Loneliness in Older People with an

Intellectual Disability

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Declaration

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

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  Andrew D Wormald B.A.(Hons), MSc.

Eleanor Rigby died and was buried along with her name
Nobody came

Dedication

To Maureen, you have supported me through fourteen years of assignments exams and theses. You never tried to stop me, and you gave me the will to go on in the darkest moments. This is for you.

To my Dad who passed away in February, you taught me how to live. I hope you were wrong. Rest In Peace.

Acknowledgements

Abstract

Background
The causes, experiences and effects of loneliness in older people with an intellectual disability have never been investigated or modelled. Loneliness in ageing populations is often investigated using the Cognitive Discrepancy Approach to loneliness (Perlman & Peplau, 1998).

Aims
This study created a model of loneliness in older people with an Intellectual Disability by investigating the antecedents, the characteristics and the consequences of loneliness.

Methods
This study uses data from two waves of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (N=753), a nationally representative study of ageing in older people with an intellectual disability. Regression-based models formerly used to study loneliness in older people in the wider population were used. The findings of the models were combined to create a unified model of the CDA.

Results
The primary predisposing antecedent of loneliness was functional limitations. Transport difficulties, poor emotional health, reporting pain, service stress and wanting to do more activities all precipitated loneliness. Education to junior certificate level, working in the community and confiding in staff were protective against loneliness. Depressive attributions moderated the paths from antecedents to loneliness. Over 26% of participants were consistently lonely, 19% overcame loneliness, 12.5% became lonely, and 42% were never lonely. Consistent loneliness was predicted by; being older, being female, experiencing pain, falling, having difficulty doing activities and voting in the last election. Chronic conditions and holidaying abroad were protective against loneliness. Never being lonely was predicted by having a person-centred plan, being of high functional ability and not wanting to do more activities. Overcoming loneliness was predicted by changes in the frequency of visits from family and friends and becoming lonely was predicted by moving within the service provider organisation. Loneliness predicted raised systolic blood pressure (SBP) and sleeping difficulties. Confiding in staff was protective against loneliness. Consistent loneliness predicted having difficulty falling asleep, confiding in others, attending church regularly, reporting more life events and reporting an excellent or very good diet. People who did moderate exercise scored significantly higher on the loneliness scale. Structural equation modelling estimated a significant path from functional limitations through to raised SBP. Other paths were from experiencing transport problems to loneliness and from service stress to loneliness. Service changes and reliance on others for transport were specific to participants with more severe levels of ID.

Discussion
Twice as many older people with an ID remain consistently lonely compared to the general population. Functional limitations were the primary determinant of which variables precipitated unsatisfying relationships. Those with few functional limitations were more likely to live an independent life, and those with functional limitations lived a service dependent life. Relying on others for transport precipitated poor relationships in the independent group. Increased risk of pain changes in service provision and mental health problems precipitated unsatisfying relationships in the service dependent group. Negative attributions form the link from poor quality relationships to loneliness, in this population. Participant's uncontrolled responses were predictable, and their coping mechanism differed from the wider population. Lonely people experienced hypervigilance, which caused disturbed sleep, raised SBP, remembering more negative lifetime events and distrust of others. Loneliness was coped with by an encouraged strategy of active ageing. Loneliness can be tackled through the individualisation of services, which will improve the lives of older people with an ID and offers the potential of cost savings to the service providers.

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List of Abbreviations

ADL	Activities of Daily Living
AMOS	Analysis of Moment Structures
AOR	Adjusted Odds Ratio
BMI	Body Mass Index
CAPI	Computer Assisted Personal Interview
CDA	Cognitive Discrepancy Approach
CES-D	Centre for Epidemiologic Studies Depression scale
CHARS	Chicago Health and Retirement Study
CI	Confidence Interval
Coeff	Coefficient
CPA	Conditional Process Analysis
CR	Critical Ratio
df	Degrees of Freedom
DNA	Deoxyribonucleic Acid
ELSA	English Longitudinal Study on Ageing
HRS	Health and Retirement Study
HSE	Health Service Executive
IADL	Instrumental Activities of Daily Living
IBM	International Business Machines
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual Disability
IDS-TILDA	Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing
IQ	Intelligence Quotient
NIDD	National Intellectual Disability Database
n.s.	Not significant
Path Coeff	Path Coefficient
PI	Principal Investigator
PIQ	Pre-Interview Questionnaire
RMSEA	Root Mean Square Error of Approximation
SBP	Systolic Blood Pressure
SC	Social Connectedness
SD	Standard Deviation
SE	Standard Error
SEM	Structural Equation Modelling
SLAN	Survey on Lifestyle and Attitudes to Nutrition
SNA	Social Needs Approach
SPSS	Statistical Package for the Social Sciences
SR	Self-Report
Std Coeff	Standardised Coefficient
Std Path Coeff	Standardised Path Coefficient

TCD	Trinity College Dublin
TILDA	The Irish Longitudinal Study on Ageing
TSI	Test for Severe Impairment
UCLA	University of California, Los Angeles
VIF	Variance Inflation Factor

1 Introduction

1.1 Introduction

This research is the first work to create a broad understanding of loneliness in older people with an Intellectual disability (ID). Each piece of analysis creates new understanding about the importance of loneliness in the lives of this population. This study adopts methods from studies in the wider population that have never been applied to data from older people with an ID. This research work is possible because it utilises the large sample interviewed by the researchers from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), and because of the broad-ranging scope of the conceptual frame. Such a broad frame means that the aims and objectives of the study could be set very wide, creating a complete insight into the subject. To allow the study objectives to be met, a framework of loneliness that was broad enough to take in the antecedents, the characteristics and the consequence of loneliness was implemented. Dissecting the framework into four parts allows analysis of the antecedents, cognitive characteristics, temporal characteristics, and consequences of loneliness. The results are structured into individual research papers to match this dissection, thus allowing a complete discussion of each piece of analysis to take place. A synthesised model of loneliness is then produced, giving a model that steps logically and coherently from elements that predispose people with an ID to loneliness through to the implications on health for this population. While division into papers creates a detailed understanding of each piece of analysis, it makes the discussion of cross-cutting issues stilted. Therefore, the final chapter ties together all the results and gives recommendations for change in policy and practice in service provider organisations.

1.2 Thesis Structure and Outline

This thesis is divided into two sections; Section One deals with the background to the study, the choice of theoretical model, and the methodology utilised within the research. Section Two consists of five research papers, each dealing with a segment of the experience of loneliness, and a discussion chapter that summarises all the findings.

Section 1: Introduction

Chapter 1

The present chapter outlines the structure of the thesis. It gives the objectives of the study and defines the main concepts referred to in the study.

Chapter 2: Literature Review

The literature review first describes the literature on loneliness in old age. This chapter then discusses the current knowledge about the antecedents to loneliness, the characteristics of loneliness, and the consequences of loneliness.   Because there is very little known about loneliness as it impacts older people with an ID, the chapter starts by focusing on the current understanding of loneliness for older people in the wider population, before focusing on older people with an ID. Due to a large number of unknowns in this population, the review focusses on factors that may have an influence on loneliness in this population and what elements may be the consequences of loneliness.

Chapter 3: Theoretical frameworks

This chapter outlines the three theoretical approaches to loneliness. It first describes the behavioural approach to loneliness and discusses its applicability for this research. It then considers the social needs approach, describing the theoretical background of the approach, looking at the focus of the approach, and discussing its applicability to the broad aims and objectives of this study. The cognitive discrepancy approach is the third theory; again the background and focus of the approach are reviewed, and its applicability to this investigation discussed. Selection of a model is subject to three criteria:

1. The approach must be broad enough to encapsulate the complex and multifaceted experience of loneliness.

2. The approach must be useable at a population-based level, allowing those at a planning and organisational level to understand the main thrusts of the causes and consequences.

 3. The theory identified should allow service providers and oversight bodies to understand the structural elements that can be modified, not just to remedy the situation but also to prevent the occurrence in the first instance.

The relevance of each approach is discussed based on the three criteria. The cognitive discrepancy approach is selected for use as the most suitable method.

Chapter 4: Methodology

The methodology chapter details how the research is going to be accomplished and with what resources. The chapter describes the IDS-TILDA, detailing the participants and the steps that were undertaken to collect data from these participants. Every variable used in the research is detailed

in this chapter. Finally, it details all the analysis undertaken and supplies an account of the benefit of regression analysis.

Section 2: Research Papers

Chapter 5: Antecedents

This research answers the question "what are the antecedents of loneliness for older people with an ID?" To answer this question, the analysis adopts the methodology of Hawkley et al.(2008). Variables are grouped into six logical blocks: demographics, socio-economic, health, stress, social network, and network quality. Each block of variables is entered into a regression analysis starting with demographics and moving to network quality. Variables that achieve a p-value equal to or less than 0.1, are classed as an antecedent variable and are retained for addition to the next block of variables. Two series of regressions were run; the first used variables that closely matched those used by Hawkely et al. (2008), and the second included variables that were ID specific, and the variables that met the p-value criteria in the first set of regressions. Discussion of the results considers their relationship to other findings, their effect on theory, and gives recommendations for service policy development.

Chapter 6: Cognitive Characteristics

This study answers the research question "does depressive thinking increase the risk of feeling lonely for older people with an ID?" This analysis follows the methodology of research reported by Burholt and Scharf (2013). In the Burholt and Scharf (2013) research, a moderated mediation model was created to test paths to loneliness, looking specifically at the conditional effects of depressive symptoms. In this research, an initial model copied the work of Burholt and Scharf (2013), and then two further models were tested using ID specific variables.

Chapter 7: Temporal Characteristics of Loneliness

This research answers two questions "what numbers of older people with an ID experience each trajectory of loneliness, or never experience loneliness?" and "what are the predictors of the trajectories of loneliness in older people with an ID?" This research is based on the work of Victor et al. (2008) and adopts their methodology, using a single-item loneliness question. Participants responses across both waves were categorised as either consistently lonely, lonely to not lonely, not lonely to lonely, and never lonely. The second question is answered through binary coding each trajectory as either present or not present. Binary logistical regression is then used to determine variables that predict each trajectory.

Chapter 8: Consequences of Loneliness

This research answers the research question "What are the effects of loneliness on how people react to and cope with loneliness?" Following the work of Hawkley and Cacioppo (2007), this analysis investigates the influence of loneliness on variables of a pre-disease paths model of health. The model has five paths: health behaviours, life event and stress exposure, coping, physiological response, rest and recuperation. Hawkley and Cacioppo (2007) argued that loneliness has a damaging effect on each of the five pathways and as a consequence reduces physiological resilience. To build the evidence for the effect of loneliness a cross-sectional scale measure of loneliness and a longitudinal single-item measure of loneliness were used. Variables that closely matched those used by Hawkley and Cacioppo (2007) were selected for inclusion in the model.

Chapter 9: Synthesis

This research answers the question "can the elements of loneliness previously reported be unified into the structure of the CDA?" This research project takes the findings of the previous studies in this series and uses structural equation modelling to create a unified model of loneliness. The analysis created three models. The first uses all the variables found associated with loneliness in the previous chapters except the depressive symptoms variable. It then created an intermediate model of loneliness with the missing depressive symptoms scores imputed, and it finally created a model of loneliness where the numbers of participants were held to only those who answered the depressive symptoms scale.

Chapter 10: Discussion

This chapter draws together the results of the research papers and discusses the findings in a broader context than the individual research papers allowed. The chapter discusses how the results fit with the cognitive discrepancy approach, and what new knowledge they add. The implications for policy and practice for services are reviewed, and a plan for reducing loneliness is created.

1.3   Introduction to the Study

Loneliness is a subjective concept that is specific to each person and yet has common features that can are measurable at a population level. Loneliness has been known and described throughout history and is a subject of popular culture, children's and adult literature. Enforced loneliness is one of the worst punishments society can bestow upon a person. Loneliness is not

isolation, and it cannot be objectively measured; a person can be lonely while living in a communal setting and yet an isolated person may be content. Loneliness is detrimental to physical health (Lynch, 1977) and has been found to cause raised blood pressure in older people (Louise C. Hawkley, Thisted, Masi, & Cacioppo, 2010). There is an increasing body of research on the antecedents, characteristics and consequences of loneliness in older people. Loneliness is often brought about by change (Weiss, 1973), and these changes are often dominated by losses, such as the loss of a spouse, loss of family members, loss of friends and the loss of health (Cacioppo & Patrick, 2008). How people are supported, and their expectations of support, influence the experience of loneliness (Pearl A. Dykstra, 2009). Individuals with an ID tend to have different support mechanisms as they are much less likely to be married or have children (M. McCarron et al., 2011). They see their families and friends less often than the general population (McCausland, 2015), and their contact with family and friends is dependent upon their reported level of ID (McCausland, 2015). People with an ID have difficulty integrating into wider society, where communication difficulties, problems with self-regulation and skills deficits have traditionally left them devalued and stigmatised (Gilmore & Cuskelly, 2014). The lives of many people with an ID tend to be dominated by service providers, and the higher the functional limitations, the more protective a staff shield is placed around them (Bane et al., 2012).

There has been little research into loneliness in this population; what research has occurred found that loneliness is linked to the amount of support a person needs and with the perceived quality of social networks (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Loneliness in this group has been linked to whom people confide in (McCausland, 2015), and inappropriate living arrangements (Balandin, Berg, & Waller, 2006). There has been no research into the cognitive processes that lead to loneliness in this population, or around how people cope with and respond to loneliness.

This study applies a sound theoretical framework to examine the loneliness in older people with an intellectual disability. There has never been a comprehensive and broad look at loneliness for this population. This research provides knowledge about loneliness in this population; it will influence the theoretical development and contain information for the development of policy and practice in ID services.

1.4   Research Aims and Objectives

1.4.1   Main Research Question

How is loneliness experienced by older people with an ID in Ireland and what are the antecedents, characteristics and consequences of loneliness for this population?

1.4.2   Aim

To create a holistic understanding of the antecedents, characteristics and consequences of loneliness in the lives of older people with an ID.

1.4.3   Objectives

● Measure loneliness as experienced by older adults with an ID.

● Create an antecedent model that describes how structural variables influence the social environment and affect which variables will precipitate loneliness in older people with an ID.

● Create a model demonstrating the role of attributions in this population.

● Understand the temporal trajectories of loneliness for older individuals with an ID.

● Create a model that illustrates how people with an ID react to loneliness and cope with loneliness.

● Create a holistic model of loneliness for older individuals with ID based on the cognitive discrepancy approach.

1.5   Definitions

1.5.1   Defining Intellectual Disability

The definition of ID in this study rests on that used for IDS-TILDA. The sampling frame for IDS-TILDA was drawn from the National Intellectual Disability Database (NIDD), and the NIDD takes its definition of ID from the WHO Classification of Mental and Behavioural Disorders (World Health Organisation, 1992) (Organization, 1992) (Organization, 1992) (Organization, 1992) (Organization, 1992) (Organization, 1992) (Organization, 1992) (Organization, 1992) (Organization, 1992) (Organization, 1992) (Organization, 1992) (Organization, 1992). The WHO classification defines Mental Retardation (now known as Intellectual Disability) as "a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills

manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities" (World Health Organisation, 1992, p.176). There is no clear-cut diagnosis for ID, and the classification index notes that functioning levels in different domains can vary. The classification index notes that "For a definite diagnosis, there should be a reduced level of intellectual functioning resulting in diminished ability to adapt to the daily demands of the normal social environment. Associated mental or physical disorders have a major influence on the clinical picture and the use made of any skills." (World Health Organisation, 1992, p. 177). A standardised IQ should be used as a guide but should not be applied rigidly. ID has a series of sub-classifications; Mild ID, Moderate ID, Severe ID and Profound ID. A Mild ID is suggested by a standardised IQ score of 50 to 69, and "The main difficulties are usually seen in academic school work, and many have particular problems in reading and writing" (World Health Organisation, 1992, p.177). Having a Moderate ID is suggested by a standardised IQ score of 35 to 49, and is described in adulthood as "moderately retarded people are usually able to do simple, practical work if the tasks are carefully structured, and skilled supervision is provided. Completely independent living in adult life is rarely achieved" (World Health Organisation, 1992, p.178). Having a Severe ID requires a standardised IQ score of 20 to 34. People with a Severe ID, "suffer from a marked degree of motor impairment or other associated deficits, indicating the presence of clinically significant damage to or maldevelopment of the central nervous system" (World Health Organisation, 1992, p. 179). A diagnosis of Profound ID requires a standardised IQ score under 20. Adults diagnosed with a Profound ID are described as; "Comprehension and use of language is limited to, at best, understanding basic commands and making simple requests. The most basic and straightforward visuospatial skills of sorting and matching may be acquired, and the affected person may be able with appropriate supervision and guidance to take a small part in domestic and practical tasks" (World Health Organisation, 1992, p.179). Beyond the four main categories of ID, there are two other classifications. The first of these is "Other Intellectual Disability." This category is used when the assessment is difficult due to other impairments. The second, "Unspecified Intellectual Disability" is when there is evidence of intellectual disability but insufficient information to categorise a person.

1.5.2   Definition of Ageing

Ageing in the IDS-TILDA study is defined as people who were aged over 40 when the sample was recruited. This definition differs from other studies in the wider population such as TILDA where ageing was defined as fifty years or over. This difference is because people with an Intellectual Disability display signs of ageing at an earlier stage than do people in the wider community (M. McCarron et al., 2011).

1.5.3   Defining Loneliness

Loneliness has been described as an individual personal experience that is embedded in given forms of social organisation and cultural fabrics (Jylhä & Saarenheimo, 2010). It is known to everyone and is part of the human condition like hunger, thirst and pain (Cacioppo, Hawkley, & Thisted, 2010), yet inconceivably for those who experience loneliness, it can be difficult to describe and difficult for the non-lonely to understand (Cacioppo and Patrick, 2008). Loneliness is so feared it can be disguised and is thus dissociated and not noticed (A. Peplau, 1988). Loneliness is usually defined in terms of the absence of the social and attempts to reconnect. Loneliness for the chronically lonely is a cause of premature death akin to smoking or obesity (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015). Yet loneliness remains ignored by the medical profession despite decades of warning (Lynch, 1977; Peplau, 1988; Lynch, 2000; Cacioppo and Patrick, 2008; Hawkley et al., 2010). Once an individual has become lonely, they become less empathetic and less trusting of others yet, almost in contradiction, they are driven to reconnect with others (Cacioppo & Cacioppo, 2014). The risk of loneliness is carried by all, and sensitivity to it is partially determined by DNA (Boomsma, Willemsen, Dolan, Hawkley, & Cacioppo, 2005). Loneliness is our inherited evolutionary warning system telling people that their social networks are inadequate and are leaving them exposed to danger and at risk of a shorter life (Cacioppo and Patrick, 2008). There is not one standard definition of loneliness; different researchers utilise a variety of definitions, including:

- Loneliness is a subjective lived experience that exists in the form of multiple realities constructed and reconstructed within the form of different life histories (C. R. Victor, Scambler, Bowling, & Bond, 2005).

- Loneliness is a personal concept. It is a feeling resulting from a deficiency in social relationships; a person can be alone but not lonely or in company and feel lonely (Shiovitz-Ezra & Leitsch, 2010).

- Loneliness is the feeling of missing intimate relationships or missing a wider network, which is conceptualised as an individual's subjective evaluation of their degree of social participation or isolation (Timonen, Kamiya, & Maty, 2010).

- Loneliness is the unpleasant experience that occurs when a person's network of relationships is felt to be deficient in some important way (Dykstra, 2009).

- Loneliness is the breach of man from what he is to what he pretends to be (Moustakas, 1961).

- Loneliness is more accurately defined as the distressing feeling that accompanies discrepancies between one's desired and actual social relationships (Hawkley et al., 2010).

All of the above definitions tend to have three common elements: a relationship component, a deficit component and a cognitive element (Letitia Anne Peplau & Perlman, 1979; Letitia A. Peplau, Perlman, & Perlman, 1982), dealing with the antecedents and experience of loneliness. The definitions do not take into account the effects of loneliness, therefore for this study, two definitions were joined. The new definition was "Loneliness is the unhappy removal from a life lived in common with others which creates a sense of hopelessness and helplessness and erects a barrier between the lonely and their social world (Dumm, 2008), contributing to serious disease and premature death (Lynch, 1977)".

Many people confuse loneliness with both isolation and depression. However, while sharing strong associations with both, loneliness is a separate concept. Loneliness is not isolation, the two concepts are not necessarily correlated (Coyle & Dugan, 2012) and people can be lonely without being isolated (Perlman & Peplau, 1981). As defined earlier, loneliness is a subjective experience: it is the brain's interpretation of the social, while isolation is an external variable which can be directly measured using variables such as distance from neighbours, the composition of the household or the number of social activities (Holt-Lunstad et al., 2015). Loneliness, by contrast, is measured by an evaluation of a divergence of the achieved from the desired, whether regarding quality or quantity of social relationships, but mainly quality (Vanhalst, Luyckx, Raes, & Goossens, 2012). Lonely people can be found within marriages, living in large households or living near many others in residential institutions. Loneliness has been found to increase not only when a person falls short of their ideal number of contacts but also once their number of contacts surpass that ideal (Russell, Cutrona, McRae, & Gomez, 2012). Isolation and loneliness both have effects on health but operate through different pathways (Cacioppo and Cacioppo, 2014).

Not only is loneliness confused with isolation, but it is also sometimes misconceived as depression. Many depression scales will include a question about loneliness, yet it is possible for people to be depressed without being lonely. According to The Mayo Clinic (2015), depression is defined as "a mood disorder that causes a persistent feeling of sadness and loss of interest." These are feelings that are general, while loneliness is a specific feeling about a discrepancy between desired and achieved social relations. A person who is made to feel lonely through ostracism, social exclusion, or bereavement feels threatened, anxious, and dysphoric, all of which promote attempts to reconnect (Cacioppo, Hawkley, et al., 2006). Depression does not drive people to reconnect in such a way. While research has found that loneliness is closely linked to

depression and those with mental health issues, tend to be lonelier than those without, loneliness is distinct from depression (Louise C. Hawkley & Cacioppo, 2010). Victor et al. (2008) found only 26% of participants who had a diagnosis of depression were also lonely, and in longitudinal studies, loneliness has been found to drive depression (Cacioppo et al., 2010). Loneliness, like depression, is aversive to the person who experiences it, yet unlike depression, it is believed to have an evolutionary basis that benefits the sufferer (Boomsma, Cacioppo, Muthén, Asparouhov, & Clark, 2007).

1.6   Conclusion

This research is the first to undertake a thorough and broad-ranging investigation of loneliness in older people with an ID. The research uses multivariate modelling techniques to match the data produced in the IDS-TILDA study to the CDA to loneliness. The results are presented in five research papers, each of which deals with a separate element of the CDA, and then considered in a final discussion chapter. The study uses the standard definitions of ID, but a modified definition of old age is used due to the premature ageing of people with an ID. A new definition of loneliness is used, accounting for the antecedents to consequences nature of this study. The next chapter reviews what is known about the loneliness in older people with an ID.

2   Literature Review

2.1   Introduction

To date, there has been very little research into loneliness in older people with an intellectual disability, to the extent that a search in Academic Search Complete, searching for keywords "loneliness" refined with "Intellectual Disability" (or "Learning Disability") and "Ageing" " returns zero results. A search for the keywords "Loneliness" refined with "Intellectual Disability" or "Learning Disability" returns just seven results, of which two deal with younger people (students or children) (Table 2-1).   A similar search on Wiley Online Library, which contains journals such as the Journal of Intellectual Disability Research, returns just four items, all of which were available in the Academic Search Complete results.

Table 2-1: Journal articles searching keywords for loneliness and intellectual disability

Title	Authors	Year
'I Get by with a Little Help from my Friends': Adults with Intellectual Disability Discuss Loneliness.	McVilly K., Stancliffe R., Parmenter, T., Burton-Smith R.	2006
Self-Efficacy, Loneliness, Effort, and Hope: Developmental Differences in the Experiences of Students with Learning Disabilities and Their Non-Learning Disabled Peers at Two Age Groups	Lackaye T., Margalit M.	2008
Constructing the social: an evaluation study of the outcomes and processes of a 'social participation' improvement project.	BROER T., NIEBOER A., STRATING, M., MICHON H., BAL, R.	2010
Reading, Writing, and Friendship: Adult Implications of Effective Literacy Instruction for Students with Intellectual Disability.	Forts A., Luckasson R.	2011
Virtual friendships and social distress among adolescents with and without learning disabilities: the subtyping approach.	Sharabi A., Margalit M.	2011
The Mediating Role of Internet Connection, Virtual Friends, and Mood in Predicting Loneliness Among Students With and Without Learning Disabilities in Different Educational Environments.	Sharabi A., Margalit M.	2011
How Do Children With Mild Intellectual Disabilities Perceive Loneliness?	Papoutsakia, K., Genab., A, Kalyva, E.	2013

Because of the dearth of specific loneliness literature in this field, this literature review creates an important foundation for this research and future research by incorporating research from related fields. This chapter starts by describing the iterative process of collecting a comprehensive knowledge base (section 2.1.1). The development of loneliness is discussed next (section 2.2), and section 2.3 describes the experience of loneliness in old age looking at the known antecedents, characteristics, and consequences. This chapter then focuses on the lives of people with an intellectual disability (section 2.8), examining how wider society may influence their lives,

and what factors shape loneliness, before looking at the potential consequences of loneliness for individuals with an ID. This chapter also highlights that there is very little known about the experience of loneliness in this population, and demonstrates that further research is necessary to give a holistic understanding of their loneliness.

2.1.1   Literature Search

The search utilised journal databases within the online reference system EBSCO particularly Cinahl, Academic Search Complete, PsycArticles and PubMed. Additionally, the databases PubMed SpringerLink and Wiley Online Library were searched, following citation lists. As discussed earlier, the use of terms such as "intellectual disability" was too restrictive, and the search was amended to "Loneliness and ageing" or "ageing." The search of the grey literature included examining the loneliness-specific websites operated by academics www.thewebofloneliness.com, established by Sean Seepersad, and www.thecampaintoendloneliness.com. Monitoring of the lists of publications by selected leading scholars John T Cacioppo http://psychology.uchicago.edu/people/faculty/cacioppo/pubs.shtml, Professor Vanessa Burholt http://www.swansea.ac.uk/staff/human-and-health-sciences/allstaff/v.burholt/#publications=is-expanded, and Professor Christina Victor http://www.brunel.ac.uk/people/christina-victor, for relevant content has been ongoing. Leading books on the subject area including *Loneliness: the experience of social and emotional isolation* (Weiss, 1973), *Loneliness: human nature and the need for social connection* (Cacioppo and Patrick, 2008) and *Loneliness as a way of life* (Dumm, 2008), were included. Additionally, an EBSCO alert has been running for literature, searching the keywords "loneliness" and "ageing". To date, a database of knowledge has been constructed consisting of 123 Journal articles and 13 books (Table 2-2).

Table 2-2: Books studied to understand loneliness and the origins of theories.

Author	Year	Title
C. E. Moustakas	1961	Loneliness.
A. Bandura and R. H. Walters	1977	Social learning theory
J. Lynch, J	1977	THE BROKEN HEART: THE MEDICAL CONSEQUENCES OF LONELINESS
L. A. Peplau, D. Perlman and D. Perlman	1982	Perspectives on loneliness
J. Lynch, J	2000	A cry unheard: new insights into the medical consequences of loneliness
C. Bigby	2004	Ageing with a Lifelong Disability: a guide to practice, program, and policy issues for human services professionals
L. M. Horowitz	2004	Interpersonal foundations of psychopathology
F. B. Evans	2005	Harry Stack Sullivan Interpersonal Theory and Psychotherapy.
J. T. Cacioppo and W. Patrick	2008	Loneliness: Human Nature and the need for social connection

T. L. Dumm	2008	Loneliness as a Way of Life
M. Hunt	2009	The story of psychology
M. Jylhä and M. Saarenheimo	2010	Loneliness and ageing: Comparative Perspectives
B. L. Mijuskovic	2015	Feeling Lonesome: The Philosophy and Psychology of Loneliness: The Philosophy and Psychology of Loneliness

2.2   What is Loneliness?

2.2.1   How Loneliness Developed

There are three major theoretical accounts of loneliness. The behavioural approach argues that loneliness is a learnt behaviour. The social needs approach (SNA) says that loneliness develops from deficits in needed relationship types. The cognitive discrepancy approach (CDA) claims that attribution is the arbiter in the middle of the mismatch between desired and achieved social relations and loneliness. Both the SNA and the CDA contend that loneliness has evolutionary roots, and assert that the brain has developed to monitor the social state like it monitors the physical state (Cacioppo and Cacioppo, 2014). Individually, people are weak, vulnerable, and would not have survived as a species without banding together (Cacioppo and Patrick, 2008). Evolution has shaped people to seek out groups for strength and security; life outside a group was dangerous. Groups share functions, increasing communities' capacity, and thus the group's chances of success. The brain is concerned about a person's welfare, and is hardwired to warn when homeostasis is unsettled, such as when hunger or pain are experienced (Cacioppo and Cacioppo, 2014). Loneliness is the brain's way of warning that there is a risk of being disconnected from the group, creating a drive to reconnect with others (Cacioppo and Patrick, 2008). However, like hungry people in the wild, lonely people have to be careful; they become hypervigilant, forced into a state of constant alert, making them wary of others, and unable to reconnect (Cacioppo and Cacioppo, 2014). Much of the work of the brain is experienced below the level of conscience and controlled by automatic processes, hardwired into the brain (Cacioppo and Cacioppo, 2014). The brain is always searching to reconnect with others, and when people reconnect successfully, they are freed from the burden of loneliness(Qualter et al., 2015).

The evolutionary concept of loneliness is purely theoretical and often over-described. There is no evidence to support an evolutionary standpoint. The source of loneliness is open to debate some argue that loneliness is permanent and unavoidable (Mijuskovic 2015), others suggest that loneliness is a learnt construct (Blossom & Apsche, 2013) and can be unlearnt and avoided. Some theorists have argued that loneliness has developed because of the loss of community living (Moustakas, 1961). The reason for loneliness has

also been questioned, and others have argued that loneliness can be beneficial giving a person chance to reflect on their lives (Dumm, 2008) giving them an understanding of the real meaning of life (Moustakas, 1960). On balance as loneliness is experienced in all cultures as aversive and has been commented on throughout history an environmental, evolutionary perspective is currently the most persuasive argument available.

2.2.2   Loneliness throughout the life course

Weiss (1973) argued that loneliness is not stable and may subside over time; a finding that longitudinal studies partially support (Gerst-Emerson & Jayawardhana, 2015; Jylhä, 2004; Christina Victor et al., 2008; Wenger & Burholt, 2004). While most research into loneliness has been cross-sectional, there is a limited amount of reports on loneliness longitudinally. Loneliness throughout the life course is often perceived as an issue for the elderly, but it is a consistent finding that a higher proportion of young adult's experience loneliness compared to older people (Dykstra, 2009, Perlman and Peplau, 1998). For instance, in Figure 2.1 below, loneliness varies across age categories. Reported loneliness is highest amongst young adults at around 45% in the 18 to 24 age category, before declining to around 20% for men at the start of old age. For women, loneliness is at its lowest in the 35 to 44-year-old category at around 28% from which point it stays fairly consistent into old age. For men, loneliness starts to rise during old age eventually catching up to the levels reported by females in late old age (28%).

Change, such as going to university, starting work, or trying new groups and environments (Weiss, 1973), may explain why more young people experience loneliness than older people (Hawthorne, 2007; Weiss, 1973). What makes loneliness different in old age is that it is defined by loss and decline (Holmén & Furukawa, 2002). Older, frail individuals may not have the wherewithal to prevent, or overcome the experience and the effects of being lonely.

Life course changes in the levels of loneliness are subject to two problems first most studies are cross-sectional in nature and therefore report the comparative loneliness of different generations. It is possible that these studies are reflecting intergenerational cultural differences as opposed to life stage differences. Longitudinal studies are few in number, and none have reported beyond specific life stages. Therefore there are no available reports on loneliness as experienced by a large group of individuals throughout their lives. The second problem is that Victor (2014) has demonstrated that feelings of loneliness fluctuate more rapidly than previously known and they may be influenced by expectations around the situation or the time of year. The current evidence does suggest

that people at stages of life where changes are frequently experienced are more likely to experience loneliness than those who are in more stable periods of life.
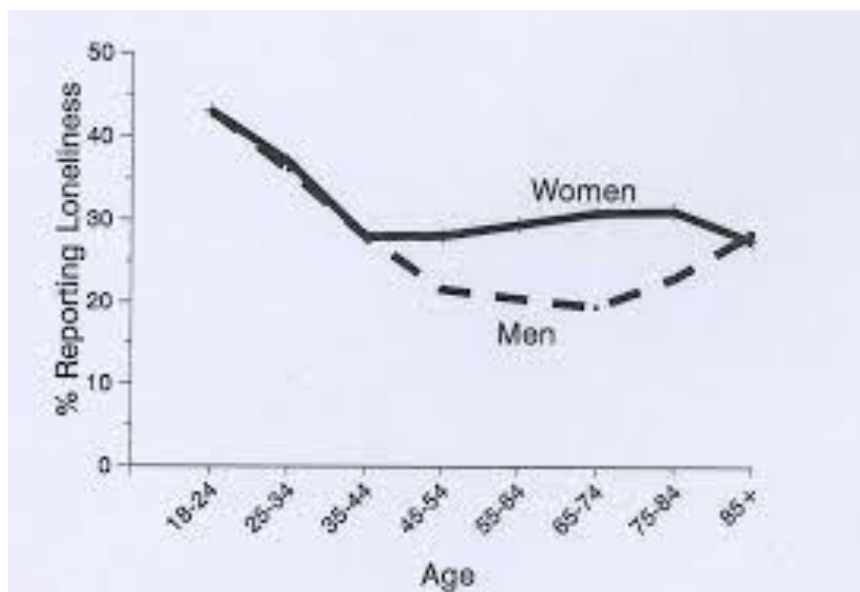
Figure 2-1:percentage of adults in age categories reporting loneliness Reproduced from "Loneliness" By D. Perlman & L.A. Peplau *Encyclopedia of mental health, 2*, p. 576 copyright 1998 by **Taylor and Francis Group LLC Books. Reprinted with Permission under license number 4270990436999.**

2.3   Loneliness in old age

Loneliness in old age can be examined through the impacts on both the individual and society. Loneliness has been cited as a cause of premature death in older people (Cacioppo and Cacioppo, 2014, Hawkley et al., 2010). Lonely people are at an increased risk of chronic physical and mental health conditions (Cacioppo et al., 2010, Hawkley et al., 2010), increased systolic blood pressure (Hawkley et al., 2010, Ong et al., 2012), as well as a lower quality of life and a lower level of life satisfaction (Barry et al., 2009; Swami et al., 2006).

The societal influences of loneliness include the contagion of loneliness as it spreads through social networks (Cacioppo, Fowler, & Christakis, 2009), and society's resources are affected as lonely people are more likely to utilise G.P. care, public nurses and Accident and Emergency departments (Gerst-Emerson and Jayawardhana, 2015). Increased use of public resources incurs additional cost on society (Fulton & Jupp, 2015), further increasing the adverse effects of loneliness on society.

2.4   Antecedents of Loneliness in Old Age

The CDA divides the antecedents of loneliness in into predisposers and precipitators. Predisposers to loneliness in old age are factors that put people at risk of loneliness but do not necessarily cause it (Burholt and Scharf, 2013). Predisposers include personality characteristics, cultural factors and situational factors (Peplau, 1988). Predisposing variables include age, gender, education, living environment, (Burholt and Scharf, 2013), living with adult children (Wenger and Burholt, 2004) changes to community, health (Victor et al., 2008), expectations of loneliness in later life (Victor et al., 2005, Pikhartova et al., 2015), marital status, and having a limited income (Drennan et al., 2008).

Culture has been found to predict loneliness better than personality characteristics (Dykstra, 2009), and it influences the antecedents of loneliness (Rokach, 2007). Culture has at least three distinct roles in the formation of loneliness: culture influences how people attribute their loneliness (Zhang, Yeung, Fung, & Lang, 2011), it influences expectations of social network (Dykstra, 2009), and culture influences how people seek support and are supported (Seepersad, Choi, & Shin, 2008; Venter, 2003). Studies investigating the effects of culture on loneliness in old age have found that older people from familistic cultures, such as those in Southern Europe, tend to experience more loneliness than those from individualistic cultures, for example, Northern European countries such as Norway (Lykes & Kemmelmeier, 2013). People from individualistic cultures are more likely to believe it is their responsibility to make their social connections and are less reliant on family supporting them (Dykstra, 2009, Lykes and Kemmelmeier, 2013). Culture also influences how people attribute their dissonance; cultures that encourage more self-blame have higher rates of loneliness (C. A. Anderson, 1999). Therefore, culture, while being distal from the person, forms the structure they live and operate in, and it shapes and forms their expectations.

Culture has been described as one of the main predisposing factors for loneliness, and much research has been undertaken to show differences in culture. Cross-cultural comparisons are tricky, and false generalisations about countries homogeneity (Matsumoto & Juang, 2016) can overshadow the intra-country differences in population responses which can be greater than inter-country differences (Hui & Triandis, 1985). Other problems include the moderacy effect, translation problems, how used to questionnaires certain groups of people are and the likelihood of disguising answers (Heine, Lehman, Peng, & Greenholtz, 2002). Therefore, cross-cultural differences in

loneliness levels antecedents and effects should be viewed with caution as anyone of some issues could be compromising the real picture.

Age is often cited as a predisposing factor for loneliness in studies, and a person's age influences the levels of loneliness experienced. However, the rise in reported loneliness is not caused by reaching a certain age, but reflects common changes that occur in people's lives around the same age. As discussed earlier, for young people, changes to social structures, which come with becoming an adult, influence the rise in loneliness. In extreme old age, it has been argued that it is the build-up of events that precipitate loneliness(Jylhä, 2004; Christina Victor et al., 2008). Gender, like age, is also reported as a variable that predisposes loneliness. There is evidence that females are more likely to accumulate losses and incur life events than males (Aartsen & Jylhä, 2011; Christina Victor et al., 2008), such as widowhood (Jylhä, 2004), and depletion of social network (Cacioppo and Cacioppo, 2014).

When the effect of gender is tested, the all-encompassing nature of these results can be deconstructed. Research indicates that men, without a partner, are the most likely to be lonely (Wright & Brown, 2017). Further, long-term single men are more likely to experience loneliness caused by social and emotional isolation when compared to married men (Pearl A Dykstra & de Jong Gierveld, 2004). Loneliness in single men in-particular may be connected to the additional beneficial social network a female partner generates (Zebhauser et al., 2014).

In Ireland living in a rural environment has also been found to be predictive of loneliness (Barry et al., 2009; Drennan et al., 2008). When living in a rural environment is combined with poor health, people become reliant on others for transport, increasing the risk of experiencing loneliness (Burholt and Scharf, 2013).

The definition of a rural environment is a difficult concept to tie down and open to methodological confusion. Is a small town a rural or urban environment? How far out of the town is classed as rural? Does urban depend on the access to facilities, such as health care, post office and banking? In Burholt and Scharf (2013), Wenger & Burholt (2004)and in Drennan et al. (2008) the definition of rural is left for the individual to decide. Therefore, findings of the effect of rural-urban differences have to be viewed with caution because without exact definition one person's rural is another person's urban.

In old age, as throughout life, marital status remains a major predisposer of loneliness with single people more likely to be lonely than married people (Victor et al., 2005). Having a good income, like having a good marriage, reduces a person's chances of becoming lonely; the lower a person's

income, the more likely a precipitating event will lead them into loneliness (Drennan et al., 2008). While wealth will not protect a person from loneliness (Zebhauser et al., 2014), those from lower socio-economic groups tend to be the loneliest (Barry et al., 2009); a limited income reduces access to available resources and social engagements (Burholt and Scharf, 2013). Finally, the expectation of loneliness can be a self-fulfilling prophecy; in a longitudinal survey people who expected to be lonely in old age were more likely to be lonely when they were old (Pikhartova, Bowling, & Victor, 2015).

Ninety-nine percent of participants within the IDS-TILDA study were not partnered, research from across Europe indicates that single people (Cleary, 2011; Drennan et al., 2008; Hansen & Slagsvold, 2016; Lykes & Kemmelmeier, 2013; C. R. Victor et al., 2005) and those that never lived within an intimate relationship are more likely to be lonely in old age (Zoutewelle-Terovan, Liefbroer, & Castle, 2017) than those who are married. Being single alone does not confer loneliness but increases the chance of loneliness when in combination with other factors such as having limited social contact or perceived poor health (Yang, 2017). For people with ID, the lack of marriage does not mean people have not adapted to their circumstances or that they experience a necessary combination of events along with being single and may receive benefits from social living.

For those who remain unpartnered long term, they may realise some theorised benefits of an extended period of loneliness. Some argue that loneliness can confer positive and rewarding benefits (Moustakes, 1961) such as self-realisation (Dumm, 2008) and a deeper understanding and appreciation of existence (Moustakes, 1961).

To protect against loneliness, the marriage has to be perceived of being of good quality (Stokes, 2017) else it confers no more benefit than being single (L. C. Hawkley et al., 2008). Single people also do not have to endure the stress of losing their partner through death or divorce which can be worse than never having been married (Weiss, 1973).

Precipitators to loneliness in old age cause a disruption to the established way of life (Victor et al., 2008, Weiss, 1973). This disruption can be a single disruptive event or a build-up of smaller events (Victor et al., 2008, Jylhä, 2004). The single largest event that precipitates loneliness is the loss of one's spouse or partner, (Aartsen and Jylhä, 2011). Loss of a partner effects people on several levels, they lose their emotional attachment, their confidant, and part of their social functioning (Weiss, 1973). It is common for the widowed to find it difficult to continue in the same social network as many of the activities and interests would have been couple-based

(Cacioppo and Patrick, 2008). Once widowed, nearly 50% of older people initially report becoming lonely, but over half of these recover from their loneliness over a ten-year period (C. Victor, 2014). In old age, loss of health can lead to either a dramatic or a slow, creeping functional decline, which leads to loss of friends from the social network, reducing the available social network (Victor et al., 2008, Cacioppo and Patrick, 2008). Similarly, a person becoming a carer for their partner may precipitate a loss of social contact, and increase the possibility of loneliness (Wenger and Burholt, 2004).

2.5   Characteristics of Loneliness in Old Age

2.5.1   Loneliness and Cognition

How people consistently ascribe outcomes across experiences is known as attribution style (Anderson et al., 1994). Attribution style has been directly linked to loneliness, with lonely people more likely blame themselves for their loneliness, and believing they cannot change their circumstances (Craig A. Anderson, Miller, Riger, Dill, & Sedikides, 1994). Up to 28% of the variance of loneliness has been accounted for by attribution style (Anderson, 1999). The more depressive an attribution style, the less likely a person will make use of social resources and the greater the effect of health on loneliness (Burholt and Scharf, 2013). Depressed people are less likely to amend their ideal network, and so are more apt to stay lonely for an extended period (Burholt and Scharf, 2013). Hawkley and Cacioppo (2010) argue that lonely people experience a negative cognitive loop (see Figure 2.2 below). The lonely expect more negative social engagement and remember more negative social events; they therefore elicit more negative social behaviour from people, which confirms their feelings, creating a self-fulfilling prophecy known as a self-reinforcing loneliness loop.
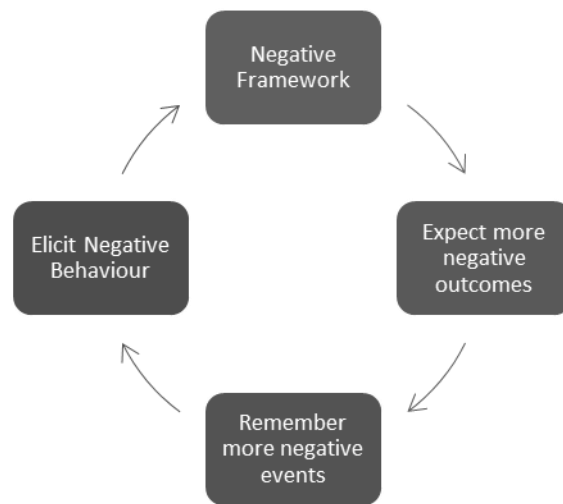
Figure 2-2: The Negative Cognitive Loop

2.5.2 The Temporal Nature of Loneliness in Old Age

Loneliness is not stable, and throughout life lonely people do not necessarily remain lonely forever. Perlaman and Peplau (1998) argued that loneliness can be temporally transient, and recent longitudinal research identifies three specific loneliness trajectories: regenerative, degenerative and existential (Victor et al., 2008). The regenerative trajectory is where people move from experiencing loneliness to not experiencing loneliness. With the degenerative trajectory of loneliness, people who were not lonely become lonely, and people classified as experiencing existential loneliness reported loneliness consistently over an extended period. In the Hillingdon Loneliness Studies, Victor (2014) (Figure 2.1) reported regenerative loneliness for 10% of participants, degenerative loneliness for another 10% of participants, and existential loneliness 14% of the population. These findings have been supported by others, reporting research with time gaps in data collection ranging from two to ten years (Wenger and Burholt, 2004, Jylhä, 2004). Further, when Victor (2014) questioned participants over five-time points in one year about feelings of loneliness, she found that feelings fluctuated considerably, and older people were more likely to be lonely around Christmas and the summer period. While feelings of loneliness fluctuate for some participants, all studies show that for a core of participants it remains a constant presence (Wenger and Burholt, 2004, Jylhä, 2004). Once loneliness is chronic, it can produce a variety of detrimental health effects, contributing to both physical (Lynch, 2000) and psychological illness (Cacioppo et al., 2010).

Comparison of the transitions in loneliness is difficult because of the wide variety of methodologies used in longitudinal studies. Studies differ on the scale used, whether a single loneliness item (Louise C Hawkley & Kocherginsky, 2017; Jylhä, 2004; C. Victor,

2014; Christina Victor et al., 2008), a 3 item scale (Louise C Hawkley & Kocherginsky, 2017) or an 8 item scale (Wenger & Burholt, 2004). Studies differ on the number of time points collected on, two (Louise C Hawkley & Kocherginsky, 2017; Christina Victor et al., 2008), three (Jylhä, 2004), four (Aartsen & Jylhä, 2011) or five (C. Victor, 2014; Wenger & Burholt, 2004). Studies also differ on the duration of time between collection points whether; 2 months (C. Victor, 2014; C. R. Victor et al., 2005), five years (Louise C Hawkley & Kocherginsky, 2017), eight years (Wenger & Burholt, 2004), and ten years (Aartsen & Jylhä, 2011; Christina Victor et al., 2008).
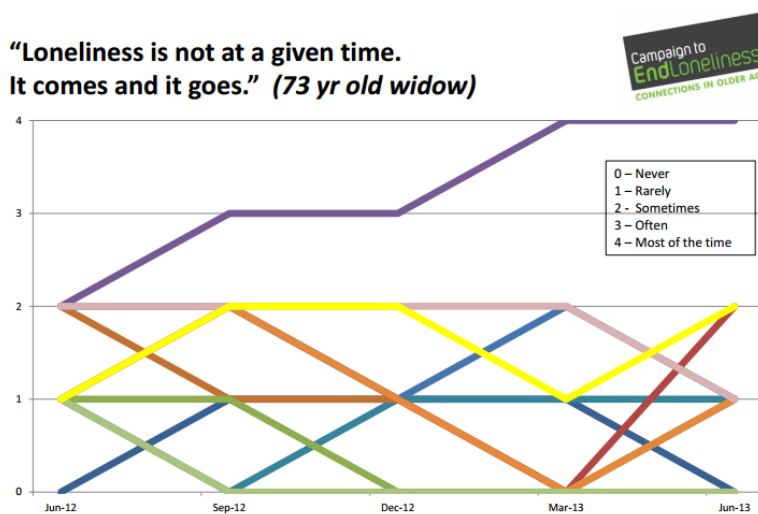
Figure 2-3: Self-reported experiences of loneliness over a 12-month period reproduced from "*Loneliness across the life course*" by C. Victor p.13 Reprinted by courtesy of The Campaign to End Loneliness.

2.6 Consequences of Loneliness in Old Age

2.6.1 Loneliness and health in old age

Research indicates that loneliness leads to activation of the autonomic nervous system, leading to heart rate increases, blood pressure increases (Hawkley et al., 2010), and sugar and fat from bodily stores are released along with the neurotransmitter catecholamine (Lynch, 2000). Loneliness may also affect how people evaluate their health (Victor et al., 2008) and their subsequent health care utilisation (Cleary, 2011). In The Irish Longitudinal Study on Ageing (TILDA), loneliness was associated with high usage of general practitioners, hospital outpatients, district nurse services and hospital emergency departments (Cleary, 2011). Lonely people have

been reported to have worse health behaviours than non-lonely people (Hawkley and Cacioppo, 2007), eating higher fat diets, exercising less, and more likely to be smokers (Cleary, 2011; Lauder, Mummery, Jones, & Caperchione, 2006).

2.6.2   The five health pathways of loneliness

Drawing upon this literature and efforts to develop more comprehensive models, the effect of loneliness on health can be considered through the use of the health pathways model (Figure 2.4 below). The health pathways model describes the effects of loneliness through five pre-disease channels, and considers their impact on physiological resilience (Hawkley and Cacioppo, 2007). They found the influence of loneliness on physiological resilience to be entirely negative, and this finding is supported by other researchers, who found that the levels of loneliness predict the quality of a person's life and their energy and vitality (Barry et al., 2009, Lynch, 1977).
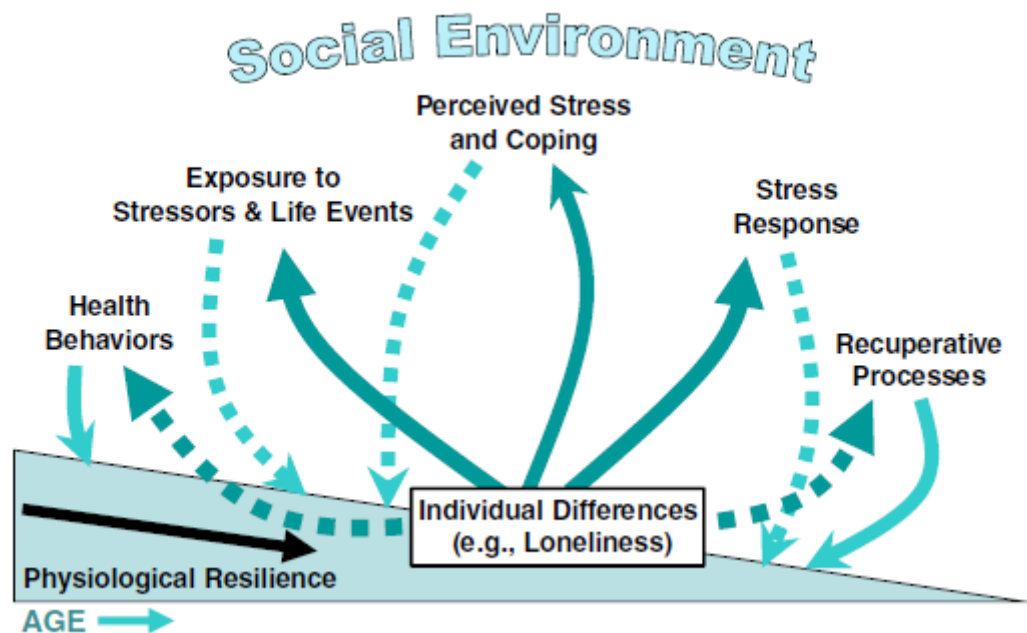
Figure 2-4: The Five Health Pathways Model. Reproduced from "Ageing and Loneliness: Downhill Quickly?" by L.C. Hawkley and J.T. Cacioppo in *Current Directions in Psychological Science 16(4)* p188. Copyright 2007 from The Association for Psychological Science. Reproduced with permission.

In Hawkley and Cacioppo's (2007)   Pathway 1, Health Behaviours, they argue that lonely people exercise less, take in more fats and calories, and are more likely to manage moods by eating, drinking and acting out sexually; they claim that loneliness lowers self-esteem, causing people to act in a self-destructive manner. Pathway 2, exposure to stressors and life events, reflects that lonelier people report being exposed to an increased number of stressful life events. The effect of each stressor is particular to an individual's circumstances, for instance, work stress has been

reported to have more of an effect on loneliness for unmarried people. Negative lifetime events have also been found to reduce a person's feelings of competence (Hensley et al., 2012), and lonely people are more likely to remember more life events as negative (Cacioppo and Caccioppo, 2014). For Pathway 3, (Hawkley and Cacioppo, 2007), lonely people are reported as being less likely to be members of groups, and are less liable to have someone in whom they can confide. Reflecting reports that non-lonely individuals report lower perceived stress, higher social uplifts, and less numerous hassles than the lonely ((Cacioppo et al., 2000)), lonely people tend to meet challenges with pessimism and avoidance (Cacioppo and Patrick, 2008). There is an accumulation of evidence supporting the negative influence of loneliness on the body's physiological response, Pathway 4. Loneliness is associated with raised systolic blood pressure (Hawkley and Cacioppo (2007); lonely older people have higher resting SBP, their SBP reacts quicker to stress, and is slower to return to pre-stress levels (Ong, Rothstein, & Uchino, 2012). Loneliness has also been found to increase SBP for up to 5 years (Hawkley et al., 2010). Loneliness may also alter DNA transcription that dampens the effect of cortisol; that is, when a person is lonely the body's defences are changed away from being prepared for a virus to being ready for defending against a bacterial attack (Hawkley and Cacioppo, 2010).

The findings for Pathway 5, recuperative processes, also support the negative thesis, finding that lonely people have less useful rest and recuperation than the non-lonely. Lonely older people take more time to go to sleep and have more night time disturbances than non-lonely (Cacioppo et al., 2000).

2.6.3   Loneliness and Mental Health

There is a complicated relationship between mental health and loneliness. Having mental health difficulties isolates people because they are stigmatised and unwanted by society (Ernst & Cacioppo, 2000). Additionally, people with mental health problems have difficulty adjusting their expectation when circumstances change, leaving them lonely where others would be able to change their expectations (Burholt and Scharf, 2013, Pikhartova et al., 2015). Not only do mental health problems create the circumstances for loneliness but loneliness has also been found to increase mental health problems. Cacioppo et al. (2010) found that loneliness reported for less than one year can be driving depression five years later. Zebhauser et al. (2014) indicated that depression, anxiety, resilience and life satisfaction were all associated with loneliness, and those with depression were three times more likely to be lonely. Subthreshold depression and case-level depression have been reported as related to loneliness within Ireland (Cleary, 2011). Further international studies have found that the lonely experience specific elements of depression including low mood, feelings of uselessness, and nervousness (Aartsen & Jylhä, 2011).

2.7   Loneliness in old age summary

Loneliness in old age leads to a lower quality of life and increased mortality, and for society it leads to increased healthcare and social service costs. The antecedents to loneliness in old age are being older, being female, rural living, and personal expectations of old age.   Precipitators can be any disruption to the established way of life, and are commonly the death of a spouse, loss of own health or mental health, or partner's health, and loss of functional abilities. Depressive thinking makes it harder for people to modify their expectations, and while loneliness can be temporally transient, the experience of loneliness tends to increase with accumulation of losses. Lonely older people tend to have worse health behaviours, become exposed to more lifetime stressors, and react more to these stressors. Lonely older people are more likely to experience raised blood pressure and poor quality sleep. Loneliness can also drive depression thus creating a vicious cycle entrapping the older person in a negative cognitive triad.

2.8   Loneliness and intellectual disability

In trying to understand the experience of loneliness among older individuals with an ID, findings from the general ageing population can be useful in guiding what kind of events are relevant to people in an older age cohort. However, many people within this population have led a different kind of life to the wider community, with many having spent significant parts of their lives living in institutions. Having led segregated lives, their relationships, expectations of ageing, and their experiences are different to the wider community, and thus the causes, experiences, and effects of loneliness may be different to the broader population.

To date, there has been very little work done to investigate the experience of loneliness in the lives of older people with an ID. There is some initial work on the antecedents to loneliness, but little on the characteristics and consequences of loneliness for this population. Exploring how loneliness is experienced by older adults with an ID is also difficult as the uniform nature of certain aspects of the social world of this group, such as education, employment and income, has been found to limit the potential for refined analyses (McCausland, 2015). Furthermore, the available data does not support that the precursors to loneliness found in the general population, such as age, gender and relationship status, also predict loneliness in the ID population (McGlinchey, McCallion, Burke, Carroll, & McCarron, 2013; McVilly et al., 2006). Further differentiating this group from the wider population is the lack of marriage (1% married) (Mary McCarron et al., 2014). Marriage is the most significant buffer against loneliness in the wider population, yet it rarely occurs in this group, despite many people with an ID wishing to be married (Healy, McGuire, Evans, & Carley, 2009).

Individuals with an ID enter old age from a socially weak position; living on the margins of society, they are more likely to have acquaintances than friends and are unlikely to have strong advocates or robust networks to support them(Bigby, 2004). While being in a weak position, this group are currently dealing with major changes to their day services and residential services, under the auspices of the Congregated Settings report Health Service Executive,(2011) and the New Directions report (Health Service Executive, 2012). These kinds of changes can have the effect of isolating them from their friendships and relationships built up over many years (Bigby, 2004). The process of re-introducing people with an ID into the general population has also been found to create an increased sense of loneliness, because once out in society they feel their difference more acutely (Broer, Nieboer, Strating, Michon, & Bal, 2010).

2.8.1   The Loneliness Experience

How much loneliness is experienced by people with an ID depends on how loneliness is measured, but there does appear to be agreement that individuals with an ID consistently report higher levels of loneliness than the general population. Balandin et al.(2006) found that people with cerebral palsy were lonelier than the general public when measured using the UCLA Loneliness Scale. Both Stancliffe et al. (2010) and McCarron et al. (2011) reported that loneliness affected almost half of participants. Of the IDS-TILDA participants who answered a self-labelling item about loneliness, 15% felt lonely most of the time, 74% some of the time and 10% occasionally. Like the general population, the levels of loneliness experienced is higher as people age: 48% of 40-50 year-olds reported loneliness, 52% of 50-64 year-olds and 57% of 65+ age group reported experiencing loneliness (McCarron et al., 2011). No longitudinal study allows an examination of the temporal trajectories of loneliness, so at the moment it is unknown how much loneliness is existential, how much regenerative and how much degenerative, as are the elements of life that predispose older people with an ID to each of these trajectories.

2.9   Antecedents of Loneliness for older people with an ID

2.9.1   Predisposing Elements

2.9.1.1   *Culture*

According to Ung (2015), culture is not defined by population categories such as race, ethnicity, gender or religion, but it is defined by shared beliefs, values and expectations within a society. The wider community has limited knowledge about ID, and people with an ID are one of the least desirable groups (Scior, 2011). Wider society undervalues and stigmatises people with an ID, viewing them as different, deviant and unpredictable; in general society still has substantial

reservations about interacting with this group (Gilmore and Cuskelly, 2014). Segregation from the wider community leads to limited social opportunities in areas such as income, access to social and emotional relationships (Gilmore and Cuskelly, 2014), and access to choices (Barron, 2001). Where choices are made available, they are often heavily influenced by family and professionals (Barron, 2001). The lower a person's functional ability, the more limited their access to choice is likely to be (Robertson et al., 2001), and having limited access to choices leads to lower opportunities for self-determination, making people passive recipients rather than actively engaged citizens. It is this social stigmatisation, isolation from the mass, and limited choice that have been described as the biggest influence on loneliness for this population (Gilmore and Cuskelly, 2014).

It is likely that people with an ID, living separated from society, formed a more communal based sub-culture (van Staden & Coetzee, 2010), where they receive support from others within the community and have low expectations of marriage and intimate relationships. Therefore the expectation is that close friends and staff will form the basis of stress relief. In wave three of IDS-TILDA, the majority of those who said they had a best friend said that friend was either another service users or a member of the service provider staff. The relationship people had with their best friend was mainly categorised as "both close and intimate" (McCausland, Carroll, McCallion, & McCarron, 2017 p.41).

2.9.1.2   *The Role of Gender*

The exploration of the role of gender has produced mixed and often seemingly contradictory results. McVilly et al. (2006) reported that the vast majority of the most lonely people with ID were women and the majority of the least lonely were men, yet they also found that gender was not predictive of loneliness. Likewise, McCarron et al. (2011) in Wave One of IDS-TILDA data collection reported that more females than males experienced feelings of loneliness. The gender difference was repeated in Wave Two (McCausland, McCallion, Cleary, & McCarron, 2016), yet analysis of the IDS-TILDA sample of 40-65 year-olds found gender was not a significant predictor of loneliness when other factors were controlled for (McGlinchey et al., 2013). This finding indicates that, as in the wider population, females are more exposed to the events that precipitate loneliness than their male counterparts.

