Exploring how life events affect stress levels and depressive symptoms among older adults with intellectual disabilities in Ireland: Results from the IDS-TILDA study

Tabitha Carlson
Exploring how life events affect stress levels and depressive symptoms among older adults with intellectual disabilities in Ireland: Results from the IDS-TILDA study

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A dissertation submitted to Trinity College Dublin in partial fulfilment of the degree of Master of Science in Disability Studies

Under the supervision of
Dr. Rachael Carroll

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Declaration

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

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

I acknowledge that this dissertation uses data collected by the intellectual disability supplement to the Irish longitudinal study on ageing. As of submission date, the data are yet unpublished, but are duly acknowledged in the text wherever included.”

Signature of Author:

Date:
Summary

This study aimed to establish how the experience of significant life events affects stress and depressive symptomology among older people with an intellectual disability (ID) in Ireland, and how this population perceives these experiences. Results from Wave 2 of the Intellectual Disability Supplement to the Irish longitudinal study on ageing (IDS-TILDA) were analysed because of its national representative sample of older people with ID.

A descriptive quantitative approach was utilized to answer the research questions. This methodology was selected because it has been proven to be a more reliable method of assessing life events and mental health status, particularly among people with ID (Hermans and Evenhuis, 2012; Radloff, 1977). A descriptive approach allowed for the prevalence of life events, stress and depressive symptoms to be established. Further, a correlational design, a sub-type of a descriptive approach, allowed for the relationship between these variables to be assessed. Thematic analysis was also employed to analyse the data gathered from an open-ended question on the perception of life events and their burden of stress.

The study population included 634 participants, taken from the sampling frame of the total IDS-TILDA Wave 2 population (n=701), is representative of all demographic groups, including gender, age, level of ID and place of residence. The inclusion criterion was completion of the depression subscale of the Hospital Anxiety and Depression Scale (HADS-D). This measurement tool was selected for its established reliability and validity for use with people with ID, and because results from Wave 1 of IDS-TILDA indicate that older people with ID are at increased risk of depression.

Multiple quantitative analyses were conducted in order to establish the distribution of life events across demographic groups, including the type of life event experienced. These results were analysed to show the relationship with stress and depressive symptoms. The thematic analysis added dimension to these findings by elucidating how older people with ID felt about their experiences.

The results showed that the majority of participants experienced at least one life event in the year prior, and a large proportion had experienced multiple life events, which were found to be significant predictors of depressive symptoms. The most commonly experienced life events were all related to receiving formal care within a community group home or residential centre. Stress reported by these experiences varied, and the thematic analysis contextualised these results, finding that some life events could be positive experiences, while the same event would be stressful for another individual. The most stressful event was major illness or injury, which was also the strongest predictor of case-level depressive symptoms, indicating a connection between physical and mental health. Some life events did not follow this pattern, however, and while some life events did not cause stress, they were significant predictors of depressive symptoms. This indicates that the relationship between life events and depressive symptoms may not be linear, and may be mediated by other factors.
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<th>Description</th>
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<tbody>
<tr>
<td>ANOVA</td>
<td>A one-way analysis of variance</td>
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<tr>
<td>CAPI</td>
<td>Computer-assisted personal interview</td>
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<tr>
<td>CES-D</td>
<td>Center for Epidemiological Studies Depression Scale</td>
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<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities</td>
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<td>DS</td>
<td>Down Syndrome</td>
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<td>HRB</td>
<td>Health Research Board</td>
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<tr>
<td>HA-ID</td>
<td>Healthy Ageing with an Intellectual Disability</td>
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<tr>
<td>HADS</td>
<td>Hospital Anxiety and Depression Scale</td>
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<tr>
<td>HADS-D</td>
<td>Depression sub-scale of the Hospital Anxiety and Depression Scale</td>
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<td>HSE</td>
<td>Health Service Executive</td>
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<tr>
<td>ID</td>
<td>Intellectual disability</td>
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<td>IDS-TILDA</td>
<td>Intellectual disability supplement to the Irish longitudinal study on ageing</td>
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<tr>
<td>ICD-10</td>
<td>International Classification of Diseases, 10\textsuperscript{th} revision</td>
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<tr>
<td>LRC</td>
<td>Law Reform Commission of Ireland</td>
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<tr>
<td>NIDD</td>
<td>National Intellectual Disability Database</td>
</tr>
<tr>
<td>PIN</td>
<td>Personal identification number</td>
</tr>
<tr>
<td>PAS-ADD</td>
<td>Psychiatric Assessment Schedules for Adults with Developmental Disabilities</td>
</tr>
<tr>
<td>PIQ</td>
<td>Pre-interview questionnaire</td>
</tr>
<tr>
<td>r</td>
<td>Pearson’s Product Moment Correlation</td>
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<tr>
<td>rho</td>
<td>Spearman’s Rank Order Correlation</td>
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<tr>
<td>TILDA</td>
<td>The Irish longitudinal study on ageing</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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Lastly, I would like to thank Pearse for his patience and enduring support.
Chapter 1

Introduction
1.1 Rationale and background

Life expectancy of people with intellectual disability (ID) has steadily been increasing with the advancement of medicine and technology (McCarron, et al., 2011). Research on this emerging population is growing, but there is still much unknown. While older people with ID have been shown to be at increased risk of mental health difficulties, few studies have examined the associated risk factors (McCarron, et al., 2011; Hermans and Evenhuis, 2012). Mental health is an integral aspect of overall well-being, and can be affected by a range of biological, physical, environmental, and sociocultural factors (WHO, 2007). Life events can be any biological, physical, environmental, or sociocultural incident that would cause distress, such as an illness or a death in the family. They have long been associated with mental health problems in the general population (Hermans and Evenhuis, 2012; Hastings, et al., 2004; Hamilton et al., 2005; Martorell et al., 2009; Hulbert-Williams and Hastings, 2008; Cooper et al., 2007), and older people with ID are at risk for experiencing them (Hermans and Evenhuis, 2012; Hamilton, et al., 2005; Patti, et al., 2005; Owen, et al., 2004; Tsakanikos, et al., 2007).

The Intellectual Disability Supplement to the Irish longitudinal study on ageing (IDS-TILDA) unearthed a disproportionate burden of mental health difficulties among older adults with ID as compared to the general ageing population (McCarron, et al., 2011). Considering the risk for experiencing mental health difficulties and the risk for people with ID to experience potentially distressing experiences, there exists a need to explore the experience of life events among this population. No research of this kind has been conducted among older people with ID Ireland thus far. Further to this, in the existing literature, there is little information on the burden of stress caused by each life event, and similarly, little information on the proportional effect of different types of life events on mental health. The existing information available also focuses heavily on proxy reports. This analysis will focus on how
older people with ID perceive their own life experiences, and will incorporate self-reported measures of mental health indicators.

1.2 Aims of the research

Thusly, this research attempts to explore these issues more in depth, with its aims being threefold: 1) to explore the prevalence of life events among older people with ID in Ireland 2) to explore the burden of stress associated with life events, and 3) to explore the relationship between live events and depressive symptomology. The findings may have important implications for mitigating adverse effects of life events, and improving the overall well-being of older people with ID.

1.3 Outline of dissertation

In the next chapter, the dissertation will detail a literature review synthesising the current research on life events and mental health difficulties among older adults with ID around the world and in Ireland, and identify the research gap within which this dissertation operates. Chapter 3 will provide a comprehensive description of the methodology used, including research design, study population, measures and procedures, and data analysis. The final chapters will reveal the results of the analysis, as well as a discussion interpreting the findings in light of the literature review. The final discussion chapter (Chapter 5) will also identify limitations of the study, an overview of the key findings and potential implications, as well as a reflection of the process of completing this dissertation.
Chapter 2

Literature review
2.0 Introduction

The following chapter will provide a synopsis of the relevant literature. A brief description of the method used to retrieve all pertinent literature will first be included. As defining intellectual disability is of fundamental importance in disability studies, a review of the historical and modern viewpoints of disability will then be discussed. Next, a description of the burden of mental health difficulties among people with ID will be provided, as well as the differing perspectives of including self-reports of people with ID in research. The prevalence of life events among people with ID, and the available information on life events experienced by older people with ID, will then be overviewed. The current research exploring the relationship between life events and mental health status will next be delineated. Finally, the gap in research will be identified, and accordingly, the justification for pursuing this dissertation research.

2.1 Method

A comprehensive literature review was conducted using the Trinity College Dublin library electronic database. Five databases – PsycINFO, PubMed, ScienceDirect, Sage Journals Online, and Social Sciences Index – were utilized in order to retrieve all relevant articles. Keywords included, “life events” OR “traumatic experience” OR “stressful experience” AND “mental health” OR “depression” OR “anxiety” OR “stress” or “affective disorder” AND “intellectual disability” OR “developmental disability.” Keywords were added or removed as the literature review developed. “Ageing” OR “older” were initially included, but omitted after few results were found. The following is a synthesis of the relevant findings.
2.2 Defining intellectual disability

Defining disability has been an integral aspect of the modern disability movement (Shakespeare and Watson, 2011). Historically, terms such as lunatic and imbecile have been employed to label people with ID, conjuring negative connotations and demarcating this population as different (O’Keeffe, 2011). Some such terms, such as mental handicap or mentally retarded, stemmed from a medical approach to disability, which long dominated discourse and focused on individual impairments and depicted disability as a condition to be “cured” (Palmer and Harley, 2012). Although now widely considered outdated, the World Health Organisation (WHO) used this approach well into the 1990s for defining ID, and prescribed guidelines for classifying level of ID through standardised intelligence quotient tests (ICD-10, 1992). Indeed, this approach has since become outdated and is inconsistent with broader movements within the disability sector to reject notions of defining disability as an individual impairment (Schalock, Luckasson, & Shogren, 2007).

The opposing social model instead focuses on social and environmental barriers that in effect disable people (Palmer and Harley, 2012). The social model also contends that disability is an aspect of diversity, and should not be prevented (Palmer and Harley, 2012). This paradigm shift was crucial to acknowledge the impact of external factors that hinder people with disabilities from participation in their communities, which is particularly important in the context of people with ID who have been physically segregated from their communities in institutions and residential centres (O’Keeffe, 2011). The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has incorporated this concept into their definition of disability, which states that long-term impairments interact with external barriers that may affect the participation of people with disabilities into active members of society (2006, See: Article 1). This has been offered as a new “rights model” of
disability, and focuses on equal rights, empowerment, and participation (Palmer & Harley, 2012).

In view of the rich historical and modern context of defining disability, this study will adhere to the definition utilized by the Law Reform Commission of Ireland (LRC), which defines ID as “a general term to include persons whose decision-making or cognitive capacity may be limited” (O’Keeffe, 2011, p. 8). The LRC used this broad definition in the absence of a universally-accepted definition of ID, and in respect of the rights-based approach highlighted by the CRPD.

2.3 Mental health among older people with ID

In comparison to the general population, people with ID are at increased risk for mental health difficulties (Fletcher, et al., 2007), and the burden of mental ill-health is thought to be underestimated in this population, as detection of such symptoms can be complicated by communication difficulties (Torr, et al., 2008). Including self-reports in intellectual disability research has been widely discussed (Foran, et al., 2013). While doing so supports the ethos of inclusion and participation of people with ID, it may also present certain issues, such as acquiescence, and may be limited by communication difficulties (Foran, et al., 2013). As such, many studies choose to utilize a proxy, medical opinion, or access patient files when gathering data on mental health. However, much of the literature acknowledges that self-reports may be more sensitive when assessing subjective measures of health, such as mental health (Foran, et al., 2013; Hulbert-Williams, et al., 2011). Proxy reports have shown to be less reliable when measuring health-related conditions (Andresen, Vahle & Lollar, 2001), and the relationship between the individual with ID and the proxy informant may affect the quality of data collected (Foran, et al., 2013).
The first report of the Intellectual Disability Supplement to the Irish longitudinal study on ageing (IDS-TILDA) employed both self-reports and proxy reports to collect data on mental health (McCarron, et al., 2011). Collectively, the findings revealed that the percentage of participants reporting a depression diagnosis was over three times that of the general ageing population (18.5% and 5%, respectively), and 47.5% reported a previous emotional, nervous or psychiatric diagnosis (McCarron, et al., 2011; O’Regan, Cronin, & Kenny, 2011). The prevalence of mental health problems was higher among women, the visually-impaired, and those living in a residential setting, and incrementally increased with age, severity of ID and loneliness (McCarron, et al., 2011).

When looking solely at self-reported mental health, Wave 1 of IDS-TILDA identified clinically significant depressive symptoms in 11.6% of participants able to self-report (McCarron et al., 2011), compared to 10% of participants in the general ageing population (O’Regan, et al., 2011). An additional 27.1% of participants with an ID indicated sub-threshold depressive symptoms (McCarron et al., 2011), while this figure was 18% in the general population (O’Regan, et al., 2011). IDS-TILDA found that women and participants aged 65 and older were more likely to display case-level depressive symptoms (McCarron et al., 2011).

2.4 Life events among older people with ID

Life events are considered to be significant experiences, such as death of family or friend, a major illness or injury, or moving residence, and are a possible risk factor for mental health difficulties (Hermans and Evenhuis, 2012; Hastings, et al., 2004; Hamilton, et al., 2005; Martorell, et al., 2009; Hulbert-Williams and Hastings, 2008; Cooper, et al., 2007). Older people with ID are more likely to experience life events than the general population because of age-related health issues, loss of ageing relatives or close friends, and because
they are less likely to make autonomous decisions about where they live (Hermans and Evenhuis, 2012; Owen, *et al.*, 2004).

