The Impact of the COVID-19 pandemic on the Mental Health of Older Adults with an Intellectual Disability in Ireland.

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Doctor of Philosophy

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Declaration

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Date: November 16th, 2023

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Dedication

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Summary

Background

On the 11th of March 2020, the World Health Organisation declared COVID-19 a global pandemic. Governments around the world took unprecedented actions to implement public health measures to control the spread of the virus and to protect the physical health of their populations. However, it is known from previous pandemics, such as Severe Acute Respiratory Syndrome (SARS) and Middle Eastern Respiratory Syndrome (MERS) that there are implications for mental health due to restrictions such as isolating and physical distancing. The impact of such measures for individuals with an intellectual disability have not previously been reported. The prevalence of mental health conditions among this population is greater than those without an intellectual disability. Using the Hobfoll's Conservation of Resources Theory as a framework, this study aims to understand the role that personal and social resources had on mental health outcomes during the first eighteen months of the COVID-19 pandemic.

Aim and Objectives

The primary research aim in this study was to understand the personal and social resources associated with mental health outcomes for older adults with an intellectual disability in the context of the COVID-19 pandemic. The secondary aim of the study was to provide evidence to inform policy makers and service planners on the promotion of mental health in the aftermath of COVID-19, and in the event of further pandemics or public health emergencies. Within this there were three research objectives. They were to identify factors associated with mental health outcomes for this population during the COVID-19 associated restrictions; to measure how resources lost during the pandemic impacted on mental health; and to measure how resources gained during the pandemic impacted on mental health.

Methods

Cross sectional quantitative data was analysed from a specifically developed COVID-19 survey embedded in Wave 4 of the Irish Longitudinal Study on Ageing (IDS-TILDA), which involved a representative sample of 682 people with an intellectual disability aged 40 years and over in the Republic of Ireland. Univariate, bivariate, and multivariate analysis was carried out using binary logistic regression models across four separate studies. The impacts of gains and losses of resources on symptoms of depression, symptoms of anxiety, loneliness, and self-rated mental health were explored.

Results

Symptoms of depression were present in 13.6% of participants. Access to mental health supports, loss of physical health resources, and gains in resources associated with resilience were positively associated with having symptoms of depression. There were greater odds of people with Down syndrome to have symptoms of depression. Symptoms of anxiety were present among 21.5% of participants, with access to mental health supports being negatively associated with symptoms. In the regression model, resource gains associated with resilience were positively associated with having anxiety symptoms. The impact of loneliness was explored among self-reporting participants and 60% reported feeling lonely during the pandemic. Experiencing COVID-19 related stress/anxiety and loss of physical health resources were associated with being lonely. Females had greater odds of feeling lonely than men. Participants who had diagnosed mental health disorders reported poorer self-rated mental health. Losses related to physical health were also associated with poorer ratings of mental health. Within the study 182/674 participants rated their mental health as fair or poor.

Conclusions

There were negative impacts to mental health among older adults with an intellectual disability in Ireland during the COVID-19 associated restrictions. Using the Conservation of Resources theory to examine how losses and gains in resources impacted on mental health provided a beneficial framework for this study. Those with Down syndrome and women experienced greater mental health impacts. The importance of access to appropriate individualised mental health supports, and the impact of losses related to physical health among participants during the pandemic was highlighted. Despite the negative impacts to mental health, many participants identified positive aspects of the pandemic, suggesting coping and resilience among older adults with intellectual disabilities.

Contents

List of Figures

List of Tables

List of abbreviations

Child and Adolescent Mental Health Services	CAMHS
Computer Assisted Personal Interviews	CAPI
Community Mental Health Teams	CMHTS
Conservation of Resources Theory	COR theory
General Anxiety Disorder Assessment (7 item)	GAD-7
General Data Protection Regulations	GDPR
Health Service Executive	HSE
International Classification of Diseases 10th edition (ICD-10)	ICD-10
International Classification of Diseases 11th edition (ICD-11)	ICD-11
International Classification of Functioning	ICF
Middle Eastern Respiratory Syndrome	MERS
Mental Health Intellectual Disability teams	MHID teams
National Public Health Emergency Team	NPHET
National Ability Supports System	NASS
National Intellectual Disability Database	NIDD
National Institute for Health and Care Excellence	NICE
Odds Ratio	OR
Patient Health Questionnaire (9 item)	PHQ-9
Personal Identification Number	PIN
Polymerase Chain Reaction test	PCR test
Post-Traumatic Stress Disorder	PTSD
Pre-Interview Questionnaire	PIQ
Public Patient Involvement	PPI
Regional Disability Data Administrator	RDDA
Residential Care Facilities	RCFs
Severe Acute Respiratory Syndrome	SARS
Severe Acute Respiratory Syndrome Coronavirus 2	SARS-Cov-2
The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing	IDS-TILDA
The Irish Longitudinal Study on Ageing	TILDA
Unique Identifier	UI
University of California, Los Angeles loneliness scale	UCLA loneliness scale
Variance Inflation Factor	VIF
World Health Organisation	WHO

Chapter 1 Introduction

1.1 Introduction to the Study

This study provides a unique and timely perspective of the impact on mental health during the COVID-19 pandemic and associated restrictions for older adults with an intellectual disability in Ireland. For individuals with an intellectual disability the pandemic, which emerged in late December 2019, resulted in unprecedented public health measures being implemented which included restrictions in movement outside homes, restrictions on visitors, closures of services such as day services and respite services, and the use of Personal Protective Equipment (PPE) which extended beyond the period of mandatory use by the general population (HSE 2023a). Individuals with intellectual disabilities experience mental health conditions at a greater prevalence than the general population and this knowledge raised concern for many who were involved in supporting people with intellectual disabilities, service providers, and policy makers, including this researcher.

This study was possible due to the researcher's involvement in the Intellectual Disability Supplement to The Irish Longitudinal Study in Ageing (IDS-TILDA) and the broad ranging scope of the conceptual framework of the study (McCarron *et al.* 2020). The researcher recognised the valuable opportunity at the cusp of the pandemic to access a cross sectional nationally representative population of older adults with an intellectual disability in Ireland. Therefore, in partnership with the Principal Investigator and the research team of the IDS-TILDA study we developed a survey to explore the impacts of COVID-19 and the associated restrictions on the lives of people with an intellectual disability. The complexity of mental health extends into many facets of life. The combination of the breadth of data which comprises the IDS-TILDA conceptual model with the additional questions in the COVID-19 survey uniquely positions this study is to make an original research contribution considering an unprecedented global pandemic.

The Hobfoll Conservation of Resources Theory (Hobfoll 1989, Hobfoll 1998) was used as the theoretical framework to underpin this study. The basic tenet of Conservation of Resources (COR) theory is that individuals strive to obtain, retain, protect, and foster the things that they value. According to the theory, psychological distress will occur in one of three instances: firstly, when individuals' resources are threatened with loss; secondly, when resources are lost; and lastly, where individuals fail to gain sufficient resources following significant resource investment. Resources in this context refer to personal characteristics, object resources, condition resources and energy resources. During the pandemic people with an intellectual disability over the age of 40 years were asked about how COVID-19 and associated restrictions impacted them in many areas of their lives.

1.2 Thesis Outline

Chapter 1 - Introduction: Introduces this thesis, the research question, aims and objectives, and is followed by study definitions of terms that are applied throughout.

Chapter 2 - Background and Context: Provides background and context and presents a review of the pertinent literature, including policy, which is relevant in addressing the aims and objectives of this study. A scoping review is presented, and the chapter concludes with an overview of the theoretical framework used within this study.

Chapter 3 - Methodology: As this study was nested within the IDS-TILDA study, background information for the longitudinal study is presented. The chapter describes in detail the methodology of this thesis, including ethical considerations, researchers' procedures in the field, and measures used. Data analysis and statistical methods applied within this study are provided.

Chapter 4 - Descriptive Analyses of Predictor Variables: Presents descriptive statistics for the predictor variables used across this thesis. These variables are presented as 'demographic' predictor variables, and as 'non-demographic' predictor variables.

Chapters 5 – 8: Each of these chapters relates to a specific dependent variable: **Symptoms of depression, Symptoms of anxiety, Loneliness, and Self-rated mental health.** These are the mental health outcomes explored within this study. Each chapter describes the methods, analysis (univariate, bivariate and multivariate), and the results. Each chapter concludes with a summary of findings.

Chapter 9 - Discussion: The results from Chapters 5-8 are discussed using the theoretical framework of the study and the research objectives to guide the discussion in the context of relevant research and policy.

Chapter 10 - Conclusion: This chapter concludes this thesis by presenting the contributions to the field that this thesis has provided. The study limitations are acknowledged and key study implications and recommendations for policy, practice, and research are provided.

1.3 Research Question, Aims and Objectives

The research question for this study was: What impact have personal and social resources had on the mental health of older adults with an intellectual disability in Ireland in the context of the COVID-19 pandemic?

The primary research aim in this study is to understand the personal and social resources associated with mental health outcomes for older adults with an intellectual disability in the context of the COVID-19 pandemic.

The secondary aim of the study is to provide evidence to inform those planning services and policy makers on the promotion of mental health in the aftermath of COVID-19, and in the event of further pandemics or public health emergencies.

Within the overall research question there are three research objectives, and they are:

1. To identify factors associated with mental health outcomes for this population during the COVID-19 associated restrictions.
2. To measure how resources lost during the pandemic impacted on mental health.
3. To measure how resources gained during the pandemic impacted on mental health.

To address objectives 1 – 3, analyses of cross-sectional quantitative data collected from IDS-TILDA participants using the COVID-19 (phase 2) survey, plus some demographic information from Wave 4 of IDS-TILDA data, were used.

1.4 Study Definitions

To clarify several terms that will be used throughout this thesis, this section provides the meanings and where relevant, definitions for several key concepts and their intended meaning within this study.

1.4.1 Definition of Intellectual Disability

Variations in terminology exist regarding the term ‘intellectual disability’ which is the term that will be used consistently throughout the study. The term ‘mental retardation’ was removed from the ICD-11 in the World Health Organisation International Classification of Diseases; however, it was replaced with ‘Intellectual Development’, the rational being that the term ‘intellectual disability’ is at odds with the World Health Organisation Family of International Classifications which distinguishes health conditions (ICD) from their consequences, which are captured under the International Classification of Functioning (ICF). It is suggested that the use of the word ‘development’ reflects onset during the developmental period. The revised description, which is accepted in this thesis is:

Disorders of intellectual development are a group of etiologically diverse conditions originating during the developmental period characterised by significantly below average intellectual functioning and adaptive behaviour that are approximately two or more standard deviations below the mean, based on appropriately normed, individually administered standardized tests. Where appropriately normed and standardized tests are not available, diagnosis of disorders of intellectual development requires greater reliance on clinical judgment based on appropriate assessment of comparable behavioural indicators (World Health Organisation 2021a).

The diagnostic requirements which are deemed as ‘essential’ within the ICD 11 include significant limitations in various domains such as perceptual reasoning, working memory, processing speed, and verbal comprehension. It is noted that the extent to which an individual is affected in any of these domains may vary substantially. It recommends the use of standardised tests of intellectual functioning and disorders of intellectual development to be found at approximately two standard deviations below the mean. The classification also recognises the presence of significant limitations in adaptive functioning, identified as conceptual skills, such as application of knowledge and communication, social skills such as managing interpersonal relationships, social responsibility, following rules, and avoiding victimisation. Also recognised are limitations regarding practical skills such as self-care, health and safety, occupational skills, use of money, transport, and technology. Variations in these areas may occur in terms of environment or age. Importantly, onset of such presentations occurs in the developmental period, and for those individuals who come to clinical attention without a prior diagnosis developmental onset may be determined using regression diagnosis. Disorders of intellectual development are categorised as Mild, Moderate, Severe, Profound, and Provisional (WHO 2019/2020). These are detailed further in Appendix 1.

The other classification system used in diagnosing intellectual disability is the DSM-5 (American Psychiatric Association 2013) which uses the term intellectual developmental disorder. It highlights the importance of adaptive functioning in having skills in cognitive domains, such as language, reading and writing; social domains such as social judgement and interpersonal communication; and in practical domains, including personal care and money management. It recommends the use of standardised IQ assessment but emphasises the need to use both clinical assessment and standardised testing of intelligence. The presence of intellectual disability is based on a measurement of two standard deviations or more below the population IQ, that is an IQ score of 70 or below.

1.4.2 Identity First Versus Person First Language

Throughout this thesis person first language is used. Traditionally, Ireland followed the United States in the use of people-first language as can be seen on the Commission on the Status of People with Disabilities in the 1990s in Ireland. The United Kingdom, spurred on by University of Leeds and others, went with identity first. The two approaches are followed with sincerity by most of those who use them so there is not one correct way. This is not in any way to disrespect the views or wishes of those who prefer the use of identity first language, but rather a reflection of the result of collaboration with the Public Patient Involvement (PPI) panel of IDS-TILDA with whom the researcher facilitated a discussion on their preference for the language used within the study and associated research projects.

During attendance at a Public Patient Involvement (PPI) panel meeting on the 26th of September 2023, the researcher facilitated a discussion to gain the views, opinions, and experiences of panel members, all of whom have an intellectual disability, on the use of language when it was necessary to describe that a person or a group of people had intellectual disabilities, as in this thesis. Panel members overwhelmingly shared the view that they would simply prefer to be described as ‘people’, as ‘individuals’ and that reference to their intellectual disability should only be made when it was necessary. The panel members acknowledged that there were times when differentiation was required and that in these instances, they wanted person first language to be used. They described negative language that they have encountered throughout their lives and spoke of the impact that this had on their mental health. The effects of this spanned many years for some in the group and continued to cause pain as they recounted such events at the meeting. One panel member describes how they introduced themselves to people, first by name, then by job title and significant achievements, followed by ‘and by the way, I also have Down syndrome’. The group highlighted how each one of them have many aspects of their person that are more relevant to know before adding that they have an intellectual disability. One panel member emphasised how there was a distinct lack of people with intellectual disabilities in ‘positions of power’, especially those that related to disability services, such as on Boards and Committees which are making decisions about the lives of people with intellectual disabilities. In addition, panel members spoke about the importance of recognising people as individuals but also developing and delivering services that take an individualised approach to planning services and supports, and that it can often be difficult to ask for help.

1.4.3 Definition of Older Adults

This study includes participants over the age of 40 years and are described using the term 'older adults' within the context of this research. Individuals with an intellectual disability present with signs of premature ageing, and despite improvements in health and social care over the past decade, are still likely to die approximately twenty years earlier than their non-intellectually disabled peers (Ng *et al.* 2017, Trollor *et al.* 2017, Cooper *et al.* 2020, Lewis *et al.* 2020). The IDS-TILDA runs concurrently with The Irish Longitudinal Study on Ageing (TILDA), which studies ageing in the general population where participants are over the age of 50 years.

1.4.4 Definition of Mental Health

Understanding mental health and mental illness is not straightforward nor does in lend itself to clear cut definitions with unanimous agreement. People who are in in good mental health may well experience an array of emotions such as sadness, happiness, anger, hurt and nervousness; this is part of a fully lived life for a human being. Most descriptions of current mental health definitions agree with the idea that health is more than the absence of disease. Many cite the importance of emotional and spiritual wellbeing and acknowledge the influence of society, culture, environment, and references to coping.

The World Health Organisation (World Health Organisation 2020) provides a definition of health as being:

A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity' and it conceptualises mental health as a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (World Health Organisation 2020, p. 1).

Defining such a concept has difficulties; What are the 'normal stresses of life'? How is productivity measured and how is contribution to a community judged? The concept is broad and cannot be defined easily, although some alternatives to the WHO definitions are offered in the literature. In a study involving 50 people with expertise in mental health, the following definition was the preferred option by almost half of those surveyed (46%) from four potential definitions, which included the WHO definition above which only 20% felt was accurate; 'Mental health is the capacity of each and all of us to feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face. It is a positive sense of emotional and spiritual well-being that respects the importance of culture, equity, social justice, interconnections and personal dignity' (Government of Canada 2006). Another definition provided states that mental health is ‘a dynamic state of internal equilibrium which enables individuals to use their abilities in harmony with universal values of society. Basic cognitive and social skills; ability to recognize, express and modulate one’s own emotions, as well as empathize with others; flexibility and ability to cope with adverse life events and function in social roles; and harmonious relationship between body and mind, represent important components of mental health which contribute, to varying degrees, to the state of internal equilibrium’ (Galderisi *et al.* 2015). This statement aims to avoid culture bound statements while accepting the influence that one’s culture can have on one’s mental health.

