
	R. Would you like a lot of people to come?			
	V. I do. I do.			
	R. What would that mean to you, if a lot of people come?			
KS1	V. 'Twould make my day – a big day for me.	People coming to party may be an affirmation that "I matter"	Importance of being visible to others, being appreciated?	
	R. So, 70 is your big day.			
	V. M. Said she might bring the little girl with her.			
	R. Oh lovely. Have you any contact with children now, K?			
KS1	V. No, no.		No contact with children now	
	R. And you are someone who is very fond of children.			

	V. I am very fond of them, I am. NS's little grandchild comes in with his daughter. He puts up his two hands to take him. I took him one day. I thought he'd cry. He would in his neck cry. Long as he won't bite you.	Very fond of children and recalls an incident where she had contact with a baby – but unsure how baby would react to her	Poor confidence with children	
	R. So you don't have much contact with children.			
KS1	V. No. And I love them, you know. I love them. I do.		Fondness for children	
	R. And would you like to have contact with children?			
	V. I would, faith, I would. I love babies. I love children. Wait till I tell you this. There was a woman with twins and she was going back to Blennerville to drown them, but for they stopping her. The children are taken away from her now.	Says she loves babies	Would like contact with children	
	R. Do you listen a lot to the news?			
KS1	V. I do, I do. Did you see that jockey? He must pay 90,000 euro now or something.	Listens to news and recounts stories she heard	Listens to news – human interest stories – curious about lives of others	
	R. Why do you like listening to the news?			
KS1	V. In case I hear of someone from home – dead or something.	Listens for death notices etc. from old community	Local radio helping to keep contact with news from old community	
	R. And you like to hear what's going on. V. I do		Importance of keeping in touch with old community	
	R. And I notice you like to tell me all the bad things that are happening.			

KS1	V. Oh God yes. I think Barry is going to be murdered tonight.	Seems to hone in on dark and dramatic stories	Drama to make life interesting	
	R. Who?			
	V. Barry.			
	R. Is that on some programme?			
KS1	V. That's on fair City.			
	R. Oh right. I don't watch fair City. You think he's going to be murdered?. Do you like the soaps?	Likes the soap operas	Vicarious living	
	V. I do.			
	R. What do you like about the soaps?			
KS1	V. It will be awful interesting tonight on Eastenders. What's his name (thinking) – I don't know what's his name – he beat the sugar out of Martin last night.			
	R. Oh goodness. When you were growing up was there anything like that on the television?			
KS1	V. No, no, no, no.	Not exposed to violence on TV growing up		
	R. Did ye have a television?			
KS1	V. We had, but nothing like that on it. No, no – rubbish.			
	R. Do you think the soaps are rubbish?			
KS1	V. Well, some of them is. More of them isn't, like. I don't like Emmerdale or I don't like Coronation street – not my cup of tea.	Knows what she likes and dislikes on TV and can voice this	Chooses her TV viewing	
	R. Why don't you like those?			
KS1	V. There's too much devils on it. Yes, too much naked people.	Seems disgusted by nudity on TV		
	R. Oh really.			
	V. At times, yes.			
	R. You never liked that kind of thing, sure you didn't?			
KS1	V. No, no, and won't.		Moral code intact	
	R. Do you think there is too much of that on television?			
	V. Mmmm. And I like cooking on television.	Likes to watch cooking programmes		
	R. What else do you like to watch?			
KS1	V. I'll tell you what I like to watch. I like to watch boxing, wrestling, and	Names what she likes to watch on	Strong individual	

	the Chippendales and bull-fighting. I love them. Love 'em. I'd sit down and watch them for hours laughs). And I love Murder She Wrote. I'd watch that for hours. There was one last night after the news but I turned it off. It wasn't suitable for anyone. I went up to bed.	TV but is offended by some programming "wasn't suitable for anyone"	preferences re tv programmes but also has sense of her own values as to what to watch	
	V. So, that's that.			
	R. Would it be ok to come back and ask you more questions if there are things you said that I'd like to follow up on?			
	V. yes, you can.			