2.9.1.3   *Effects of disability*

The reported level of ID has not been shown to predict the degree of loneliness experienced (McGlinchey et al., 2013), but the amount of support a person requires has been found to predict loneliness (McVilly et al., 2006). Other research has found that the more severe a person's disability, the more likely they are to live in a residential setting (McCarron et al., 2011), and the

less likely they are to come in contact with friends and wider society (Kozma, Mansell, & Beadle-Brown, 2009). Those with increased needs tend to be protected by staff (Bane et al., 2012), leaving those with greater disabilities less opportunity to develop friendships in the usual way through choice, reciprocity, and talking. Even if people with severe forms of ID do have friends, they are less likely to have private personal space in which to meet (R. P. Hughes, Redley, & Ring, 2011).

The communication ability of a person may also increase the risk of loneliness (Daniel & Billingsley, 2010). Those who have communication difficulties experience more severe problems communicating with unfamiliar partners, who have insufficient time to spend understanding what is said (Ballin & Balandin, 2007). People with disabilities are far less likely to be able to read, which further contributes to social isolation and loneliness, and closes off an avenue of emotional release available to the general population (Fish, Rabidoux, Ober, & Graff, 2006; Forts & Luckasson, 2011). Therefore, while an individual's level of ID per se does not cause loneliness, the associated increases in functional limitations leave a person more vulnerable to living a life that excludes them from typical relationship development opportunities. Those with more severe functional limitations have to rely on others for transport, which is an issue that has been linked with loneliness in the wider population and for people with an ID (Burholt and Scharf, 2013, Drennan et al., 2008, Balandin et al., 2006). Specifically, in Ireland, lack of access to public transport has been further highlighted as a concern that prevents the development and maintenance of friendships (Bane et al., 2012).

The cognitive discrepancy approach to loneliness divides loneliness into predisposing elements and precipitating events (Perlman & Peplau, 1998). Traditionally gender, age and living environment have been found to be predisposing elements in loneliness research (Burholt & Scharf, 2013). Both cognitive impairment and disability are found to be related to loneliness but are not considered as predisposing variables merely items that influence desired or achieved social relations (Burholt et al., 2016).   The traditional demographic variables are selected because they are elements in life that people view divisions within society. Perlman & Peplau (1998) also discuss the role of culture as a predisposing element in the development of loneliness. There has been much research into the influence of different cultures on loneliness (Fokkema, De Jong Gierveld, & Dykstra, 2012; Rokach, 2007; van Staden & Coetzee, 2010). A cultural artefact of western cultures is the separation of people with disabilities from wider society, based on both physical and cognitive disability. Therefore when studying people with disabilities, their physical and cognitive abilities become demographically interesting elements. As this research is exploratory research, the intention was to understand if either demographic had an influence on loneliness.

2.9.1.4   *Living circumstances*

Like the general population, where people live and how happy they are in that community has an effect on the lives of individuals with an ID. McPhedran (2011) found that those that live in rural areas tended to be financially worse off than those living in cities, but conversely, they tended to be better integrated into the local community. Integration into a local community makes people feel safe, and if people do not feel safe in their community, they are more likely to be lonely (Stancliffe et al., 2010). The types of accommodation a person lives in represent an additional housing dimension for this population. What type of housing people live in is influenced by their age, and their level of ID; housing, in turn, dictates a person's lifestyle and their integration into the local community. Those living with family tend to be younger with less severe ID, and those in the residential accommodation are older with more severe forms of ID (McCarron et al., 2011). The association of living accommodation and loneliness is nuanced by the effect of age. In the IDS-TILDA study participants, those who were loneliest in the 40-49 age group were living in a community house, yet the most lonely in the 50-64 age bracket and the 65+ age bracket lived in residential settings (McCarron et al., 2011). McGlinchey et al. (2013), examining participants aged 40-65, found that living accommodation was not predictive of loneliness, and McVilly et al. (2006) also reported living accommodation as not predictive of loneliness. However, McCausland et al. (2016) did say that living accommodation was a significant predictor of contact with family or friends, which Stancliffe et al. (2010) found to be significantly predictive of loneliness. Living in grouped accommodation has also been found to be detrimental to developing and maintaining friendships (Bane et al., 2012) with the lower capacity housing predicting more involvement in the wider community (Kozma et al., 2009). Also, whom people with an ID share their accommodation with has been found to affect satisfaction with their social world, and not matching people on levels of sociability can lead to fewer social activities than some people require (Wiltz & Kalnins, 2008).

2.9.2   Precipitating Events

There has been little research that directly analyses which events create the discrepancy between the desired and actual social life for older people with an ID. However, the betrayal of friendships is reported as an important variable by both The Money, Friends and Making Ends Meet Research Group (2012) and McVilly (2006).

2.9.2.1   *Relationships*

Like the general population, family and friends are crucial in the lives of peoples with an ID and high-quality relationships prevent loneliness (Bane et al., 2012, The Money, and Friends Research Group , 2012). Research has demonstrated that the more contact with family and friends, the less

likely people in this population are to be lonely (McVilly et al., 2006, Stancliffe et al., 2010). Family contact is often determined by the proximity of family members, the age of parents, and the social ability of the person with an ID (Kozma et al., 2009, Bigby, 2004). Only 42% of IDS-TILDA participants reported monthly contact with family, as opposed to 96% of older general population participants in the TILDA study. Gaining new friendships may be more difficult for people with an ID, and nearly one-third of IDS-TILDA participants who reported feeling lonely also reported difficulty in making friends (McCarron et al., 2011). The ability to make friends can be negatively affected by poor understanding of social situations and social signals, poor social status, and communication problems (Daniel and Billingsley, 2010, Ballin and Balandin, 2007). Once people with ID form friendships they tend to be stable and highly valued (Daniel and Billingsley, 2010, Kozma et al., 2009). Consistent with loneliness theories, the quantity and quality of contact within the network appears to fundamentally influence loneliness (McVilly et al., 2006). The least lonely in the McVilly et al. (2006) study were reported as having more consistent long-term friendships, their best friend was more likely to be another person with an ID, and lonelier participants indicated their relationships failed to meet a broad range of their emotional and practical needs.

Employment has been found to offer opportunities for people with ID to increase and deepen their social ties. The type of work has been determined to be incidental to their social network, and whether they are in day service provision or a job placement both offer the opportunity for social connections (Hall & Kramer, 2009). Some research, however, has found that those in day services are lonelier than those in employment (McVilly et al., 2006), but analysis of the IDS-TILDA data concluded that occupation type was not a predictor of loneliness (McGlinchey et al., 2013).

How the network is populated, and the overall size of the network, for people with ID tends to be different to the general population (Lippold and Burns, 2009, Bane et al., 2012). For people with an ID, the associates in their network are dependent on the person's living arrangements and their personal characteristics (Kozma et al., 2009). Individuals with an ID are reported to have smaller social networks than the general population (The Money, and Friends Research Group 2012, Lippold and Burns, 2009). When participants in studies are asked to place those closest to them in an inner circle, those who are friends in a middle circle and acquaintances in an outer circle, the associates in the circles of people with ID tends to differ from the general population (Lippold and Burns, 2009). While brothers, sisters and parents were listed in both, there are very rarely own children listed, or own spouse, for people with ID, but day service staff, residential staff or paid-for friends frequently appear. The IDS-TILDA study has highlighted that 99% of individuals with an ID in Ireland are not married and only 2% have children (McCarron et al., 2011). It is argued by McCausland (2015) that paid staff and co-residents effectively take the place of immediate family and other friends. McCausland's (2015) argument is consistent with the

findings that friends for people with ID are the people who look out for them, people who support them, and those with whom activities are done (Bane et al., 2012).

2.9.3   Social Activities

The social activities of individuals with an ID tend to include others with an ID, and paid staff (McCausland, 2015). Families, however, can be a strong positive influence without actually being involved in the social activities (McCausland, 2015). The influences on social participation rates are multifactorial, with age, gender, residence, functional ability, physical health, mental health and social support being important elements in a person's social participation (McCausland, 2015). The social activity rates of individuals with an ID have been found to be higher than for the general population (Lippold and Burns, 2009). However, McCausland (2015) reported that for the IDS-TILDA participants, social participation rates are lower than for the general population. Half of the participants were found to engage in five or more community-based activities a month, yet only 1 in 4 activities were with members of the wider community, suggesting that interaction with the broader community is limited.

2.10   Consequences of Loneliness in Older People with an ID

There has been no research investigating the consequences of loneliness for older people with an ID. Hawkley and Cacioppo's (2007) model of health pathways discussed earlier suggests that for individuals with an ID, the high rates of loneliness experienced (McCarron et al., 2011, Stancliffe et al., 2010) may be impacting their health and physiological resilience.

2.10.1   Loneliness and Health in older people with an ID

Gilmore and Cuskelly (2014) argued that the most extreme outcome reported for the lonely was suicide, and it has been found that lonely individuals with an ID are more likely to experience feelings of suicidality than the non-lonely (Merrick, Merrick, Lunsky, & Kandel, 2006). A measure of energy and vitality was included in the second wave of IDS-TILDA which consisted of four questions measuring psychological status. While people with an ID did record lower scores than the general population (McCarron et al., 2014), scores were not significantly lower than those reported for the general population in the Survey of Lifestyle Attitudes and Nutrition (Barry et al., 2009). When what is known about the health of this population is divided into the five pathways (see Figure 2.4 above) there is mixed and limited evidence to understand the influence of loneliness. Pathway 1, health behaviours, suggests there should be an increased prevalence of poor health behaviours in people with ID. Findings are that individuals with an ID completed very limited vigorous physical exercise, and 66% were classified as overweight or obese. However,

participants had healthy diets, smoked less, and drank less alcohol as compared to the general population (McCarron et al., 2014). Under Pathway 2, in general, people with an ID have been reported as more exposed to stressful life circumstances (Gilmore and Cuskelly, 2014), and in IDS-TILDA, more than two-thirds of participants reported negative life events in the previous year. As for Pathway 3, while the general population utilise health care to try to alleviate and cope with their loneliness (Cleary, 2011), most people with ID would not have the option to book or attend medical services freely. Therefore, it is less likely that loneliness will predict health care utilisation (McCallion et al., 2013). There is no evidence to suspect any physical response to loneliness (Pathway 4), Wave Two of IDS-TILDA found that participants are 50% less likely to have hypertension than individuals in the general population, and five times less likely to have had a heart attack (McCarron et al., 2014). Finally, in Pathway 5 it would be expected that lonely people would have less rest and recuperation, and sleep disturbances have been associated with mental health conditions in people with Downs Syndrome (Esbensen, 2016).

2.10.2   Loneliness and Mental health

Loneliness in the general population has been found to have a strong connection with mental health concerns, and within the IDS-TILDA data, it has been reported that case-level depression was more common in those who reported experiencing loneliness than those who did not (McCarron et al., 2011).

2.10.3   Summary

This section has described what is known about loneliness in older people with an ID through the lens of very limited research, with more research being available about antecedents than about the experience, or the consequences, of loneliness.

2.10.3.1   *Antecedents of Loneliness*

Antecedent findings are mixed. For example, some research finds females more lonely (McVilly et al., 2006, McCarron et al., 2011, McCarron et al., 2014), and other research finds that being female is not predictive of loneliness (McGlinchey et al., 2013). Functional limitations, as opposed to the level of ID, appears to be more key to understanding the limits to social activity, and transport appears linked to loneliness, as poor transport prevents people from maintaining and developing their social interests (Drennan et al., 2008). Where people with ID live has been found to have an influence on their loneliness experience, but this is nuanced by their age (McCarron et al., 2011). Relationships are important, both the quality and quantity appear fundamental, and betrayal by a friend has been identified as a precipitating event for loneliness (McVilly et al., 2006, The Money, and Friends Research Group, 2012). Social networks, however, are constructed

differently to the wider population, and tend to include paid staff and co-residents in place of the immediate family (Lippold & Burns, 2009). Social participation also tends to be with others with an ID, and there is poor integration into the wider community (McCausland et al., 2016).

2.10.3.2 *The Characteristics of Loneliness.*

There has been no specific research into the type of attributions used by the lonely with ID, but case-level depression has been found to be associated with loneliness (McCarron et al., 2011). The experience of loneliness remains un-researched, and it is unknown whether people with ID remain consistently lonely or fluctuate in and out of feeling lonely.

2.10.3.3 *The Consequences of Loneliness.*

There has been no research into the implications of loneliness for people with ID, but the evidence suggests that some of the outcomes may be affected by the lack of personal choice (McCallion et al., 2013).

2.11   Conclusion

Loneliness is a subjective experience that operates at the level of the individual, while being influenced at the level of the society. The consequences of loneliness amount to reduced quality of life and reduced physiological resilience. Loneliness is at its zenith in adolescence, and it declines throughout adulthood until it starts to rise again in old age. While the overall model of how loneliness operates may be the same, the variables that account for entry into loneliness in this period are ones of decline and loss.   It would seem that older people with an ID experience greater levels of loneliness than the general older population, and live in a culture separated from and stigmatised by the wider community, creating different expectations. There has only been a small amount of research into loneliness in this population, and not enough is known to build a picture of the causes and consequences of loneliness in Ireland for older adults with an ID. Currently, the lives of older people with an ID are in transition, not just because of the cumulative losses incurred through the ageing process, but also because of changes to service delivery structures. It has been demonstrated that older people with an ID are capable of understanding and reporting on loneliness, yet there has been no longitudinal research to provide information on the temporal nature of loneliness. What research there has been finds that while social networks are different in their constitution from older people in the wider populace, the quality of the network is still of primary importance. Other variables that predispose people to loneliness, such as lived environment, disability or employment, are constructed differently to the wider population yet still may provide the same outcome, and variables such as gender, education and income may have no influence at all.

Loneliness is known to have detrimental effects on health in the general population. To date, there has been little research undertaken to test this in the older ID population, and there is not enough research available to build a comprehensive understanding of the amounts of loneliness experienced, particularly its antecedents, characteristics, or consequences. To this end, this research will (1) analyse the antecedents of loneliness, both predisposing variables and precipitating events, (2) consider the role of depressive thinking in moderating the path between the antecedents and the experience of loneliness, and (3) consider the experience of loneliness through its temporal trajectories. Determining the consequences of loneliness will be done by utilising the five pathways through which loneliness affects health, and thus resilience, and a synthesised structural model will be created to help guide understanding of loneliness in ageing people with ID. The next chapter deals with the selection of a theoretical model.

3 Theoretical frameworks

3.1 Introduction

The purpose of this chapter is to discuss the major psychological theories used in loneliness research and to select the approach that gives the best option to answer the research question. There is a lack of research into loneliness as experienced by older people with an intellectual disability (ID), which may be because this group are not convenient to access, being protected as they are from researchers by a myriad of service organisations and ethics committees. When a researcher can gain access to this population, there are potential difficulties with communication, understanding and attention deficits, which make researching this community seem like an onerous task. The aim of this study is to create a complete understanding of how loneliness affects the lives and health of older people with an ID. This aim requires a broad-ranging framework, capable of capturing and placing the effects of a complex mix of issues into a meaningful, understandable, and usable source of information about loneliness in this population.

The examination of loneliness has produced many studies but has involved the creation of very few theoretical frameworks to aid in its understanding. Three key perspectives can be used to describe and understand loneliness, the Behavioural Approach, the Social Needs Approach and the Cognitive Approach (Letitia A. Peplau et al., 1982). The Behavioural Approach is the only one of the three approaches not to have a specifically developed theory of loneliness. Researchers use Social Cognitive Theory (Bandura, 1986) to describe the characteristics of loneliness, and this theory asserts that behaviours are learnt from observation of self and others. Central to this approach is the maintenance of behaviours through the triad of the person, the environment, and the action. The Social Needs Approach to loneliness was developed by Weiss (1973), and was the seminal theory that instigated the growth of research into loneliness. Weiss's (1973) theory developed from Harry Stack Sullivan's Interpersonal Theory, arguing that loneliness exists because of the lack of fulfilment of certain kinds of relationships. The theory defines two distinct loneliness syndromes: the loneliness of emotional isolation and the loneliness of social isolation. The cognitive approach developed out of Weiner's Attributional Framework, and it argues that people experience loneliness because of a mismatch between their achieved and their desired social network in either quality or quantity. This disconnect in the social network causes a dissonance that forces people to make an attribution about their situation, and the attribution they make determines whether they experience loneliness. The cognitive approach argues that loneliness, when experienced, is such an aversive condition that it has measurable adverse consequences.

Both the Social Needs Approach and the Cognitive Approach claim an evolutionary basis for loneliness, arguing that loneliness is innate because it enhances the chance of survival. The cognitive researchers emphasise the role of the fear system, which drives people to seek protection from the attack of predators in groups (Cacioppo, Hawkley, et al., 2006). Social Needs researchers argue that loneliness develops from the proximity-seeking behaviours of childhood, which are critical to the attachment system and keep a child protected and safe (Evans, 2005). The Behavioural approaches maintain that loneliness is a behaviour that people learn through observation of others, and thus is not driven by an evolutionary function.

3.2   Behavioural Approach

Behavioural theories are founded on the philosophies of Aristotle, St. Thomas Aquinas and John Locke, who considered that when a person is born the brain is tabula rasa or a clean slate. Behavioural psychologists believed that all behaviours were learnt by observing others (Hunt, 2009). Probably the most famous experiments in Behaviourism are those done by Pavlov, who trained dogs to drool at just the sight of a lamp or the sound of a siren. Skinner called this 'operant conditioning,' and Pavlov demonstrated that the drooling behaviours were programmable in or out of the dogs. Over time it became apparent that some actions were innate and did not have to be learnt for example, a baby does not need to be taught to suckle for milk, and a pigeon can only activate feeding stations by pecking and cannot be taught to push a lever for food (Hunt, 2009). It was out of this zeitgeist that Albert Bandura developed Social Learning Theory (Bandura & Walters, 1977), which later became Social Cognitive Theory (Bandura, 1986).

Bandura and Walters (1977) said that behavioural methods did not supply a complete understanding of human cognition, as they treated people as being driven by the environment rather than having a certain amount of self-direction. According to Social Learning Theory, the action is best understood as a continuous reciprocal interaction between behaviour and its controlling mechanisms (Bandura and Walters, 1977). Bandura and Walters (1977) argue that people learn mostly through the vicarious learning of both skills and emotions. Emotional responses are established by observing reactions of pleasure or pain to a situation. Watching the opposite emotional response to a situation causes the response to be extinguished. In Social Cognitive Theory, Bandura (1986) says that people learn in a social environment and that there is a dynamic and reciprocating triad (Figure 3.1) of the person, the environment, and the behaviour. Bandura (1986) thought the environment was the most important element, and that a change in

environment would lead to a change in behaviour. The theory does not just consider how people commence a behaviour, but also how they maintain, sustain, and further develop that behaviour.
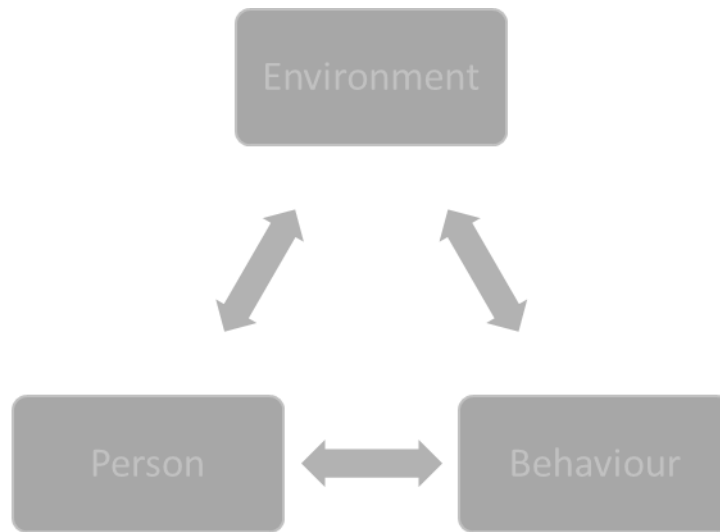
Figure 3-1: Bandura's (1986) Cognitive Triad

3.2.1 Social Cognitive Theory and Loneliness

Social Cognitive Theory argues that events can occur that isolate an individual from their support group, whether an event is the death of a spouse, moving location, or some form of ostracism. When separated, people become lonely; they blame themselves for their loneliness, and their self-perception becomes that of an outsider to the group around them. Once a person feels they are an outsider they then start acting and behaving like an outsider, further alienating themselves from the group (Blossom & Apsche, 2013). Blossom and Apsche (2013) give an example of how loneliness develops, they argue that some children diagnosed with behavioural problems are only reacting to the loneliness they are experiencing. They contend that the loneliness these children experience commences with a punishment which excludes the child from the group (environment). The child internalises this exclusion as themselves being the deviant (person). Children who are isolated fail to thrive, and like Harlow's monkeys, which when isolated without a source of comfort became aggressive and violent, the children without the comfort of peers become violent and aggressive (behaviour). This behaviour then serves to separate them further from the group (environment), and they (person) learn to gain attention through this behaviour and so become further isolated from the group (Blossom and Apsche, 2013). Social Cognitive Theory (Bandura, 1986) was used to investigate loneliness in older people living in nursing homes by Cohen-Mansfield and Parpura-Gill (2007), they found that limited opportunities for social contacts, lack of financial resources, poor mobility, and a lack of self-efficacy in social situations all predicted loneliness. The most significant of these in predicting loneliness was a lack of self-

efficacy in social situations. Loneliness was the largest predictor of depression (Cohen-Mansfield & Parpura-Gill, 2007) and they argue that loneliness and depression form a vicious cycle in which loneliness leads to depressed effect which reduces energy levels. Reduced energy levels then lead to reduced interaction with people (behaviour), which in turn result in fewer social activities (environment) and fewer social activities reduce self-efficacy (person), leading to further loneliness.

3.2.2   Applicability of Social Cognitive Theory

The strength of the theory is the cognitive triad, which is logical and compelling; offering insight into how loneliness develops, is maintained, and can be further deepened. The cognitive triad also gives an understanding of which environmental changes can help people break from a spiral of loneliness. The main weakness of Social Cognitive Theory is its narrow focus on the cognitive triad, to the exclusion of other antecedents and consequences of loneliness.

Additionally, placing the environment as the key determinant of behaviour and arguing that a change in environment leads to a change in behaviour (Bandura and Walters, 1977) limits the scope of the theory. McLeod (2011), has highlighted that not all changes of environment result in a behaviour change, and for the lonely, it would mean that loneliness could be extinguishable by moving a person to a new area or to a nursing home where there are lots of potential friends. However, environmental change is one of the primary causes of loneliness (Weiss, 1973), and research has shown that those who relocate after retirement are amongst the loneliest (Wenger & Burholt, 2004). Other investigations find that if personal relationships are attended to and changed, then loneliness can be overcome without adjusting the environment (Broer et al., 2010; Lawlor et al., 2014). Finally, Mijuskovic (2015) points out that since Social Cognitive Theory is based on operant conditioning, a person should be able to administer a series of aversive stimuli, such as electric shocks, every time they feel lonely or think of loneliness, thus eliminating loneliness altogether. Much of Social Cognitive Theory is accounted for within the Cognitive Discrepancy Approach, which acknowledges a cognitive loop very similar to that described in Hawkley and Cacioppo (2007).

3.3   The Social Needs Approach

The Social Needs Approach asserts that all people have an inherent need for human relationships and intimacy (Weiss, 1973). This area of research has developed from Sullivan's (1953) Interpersonal Theory, in which loneliness is defined as "the experience of the failure to achieve an intimate relationship" (Evans, 2005 pg. 206). Sullivan argues that loneliness is the outcome of

changes in adolescence; these changes see the development of the need for intimacy as a key driver in the lives of adolescents. Loneliness then develops as a result of the denial of this need, and it becomes an organising force. The change commences in preadolescence but starts to be a major organising force in early adolescence, where companions are sought out even if they cause anxiety (Evans, 2005). These descriptions of the development of loneliness are given foundations by Bowlby (S. Albert & Bowlby, 1982), who advanced this area of research by describing the underlying mechanisms (Mercer, 2011).

Bowlby's Attachment Theory is one of the most influential psychological theories and has generated thousands of research projects and papers. It has changed how psychologists view child development and has led to global changes in how child-parent relationships are considered (Hunt, 2009). Bowlby believed attachment with caregivers is necessary throughout life, and poor attachment in childhood can lead to psychopathology in later life(Cassidy, 2008). The attachment style a child cultivates with its caregivers leads to the creation of cognitive maps that govern the development of all future social relationships and expectations (Cassidy, 2008).

Bowlby argued that the attachment system improves the survival of children through the proximity-promoting behaviours utilised by young children (Cassidy, 2008). The attachment system works in conjunction with other cognitive systems, such as the fear system. The fear system covers childhood anxieties such as darkness, lurching movements and aloneness, which are innate in a child's psychology through Darwinian adaptation. These concerns cause the child to seek the proximity of adults known to the child and thus increase the survival chances of the child (Cassidy, 2008).

3.3.1 Social Needs Approach and Loneliness

Weiss (1973) argued that three proximity-promoting behaviours sponsor the survival of individuals: proximity to others gives a sense of well-being or pleasure, whereas distance from others causes discomfort or distress and the drive to re-establish contact with those known to one. This theory maintains that being without a needed relationship, a set of relationships, or specific relationship provision causes loneliness. Weiss (1973) believed that loneliness is a series of syndromes that have in common a yearning for a relationship (Figure 3.2 above). He defined two syndromes: the loneliness of emotional isolation and the loneliness of social isolation, but said there were probably more. The loneliness of emotional isolation develops from the inherited proximity-promoting behaviours of the young child, and is an extension of the distress felt from being separated from the primary attachment figure. People living through this loneliness syndrome experience a pervasive apprehensiveness which creates instant and intense feelings of loneliness. Like Sullivan (Evans, 2005), Weiss (1973) argued that around the time of adolescence

the attachment need for parents is lost, and the search for a new attachment figure begins. The loneliness of social isolation develops from the preadolescent's need to be in proximity to a social group. Children feel a need to belong and to be accepted, and when children become separated from friends, they feel bored. The loneliness of social isolation is a pain that gains strength over time. If the person does not make contact with their social network, or manage to develop a new social network, they experience the loneliness of social isolation, even when others are available to them (Weiss, 1973).
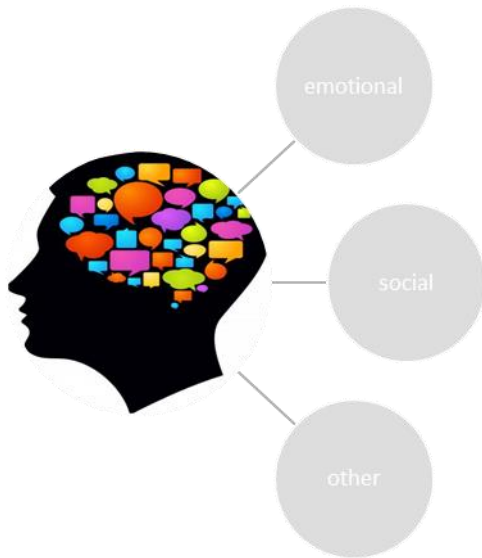
Figure 3-2: The Social Needs Approach (Weiss, 1973)

Therefore loneliness is not about being alone as such, but about lacking the benefits that different types of relationships provide, and both kinds of loneliness syndrome described by Weiss (1973) serve different needs. An emotional attachment first fulfils an innate drive, and in doing so, it provides a person with feelings of security and well-being, and is linked to sexual accessibility. The social attachment provides a person with the feelings of being connected to a group, which bring pleasure through shared social gatherings and activities. Social attachment offers a person social knowledge, which may protect them from making mistakes. Both of these are separate drives, and an increase in one drive cannot compensate for the lack of provision in another, so if a person separates from their spouse, increasing the number of friends in their social circle will not replace the innate need for an intimate attachment. Likewise, if a person moves to a new area with their emotional attachment, and loses their social circle, then taking on a second emotional attachment figure will not compensate for the lack of a social circle (Weiss, 1973).

The association of patterns of attachment in childhood and loneliness in later life offers evidence in support of the Social Needs Approach (Raikes & Thompson, 2008). Also, there is evidence to support the idea of separate syndromes of the loneliness of social isolation and the loneliness of

emotional isolation (Raikes and Thompson, 2008). In the general adult population, the most commonly reported cause of loneliness is the loss of a spouse. The effect of the loss of a partner appears to cross all national and cultural boundaries, and the widowed are up to five times more likely to report being lonely than the married (Victor et al., 2008, Barry et al., 2009). Emotional isolation has not only been detected in the widowed, but also in those that have never married and those isolated from their children and other relatives. A subset of emotional loneliness for families has been described and is referred to as a family loneliness (Drennan et al., 2008). There is support for the concept of the separate loneliness syndromes in older adults, with widowhood being found not to be linked to social isolation (Golden et al., 2009). Additionally, socially isolated people are one and a half times more likely to suffer from some level of psychological distress (Barry et al., 2009). The predictors of social loneliness have been found to be greater age, poorer health, and living in a rural area with a lack of contact with friends (Drennan et al., 2008).

In adults with an ID, loneliness and social isolation are relatively easy to identify, with the lack of contact with friends being a regularly cited cause of loneliness, and those who do not maintain friendships are among the most lonely (McVilly et al., 2006). The subtype of family loneliness has also been identified in adults with an ID, with loneliness more common in those that have poor contacts with family (Stancliffe et al., 2010, McVilly et al., 2006). However, this link with family is nuanced, as those who live at home have also been reported as some of the loneliest (McVilly et al., 2006).

3.3.2   Applicability of the Social Needs Approach

The categorisation of loneliness into distinct syndromes has been problematic for researchers. Stein and Tuval-Mashiach (2015) note that the Social Needs Approach looks at the sources of loneliness without dealing with its essence; it merely concerns itself with the antecedents of loneliness. Horowitz (2004)notes that while loneliness may be a single problem, it does not have a single cause, and likewise, Perlman and Peplau (1998) argue that loneliness is not attributable to a sole source, since there are a variety of elements that bring about loneliness. Baumeister and Leary (1995) contend that rather than people requiring separate social or emotional relationships, they need regular social contact with people to whom they feel connected. Even if there is a significant event in a person's life that precipitates loneliness, there will be other underlying factors that predispose some and not others to experience the pain of loneliness. Much of the data supporting the concept of multiple loneliness syndromes in the general population are tautologous, being derived from studies that are tied to this theory, so dividing their results into the syndromes described within the theory. Hawkley and Cacioppo (2010) contended that loneliness could be considered a single construct due to the considerable overlap between the

syndromes of social and emotional isolation. Additional to the problem of the utility of dividing loneliness between multiple syndromes, the Social Needs Approach has two other major issues. First, the Social Needs Approach does not allow for the study of the consequences of loneliness and, second, it fails to consider why people in similar situations do not all experience loneliness.

Dividing loneliness into separate syndromes may be problematic for older individuals with an ID. Research into relationships and their link to loneliness in this population have found that a general confusion over relationships exists and there is a lack of understanding of the division between social friends, intimate relationships and acquaintances (Bane et al., 2012). The small numbers of intimate relationships and marriages within the ID population (McCarron et al., 2011), and the possible shrinkage of expectations of an intimate relationship (Weiss, 1973), would make it difficult to investigate the loneliness of emotional isolation. Dividing the experience of loneliness into the separate syndromes may also generate questions of a level of detail that may create confusion rather than clarity in any results. The Social Needs Approach, like Social Cognitive Theory, has the problem that the Cognitive Discrepancy Approach accounts for much of its stance. The Cognitive Discrepancy Approach explains that people experience loneliness because of the failure to meet the need for attachment and social integration (Hawkley and Cacioppo, 2007).

3.4   The Cognitive Approach

The Cognitive Discrepancy approach to loneliness argues that what determines if a person experiences loneliness is not whether they are just missing specific relationships, but how they feel about lacking these connections (Peplau, 1988). It is an attribution approach based on Weiner and colleagues' Attributional Framework (Peplau and Perlman, 1979). Weiners Attributional Framework developed from two sources: John Atkinson's Expectancy Value Framework and Fritz Heider's Model of Effective Forces (Weiner, 1974). Within attribution frameworks, how a person attributes their problems (internal or external), whether they see them as permanent or temporary, whether they believe they have control over their situation, and whether a person has an optimistic or pessimistic outlook about the problem are all important in determining the outcome (Peplau and Perlman, 1979).

3.4.1   The Cognitive Discrepancy Approach to Loneliness

There are two underlying principles to the Cognitive Discrepancy Approach. First, loneliness is a response to a gap between the desired and the achieved levels of social contact, and second, cognitive influences, especially attributions, have a moderating influence on loneliness

experiences (Perlman and Peplau, 1981). While the Social Needs Approach to loneliness argues that loneliness is a multiplicity of syndromes, the Cognitive Discrepancy Approach considers loneliness as a single construct.
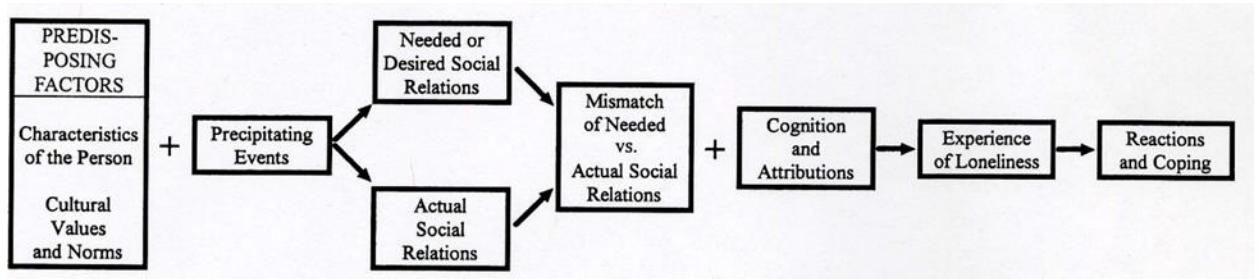
Figure 3-3: Perlman and Peplau's (1998) Cognitive Discrepancy model of the experience of loneliness reproduced from "Loneliness" By D. Perlman & L.A. Peplau *Encyclopedia of mental health, 2*, p. 572 copyright 1998 by **Taylor and Francis Group LLC Books. Reprinted with Permission under licence number 4270990436999.**

As can be seen in Figure 3.3, the Cognitive Discrepancy Approach creates a broad framework that includes the cognitive elements and characteristics of loneliness and accounts for the antecedents and consequences of loneliness. The framework creates a logical pathway, giving clarity as to how the antecedents to loneliness combine to create the experience of loneliness, and to how people react to and cope with that loneliness. In laying out this consistent pattern of underlying elements, it allows explanation of the major themes involved in the experience of loneliness. In the Cognitive Discrepancy Approach, it is precipitating events that create the mismatch between expected and desired social relations, and which events create the mismatch depends on the predisposing elements; these are factors that are distal to the life events of the person. Predisposing elements consist of the characteristics of the person, the cultural values and the social norms borne out of social expectations, both those of the host culture and those that influence the cognition of the individual (Peplau, 1988). A precipitating event can be a single major life event such as relocation to a new area, retirement, death of a spouse, or it can be a combination of factors such as the declining quantity of friendships in old age combined with worsening health (Perlman & Peplau, 1998). Once the person recognises a mismatch between desired and actual social relationships, how they attribute this mismatch, and their cognitive style, will decide whether they suffer the experience of loneliness (Perlman and Peplau, 1998). Once the person experiences feelings of loneliness, they are in a state described as hypervigilance (Cacioppo and Cacioppo, 2014) that directly affects how a person reacts and copes physically and mentally in day to day life with their loneliness. Each of these steps highlights areas for research that provide a refined understanding of the complete experience of loneliness from the

antecedents to the characteristics and then the consequences of loneliness. Different researchers have emphasised and studied specific areas within the framework (Stein & Tuval-Mashiach, 2015). To date, Cacioppo and colleagues (Boomsma et al., 2005) have demonstrated how genetic evolution has developed the sensitivity to the antecedents of loneliness within social species, creating an evolutionary explanation of loneliness. Russell et al. (2012), have emphasised the importance of the cognitive element and Anderson (C. A. Anderson, 1999; Craig A. Anderson et al., 1994) has looked at the attribution. Burholt and Scharf (2013) have investigated how antecedents combine to create the mismatch between desired and achieved social relations, and how cognitive style then moderates the path between mismatch and loneliness.

3.4.2   Applicability of the Cognitive Discrepancy Approach

The Cognitive Discrepancy Approach acknowledges the multiplicity of combined and intertwined characteristics, events and attributions that are the cause of loneliness and the dynamism of reactions to loneliness. It is the most common approach to understanding the experience of loneliness in empirical social research (Stein and Tuval-Mashiach, 2015), yet it has not been without critics, who consider it too broad in its definition of loneliness (Stein and Tuval-Mashiach, 2015). However, in this case, its broadness is its strength, as the requirements for this research are to understand the antecedents, characteristics and consequences of loneliness.

3.5   Selection of a model

Table 3-1: Strengths and Weaknesses of Loneliness Theories

Social Cognitive Theory	**Strengths**
	The cognitive triad describing the interaction of behaviour, environment and person
	Weaknesses
	No consideration of the effects of loneliness
	Environment is the key determinant of antecedents
Social Needs Approach	**Strengths**
	Provides insight into the pathways of antecedents of loneliness
	Highly respected and widely utilised theory
	Weaknesses
	Looks at the sources of loneliness without dealing with the essence.
	Loneliness is not attributable to a single source
	Does not deal with the consequences of loneliness
	Does not consider why people in similar situations differ on their experiences of loneliness.
	Research can be tautologous.
Cognitive Discrepancy Approach	**Strengths**
	Accounts for the Antecedents, Characteristics and Consequences of loneliness
	Allows different pathways to loneliness
	Acknowledges the role of distal variables in the antecedents of loneliness
	Widely used approach
	Weaknesses
	Some researchers consider it too broad.

Rokach and Sha'ked (2015) have identified that are three essential features of loneliness. First, loneliness is universal, that is it is fundamental to being human. Second, loneliness is a subjective experience that is influenced by personal and situational variables and, finally, loneliness is a complex and multifaceted experience which is always painful, severely distressing, and individualistic. In selecting a theory that will help give new insight into the experience of loneliness for people with an ID, three criteria have been identified. First, the model must be broad enough to encapsulate the complex and multifaceted experience of loneliness. Stein and Tuval-Mashiach (2015) noted that a theory should encapsulate the antecedents, the characteristics and the consequences of a phenomenon. The second criterion is that the theory must be useable at a population-based level, allowing those at a planning and organisational level to understand the main thrusts of the causes and consequences. The third criterion is that the theory identified should allow service providers and oversight bodies to understand the structural elements that can be modified, not just to remedy the immediate situation but also to prevent the occurrence in the first instance.

All three theories discussed (see Table 3-1 above) offer the opportunity to understand loneliness at a population level. However, Social Cognitive Theory, while providing insight into the thought

processes and characteristics of loneliness that create and maintain loneliness, provides no insight into either the antecedents or the consequences of loneliness. The social needs approach supplies information on the variables that are the precursors to loneliness but does not provide any insight into the maintenance or effects of loneliness. Therefore the only theory that matches the criteria is the Cognitive Discrepancy Approach. The Cognitive Discrepancy Approach is broad enough to give a population-level understanding of what leads to loneliness, what the characteristics of this loneliness are, and what the effects of loneliness for individuals with an ID are.

This approach also offers models to comprehend the antecedents, characteristics and consequences of loneliness from other ageing populations that can be utilised to give an understanding of the whole loneliness experience for older people with an ID. The data from these models can then be contrasted with the results of these populations. Hawkley and Cacioppo's (2008) Filtration Model of loneliness (Figure 3.4) will be applied to analyse which variables are the antecedent to loneliness, and how they operate as either predisposing or precipitating variables.
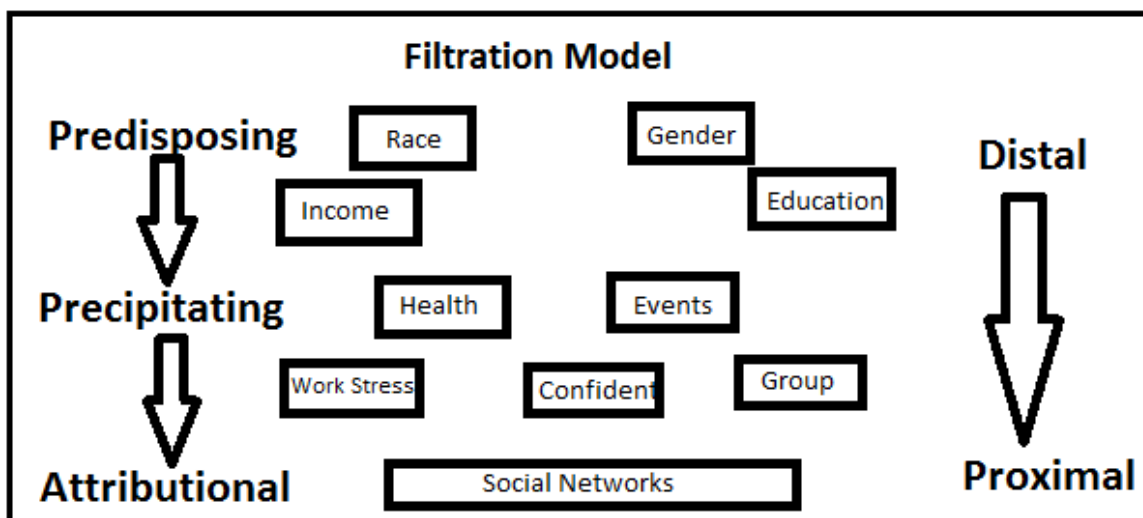
Figure 3-4: Filtration model of loneliness as described in Hawkley et al., (2008)

Burholt and Scharf (2013) used Conditional Process Analysis to model the moderating role of cognition in loneliness; their model (Figure 3.5) will be adapted and used to create an understanding of the role of negative attributions in this group.
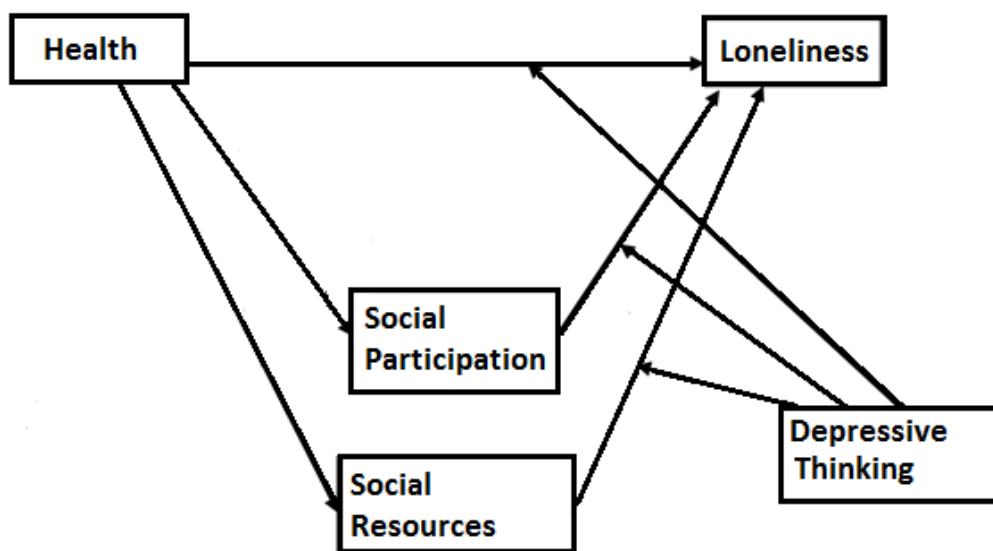
Figure 3-5: Role of depressive thinking in loneliness. Adapted from "Poor Health and Loneliness in Later Life: The Role of Depressive Symptoms, Social Resources, and Rural Environments" by V. Burholt and T. Scharf, 2013 in *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences, 69(2)* p.318. Copyright by The Gerontological Society of America. Reprinted by courtesy of the copyright holder under a creative commons license (http://creativecommons.org/licenses/by-nc/3.0/).

To understand the temporal nature of loneliness in this population, Victor et al.'s (2008) categorization of loneliness into existential, degenerative and regenerative will be utilised (Table 3-2). These trajectories will create knowledge about how much loneliness fluctuates over an extended period.

Table 3-2: Categorisation of the temporal experience of loneliness (Victor et al., 2008)

Categorisation of Loneliness	Description
Existential	Or consistent loneliness, is where loneliness is a lifelong nagging fear
Degenerative	Loneliness increases over time and is found to develop from a build up of events
Regenerative	Loneliness is caused by traumatic event, such as sudden illness or loss of a partner, but people recover from event

The consequences of loneliness will be analysed using a health pathways model (Figure 3.6) previously employed by Hawkley and Cacioppo (2007). The five pathways of health behaviours, exposure to stressors, perceived stress and coping, stress response and recuperative processes have a negative interaction with physiological resilience caused by loneliness.
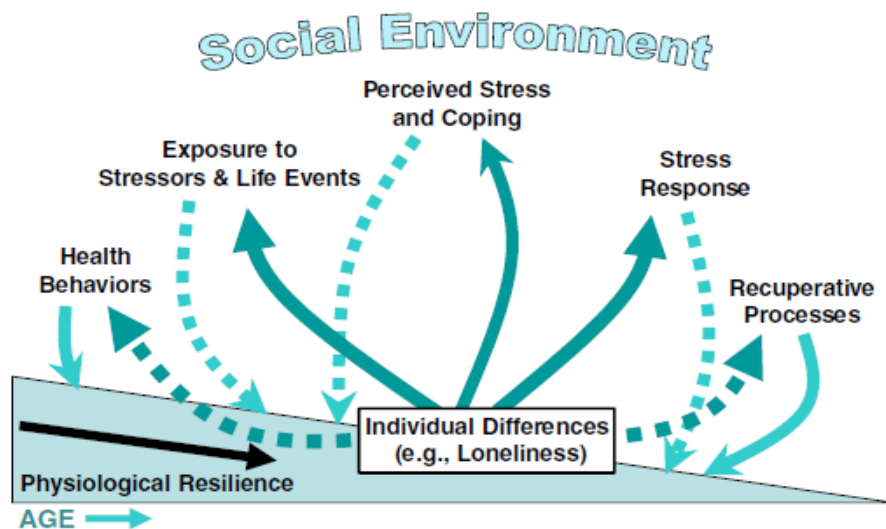
Figure 3-6: The Five Health Pathways Model. Reproduced from "Ageing and Loneliness: Downhill Quickly?" by L.C. Hawkley and J.T. Cacioppo in *Current Directions in Psychological Science 16(4)* p188. Copyright 2007 from The Association for Psychological Science. Reproduced with permission.

Finally, an overarching model will be created to explain how the whole experience of loneliness for this population.

3.6   Conclusion

This study aims to create a broad understanding of loneliness as experienced by older people with an ID, encapsulating the antecedents, characteristics and consequences. The three leading theories of loneliness are The Social Cognitive Theory developed by Albert Bandura, The Social Needs Approach developed by Weiss, and the Cognitive Discrepancy Approach by Anne Peplau and Daniel Perlman. Social Cognitive Theory describes the cognitive triad utilised by people who experience loneliness. The cognitive triad is both the theory's strength and its weakness. The triad is logical and gives a succinct explanation as to loneliness develops, how it is maintained, and how it can deepen over time. However, the fixation on the triad leaves the theory very narrowly focused and does not permit a broad insight into either the antecedents or consequences of loneliness in this population.   The Social Needs Approach offers a powerful insight into specific antecedent relationship deficits that can lead to loneliness. The approach though fails to consider the broader picture of loneliness, and does not account for the role of attributions, or how people respond to loneliness. People with an ID rarely have the opportunity for stable intimate relationships, and they can display confusion in understanding relationship boundaries, therefore

a population level study may not provide a clear insight into relationships. The Cognitive Discrepancy Approach argues that loneliness is caused by attributions about a mismatch between an individual's achieved and desired social relations. The Cognitive Discrepancy Approach takes into account the antecedents that lead to the mismatch, the attribution that moderates the path to loneliness, the characteristics of the loneliness experience and the consequences of loneliness. Use of the Cognitive Discrepancy Approach allows for a broad understanding of loneliness at a population level, and it will allow policy makers to understand what areas of service provision are modifiable to overcome and prevent loneliness. The Cognitive Discrepancy Approach is an approach to understanding loneliness that is widely used. Models specific to each element of loneliness have been developed to increase understanding of the phenomenon and will be utilised within this study to improve the clarity, understanding and contrastibility of the results. The next chapter describes the methodology adopted to investigate loneliness in this population using the Cognitive Discrepancy Approach.

4 Methodology

4.1 Introduction

This chapter describes the methodology utilised to investigate loneliness in older people with an intellectual disability. It starts by giving a brief synopsis of the study. In section 4.2 the data set is described, including the ethical standards adhered to, the participants, and their recruitment. The major scales used are then described (Section 4.3), including a detailed description of the loneliness scale. Finally, a brief overview of the analysis to be undertaken and the use of regression analysis, which is the cornerstone of the analysis work undertaken, is described.

This study utilised data collected as part of the Intellectual Disability Supplement to The Irish Longitudinal Study on Aging (IDS-TILDA), which is investigating the ageing process of older adults with an intellectual disability over many phases of data collection.

A specially simplified and shortened version of the Revised UCLA Loneliness Scale has been developed to allow improved performance (Hughes et al., 2004) of the scale within survey interviews. The loneliness scale used on this research was embedded within the social connectedness section of the study. Embedding loneliness questions within a larger study is common practice in loneliness research, and loneliness scales have been included in many other large population-based studies, such as The Irish Longitudinal Study on Ageing (TILDA), The English Longitudinal Study on Aging (ELSA) and the Health and Retirement Study (HRS). Doing so produces a wealth and depth of data that may not otherwise be possible.

IDS-TILDA dataset

It was decided to use the IDS-TILDA data set for three specific reasons:

1. Information on loneliness in people with an intellectual disability is hard to glean because gaining access to this group can be an onerous and lengthy task.

2. The ability to achieve a large enough random sample from across the Republic of Ireland, that gives enough power to carry out statistical modelling, would have been a lengthy and costly process.

3. The necessary data is already contained within the IDS-TILDA data set.
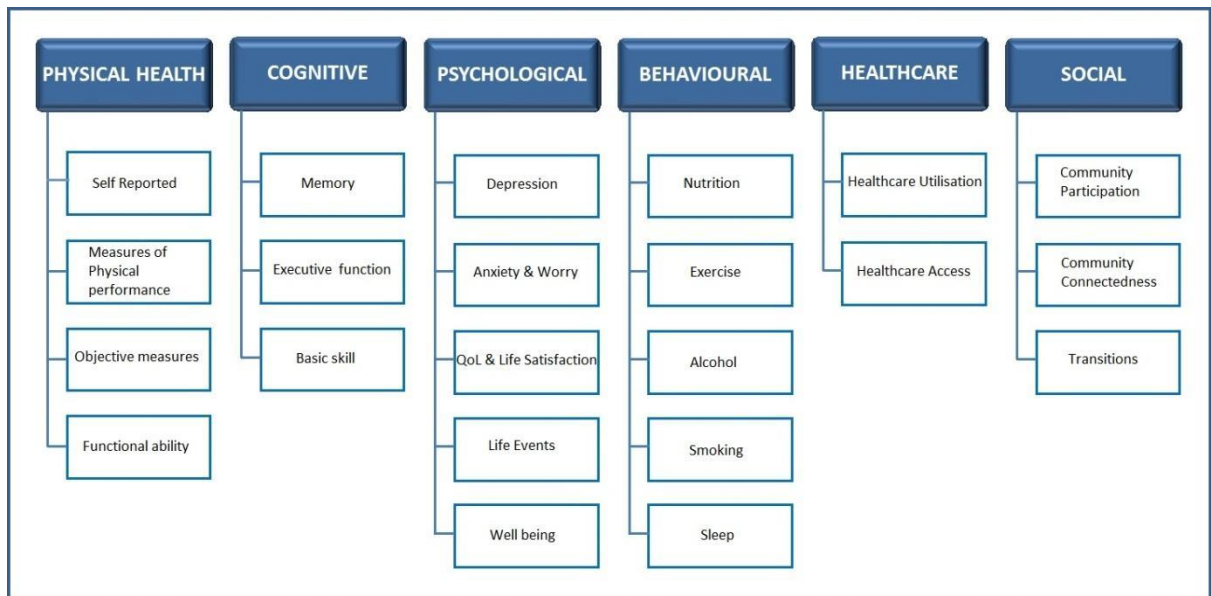
Figure 4-1:Conceptual framework from IDS-TILDA wave 2

The IDS-TILDA is a longitudinal study that commenced data collection in 2010 and had a repeated follow up in 2013. There is a broad amount of information available in the IDS-TILDA data set (see Figure 4.1), encompassing the six domains of physical health, cognitive functioning, psychological function, behavioural, healthcare, and social. Use of the dataset will allow for an in-depth analysis of the causes, characteristics and effects of loneliness, giving a wide-ranging and holistic understanding of loneliness in this population.

Whilst the framework largely remained the same between both waves, questions that did not require repeating, such as aetiology of ID and date of birth, as well as sections that may be burdensome to administer like the happiness index, were removed. Additional items were added in wave two, such as life events and the addition of a health fair to gather actual health metrics. In total, 77 questions were added, 16 were modified, and 98 were removed.

4.2   Participants

4.2.1   Sampling Frame

The sample was drawn from the National Intellectual Disability Database (NIDD). The NIDD is managed by the Health Research Board and collects information on all people in the Republic of Ireland who are eligible to receive services. The database outlines the specialised health services used or required by people with an ID. The database answers three questions about people with an ID: what is the demographic profile, what are the services used, and how many are waiting for

services (Health Research Board, 2015). The database at study commencement had 26,066 participants (McCarron et al., 2011), of all levels of disability and across all living circumstances.

Expecting a yield on invitations of less than 50%, 1800 participants were randomly selected. PIN numbers were released from the NIDD for people aged over 40 to the regional disability database administrator, who verified the veracity of the PIN numbers and posted out invitation packs on behalf of the IDS-TILDA, thus retaining the confidentiality of the invited.   The invitation packs consisted of information explaining the project and consent forms in both easy read and detailed versions. The packs directed interested parties to information events that were being conducted at locations around the country on the research project. Finally, services were encouraged to identify a link person to aid in the planning of interviews.

Wave 1 recruited 753 participants in 2010, which was a 46% return on invitations and was in line with expectations, representing 8.9% of the population of people with an intellectual disability in Ireland over the age of 40.   Forty-five percent of participants were male, and fifty-five percent were female. Participants ranged in age from 41 to 90 years of age, with the average age being 54.7 years (SD=9.552, 95% CI=54.06, 55.43). The levels of intellectual disability are spread across the levels with 24% having a mild intellectual disability, 46% a moderate level of disability, 24% a severe level of disability, and 5% a profound level of intellectual disability. The final Wave 1 sample was demographically and geographically representative of the NIDD.

Wave 2 data collection commenced in 2013, and 719 of the original 753 participants were contacted. 708 participants completed at least one element of Wave 2 data collection, representing a response rate of 94%. Of the 45 participants who did not participate in Wave 2, 34 were deceased, and 11 refused to take part. The data were not replenished with new participants for Wave 2, leading to an overall increase in the mean age of participants. The sample remained largely representative of the NIDD. The average age had risen to 56.6 years (SD=9.313, 95% CI=55.90, 57.29), males accounted for 44% of the participants and females 56% of participants, 22% had a mild ID, 43% had a moderate ID, 27% a severe or profound ID, whilst 8% were either unknown or not verified.

4.2.2   Ethics

For the IDS-TILDA study, ethical approval and consent was obtained at four different levels

1. The principal investigator (PI) and management team obtained ethical approval and consent for the study from the Faculty of Health Sciences Ethics Committee at Trinity College Dublin (Appendix A1).
2. The PI and management team obtained ethical approval from the Ethics

Committees for the 138 service providers who support the people who
would be invited to take part in the study.

3. The IDS-TILDA obtained consent from those randomly selected from the
    NIDD to take part in the study, or their representatives (Appendix B2).

4. The researcher used a system of process consent to reaffirm a participants'
    consent at the start, during, and at the end of each interview.

Four ethical principles guide the IDS-TILDA study; beneficence, non-maleficence and justice.
Autonomy encompasses the idea that all participants have the right to self-rule. Features within
the design of the study that help enshrine this value are self-consent, having the right to
withdraw, the inclusion of accessible materials, and no use of deception. Beneficence is creating
benefit for participants; this study does so by increasing knowledge on loneliness, aiming to
improve policies and practices which should, in turn, improve lives for participants. Non-
maleficence means no harm must be done to participants. In the design of the study, scales were
checked and adapted to remove any possible harm, and use of a CAPI (computer assisted
personal interview) prevented participants feeling overwhelmed by paperwork. During the
interview phase, researchers monitored participants for signs of distress, tiredness or boredom,
and utilised tactics to alleviate any distress, including finding support for the participant, offering
breaks during the interview, or breaking the interview into several smaller interviews. Finally, the
principle of Justice, which in research refers to treating all participants equally and justly: the
study designers ensured the simplification of questions, ensuring most participants could
understand them. Researcher assistants used show cards to aid communication and
understanding during the interview, thus maximising the voice of the participants.

4.2.3   Recruitment and Consent procedures

Participants were sent an invitation pack for Wave 1 (Appendix B), which was sent by the regional,
national disability database administrator to maintain the anonymity of those invited to take part.
The researcher liaised with the local database administrator to ensure the timely delivery of
information packs in the Midwest region.

Consent was a multi-layered arrangement which was dependent upon the individual's capacity to
consent. Each participant was encouraged to read and study the research materials provided,
either independently or with support. Each information pack contained both individual consent
forms and family agreement forms. If the individual was able to consent, then they completed
the consent form and returned it in a Stamped Addressed Envelope to the IDS-TILDA office.
Where an invitee felt they did not have the capacity to consent, or the keyworker/support worker
or family members believed they did not have the ability to consent then a family information

pack, which included a family agreement form, was forwarded to the family. Two hundred and eighty-five participants self-consented and four hundred and sixty-eight were deemed unable to self-consent, and a family agreement form was considered necessary.

The researcher received notification of people who had given their consent to take part in the study, contacted the person to confirm their agreement and to arrange the interview. Having arranged the interview the researcher sent out a pack containing details about the study, a card confirming the time and date of the interview and a pre-interview questionnaire. The researcher contacted the participant 24 hours before the interview to confirm the interview was taking place.

Before the interview started, participants and proxies completed a consent form. Throughout the interview, the researcher monitored both visual and auditory signals for signs of fatigue, distress and attention issues, and reaffirmed that consent was still in place. If the participant or proxy required a break, or if the researcher felt a break was required, then the interview would be temporarily suspended. If an interviewee could not complete the interview in a single visit, then upon return, written consent would again be obtained. The researcher closed the interview by asking participants if they would consent to take part in future waves of data collection and would consent to be contacted about more specific research. At this stage, one participant refused to give forward consent for future waves of data collection.

A list of consenting participants was supplied to the researcher before at the start of Wave Two of data collection. The researcher contacted these participants, reaffirmed their agreement to participate in Wave Two, and arranged an interview. The researcher sent a pack to participants containing information on the IDS-TILDA study, a card containing the data and time of the interview and a pre-interview questionnaire. Twenty-four hours before the interview the researcher contacted participants to confirm the interview. Participants and proxies reaffirmed consent for Wave Two and completed a new consent form before the interview commenced. Throughout the interview, the researcher checked that consent was still present. A participant's right to withdraw from the study was made known to the participant at the start of the interview, at the end of the interview, and if at any stage a participant appeared concerned with the process. The researcher closed the interview with the same method used in Wave One, by asking the participants if they agreed to contacted about Wave Three of data collection, and if they would consent to participate in individual, detailed research projects.

4.2.4   Field Training

All research assistants attended two-day training sessions for each wave of data collection. Each member of the field staff had extensive experience in working with and interviewing people with

an intellectual disability. An experienced researcher shadows all new researchers for at least one interview.

4.2.5   Data Collection

Data collection had three levels in waves one and two. First, a pre-interview questionnaire is sent by the researcher to participants for completion before the interview, and for collection at the interview. The pre-interview questionnaire contains questions about medical history which may require help from a third party. The researcher collects the second level of data, which is the main interview, via the use a computer aided personal interview (CAPI). The third phase of data collection includes additional, detailed research such as the carer's interview, the health roadshow or the end of life interview. For each project, a separate researcher arranged to meet specific participants to gather detailed information on specific topics. The health roadshow collected data on physical function, bone mass, weight and height. Each project was only carried out once and was attached to specific waves of data collection.