The latter is particularly unique to older people with ID. While moving individuals with ID out of congregated settings into the community now dominates discourse, a substantial proportion of individuals with ID are still living in residential centres (HSE, 2011; HRB, 2013). Wave 1 of IDS-TILDA reported that 40.2% of participants lived in a 7-day residential centre (McCarron, *et al.*, 2011) in contrast to the majority of the general ageing population, who live alone or with a spouse or partner (Kamiya and Timonen, 2011). People with ID living in residential settings are therefore exposed to additional risk of life events, such as change of staff and residents in the home, that are not applicable to the general population (Owen, *et al.*, 2004).

The Dutch Healthy Ageing and Intellectual Disabilities (HA-ID) study found that the majority of participants aged 50 and older had experienced one or more life events rated as negative in the preceding year (Hermans and Evenhuis, 2012). Of the 988 participants, 71.6% had experienced at least one negative life event, while 50.9% had experienced two or more negative life events (Hermans and Evenhuis, 2012). When looking at an older population with Down Syndrome (DS) in the United States, people with DS were more likely to experience life events than people without DS (Owen, *et al.*, 2004). People with DS aged 50-59 experienced significantly more moves or nursing home placements (*n*=115) compared to people without DS in the same age group (*n*=11) as well as those aged 60-86 (*n*=15) (Owen, *et al.*, 2004). Medical changes, such as hospitalisations or fractures, were also more common among people with DS (*n*=146) compared to people without DS aged 50-86 (*n*=73), and functional decline associated with dementia was a prominent issue among people with DS (Owen, *et al.*, 2004). This was expected as people with DS have been shown to be increased risk for developing dementia (Strydom, *et al.*, 2010; Stern, *et al.*, 2012).
2.5 Number of life events and mental health

A growing body of evidence positively correlates mental health problems among adults with ID with life events (Hermans and Evenhuis, 2012; Hastings, et al., 2004; Hamilton, et al., 2005; Martorell, et al., 2009; Hulbert-Williams and Hastings, 2008; Cooper, et al., 2007). When exposed to one or more life events in the previous 12 months, adults with ID aged 17-92 in England were 2.23 times more likely to display symptoms of affective disorders than individuals who did not experience life events (95% CI=1.56-3.18) (Hastings, et al., 2004). Research from the United States, Spain, Australia, Wales, and Scotland also indicate that the number of life events increases risk for mental health problems among people with ID, particularly affective disorders, such as depression and anxiety (Esbensen and Benson, 2006; Martorell, et al., 2009; Hamilton, et al., 2005; Cooper, et al., 2007). For example, in Wales, people with ID residing in a hospital setting were more likely to display behavioural problems and affective disorder symptomology as the number of life events experienced (Owen, et al., 2004).

When focusing solely on an ageing population with ID, results from the Netherlands have aligned with these findings, as people with increased depressive and anxiety symptoms experienced more life events (Hermans and Evenhuis, 2012). All of these studies, however, utilize data from proxy reports. Currently, one study in the UK has employed self-reported life events and psychopathology among adults with ID (Hulbert-Williams, et al., 2011). Their analysis found a positive correlation between negatively-perceived life events and depression and anxiety (rho= 0.54, p<0.001) (Hulbert-Williams, et al., 2011).

There is also indication that not only the number of life events experienced affects mental health, but also the type of life event. The HA-ID study in the Netherlands showed significant associations between increased depression symptoms and decline or loss of mobility (OR=1.61; 95% CI=1.10-2.36; p<0.05), and loss of leisure-time activities
(OR=2.92; 95% CI=1.75, 4.86; p<0.01) (Hermans and Evenhuis, 2012). Increased anxiety symptoms were associated with problems with a fellow resident (OR=1.85; 95% CI=1.25-2.72; p<0.01), and change at work or day service (OR=1.65; 95% CI=1.11-2.46; p<0.05). Minor illness or injury was associated with both increased depression symptoms (OR=1.58; 95% CI=1.07-2.32; p<0.05), as well as increased anxiety symptoms (OR=1.49; 95% CI=1.01-2.20; p<0.05).

### 2.6 Gap in research

Given the findings from other populations of ID, it is important to explore the relationship between life events and mental health difficulties in Ireland. There also exists a need to understand the burden caused by these life events, as individual perceptions of stress have not yet been explored in this area of research. Using the data collected by Wave 2 of the IDS-TILDA study, this dissertation will address this gap in research by exploring the association between life events and depressive disorder symptomology, as well as the burden of stress associated with each type of life event. Overall, this analysis aims to explore the types of life events that may adversely affect stress levels and depression symptoms, or alternatively, have a protective effect. The analysis incorporates self-reported mental health status when possible in order to promote the inclusion of people with ID in the research about them. The findings hope to inform policy and service provision by presenting a greater understanding of the prevalence and effect of life events so that appropriate measures may be taken to prevent or mitigate harmful effects.
2.7 Conclusion

This chapter provided an outline to provide justification for conducting this research. The historical trends of defining disability were described in context of this study, and rationale for the selected definition of ID was provided. The risk for mental health difficulties, in particular depression, was described, focusing on the findings from the IDS-TILDA Wave 1 study in comparison to the general ageing population in Ireland. The literature on life events experienced by people with ID was then described, followed by the current research on how the number of life events may affect mental health. The literature review identified a gap in research for which to conduct this research. This dissertation aims to explore how life events affect mental health among older adults with ID in Ireland, and how this population perceives these life events.
Chapter 3

Theoretical perspective, methodology and methods
3.0 Introduction

This chapter will delineate the research questions and aims of the study, and the methodology selected to meet the study objectives. Relevant terms commonly referred to in the analysis will be defined. The research design employed by the IDS-TILDA study will be described in detail, as well as the research design utilized by this analysis. Similarly, the IDS-TILDA sampling frame and recruitment strategy will be outlined, as well as the inclusion and exclusion criteria used by this study. Complete detailing of the sample characteristics of the IDS-TILDA population will then be provided, and compared to the sample population utilized in this study. Several measurement tools were used to obtain the data used in this dissertation, and this chapter will describe these tools and the broader data collection methods utilized by IDS-TILDA. The rigour of these tools, as well as the measures taken to ensure the highest rigour of this study will also be described. A thorough description of the data analysis methods will then be provided. Finally, ethical considerations will be described in detail, particularly as this research involves a vulnerable population of people with ID.

3.1 Research aims

This study aims to explore the prevalence of life events among older people with ID in Ireland, how these affect stress levels and depressive symptomology, and how this population perceives these significant experiences.
3.2 Research questions

This research intends to answer the following questions:

1) What is the prevalence of life events among older people with ID in Ireland?
2) How do people with ID perceive life events they experience in terms of stress?
3) What is the relationship between number of life events and depressive symptomology?
4) What is the relationship between type of life event and depressive symptomology?

3.2 Definitions of relevant terms

As described in detail above, defining an intellectual disability is a complex issue, wrought with historical tension. Again, this study will refer to an intellectual disability as “a general term to include persons whose decision-making or cognitive capacity may be limited” (O’Keeffe, 2011). This definition, as described by the LRC, is used in light of the current rhetoric in the disability movement, acknowledging that ID is not only a disability characterized by intellectual functioning, but also one that is influenced by other environmental and social factors (Schalock, et al., 2007). Intellectual disability is commonly classified by degree of severity using the terms, mild, moderate, severe, and profound. While these terms are rooted in a medical model approach to disability, focusing on performance on standardized intelligence tests (WHO, 1992), in the context of this study, they will be utilized merely as descriptive terms.

The Health Service Executive (HSE) defines a residential centre as a setting where individuals live with ten or more people (2011). These settings are typically demarcated from the larger community both physically and psychologically (2011). Living in a community group home is one aspect of a broader movement to support inclusion and participation for
people with ID (HSE, 2011). This involves living in “dispersed housing”, or living in ordinary houses or apartments in neighbourhoods that the majority of the population live in, rather than segregated settings (HSE, 2011, p. 8). Dispersed housing also emphasises that the individual maintain autonomy when choosing where to live and with whom (HSE, 2011).

Further to this, community living involves person-centred support systems that promote inclusion in the community, applicable in-home adaptations and technologies, external employment opportunities, external, and community-based health professionals (HSE, 2011). For the purposes of this analysis, a community group home will be one that adheres to these principles and houses fewer than 10 residents. Independent living or living with family will be analysed in tandem, and denote living alone, with a partner or spouse, or with family.

**Life events** are defined as any event occurring in the previous 12 months that would have caused significant distress, such as major illness or injury, death of a relative, or change of key worker (Mulryan, et al., 2014; Hermans and Evenhuis, 2012). Two or more life events will often be referred to as “multiple life events” in this analysis. “**Mental health** is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community” (WHO, 2007). In this study, mental health status will be assessed through the presence of depression symptoms. This analysis aims to specifically identify depressive symptomatology, and not to suggest diagnosis of psychiatric, emotional or behavioural disorders.

### 3.3 Research design

IDS-TILDA is a unique study, being the first longitudinal study on older people with ID in Europe and likely, internationally. IDS-TILDA was designed with the aim of understanding the specific characteristics and experiences of this population, and the overall
findings will have vital policy and service-delivery implications. The intellectual disability supplement was designed in close conjunction with TILDA, which focuses on the general older population in Ireland, in order to make direct comparisons between the two groups (Kelly, et al., 2010). The underlying hypothesis is that older people with ID have similar experiences as the general population as they age (McCarron, et al., 2011). In addition, IDS-TILDA was designed with the ethos of promoting inclusion and participation of people with ID into society, as this has long been a challenge for people of all ages with ID, as previously discussed. People with ID were therefore involved in all phases of the research design. An international scientific committee was also consulted throughout the development of the study.

IDS-TILDA provides an ideal database for measuring the relationship between life events and mental health in this population because of its national representative sample of older people with ID in Ireland. This dissertation upholds the ethos of IDS-TILDA by incorporating self-reports when possible, ensuring that the voices and experiences of older people with ID are accurately conveyed. The dissertation assumes that older people with ID are competent research participants, and can provide comparably reliable information about their experiences and health status than that reported by proxy.

IDS-TILDA Wave 2 aimed to explore more in-depth the risk factors associated with mental health difficulties, and collected data on pertinent life events. IDS-TILDA utilizes both quantitative and qualitative methodology. This dissertation will employ descriptive quantitative methodology. This approach seeks to provide information about a phenomenon, which will allow the research to describe the prevalence of life events, stress, and depressive symptoms among older people with ID in Ireland (Easton and McColl, 1997). Correlational research is often considered to be a type of descriptive research, and establishes evidence of relationships between variables (Easton and McColl, 1997). This was deemed most
appropriate to answer the research questions focusing on the relationship between life events and stress or mental health status.

The suitability of the selected methodology was confirmed by the relevant literature. Quantitative methodology is considered to be the most appropriate approach to assess mental health status, as well as to gather information on life events, particularly among people with ID (Hermans and Evenhuis, 2012; Radloff, 1977). A standardised measurement tool that has been used and tested extensively will be used to establish the presence of depressive symptomology (Zigmond and Snaith, 1983). Life events were collected through a quantitative questionnaire, as this eliminates the need for recall and therefore improves reliability (Hermans and Evenhuis, 2012). The level of stress caused by each life events was collected using a Likert scale, and participants were asked to elaborate on how they felt about their experience through an open-ended question.

The data gathered from this open-ended question will be analysed using Braun and Clark’s thematic analysis framework (2006; See Appendix I). As one’s mental health is subjective (Foran, et al., 2013), analysing this data will allow for “uncovering meaning”, rather than a pre-existing truth (O’Day and Kileen, 2002). This approach can be utilized to answer the research question pertaining to participants’ perception of life experiences. Braun and Clark’s thematic analysis (2006) will provide a framework to understand how older people with ID perceive life experiences, and how this may affect their mental health. Incorporating thematic analysis into the descriptive analysis will add depth to the findings, and will provide the best opportunity to answer the research questions given the available data.
### 3.4 Sampling methods

#### 3.4.1 Population

The sampling frame used by IDS-TILDA was the National Intellectual Disability Database (NIDD) which is unique to Ireland. It is a database of all individuals with all levels of ID in the Republic of Ireland that are eligible or receive services (HRB, 2013). As of December 2012, 27,622 individuals were registered in the database, and of those, 40.6% were aged 35 or older (Kelly, 2012). The pilot IDS-TILA found that age-associated illnesses, such as dementia, affect this population at an earlier age than the general population, and as such, IDS-TILDA sampled individuals aged 40 and older for Wave 1 (McCarron, et al., 2009).

Each individual registered on the NIDD is assigned a personal identification number (PIN), and staff at NIDD randomly selected 1,800 PINs in anticipation of a 50% or less response rate. The PINs were released to a regional disability database administrator who in turn mailed invitation packs to participants, after verifying their information. The packs included easy to read information sheets about the study and consent forms for the potential participant and their family or support staff. If willing to participate, they were asked to fill out the consent form, or to give co-consent, and to mail the packet to the IDS-TILDA office in an addressed, stamped envelope. See McCarron, et al. (2011) for detailed information on the IDS-TILDA study methodology.