Throughout this thesis the term ‘mental health disorder’ is used to refer to where participants have a diagnosis of a mental illness made by a medical professional and this diagnosis has been confirmed either by the participant directly, their support person or a family member.

1.4.5 Definition of COVID-19 Associated Restrictions

In response to the COVID-19 pandemic, governments across the world implemented a range of public health measures to reduce the spread of the virus between people. The implementation of these measures differed significantly across countries and were unique to each country or region based on the status of the virus in that region. In Ireland, on March 13th, 2020, the Government of Ireland announced unprecedented closures across a range of public and private services as a national ‘lockdown’ came into effect. As the pandemic progressed there were various surges and waves in its trajectory, and public health measures were implemented and adapted accordingly by the Government under the guidance of the National Public Health Emergency Team (NPHET). Within the context of this study the term ‘associated restrictions’ refers to the public health measures that were implemented in response to the virus and that were present from the onset of the pandemic to when data collection was completed in September 2021. Throughout this timeframe participants had experienced a range of public health measures that had impacted on the lives of all people in society. Within the literature review of this thesis, a detailed account of the COVID-19 associated restrictions are presented.

1.4.6 Resources

The theoretical framework being used within this study is Hobfoll’s Conservation of Resources theory which states that individuals strive to obtain, retain, foster, and protect those things they centrally value. Resources are defined as things one values, they are further categorised as objects, conditions, personal and energy resources within the theory. This theory states that in responding to stress people employ key resources but they also build a reservoir of sustaining resources for use in the future or when needed. Furthermore, to meet stressful challenges, people obtain and retain personal, social, and material resources (Hobfoll 1989, Hobfoll 1998, Hobfoll *et al.* 2018b). This study utilised the opportunity to gather data across several resources present in the lives of older adults with intellectual disabilities which were then explored using the COR theory. This allowed for the concept of mental health to be understood, not as linear concepts where the presence of resources may be attributed to how individuals experienced the pandemic and associated restrictions, but aligned with the complexity of the concepts by creating an understanding of how gains and losses in resources confounded the impact on mental health for older adults with an intellectual disability in Ireland.

1.5 Conclusion

This research was at the forefront of investigating impacts on the mental health of older adults with an intellectual disability in Ireland during restrictions imposed due to the COVID-19 pandemic, which was declared a global pandemic on March 11th, 2020. It also provides findings on the resources which participants gained and lost during the associated restrictions and how these impacted on mental health outcomes. Restrictions were aimed at reducing the risk of transmission of the disease and to reduce more adverse consequences in the event of being infected. This study recognises the complexity of mental health in older adults with an intellectual disability and the multifactorial relationship between resources that participants both lost and gained because of public health measures. It therefore employs a theoretical framework which provides a structure under which these resources may be examined and understood in terms of impact on mental health through the lens of the COVID-19 pandemic.

Chapter 2 Background and Context

Introduction

This chapter commences with an outline of the literature review methods used within this chapter, followed by an overview of mental health policy both in Ireland and internationally and sets the context in which mental health services are currently situated and guided. Next, a synopsis of the trajectory of the coronavirus and public health measures that were implemented nationally and internationally will be provided, with greater detail on the measures that were implemented in Ireland from the onset of restrictions to the completion of data collection for this study. A broad review of the literature is presented to provide context and background information on the COVID-19 pandemic and the mental health of people with intellectual disabilities as the pandemic progressed. This is followed by a scoping review of the literature on the impact of COVID-19 on the mental health of adults with an intellectual disability during the COVID-19 lockdowns across the world. The chapter concludes with an overview the Conservation of Resources (COR) theory which is the theoretical framework for this thesis.

2.1 Literature Review Methods

To present policy context which was pertinent and current, legislation and policy at national and international level was included in the scope of this review; the following dimensions were identified.

a) Policy related specifically to mental health and intellectual disability.
b) The implementation and operationalisation of mental health and intellectual disability services in Ireland and internationally prior to the COVID-19 pandemic.

The focus of the review was to provide a snapshot of the operational stage that specialist intellectual disability and mental health services were at when the pandemic emerged.

Recognising that COVID-19 was a novel coronavirus and that previous literature on the virus and intellectual disabilities was not well developed, the initial literature review consists of a brief description of the virus, its origin and the advice that was provided primarily by the World Health Organisation, whose advice and recommendations informed public health measures globally. The potential for more adverse outcomes for individuals with intellectual disabilities was a concern from the onset and literature has been presented on why this population was at greater risk. As the pandemic progressed, emerging literature on mental health among adults with intellectual disabilities was updated and has also been presented. To inform these reviews the following search sources were used.

- Academic databases (PsycInfo, Embase, Web of Science, Medline and CINAHL)
- Grey literature search
- Government and public health agency publications

Key search terms used included intellectual disability/learning disability (and related synonyms), COVID-19 (and related synonyms).

As this study was related to the COVID-19 pandemic, literature covering December 2019 – January 2024 has been included.

A detailed search strategy is provided for the scoping review in Chapter 2 (section 2.13)

2.2 Policy Context: Mental Health and Intellectual Disability

The likely impact on the mental health of the global population was identified at the early stages of the COVID-19 pandemic by the United Nations (United Nations 2020), when authors urged that the response to COVID-19 be inclusive of people with disabilities. Within this policy brief, the risk of deepening pre-existing inequalities for people with disabilities was highlighted and areas for action were identified in the response to COVID-19. The areas for action included combining mainstream and disability specific measures to ensure systematic inclusion of people with disabilities, accessibility of information, facilities, services and programmes, meaningful consultation with people with disabilities, and accountability mechanisms so that investments in the response can be monitored to ensure that funds are reaching persons with disabilities (United Nations 2020). However, despite early identification of the potential implications which may be experienced by people with disabilities, a rapid review of the literature concluded that there were important areas that were left unaddressed or not prioritised that have resulted in persons with disabilities being disproportionately impacted by the pandemic (Hillgrove *et al.* 2021).

There is a high prevalence of emotional, nervous, and psychiatric conditions among older adults with intellectual disabilities, with diagnoses reported to be as high as 52% (Buckles *et al.* 2013, Cooper *et al.* 2015, McCarron *et al.* 2017a, Cooper *et al.* 2020). Prevalence of diagnosed depression in older adults with an intellectual disability in Ireland was noted to be 15.8% (Sheerin *et al.* 2017) in comparison to 5% reported within the general population (Canney *et al.* 2017). Using a COVID stress scale, Asmundson *et al.* (2020) reported that the presence of a pre-existing mental health condition, specifically anxiety-related and mood disorders, increased stress relating to COVID-19. This finding may be significant for individuals with an intellectual disability due to the existing prevalence of mental health conditions within this population. Older people with an intellectual disability experience greater frequency of life events and associated burden, particularly for individuals living in institutional settings and those experiencing a psychiatric condition (Bond *et al.* 2019). Such events include the death of a close family member, changes of key staff, or experience of major illness or that of a relative, caregiver or friend (Hermans & Evenhuis 2012, Bond *et al.* 2019) and COVID-19 may present higher incidence of some of these life events. Cooper *et al.* (2007) report that the experience of several life events within the previous twelve months may have an association with the clinical diagnosis of mental ill health for adults with an intellectual disability. Due to the high prevalence and specialised needs of individuals with an intellectual disability there have been national and international policies published recognising the unique needs of this group and identifying the resources to be implemented to address these (DoHC 2006, DoH 2013, 2020).

Launched in 2013, the Healthy Ireland Framework 2013-2025 (DoH 2013) provided for the first-time a cross-government focus to deliver the vision for a healthy Ireland. There were 14 government parties involved in the development of this vision and with the responsibility for its implementation. Within this national framework, the WHOs definition of mental health is adopted and there was an acknowledgement that wellbeing is integral to health, where positive mental health reflects the quality of life and the various factors that influence this. Mental health was recognised as a growing issue in health, social, and economic terms and improving mental health was identified as a priority. The Healthy Ireland Framework (DoH 2013) recognised findings from the TILDA study where there is prevalence of mental health conditions such as depression and anxiety in one out of every 20 people over the age of 50 years in Ireland (Barrett *et al.* 2011). However, prevalence was much higher in the comparable population with intellectual disabilities (McCarron *et al.* 2011). The framework set out a commitment to reduce health inequalities among the vulnerable and at-risk groups in society; people with disabilities were identified within these groups. The importance of developing awareness and to act on the social determinants of health, such as social connectedness, was seen as a crucial aspect of empowering disadvantaged groups in terms of health.

Solutions for addressing poor mental health recognised the close relationship between physical and mental health. This is an area in need of considerable attention in the lives of older adults with an intellectual disability in Ireland who are reported to have high levels of chronic conditions and sedentary behaviours (McCarron *et al.* 2017a, Cooper *et al.* 2020, van den Bemd *et al.* 2022) and obesity (Lynch *et al.* 2022). Moussavi *et al.* (2007) found that the comorbid state of depression with chronic diseases such as arthritis, asthma and diabetes incrementally worsen health compared with depression alone. Findings from the Wave 4 IDS-TILDA study report the prevalence of each of these conditions as follows: arthritis at 15%; diabetes at 9.6%; lung disease and asthma at 8.6%. In addition to these chronic conditions, there were high prevalence of others reported including: overweight/obesity (66.6%); cardiovascular disease (52.3%); high cholesterol (38.6%); epilepsy (38.6%) and hypertension (21.6%) (McCarron *et al.* 2020).

In 2017, the Sláintecare report was published setting out a high-level policy roadmap to deliver whole system reform and universal healthcare in Ireland (Oireachtas Committee on the Future of Healthcare 2017). The report represented a cross party consensus on major health reform in the country. Within this report the committee acknowledges that the area of mental health services remains under-resourced, and there exists an over reliance on medications as opposed to the provision of counselling and psychological support services. In addition to the burden of chronic physical health conditions, the report highlights the higher rates of depression and anxiety among those experiencing chronic health conditions and there is growing evidence to support this relationship (Aquin *et al.* 2017, Herrera *et al.* 2021). Again, and building on the importance of the link between co-morbidities and depression set out in the Healthy Ireland Framework (DoH 2013) this is particularly relevant for individuals with an intellectual disability, who experience co-morbidities and multi-morbidities at a much greater prevalence than the general population (McCarron *et al.* 2014, Cooper *et al.* 2015, McCarron *et al.* 2017a, Cooper *et al.* 2020).

Mental health services in Ireland are largely publicly provided, difficult to access and focus on acute care (Oireachtas Committee on the Future of Healthcare 2017). This overview of mental health services highlights two significant difficulties for people with intellectual disabilities and mental health needs, regarding access and receipt of services when conditions have deteriorated significantly. While there is a focus on a shift from institutions to community mental health services, the committee recognise a lack of resources, an over reliance on pharmacological interventions, with an absence of provision of talk therapies. The report outlines deficits across other areas of mental health services, including Child and Adolescent Mental Health Services (CAMHS). In 2016, there were 214 young people waiting over 12 months for CAMHS and 1,075 young people were waiting over three months for services, during which time conditions can worsen and be extremely distressing. Regional disparities in mental health services were also highlighted.

In Ireland in 2004, based on the policy 'Planning for the Future' a redesignation of several services which were provided to individuals with an intellectual disability under the protections of the Mental Treatment Act 1945 took place. People were discharged through de-designation, and the facility in which they were living re-categorised to no longer be what was previously termed a mental hospital. This re-designation did not remove the mental health difficulties which existed for these people, but the Act under which they were protected. As acknowledged by the 'Vision for Change' Policy this implementation of policy has resulted in major mental health consequences for this group of service users including repeat re-admissions to acute mental health services, homelessness, and involvement in petty crime (DoHC 2006). The policy goes on to highlight the fact that it is only in the last number of decades that it has become widely accepted that individuals with intellectual disabilities experience mental health conditions, and that these conditions have historically been overshadowed by the presence of an intellectual disability. The framework presented in a 'Vision for Change' to meet the mental health needs of people with an intellectual disability, a population that has a reported prevalence of as high as 50% (McCarron *et al.* 2011, McCarron *et al.* 2014, Cooper *et al.* 2015, McCarron *et al.* 2017a, Cooper *et al.* 2020) included health promotion, early detection and intervention, crisis management and Community Mental Health Teams (CMHTS) for people with intellectual disability, referred to as Mental Health Intellectual Disability (MHID) teams.

Recommendations set out by the committee in the Sláintecare report (Oireachtas Committee on the Future of Healthcare 2017) include mental healthcare expansion, part of this being to adequately staff intellectual disability mental health services. Concurrently, the Irish policy for mental health services in Ireland 'A Vision for Change' (DoHC 2006) was undergoing a review process after ten years, in which the need and commitment to provide specialist intellectual disability mental health teams across the country had been set out and had emphasised the important shift of mental health services into a community-based model of care. Among several crucial plans set out in 'A Vision for Change' (DoHC 2006) for people with intellectual disabilities was the formation of well-resourced specialist teams with expertise in mental health and intellectual disabilities. The policy acknowledges the specialist needs of individuals with an intellectual disability. It also attributes the development of general adult mental health services being inhibited because of resources being stretched to provide specialised services to people with intellectual disabilities (DoHC 2006). These MHID teams were to be comprised of professionals specialised in the field of intellectual disability and were to include: one consultant psychiatrist, one doctor in training, two psychologists, two Clinical Nurse Specialist (CNS) and registered nurses with specialist training, two social workers, one occupational therapist, and administrative support. Other mental health and health professionals such as speech and language therapists should be brought in as required. Moreover, to also be made available were five acute inpatient beds in a specially designed unit, and several rehabilitative and continuing care beds. Ten of these beds should be made available in approved centres under the Mental Health Act 2004.

In Ireland, the General Practitioner (GP) is the gatekeeper to accessing healthcare services and the first port of call for people with an intellectual disability to access mental health services. The lack of specialised training among GP's and generic healthcare professionals in supporting people with an intellectual disability has been identified as a barrier to appropriate services for people with intellectual disabilities (Pouls *et al.* 2022). Research has found that even among professionals within the mental health field there have been challenges identified in supporting individuals with an intellectual disability and mental health conditions. Challenges include organisational issues and complex presenting problems, although they do express a desire to improve on their knowledge and skills to work effectively with this group (Ee *et al.* 2021). However, there are greater discrepancies in mental health services utilisation between those with and without an intellectual disability reported for those in low- and middle-income countries. Where stigma and discrimination have been cited as barriers to accessing healthcare (Mkabile & Swartz 2020).

National mental health policy in Ireland, and the United Kingdom do not include people with mild intellectual disability within the specialist mental health and intellectual disability services plan. Rather, people with mild intellectual disabilities are under the umbrella of general adult mental health services. This is a particular area of concern among many who recognise the requirement for individualised, needs based mental health services. Authors of a report in the United Kingdom present a model of mental health care and describe the levels at which improvements should be made for the needs of those with mild intellectual disabilities to be met. These include improvements in the skill set of general adult psychiatrists in areas such as: knowledge of co-morbidities, pharmacology and in particular interactions between medications which are commonly prescribed within the intellectual disability population, and links with intellectual disability experts, such as liaison nurses (Shankar *et al.* 2020).

In Ireland, the delivery of mental health services to many people with an intellectual disability comes from voluntary organisations which are partly funded by the Health Service Executive (HSE). These organisations deliver care via multi-disciplinary teams using a person-centred approach addressing the general needs of service users with intellectual disabilities. However, they may not address specialist mental health needs. It was identified that many geographical areas, due to the division of catchment areas, lacked important access to resources such as psychiatrists. The recommendations were made that one specialist adult MHID team per 150,000 population should be in place to address the mental health needs of this population (DoHC 2006). However, in a report published in 2015 which reviewed the progress of the national mental health strategy nine years later, it found that implementation of these recommendations fell short and there continued to be a lack of available services for those who require specialist mental health support (Mental Health Reform 2015). The United Nations Convention on the Rights of Persons with Disabilities states that people with an intellectual disability should have the same access to services as those in the general population (United Nations 2006). According to Ramsay *et al.* (2016) the access to quality services for those experiencing mental health difficulties and an intellectual disability remains a challenge despite the high prevalence rates.