The researcher collected the main interview using a CAPI, which was reported as less intimidating than a large, paper-based survey (McCarron et al., 2011). The type of interview conducted was dependent upon the individual's ability to communicate and their level of intellectual disability. There are five methods of interview possible: direct with the participant, direct with the participant but with a small amount of assistance from a third party, direct with the participant but with a proxy answering most of the questions, and a proxy-only interview. To improve communication and understanding throughout the interview process, the researcher had show cards available.

4.2.6   Data Cleaning

Before starting the main interview, the researcher checked the Pre-Interview Questionnaire (PIQ) for completeness. Manual completion of the CES-D scale (Appendix C4) and the PAS-ADD depression scales was done during the interview process, and they were checked and entered into an SPSS data set later.   After completion of the interview, the researcher checked the PIQ in detail for anomalies and made any necessary corrections. The main interview was already in digital form, so did not require any immediate action from the researcher. Research assistants cross-checked the PIQ SPSS files and corrected any problems. During the checking process, any systematic errors were reported to the team manager, who in turn informed the researcher to prevent future mistakes. Researchers merged the interviews into a master file, and then cross-validated the master file. The researcher aided in cleaning sections of the main questionnaire and the CES-D scale at a later date.

4.3 Measures

This section describes all the variables and scales that utilised throughout the study.

4.3.1 The Loneliness and Social Connectedness Scale

The loneliness scale was embedded within the Social Connectedness section of the interview (see Table 4-1.). Completion of the loneliness scale required participants to have the ability to self-report feelings of loneliness.

Table 4-1: Loneliness scale questions

Section	Question	Wording	Response set
Social Connectedness	SC8	Do you ever feel lonely?	Yes/No
	SC9	How often do you feel lonely?	Most of the time/ Some of the time/ Hardly ever or Never
	SC10	Do you ever feel left out?	Yes/No
	SC11	How often do you feel left out?	Most of the time/ Some of the time/ Hardly ever or Never
	SC12	Do you find it difficult to make friends?	Yes/No
	SC13	How often do you feel you lack friendship	Most of the time/ Some of the time/ Hardly ever or Never
	SC14	Do you ever feel isolated?	Most of the time/ Some of the time/ Hardly ever or Never

The scale consists of seven questions (Appendix C2) and is constructed using the three item loneliness scale (M. E. Hughes, Waite, Hawkley, & Cacioppo, 2004) that was developed specifically for use in large scale interviews and a self-labelling loneliness item. Dividing each question into two parts made them simpler to understand for participants. The first part had a lead in of "Do you ever feel….." with a yes/no response. The second part of the question asked "how often do you feel….." with a three-point response set. The third item in the three item loneliness scale, "do you ever feel isolated", was asked without being deconstructed.

The Three-Item Loneliness Scale is based on the Revised UCLA Loneliness Scale (Russell, 1996), and has been shown to demonstrate a high correlation with the revised UCLA (0.82), meaning that direct comparisons with those that have used the Revised UCLA Loneliness Scale are possible. The response scale was reduced to three items to further simplify response options in the interview situation. The 3 item loneliness scale is widely reported, and it was incorporated into

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The Irish Longitudinal Study on Aging (TILDA), the Health and Retirement Study (HRS) and the English Longitudinal Study on Aging (ELSA). Use of the scale in other studies, means the results from the IDS-TILDA are directly comparable to these studies. The mean score on this scale was 3.86 (SD=1.23, 95% CI=3.73, 4.00). Fifty-seven percent of participants scored three, meaning they experienced no feelings of loneliness. The mean score in TILDA is 4.11 (SD=1.48) (Burholt and Scharf, 2013); in ELSA Wave Two it is 4.06, in the HRS 2002 it is 3.84 (SD=1.33) (Steptoe, Shankar, Demakakos, & Wardle, 2013), HRS2004 is 3.80 (SD=1.32), and HRS2006 is 4.29 (SD=1.53) (Luo, Hawkley, Waite, & Cacioppo, 2012). There are no significant differences in the scores between IDS-TILDA and HRS2002 scores (t=0.252, df=2416, p=0.801), and IDS-TILDA and HRS2004 scores (t=0.750, df=1990, p=0.453). There is a significant difference in the scores with TILDA (t=2.959, df=6928, p=0.003), ELSA (t=2.382, df=6815, p=0.017) and HRS2006 (t=4.701, df=1855, p<0.001).

The use of a self-labelling question was incorporated into the study to replace Russell's Self-Labelling subscale (Appendix C3), incorporated into the Revised UCLA Loneliness Scale (Russell, 1996). The subscale consists of four items and incorporates relatively complicated statements e.g. "People are around me but not with me" which may have proved difficult for individuals with an intellectual disability to understand.

Wave One contained three questions on loneliness, two from the three item loneliness scale, and the self-labelling loneliness item (Appendix C1). The construction of the three items into a unitary scale was unsatisfactory when subjected to testing for internal consistency, reporting a Cronbach's Alpha of only 0.665. The researcher decided to use only the self-labelling item in longitudinal analysis, to allow a consistent measure across the waves of data collection. The use of a self-labelling item is common in longitudinal research, and means the results are directly comparable with other longitudinal studies such as the Hillingdon Studies (Victor, 2014). When considering loneliness in a cross-sectional nature, loneliness is measured using the full four-item scale.

4.3.1.1   *Responding to the Loneliness Scale*

For people with an intellectual disability, there are potential problems in responding to subjective questions, in understanding questions about loneliness, and in reliably communicating answers. The concerns include acquiescence, difficulty responding to Likert-type scales, and response reliability (Gilmore and Cuskelly, 2014). McVilly et al. (2006) argued that people with an ID are capable of understanding the concepts around loneliness, and provided evidence of studies that have utilised standard scales to gain insight into loneliness in individuals with an ID. However, they adapted a scale originally developed for children to gain more insight into the lived experience of loneliness. Their participants were 52 adults aged 16-52 with limited to intermittent

support needs. All the participants were able to express themselves verbally, and none had physical or sensory impairments. They found that all participants were competent in answering the scale; in test-retest, the reliability measures demonstrated consistency. Cross-checking participants' scores with a proxy assessment of a person's loneliness revealed a consistency of response. Likewise, Balandin et al. (2006) analysed responses of people with cerebral palsy on the UCLA Loneliness scale and found the scale adequately represented loneliness as experienced by this group. These results suggest first that individuals with intellectual disabilities were capable of understanding the concept of loneliness. Secondly, they were capable of expressing their experiences of loneliness, thirdly, they were not answering in a fashion to suit the researcher, and finally, they were capable of answering consistently over time and therefore recording reliable loneliness scores.

4.3.1.2 *The Loneliness Sub-Sample*

Table 4-2 displays the demographic breakdown of participants who responded to the self-labelling loneliness item in Wave One, Wave Two, and both waves of data collection. Consistent with the main study findings, the mean age of participants in this subsample increased between the two waves of data collection from 54 years in Wave One to 56 years in Wave Two.(McCarron et al., 2014). The study included mostly participants with either a mild or moderate intellectual disability (85%), and relatively few participants lived in congregated settings (24%), compared to the main study (46.4%) (McCarron et al., 2011). Drawing participants from mild and moderate categories of ID was consistent with other studies investigating loneliness in people with an intellectual disability (R. J. Stancliffe, Wilson, Bigby, Balandin, & Craig, 2014).

All four items of the loneliness scale were answered completely by 282 participants in Wave Two. The mean score on the scale was 5.28 (Standard Deviation = 1.59, 95% CI=5.094, 5.477, skewness 1.43, kurtosis 1.93), and scores ranged between 4 and 12. The scale demonstrated satisfactory internal consistency (Cronbach's Alpha = 0.722).

To increase the sample size, and the statistical power of the scale, it was decided to impute data on a person-mean basis, if participants were missing one out of the four items. A total of thirty-five people were missing a single item. The most commonly missed item was "Do you ever feel isolated?" with nineteen participants failing to respond to this question. Seven participants did not answer the question "How often do you feel left out?" Moreover, five people failed to respond to the question "How often do you feel lonely?". Four people failed to respond to the question "How often do you feel you lack friendships?" Of the nineteen participants who failed to answer the question "Do you ever feel isolated?", eleven were unable to understand the question, four said they did not know, two gave an unclear response, one refused to answer, and

one was not present. Once the missing answers were imputed, the scale continued to demonstrate satisfactory internal consistency (Cronbach's Alpha = .715). With the 35 participants added there were now 317 participants available with a mean score 5.30 (SD = 1.58, 95% CI=5.125, 5.475, skewness = 1.34 kurtosis = 1.58).

Table 4-2: Demographic information of respondents to the self-reporting loneliness item

		Wave 1		Wave 2		Answered in Both Waves	
N		384		347		297	
Mean Age		53.99		56.27		53.59	Based on age in wave one
	SD	8.90		8.92		8.71	
	95% CI Lower	53.10		55.33		52.28	
	Upper	54.89				54.91	
Gender							
	Male	167	43.5%	150	43.2%	121	40.7%
	Female	217	56.5%	197	56.8%	176	59.3%
Level of ID							
	Mild	143	37.2%	122	35.2%	115	38.7%
	Moderate	183	47.7%	172	49.6%	140	47.1%
	Other	58	15.1%	53	15.2%	42	14.1%
Living Circumstances							
	Independently	63	16.4%	52	15.0%	47	15.8%
	With family	37	9.6%	33	9.5%	33	11.1%
	Community housing	179	46.6%	157	45.2%	140	47.1%
	Congregated Setting	85	22.1%	86	24.8%	60	20.2%
	Other	20	5.2%	19	5.5%	17	5.7%

To ensure that the four-item scale represented a single construct the items were subjected to principal component analysis (PCA) using SPSS version 23.0. Assessment of the suitability of the data for PCA revealed all correlation coefficients were greater than 0.3, and the Kaiser-Meyer-Oklin value was 0.734, exceeding the recommended value of 0.6 (Field, 2009). Additionally, Bartlett's test of Sphericity (Bartlett, 1954) reached statistical significance, giving additional support to the factorability of the data.

PCA revealed the presence of a single factor with an Eigenvalue exceeding 1, explaining 54% of the variance. An inspection of the scree plot revealed a clear break after this component. The parallel analysis showed only a single component with an Eigenvalue exceeding the corresponding criterion values for randomly generated data matrix of the same sample size, further supporting the presence of a single factor.
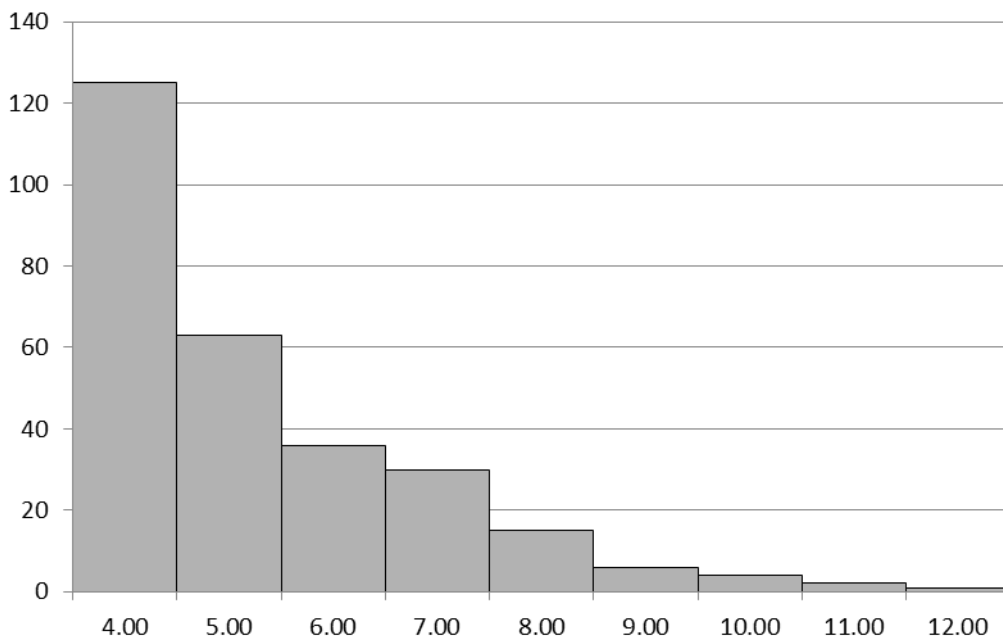
Figure 4-2:Histogram of loneliness scale scores

The demographic breakdown of those who participated in the loneliness scale is displayed in Table 4-3, below. The average age of 56.16 (SD=8.578) was not significantly different for those who did not complete (mean=56.95, SD=9.875). This subpopulation had a higher percentage of females (59.3%) than the main population (56%), but there was no significant difference in the gender balance (χ^2=2.671, p=0.102). There was an overrepresentation of those with mild and moderate disability in those who completed the loneliness scale compared to those who did not respond to the loneliness scale (χ^2=179.190 p<0.001). In keeping with the levels of ID, more people in this sample lived independently or with family than in the main sample (χ^2=115.105, p<0.001).

Table 4-3: Demographic breakdown of participants answering the complete loneliness scale in wave 2

		Wave 2 Statistic	Percent
Age		56.16	
	95% CI Lower	55.22	
	95% CI Upper	57.11	
Gender			
	Male	129	40.7
	Female	188	59.3
Level of ID			
	Mild	119	37.5
	Moderate	154	48.6
	Other	44	13.9
Living Circumstances			
	Family	50	15.8
	Independently	35	11.0
	Community House	144	45.4
	Residential	21	6.6
	Other	67	21.1

4.4   Independent Variables

Table 4-4 lists the variables used in each analysis. While some variables are used in multiple sets of analysis, such as age, social network and general pain, other variables, such as waking too early, cognitive ability and fear of falling, are used only once.

Table 4-4: Variables utilised in each analysis

Antecedents	Cognitive Characteristics	Temporal Trajectories	Consequences	Synthesis Model
Age	General Pain	Age	Vigorous Activity	Functional Limitations
Gender	Social Participation	Gender	Moderate Activity	Education
Education	Social Network	Marital Status	Mild Activity	Transport
Chronic Conditions	Depressive Symptoms	Social Participation	Smoking	Working in the Community
Foot Pain	Functional Limitations	Social Network	Body Mass Index	Emotional Health
General Pain	Level of Pain	General Pain	Self-Reported Diet	Level of Pain
Activities of Daily Living Scale	Transport	Chronic Conditions	Life Events	Service Stress
Instrumental Activities of Daily Living Scale		Functional Limitations	Relationship Stress	Wanting to do More Activities
Spouse		Falls	Social Stress	Confiding in Staff
Working in the Community		Fear of Falling	Service Stress	Depressive Symptoms
Church Attender		Activities with Family	Church Attender	Sleep Scale
Group Membership		Activities with Friends	Confiding in Family	Systolic Blood Pressure
Life Events		Social/Civic Inclusion	Confiding in Friend	
Relationship Stress		Personal Plan	Confiding in Staff	
Service Stress		Wanting to do More Activities	Confiding in Other	
Social Stress		Life Events	Systolic Blood Pressure	
Social Network			Trouble Falling Asleep	
Confide in Spouse			Interrupted Sleep	
Functional Limitations			Waking too Early	
Cognitive Ability			Daytime Sleeping	
Transport			Sleep Scale	
Living Arrangements			Functional Limitations	
Falls			Gender	
Emotional Health				
Civic Engagement				
Giving Help				
Friends outside the House				
Receiving Help				
Difficulty Doing Activities				
Wanting to do More Activities				
Social Participation				
Confiding in Staff				
Confide in Family				
Confide in Friend				
Confide in Other				

Education: The Pre-Interview Questionnaire captured the level of education received; For the question "Highest level of education completed?", participants were given a range of answers (Table 4-5). Education was binary coded between participants who said they had completed their junior certificate and recorded other or higher and those who had not. There was a significant correlation between loneliness and education (rho=-.123, p=0.041)

Table 4-5: Levels of education completed in the loneliness sub-population

Level	N	Percent
Some Primary	108	39.0
Primary or equivalent	81	29.0
Intermediate/junior/group certificate	6	2.2
Leaving Certificate	2	.7
Diploma/certificate	2	.7
Primary Degree	2	.7
Post Graduate	0	
Other	37	11.7
None	39	12.2
Total	277	

Chronic Conditions: A measure of chronic conditions was created following the methodology utilised by Burholt and Scharf (Burholt and Scharf, 2013). The measure uses seven general practitioners diagnosed chronic conditions: hypertension (including high blood pressure), diabetes, cancer, lung disease (including asthma), heart disease (including, angina, heart attack, congestive heart failure, heart murmur, abnormal heart rhythm and other heart problems), stroke (including mini-stroke), and arthritis. A chronic condition score was generated by scoring each condition present for each participant, a higher score meaning a person had more diagnosed conditions. Total scores ranged from zero to four (mean=0.653, SD=0.845, 95% CI=0.560, 0.746) with the majority of participants reporting no Chronic Conditions (rho=0.082, p=0.146).

Foot Pain: participants were asked, "Do you have any pain in your feet?" This question had a yes/no response option. Answers were binary coded to Yes=1 (n=65) and No=0 (n=247). There was a significant correlation between foot pain and increased scores on the loneliness scale (rho=0.161 p=0.004).

General Pain: The measure of general pain, "Are you often troubled with pain?" had a Yes/No response, and answers were binary coded Yes=1 (n=213) and No=0 (n=98). There was a significant correlation between general pain and loneliness (rho=0.214 p<0.001).

Level of Pain: was measured as "how bad is the pain, most of the time is it..."with the response options Mild, Moderate or Severe. Participants who had answered they had no pain in the general pain variable were scored as zero, those who reported mild pain were scored as one, those with moderate pain were scored as two, and severe pain scored as three. The mean score=0.545 (SD=0.910, 95% CI=0.438, 0.651) and the variable significantly correlated with loneliness (rho=0.216, p<0.001).

Activities of Daily Living Scale (ADL): is a measure of basic tasks required in everyday life including dressing, walking, getting around the home, bathing, oral hygiene, eating, getting in and out of bed, toileting and medication, scored on a four-point Likert-type scale. The scale used here was developed for use in the Health and Retirement Study (HRS) (Fonda & Herzog, 2004), based on the Barthel ADL Index (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). The scale has a good internal consistency reported and in seven reported studies had a Cronbach's Alpha between 0.85 and 0.87 (Fonda and Herzog, 2004). The Cronbach's Alpha for this study was 0.86.

 Scores for each item were totalled: the higher the score, the less able a person was to carry out ADL's. Scores ranged from nine to thirty-six (n=309, mean = 12.2, SD=4.73, 95% CI=11.746, 12.838). Table 4-6 below shows the scores are skewed (skewness = 2.60) towards the lower range of scores with nearly half of participants scoring either nine or ten on the scale. The distribution of scores was in keeping with that described for the HRS studies (Fonda and Herzog, 2004). The correlation with loneliness was non-significant (rho=.044, p=0.442)

Table 4-6: Quartiles of the scores on the ADL scale

Quartile	N	Score Range	Percent
1	95	9	30.7
2	57	10	18.4
3	57	11-12	18.4
4	100	13-36	32.5

Instrumental Activities of Daily Living (IADL) Scale: measures items that are not essential for functioning, and indicate if a person can function independently. The scale used was originally developed for use in the HRS study (Fonda and Herzog, 2004) and was drawn from Lawton and Brody's inventory (Lawton & Brody, 1970). The scale used excluded the items driving and using a microwave, consisting of five items: preparing a meal, shopping for groceries, making telephone

calls, managing money and doing household chores. All the elements were measured with a four-point Likert-type response option (No difficulty (1)/Some difficulty (2)/A lot of difficulty (3)/ Cannot do at all (4)). The scale was previously reported to demonstrate good internal consistency and seven reported studies report a Cronbach's Alpha between 0.69 and 0.85 (Fonda and Herzog, 2004). In this study, there was also good internal consistency with a Cronbach's Alpha of 0.83. The scores were totalled and the higher the score, the less able a person is to carry out IADL's. Three hundred and one participants completed the IADL scale. Scores ranged from five to twenty (mean = 11.83, SD = 4.19, 95% CI=11.313, 12.264). Table 4-7 below presents the range of scores in each quartile. The distribution of scores is in keeping with previous reports (Fonda and Herzog, 2004). The correlation with loneliness was not significant (rho=.034, p=0.518).

Table 4-7: IADL Scale scores presented in quartiles

Quartile	N	Score Range	Percent
1	80	5-8	26.6
2	86	9-12	28.5
3	73	12-15	24.3
4	62	16-20	20.6

Marital status/Spouse: Variable was selected to match Hawkley et al. (2008). The variable derived from the question "Do you have family?" – which had the response options Spouse/Partner, Mother, Father, Brother(s), Sister(s), Aunt/Uncle, Nieces, Nephews, Cousin, Not Applicable and other. Participants were then binary coded as either having Spouse/Partner or not having a Spouse/Partner. In Wave One, three hundred and seventy-eight single participants and six married participants responded to the self-report loneliness question. The correlation with reporting some level of loneliness was not significant (rho=-0.013, p=0.827). Six participants also reported being married in Wave Two, and the correlation with loneliness was non-significant (rho=-0.003, p=0.921).

Working in the community: The variable derived from the question "Which of these would you say describes your current situation?" Table 4-8 shows the response options and the number of participants in each category. A binary coded variable was set up with those who indicated they worked in the community coded as 1 and all others 0. The correlation with loneliness was not significant (rho=-0.088, p=0.119).

Table 4-8: Numbers in employment categories

Occupation	N	Percent
Working in the Community	24	7.6
In a Service	244	77.0
Not Working	33	10.4
Other	18	5.7
Multiple Occupations	3	0.9

Church Attender: Hawkley et al. (2008) included a measure of attending church at least twice a month in their analysis of antecedents. In this study participants were asked, "How often, if at all, do you do any of the following activities?" Attending church, or a place of worship, was one of the options. Those who indicated they attended twice a month or more were categorised as attending church (n=214). The correlation with loneliness was not significant (rho=0.059 p =0.297).

Group Membership: Came from the question: "Are you a member of any of these organisations, clubs or societies?" The response options were being a member of: a Political Party, Trade Union, or Environmental Groups, Tenants Groups, Resident Groups, Neighbourhood Watch, Church or Religious Groups, Charitable Associations (e.g. St Vincent De Paul's), Education, Arts or Music groups or Evening Classes, Retirement Clubs, Special Olympics Network, Arch Club, Advocacy Group, Other or Not Applicable. Group membership was binary coded as present (n=170) if participants indicated they were a member of any group. The correlation with loneliness was not significant (rho=0.009 p=0.875.).

Life Events: Life events were included in the antecedents analysis, matching the count of life events utilised by Hawkley et al. (2008). The life events scale used was an adapted version of the Hermans and Evenhuis (2012) life events scale for older people with intellectual disabilities. The scale here used nineteen of the twenty-eight items (Table 4-9).   Participants were asked if they had experienced any items on the list of life events in the previous 12 months. Participants who indicated the presence of a life event were then asked how stressful they found that life event. Stress was scored on a three-point scale; one, a lot, two, a little and three, none. In total 311 participants responded to the scale; one-hundred and twenty-three had experienced no life event

in the previous 12 months. Of the one-hundred and eighty-eight participants who had experienced a life event, the most common event was a change of staff (n=64) followed by moving within the participant's service organisation (n=40) and change of keyworker (n=39). Of those who experienced life events, more than half experienced only 1 or 2 events (n=135). The correlation between the number of life events experienced and loneliness was non-significant (r=0.110, p=0.052).

Table 4-9: Life Events Scale

Life Event	Yes	Stress Subscale
Change of staff in my home where I live or day service I attend.	64	Service Stress
New resident moved into my home	29	Social Stress
Change of my key worker	39	Service Stress
Change at or from work or day service	28	Service Stress
Death of a parent	29	Relationship Stress
Death of a sibling	15	Relationship Stress
Death of other relative	18	Relationship Stress
Death of a friend	31	Relationship Stress
Death of a pet	6	Relationship Stress
Major illness of a relative , caregiver or friend	17	Relationship Stress
Death of a significant other (other than a relative or friend)	7	Relationship Stress
Moving within service organisation	40	Service Stress
Moving from my family home to a service supported home (community group home/residential setting)	2	Relationship Stress
Change in frequency of visits from or to family/friend	7	Social Stress
Major illness or injury	19	Relationship Stress
Break up of a steady relationship/ Divorce	1	Relationship Stress
Experience of crime (mugged or burgled)	1	Social Stress
Problems with justice and/or authorities	0	Social Stress
Other event or change of routine which may have caused distress	30	Social Stress
No significant Life Event experienced	123	

Life Event Stress Exposure

In this study life events were divided into three categories: social stress, relationship stress and service stress (Table 4-10). People were scored zero for not having had a life event or not finding the life event stressful. They were scored one for finding the life event a little bit stressful and two, for finding the life event very stressful. Service stress scores ranged from one to four with fifty-eight out of the sixty-four who found changes within services stressful scoring either one or two. The correlation between service stress scores and loneliness was significant (rho=0.133, p=0.018). Scores for those who found relationship events stressful also ranged from one to four, with fourteen participants scoring four. The correlation with loneliness was not significant (rho=-0.025, p=0.661). Social Stress scores ranged from one to three with only one person scoring three; twenty-four scored two and fourteen scored one. The correlation between social stress scores and loneliness was not significant (rho=0.030, p=0.600).

Table 4-10: Stress Subscales Number of Scoring Participants

Score	Service Stress	Relationship Stress	Social Stress
1	29	32	14
2	29	42	24
3	5	2	1
4	1	14	

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Social Network: The social network variable was utilised in several chapters with the role of friends not included in the social network (analysed separately). The social network variable was created from questions measuring how often the participant reported having contact with, Spouse/Partner, Mother, Father, Brother, Sister, Aunt/ Uncle, Niece/ Nephew, Cousin or Others. Participants were scored one for each category with whom they had contact. The scores ranged from zero to eight (mean=3.060, SD=1.547, 95% CI=2.889, 3.231). The correlation with loneliness was not significant (rho=-0.022, p=0.702).

Confiding: Confiding is regularly associated with loneliness, and some measures of confiding were used in the analyses in multiple results chapters within the study. Participants were asked "Do you have someone with whom you can confide?" with Yes/No response options 96% of participants said they did have someone with whom they could confide. Participants who answered yes were next asked, "Who do you confide in?" Participants had the response options of; Spouse/Partner/Boyfriend/Girlfriend, Parent, Sibling, Grandparent, Aunt/Uncle, Cousin, Friend, Neighbour, Key Worker/Support Worker, Advocate, Other. Data was categorised in two ways. Participants were first divided between confiding in a spouse and not confiding in their spouse. Five participants indicated that they confided in their spouse or partner; the correlation with loneliness was non-significant (rho=-0.003, p=0.921).

The confide in spouse variable was used in the first series of the antecedents regressions. For the second series of regressions in the antecedents analysis, and the analysis of coping with loneliness, the confiding data was re-divided into Family, Friend, Key Worker/Advocate and Other (Table 4-11). For this analysis spouse was included in the family category. Each category was binary coded; one indicated the positive presence of the participant within the category. Participants were allowed to select multiple confidants; the majority (n=229) selected one group. Correlations with loneliness were confide in staff (rho=-0.091, p=0.105), confide in family

(rho=0.037,p=0.517), confide in friend (rho=0.110, p=0.050), confide in other (rho=0.066, p=0.239).

Table 4-11: Whom People Confide In

Confide In	N	Percent
Family	96	25.4
Friend	37	9.8
Key Worker/Advocate	210	55.6
Other	35	9.3

Functional Limitations: This variable was used in the antecedents chapter as an ID-specific demographic variable using the eleven-item HRS study scale (Fonda and Herzog, 2004) (Appendix C4). The scale was developed based on previous work undertaken by Rosow and Breslau (1966) and Nagi (1976). Participants were asked whether they had a problem doing each activity and were scored on a four-point Likert-type scale, scoring one for no difficulty, two for some difficulty, three for a lot of difficulty and four for cannot do at all. Scores had a potential range of eleven to forty-four, eleven being no difficulty doing activities and forty-four cannot do activities at all. The scale has a good internal consistency with the reported Cronbach's Alpha for seven reported studies ranging from 0.81 to 0.87. For this study, the Cronbach's Alpha measured 0.91. Scores ranged from eleven to forty-one, and the mean score was 18.000 (n=290, SD=7.364, 95% CI=17.149, 18.851). The distribution of scores was in line with that reported (Fonda and Herzog, 2004). Just over half of participants scored under fifteen (Table 4-13). Of those who failed to complete the scale, four failed to answer any questions, one person failed to answer three questions, and seven failed to answer two questions. The most commonly missed question was "please indicate what level of difficulty do you have climbing several flights of stairs," with eleven participants failing to answer this question, followed by "pulling or pushing large objects like a living room chair," which ten failed to answer. There is a significant correlation between the Loneliness Scale and the functional limitations scale (r=.118, p=0.046).

Table 4-12: Questions in the Functional Limitations Scale

Question
Please indicate the level of difficulty, if any, you have with walking 100 yards
with running or jogging about 1.5 kilometres
sitting for about two hours
getting up from a chair
climbing several flights of stairs
climbing one flight of stairs
stooping, kneeling or crouching.
reaching or extending your arms above shoulder level.
pulling or pushing large objects like a living room chair
lifting or carrying weights over 10 pounds
picking up a small coin from the table

Table 4-13: Functional Limitation scale scores categorised into quartiles

Percentile	N	Score range
25	92	11-13
50	62	14-15
75	68	16-20
100	68	21-41

Cognitive Ability was included as an ID-specific demographic variable in the antecedents chapter. Cognitive ability questions were measured using the Test for Severe Impairment (TSI) (M. Albert &

Cohen, 1992). The test comprises of twenty-four questions divided into eight domains (Table 4-14) and each correct answer scores one point. The test has been validated for use in individuals with an intellectual disability (Cosgrave et al., 1998). Three hundred and six participants completed the TSI scale (mean = 20.82, SD=3.31, 95% CI=20.45, 21.19).

Table 4-14: Questions in the TSI Scale (Albert and Cohen, 1992)

Cognitive Domain	Test	Response
Motor Performance	Show me how to use this comb	Correctly demonstrates combing
	Can you put the top on this pen	Correctly puts top on pen
	Write your name	Correctly writes name(first or last name)
Language Comprehension	Point to your ear	Correctly point to ear
	Close your eyes	Correctly closes eyes
	Pens-Red Green and Blue Show me the red pen	Correctly shows the red pen
	Pens-Red, Green & Blue Show me the Green pen	Correctly shows the green pen
Language Production	Point to nose What is this called?	Correctly names nose
	Hold up red pen. What colour pen is this	Correctly names red pen
	Hold up green pen. What colour pen is this	Correctly names green pen
	Hold up key. What is this called	Correctly names key
Memory Immediate	Hand Open. Which hand is the clip in?	Correctly points to clip
	Hand closed. Which hand is the clip in?	Correctly points to clip
	Move hands behind back, which hand is clip in?	Correctly points to clip
General Knowledge	How many ears do I have?	Correctly states 2
	Can you count to 10 starting at 1	Correctly counts to 10
	How many weeks are there in a year?	Correctly states 52
	Sing along with me	Correctly sings most of the words
Conceptualisation	Which Object is different	Selects correct Object
	Put this pen next to the pen that is the same colour	Correctly places the red pen
	Moving paperclip from one hand to the next.	Correctly points to the correct hand
	Which hand will I put it in next	Points to correct hand
Delayed Memory	Which of these objects have we not worked with already?	Correctly points to thread?
Motor Performance	Hand Shake	Shakes hand Correctly

Table 4-15 gives the quartile scores for the loneliness sub-population on the TSI Scale. Most of the scores are above twenty showing a high level of cognitive functioning within this sub-population. The correlation with loneliness was non-significant (rho=-0.022, p=0.706).

Table 4-15: Quartiles of TSI scores for the Loneliness sub-population

Quartile	N	Score Range	Percent
1	67	0-19	22.2
2	61	20-21	19.2
3	70	22	22.1
4	104	23-24	33.7

Transport: Transport was included as a socio-economic variable in the antecedents chapter. "Do you feel there is a lack of transport facilities in your area?" With a yes/no response option scored Yes =1 (n=59) and No = 0 (n=258). There was a significant correlation with loneliness (rho=0.174 p=0.002).

Transport difficulties: Transport difficulties were utilised in the cognitive characteristics chapter. Information was gained from the question "Does the lack of transport facilities in your area affect your lifestyle?" This question was asked of participants who indicated they had transport problems in the previous question. There were three response options to this question; A Great Deal, To Some Extent and Not at All. Participants who had answered No to the previous question were scored as zero. Participants who responded that transport caused no problems at all were scored one, where transport had some effect on lifestyle it was scored as two, and where transport created many lifestyle issues it was scored as three. The mean score was 0.338 (SD=0.729, 95% CI=0.252, 0.424). Transport difficulties correlated significantly with loneliness (rho=0.213, p<0.001).

Living Arrangements: Living arrangements were entered as a socio-economic variable in the antecedents analysis. Participants were asked, "Where do you live most of the time?" From the replies given to the residence question (Table 4-16), living arrangements were assigned to four groups: Living with Family (n=50), Living Independently (n=35), Living in a Community House (n=144) and Living in a Residential setting (n=88). The variable responses were dummy coded; the correlations with loneliness were living in a community house (rho=-0.041, p=0.467), living with family (rho=-0.095, p=0.092), living independently (rho=0.019, p=0.741) and living in a residential setting (rho=0.110, p=0.095).

Table 4-16: Living Arrangements for people with an ID

Living Arrangement	N	Percent
At home with both parents	11	3.5
At home with one parent	9	2.8
At home with sibling	27	8.5
At home with other relative	3	.9
Living independently	18	5.7
Living semi-independently	17	5.4
5-day community group home	10	3.2
7-day (48-week) community group home (goes home for holidays)	33	10.4
7-day (52-week) community group home	101	31.9
Community group home	14	4.4
5-day residential centre	1	.3
7-day (48-week) residential centre (goes home for holidays)	6	1.9
7-day (52-week) residential centre	58	18.3
Intensive placement (challenging behaviour)	1	.3
Other (please specify)	8	2.5
Total	317	100.0

Falls: Falls were included as a health variable in the analysis of antecedents. Participants were asked about any recent history of falling; "in the past month have you had any fall including a slip or trip, in which you lost your balance and landed on the floor or ground or lower level?" Responses were binary coded: in Wave One Yes=1 (n=56) and No=0 (n=326), the correlation with reporting some level of loneliness was significant (rho=0.148, p=0.011). In Wave Two Yes=1 (n=46) and No=0 (265), the correlation with loneliness was non-significant (rho = 0.063, p=0.268).

Emotional health: Participants were asked, "Would you say your emotional or mental health is...?" Responses were measured on a five-point Likert-type scale with the response options of excellent, very good, good, fair and poor. Over 80 percent of participants rated their emotional health positively (excellent, very good or good) only 17% reported fair or poor emotional health. The correlation with loneliness was non-significant (rho=0.108 p=0.059)

Civic Engagement: This variable was included as a social role in the analysis of antecedents of loneliness. Participants indicated in which activities of civic engagement they were involved.

Participants selected from items such as "Did you vote in the last general election?" "Do you own a mobile phone?" or "Do you use the internet and or email." Two hundred and ninety-three participants reported some level of social or civic engagement; six said they had no civic engagement, and eighteen failed to respond. The variable was binary coded to no civic engagement = 1 and civic engagement = 0. The correlation with loneliness was not significant (rho=0.103 p=0.076)

To analyse the trajectories of loneliness, specific activities were correlated with consistent loneliness, and two were included in subsequent analyses: "Did you holiday abroad in the previous 12 months?" and "Did you vote in the last election?" Voting in the last election was binary coded Yes=1 (n=198) and No=0 (n=186). The correlation between voting and reporting some level of loneliness in Wave One was not significant (rho=0.066, p=0.195). Holidaying abroad was coded Yes=1 (n=111) No=0 (n=273), and here the correlation with reporting some experience of loneliness in Wave One was significant (rho=-0.186, p=0.001).

Giving Help: Giving help was included in the antecedents analysis. Participants were asked, "In the last two years, did you give any kind of help to your friends, and neighbours (who did not pay you)?" Answers were binary coded to Yes = 1 (n=69) No= 0 (n=244). The correlation with loneliness was non-significant (rho = -0.067, p=0.237)

Friends Outside of House: Participants were asked "Are your friends…" and were given the options friends within your house, friends outside your house, keyworker or staff. Participants could select multiple options. The responses were binary coded to; has friends outside of house=1 (n=233), and, no friends outside of house=0 (n=83). The correlation with loneliness was not significant (rho=0.045, p=0.429)

Receiving Help: Participants were asked, "In the last two years, did your neighbours or friends give you any kind of help?" answers were binary coded Yes = 1 (n=62), and, No = 0 (n = 251). The correlation with loneliness was not significant (rho=-0.058, p=0.303).

Difficulty Doing Activities: Having difficulty doing activities was analysed as an ID-specific stress variable in the antecedents analysis. Participants were asked about any difficulties they may have doing activities, "Do you experience any difficulties participating in social activities outside your home?" Participants' answers were binary coded in Wave One Yes=1 (n=132), and, No=0 (n=244). The correlation with experiencing some level of loneliness was (rho=0.157, p=0.007) significant in wave one and in Wave Two; Yes = 1 (n=100), and No = 0 (n=217); (rho =0.122 p=0.030).

Wanting to do more Activities: Desire for activities was an ID-specific stress variable in the antecedents analysis. Participants were asked "Are there particular activities you would like to do

more?" Responses were binary coded as Yes=1 (n=127), and, No=0 (n=190). There was a significant correlation with loneliness (rho = 0.279, p<0.001).

Social Participation: Social participation was measured using a list of seventeen activities (Table 4-17). Timonen et al. (2010) categorised this social participation as active and social leisure. Participants indicated if they took part in the activity and how often they took part (Daily, scored one; once a week, scored two; twice a month, scored three; once a month, scored four; every few months, scored five; and once or twice a year scored six). Scores were reversed and totalled, so a high score meant more activities that are more regular. Scores ranged from zero to seventy (mean=31.202, SD=12.682, 95% CI=29.800, 32.603). The correlation with loneliness was not significant (rho=-0.005, p=0.926).

Table 4-17: Measurement of social participation

How often if at all do you do the following activities
Go to the cinema, theatre, an opera or a concert
Eat out
Go to an art gallery or museum
Go to church or other place of worship
Go to the pub for a drink
Go to a coffee shop for light refreshments
Go shopping
Participate in sports activities or events
Go to sports events
Go to the library
Go to social clubs e.g. play bingo/play cards
Go to the hairdressers
Perform in local arts groups and choirs
Spend time on hobbies or creative activities
Visit family and friends in their home
Talk to family or friends on the phone
Other Activities

Depressive symptoms: The Centre for Epidemiologic Studies Depression Scale (CES-D) used in both waves measures depressive symptoms experienced in the last week (Appendix C5). The scale was originally developed in 1977 by Laurie Radloff and revised in 2004 by William Eaton and colleagues, and is an available public domain resource (Ce(Research, 2015)(Research, 2015)(Research, 2015)(Research, 2015)(Research, 2015)(Research, 2015)(Research, 2015)(Research, 2015)(Research, 2015)(Research, 2015)(Research, 2015)nter for Innovative Public Health Research, 2015). It has been widely used in research into loneliness and was used by Burholt and Scharf (2013) as a measure of cognitive attribution style. The CES-D is a 20 item scale that measures all the major facets of depression, including depressive mood, feelings of guilt and worthlessness, psychomotor retardation, loss of appetite, and sleep disturbance. The scale is initially coded on a paper-based response sheet and then is later entered by researchers into a spreadsheet. Wave One data cleaning was previously described by McCarron et al. (2011). The

data collected in Wave Two was cleaned for coding errors by cross-checking the hard-coded responses with the electronic data set; 21 records were found to contain coding mistakes and were re-coded. One hundred and twenty-four complete records were reported for participants in the loneliness sub-population. To improve power, in keeping with previous research data was imputed on an item mean basis where two items or fewer were missing. Data from an additional seventeen participants was added. No pattern to the missing data was detected. Items 4, 8, 12 and 16 were reverse scored, and the scale was totalled with item 14 "During the past week have you felt lonely?" excluded. The scale had a Cronbach's Alpha of 0.808. Scores ranged from zero to forty-five (mean=7.695, SD=7.320, 95% CI=6.476, 8.914). The correlation with loneliness was significant (rho=0.345, p<0.001).

Age: was collected in Wave One and was categorised into three groups; 40-49, 50-64 and 65+. Of those who responded to the self-labelling loneliness item in Wave One 38.8% (n=149) were aged 40-49, 48.4% (n=186) were aged 50-64 and 12.8% (n=49) were aged 65+.   Of those who answered the loneliness scale in Wave Two 27.4% (n=87) were aged 40-49, 53.9% (n=171) were 50-64, and 18.6% were 65+. The correlation of the loneliness scale and age category was not significant (rho=-0.034, p=0.542)

Living Environment: participants were asked "Please identify if this location is in …?" with the response options Dublin or a city or town elsewhere in Ireland and a rural location. Utilising Wave One data participants who lived in either Dublin or a town or city elsewhere in Ireland were classified as urban (n=220), and those located in a rural location, rural (n=31).   The correlation with reporting some loneliness in Wave One and living environment was not significant (rho=0.011, p=0.869)

Gender: Participants indicated whether they were male, coded 0 or female, coded 1. Of participants who answered the self-labelling loneliness item in Wave One, one-hundred and sixty-seven were male and two-hundred and seventeen were female. The correlation with reporting some level of loneliness was significant (rho=0.205, p<0.001). In Wave Two one-hundred and twenty-nine females and one-hundred and eighty-eight males responded to the loneliness scale. The correlation of gender with the loneliness scale was not significant (rho=0.092, p=0.102).

Fear of falling: Participants were asked in Wave One: "Are you afraid of falling?" with a yes/no response option; one participant had missing data. The variable was used with Wave One data only and was binary coded Yes =1 (n=165) and No=0 (n=217). The correlation with experiencing some degree of loneliness was not significant (rho=0.108, p=0.065).

Who activities are done with: In Wave One participants were asked: "Who do you do your activities with?" They were able to select from a list including family, keyworker, friends with whom they live and friends from outside their house. Participants could select multiple options. Two binary-coded variables were created: doing activities with friends outside the home (n=146), and doing activities with family (n=217). The correlation with reporting some level of loneliness was not significant for doing activities with friends (rho=0.006, p=0.919), or for doing activities with family (rho=0.060, p=0.304).

Personal Plan: In Wave One respondents were asked: "Do you have a personal plan?" with a Yes/No response option. The variable was binary coded to Yes = 1 (292), No= 0 (n=66). The correlation with reporting some level of loneliness in Wave One was significant (rho=-0.137, p=0.024), meaning that not having a personal plan increased the chance of reporting some level of loneliness.

Independent Advocate: Participants were asked in Wave One: "Do you have an independent advocate?" with a Yes/No response option. The variable was binary coded to Yes=1 (n=99), and, No=0 (n=240). The correlation with some experience of loneliness in Wave One was not significant (rho=0.089, p=0.155).

Vigorous Activity: The vigorous activity question was drawn from "Do you do any vigorous activity?" binary coded Yes=1 (n=29), and, No=0 (n=288). The correlation with the loneliness scale was not significant (=-0.008, p=0.892)

Moderate Activity: Variable was derived from "Do you do moderate activity?" with a yes/no response, and was binary coded to Yes=1 (n=82), and, No=0 (n=235). The correlation with the loneliness scale score was not significant (rho=0.056, p=0.324).

Mild Activity: Variable was derived from "Do you do mild activity?" with a Yes/No response binary coded Yes=1 (187), and, No=0 (87). The correlation with the loneliness scale score was not significant (rho=-0.028, p=0.620).

Smoking: The smoking variable came from the question "Do you smoke at present?" With a Yes/No response. The variable was binary coded to Yes =1 (n=31), and, No=0 (n=282). The correlation with the loneliness scale score was not significant (rho=0.067, p=0.234).

Body Mass Index (BMI): This variable was measured using data collected in the health fair (n=248), based on either the height /weight methodology or using the ulna measurement. The ulna measurement strategy requires the use of a conversion table where ulna length is converted to height. The standard height/weight methodology can then be applied (Elia, 2003). BMI scores

ranged from 17.61 to 52.52 (mean=30.451, SD=5.601, 95% CI=29.750, 31.151). The correlation with loneliness was not significant (rho=0.074, p=0.246). Participants who had a BMI of less than 18.5 were classified as underweight (n=2), and those with a BMI between 18.5 and 25 were classified as normal (n=41). Participants with a BMI in the range of 25 to 30 were categorised as overweight (n=78), and participants with a BMI of 30 or higher were classified as obese (n=127).

BMI was binary coded with underweight, normal weight and overweight (n = 121) coded zero, and obese (n=127) coded one.

Self-reported diet: The variable was created from the question: "In general, how healthy is your overall diet?" with the response set of excellent, very good, good, fair or poor binary coded as excellent and very good (n=194) coded as one, and good, fair or poor (n=118) coded as zero. The correlation with the loneliness scale was not significant (rho=0.011, p=0.853).

Systolic Blood Pressure (SBP): Blood pressure was measured in the health fair section of data collection using a Digital Automated Oscillometric Blood Pressure Monitor (Omron 10). Readings were recorded in millimetres of mercury (mmHg). Four readings were taken; two with participants standing and two with participants sitting. Previous research has found that the effects of loneliness on SBP are more pronounced when the person has been slightly stressed (Ong et al., 2012), therefore the second standing reading was used (n=224). The mean reading was 122.75mmHg (SD=19.226, 95% CI=120.21, 125.28); scores ranged from 79mmHg to 180mmHg. The correlation with the loneliness scale score was significant (rho=0.178, p=0.008). Participants were binary coded into two categories, those with a score over 120mmHg were coded as High Blood Pressure (n=107), coded as one, and those without high blood pressure (n=117), coded as zero.

Trouble falling asleep was measured using the question "How often do you have trouble falling asleep at night?" with the response options of Most of the time, Sometimes, Rarely or Never. Participants were scored 1 for Most of the time, 2 for Sometimes, 3 for rarely and 4 for Never. Three hundred and six participants completed this question (mean=3.42, SD=0.869, 95% CI=3.32, 3.51). The correlation with the loneliness score was significant (rho=-0.137, p=0.015).

Interrupted sleep was measured using the question "Is your sleep interrupted during the night by periods of wakefulness?" with the response options and scoring of Most of the time (1), Sometimes (2), Rarely (3) and Never (4). Mean scores were lower for this question (n=312, mean=3.07 and SD=0.978, 95% CI=2.96, 3.18). The correlation with the loneliness scale score was significant (rho=-0.116, p=0.041).

Waking too early was measured using the question "How often do you have trouble with waking up too early and not being able to fall asleep again?" Responses and scoring were the same as for the other sleep variables. Mean score was 3.46 (n=308, SD=0.826, 95% CI=3.37, 3.56) and the correlation with the loneliness score was significant (rho=0.126, p=0.027).

Daytime sleeping was measured using the question "How likely are you to fall asleep or doze during the day?" with the same response options as above. Mean score was 1.95 (n=310, SD=1.022 95% CI=1.84, 2.07). The correlation with loneliness was not significant (rho=0.077, p=0.174).

Sleep Scale: Trouble falling asleep, interrupted sleep and waking too early were combined into a sleep scale variable. Scores ranged from 3 to 12 (n=308, mean=9.961, SD=2.094, 95% CI=9.726, 10.196). The correlation with the loneliness scale was significant (rho=-0.146, p=0.010).

4.5   Analysis

Data analysis was undertaken using SPSS v23.0 and AMOS v23.0. A detailed description of the analysis completed is included in each relevant chapter.

4.5.1   The Antecedents of Loneliness

Perlman and Peplau (1998) define two classes of antecedent variables: predisposing variables and precipitating variables. Variables that predispose a person to loneliness are variables such as personal characteristics and cultural values and norms. Precipitating variables are the events that cause loneliness and can be either chronic or acute. The role of predisposing variables is to influence which variables will precipitate loneliness. Hawkley et al. (2008) devised a method of producing a list of variables that moved from those more likely to be predisposers, to variables that are more liable to be precipitators. To create this list Hawkley et al. (2008) divided variables into seven theoretical blocks: demographic, socio-economic, health, social roles, stress exposure, social network, and network quality. Seven levels of regression analyses were run, with each level having two regressions. One block of variables was included at each level of analysis starting with demographic variables. The first regression at that level was completed with all variables in that block, plus any variables that were significant from a preceding block. Any variables that achieved a p-value less than 0.1 in the analysis were retained for a second regression. The second regression included only variables that were significant at this level of analysis, or were significant at the previous level. Variables that were significant at this point were retained and added to the next block of variables. Any variable that achieves a p-value below 0.1 is deemed to be an antecedent of loneliness. Finally, for each series of variables, a regression was run using all the

variables from all the blocks in that set. The first group of variables were ones that closely match those used by Hawkley et al. (2008), and the second group were variables that were suggested by the literature as being specific to people with an ID. This chapter creates a list of variables that indicate predisposing variables, precipitating variables, and variables that indicate a mismatch between desired and achieved social relations.

4.5.2   The Cognitive Characteristics of Loneliness

According to the CDA, cognitive attribution is the arbiter between the mismatch between desired and achieved social relations and loneliness. Burholt and Scharf (2013) argued that depressive symptoms as measured by the CES-D scale are a reliable proxy for cognitive attributions. Burholt and Scharf (2013) demonstrated that depressive symptoms moderate the pathway between health and loneliness, mediated by social network and social participation. The analysis was conducted using conditional process analysis developed by Andrew Hayes (2013). Conditional process analysis is a macro for use in SPSS and other statistical analysis programmes; it uses regression techniques to simplify the creation and interpretation of mediation and moderation analysis. This study followed the method of Burholt and Scharf (2013), creating a model that analyses the moderating effect of depressive symptoms on a path between health and loneliness, mediated by social participation and social network. The analysis then adapted the methodology to ID specific models. This analysis demonstrated how the paths to the experience of loneliness were conditional upon the level of depressive symptoms, and thus upon attribution.

4.5.3   The Temporal Characteristics of Loneliness

Weiss (1973) explained that the experience of loneliness was not stable, and feelings of loneliness could subside over time. The experience of loneliness is considered through the temporal trajectories of loneliness following Victor et al. (2008). Victor et al. (2008), proposed that people could be consistently lonely, they could move from being lonely to not being lonely, or they could move from being not lonely to being lonely. The additional classification of never being lonely was created to track those participants who said they had no feelings of loneliness in both waves of data collection. The analysis used longitudinal data to investigate the four loneliness trajectories, and estimated which variables predicted each trajectory using binary logistic regression.

4.5.4   The Consequences of Loneliness

How people react and cope with loneliness is the final element of the CDA. To understand the effect of loneliness on health Hawkley and Cacioppo (2007) argued that modelling five pre-disease pathways was the best way to comprehend the malign influence of loneliness. This analysis utilised three statistical techniques to examine the relationship between loneliness and variables

in each of the pre-disease pathways. Proportions were analysed with chi-square to understand if lonely participants were more likely to experience a specific effect. Analysis of covariance investigated if the mean loneliness scores of participants reporting an effect was greater than those who did not experience an effect. Binary logistic regression was used to see if loneliness was a significant predictor of each variable in the pre-disease pathways.

4.5.5   Synthesised Model

This study drew together the results of the antecedents analysis, the cognitive characteristics research, the reactions and coping analysis, and created a model of loneliness in older people with an ID based on the Cognitive Discrepancy Approach. An a priori model was created, based on the three models produced that were the best fit for the data. The models created allowed an understanding of the effect of depressive attributions on the models, and an understanding of which variables are specific to participants with greater support needs. AMOS v 23 was used to conduct this analysis. AMOS v23 uses maximum likelihood method for estimating coefficients.

4.5.6   Regression Analysis

Regression analysis was utilised throughout the study, in the analysis of the antecedents of loneliness, multiple linear regressions are utilised to examine the effects of variables in predicting a participant's loneliness score. To understand the effect of attribution style on loneliness, Conditional Process Analysis is used to investigate the moderating role of depressive thinking style on loneliness. Conditional Process Analysis is a tool developed to simplify the use of statistical procedures in answering complex questions such as "in what pathway" and "under what circumstances" in the social sciences (Hayes, 2013). To understand which variables predicted the temporal trajectories of loneliness, binary logistic regression was utilised to examine each of the four trajectories. Binary logistic regression was again utilised in investigating whether loneliness is predictive of the health variables in the pre-disease pathways. Finally, a structural equation modelling analysis which utilises regression analysis to create a holistic understanding of loneliness for this population, from predisposing factors through to the consequences of loneliness, was used.

While there are many strong reasons for utilising regression analysis, the primary reason for its use in this research is to recreate the analysis employed in other populations. Using established techniques such as regression analysis means the results are comparable with those from different populations, and they are easier for others to interpret (Hayes, 2013). Regression techniques rely on an onerous list of assumptions to ensure the correct inferences are drawn.

The assumptions to be taken into account when using regression are sample size, multicollinearity, singularity, outliers, the normality of residuals, linearity, homoscedasticity and independence of residuals (Pallant, 2007). Hayes (2013) argues that violating assumptions is not a disaster for regression analysis, and as long as the researcher is aware of the violation, then it is better to use a well-understood technique than a rarely used or understood technique. Where there is a doubt that the above assumptions are going to be met, the use of bootstrap confidence intervals validates the assumptions and prevents misleading inferences from being drawn (Carpenter & Bithell, 2000). In this research, scores in the Loneliness Scale had a positive skew that could not be satisfactorily corrected with statistical techniques, such as logarithmic transformation. Therefore, it was decided to use the original scale scores and create bootstrap confidence intervals to validate the findings.

Bootstrapping is a resampling method where the original sample is treated as a miniature of the population, and it respects the irregularity of the sampling distribution, creating more accurate confidence intervals than those generated using normal theory (Hayes, 2013). The number of bootstraps necessary is not an exact science, and recommendations differ on the number of samples that need to be generated suggestions range from 1000 samples (Carpenter and Bithell, 2000) to 5000 samples (Hayes, 2013).

While bootstrapping works fine with small samples, the power of the data to produce meaningful results and detect effects in regression is dependent on the number of participants available (Field, 2009). To obtain small effect sizes requires 400 participants with just one predictor, and to report medium effect sizes for 20 predictor variables a sample of 200 participants is needed, which is in keeping with the available data set (Field, 2009).

4.5.7   Analysis Chapters

The analysis of loneliness is divided into five papers each containing specific details about the variables used, and the analysis conducted. The analysis covers the antecedents of loneliness, the cognitive characteristics of loneliness, the temporal characteristics of loneliness, the consequences of loneliness, and a synthesised model of loneliness (see Table 4-18). Analysing the complete experience in this manner enabled the testing of the applicability of Perlman and Peplua's (1998) Cognitive Discrepancy Approach.

Table 4-18: Chapters detailing Analysis

Description	Chapter
Antecedents	Chapter 5
Cognition	Chapter 6
Experience	Chapter 7
Consequences	Chapter 8
Synthesised Model	Chapter 9

This study is the first to investigate loneliness in older people with an ID in such great detail. The study of such a large cohort, from such a protected group, allows the use of statistical techniques only usually employed by those studying loneliness in wide-ranging surveys in the general population. The inclusion of the three item loneliness scale (Hughes et al., 2004) and a self-labelling loneliness question, make the results of the analysis carried out directly comparable with those of studies conducted in the general population. The study uses well-recognised variables and well-tested scales, making the results easier for others to understand and interpret. Likewise, the adoption of modelling methods used in the wider population means the results are comparable to other studies and easier for others to follow. This study does deviate from the other work in that it synthesises the results into a single model through SEM, and it is the first research to utilise this methodology. The organisation of the results into five papers gives a focus and clarity to the results of each section of the CDA. The next section starts with the analysis of the antecedents of loneliness.

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Section 2

5 The Antecedents of Loneliness

5.1 Introduction

The antecedents of loneliness are all events that occur before the mismatch between desired and achieved social relations (Perlman and Peplau, 1998). The antecedents encapsulate the area of the Cognitive Discrepancy Approach (CDA) from predisposing elements through to the mismatch between desired and achieved levels of social relations (Figure 5.1). This research ascertained the antecedents of loneliness in this population of older people with an Intellectual Disability (ID). The method used to determine the antecedents reproduced the work of Hawkley et al. (2008), where potential predictor variables were sorted into logical blocks (Table 5.1 below) that were sequenced from those distal to the person to those most proximal. Each block was subject to linear regression; significant predictor variables were retained and added to the next block until they lose the predictive ability. Hawkley et al. (2008) found that distal variables influence the role of the proximal variables, i.e. distal socioeconomic variables, such as education, influence proximal social variables such as network satisfaction through relationship taxing variables such as social stress.

Figure 5-1: Elements of the CDA adapted from "Loneliness" By D. Perlman & L.A. Peplau *Encyclopedia of mental health, 2*, p. 572 copyright 1998 by **Taylor and Francis Group LLC Books. Reprinted with Permission under licence number 4270990436999.** (Peplau and Perlman, 1979) investigated in this Antecedents research

This research first modelled variables used by Hawkley et al. (2008), and then tailored the variable list to those that the literature suggests as more likely antecedents of loneliness in this population (Table 5-1).

This research answered the question "what are the antecedents of loneliness for older people with an ID?"

Table 5-1: Comparison of Variables used in the Development of the Antecedents of Loneliness

Hawkley et al. (2008) variable	Matching Variable used	ID Specific Additional Variable
Demographic Measures		
Age	Age	Functional Limitations
Gender	Gender	Cognitive Ability
Race		
SocioEconomic Measures		
Education to High School Diploma	Education to Junior Certificate	Transport Availability
Income		Residence
Household Income		
Health Measures		
Chronic Conditions	Chronic Conditions	Falls
Symptoms (e.g. Pain and Headaches)	Foot Pain and General Pain	Self-reported Emotional Health
Activity of Daily Living Restrictions (ADL)	ADL & Instrumental Activities of Daily Living (IADL)	
Social Roles		
Spouse/Partner	Spouse/Partner	Civic Engagement
Work	Working in the Community	Giving Help
Regular Church Attender	Churchgoer	Receiving Help
Group Membership	Group Membership	Socialising with Friends
Stress Exposure		
Life Event Count	Life Event Count	Difficulty Doing Activities
General Stress	Service Stress	Wanting To Do More Activities
Money and Financial Stress	Relationship Stress	
Employment Stress	Social Stress	
Love and Marriage Stress		
Family and Children Stress		
Social Life and Recreation Stress		
Health Stress		
Residence Stress		
Social Network		
Network Size	Social Network	Social Participation
Frequency of Contact		
Network Quality		
Spousal Confidant	Spousal Confidant	Confide in Staff
Network Satisfaction		Confide in Family
		Confide in Friend
		Confide in Other

5.2 Methods

5.2.1 Participants

A full description of participants can be found in the Methodology chapter, section *4.2 Participants*, page 51.

This study utilised participants from wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) dataset. The sample was a randomly selected sample of people aged 40 or over from the National ID Database (NIDD). Wave One of the IDS-TILDA recruited 753 participants in 2010. Wave Two data collection commenced in 2013, and 708 of the original 753 participants responded.   The sample is largely representative of the NIDD. The average age is 56.6 years; males accounted for 44% of the participants and females 56%, 22% had a mild ID, 43% had a moderate ID, 27% had a diagnosis of severe or profound ID, and 8% had diagnoses that were either unknown or not verified.

5.2.2 Measures

All the variables described below were previously fully described in the Methodology Chapter, section *4.3 Measures*, page 56. All variables were taken from wave 2 of the IDS-TILDA study

Loneliness and Social Connectedness: was measured using the seven question loneliness scale which includes a self-labelling item and the Three-Item Loneliness Scale (Hughes et al., 2004) (Appendix C2).

Independent Variables

There were two categories of independent variables, those that approximated the variables used by Hawkley et al. (2008) and those the literature suggests would be antecedent of loneliness in older people with an ID.

5.2.2.1 *Series 1, Hawkley et al. (2008) led variables*

Demographic Variables were *age* and *gender*. There was one Structural/Socio-economic variable which was *Education*. Education was binary coded between participants who said they had completed their junior certificate and those who had not. The Health variables were; *Chronic Conditions*, measured following the methodology utilised by (Burholt and Scharf, 2013); *Foot pain*, binary coded to Yes=1 and No=0; *General pain*, similarly binary coded; The *Activities of daily living scale* (ADL), consisting of nine questions,   such as "do you have difficulty with dressing?" which measure a person's ability to carry out basic daily activities (Fonda and Herzog, 2004);

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Instrumental Activities of Daily Living (IADL) scale which analyses a person's ability toward independent living (Fonda and Herzog, 2004). The Social Role grouping consisted of four variables, all binary coded to indicate the presence of a feature in a person's life, *Spouse, Working in the community, Church Attender* and *Group membership*. The Stress Exposure block included a measure as to whether a person had experienced any significant *life events* in the previous twelve months. Any life event experienced was rated for the level of stress caused and categorised into *relationship stress, service stress* and *social stress*. The Social Network block was analysed with a *Social Network* variable that measured the size and frequency of social contact with family and friends. The matching Network Quality variable was *Confide in spouse* where married participants indicated if they confided in their spouse.