A total of 753 individuals participated in Wave 1, with 38% giving self-consent (n=285) and 62% giving co-consent (n=468). Participants were asked to reaffirm their consent in Wave 2. The second Wave of data collection maintained a high retention rate, with 94.0% of participants remaining in the study (n=701), including 34 deaths. In the two years between data collection, IDS-TILDA employed a rigorous strategy to maintain contact with participants, such as holiday greetings and IDS-TILDA newsletters. This regular contact likely contributed to the high retention rate maintained by Wave 2 (McCarron, McCallion, &
Burke, 2014). Details of the recruitment and data collection process can be found in Appendix II.

3.4.2 Sampling selection

The IDS-TILDA Wave 2 population provided the sampling frame for this dissertation. Only participants who completed the depression subscale of the Hospital Anxiety and Depression scale (HADS-D) were included in this analysis (n=634) (Zigmond and Snaith, 1983). This additional criterion was included in order to increase accuracy of the relationship between depressive symptomology and life events.

3.4.3 Sample characteristics

The study population consisted of 272 males and 362 females with a mean age of 56.50 (SD=9.42). Of the 634 participants, 143 had a mild ID, 273 had a moderate ID, and 170 had a severe or profound ID. The level of ID was unverified, unknown, or missing in the remaining 48 participants. The majority of participants lived in community group homes (44.5%) or residential centres (39.6%), while the remaining 15.9% lived independently or with family. The study population is representative of the total population that participated in IDS-TILDA Wave 2, although there is a slightly higher proportion of females in the study population. Details of population characteristics, and comparison to the total IDS-TILDA Wave 2 population, can be found in Table 1.
Table 1. Demographic details of study population and total IDS-TILDA Wave 2 population

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Study population</th>
<th>Total Wave 2 population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (Valid %)</td>
<td>n (Valid%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>634 (100%)</td>
<td>701 (100%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>272 (42.9%)</td>
<td>311 (44.4%)</td>
</tr>
<tr>
<td>Female</td>
<td>362 (57.1%)</td>
<td>390 (55.6%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42-49</td>
<td>182 (28.7%)</td>
<td>196 (28.0%)</td>
</tr>
<tr>
<td>50-64</td>
<td>317 (50.0%)</td>
<td>357 (50.9%)</td>
</tr>
<tr>
<td>65+</td>
<td>135 (21.3%)</td>
<td>148 (21.1%)</td>
</tr>
<tr>
<td><strong>Place of residence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent/Family</td>
<td>101 (15.9%)</td>
<td>113 (16.2%)</td>
</tr>
<tr>
<td>Community group home</td>
<td>282 (44.5%)</td>
<td>303 (43.3%)</td>
</tr>
<tr>
<td>Residential centre</td>
<td>251 (39.6%)</td>
<td>283 (40.5%)</td>
</tr>
<tr>
<td><strong>Level of ID</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>143 (24.4%)</td>
<td>154 (23.8%)</td>
</tr>
<tr>
<td>Moderate</td>
<td>273 (46.6%)</td>
<td>301 (46.5%)</td>
</tr>
<tr>
<td>Severe/profound</td>
<td>170 (29.0%)</td>
<td>192 (29.7%)</td>
</tr>
</tbody>
</table>

*a* Level of ID was unverified, unknown, or missing in 7.6% of the study population \((n=48)\), and 7.7% of the total Wave 2 population \((n=54)\)

### 3.5 Methodology

#### 3.5.1 Data collection methods

Upon receipt of consent for Wave 1, IDS-TILDA assigned each potential participant to a field researcher caseload. All field researchers had previous experience with people with ID. The field researcher then contacted the potential participant to thank them and inform them of the next phase. This involved sending a pre-interview questionnaire (PIQ), scheduling a face-to-face interview, and ensuring that necessary supports for participants were in place for the interview. The PIQ was sent to participants approximately one week before the face-to-face interview. The PIQ collected information that included demographic information, health status, healthcare utilisation and medication usage. Sending the PIQ beforehand was intended to increase reliability by allowing ample time for participants to gather the information, as well as ensuring participants had the necessary support to complete it. This information was not collected again for Wave 2, but key participant information, such
as level of ID and date of birth, was verified through a checklist each interviewer conducted prior to commencing the face-to-face interview.

The face-to-face interviews were conducted using a computer-assisted personal interview (CAPI) programme. Each field interviewer received extensive training in conducting standardised interviews with CAPI, as well as training on the purpose and ideology of IDS-TILDA. This training was administered during a three day session and instructed on specialised training to address issues such as assent, confidentiality, and data protection in the context of research on people with ID. Participant responses were gathered using the utmost flexibility and sensitivity to the needs and preferences of the participant. Data were collected through self-reported answers, self-reported with the support of a proxy, or proxy-only responses. The data used in this dissertation were obtained through both the PIQ/pre-interview checklist and CAPI.

### 3.5.2 Data collection tools

Data on age, gender, and level of ID were collected via the PIQ in Wave 1, and key demographic information was verified by the interviewer before the Wave 2 interview.

### 3.5.2a Life events

A life events checklist was adapted from the Dutch HA-ID study (Hermans and Evenhuis, 2012) in order to be most relevant to the population studied in Ireland. Revisions were informed by consultation with an advisory committee and an advocacy group comprised of people with ID. It asked if 20 events had occurred in the previous 12 months, including an opportunity for participants to identify other significant events not addressed in the questionnaire. For each life event experienced, the participant was asked what level of stress it had caused using a shortened Likert scale with three options: a lot of stress, a little stress,
and no stress. While other relevant studies explicitly ask whether the life event was perceived as a positive or negative occurrence, the IDS-TILDA checklist used level of stress caused. This was again informed by consulting the literature and an advisory committee. The checklist was administered using the CAPI during face-to-face interviews. Participants self-reported when possible, and a proxy was used when necessary.

3.5.2b Mental health status

Mental health will be analysed using results from the depression subscale of the Hospital Anxiety and Depression Scale (HADS-D) (Zigmond and Snaith, 1983). In an attempt to maintain temporal relevance, prior diagnoses of depression or other such mental health difficulties will not be analysed. The Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977) was also used to gather information on depression symptoms, but will not be used for this analysis pending concerns of its validity, namely the risk for false positive responses, or identifying individuals as having depressive symptoms when they are not present in actuality (Orme, Reis, & Herz, 1986).

The Hospital Anxiety and Depression Scale (HADS) is often used in the medical field to assess levels of anxiety and depression (Zigmond and Snaith, 1983). The HADS replaced the Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD; Moss, et al., 1993), which was utilized in Wave 1 but proved ineffective for this population. The HADS was chosen for Wave 2 based on the literature, including the HA-ID study, and was also utilized by TILDA.

The HADS is designed to specifically measure mental health, rather than symptoms that may manifest from physical conditions, such as fatigue (Zigmond and Snaith, 1983). It is also purposefully brief and easy to understand, both of which are important factors when applying to people with ID (Snaith and Zigmond, 1994). The anxiety subscale asks questions
on “the state of anxious mood, restlessness and anxious thoughts” while the depression subscale largely focuses on “the state of loss of interest and diminished pleasure response” (Snaith and Zigmond, 1994, p. 2).

The HADS instrument was administered to all IDS-TILDA participants: those who self-reported, those who self-reported with proxy support, or those who utilized a proxy for all responses. The HADS contains 14 questions, seven of which are directed toward anxiety symptoms and seven toward depression. Each question may be scored from 0-3. The highest score is therefore 21, as anxiety and depression are assessed separately. Again, higher scores indicate increased depressive and anxiety symptoms. Scores from 0-7 are considered non-symptomatic, and scores from 8-10 are considered to indicate sub-clinical symptoms. In the HADS scale manual, Snaith and Zigmond (1994) suggest interpretation of scores from 11-14 to be “moderate” symptoms, and 15-21 to be “severe” symptoms. For the purposes of this analysis, IDS-TILDA participants who scored over 11 were considered to have “case-level” symptoms. These cut-offs were employed by the IDS-TILDA study in order to make better comparisons with TILDA results. Only results form the depression subscale will be utilized, firstly because of the risk for depression among older adults with ID as found in Wave 1 of the IDS-TILDA study, and also because the anxiety subscale has not been extensively assessed for suitability for people with ID.

3.6 Data analysis

Analyses were conducted with the Statistical Package for the Social Sciences (SPSS) version 20.0 (Chicago, IL, USA). All participants had been assigned a non-identifying number to ensure anonymity and consistency between Waves 1 and 2. The CAPI allowed for responses to be coded at the interview, and a third party collated the data, after which several IDS-TILDA researchers checked the data for accuracy. A dataset including only the study
population and relevant demographic, life event and mental health variables was utilized throughout the analysis. Frequency distribution was conducted by the researcher and an additional IDS-TILDA researcher in order to identify data entry or coding errors (Pallant, 2010). Descriptive analyses were first used in order to establish the characteristics of the study population, as well as the distribution of depressive symptomology.

3.6.1 Research question 1: Prevalence of life events

To establish a baseline for understanding the distribution of life events across demographic groups, frequencies and cross-tabulations were computed. The frequency of life events by age, type of residence, level of ID and HADS-D score were analysed using a one-way analysis of variance (ANOVA). The ANOVA test allowed for comparison of the variability in number of life events experienced between the demographic groups with the variability in number of life events within the demographic groups (Pallant, 2010). The null hypothesis was that there was no difference in mean number of life events experienced between groups. The frequency of life events by gender was analysed using an independent-samples t-test. As gender is a dichotomous variable, the t-test compared the mean number of life events between the two genders (Pallant, 2010). Again, the null hypothesis stated that there was no difference in the mean number of life events experienced between males and females. Frequencies of the number of people who experienced each type of life event were also conducted.

3.6.2 Research question 2: Relationship between type of life event and stress

Cross-tabulations were also calculated analysing the level of stress caused by each type of life event. The data obtained from the open-ended question on the perception of life
events and resultant stress were coded manually using Braun and Clark’s thematic analysis framework (2006; See Appendix I). Consistent with this approach, after reading through all responses, initial codes were identified, which were then collated into potential themes. The two initial codes were first used to identify if life events were perceived as negative or not negative (i.e., positive or neutral). From these initial codes, seven themes were identified. These themes were checked against the data set to ensure congruency, and a thematic ‘map’ of the analysis was created. These themes were refined and defined in order to present a complete picture of the data.

3.6.3 Research question 3: Relationship between multiple life events and depression symptoms

Cross-tabulations were first conducted in order to establish a baseline understanding of the distribution of depressive symptoms among those who experienced life events. To understand the relationship further, an ANOVA test was again conducted in order to compare the mean number of life events experienced across the reported depressive symptom categories (Pallant, 2010). The null hypothesis stated that there was no difference in means between groups.

Correlations were used to quantify the association between number of life events and depression symptoms. Guided by the literature, the underlying assumption of the correlational tests was that as the number of life events increase, so too do depressive symptoms (Hermans and Evenhuis, 2012). Demographic variables were also used in these analyses to assess if these factors are related to depressive symptoms as well. Pearson’s Product Moment correlation coefficient (r) was used to establish the relationship between the number of life events and total HADS-D scores. Age, gender, level of ID and place of residence were also included in this analysis. The strength of the relationship was interpreted
using the following guidelines: \( r=010-0.29 \), small; \( r=0.30-0.49 \), medium; \( r=0.50-1.00 \), large (Pallant, 2010).

Finally, a binary logistic regression analysis was conducted to predict the likelihood of reporting increased depression symptoms (i.e., case-level and subclinical symptoms) when experiencing multiple life events. “Increased depressive symptomology” as opposed to case-level symptoms only was selected for the dependent variable to provide more pronounced findings results. Case-level or subclinical depressive symptomology were used as the response variable for each test. A general model using the number of life events, age, gender, level of ID and type of residence as the covariates was completed, which provided a general outlook on how these variables predict the likelihood of increased depressive symptomology.

### 3.6.4 Research question 4: Relationship between type of life event and depression symptoms

A chi-square test for independence was used to explore the relationship between each type of life event and the categories of depressive symptoms (i.e., non-symptomatic, subclinical, and case-level). This analysis was selected as both variables are categorical, and was performed through cross-tabulation tables. As depressive symptoms were categorised into three categories, the Pearson Chi-square value was used to describe associations, as opposed to Yates’ Correction for Continuity, which compensates for overestimations of the chi-square value when two dichotomous variables are utilized (Pallant, 2010). To assess the effect size, Cramer’s V coefficient was used in order to account for the degrees of freedom using larger than 2 by 2 tables (Pallant, 2010). Cramer’s V coefficients equal to 0.07 were considered to have a small effect, those equal to 0.21, a medium effect, and 0.35, a large effect (Pallant, 2010).

Binary logistic regression analyses furthered understanding of the relationship between type of life event and mental health. To understand the relationship between specific
types of life events and depressive symptoms, analyses using each type of life event \((n=19)\) as the single covariate were conducted to obtain crude odds ratios (ORs), using case-level depressive symptoms as the response variable. This provided information on the individual types of life events as singular predictors of case-level depressive symptoms. To obtain adjusted ORs to control for relevant demographic information – age, gender, level of ID, and place of residence – these variables were added as covariates.