In June 2020, the Department of Health published the long-awaited successor to the 'A Vision for Change' report titled 'Sharing the Vision: A Mental Health Policy for Everyone'. The report found that a significant gap remained in the delivery of specialist services in the mental health and intellectual disability sector, for both adults and children, and that the primary focus must now be on the development and delivery of these services (DoH 2020). These gaps can be corroborated by findings from Ramsay *et al.* (2016) which show that although access to services such as psychiatry is available to those with an intellectual disability, there are geographical differences in the availability of services, particularly in the southern region of Ireland. Implementing the recommendations from the Sharing the Vision policy will increase the availability of specialist services nationally in clearly defined catchment areas which may improve access to specialist services nationally. Ramsay & Dodd (2018) reiterate that policy alone is not sufficient to make significant advances in service delivery, and the actions from the new policy must now be realised if we are to avoid similar trends to those in the Mental Health Reform (2015) report, where it examined the slow progress that was made nine years after a Vision for Change had been published.

According to Ramsay & Dodd (2018) the appointment of a clinical lead specialist in mental health and intellectual disability in 2016 combined with the publication of 'Sharing the Vision' may have yielded some advances in delivering services to people with mental health difficulties and intellectual disability who require specialist services. Sharing the Vision (DoH 2020) evaluates the progress of the original policy and identifies clearly that implementation of MHID teams has fallen short on proposed timelines for completion. Of the twenty-one MHID teams that were planned nationally, there were only twelve of these teams in existence. Of these twelve there was only partial representation of the healthcare professionals that were identified as being required. Since this publication, The National Model of Mental Health Service for Adults with intellectual disabilities (HSE 2021) is contributing to the developments of teams nationally. The 'Sharing the Vision' implementation plan 2022-2024 outlines the actions and recommendations required to realise these specialist teams with a specific focus on the delivery of these nationally (DoH 2022). As a result of resources challenges, the implementation plan for current policy 'Sharing the Vision' (DoH 2022) has stated that at minimum, these teams should include: a psychiatrist, a clinical nurse specialist, a psychologist, and administrative support. The revised policy accepts considerable gaps within mental health service provision for people with intellectual disabilities (DoH 2022).

According to Weise *et al.* (2018) it is important that this population have access to quality assessment and treatment. However, for these criteria to be met the workforce which facilitates this service requires increased knowledge and expertise in this area. Ramsay & Dodd (2018) also acknowledge that the lack of clinicians with expertise in both mental health and intellectual disability have impacted on the assessment and treatment of this cohort. The National Institute for Health and Care Excellence (NICE) Guidelines published in 2016 which address mental health problems in people with intellectual disability in terms of prevention, assessment and management specify that a person with expertise in both should be responsible for assessment. However, the guidelines do not indicate what this entails (NICE 2016). Whittle *et al.* (2017) identifies that the deficit in clinicians' knowledge is one of the barriers to accessing quality services, but also the availability of services. Of significance for people with mild intellectual disability, a recurring theme is that specialist mental health services are not planned to be made available to this population. Instead, they would receive generic mental health services through the same mechanisms as the general population. This is similar to the approach taken in the United Kingdom for individuals with a mild intellectual disability where specific NICE guidelines exist. Clinical Guidelines (CG113 and CG123) (NICE 2011a, b) suggest that those with a mild intellectual disability receive the same interventions as those without an intellectual disability. In their systematic review on the organisation of health services for people with an intellectual disability, Balogh *et al.* (2016) conclude that there is a paucity in well-designed studies focussing on this area and very few studies targeting mental health needs.

The international perspective from countries such as the United States, Canada, Europe, and Australia in relation to supporting the mental health requirements of individuals with an intellectual disability, is that the needs of this population are often poorly supported by general healthcare services. This highlights the need for specialist teams for the provision of such services (Scheepers *et al.* 2005, Sullivan *et al.* 2011, Schützwohl *et al.* 2016, Sirotich *et al.* 2017).

Across Ireland and Australia, policy development appears to be the driving force for service change moving forward, but this is not comparable with countries such as Norway, where there appears to be a lack of policy aimed at addressing the mental health needs of people with an intellectual disability (Bakken *et al.* 2018). Like the findings in Ireland and Australia, Bakken *et al.* (2018) recognise that the geographical availability of services impact on the quality of care provided. Within the United Kingdom the provision of care to people with intellectual disability and mental health concerns has transitioned from hospital-based care to community settings (Perera & Courtenay 2018). This transition has been accredited to policies and reports in the United Kingdom such as Transforming Care for People with Learning Disabilities published in 2015, which addressed the importance of moving away from inpatient care for those with mental health needs and intellectual disabilities. It focused on the closure of long-term hospital placements for this cohort and tailoring supports in locally delivered services. However, it recognised that where there is an acute need for appropriate hospital placements these will be made available (National Health Service 2015). Similarly, in Ireland the provision of acute beds for people with mental health and intellectual disability has been recommended as a priority (DoH 2020).

The changes recommended by policies both nationally and internationally, will be pivotal to advancing services for people with mental health difficulties and an intellectual disability. However, the realisation of these policies is that they require a skilled workforce to assess and support these systems (Ramsay & Dodd 2018). This will aim to avoid practices identified in Sláintecare (Oireachtas Committee on the Future of Healthcare 2017) that suggest there is an over reliance on the use of antipsychotic medications and polypharmacy for individuals with an intellectual disability (O'Dwyer *et al.* 2016, O'Connell *et al.* 2020) and off-label use is common (Koch *et al.* 2021). Changes in national legislation such as the enactment of the Assisted Decision-Making Act (2015) and the publication of the National Consent Policy (Health Service Executive 2022) are fundamental in terms of supporting people with an intellectual disability to ensure that informed consent is obtained in relation to treatment options, and that their voice is central to the decisions made regarding their mental health.

The need had been recognised and there had been efforts made both internationally and in Ireland towards the development of specialised mental health services for individuals with intellectual disabilities prior to the COVID-19 pandemic. However, the fact remained that services were not meeting the needs of this population who present with a much greater prevalence of mental health conditions and are subject to high use of antipsychotic medication and polypharmacy. Research indicates that those with pre-existing mental health conditions are at higher risk of experiencing more adverse mental health outcomes due to loneliness, fear, isolation, and Post Traumatic Stress Disorder (PTSD) associated with restrictive public health measures and fear surrounding infection. The shortfalls identified within mental health services for people which were in existence prior to COVID-19 raise considerable concerns for the mental health of people with intellectual disabilities in the aftermath of the pandemic.

2.3 SARS-Co-V-2 and People with an Intellectual Disability

Coronavirus disease 19 (COVID-19) originated in Wuhan city, China in early December 2019, and rapidly spread to almost every country across the globe. COVID-19 is an infectious disease associated with a strain of coronavirus (SARS-CoV-2) and it was declared a ‘public health emergency of international concern’ by the WHO on 30th of January 2020 and declared a pandemic on 11th of March 2020. Coronaviruses are a family of viruses which may cause illness in animals or humans, some of which are known to cause respiratory infections including the common cold as well as more severe diseases such as Middle Eastern Respiratory Syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS). The virus infects the human respiratory epithelial cells by binding through Angiotensin-Converting Enzyme 2 (ACE2) receptors and has an incubation period ranging from between 2-14 days. It spreads through droplet transmission, which can occur when a person with the virus coughs, sneezes or speaks. It may also spread if a person breathes in droplets from an infected person, or if they touch a surface that has been contaminated with the virus and they then touch their nose, mouth, or eyes (World Health Organization 2020). The major clinical symptoms of the disease are fever, non-productive cough, fatigue, malaise, and breathlessness, and severe illness such as pneumonia, and acute respiratory distress syndrome. For most people that became infected with the disease, mild to moderate respiratory illness occurred and they recovered without special treatment. However, for some they became seriously ill and required medical attention. COVID-19 has presented unparalleled levels of infections and death; as of November 2023, there have been over 697,646,258 infections and 6,937,339 deaths worldwide (Worldometer 2023).

From the earliest stages of the pandemic those identified as being most at risk included older people and those with underlying medical conditions (World Health Organization 2020). Risk associated with COVID-19 was based on two key aspects; firstly, the risk of contracting the disease, and secondly, the risk of more adverse outcomes if infected with the disease. There were some differences in approaches taken internationally for inclusion within the various risk categories, but similarities included risk associated with increasing age or having pre-existing medical health conditions such as organ replacement, receiving cancer treatment, severe cystic fibrosis, or severe respiratory conditions. Some less severe health conditions such as less severe asthma, COPD, heart disease, diabetes, or obesity, placed individuals in the highest risk categories, and this was the approach by the governments in Ireland, the United Kingdom, the United States, Canada, and Australia (CDC 2020, DoH Australia 2020, Government of Canada 2020, HSE 2020, NHS 2020). Reports from the United States and from the United Kingdom indicated high rates of mortality among people with an intellectual disability. In the United States, Gleason *et al.* (2021) reported that other than age, having an intellectual disability was the strongest independent risk factor for contracting the disease and for dying from the disease. This cross-sectional study utilised data collected from between January 2019 and November 2020 across 547 health care organisations in the United States. There was a higher prevalence of co-morbidities such as pulmonary circulatory disorders, hypertension, lung disease, diabetes, and obesity among patients with intellectual disabilities that were admitted with COVID-19, and these also presented as increased risk factors for more adverse outcomes associated with the virus.

Conversely, one peer reviewed study carried out in Liverpool, England, in an acute care setting in which a learning disability acute liaison team operated, reported that when the period from March 2020 and March 2021 was compared to a similar period prior to the pandemic, there was no significant increase in the number of deaths in people with intellectual disabilities (Jones 2022). There were 65 people with intellectual disabilities admitted; of those, 22 died and of those there were 13 COVID-19 related deaths - eight (62%) were male and five (38%) were female. Four of these admissions related to people over the age of 85 years, none of whom died. Regarding the COVID-19 related deaths: 3/13 (23%) were 18-49 years; 5/13 (39%) were 50-69 years; 5/13 (39%) were 70-85 years and in the over 85 years group there were no deaths. These results present findings which are quite different to some of the studies presented where very high levels of mortality have been reported globally in people with intellectual disabilities. The authors suggested it is possible that there was a reduced number of people presenting at the emergency department, and therefore, increased deaths would have been recorded in the community figures. This paper also highlights the steps taken by the learning disability acute liaison team to support reasonable adjustments, such as supporting communication with the person, their family, and the hospital team. Like the relatively low numbers of deaths recorded by Jones (2022), findings from a longitudinal study in Ireland found that from a sample of 739 people over the age of 40 years with an intellectual disability, there were only three COVID-19 related deaths (COVID-19 not the confirmed cause of death) between March 2020 and September 2021 (McCarron *et al.* 2020, McCausland *et al.* 2021a)

The presence of an intellectual disability does not in itself imply vulnerability. However, people with an intellectual disability over the age of 40 years are more likely to experience co-morbidities or multi-morbidities in comparison to the general population and this presented as a risk (Krahn et al. 2006, McCarron et al. 2014). In the general ageing population, the use of measures to assess frailty is commonly used to predict adverse outcomes, including admission to long term care, hospital use and death (McKenzie *et al.* 2015). However, due to the pre-existing co and multimorbidities, physical difficulties, and cognitive function of many older adults with intellectual disabilities, commonly used frailty measures are less accurate and appropriate among this population. The importance of this came to the fore at the earliest stages of the COVID-19 pandemic, when the use of frailty measures was used to clinically assess hospital admissions. Festen *et al.* (2021) highlighted the issues with using the Clinical Frailty Scale in hospitals in the Netherlands, and elsewhere to determine patients need for intensive care in hospital during the COVID-19 pandemic. They found that as people with intellectual disabilities experience varying degrees of dependence which are distinct from age-related physical deterioration that use of the CSF scale could have serious consequences for triage and clinical decision making for those with intellectual disabilities during the COVID crisis. Researchers present alternative frailty indexes which utilise a cumulative model to assess frailty among the intellectual disability population such as the ID-frailty index (Festen *et al.* 2021). As already mentioned, there is a higher prevalence of some chronic health conditions among older adults within the IDS-TILDA study when compared, where possible, to their counterparts in the general population TILDA study. Findings from the Wave 4 IDS-TILDA study (McCarron *et al.* 2020) report prevalence of each of these conditions as follows, arthritis at 15%, diabetes at 9.6% and lung disease/asthma at 8.6%. In addition to these chronic conditions, there were high prevalence of other conditions reported. Overweight/obesity (66.6%) and cardiovascular disease (52.3%) were the most common high-risk co-morbidities, along with high cholesterol (38.6%), epilepsy (38.6%) and hypertension (21.6%). When comparing findings with the general population in Ireland, and noting that TILDA participants are 50 years plus, the prevalence of cardiovascular disease was higher in the intellectual disability population (in TILDA, prevalence was 44.7% at 50-69 years of age and 66.6% at 70+ years of age), but lower for hypertension (TILDA prevalence: 42.9% at 50-69 years of age and 61.1% at 70+ years of age) and chronic kidney disease (TILDA prevalence: 5.7% at 50-69 years of age and 28% at 70+ years of age). Rates of stroke/TIA were slightly lower in TILDA than in IDS-TILDA. In addition to these co-morbidities, people with Down syndrome show signs of chronic immune dysregulation, including higher prevalence of autoimmune disorders, increased rates of hospitalization during respiratory viral infections, and higher mortality rates from pneumonia and sepsis (Espinosa 2020). This predisposition to respiratory conditions placed individuals with Down syndrome within a high-risk situation if the disease was contracted.

Malle *et al.* (2021) conducted a retrospective study in the United States involving patients hospitalised with COVID-19. Twelve patients had Down syndrome. The authors of this study concluded that patients with Down syndrome had a more severe presentation of COVID-19. They were ten years younger than those without, they were more likely to develop sepsis and to require mechanical ventilation. At study completion, 3/12 participants (25%) were deceased in comparison to 4/60 (6.7%) in the group who did not have Down syndrome. A study exploring the differences between the presentation, severity and treatment of COVID-19 in people with Down syndrome in India with those in higher income countries found that patients with COVID-19 that had Down syndrome were nine times more likely to die when compared to similar groups in several higher income countries (Pinku *et al.* 2022). This study highlighted the initial concern raised by the United Nations that marginalised groups, and in particular those in poorer countries, are at higher risk from the global pandemic.

A study conducted in the Netherlands, in which data was collected on confirmed Polymerase Chain Reaction (PCR) tests in people with intellectual disabilities between March 2020 and June 2021, investigated severe outcomes for this population (Koks-Leensen *et al.* 2023). Within this study, outcomes for 2,586 people were reviewed. Results included 161 individuals who experienced severe illness, which was defined as requiring oxygen therapy, or where hospital admission was considered or actual, or both. Ninety-nine people included in the study died. Of note, this study found that people with intellectual disabilities were three and a half times more likely to die than the general population and that this was elevated in persons over the age of 40 years. This is supportive of the findings in the IDS-TILDA study which recognises the premature ageing and occurrence of age-related conditions at an earlier age than the general population. More severe outcomes were associated with having Down syndrome, older age, comorbidities and multimorbidity. Mortality for people with Down syndrome was also reported at higher levels than the general population in Brazil; after adjusting for sociodemographic and medical factors, patients with Down syndrome had 1.8 times higher odds of dying from COVID-19 (odds ratio 1.82, 95% CI 1.22, 2.68) and 27% longer recovery times than patients without Down syndrome (Leung *et al.* 2023).