5.2.2.2   *Series 2, ID Specific Variables*

The ID specific variables were divided into conceptual blocks replicating the structure of Hawkley et al. (2008). The Demographic Variables conceptual block consisted of *Functional Limitations* (Fonda and Herzog, 2004), measuring a participant's physical limitations and *Cognitive Ability* was used to indicate the level of intellectual ability, measured using the Test for Severe Impairment (Albert and Cohen, 1992). The Socio-Economic Variables consisted of *Transport*, which indicated transport difficulties and *Living Arrangements*, which indicated a participant's primary residence. The Health variables block consisted of *Falls*, which indicated whether participants had fallen in the last month, and a self-rated measure of *Emotional health*. The Social Role variables were; *Civic Engagement* where participants indicated if they undertook any civic activities. *Giving Help* and *Receiving Help* where participants indicated if they gave or received help from friends and neighbours and *having friends outside the house*. Stress exposure was considered by asking people if they had any *difficulty doing activities* outside their homes and asking if they *want to do more activities*. Social Network on this occasion was measured by rates of *social participation*. Finally Network Quality included who people confided in and was divided into *Confide in Family, Confide in Friend, Confide in staff* and *Confide in Other*.

5.3   Analysis

All analysis was conducted using IBM SPSS v23.0.

Two series of logistic regressions were carried out, replicating the methodology of Hawkley et al. (2008). The first set contained variables that closely matched those used by Hawkley et al. (2008)

(Appendix D1). The second round of regressions used variables identified as being more likely to be an antecedent of loneliness in people with ID, or a variable that had achieved a p-value of 0.1 in the first series. Variables were clustered into the blocks of Demographic Variables, Socio-Economic Variables, Health Variables, Social Roles, Stress Exposure Social Network, and Network Quality. Linear regressions were run with variables entered one block at a time. Variables achieving a p-value of 0.1 or above were retained for the next regression. Variables that were significant and those that had proved significant at the previous level were entered into a secondary regression, and variables that achieved a p-value above 0.1 in the secondary regression were retained and added to the variables of the next block. Finally, for each series, a regression was created with all the variables utilised. Bootstrap Confidence Intervals were set at a level of 5,000 cases Bias Corrected and Accelerated.

5.4   Results

5.4.1   Series 1, Hawkley et al. (2008) led variables

5.4.1.1   *Correlations*

Correlations between variables were checked for collinearity; none were of an order that would cause concern (Table 5-2). The strongest correlations were between life events and the related stress levels for each life event. Service stress had the strongest correlation (rho=0.509, p<0.01), followed by relationship stress (rho=0.449, p<0.01), and social stress (rho=0.356, p<0.01). The association between stress levels and life events are unsurprising and were expected, considering the construction of both sets of measures. There were also significant correlations between service stress and social stress (rho=0.211, p<0.01) and between service stress and relationship stress (rho=0.188, p<0.01). Relationship Stress was also significantly but negatively correlated with group membership (rho=-0.146, p<0.05). Social stress was additionally associated with being married (rho=0.147, p<0.05). Participants who scored higher on the ADL scale were also more likely to record higher scores on the IADL scale (rho=0.495, p<0.01), and ADL score was negatively correlated with working (rho=-0.304, p<0.05), meaning those with a high ADL score were less likely to be working. Both ADL (rho=0.166, p<0.01) and IADL (rho=0.123, p<0.05) scores were significantly associated with general pain. IADL score was also negatively correlated with both group membership (rho=-0.146, p<0.05) and social network (rho=-0.125, p<0.05).

General pain had its strongest association with foot pain (rho=0.438, p<0.01), but was also positively correlated with age (rho=0.166, p<0.01) and chronic conditions (rho=0.133, p<0.05). Chronic conditions were positively associated with age (rho=0.280, p<0.01) and with gender (rho=-0.170, p<0.01). Chronic conditions were negatively related to being a church attender

(rho=-0.142, p<0.05). Having a spousal confidant was significantly correlated with being married (rho=0.438, p<0.01) and positively associated with the likelihood of group membership (rho=0.130, p<0.05). Finally, Social Network was related to Group Membership (rho=.234, p<0.01), and with having experienced more stressful relationship based life events (rho=.138, p<0.05).

Table 5-2: Non-Parametric Correlations of Variables in the Hawkley et al. (2008) group of filtrations

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Age																	
2. Gender	0.094																
3. Education to Junior Cert	-0.144*	0.076															
4. Chronic Conditions	0.280**	0.170**	0.037														
5. Foot Pain	0.100	0.079	-0.062	-0.001													
6. General Pain	0.166**	0.011	-0.114	0.133*	0.438**												
7. ADL Score	0.018	0.063	-0.046	-0.022	0.062	0.151*											
8. IADL Score	0.091	-0.121	-0.112	-0.008	-0.013	0.123*	0.495**										
9. Spouse	-0.035	0.033	-0.060	0.045	0.011	-0.090	-0.070	0.037									
10. Working in Community	-0.072	0.008	-0.030	0.032	-0.025	-0.062	-0.158*	-0.304**	0.074								
11. Church Attender	-0.062	0.024	-0.022	-0.142*	0.088	0.070	-0.018	0.015	-0.053	-0.053							
12. Group Membership	-0.120	0.092	0.006	0.032	-0.022	-0.037	-0.115	-0.146*	0.116	0.032	0.010						
13. Life Events	-0.004	-0.033	-0.118	-0.064	0.091	0.116	0.008	0.063	0.052	-0.054	-0.020	0.095					
14. Relationship Stress	-0.025	0.045	-0.051	-0.005	0.047	0.067	0.050	-0.069	-0.007	-0.041	-0.079	0.158*	0.449**				
15. Social Stress	-0.056	-0.040	-0.115	-0.060	-0.028	-0.059	-0.005	0.014	0.147*	0.008	-0.000	0.076	0.356**	0.140*			
16. Service Stress	0.085	0.052	-0.048	-0.060	0.111	0.074	0.038	0.060	0.029	-0.014	-0.022	0.043	0.509**	0.188**	0.211**		
17. Social Network	-0.145*	0.080	0.084	-0.030	-0.082	-0.019	-0.044	-0.125*	0.015	-0.032	-0.003	0.234**	0.092	0.138*	0.103	-0.044	
18. Confide in Spouse	-0.102	-0.007	-0.063	-0.001	-0.010	0.023	0.042	-0.043	0.438**	0.058	-0.060	0.130*	-0.020	-0.087	0.034	0.011	-0.035

*p<.05, **p<.01

The results of the regressions can be found in Appendix D2. Each block of analysis has two regressions (a & b). The a regression includes all variables in that block plus variables that had a p-value less than 0.1 in the previous regression. The b regression includes all variables that had a p-value of less than 0.1 in the a regression, plus any variable that in the previous block had a p-value less than 0.1. The inclusion of variables in the b regression that were carried forward from a previous block, but failed to reach the cut-off of 0.1 in the a regression, tests whether the variable lost predictive power to the variables that met the criteria in the a regression, or to those that failed to meet the criteria. There is no 2b regression as there was only one variable in 2a and there are no 6b and 7b regressions as they would have been repeats of 5b.

Demographics

The demographics block contained the age and gender variables. Neither age (B=0.04, SE=0.10, p=n.s., 95% CI=-0.024, 0.017) nor gender (B=0.284, SE=0.178, p=n.s., 95% CI =-0.072, 0.639) were significantly predictive of loneliness. Combined, they were responsible for 0.8% (r^2=0.008) of the loneliness variance. Neither variable was retained for further analysis.

Socio-Economic

Education to junior certificate level (B=0.491, SE=0.216, p<0.05., 95% CI =-0.894, -0.057) was the only variable included in this block. Having received an education to junior certificate level was protective against loneliness and was significantly predictive of loneliness variance. Having an education to junior certificate level accounted for 1.4% (r^2=0.014) of the loneliness variance and was retained for further analysis.

Health

The variables included in health block were the retained education to junior certificate level variable, plus the health variables, chronic conditions, foot pain, general pain, ADL and IADL scale scores. Only general pain (B=0.651, SE=0.226, p<0.01, 95% CI =0.200, 1.102) was significantly predictive of loneliness. When the follow-up regression was run containing the education to junior certificate variable and the general pain variable, the education to junior certificate level variable (B=-0.389, SE=0.214, p=n.s., 95% CI =-.798, 0.048) failed to reach significance and was excluded from further analysis. The health variables combined explained 7.3% (r^2=0.73) of the loneliness variance which reduced to 6.1% (r^2=0.061) in the b regression.

Social Roles

Social Role variables were having a spouse, working in the community, being a church attender and group membership, while retained from the previous regression was general pain. General pain (B=0.672, SE=0.205, p<0.01, 95% CI =0.287, 1.064) was significantly predictive of loneliness while working in the community (B=-0.470, SE=0.258, p<0.1, 95% CI =0.975, =.068) reached a p-value below 0.1, allowing its retention for further analysis. Working in the community reduced the chance of experiencing loneliness. The variables explained 5.7% (r²=0.057) of the loneliness variance. In regression 4b, general pain and working in the community accounted for 4.6% (r²=0.046) of the loneliness variance.

Stress Exposure

The stress exposure block of variables included the retained variables, general pain and working in the community plus life events, relationship stress, social stress and service stress. General pain (B=0.718, SE=0.199, p<0.01, 95% CI =0.333, 1.101) and service stress (B=0.347, SE=0.149, p<0.05, 95% CI =0.054, 0.653) were significant predictors of loneliness, and working in the community (B=-0.434, SE=0.256, p<0.1, 95% CI =-0.911, 0.094) achieved the p-value lower than 0.1. The variables explained 7.9% (r²=0.079) of the variance of loneliness. The retained variables explained 6.6% (r²=0.066) of the loneliness variance in model 5b.

Social Network

The variables included were the retained variables of general pain, working in the community and service stress, with the social network variable added. The three retained variables achieved the required p-values and accounted for 6.7% (r²=0.067) of the loneliness variance.

Network Quality

Network quality included the three retained variables as above, with the addition of the variable spousal confidant. The three retained variables maintained their respective levels of p while spousal confidant failed to achieve the required level. The four variables accounted for 6.6% (r²=0.066) of the loneliness variance. No b regression of network quality was necessary.

Full Regression

In the full regression, general pain (B=0.775, SE=0.226, p<0.01, 95% CI =0.328, 1.283) was significantly predictive of loneliness, and working in the community (B=-0.540, SE=0.324, p<0.1, 95% CI =-1.174, 0.075) and service stress (B=0.348, SE=0.190, p<0.1, 95% CI =-0.024, 0.722) both achieved p values of below 0.1. The total variance explained was 12.5% (r²=0.125).

Table 5-3: Non-Parametric Correlation of variables in the ID specific group of regressions

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
1. Functional Limitations																							
2. Cognitive Ability	-0.258**																						
3. Transport	-0.050	-0.010																					
4. Live in Community House	0.001	-0.166**	-0.160**																				
5. Live with Family	-0.149*	0.127*	0.082	-0.395**																			
6. Live in Residential	0.153**	-0.064	0.011	-0.566**	-0.268**																		
7. Live Independently	-0.044	0.205**	0.142*	-0.321**	-0.152**	-0.218**																	
8. Education to Junior Cert	-0.030	0.044	-0.049	0.002	-0.012	-0.083	0.128*																
9. General Pain	0.266**	-0.123*	0.080	0.104	-0.144*	0.017	-0.021	-0.106															
10. Fall	0.254**	-0.126*	-0.017	-0.034	-0.010	0.049	-0.005	0.068	0.111														
11. Emotional Health	0.099	-0.095	0.064	0.027	0.008	0.022	-0.083	-0.043	0.130*	0.074													
12. Working in Community	-0.244**	0.106	0.170**	-0.093	0.105	0.036	-0.025	-0.037	-0.065	-0.087	0.043												
13. Civic Engagement	0.095	-0.153**	-0.009	0.012	-0.062	0.020	0.024	0.025	0.167**	0.0057	-0.018	-0.041											
14. Give Help	-0.040	0.095	0.049	-0.160**	0.084	0.035	0.105	0.067	-0.019	-0.012	-0.019	0.205**	-0.078										
15. Friends O/S House	-0.104	0.125*	0.101	-0.180**	0.141*	-0.030	0.165**	0.074	-0.009	0.039	-0.088	0.144*	-0.027	0.233**									
16. Receieving Help	-0.031	0.108	0.015	-0.112*	0.090	-0.040	0.129*	0.027	0.040	0.029	0.009	0.146**	-0.073	0.437**	0.209**								
17. Difficulty doing Activities	0.313**	-0.079	0.077	0.049	-0.070	0.034	-0.044	-0.083	0.143*	0.087	0.149**	-0.092	-0.046	-0.010	-0.062	-0.007							
18. Wanting More Activities	0.023	0.050	0.088	-0.110	-0.075	0.190**	-0.010	-0.037	0.082	-0.014	0.112*	0.043	-0.016	0.020	0.148**	0.020	0.104						
19. Service Stress	0.124*	-0.089	-0.053	-0.004	-0.109	0.078	0.022	-0.067	0.032	0.016	0.021	-0.022	-0.005	-0.050	-0.063	-0.090	-0.053	-0.008					
20. Social Participation	-0.220**	0.144*	0.038	0.005	-0.041	-0.049	0.109	-0.003	-0.092	-0.164**	-0.164**	0.064	-0.230**	0.248**	0.188**	0.075	-0.150**	0.163**	-0.057				
21. Confide in Staff	0.021	-0.050	-0.070	0.236**	-0.368**	0.025	0.017	-0.060	0.051	-0.025	-0.078	-0.023	-0.049	-0.063	-0.043	-0.071	-0.032	0.016	0.108	0.095			
22. Confide in Family	-0.069	0.181**	0.073	-0.132*	0.318**	-0.102	-0.013	0.042	-0.011	-0.055	-0.076	0.045	0.009	0.001	0.050	-0.010	-0.019	-0.027	-0.069	0.087	-0.241**		
23. Confide in Friend	-0.001	0.070	0.230**	-0.016	-0.023	0.038	-0.003	-0.058	0.073	0.099	-0.042	0.045	-0.054	0.026	0.128*	0.122*	-0.078	0.157**	-0.008	0.116*	-0.073	-0.047	
24. Confide in Other	0.054	0.046	0.142*	-0.139*	0.068	0.051	0.069	0.034	-0.021	-0.001	0.029	-0.025	-0.050	0.031	0.050	0.053	0.172**	0.114*	-0.100	-0.036	-0.196**	-0.079	-0.03

*p<.05, **p<.01

5.4.2   Series 2, ID Specific Variables

5.4.2.1   *Correlations*

Correlation between the predictor variables were checked before running the regressions (Table 5-4). None of the correlations were of a magnitude to cause concerns about collinearity. The two variables most likely to have significant correlations with other variables are social participation and functional limitations. Functional limitations are associated with difficulty doing activities (rho=0.313, p<0.01), social participation (rho=0.220, p<0.01), working in the community (rho=-0.244, p<0.01), live-in residential accommodation (rho=0.153, p<0.01), live with family (rho=-0.149, p<0.05) as well as falling (rho=0.244, p<0.01), pain (rho=0.266, p<0.01), cognitive function (rho=-0.258, p<0.01) and service stress (rho=0.124, p<0.01). These associations emphasise the negative impact of functional ability on the lives and health for people with an ID.

Social Participation is associated with giving help (rho=0.248, p<0.01), civic engagement (rho=-0.230, p<0.01), difficulty doing activities (rho=-0.150, p<0.01), wanting to do more activities (rho=0.163, p<0.01), emotional health (rho=-0.164, p<0.01), and falling (rho=-0.164, p<0.01).

The strongest association in this series of variables is between living in a community house and living in residential (rho=-0.566, p<0.01), and all the other residence associations are significant. Other associations with residence include living independently and cognitive function (rho=0.205, p<0.01), socialising with friends (rho=.165, p<0.01), receiving help (rho=0.129, p<0.05), education (rho=0.128, p<0.01), and transport (rho=0.142, p<0.01). Living in residential was correlated with wanting to do more activities (rho=0.190, p<0.01). Living in a community house was significantly correlated with confiding in staff (rho=0.236, p<0.01), socialising with friends (rho=-0.180, p<0.01), transport (rho=0.160), giving help (rho=-.160, p<0.01), confiding in other (rho=-0.139, p<0.05), confiding in family (rho=-0.132, p<0.05), cognitive function (rho=-0.166, p<0.01) and receiving help (rho=-0.112, p<0.05). Living with family was associated with confiding in staff (rho=-0.386, p<0.01), confiding in family (rho=0.318, p<0.01), cognitive function (rho=0.127, p<0.05), pain (rho=-0.144, p<0.05) and socialising with friends (rho=0.141, p<0.05).

Cognitive function was negatively associated with pain (rho=-0.123, p<0.05), and was also correlated with falls (rho=-0.126, p<0.01), civic engagement (rho=-0.153, p<0.01), social participation (rho=0.144, p<0.05), confiding in family (rho=0.181, p<0.01), and socialising with friends (0.125, p<0.05).

Socialising with friends was significantly associated with social participation (rho=0.188, p<0.01), wanting more activities (rho=0.148, p<0.01) and confiding in friends (rho=.128, p<0.05).

Pain was related to civic engagement (rho=0.167, p<0.01), difficulty doing activities (rho=0.143, p<0.01) and emotional health (rho=0.130, p<0.05). Emotional health had additional significant associations with difficulty doing activities (rho=0.149, p<0.01), and wanting to do more activities (rho=0.112, p<0.05).

Transport was associated with confiding in friends (rho=0.230, p<0.05), working in the community (rho=0.170, p<0.01), and confiding in others (rho=0.142, p<0.05).

There were also significant associations between other related variables: receiving help and giving help (rho=0.437, p<0.01), and all the confiding variables were strongly correlated with each other. Those who give help (rho=0.233, p<0.01) and those receive help (rho=0.209, p<0.01) were more likely to socialise with friends. The associations of giving and receiving help underline the level of ability and independence of those who give and receive help.   Giving help (rho=0.205, p<0.01), receiving help (rho=0.146, p<0.01), and socialising with friends (rho=0.144, p<0.01) were also associated with working in the community.

5.4.2.2 *Regression Analysis*

The results of the regressions run to test for antecedents utilising ID-specific variables are contained in Appendix D3. Variables that had a p-value below 0.1 in the Hawkley et al. (2008) led analysis were added to the variables tested. If a variable was found to be a significant predictor in the first series, and regressions did not prove significant in the a regression, it was re-entered into the b regression to remove the effect of any variables that were pruned after the a regression.

Demographics

Demographic variables entered were functional limitations and cognitive ability. Functional limitations (B=0.027, SE=0.016, p<0.1, 95% CI=-0.003, 0.060) surpassed the required p-value of 0.1 and was retained. Both variables accounted for 1.6% (r^2=0.016) of the loneliness variance, and when included as a single item in a regression, functional limitations accounted for 1.5% (r^2=0.015) of the loneliness variance.

Socio-Economic

Socio-economic variables were transport, residence type, education, and the retained functional limitations. Only transport (B=0.478, SE=0.267, p<0.1, 95% CI =-0.045, 1.026) achieved the cutoff p-value of 0.1. Combined, the variables accounted for 5.9% (r^2=0.059) of the loneliness variance. Functional limitations was kept for the follow-up regression as it had proved significant in the previous series of regressions. The b regression included functional limitations, transport, and education; both functional limitations (B=0.030, SE=0.015, p<0.05, 95% CI =0.001, 0.062) and

transport (B=0.517, SE=0.262, p<0.05, 95% CI =0.011, 1.034) achieved significance, and Education (B=-0.397, SE=0.227, p<0.1, 95% CI =-0.836, 0.061) achieved the required p-value of 0.1 and accounted for 4.6% (r^2=0.046) of the loneliness variance.

Health

The health variables were general pain, falls and emotional health, plus the retained variables of functional limitations, transport, and education. Both general pain (B=0.537, SE=0.221, P<0.05, 95% CI =0.102, =0.970) and emotional health (B=0.266, SE=0.128, p<0.05, 95% CI =0.004, 0.508) achieved statistical significance, and transport (B=0.439, SE=0.244, p<0.1, 95% CI =-0.041, 0.915) maintained a p-value below 0.1. The variables accounted for 9.4 % (r^2=0.094) of the loneliness variance. The b regression included the variables functional limitations, transport, education, general pain and emotional health. Emotional health (B=0.267, SE=0.126, p<0.05, 95% CI =0.014, 0.505) and general pain (B=0.560, SE=0.213, p<0.01, 95% CI =0.129, 0.068) both achieved statistical significance, and transport (B=0.450, SE=0.246, p<0.1, 95% CI =-0.033, 0.937) achieved the cut-off p-value below 0.1. Functional limitations (B=0.014, SE=0.014, p=n.s., 95% CI =-0.013, 0.042) failed to attain the p-value of 0.1 and was eliminated from future regressions.   The variables accounted for 6.9% (r^2=0.069) of the loneliness variance.

Social Roles

The social role variables were working in the community, civic engagement, receiving help, doing activities with friends and giving help, plus the three retained variables; transport, general pain and emotional health. Only transport (B=0.530, SE=0.238, p<0.05, 95% CI =0.079 1.014) and general pain (B=0.561, SE=0.209, p<0.01, 95% CI =0.159, 0.969) were statistically significant and were selected for a second regression, along with Emotional Health and Working in the Community. The total variance explained was 7.1% (r^2=0.071). The second regression (4b) had statistically significant variables: transport (B=0.628, SE=0.224,p<0.01 95% CI =0.194, 1.081), general pain (B=0.493, SE=0.191, p<0.05, 95% CI =0.118, 0.863) and working in the community (-0.621, SE=0.250 p<0.01, 95% CI =-1.096, -0.123), while emotional health (B=0.189, SE=0.109, p<0.1, 95% CI =-0.023, 0.401) attained a p-value of 0.1. The variables accounted for 7.7% (r^2=0.077) of the loneliness variance.

Stress Exposure

The stress exposure variables were having difficulty doing activities, wanting to do more activities, and service stress, which were added to the retained variables of transport, general pain, working in the community and emotional health. Transport (B=0.563, SE=0.216, p<0.05, 95% CI =0.147, 0.991), general pain (B=0.408, SE=0.189, p<0.05, 95% CI =0.033, 0.779), working in the community

(B=-0.615, SE=0.282, p<0.025, 95% CI =-1.168, -0.056), wanting to do more activities (B=0.780, SE=0.177, p<0.01, 95% CI =0.436, 1.116) and service stress (B=0.285, SE=0.121, p<0.05, 95% CI =0.051, 0.521) all were statistically significant. The regression accounted for 15.9% (r^2=0.159) of the loneliness variance. The second regression (5b) included the variables of transport, general pain, emotional health, working in the community, wanting to do more activities, and service stress. Emotional health (B=0.141, SE=0.104, p=n.s., 95% CI =-0.065, 0.344) failed to meet the minimum required standard and was removed from the future analysis. The regression accounted for 15.4% (r^2=0.154) of the loneliness variance.

Social Network

The Social Network regression included social participation and the retained variables of transport, general pain, working in the community, wanting to do more activities, and service stress. Social participation (B=-0.007, SE=0.007, p=n.s., 95% CI =-0.020, 0.007) was not a significant predictor of loneliness, and the regression accounted for 15.9% (r^2=0.159) of the loneliness variance. The second regression (6b) included the retained variables, and the regression accounted for 15.6% (r^2=0.156) of the loneliness variance.

Network Quality

The variables confide in staff, confide in family, confide in friends and confide in others plus the retained variables were included in the network quality regression. Transport (B=0.509, SE=0.219, p<0.05, 95% CI =0.095, 0.953), general pain (B=0.573, SE=0.183, p<0.01, 95% CI =0.223, 0.935), working in the community (B=-0.636, SE=0.275, p<0.05, 95% CI =-1.175, -0.097), wanting to do more activities (B=0.828, SE=0.180, p<0.01, 95% CI =0.487, 1.195), service stress (0.353, SE=0.124, p<0.01, 95% CI =0.106, 0.594) and confiding in staff (B=-0.479, SE=0.196, p<0.05, 95% CI =-0.856, -0.094), were all significantly predictive of loneliness. The regression explained 17.9% (r^2=0.179) of the loneliness variance. The second regression (7b) explained 17.8% (r^2=0.178) of the loneliness variance.

Full Regression

A final regression was run using all the variables tested within this series. general pain (B=0.695, SE=0.222, p<0.01, 95% CI =0.290, 1.077), wanting to do more activities (B=0.853, SE=0.226, p<0.01, 95% CI =0.364, 1.332) and confiding in staff (B=-0.645, SE=0.230, p<0.05, 95% CI =-1.070, -0.212) were significant predictors of loneliness. Education (B=-0.444, SE=0.261, p<0.1, 95% CI =0.952, -0.008) and service stress (B=0.316, SE=0.167, p<0.1, 95% CI =0.057, 0.658) were below the p-value of 0.1. The regression accounted for 27.6% (r^2=0.276) of the loneliness variance.

5.5   Discussion

In older people with an ID, functional limitations are the primary predisposing variable. Functional limitations dictate which of the precipitating variables of transport, general pain, emotional health and service stress lead people to want to do more activities. Functional limitations also determine the level of education a person has received and whether they work in the community, both of which protect against loneliness. The results support the work of Hawkley et al. (2008) as an effective way of analysing the antecedents of loneliness, yet they demonstrate the specific nature of the antecedents of loneliness for older people with an ID. To help reduce the risks of loneliness, service providers need to adapt service provision to facilitate the lives of those with greater functional limitations, allowing them to circulate in the community and develop their own social roles. To enhance the lives of all people with an ID, transport problems need to be addressed to allow people to maintain and develop friendships and social networks.

5.5.1   Antecedents of Loneliness

Perlman and Peplau (1998) divided antecedent variables into two groups: those that predispose a person to loneliness, and those that precipitate loneliness. Functional limitations, educational attainment and working or not working in the community are variables that predispose a person to whichever events will precipitate loneliness. Transport difficulties, pain, emotional health problems, and service stress are variables that precipitate loneliness in older people with an ID. Wanting to do more activities is indicative of the break between achieved and the desired social relationships.

The data suggest there were three specific routes to loneliness in this population (Figure 5.2). The first route is for those with low levels of functional limitations. They were likely to get a good education, live a relatively independent life and work within the community. Their precipitating event was poor transport, and if they experienced poor transport, they were likely to become lonely because they could not meet their social desires. The next route was for those who were lower on levels of functional ability; they lived a service-dependent life. For the better able among this group, they found their level of social expectation was not met and therefore they want to do more activities, subsequently feeling lonely. For the others in residential care, the functional limitations increased their amount of pain experienced, which combined with emotional health difficulties to make them more reliant on the service. When changes occurred, they felt lonely

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because of the loss of resources. For all three groups confiding in the wrong people increased the chance of precipitating events creating loneliness.
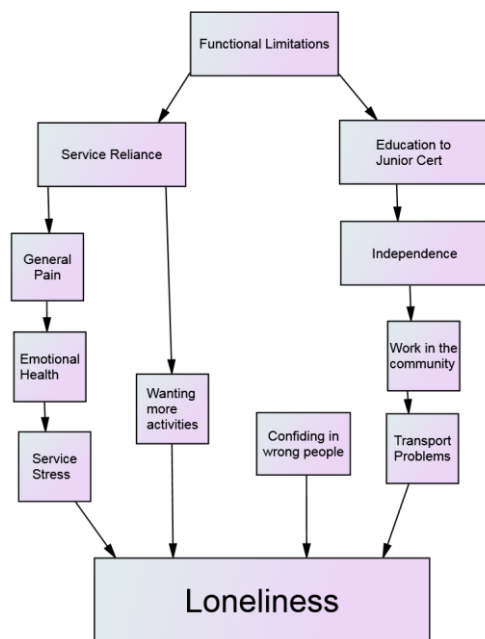

Figure 5-2: Antecedent pathways to loneliness

Through the use of both ID-specific and general population variables the research was able to hone a list of variables that were a more accurate representation of loneliness than if just general population variables were included. The Hawkley et al. (2008) led series of regressions produced the antecedents of education to junior certificate level, general pain, working in the community, and service stress as variables that significantly predicted loneliness. The variables combined predicted 12.5% of the loneliness (r^2=0,125). The ID-specific variables combined to predict 27% of the loneliness variance (r^2=0.276), and produced functional limitations, education to junior certificate level, transport, general pain, emotional health, working in the community, service stress, wanting to do more activities, and confiding in staff as variables that predicted loneliness.

Neither age nor gender were predictors of loneliness in the first block of demographic variables. The failure of gender to predict loneliness in this population is a continuation of the position, reported by McVilly et al. (2006), where more females in the population were lonely, but being female failed to predict loneliness. Both gender (rho=0.170, p<0.01) and age (rho=0.170, p<0.01) were associated with the number of chronic conditions experienced, and in other populations the increased exposure of both the old and females to increased numbers of chronic conditions has been cited as the reason both variables are antecedent to loneliness. In this population chronic

conditions were not related to loneliness, which may explain the lack of a role for gender and age in this analysis.

Functional limitations were the leading life-defining variable. The results clearly split the population into two groups: those with low levels of functional limitations and those with greater functional limitations. When functional limitations are discussed in the general population (Wenger and Burholt, 2004; Cacioppo et al., 2010), it is usually as an outcome of declining health (Jylhä, 2004; Hawkley et al., 2008). Discussions of functional limitations in the ID literature are linked to reduced social integration (Jylha, 2004) and reduced access to choices (Robertson et al., 2001). Functional limitations define the life chances of participants in areas such as residence type and the amount of social activity a person undertakes (Gilmore and Cuskelly, 2014). This research supports this, and in older people with an ID, functional limitations were life- and opportunity-defining, determining access to many areas of life.

Education in this population was a function of having fewer functional limitations, and its position as an antecedent in these results demonstrated that receiving a good education was only open to those without functional limitations. The role of education as being protective against loneliness matches the findings of Hawkley et al. (2008) and others (Victor et al., 2005; Timonen et al., 2010; Burholt and Scharf, 2013). Two explanations have been advanced for the role of education in loneliness in the wider population: the first argues that education operates through feelings of competence (Hensley et al., 2012) and the second is that education affords social opportunity (Hawkley et al., 2008). In this population, having a mainstream education offers not only feelings of competence but also offers vicarious social skills training not open to those who do not stay on in education or are in special needs education (Gilmore and Guskelly, 2014). Education lost power to be a significant predictor of loneliness once general pain was added to the regression, therefore education no longer protects against loneliness if a person is experiencing pain. In fact, those who have functional limitations are more likely to experience pain and are less likely to have received a good education.

Like education, working in the community was also an outcome of functional limitations. Only those with few functional limitations got to work in the community. Even though working in the community was associated with higher functioning participants, it was protective against loneliness, which is in keeping with other research (McVilly et al., 2006). Working in the community associated strongly with social skills, such as giving and receiving help, and others have reported that working in the community increases social skills (Gilmore and Cuskelly, 2014). Further research is necessary to see if those who work in the community have better social skills when their levels of functional limitations are taken into account.

Transport difficulties were pertinent to a more independent living group (rho=0.142, p<0.05) who work in the community (rho=0.170, p<0.05). In the general population, lack of transport leaves people unable to access social resources (Burholt and Scharf, 2013), and for individuals with an ID transport difficulties have been associated with having difficulty in maintaining and developing relationships (Bane et al., 2012). Both of these views garner support from this research, with transport difficulties leading this group to have lower than expected social participation rates.

General pain precipitates loneliness in those with a greater number of functional limitations. Pain was a major contributor to loneliness in this population, explaining 4.7% of the loneliness variance, and once introduced into both series of regressions it remained consistently predictive of loneliness. Chronic pain has been found to be a predictor of severe loneliness in the wider Irish population (Cleary, 2011). Participants in this study who experienced pain were more likely to report having difficulty doing activities (rho=0.129 p<0.05). Experiencing pain leaves a sufferer in a state where they are isolated because they are unable to focus on social activities, and others are isolated from understanding their suffering as the experience is invisible and cannot be comprehended by others (Biro, 2011). Pain experienced can represent the experiencing of health symptoms (Hawkley et al., 2008) and in this population may be a better indicator of health than chronic conditions.

Emotional health is another area regularly linked to loneliness (Victor et al., 2008; Barry et al., 2009; Aartsen and Jylhä, 2011; Coyle and Dugan, 2012). People with emotional health difficulties have trouble adjusting their expectations when changes happen in their social circumstances (Burholt and Scharf, 2013). Emotional health lost its predictive ability once service stress was introduced, indicating that emotional health difficulties in this population increased the perceived problems of change.

Service changes caused a level of stress that precipitated loneliness in service users who were reliant on services. This research is the first to look at the role of the stress caused by changes in service provision for people with an ID. Service stress is a measure of how difficult participants found service-related changes in the previous 12 months, and represented a loss in personal social resources that enhanced the chances of becoming lonely (Aartsen and Jylhä, 2011). Service stress was associated with functional limitations (rho=0.124, p<0.05), showing the losses were felt most by those who were most reliant on services. The effect of service stress was repeated in both series of regressions and remained a significant predictor of loneliness throughout, adding 2% to the predictive power of the regression. Service stress was the only stressor that proved to be a significant predictor of loneliness, and it establishes the importance of stable service provision to people with an ID. The role of stressors has had mixed results with Hawkley et al.

(2008) finding work stress to be predictive of loneliness, and other researchers have found stressors not to be predictive of loneliness (Zebhauser et al., 2014).

The benefit of using a confidant was not straightforward in this population and confidants were only useful if they could initiate changes. In other populations the role of confidant has only been associated with protection against loneliness (Victor et al., 2005; Hawkley et al., 2008). Within the IDS-TILDA data, most people reported having someone to confide in, and having a parent as confidant was linked to lower loneliness levels (McCausland, 2015). The regression reports that confiding in family protected against loneliness, but its effect was not robust enough to be a significant predictor. Confiding in staff was protective against loneliness. Whom individuals confided in is linked to housing type: those that lived in service accommodation tended to confide in staff, and those that lived with family or independently tend to confide in the family. The role of confidant is not straightforward; the analysis shows that confiding in staff or family is useful in protecting against loneliness, and confiding in friends or others is not helpful. Both staff and family are people in a position to initiate change in the lives of older people with an intellectual disability, whereas friends and others do not have this ability.

In older populations, the level of social participation has been regularly associated with loneliness (Victor et al., 2008; Russell et al., 2012; Lykes and Kemmelmeier, 2013). While social participation was not predictive of loneliness in this population, wanting to do more activities was. Hawkley et al. (2008) found that people who were unable to satisfy the desire to engage in social activities were more likely to be lonely. Rather than being a stressor, wanting to do more activities represented the mismatch between achieved and desired social relations.

Use of this methodology has allowed the role of variables to be discerned, creating a list of antecedent variables that is more comprehensive than if a single regression had been tested. If a single regression containing all the variables were used, the list of predictor variables would have been limited to general pain, wanting to do more activities, and confiding in staff.

These findings are in keeping with the CDA (Perlman and Peplau, 1998) and demonstrate how predisposing elements influence the precipitating factors. This work supports the work of Burholt and Scharf (2013), who found that there are distinct paths to loneliness.

Knowing which variables are antecedent to loneliness in this population will allow service providers to look at their future structures, and their placements of people with an ID. Particular attention is needed to reduce the adverse effects of functional limitations, with specific efforts being made to find out what life enhancements are necessary for those with greater limitations to mitigate the risk of loneliness. Transport is another issue that needs to be addressed; while

services cannot deliver public transport they can ensure that people who use public transport are trained in its use, so they feel secure to use this transport as and when they desire. Additional to travel training, some applications have been developed which allow people to let others monitor their progress on a specific journey. The use of such technology may enhance the free use of the public transport that is available. Additionally, services which plan living accommodation for those who live independently or semi-independently should ensure they are close to good public transport links.

Of particular interest to those who organise services should be the protective role of working in the community, education, and confiding in staff and family. Working in the community increases the person's quality of activities and self-worth, and where specific work cannot be located voluntary work could be considered. Voluntary work is known to be to be protective against loneliness (Victor et al., 2008). Confiding in staff or family means people are confiding in someone who can facilitate changes that are needed in their lives. Education increases confidence and gives access to social resources.

5.5.2   Limitations

The amount of the variance explained using the ID-specific variables at 27% is well below the 45% Hawkley et al. (2008) explained. The selection of variables was limited by two factors: first the fact that the only variables utilised are those suggested by the literature. The findings do offer future research a base point from which they can expand the search for antecedents within this group. The second factor is that selection of variables from a broad ranging, multi-use survey does mean that the variables selected may not be the ones the researcher may have chosen, or may not be formatted specifically for the topic. Further qualitative research at this stage would expand the range of antecedents.

The lack of a measure of network satisfaction is an obvious weakness, and one future researchers need to include in their analysis of loneliness in this population. However, the IDS-TILDA data supplies a large population that would have been unavailable to a single researcher, and the increase in power and generalisability of the findings outweigh the compromise of variable selection.

The methodology utilised does not analyse the pathways suggested by the bivariate and multivariate analysis. To overcome this, Structural Equation Modelling needs to be utilised to analyse the pathways to loneliness. The benefit of using this repeated regressions methodology has been that it has created a detailed list of predictors of loneliness.

This research only includes those participants who were able to answer the loneliness questions for themselves, and so those who have higher functional limitations have been underrepresented; future research should investigate methods for assessing loneliness in those unable to answer for themselves.

Finally, the role of pain in loneliness is evident in this study, yet there is little research to support this finding. Further research is needed to gain greater insight into the role of pain in loneliness in older people with an ID.

5.5.3   Conclusion

The results suggested that there were three routes to loneliness in this population. Participants who had fewer functional limitations tend to lead a life more independent from the service. They are more likely to be educated to junior certificate level and work in the community. For this group, transport problems create the mismatch between desired and achieved social relations. This group were associated with less social participation than those who have no transport problems. Participants who were less functionally able tended to end up reliant on service providers. The participants in this group who were more able and living in residential settings were associated with a desire to want to do more activities. The individuals whose functional limitations lead to increased pain and emotional health problems were most affected by changes in service provision, which precipitates their loneliness. For all groups, confiding in people who can make help initiate change is protective against loneliness.

This research answered the question "what are the antecedents of loneliness for older individuals with an ID?" To do this, it adopted a methodology used by Hawkley et al. (2008) to divine the antecedents of loneliness in the general population. This method involved categorising variables into logical blocks, grouped from the distal to the proximal. The blocks of variables were entered as predictor variables one block at a time. Any significant variables were retained and added to the next block. Non-significant variables were pruned from future analysis. Two separate series of regressions were conducted. The first set included variables that closely matched those used by Hawkley et al. (2008). The second round incorporated any variables that were found to be significant predictors in the Hawkley et al. (2008) led series of regressions and ID-specific variables.

The first series of regressions discerned that general pain and service stress were predictors of loneliness, and education to the junior certificate level and working in the community were protective against loneliness. The second series of regressions added functional limitations, transport difficulties, and emotional health problems as predictors of loneliness. Confiding in staff

was protective against loneliness. Figure 5.3 shows how the variables fit into the antecedents section of the CDA.
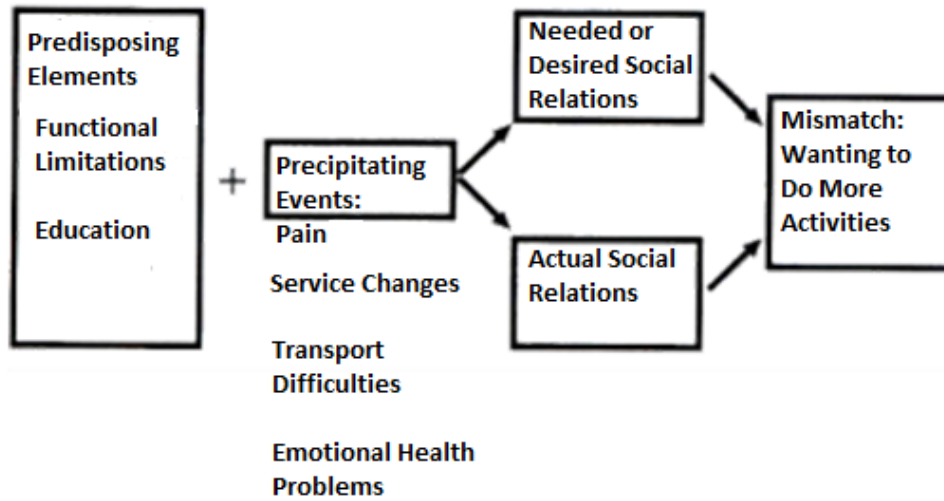
Figure 5-3: Updated Antecedents section of the CDA. Adapted from "Loneliness" By D. Perlman & L.A. Peplau *Encyclopedia of mental health, 2*, p. 572 copyright 1998 by **Taylor and Francis Group LLC Books. Reprinted with Permission under licence number 4270990436999.**

This is the first research to produce a list of antecedents of loneliness in older people with an ID, and to look at the influence of distal variables on more proximal variables within this population. The results support the premise of the CDA; it is clear that while there are some differences in variables from the general population, the overall structure of antecedents of loneliness is similar to the wider population.

6 The Cognitive Characteristics of Loneliness

6.1 Introduction

Cognitive attribution is the central pillar to Perlman and Peplau's (1998) Cognitive Discrepancy Approach (CDA). Perlman and Peplau (1981) argue, that while a person may have a gap between their desired social life and their actual social life, this does not inevitably lead to loneliness and their expectations may be modified by their cognitive reaction to the situation.

Depression and loneliness have long been associated (Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006) and the attributions made by depressive thinkers and the attributions of the lonely share common ground. Specific attribution styles that have been associated with loneliness are rumination (Vanhalst et al., 2012), self-blame (Craig A. Anderson et al., 1994), comparison with others (Perlman & Peplau, 1998), and feelings of helplessness. A person's attribution style has been found to be a strong predictor of loneliness accounting for up to 28% of the loneliness variance (C. A. Anderson, 1999).

Beck (1972), argued that depression is a cognitive process, that moderates how intensely people react to levels of social contact and support. Beck and Alford (2009), say that people with depression are more likely than those without to hold dysfunctional beliefs and negatively process information. People with depression do not believe they have the ability to effect change in their lives and are less likely to alter their benchmark for social satisfaction. Beck and Alford (2009) also claim that those with depression try to escape from their problems rather than solve them and over time they become increasingly dependent on others. At the heart of Beck's (1972), theory is the cognitive triad in which a negative view of the world, of self, and the future, all interact to reinforce a person's depression. Similar triads have been described in loneliness research in which loneliness, depression, and energy levels interact to further exacerbate loneliness (Cohen-Mansfield & Parpura-Gill, 2007)

Burholt and Scharf (2013) argue that depressive thinking is likely to moderate pathways to loneliness because those with depressive thinking are less likely to change their expectations, more liable to self-blame, and they are less likely to believe that they can intervene successfully in their lives. They found that depression amplifies the effect of chronic health conditions on loneliness by moderating the path between social resources and loneliness.

The moderating role of depression in loneliness is a concept that has never been tested in older people with an ID. This study answers the research question "does depressive thinking increase

the risk of feeling lonely for older people with an ID?" as well as a hypothesis that depressive symptoms will have a moderating effect on the pathways to loneliness for older people with an ID.

6.2   Methodology

6.2.1   Participants

A full description of participants can be found in the Methodology chapter, section *4.2 Participants*, page 51.

This study utilizes participants from wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) dataset. The sample was randomly drawn from people, aged over 40, on the National ID Database (NIDD). Wave 2 data collection commenced in 2013 and 708 responded to Wave 2. The sample was largely representative of the NIDD.

Use of The Centre for Epidemiologic Studies Depression Scale (CES-D) meant only participants who self-reported were included (N=142).   The demographic makeup of the restricted sample was tested analysing gender, living circumstances, age and level of ID, against those who didn't respond to the scale.

Table 6-1 gives the cross tabulations chi-squared statistic and p-values for participants who completed the CES-D scale against those who did not within the loneliness subpopulation. In this sample females were proportionally more likely to be represented than males (χ^2=6.732, p<0.01). The population also were proportionally more likely to be from the younger age categories (χ^2=7.727, p<0.05). There was no significant difference in the reported level of ID (χ^2=3.321, p=n.s.) or the living circumstances (χ^2=8.384, p=n.s.) of the participants who answered the CES-D scale.

Table 6-1: Cross-tabulations of the loneliness subpopulation, who did not complete the CES-D Scale.

| Variable | Category | Completed CES-D scale | | | |
		Yes	No	χ^2	p
Gender	Male	46	83	6.732	0.009
	Female	96	92		
Living Arrangements	Family	15	35	8.384	0.078
	Independent Community	18	17		
	House	64	80		
	Residential	8	13		
	Other	37	30		
Age	40-49	44	43	7.727	0.021
	50-64	81	90		
	65+	17	42		
Level of ID	Mild	58	61	3.321	0.345
	Moderate	67	87		
	Other	4	7		

6.2.2   Measures

All the variables described below were initially fully described in the Methodology Chapter, section *4.3 Measures*, page 56.

Loneliness and Social Connectedness: was measured using a seven-item scale consisting of the Three-Item Loneliness Scale (Hughes et al., 2004) and a self-labelling loneliness item (Appendix C2).

Independent Variables

The independent variables used in this chapter were selected to either match the work of Burholt & Scharf (2013) or to test ID specific relationships with loneliness, noted in the Antecedents chapter.

Pain was used to represent the health symptoms variable employed in Burholt and Scharf (2013), and is a binary coded self-reported measure. *Social Participation* is a composite score, measuring the amount, and frequency of 17 activities, such as "go to the pub for a drink". A high score indicates more activities that were more regular. *Social Network* measures the size of the social network and the frequency of contact. *Depressive Symptoms* are measured using the CES-D scale(Centre for Innovative Public Health Research, 2015) (Appendix C5). The scale was originally developed in 1977 by Radloff and revised in 2004 by William Eaton and colleagues, and has been widely used in research into loneliness, (Burholt & Scharf, 2013). *Functional Limitations* are

measured using an 11 item scale (Fonda & Herzog, 2004). *Level of Pain* was a self-rating of pain severity, and similarly, *Transport problems* was a self-report measure of how much disruption to the lives of participants transport problems caused.

6.2.3 Analysis

The analysis was conducted using IBM SPSS v23

6.2.3.1 *Conditional Process Analysis*

Conditional Process Analysis (CPA) is a macro tool for SPSS, and other statistical programmes, that incorporates ordinary least squares regression. It is designed to simplify the use of statistical procedures in answering complex questions, such as "In what pathway" and "under what circumstances". CPA is the analytical integration of moderation and mediation, and it is used to describe the mechanisms by which one variable transmits its effects on another.

Mediation analysis looks to see if the influence of predictor variable (X) on outcome variable (Y) is caused by a third mediating variable (M). In a simple mediation, there are three pathways a, b and c'. The a pathway, is the pathway between the X and M variables, and quantifies how much two cases that differ by one unit on X are estimated to be higher, or lower, on M. If X is a binary variable this is the mean difference in the two conditions. The b pathway, between M and Y, calculates the amount that two cases that differ by one unit on M, but are equal on X, are estimated to differ by b units on Y. The two coefficients a and b when multiplied form the indirect path (Hayes, 2013). The direct path, X to Y, measures how two cases that differ by one unit on X, but are equal to M, are estimated to vary by c' units, on Y (Hayes, 2013). The total effect is calculated as c'+ab, and measures how much two cases that differ by one unit on X, are estimated to differ on Y. The calculation of mediation requires the running of two regression analyses, the first estimates the effect of X on M, and the second the effect of X on Y, when M is held constant.

Moderation analysis estimates the size of an effect between two variables (X & Y), to see if this is reliant on a third variable (V). "An association between two variables is said to be moderated when its size, sign or strength are dependent on a third variable" (Hayes, 2013, p. 8). The effect is analysed by testing for an interaction between the independent variable (X) and the moderator variable (V). To test the moderation, the coefficients of a regression model are estimated on which the effect of X on Y is allowed to vary linearly with V, by including the product of X and V as a predictor of Y . In moderation analysis there are three pathways to account for, b1, b2 and b3; b1 represents the association between X and Y conditioned on V=0, b2 represents the conditional effect of V on Y when X =0, it quantifies how much two cases that differ on one unit of V are estimated to differ on Y, conditioned on X=0, b3 is the coefficient of the product of X and V. If b3

is statistically different from zero, X's effect of on Y depends on V. The effect of the independent variable on the dependent variable is reported at different levels of the moderator variable.

CPA pieces together the mediation and moderation, to give a complete and concise output that produces path coefficients, direct and indirect effects, and conditional effects. Moderation tests estimate the effects of the moderating variable, across a range of levels, using a pick a point approach. The use of such a technique indicates over what range of the moderator the effect of X on Y is significant or non-significant . The conditional indirect effect, analyses the moderation of the mediated pathway, and the formula is $M_i=a_i(b1_i+b2_iV)$. The conditional direct effect, is the moderated direct path, and the formula is Y=c1'+c3'V (Hayes, 2013).

In this analysis, the focus was on the moderation of both the mediated pathway, and the direct path. The output of interest was the conditional effects of the moderator, at the 10th, 25th, 50th, 75th and 90th percentiles of scores on the CES-D scale. The conditional effects, estimate the effect of CES-D when X=0.

6.2.3.2   *Burholt and Scharf (2013) led analysis*

A model based on the work of Burholt and Scharf (2013) was created (Figure 6-1). In this model, Pain is the X variable, and Loneliness the Y variable. There are two parallel mediating variables (M), Social Resources and Social Participation, and the moderating variable (V), is depressive thinking . The CPA model number selected is model 15. In this model, it is proposed that the path between pain and loneliness is mediated by social participation and social resources. Both the direct and indirect pathways are conditional upon the effect of depressive thinking.

In the Burholt and Scharf (2013) led model, the argument is that depressive symptoms influence the paths (size or sign), between social participation and loneliness, social network and loneliness and health and loneliness. The effects at different levels of depressive symptoms, are reported in the conditional effects tables. Prior to the variables being entered into CPA, correlations were calculated.
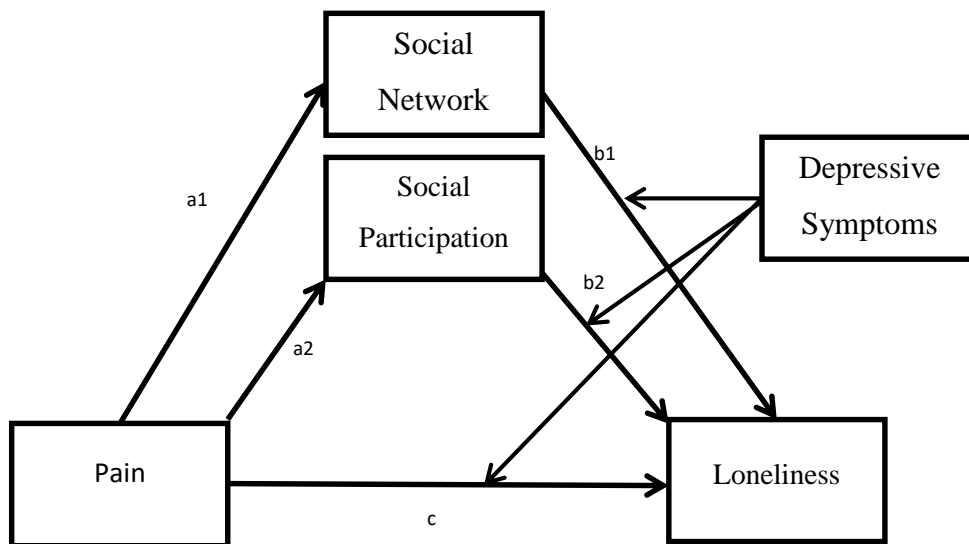
Figure 6-1: Analytic plan of the Burholt and Scharf (2013) led analysis of the moderating role of depressive thinking on the mediated pathways between health and loneliness

6.2.3.3 *Antecedent Pathway Analysis*

Prior to running CPA, the correlations between variables were checked for multicollinearity. The first analysis looked at a model estimating the effect of functional limitations (X), on loneliness (Y), mediated by Pain (M). The second analysis, estimated a path between working in the community (X), and loneliness (Y), mediated by transport accessibility (M). Both the direct and indirect paths were tested for moderation, by depressive symptoms (V). Bootstrap Bias-Corrected and Accelerated confidence intervals were set to 5,000 cases.

6.3 Results

6.3.1 Burholt and Scharf (2013) led model

Correlations between variables in the model were checked (Table 6-2). There were significant correlations between Social Network and Social Participation (rho=0.38 p<0.01), Depressive Symptoms and Loneliness (rho = 0.35 p<0.01), Depressive Symptoms and Pain (-0.26 p<0.01) and Loneliness and Pain (rho=-0.21 p<0.01). None of the correlations are of a magnitude as to cause concerns about collinearity.

Table 6-2: Correlation of variables in the Burholt and Scharf (2013) led moderated mediation model.

	1	2	3	4
1. Loneliness				
2.Pain	-0.21**			
3. Social Participation	-0.01	0.09		
4. Social Network	-0.02	0.05	0.38**	
5. Depressive Symptoms	0.35**	-0.26**	-0.07	-0.10

*p<0.05, **p<0.01

The results of this analysis (Figure 6-2), show that depressive symptoms moderate the direct path between pain and loneliness. Analysis of the conditional direct effects (Table 6-3), reveals that the effects of depressive symptoms, at the 75th and 90th percentiles, have a significant effect on the path between Pain and Loneliness. Depressive symptoms did not significantly moderate the pathways between Social Participation and Loneliness and Social Network and Loneliness.

*p<0.05, **p<0.01
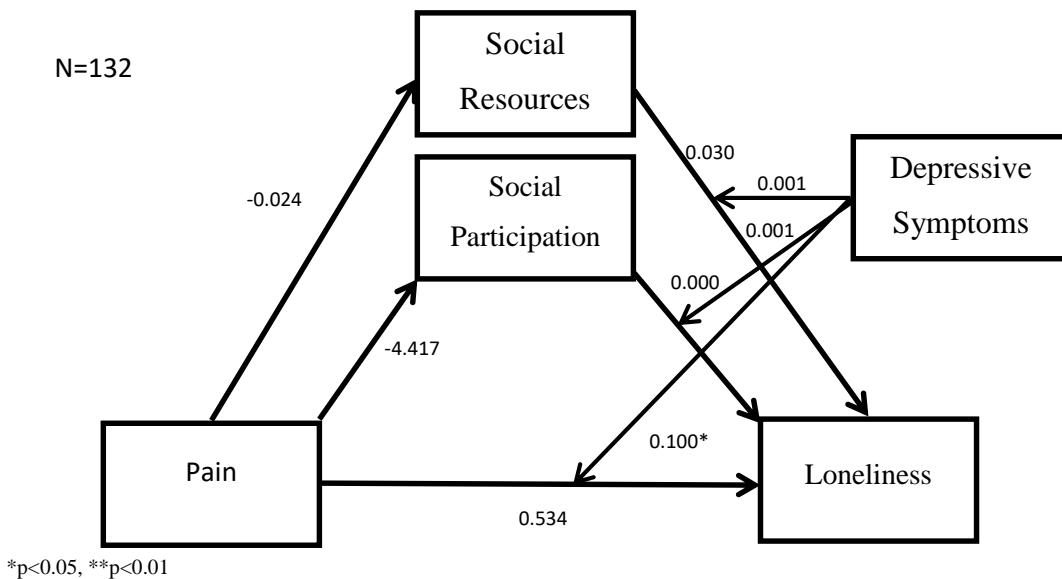
Figure 6-2: The role of depressive symptoms based on the pathway supplied by Burholt & Scharf (2013). Adapted from "Poor Health and Loneliness in Later Life: The Role of Depressive Symptoms, Social Resources, and Rural Environments" by V. Burholt and T. Scharf, 2013 in *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences, 69(2)* p.318. Copyright by The Gerontological Society of America. Reprinted by courtesy of the copyright holder under a creative commons license (http://creativecommons.org/licenses/by-nc/3.0/).

Table 6-3: Conditional direct and indirect effects of Depressive symptoms on the paths Pain, Social Participation, Loneliness and Pain, Social Network, Loneliness.

| | | Bootstrapping | | |
| | | | 95% Confidence Intervals | |
Direct Path Pain	Coefficient	S.E.	Lower	Upper
10th Percentile	-0.202	0.403	-0.999	0.595
25th Percentile	0.092	0.336	-0.537	0.756
50th Percentile	0.385	0.290	-0.190	0.959
75th Percentile	0.776	0.280	0.221	1.331
90th Percentile	1.460	0.397	0.673	2.247
Indirect Path Social Participation				
10th Percentile	0.017	0.117	-1.211	0.280
25th Percentile	0.011	0.086	-0.154	0.199
50th Percentile	0.005	0.063	-0.113	0.149
75th Percentile	-0.003	0.064	-0.139	0.141
90th Percentile	-0.017	0.133	-0.349	0.243
Indirect Path Social Network				
10th Percentile	-0.001	0.049	-0.109	0.096
25th Percentile	-0.001	0.035	-0.078	0.069
50th Percentile	-0.001	0.030	-0.072	0.055
75th Percentile	-0.001	0.040	-0.100	0.072
90th Percentile	-0.001	0.078	-0.193	0.146

6.3.2 Antecedents Led Analysis

Two Pathways were tested in the antecedents directed analysis.

6.3.2.1 *Analysis of the Functional Limitations, Pain, Loneliness Pathway*

Loneliness was significantly correlated with Depressive Symptoms (rho=0.35, p<0.01), and Pain (rho=0.23, p<0.01) (Table 6-4). Other significant correlations were between Functional Limitations and Pain (rho=0.40, p<0.01) and Depressive Symptoms and Pain (rho=0.29, p<0.01).

Table 6-4: Correlations of variables in the Functional Limitations, Pain, Loneliness Pathway

	1	2	3
1. Loneliness			
2. Functional Limitations	0.12		
3. Pain	0.23**	0.40**	
4. Depressive	0.35**	0.050	0.29**

*p<.05, **p<.01

Results of the CPA (Figure 6-3) demonstrated a significant pathway (ab) between Functional Limitations and Loneliness mediated by Pain (effect =0.019, SE =0 .011, 95% CI=- 0.002, 0.045). The direct path (c) between Functional Limitations and Loneliness was not significant (effect =0.019, SE =0.011, 95% CI= -0.020, 0.058). The ratio of total effects to indirect effects is effect =

0.498 (SE = 12.60, 95% CI= -0.887, 5.885), meaning 49.8% of the effect of functional limitations on loneliness occurs indirectly through Pain. The kappa-squared value = 0.082 (SE =0.044, 95% CI=0.010, 0.181), means the indirect effect of functional limitations through pain is around 8.2% of its maximum possible value.

N=136

*p<.05, **p<.01
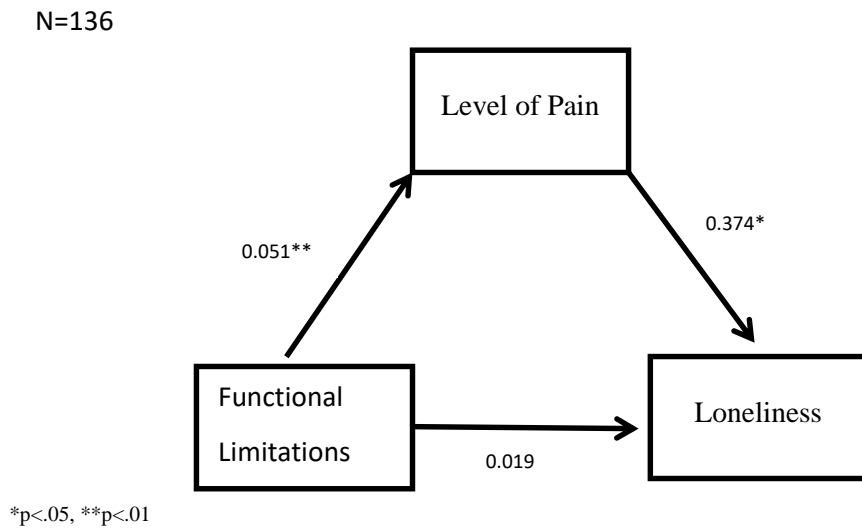
Figure 6-3: Path coefficients of the mediated path between functional limitations and loneliness

In the next stage, Depressive Symptoms as measured by the CES-D scale were entered into the model. The results (Figure 6-4), showed that the direct path between Functional Limitations and Loneliness is conditional on the level of Depressive Symptoms. The conditional effects table (Table 6-5), indicates that there is a significant effect at the 90th percentile of depression scores. The results indicate that the mediation of the indirect path from functional limitations to loneliness is not conditional upon the level of depressive symptoms experienced.