3.7 Validity

All possible measures were taken in order to maintain the highest rigour for this analysis. In quantitative analysis, the most commonly used constructs to assess the quality of a study are validity and reliability. Validity refers to the accuracy of the data measurement tools to measure what they are intended to measure (Pallant, 2010). There is no specified indicator of validity (Pallant, 2010), but appropriate measures were employed to ensure the analysis maintained course to measure what was intended, as set forth in the research questions. Study protocol was developed prior to conducting this research, and reviewed by the supervisor (Appendix III). This provided a reference to guide the analysis, ensuring that the study adhered to the research questions that it aimed to answer.

Validity for the data measurement tools was also assessed. For the life events checklist, content validity was established through a rigorous development process. The original life events checklist utilized by Hermans and Evenhuis (2012) was a composite checklist comprised of the Brugha life events checklist, the checklist used in the PAS-ADD, life events mentioned in relevant studies (Hastings, et al., 2004; Moss, et al., 1993; Owen, et al., 2004; Tsakanikos, et al., 2007), and included input from support staff of people with ID (Hermans and Evenhuis, 2012). The IDS-TILDA life events checklist was then adapted in order to ask the most relevant questions for the population in Ireland (Mulryan, et al., 2014).
This involved collaboration among researchers and with the scientific advisory committee. The checklist was also presented to an advocacy group comprised of people with ID. This process was meant to ensure validity of the resultant checklist.

When analysing the validity of the HADS, the sensitivity and specificity are adequate for diagnosing both anxiety and depression in the general population (Zigmond and Snaith, 1983; Snaith and Zigmond, 1994; Moorey, et al., 1991; Clark and Fallowfield, 1986; Bjelland et al., 2002). For diagnosing depression, the HADS-D sensitivity is 0.83 and specificity is 0.79 (Bjelland et al., 2002). For use with people with ID, Dagnan, et al., (2008) concluded that results from the HADS were comparable to other measurement tools. The authors analysed the depression subscale in particular, which was deemed to be valid, although they warned that the wording may need adaption upon further review of its psychometric properties (Dagnan, et al., 2008).

3.8 Reliability

Reliability is another construct used to assess a study’s quality, and is pre-requisite for validity (Pallant, 2010). It indicates to what degree a data measurement tool is free from random error (Pallant, 2010). Internal consistency is one method by which reliability is assessed, and is measured by Cronbach’s alpha coefficient (α). This is essentially a correlation coefficient, and indicates how a single construct is measured by each of the questionnaire items (Pallant, 2010). In order to consider the internal consistency acceptable, Cronbach’s alpha coefficient should be at least α=0.70, although α=0.80 is preferable (Pallant, 2010). As the coefficient is dependent upon the number of items in a scale, Cronbach’s alpha should be used for checklists with at least ten answer-items to avoid obtaining a small value (Pallant, 2010).
Cronbach’s alpha coefficient was explored for the applicable data measurement tools: the life events checklist and the HADS. For the life events checklist, Hermans and Evenhuis (2012) report a Cronbach’s alpha coefficient of \( \alpha = 0.81 \). When replicated in this study, the Cronbach’s alpha decreased to \( \alpha = 0.52 \). A small coefficient was expected as the checklist does not measure a single construct. There were negative correlations in the inter-item correlation matrix, indicating that some life events could be perceived as positive and some as negative.

No information was available on how the internal consistency was determined in the Hermans and Evenhuis (2012) study, but its reported internal consistency will be accepted to establish reliability of the checklist.

When analysing the reliability of the HADS for use with people with ID, Dagnan, et al. (2008) found a Cronbach’s alpha of \( \alpha = 0.73 \), which, when replicated in this study, increased to \( \alpha = 0.80 \), which is satisfactory (Pallant, 2010). When looking solely at the HADS-D scale, Cronbach’s alpha decreased to \( \alpha = 0.68 \), which is similar to results from the Dagnan, et al. (2008) study, which found a Cronbach’s alpha equal to \( \alpha = 0.60 \). In this study, if the statement, “I have lost interest in my appearance” was removed from the scale, Cronbach’s alpha would increase to \( \alpha = 0.71 \). However, the overall decrease in the value was predicted as the sub-scale only contains seven items as opposed to the recommended ten items to produce the most accurate measurement of internal consistency (Pallant, 2010). Inter-item correlation was then reviewed to confirm the reliability of the HADS-D. The mean correlation score between checklist items was 0.35, which lies within the range of optimal mean scores of 0.2 to 0.4 to establish sufficient reliability (Pallant, 2010). Therefore, the reliability of the HADS-D was deemed acceptable for use.
3.9 Ethical considerations

This study aimed to attain the highest ethical standards, as prescribed in various international instruments and by Trinity College Dublin. The study was guided by the ethical principles of informed consent, anonymity and confidentiality, and beneficence.

3.9.1 Ethical approval to conduct research

The IDS-TILDA study sought and was granted ethical approval from the Faculty of Health Sciences Ethics Committee at Trinity College Dublin in 2009 for the duration of the initial longitudinal study, which was to include three waves, spanning from 2010 to 2016 (Appendix IV). The IDS-TILDA study sought ethical approval for Wave 2 to ensure modifications from Wave 1 met with ethical approval. The Faculty of Health Sciences Committee at TCD granted approval for Wave 2 in 2013 (Appendix V). Through a thorough process, the 138 Service Provider Ethical Boards involved in the study reaffirmed ethical approval. More information about these processes can be found in McCarron, et al., 2011 and McCarron, et al., 2014. This dissertation was conditionally approved by the Trinity College Social Work and Social Policy Ethics Committee in 2014, provided that the dissertation addresses confidentiality and data protection issues to the satisfaction of the supervisor (Appendix VI). These and other ethical considerations are addressed below.

3.9.2 Informed consent

This dissertation focuses on a population that is considered a vulnerable population in the context of human-subject research (Graumann, 2012). The issue of informed consent of individuals with reduced capacity and communication difficulties has been widely reviewed (Graumann, 2012). Historically, international instruments designed to protect individuals
from coercive participation in research, such as the Nuremburg Code, the original 1964 Helsinki Declaration, and the International Covenant on Civil and Political Rights, categorised people with ID as “unable to consent” and therefore participation in research would be wrought with ethical issues such as manipulation and maleficence (Graumann, 2012). More recently, the CRPD (2006) introduced the concepts of universal legal capacity and co-consent. Including people with ID in research that aims to benefit them respects and promotes their right to legal capacity and utilising the principle of co-consent protects their rights as individuals with reduced capacity.

As such, the IDS-TILDA study maintained a rigorous protocol for obtaining consent throughout the research process. Consent forms were mailed to potential participants, informing them of the aims of the study, as well as any possible risks and benefits of participation in the study. An additional information leaflet for family members or carers was also mailed, which included forms to provide co-consent or proxy consent if necessary. Initial consent was obtained for Wave 1, either through self-consent, co-consent, or if unable to self-consent, consent was obtained through a family member or guardian. Participants and family members, carers, or guardians present at the interview were assured that participation was voluntary, and they could stop the interview at any time. This practice was maintained throughout Wave 2.

3.9.3 Anonymity and confidentiality

Anonymity and confidentiality were ensured throughout all phases of the IDS-TILDA study, from recruitment to data collection to data storage. Pursuant to the EU Data Protection Directive 95/46/EC (2003), all data utilized for this dissertation was accessed using encrypted computer storage housed in a locked facility. The dataset, which does not contain personal or identifying information, will be stored for 5 years after the study, and all participants were
made aware of the data protection practice. Participants were also made aware that other researchers may have access to the data, and agreed to such during the consent process.

3.9.4 Beneficence

In research, the principle of beneficence prescribes that actions must promote the well-being of others, and further, that the research must ‘do no harm’ (Graumann, 2012). This dissertation, and the general IDS-TILDA study, both aim to produce findings that will ultimately improve the well-being of older people with ID in Ireland and abroad.

3.10 Conclusion

This chapter described the research aims and questions of this study. A detailed description of the methodology employed to answer these questions, and the justification for selecting a descriptive quantitative analysis to meet the study objectives was also provided. All variables and terminology were then defined. As the dissertation utilizes data collected by the IDS-TILDA study, its research design, sampling frame, and recruitment were described in detail. The research design of this dissertation was also explained, as well as the inclusion criterion for the sample population. The demographics of the sample population were compared to the overall population of the IDS-TILDA study to ensure a representative sample. The chapter also outlined the data collection methods and tools utilized by the IDS-TILDA study, as well as a description of the methods utilized to maintain the highest rigour possible in this dissertation. The data analysis methods and justification for selecting each test was then provided, before describing the ethical considerations involved.
Chapter 4

Findings
4.0 Introduction

The following chapter will present the findings of this research. Firstly, a description of the study population will be briefly reviewed. The results of the HADS-D will be presented, followed by a description of the prevalence of life events experienced by older people with ID in Ireland. An analysis of the types of life events will also be offered, as well as a description of the relationship between types of life events and reported stress. This will include results from the thematic analysis. Next, results of the analyses to assess the relationship between the number of life events and depressive symptomology will be provided, as well as the relationship between the types of life events experienced and depressive symptomology.

4.1 Mental health status

A total of 634 participants completed the HADS-D, which provides a representative sample of gender, age, level of ID and type of residence. A complete description of the study population can be found in Table 1. Of the 634 who completed the HADS-D, 4.6% reported case-level symptoms \((n=29)\) and 7.1% reported sub-clinical depressive symptoms \((n=45)\). Full results can be found in Table 2.
Table 2. Demographic details of sample by life events experienced

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Total n (Valid %)</th>
<th>At least 1 life event n (Valid %)</th>
<th>2+ life events n (Valid %)</th>
<th>No life event n (Valid %)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>634 (100%)</td>
<td>438 (69.1%)</td>
<td>268 (42.3%)</td>
<td>196 (30.9%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>272 (42.9%)</td>
<td>192 (70.6%)</td>
<td>120 (44.1%)</td>
<td>80 (29.4%)</td>
</tr>
<tr>
<td>Female</td>
<td>362 (57.1%)</td>
<td>246 (68.0%)</td>
<td>148 (40.9%)</td>
<td>116 (32.0%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42-49</td>
<td>182 (28.7%)</td>
<td>121 (66.5%)</td>
<td>76 (41.8%)</td>
<td>61 (33.5%)</td>
</tr>
<tr>
<td>50-64</td>
<td>317 (50.0%)</td>
<td>219 (69.1%)</td>
<td>138 (43.5%)</td>
<td>98 (30.9%)</td>
</tr>
<tr>
<td>65+</td>
<td>135 (21.3%)</td>
<td>98 (72.6%)</td>
<td>54 (40.0%)</td>
<td>37 (27.4%)</td>
</tr>
<tr>
<td><strong>Type of residence</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent/Family</td>
<td>101 (15.9%)</td>
<td>57 (56.4%)</td>
<td>28 (27.7%)</td>
<td>44 (43.6%)</td>
</tr>
<tr>
<td>Community group home</td>
<td>282 (44.5%)</td>
<td>196 (69.5%)</td>
<td>122 (43.3%)</td>
<td>86 (30.5%)</td>
</tr>
<tr>
<td>Residential centre</td>
<td>251 (39.6%)</td>
<td>185 (73.7%)</td>
<td>118 (47.0%)</td>
<td>66 (26.3%)</td>
</tr>
<tr>
<td><strong>Level of intellectual disability</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>143 (24.4%)</td>
<td>88 (61.5%)</td>
<td>50 (35.0%)</td>
<td>55 (38.5%)</td>
</tr>
<tr>
<td>Moderate</td>
<td>273 (46.6%)</td>
<td>195 (71.4%)</td>
<td>117 (42.9%)</td>
<td>78 (28.6%)</td>
</tr>
<tr>
<td>Severe/profound</td>
<td>170 (29.0%)</td>
<td>121 (71.2%)</td>
<td>79 (46.5%)</td>
<td>49 (28.8%)</td>
</tr>
<tr>
<td><strong>HADS-Depression scores</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-symptomatic (0-7)</td>
<td>560 (88.3%)</td>
<td>378 (67.5%)</td>
<td>225 (40.2%)</td>
<td>182 (32.5%)</td>
</tr>
<tr>
<td>Sub-clinical (8-10)</td>
<td>45 (7.1%)</td>
<td>36 (80.0%)</td>
<td>24 (53.3%)</td>
<td>9 (20.0%)</td>
</tr>
<tr>
<td>Case-level (≥11)</td>
<td>29 (4.6%)</td>
<td>24 (82.8%)</td>
<td>19 (65.5%)</td>
<td>5 (17.2%)</td>
</tr>
</tbody>
</table>

4.2 Prevalence of life events

Over two-thirds (69.1%) of all participants experienced at least one significant life event in the previous 12 months (n=437) (Table 2). Data were missing for 3 participants. A large proportion of participants reported experiencing multiple life events (42.3%), with one participant experiencing 9 life events (Fig. 1). Table 2 provides details on the distribution of the number of life events experienced across demographic groups. Proportionally, males, participants aged 50-64, participants living in residential centres, those with severe/profound ID, and those presenting case-level depressive symptoms were more likely to experience multiple life events.
The overall mean number of life events experienced was 1.60 (SD=1.59) (Table 3). A one-way between-groups analysis of variance (ANOVA) was used to assess the mean number of life events across demographic groups (Table 3). There was no statistically significant difference between mean number of life events and gender, age, or level of ID. There was a significant difference in the mean number of life events experienced and type of residence, however: \( F(2, 634) = 9.6, p<0.001 \). Calculated, the eta squared was 0.03, indicating a small difference in mean scores. Post-hoc comparisons using the Tukey HSD test showed that there was a significant difference at the \( p<0.001 \) level between the mean number of life events experienced by those living independently or with family (\( M=0.99, SD=1.18 \)) and those who lived in community group homes (\( M=1.67, SD=0.68 \)) or residential care (\( M=1.77, SD=1.58 \)). There was no statistical difference between those who lived in community group homes and residential care.
Table 3. Differences in number of life events by population characteristic (One way ANOVA)