Appendix I

Axial Coding - sample

	KH/F/50			
	(Communication assessment on 6/6/11 using photographs. Same photographs used at interview. CA revealed repeating and checking back that you have understood the communication was facilitative to KH).			
	R. Did you enjoy looking through the photographs? We looked back on when you were young.			
KH1	V. Yeah. I could walk when i was young. I can't walk now.	Can no longer walk – deterioration with age	Regret – loss of function with age	22
	R. What was different back then, when you were young?			22
KH1	V. I could walk. I'd like to walk again.		Sadness because she will never walk again	22
	R. Did things change a lot when you couldn't walk?			22
	V. Yeah.			22
	R. And did that make you sadder?			22
KH1	V. Sadder.			22
KH1	R. Was there anything good about getting older?			56
KH1	V. No.		Nothing good about getting older	56

	R. Can you think of anything that is better now than it was when you were younger?			56
	V. Going to school.			56
	R. Going to school – was that good or not good?			56
	V. Good.	Going to school was experienced as good	Role of schoolgirl clearly defined in childhood	56
	R. That was good. And where did you go to school?			56
KH1	V. Cromane – I was going there when I was ten and when I was ten then I went to Dublin.	Moved to special schooling at 10	Loss in childhood due to move from family home, parents, siblings, school and community	56
	R. And what was the name of the school you were in, in Dublin?			56
	V. St. Michael's.			56
	R. In Dunlaoighre?			56
	V. Yeah.			56
	R. And was that a school for people with disabilities?			56
KH1	V. Yeah.		Awareness of her disability	56
	R. Was everyone there in wheelchairs or just some people?			56
	V. Some people.			56
	R. Did you learn much there?			56
	V. I did. I think.			56

	R. So, school days were good days?			56
KH1	V. Yeah.	School days were good days		56
KH1	R. And then when you finished school what happened next?			13
KH1	V. When I came home, they sent down a wheelchair for me.			13
	R. From Dublin?			13
	V. Yeah.			13
	R. When you went to Dublin were you in a wheelchair?			13
	V. No.			13
	R. No. But by the time you finished school you were in a wheelchair?			13
	V. Yeah.			13
	R. And when you came down from Dublin, they sent down a chair?			13
	V. Yeah.			13
	R. And from that time on were you in the chair all the time?			13
	V. Yeah, I was.			13
	R. What was that like?			13
	V. Not too good.			13
KH1	R. So, school days were good, being a child was good and once you left school and came home, were things not as good then?	Change from childhood years – wheelchair represented decline	Negative change occurring since leaving school	56
KH1	V. No.			
KH1	R. Can you think of anything good that happened from the time you left school until now?			42

	V. No. I went to Lourdes. That was alright.	Lourdes was only good thing that happened since childhood	Travelled to Lourdes in late teens	42
	R. You went to Lourdes and that was a good thing. So you got to travel?			42
	V. Yeah. I can't travel now.	Can't travel now		42
KH1	R. Why can't you travel now?		Too nervous to travel now because of support needs	42
	V. I'd be nervous.			42
	R. Would you be nervous to travel?			
	V. Yeah.			
KH1	R. Do you think you would need a lot of support?			13
	V. Yeah. People with me.		Needs people to support her with ADLs	13
	R. When you went to Lourdes the first time, was there people with you then to help you?			13
	V. There was.			13
	R. Were you nervous then?			13
KH1	V. No.	Not nervous to travel when she was younger although needed support then too		13

	R. You were quite young. Were you in your 20's			13
	V. No. I was 18 when I went.			13
	R. Oh. You were only 18. And you were not nervous at all when you were travelling?			13
	V. No.		Nervousness re travel developed over time	13
	R. But now you would be more nervous travelling?			13
	V. Yeah.			
KH1	R. You travelled to England though didn't you, as an adult? (photos viewed at CA had revealed this).			51
	V. Yeah.			51
	R. Did you go by ferry or by plane?			51
	V. We went by ferry once with Mary and then we went by plane ourselves a couple of times.	Travelled to UK when younger		51
	R. So, you were able to fly up to recently?	Was able to fly in the past		51
	V. Yeah.			51
	R. And now how would you feel about flying?			51
	V. I don't know. I'd be alright I suppose (pauses)..I'd like to fly in a plane again.			51
	R. So, you would like to travel more?			51
	V. Yeah.			51
	R. Where would you like to travel to?			51