Although there was a large amount of research published throughout the early stages of the pandemic related to mortality and morbidity among those with intellectual disabilities, there has been very little disaggregated data available to the public for comparison among those with and without intellectual disabilities. However, need for disaggregation of all data was identified and called for early in the pandemic to improve transparency, and for development and implementation of appropriate interventions (Hassiotis *et al.* 2020). While the data does widely suggest a disproportionate prevalence of morbidity among those with intellectual disabilities, it is not clear that mortality data correlates to age profile. This is a very significant variable when presenting mortality and morbidity data, considering the well documented co/multimorbidities which present at earlier ages and among a population that continue to die up to twenty years earlier than the general population. In Ireland in June 2020, mortality rates in the general population were 23 per 100,000 compared with 41 per 100,000 for people with disabilities, however 92% of those with disabilities who died were over the age of 65 years (Crowther 2021).

2.4 COVID-19 and Associated Restrictions

In response to the COVID-19 pandemic, governments across the world implemented a range of public health measures to reduce the spread of the virus. The implementation of these measures differed across countries and were unique to each country or region based on the status and trajectory of the virus at any time. In Ireland, on March 13th, 2020, the Government of Ireland announced unprecedented closures across a range of public and private services as a national 'lockdown' came into effect. As the pandemic progressed there were various surges and waves in its trajectory, and public health measures were implemented and adapted accordingly by the government under the guidance of the National Public Health Emergency Team (NPHET). Within the context of this study the term 'associated restrictions' refers to the public health measures that were implemented in response to the virus and that were present from the onset of the pandemic to when data collection for this study was completed by the end of September 2021.

Initially, a reopening plan, 'Roadmap for reopening Society and Business' (Government of Ireland 2020b) was published in May 2020 which contained details of restrictive measures set out across five phases due to run from mid-May to mid-August. Details of this roadmap and levels of restrictions are included in Appendix 2. This plan was published with a view to re-opening society and acknowledged the impact that such restrictions had on people's daily lives. A detailed timeline of the restrictions that were implemented by the Government of Ireland from the onset of the pandemic until February 2022 when most public health measures were removed is included in the Appendices of this thesis (Appendix 2). Of note, there were public health measures that remained beyond this timeframe and were not removed until April 2023, which directly impacted the lives of many people with an intellectual disability living in residential care facilities, or in homes in the community supported by staff (HSE 2023a). The prolonged measures include the wearing of masks by staff working in this sector which had ceased to be mandatory for the general population in February 2022. Public health measures issued with immediate effect on the 13th of March 2020 included closures of schools, colleges, childcare facilities, cultural venues, and restrictions on mass gatherings. Also included in these closures were day, respite, and children's services for people with disabilities. People were advised to 'Stay at Home' other than for essential shopping and work, and permitted exercise was within 2kms of people's homes. Data for this study was collected between May 2021 and September 2021 following the third surge of the virus in Ireland. Public health measures that were implemented throughout the COVID-19 pandemic were in a constant state of change which related to the spread of the virus and its trajectory. The timeline of restrictions in Ireland, in Appendix 3, provides a picture of the unprecedented restrictions that had taken place in people's lives during the COVID-19 pandemic across all aspects of life, including seeing friends and family, homelife, work and education, health and wellbeing, and the lack of control and autonomy by individuals for the benefit of public health.

The term 'cocooning' was coined for the measures that were to be taken by people over the age of 70 years and for those that were medically vulnerable. This concept was given different names across countries such as 'shielding' in Northern Ireland but generally refers to the guidance to always stay at home, avoid face to face contact with others where possible, and to limit exercise to own personal spaces (NPHET 2021). In Ireland, most people with an intellectual disability live at home with their families (McConkey & Craig 2018) and the imposed restrictions resulted in many ageing caregivers being required to cocoon. This is likely to have posed challenges for both groups – ageing caregivers and their adult child/sibling with an intellectual disability. Guidance from the HSE on COVID-19 placed individuals with an intellectual disability in the high-risk category in addition to residents of nursing homes and other long stay settings (HSE 2020a). In response to the pandemic, the HSE rapidly published guidelines for Residential Care Facilities (RCFs). This includes residential services for people with an intellectual disability. In 2020, there were 7,006 people with an intellectual disability living in residential services in Ireland (Casey *et al.* 2021). In response to COVID-19, the HSE (2020b) published infection prevention and control guidelines for disability service providers. These guidelines detailed: restrictions on movement both within and outside the home, the use of personal protective equipment to prevent the transmission of COVID-19 in such settings, and management of suspected and confirmed cases. Directions were also made that outward transfer of residents for attendance or care off site should be minimised, residents with a positive COVID-19 result should be managed in their facilities, and that hospital transfer should only take place after discussion between medical/clinical staff in both settings, the person, and their family. In addition, guidance was given that end of life and care preferences be identified, documented, and updated and no new admissions to take place into RCFs (Health Service Executive 2020). Visiting in Long Term Residential Care Facilities was suspended other than on critical or compassionate grounds.

For people with an intellectual disability who were living in residential care, the restrictions on visitors to their homes, the restrictions on visiting loved ones living in nursing homes or other care facilities, the use of PPE, and closure of respite and day services went beyond the restrictions imposed on the rest of society. This study took the opportunity to understand the impact that restrictions may have had on older adults with an intellectual disability in Ireland.

2.5 Mental Health and Previous Pandemics

In March 2020, as the global emergency was declared, and this study commenced, there was no research located from previous pandemics related to mental health and people with intellectual disabilities. However, there were studies which reported on mental health impacts among the general population, both during and after previous pandemics including MERS, SARS, and Ebola. From these pandemics, studies reported both short and long-term consequences for mental health following quarantining, restrictions in movement, and fears associated with contracting the disease (Maunder *et al.* 2003). Brooks *et al.* (2020) carried out a rapid review on the psychological impacts of quarantine among the general population based on evidence from previous pandemics. Findings from their review indicated that the duration of the quarantine period was a factor in poorer mental health outcomes. Symptoms of PTSD, avoidance and anger were reported from the three studies included in the review. In addition, frustration, fears of infection and inadequate information were also found to be stressors (Brooks *et al.* 2020). Depression was experienced and was associated with poor quality of life during a one year follow up study post MERS (Ahn *et al.* 2022). Findings from a comparative study on the mental health impacts following MERS and SARS found that depression was the most prevalent mental health impact among survivors, healthcare workers, and the public. Symptoms were reported both at the time of the pandemic and up to 12 months afterwards (Delanerolle *et al.* 2022). Another study conducted by Park *et al.* (2020) also reported PTSD and depression amongst survivors twelve months post-MERS.

2.6 COVID-19 and Mental Health – Early Evidence

Early in the pandemic, Luckasson & Schalock (2020) described the necessity for a balanced approach to addressing the needs of individuals with intellectual disabilities in response to the COVID-19 pandemic. The authors highlighted the struggles that occurred over the decades and the improvements that were implemented through public and organisational policy, as well as in the areas of human and legal rights, self-advocacy, choices, and community inclusion. They stated that the response to the COVID-19 pandemic for people with disabilities must not represent regression of the progress that has taken place and must not be to the detriment of those at the centre of such policy. The pandemic highlighted the challenges which present in the delivery of services to individuals with an intellectual disability whilst adhering to public health measures, such as congregated residential settings and day services, resulting in many individuals having to remain at home, either with family caregivers or in residential settings for many months (Bradley 2020, Inclusion Ireland 2020). Many services for individuals with intellectual disabilities were closed as governments and organisations implemented public health measures to curb the spread of the coronavirus. Day service closures as well as closures impacting residential and respite services were a significant cause of anxiety, concern and stress for individuals and their families who relied on them (Evans 2020).

Mental health outcomes such as anxiety, depression, PTSD, fear, and loneliness have all been reported among the general population regarding COVID-19 (Fiorillo & Gorwood 2020, Mamun & Griffiths 2020). The literature available on COVID-19, mental health, and people with intellectual disabilities, during the early stages of the pandemic were predominantly conceptual or reflective pieces highlighting the potential for adverse mental health outcomes for people with intellectual disabilities during and post COVID-19. A small study conducted in Ireland by a group of individuals with intellectual disabilities explored the experiences of adults with intellectual disabilities in Ireland during the initial lockdown of the COVID-19 crisis. Participants reported frustration at the disruption to their daily routine, including the closure of work and day services, and difficulties with understanding preventative measures were also expressed by participants. Participants shared feelings of isolation causing anxiety, fear, and panic. They reported missing seeing family and friends, missing sports, and holidays. Individuals had varying experiences on the impact of using technology to maintain social contacts and some reported positive aspects of lockdown such as resilience and increased flexibility in their day (Murphy *et al.* 2020). In Spain, an online survey was conducted that sought the perceptions of adults and young adults on the effects of the COVID-19 pandemic on their lives (Amor *et al.* 2021).

Participants reported feeling afraid (348/582) and more anxious (347/582) because of the virus and associated lockdowns.

Tromans *et al.* (2020b) carried out a cross-sectional observational study primarily in England, responses were also received from Wales and Ireland. The study explored the priority concerns among a range of professionals and experts, including healthcare professionals and carers of people with intellectual disabilities. Responses were sought across several domains and were reviewed and rated by an expert panel. Priority statements identified within the 'mental health and challenging behaviour' domain, and 'social circumstances and support' domain were consistent with several of the findings from the studies already presented. Concerns such as access to mental health services may have been well founded based on the closures of acute services for individuals with intellectual disabilities reported by Tromans *et al.* (2020a). There was much concern among contributors to the study related to individuals with intellectual disabilities, who also experience mental health conditions at a greater prevalence than the general population (Buckles *et al.* 2013, Cooper *et al.* 2015, McCarron *et al.* 2017a). Courtenay *et al.* (2020) presented concerns regarding mental health among individuals with an intellectual disability during lockdown. These included risks of obsessional behaviours exacerbated due to increased adherence to hygiene, anxiety and paranoia related to exposure to COVID-19 information, which had the potential to result in behavioural changes, any of which may act as triggers to mental illness.

Alexander *et al.* (2020) presented a concerning perspective, from the United Kingdom, related to changes in legislation because of COVID-19. Concerns were raised regarding the enforcement of the Coronavirus Act (Government of UK 2020) and the implications of such an act for individuals who rely on the support of others to exercise and take part in activities within the community. Individuals who may potentially not adapt well to changes in routine and for whom there were concerns that such changes may impact significantly on quality of life or could manifest in behaviours of concern. The prevention of inappropriate admissions to psychiatric facilities was discussed and measures to mitigate the risks of such unnecessary admissions was also presented. There was an emphasis on the importance of positive behavioural support plans. Authors suggested guidance at that time relating to risk categorisation from Public Health England should adapt the criteria to include people with intellectual disabilities who had severe and enduring mental health problems or those who had a substantial risk of an increase in challenging behaviour.

Tang *et al.* (2020) reported that patients faced with quarantine because of COVID-19, experienced symptoms of depression and anxiety. The restrictive measures related to COVID-19 had significantly impacted all aspects of life and based on previous pandemics worldwide, were likely to impact mental health during the COVID-19 pandemic. In China, a study surveyed participants during the early stages of the pandemic using Event Scale-Revised (IES-R) and the Depression, Anxiety and Stress Scale (DASS-21). These were administered twice with a four-week interval between surveys. Findings showed results above the cut off score (24) for PTSD. Results for participants for each condition measured were moderate-to-severe: stress (8.1%), anxiety (28.8%), and depression (16.5%) (Wang et *al.* 2020). Research carried out during previous outbreaks, found that patients infected with SARS experienced feelings such as fear, loneliness, boredom, and anger (Maunder *et al.* 2003).

Large numbers of people were faced with circumstances causing isolation, loneliness and other factors that had the potential to negatively impact mental health during COVID-19 (Fiorillo & Gorwood 2020, Mamun & Griffiths 2020). During the initial COVID-19 lockdown, a study by Schuengel *et al.* (2020), applied a quasi-experimental interrupted time series design to analyse records from an intellectual disability service in the Netherlands. Data from incident reports on medication errors and incident reports on aggression and unexplained absences were examined. From the study findings, a reduction in aggressive incidence and unexplained absences was reported. However, these incidents began to increase significantly at the latter stages of the lockdown. Sustained restrictions may have resulted in a continuation of such aggressive incidents for individuals in long-term care, suggesting that an individual's initial ability to adhere to public health measures could not be maintained for significant periods. As this review was based on administrative data, individuals' experiences are not captured and hypotheses for findings are not substantive.

Asmundson *et al.* (2020) reported that people with pre-existing mental health conditions were at a greater risk of experiencing more adverse mental health conditions in response to the pandemic than those who did not have a mental health illness previously. This was a cause for concern among individuals with intellectual disability and placed them at a higher risk in terms of mental health impacts due to reported high prevalence of mental health conditions within the population. However, a study by Hamm *et al.* (2020) reported resilience and no changes to mental health within a group of older adults with pre-existing mental health conditions during the early stages of the pandemic. Contrary to findings from Hamm et *al.* (2020), a study in Norway, using data related to GP consultations among adults with pre-existing mental health conditions, compared records between pre-COVID-19 and March-December 2020. They found a significant increase in consultations during the pandemic period. The largest increase was among those diagnosed with PTSD. Consultations increased by 37% and 47% by men and women, respectively. There were only minor changes observed for those with depression and OCD (Jensen *et al.* 2023). From a qualitative study involving adolescents with pre-existing mental health conditions, the impacts of the COVID-19 restrictions were explored. Loneliness, social isolation and disrupted routines were found to prompt adverse mental health outcomes, which included anxiety, depression and eating disorders (Sobalvarro *et al.* 2023).

2.7 COVID-19 and Mental Health - Literature as the Pandemic Progressed

When findings were compared between TILDA, during the first wave of the virus on the impact of COVID-19 on older adults without intellectual disabilities (Ward *et al.* 2021a), with results from IDS-TILDA (McCarron *et al.* 2020), the results showed that loneliness, stress and anxiety were twice as high in those with an intellectual disability (40 years+). In Ireland, another study was conducted as part of a research project assessing psychological and social adjustments to the pandemic (data collection between 19th of March 2021 – 9th April 2021) and used a nationally representative sample of adults (n=1110). Researchers explored the prevalence of twelve common mental health disorders and associations between each disorder and suicide attempts. Overall, 42.5% (95% CI 39.6–45.4%) of participants screened positive for any one of the twelve mental health disorders. This was one of the highest prevalence of mental health conditions reported in the general population in Ireland (Hyland *et al.* 2022) and may have been related to impacts of the pandemic.

As the COVID-19 pandemic progressed the field of evidence on mental health was continually updated, and trajectories for mental health impacts were studied. Research began to reflect how mental health impacts were experienced and how they also changed over the course of the pandemic. Using a longitudinal study design, Lowe *et al.* (2023) collected data at two week intervals over the initial six month period of the pandemic. Symptoms of loneliness, anxiety and depression were tracked across the study period. Symptoms of anxiety ranged from between 50% and 32% and symptoms of depression were between 46% and 32%. Levels of depression and anxiety were reported to be considerably higher than pre-pandemic. Symptoms of depression were observed to be high at commencement of the study, decreased into the summer months as public health measures relaxed but increased again later in 2020 as restrictions were reinstated. Demographic variables were included within the study and lower rates of anxiety and depression were found among older ages, and being female was associated with higher anxiety symptoms.

In Spain, Sánchez-Martín *et al.* (2023) used longitudinal data which was collected at two and three time points during the pandemic. Mental health assessments used were the Depression, Anxiety and Stress Scale (DASS-21) and the Impact of Event Scale-Revised (IES-R) to measure post traumatic symptoms. The total study population which took part at two and three time points was n=656 and n=335 participants, respectively. Between the first two time points of the study, there was an increase across all four mental health measures. At the third time point there was a further increase in depression and post traumatic symptoms. Anxiety remained stable between time 2 and time 3. Demographic factors associated with worsening psychological symptoms over the six-month period were found among women, younger age groups and those with previous mental health diagnosis.

In the Netherlands, van den Boom *et al.* (2023) reported on data related to loneliness, general mental health, and life satisfaction. This study involved a large sample (n=92 062) of people over the age of 16 years, with the majority being over the age of 40 years. Data was gathered from April 2020 through to January 2022. Over the study period, a range of public health measures were implemented with varying degrees of strictness based on surges and waves of the virus. Findings from the study report that loneliness appeared to increase as restrictions intensified, and as measures were relaxed, self-reported loneliness reduced. However, authors observed that a decrease in loneliness occurred at a slower rate following the second wave when compared to the first wave. Findings report that as loneliness increased general mental health and life satisfaction decreased, and vice versa. General mental health reached similarly low levels across lockdowns, even though the stringency of public health measures were reduced by the third lockdown Self-reported mental health remained at similarly low levels to the first and second lockdowns, although reported loneliness had improved. Age was found to be significant within the study, lower general mental health was found among those aged 16-54 years when compared to those over the age of 55 years, and lower life satisfaction among those aged 16-39 years compared to those over the age of 40 years. Within the study, increased stringency of measures was significantly associated with increased loneliness, decreased mental health, and decreased life satisfaction.