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Mean number of life events (SD)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>1.60 (1.59)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td>0.418a</td>
</tr>
<tr>
<td>Male</td>
<td>1.66 (1.58)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.56 (1.59)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>0.492</td>
</tr>
<tr>
<td>40-49</td>
<td>1.49 (1.52)</td>
<td></td>
</tr>
<tr>
<td>50-64</td>
<td>1.63 (1.60)</td>
<td></td>
</tr>
<tr>
<td>65+</td>
<td>1.66 (1.66)</td>
<td></td>
</tr>
<tr>
<td><strong>Type of residence</strong></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Independent/Family</td>
<td>0.99 (1.18)</td>
<td></td>
</tr>
<tr>
<td>Community group home</td>
<td>1.67 (1.68)</td>
<td></td>
</tr>
<tr>
<td>Residential centre</td>
<td>1.77 (1.58)</td>
<td></td>
</tr>
<tr>
<td><strong>Level of intellectual disability</strong></td>
<td></td>
<td>0.062</td>
</tr>
<tr>
<td>Mild</td>
<td>1.29 (1.42)</td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>1.69 (1.68)</td>
<td></td>
</tr>
<tr>
<td>Severe/profound</td>
<td>1.72 (1.59)</td>
<td></td>
</tr>
<tr>
<td><strong>HADS-Depression scores</strong></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Non-symptomatic (0-7)</td>
<td>1.49 (1.48)</td>
<td></td>
</tr>
<tr>
<td>Sub-clinical (8-15)</td>
<td>2.27 (2.03)</td>
<td></td>
</tr>
<tr>
<td>Case-level (≥16)</td>
<td>2.86 (2.05)</td>
<td></td>
</tr>
</tbody>
</table>

* Obtained through t-test

The most common types of life events experienced were change of staff in home or day service (30.9%), change of key worker (21.7%), and moving within service organisation (19.5%) (Table 4). Of the 18 life events asked, no participant had experienced problems with justice and/or authorities. Only one participant reported experiencing crime and one additional participant reported break up of a steady relationship/divorce.

4.3 Stress and associated life events

Quantitative data analysis of stress caused by each of these life events indicated that 58.4% of those who had experienced a change of key worker and 48.4% of those who experienced a change at work or day service reported that this experience caused no stress. Major illness or injury and the death of a parent caused the majority of participants a lot of stress (57.4% and 51.9%, respectively). See Table 4 for the complete findings.
<table>
<thead>
<tr>
<th>Event Description</th>
<th>Frequency</th>
<th>A lot of stress</th>
<th>A little stress</th>
<th>No Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (Valid%)</td>
<td>n (Valid%)</td>
<td>n (Valid%)</td>
<td>n (Valid%)</td>
</tr>
<tr>
<td>Change of staff in home where I live or day service I attend</td>
<td>196 (31.1%)</td>
<td>43 (21.9%)</td>
<td>73 (37.2%)</td>
<td>80 (40.8%)</td>
</tr>
<tr>
<td>Change of key worker</td>
<td>137 (21.7%)</td>
<td>18 (13.1%)</td>
<td>39 (28.5%)</td>
<td>80 (58.4%)</td>
</tr>
<tr>
<td>Moving within service organisation</td>
<td>123 (19.5%)</td>
<td>30 (24.4%)</td>
<td>35 (25.8%)</td>
<td>58 (47.2%)</td>
</tr>
<tr>
<td>Change at or from work or day service</td>
<td>91 (14.4%)</td>
<td>16 (17.6%)</td>
<td>31 (34.1%)</td>
<td>44 (48.4%)</td>
</tr>
<tr>
<td>New resident moved into home</td>
<td>90 (14.3%)</td>
<td>22 (24.4%)</td>
<td>25 (27.8%)</td>
<td>43 (47.8%)</td>
</tr>
<tr>
<td>Death of a friend</td>
<td>78 (12.4%)</td>
<td>26 (33.3%)</td>
<td>35 (44.9%)</td>
<td>17 (21.8%)</td>
</tr>
<tr>
<td>Major illness or injury</td>
<td>62 (9.8%)</td>
<td>35 (57.4%)</td>
<td>17 (27.9%)</td>
<td>9 (14.8%)</td>
</tr>
<tr>
<td>Death of a parent</td>
<td>52 (8.2%)</td>
<td>27 (51.9%)</td>
<td>9 (17.3%)</td>
<td>16 (30.8%)</td>
</tr>
<tr>
<td>Other event or change of routine*</td>
<td>37 (5.9%)</td>
<td>18 (48.6%)</td>
<td>13 (35.1%)</td>
<td>6 (16.2%)</td>
</tr>
<tr>
<td>Major illness of relative, caregiver or friend</td>
<td>32 (5.1%)</td>
<td>15 (46.9%)</td>
<td>10 (31.2%)</td>
<td>7 (21.9%)</td>
</tr>
<tr>
<td>Change in frequency of visits from or to family/friend</td>
<td>29 (4.6%)</td>
<td>10 (35.7%)</td>
<td>6 (21.4%)</td>
<td>12 (42.9%)</td>
</tr>
<tr>
<td>Death of a sibling</td>
<td>28 (4.4%)</td>
<td>16 (57.1%)</td>
<td>4 (14.3%)</td>
<td>8 (28.6%)</td>
</tr>
<tr>
<td>Death of other relative</td>
<td>25 (4.0%)</td>
<td>10 (42.3%)</td>
<td>8 (32.0%)</td>
<td>7 (26.9%)</td>
</tr>
<tr>
<td>Death of a significant other (other than a relative or friend)</td>
<td>23 (3.6%)</td>
<td>6 (28.6%)</td>
<td>8 (38.1%)</td>
<td>7 (33.3%)</td>
</tr>
<tr>
<td>Death of a pet</td>
<td>8 (1.3%)</td>
<td>4 (50.0%)</td>
<td>2 (25.0%)</td>
<td>2 (25.0%)</td>
</tr>
<tr>
<td>Moving from my family home to a service supported home</td>
<td>3 (0.5%)</td>
<td>1 (33.3%)</td>
<td>1 (33.3%)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td>Experience of crime (mugged or burgled)</td>
<td>1 (0.2%)</td>
<td>1 (100.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Break up of a steady relationship/Divorce</td>
<td>1 (0.2%)</td>
<td>1 (100.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems with justice and/or authorities</td>
<td>0 (0.0%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: Level of stress caused by death of a parent and death of a sibling were reported in one question.*
Upon completing the life events checklist, participants were asked to elaborate on their responses. A total of 176 participants provided additional information on the effect that these life events had on their mental health. Of these, 54 responses were removed from the analysis, as they repeated life events asked in the checklist and did not provide additional information about the effect of such life events. These answers were coded using a thematic analysis (See Appendix VII for details). Firstly, responses were categorised into negative responses (those that would have caused stress) and positive or neutral responses (those that did not cause stress, or those that had a positive effect). An additional 7 themes were identified from the responses, moving residence, change in service/staff, change in family relationships, change in routine, change in health status, change in relationship with friend/resident, and bereavement (Fig. 2 and Fig. 3).

Of those who reported positive or neutral responses toward the life events experienced, those who self-reported acknowledged negative experiences, but also suggested an ability to cope with such experiences. One participant said, “My mother is not well at the minute, but it’s not causing me stress. I am thinking about it, but I’m okay.” Many proxy reports stated that participants were not cognisant of adverse events. “She was not stressed by family illness as she was not aware.” It was unclear in these responses if the participants were not told about such events, or if they did not fully understand them. Others acknowledged the importance of choice in routine or behaviour: “For health reasons, [the participant’s] pipe smoking was discontinued for approximately 9 months, and [the participant] was upset. He recommenced smoking his pipe after this time and appears more content in himself.”
Fig. 2 Results of coding positive/neutral responses

- Moving residence ($n=8$)
- Change in service/staff ($n=3$)
- Change in family relationships ($n=11$)
- Change in routine ($n=2$)
- Change in health status ($n=8$)
- Change in relationship with friend ($n=1$)
- Bereavement ($n=6$)

Fig. 3 Results of coding negative responses

- Moving residence ($n=12$)
- Change in service/staff ($n=5$)
- Change in family relationships ($n=21$)
- Change in routine ($n=4$)
- Change in health status ($n=17$)
- Change in relationship with friend ($n=5$)
- Bereavement ($n=25$)
Among those who perceived the life events they had experienced as negative, many referred to multiple life changes, which caused significant distress. One proxy reporter stated it was “difficult to isolate why behaviour has changed, but lots of changes happened in [the participant’s] life recently.” Bereavement of parents, siblings, friends or fellow residents was commonly reported as a source of significant distress. Communication losses and decreased mobility as a result of dementia also emerged as a theme within change in health status, and caused participants annoyance and frustration. Experiencing life events in the context of previous experiences was also reported. “[The participant] suffered a lot of bullying as a youngster in school. Was moved to a nursing home where he suffered bullying and abuse from a staff member.”

Overall, more participants perceived life events as negative experiences than positive or neutral. This is consistent with the quantitative results on stress, which show that the majority of life events caused a lot or a little stress. For some life events, however, such as moving within service organisation, the level of stress was varied. Moving within service organisation was stressful for 52.2% of participants, and not stressful for 47.8%. Again, this is reflected in the qualitative data. While one proxy stated, “move caused excitement and improvement in [the participant’s] quality of life”, another stated, “Initially the move caused [the participant] a lot of stress, would have to keep going back to old unit. Has settled a lot and like new house but would not go to another for fear they move her again.” Similarly, a new resident moving into the home caused some stress for 52.2% of participants, and none for 47.8%. One proxy reported that staff could not see that a new resident affected the participant, while another reported that “two new residents moved into [the participant’s home.] [The new resident] likes [the participant] a lot and he does not like her and gets stressed.”
4.4 Life events and mental health status

The relationship between life events and depressive disorder symptomology was explored through several analyses. To understand how the number of life events is related to depressive symptoms, descriptive statistics were first used to produce graphical representations. An ANOVA analysis was then used to understand how the frequency of life events experienced varies by scores on the HADS-D. Correlational analyses were then performed in order to explore the relationship between the number of life events experienced and scores on the HADS-D. Binary logistic regression analyses were then used to predict the likelihood of reporting increased depression symptoms (i.e., case-level and subclinical symptoms) when experiencing multiple life events. Next, analyses were conducted to explore the relationship between the specific types of life events and mental health status. A Chi square test for independence was first conducted in order to see if there were statistically significant associations between types of life events and depressive symptoms. Logistic regression analyses furthered understanding of this relationship by providing information on how each type of life event predicts depressive symptomology.

4.4.1 Number of life events and depressive symptoms

The majority of participants who reported case-level depressive symptoms had experienced at least one life event (Table 2). Fig. 4 shows distribution of depressive symptoms in comparison to the number of life events experienced. Of the 29 persons who reported case level depression symptoms, 82.8% had experienced at least one life event (n=24), while 65.5% had experienced multiple life events (n=19). For the 45 reporting subclinical symptoms, 80% experienced at least one life event (n=36) and 53.3% experienced 2 or more life events (n=24). All of these results can be found in Table 2.
Fig. 4 Association of depressive symptoms and number of life events
A one-way ANOVA analysis was then performed to show how the frequency of life events experienced varied by HADS-D scores (Table 3). There was a significant difference at the \( p<0.001 \) level between mean number of life events experienced and HADS-D: \( F(2, 631) = 15.1, p<0.001 \). The actual difference in mean number of life events experienced among those who completed the HADS-D was 0.05, as calculated by eta squared. The effect size for both tests indicate that a small but statistically significant difference in means. Using the Tukey HSD test for post-hoc comparisons, the mean number of life events experienced among HADS-D participants who were non-symptomatic (\( M=1.49, SD=1.48 \)) was significantly different from those with sub-clinical depressive symptoms (\( M=2.27, SD=2.03, p=0.004 \)) and those with case-level depression symptoms (\( M=2.86, SD=2.05, p=0.000 \)). There was no significant difference in means between sub-clinical symptoms and case-level symptoms.

A correlational analysis was then used to identify if there is a significant association between the number of life events experienced and mental health status. Pearson’s correlation coefficient indicates that there is a small positive correlation between the number of life events experienced and total HADS-D scores (\( r=0.18, n=634, p<0.001 \)). These results indicate that as the number of life events increases, so too does the HADS-D score. In other words, multiple life events are positively correlated with increased depressive symptoms.