KH1	V. Lourdes, England.	Would like to travel again to England and Lourdes	Goal to travel	51
	R. Is there any place else you would like to go?			51
	V. Spain or France.			51
	R. What would attract you to countries like Spain and France? What would you like about it?			51
	V. What would I like about it.... the sun (laughs).	Would like to travel to the sun		51
KH1	R. If you went to Spain or France – who would you like to go with?			43
KH1	V. I don't know (pauses) .. ammmm.. my brother.	Would like to travel with brother	Importance of family contact and support	43
	R. Your brother P? So, would it be family you would like to go with, not staff?			43
	V. Staff too.	Would like staff support too		43
	R. You wouldn't mind staff either?			43
	V. I wouldn't mind that either ..as long as.... anyone....if I could go with anyone...it would be alright.	Need for support acknowledged	Will take support from anyone	43
	R. The important thing is to get going?			43
	V. Aha.			43
KH1	R. So, you still have ideas about things you would like to do in the future?			51
	V. No. I'd like to be playing games.			51
	R. What kind of games?			51

	V. Hockey, tennis and bocca. I'm good at that.	Hockey, tennis, bocca	Likes games	51
	R. Do you see yourself playing games while you are still in the wheelchair or do you think you could get out of the wheelchair to play?			51
	V. Out.			51
	R. Could you play tennis while still in the wheelchair?			51
KH1	V. I could.	Acknowledges she can play games while in the wheelchair		51
	R. Yes, you could, Yeah. Have you ever played hockey in the chair?			51
	V. No.			51
	R. I've seen it played (in wheelchairs) on the television. Have you?			51
	V. Yeah, Yeah.			51
	R. So, you could play in the chair			51
	V. Yeah.			51
KH1	R. So, in the future you would like to see yourself playing more games – so that's another idea you have for the future.	Wants to keep playing games		51
	V. Yeah.			51
	R. So, looking back on the time from when you were a child until now, have any of these things happened. You went to England a couple of times and you went to Lourdes, but you didn't get to play many games, did you?			51
	V. No.			51

KH1	R. So, would you still like to see that happening?		Open to new possibilities	51
	V. Yeah.			51
KH1	R. What other changes have happened for you over the last number of years?			11
	V. I'd like to go to Mass.		Importance of religion	11
	R. You'd like to go to Mass.			11
	V. Yeah.			11
	R. Every Sunday?			11
	V. Yeah.			11
	R. Is that happening at the moment?			11
	V. No.	Not getting to practice her faith as she wishes to		11
	R. Why is that not happening?			11
KH1	V. I don't know.	Doesn't know why she can't go to mass every week	Lack of control	11
	R. When you were at home did you go to mass every Sunday?			
	V. Every second Sunday. Mass now is on Saturday evening, 6 o' clock.			
	R. And did you go on Saturdays when you were at home?			
KH1	V. I did, when Mom and Michael were alive.		Loss of routine based family life	
KH1	R. So that's the big change really, Mom and Michael passing away.			22

	V. It is. , Yeah. Pity.		Loss of close family members	22
	R. It is a pity. From the time you were a child right up to the time that Mom and Michael passed away did other people that were important to you die – or leave?			22
KH1	V. They did. My uncle and my father.			22
	R. That’s right. I saw pictures there of Dad...Is that one of Dad there? (point to photo)			22
	V. That’s him there.			22
	R. How old were you when he died?			22
	V. 18	A teenager when Dad died		22
	R. So you were quite young when Dad died?			
	V. Look at me there (shows photo).			
KH1	R. You are beautiful there. That is one of the nicest pictures I’ve seen. You just look like a film star – beautiful red hair. What are your dogs’ names? (point to dogs in photo)			46
	V. Rover.			46
	R. I suppose Rover died?			46
	V. He did.			46
	R. Did you miss Rover after he died?			46
	V. I did.		Loss due to family pets dying	46
	R. Did you get another dog?			46
	V. We got a one, Yeah.			46