2.8 Accessing Mental Health Services

A number of studies were carried out during the pandemic which aimed to understand the experiences of people with intellectual disabilities accessing mental health services (Purrington & Beail 2021, Baxter *et al.* 2023a). They found that there were increased wait times for appointments (from 250 days to 392 days) and that psychological distress increased while participants waited to access these services. Notably, there were reduced rates of referral for mental health services over the pandemic in a number of studies. Authors suggested that these reductions were not an indication of reduced need, rather, that it was a reflection on people's adherence to public health guidance, to stay at home, and to only access health services in emergency situations (Tromans *et al.* 2020a, Purrington & Beail 2021). However, such suggestions were not substantiated.

Similar reductions in referrals were found within a study conducted in the United Kingdom. A significant ($p \leq 0.05$) decrease in referrals across a variety of mental health services was reported, including for those with an intellectual disability. Within this study, a retrospective cohort data analysis on electronic referrals and admissions to psychiatric services was conducted. Records were reviewed for a period of eight weeks prior to and post the first lockdown (Tromans *et al.* 2020a). Acute intellectual disability beds remained consistent within the study period (pre-lockdown $n \leq 5$; lockdown $n \leq 5$). However, referrals to mental health services for individuals with an intellectual disability reduced during the period (pre-lockdown $n=539$; lockdown $n=308$). Authors suggest that individuals may have experienced improvements in wellbeing due to a reduction in societal pressures, or an increase in societal/familial support within their household. This may be plausible due to the novel nature of the first lockdown. However, there were further concerns that individuals and their families were adhering to public health guidance to 'stay at home' and were not presenting at emergency departments unless completely necessary, thus not identifying mental health difficulties as a serious condition. Authors of this study also suggested a rationale for the apparent reduction in acute admissions, referred to as 'lockdown paradox' ((Tromans *et al.* 2020a). There was also an initial reduction in incidence of aggression and unexplained absences reported by Schuengel *et al.* (2020) in services for people with intellectual disabilities during the lockdown period. However, following relaxing of lockdown measures an increase in aggressive incidents was reported. These findings represent a worrying trend if this slope continued to increase. Conversely, in Canada, there were higher use of mental health services by people with intellectual and developmental disabilities reported during the pandemic when compared to the general population. Although service utilisation decreased for both groups when compared to pre-pandemic levels. There were increased numbers of people with intellectual and developmental disabilities presenting at emergency departments, and hospitalisations for mental health difficulties (Durbin *et al.* 2022). For individuals with an intellectual disability who required hospitalisation during the COVID-19 pandemic, the effect of being segregated and alone in hospital wards due to visiting restrictions was highlighted by Altshuler & Zeldin (2020).

O'Connor *et al.* (2021) reported the need for planning mental health services in response to the COVID-19 pandemic. The authors highlighted that people with intellectual disabilities were at greater risk due to potential difficulties understanding public health measures, disruption to routines, and reduced access to supports. Risks associated with living in congregated settings were also identified. These included becoming infected with COVID-19, and witnessing mortality and morbidity in others which may have lasting mental health impacts. COVID-19 was both a physical health crisis and a mental health emergency (Kelly 2020) and there were calls for resources to remain in place for those who may be more vulnerable during such a crisis, such as those who are homeless, those living in an institutional setting, people with disabilities, and those who may have less control over their day to day lives. Gulati *et al.* (2021) echoed the importance of ensuring that resources stay in place for those with disabilities, raising concerns where staffing was redeployed away from mental health and intellectual disability services in response to the pandemic. In addition to the imposition of restrictions in movement for many people across the world, individuals with intellectual disability were disproportionately impacted, with many living in residential care facilities where additional restrictions on movement and visitors were imposed (Health Service Executive 2020).

2.9 The Role of Technology during the Pandemic

During the pandemic, technology became an important solution to addressing need within health services. The use of telehealth became widespread and most consultations that would have usually taken place face to face were now being conducted virtually. In Ireland, the Government recognised the need for investment into this sector and invested €1.1 million in 2020 towards helping people to manage their mental health (Government of Ireland 2020a). The use of technology to provide mental health supports to people with intellectual disabilities may also have been a potential solution to addressing geographical barriers, or issues with accessing transport which were previously reported by Ramsay & Dodd (2018). There has been longstanding demand for increased use and access to telemedicine to provide mental health services for people with disabilities (Troller & Ching 2014) and the pandemic accelerated its use due to necessity. Hughes & Anderson (2020) report on the difficulties for psychiatrists conducting medical state exams when face to face contact was not possible and where consultations were conducted remotely, they found that some patients were in a state of hyperarousal with marked increases in anxiety.

There have been a number of studies during COVID-19 reporting on clinicians' experience and opinions of the use of telemedicine for mental health services. In the United States, Lind *et al.* (2023) surveyed mental health clinicians to explore the impact that the COVID-19 pandemic had on the availability and provision of mental health services to residents in long term care. Among the 126 participants, 77% reported that they provided in-person services, however, virtual services were provided at almost the same rate of 77.2%. Over half of the clinicians stated a preference for returning to in-person services only, and 30.2% reported that a combination of in-person and telehealth was their preferred option. Among clinicians, 44% reported greater ‘exhaustion’ from providing mental health supports via video platform. Data for this study was collected in the early stages of the pandemic in the United States from a long-term care service. Long-term settings were particularly impacted by the pandemic with high levels of mortality reported. Lind *et al.* (2023) also provides clinicians perspectives on difficulties with telehealth appointments. These include poor access to technology to provide virtual appointments, concerns related to confidentiality, and inability to conduct neurological examinations. They also identified difficulties for some people with visual or hearing impairments, as well as those with cognitive impairments having greater difficulties to participate fully at appointments.

Geraldina *et al.* (2023) provided the perspective of psychologists in their study which explored challenges of mental health online services during the COVID-19 pandemic. Thematic analysis from interviews found that confidentiality was also recognised as a concern for clinicians, with difficulties in ensuring that there was not another person in the room or able to hear the consultation. They also found that building rapport was challenging, where difficulties related to reading emotions of patients, and for the psychologists, expressing empathy via videocall was more difficult than in-person. This was worsened when technological issues presented such as the screen freezing, or slower connections. Whilst psychologists within this study expressed that telehealth was an appropriate way in which to deliver services during the pandemic, when restrictions were removed their preference was that there would be a return to in-person consultations. With regard to telehealth and mental health illness, they also expressed greater concern for persons with moderate or severe psychological problems, or in emergency mental health presentations. These studies provide interesting views from the perspective of mental health professionals to telemedicine as an alternative option to in-person consultation during the pandemic.

The use of technology among older adults with an intellectual disability was much lower than the general population prior to the COVID-19 pandemic. Data from the IDS-TILDA study has consistently reported low rates of owning mobile phones, access to, and use of the internet (McCarron *et al.* 2011, McCarron *et al.* 2014, McCarron *et al.* 2017b). Despite recognised benefits to the use of assistive technologies there were many barriers which remained present pre pandemic (Boot *et al.* 2017, Boot *et al.* 2020). These included: funding issues, lack of awareness among those with intellectual disabilities regarding options which were available, and lack of assessment for assistive technology. With the emergence of the COVID-19 pandemic there was an urgency to implement new ways to remain socially connected and to reduce spread of the virus through face-to-face contacts. An increase in the use of technology-based solutions were implemented across research, education, healthcare, and society. The use of online platforms to remain in contact with family and friends became the new norm. An increase in the use of technology was also reported by individuals with an intellectual disability from the early stages of the pandemic (McCarron *et al.* 2020). Research conducted among people with intellectual disabilities has provided insights into how use of technology has been an enabler and facilitator for communication and remaining in contact with friends, family and engaging in online courses, many of which are primarily positive. However, there have also been challenges and barriers expressed, such as feeling uncomfortable and shy, and for some, their families were not able to access technology (Wehmeyer *et al.* 2006, Lake *et al.* 2021, Roitsch *et al.* 2021, Chadwick *et al.* 2023, McCausland *et al.* 2023a).

Lake *et al.* (2021) conducted a study exploring the mental health and wellbeing of adults with intellectual disabilities during the pandemic. Participants were recruited based on attending an earlier virtual course and therefore already had a level of comfort with using online platforms. Through qualitative interviews participants shared very positive experiences, such as attending online facilitated peer sessions which provided support with pandemic 'problem solving' scenarios. This included support with understanding public health measures, particularly as measures were regularly changed and updated. They also attended virtual exercise classes and accessed mental health services through technology. Participants reported that accessing this resource reduced isolation and promoted wellbeing during the lockdowns. However, not all people with intellectual disabilities experienced the same level of satisfaction with using technology. Participants in a study by Embregts *et al.* (2020b) had varying views, these included very positive experiences such as making vlogs and setting up meeting times with friends to chat. However, for some participants they struggled to maintain friendships remotely, and missed physical contact. Videoconferencing was described as 'uncomfortable' and made it difficult to understand the other person. In general, the use of technology was viewed as an acceptable alternative but did not replace face to face contact. It was summed up by a participant in the study by Chadwick *et al.* (2023) as, 'I would be lost without it but it's not the same'. This echoes the views and experiences of many people with intellectual disabilities from the research.

During the second year of the pandemic, a study carried out in the United Kingdom, explored participants experiences of internet use during the pandemic, particularly during national restrictions. Within this study, 571 participants with intellectual disabilities were interviewed remotely. Measures included related to social connections and loneliness. Reasons for internet use included contact with family and friends (66.4%), use of social media (60.6%) and doing online activities with other people (58.6%). People who reported that they were 'never' or 'hardly ever' lonely were more likely to engage in online activities with others and play video games online with others, than people who reported that they were 'sometimes', 'often' or 'always lonely' (Caton *et al.* 2023).

2.10 Family Members and Support Workers Perspectives

There was considerable concern and worry from parents about their adult children with intellectual disabilities related to long term care planning during the pandemic (Boeije *et al.* 2023). Prior to COVID this was a worry for ageing parents who now must consider how their child is going to be cared for when they pass away. As people with intellectual disabilities are now living longer than in the past, a very positive reflection on health and social care, this presents new challenges for parents. There are also pressures reported by siblings who anticipate taking on the caregiving role, many of whom report close relationships with their family member who has an intellectual disability (Heller & Arnold 2010). Parents were faced with having to provide care and support full time due to service closures. Half of the parents interviewed reported that the pandemic had triggered concerns about the future. The risks associated with contracting the virus and the risks for older people made them worry about what would happen if they died.

There were also difficulties reported by parents who had adult children in residential services. They felt that they could not support, or care for their loved one due to visiting restrictions. Interestingly, learning disability nurses, in the United Kingdom, also noted the loss of the additional support that family members usually provided to their loved one in residential services. They discussed how family members often support their adult child while in hospital, and how this was not possible during COVID due to strict visiting restrictions (Bond *et al.* 2021). Some parents described how their adult child had to move from where they lived independently, into the family residence due to COVID, and this highlighted for the parent that the social network of their child was quite limited. Exhaustion was reported by parents as a result of the demands of providing fulltime care and support (Boeije *et al.* 2023).

Further studies have reported that parents of adult children with intellectual disabilities felt stress increase, this was related to reduced supports being available, and closure of services during the pandemic, which increased the burden felt by families. Staff also reported concerns related to the loss of supports from family and friends of people with intellectual disabilities, as well as loss of supports from additional services, such as primary care and support provided by the voluntary sector (Sheehan et *al*. 2020). There were also concerns expressed related to the safety of the physical environment in the home, with adults spending more time at home, and concerns for their adult child when left alone there (Navas *et al.* 2022, Vereijken *et al.* 2022, Caudill *et al.* 2023). For individuals living at home with ageing caregivers, additional effects have been borne from restrictions implemented through public health such as cocooning, shielding and stay at home directions. While attempting to adhere to shield and stay at home measures, some families made the decision to carry out higher levels of care with their family member with an intellectual disability for fear of introducing the virus into their family home by using home help supports (Hughes & Anderson 2020).

In South Korea, Kim et al (2021a) conducted a qualitative study exploring parents' concerns for their adult child (47 years+) with intellectual disabilities (n=19) surrounding the pandemic and associated restrictions. Primary worries were related to fear of their child being infected with the virus. This was associated with suspected lack of awareness by the person with intellectual disabilities about how serious the coronavirus could potentially be. Parents were also conscious of physical health conditions which could result in susceptibility to adverse outcomes if infected, conditions such as epilepsy and heart problems were mentioned. There were also worries raised regarding the person's ability to adhere to public safety measures. There were social challenges identified as areas of concern including loss of daily routine, including closure of disability services. Notably, it was the skills that the person had developed in order to access services, such as using the bus, parents worried that these skills would diminish when not being practiced. Similar concerns with regard to loss of independence was noted by Bond et *al*. (2020) where caregivers of people with intellectual disabilities reported increases in depression and anxiety, stereotyped behaviours, and increases in aggressive behaviours among their loved ones (Linehan 2022). Kim et al. (2021a) reported that there were worries by parents that their child was experiencing isolation. Family members realised that attending services was their adult child's primarily source of social interaction, where they met friends, and teachers, and where their means of communication was understood. Parents remarked that they were finding it difficult to connect with their adult child at home as they were not used to spending so much time together. The person experienced boredom and spend much time in their rooms. There were more emotional ‘ups and downs’, they reported shouting, biting their fingers and hitting their heads. Frequency of these behaviours which challenge were increasing, and parents felt that engaging in activities in the day centre kept people active and engaged and removed the build-up of stress. However, a number of parents reported that there had also been adaption noted among their adult children. They developed new routines and activities and one parent described how she had taught her child to eat independently and to spend time alone in the house when she went out, and that their independence had been improved (Kim *et al.* 2021a). However, the opposite was reported by some support workers, where they described having to complete tasks which the individual would normally complete themselves, such as making tea and preparing meals. This was as a result of infection prevention and control measures to reduce the risk of spreading the virus in residential settings (Marloes et al 2023). An example of the difficulties experienced by families is provided by Wright *et al.* (2020) which reports the mother of an adult child with Autistic Spectrum Disorder (ASD) in the United States calling emergency services as a result of not being able to manage her son’s aggression, impulsivity and anxiety due to day service closures.

In Canada, an innovative and solution focussed approach to supporting families of adults with intellectual disabilities was reported by Lake *et al.* (2022). This study evaluated participants (n=126) experiences of engaging in a six-week virtual course. The course was delivered by two mothers of adults with intellectual and developmental disabilities and two psychologists, with support from operational staff. The curriculum involved COVID updates specific to the intellectual and developmentally disabled community, and wellness activities, such as mindfulness. These sessions provided opportunity for peer support and interaction with other families who understood the difficulties that their community was faced with. Another important topic which was included was coping with, and how to communicate about grief and loss. This is an area that is particularly relevant for those with intellectual disabilities. Studies have reported problems in supporting people with intellectual disabilities who are bereaved, and presentations of grief have been reported as having complex and atypical presentations (Brickell & Munir 2008, Gray & Abendroth 2015). Family members who accessed this course reported high levels of satisfaction and improvements in wellbeing. According to authors of the study, this course was particularly beneficial, given the implementation of strict public health measures that were in place at the time of the study.

2.11 Impacts on Physical Activity and Diet

Researchers carried out a systematic review of studies related to the role of nutrition and its association with mental health and health related problems during the COVID-19 pandemic.