N=135
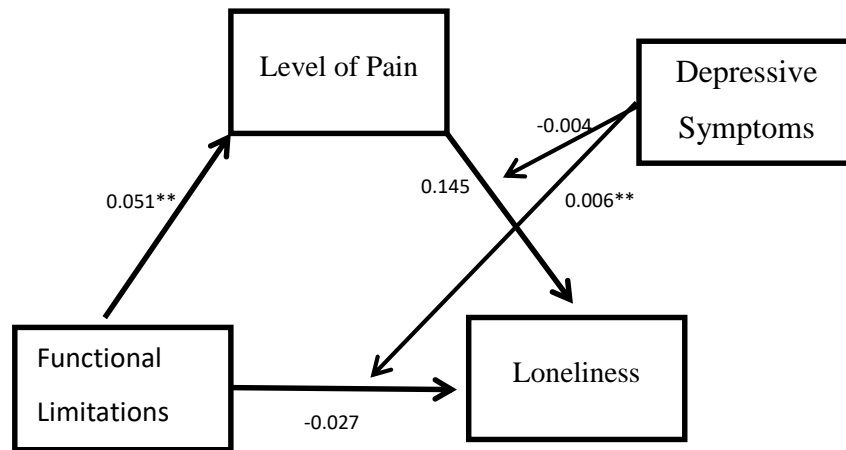
*p<0.05, **P<0.01

Figure 6-4: Analysis of the moderated mediated path between Functional Limitations and Pain

Table 6-5: Conditional direct and indirect effects of Functional Limitations on Loneliness at five percentile points of depression

		Bootstrap		
			95% Confidence Intervals	
Direct Path	Coefficient	S.E.	Lower	Upper
10th Percentile	-0.032	0.025	-0.083	0.018
25th Percentile	-0.015	0.021	-0.058	0.027
50th Percentile	0.002	0.019	-0.035	0.039
75th Percentile	0.024	0.018	-0.011	0.060
90th Percentile	0.064	0.025	0.014	0.114
Indirect Path				
10th Percentile	0.007	0.012	-0.012	0.038
25th Percentile	0.007	0.010	-0.009	0.032
50th Percentile	0.006	0.009	-0.010	0.027
75th Percentile	0.005	0.009	-0.012	0.025
90th Percentile	0.004	0.014	-0.021	0.031

6.3.2.2 *Analysis of the Working in the Community, Transport, Loneliness Pathway*

Before running CPA the correlations between the variables were checked (Table 6-6). Loneliness was significantly correlated with Depressive Symptoms (rho=0.35 p<0.01), and Transport was significantly correlated with Working in the Community (rho=0.18 p<0.05).

Table 6-6: Correlations of the Working in the Community, Transport, Loneliness Pathway

	1	2	3
1. Loneliness			
2. Working in the Community	-0.12		
3. Transport	0.17	0.18*	
4. Depressive Symptoms	0.35**	0.09	0.11

*p<0.05, **p<0.01

The first Analysis tested the indirect pathway, between Working in the Community and Loneliness Mediated by Transport (Figure 6-5). The indirect path proved significant (effect=0.323, SE =0.245, 95% CI=0.015, 1.087). The direct path was also significant (effect=-0.586, SE=0.430, 95% CI=-1.759, -0.057). The ratio of indirect effect to total effect was, effect=-0.551 (SE=7.483, 95% CI=-19.474, 0.026). This means 55.1% of the effect of working in the community on loneliness occurs through transport issues. The kappa-squared effect=0.070 (SE=0.044, 95% CI=0.008, 0.196), means the indirect effect of working in the community through transport is around 7.0% of its maximum possible value.

N=127

*p<0.05, **p<0.01
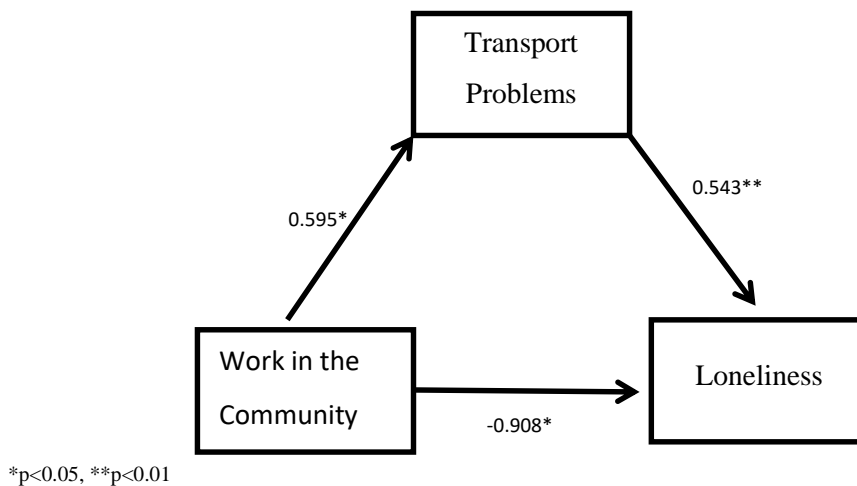
Figure 6-5: Coefficients of the mediated path between working in the community and loneliness

The analysis of the moderating role of depressive symptoms found that the interactions between both transport and depressive symptoms, and working in the community were not significant (Figure 6-6). Examination of the conditional effects table (Table 6-7), shows that moderating effect of depressive symptoms is significant, at the 75th and 90th percentiles, for both the direct and indirect effects.

Transport

Depressive Symptoms

0.027

-0.062

0.601*

0.153

Work in the Community

Loneliness

-0.413
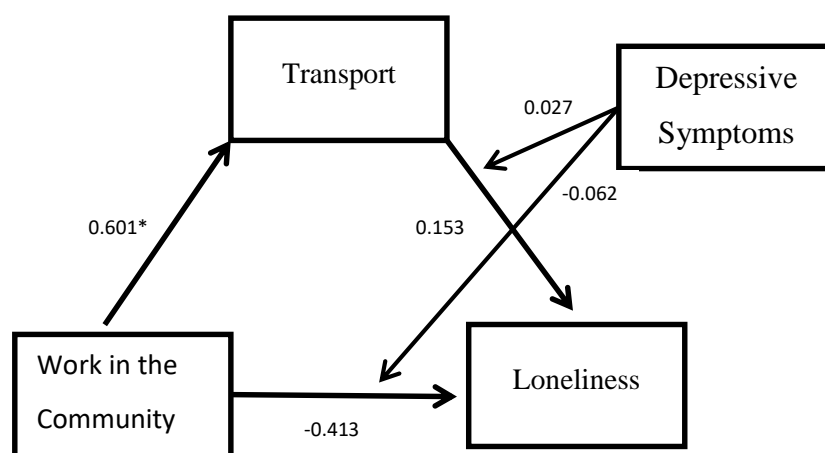
*p<0.05, **p<0.01

Figure 6-6: Analysis of the moderated mediated path between Working in the Community and loneliness

Table 6-7: Conditional direct and indirect effects of Working in the Community on Loneliness at five percentile points of depression

| | | Bootstrap | | |
| | | | 95% Confidence Intervals | |
Direct Path	Coefficient	S.E.	Lower	Upper
10th Percentile	-0.413	0.602	-1.604	0.779
25th Percentile	-0.599	0.501	-1.591	0.393
50th Percentile	-0.786	0.428	-1.633	0.061
75th Percentile	-1.035	0.400	-1.827	-0.243
90th Percentile	-1.470	0.552	-2.563	-0.377
Indirect Path				
10th Percentile	0.092	0.196	-0.181	0.674
25th Percentile	0.137	0.175	-0.078	0.702
50th Percentile	0.182	0.167	-0.016	0.725
75th Percentile	0.242	0.177	0.015	0.860
90th Percentile	0.346	0.230	0.025	1.151

6.4   Discussion

The results established that depressive symptoms do moderate the pathways to loneliness in this population. Evidence came from the significant conditional role of depressive symptoms in the moderation of the direct paths between pain and loneliness, and functional limitations and loneliness. The moderating role of depressive symptoms is central to the Cognitive Discrepancy Approach (Perlman & Peplau, 1998).   Burholt and Scharf (2013) demonstrated that depressive

symptoms, as measured by the CES-D scale, form a measure of attributions in the wider Irish population. Their work supported the concept that attributions influence the paths to loneliness. This research examined the role of depressive symptoms in people with an ID who completed the CES-D scale. The findings reflect the literature which argues that attribution style is important when understanding loneliness (Anderson, 1999). The results do not support the view that depressive symptoms moderate the pathway between Social Participation or Social Resources and Loneliness in this population.   This does not diminish the findings on the role of depressive symptoms but emphasises the lack of understanding about the route to loneliness for people with ID.

The results of the CPA demonstrate that the direct pathways to loneliness from pain (coefficient=0.100 p<.05) and functional limitations (coefficient=0.006, p<0.01) are conditional on the level of depressive symptoms experienced. In the analyses of the direct path between the X variable and loneliness, the greater the depressive symptoms, the larger the path coefficient. In the analysis of the model involving working in the community and loneliness, neither the direct nor indirect paths were found to be significantly conditional upon depressive symptoms. However, a significant effect of depressive symptoms was observed in both pathways at the 75th and 90th percentiles.

6.4.1   Burholt and Scharf (2013) led Analysis

The Burholt and Scharf (2013) led analysis showed that the more a person experiencing pain thinks in a depressive manner, the more likely they will be lonely. In this analysis the direct path from pain to loneliness coefficient values increase in line with percentile values, with scores at the 75th percentile (coefficient=0.776 95% CI= 0.221, 1.331) and the 90th percentile (coefficient=1.460, 95% CI= 0.673, 2.247) being significant. It is also noteworthy that where people experienced very low levels of depressive symptoms, at the 10th percentile, the sign of the coefficient is a minus, indicating that low levels of symptomology were protective against loneliness for this group (coefficient=-0.202, 95% CI= -0.999, 0.595).

Neither of the parallel mediated pathways were conditional on depressive symptoms, but the conditional effects table does report a continuous change in effect that is in keeping with the CDA. In their analysis of loneliness in the general older Irish population, Burholt and Scharf (2013) found that depressive symptoms amplified the pathway between health and loneliness, and the pathway mediated by social resources, between health and loneliness (Burholt and Scharf, 2013). The analysis of the same variables here found that depressive thinking had no role in moderating the pathways between either social network and loneliness, or social participation and loneliness. The argument used by Burholt and Scharf (2013) was that poor health reduced

social resources and that depressive symptoms increased the chances that people would not be able to alter their expectations for their social world. In this sample, three distinct problems may be confounding these results. First, Social Participation and Social Network measures, as constructed for the general population, may not be an effective way of capturing the important aspects of the social life in people with an ID. Second, in people with an ID, the amount of pain they experience might not be symptomatic of a change in health condition, but may be a part of their lifelong conditions and therefore might not additionally affect social participation levels. This is supportive of research that found that social participation by people with an ID is linked with adaptive behaviour, social competence and functional limitations as opposed to health (Kozma et al., 2009). In addition, here the correlations between general pain and social network were weak and the pathway coefficients were small. In a striking contrast, Burholt and Scharf (2013) found significant pathways between health and social participation and health and social resources.

6.4.2   Antecedents led models

Both models demonstrate that whether a person is living a service-based life or is living an independent life, depressive symptoms moderate the direct path to loneliness. Where their lives are influenced by problems, pain or transport, the greater they view that problem as being, the more likely they will be lonely. The first model looked at the moderating effect of depressive symptoms on a path mediated by the levels of pain experienced from functional limitations to loneliness. This model used variables defined as distal from the person yet intrinsic to the lifestyle of people with an intellectual disability. The second model estimated a model where depressive symptoms moderated a path mediated by transport problems from working in the community to loneliness. This model analysed variables more proximal to the person and more closely related to the day-to-day lives lived.

The analysis of the model from functional limitations to loneliness found that this pathway was mediated by the level of pain experienced (effect=0.019, SE=0.011, 95% CI=-0.002, 0.050), and that nearly half the effect of functional limitations on loneliness was created by pain (effect=0.498, SE=12.60, 95% CI= -0.887, 5.885). This model revealed that those with higher functional limitations were not lonelier per se than those with lower levels of functional limitations when the effect of pain was accounted for. The literature suggests a complex connection between pain, depression and loneliness (Jaremka et al., 2014), and supports reports concerning the isolating effects of pain (Biro, 2011). The direct pathway between functional

limitations and loneliness was conditional on depressive symptoms while the indirect pathway was not. This suggests that those with higher functional limitations were more likely to experience pain, and how they experienced this pain isolated people directly. Other research has found that loneliness promotes the development of pain (Jaremka et al., 2014) and depression (Cacioppo et al., 2010). It is possible that there is a cognitive triad where pain, loneliness and depression interact with each other, similar to those triads hypothesised by Cohen-Mansfield and Parpura-Gill (2007) and Beck (1972).

The direct path from functional limitations was conditional upon depressive symptoms. The conditional effects table revealed that those at the highest end of depressive symptoms, with high functional limitations, were more likely to be lonely.   Previous research with older people residing in nursing homes has found functional limitations, loneliness and depression are linked to each other (Jongenelis et al., 2004). Others have also found reciprocating relationships between loneliness and functional health, loneliness and depression, and loneliness and self-rated health (Luo et al., 2012). In people with an ID higher functional limitations usually signal an experience of less lifestyle control. In the wider population, it has been found that where people do not have control of their lives they are more likely to experience paralysis of will (Beck and Alford, 2009) and feel they are unable to alter their circumstances and change their life or their expectations. These feelings of hopelessness are characteristic of depression and are known to be associated with loneliness (Cacioppo and Patrick, 2008). For people with an ID, feelings of helplessness are the component that directly moderates loneliness in those with higher functional limitations.

Experiencing depressive symptoms also increases the chances of feeling lonely for those who do not work in the community, and for those who work in the community and have difficulty with transport. While the interactions were not significant (direct path coefficient=-0.062, indirect path coefficient=0.027) analysis of the conditional effects tables reveal that from the 75th percentile of depressive symptom scores there was a significant effect on the paths. The reversal in signs of the coefficients implied that for those who work in the community and have transport issues, if they have high depressive symptoms, they were more likely to be lonely. Meanwhile, those who do not work in the community and have high depressive symptoms were more likely to feel lonely. This suggests that those with depressive symptoms are more likely to experience the wish to escape their current situation, but feel helpless to make changes (Beck and Alford, 2009). Transport issues for people with an ID were documented as negatively affecting the social lives of people with an ID (Bane et al., 2012). In the general population poor public transport also leaves people unable to access resources (Burholt and Scharf, 2013). Anything that constrains a person's chance for broadening their social contacts increases the likelihood of a person feeling lonely (Perlman and Peplau, 1998).

This population has been reported as experiencing higher levels of depression than the general population (McCarron et al., 2014), and since the cognitions of depressive symptomology are shown to enhance people's possibility of experiencing loneliness, then service providers should tackle people's depressive symptoms, which should create benefits all round.

6.4.3   Limitations

This study used data that was exclusively from the top functioning people with an ID, limiting the generalisability of the findings.   However, these findings do reflect those from the general population and indicate the importance of depressive-style thinking in the development of the experience of loneliness.   Future research is needed into how a broader section of the population of older people with an ID can be included in loneliness research.

This is the first study to ever consider the role of attributions in people with an ID as they relate to loneliness. Depressive symptoms in this study did not moderate the mediated pathways, indicating that either some variables can directly cause loneliness, or because they are self-reported measures, they may already include an element of attribution that may negate the effect of depressive symptoms. Further research is necessary to better understand attributions in people with an ID and their effect on loneliness.

The measures of social participation and the social network used also limit the scope of the findings, and better tailored measures of social relationships are needed. Wave 3 of the IDS-TILDA does include additional measures of social network.

Finally, the available variables limited the number of paths to loneliness that could be analysed. However, this study was able to test models that included variables intrinsic to the living conditions of the person, distal variables, and a model that included more proximal variables moderated by depressive symptoms.

6.4.4   Conclusion

The results support the view that cognitive attributions are a determining factor between feelings of discrepancy in social relations and loneliness, and provide evidence of moderation in pathways between functional limitations, pain, transport, and not working in the community and loneliness. Service providers must recognise that tackling depression in people with an ID will help combat loneliness.

7 Temporal Characteristics of Loneliness

7.1 Introduction

A study of the longitudinal experience of loneliness for older people with an ID has never been conducted. Research with older people has shown that loneliness is an unstable but ever increasing experience, mandated by losses to social resources (Jylhä, 2004; Christina Victor et al., 2008). Understanding the trajectories of loneliness is important because consistent loneliness is considered causal for many health problems. Knowledge of what predicts changes informs as to which events help people escape loneliness and which create feelings of loneliness. Knowing what the formula is to avoid loneliness is helpful in planning the lives of people. Understanding which elements of life offer protection from loneliness or move people out of loneliness is important for the development of services. This research will examine whether research findings on the experience of loneliness from the wider population also apply to the ID population.

7.1.1 Temporal continuity of loneliness

Weiss (1973), argued that loneliness is not be stable and subsides over time; a finding that longitudinal studies partially support (Jylhä, 2004; Christina Victor et al., 2008; Wenger & Burholt, 2004). For an ever-increasing minority, loneliness either remains stable or increases. For example, Jylha (2004) reported that the percentages of older people reporting loneliness rose from 30% to 45% and only 7% recovered from loneliness over 20 years. Three loneliness trajectories have been identified: regenerative, degenerative and existential (Christina Victor et al., 2008). The regenerative trajectory is where people move from experiencing loneliness to not experiencing loneliness; degenerative loneliness, from being not lonely to being lonely; and existential loneliness where loneliness is consistent and a continuing and ongoing nagging fear. Loneliness rates were reported by Victor et al. (2014) in the Hillingdon Loneliness Studies as Regenerative 10%, Degenerative 10% and Existential 14%. The Hillingdon studies also include 59% who were never lonely and a fluctuating category where people oscillate between reporting loneliness and reporting no loneliness (7%) (C. Victor, 2014).

This research answers two questions "what numbers of older people with an ID experience each trajectory of loneliness or never experience loneliness?" and "what are the predictors of the trajectories of loneliness in older people with an ID?"

7.2 Method

7.2.1 Participants

A full description of participants can be found in the Methodology chapter, section *4.2 Participants*, page 51.

This study utilised participants from waves one and two of data collection of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) dataset. The sample was randomly drawn from people aged over 40 on the National ID Database (NIDD). Wave One of the IDS-TILDA recruited 753 participants in 2010 and was broadly representative of the NIDD. Forty-five percent of participants were male, and fifty-five percent were female. Participants ranged in age from 41 to 90 years old with the average age being 54.7 years. The levels of reported ID spread across the categories with 24% having a mild ID, 46% a moderate degree of disability, 24% a severe level of disability and 5% having a profound level of ID.

Wave Two data collection commenced in 2013, and 708 participants responded. The sample remained largely representative of the NIDD.

7.2.2 Measures

Full descriptions of each variable are contained within the methodology chapter. Following is a brief outline of each variable, section *4.3 Measures*, page 56.

Self-labelling Loneliness Item: A self-labelling loneliness item was embedded within both waves of the survey. Table 7-1, reports that there were proportionally more females (59.3%) in this sub-population. The average age of those included was 55.6 years, and the vast majority of participants were either classified as having a mild disability (38.7%) or moderate disability (47.1%). Nearly half of participants in this sub-population resided in community housing (47.1%).

Table 7-1: Demographic information of respondents self-reporting loneliness.

		Wave 1		Wave 2		Answered in Both Waves	
N		384		347		297	
Mean Age		54yrs		56.25yrs		55.67yrs	
Gender							
	Male	167	43.5%	150	43.2%	121	40.7%
	Female	217	56.5%	197	56.8%	176	59.3%
Level of ID							
	Mild	143	37.2%	122	35.2%	115	38.7%
	Moderate	183	47.7%	172	49.6%	140	47.1%
	Other	58	15.1%	53	15.2%	42	14.1%
Living Circumstances							
	Independently	63	16.4%	52	15.0%	47	15.8%
	With family	37	9.6%	33	9.5%	33	11.1%
	Community housing	179	46.6%	157	45.2%	140	47.1%
	Congregated Setting	85	22.1%	86	24.8%	60	20.2%
	Other	20	5.2%	19	5.5%	17	5.7%

Independent variables

All independent variables were taken from wave 1 of data collection, except life events which were taken from wave 2.

7.2.3   Old age variables

The old age variables represent variables that are commonly found as predictive of loneliness in the general population. General demographic variables were; *Age* was categorised into three groups 40-49, 50-64 & 65+; *Living Environment* dichotomized and coded between participants living in urban or rural environments; *Gender* binary coded to, male 0 and female 1 and *Marital Status*, participants responses were binary coded as either married/partnered, coded 1 or not currently married/partnered, coded 0. *Social Participation* was measured using a list of 15 activities, scores were totalled, and those with one standard deviation below the mean classified as low on social participation, scores greater than one standard deviation from the mean were coded as high on social participation and the remainder categorised as average social participation. *Social Network* was measured using a modified Berkman-Syme style measure of social network (Burholt & Scharf, 2013). Scores one standard deviation below the mean were categorised as a small network and scores one SD above the mean, large network with the remainder classified as an average social network. Health issues were represented by; *General Pain*, measured using a single item self-report question on pain, responses were binary coded yes=1 and no=0;   A measure of *chronic conditions* was created, using seven general practitioner diagnosed chronic conditions including hypertension and heart disease, following the methodology utilised by (Burholt & Scharf, 2013); *Functional limitations* were measured using an

11 item self-reported scale that analyses participants physical abilities (Appendix C5) (Fonda and Herzog, 2004). Scores were totalled and categorised with participants scoring one SD below the mean classed as low functional limitations, those one SD above, high functional limitations and the remainder classified as average functional limitations.

7.2.4   ID Specific Variables

The ID specific variables represent those variables that the literature suggests may be predictive of loneliness in this population. Binary coded variables were created for those who had *fallen* in the month prior to wave one, those who experienced *difficulties doing activities*, participants who had a *fear of falling*, *doing activities with friends* and *doing activities with family*. Social/civic inclusion was investigated with a seven item list which included vote in last general election and own a mobile phone. *Holidaying abroad* and *voted in the last election* were significantly associated with the loneliness item and were included in subsequent analyses. The dichotomous variables, having a *personal plan, having an Independent advocate* and *wanting to do more activities* were all binary coded and included in the analysis.

In *Wave Two* information regarding *life events* experienced during the previous twelve months were collected. Participants were given a list of twenty possible options including items such as death of a parent, each option was binary coded.

7.2.5   Analysis

All analysis was conducted using IBM SPSS v23.0.

Participants' responses to the self-labelling loneliness item were grouped as follows: Never Lonely, Scored 0 in both waves of data collection. Not lonely to Lonely, Scored 0 in wave1 and either 1 or 2 in wave2,. Lonely to Not Lonely, Scored 1 or 2 in wave1 and 0 in wave 2,. Consistently Lonely, Scored 1 or 2 in both waves,. Dichotomized variables were created and labelled Consistently Lonely, Never Lonely, Lonely to Not Lonely and Not Lonely to Lonely.

Analysis was then conducted to investigate which variables predict each of these trajectories of loneliness.

The first analysis considered the consistent loneliness category. Variables that predict consistent loneliness in the general population were selected. The characteristics of the sample were tested for differences with the use of cross tabulations. Correlations with consistent loneliness and correlations between independent variables were calculated. Binary logistic regression was conducted utilising the dichotomised consistent loneliness variable as the dependent variable.

Variables were then selected, the literature suggested, with associations between ID and loneliness. Cross-tabulations were performed, correlations with consistent loneliness analysed and inter variable correlations analysed. A binary logistic regression was conducted with consistent loneliness as the outcome variable. The predictor variables comprised the ID specific variables and those variables that were significant predictors of consistent loneliness in the first analysis. Analysis then investigated which variables predicted never being lonely. Variables that were found to reduce the chance of consistent loneliness in the two previous regressions were selected as potential predictors. Correlations with never being lonely were analysed and a further binary logistic regression was conducted.

The changing loneliness variables were investigated by first correlating the individual items in the life events scale with the change from lonely to not lonely, and the not lonely to lonely variables. Binary logistic regression was conducted using the items that were found to correlate significantly with the trajectories of change, as predictor variables of each trajectory.

7.3   Results

7.3.1   Temporal Nature of Loneliness

Table 7-2 reports the movement of participants' feelings of loneliness between the two waves of data collection. Forty-two percent (n=125) of participants reported never or rarely being lonely in both waves of data collection. Twelve percent (n=37) of participants reported no feelings of loneliness in Wave One but experiencing feelings of loneliness in wave two. Nineteen percent (n=57) reported feelings of loneliness in wave 1, but no feelings of loneliness in wave two. Finally Twenty six percent (n=78) of participants reported feelings of loneliness in both waves of data collection.

Table 7-2: Changes in the reported feelings of loneliness in participants between wave 1 and wave2 of data collection

	N	Percent
Never Lonely	125	42.1
From not Lonely to Lonely	37	12.5
From Lonely to Not Lonely	57	19.2
Consistently Lonely	78	26.3
Total	297	100.0

7.3.2   Predictors of Consistent Loneliness

Analyses Using General Population Recommended Variables

Table 7-3 reports the cross-tabulations of variables in the general population recommended analysis with the consistent loneliness variable. The number of participants in the marital status cross tabulation failed to reach the minimum number required in each cell. Females were proportionally more likely than males to be consistently lonely (χ^2=5.871, p<0.05) and those who reported General Pain were more likely to be consistently lonely than those who did not (χ^2=6.618, p<0.05). An independent sample t-test was conducted on the numbers of chronic conditions participants experienced for the consistently lonely (mean=0.513) and the not consistently lonely (mean=0.619); there was no significant difference between the mean scores (t=1.618, df=295, p=0.100).

Table 7-3: Cross-tabulations of general population variables with consistent Loneliness.

Variable	Category	Consistently Lonely			
		Yes	No	χ^2	p
Age	40-49	29	91	2.646	0.266
	50-64	43	100		
	65+.	6	28		
Environment	Rural	8	23	0.023	0.879
	Urban	54	166		
Gender	Male	23	99	5.871	0.015
	Female	55	120		
Marital Status Binary	Single	218	77	0.586	0.444
	Married	1	1		
Social Participation	High	13	27	2.953	0.228
	Medium	53	170		
	Low	12	22		
Social Network	Low	9	38	1.459	0.482
	Ave	53	139		
	High	16	42		
General Pain	No	43	155	6.618	0.010
	Yes	35	63		
Functional Limitations	Low	13	43	0.238	0.888
	Average	44	122		
	High	10	29		

Table 7-4 displays the associations of consistent loneliness with the recommended general population variables. Both gender (rho=0.172, p<0.01) and Chronic conditions (rho=-0.150, p<0.05) were correlated with consistent loneliness. The gender finding confirmed cross

tabulation results that females were more likely to be consistently lonely than males. Also, those with more chronic conditions were less likely to report being consistently lonely between both waves of data collection.

Table 7-4: Correlations between consistent loneliness and general population variables

	Consistent Loneliness	p
Age	0.065	0.321
Living Environment	-0.015	0.822
Gender	0.172	0.009
Marital Status	0.054	0.414
Social Participation	0.007	0.911
Social Network	-0.005	0.940
General Pain	0.122	0.065
Chronic Conditions	-0.150	0.022
Functional Limitations	0.045	0.496

Before conducting the regressions, correlations between the independent variables were checked (Table 7-5). The largest significant correlation was between functional limitations and social participation (rho=0.267, p<0.01) however it did not reach a level that would cause concerns about collinearity. Functional limitations was also correlated significantly with social network (rho=-0.176, p<0.01). Other noteworthy associations were found between age and the number of chronic health conditions (rho=0.227, p<0.01), age and social network (rho=-0.207, p<0.01), social network and social participation (rho=0.186, p<0.01), general pain and gender (rho=0.162, p<0.01), and general pain and functional limitations (rho=0.166, p<0.01).

Table 7-5: Correlations between general population variables

	1. Age	2	3	4	5	6	7	8
2. Environment	-0.014							
3. Gender	0.054	-0.041						
4. Marital Status Binary	0.046	-0.034	-0.015					
5. Social Participation	-0.042	-0.025	-0.075	0.085				
6. Social Network	-0.207**	-0.020	0.030	0.065	0.186**			
7. General Pain	0.011	-0.075	0.162**	-0.058	-0.000	0.028		
8. Chronic Conditions	0.227**	0.037	0.051	-0.004	0.003	0.003	0.071	
9. Functional Ability	0.139*	-0.030	-0.045	-0.061	0.267**	0.176**	0.166**	0.084

*p<0.05, **p<0.01

Logistic regression included 245 participants, with complete data, used the dichotomised independent variable of consistently lonely, or not consistently lonely, and the independent variables of age, living environment, gender, marital status, social participation, social network,

chronic conditions, general pain and functional limitations. The model containing all predictors was statistically significant χ^2 = (13, N 245) = 23.759, p<0.05. The variables accounted for between 9.2% (Cox and Snell R Square) and 13.6% (Nagelkerke R Squared) of variance and correctly classified 76.7% of cases. As shown in Table 7-6, four variables made a significant contribution to the model (being aged between 50-60, gender, general pain and number of chronic conditions). The largest predictor of consistent loneliness was being aged 50-64 when Wave One data was collected, with an adjusted odds ratio (AOR) of 2.11. Participants who reported a greater number of chronic health conditions were less likely to report loneliness over both waves of data collection.

Table 7-6: Logistic Regression Predicting the Likelihood of experiencing consistent loneliness

N=245		%	P	AOR	95% CI
Age					
	40 - 50	41	0.118	1.00	
	50-64	49	0.040	2.11	1.036 – 4.298
	65+	9	0.494	1.53	0.454 – 5.129
Living Environment					
	Urban	87		1.00	
	Rural	13	0.753	1.166	0.448 – 3.033
Gender					
	Male	40		1.00	
	Female	60	0.022	2.22	1.124 – 4.368
Marital Status					
	Single	99		1.00	
	Married	1	0.543	2.713	0.109 – 67.795
Social Participation					
	Low	12	0.535	1.00	
	Average	78	0.636	0.792	0.321 – 1.954
	High	10	0.294	1.361	0.380 – 4.874
Social Network					
	Small	18	0.518	1.00	
	Average	64	0.904	1.531	0.648 – 3.615
	Large	18	0.444	1.073	0.342 – 3.360
General Pain					
	No	67		1.00	
	Yes	33	0.049	1.903	1.004 – 3.608
Chronic Conditions			0.012	0.598	0.400 - 0.893
Functional Limitations					
	Low	22	0.512	1.00	
	Average	64	0.666	0.832	0.360 – 1.921
	High	13	0.537	1.426	0.463 – 4.398

ID Specific Variables

A second logistic regression utilised the significant variables from the first regression with additional independent variables drawn from ID literature. The additional variables were: fall in the last month, experiencing difficulty doing activities, fear of falling, doing activities with family, doing activities with friends outside your house, having a person centred plan, having an independent advocate, voted in last elections, holidayed abroad in the previous 12 months and wanting to do more activities.

Cross tabulations between the ID specific variables and the consistent loneliness variable are reported in Table 7-7. Participants who had experienced falls (χ^2=11.481, p<0.01) were proportionally more likely to be consistently lonely than those who had not. Participants who had difficulty doing activities (χ^2=6.848, p<0.01), participants who had a fear of falling (χ^2=4.902, p<0.05), those who voted in the last election (χ^2=4.190, p<0.05), and those who want to do more activities (χ^2=5.018, p<0.05) were all more likely to be lonely. Those who holidayed (χ^2=3.876, p<0.05) were less likely to be lonely than those who did not.

Table 7-7: Cross tabulations of ID specific variables with consistent loneliness

		Consistently Lonely			
Variable	Category	Yes	No	χ^2	p
Falls	No	57	198	11.481	0.001
	Yes	20	21		
Difficulty doing activities	No	43	156	6.848	0.009
	Yes	34	58		
Fear of Falling	No	36	134	4.902	0.027
	Yes	42	84		
Do activities with Family	No	44	124	0.000	1.000
	Yes	34	95		
Activities with friends o/s the home	No	40	140	3.340	0.068
	Yes	38	79		
Personal plan	No	17	33	1.984	0.159
	Yes	52	172		
Independent advocate	No	41	135	3.534	0.060
	Yes	29	53		
Voted in last Election	No	28	110	4.190	0.041
	Yes	50	109		
Holiday abroad	No	61	143	3.876	0.049
	Yes	17	76		
Wanting to do more activities	No	24	95	5.018	0.025
	Yes	51	103		

The variables were checked and falls (rho=0.208, p<0.01), difficulty doing activities (rho=0.162, p<0.01), fear of falling (rho=0.136, p<0.05), independent advocate (rho=0.126, p<0.042), voted in

the last election(rho=0.126, p<0.05) and wanting to do more activities (rho=0.144, p<0.05) were all positively associated with consistent loneliness. Having holidayed abroad (rho=-0.122, p<0.05) was significantly negatively correlated with consistent loneliness.

Table 7-8: Correlations between ID specific variables and consistent loneliness

	Consistently Lonely	p
Fall	0.208	0.000
Difficulty doing activities	0.162	0.006
Fear of falling	0.136	0.019
Do activities with Family	-0.002	0.974
Do activities with friends o/s the home	0.114	0.050
Personal plan	-0.096	0.113
Independent advocate	0.126	0.042
Voted in last election	0.126	0.029
Holidayed abroad	-0.122	0.035
Want to do more activities	0.144	0.017

The independent variables were checked for collinearity, (Table 7-9) while there were some significant correlations, none were of a magnitude as to create concerns about collinearity; the most noteworthy were between wanting to do more activities and experiencing general pain (rho=0.280 p<0.01). There were also significant correlations between general pain and fear of falling (rho=0.235 p<0.01), fear of falling and difficulty doing activities (rho=0.206, p<0.01), and wanting to do more activities and doing activities with friends (rho=0.210, p<0.01). Age and chronic conditions were significantly associated (rho=0.227 p<0.01), as was age and fear of falling (rho=0.132 p<0.05). Age was additionally related to doing activities with family (rho=0.166, p<0.01). Gender was associated with general pain (rho=0.162, p<0.01), fear of falling (rho=0.124, p<0.05)and holidaying abroad (rho=-0.130, p<0.05). Apart from age, chronic conditions were significantly associated with difficulty doing activities (rho=0.142, p<0.05), with voting (rho=-0.168 p<0.01), doing activities with friends (rho-0.136 p<0.05) and difficulty doing activities (rho=0.125 p<0.05).There were also significant correlations between doing activities with friends and doing activities with family (rho=-0.197 p<0.01) and having an independent advocate (rho=0.163, p<0.01); having an independent advocate was also significantly correlated with doing activities with family (rho=-0.163, p<0.01). Finally, there was a significant correlation between fear of falling and wanting to do more activities (rho=0.149, p<0.05). Including all the proposed variables in the regression analysis, therefore, appeared appropriate.

Table 7-9: Correlations between ID specific independent variables

	Age	2	3	4	5	6	7	8	9	10	11	12	13
2. Gender	0.054												
3. General Pain	0.011	0.162**											
4. Chronic Health	0.227**	0.051	0.071										
5. Fall	0.050	-0.002	0.073	0.004									
6. Difficulty doing activities	0.094	0.060	0.125*	0.142*	0.0029								
7. Fear of Falling	0.132*	0.124*	0.235**	0.010	0.072	0.206**							
8. Do activities with family	0.166**	-0.014	0.020	0.072	-0.025	0.027	0.109						
9. Do activities with friends o/s home	-0.094	0.071	0.136*	0.009	0.016	-0.016	0.017	-0.197**					
10. Personal plan	0.022	-0.022	-0.010	0.042	-0.040	-0.042	-0.027	0.019	0.023				
11. Independent advocate	-0.056	0.023	0.057	-0.019	0.077	0.075	0.118	-0.163**	0.163**	0.040			
12. Voted in last election	-0.041	-0.078	-0.168**	-0.053	0.098	-0.084	-0.009	-0.081	0.102	-0.026	0.042		
13. Holiday abroad	0.014	-0.130*	0.003	-0.029	-0.082	-0.044	-0.023	-0.082	0.050	-0.023	0.059	0.076	
14. Want more activities	-0.011	0.091	0.280**	-0.054	-0.008	0.096	0.149*	-0.006	0.210**	-0.092	0.020	-0.045	0.082

*p<0.05, **p<0.01

The resulting regression model (Table 7-10) was statistically significant χ2 (15, N= 227) = 52.434, p<.001, indicating that it was possible to distinguish between those who were consistently lonely and those who were not. The model as a whole explained between 21% (Cox and Snell R square) and 30% (Nagelkerke R squared) of the variance around consistently loneliness and correctly classified 78% of cases. Table 7-10 gives the significance levels, adjusted odds ratios (AOR) and confidence intervals for independent variables. Four of the independent variables make a statistically significant contribution to the model (having had a fall in the month before participating in Wave One, experiencing difficulties doing activities, holidaying abroad in the previous 12 months and not voting in the last general election). The strongest predictor of reporting consistent loneliness was having had a fall in the past month with an AOR of 3.14. This result means participants who reported having a fall were three times more likely to report consistent loneliness than those who had not had a fall in the past month controlling for all other factors in the model.

Table 7-10: Logistic Regression of ID specific Variables predicting consistent loneliness

N=227		%	p	AOR	95% Confidence Intervals
Age	40-49	39	0.509	1.00	
	50-64	49	0.254	1.55	0.731-3.271
	65+	12	0.808	1.16	0.358 - 3.735
Gender	Male	40		1.00	
	Female	60	0.092	1.88	0.902 - 3.918
General Pain	No	67		1.00	
	Yes	33	0.227	1.58	0.753 - 3.304
Chronic Conditions			0.103	0.68	0.427 - 1.082
Fall in last month	No	86		1.00	
	Yes	14	0.013	3.14	1.277 - 7.725
Experience difficulty doing activities	No	70		1.00	
	Yes	30	0.011	2.62	1.248 - 5.505
Fear of Falling	No	58		1.00	
	Yes	42	0.337	1.41	0.698 – 2.855
Doing activities with family	Yes	42		1.00	
	No	58	0.337	1.36	0.688 - 2.769
Do activities with friends outside house	No	60			
	Yes	40	0.270	1.42	0.692 - 2.932
Personal Plan	No	18		1.00	
	Yes	82	0.273	0.63	0.277 - 1.432
Have an Independent Advocate	No	68		1.00	
	Yes	32	0.396	1.50	0.728 - 3.068
Vote in Last Election	Yes	55		1.00	
	No	45	0.005	0.35	0.168 -0.729
Holidayed Abroad	Yes	33		1.00	
	No	67	0.020	2.60	1.164 - 5.801
Want to do more activities	Yes	58		1.00	
	No	42	0.198	0.61	0.287 - 1.295

7.3.3   Predictors of Never Being Lonely

Which variables predict never being lonely was investigated using binary logistic regression by including variables with AORs that suggested were protective against consistent loneliness. Correlations with never being lonely were conducted (Table 7-11). Wanting to do more activities was significantly negatively correlated with never being lonely (rho=-0.221, p<0.01) as was functional limitations (rho=-0.141, p<0.05) whilst having a personal plan was positively associated with never being lonely (rho=0.140, p<0.05).

Table 7-11: Variable correlations with the never being lonely variable

	Never lonely	p
Social Participation	0.000	0.997
Chronic Conditions	0.052	0.376
Functional limitations	-0.141	0.017
Personal plan	0.140	0.020
Voted in last Election	0.015	0.800
Want to do more activities	-0.221	0.000

The regression model was statistically significant χ² (8, N= 241) = 20.515, p<.01, indicating that it was possible to distinguish between those who were never lonely and those who were not (Table 7-12). The model as a whole explained between 8.2% (Cox and Snell R square) and 10.9% (Nagelkerke R squared) of the variance around never being lonely and correctly classified 63.1% of cases.

Three variables were significant predictors of never being lonely; functional limitations, person centred plan and wanting to do more activities. Being of average or high functional limitations significantly reduced a person's chance of never being lonely. Having a person centred plan increased the chances of never being lonely and wanting to do more activities significantly decreased the chances of never being lonely.

Table 7-12: Binary logistic regression for predictors of never being lonely

N=241		%	p	AOR	95% Confidence Intervals
Social Participation	Low	12		1.00	
	Med	35	0.509	0.732	0.290 - 1.848
	High	53	0.694	0.835	0.340 – 2.050
Chronic Health			0.349	1.173	0.840 – 1.637
Functional Limitations	Low	22		1.00	
	Average	63	0.030	0.468	0.236 - 0.928
	High	15	0.027	0.338	0.129 - 0.884
Person Centered Plan	No	18		1.00	
	Yes	82	0.035	2.25	1.058 – 4.785
Voted in Last Election	No	46		1.00	
	Yes	54	0.682	0.890	0.510 – 1.554
Wanting to do More Activities	No	43		1.00	
	Yes	57	0.004	0.447	0.259 -0 .774

7.3.4   Changes in Loneliness

The items from the life events scale were correlated with the Lonely to Not Lonely variable and the Not Lonely to Lonely variable. Only moving within the service organisation was associated with moving from not lonely to lonely (rho=0.145 p<0.05). Change in the frequency of visits from family or friends (rho=0.134 p<0.05) and major illness or injury (rho=0.115 p<0.05)   correlated with moving from lonely to not lonely.

7.3.4.1   *Lonely to Not Lonely*

The regression model was statistically significant χ^2 (2, N= 293) = 7.043, p<0.05, indicating that it was possible to distinguish between those who moved from Lonely to Not Lonely and those who did not (Table 7-13). The model as a whole explained between 2.4% (Cox and Snell R square) and 3.8% (Nagelkerke R squared) of the variance around lonely to not lonely and correctly classified 81.6% of cases. Changes in the frequency of visits was a statistically significant predictor of change in the loneliness experience. Those who said they had changes in frequency of visits were 4.3 times more likely to move from lonely to not lonely than those who did not.

Table 7-13: Binary logistic regression for variables predicting moving from lonely to not lonely

N=293		%	p	AOR	95% Confidence Intervals
Frequency of Visits	No	97		1.00	
	Yes	3	0.044	4.366	1.039 – 18.348
Major Illness or Injury	No	94		1.00	
	Yes	6	0.072	2.678	0.915 – 7.841

7.3.4.2   *Not Lonely to Lonely*

The regression model was statistically significant χ^2 (1, N=293) = 5.121, p<0.05, indicating that it was possible to distinguish between those who moved from being Not Lonely to lonely and those who did not (Table 7-14). The model as a whole explained between 1.7% (Cox and Snell R square) and 3.3% (Nagelkerke R squared) of the variance of the Not Lonely to Lonely variable and correctly classified 87.7% of cases.

Moving Within the Service Organisation was a significant predictor of going from Not Lonely to Lonely and those who indicated they had moved within the organisation were 2.8 times more likely to become lonely than those who did not.

Table 7-14:Binary Logistic regression with variables predicting movement from not lonely to lonely

N=293		%	p	AOR	95% Confidence Intervals
Moving within the Service Organisation	No	88		1.00	
	Yes	12	0.017	2.840	$1.210 - 6.665$

7.4   Discussion

Loneliness in this population is caused by changes and disruptions, and it is maintained by not having the ability to fulfil social desires because of decline, pain, and reliance on others. Perceived quality of network is the key to the prevention of and redemption from loneliness, and can be achieved through the individualisation of a person's services.

Twice as many older people with an ID remain consistently lonely than do older people in the general population. This is the result of predisposing elements, such as age and being female, combining with precipitating events such as pain, falling and having difficulty doing activities. Pain isolates a person emotionally and physically, falling represents decline in abilities, and those that have difficulty doing activities are reliant on others. Loneliness is brought about by changes to services which disrupt people's social supports. On the positive side, more people moved out of loneliness than into loneliness, partially as a result of improvements in contacts with families. Those who are able to avoid loneliness are more likely to have fewer functional limitations and have a person-centred plan. This research investigated the temporal experience of loneliness in older people with an ID. The results showed that 26% of people were consistently lonely, 19% recovered from loneliness, 13% of participants became lonely and 42% of participants never experienced feelings of loneliness. The predictors of consistent loneliness in older people with an ID were being aged 50 to 64, being female, experiencing general pain, having a smaller number of chronic conditions, falling, experiencing difficulty doing activities, voting in the last election and not holidaying abroad. The predictors of never being lonely were low functional limitations, having a person-centred plan, and not wanting to do more activities. Those classified as moving from lonely to not lonely were predicted by a change in the frequency of visits from family and friends. Moving from not lonely to lonely was predicted by moving within the service organisation.

7.4.1   Consistent Loneliness

Loneliness in this population is not temporally stable and people can recover from feelings of loneliness. However, it remains a stable construct for nearly double the amount of older people with an ID than it does for older people in wider society. Consistent loneliness has previously been found to cause significant health problems for those who experience it (Cacioppo et al., 2000, Hawkley and Cacioppo, 2010), which means double the number of people with an ID are being exposed to health problems than in the general population. Four specific trajectories of loneliness were examined: never lonely, consistently lonely, moving from lonely to not lonely, and moving from not lonely to lonely. For a substantial minority of people, the experience of loneliness was indeed a constant and ever-present reality. Worryingly, for those with ID the percentages of individuals reporting consistent loneliness were much greater than reports for the general population.   Victor (2014) reported 14% of participants as always lonely when questioned at multiple points over a single year, and examining loneliness over ten years Jylha (2004) reported 17% of participants as lonely at both time points. The high levels of consistent loneliness found in this study confirm other findings, which report people with an ID as lonelier than the general population, despite having more social activities (Stancliffe et al., 2010; Bane et al., 2012). High levels of loneliness in this population are maintained because, the older people are, the more likely they are to be reliant on others and to be unable to overcome disruptive events.

As people with an ID age they are more likely to experience events that leave them unable to break free from feelings of loneliness. Participants aged between 50 and 64 (AOR=2.11, $p<0.05$, 95% CI=1.036, 4.298) were twice as likely to experience consistent loneliness than those aged 40 to 50, and those aged 65+ are one and a half times more likely to feel consistently lonely than those in the 40 to 50 age group (AOR=1.513, $p>0.05$, 95% CI=0.454, 5.129). This finding is in keeping with research into general ageing populations, which has found that as people move into old age, they are more likely to experience loneliness (Jylhä, 2004). Researchers have claimed an accrual of losses precipitates loneliness in old age, with many of the losses being beyond the control of the individual (Wenger and Burholt, 2004). Here too, increasing age is significantly associated with an increase in chronic conditions (rho=0.227, $p<0.01$), a reduction in social network size (rho=-0.207, $p<0.01$), increased functional limitations (rho=0.139, $p<0.05$) and a fear of falling (rho=0.132, $p<0.05$). While chronic conditions were protective against consistent loneliness, fear of falling, increased functional limitations and a reduced social network are indicative of increased reliance on others, which in itself creates a feeling that all desired social activities cannot be achieved.

The second predisposing variable is gender and, similar to reports for the general Irish ageing population (Timonen et al., 2010), females in this study were twice as likely to be consistently lonely as males (AOR=2.22, $p<0.05$ 95% CI=1.124, 4.368). Two arguments are offered to explain

this finding. First, females report as lonelier because women live longer than men and have an increased chance of accruing the losses that create loneliness (Hawkley et al., 2008). To date, there is no evidence that females with ID outlive males (McCarron et al., 2015, Lauer and McCallion, 2015). The second explanation is that men are less likely to admit to loneliness, when asked in a direct question. In this population, females are more likely to experience events that isolate them and make them reliant upon others. Being female positively associates with experiencing pain (rho=0.162, p<0.01), which isolates a person from their network, both emotionally and physically, and with experiencing fear of falling (rho=0.124, p<0.05).

Pain isolates a person both physically and emotionally; a person suffering cannot focus outward on social activities, and others cannot understand the experience of pain (Biro, 2011). General pain for people with an ID is often untreated and underreported (McCarron et al., 2011) and it can be more profound in this population as an inability to adequately communicate their experiences can lead to misdiagnosis by healthcare professionals, and in under-treatment (McGuire, Daly, & Smyth, 2010), which in some cases may result in behaviour that further isolates the individual from the group. Those experiencing general pain were nearly twice as likely to experience feelings of loneliness (AOR=1.903, p<0.05, 95% CI=1.004, 3.608). This finding replicates results in findings of the antecedents of loneliness in this population by the same author, and extends other Irish findings (Cleary, 2011).

Loneliness is often brought on by a single precipitating event, and having a fall is such an event in the lives of older people with an ID. Falling represents not only a disruption to the established way of life but also an increased reliance on others. The effects of having a fall are quite striking in that a person who fell in the month before Wave One was three times more likely to be lonely than a participant who did not fall (AOR=3.14, p<0.05, 95% CI=1.277, 7.725). Falling was not significantly associated with any other variable, further demonstrating that the disruption caused is significant enough to create the separation between desired and achieved social contact (Weiss, 1973, Victor et al., 2008, Perlman and Peplau, 1998). No previous research has reported such a connection between falling with loneliness, and this deserves further and systematic investigation to extend the understanding of loneliness in older people with an ID.

Those who experience difficulties doing activities rely on others to assist them (McCarron et al., 2011), and a reliance on others means people have a restricted access to their desired social outlets (Burholt and Scharf, 2013). People who reported experiencing difficulty doing activities were more than twice as likely to be lonely than those who did not (AOR=2.62, p<0.05, 95% CI=1.164, 5.801. Those who had difficulty doing activities were more likely to experience pain (rho=0.125, p<0.05), have an increased number of chronic health conditions (rho=0.142), and

have a fear of falling (rho=0.206, p<0.01). This finding concurs with McVilly et.al (2006), who found that the loneliest category of people with ID were those who needed the most support in doing activities. Having difficulty doing activities disrupts the perceived quality of relationships.

The importance of quality social relationships were shown in the role of holidaying abroad, which reduced the risk of consistent loneliness (AOR=2.600, p<0.05, 95% CI=1.164, 5.801). Because a person with an ID is unlikely to be able to plan and execute a holiday abroad alone, it indicates a level of stability and quality in relationships. A second indicator of the importance of perceived quality relationships is in the variable chronic conditions, where an increase in the number of chronic conditions is protective against loneliness (AOR=0.598, P<0.05, 95% CI=0.400, 0.893).

Chronic conditions lead to improved quality relationships because as people age and the number of chronic conditions increases, this leads to people receiving closer attention from staff and being drawn into the caring centre of services. This finding is contrary to findings in the general population where the number of chronic health issues leads to further isolation and an increased risk of being consistently lonely (Burholt and Scharf, 2013). Chronic conditions are associated with age (rho=0.227, p<0.01) and having difficulty doing activities (rho=0.142, p<0.05). The greater the number of chronic conditions a person has, the more likely they are to receive close attention from staff (Bane et al., 2012). This close level of attention, leads to relationships developing between service users and staff, which help overcome loneliness.

Voting in the last election is an act of active solitude, where people find ways to busy themselves to deal with their loneliness (Perlman and Peplau, 1998). Acts of active solitude do not have any personal value or benefit but instead may contribute to greater feelings of loneliness (Cacioppo and Patrick, 2008). Those who voted were more likely to be consistently lonely (AOR=0.350, p<0.05, 95% CI=0.168, 0.729). Voting is an activity with public benefits but no emotional bond for older people with an ID. What actually benefits a person with an ID can be further understood by considering the participants that never reported feelings of loneliness.

7.4.2   Never Lonely

While more people with an ID reported consistent loneliness, the numbers who were never lonely were in line with expectations from the general population. The percentage of people reporting no feelings of loneliness in both waves of data collection at forty-two percent was in the mid-range of the general findings of Victor (2014) and Jylha (2004), at fifty-two percent and thirty-nine percent respectively. Those who are never lonely are among the most able and have an individualised service that fulfilled their social desires.

Functional limitations predispose the kind of life a person with an ID can lead. People with few functional limitations lead a more independent lifestyle, which allows them to develop social lives to their liking. Participants who were of average functional limitations (AOR=0.468, p<0.05, 95% CI=0.236, 0.928), and high functional limitations (AOR=0.338, p<0.05, 95% CI=0.129, 0.884), were both less likely to be never lonely than those of low functional limitations.   Others have reported that functional limitations operate through limiting the amount of social interaction available to a person, in both the ID population (Gilmore and Cuskelly, 2014), and the general population (Wenger and Burholt, 2004). In this population, functional limitations were associated with both the amount of social participation (rho=0.267, p<0.01) and social network (rho=0.176, p<0.01).

Individualising a person's service through person-centred planning gives people a degree of control over the types and amounts of activities they take part in, increasing their chances of never being lonely (AOR=2.25, p<0.05, 95% CI=1.058, 4.785). Person-centred planning has been demonstrated to support self-determination (Robertson et al., 2001), and gives people a choice over the construction of social lives (Broer et al., 2010). Individually tailoring interventions to prevent and reduce loneliness has been successful in combatting loneliness in both the general population (Lawlor et al., 2014) and the ID population (Broer et al., 2010), therefore, tailoring a person's service to meet their needs will also help overcome their loneliness.

People who are never lonely have a social life that meets their desires. Those who wanted to do more activities are only half as likely to be lonely as those who did not want to be lonely (AOR=0.446, p<0.01, 95% CI=0.259, 0 .774). Not wanting to do more activities reflects no mismatch between desired and achieved social relations, supporting the CDA to loneliness (Perlman and Peplau, 1998).

7.4.3   Changes in Reported Loneliness

Individualisation of services created a situation where more people moved out of loneliness between the two waves of data collection than moved into loneliness (19% and 12.5% respectively). This finding was inconsistent with research on other older population groups, where, as participants aged, more people moved into loneliness than recovered from loneliness (Jylhä, 2004; Wenger and Burholt, 2004; Aartsen and Jylhä, 2011; Victor, 2014). Those who reported changes in the frequency of visits from family or friends were more likely to move from being lonely to not lonely than those who did not. Other research has found strong links between loneliness and links to family and friends in people with an ID (McVilly et al., 2006), with increased contact with family and friends being associated with less loneliness (Stancliffe et al., 2010).

Moving within the service organisation disrupted the lives of people with an ID and caused them to move from not having feelings of loneliness to experiencing feelings of loneliness (AOR=2.840, p<0.05, 95% CI=1.210, 6.665). Disrupting a person's life is often found to precipitate loneliness (Weiss, 1973, Victor et al., 2008). Situational life changes lead to temporary experiences of loneliness from which people often recover (Peplau, 1988). The loneliness created by moving within the service provider should only be temporary, and people will adjust their expectations to the new situation, but this will need further investigation.

The results support the perspective that the experience of loneliness can be chronic, temporal transient, or situational (Peplau, 1988), adding new information to the discourse on a previously un-researched population further strengthens these assertions.

7.4.4   Implications

Service providers need to take prompt action to tackle the high levels of consistent loneliness found in this study. This can be done through the effective use of the person-centred planning process to give a person a sense of control and ownership of their social experiences. However, over 96% of participants had personal plans, and person-centred planning is failing to deliver beneficial results for a large number of individuals. Service providers need to be cognisant of who the people most likely to be consistently lonely are, and develop strategies within the person-centred planning process that ensure people who are having difficulty in doing activities, those in pain, and those whose abilities are deteriorating, are facilitated in achieving their social goals. When service disruption occurs, the consequences on each individual should be considered, and resources should be mobilised to minimise the disruption and ensure people are able to adjust to the changed environment as quickly as possible.

7.4.5   Limitations

The use of a single item loneliness measure may be more limiting than an established loneliness scale, but in this case its use better permitted comparison across studies which also used a single item measure.

The results only explain a limited amount of the variance of each trajectory. So while they provide insights not currently available in the literature, more research is needed to explain more of the variances. Qualitative research approaches may create a broader understanding and generate further useful areas for quantitative research.

7.4.6   Conclusion

This research is the first to report on the temporal nature of loneliness in older people with an ID. The results show that individuals with an ID experience nearly twice the reported levels of consistent loneliness than the general population. Females and older individuals are more likely to be exposed to the events that precipitate consistent loneliness, which is predicted by isolation, decline, and reliance on others. Perceived quality of networks are protective against consistent loneliness. On the positive side, more people moved out of loneliness than moved into loneliness, which is an unusual finding in an ageing cohort. This benefit was brought about by use of personalised planning to give people control over their social lives. Moving within the service organisation precipitated the move into loneliness, and service providers need to ensure the effects of change are considered at an individual level.

These results support the CDA to loneliness and previous research into the temporal trajectories of loneliness. The results highlight that while the variables may be different for people with ID, the outcomes are the same. Such findings should cause service providers to take note of the serious nature of the loneliness problems of many of the people for whom they are tasked with caring. This research should guide services on how to start planning for the prevention and the eradication of loneliness.

8   Consequences of Loneliness: Reactions and Coping

8.1   Introduction

The final element of the Cognitive Discrepancy Approach to Loneliness (CDA) is Reactions and Coping (Perlman & Peplau, 1998). How a person reacts to the effects of loneliness and how they cope with loneliness are areas that have never been considered in older individuals with an ID.

When loneliness persists over a long time, it has grave consequences for health and wellbeing. Loneliness has adverse effects on a person's health (Lynch, 1977) and has been associated with increased systolic blood pressure (SBP) (Ong et al., 2012), and chronic loneliness has been found to increase SBP (Louise C. Hawkley et al., 2010). Moreover, loneliness has been reported as altering a person's lifestyle and their reactions to stress (Louise C. Hawkley & Cacioppo, 2007). In their social environment model Hawkley and Cacioppo (2007) argue that there are five distinct pre-disease paths through which loneliness negatively influences a person's physiological resilience (Figure 8-1). The five paths are health behaviours, exposure to stressors and life events, perceived stress and coping, stress response and recuperative processes.
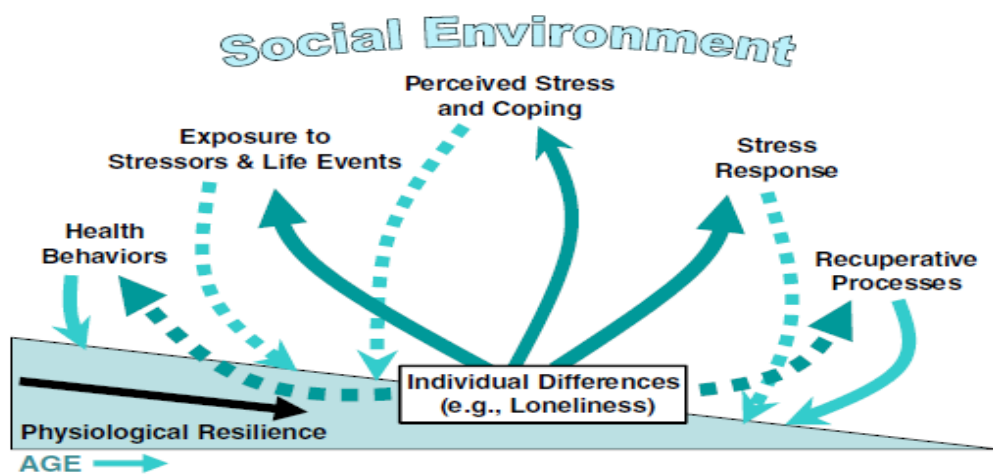
Figure 8-1: Hawkley and Cacioppo's (2007) paths to reduced physiological resilience. Reproduced from "Ageing and Loneliness: Downhill Quickly?" by L.C. Hawkley and J.T. Cacioppo in *Current Directions in Psychological Science 16(4)* p188. Copyright 2007 from The Association for Psychological Science. Reproduced with permission.

In describing this model Hawkley and Cacioppo (2007) discussed variables for each path that they argued had a detrimental effect on the person (Table 8-1). They argued that lonely people have worse health behaviours than the not lonely, and are less likely to take part in vigorous exercise,

eat a less healthy diet, have a higher BMI and were more likely to smoke. In the exposure to life events and stressors path, they said that lonely older people were exposed to a larger number of life events and they found these life events more stressful. In the coping path, they found that lonely people were less likely to seek support but were more likely to be members of a religious group. For the stress response path, Hawkely and Cacioppo (2007) reported that lonely older people had raised SBP. Finally, in the recuperative processes path, they indicated that lonely people had poorer sleep quality. This model was hypothesised describing research that involved a variety of different methodologies leaving no consistent way of interpreting the results. Lauder et al. (2006) produced a method of analysing the health behaviours of lonely people, through the use of proportions, ANCOVA, and Binary logistic regression.   The use of three different techniques allows an understanding of the relationship between loneliness and the variable to be understood. The use of proportions gives an understanding of how the numbers in each category of loneliness are dispersed, in the effect being analysed. ANCOVA allows an understanding of the mean scores, taking into account any variables that may influence the result. Binary logistic regression was run with the path variable as the dependent variable, providing an understanding of the role of loneliness in the variable.