	R. Do you like dogs?			46
	V. I do. I like dogs.		Importance of pets	46
	R. You have more pictures of dogs. What was the next dog called?			46
	V. Prince.			46
	R. But now that you are here you have no dog?			46
	V. No.			46
	R. When you were at home, before Michael died, did ye have a dog?			46
KH1	V. We did.	Always had a dog		46
	R. And what happened the dog?			46
	V. He died. He got cancer in the throat.			46
	R. Did he have to be put down?			46
	V. Yeah.			46
	R. Each time one of your dogs died did you feel lonely after them?			46
KH1	V. I did. I feel lonely after Prince. He was nice. He was a Jack Russell.	Loneliness experienced after each pet died	Loneliness due to loss of pets	46
	R. I saw a picture of him actually. Was he your favourite?			
	V. Yeah.			
	R. Is that a picture of him (showing photo)?			
	V. No, that's F's. dog (sister).			
KH1	R. Oh that's Paddy (name on photo). Paddy the dog. I will have to look for Prince. (Showing photo) –			22

	look at a photograph of all of ye when ye were very small. Isn't that a beautiful picture? Are you the baby there?			
	V. Yeah, look at me.			22
KH1	R. Oh Yeah. Yourself and Michael are the babies and there are your two sisters and your brother. They were always there when you were growing up, weren't they?			22
	V. They were.			22
KH1	R. And then they went to England... your sisters. Did that make a difference..... to your life?	Sisters left to go to England as young adults		22
	V. It did.			22
	R. In what way did that make a difference?			22
	V. I don't know. When I was young they were there.		Loss due to siblings departing as young adults	22
	R. When you were young they were there and then they were gone?			22
	V. Yeah.			22
	R. Did you miss them?			22
	V. Yeah.	Missed siblings once they left home	Multiple experiences of loss from middle childhood	22
	R. You obviously spent a lot of time together growing up.			22
KH1	V. We did.			22
	R. And they went to England. Did they stay in England then?			22
	V. Yeah.			22

	R. Married in England?			22
	V. Yeah.			22
	R. Do you miss them?			22
KH1	V. I do sometimes.	Sisters married in England and started a new life	No positive change with age while siblings got on with life	22
	R. It makes a big difference that they are over there and you are over here, doesn't it?			
KH1	V. Yeah. (Picks up a photo) That one would be nicer than the one I have.	Importance of family photos	reminiscing	
	R. Oh, you think that would be nicer in the frame – it is a beautiful picture. Perhaps you could get another frame for it because it has all the family in it.			
	V. Yeah.			
	R. (Looking at photo) Isn't that a really old car? That was 1967 actually (year written on photo)			
	V. That's old.			
	R. Can you remember back when ye had that car?			
	V. Ha			
	R. Was that your car or the neighbour's car?			
	V. I don't know was it our car. I don't remember it now.			
	R. (Looking at photo) And this is an absolutely beautiful picture with your lovely long hair.			
KH1	V. It is. That's nice.	Recognises her positive attributes		

	R. It was 1971 so you were about 10 there.			
KH1	V. I was walking back then.	“when I was walking” is reference for time	Holding on to memories of better times	56
	R. Were you happier then?			56
	V. I was. I was happy.		Happy when younger	56
	R. So, since you went into that chair have you been happy?			56
	V. No.	Wheelchair as source of unhappiness		56
	R. It’s been a bit of a challenge for you, hasn’t it?			
	V. Yeah.			
	R. Is that your Mom and Dad in that picture?			
KH1	V. It was. That’s F. (sister), and Mom. Oh no, that was my uncle and Mom and P. (brother) and me and M (brother).	Recognises and names all family members in photo		