There were 32 articles included in the synthesis of findings. Studies reported elevated levels of disruption to diets, inadequate nutrition, unhealthy diet behaviours, and inadequate intake of essential micro and macro nutrients, and there were associations with poor diet, sedentary behaviours and reduced physical activity. Poor eating patterns which developed during the pandemic were associated with mental health outcomes such as depression, anxiety, and sadness, from studies included in the review (Sharma & Sharma 2023). Barriers have been reported regarding access to nutritious foods and healthy diets among people with intellectual disabilities living in residential services. These included, insufficient knowledge on nutrition among staff, a need for guidance in planning, shopping and preparing meals, and practical cooking skills both among staff and residents (Røstad-Tollefsen *et al.* 2021). The WHO describes obesity as a worsening health crisis and a major contributor to global rates of chronic disease (World Health Organisation 2021b). In Ireland, 37% of the population is overweight and a further 23% are obese (HSE 2015). From the longitudinal study on ageing in Ireland, 71.3% of older adults (50 years+) within the general population were classified as overweight/obese (Knight *et al.* 2021). There is also ample evidence to suggest that older adults with intellectual disabilities experience greater health disparities when compared to the general population (Krahn & Fox 2014, Hatton & Emerson 2015, Videlefsky *et al.* 2019), and have high incidence of co-morbidities and multi-morbidities (McCarron *et al.* 2013, Tyrer *et al.* 2019). Burke *et al.* (2019) highlighted the complex health needs of people with intellectual disabilities as well as a range of issues such as obesity, osteoporosis, falls and fractures, oral health problems, and polypharmacy which further compromises the health and wellbeing of this population. The prevalence of physical health conditions placed many with intellectual disabilities at greater risks from adverse outcomes if COVID-19 was contracted.

Han *et al.* (2021) suggests that simply going for a walk can increase the mental health and health perceptions of older adults, although moderate/vigorous leisure walking was optimum for benefits. With the implementation of strict measures which confined those who were at risk and medically vulnerable to their homes and gardens, engaging in even the simplest of acts such as going for a walk was not possible. In studies investigating sedentary behaviours among those with intellectual disabilities, high rates of such behaviours and inadequate physical activity have been found prior to the pandemic (Melville *et al.* 2017). Lowe (2023) found that pandemic related changes to physical activity were not significant with symptoms of anxiety. However, this was found to be significant with depressive symptoms. Depressive symptoms associated with changes in physical activity related to COVID-19 persisted for the duration of their study. In defining sedentary behaviour for people with intellectual disabilities, Owen *et al.* (2011)

presented an ecological model with four sedentary behaviour categories, these were household related such as watching TV, leisure time such as increased screen based and sitting activities, transport such as driving or sitting on public transport and occupation, for example screen based computer work. Kim et *al.* (2021a) found that parents of adults with intellectual disabilities also expressed concerns with regard to physical activities, and that the day centres were their main source of access to physical activities. Additionally, parents noted issues related to unhealthy eating habits, resulting in weight gain for some persons with intellectual disabilities. Parents felt bad about drawing attention to their children's weight and poor diet.

2.12 Additional Experiences During the Pandemic

Throughout much of the literature reviewed which related to people with intellectual disabilities during the pandemic: individuals with intellectual disabilities; carers/families; and healthcare workers identified some positive observations, despite negative experiences. Scheffers *et al.* (2020) conducted a literature review on resilience and how it can contribute to the quality of life for people with intellectual disabilities. Internal sources of resilience included physical health, self-acceptance, and autonomy, while external sources included social networks and daily activities. Both the experience of life events and the resources available to individuals with an intellectual disability are likely to have implications for how people have been impacted by COVID-19. Despite evidence to suggest that ageing is positively associated with poorer physical health and decreased mobility in people with an intellectual disability, Lehmann *et al.* (2013) reported relatively high levels of wellbeing in this population. Lake *et al*. (2020) reported resilience within the findings of their study, despite participants recognition of significant challenges that they were presented with during the pandemic. Participants were very grateful for having access to technology. They described accessing virtual exercise classes, pandemic problem-solving group sessions delivered online, and using technology to access clinical health care and mental health supports. Murphy *et al.* (2020) also reported positive aspects of lockdown such as resilience and increased flexibility in their day.

2.13 Scoping Review - The impact of COVID-19 associated restrictions on the mental health of adults with an intellectual disability

2.13.1 Aims and Objectives

The aim of this scoping review was to bring together, appraise and summarise existing studies on the impact of COVID-19 associated restrictions on the mental health of adults with an intellectual disability. The research question was: what impact has COVID-19 associated restrictions had on the mental health of adults with an intellectual disability?

2.13.2 Methods

A scoping review of literature was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines to identify studies relevant to the research question. The review was registered on PROSPERO (CRD42020213996, 30/10/2020).

Research Question

The PEOS (Population, Exposure, Outcome, Study type) framework was used to define the research question. There were two research objectives for this review:

1. To identify the effect, if any, that COVID-19 associated restrictions had on the mental health of adults with an intellectual disability.
2. To identify resources that were lost and/or gained that were associated with any noted changes in the mental health of adults with an intellectual disability.

- Population: Adults with an intellectual disability
- Exposure: COVID-19 associated restrictions
- Outcome: Mental health
- Study type: All study types

Eligibility Criteria

The initial search was restricted to 2020 due to it being a novel coronavirus. However, the search was later re-run to include January – September 2021. A final updated search was carried out and included October 2021 – January 2024. Therefore, the complete scoping review included studies from January 2020 – January 2024. All types of studies were captured including primary studies, peer reviewed, and grey literature. Study designs included were randomised controlled trials, cohort, and cross-sectional studies, and were restricted to English language. If studies included both people with and without intellectual disabilities, they were included if results for people with intellectual disabilities were reported separately. Similarly, if studies included both adults and children with intellectual disabilities, they were included if findings were reported separately. The criteria for study inclusion are provided in Table 2.1 on article eligibility criteria.

	Inclusion Criteria	**Exclusion Criteria**
Population	• Studies of adults with an intellectual disability.	• Studies that did not include people with intellectual disabilities. • Studies that only included people under 18 years with intellectual disabilities
Study Type / Study design	• All types of studies were included including primary studies, peer reviewed, grey literature.	• Any type of review
Language	• English	• Non-English
Subject	• COVID-19 associated restrictions. • Mental health of adults with an intellectual disability.	• Studies with no reference to aspects of mental health. • Studies with no reference to COVID-19
Timeframe	January 2020 – January 2024	Any study prior to January 2020

Table 2.1 Scoping review article eligibility criteria

Information Sources

The following five databases were used to perform the search:

- PsychInfo
- Embase
- Web of Science
- Medline
- CINAHL

In addition, the following sources were explored for grey literature sources:

- Health Services Executive (HSE) Libraries online
- RIAN
- LENUS
- ProQuest Dissertations
- Mental Health Ireland
- Open Grey
- Google Scholar

Backward searching of publications that met the eligibility criteria was also used to identify any further eligible papers.

Search Strategy

The search strategy was refined into two concepts. Concept 1 was ‘intellectual disability’, and Concept 2 was ‘COVID-19’. Searches were designed to identify any research relating to individuals with intellectual disabilities and COVID-19 and papers related to mental health were selected from these. This approach was taken in preference to attempting to employ search terms such as ‘mental health’ as this would have involved a vast number of search terms.

Having identified in initial scoping reviews, that there was a paucity of research about mental health, COVID-19, and individuals with an intellectual disability, it was decided not to restrict by study type to report findings on all studies relevant to the topic. A three-strand approach was used to create a systematic search. An initial scoping search was carried out in PubMed and CINAHL to identify appropriate control language using MeSH and CINAHL headings. A secondary scoping search identified appropriate keywords related to intellectual disability and COVID-19. A final search used a combination of the keywords and control language based on the two central concepts. These search strings were then combined using the Boolean operators ‘AND’ or ‘OR’. Table 2.2 provides an example of the search string used for Embase.

Concept	Index	Keywords
Concept 1: COVID-19	'coronavirus disease 2019'/exp	'Severe acute respiratory syndrome coronavirus 2' OR 'coronavirus disease 2019' OR 'covid 19' OR 'covid-19' OR 'covid 2019' OR '2019-nCoV' OR 'coronavirus-2019' OR 'SARS-CoV-2' OR 'wuhan coronavirus' OR 'wuhan flu' OR 'novel coronavirus' OR 'coronavirus pandemic' OR 'nCoV 2019' OR '2019 novel coronavirus' OR 'COVID19' OR ‘coronavirus’
Concept 2: Intellectual Disability	'intellectual impairment'/exp OR 'mental deficiency'/exp OR 'mentally disabled person'/exp	'intellectual disabilit*' OR 'intellectually disabled' OR 'intellectual impairment' OR 'intellectually impaired' OR 'learning disabilit*' OR 'mental handicap*' OR 'mental retard*' OR 'mentally retarded' OR 'mentally disabled' OR 'learning disorder*' OR 'mental deficien*' OR 'mentally deficient' OR 'trisomy 21' OR 'down syndrome*' OR 'mongol*' OR 'down disease*' OR 'trisomy twenty one' OR 'trisomy twenty-one' OR 'intellectual deficien*' OR 'mental impair*' OR 'mentally impaired' OR 'intellectual dysfunction' OR 'coffin siris syndrome' OR 'cri du chat syndrome' OR 'de barsy syndrome' OR 'de lange syndrome' OR 'landau-kleffner syndrome' OR 'prader willi syndrome' OR 'schinzel giedion syndrome' OR 'phenylketonuria' OR 'angelman syndrome' OR 'williams syndrome' OR 'wagr syndrome' OR 'trisomy 13' OR 'rubinstein-taybi syndrome' OR 'developmental disorder*' OR 'developmental disabil*' OR ‘intellectual development disorder*’

Table 2.2 Embase search string

2.13.3 Study Selection and Risk of Bias

The entire search process is fully documented and reported using the Preferred Reporting items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher *et al.* 2009) Figure 2.1. All studies that met the inclusion criteria were downloaded to EndNote software for the management of citations and references before being uploaded to Covidence (available at https://www.covidence.org/) for screening and selection. Duplicates were removed. Two reviewers independently screened citations (FF, FS). A third person was identified to act as adjudicator to settle disparities. The title and abstracts of papers were screened to determine relevance to the subject area. This was then confirmed by an additional full text screening by both reviewers. Other literature sources were identified using secondary references. The risk of bias (quality) assessment was dependent on the types of studies included.

The first and second author independently (FF, FS) carried out a quality assessment of all included studies. If there were any discrepancies, consensus could be reached by involving the third reviewer. There were, however, no significant disagreements, and the third reviewer was not required. The methodological quality of all studies was assessed using the Mixed Methods Appraisal Tool (MMAT). The MMAT allows for the appraisal of qualitative, quantitative and mixed method studies, and was developed to address challenges of critical appraisal in systematic mixed studies reviews (Hong *et al.* 2018). It has been found to be a reliable tool in appraising the quality of papers in mixed studies reviews (Pace *et al.* 2012). The validity of the tool has also been assessed and has been found to be a valid and reliable instrument for assessing the quality of studies in mixed study reviews (Hong *et al.* 2019). Researchers who developed the MMAT tool (version 18) recommend against presenting an overall score, one rationale being that this does not highlight the specific aspects of the reviewed studies that are problematic. This approach is supported in a review of critical appraisal tools (Crowe & Sheppard 2011).

2.13.4 Data Extraction and Analysis

For studies that met the eligibility criteria, data extraction from the included studies was undertaken by the first reviewer. An excel spreadsheet served as the data extraction tool which captured eight different categories from each study. The following categories were used, and were based on the PEOS framework:

- **Population:** Sex, level of intellectual disability, living circumstances, sample size, country.
- **Exposure:** COVID-19 associated restrictions.
- **Outcome:** Mental health, loss and/or gain of resources associated with mental health.
- **Study type:** Study type/design, measures used.

Subsequently, extracted data were synthesised in one evidence table. This was because all included studies contained information relating to the two research objectives, both the impact of the restrictions on the mental health of adults with an intellectual disability and potential resource loss and/or gain noted with mental health impacts. No meta-analysis could be conducted due to methodological and clinical heterogeneity; therefore, narrative syntheses were developed.

2.13.5 Results

The initial search (database and grey literature) yielded 1550 records, following removal of duplicates. Screening of title and abstract resulted in 1485 records being excluded with 65 remaining for full-text assessment. The main reason for exclusion was in relation to the study design, where most papers were observational or conceptual**.** Six studies met the criteria and were included in the initial scoping review (January 2020-September 2021). The findings from all six studies identified an impact on the mental health of adults with an intellectual disability and identify gains and/or losses of resources which have may impacted on mental health. Included studies provided perspectives from: South Korea (1), United States and Chile combined (1), Jersey and Guernsey, United Kingdom (1), Italy (1), the Netherlands (1) and Ireland (1). A summary of studies included in the initial scoping reviews (January 2020-September 2021) is presented on the Summary of Findings (initial review) Table 2.3.

An updated scoping review which included studies from October 2021 – January 2024 yielded 1679 records (database). Following removal of duplicates, 1459 studies were screened for title and abstract. Eighty-five studies remained for full-text review with 76 being excluded. Resulting in nine studies which provided a complete account of all available studies that satisfied the research objectives of this review. These studies presented perspectives from: England (1), Germany (1), United States (2), United Kingdom and United States combined (1), Ireland (2), New Zealand (1), and The Netherlands (1). A summary of studies included in the updated scoping review (September 2021-January 2024) is presented in the Summary of Findings (updated review) Table 2.4.

Article Detail	Study Type / Measures	Gender	Level of ID	Living Arrangements	Sample Size	Country	Impact on Mental Health and Wellbeing	Determinants/ Risk Factors
Kim, M.A. et al. 2021 Changes in Life Experiences of Adults with Intellectual Disabilities in the COVID-19 Pandemic in South Korea	Purposive sampling. Qualitative. Interviews (main guiding question, followed by prompts)	8=female 7=male	5-mild 7-moderate 3-severe	14-living with family 1-living alone	15	South Korea	Negative: lonely and isolated. Stress, worry & depression. Family conflict. Lack of confidence & feeling uncomfortable. Feeling imprisoned. Positive: Contributing to household brought joy. Those who were able to call/message/socials friends felt better. Some felt more relaxed with reduction in busy schedule, got used to being at home.	Loss of vocational programmes and routine - poor sleeping patterns. Boredom, increased screen time, spent much time alone. Poorer eating habits. Unable to connect socially with friends. Not allowed to go out by parents. Not owning a cell phone, being shy. Financial problems. Alternative activities, contributing to household - chores. Spending more time with family. Some increased walking, and strong desire to connect.
Rosencrans, M. et al. 2021 The impact of the COVID-19 Pandemic on the Health, Wellbeing, and Access to Services of People with Intellectual and Developmental Disabilities.	Recruitment via Disability agencies. Link posted on social media. 20-minute online survey. 6 questions re functional limitations. If mental health problems endorsed - list of symptoms were provided.	U.S: male-51.2% female-47.3% Chile: male-62.5% female-37.5%	All	U.S: Alone-17.3% Other people (not family) - 12.4% Group home-3.7% With family-59.2% Chile: Alone-3.1% With family-96.9%	U.S.-404 Chile - 64	U.S and Chile	U.S: 41% Chile: 51.6% - increased mental health problems since the pandemic. US: Worry (28%) stress 27%) sad (23%) nervous (22.5%) annoyed easily (19.3%) sleeping problems (18.8%). 22.8% reported experiencing 5+ symptoms. Chile: Sad (31.3%) stressed (28.1%) impatient & sleeping problems (both 26.6%) worried & easily annoyed (both 23.4%) 25% reported experiencing 5+symptoms	Accessed mental health therapy. U.S: 42% Chile: 25% Variety of responses re quality of mental health support. Determinants: Loss of day service, mental health symptoms, daily difficulties due to disability status, living circumstances were significant. No significance between age and gender with mental health symptoms

Table 2.3 Summary of Findings (initial scoping review)

Article Detail	Study Type / Measures	Gender	Level of ID	Living Arrangements	Sample Size	Country	Impact on Mental Health and Wellbeing	Determinants/ Risk Factors
Peacock-Brennan, S. et al. 2021 The Experience of COVID-19 "Lockdown" for People with a Learning Disability: Results from Surveys in Jersey and Guernsey	Anonymous paper based accessible survey. (3 quant. questions, 6 qual. questions). Sent via post to all 'known' people with learning disabilities on the islands.	Unknown	Unknown	Family (n=35, 36%) Group home (n=27) Support living setting (n=21) Own home (n=4)	Jersey=57 Guernsey=39	Jersey & Guernsey, UK	Experience of lockdown: feeling safe n=65, (68%), happy n=51 (53%), calm n=49 (51%), worried n=33 (34%), lonely n=16 (17%).	Being connected with people & importance of relationships. Valued new time spent with family & contact with services. Missing friends, social activities. Lack of contact, inconsistency of info. Positive: help from staff, time with family, new hobbies, 'peace' & a 'lie-in', person-centred activities. Evaluation of support: n=63 (63%) reported feeling happy.
Villani et al. 2020. Impact of COVID-19-Related Lockdown on Psychosocial, Cognitive, and Functional Well-Being in Adults with Down Syndrome	Psychosocial, cognitive, and functional well-being - InterRAI-ID Includes: Depressive symptoms (DRS), aggressive (ABS). Social Withdrawal Scale (SOCWD), and (IADLH).	Male=50% female=50%	Unknown	Parents/guardians n=30 Siblings n=7 Non-relatives n=9	46	Italy	Post lockdown: significant worsening found in SOCWD (p=0.024), IADLH (p=0.034), & DRS (p=0.014) scales, a significant improvement was found in ABS scale (p=0.034). Decrease in aggressive behaviour replaced by depressive burden &/or social withdrawal.	Activities of Daily Living Hierarchy (ADLH), Cognitive Performance Scale (CPS), Communication Scale (COMM) and PAIN scales did not show significant changes pre-post lockdown.