Table 8-1: Variables described by Hawkley and Cacioppo (2007) in their health pathways model.

Description	Variable Name	Details from Hawkley and Cacioppo (2007)
Path 1 Health Behaviours	Vigorous Physical Activity	Non-lonely older adults were 37% more likely to have taken part in vigorous physical activity in the previous two weeks
	Healthy Diet	Lonely older people reported a less healthy diet.
	BMI	BMI of the not-lonely group was 26.26 and 27.08 in the Lonely group. Analysis of covariance revealed that the higher mean BMI in the lonely was significant.
	Smoking	Loneliness found to be associated with smoking
Path 2 Exposure to Stressors	Objective stressors	Lonely older adults had a larger number of current objective stressors 6.0 as opposed to 4.8 for non-lonely older adults
	Potency of Stressors	Lonely people report the effect of stressors as more potent
Path 3 Coping	Emotional support	Lonely people are less likely to seek out emotional support
	Religious Affiliation	Lonely adults over 57 more likely to be members of a religious group.
Path 4 Physiological Response	SBP	Loneliness is a significant predictor of systolic blood pressure. Age x Loneliness Interaction SBP was higher by 0.7mmHg per standard deviation of loneliness for each additional year of age
Path 5 Rest and Recuperation	Time to Fall Asleep	Lonely older adults took longer to fall asleep than did non-lonely
	Day Time Fatigue	Lonely younger and older adults suffer more daytime fatigue
	Sleep dysfunction	Lonely older adults had higher Global score of sleep dysfunction Measured using the Pittsburgh Sleep Quality Index (PSQI). Combination of all scores from 7 questions found sleep disturbances were
	Sleep disturbances	Higher in lonely older adults. How often is your sleep disturbed by waking in the night or early morning? Use of bathroom? Breathing problems? Coughs or snores? Feeling too cold? Feeling too hot? Bad dreams? Pains? Other?

How lonely older people with an ID react to and cope with loneliness has never been investigated, and answers the research question, "What are the effects of loneliness on how people react to and cope with loneliness?" as well as the hypothesis, loneliness will have an adverse impact on each of the five paths that influence physiological resilience.

8.2   Methods

8.2.1   Participants

A full description of participants can be found in the Methodology chapter, section *4.2 Participants*, page 51.

Participants for this study were drawn from Wave One and Wave Two of IDS-TILDA data collection. The sample was randomly drawn from people aged 40 and over from the National ID Database (NIDD). Wave One of the IDS-TILDA recruited 753 participants, the sample was demographically and geographically representative of the NIDD. Wave Two data collection commenced in 2013, and 708 of the original 753 participants responded. The sample remained largely representative of the NIDD.

8.2.2   Measures

A full description of each variable was previously reported in the Methodology Chapter, section *4.3 Measures*, page 56.

Loneliness and Social Connectedness

The loneliness and social connectedness scale consisted of seven questions, including the Three-Item Loneliness Scale (Hughes et al., 2004) and a self-labelling loneliness item (Appendix C2). To allow the variable to be used in a binary logistic regression, the variable was binary coded following the methodology of Pikhartova et al. (2015). Categorising for binary coding entailed labelling those in the bottom three quartiles, scoring between 4 and 6 as not lonely (n=246), which equated to 77.6% of participants who had answered the loneliness scale. Lonely participants were the top quartile who scored greater than six on the scale (n=71) and were 22.4% of participants of this subpopulation.

Consistent loneliness: The two-part self-labelling loneliness item was embedded within both waves of the survey. Participants who were either sometimes or almost always lonely in both waves of data collection were categorised as being consistently lonely.

All variables in the health variables were taken from the second wave of data collected. Variables were selected that approximated those described by Hawkley and Cacioppo (2007).

Path 1 - Health Behaviours

Path 1 included four binary coded variables, *Vigorous Activity, Moderate Activity, Mild Activity* and *Smoking*. A measure of *Body Mass Index* (BMI) was created for each participant using either

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height/weight or ulna measurement (Elia, 2003). BMI was binary coded with underweight, normal weight and overweight coded zero and Obese coded one. *Self-reported diet* was binary coded between excellent and very good, and good, fair or poor coded zero.

Path 2 – Exposure to Stressful Events

The numbers of *Life events* experienced over the previous 12 months were counted, and participants were classified as either high on the number of life events experienced or normal. Participants who had experienced a life event were asked how stressful they found the event and were scored as to the level of stress experienced. The stresses caused by life events were divided into three categories *Social Stress, Relationship Stress* and *Service Stress*.

Path 3 - Coping

The coping mechanisms tested were being a *Church Attender* and *confiding* in different groups, family, friend, staff and other, responses were binary coded.

Path 4 – Health

Systolic Blood Pressure (SBP) has been demonstrated as being affected by loneliness (Ong et al., 2012). SBP was measured using an Omron 10 device the results were binary coded into two categories, those with a score over 120mmHg were coded as high SBP and those without high blood pressure.

Path 5 – Recuperation

There were four sleep variables *Trouble Falling Asleep, Interrupted Sleep, Waking Too Early* and *Daytime Sleeping*. Variables were dichotomised based on percentile. An overall *sleep scale* was tested. Scores were binary coded between having difficulty sleeping, and no difficulty sleeping.

Co-Variates

Functional Limitations were included as a covariate in the analysis because they feasibly offer a viable alternative to loneliness as a cause of many of the health variable. It would be possible to argue that loneliness was only an outcome of functional limitations for this variable.

Gender was included as a covariate because previous analysis found gender to be a significant predictor of consistent loneliness and analysis often associates gender with loneliness. Being female potentially represents many of the alternative explanations associated with the variables tested.

8.2.3   Analysis

All statistical analysis was undertaken using SPSS v23.0

Two loneliness variables were used to examine how participants react to and cope with loneliness, the cross-sectional loneliness and social connectedness scale variable, which gives a complete coverage of loneliness and the consistent loneliness variable.

Analysis followed the three step approach undertaken by Lauder et al. (2006).

Cross tabulations were constructed. Each path variable was cross tabulated, first with the loneliness scale variable, and then the consistent loneliness variable. This produces proportions of the lonely that were relative to each variable. The tables were tested for independence using chi-square.

Separate analyses of covariance (ANCOVA) were conducted. The ANCOVAs included the loneliness scale score as the dependent variable and a path variable as the independent variable. Functional limitations and gender were covariates.

Binary logistic regression was used to investigate the role of loneliness as a predictor variable of each path variable, functional limitations and gender were listed as covariates. Two series of binary logistic regressions were calculated one incorporating the loneliness scale variable and the second the consistent loneliness variable. The Naglekerke R^2 was calculated, excluding covariates, for each path variable, where either the loneliness scale score, or consistent loneliness was found to be a significant predictor, of a path variable. Calculating the Naglekerke R^2, in this manor, allows the fit of the loneliness variable into each health variable to be understood. Nagelkerke R^2 is one of the two pseudo-R^2 measures available in SPSS v 23.0, and offers the benefit over the Cox-Snell method of being scaled 0-1.

For all analysis, ninety-five percent bootstrap Bias-Corrected and Accelerated confidence intervals were produced with 5,000 cases.

8.3   Results

Cross tabulations were calculated, for each health variable against both the dichotomised loneliness scale variable and the consistent loneliness variable (Table 8-2). All cells have more than five participants, allowing chi-squared analysis to be conducted. Analysis of the loneliness scale score found in path 3, that the not lonely on the loneliness scale are more likely to confide in staff (χ^2=6.625 p<0.05). In path 4, those who are lonely, are more likely to have raised SBP

(χ^2=4.424, p<0.05). Analysis of path 5 revealed that those who were lonely were proportionally more likely to have difficulties falling asleep (χ^2=9.176, p<0.01), and waking too early (χ^2=6.539, p<0.05).

Consideration of the cross-tabulations with consistent loneliness shows that in path 2, the consistently lonely, are proportionally, more likely to have a high number of life-events reported (χ^2= 4.847, p<0.05), and are more likely to find service related events stressful (χ^2=4.045, p<0.05). Path 3, Coping with loneliness, shows that the consistently lonely are more likely to be regular church attendees (χ^2=5.392, p<0.05), and they are more likely to confide in others (χ^2=8.677, p<0.01). Those who were consistently lonely, were proportionally more likely to report having trouble getting to sleep (χ^2=5.721, p<.05).

Table 8-3 displays the results of the analysis of covariance, for each variable, in each path. The mean loneliness scores are the loneliness scale scores for each dichotomised group of participants. In each analysis gender and functional limitations were held constant. The largest difference between mean loneliness scores was for those who had difficulty falling asleep (mean = 6.000) and those that did not have difficulty falling asleep (Mean = 5.150). In path 1, participants who do moderate activity have significantly higher loneliness scores (mean = 5.524), than those that don't (mean = 5.221, F=4.171, p<0.05). There were no significant results in Path 2. In Path 3, coping, those who confide in staff (mean = 5.152) have significantly lower scores on the loneliness scale than those who do not (mean = 5.589, F=5.716, p<0.05).

Analysis of SBP in Path 4 reveals, that those who had high SBP scores, had higher mean loneliness scores (mean=5.570) than those who were not lonely (mean=5.137), but the figure failed to reach a level of significance (F=10.207, p>0.05). In Path 5 those who had trouble falling asleep had significantly higher loneliness scores than those that did not have trouble falling asleep (F=13.907, p<0.01). People that reported having disturbed sleep (mean=5.456) had significantly higher loneliness scores than those who did not (mean=5.178, F=3.930, p<0.05). When the individual items of the sleep scale were combined those that recorded higher scores had significantly higher scores on the loneliness scale (F=10.284, p<0.01).

Table 8-2: Cross-tabulations of independent variables the loneliness scale and those consistent loneliness

Health Variable		Loneliness Scale				Consistent Loneliness			
		Yes	No	χ²	P	Yes	No	χ²	p
Path 1 Health Behaviour									
Vigorous Activity	Yes	6	23	0.054	0.817	11	17	2.227	0.136
	No	65	223			64	182		
Moderate Activity	Yes	23	59	2.032	0.134	21	54	0.020	0.886
	No	48	187			54	145		
Mild Activity	Yes	48	168	0.012	0.913	47	140	1.485	0.223
	No	23	78			28	59		
Smoke	Yes	9	22	0.881	0.348	7	20	0.025	0.875
	No	61	221			67	178		
Obese	Yes	31	96	0.299	0.585	33	75	2.656	0.103
	No	26	95			23	87		
Diet	Yes	42	152	0.182	0.669	52	116	2.152	0.113
	No	28	90			23	81		
Path 2 Stress Exposure									
Life Events	Yes	15	38	1.384	0.239	19	28	4.847	0.028
	No	54	204			55	168		
Relationship Changes	Yes	18	72	0.416	0.519	24	55	0.505	0.477
	No	53	174			51	144		
Social Changes	Yes	12	27	1.793	0.181	11	24	0.332	0.564
	No	59	219			64	175		
Service Stress	Yes	18	46	1.513	0.219	21	34	4.045	0.044
	No	53	200			54	165		
Path 3 Coping									
Attend Church	Yes	13	33	1.064	0.302	17	23	5.392	0.020
	No	58	213			58	176		
Confide in Family	Yes	23	73	0.193	0.660	23	58	0.061	0.806
	No	48	173			52	141		
Confide in Friend	Yes	12	25	2.427	0.119	9	25	0.016	0.900
	No	59	221			66	174		
Confide in Other	Yes	11	24	1.846	0.174	15	15	8.677	0.003
	No	60	222			60	184		
Confide in Staff	Yes	38	172	6.625	0.010	50	138	0.182	0.670
	No	33	74			25	61		
Path 4 Health Effects									
High SBP	Yes	32	75	4.424	0.035	26	68	0.122	0.726
	No	21	96			27	79		
Path 5 Recuperation									
Trouble Falling Asleep	Yes	21	35	9.176	0.002	21	31	5.721	0.017
	No	48	206			52	165		
Disturbed Sleep	Yes	31	79	3.223	0.073	30	66	1.165	0.280
	No	39	163			44	131		
Wake Too Early	Yes	19	35	6.539	0.011	16	31	1.290	0.256
	No	49	205			57	163		
Dozing	Yes	49	177	0.386	0.535	49	153	3.402	0.065
	No	21	63			24	43		
Sleep Scale	Yes	27	49	10.607	0.001	24	43	3.238	0.072
	No	41	191			49	151		

Table 8-4 gives the results of analysis of each of the individual binary logistic regression analysis. In this analysis each binary coded variable was the outcome variable, and the binary coded loneliness scale score was the independent variable, with gender and functional limitations entered as covariates. The results indicate the strength of influence of the loneliness variable, with gender and functional limitations held constant. The table details the adjusted odds ratio

(AOR), the B statistic (the original scale coefficient), the standard error of the B value (created with bootstrap analysis), the bootstrap created confidence intervals, and the Naglekerk R^2, for variables where loneliness was a significant predictor. Using this analysis shows the influence of loneliness within each outcome variable.

In Path 3, those who were lonely were less than half as likely to confide in staff as the not lonely participants (AOR=0.464, B=-0.769, SE=0.292, 95% CI=-1.333, -0.237). Loneliness accounted for 2.8% of the confiding in staff variance (Naglekerke R^2=.028).

Analysis of SBP in Path 4, reveals that being categorised as lonely is a significant predictor of having raised SBP. The lonely were twice as likely to have raised blood pressure, with loneliness accounting for 2.6% of the SBP variance (AOR=2.051, B=0.718, SE=0.355, 95% CI =0.019, 1.512, Nagelkerke R^2=0.026). In Path 5 being lonely was a significant predictor of having trouble falling asleep (AOR=2.543, B=0.933, SE=0.342, 95% CI=0.262, 1.631). Loneliness accounted for 4.4% of the variance of the difficulty in falling asleep variable (Naglekerke R^2=0.044). Loneliness was also a significant predictor of waking too early, accounting for 3.2% of the variance (AOR=2.225, B=0.800, SE=0.348, 95% CI =0.103, 1.480, Nagelkerke R^2=0.032). When the individual items of the sleep scale were combined, being lonely was a significant predictor of having sleep difficulties, accounting for 4.7% of the sleep scale variance (AOR=2.526, B=0.927, SE=0.315, 95% CI =0.307, 1.574, Nagelkerke R^2=0.047).

Table 8-3: Analysis of covariance of loneliness scores for each health variables.

Health Variable		Mean Loneliness Score	Sum of Squares	F	p
Path 1 Health Behaviour					
Vigorous Activity	Yes	5.310	0.142	0.055	0.815
	No	5.299			
Moderate Activity	Yes	5.524	10.670	4.171	0.042
	No	5.221			
Mild Activity	Yes	5.264	0.941	0.363	0.206
	No	5.376			
Smoke	Yes	5.687	9.244	3.604	0.059
	No	5.262			
Obese	Yes	5.433	2.703	0.964	0.327
	No	5.206			
Diet	Yes	5.284	0.050	0.019	0.890
	No	5.348			
Path 2 Stress Exposure					
Life Events	Yes	5.604	4.503	1.752	0.189
	No	5.236			
Relationship Changes	Yes	5.189	2.313	0.893	0.345
	No	5.343			
Social Changes	Yes	5.615	4.592	1.779	0.183
	No	5.255			
Service Stress	Yes	5.688	7.496	2.915	0.089
	No	5.201			
Path 3 Coping					
Attend Church	Yes	5.674	5.668	2.199	0.139
	No	5.236			
Confide in Family	Yes	5.313	0.095	0.037	0.848
	No	5.294			
Confide in Friend	Yes	5.730	4.431	1.716	0.191
	No	5.243			
Confide in Other	Yes	5.743	5.751	2.945	0.087
	No	5.245			
Confide in Staff	Yes	5.152	14.557	5.716	0.017
	No	5.589			
Path 4 Health Effects					
High SBP	Yes	5.570	10.207	3.551	0.061
	No	5.139			
Path 5 Recuperation					
Trouble Falling Asleep	Yes	6.000	34.455	13.907	<0.001
	No	5.150			
Disturbed Sleep	Yes	5.456	10.070	3.930	0.048
	No	5.178			
Wake Too Early	Yes	5.722	9.949	3.873	0.050
	No	5.213			
Dozing	Yes	5.266	1.150	0.442	0.507
	No	5.429			
Sleep Scale	Yes	5.816	25.841	10.284	0.001
	No	5.134			

Table 8-5, displays the results of the binary logistic regressions carried out, where each health variable was the outcome variable, consistent loneliness the predictor variable, and gender and functional limitations were covariates. The results indicate the strength of influence of the consistent loneliness within each health variable. The table details the adjusted odds ratio (AOR), the B value (the original scale coefficient), the standard error of the B value (created with bootstrap analysis), the bootstrap created confidence intervals, and the Naglekerk R^2, for variables where loneliness was a significant predictor

In Path1, consistent loneliness predicted, rating diet as either very good or excellent (AOR=2.060, B=0.723, SE=0.328, 95% CI =0.118, 1.457). Consistent loneliness accounted for 1.3% of the reported diet variance (Naglekerke R^2=0.013). Consistent loneliness failed to predict any of the health variables In Path 2. Analysis of Path 3, estimates that consistent loneliness is a significant predictor of attending church regularly (AOR=2.278, B=0.823, SE=0.391, 95% CI =0.043, 1.592), accounting for 3.2% of the variance (Naglekerke R^2=0.032). Consistent loneliness was a significant predictor of confiding in others (AOR=3.392, B=1.221, SE=0.437, 95% CI =0.347, 2.183), accounting for 5.7% of the variance (Nagelkerke R^2=0.057). In Path 5, consistent loneliness was a significant predictor of having trouble falling asleep (AOR=2.205 B=0.791, SE=0.344, 95% CI =0.072, 1.473), and consistent loneliness accounted for 3.2% of the variance (Nagelkerke R^2=0.032).

Table 8-4: Binary Logistic regression for each path variable with the loneliness scale as predictive variable.

Health Variable	AOR	B	S.E.	p	Lower	Upper	R^2
		Bootstrap			95% Confidence Intervals		
Path 1 Health Behaviour							
Vigorous Activity	0.970	-0.030	0.958	0.946	-0.935	0.668	
Moderate Activity	1.873	0.627	0.333	0.054	-0.056	1.285	
Mild Activity	0.948	-0.053	0.312	0.867	-0.629	0.558	
Smoke	1.884	0.557	0.476	0.203	-0.382	1.397	
Obese	1.192	0.176	0.348	0.603	-0.513	0.870	
Diet	0.930	-0.072	0.295	0.798	-0.653	0.531	
Path 2 Stress Exposure							
Life Events	1.418	0.349	0.378	0.339	-0.433	1.043	
Relationship Stress	0.758	-0.277	0.345	0.403	-1.003	0.322	
Social Stress	1.627	0.487	0.428	0.231	-0.410	1.261	
Service Stress	1.359	0.307	0.344	0.353	-0.398	0.949	
Path 3 Coping							
Attend Church	1.319	0.277	0.375	0.450	-0.494	0.972	
Confide in Family	1.172	0.158	0.311	0.603	-0.487	0.765	
Confide in Friend	1.433	0.360	0.444	0.393	-0.549	1.104	
Confide in Other	1.673	0.515	0.413	0.181	-0.354	1.260	
Confide in Staff	0.464	-0.769	0.292	0.008	-1.333	-0.237	0.028
Path 4 Health Effects							
Systolic Blood Pressure	2.051	0.718	0.355	0.039	0.019	1.512	0.026
Path 5 Recuperation							
Falling Asleep	2.543	0.933	0.342	0.005	0.262	1.631	0.044
Disturbed Sleep	1.613	0.478	0.342	0.091	-0.100	1.073	
Wake Too Early	2.225	0.800	0.348	0.015	0.103	1.480	0.032
Dozing	0.858	-0.153	0.320	0.617	-0.764	0.534	
Sleep Scale	2.526	0.927	0.315	0.002	0.307	1.574	0.047

Table 8-5: Binary logistic regressions conducted on health variables with consistent loneliness as the predictor variable.

| Health Variable | AOR | B | SE | p | 95% Confidence Intervals | | R² |
		Bootstrap			Lower	Upper	
Path 1 Health Behaviour							
Vigorous Activity	2.029	0.708	0.462	0.098	-0.263	1.634	
Moderate Activity	1.411	0.344	0.341	0.298	-0.381	1.016	
Mild Activity	0.787	-0.239	0.321	0.436	-0.866	0.430	
Smoke	1.145	0.135	0.819	0.788	-0.818	0.934	
Obese	1.249	0.222	0.373	0.526	-0.512	0.976	
Diet	2.060	0.723	0.328	0.020	0.118	1.457	0.013
Path 2 Stress Exposure							
Life Events	1.872	0.627	0.397	0.091	-0.180	1.367	
Relationship Changes	1.136	0.127	0.344	0.698	-0.601	0.763	
Social Changes	1.224	0.202	0.476	0.646	-0.754	1.030	
Service Stress	1.755	0.563	0.361	0.105	-0.179	1.258	
Path 3 Coping							
Attend Church	2.278	0.823	0.391	0.023	0.043	1.592	0.032
Confide in Family	1.246	0.220	0.325	0.492	-0.415	0.824	
Confide in Friend	0.730	-0.315	0.620	0.484	-1.131	0.321	
Confide in Other	3.392	1.221	0.437	0.001	0.347	2.183	0.057
Confide in Staff	0.738	-0.303	0.316	0.318	-0.924	0.347	
Path 4 Health Effects							
Systolic Blood Pressure	1.339	0.336	0.370	0.356	-0.402	1.133	
Path 5 Recuperation							
Falling Asleep	2.205	0.791	0.344	0.015	0.072	1.473	0.032
Disturbed Sleep	1.417	0.349	0.299	0.235	-0.250	0.941	
Wake Too Early	1.317	0.276	0.366	0.433	-0.476	0.922	
Dozing	0.541	-0.615	0.339	0.057	-1.233	0.011	
Sleep Scale	1.642	0.496	0.323	0.120	-0.158	1.127	

*$p<.05$, **$p<.01$

8.4 Discussion

Older people with an ID experience a heightened state of alert, known as hypervigilance, in reaction to loneliness that promotes poor sleep, raised SBP, a distrust of others and the remembering of more negative lifetime events. Because of the distrust of others, they seek support from people who are unable to help initiate change in their lives. Lonely older people with an ID cope by filling their time with activities aimed at improving their situation, a strategy known as active solitude or active coping. Using data from the IDS-TILDA this study utilised Hawkley and Cacioppo's (2007) model of the effects of loneliness on five pre-disease paths that influence physiological resilience. The five paths described by Hawkley and Cacioppo (2007) were Path 1, health behaviours; Path 2, Stress Exposure; Path 3, Reactions and Coping; Path 4, Health Effects and Path 5, Recuperation. It was argued by Hawkley and Cacioppo (2007) that loneliness

exerts a negative influence on variables within each of these paths, and in combination they have a toxic effect on physiological resilience. Variables from the IDS-TILDA study were selected that closely matched those described by Hawkley and Cacioppo (2007). To ensure all the variables were subject to a consistent analysis strategy a methodology that had been previously used, by Lauder et al. (2006), to examine the role of loneliness on health behaviours, was adopted. The method included analysing the proportions of participants categorised as lonely or non-lonely, and experiencing or not experiencing a health event. The mean differences in loneliness scores were investigated through analysis of variance with the covariates of gender and functional limitations held constant. Binary logistic regressions were created with the dependent variable being one of the health variables, and either loneliness or consistent loneliness being the independent variable, while gender and functional limitations were held constant.

This study had five major findings. First, loneliness predicted sleeping difficulties, primarily difficulty getting to sleep, which was predicted by both loneliness and consistent loneliness. Second, loneliness predicted high levels of systolic blood pressure. Third, older people with an ID coped with loneliness by keeping busy and fourth, being lonely influenced whom people confide in and their attendance at religious services. Finally, people who were lonely reported more life events over a twelve month period. This research offers the first evidence in how older people with an ID react to and cope with loneliness.

8.4.1   Key findings on the impact of loneliness on health

Loneliness affects sleep because of the unconscious scanning for social threats caused by hypervigilance (Hawkley and Cacioppo, 2010). Those who had trouble falling asleep were more likely to be categorised as lonely on the loneliness scale variable (chi-squared=9.176 p<.01), to have significantly higher loneliness scores (F=13.907, p<.01), and being classified as lonely was predictive of having trouble falling asleep (AOR=2.543, B=0.933, SE=0.342, 95% CI =1.63, 0.04). This relationship with falling asleep was also supported in the analysis of consistent loneliness, where those who reported having trouble falling asleep were more likely to be classified as consistently lonely (chi-squared =5.721, p<.05), and were more than twice as likely to have trouble falling asleep (AOR=2.205, B=0.791, SE=0.344, 95% CI =1.473, 0.032). Other sleep problems for the lonely were found in the loneliness scale analysis but were not corroborated in the analysis of consistent loneliness. Those categorised as lonely on the loneliness scale were more liable to report waking too early (chi-squared=6.539, p<0.05), and they had higher loneliness scale scores (F=3.873, p=0.05). Loneliness was found to be predictive of waking too early (AOR=2.225, B=0.800, SE=0.348, 95% CI =0.103, 1.48).

These results support research from the wider population. When people have had their sleeping checked by the use of electronic devices such as nightcaps, researchers have found that lonelier participants have a more disrupted sleep (Kurina et al., 2011), they take longer to fall asleep and have poorer sleep quality (Cacioppo et al., 2000). Sleep counteracts the forces that drain the body, and lower quality sleep does not allow the restorative processes to operate. (Hawkley and Cacioppo, 2007)

Hypervigilance not only reduces sleep quality but it is associated with increased vascular resistance (Cacioppo and Cacioppo, 2014), and increased vascular resistance leads to increased SBP (Hawkley and Cacioppo, 2007). Disrupted sleep has also in turn been found to cause raised SPB (Bonnet & Arand, 2003).

Whatever the mechanism in this population, loneliness caused raised SBP, offering striking evidence about the effects of loneliness. People who were lonely on the loneliness scale score were proportionally more likely to have high SBP (chi-squared=4.424, p<0.05) and loneliness was significantly predictive of raised SBP with the lonely twice as likely to have raised SBP (AOR = 2.051, B=0.718, SE=0.355, 95% CI =0.019, 1.512). This evidence supports research from the wider population where it has been found that for every standard deviation rise in loneliness, SBP is increased significantly (Ong et al., 2012). The effects of loneliness are long lasting and loneliness has been found to raise SBP for over five years after onset (Hawkley et al., 2010). Regular medical intervention in people with an ID keeps their SBP readings below that reported for the wider population (McCarron et al., 2014). The effect of medical intervention meant consistent loneliness was not a significant predictor of having raised SPB, but those who were consistently lonely in this population were still more likely to have raised SBP (AOR=1.339, B=0.336, SE=0.370, 95% CI =-0.402, 1.133). There are other possibilities as to why lonely people have raised SBP and this result may later be found to be an epiphenomenon, but at the moment the weight of evidence supports a causal explanation.

Hypervigilance causes people to be wary of others (Cacioppo and Cacioppo, 2014) and when staff change or service provision changes then the lonely may be wary of staff that are unfamiliar to them, and inadvertently employ coping strategies that perpetuate their loneliness. Whom a person confided in influenced their chances of becoming lonely, and being lonely influenced whom people confided in, creating a cycle of protection or harm. Those who confided in staff were less likely to be lonely (AOR=0.464, B=-0.769, SE=-0.769, 95% CI =-1.333, -0.237), and those who were lonely were more than one and a half times more likely to confide in others (AOR=1.673, B=0.515, SE=0.413, 95% CI =-0.354, 1.260). People who confided in staff were

confiding in someone who could make a difference to underlying issues, whereas the others may not be in a position to have a direct effect on a person's circumstances.

Hypervigilant people remember more negative lifetime events (Cacioppo and Cacioppo, 2014), and in keeping with this, participants who recorded a high number of life events were more likely to be categorised as being consistently lonely (chi-squared=4.087, p<0.05) and consistently lonely participants were over one and half times more likely to have experienced life events (AOR=1.872, B=0.627, SE=0.397, 95% CI =-0.180, 1.367). Life events were experienced as being more stressful by the lonely (relationship stress AOR=1.136, Social stress AOR=1.224, Service stress AOR=1.755). Earlier research reported that the lonely are subject to more stressful life events (Hawkley et al., 2007), but the evidence here argues for a greater remembering of negative life events by the lonely. It is feasible that the increased remembering of life events is due to a general negative attribution style found in the lonely, but this requires further investigation. Service providers should be monitoring the major changes that people are subjected to and ensure supports are put in place, particularly when the changes are brought about by service provision.

People with an ID cope with their loneliness employing an active coping strategy. To do this they undertake activities that are aimed at keeping them busy and changing their environment. This finding is divergent to findings in the general population where the lonely have been described as utilising a coping state of sad passivity, where they eat worse diets, exercise less, and are generally more lethargic than the non-lonely (Hawkley et al., 2008). Lonely participants, in this study, attended church more often (chi-squared=4.538, p<0.05), and those consistently lonely over an extended period of time were more than twice as likely to be a regular church attendee (AOR=2.278, B=0.823, SE=0.391, 95% CI =0.043, 1.592). The lonely did more moderate exercise (AOR=1.873, B=0.627, SE=0.333, 95% CI =-0.056, 1.285), and those who did moderate exercise had higher loneliness scores than those who did not do moderate activity (F=4.171, p<0.05). Likewise, those who were consistently lonely were more likely to do vigorous activity (AOR=2.029, B=0.708, SE=0.462, 95% CI =-0.263, 1.634) and moderate activity (AOR=1.411, B=0.344, SE=0.341, 95% CI =-0.381, 1.016) than those who were not. Additionally, participants in this population were more likely to report their diet as either very good or good (AOR=2.060, B=0.723, SE=0.328, 95% CI =0.118, 1.457). Health behaviours are an area where staff and services often have a direct influence on the life of people with an ID, and staff may intervene if they feel that a person was lonely and encourage them to participate in more activities to improve their social lives and support their health.

8.4.2   Limitations

In analysing the data as reactions to and coping with loneliness, this research is implying causality on the data. To show causality three criteria need to be met; covariation, temporal ordering and elimination of competing theories (Hayes, 2013). This analysis cannot prove causality since it is not an experiment controlling the above conditions. Steps have been taken in the analysis to meet the three criteria. Covariation was dealt with through the type of analysis conducted that showed the variables did have covariation. The analysis addressed temporal ordering by drawing support for the cross-sectional analysis, by using the longitudinal consistent loneliness variable and confirming the results of theorists who have analysed temporal ordering in more detail. Two competing theories were accounted for through the utilisation of the covariates gender and functional limitations.   Obviously, there are more than two possibilities for competing causes of the variables health paths, and these need to be considered with further investigation of the data. This analysis is the first work to look at how older people with an intellectual disability react to and cope with loneliness, and the results confirmed those from the general population, indicating their validity.

It is not known how the positive benefits derived from confiding in staff operated. The explanation of staff being able to make changes in the lives of service users is unsupported.   The role of staff needs further investigation to find if and how staff react to a service user whom they feel is lonely.

The finding that confiding in staff is protective against loneliness was considered to be significant when using the cross-sectional scale but not when using the longitudinal consistent loneliness variable. The finding for the confiding in staff variable was also reflected in other variables. In the case of the confiding in staff variable, the result is supported by the analysis of the consistent loneliness variable, though not significantly, and this is true for other variables. Where variables such as SBP and sleep difficulties were involved it may be that the issues raised may be being dealt with through medication, which would mask the true nature of the association. In general, the results did follow the trend suggested by Hawkley and Cacioppo (2007). Further research is needed to investigate if there has been increased use of medications by those who are consistently lonely.

8.4.3   Conclusion

Loneliness invokes hypervigilance, which creates sleep disruption, raised SBP, wariness of other people, and negative event recall. Loneliness is coped with by engaging in more pastimes, and healthier pastimes, in an attempt to deal with the experience of loneliness. This study was the

first into how older people with an ID react to and cope with loneliness. The research used a model of reactions to and coping with loneliness described by Hawkley and Cacioppo (2007). The model analysed the effects of loneliness on physiological resilience through five pre-disease paths. The paths are health behaviours, exposure to live events, coping, stress response, and recuperation. The model hypothesised that loneliness acts through the five paths to reduce physiological resilience. The study supported the work of Hawkley and Cacioppo (2007), inferring that loneliness caused sleep disruption and raised SBP. Other researchers have proposed a path between loneliness and raised SBP which is mediated by sleep disruption. The analysis also found that those who remain lonely were those who confided in people who may not be able to help them out of their current situation. Those who were consistently lonely were more likely to recall a greater number of life events and find them more stressful. The only path where evidence did not support previous findings was Path 1, where both moderate exercise and improved diet appear to be enhanced by loneliness. However, these may be because of staff interventions with the lonely and an attempt to psychologically satisfy wishes. The analysis in the health behaviours path did find that that those classified as lonely were more likely to smoke and had a slightly raised BMI. These two are measures not subject to self-bias in reporting, and are therefore more trustworthy.

Overall, Hawkley and Cacioppo's (2007) pre-disease paths model of reacting and coping with loneliness has proved a useful tool in this investigation, and the results match those found in the general population. Loneliness was found to predict sleeping difficulties, raised SBP, and not confiding in staff. Consistent loneliness predicted difficulty falling asleep, attending church services regularly, confiding in others, and reporting an excellent or very good diet.

9 Synthesis Model

9.1 Introduction

This research draws together the results from previous studies, by the current author, and creates a model of loneliness in older people with an ID, based on the Cognitive Discrepancy Approach (CDA) to loneliness Perlman and Peplau (1998)(Figure 9-1).

The CDA model provides a framework for understanding the development of loneliness in any population. It explains how predisposing factors such as characteristics of the person, and cultural values and norms influence which precipitating events are likely to cause a break between needed social relations and achieved social relations. This break causes a cognitive discrepancy. The discrepancy can be rectified if a person can adjust their expectations through cognitive attributions and loneliness will be avoided. If a person cannot make cognitive attributions that rectify the mismatch they will become lonely. Previous research has found that the type of attributions made match well to depressive symptomology and the higher a person's depressive symptoms, the more likely they are to be unable to adjust their expectations. Once a person experiences loneliness how they react and cope with loneliness can lead to ill health and physiological decline.
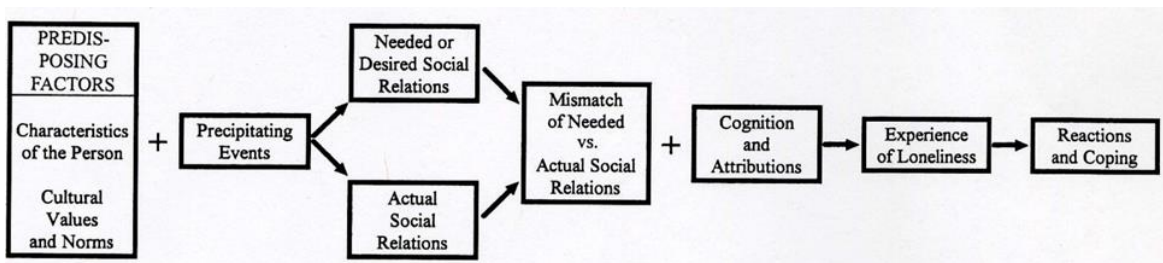
Figure 9-1: The Cognitive Discrepancy Approach to Loneliness (CDA) Perlman and Peplau (1998). Reproduced from "Loneliness" By D. Perlman & L.A. Peplau *Encyclopedia of mental health, 2*, p. 572 copyright 1998 by **Taylor and Francis Group LLC Books. Reprinted with Permission under licence number 4270990436999.**

Analysis of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) dataset, by the current author, found that the lives of older people with an ID can be mapped to various elements of the CDA. In previous yet to be published research the Antecedents of loneliness were investigated, for this population, through the use of repeated regressions. Variables that predispose participants to loneliness were found to be functional limitations, education and working in the community. Precipitating events were poor access to transport, experiencing pain, service changes and emotional health problems. This research also

associated a variable with the mismatch between desired social relations and actual social relations, which is wanting to do more activities. A second research project modelled the role of attributions, through the use of moderation analysis, as a proxy for cognitive attribution, and found that some pathways to loneliness are conditional upon the level of depressive thinking. How people react to and cope with loneliness was analysed through the use of binary logistic regression, and the loneliness predicted that loneliness has negative outcomes on both sleep difficulties and raised systolic blood pressure (SBP). This research project takes these findings and fits them together using structural equation modelling into a single unified model. This research answers the question "can elements of loneliness previously reported be unified into the structure of the CDA?"

9.2   Methodology

9.2.1   Participants

For a full description of the participants in the study please refer to the Methodology Chapter section *4.2 Participants,* page51.

This analysis utilised participants from the IDS-TILDA dataset, wave 2. The sample was randomly drawn from the National ID Database (NIDD), Wave One of the IDS-TILDA recruited 753 participants in 2010. Wave Two data collection commenced in 2013, and 708 participants responded. The sample is largely representative of the NIDD. The average was 56.6 years; males accounted for 44% of the participants and females 56%, 22% had a mild ID, 43% had a moderate ID, 27% had a diagnosis of severe or profound ID, and 8% had diagnoses that were either unknown or not verified.

9.2.2   Measures

All the measures used have been previously described, in detail, in the methodology chapter section 4.3 Measures, page 56. Each variable used in this chapter had previously been found to be significantly associated with loneliness in the previous chapters.

Loneliness and Social Connectedness:

The measure of loneliness for this analysis was the self-reported seven item loneliness scale. The scale consisted of the Three-Item Loneliness Scale (Hughes et al., 2004) and a self-labelling loneliness item (Appendix C2).

Independent Variables

Functional Limitations were measured using an 11 item self-reported scale measuring a participant's physical abilities (Appendix C4) (Fonda and Herzog, 2004). *Education* indicates those who have received an education to junior certificate level and those who had not. *Transport* was a self-report measure of how much disruption participants perceived transport problems caused. The effect of transport problems was categorised as either not at all, a great deal, to some extent and not at all. Participants working life was binary coded between *working in the community* and not working in the community. Self-reported *emotional health* was binary coded between excellent, very good or good and fair or poor emotional health. The *level of pain* participants experienced was a self-report measure and was graduated from no pain to severe pain. Participants had indicated the life events they had experienced in the previous 12 months, for each event experienced they were asked how much stress this caused them. The events that were related to service provider events were totalled together for each participant and labelled as *service stress*. Participants also reported if they wanted *to do more activities,* responses were binary coded. Who participants confided in was was binary coded between *confiding in staff* and not confiding in staff. A persons attribution style was measured using the CES-D scale (Centre for Innovative Public HealthResearch, 2015) (Appendix C5), which measures *Depressive Symptoms.* A persons sleeping habits were self-reported and combined in a *sleep scale*, high scores on the scale represent fewer problems sleeping. Participants *Systolic Blood Pressure (SBP):* was measured using a Digital Automated Oscillometric Blood Pressure Monitor (Omron 10), to indicate any possible negative health associations.

9.2.3   Analysis

The analysis was conducted using IBM AMOS version 23.0.

AMOS is a SEM programme developed to allow path analysis. AMOS utilises the maximum likelihood method of regression analysis to calculate regression coefficients, and allows the creation of paths in a user-friendly and easy to follow method. Once a model has been specified, AMOS will suggest ways the model can be improved, in modification indices. To produce modification indices, AMOS requires complete data sets. Stochastic regression imputation was used to impute missing data. Error terms are attached to each variable to account for the variance in measurement. Regression weights for error terms need to be fixed, and as a matter of convention, they are set to 1. To assess if a model is a good fit to the data several indicators are taken into account, including; parameter estimates, which are regression coefficients and co-variances, and model fit parameters including chi-squared. A non-statistically significant chi-squared result suggests the model does not differ significantly from the data. The chi-squared statistic is unreliable on larger data sets and is more likely to show statistical difference where

none exists. Therefore, other measures of model fit are taken into account including a comparative fit measure, where scores should be greater than 9.0 and a RMSEA measure requiring a score below 0.08. Finally, when bootstrap confidence intervals are created then a Bowen-Stein measure for the fit of data can be generated and a p-value greater than 0.05 suggests the model fits the data.

Results reported are in both, non-standardised path coefficients and standardised path coefficients. A non-standardised path coefficient estimates the amount of increase in the outcome variable when the predictor variable rises by 1. Standardised coefficients are standardised to the standard deviation reporting the increase in the outcome variable when the predictor variable rises by one standard deviation. The critical ratio reported in tables is the coefficient divided by the standard error, and is used for calculating the p-value. All confidence intervals reported are based on the standardised coefficient. The amount of the outcome variable predicted by the predictor variables is reported as r^2. There are two ways to interpret the r^2 statistic. The first method is to multiply by one hundred; this gives the percentage of the outcome variable explained. The second method is to minus the statistic from one and then multiply by one hundred to understand the amount of the variable explained by the error term. The r^2 values are reported in r^2 tables and directly above outcome variables in the path diagrams.
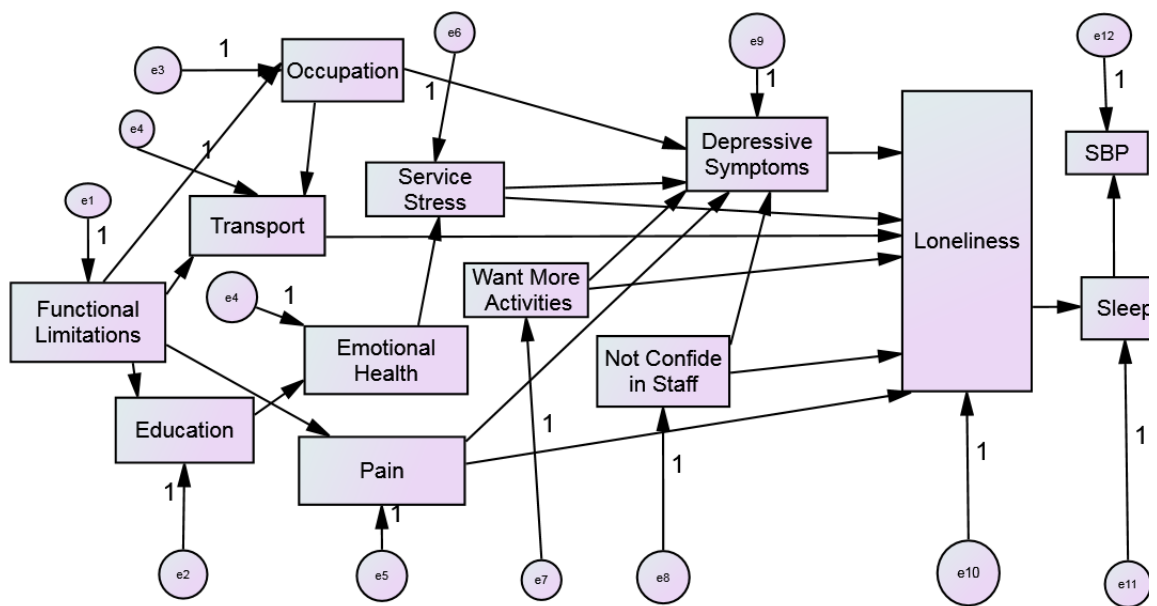
Figure 9-2: Ideal Model of Loneliness

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An ideal model of loneliness was generated (Figure 9-2). To overcome the low numbers of participants who completed the CES-D scale, three models of loneliness are created. All three models are based on the idealised a priori model (Figure 9-2). The first model is created excluding the measure of attributions thus allowing the full data set to be used. The second model is developed by imputing the missing scores on the attribution scale, and the third model uses only non-imputed scores on the attribution scale, restricting the numbers of participants and the type of participant included in the model.

Parsimonious models were constructed by referencing the modification indices, the path coefficients, co-variances and measures of model fit. The first model allows an understanding of the model without either the limiting effect of the reduced number of participants, or the compromised data where a large amounts of data has been imputed. An intermediate model was then created where the full data set was utilised with the missing data for the depressive symptoms scale being imputed. This model was used to guide an understanding of the loneliness model, if all participants had answered the CES-D scale. Imputing such a large number of scores is not a viable solution to present as a completed model, so a third model was produced with the data set reduced to those who had responded to the depressive symptoms scale. Missing data for other variables was imputed using the stochastic regression imputation method. Bootstrap analysis was used and set to 5,000 cases.

9.3   Results

9.3.1   Loneliness model excluding depressive symptoms
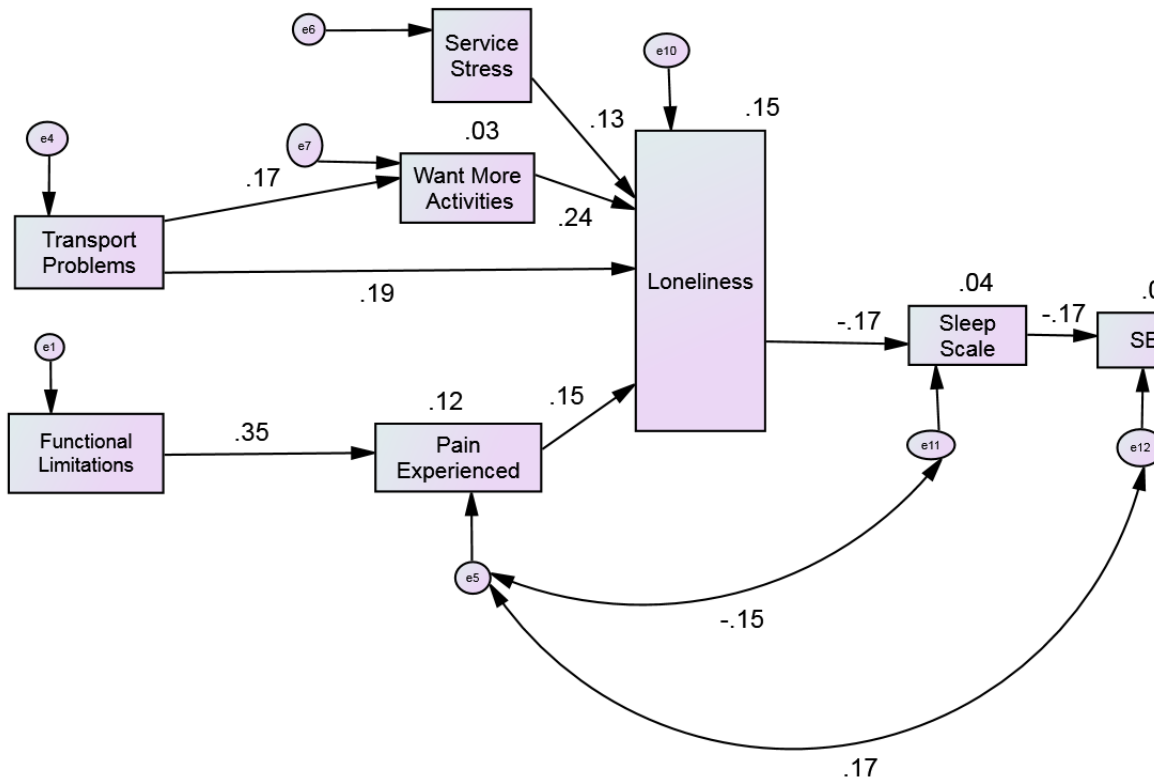
Figure 9-3: Loneliness model excluding depressive symptoms variable displaying standardised path coefficients and the r² for each variable

This model reports the variables, pathways, co-variances and r² estimates for the retained variables. The model fits the data well, the chi-squared (χ^2=24.188, p=0.149) and the Bollen-Stein p-value (p=0.227) are both greater than 0.05, indicating the model does not differ significantly from the data. The comparative fit (0.958) and RMSEA (0.033) both achieve their required values. All the paths in the model are statistically significant below a value of p<0.05 (Table 9-1). The variables that predict loneliness estimate approximately 15% of the loneliness variance (r²=0.152, p=0.002, 95% CI=0.064, 0.237), loneliness accounts for 3.5% of the variance in sleep scale scores (r²=0.035, p=0.007, 95% CI =0.004, 0.100), and sleep scale scores account for 3% (r²=0.032, p=0.001, 95% CI=0.005, 0.078) of the SBP scores. Transport accounts for 3% of wanting to do more activities (r²=0.030, p<0.001, 95% CI=0.004, 0.076), and functional limitations are found to account for 12% of the pain experienced scores (r²=0.122, p<.0.001, 95% CI=0.053, 0.216).

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The model shows four distinct pathways to loneliness, of which the pathway with the largest critical ratio is from wanting to do more activities (coefficient=0.766, SE=0.169, CR=4.528, p<0.01, 95% CI =0.137, 0.340). The variable with the next largest critical ratio in the path to loneliness is transport (coefficient=0.419, SE=0.114, CR=3.692, p<.01, 95% CI=0.071, 0.319), then Pain (coefficient=0.262, SE=0.090, CR=2.919, p<0.01, 95% CI=0.046, 0.261) and finally Service Stress (coefficient=0.288, SE=0.111, CR=2.605, p<.05, 95% CI=0.013, 0.252).

The co-variances between the error of pain experienced and the sleep scale (coefficient=0.253, S.E.=0.099, p<0.05, 95% CI=-0.492, -0.051), and SBP (coefficient=2.754, p<0.01, 95% CI=0.961, 4.736), are both significant (Table 9-2). The indirect effects table (Table 9-3) reports the indirect effects for the pathways from functional limitations to loneliness, transport to loneliness and loneliness to SBP. The table shows that the mediated pathway from functional limitations to loneliness through pain is significant (coefficient=0.011, p<0.01, 95% CI=0.016, 0.104). The indirect path from transport to loneliness is also significantly mediated, by wanting to do more activities (Coefficient=0.089, p<0.01, 95% CI=0.015, 0.079). The indirect path from loneliness to SBP is significantly mediated by sleep scale (coefficient=0.373, p<0.01, 95% CI=0.007 0.068). Finally, within the model a serially mediated pathway from functional limitations to SBP is significant (Coefficient=0.004, p<.01, 95% CI=0.000, 0.006).

Table 9-1: Path coefficients of the loneliness model excluding depressive symptoms

Pathway			Path Coeff	S.E.	C.R.	Std Path Coeff	Bootstrap 95% Confidence Intervals			
							SE	Lower	Upper	p
Pain Exp.	←	Functional Limitations	0.042	0.006	6.806	0.350	0.060	0.230	0.465	0.000
Want More	←	Transport Problems	0.116	0.037	3.128	0.173	0.055	0.062	0.276	0.002
Loneliness	←	Service Stress	0.288	0.111	2.605	0.135	0.061	0.013	0.252	0.029
Loneliness	←	Want More	0.766	0.169	4.528	0.238	0.052	0.137	0.340	0.000
Loneliness	←	Pain Exp.	0.262	0.090	2.919	0.151	0.055	0.046	0.261	0.005
Loneliness	←	Transport	0.419	0.114	3.692	0.194	0.063	0.071	0.319	0.001
Sleep Scale	←	Loneliness	-0.222	0.073	-3.046	-0.168	0.066	-0.296	-0.046	0.007
SBP	←	Sleep Scale	-1.676	0.532	-3.154	-0.175	0.052	-0.275	-0.068	0.001

Table 9-2: Covariance between errors in the loneliness model excluding the depression variable

Parameter			Covariance	SE	CR	Bootstrap 95% Confidence Intervals		
						Lower	Upper	P
Sleep Scale error	⇔	Pain experienced error	-0.253	0.099	-2.556	-0.492	-0.051	0.013
SBP error	⇔	Pain experienced error	2.754	0.935	2.946	0.961	4.736	0.001

Table 9-3: Indirect effects in the loneliness model excluding the depression variable

Parameter			Coeff	Std Coeff	Bootstrap 95% Confidence Intervals		
					Lower	Upper	p
Functional Limitations	→	Loneliness	0.011	0.053	0.016	0.104	0.004
Functional Limitations	→	SBP	0.002	0.002	0.000	0.006	0.004
Transport	→	Loneliness	0.089	0.041	0.015	0.079	0.001
Loneliness	→	SBP	0.373	0.029	0.007	0.068	0.004

9.3.2 Intermediate loneliness model

The intermediate model of loneliness modelled in Figure 9-4, allows the influence of all the participants to be understood, with depressive symptoms included. The table reports path coefficients, co-variances and r^2 values for the variables included in the final model. The inclusion of depressive symptoms in the model has created two path modifications. The path from functional limitations to loneliness, that was mediated by pain, has the addition of the depressive symptoms variable; this is serial mediation. There is now no direct path to loneliness from pain experienced. The second path to change is that from transport problems to loneliness, which is now subject to parallel mediation, one arm includes wanting more activities as it did previously, and the new path depressive symptoms.   The model fits the data well, the chi-squared (χ^2=30.243, p=0.177) and the Bollen-Stein p-value (p=0.268) are both greater than 0.05 indicating the model does not differ significantly from the data. The comparative fit (0.973) and RMSEA (0.029) both achieve their required values.
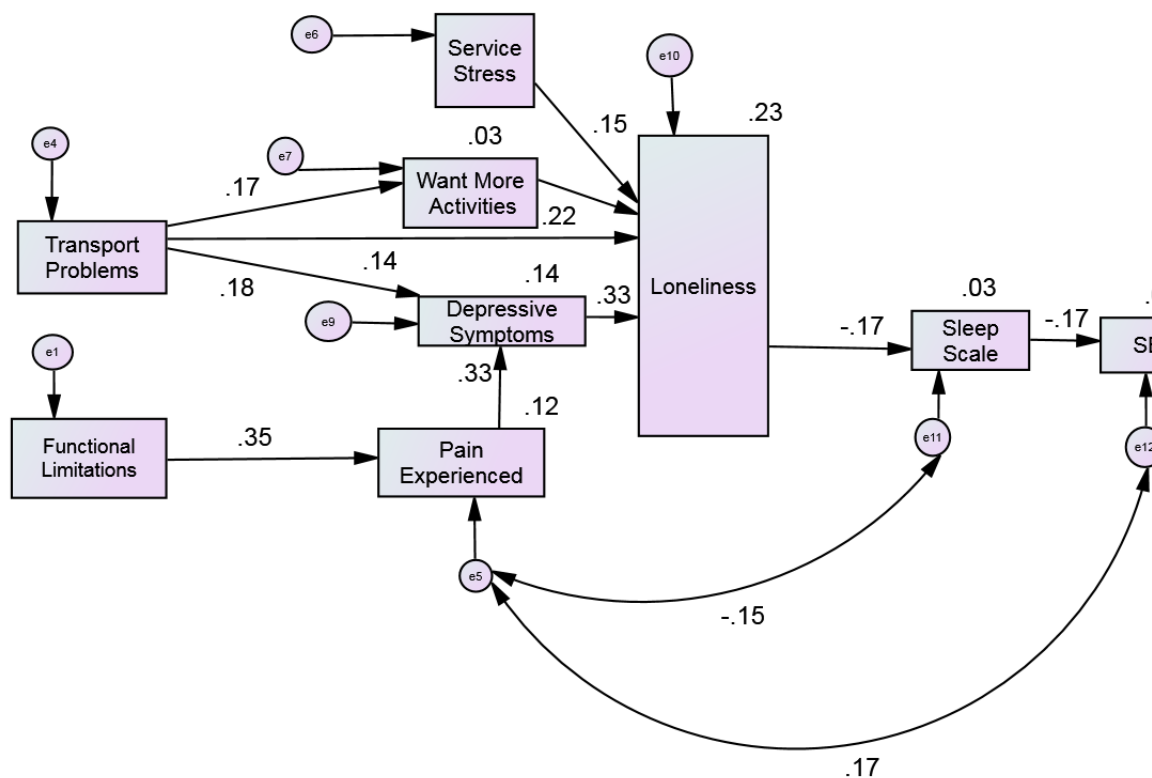
Figure 9-4: Intermediate model of loneliness with imputed depressive symptoms scores

The model predicts 23% of the Loneliness variance which is an improvement of 8% on the model without depressive symptoms included (r^2=0.232, p=0.001, 95% CI=0.130, 0.330). Fourteen percent of the variance of depressive symptoms is predicted by transport problems (r^2=0.143, p<0.001, 95% CI=0.070, 0.233). Functional limitations predict 12% of the pain variance (r^2=0.122, p<0.001, 95% CI=0.053, 0.216), and transport predicts 3% of the wanting to do more activities variance (r^2=0.030, p<.0.001, 95% CI=0.004, 0.076). Loneliness predicts 3% of the sleep scale variance (r^2=0.033, p=0.007, 95% CI=0.003, 0.096), which in turn predicts 3% of the variance of SBP (r^2=0.031, p=0.001, 95% CI=0.005, 0.078).

The paths within the model are reported in Table 9-4. The path with the largest critical ratio is between functional limitations and pain (coefficient=0.042, SE=0.006, CR=6.806, p<.01, 95% CI=0.230, 0.465), and the second largest is from depression to loneliness (coefficient=0.070, SE=0.011, CR=6.547, p<0.01, 95% CI=0.210, 0.453). The path from pain to depression has the next largest critical ratio (coefficient=2.699, SE=0.425, CR=6.355, 95% CI=0.222, 0.433). Of the remaining direct paths to loneliness want more activities has the highest critical ratio (coefficient=0.717, SE=0.161, CR=4.456, p<0.01, 95% CI=0.121, 0.323), then the path from service

stress to loneliness (coefficient=0.312, SE=0.105, CR=2.967 p<0.05, 95% CI=-0.032, 0.258), and finally the path from transport to loneliness (coefficient=0.308, SE=0.110, CR=2.805, p<0.05, 95% CI=0.026, 0.259). The two remaining paths in the antecedents side of the model are also significant, and are transport to depression (coefficient=1.852, SE=0.529, CR=3.498, p<.01, 95% CI=0.072, 0.300), and transport to wanting more activities (coefficient=0.116, SE=0.037, CR=3.128, p<.01, 95% CI=0.062, 0.276). Of the variables on the consequences side of the model the larger critical value is from the sleep scale to SBP(coefficient=-1.676, SE=0.532, CR=-3.152, p<0.01, 95% CI=-0.275, -0.068). The path from loneliness to sleep scale scores is also significant (coefficient=-0.222, SE=0.073, CR=-3.060, p<.01, 95% CI=-0.297, -0.046). The co-variances in the model remained as reported in the previous analysis.

The indirect effects table (Table 9-6) gives the coefficients and level of significance for the three mediated paths. The first is the path from functional limitations to loneliness ,that is mediated in serial by pain experienced, and then by depressive symptoms (coefficient=0.008, p<.01, 95% CI=0.019, 0.071). The next is the path from transport to loneliness, which has two parallel mediated paths through depressive symptoms and through wanting more activities (Coefficient=0.212, p<.01, 95% CI=0.049, 0.167), and the mediated path from loneliness to SBP (coefficient=0.373, p<0.01, 95% CI=0.007, 0.068).