Appendix J

Selective Coding- sample

	V. In some ways.			11
	R. In other ways I suppose you are not making as many decisions.			11
	V. I'm happy now...mmm .. (appears pensive)	Resigned to poor control over life decisions	Resignation -	11
	R. Do you feel that you make enough decisions? Do you feel you have full choice about how you live your life?			11
KS1	V. I am taken out for dinner and everything with them. I am being taken over to Debenhams on Saturday with Breda and Eleanor for my birthday clothes.	Outings – dinner out and shopping. “with them” seems to imply she is going along – not the focus of the outing	Focus on the positive-planned outings but strong sense of resignation to “as good as it gets” given where she finds herself	11
	R. And when you were at home, you didn't go shopping for clothes, you told me.			11
KS1	V. Oh no. I couldn't. My mother was too old.			11
	R. But even when you were younger she used to shop for your clothes.			11
KS1	V. The poor woman, she used to. The creature.	Did not choose own clothes throughout life	Others making choices – lifelong experience	11
EC1	R. How are you today?			11

EC1	V. Home.	Wants to go home	Home very important	11
	R. You want to go home?			11
EC1	V. Home, home.			11
	R. When you were younger did you always go home for the holidays?			11
	V. (nodded)	Used to go home for holidays when younger but not now		11
KH1	R. What other changes have happened for you over the last number of years?			11
	V. I'd like to go to Mass.		Importance of religion	11
	R. You'd like to go to Mass.			11
	V. Yeah.			11
	R. Every Sunday?			11
	V. Yeah.			11
	R. Is that happening at the moment?			11
	V. No.	Not getting to practice her faith as she wishes to		11

	R. Why is that not happening?			11
KH1	V. I don't know.	Doesn't know why she can't go to mass every week	Lack of control	11
KH1	R. And you started going into the Monastery as an adult – did you like going in there?			11
	V. I did – Yeah.	Liked day service		11
	R. Was that something you chose for yourself?			11
KH1	V. No. Do you know R. O' C? She told me go in there (community nurse).		Did not choose to go to day service	11
KH1	R. So, if you had a choice to live here or live at home, which would you pick?			11
KH1	V. Live at home.		Would choose to live at home	11
TL1	R. Oh, you'll go home with your family is it?			11
	V. Yeah.			11

Appendix K

Theoretical Sampling

The Researcher struggled with a constant theme arising from the data, that is, self reports of happiness. Theoretical sampling was used to check out how participants explained happiness. The following is a transcript from one such interview:

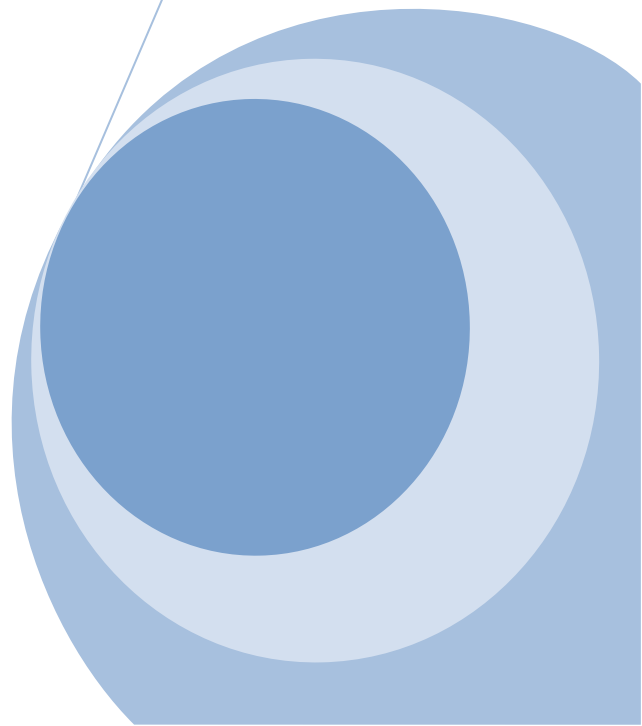
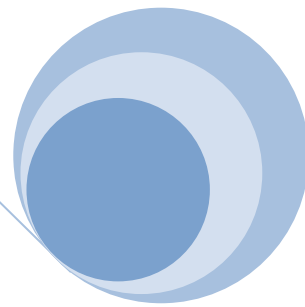
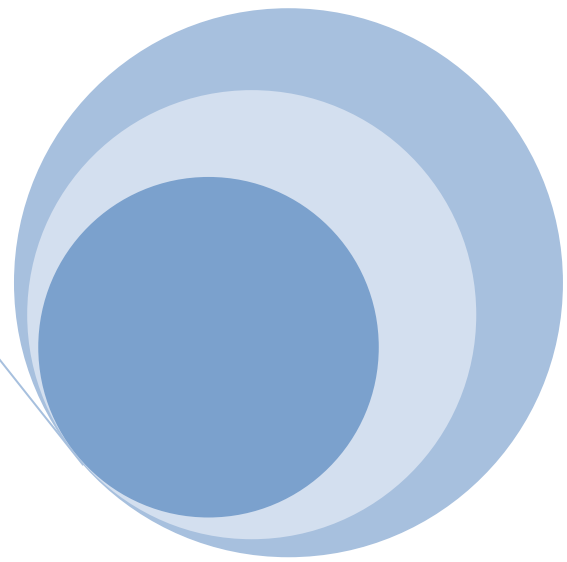
30/4/13:

Researcher:	<i>You told me you are happy with your life. Do you still feel this way?</i>
Participant:	<i>Yes I do.</i>
Researcher:	<i>Can you tell me how is it you remain happy because you have not had an easy life.</i>
Participant:	<i>I just keep it simple – go for a coffee or a chat, go for a walk. Talk to people. Don't complicate things.</i>

APPENDIX L

**Wellness in Ageing
Tool –Intellectual
Disability**

11/26/2018



Instructions to Key Workers: Complete the 20 item questionnaire with the person you support when concerns around age-related change in psychosocial functioning arise. Responses will inform individual support plans and goal setting. Repeat the questionnaire as appropriate to review and revise supports required as the person gets older.

Section A: Responses to 20 questions.

Section B: Summary of supports required.

Section C: Complete an Individual Support Plan for each area where support is required.

Name:

Address:

Date of birth:

Age:

Key worker:

Completed by (if person other than key worker):

Date of completion:

Date for review:

A)

Self Determination

1. How is this person supported to live a self-directed life?

2. How is age-related change impacting on self-efficacy?

3. What further supports are required to maximise opportunity and ability to live a life of this person's choosing?

Loss

4. How is this person supported to manage personal loss?

5. What further supports are required to assist the person in managing past and ongoing losses?

Social Experiences

6. How is this person supported to have meaningful social experiences?

7. How is age-related change impacting on ability to engage in meaningful social experiences?

8. What further supports are required in order to assist the person to continue engaging in meaningful social experiences?

Social Relationships

9. How is this person facilitated to develop and to maintain valued relationships?

10. How is age-related change impacting on social relationships?

11. What supports are required to help the person maintain social relationships now and into the future?

Spiritual Life

12. How is this person supported around personal spiritual beliefs and practices?

13. How is age-related change impacting on how this person experiences a spiritual life?

14. What further supports are required to facilitate this person to engage more fully with personal spiritual beliefs and practices?

Personal Safety

15. How is this person supported to feel safe and secure?

16. How is age-related change impacting on how this person experiences safety and security?

17. What additional supports are required to help this person feel safe and secure?

Coping Patterns

18. Describe this person's coping patterns.

19. How has age related-change impacted on ability to cope?

20. What further supports are required to assist this person to cope well?

(B) Summary of supports required: (refer to Q. 3,5,8,11,14,17,20)

(COMPLETE AN INDIVIDUAL SUPPORT PLAN FOR EACH AREA WHERE SUPPORT IS REQUIRED)