Binary logistic regression analyses were then used to predict the likelihood of reporting increased depression symptoms (i.e., case-level and subclinical symptoms) when experiencing multiple life events. The other covariates used were age, gender, level of ID, and type of residence. The model was statistically significant, \( \chi^2(8, n=586)=54.45, p<0.001 \). It predicted 88.2% of the cases correctly, and explained between 8.9% (Cox & Snell R square) and 17.4% (Nagelkerke R squared) of the variance of depression symptoms. Age, level of ID, and number of life events experienced made a statistically significant
contribution to the model, with level of ID being the strongest predictor (Table 5). People with severe or profound ID were more likely to report increased depressive symptoms (OR=3.91; 95% CI 1.49-10.25, p<0.05), as well participants aged 65 and older (OR=3.38; 95% CI 1.48-7.71, p<0.05). People who experienced more life events were also more likely to present with case-level depressive symptoms (OR=1.44; 95% CI 1.24-1.67, p<0.001).

| Table 5. Logistic regression predicting likelihood of reporting increased depressive symptoms |
|-------------------------------------------------|---------------|-------------|-------|-----------------|--------------|-----------------|
| Log odds | S.E. of log odds | Wald | df | p-value | Odds ratio | 95% CI for odds ratio |
| Gender (female) | 0.35 | 0.28 | 1.50 | 1 | 0.222 | 1.41 | 0.81 - 2.46 |
| Age | | | | | | |
| Age (50-64 years) | 0.75 | 0.38 | 3.86 | 1 | 0.050* | 2.12 | 1.00 – 4.49 |
| Age (65+ years) | 1.25 | 0.42 | 8.94 | 1 | 0.003* | 3.49 | 1.54 – 7.91 |
| Level of ID | | | | | | |
| Level of ID (moderate) | 1.40 | 0.49 | 3.26 | 1 | 0.071 | 2.35 | 0.93 - 5.94 |
| Level of ID (severe/profound) | 1.40 | 0.49 | 8.27 | 1 | 0.004* | 4.06 | 1.56 - 10.55 |
| Type of residence | | | | | | |
| Type of residence (community group home) | 0.58 | 0.64 | 0.81 | 1 | 0.368 | 1.78 | 0.51 – 6.30 |
| Type of residence (residential centre) | 0.84 | 0.64 | 1.80 | 1 | 0.180 | 2.37 | 0.67 – 8.39 |
| Number of life events | | | | | | |
| Number of life events (Only 1) | 0.34 | 0.42 | 0.65 | 1 | 0.422 | 1.41 | 0.61-3.23 |
| Number of life events 5.73(2 or more) | 1.03 | 0.37 | 7.98 | 1 | 0.005* | 2.80 | 1.37-5.73 |
| Constant | -5.16 | 0.81 | 41.06 | 1 | 0.000 | 0.006 |

Note: The baseline categories are males, 40-49 years, mild ID, living independently or with family, and not experiencing a life event (n=586)
*p<0.05, **p<0.001
4.4.2 Types of life events and depressive symptoms

A chi square test for independence was then used to see if there was an association between type of life event and depression symptoms (Table 6). There were small significant associations between experiencing a change of staff in home ($\chi^2 (2, n=631)=10.57, p=0.005$, Cramer’s V=0.129), change of frequency of visits with family/friend ($\chi^2 (2, n=631)=11.88, p=0.003$, Cramer’s V=0.137), and death of significant other ($\chi^2 (2, n=631)=8.18, p=0.017$, Cramer’s V=0.114), and depressive symptoms, at the $p<0.05$ level. Further, there were medium significant associations between depressive symptoms and experiencing a new resident moving into home ($\chi^2 (2, n=631)=23.53, p=0.000$, Cramer’s V=0.193) and major illness or injury ($\chi^2 (2, n=631)=49.75, p=0.000$, Cramer’s V=0.281), at the $p<0.001$ level.

<table>
<thead>
<tr>
<th>Change of staff in home where I live or day service I attend</th>
<th>Frequency n (Valid%)</th>
<th>Pearson chi-square value</th>
<th>p-value</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change of key worker</td>
<td>196 (31.1%)</td>
<td>10.57</td>
<td>0.005*</td>
<td>0.129</td>
</tr>
<tr>
<td>Moving within service organisation</td>
<td>137 (21.7%)</td>
<td>2.21</td>
<td>0.331</td>
<td>0.059</td>
</tr>
<tr>
<td>Change at work or day service</td>
<td>123 (19.5%)</td>
<td>6.55</td>
<td>0.038</td>
<td>0.102</td>
</tr>
<tr>
<td>New resident moved into home</td>
<td>91 (14.4%)</td>
<td>3.56</td>
<td>0.169</td>
<td>0.075</td>
</tr>
<tr>
<td>Death of a friend</td>
<td>78 (12.4%)</td>
<td>5.50</td>
<td>0.064</td>
<td>0.093</td>
</tr>
<tr>
<td>Major illness or injury</td>
<td>62 (9.8%)</td>
<td>49.75</td>
<td>0.000**</td>
<td>0.281</td>
</tr>
<tr>
<td>Death of a parent</td>
<td>52 (8.2%)</td>
<td>0.935</td>
<td>0.627</td>
<td>0.038</td>
</tr>
<tr>
<td>Other event or change of routine</td>
<td>37 (5.9%)</td>
<td>0.529</td>
<td>0.768</td>
<td>0.029</td>
</tr>
<tr>
<td>Major illness of relative, caregiver or friend</td>
<td>32 (5.1%)</td>
<td>0.40</td>
<td>0.819</td>
<td>0.025</td>
</tr>
<tr>
<td>Change in frequency of visits from or to family/friend</td>
<td>29 (4.6%)</td>
<td>11.88</td>
<td>0.003*</td>
<td>0.137</td>
</tr>
<tr>
<td>Death of sibling</td>
<td>28 (4.4%)</td>
<td>2.38</td>
<td>0.305</td>
<td>0.061</td>
</tr>
<tr>
<td>Death of other relative</td>
<td>25 (4.0%)</td>
<td>2.05</td>
<td>0.358</td>
<td>0.057</td>
</tr>
<tr>
<td>Death of a significant other (other than a relative or friend)</td>
<td>23 (3.6%)</td>
<td>8.18</td>
<td>0.017*</td>
<td>0.114</td>
</tr>
<tr>
<td>Death of a pet</td>
<td>8 (1.3%)</td>
<td>0.70</td>
<td>0.705</td>
<td>0.033</td>
</tr>
<tr>
<td>Moving from my family home to a service supported home (community group home/residential setting)</td>
<td>3 (0.5%)</td>
<td>0.70</td>
<td>0.705</td>
<td>0.033</td>
</tr>
<tr>
<td>Experience of crime (mugged or burgled)</td>
<td>1 (0.2%)</td>
<td>0.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Break up of a steady relationship/Divorce</td>
<td>1 (0.2%)</td>
<td>0.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems with justice and/or authorities</td>
<td>0 (0.0%)</td>
<td>0.2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: Tests were not conducted for life events reporting less than 20 positive responses.
*p<0.05, **p<0.001
Types of life events were then analysed as predictors of reporting increased depressive symptomology using binary logistic analyses. See Table 7 for results. The same life events found to have significant associations with depressive symptoms as measured by Chi square were also significant predictors of depressive symptoms, except for death of a significant other. Its significance was lost when analysed through a logistic regression.

Change of staff in home or day service, new resident moved into home, and change in frequency of visits from or to family/friend were all significant at the $p<0.05$ level, and major illness or injury was significant at the $p<0.001$ level. Major illness or injury was the strongest predictor of increased depressive symptoms. When controlling for gender, age, level of ID and type of residence, participants who had experienced a major illness or injury were over ten times more likely to report increased depressive symptoms than those who had not ($OR=10.42; 95\% \text{ CI}= 4.24-25.59, p<0.001$).

Table 7. Types of life event as predictors of case-level depressive symptoms

<table>
<thead>
<tr>
<th>Event</th>
<th>Crude OR [95% CI]</th>
<th>p-value</th>
<th>Adjusted OR [95% CI]</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change of staff in home where I live or day service I attend</td>
<td>2.90 [1.37-6.16]</td>
<td>0.006*</td>
<td>2.83 [1.21-6.31]</td>
<td>0.016*</td>
</tr>
<tr>
<td>Change of key worker</td>
<td>1.39 [0.60-3.22]</td>
<td>0.437</td>
<td>1.62 [0.67-3.95]</td>
<td>0.284</td>
</tr>
<tr>
<td>Moving within service organisation</td>
<td>1.33 [0.56-3.19]</td>
<td>0.522</td>
<td>0.83 [0.30-2.32]</td>
<td>0.722</td>
</tr>
<tr>
<td>New resident moved into home</td>
<td>4.73 [2.18-10.29]</td>
<td>0.000**</td>
<td>3.92 [1.63-9.42]</td>
<td>0.002*</td>
</tr>
<tr>
<td>Change at work or day service</td>
<td>1.61 [0.64-4.06]</td>
<td>0.317</td>
<td>1.24 [0.44-3.51]</td>
<td>0.683</td>
</tr>
<tr>
<td>Death of a friend</td>
<td>2.38 [0.98-5.76]</td>
<td>0.056</td>
<td>2.39 [0.89-6.42]</td>
<td>0.084</td>
</tr>
<tr>
<td>Major illness or injury</td>
<td>9.15 [4.16-10.13]</td>
<td>0.000**</td>
<td>10.42 [4.24-25.59]</td>
<td>0.000**</td>
</tr>
<tr>
<td>Other event or change of routine*</td>
<td>0.56 [0.07-4.24]</td>
<td>0.575</td>
<td>0.86 [0.11-6.98]</td>
<td>0.887</td>
</tr>
<tr>
<td>Death of a parent</td>
<td>0.39 [0.05-2.89]</td>
<td>0.622</td>
<td>0.59 [0.07-4.65]</td>
<td>0.614</td>
</tr>
<tr>
<td>Death of a sibling</td>
<td>0.76 [0.10-5.79]</td>
<td>0.790</td>
<td>0.99 [0.12-2.18]</td>
<td>0.960</td>
</tr>
<tr>
<td>Major illness of relative, caregiver or friend</td>
<td>0.68 [0.09-5.17]</td>
<td>0.709</td>
<td>0.88 [0.11-7.16]</td>
<td>0.903</td>
</tr>
<tr>
<td>Change in frequency of visits from or to family/friend</td>
<td>5.24 [1.83-14.96]</td>
<td>0.002*</td>
<td>5.19 [1.68-16.05]</td>
<td>0.004*</td>
</tr>
<tr>
<td>Death of other relative</td>
<td>0.86 [0.11-6.58]</td>
<td>0.883</td>
<td>1.92 [0.23-16.28]</td>
<td>0.549</td>
</tr>
<tr>
<td>Death of a significant other (other than a relative or friend)</td>
<td>3.35 [0.94-12.00]</td>
<td>0.063</td>
<td>2.75 [0.71-10.65]</td>
<td>0.142</td>
</tr>
</tbody>
</table>

Note: Death of a pet, moving from a family home to service supported home, experience of crime, break up of steady relationship/divorce, and problems with justice were excluded from analysis due to insufficient data

Note: Odds ratios were adjusted for gender, age, level of ID and type of residence

*p<0.05, **p<0.001
4.5 Conclusion

This chapter presented the findings from this research study. The results of the HADS-D were first provided, followed by a report of the prevalence of life events experienced. The types of life events that older people with ID experienced were then provided, as well as the level of stress caused by these life events. The relationship between experiencing these life events and depressive symptomology was presented through several analyses, including an ANOVA test, Pearson’s correlation coefficient, chi square test for independence, and logistic regression analyses. The results indicate that there is a relationship between number of life events experienced and depressive symptomology, as well as the relationship between types of life events and depressive symptomology, with major illness or injury acting as the strongest predictor of case-level depressive symptomology.
Chapter 5

Discussion
5.0 Introduction

In this chapter, the findings will be discussed in relation to the research questions of this dissertation. The results of the HADS-D will first be analysed, including a critical analysis of its validity for use in this population. In order to answer the first research question, the types of life events will be reviewed, as well as an analysis of possible reasons for the prevalence of these experiences. The burden of stress associated with these life events will then be analysed, incorporating the results from the thematic analysis into the quantitative results, which will seek to answer the second research question. Next, the relationship between the number of life events and depressive symptoms will then be discussed in light of the literature, as well as the relationship between type of life events and depressive symptoms in order to answer the third and fourth research questions. Concluding thoughts will be offered, as well as recommendations for future research and possible policy and service-provision implications. Finally, a reflection on the learning process in completing this dissertation will be provided.

5.1 Mental health status

The prevalence of case-level depressive symptoms was 4.6%, with a further 7.1% indicating subclinical symptoms. Results from a logistic regression analysis showed that age and level of ID were significant predictors of increased depression symptoms. Those with severe or profound ID were four times more likely to report increased depressive symptoms than those with mild or moderate ID (OR=4.06; 95% CI=1.56-10.55; p<0.05). Similarly, the oldest age group over 65 were 3.49 times more likely to report depressive symptoms (95% CI=1.54-7.91, p<0.05). This is in line with results with the IDS-TILDA Wave 1 study, which found that depression increased with age and level of ID (McCarron, et al. 2011).
The prevalence of self-reported case-level depression symptoms as measured by the CES-D in Wave 2 of the IDS-TILDA study, however, was much higher at 14.6%, which was a 3% increase from the prevalence seen in Wave 1 of the IDS-TILDA study (Mulryan, et al., 2014). When using these findings, the burden of depressive symptoms are higher than found in the general ageing population in Ireland, which found that 10% of participants reported case-level depression symptoms (O’Regan, et al. 2011), but lower when using the 4.6% identified by the HADS-D as having case-level depression in this analysis.