Table 9-4: Path coefficients of the intermediate loneliness model

Pathway			Coeff	S.E.	C.R.	Std Path Coeff	Bootstrap 95% Confidence Intervals			
							SE	Lower	Upper	p
Pain	←	Functional Limitations	0.042	0.006	6.806	0.350	0.060	0.230	0.465	0.000
Want more activities	←	Transport	0.116	0.037	3.128	0.173	0.055	0.062	0.276	0.002
Depressive Symptoms	←	Pain	2.699	0.425	6.355	0.331	0.054	0.222	0.433	0.000
Depressive Symptoms	←	Transport	1.852	0.529	3.498	0.182	0.059	0.072	0.300	0.001
Loneliness	←	Service Stress	0.312	0.105	2.967	0.146	0.057	0.032	0.258	0.015
Loneliness	←	Transport	0.308	0.110	2.805	0.143	0.060	0.026	0.259	0.017
Loneliness	←	Want more activities	0.717	0.161	4.456	0.223	0.051	0.121	0.323	0.000
Loneliness	←	Depressive Symptoms	0.070	0.011	6.547	0.328	0.063	0.210	0.453	0.000
Sleep Scale	←	Loneliness	-0.222	0.073	-3.060	-0.168	0.066	-0.297	-0.046	0.007
SBP	←	Sleep Scale	-1.676	0.532	-3.152	-0.174	0.052	-0.275	-0.068	0.001

Table 9-5: Covariance between errors in the intermediate model of loneliness

Parameter			Covariance	SE	CR	95% Confidence Intervals Lower	Upper	P
Sleep Scale error	⇔	Pain experienced error	-0.253	0.098	-2.556	-0.492	-0.051	0.013
SBP error	⇔	Pain error	2.754	0.935	2.946	0.961	4.736	0.001

Table 9-6: Indirect effects in the intermediate loneliness model

Parameter			Coeff	Std Coeff	95% Confidence Intervals Lower	Upper	p
Functional Limitations	→	Loneliness	0.008	0.038	0.019	0.071	0.000
Functional Limitations	→	SBP	0.003	0.001	0.000	0.004	0.002
Transport	→	Loneliness	0.212	0.098	0.049	0.671	0.000
Loneliness	→	SBP	0.373	0.029	0.007	0.068	0.004

9.3.3 Final Loneliness model utilising only participants who completed the depressive symptoms scale
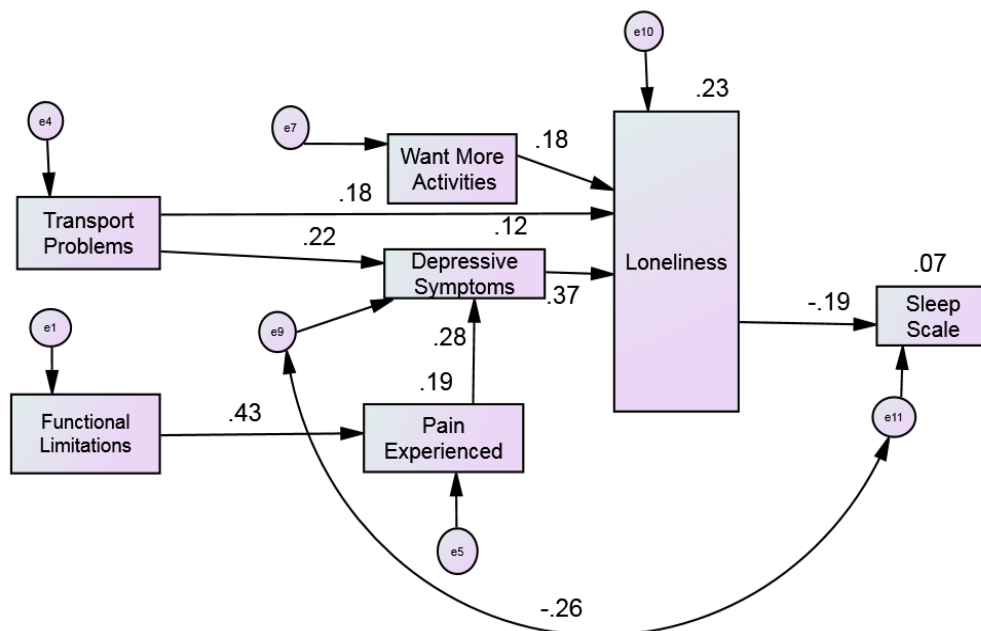
Figure 9-5: Final Loneliness model including depression.

Figure 9-5 displays the model for loneliness developed, and shows the path estimates, the covariance and the r² value for each variable. This model has a reduced sample size (N=141), because it only includes data for those participants who completed the depressive symptoms scale. The model fits the data well, the chi-squared (χ^2=20.331, p=0.087) and the Bollen-Stein p-value (p=0.239) are both greater than 0.05, indicating the model does not differ significantly from the data. The comparative fit (0.936) and RMSEA (0.063) both achieve their required values. The model differs from the previous model in several aspects. On the left-hand side of the model where the predictors of loneliness are displayed, service stress is no longer a significant predictor of loneliness, and the path from transport to loneliness is no longer mediated by wanting to do more activities. The estimated covariance is now between the error in depressive symptoms and the error attached to the sleep scale. On the right-hand side of the model that deals with the effects of loneliness the path to SBP is removed from the model.

The model describes 22.7% of the loneliness variable (r²=0.227, p=0.12, 95% CI=0.078, 0.413), which is 0.5% less than the previous model. This model also accounts for 7% of the sleep scale variance (r²=0.070, p=0.080, 95% CI=-0.04, 0.218), an increase of 4% over the last model, however, this does not reach a level of significance for this subpopulation of the data. The amount of pain explained by functional limitations rose to 18.7% from 12.2% (r²=0.187, p=0.007, 95% CI=0.064, 0.396). The amount of the variance of depressive symptoms explained fell to 12.3% (r²=0.123, p=0.012, 95% CI=0.029, 0.303).

The path coefficients reported in Table 9-7 report that the largest predictor of loneliness is depressive symptoms (coefficient=0.078, SE=0.016, CR=4.801,p<0.05, 95% CI=0.129, =0.555), but the strongest path in the model is the path between functional limitations and pain (coefficient=0.052, SE=0.009, CR=5.667, p<0.01, 95% CI=0.253, 0.629). Of the remaining pathways neither the direct path from transport to loneliness (coefficient=0.343, SE=0.146, CR=2.356, p=n.s., 95% CI=-0.047, 0.360) or the path from loneliness to the sleep scale (coefficient=-0.247, SE=0.108, CR=-2.280, p=n.s., 95% CI=-0.449, 0.047) are significant. The path from transport to loneliness was retained, because when removed the modification indices suggested the path should be created, to meet the model fit criteria. The path from loneliness to the sleep scale was retained, because the indirect path from functional limitations to the sleep scale remains significant. The other pathways in the model are pain to depression (coefficient=2.202, SE=0.609, CR=3.616, p<0.01, 95% CI=0.121, 0.483), transport to depression (coefficient=1.956, SE=0.691, CR=2.833, p<0.05, 95% CI=0.002, 0.407), and wanting more activities to loneliness (coefficient=0.560, SE=0.230, CR=2.441, p<0.05, 95% CI=0.039, 0.325).

The indirect effects reported in Table 9-9 show that the pathway from functional limitations to loneliness, serially mediated by pain and depression is significant (coefficient=0.009, p<0.01, 95% CI=0.013, 0.156). The path from transport to loneliness, mediated by depression remains significant (coefficient=0.152, p<.05, 95% CI=-0.065, -0.001). Finally, the serially mediated path, from functional limitations to the sleep scale, through pain experienced, depressive symptoms and loneliness is significant (coefficient=-0.02, p<0.05, 95% CI=-0.065, -0.001).

Table 9-7: Path coefficients of the final loneliness model

Pathway			Coeff	S.E.	C.R.	Std Path Coeff	Bootstrap 95% Confidence Intervals			
							SE	Lower	Upper	p
Pain	←	Functional Limitations	0.052	0.009	5.667	0.432	0.089	0.253	0.629	0.007
Depressive Symptoms	←	Transport	1.956	0.691	2.833	0.217	0.107	0.002	0.407	0.048
Depressive Symptoms	←	Pain	2.202	0.609	3.616	0.276	0.091	0.121	0.483	0.003
Loneliness	←	Transport	0.343	0.146	2.356	0.179	0.100	-.0.047	0.360	0.122
Loneliness	←	Want more activities	0.560	0.230	2.441	0.181	0.074	0.039	0.325	0.014
Loneliness	←	Depressive Symptoms	0.078	0.016	4.801	0.365	0.107	0.129	0.555	0.010
Sleep Scale	←	Loneliness	-0.247	0.108	-2.280	-0.192	0.113	-0.449	0.047	0.082

Table 9-8: Covariance between errors in the final model of loneliness

Parameter			Covariance	SE	CR	Bootstrap 95% Confidence Intervals		
						Lower	Upper	p
Sleep Scale error	<-->	Depressive symptoms error	-3.283	1.163	-2.824	-6.791	-0.046	0.048

Table 9-9: Indirect effects in the final loneliness model

Parameter			Coeff	Std Coeff	Bootstrap 95% Confidence Intervals		
					Lower	Upper	p
Functional Limitations	→	Loneliness	0.009	0.044	0.013	0.156	0.001
Functional Limitations	→	Sleep Scale	-0.002	-0.008	-0.065	-0.001	0.031
Transport	→	Loneliness	0.152	0.079	0.003	0.216	0.028

9.4   Discussion

Combining the findings of previous work on the IDS-TILDA data into a single cohesive model gives a greater understanding of how the elements of loneliness, from those factors that predispose a person to loneliness, through to the consequences of loneliness, form together. The models developed gave a clear sense of the links between many of the issues involved in loneliness. The models give a strong indication of the importance of functional limitations in predisposing which variables are most likely to precipitate loneliness in this population. In those who had greater functions limitations, loneliness was precipitated by pain, the effect of which was enhanced by depressive symptoms. The effects of loneliness for those higher on functional limitations created sleep disturbances, which in turn increased raised SBP. Other results indicated that service changes were pertinent to those of higher functional limitations. Having transport difficulties could directly influence loneliness; it could be enhanced with wanting to do more activities, and it could be boosted by depressive symptoms. The results also demonstrated that some routes to loneliness were dependent on attributions not covered by depressive symptoms.

9.4.1   Loneliness Model Excluding Depressive Symptoms

The loneliness model excluding depressive symptoms allowed an understanding of a working model of loneliness without the restrictive influence of the depressive symptoms scale on the number and ability levels of participants. This model allowed for the refinement of the a priori model through the removal of less influential pathways and variables.   Three fundamental precipitating variables can be realised in the model: pain, transport difficulties, and service stress, and each is part of an explanatory path.

Three dominant routes to loneliness emerged supporting the previous work by this author and the CDA. This model shows that those who score higher on functional limitations are more likely to be lonely because of increased pain (coefficient=0.053, p<0.01, 95% CI=0.016, 0.104). Pain and loneliness are known to group together (Jaremka et al., 2014), and pain isolates a person from others (Biro, 2011). For people with an ID the under-reporting and under-treating of pain (McGuire et al., 2010) enhances its importance in the creation and maintenance of loneliness. The model illustrated that for older people with an ID, having transport difficulties both directly (coefficient=0194, p<0.01, 95% CI=0.071, 0.319) and indirectly affected loneliness (coefficient=0.041, p<.01, 95% CI=0.015, 0.079), leaving people feeling like they were unable to achieve the activities they desire. Reported findings in the general population show that transport difficulties promoted the chances of becoming lonely through limiting access to resources (Burholt and Scharf, 2013). The model demonstrated the impact of service changes on a person's life and the greater the stress experienced by service changes, the more likely they were to score

highly on the loneliness scale (coefficient=0.135, p<0.05, 95% CI=0.013, 0.252). Changes to life have been hypothesised as causal in the development of loneliness (Weiss, 1973) and for people with an ID, changes in service provision or changes in staffing can be out of their control, further exacerbating feelings of helplessness and hopelessness . This model highlighted that it is not the amount of changes that create the loneliness but how stressful the person finds the changes, and that changes can create a loss of personal resources that enhance the chances of becoming lonely (Aartsen and Jylhä, 2011). Research in the general population has reported that the loneliness caused by change is not necessarily lasting (Cacioppo et al., 2010) and many people adapt to their new circumstances, even the widowed adapt over time (Pikhartova et al., 2015).

Once lonely, older people with an ID experienced raised blood pressure which was created by the existence of disrupted sleep (coefficient=0.029, p<0.01, 95% CI=0.007, 0.068). The connection between sleep difficulties and SBP matched research from the general population, where sleep difficulties have been found to cause raised SBP (Bonnet and Arand, 2003). Those who scored highly on the loneliness scale were more likely to have a low score on the sleep scale, indicating more sleep difficulties and those with more sleep difficulties were likely to have a higher SBP reading. This is the first loneliness research to implicate this route to raised SBP in loneliness research, and it demonstrates the role of hypervigilance, giving a clear indication of one route that loneliness has with knock on health effects.

This model replicates the elements of the CDA, excluding the depressive attributions and cognition element. In the CDA, Perlman and Peplau (1998) described predisposing elements as the characteristics of the person and cultural values or norms. For individuals with an ID, functional ability defines many of their life chances and is a lifelong characteristic of the individual. Precipitating events are events that cause the break between desired and achieved social relationships, and these are denoted by transport, pain experienced and service stress, which is the stress caused by service changes. Wanting to do more activities represents the break between desired or needed social relations and achieved social relations. The experience of loneliness is represented by the loneliness scale, and finally, the reactions and coping element are represented by the sleep scale and SBP. While this model gives a good indication of how the data fit the CDA without the inclusion of a measure of attribution, then the model is incomplete.

9.4.2   The Intermediate Model of Loneliness

The addition of depressive symptoms to the model found that depressive symptoms are a large influencing factor on the pathway to loneliness, and people who were experiencing more pain and a more depressive mindset were more likely to score higher on the loneliness scale. This effect of the type of the cognitive attribution is a central pillar to the CDA, and the data presented

here for older people with an ID supports the CDA. Peplau and Perlman (1981) argue that while a person may have a gap between their desired life and their actual life, this does not inevitably lead to loneliness and expectations may be modified by their cognitive reaction to the situation. This model suggests that, dependent upon an individual's route to loneliness, a change in mindset may prevent them from becoming lonely and save them from the knock-on effects of poor sleep and raised SBP.

The CES-D scale was utilised in this study to infer attributional style, and has also been successfully used in other loneliness research to represent attributional style in the CDA (Burholt and Scharf, 2013). The intermediate model included the depressive symptoms scale, with all the missing values imputed. Imputing missing scores on this scale means that one hundred and seventy-six scores were imputed. This strategy is clearly not a sustainable final solution, but it does help to partition out the differences in the results caused by the inclusion of the depressive symptoms scale, and the effect of the higher functioning of those who completed the depressive symptoms scale.

The addition of depressive symptoms increased the amount of the loneliness variance explained to 23%; this was an 8% increase over the model, excluding depressive symptoms. None of the previously excluded variables fit into the new model, and none of the variables from the previous model were excluded, but new pathways were added to the model. First, a direct path from depressive symptoms to loneliness was added (coefficient=0.328, p<01, 95% CI=0.210, 0.453). The pathway from functional limitations to loneliness through pain required rerouting to account for a mediating effect through depressive symptoms (coefficient=0.038, p<.001, 95% CI=0.010, 0.071). This showed how depressive symptoms enhance the feelings of pain in this population. It is probable that pain enhances negative attitudes and thus feeds depression. The third path to loneliness, from transport difficulties, mediated by depressive symptoms, was also included (coefficient=0.098, p<0.01, 95% CI=0.049, 0.167). This pathway again demonstrated how problems enhanced the negative mindset of people, increasing feelings of helplessness and hopelessness. Together, transport problems and pain contributed a large amount to depressive symptoms (14%), demonstrating the importance of precipitating events in driving depression. The results supported the role of a cognitive triad between the environment, depression and loneliness, which all lock a person into becoming consistently lonely.

9.4.3   The Final Model of Loneliness

All the elements of the CDA are contained within the final model of loneliness, showing that the CDA can be applied to all people with an ID, having demonstrated its value for those with lower levels of functioning and those with higher levels. The final model was limited to the participants

who completed the CES-D scale, who are a sub-population containing only those with the highest ability levels. The model contained an indirect path from functional limitations to the sleep scale (coefficient=-0.008, p<.05, 95% CI=-0.065, -0.001), maintaining the integrity of the CDA.

The antecedents elements that are lost from the model supported the arguments of others (Bane et al., 2012, Gilmore and Cuskelly, 2014), and they showed that those with lower ability levels were reliant on staff for their social world. Therefore, when service changes happen, these people with greater support needs are more affected because they lose a vital element of their social world.   Those who are most reliant on staff, have the additional burden of not having control of their transport and therefore have little choice in their social life (Gilmore and Cuskelly, 2014), and this model showed that the link between transport problems and wanting to do more activities was based on those with lower ability levels. Exercise has been shown to have beneficial effects on SBP which ceased to be an outcome from loneliness, demonstrating that the favourable effects of the strategy of active coping are realised by those who are more able bodied.

Pain is under-reported in people with an ID (McGuire et al., 2010) and its retention in the model, contained in the indirect path from functional limitations to loneliness (coefficient=0.044, p<.01, 95% CI=0.013, 0.156), showed that its effect impacted the lives of people of all ability levels with greater functional limitations. The retention of the second indirect path, from transport difficulties to loneliness, mediated by depressive symptoms (coefficient=0.079, p<.05, 95% CI=0.003, 0.216), evidenced that in higher functioning individual's problems, achieving their social desires will enhance, and will be enhanced by, a person's cognitive attribution. In more independent individuals, problems will have effects that are more akin to those found in the general population, limiting a person's access to social resources (Burholt and Scharf, 2013). Finally, the direct path to loneliness from wanting to do more activities (coefficient=0.181, p<.05, 95% CI=0.039, 0.325) clearly demonstrated that even in those with higher functioning the effect of not achieving the desired social world leads to loneliness, and was supportive of the CDA (Perlman and Peplau, 1998). The path to loneliness from wanting to do more activities was not reliant upon depressive symptoms, demonstrating that attributions other than those included in the depression scale are responsible for loneliness. Rumination is a cognitive process where peers unintentionally focus on their problems (Vanhalst et al., 2012), and in this population it is likely to be the missing component in the cognitive process, where people spend time focusing on the missing social components that generate their loneliness. The process of rumination in this population requires further investigation.

9.4.4   Limitations

Use of the depressive symptoms scale limits the size of the sample that can be analysed and it also focuses the sample on the higher functioning population. The effect of this limitation has been minimised through the strategy adopted. By first removing the depressive symptoms variable from the sample, then including an imputed version of the depressive symptoms scale, it allowed an understanding of which pathways to loneliness and which variables are relevant. Further research is necessary into the role of attributions in this population.

The lack of any independent variable to explain the role of social participation and social network in this population detracts from the understanding of the antecedents of loneliness. However, future waves of data collection are employing more tailored and sophisticated measures, which should hopefully provide some answers as to the role of the social experience.

This model failed to account for temporal characteristics of loneliness

The CDA is a good approach to model the causes and effects of loneliness, but it does fail to give an understanding of the essence or feelings of the experience of loneliness and the pathways to loneliness. The essence of loneliness could only be attained through qualitative research; further research is necessary to understand how loneliness feels to the lonely in this population.

9.4.5   Conclusion

The complete experience of loneliness can be unified into a single synthesised model. The unified models of loneliness further enhance the understanding of loneliness in this population. The first model brought forward the dominant features of loneliness without using the measure of depression. The model demonstrated predisposing elements, precipitating events, attributions and consequences of loneliness, fitting the literature, and offered new insights into the development of loneliness and the consequences of loneliness. Those with greater functional limitations experience loneliness because of increased pain. Pain is an important variable in this population and these results further evidence the effect of the under-reporting and under treatment in this population (McGuire et al., 2010). Transport problems prevent people from achieving their social desires, and those who find service changes stressful lose valued social resources. Three dominant antecedent pathways were estimated: from functional limitations to loneliness, from transport difficulties to loneliness, and from service stress to loneliness. These variables accounted for 15% of the loneliness variance. The model contained the consequent variables of sleep scale and SBP, and estimated that the hypervigilance caused by loneliness led to sleeping difficulties, which in turn led to raised SBP. Creating a model that does not use the depression scale was beneficial because it removed the restrictions placed on analysis of the

reduced data set available, or the uncertainties of imputing large amounts of missing data into the depression scale. The consequent path from loneliness is in keeping with the literature from sleep studies and demonstrating that hypervigilance causes disrupted sleep which leads to raised SBP.

A second model was created, incorporating the depressive symptoms variable. Rather than lose large numbers of participants, this model was created by imputing the missing depression scores. This model has the advantage of analysing the effect of depressive thinking without losing the information of the participants who failed to complete the depressive symptoms scale. In this model the critical role of depressive symptoms in enhancing feelings of loneliness was clear, and depressive symptoms added 8% to the explanatory power of the antecedent variables. Depressive symptoms were found to mediate the pathway between functional limitations and loneliness, and between transport and loneliness. Depressive symptoms did not mediate a path from wanting to do activities or service stress, emphasising that loneliness is not depression, and that there is a role for other attributions, such as rumination. There was no change to the consequence pathway.

The final model demonstrated that pain affects all levels of ability and is a precipitating event for those with more functional limitations, whatever their ability. Services changes have more effect on those of lower ability levels because of their reliance on services, and the reliance on services leaves them feeling that their social lives are restricted. Those who are of lower ability levels are less able to benefit from the strategy of active coping, and SBP was no longer retained for this model. The model accounted for only participants who had completed the depressive symptoms scale; a higher functioning, more independent group. The changes to this model reflected which variables were applicable to higher operating individuals, and the pruned variables are those applicable only to those of a lower ability level.
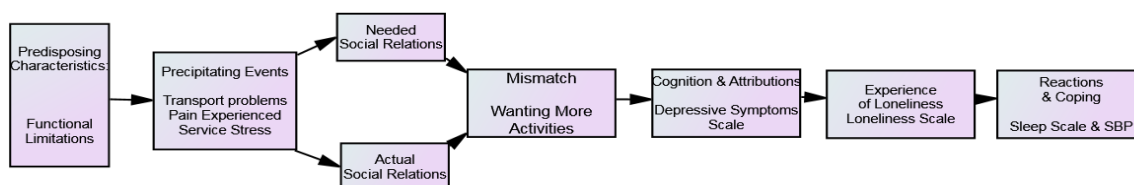
Figure 9-6: CDA diagram applied to people with an ID. Adapted from "Loneliness" By D. Perlman & L.A. Peplau *Encyclopedia of mental health, 2*, p. 572 copyright 1998 by **Taylor and Francis Group LLC Books. Reprinted with Permission under licence number 4270990436999.**

The structural equation models created support the CDA approach to loneliness. The models have variables at all levels of the CDA (Figure 9-6). Functional limitations represent predisposing elements: transport, pain experienced and stress caused by service changes are precipitating events, wanting to do more activities is the mismatch between desired and achieved social relations, while the depressive symptoms represent the cognitive attribution. The loneliness experience is represented by the loneliness scale and reactions and coping with loneliness are represented with sleep scale and SBP.

This is the first model that explains loneliness in older people with an ID.

10 Discussion

10.1 Introduction

Loneliness is the outcome of predisposing elements, aligning with precipitating events and attributions (Perlman and Peplau, 1998). Loneliness causes behaviours that negatively impact physiological functioning influencing long-term health (Hawkley and Cacioppo, 2007). In older people with an intellectual disability (ID), functional limitations determine an individual's circumstances and the events that will cause frustration with their social world. Negative attributions about perceived social discrepancies generate feelings of loneliness. Reactions to loneliness occur at both a conscious and subconscious level. Subconscious reactions caused by the brain's high alert state lead to poor sleep, raised systolic blood pressure, increased negative memories for events and a failure to trust those best placed to help. Conscious reactions to loneliness lead people to fill their time with activities in an unsuccessful attempt to overcome their feelings. People with an ID have greater difficulty in overcoming loneliness because they have less ability or freedom to influence their lives directly, and if they lack the knowledge on who can help them then they are more likely to remain lonely.

This study has brought new understanding and insights to the knowledge of loneliness for older people with an ID. The research has been able to specify and distinguish predisposing and precipitating variables, identifying which variables are important in understanding the quality of relationships. It has demonstrated how attributions work for this population and how people react to, and cope with, loneliness. This chapter discusses the issues cutting across the reported results to give a complete and unified understanding of how loneliness develops and impacts the lives of older people with an ID.

10.2 Loneliness

Older individuals with an ID experience the same level of loneliness but experience it more consistently than those in the wider population. This study is the first to utilise a widely-used scale and cohort to investigate loneliness as experienced by older people with an ID. The scale has previously been used and reported in the Health and Retirement Study (2002, 2004 & 2006)(Luo et al., 2012), the English Longitudinal Study on Ageing (ELSA) (Steptoe et al., 2013) and The Irish

Longitudinal Study on Ageing (TILDA) (Burholt and Scharf, 2013). The findings are consistent with loneliness reported in these studies where the same methodology was applied.

Loneliness scores on the three-item loneliness scale were not significantly different from scores reported on the HRS(2002) and the HRS(2004). The scores did differ significantly from the TILDA, ELSA and HRS(2006) scores. Differences between IDS-TILDA and TILDA, ELSA and HRS(2006) were due to differences in collection methods. The IDS-TILDA scores, the HRS(2002) and the HRS(2004) scores were all collected during a face to face interview whereas the TILDA, ELSA and HRS(2006) scores were all collected via a self-completed questionnaire without an interviewer being present. The difference between the HRS(2002), HRS(2004) and the HRS(2006) scores was reported in the HRS study, where it was suggested that the method of data collection was the cause of the difference in scores (Luo et al., 2012). The larger grouping of results described adds strong support to that opinion. It is conceivable that the IDS-TILDA, HRS(2002) and the HRS(2004) cohorts scored lower on the loneliness scale and therefore experience less loneliness. However, this explanation is improbable because of the clean break in scores between the different methodologies, which means that social desirability produced the underreporting of loneliness (Coyle and Dugan, 2012).

Where people with an ID were found to differ from the wider population was in the consistency of their loneliness, experiencing nearly twice the level of consistent loneliness of other populations.   Analysis of the trajectories of loneliness reported that 26% of participants were consistently lonely, 42% were never lonely, 19% went from being lonely to not being lonely, and 12% went from not being lonely to being lonely. Other populations of older people have reported between 14% (Victor, 2014) and 17% (Jylhä, 2004) of participants as consistently lonely. The methodology of reporting consistent loneliness as measured with a single loneliness question was the same in this study and Victor (2014), meaning direct comparisons are possible.

It is possible that the difference in consistent loneliness may have been due to a misreporting of loneliness caused by confusion in understanding the concept of loneliness. Stancliffe et al. (2014) reported that people with an ID could have difficulty answering questions on loneliness scales due to the difficult nature of the questions used and the number of response options in the scales used. It is, therefore, possible that some participants may have been selecting a mid-scale option so as not to appear to be without an understanding of the question or scale. However, Stancliffe et al. (2014) did find that people with an ID were able to complete loneliness scales where the questions used were straightforward and the response options limited to three choices. Research by McVilly et al. (2006) showed that individuals with an ID do have an understanding of the concept of loneliness. To help participants, the loneliness scale utilised in this study was

simplified to maximise understanding with questions split into two parts, first a simple yes/no option and then a three item response option. The research reported here found that loneliness scores fell within the expected range, suggesting participants had no difficulty with the concept.

10.2.1   Predisposing Variables

The most important variable that predisposes a person to loneliness is functional limitations. Functional limitations operated akin to race in other populations (Hawkley et al., 2008), which increased the chances of becoming lonely and defined the social opportunities, accommodation and working life for individuals with an ID (Gilmore and Cuskelly, 2014). The role of functional limitations, therefore, differed from that found in the wider population. In the broader population, functional limitations are a measure of deterioration (Wenger and Burholt, 2004). For older people with an ID functional limitations have determined their life course and they now determine which variables will precipitate their loneliness. Functional limitations play a part in the attributions, the experience of loneliness and even reactions to loneliness.

Participants with good functional ability received a good education and worked in the wider community. These individuals were more likely to become lonely if poor transport hampered their social life. Participants with greater functional limitations did not receive the same level of education and were more likely to live a service-dominated life. There were two precipitating routes to loneliness for this group: those who endured pain and those who suffered emotional health problems. For those with emotional health concerns, changes within the services created stress which then induced loneliness, and the synthesis model highlights that service changes are most stressful for those with greater functional limitations.

The association between functional limitations and instrumental activities of daily living means that those with more functional limitations were less likely to be able to carry out the activities necessary for an independent life. People with an ID who are dependent on others have been found to be the loneliest (McVilly et al. 2006), and this research extends those findings, demonstrating that functional limitations not only increase the chances of being lonely but also decrease the chance that participants would never be lonely.

The synthesis model emphasised the importance of functional limitations in the precipitating paths that encompassed all levels of the cognitive discrepancy approach to loneliness. These paths take in pain, depression, loneliness and sleep difficulties, before culminating in raised systolic blood pressure. In the last model, where people with lower functional abilities were less likely to be included, the link to systolic blood pressure was absent, implicating another role for functional limitations, for which further research is necessary.

Overcoming functional limitations is not beyond the capacity of those who offer support to this population. Staff are crucial in facilitating the social lives of people with an ID and staff practices and empowerment are critical in promoting choice (Kozma et al., 2009). People need support to facilitate their needs and guide their choices (Wiltz and Kalnins, 2008); they do not need cocooning, and staff need training on how to support relationships (Bane et al., 2012). The effects of functional limitations can be defeated when staff are trained and empowered to facilitate the social world the individual requires.

The second most important predisposing variable for loneliness was being female, which is of importance because of the link to experiencing pain. Being female is often found to be associated with loneliness in the general population (Holmén et al., 2000, Jylhä, 2004) and this research gave mixed results. Females were significantly more likely to be lonely than males, and being female was predictive of consistent loneliness. Females were more liable to be lonely than men, in keeping with other ID research (McVilly et al., 2006). In the general population, it has been argued that women are more likely to be lonelier because they tend to outlive men and therefore accrue more of the precipitators of loneliness (Wenger and Burholt, 2004). To date, there is no evidence that females with an ID outlive males (Lauer & McCallion, 2015; Mary McCarron, Carroll, Kelly, & McCallion, 2015), but being female was strongly associated with increased pain. These results find that females are more likely to experience pain. Pain is difficult for a person to surmount because it psychologically introverts a person, cutting them off from friends and family, thus maintaining their loneliness (Biro, 2011). The association with pain demonstrates that similar to the wider population (Cacioppo and Cacioppo, 2014), females were more likely to experience loneliness-precipitating events like pain.

Age in this population was linked to an accumulation of losses, and it was this amassing of losses that maintained consistent loneliness. This finding is in keeping with previous research in the general population (Wenger and Burholt, 2004). Only Victor et al. (2008) found extreme old age protective of loneliness, and these results support their finding with those aged 65 plus less likely to be lonely than those aged between 50 and 64.

The protective role of education was a by-product of a person's functional limitations. McVilly et al. (2006) found individuals who attend special education schools are more likely to be lonely than those who do not; this finding went unexplained. There are two possible reasons for the role of education. In the wider population, education is linked to larger social networks, more group participation and less stress (Hawkley et al., 2008). Therefore, in this population education may have added something to a person's life, which protects them against loneliness, or education may be just an artefact of functional limitations. If education adds a protective element, those

who have a higher level of education would have stronger social networks, less stress or better social knowledge such as knowing in whom to confide. If education were a relic of functional limitations, then it would have been associated with items that functional limitations are known to influence.   Education in this study associated with being female and living accommodation, those with better education were more likely to live independently and less liable to live in a service-controlled environment. The data offered no evidence to support the argument that education adds a special element, such as increased social network or increased activities. The association with living arrangements supports the argument that education is merely an artefact of functional limitations,   but further research is necessary to test this.

Similar to being educated to junior certificate level, working in the community reduced the chances of being lonely for those with fewer functional limitations. McVilly et al. (2006) found those who worked in ID specific workshops were lonelier than those who worked in the community. As with education, if working in the community added something to the lives of people with an ID it would have associated with increased social network and integration. If working in the community were an outcome of functional limitations, it would relate to elements and events that functional limitations are known to influence. In this case, both sets of relationships were apparent; those who work in the community were more likely to give help, receive help and have friends outside of the house they live in, and working in the community was related to instrumental activities of daily living (IADL). The association with IADL's demonstrates that those who worked in the community were more able to function independently and socialise independently, yet working in the community did enhance social networks and community integration. At this moment working in the community is the domain of those with fewer functional limitations, and those with greater functional limitations could enjoy the benefits of community employment with adequate support.

10.2.2   Precipitating Variables

Transport problems limit access to social resources, impacting those participants working in the community and those living in residential settings. Transport problems mediate the path between working in the community and loneliness. The mediating role of transport means, for those who work in the community, the greater the perceived level of transport problems the more likely they were to be lonely. There were three possible routes to loneliness from transport problems; direct, mediated by wanting to do more activities and mediated by depression. The path mediated by wanting to do more activities is specific to lower functioning individuals, and for those living in residential settings, poor transport creates a feeling that their activities are inadequate. In the wider population, transport is a particular problem for those living in rural communities as it limits

access to social resources (Drennan et al., 2008, Burholt and Scharf, 2013). Similarly, poor transport has been found to increase the problems of creating and maintaining friendships for people with an ID (Bane et al., 2012). The current study supported the findings that transport problems limit a person's possible social life and this is the first study to show a link to loneliness for individuals with an ID.

Transport problems and loneliness were negatively associated with living in a community house, meaning that those who live in community housing are less likely to report transport difficulties and less liable to be lonely. The association with transport indicates that people who live in community houses have access to reliable transport to fulfil their social lives, and it demonstrates that if adequate transport is supplied this route to loneliness can be minimised.

Participants who were less functionally able were reliant on service providers for their social lives, and for these participants there were two routes to loneliness. Participants who were abler found the strictures of institutional living left them feeling their social relationships were inadequate, creating a desire to want to do more activities. Poor transport availability was the cause of feelings that social events were inadequate. For some participants, functional limitations led to increased pain, which precipitated feelings of loneliness. Pain causes people to be distracted from tending to their social lives, focusing them internally (Biro, 2011). Pain was the most important health variable, predicting 4.7% of the loneliness variance, and those who experience pain were more likely to be consistently lonely. Loneliness can be the cause of pain (Jaremka et al., 2014). However, this research offers no evidence that loneliness increases pain, and pain is more likely the precipitator of loneliness. This finding extends and supports the knowledge about pain in the wider population and adds new insights to the literature about loneliness in the ID population, demonstrating that pain is a powerful precipitating event that overwhelms the person's ability to socialise.

Those with emotional health problems had difficulty dealing with change. In the wider population, difficulty adjusting expectations to match new circumstances is known to be an outcome of emotional health problems (Burholt and Scharf, 2013). Like pain, emotional health difficulties are associated with having a larger number of functional limitations. Emotional health problems are often an outcome of loneliness (Cacioppo et al., 2010) and service providers need to be aware that in tackling emotional health issues they will be helping to tackle loneliness, and in tackling loneliness, they will be tackling emotional health problems.

Older People with an ID found changes in service provision so toxic that the associated level of stress precipitated loneliness. Service stress was more potent for those reliant on services and was the only stressor that proved to be a significant predictor of loneliness, demonstrating the

importance of stable service provision to people with an ID. There have been mixed findings on the role of stressors: Hawkley et al. (2008) found stress to be predictive of loneliness, yet other researchers have found stressors not to be predictive of loneliness (Zebhauser et al., 2014). This research was the first to look at the role of the stress in the lives of people with an ID, and it has found that stress brought on by a change in service provision precipitates loneliness while relationship stress and social stress do not.

Lonely participants confided in people who cannot help them, while the non-lonely confided in those who could help. Whom individuals confide in was linked to housing type, and those living in service accommodation confided in staff while those living with family or independently confided in the family. This finding further extends the work of McCausland (2015) who found having a parent as confidant was linked to lower loneliness levels of loneliness. Confiding was previously reported to be protective against loneliness (Hawkley et al., 2008), and the results here suggest that the role is not as straightforward as previously found. Hawkley et al. (2008) argued that confiding in a spouse was an indication of a quality marriage; therefore, confiding in staff and family reflects a level of quality in these relationships.

Some events not detected as precipitating events for the onset of loneliness did predict being consistently lonely. Falling represented a disruption to the way of life and indicated a permanent decline in abilities. Falling represented a decline that was powerful enough to maintain the mismatch between desired and achieved social relationships. The finding that falling was antecedent to loneliness was new, but its association with functional ability does fit with McVilly et al. (2006) who reported the loneliest as those who are reliant on others. Declines in physical function and health have been noted as a cause of loneliness in the wider population increasing the chance of isolation and loneliness (Wenger and Burholt, 2004). It may not be possible to prevent functional decline, but where people commence falling carers should be aware of the implications of decline and put in place strategies that can reduce the effect. The effect of falling in some had created a fear of falling where people felt they had difficulty doing activities which extended feelings of loneliness. Therefore, the strategies put in place to aid in the continued safety of individuals should not leave them feeling that their social life is being adversely affected by these strategies. Falling is a good measure of decline in people with an ID and can be considered equivalent to the number of chronic conditions used as a measure of decline in the general population.

10.2.3   Quality Relationships

In this population, indicators of quality social relations were: whom people confide in, holidaying abroad, plus changes that reduced the chances of loneliness.

Network quality is often measured by having someone to confide in (Victor et al., 2005, Hawkley et al., 2008). The role of confiding in older people with an ID was more sophisticated than found to date in the general population. The analysis demonstrates that confiding in someone who can aid in making changes is beneficial, and confiding in those who cannot make changes is not. This difference in the role of confidants may be because people with an ID are not always able to affect change for themselves, but it is likely that in the general population a useful confident is someone who can influence change.

Going on holiday abroad can also be considered a sign of a quality network. It is unlikely that a person with an ID will organise a solo trip abroad and they must rely on being part of an organised group, either family or service group, which is strong enough to create such a journey.

Changing the frequency of visits from family or friends was predictive of moving from being lonely to not being lonely, and indicated a perceived improvement in the quality of relationships. There was no direction required in this finding to say whether the changes were increases or decreases in visits because research has shown that people who have more social experiences than their desired number of social relationships are as likely to become lonely as those whose social experiences are suboptimal (Russell et al., 2012). While the evidence would suggest an actual change in the frequency of visits, it is possible that the real difference is in expectation of visits or feelings around those visits. These participants may have been a group who came to loneliness through changes in their circumstances, such as moving within the service organisation and may have incidentally changed the frequency of visits from family or friends causing loneliness. Once settled into the new conditions, a person's loneliness may then have reduced as they accepted their new positions adapted their expectations, made new friends and felt an increased quality in their relationships. More investigation is needed, but the finding is consistent with Weiss (1973).

Having an increased number of chronic conditions may also produce a higher number of quality relationships as a by-product. In the analysis of consistent loneliness, the number of chronic conditions was found to be protective against loneliness. This finding is because as the number of chronic conditions increased the person received more attention and was drawn into the caring centre of services, making them feel that they have stronger bonds with those caring for them. Whereas, the number of chronic conditions is often used as a measure of decline in the wider population because increasing chronic conditions tend to isolate people from others (Cleary, 2011, Burholt and Scharf, 2013).

10.2.4   Social Relationships and Activities

Measures of social network and social participation demonstrate no inclination to be predictive of loneliness in this population. In studies of the wider population, both social participation rates and social network size are usually associated with loneliness (Zebhauser et al., 2014, Hawkley et al., 2008). This difference was because this study utilised measures aimed at networks in the wider population. The structure of the social network for people with an ID is different to that of the general population as people with an ID rarely get married and rarely have children (McCarron et al., 2011). Individuals with an ID see less of their friends and family than people who do not have an ID (McCausland, 2015) and their inner circle tends to include a preponderance of staff (Lippold & Burns, 2009). Likewise, social participation rates were not a measure of active engagement and were more of a measure of the service they receive or their living circumstances.

10.2.5   Responses to Loneliness

Older people with an ID responded to loneliness by experiencing a subconscious increased alert state known as hypervigilance. Hypervigilance is known to produce sleeping difficulties, raised systolic blood pressure, negative social memory and it causes people to be wary of others (Cacioppo and Cacioppo, 2014), all of which were apparent in this study. Individuals coped with loneliness by utilising a strategy of active solitude.

The evidence in this study is that the hypervigilance brought on by loneliness produces sleeping difficulties which in turn produces raised SBP. Loneliness has been found to predict sleeping difficulties in community-living participants in the general population (Hawkley and Cacioppo, 2007) and studies of older people living in congregated communities (Kurina et al., 2011). Findings of self-report sleeping difficulties have been corroborated by the use of night cap technologies (Cacioppo et al., 2000).   In the wider population loneliness has been described as a cause for raised SBP and consequent heart disease (Lynch, 1977), and evidence has been produced that demonstrates loneliness drives SBP increases in older people (Ong et al., 2012, Hawkley et al., 2010). Disrupted sleep also drives raised SBP (Bonnet and Arand, 2003) and the evidence in the study was that not only were those who are lonely more likely to have raised SBP but that disrupted sleep mediated between loneliness and raised SBP. This mediating mechanism of sleep disruption explaining how loneliness causes elevated SBP was a new finding, opening a new path that requires further investigation.

Regular medical intervention disguised the effect of loneliness on raised SBP with the consequence that raised SBP was not predicted by consistent loneliness.   It has been reported by

McCarron et al. (2011) that 92% of participants receive GP care regularly, and hypertension is 50% lower than the general population due to the routine checking of blood pressure (McCarron et al., 2014). This research is the first to look at the body's physiological response to loneliness in older people with an ID. The results supported those expected from the general population and added new knowledge to the literature on loneliness in older individuals with an ID, but more research on these issues is needed to support these findings.

Hypervigilance in this population also causes participants to remember more negative lifetime events. One of the subconscious effects of hypervigilance is that it creates a bias to remember more negative events (Cacioppo and Cacioppo, 2014), in this population consistently lonely participants, were one and a half times more likely to report negative life events than those who are not lonely. It is possible that lonely people are subject to more losses and this prevents them from recovering from their loneliness. If the number of life events were directly related to the creation of loneliness, then they would have been an antecedent to loneliness. The number of life events was not found to be antecedent to loneliness, and therefore people who are already lonely are remembering more events than individuals who are not lonely.

Implicit hypervigilance has a role in whom people will trust and in whom they will confide (Cacioppo and Cacioppo, 2014). Those who are lonely are wary of the threat others cause; in the case of this group of participants it means they were more likely to confide in the wrong people. Those who were not lonely were more likely to confide in staff or family, and those who were lonely were more likely to confide in others or friends. Hawkley et al. (2008) argued that lonely people were less likely to seek emotional support. In this study, the lonely did seek emotional support but sought it from long term trusted acquaintances rather than staff who change regularly. Seeking support from the wrong people is in keeping with Weiss (1973) who argued the lonely suffer due to a lack of social information available from others. This research extends this argument because even where the resource is available, the participants are unable or unwilling to recognise that support, because of hypervigilance.

Older people with an ID who are lonely over an extended period cope with their loneliness by engaging in a strategy of being active. Perlman and Peplau (1998) described different ways participants cope with loneliness: active solitude and sad passivity were two of those coping mechanisms. Active solitude is where people find constructive ways, such as reading, exercising or working to cope with their loneliness. Lethargy, overeating and inactivity define sad passivity. Previous research with older adults in the wider population has found that people usually cope with loneliness through sad passivity by decreasing activity, smoking and eating poor diets (Lauder et al., 2006, Hawkley et al., 2008). This research does not support these findings and

rather supports the concept of active solitude or active coping. Active coping is where efforts are made to alter the lonely person's environment through various activities (Schoenmakers, van Tilburg, & Fokkema, 2012) whereas active solitude is where a person busies themselves with the goal of passing the time. Consistently lonely participants were proportionally more likely to do moderate exercise, report diet as excellent or very good, attended church more regularly and were more likely to have voted in the last election. Either people with an ID decide for themselves to alter their environment, or they are encouraged to participate in activities that may help reduce their loneliness.

Research has demonstrated that others will enthusiastically encourage lonely people to be active (Schoenmakers et al., 2012) and for older individuals with an ID staff employed to care for them are the most likely people to encourage increased activity when they believe someone is lonely, in the hope they will find new social connections. This finding is new to the loneliness field but, further research is necessary to corroborate this and to determine what interventions would better reduce loneliness.

10.2.6   The Role of Variables

This study was the first to move beyond the straightforward production of individual variables related to loneliness by applying advanced statistical techniques to estimate how the variables interacted with each. The study utilised both Conditional Process Analysis (CPA) and Structural Equation Modelling (SEM) to investigate which paths to loneliness were reliant upon an intervening third variable, mediation, and which paths to loneliness were conditional upon a third variable, moderation. The analysis considered how the proposed paths fitted together to create an all-encompassing model of loneliness.

The conditionality of pathways on depressive symptoms was measured in three models using CPA. The estimations found that the direct paths to loneliness from experiencing pain, functional limitations and working in the community were reliant on the type of attributions made; that is depressive symptoms moderated pathways to loneliness. This research created a new understanding of the importance of attribution in the path to loneliness for older people with an ID. This work also supports the findings of Burholt and Scharf (2013) who argued that depressive symptoms as measured by the CES-D scale were a good way to measure of attribution. The results confirm the value of utilising moderation when investigating attributions and it demonstrated the utility of measuring attribution with depressive symptoms.

In their model, Burholt and Scharf (2013) had found that depressive symptoms moderated the direct and indirect path of health and loneliness mediated through social resources. They did not

find an effect of depressive symptoms on the indirect path that included service participation. Burholt and Scharf (2013) concluded that even though one pathway did not demonstrate the hypothesised moderation, the model had reported a significant interaction between health and depressive symptoms and so accepted the positive result of the single effect. Similarly, the two models listed above found significant interactions with depressive symptoms on the direct paths and not the indirect paths, and it is reasonable to conclude that attributions do intervene between the antecedents and loneliness. Because all the pathways to loneliness were not dependent on depressive symptoms, the results demonstrate that loneliness is a separate construct to depression and indicate it is possible to arrive at loneliness without being depressed.

The analysis of the conditional effect of attribution also considered the mediating role of variables. Three models included mediation: the first had pathways from pain to loneliness mediated in parallel by social network and social activities. The estimations of these pathways found there was no mediation in this model, but did demonstrate a significant path from experiencing pain to reduced social activity. This result further showed that the data on the social network and social activity was unsuitable for understanding the lives of older people with an ID. The second model estimated that the path to loneliness from functional limitations was mediated by the perceived level of pain experienced. In the third example, for those who were working in the community, the more a person thought their transport was problematic, the more they were likely to be lonely.

The synthesised models, using SEM, further enhanced the understanding of how the elements of loneliness fit together and make it clear that depressive thinking was one of the key items that need to be confronted in the fight against loneliness. The models estimate there are alternative routes to loneliness than through depressive symptoms. Combining the results from the attribution analysis and the synthesis model, it is clear that attributions can be modelled in a variety of ways but all report that the more negative the thought process, the greater the chance of loneliness occurring. A good example of this is the path from functional limitations to loneliness, which was found to be mediated first by the perceived level of pain experienced and then by depressive symptoms. For those with high functional limitations and no pain , the path to loneliness was conditional upon depressive symptoms. That means that for those with high functional limitations but no pain, if they have a high level of depressive symptoms they will have an increased chance of becoming lonely and if they experience pain, depressive symptoms enhance the feelings of pain.

In the SEM, the elements of loneliness combine to demonstrate a path from predisposing elements through precipitating events, attribution, experiences and outcomes of loneliness

matching the structure of the CDA. This is the first research to create a unified model of loneliness utilising SEM. Burholt and Scharf (2013) reported a unitary model of loneliness, but this was pieced together from the results of CPA. The use of SEM allowed complete testing of the model which is not available in other analyses such as regression analysis and saved the researcher from having to piece together separate analyses. In estimating the model, SEM tests the fit of the model to the data, improving the understanding of how well the proposed model actually fits the data supplied; the manual piecing together of a model will not create this calculation.

The first model demonstrated that it was possible to create a unified model of loneliness for this population. The model included elements of attribution but excluded depression, displaying four distinct paths to loneliness accounting for 15% of the loneliness variance and a single consequence path away from loneliness. The consequent path extended the work done with CPA, showing that those with higher functional limitations experience loneliness due to an increased experience of pain, and the loneliness leads to increased sleep problems, which in turn lead to raised SBP. This finding is in keeping with other research and demonstrates how pain isolates a person, leading to loneliness (Jaremka et al., 2014), and how loneliness primes poor sleep, which in turn causes raised blood pressure supporting the work of others (Bonnet and Arand, 2003).

The second model was the paramount model, maximising the use of variables and participants. This model demonstrated the significant contribution made to loneliness by depressive symptoms. In this population, depression was the largest predictor of loneliness, accounting for an 8% increase in the total loneliness variance explained. In this model, depressive symptoms mediate the paths from functional limitation to loneliness and from transport to loneliness. Depression further extends the path that was originally developed in the CPA, demonstrating a path from functional limitations to raised SBP which is serially mediated by pain experienced, depression, loneliness and sleep difficulties. This role of depression is in keeping with other research (Hawkley and Cacioppo, 2010), and this demonstrates that the path to loneliness exists because of attributions made. The final model supported the argument that service changes have more effect on people with greater functional limitations, through the loss of the service stress variable in the model. Removal of the SBP variable from the model indicates that poor sleep has more effect on those with more functional limitations. Other research looking at the effect of loneliness on SBP has not indicated a link between functional ability and SBP in loneliness. People with greater functional limitations are less likely to take part in moderate exercise, and one feature of how people coped with loneliness was participating in moderate exercise, which reduces the risk of raised SBP (The Mayo Clinic, 2004). This link has never been investigated for individuals with an ID and requires further investigation.

The SEM gave support to the CDA as a useful format for understanding loneliness. The models presented do not use all the variables that have been found predictive and consequent of loneliness. The unused variables offer the chance of alternative routes to loneliness in this population that the research was unable to fulfil.

10.3   Support for, and, the development of theory

This research supports the CDA as a useful way to understand loneliness in people with ID. It has established that, in groups that are sub-populations to the general population, this provides a useful structure to understand loneliness. The study supported each element of the CDA, and the structure synthesised through SEM included a pathway that led from predisposing elements all the way through to the response to loneliness. This synthesised model was the first loneliness model created for older people with an ID.

The CDA model proposes that some antecedent variables predispose a person to those variables which will precipitate loneliness. The results indicate that functional limitations are the principal predisposing element for people with ID. This finding is useful for other researchers because it means they can think outside of the core demographic variables of age, gender and race, and should explore other types of predisposing elements. The types of precipitating events reported are both chronic and acute, which is in keeping with the CDA. The analysis added new variables to those already known, which included falling and having difficulty doing activities.

Wanting to do more activities consistently represented the mismatch between desired and achieved levels of social relations, removing the need to infer a mismatch from the poor social network or lack of participation. The direct approach offered by asking if people wish to do more activities, in order to explore the mismatch between achieved and desired social relations, has not been used before and may be useful to researchers investigating other populations.

The central role of attributions is fundamental to the CDA, and this research supports that stance. Burholt and Scharf (2013) had argued that depressive symptoms as measured by the CES-D scale were a decent guide for attribution style. This research supported use of the CES-D, however, the CES-D is relatively complicated with some difficult terms that prove challenging to many participants, which has the effect of reducing the numbers who can complete it and the groups to which findings can be generalised. This research has added new variables as measures of attribution that might be considered by other researchers and with other populations. Self-reported effects of an experience are an expression of a person's attribution about an event and are easier to gather than complex scales. The results from SEM demonstrate that paths to

loneliness that are not conditional upon an attribution can be mediated by an attribution; either way, the route to loneliness exists because of an attribution.

This research further supports the differentiation of loneliness from depression and demonstrates how depressive symptoms influence attributions which affect loneliness. What this research demonstrates is that the more depressive a person's thinking, the more likely they are to make negative attributions. However, because not every path to loneliness has been mediated or moderated by depressive symptoms, then loneliness is not reliant on depression.

This research demonstrates that the experience of loneliness is not stable for everyone and is prone to fluctuate in people's lives as change happens, and is furthermore supportive of the work of others in looking beyond the simple cross-sectional analysis of loneliness and examining its temporal nature. In doing so, it highlights that loneliness is a dynamic experience. The use of the consistent loneliness variable in the analysis of reactions and coping demonstrated shows the value of analysing both. The results indicate that some variables might create the initial loneliness and yet the effect of others are so powerful they maintain an individual's loneliness. The analysis is also useful for understanding how interventions, whether medical or otherwise, can influence the results from analysis; raised SBP was an obvious example of this. The effect of loneliness on raised SBP was apparent when looking at cross-sectional loneliness but disappeared when considering consistent loneliness.

The SBP findings and the findings around sleep difficulties demonstrate that loneliness does have knock-on consequences for health. This analysis found that a link exists from loneliness to disrupted sleep which produces the raised SBP. The results also highlight that sad passivity is not the only response to loneliness and that active solitude or active coping are also likely outcomes that should be considered more often by researchers.

10.4   Recommendations for Policy and Practice

The most critical issue that requires urgent attention is the high level of consistent loneliness found within this population. Consistent loneliness was found in 26% of the population, nearly double that reported in the wider population (Victor, 2014). Tackling consistent loneliness will have physical and mental health benefits for older people with an ID. This study has demonstrated that loneliness produced sleep difficulties and raised SBP. Tackling consistent loneliness would have health benefits for participants and financial benefits for service providers and society.

There is little research into the costs of loneliness for society, but one research study in the UK has estimated the medium term cost of loneliness is over £12,000 per lonely person (Fulton & Jupp, 2015). These costs could not be transferred to this population because they relate to the expenses of dealing with and treating individuals who are currently community-based. They do however demonstrate that tackling loneliness has cost benefits; one such benefit in the context of older people with an ID is a reduction in medical interventions

Polypharmacy has been flagged as an issue for individuals with an ID (O'Dwyer, Peklar, McCallion, McCarron, & Henman, 2016) and tackling loneliness can potentially prevent the need for certain medications. This study has demonstrated that loneliness led to sleep difficulties and raised SBP. If people are having their sleep problems and blood pressure managed through pharmacological intervention, then there are potential savings of two medicines. Loneliness has been revealed to drive depression (Cacioppo et al., 2010); if this is the case in this population, then there is a potential saving in medication and treatment for depression. There is also research to suggest that pain is increased because of loneliness (Jaremka et al., 2014) and again there is a potential saving on pain interventions.

The best way to tackle consistent loneliness would be to facilitate individuals to take control of their social experience through person-centred planning. Person-centred planning is the ideal tool for dealing with many of the antecedents to consistent loneliness especially; the restrictions brought about by functional limitations, community integration, transport problems, contact with family and friends, wanting to do more activities, change in service structures and change in health.

Two types of change negatively affect service users: service changes and personal health changes. Services are currently being encouraged to integrate people with ID into the community more, which is of undoubted long term benefit. However, services need to be cognisant of the effects of changing an environment to which someone has adapted over an extended period. Moving people within organisations leaves them at risk of missing friends, staff and places. They risk losing social resources and valued social roles. Personal health changes were found to negatively affect people and were denoted by falling. Falling precipitates loneliness and is indicative of declining health and increased reliance on others. Service providers should ensure that personal plans include supports to overcome this loss of personal independence.

Particular attention is needed to reduce the adverse effects of functional limitations with specific efforts being made to find out what life enhancements are necessary for those with greater limitations to mitigate the risk of loneliness. When changes occur, service providers should be

aware that those with higher functional limitations are often left behind, losing the social resource of their higher functioning friends.

Transport is another issue that needs to be addressed through personal planning. Services cannot deliver public transport but they can ensure adequate training for people who use public transport, so they feel secure in using this transport as and when they desire. Service providers can also ensure that satisfactory transport links are available in the new location when planning moves for individuals with an ID.

Of particular interest to those overseeing personal planning should be the protective role of working in the community. Working in the community gives a person a valued social role; it increases the person's quality of activities and self-worth. Volunteering in the community is an alternative to employment that is known to be protective against loneliness (Victor et al., 2008). For participants who have difficulty doing activities outside the home, the personal planning process can be used to identify which supports can be put in place to reduce the number of challenges for individuals.

A person who indicates they want to do more activities should get support to organise the level of activities they desire. Services should monitor individuals who indicate they are not satisfied with their current level of activities or relationships, as this research has demonstrated it is a clear indication of the mismatch between desired and achieved activities. When wanting to do more activities is combined with negative attributions the risk of loneliness is very high.

Outside of the personal planning process, services should tackle depression in older people with an ID. This population has been reported as experiencing higher levels of depression than the general population (McCarron et al., 2014), and since the cognitions of depressive symptomology were shown to enhance people's possibility of experiencing loneliness, service providers should actively pursue the elimination of depression.

Service providers should also give serious consideration to those who were not able to participate in this study. These people had more severe disabilities and did not have the capacity to respond to the questions on loneliness. It is likely that these participants will experience greater levels of loneliness, and more consistent loneliness, than those reported in this study because they are liable to encounter more of the factors that are antecedent to loneliness. They will have greater functional limitations and experience more pain. People with more severe disabilities have fewer friends, and fewer contacts with friends (McCausland, 2015). Increased functional limitations mean they will have more difficulties participating in activities and greater problems again if transport is problematic. Regular staff changes or changes within their service provision will have

an even greater impact on their lives than on the lives of those who participated. Their inability to report on loneliness means they will also have difficulty confiding in people; only 31% of participants in the severe to profound range of ID had someone to confide in (McCausland, 2015), and therefore have difficulty instigating change .

The participants who did not answer the loneliness questions have reduced access to elements that are protective against loneliness and will be less likely to work in the community or have a good education, and are more liable to have poorer quality networks. They are less likely to have an insightful PCP plan and are more likely to experience higher levels of depression. Increased loneliness will lead this group to have increased sleep problems, a greater chance of raised SBP, and consequently a greater reliance on medication to tackle these problems. Additionally, having a greater incidence of functional limitations, they are less likely to benefit from the strategy of active coping.

10.5   Defeating Loneliness

Eradication of loneliness may not be possible but reductions in the amount of loneliness experienced and the consistency of loneliness are, through focusing on the needs of the individual. There are five key recommendations from this study that need to be initiated:

1) Focus personal planning on the needs of the person.

2) Tackle the high levels of depression.

3) Train staff to facilitate individual social lives.

4) Encourage the development of community-based social roles.

5) Consider the effect on individuals when making organisational decisions.

10.6   Limitations

This study only considers loneliness in those able to self-report and accounts for less than half the participants in the IDS-TILDA dataset. Therefore, the findings provided can only be generalised to higher functioning individuals. Those who were unable to self-report are potentially some of the loneliest individuals; these are participants with more severe forms of ID where their contact beyond staff is limited and their experience of the outside world restricted.

Further research is necessary to ascertain if it is possible to understand loneliness in this population. Research should examine whether proxy answers can be used to guide an understanding of loneliness or whether information contained within what is already known can be used to inform us about the risk of loneliness in older people with more limiting forms of disability.

Loneliness, as measured here, is only a single construct. This research has been very useful in giving a general guide to loneliness. However, as loneliness is a consequence of inadequate relationships, it would be helpful to know which relationships older people with an ID miss. There are potentially three inadequate relationship types, friendships, family and intimate relationships. Further research is necessary to define which relationship types are considered inadequate.

This study is quantitative in nature and does not consider the experience of loneliness as viewed through the eyes of one who lives with loneliness. The use of qualitative research would give depth and greater understanding of loneliness in this population.

Self-reporting data are always open to misreporting, this can be through deliberate under-reporting of a phenomenon or because people do not understand the concept. The differences in loneliness scores between studies are indicative of this. In studies where participants were being interviewed the loneliness scores were significantly lower than in research where participants completed a self-completion questionnaire in private. Studies suggest men are the most likely not to report issues such as loneliness, which creates a systematic bias in the results and may under-report factors unique to men. Reporting in private is an option for the wider community, but in individuals with an ID, this is not a feasible option for many of the participants are not literate. Having a staff member complete the loneliness questions in a self-complete interview with the participant may apply more social pressure to the participant. The best option appears to be a trained interviewer who can empathise with the participant.

The antecedents of loneliness described in this thesis explain only 27% of the loneliness variable, while Hawkley et al. (2008) managed to explain 45%. There is clearly room for refinement in the scales investigated and the need for further variables to be investigated. To understand what additional variables may work it is important to understand why certain variables did not explain the amount of variance they were expected to. The difference in explanatory power can be categorised as either; differences in the amount of variance explained by each variable, or variables that didn't work with the population tested. In both categories, Hawkley et al. (2008) were able to provide variables with greater predictive power and variables better defined for the

population. Noteworthy variables in Hawkley et al. (2008) were; stress exposure which added 11% to the variance explained, social contacts which added 5%, network quality added 5% and finally health conditions adding 7% to the loneliness variance.

There were two variables in the analysis of IDS-TILDA data that represented stress, wanting to do more activities and service stress, combined they added 7.2% to the explanation of the loneliness variance. The measurement and reporting of stress in loneliness research has had mixed results, with stress sometimes reported as important in the creation and maintenance of loneliness(Cacioppo et al., 2000) and sometimes not (Cacioppo et al., 2010). Stress Exposure in Hawkley et al. (2008), were measured using a similar methodology to that used here but was categorised differently. Zebhauser et al. (2014) merely used a count of stressful life events neither of which Hawkley et al. (2008) or this analysis found predictive of loneliness. The main two predictive elements in the analysis by Hawkley et al. (2008) were love and marriage stress and social life and recreation stress. The difference in the variance explained is, therefore, a legacy of the type of life events people experienced. In the IDS-TILDA study, a total of 20 items are in the checklist of life events, whereas Hawkley et al. (2008) used a 51 item checklist. Therefore, increasing the number of items measured, with a broader spread of life events and the related stress levels, should increase the predictive power.