(C) INDIVIDUAL SUPPORT PLAN

Name:
Date:
Selection: area where support is needed:
Rationale for support:
Documentation supporting Individual Support Plan
Supports required for Optimisation of experience/engagement
Supports required for environmental Compensations
Review date:
Signed:

Appendix M

Strengths and weaknesses of the study

Strengths

- In order to ensure that those who wished to participate were supported to do so, flexible approaches were used in data collection. Photographs were used to aid recall of people and events and to contextualize the conversation at interview. The use of the communication aid ‘Talking Mats’ proved very useful for some participants and provided a means for those with poor verbal skills to engage in the research. As such, sensitivity to preferred communication means and style and flexibility around how interviews were conducted proved valuable in enhancing engagement and broadening communication so that areas of importance to individuals could be brought forward.
- The validity of outcome data is enhanced because of the inclusive research model built into the study design. Consultation around subjective experience is key to developing a psychosocial theory of ageing and every effort was made to maximise participation in the study. Dukes and Sweeney (2009) argued that in relation to service development in the area of intellectual disability the opinions of those whose lives are most affected must be sought and valued. People who are themselves ageing with lifelong intellectual disability must be supported to have their voices heard as in terms of developing a psychosocial theory of ageing, personal individual accounts of experiences are paramount. Sensitive study design played a critical part in eliciting experiences and opinions. In developing the study design the researcher aimed to ensure meaningful engagement and to allow scope for areas of individual concern to be raised. Most importantly the researcher strove to be true to the meaning people placed on their own lives.
- Methodological eclecticism i.e., the use of a variety of sources to elicit information such as life story books and photographs, was used to good effect in this study and allowed for rich data to be captured.
- Reflexivity was central to data collection and data analysis. The researcher continuously aimed to be respectful and faithful to the meaning individuals give to

their lives while mindful of her own position relative to the area under study and to participants, as a group and as individuals.

- The researcher had the privilege of knowing many of the participants for a considerable number of years before embarking on the study. As such communication was greatly facilitated as the researcher had come to know individual vocabularies, how participants pronounce certain words, place names, and names of family and staff, and was therefore in a position to provide gentle prompts about context in relation to past events when participants' required this for recall.
- Participants were readily available for ongoing theoretical sampling and checking back in relation to how the data was understood by the researcher.
- Possibly the greatest strength of the research study is that findings are grounded in the voices of those that are currently living the experience of ageing with lifelong intellectual disability.

Weaknesses

- Clearly participants of the study comprised a very specific cohort, most having spent their entire lives in a reasonably small geographic area. Many shared services since school age. A very small number (3) grew into adulthood outside of Ireland, and in some areas of living and ageing different influences were observed in relation to these three people. It is inevitable then that there are some cohort effects in the findings of the study.
- Determination of an 'old age' start point for the population was based on data available from the empirical research (Lavin *et al*, 2006; Royal College of Psychiatrists and British Psychological Society 2009; Ryan *et al.* , 2013). However, many aspects of life style planning, health care supports and interventions, medical knowledge and practice are rapidly changing for this cohort of people and the lower cut off age of 35 years for people with Down's syndrome may have been too low. Six people in the current study were aged between 35 and 39. Some participants in the lower age range struggled to see themselves as people that were ageing, although life expectancy still indicates a lower age for this population. Perhaps in future ageing

studies, consideration may be given to raising the age somewhat for those with Down's syndrome to 40 years of age.

- No account was taken of difference between the sexes. Studies such as Walsh (2002) and Walsh and LeRoy (2004) looked at gender issues with some interesting results. Areas for future research may have been observed if gender issues had been explored. For example, Grant (2004) says that little is known about the effects of the menopause on women with intellectual disability. Two women in the current study talked about menopause and indicated that the effects are experienced as a significant stressor. One participant bemoaned that she had had to contend with the inconvenience of menopause while her male counterparts did not. In-depth study on the additional stress of menopause as one is also managing other ageing effects was beyond the scope of this study, but the accounts of these two women certainly give rise to questions of whether there are significant gender differences in relation to the psychosocial aspects of ageing.