As the study is based upon accurate measurement of depressive symptoms, the discrepancy between the results must be noted. There are numerous possibilities for this difference, namely the validity of both scales for use with people with ID. Concerns surrounding use of the CES-D have been presented, particularly the potential of producing false positive responses (Orme, et al., 1986). The CES-D may therefore be identifying symptoms of other affective disorders, or associated psychosomatic symptoms, rather than solely identifying depressive symptoms, an issue which the HADS was specifically designed to avoid (Zigmond & Snaith, 1983).

The rigour of the HADS-D should be reviewed as well. Firstly, there are concerns about the relevance of included items, such as the question on decreased interest in appearance. As noted above, the internal consistency is improved when this item is removed, albeit marginally (α=0.679 to α=0.712 when item removed). Another item asks how frequently an individual “can enjoy a good book or radio or television programme” (Snaith and Zigmond, 1994). One participant reported that he or she “never had interest in TV, radio or books so reported very seldom as best possible answer.” These results may indicate that the HADS-D includes questions irrelevant to people with ID, and may need to be adapted in order to improve accuracy (Dagnan, et al., 2008). Further investigation should be conducted to assess the differences in these results. For the purposes of this study, however, the inter-
item correlation of the HADS-D (0.35) supports the reliability of the scale for use, and the available literature supports its validity for use among people with ID. This provides sufficient justification to present this study’s findings as accurate.

5.2 Prevalence of life events experienced by older people with ID

The prevalence of life events experienced by older adults with ID in Ireland is markedly similar to that found among older adults with ID in the Netherlands (Hermans and Evenhuis, 2012). Both analyses show that approximately two-thirds of the populations were exposed to at least one negative life event, and a substantial proportion experienced 2 or more negative life events (Hermans and Evenhuis, 2012).

Whereas age, gender, or level of ID were not significant predictors of experiencing multiple life events among older adults in this study, the Dutch HA-ID study found that participants over the aged of 65 were more likely to experience multiple life events than those aged between 50 and 64 (Hermans and Evenhuis, 2012). Participants with mild or moderate ID were also more likely to experience negative life events than those with severe or profound ID (Hermans and Evenhuis, 2012).

In Ireland, the single most important indicator of experiencing a life event was place of residence. Individuals who live in residential care and community group homes experienced more life events than those who live independently or with family ($M=1.77$, $SD=1.58$; $M=1.67$, $SD=.68$; and $M=0.99$, $SD=1.18$; $p<0.001$). This study found that older people with ID are at risk for experiencing multiple live events, and this risk increases for individuals living in community group homes, and even more so for those living in residential centres.

When viewing these findings by type of life event, the association between multiple life events and living situation becomes clearer. Four of the five most common life events
experienced – change of staff in home or day service, change of key worker, moving within service organisation, new resident moved into home - are all related to residence. The prevalence of life events and older adults with ID receiving formal care aligns with international literature. Change of staff in home, change of key worker, and new resident moved in were also among the frequently experienced life events among older Dutch adults with ID (Hermans and Evenhuis, 2012) and older adults with Down Syndrome in the US (Owen, et al., 2004; Patti, et al., 2005).

The prevalence of older people with ID experiencing staff changes is better understood when viewed in the larger context of policy changes in Ireland. After the global economic crisis in 2008, the Irish health care budget was dramatically reduced, with an initial cut in spending of 12% (Burke, et al., 2014b) According to WHO, this was the largest decrease in health spending in Europe during the recession (Burke, et al., 2014b). Since 2008, the health budget has been cut by 2.3 billion euro and there at least 12,000 fewer HSE employees than in 2007, with an additional 2,600 staff expected to be made redundant by the end of 2014 (Burke, et al., 2014b). Retirement and restructuring services without staff replacement has become increasingly more common (Burke, et al., 2014b), and staff of residential centres and community group homes have not been exempt from these changes.

Other commonly experienced life events, such as new resident moved into home, can also be explained by the shift in services to deliver community-based care that promotes inclusion (HSE, 2011). Moving individuals from residential settings to community group homes or independent living arrangements is an evolving process, and the IDS-TILDA study found that approximately one in six individuals had moved residence between studies (17% of Wave 2 sample, n=120) (McCallion, et al., 2014). Of these, 66 were moves to another comparable setting, 31 were to a more community-based setting, such as moving from residential centre to a community group home or independent living, and 15 were to a more
restrictive setting, such as from a community group home or independent/family living to a residential setting, or from independent/family living to a community group home (McCallion, et al., 2014). If participants did not move residence themselves, these findings suggest many participants still experienced the effects of such movement.

The life events that were not commonly experienced should also be analysed. Some of the most infrequently experienced life events were related to social networks. For example, the prevalence of experiencing the death of a significant other was under 4% in this study. In contrast, the general TILDA study found that a large majority of women from the oldest age group, for example, had been widowed (63%), although this point prevalence measurement was not limited to the year prior (Kamiya and Sofroniou, 2011). Still, Wave 1 of the IDS-TILDA found that only four older people with ID were married or had a partner (McCarron, et al., 2011). The low prevalence of participants experiencing the death of a significant other may simply be attributed the small numbers of individuals that have a significant other.

Similarly, older people with ID are at increased risk of social isolation as a result of limited social networks as found in Waves 1 and 2 of the IDS-TILDA study (McCausland, et al., 2014; McCarron, et al., 2011). This risk increases with age and among those with severe/profound ID or those living in residential centres (McCausland, et al., 2014). Few participants may have experienced death of a relative simply because they do not have frequent connections with extended family. Results from the thematic analysis also indicate that participants were not always cognisant of or privy to events related to family: one proxy stated, “She was not stressed by family illness as she was not aware.”

In referring back to the first research question seeking to understand the types of life events older people with ID in Ireland are exposed to, it appears that not only is this population at risk for experiencing multiple life events, many of these life events are directly related to living situation, and are unique to people with ID.
5.2 Stress caused by types of life events

Analysis of the level of stress caused by these life events produced rather interesting findings. While the most frequently experienced life events were related to residence, these were also the life events that caused the least amount of stress. While this study did not conduct analyses to see if these changes were as a result of a move, it is likely that some of the residence-related changes occurred in tandem with moving residence. A large proportion of moves experienced by IDS-TILDA participants were to a less-restrictive setting (47.0%) (McCallion, et al., 2014). It is therefore a positive indication that associated changes were not stressful for the majority of participants. Indeed, as reflected in the thematic analysis, one proxy reported that the “move caused excitement and improvement in [the participant’s] quality of life.”

However, other reports from the thematic analysis indicate that moving was certainly a cause of stress for some. One participant initially struggled to adjust to her new environment, which caused a great deal of stress. She had since settled, but was fearful of another move. This also implies that life events can be dynamic experiences, and the effect of such experiences may be more complex than can be obtained through categorical data. The effect of significant life experiences should also be viewed within the context of the individual, such as personality and past experiences. One proxy reported that the participant had suffered abuse throughout his childhood, which continued into his adulthood when we suffered abuse from a staff member at a nursing home. Because of his past experiences, life events, such as a move, may impact him very differently than someone with a different background.

Major illness or injury was the most stressful experience for participants. The thematic analysis showed that many participants were discouraged by communication losses and decreased mobility as a result of dementia, which people with ID, particularly those with
Down Syndrome, have been shown to be at increased risk for developing (Mulryan, et al., 2014; Stern, 2012; Strydom, et al., 2010). This risk increases with age and is up to five times higher than among people without ID (Strydom, et al., 2010). Wave 1 of IDS-TILDA reported that one in three participants already had difficulty communicating with health professionals (McCarron, et al., 2011), so developing further communication breakdowns may indeed be a source of great frustration. The high burden of stress associated with major illness and injury, and as revealed in the thematic analysis, communication difficulties, has important implications for service provision. Cognisant of the risk for degenerative disorders, and the stress associated with communication struggles as a result, alternative communication strategies could be useful to mitigate adverse effects.

Death of a parent was also among the most stressful for respondents. Death has emerged as a concern for older people with ID as they age (Burke, et al., 2014a). Using data collected in the IDS-TILDA study, 24.7% of self-reporting participants expressed concerns about growing older, and of these, 19% cited death and bereavement as a worry (Burke, et al., 2014a). Anxiety about losing parents who also acted as primary carers was a particular concern. Other data from the IDS-TILDA study have found that older adults with ID rely upon immediate family members, such as parents and siblings, for care to a much greater extent than the general population, who would typically rely upon partners or children for care (McCarron, et al., 2011).

Overall, the burden of stress caused by life events was rather varied. The heterogeneity in reported stress could be attributed to a number of factors. As discussed in Chapter 2, gathering data on subjective measures among people with ID may be met with certain challenges, including response bias, acquiescence, and communication difficulties (Torr, et al., 2008; Foran, et al., 2013). Proxy responses, in contrast, may be less reliable and can be affected by the relationship with the participant (Andresen, et al., 2001). The results
from the thematic analysis offered explanations to many of these responses, however. A limited number of participants answered the open-ended question, but the available data contextualised the quantitative results in a way that has not yet been examined in other studies. This analysis benefitted from this information, and incorporation into future research is recommended.

This analysis provides an answer to the second research question about how older people with ID perceive the life events they experience, and how this affects stress levels. While the majority of participants reported some amount of stress as a result of experiencing life events, indeed, the results of this study indicate that the relationship between the two may be mediated by a range of contextual factors that should also be considered.

5.3 The effect of life events on depressive symptomology

The findings show that the majority of participants who reported case-level depressive symptomology had experienced multiple life events, and that participants who experienced 2 or more life events were 2.8 times more likely to display case-level or subclinical depressive symptomology than those who did not experience a life event (OR=2.80; 95% CI 1.37-5.73, p<0.05). Fig. 3 shows that the burden of case-level and subclinical depression symptoms is largely spread across individuals who had experienced one or more life events, particularly those that experienced four or more life events. Results from the ANOVA analysis also show that HADS-D participants with increased depressive symptoms experienced more life events than those who were non-symptomatic.

These results align with the international literature that has established that depressive symptoms increase with the number of life events experienced by adults with ID (Hermans and Evenhuis, 2012; Hastings, et al., 2004; Hamilton, et al., 2005; Martorell, et al., 2009;
Hulbert-Williams and Hastings, 2008; Cooper, et al., 2007). Again, it should be noted that these results share the common use of proxy reports only. The HADS-D included self-reports, as well as proxy reports, however. The results from this study could provide justification for including self-reports in future relevant research, as advocated by Hulbert-Williams and Hastings (2008). Hulbert-Williams and Hastings (2008) also contend that the relationship between life events and mental health is not necessarily linear. Instead, they suggest that mediating factors, such as social support, personality traits or physical health, interact with these variables (Hulbert-Williams and Hastings, 2008). The IDS-TILDA study gathered data on all of this information, and further analysis of the interactions between these variables would be valuable. As a longitudinal study, the IDS-TILDA study also provides an opportunity to explore how these experiences and their effects change over time. This particular study does not offer any information on causality between life events and depressive symptoms, but the nature and direction of this relationship should be studied in further research.

This analysis answers the third research question by showing that experiencing multiple life events is a potential risk factor for mental health difficulties. Future research should be conducted to assess if there is a causal relationship between the two, as well as to explore the interaction of mediating factors.

5.4 Relationship between type of life event and depressive symptomology

This study also found that the type of life event as plays an important role in the relationship with depressive symptoms. Major illness or injury, new resident moved into home, and change in frequency of visits with family or friend were significant predictors of case-level depressive symptoms when adjusting for demographic variables. The findings on
major illness or injury overlap with the Dutch HA-ID study (Hermans and Evenhuis, 2012), although the IDS-TILDA study found a much more pronounced relationship with depressive symptoms (OR=10.42; 95% CI=4.24-25.59, *p*<0.001, compared to OR=1.58; 95% CI=1.07-2.32; *p*<0.05). The large confidence interval produced in this study should be noted, particularly when compared with that of the HA-ID study. This indicates that the true value of the odds ratio lies within this interval, with 95% certainty, and therefore, larger intervals indicate decreased accuracy of the measurement.

As is, the association between major illness or injury and mental health is also reflected in the analysis on stress. This was reported to cause a lot of stress among the majority of participants. As discussed above, participants reported frustration with functional decline and communication breakdowns, and these results indicate this may translate into a decline in mental health as well. The indication that physical ill-health affects mental health in this population is interesting, as the link between the two has been well-established in the general ageing population, but studies have not found this link in older people with ID (Cooper, et al., 1999; Cooper, et al., 2007). This finding has important service-provision implications, and suggests the need to include people with ID in public health efforts in order to prevent these health difficulties that clearly significantly affect depressive symptoms. Further analysis into the specific illnesses and injuries that are adversely affecting this population should be conducted in relation to depression.

Conversely, the results indicating those who experienced a new resident moving into their home and change of staff in home were at increased risk for depressive symptoms was somewhat surprising, considering these were not reported to be a particularly stressful event. These results may support the theory that the relationship between life events and depression is not necessarily linear, and can be mediated by other factors (Hulbert-Williams and Hastings, 2011). As discussed earlier, life events should also be viewed within the context of
the individual. The occurrence of these life events implies a lack of choice. As seen in the thematic analysis, this could be rather upsetting for some individuals. Upon a new resident moving into a participant’s home, a proxy reported, “[The new resident] likes [the participant] a lot and he does not like her and gets stressed.” In this context, the lack of autonomy in making decisions about where and with whom one lives could understandably cause mental health difficulties.