Measures of social network and social participation usually associate strongly with loneliness in the general population, this is not the case for people with an ID in this study. In the Hawkley et al. (2008) study social network size added 5% to the amount of variance explained. In this study, neither measures of social network or social participation were significantly predictive of loneliness. The measurement of a meaningful social network in people with an ID has proved problematic for others (Emerson & Hatton, 2007) and they often find the network of participants to be weak or small (Ballin & Balandin, 2007; Bigby, 2004; van Asselt-Goverts, Embregts, Hendriks, Wegman, & Teunisse, 2015). Networks of people with an ID tend to be differently constructed to the wider population (Lippold & Burns, 2009), and inclusive of professionals (Broer et al., 2010; Lippold & Burns, 2009; van Asselt-Goverts et al., 2015) and of the co-residents, who are often not socially matched (Kozma et al., 2009). It has been noted that older people with ID lack both an intimate partner and social network that matches with wider society (McCausland et al., 2016). The measure of social network

size for people with an ID can be seen to have three problems, consistently small numbers, instability in the network, and a lack of psychological connection to network members.

Measures of social participation as a measure of social activity are equally problematic (Emerson & Hatton, 2007). Participation rates have been found to be linked to a person's traits rather than their needs (Kozma et al., 2009; McCausland et al., 2016). While people may have high participation rates (Lippold & Burns, 2009), they mainly socialise with those that they live with (Kozma et al., 2009), meaning that many of the activities may hold no psychological benefit to those partaking. Measures of the social for people with an ID need to allow participants to indicate which social items and members are important to them.

Network satisfaction accounted for 5% of the loneliness variance for Hawkley et al. (2008), yet network satisfaction has rarely been considered in people with an ID. Recent work has shown that people with an ID can answer questions on network satisfaction (van Asselt-Goverts et al., 2015), a measure that allows people to rate their satisfaction with different social elements would increase the amount of the loneliness variance explained.

The measurement of chronic health issues included items that weren't relevant to people with an ID and was affected by underdiagnosis of the diagnosed conditions (Mary McCarron et al., 2014). Underdiagnosis can be due to a-typical symptom presentation (de Winter, van den Berge, Schoufour, Oppewal, & Evenhuis, 2016) and communication problems (Ballin & Balandin, 2007). Such underdiagnosis is problematic in the analysis of the effects of declining health on the population. The current chronic conditions scale utilised consisted of seven conditions: hypertension, diabetes, cancer, lung disease, heart disease, stroke, and arthritis. A more accurate scale would be one that represents the conditions most likely experienced by people with an ID. The conditions that afflict people with an ID are obesity, constipation, epilepsy, osteoporosis, cataracts, hypertension, and gastro reflux. (wave 3 report). An alternative approach would be to develop a scale that represents the conditions that increase in prevalence as people age within this population being; constipation, obesity, osteoporosis, epilepsy gastro reflux,

eye disease and dementia. Either of these options offers a scale that would be a more accurate representation of chronic conditions in older people with an ID.

Depression adds 8% to the explanatory power of loneliness in the synthesis model. If it had been included in the Antecedents variables, it would have increased the amount of variance explained up to 35%. The understanding of the relationship between loneliness and depression is not taken forward by using depression as a measure of attribution in this study. A more accurate measure of peoples attributions towards the social would more strongly associate with loneliness.

This research also fails to look at the effect of loneliness on depressive symptoms, there is increasing evidence of a circular relationship between loneliness and depressive symptoms (Cacioppo, Hughes, et al., 2006), and requires further investigation.

The role of other mental health conditions in loneliness also requires investigation as mental health beyond depression is known to influence loneliness. The IDS-TILDA in wave 3 reports on three other conditions; anxiety, mood swings and manic depression.

Research suggests that a measure of anxiety would increase the explanatory power of the models. Loneliness has been closely associated with social anxiety in several studies (Cleary, 2011, Zebhauser et al., 2015), and is a distinct trait that has been found to affect loneliness (Fung, Paterson, & Alden, 2017). IDS-Tilda wave 3 analysis reports that 15.1% of participants scores on the Glasgow Anxiety Scale indicated the presence of anxiety.

Having free choice over life decisions can influence a person's attributions. Recent findings from the IDS-TILDA wave three suggest that people within this population feel they have greater choice than previously possible in both the small decisions from the food eaten on a daily basis through to the larger choices of choosing where to live (McCausland et al., 2017). How the service operates influences, the level of choice people receive (Kozma et al., 2009) and in terms of socialising people have highly restricted choices (McCausland, 2015) which often leads to people having no choice over who their friends are (R. P. Hughes et al., 2011). Yet it is argued that people in this population often need help making choices (Wiltz & Kalnins, 2008).

The effects of loneliness in this population require further investigation. This research demonstrated that loneliness is associated with raised blood pressure. The amount of

association while significant is small, suggesting other factors have a much stronger association with raised SBP. Further investigation is necessary to understand if the influence of loneliness contributes any significant amount to the ongoing health problems caused by raised SBP.

Loneliness has been associated with other health issues caused by increased cortisol levels and changes in DNA transcription (Cacioppo & Cacioppo, 2014). Further investigations are necessary to see if these changes are in existence for this population and whether the changes have any effect on health beyond what is already known about the effects of other stressors.

Regression analysis works on the level of correlation and is measuring the amount of covariance between two variables. It should be highlighted that association is not causation. As discussed in chapter 8, *limitations*, to show causality three criteria need to be met; covariation, temporal ordering and elimination of competing theories (Hayes, 2013). This data does show co-variation in the variables. Temporal ordering is very difficult to produce in social sciences research as it would be unethical to inflict pain on someone to see if this did cause loneliness. Temporal ordering is created through the use of longitudinal data, through the type of analysis used such as mediation analysis which infers direction on the results and through the use of support from the findings of others. The elimination of competing theories can never be absolute. However, the use of covariances and the supporting evidence from other researchers increase the probability of the ordering. While this research does not prove causation, and in the most looks at the association, supported by the work of others and fitting to current theoretical models does infer causation on the results.

Statistical significance of the results means that the chances of the results occurring by chance or because of sampling error statistically unlikely. The results can be confidently said represent the characteristics of the population. In setting a significance level, we reduce the chance of variables associating by chance. In the antecedents chapter where the significance level is set to $p<0.1$, there is a much greater chance of a chance association than the rest of the study where significance levels were set at $p<0.05$. However, relying on significance levels does increase the chance that a variable that is important may be missed and so significance levels are always a balancing act between

this inclusion and exclusion. Ideally, the results should be supported by the research of others and a strong theoretical position, which happens here and by further qualitative analysis as done by McVilly et al. (2006). Caution should be applied to the results, and it may be the case that some of the associations claimed, with loneliness, here may be an occurrence of chance or also some other associations may have been excluded.

The longitudinal analysis reported here is based only on two waves of data, and it can be expected that the inclusion of wave three data will create a much more complex vibrant mix of changes in loneliness than is reported here as shown in Victor (2014). The most likely effect is that the levels of consistent loneliness will be reduced and will be more in line with general population-based results. It is also likely that the amount of those that were never lonely will have also decreased, thus raising the possibility that more people with an ID report experiences of loneliness than has been reported in the general population. It should be noted that other results may have been over a longer time periods, typically 10 years they are based on just two collection points (Jylhä, 2004; Christina Victor et al., 2008).

Heinrich and Gullone (2006) argue that the prevention of social relationship deficits should be a priority for clinicians. To do this, they recommend the attributional elements that lead to loneliness should be tackled (Heinrich & Gullone, 2006). This research has shown that depressive thinking style and a belief the problems that encompass them are problematic and mediate the pathways to loneliness. Attribution is a clear link to loneliness and needs to be tackled by clinicians. Loneliness is not depression and clinicians should remember that a person's attributions in loneliness are linked to the social and not the general so a specific concentration on changing attributions around the social should be key. Research has indicated by concentrating on the individual and guiding them to take steps to overcome these attributional elements has the greatest chance of success (Broer et al., 2010; Lawlor et al., 2014).

The creation of such a measure has three problems that need addressing, 1. Diagnosis, 2. Treatment, 3. Philosophical.

When measuring loneliness, this research has demonstrated that people will answer the questions differently depending on the context in which they are being asked them, this renders the use of a single measurement scale useless. Loneliness research is fraught

with these problems. You also need to define at what point a person is clinically lonely. Is a person clinically lonely who fits the criteria on a single occasion or do they have to report loneliness over an extended period of time. The work of Victor (2014) demonstrates that the experience of loneliness fluctuates, this fluctuation may be situational it may be seasonal, and is likely both. The widow who attends a daycare facility may experience no feelings of loneliness when at the daycare, but on arriving home to a cold, empty house may be overwhelmed by loneliness. It is possible that another widow would feel lonely at the daycare facility, where they have failed to make significant friends, but is fine when returning home because they expect to be alone at home. Loneliness may be seasonal, people may feel lonely at certain times of the year or around specific events. Some people may be lonely in the summer and fine in the winter and others vice versa. Lonely people are known to use health services more (Cleary, 2011) and so may be misdiagnosed as lonely when appearing at a GP on repeated occasions throughout the year. Clinical diagnosis tends to be carried out by GP's and may completely exclude groups such as those with an Intellectual Disability because they are rarely free to attend such services of their own volition.

As loneliness, for many is not stable, treatment would be problematic. The medical model relies heavily on medications to cure problems. Would medications be available that treat the deep inner loneliness of someone who has lost their life partner, this may be an incurable feeling. Can a course of socialisation be prescribed? As this study shows, doing more social activities does not necessarily associate with less loneliness, activities have to be meaningful to the person.

Finally, it has to be questioned if society wants a clinical measure of loneliness? To create a clinical measure puts loneliness in the hands of the clinicians and out of the hands of wider society. Most people in their life will at some point feel lonely, whether it is the student moving to college, the old person housebound due to ill health or the disabled person trapped in an institution wondering about the world outside. It is surely incumbent upon society to develop solutions to help all have choices and a feeling of an accessible and available social life that meets their expectations and not pass over solutions to the medical profession.

Those who support people with an ID should consider the effects of pain on people and better procedures to diagnose pain should be introduced. Those who make policy and placement decisions should consider a person's location, and ask are they able to achieve their goals as independently as possible within their current lifestyle or do changes need to be recommended to allow the removal of obstacles.

10.7   Conclusion

Loneliness in older people with an ID is the unhappy removal from a life lived with others (Dumm, 2008), that contributes to sleeping difficulties and raised SBP, negatively influencing the quality of life and long-term health. Tackling consistent loneliness would reduce the medication burden for lonely loneliness / lonely people? to which these outcomes add. Loneliness is experienced when negative attributions occur after a mismatch is noted between the desired and achieved levels of social relations. Which variables precipitate this mismatch is predisposed by a person's functional limitations. Individualising the response to loneliness is the best way to tackle loneliness and could be achieved through the person-centred planning process. Remedies could be delivered that improve the quality of people's networks by attacking the precipitating events.   The effects of service changes, falling and pain, are three variables that could be addressed, and the effect of having greater functional limitations can be overcome.

This study has considered loneliness in older people with an intellectual disability through the CDA, which considers loneliness from its roots in predisposing variables to its consequences in how people react and cope with it. The research measured loneliness using a four item loneliness scale consisting of the three item loneliness scale (Hughes et al., 2004) and a single item self-report measure of loneliness.

Nearly double the amount of consistent loneliness was experienced in this population when compared to studies of older people in the wider population. Participant's depth of loneliness experienced was no greater than in the general population. Once older individuals with an ID become lonely, they are more likely to remain lonely and suffer the knock-on consequences of poor sleep and raised blood pressure. On the positive side, fewer people became lonely than managed to escape the experience of loneliness.

The CDA divides the antecedents of loneliness between predisposing factors and precipitating events. Predisposing factors of loneliness functional limitations and education and being female and being aged between fifty and sixty predisposed a person to consistent loneliness. Being in pain as a consequence of high functional limitations mediated the path to loneliness, while

transport problems mediate a path between working in the community and loneliness for those with few functional limitations. Service changes and the stress they create precipitate loneliness for those reliant on services for their social lives, especially those with emotional health difficulties. While the usual measures of social network and social activity had no relation with loneliness, variables that indicated network quality were protective against loneliness.

Attributions are the link between a perceived mismatch in social relations and experiencing loneliness. People with depressive symptoms are more likely to make negative attributions and are therefore more liable to be lonely. Pathways to loneliness can be either conditional on the type of attribution made, or can be mediated by the attribution.

Once lonely, nearly twice as many people remained consistently lonely as has been reported for the general population. Uniquely, more participants moved out of loneliness than became lonely. Consistent loneliness was precipitated by falling or being in pain, while variables that demonstrated improvements in the quality of relationships of relationships were protective against consistent loneliness. The best way to avoid having feelings of loneliness is to have few functional limitations or a person-centred plan.

Once lonely, participants subconsciously experience hypervigilance, and they were more likely to experience sleep difficulties and high SBP. Further problems that occurred because of hypervigilance were remembering more negative events and trusting the wrong people in whom to confide. Lonely people were encouraged to cope actively with their loneliness through getting involved in more exercise, attending mass or voting.

When the variables were synthesised using both CPA and SEM, it became apparent that all levels of the CDA fit together and were in keeping with the data supplied.

As people age and accumulate losses, it may not be possible to prevent temporary feelings of loneliness. However, strategies can be incorporated to deal with these events as they occur and to mitigate the effects of functional limitations. In the end:

> *"The only real cure for loneliness is to establish relationships that meet our desires for a sense of intimacy and connectedness with others." (Perlman and Peplau, 1998 p.581).*

11 References

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Appendices

Appendix A1 – Ethical Approval

Ethical approval for initial IDS-TILDA longitudinal study (2010-2016)

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Head of School of Medicine
Vice Provost for Medical Affairs

Ms. Fedelma McNamara
School Administrator

Email: fmcnamar@tcd.ie

Prof. Mary McCarron
School of Nursing and Midwifery,
Trinity College Dublin,
24 D'Olier Street, Dublin 2
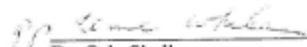
10th July, 2008

Study Title: An Intellectual Disability Supplement to the Irish Longituddinal Study on Ageing (TILDA)

Dear Prof. McCarron,

Further to the meeting of the Faculty of Health Sciences Research Ethics Committee on 27th May 2008, I am pleased to inform you that the above project has been approved without further audit.

Yours sincerely,

Dr. Orla Sheils
Chairperson
Faculty of Health Sciences Ethics Committee

Professor Mary McCarron
Dean of the Faculty of Health Sciences and Principal Investigator of IDS-TILDA,
Chemistry Building,
Trinity College Dublin,
Dublin 2.

7 February 2013

Study: Intellectual Disability to the Irish Longitudinal Study on Ageing (IDS-TILDA) – Wave 2

Dear Professor McCarron,

Further to the review of the modifications submitted for the IDS-TILDA Study Wave 2, I am pleased to inform you that the continuance of your ethical approval has been re-affirmed by the Faculty of Health Sciences Research Ethics Committee.

Wishing you the best of luck with your study.

Yours sincerely,

PP cↄayl

Dr. Ruth Pilkington
Chairperson
Faculty Research Ethics Committee

Appendix B1 - Participant Cover Letter

Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College
School of Nursing & Midwifery
24 D'Olier Street, Dublin 2.
Tel: + 353 1 896 3186/3187
Fax: + 353 1 896 3001   Email: idstotilda@tcd.ie

<Insert date>

Dear Participant,

We are writing to tell you about a large study we will be carrying out on growing older with intellectual disability in Ireland.

This is a very important study which will involve 800 people with intellectual disability.

It will help us to learn more about what is important to people as they grow older.

We will learn about people's health, work and lifestyles.

We would like to invite you to take part in this study.
We are sending you an information booklet about this study and a consent form.

A consent form is something a person signs which means that they are happy to help and take part.

Please read the information booklet or ask someone to help

you to read it. This will help you to understand the study better.

It is your choice to take part in the study.

If you would like to take part, please read and sign the consent form, or ask someone to help you.

We would be delighted if you decided to take part in this study. If you want to ask us any questions then please call us on (01) 8963186 or 8963187.

We look forward to hearing from you.

Yours sincerely,

Prof. Mary McCarron.

Professor Mary McCarron
Principal Investigator
Intellectual Disability Supplement to TILDA

Appendix B2 – Consent Form

<div style="border:1px solid #000;">

Consent form

Please read the information below and sign this consent form if you wish to take part in this study.

I agree with the following statements:

Please tick ☑

I have gone through the information about this study ☐

I knew who to contact if I had any questions. ☐

Any questions that I might have had were answered. ☐

I know that it is my choice to take part in this study. ☐

I understand that I will be asked questions about my:

- life
- health
- work
- friends

and things I like to do. ☐

1
</div>

I understand that I do not have to answer questions I don't feel happy with.

☐
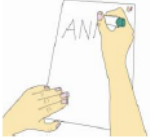
As part of the study, I know that I will be asked to try and do some things such as write my name.

☐

I understand that I will be asked to have some measurements taken such as my height and weight.

☐

I understand that I can stop taking part in this study when I want to. I do not have to give a reason.

☐

I understand that all information I give during this study will be kept safe and private. I will not be named in any reports.

☐

I understand that there are no known risks with this study.

☐

I am happy to take part in this study.

☐

2

Your consent

Your name: _____   Your phone number: _____

Your address:

_____

_____

_____

_____

_____

                                                          Please tick ✅

When is the best time to contact you?   Morning time   ☐

                                                                            Afternoon time ☐

                                                                             Evening time   ☐

Please sign your name: _____   Date: _____

The person supporting you

I have supported the person named above to fill out this form. I believe they understand the information and have freely agreed to take part in this study.

Print name: _____

Relationship to the person named above: _____

Phone number:_____

Signature: _____   Date:_____

Please return this consent form in the envelope provided.

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Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College
School of Nursing & Midwifery
24 D'Olier Street, Dublin 2.
Tel: + 353 1 896 3186/3187
Fax: + 353 1 896 3001   Email: idstotilda@tcd.ie

<Insert date>

Dear family member/guardian,

The Intellectual Disability Supplement to TILDA is the most comprehensive study on ageing in persons with intellectual disability ever to be undertaken in Ireland. For the first time, there is a large and growing population of older people with intellectual disability in Ireland and elsewhere. Although this is an incredible success, we know little about the ageing of this population group.

This study will explore the health, lifestyles, living circumstances and quality of life for about 800 people with intellectual disability as they grow older. It will also see how their circumstances change over a 10-year period. The study is being carried out by Trinity College Dublin and is part of a major Irish longitudinal study on ageing (TILDA) in the general population, which is led by Professor Rose Anne Kenny.

We have chosen your family member/person with intellectual disability to take part in this study. This is voluntary, however it is a very important study and we will get better information if we have a large number of people taking part.

Please find attached an information leaflet about the study and what it involves. If your family member/person with intellectual disability decides to take part in this study, an interviewer with a lot of experience of working with people with intellectual disability will arrange a suitable time to conduct the interview with them. We hope you agree to your family member/person with intellectual disability taking part in this study. If so, please sign the attached agreement form and return it in the stamped addressed envelope enclosed. If you have any questions, please do not hesitate to contact me or a member of the research team on 01-896 3186/3187.

Yours sincerely,

Prof. Mary McCarron.

Professor Mary McCarron
Principal Investigator
Intellectual Disability Supplement to TILDA

Appendix B3 – Family Information Leaflet

What is the study about?
The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS to TILDA) is the most important study on ageing ever undertaken in Ireland.

It will look at the health, lifestyles and quality of life of about 800 people with intellectual disability as they grow older. It will also observe how their circumstances change over a 10-year period.

The information will be used to develop suitable health and social services that will benefit all people with intellectual disability as they age in Ireland.

We are inviting people with intellectual disability to take part in this study which we are carrying out.

How are participants selected for the study?
People who are registered on the National Intellectual Disability Database (NIDD) and are aged over 40 years may be selected to take part in the study. The sample will be randomly selected from this database.

Does the person with intellectual disability that is selected have to take part?
No. Taking part is voluntary. However, this is a very important study and the information we collect will be better if we have a large number of people taking part. We are inviting men and women aged 40 years and older with an intellectual disability to take part. The person with intellectual disability selected can decide to withdraw from the study at any time.

What if the person with intellectual disability does not take part?
If the person with intellectual disability does not take part or later decides to withdraw, then their decision will in no way affect the current or future services or supports offered to them.

What does the study involve?
A researcher with experience of working with people with intellectual disability will visit the person with intellectual disability and ask questions about their health, lifestyle, living circumstances and quality of life.

We understand that some people may not be able to give this information on their own and may need support. If this is the case then the person with intellectual disability may ask someone (for example, a family member, guardian or key worker) to support them in giving this information.

We will also ask the person with intellectual disability to try and carry out some tasks such as:

- brushing their hair
- writing their name
- naming some colours

The interview will take about 90 minutes. However, this will be different for each person.

At the end of the interview we will arrange a suitable time to take some important physical measurements such as height and weight. We will use these results to find out much more about the health of people with intellectual disability than we could by just asking questions about diet and lifestyles alone. The measurements will take about 15 minutes.

Are there any risks involved?
There are no known risks involved in this study. We will explain each stage of the study to the person with intellectual disability using suitable information booklets and show cards.

At all times, the well-being of the person with intellectual disability will take priority over the research activities. If the person with intellectual disability tells us or indicates that they do not want to take part, or if they decide to withdraw, we will fully respect their decision.

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Is the study confidential?

Yes. We will treat all the information from the study as strictly confidential and we will not publish the name of the person with intellectual disability or pass it on to anyone outside of the research team. The Faculty of Health Sciences Research Ethics Committee, of Trinity College, Dublin, has approved this study after ensuring that proper safeguards are in place.

Who is involved in the study?

This study has been set up by people who have a lot of experience of working with people with intellectual disability.

The advisory team consists of:

- Family Members
- Researchers
- Nurses
- Physicians
- Psychologists
- Psychiatrists
- Service Providers

People with intellectual disability also play an important role in our advisory team through participation in consultative workshops. These workshops will be ongoing with groups throughout the country as the study progresses.

Where can I get more information?

If you have any questions, or if you want more information about the study, please do not hesitate to call or email one of the contacts listed below.

Professor Mary McCarron
Principal Investigator
Phone: 01- 896 3186/3187
Email: mccarrm@tcd.ie

Ms Janet Swinburne
Project Manager / PhD Student
Phone: 01- 896 3186/3187
Email: swinburj@tcd.ie

Or write to:

Intellectual Disability Supplement to TILDA,
The University of Dublin,
Trinity College,
School of Nursing & Midwifery,
24 D'Olier Street,
Dublin 2.

Fax: 01- 8963001
Email: idstotilda@tcd.ie

The Intellectual Disability Supplement to TILDA is funded by the Health Research Board.

An Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS to TILDA)

Trinity College Dublin

Appendix C1 – Wave One Loneliness Questions

SC 3	(SELF-REPORT ONLY)

INTRO: The next few questions are about how people sometimes feel.

IWER: [SHOW CARD YN1].

IWER: Do you ever feel lonely?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

Yes	☐ 1	(Go to SC 4)
No	☐ 5	(Go to SC 5)

Unable to understand	☐ 93
Unclear response	☐ 97
Don't Know	☐ 98
Refused to answer	☐ 99

(IDS-TILDA/UCLA Loneliness Scale)

SC 4	(SELF-REPORT ONLY)

IWER: How often do you feel lonely? Would you say…?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

most of the time	☐ 1
sometimes	☐ 2
rarely	☐ 3

Unable to understand	☐ 93
Unclear response	☐ 97
Don't Know	☐ 98
Refused to answer	☐ 99

(IDS-TILDA)

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SC 5	(SELF-REPORT ONLY)

IWER: [SHOW CARD YN1].

IWER: Do you ever feel left out?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

Yes		1	(Go to SC 6)
No		5	(Go to SC 7)

Unable to understand		93
Unclear response		97
Don't Know		98
Refused to answer		99

(IDS-TILDA/UCLA Loneliness Scale)

SC 6	(SELF-REPORT ONLY)

IWER: How often do you feel left out? Would you say...?
IWER: READ OUT AND CODE THE ONE THAT APPLIES

most of the time		1
sometimes		2
rarely		3

Unable to understand		93
Unclear response		97
Don't Know		98
Refused to answer		99

(IDS-TILDA)

SC 7	(SELF-REPORT ONLY)

IWER: [SHOW CARD YN1].

IWER: Do you find it difficult to make friends?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

Yes		1
No		5

Unable to understand		93
Unclear response		97
Don't Know		98
Refused to answer		99

(IDS-TILDA/UCLA Loneliness Scale)

Appendix C2 - Wave Two Loneliness Questions

SC8	**(SELF-REPORT ONLY)**
	INTRO: The next few questions are about how people sometimes feel.
	IWER: Do you ever feel lonely?
	IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

Yes	☐ 1	(Go to SC 9)
No	☐ 5	(Go to SC 10)

Unable to understand	☐ 93
Unclear response	☐ 97
Don't Know	☐ 98
Refused to answer	☐ 99
SR not present/ proxy unable to complete	☐ 0

(IDS-TILDA/UCLA Loneliness Scale)

SC9	**(SELF-REPORT ONLY)**
	IWER: How often do you feel lonely? Would you say…?
	IWER: READ OUT AND CODE THE ONE THAT APPLIES

most of the time	☐ 1
some of the time	☐ 2
Hardly ever, never	☐ 3

Unable to understand	☐ 93
Unclear response	☐ 97

	Don't Know	☐ 98	
	Refused to answer	☐ 99	
	SR not present/ proxy unable to complete	☐ 0	

(IDS-TILDA)

SC10	**(SELF-REPORT ONLY)**

IWER: Do you ever feel left out?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

Yes	☐ 1	**(Go to SC 11)**
No	☐ 5	**(Go to SC 12)**

Unable to understand	☐ 93
Unclear response	☐ 97
Don't Know	☐ 98
Refused to answer	☐ 99
SR not present/ proxy unable to complete	☐ 0

(IDS-TILDA/UCLA Loneliness Scale)

SC11	**(SELF-REPORT ONLY)**

IWER: How often do you feel left out? Would you say…

IWER: READ OUT AND CODE THE ONE THAT APPLIES

most of the time	☐ 1
some of the time	☐ 2
Hardly ever,never	☐ 3

Unable to understand	☐ 93
Unclear response	☐ 97

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	Don't Know	98
	Refused to answer	99
	SR not present/ proxy unable to complete	0

(IDS-TILDA)

SC12	**(SELF-REPORT ONLY)**

IWER: Do you find it difficult to make friends?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

Yes	1
No	5

Unable to understand	93
Unclear response	97
Don't Know	98
Refused to answer	99
SR not present/ proxy unable to complete	0

(IDS-TILDA/UCLA Loneliness Scale)

SC13	(SELF REPORT ONLY)

How often do you feel you lack friendship / friends?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

most of the time	1
some of the time	2
Hardly ever or never	3

Unable to understand	93
Unclear response	97
Don't Know	98
Refused to answer	99

	Don't Know ☐ 98
	Refused to answer ☐ 99
	SR not present/ proxy unable to complete ☐ 0
	(IDS-TILDA)
SC12	**(SELF-REPORT ONLY)**
	IWER: Do you find it difficult to make friends?
	IWER: **PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'**
	Yes ☐ 1
	No ☐ 5
	Unable to understand ☐ 93
	Unclear response ☐ 97
	Don't Know ☐ 98
	Refused to answer ☐ 99
	SR not present/ proxy unable to complete ☐ 0
	(IDS-TILDA/UCLA Loneliness Scale)
SC13	(SELF REPORT ONLY)
	How often do you feel you lack friendship / friends?
	IWER: READ OUT AND CODE THE ONE THAT APPLIES
	most of the time ☐ 1
	some of the time ☐ 2
	Hardly ever or never ☐ 3
	Unable to understand ☐ 93
	Unclear response ☐ 97
	Don't Know ☐ 98
	Refused to answer ☐ 99

	SR not present/ proxy unable to complete ☐0
	(IDS-TILDA)
SC14	(SELF REPORT ONLY) Do you ever feel isolated? (Never asked out to socialise e.g. out for coffee, I live very far away from other people) **IWER: READ OUT AND CODE THE ONE THAT APPLIES** 	most of the time	☐1
some of the time	☐2
Hardly ever or never	☐3	 	Unable to understand	☐93
Unclear response	☐97
Don't Know	☐98
Refused to answer	☐99
SR not present/ proxy unable to complete	☐0 | (UCLA/IDS-TILDA
SC15	(SELF REPORT ONLY) **IWER:** Do you have someone with whom you can confide? (e.g. someone that you feel at ease with, can talk to about private matters, and can call on for help) **IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'** 	Yes	☐1	(Go to SC 16)
No	☐5	(Go to SC 17) | | Not applicable (e.g. completely dependent on others to interpret needs and wants etc)	☐94	(Go to SC 17)
Unclear response	☐97	(Go to SC 17)
Don't know	☐98	(Go to SC 17)
Refused to answer	☐99	(Go to SC 17)
SR not present/proxy unable to complete	☐0	(Go to SC 17)	

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Appendix C3 – Self Labelling Loneliness Sub Scale

Within the revised version of the UCLA loneliness scale a four item self-labelling subscale was created (Letitia A. Peplau & Cutrona, 1980):

Table C3- 1: UCLA-R Self-labelling Loneliness Subscale

Question No	Question
1	I feel in tune with people around me
13	No one really knows me well
15	I can find companionship when I want it to
18	People are around me but not with me

<table>
<tr><td colspan="2" style="text-align:center">**Section 14: I(ADL) & Helpers (FL)**</td></tr>
<tr><td colspan="2" style="text-align:center">*Functional Limitations*</td></tr>
</table>

FL1	**INTRO:** We need to understand the difficulties people may have with various activities.

NOTE: If the SR is confined to bed or a wheelchair, read the following statement: *"I am required to ask about all of these activities. I realise that you may not be able to do some of them, but I would appreciate it if you could try to answer each question as best you can".* Exclude any difficulties that you expect to last less than three months.

NOTE: Please refer to protocol definitions throughout this section. Pleased record any information pertaining to the SR's/ proxy's definition of level of difficulty in the textboxes provided throughout the section.

IWER: Please indicate the level of difficulty, if any, you have **with walking 100 yards**.

IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐ 1	(Go to FL3)
Some difficulty	☐ 2	(Go to FL 2)
A lot of difficulty	☐ 3	(Go to FL 2)
Cannot do at all	☐ 4	(Go to FL 2)

Unclear response	☐ 97	(Go to FL3)
Don't know	☐ 98	(Go to FL3)
Refused to answer	☐ 99	(Go to FL3)

(SHARE/NDS)

FL2	[Please record description of the difficulty here]

FL3	**IWER:** [Please indicate the level of difficulty, if any,] you have **with running or jogging about 1.5 kilometres (1 mile).**

IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐ 1	**(Go to FL 5)**
Some difficulty	☐ 2	**(Go to FL 4)**
A lot of difficulty	☐ 3	**(Go to FL 4)**
Cannot do at all	☐ 4	**(Go to FL 4)**

Unclear response	☐ 97	**(Go to FL 5)**
Don't know	☐ 98	**(Go to FL 5)**
Refused to answer	☐ 99	**(Go to FL 5)**

(SHARE/NDS)

FL4	[Please record description of the difficulty here]

FL5	**IWER:** [Please indicate the level of difficulty, if any,] you have **with sitting for about two hours.**

IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐ 1	**(Go to FL 7)**
Some difficulty	☐ 2	**(Go to FL 6)**
A lot of difficulty	☐ 3	**(Go to FL 6)**
Cannot do at all	☐ 4	**(Go to FL 6)**

Unclear response	☐ 97	**(Go to FL 7)**
Don't know	☐ 98	**(Go to FL 7)**
Refused to answer	☐ 99	**(Go to FL 7)**

(SHARE/NDS)

FL6	[Please record description of the difficulty here]

FL7	IWER: [Please indicate the level of difficulty, if any,] you have **with getting up from a chair after sitting for long periods**.
	IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐ 1	**(Go to FL9)**
Some difficulty	☐ 2	**(Go to FL 8)**
A lot of difficulty	☐ 3	**(Go to FL 8)**
Cannot do at all	☐ 4	**(Go to FL 8)**

Unclear response	☐ 97	**(Go to FL 9)**
Don't know	☐ 98	**(Go to FL 9)**
Refused to answer	☐ 99	**(Go to FL 9)**

(SHARE/NDS)

FL8	[Please record description of the difficulty here]

FL9	IWER: [Please indicate the level of difficulty, if any,] you have **with climbing <u>several</u> flights of stairs without resting.**
	IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐ 1	**(Go to FL 11)**
Some difficulty	☐ 2	**(Go to FL 10)**
A lot of difficulty	☐ 3	**(Go to FL 10)**
Cannot do at all	☐ 4	**(Go to FL 10)**

Unclear response	☐ 97	**(Go to FL 11)**
Don't know	☐ 98	**(Go to FL 11)**
Refused to answer	☐ 99	**(Go to FL 11)**

(SHARE/NDS)

FL10	Please record description of the difficulty here]

FL11	**IWER:** [Please indicate the level of difficulty, if any,] you have **with climbing <u>one</u> flight of stairs without resting.**
	IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐	1	**(Go to FL 13)**
Some difficulty	☐	2	**(Go to FL 12)**
A lot of difficulty	☐	3	**(Go to FL 12)**
Cannot do at all	☐	4	**(Go to FL 12)**

Unclear response	☐	97	**(Go to FL 13)**
Don't know	☐	98	**(Go to FL 13)**
Refused to answer	☐	99	**(Go to FL 13)**

(SHARE/NDS)

FL12	Please record description of the difficulty here]

FL13	**IWER:** [Please indicate the level of difficulty, if any,] you have **with stooping, kneeling, or crouching.**
	IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐	1	**(Go to FL 15)**
Some difficulty	☐	2	**(Go to FL 14)**
A lot of difficulty	☐	3	**(Go to FL 14)**
Cannot do at all	☐	4	**(Go to FL 14)**

Unclear response	☐	97	**(Go to FL 15)**
Don't know	☐	98	**(Go to FL 15)**
Refused to answer	☐	99	**(Go to FL 15)**

FL14	Please record description of the difficulty here]

FL15	**IWER:** [Please indicate the level of difficulty, if any,] you have **with reaching or extending your arms above shoulder level.**
	IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐	1	**(Go to FL 17)**
Some difficulty	☐	2	**(Go to FL 16)**
A lot of difficulty	☐	3	**(Go to FL 16)**
Cannot do at all	☐	4	**(Go to FL 16)**

Unclear response	☐ 97	**(Go to FL 17)**
Don't know	☐ 98	**(Go to FL 17)**
Refused to answer	☐ 99	**(Go to FL 17)**

(SHARE/NDS)

FL16	Please record description of the difficulty here]

FL17	**IWER:** [Please indicate the level of difficulty, if any,] you have **with pulling or pushing large objects like a living room chair.**

IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐ 1	**(Go to FL 19)**
Some difficulty	☐ 2	**(Go to FL 18)**
A lot of difficulty	☐ 3	**(Go to FL 18)**
Cannot do at all	☐ 4	**(Go to FL 18)**

Unclear response	☐ 97	**(Go to FL 19)**
Don't know	☐ 98	**(Go to FL 19)**
Refused to answer	☐ 99	**(Go to FL 19)**

(SHARE/NDS)

FL18	Please record description of the difficulty here]

FL19	**IWER:** [Please indicate the level of difficulty, if any,] you have **with lifting or carrying weights over 10 pounds/5 kilos, like a heavy bag of groceries.**

IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐ 1	**(Go to FL 21)**
Some difficulty	☐ 2	**(Go to FL 20)**
A lot of difficulty	☐ 3	**(Go to FL 20)**
Cannot do at all	☐ 4	**(Go to FL 20)**

Unclear response	☐ 97	**(Go to FL 21)**
Don't know	☐ 98	**(Go to FL 21)**

	Refused to answer	☐ 99	**(Go to FL 21)**

(SHARE/NDS)

FL20	Please record description of the difficulty here]

FL21	**IWER:** [Please indicate the level of difficulty, if any,] you have **with picking up a small coin from a table.**

IWER: READ OUT AND CODE THE ONE THAT APPLIES

No difficulty	☐ 1	**(Go to FL 23)**
Some difficulty	☐ 2	**(Go to FL 22)**
A lot of difficulty	☐ 3	**(Go to FL 22)**
Cannot do at all	☐ 4	**(Go to FL 22)**

Unclear response	☐ 97	**(Go to FL 23)**
Don't know	☐ 98	**(Go to FL 23)**
Refused to answer	☐ 99	**(Go to FL 23)**

(SHARE/NDS)

FL22	Please record description of the difficulty here]

FL23	**Any Other Information (Functional Limitations):**

Appendix C5 - CES-D Scale

Survey Respondent ID Number	Researchers ID Number
W 1	I D S

Section 5: Mental Health (MHD)

MHD 1

NOTE: This section on mental health is only administered if the SR has had the capacity to answer most of the questions themselves in previous sections (Section 1-4).

(SELF-REPORT ONLY)

IWER: SHOW CARD MHD1.

IWER: The next section of the interview is about people's mood, feelings and well-being. I am going to read a list of some of the ways you may have felt or behaved in the last week. Please look at card MHD1 and indicate how often you have felt this way during the past week.

IWER: READ OUT AND CODE ONE BOX ON EACH LINE.
IWER: PROMPT IF NECESSARY - 'WOULD YOU RARELY, SOME OF THE TIME...?'

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	All of the time (5-7 days)	Unclear response	Don't know	Refused to answer
(During the past week) you were bothered by things that usually don't bother you?	0	1	2	3	97	98	99
(During the past week) you did not feel like eating; your appetite was poor?	0	1	2	3	97	98	99
(During the past week) you felt that you could not shake off the blues even with help from your family?	0	1	2	3	97	98	99
(During the past week) you felt that you were just as good as other people?	0	1	2	3	97	98	99
(During the past week) you had trouble keeping your mind on what you were doing?	0	1	2	3	97	98	99
(During the past week) you felt depressed?	0	1	2	3	97	98	99
(During the past week) you felt that everything you did was an effort?	0	1	2	3	97	98	99
(During the past week) you felt hopeful about the future?	0	1	2	3	97	98	99

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	All of the time (5-7 days)	Unclear response	Don't know	Refused to answer
(During the past week) you thought your life had been a failure?	0	1	2	3	97	98	99
(During the past week) you felt fearful?	0	1	2	3	97	98	99
(During the past week) your sleep was restless?	0	1	2	3	97	98	99
(During the past week) you were happy?	0	1	2	3	97	98	99
(During the past week) you talked less than usual?	0	1	2	3	97	98	99
(During the past week) you felt lonely?	0	1	2	3	97	98	99
(During the past week) you felt people were unfriendly?	0	1	2	3	97	98	99
(During the past week) you enjoyed life?	0	1	2	3	97	98	99
(During the past week) you had crying spells?	0	1	2	3	97	98	99
(During the past week) you felt sad?	0	1	2	3	97	98	99
(During the past week) you felt that people disliked you?	0	1	2	3	97	98	99
(During the past week) you could not get going?	0	1	2	3	97	98	99

(CES-D)

MHD 2 Any Other Information (Mental Health - Depression):

RESP	01
Proxy	02
R & P	03
Researcher	04

IWER: Return to MH 1 – Main Questionnaire

Table 2. Unstandardized Coefficients (SE) From Regression of Loneliness on Covariates in Linear Regression Models (N = 225)

Covariate	Model 1: Demographics		Model 2: Socioeconomic Status		Model 3: Health and Functioning	
	1A	1B	2A	2B	3A	3B
Age	−0.10 (0.15)					
Female	−2.49 (1.29)					
Race/ethnicity: White						
Black	2.79 (1.53)†	2.72 (1.53)†	1.24 (1.58)			
Hispanic	4.15 (1.65)*	4.41 (1.61)*	2.69 (1.67)			
Diploma			−3.71 (1.61)*	−4.36 (1.56)*	−4.57 (1.49)*	−5.03 (1.48)*
Household income			−1.55 (0.73)*	−1.73 (0.71)*	−1.00 (0.70)	
Chronic conditions					0.02 (0.82)	
Number of symptoms					0.25 (0.07)*	0.30 (0.06)*
Activity of daily living restrictions					2.07 (1.46)	
Spouse/partner						
Work role: Working						
Retired						
Not working						
Regular church attender						
Group member						
Life event count						
Chronic stressors						
General						
Money and financial						
Employment						
Love and marriage						
Family and children						
Social life and recreation						
Health						
Residence						
Network size						
Frequency of contact						
Marital relationship: Not married						
Spousal non-confidant						
Spousal confidant						
Network satisfaction						
R²	.05	.03	.08	.07	.16	.14

Covariate	Model 4: Social Roles		Model 5: Stress Exposure		Model 6: Social Contacts	
	4A	4B	5A	5B	6A	6B
Age						
Female						
Race/ethnicity: White						
Black						
Hispanic						
Diploma	−4.23 (1.50)*	−4.38 (1.49)*	−3.98 (1.40)*	−3.80 (1.40)*	−2.89 (1.36)*	−3.19 (1.35)*
Household income						
Chronic conditions						
Number of symptoms	0.28 (0.06)*	0.30 (0.06)*	0.22 (0.06)*	0.26 (0.06)*	0.28 (0.05)*	0.29 (0.05)*
Activity of daily living restrictions						
Spouse/partner	−1.51 (1.28)					
Work role: Working						
Retired	0.51 (1.45)					
Not working	1.78 (1.76)					
Regular church attender	−0.30 (1.27)					
Group member	−2.89 (1.28)*	−2.93 (1.23)*	−2.94 (1.19)*	−2.81 (1.15)*	−1.65 (1.14)	
Life event count			1.24 (0.76)			
Chronic stressors						
General			−1.71 (1.54)			
Money and financial			1.71 (1.39)			
Employment			2.25 (1.54)			
Love and marriage			3.82 (1.27)*	4.71 (1.21)*	4.13 (1.18)*	4.19 (1.18)*
Family and children			−0.03 (1.22)			

Table 2. Unstandardized Coefficients (*SE*) From Regression of Loneliness on Covariates in Linear Regression Models (*N* = 225) (*Continued*)

Covariate	Model 4: Social Roles		Model 5: Stress Exposure		Model 6: Social Contacts	
	4A	4B	5A	5B	6A	6B
Social life and recreation			3.36 (1.26)*	3.92 (1.22)*	3.93 (1.18)*	3.88 (1.18)*
Health			0.28 (1.21)			
Residence			0.84 (0.56)			
Network size					−1.10 (0.25)*	−1.15 (0.24)*
Frequency of contact					−0.40 (0.70)	
Marital relationship: Not married						
Spousal non-confidant						
Spousal confidant						
Network satisfaction						
*R*²	.18	.16	.31	.27	.33	.32

Covariate	Model 7: Relationship Quality	Model 8
	7A	
Age		−0.23 (0.14)
Female		−3.11 (1.35)*
Race/ethnicity: White		
Black		0.86 (1.45)
Hispanic		−0.84 (1.56)
Diploma	−2.58 (1.32)*	−2.07 (1.37)
Household income		−0.06 (0.74)
Chronic conditions		0.47 (0.81)
Number of symptoms	0.25 (0.05)*	0.21 (0.06)*
Activity of daily living restrictions		1.43 (1.36)
Spouse/partner		1.62 (1.79)
Work role: Working		
Retired		2.75 (1.57)
Not working		1.58 (1.64)
Regular church attender		1.24 (1.19)
Group member		−1.78 (1.21)
Life event count		0.72 (0.75)
Chronic stressors		
General		−1.11 (1.58)
Money and financial		1.92 (1.37)
Employment		3.28 (1.59)*
Love and marriage	3.58 (1.16)*	1.78 (1.25)
Family and children		−0.10 (1.19)
Social life and recreation	3.39 (1.16)*	3.19 (1.22)*
Health		0.72 (0.53)
Residence		−0.59 (1.15)
Network size	−1.13 (0.24)*	−0.99 (0.26)*
Frequency of contact		−0.28 (0.72)
Marital relationship: Not married		
Spousal non-confidant	0.80 (1.70)	
Spousal confidant	−2.50 (1.17)*	−4.79 (1.73)*
Network satisfaction	−2.98 (1.11)*	−2.92 (1.15)*
*R*²	.37	.45

Notes: "A" models introduce blocks of conceptually related variables. "B" models drop individual nonsignificant predictors within blocks. See text for a description of directional hypotheses.

*$p < .05$; †$p < .1$.

Appendix D2 – Results of the Regressions utilising variables taken from Hawkley et al. (2008)

Demographics	Bootstrap					Socio-Econo	Bootstrap				
	1			95% Confidence Intervals		2			95% Confidence Intervals	
	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
Age	-0.004	-0.010	0.675	-0.024	0.017					
Gender	0.284	-0.178	0.113	-0.072	0.639					
Education						-0.491	0.216	0.022	-0.894	-0.057
r²	0.008					0.014				

Health	Bootstrap						Bootstrap				
	3a			95% Confidence Intervals		3b			95% Confidence Intervals	
	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
Education	-0.252	-0.219	0.252	-0.670	0.154	-0.389	-0.214	0.069	-0.798	0.043
Chronic Conditions	-0.001	-0.108	0.994	-0.205	0.202					
Foot Pain	0.334	-0.255	0.193	-0.147	0.823					
General Pain	0.651	0.226	0.004	0.200	1.102	0.749	0.21	0.001	0.345	1.148
ADL	0.002	-0.022	0.907	-0.401	0.046					
IADL	0.007	-0.027	0.792	-0.048	0.059					
r²	0.073					0.061				

Social Roles	Bootstrap						Bootstrap				
	4a			95% Confidence Intervals		4b			95% Confidence Intervals	
	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
General Pain	0.672	0.205	0.000	0.287	1.064	0.671	0.203	0.001	0.290	1.070
Spouse	0.503	0.828	0.522	-1.049	2.264					
Working in the Community	-0.470	0.258	0.068	-0.975	0.068	-0.443	0.249	0.070	-0.905	0.057
Church Attender	0.357	0.268	0.181	-0.138	0.877					
Group Membership	0.167	0.180	0.354	-0.198	0.538					
r²	0.057					0.046				

Stress Exposure	Bootstrap						Bootstrap				
	5a			95% Confidence Intervals		5b			95% Confidence Intervals	
	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
General Pain	0.718	0.199	0.001	0.333	1.101	0.664	0.201	0.001	0.288	1.050
Working in the Community	-0.434	0.256	0.092	-0.911	0.094	-0.429	0.259	0.094	-0.912	0.097
Life Events	-0.101	-0.103	0.329	-0.312	0.094					
Rel Stress	-0.038	-0.108	0.729	-0.233	0.189					
Social Stress	0.249	-0.202	0.213	-0.125	0.636					
Service Stress	0.347	0.149	0.016	0.054	0.653	0.301	0.135	0.025	0.042	0.562
r²	0.079					0.066				

Social Network		Bootstrap					Network Quality	Bootstrap				
	6				95% Confidence Intervals		7				95% Confidence Intervals	
	B	SE	p	Lower	Upper		B	SE	p	Lower	Upper	
General Pain	0.660	0.202	0.001	0.277	1.064		0.666	0.204	0.002	0.266	1.089	
Working in the Community	-0.426	0.260	0.094	-0.914	0.096		-0.421	0.258	0.101	-0.903	0.117	
Service Stress	0.296	0.136	0.031	0.023	0.554		0.304	0.136	0.023	0.058	0.542	
Social Network	-0.032	-0.059	0.583	-0.148	0.081							
Spousal Confidant							-0.264	0.622	0.631	-1.408	1.054	
r²	0.067						0.066					

	Total	Bootstrap			
8				95% Confidence Intervals	
	B	SE	p	Lower	Upper
Age	-0.018	-0.012	0.124	-0.041	0.007
Female	0.019	-0.193	0.916	-0.358	0.374
Education	-0.341	-0.232	0.148	-0.733	0.080
Chronic Cond	0.054	-0.119	0.645	-0.183	0.299
Foot Pain	0.193	-0.254	0.447	-0.271	0.644
General Pain	0.775	0.226	0.001	0.328	1.283
ADL	0.005	-0.022	0.824	-0.036	0.048
IADL	-0.014	-0.028	0.631	-0.069	0.039
Spouse	1.112	-1.129	0.277	-0.968	3.397
Working in the Community	-0.540	0.324	0.089	-1.174	0.075
Church Attender	0.131	-0.250	0.575	-0.336	0.579
Group Membership	-0.008	-0.192	0.968	-0.369	0.387
Life Events	-0.098	-0.110	0.379	-0.314	0.109
Reln Stress	-0.032	-0.110	0.764	-0.240	0.190
Social Stress	0.191	-0.194	0.323	-0.149	0.489
Service Stress	0.348	0.190	0.071	-0.024	0.722
Social Network	-0.017	-0.065	0.785	-0.150	0.122
Spousal Confidant	-0.889	-0.725	0.138	-2.103	0.654
r²	0.125				

Demographics	Bootstrap					Bootstrap				
	1a			95% Confidence Intervals		1b			95% Confidence Intervals	
	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
Functional Limits	0.027	0.016	0.091	-0.003	0.060	0.027	0.257	0.000	4.345	5.351
Cognitive Ability	-0.007	0.030	0.811	-0.068	0.053					
r^2	0.016					0.015				

Socio-Economic	Bootstrap					Bootstrap				
	2a			95% Confidence Intervals		2b			95% Confidence Intervals	
	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
Functional Limits	0.025	0.016	0.108	-0.004	0.055	0.030	0.015	0.046	0.001	0.062
Transport	0.468	0.261	0.075	-0.016	0.967	0.517	0.262	0.046	0.011	1.034
Residence Family	-0.093	0.264	0.753	0.595	0.418					
Residential	0.371	0.257	0.159	-0.122	0.877					
Independent	0.268	0.358	0.416	-0.365	1.010					
Education	-0.387	0.236	0.101	-0.877	0.115	0.397	0.227	0.080	-0.836	0.061
r^2	0.059					0.046				

Health	Bootstrap					Bootstrap				
	3a			95% Confidence Intervals		3b			95% Confidence Intervals	
	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
Functional Limits	0.014	0.015	0.320	-0.013	0.045	0.014	0.014	0.323	-0.013	0.042
Transport	0.439	0.244	0.073	-0.041	0.915	0.450	0.246	0.069	-0.033	0.937
Education	-0.318	0.222	0.154	-0.744	0.124	-0.297	0.221	0.180	-0.724	0.136
General Pain	0.537	0.221	0.016	0.102	0.970	0.560	0.213	0.008	0.129	0.968
Falls	0.173	0.302	0.565	-0.409	0.768					
Emotional Health	0.266	0.128	0.039	0.004	0.508	0.267	0.126	0.032	0.014	0.505
r^2	0.094					0.092				

Social Roles	Bootstrap					Bootstrap				
	4a			95% Confidence Intervals		4b			95% Confidence Intervals	
	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
Transport	0.530	0.238	0.025	0.079	1.014	0.628	0.224	0.007	0.194	1.081
General Pain	0.561	0.209	0.009	0.159	0.969	0.493	0.191	0.013	0.118	0.863
Emotional Health	0.128	0.117	0.273	-0.109	0.360	0.189	0.109	0.082	-0.023	0.401
Working in the Community	-0.330	0.288	0.239	-0.901	0.249	-0.621	0.250	0.013	-1.096	-0.123
Civic Engagement	0.159	0.638	0.802	-1.252	1.345					
Give Help	-0.093	0.225	0.677	-0.522	0.355					
Friends O/S House	-0.149	0.245	0.542	-0.642	0.317					
Receive Help	-0.193	0.197	0.326	-0.579	0.200					
r^2	0.071					0.077				

Stress Exposure	Bootstrap			Bootstrap		
	5a		95% Confidence Intervals	5b		95% Confidence Intervals

	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
Transport	0.563	0.216	0.011	0.147	0.991	0.582	0.218	0.006	0.173	1.030
General Pain	0.408	0.189	0.034	0.033	0.779	0.434	0.181	0.015	0.083	0.787
Emotional Health	0.125	0.108	0.248	-0.087	0.332	0.141	0.104	0.180	-0.065	0.344
Working in the Community	-0.615	0.282	0.025	-1.168	-0.056	-0.660	0.263	0.013	1.164	-0.146
Difficulty Doing Activities	0.242	0.203	0.238	-0.139	0.657					
Want to do more activities	0.780	0.177	0.000	0.436	1.116	0.801	0.171	0.000	0.469	1.134
Service Stress	0.285	0.121	0.019	0.051	0.521	0.276	0.121	0.025	0.036	0.509
r²	0.159					0.154				

Social Network		Bootstrap						Bootstrap			
	6a			95% Confidence Intervals		**6b**			95% Confidence Intervals	
	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
Transport	0.585	0.226	0.010	0.169	1.063	0.578	0.222	0.007	0.165	1.048
General Pain	0.526	0.186	0.005	0.167	0.899	0.544	0.185	0.004	0.181	0.904
Working in the Community	-0.629	0.267	0.020	-1.167	-0.099	-0.647	0.271	0.019	-1.175	-0.109
Want to do more activities	0.862	0.182	0.000	0.506	1.222	0.836	0.177	0.000	0.487	1.177
Service Stress	0.316	0.124	0.010	0.076	0.558	0.320	0.125	0.009	0.082	0.569
Social Participation	-0.007	0.007	0.341	-0.020	0.007					
r²	0.159					0.156				

Network Quality		Bootstrap						Bootstrap			
	7a			95% Confidence Intervals		**7b**			95% Confidence Intervals	
	B	SE	p	Lower	Upper	B	SE	p	Lower	Upper
Transport	0.509	0.219	0.022	0.095	0.953	0.538	0.220	0.012	0.129	0.988
General Pain	0.573	0.183	0.004	0.223	0.935	0.571	0.182	0.001	0.215	0.920
Working in the Community	-0.636	0.275	0.017	-1.175	-0.097	-0.651	0.273	0.017	-1.174	-0.110
Want to do more activities	0.828	0.180	0.000	0.487	1.195	0.849	0.176	0.000	0.507	1.208
Service Stress	0.353	0.124	0.005	0.106	0.594	0.349	0.123	0.006	0.105	0.585
Confide in Staff	-0.479	0.196	0.015	-0.856	0.094	-0.497	0.187	0.006	-0.861	-0.132
Confide in family	-0.037	0.178	0.829	-0.380	0.323					
Confide in Friend	0.062	0.263	0.812	-0.450	0.578					
Confide in others	0.193	0.361	0.594	-0.457	0.969					
r²	0.178					0.178				

Total		Bootstrap			
	8			95% Confidence Intervals	
	B	SE	p	Lower	Upper
Functional Limits	0.004	0.019	0.841	-0.030	0.045
Cognitive Ability	0.008	0.040	0.829	-0.077	0.091
Transport	0.170	0.279	0.565	-0.414	0.766
Residence Family	-0.082	0.304	0.792	-0.687	0.518
Residential	0.147	0.429	0.718	-0.664	0.968
Independent	0.514	0.382	0.176	-0.180	1.284
Other	0.180	0.297	0.544	-0.432	0.720
Education to JC	-0.444	0.261	0.091	-0.952	-0.008
General Pain	0.695	0.222	0.005	0.290	1.077

Falls	-0.025	0.306	0.927	-0.649	0.566
Emotional Health	0.160	0.137	0.253	-0.126	0.412
Working in the Community	-0.446	0.434	0.293	-1.449	0.419
Civic Engagement	0.935	0.783	0.188	-0.390	2.632
Help Neighbours	0.073	0.261	0.779	-0.487	0.619
Friends O/S House	-0.450	0.270	0.110	-0.929	0.032
Help Friends	-0.346	0.234	0.133	-0.784	0.134
Difficulty Doing Activities	0.346	0.245	0.166	-0.128	0.809
Want to do more activities	0.853	0.226	0.001	0.364	1.332
Service Stress	0.316	0.167	0.068	-0.057	0.658
Social Participation	0.000	0.010	0.995	-0.020	0.020
Confide in Staff	-0.645	0.230	0.004	-1.070	-0.212
Confide in family	0.034	0.234	0.881	-0.421	0.439
Confide in Friend	-0.037	0.330	0.897	-0.727	0.675
Confide in others	0.473	0.409	0.219	-0.278	1.429
r^2	0.276				

Appendix D4 - Burholt and Scharf (2013) Antecedents and Cognitive Characteristics Model of Loneliness.

Reproduced from "Poor Health and Loneliness in Later Life: The Role of Depressive Symptoms, Social Resources, and Rural Environments" by V. Burholt and T. Scharf, 2013 in *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences, 69(2)* p.319. Copyright by The Gerontological Society of America. Reprinted by courtesy of the copyright holder under a creative commons license (http://creativecommons.org/licenses/by-nc/3.0/).
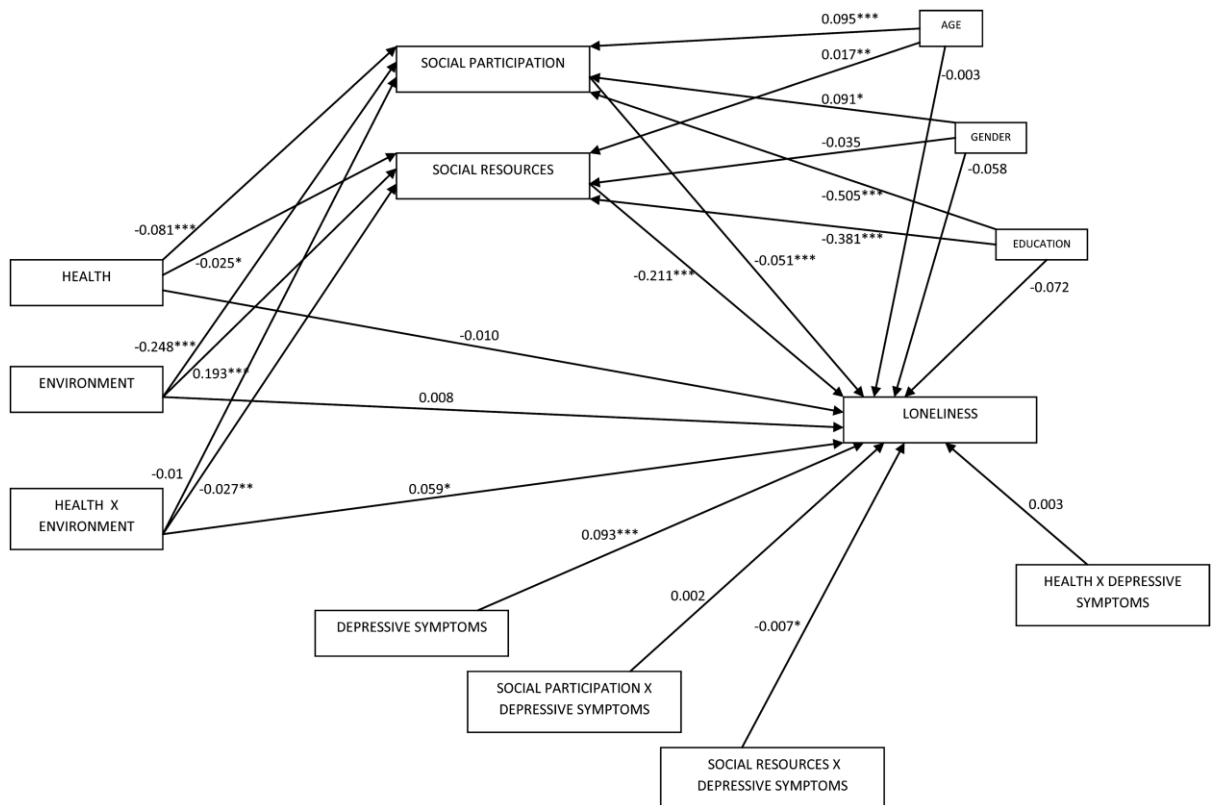
Appendix E1 – Presentations and Publications

Oral Presentations

Irish Gerontological Society; Post Graduate Study Day in Ageing Research, May 2014 "*An examination of loneliness and its health effects as experienced by older people with an intellectual disability.*"

The International Association of Gerontology and Geriatrics European Region Congress 2015, Dublin, April 2015 "*Understanding Loneliness in Older People With an Intellectual Disability*"

Presentations Contributed To

IASSIDD 15th World Congress, August 2016, Philip McCallion An investigation into the temporal nature of loneliness in older people with ID.

Other Presentations

Mary Immaculate College (UL), April 2016, *Loneliness in Older People*

Trinity College Dublin, School of Nursing and Midwifery, PhD Student day, December 2016, *The Quantitative Analysis of Survey Data*.

Articles

Wormald, A. (2014) Understanding Loneliness in Older People with an Intellectual Disability, Frontline, 96.

Wormald, A. (2017) Avoiding Loneliness in Older People with an Intellectual Disability– Lessons from the IDS-TILDA study. Frontline 105.

Posters Presented

IASSIDD Health SIRG Conference, June 2017, *"The influence of loneliness on age related decline in older people with an Intellectual Disability (ID)"*