Table 2.3 Summary of Findings (initial scoping review)

Table 2.3 Summary of Findings (initial scoping review)

Article Detail	Study Type / Measures	Gender	Level of ID	Living Arrangements	Sample Size	Country	Impact on Mental Health and Wellbeing	Determinants/ Risk Factors
Embregts et al. 2020. A Thematic Analysis into the Experiences of People with a Mild Intellectual Disability During the COVID-19 Lockdown Period	Qualitative methodology, using semi-structured individual interviews. Interview guide main topics: Impact of the measures to prevent the spread of COVID-19, Perceptions of family and professional support and, Fear of the disease itself, and themselves or loved ones catching it. Interviews lasted 16-36 minutes.	4 females 2 males	Mild	Individual apartment in supported accommodation in community=3 Independent in the community = 3	6	Netherlands	Boredom, 'felt as though walls were closing in', found working from home 'confusing', stress due to large amounts of information & difficult language re public health measures. Loneliness and health anxiety.	Missing social contact and having people close - different experiences with technology. Being housebound has changed my daily life - lost their voluntary work roles, missed going outside & taking part in activities, loss of daily structure. Others found it helpful to be able to organise their own day. Hard to understand the preventive measures - difficulties with shopping, safe distances, dealing with changes in acceptable behaviour, fear of infecting parents
McCarron et al. 2020 Understanding the Impact of COVID-19 on the Health and Wellbeing of	Longitudinal study with COVID-19 survey imbedded in Wave 4 data collection.	Male n=332 female n=378	mild n=196 moderate n=276 severe/ profound n=188	Independent/family n=122 Community group home n=348 Residential setting n=231	710	Ireland	Negative: 55.3% reported stress/anxiety. Loneliness (26.9%) and isolation (15.9%), fear of getting COVID-19 (15.7%) Positive: More rest/relaxation, improved	Negative: Females, those <50years & people living with family/independently reported higher stress/anxiety. Higher rates of anxiety in participants with pre-existing anxiety

Article Detail	Study Type/ Measures	Gender	Level of ID	Living Arrangements	Sample Size	Country	Impact on Mental Health and Wellbeing	Determinants/ Risk Factors
Baxter R., Rawlings G.H., Yates L. & Beail N. (2023) Waiting for psychological therapy during the covid-19 pandemic: experiences of adults with an intellectual disability.	Qualitative telephone interviews. Interview schedule - 3 sections plus open-ended question	4 women 3 men	Not specified but must have ability to consent and take part via phone	N/A	7	England	Impact on mental health as a result of 'waiting' for face-to-face psychological therapy which was restricted due to COVID. Reasons for referral = depression (n = 4), anxiety (n = 1), voice hearing (n = 1) and trauma (n = 1). All difficulties continued while waiting. Wait described as 'painful', additional stressors while waiting. Coping strategies were also described. Most did not identify a deterioration in MH.	6/7 reported COVID negatively impacted - unable to engage in usual activities, access services, see friends/family. 'Not having someone to talk to'. Additional stressors e.g., Physical health, housing, and social care issues. Participants described tolerating the wait. Coping strategies - internal and external. Limitations to coping strategies. Support from LD team - positives and negatives
Bosebeck, F., Worthmann, H., Moller, C. & Konrad, C. (2023) The social, psychological, and physical impact of COVID-19 restrictions for institutionalized adults with intellectual and developmental disabilities.	Online survey	367 female 443 male 38 inter	Mild: 108 Medium: 284 Severe: 267 Most severe: 165	Residential/ congregated setting	848	Germany	Deterioration of mood and emotionality in over one third of people. Mood disturbances, frustration, ability to express changes in emotion, missing familiar people. Problems with motivation, self-confidence and making contacts. For some this led to behavioural disturbances. Weight gain in 21% of residents.	Restrictive measures - particularly in congregated setting. Loss of daily routines, loss of outpatient care services. Lack of cultural events - social breakdown, interpersonal encounters, elimination of structures. Changes living circumstances.

Table 2.4 Summary of Findings (updated scoping review)

Article Detail	Study Type/ Measures	Gender	Level of ID	Living Arrangements	Sample Size	Country	Impact on Mental Health and Wellbeing	Determinants/ Risk Factors
Baxter R., Rawlings G.H., Yates L. & Beail N. (2023) Waiting for psychological therapy during the covid-19 pandemic: experiences of adults with an intellectual disability.	Qualitative telephone interviews. Interview schedule - 3 sections plus open-ended question	4 women 3 men	Not specified but must have ability to consent and take part via phone	N/A	7	England	Impact on mental health as a result of 'waiting' for face-to-face psychological therapy which was restricted due to COVID. Reasons for referral = depression (n = 4), anxiety (n = 1), voice hearing (n = 1) and trauma (n = 1). All difficulties continued while waiting. Wait described as 'painful', additional stressors while waiting. Coping strategies were also described. Most did not identify a deterioration in MH.	6/7 reported COVID negatively impacted - unable to engage in usual activities, access services, see friends/family. 'Not having someone to talk to'. Additional stressors e.g., Physical health, housing, and social care issues. Participants described tolerating the wait. Coping strategies - internal and external. Limitations to coping strategies. Support from LD team - positives and negatives
Bosebeck, F., Worthmann, H., Moller, C. & Konrad, C. (2023) The social, psychological, and physical impact of COVID-19 restrictions for institutionalized adults with intellectual and developmental disabilities.	Online survey	367 female 443 male 38 inter	Mild: 108 Medium: 284 Severe: 267 Most severe: 165	Residential/ congregated setting	848	Germany	Deterioration of mood and emotionality in over one third of people. Mood disturbances, frustration, ability to express changes in emotion, missing familiar people. Problems with motivation, self-confidence and making contacts. For some this led to behavioural disturbances. Weight gain in 21% of residents.	Restrictive measures - particularly in congregated setting. Loss of daily routines, loss of outpatient care services. Lack of cultural events - social breakdown, interpersonal encounters, elimination of structures. Changes living circumstances.

Table 2.4 Summary of Findings (updated scoping review)

Article Detail	Study Type/ Measures	Gender	Level of ID	Living Arrangements	Sample Size	Country	Impact on Mental Health and Wellbeing	Determinants/ Risk Factors
Smith M.S., Fracht A., Mairose D., Phillips A. & Stein M.A. (2023) COVID-19 pandemic experiences of group home residents with intellectual disabilities: Findings from inclusive, qualitative interviews with self-advocates in Massachusetts.	Qualitative interviews self-advocates, followed by focus groups, Adapted Braun and Clarke for analysis.	3 male 3 female	N/A - participants self-consented (where guardian legal consent was required, they were excluded)	Group homes	6	MA – United States	Negative feelings. Frustration and isolation. Feelings of being disappointed and 'mad'. Bored. Positive feelings - resilience	Community access restrictions. Closure of day services. Lockdowns in homes/rooms - due to positive infections. Limited opportunities to access communities. No trips and not seeing family. Staff shortage/issues with mobility equipment. Bereavement. Feeling worried about contracting COVID and adherence of staff to precautions. Lack of explanations re: information on COVID and precautions. Positive - moved to a better home
Vaccarino, F, Vaccarino, Z., Armstrong, D., Borkin, E., Hewitt, A., Oswin, A., Quick, C., Smith, E. & Glew, A. (2023) Self-advocates with Down syndrome research: The lived experiences of COVID-19 lockdowns in Aotearoa New Zealand	Mixed methods	20 male 20 female	N/A	82.5% lived in usual home (with parents or flatmates). 17.5% did not live in usual home and had to move back with parents.	40	New Zealand	Loss of independence. Feeling restricted. Felt down, hopeless, upset, really angry, sad, annoyed. Over half coped 'well'. Others didn't cope well found it emotionally draining, tiring, nervous, scared confused. Being isolated from friends. Resilience.	Understanding info on COVID. Not being able to see family/friends. Lost independence. Missed athletics, bowling, Special Olympics, arts, and leisure activities. Positives - enjoyed being home with family, range of new activities - watching TV, iPad, watching movies, cooking with family, reading, and using tech. to stay in touch & classes. 92.5% - no support from providers/caregivers. 88% didn't work during lockdown.

Table 2.4 Summary of Findings (updated scoping review)

Article Detail	Study Type/ Measures	Gender	Level of ID	Living Arrangements	Sample Size	Country	Impact on Mental Health and Wellbeing	Determinants/ Risk Factors
Voermans, M.A.C., den Boer, M.C., Wilthagen, T. and Embregts, P.J.C.M. (2023) Long-term social restrictions and lack of work activities during the COVID-19 pandemic: impact on the daily lives of people with intellectual disabilities,	Interpretative Phenomenological Analysis (IPA) semi structured interviews	5 men 3 women	N/A	2 lived independently, 1 lived with parents, 5 in community homes with support.	8	The Netherlands	3 themes: Social isolation and loneliness, inner turmoil, and relational struggles (negative thoughts and feelings, lack of autonomy - participation in society), Sustaining oneself and self-worth (tried to remain hopeful, but sometimes frustration, sense of drudgery, easily bored, awareness of importance of enjoying the little things)	Lack of access to work activities. Lack of social connections. Frustration re ever-changing news about vaccination strategy. Lack of variety in days. Lack of work activity - deprived of opportunities to learn new things and keep developing as a person, one p set up radio station with friend - proud, one p learned English through an app and attended online course. Missed making a difference in the lives of others - customers in employment, but one p identified helping parents and doing housework. One p felt bad that he was receiving benefits and doing to earn them. Positives do not outweigh the psychological and societal impact of restrictions

Table 2.4 Summary of Findings (updated scoping review)

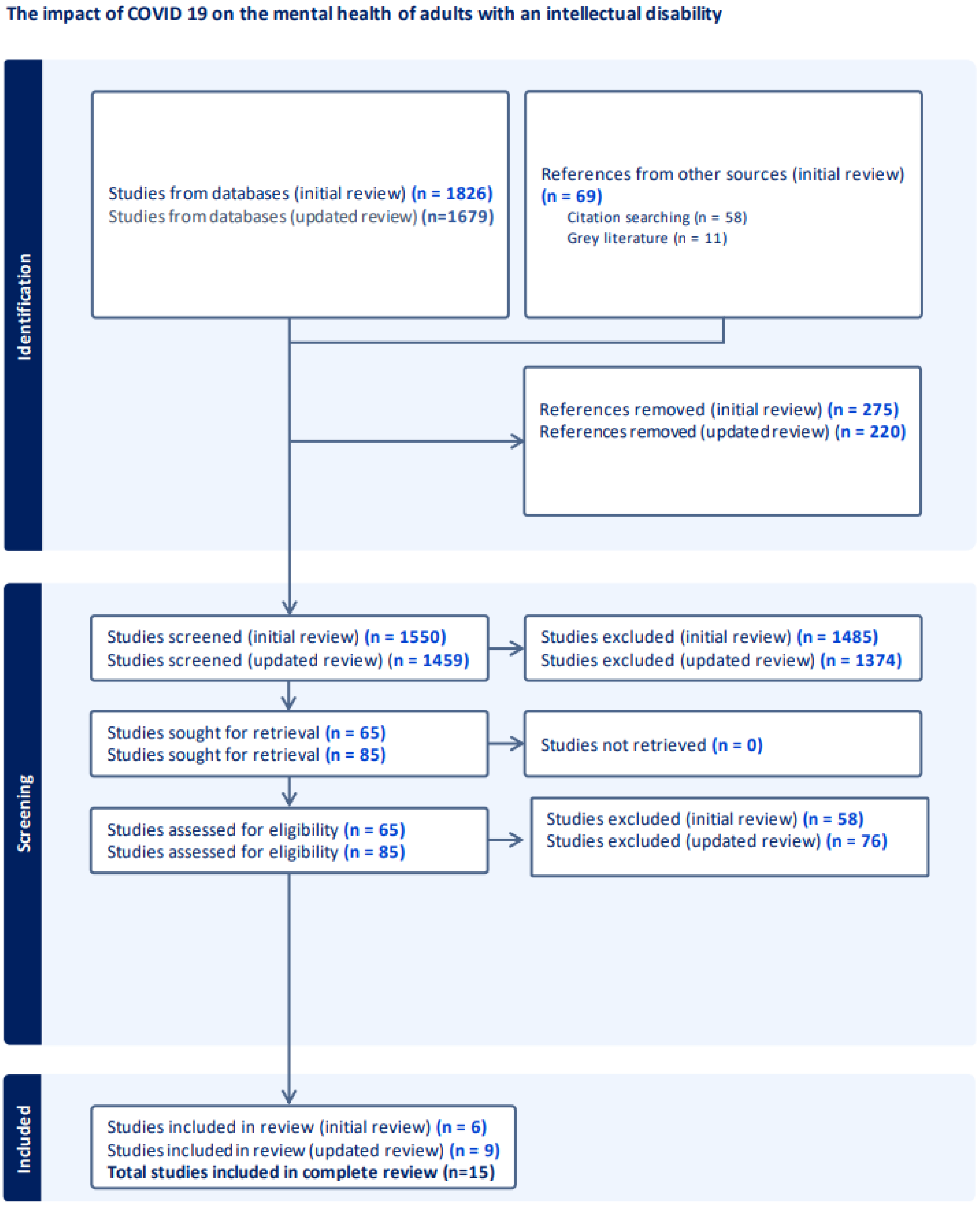


Figure 2.1 PRISMA flowchart

Research Objective 1

The first research objective sought to identify the effect, if any, that COVID-19 associated restrictions had on the mental health of adults with an intellectual disability. The PEOS for Research Objective 1 is presented in Table 2.4. Fifteen studies included in this scoping review reported some type of effect on mental health during COVID-19, whether positive or negative.

To identify the effect, if any, that COVID-19 associated restrictions had on the mental health of adults with an intellectual disability	
Participants	Adults (over the age of eighteen years) with an intellectual disability
Exposure	COVID-19 associated restrictions
Outcomes	Mental health
Study type	All study types are included

Table 2.4 Study selection criteria for Research Objective 1

There were impacts on mental health described within all fifteen of the included studies. Impacts described in the initial review were worry, stress and anxiety, depression, fear, frustration, and anger (Embregts *et al.* 2020a, McCarron *et al.* 2020, Kim *et al.* 2021b, Peacock-Brennan *et al.* 2021, Rosencrans *et al.* 2021). Similar impacts were reported from the studies in the updated review. These included deterioration in mood and emotions, fear, loneliness, stress and anxiety, aggression, isolation and feelings of hopelessness (McCausland *et al.* 2021a, Hartley *et al.* 2022, Baxter *et al.* 2023b, Bösebeck *et al.* 2023, Dodds & Maurer 2023, McCausland *et al.* 2023b, Smith *et al.* 2023, Vaccarino *et al.* 2023, Voermans *et al.* 2023).