Change in frequency of visits from or to family/friend was also seldom reported as stressful for many participants (42.9%), but participants who had experienced this event were over three times more likely to report increased depressive symptoms (OR=3.31; 95% CI=1.32-8.26; p<0.05). As discussed previously, the limited social networks of older people with ID and resulting risk of social isolation and loneliness, as found by the IDS-TILDA study, could contribute to these findings (McCausland, et al., 2014). Results from Wave 1 and Wave 2 found an overall decrease in rates of regular contact with family, with only half of older people with ID maintaining regular face-to-face contact with family members they do not live with (52.3% in Wave 2 and 53.5% in Wave 1) (McCausland, et al., 2014). Furthermore, over 40% of individuals reported they did not have friends outside of their home (43.4%), increasing among those with severe/profound ID and those living in residential centres, and to a lesser extent, those living in community group homes (McCausland, et al., 2014). These findings could contribute to isolation and loneliness, and while perhaps this did not cause a lot of stress, it certainly appears to be associated with increased depressive symptoms.

Similarly, these three life events that caused little stress, but were shown to be predictors of depressive symptoms, are all related to place of residence. As discussed above, residence is strongly associated with depressive symptoms. Therefore, the living situation of these participants may be a more important factor in presenting case-level depression, and not
necessarily the experience of associated life events. Overall, these results indicate that stress, or lack thereof, may not be a significant indicator of depressive symptoms. As discussed above, experiencing stress may be affected by a range of factors that may help participants cope with immediate stimuli (Hulbert-Williams and Hastings, 2011). This is a significant finding to consider in future research in this area, as the majority of research thus far assumes a linear relationship between life events and mental health difficulties, and rarely includes analysis of other variables that may interact with the relationship (Hulbert-Williams and Hastings, 2011). Such factors identified in this study include personality and past experiences. Overall, this analysis answers the final research question by finding that certain life events are significant predictors of increased depressive symptoms, but suggests that this relationship be investigated further.

5.5 Limitations

The major limitation of this study is that it cannot provide information on causality, as discussed above. It also employed a very specific measurement to act as proxy for mental health status, i.e., the HADS-D. As this is a screening tool, and not a diagnostic one, inferences made from the findings of this study must be with caution. The justification for the selection of the HADS-D was outlined in detail in an earlier chapter (See: Chapter 3.5.2b), but as the IDS-TILDA study utilized other indicators of mental health status, including ratings of health and diagnosis of a psychopathologic disorder, a more rigorous analysis of life events and other mental health indicators should also be completed.
5.6 Recommendations and implications

This should be a preliminary analysis of the extensive data collected by the IDS-TILDA study, and there exists a need to explore further the role of significant life events in the lives of older adults with ID. It is recommended that future research incorporate individuals with ID in the research process, as opposed to the general trend thus far to obtain information on life events among people with ID through informants or medical files. Involving people with ID in research on subjective measures provided meaningful insight into how older people with ID perceive life experiences and their mental health status. To this end, further research should also consider obtaining qualitative data, as doing so provided depth to this analysis. Finally, research should also account for the presence of interacting variables in the relationship between life events and mediating factors in order to establish the nature of the association.

Beyond research, these findings may also have important implications for policy changes and service-provision. The strong association between residence – and associated life events – and depressive symptoms should provide further evidence for the need to move individuals with ID out of institutional settings and into truly inclusive community settings. Autonomy and choice should be of high priority, as this study found that limited independence could be a great source of stress. The strong association between experiencing a major illness or injury and depressive symptoms also suggests the need for including people with ID into preventive public health interventions. This may include producing accessible health materials and involving people with ID in community health activities. The risk for dementia and resulting communication breakdowns, which was also shown to be a significant cause of distress in this study, also suggests the need for proactive strategies, such as developing alternative communication methods, in order to prevent stress and mental health difficulties.
5.7 Conclusions

This study produced important findings that indicate life events are a significant indicator of depressive symptoms among older adults with ID in Ireland. This study met its aim to explore how life events affect stress and depressive symptoms among older adults in Ireland, and how this population perceives these experiences. The research questions were all answered as follows:

1) In response to what life events older people with ID experience, this study indicates that a substantial proportion experienced multiple life events in the year prior, the majority of which were directly related to receiving formal care and place of residence, such as change of staff in home and moving within service organisation. These findings are consistent with the existing literature (Hermans and Evenhuis, 2021; Owen, et al., 2004).

2) People’s perception of life events and resultant stress was rather varied, although the majority of participants reported experienced some stress from each of the life events. This is likely a result of external factors, such as personality and other life experiences. As stress is subjective, proxy reports may have over- or under-estimated the effect of these life events on the participant as well (Andresen, et al., 2001). Conversely, issues such as acquiescence may have affected some self-reports (Foran, et al., 2013). Regardless, the qualitative data gathered from the IDS-TILDA study provided richness to the analysis not possible when relying solely on quantitative data. This type of analysis has not yet been used in the relevant literature on life events among people with ID, and should be considered in future studies.
3) This study aligns with relevant literature, finding a significant relationship between multiple life events and depressive symptomology. Through several analyses, it is evident that participants who experienced multiple life events were more likely to report increased depressive symptoms. By incorporating self-reported measures of depressive symptomology, as opposed to the majority of relevant studies that employ proxy-only responses, this study provides justification for use of self-reports in future research. This analysis does not provide information on the nature of this relationship, however, and acknowledges the need for exploring the presence of mediating factors, as well as causality.

4) The type of life event experienced was also found to be an important factor in predicting depressive symptoms. Major illness or injury was the strongest predictor of increased depressive symptoms, which aligns with the Dutch HA-ID study (Hermans and Evenhuis, 2012). Communication breakdowns and decreased mobility may contribute to mental health difficulties, and further analysis should be conducted into the relationship between physical ill-health and mental ill-health. While change of staff in home, new resident moving into the home, and change in frequency of visits with family or friends were not stressful for many participants, those who experienced these events were more likely to present increased depressive symptoms. Lack of autonomy in making life decisions and limited social networks, by-products of living in residences that are not truly inclusive, may contribute to mental health problems.
5.8 Reflection

The development and completion of this research provided invaluable experience within a large-scale, national research project. While expecting to primarily improve quantitative analysis skills, which I certainly did, the guidance provided by experienced researchers on methodological issues proved to be the most fruitful. The rigour with which the IDS-TILDA study was conducted offered a better understanding of the level of detail needed to conduct high-level research. The subject of the dissertation was also interesting, as I had not previously extensively studied issues surrounding ID. Viewing ID through significant experiences provided insight into their lives, and contextualising the findings against the research proved to be an interesting research project. It also allowed for application of concepts learned throughout the Master’s programme, such as ethical issues surrounding people with ID as research participants.

5.8 Overview

This chapter provided an analysis of the findings in relation to the research questions of this dissertation, as well as the existing literature. The suitability of the HADS-D for use with people with ID was explored in depth, concluding that its reliability and validity are sufficient. The types of life events frequently, and indeed, infrequently, experienced were described, as well as reasons contributing to these experiences. An analysis of the level of stress caused by life events was presented, which was bolstered by the results from the thematic analysis. The relationship between multiple life events and increased depressive symptoms was then described, and compared to similar findings in the literature. Similarly, the relationship between types of life events and depressive symptoms was analysed in depth. Limitations of the study and recommendations for future research were made, as well as a synthesis of how the study met its aims and answered its research questions was provided.
References


Appendices
Appendix I
### Braun and Clark’s Thematic Analysis Framework

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of the process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Familiarizing yourself with the data:</td>
<td>Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.</td>
</tr>
<tr>
<td>2. Generating initial codes:</td>
<td>Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.</td>
</tr>
<tr>
<td>3. Searching for themes:</td>
<td>Collating codes into potential themes, gathering all data relevant to each potential theme.</td>
</tr>
<tr>
<td>4. Reviewing themes:</td>
<td>Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis.</td>
</tr>
<tr>
<td>5. Defining and naming themes:</td>
<td>Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.</td>
</tr>
<tr>
<td>6. Producing the report:</td>
<td>The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.</td>
</tr>
</tbody>
</table>

(Braun and Clarke, 2006, p. 87)
Appendix II
IDS-TILDA recruitment strategy and data collection process

26,066 people registered on the National Intellectual Disability Database (NIDD)

1,800 PINs randomly selected of people aged 40 years and over

753 people with and ID aged 40 years and over consented to take part in the IDS-TILDA study

708 participants consented to continue at Wave 2 of the study

94% retention rate achieved through keeping-in-touch strategy, including regular newsletters and cards to participants

Data Collection Process for Wave 2

- Individual fieldworkers assigned caseloads
- Contacts participant to arrange interview
- PIQ sent to participant for completion
- Main interview completed & PIQ collected
- Data entered and data files uploaded

- 602 completed Health Fair for Objective Measures
- 65 Family Carer Interviews
- 45 End of Life Care Interviews

McCarron, McCallion & Burke (eds.), 2014, p. 12
Study flow chart

Background research

• Conduct comprehensive literature review
• Establish research aims and questions
• Identify appropriate methodology

Ethics Application

• Trinity College Dublin Faculty of Social Work and Social Policy Ethics Committee

Approval achieved

• Yes: Proceed
• Conditional yes: Discuss identified issues with supervisor and devise plan to address all potential issues
• No: Review and resubmit

Preliminary data review

• Create dataset
• Assess quality of coding
• Explore distribution of variables, including identifying outliers

Data analysis

• Conduct all analyses
• Consult with supervisors
• Refine research questions
• Conduct additional analyses as needed

Increasing rigour

• Perform internal reliability analyses of quantitative questionnaires
• Qualitative coding assessed and confirmed by external researcher

Produce report

• Write up findings and implications
• Amend according to supervisor feedback

Dissemination of results

• Complete report
• Develop and complete dissertation
• Present findings to IDS-TILDA team
• Allow for reproduction by IDS-TILDA and TCD
Appendix IV
Ethical approval for initial IDS-TILDA longitudinal study (2010-2016)

THE UNIVERSITY OF DUBLIN
TRINITY COLLEGE

SCHOOL OF MEDICINE
FACULTY OF HEALTH SCIENCES

Professor Dermot Kelleher, MD, FRCPI, FRCP, F Med Sci
Head of School of Medicine
Vice Provost for Medical Affairs

Ms. Fedelma McNamara
School Administrator

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
Appendix V
Ethical approval for Wave 2 of IDS-TILDA study (2013)

Professor Mary McCarron
Dean of the Faculty of Health Sciences and Principal Investigator of IDS-TILDA,
Chemistry Building,
Trinity College Dublin,
Dublin 2.

28 January 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 ethical approval has been granted by the Faculty of Health Sciences Research Ethics Committee.

Wishing you the best of luck with your study.

Yours sincerely,

[Signature]
Dr. Ruth Filkington
Chairperson
Faculty Research Ethics Committee
Appendix VI
Ethical approval for dissertation research

<table>
<thead>
<tr>
<th>Application</th>
<th>REAC Ref</th>
<th>Category</th>
<th>Recruitment / Volunteerism</th>
<th>Time</th>
<th>Supervisor</th>
<th>Meeting</th>
<th>REAC Outcomes</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>Tadhra Carroll,</td>
<td>$15</td>
<td>MSc Cl 1</td>
<td>The research involves the mental and emotional health and well-being of individuals with intellectual disability</td>
<td>12.05.14</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix VII
Key quotes:

- For health reasons, [the participant’s] pipe smoking was discontinued for approximately 9 months, and [the participant] was upset. He recommenced smoking his pipe after this time and appears more content in himself.
- Not stressed by family illness as SR was not aware
- My mother is not well at the minute but it’s not causing me stress. I am thinking about it, but I am okay.
- Changes of family visits has actually been an improvement in circumstances
- I sometimes have bad days but not too often.
- Moved home twice but didn’t cause any stress. Moved initially from an institution having lived there for most of her life, at least 40 years
- Move was a positive one. Was in bad condition before he moved and within a month he was fantastic.
- [The participant] is usually a happy sociable person. Her illness caused her a lot of pain and discomfort but she bore this with great dignity.
- Change in [staff] roster was good, not stressful, helped [the participant] to get more free time.
- Death of a sibling did not appear [to stress the participant]. She showed very little emotion.
Key quotes:

- I sometimes get sad and think about my mother in the grave.
- Difficult to isolate why behaviour has changed, but lots of changes happened in [the participant’s] life recently.
- Bereavement was quite difficult as was house move as it also involved moving to an unsuitable place first.
- Initially the move caused [the participant] a lot of stress, would have to keep going back to old unit. Has settled a lot and like new house but would not go to another house for fear they move her again.
- [The participant] suffered a lot of bullying as a youngster in school. Was moved to a nursing home where he suffered bullying and abuse from a staff member.
- [The participant’s] institution was closed by HIQA very quickly with very little notice. [The participant] very distressed at the time.
- Upset about falling out with his brother and no longer has any contact with them.
- Death of father caused a lot of anxiety, and this anxiety is still causing problems. There was a significant change in personality.
- [The participant] likes her routine and changes to this cause her stress. Her upcoming operation is a source of anxiety for her as she has not been in hospital before this and her needs will change with much more input and support needed from staff.
- Communication losses within dementia are causing annoyance.
- Two new residents moved into [the participant’s] home. One likes him a lot and wants to spend a lot of time with him and he does not like her and gets stressed.