Results from initial scoping review January 2020-September 2021

Negative Impacts on Mental Health

McCarron *et al.* (2020) reported higher rates of COVID-19 related stress/anxiety among those who had a pre-existing doctor's diagnosis of anxiety (26.7%) compared to those who did not report COVID-19 related stress/anxiety (12.6%). McCarron *et al.* (2020) used the Glasgow Anxiety Scale for use with people with learning disabilities (GAS-LD), completed by self-reporting participants (n=319), and the Glasgow Depression Scale for people with learning disabilities (GDS-LD) for all participants (n=710) as part of a larger longitudinal study which had a specifically developed COVID-19 survey embedded into Wave 4 data collection. The GAS-LD measures for symptoms of anxiety and symptoms were found among 21.6% (69/319) of participants within this study. From the GDS-LD the rate of depression reported by self-reporting participants was 7.2% (23/321), and 7.7% (30/388) reported by the Carer Supplement to the GDS-LD.

Throughout qualitative studies which gathered the experiences and perceptions of adults with intellectual disabilities, they described being worried about a variety of aspects of life which were impacted during the pandemic, and this caused stress and anxiety. Kim *et al.* (2021b) carried out thematic analysis in their study which consisted of fifteen qualitative interviews. They used purposive sampling within the study, participants had various levels of intellectual disability, were between the ages of 19-38 years, and lived in South Korea. Participants shared their experiences of the changes that occurred in their lives since the start of the pandemic. At the time of data collection, the day services that they attended had been closed for four months. In addition to worry and stress, participants also spoke of other negative impacts on their mental health including boredom, loneliness, and isolation. Participants felt 'imprisoned' because of public health measures. Eleven of the fifteen interviews within this study were conducted face to face while adhering to strict IPC measures as participants expressed that they would feel more comfortable than using videocalls. An interview guide was provided within this article and although it is a relatively small sample, this research provided direct experiences of the impacts on the mental health of adults with intellectual disabilities. Of note is the fact that it included people with mild, moderate, and severe intellectual disabilities.

Another small scale qualitative study conducted in the Netherlands by Embregts *et al.* (2020a) involved interviews using video conferencing to explore the experiences of participants who had a mild intellectual disability. In this study participants identified boredom, confusion, stress, loneliness, and health anxiety. One participant described it as "I felt as though the walls were closing in". Participants were four females and two males between the ages of 26-58 years. Participants within this study were high functioning and very independent, living in their own apartments. Interviews lasted between 16-36 minutes and took place in the very early stages of the first COVID-19 lockdown between March 15th and May 11th, 2020. Authors of the study stated that public health measures and restrictions in the Netherlands were not as strict as they were in other European countries at that time. Participants felt confusion around public health measures and how to adapt to working at home. Anxiety was particularly related to health and spreading the virus.

In a study conducted on the two islands of Jersey and Guernsey, United Kingdom, where restrictions were implemented differently than on the mainland United Kingdom, similar impacts on mental health were reported among adults with intellectual disabilities on both islands. There was no demographic data collected for participants within the study, and authors were contacted to confirm that those surveyed were over the age of 18 years; this confirmation was received. Although authors of the study say that only a minority of participants reported feeling worried, this was experienced by 34% of participants in findings from both islands, with loneliness reported by 17%. It is also stated that life at the time of data collection had largely returned to normality. One third of participants feeling worried is, therefore, notable.

Two further studies in this review gathered quantitative data to explore the impacts on the mental health of adults with an intellectual disability during COVID-19 (Villani *et al.* 2020, Rosencrans *et al.* 2021). Their study involved two groups, one from the United States (n=404) and the other from Chile (n=64). Although the same survey was completed by both groups, comparability was not possible due to the utilisation of different methodologies. Although researchers had planned to involve participants with intellectual disabilities, due to legal barriers in Chile which significantly slowed the progress of the study, the option for responses to be completed by caregivers only was opted for. There were interesting demographics related to living circumstances of participants in the Chilean cohort, with 96.9% of the individuals for whom caregivers were responding on behalf of were living at home, and 3.1% were living alone. Within the United States sample, 17.3% were living alone, 12.4% were living with other people (not family), 3.7% living in group homes and 59.2% were living with family. Data collected within this study was part of a longitudinal study, and participants from the United States were recruited primarily via their links with Disability Developmental agencies (80%). But, in Chile, only 20% were recruited through links with such agencies. Data was collected using a 20-minute online survey which was completed with participants directly, or with the support of another where required. In the United States there was a 41% increase in mental health problems, and in Chile there was a 51.6% increase since the start of the pandemic (Rosencrans *et al.* 2021). Participants were also presented with a list of possible impacts to mental health and symptoms and were asked to choose which they had experienced. Results from the United States were symptoms of worry (28%), stress (27%), sadness (23%), nervous (22.5%), annoyed easily (19.3%), and sleeping problems (18.8%). Participants could choose all that applied and 22.8% reported experiencing 5+ symptoms. Results from caregivers in Chile were symptoms of sadness (31.3%), stress (28.1%), impatient and sleeping problems (both 26.6%), and worried and easily annoyed (both 23.4%). One quarter (25%) reported that the adult person with an intellectual disability for whom they were responding on behalf of had been experiencing 5+ symptoms.

In Italy, Villani *et al.* (2020) assessed the psychosocial, cognitive and functional wellbeing of 46 adults with Down syndrome with a mean age of 46 years; half of the sample were female (50%). The interRAI-ID instrument, which contains over 350 data elements and includes measures of social withdrawal, functional impairment, aggressive behaviour, and depressive symptoms was carried out with all participants. Assessments were evaluated between two (three for some) time points, one pre COVID-19 lockdown and the other post COVID-19 lockdown. While initial analysis of results indicated a positive finding of a significant (p=0.034) improvement in aggressive behaviour using Aggressive Behaviour Scale (ABS) among participants in the post lockdown period, there was a significant increase in other areas. Worsening of scores on several scales reverberated on the functional and psychosocial wellbeing of participants. This included depressive symptoms assessed using Depression Rating Scale (DRS), negative symptoms e.g., withdrawal, lack of motivation, reduced social interaction assessed using the Social Withdrawal Scale (SOCWD), and Instrumental Activities of Daily Living Hierarchy (IADLH). Authors suggested that the reduction in aggression may have presented because of increased depressive burden and anhedonia. These findings present concerning impacts on mental health for participants of this study. Although those participating also had complex care needs and may not be representative, the findings remain important evidence for further study. Findings from the above six studies present a considerable number of negative mental health impacts felt by adults with an intellectual disability during studies published between January 2020 and September 2021.

Positive Impacts on Mental Health

The study conducted by Rosencrans *et al.* (2021) did not identify any positive impact on mental health during the COVID-19 pandemic among participants in the United States or Chile. The online survey focussed on exploring mental health problems and services. From the remaining five studies in this review there were some positive aspects of the COVID-19 lockdown presented. However, the improvement in aggression among a group of participants with Down syndrome reported by Villani *et al.* (2020), should be interpreted with caution as this was linked with an increase in depressive burden and may therefore not necessarily be considered a positive impact. Participants from the study conducted by McCarron *et al.* (2020) reported positive aspects during the pandemic (58%). These included having more rest periods during the day (36%), learning new skills/hobbies (42%), use of technology (14%), and better relations with staff (26%). Embregts *et al.* (2020a) reported that some participants (n=2) also found some benefits from the use of technology and that lockdowns provided opportunity for more flexibility away from routines.

The mixed methods study carried out by Peacock-Brennan *et al.* (2021) provided participants with a list of feelings and asked participants how they felt during lockdown. There were three positive feelings and two negatives, which may have skewed the result in favour of identifying more positives than negatives. Responses were provided using a five-point Likert Scale and 63 participants (66%) reported feeling happy. This survey was paper based and was designed to be accessible using Picture Communication Symbols. However, no people with intellectual disabilities were consulted in the survey design as would have been desirable. Kim *et al.* (2021b) described positive feelings that were experienced by participants within their study, joy was one of these positive feelings, however, this was associated with contributing towards the household due to having to spend more time at home. Some participants felt more relaxed and got used to being at home, and this was linked to not being tied to the busy schedule which they had before the COVID-19 pandemic.

Findings from updated scoping review October 2021 – January 2024

Negative Impacts on Mental Health

There were a range of negative impacts on mental health reported within all nine studies identified in the updated review. These included: deterioration in mood and emotions, fear, loneliness, stress/ anxiety, aggression, isolation and feelings of hopelessness (McCausland *et al.* 2021a, Hartley *et al.* 2022, Baxter *et al.* 2023b, Bösebeck *et al.* 2023, Dodds & Maurer 2023, McCausland *et al.* 2023b, Smith *et al.* 2023, Vaccarino *et al.* 2023, Voermans *et al.* 2023). Loneliness, isolation and feeling restricted were reported in studies (McCausland *et al.* 2021a, Dodds & Maurer 2023, Smith *et al.* 2023, Voermans *et al.* 2023). Mood and emotional disturbances were experienced by individuals (Hartley *et al.* 2022, Bösebeck *et al.* 2023, Vaccarino *et al.* 2023). Stress and anxiety were also prominent impacts experienced (McCausland *et al.* 2021a, Hartley *et al.* 2022, McCausland *et al.* 2023b). Fear associated with contracting the virus and anger was reported by Dodds & Maurer (2023).

In the United States, Dodds & Maurer (2023) interviewed 14 participants, 9 men and 5 women. They used purposeful sampling and conducted semi-structured interviews. Most participants had a mild intellectual disability and lived with family. Data was collected during the largest spike in infections, during a time of high rates of COVID-19 related deaths in Los Angeles, where the study took place. Feelings of loneliness and isolation were reported within this study and were associated with not being able to spend time with family due to loved ones having contracted the virus and fear of infection. One participant described that although they were engaged in contact with friends and family via videocalls, they still felt isolated. Social isolation and loneliness were also prominent feelings reported by Voermans *et al.* (2023) and this was also associated with fear of infection. Although several participants had the opportunity to return to work activities following lockdown, they decided against returning. One participant described themself as ‘high risk’ due to lung disease, and another felt that if they contracted the virus, quarantining would reduce their opportunity for social engagement. Although these participants knew that their decision would increase feelings of loneliness as a result of reducing social connections, they believed the potential risk of infection could have greater impact.

In the United States, Smith *et al.* (2023) interviewed six individuals, three men and three women, between the ages of 32-54 years. Despite participants sharing their homes with others, participants reported isolation, and described spending much time on their own in their rooms due to fellow housemates becoming infected with the virus. Public health measures meant that participants could not access their communities to do their shopping, engage in social activities or attend day services, all of which increased participants feelings of loneliness and isolation. Further reports of loneliness and isolation were found by McCausland *et al.* (2021a) where among a sample of 682 participants, 56.4% said that the felt lonely during the pandemic. Using the UCLA loneliness scale (Russell et al. 1980) one in five participants (19.5%) answered that they felt lonely 'most of the time' and three-quarters (74.7%) felt lonely 'some of the time'. Authors of this study reported an increase in loneliness since 2017 where data was collected during a previous wave of this longitudinal study, when loneliness was present among 43.3% of participants. Within the same study a key source of stress/anxiety was isolation which was reported by 32.4% of participants. Longitudinal data collected from participants within this study was also collected during the early stages of the COVID-19 pandemic and the report was included in the original scoping review for the current study (McCarron *et al.* 2020).

Two studies included within this review use the same data set (McCausland *et al.* 2021a, McCausland *et al.* 2023b) and subjective measures for stress/anxiety were present among 69% of participants. Stress and anxiety were also reported by Hartley *et al.* (2022) among participants with Down syndrome by caregiver proxy respondents. Almost half of participants were male (44%), had a mild intellectual disability (46%), and lived with family (47%). Caregivers completed an online survey consisting of an adapted version of the Coronavirus health impact survey (CRISIS V0.3; crisissurvey.org) which assessed the impact and extent of life changes because of the pandemic. Respondents reported that compared to prior to COVID-19, 33% of the adults with Down syndrome were more irritable or easily angered, however, 62% were reported to have no change in irritability. Among adults with Down syndrome, 44% experienced slightly more anxiety, a further 8% experienced 'a lot' more anxiety, and 41% reported 'slightly' to 'a lot' more feelings of being sad, depressed, and unhappy (Hartley *et al.* 2022).

Mood and emotional disturbances were reported within a number of other studies. In New Zealand, a group of self-advocates with Down syndrome presented a study that was co-designed and co-conducted. Forty face-to-face interviews took place and content analysis carried out.

Loss of independence was common among participants and was identified as being the cause of emotional disturbance. Participants reported ‘feeling down’, ‘feeling hopeless’, ‘upset’, and feeling ‘really angry, sad, or annoyed’ (Vaccarino *et al.* 2023). Using proxy respondents, Bösebeck *et al.* (2023) reported a considerable deterioration in mood by almost half (49%) of participants. Respondents were required to be the direct caregiver for the participant for whom they were responding on behalf of, and an online survey was used. There was a deterioration in mood and emotionality in over one third of adults with intellectual disabilities. Mood disturbances were considered under the following headings: frustration, ability to express changes in emotion, and yearning for familiar people.

Positive Impacts on Mental Health

Nine studies within this review found some positive aspects or experiences during the COVID-19 pandemic (McCausland *et al.* 2021a, Hartley *et al.* 2022, Baxter *et al.* 2023b, Dodds & Maurer 2023, McCausland *et al.* 2023b, Smith *et al.* 2023, Vaccarino *et al.* 2023, Voermans *et al.* 2023, Jodra & García-Villamisar 2024). However, these positives aspects did not negate the negatives that were experienced. In a study conducted in both the United States and the United Kingdom which included 171 participants, Hartley *et al.* (2022) found that 12% of participants were reported to be ‘slightly’ to a ‘lot’ more cheerful/happy when compared to prior to the pandemic, according to proxy responses. There were also positive aspects of the pandemic identified by McCausland *et al.* (2021a) with 90% of participants identifying experiences such as ‘more rest/relaxation time’, ‘better relations with staff/supportive people’, and ‘engaging in new hobbies’. Findings from this longitudinal study show an increase in positive aspects of the pandemic when compared to data collected from the same study during the initial stages of COVID-19 lockdowns in Ireland. One notable positive outcome during the pandemic was an increase in the use of technology, in particular, the use of technology to remain in contact with family. There were increases noted with regard to access to technology and use of technology in general (McCausland *et al.* 2023b). Findings from this study report an interesting increase in family contact post-lockdown when compared to pre-pandemic contacts. Several rationales for this increase are suggested by the authors, such as increased availability of family members due to changing work practices and patterns or increased concern for family members. However, these are unsubstantiated and require further exploration.

Findings from a qualitative study in the United States, where six participants were interviewed, reported that participants identified feeling more resilient (Smith *et al.* 2023). Two participants moved home during the pandemic to homes where they were much happier. Positives of these moves included increased independence and a quieter more peaceful home. Participants also changed their work activities, choosing not to return to day programmes when they reopened, and choose alternative activities which they found greater satisfaction from. Another participant within this study identified the key role which technology had in helping them cope during restrictions, but noted their desire to return to in-person training as they missed physical interaction and talking with others in the community. The concept of 'coping' and finding positive ways to do so was also expressed by participants in New Zealand (Vaccarino *et al.* 2023). Responses with regard to 'how participants coped' during the pandemic ranged from 'super brilliant' to 'awful'. Over half of the participants reported that they coped 'very well'. Resilience was identified by participants, and they provided examples of how they adapted to lockdown (Vaccarino *et al.* 2023). In the Netherlands, Voermans *et al.* (2023) used an interpretative phenomenological analysis design to explore the impact of the pandemic on the daily lives of eight participants. Participants stressed that although there were positive aspects to the pandemic, these did not outweigh the negative societal and psychological impacts caused by restrictions. One participant identified that they would be better able to manage difficult situations in the future as a result of the COVID-19 crisis, however, it was difficult to remain hopeful. Another participant described how they replaced the loss of their day programme with creating their own daytime activity, which gave feelings of purpose. Dodds & Maurer (2023) also address the concept of coping and presented a number of practices that participants engaged in which aided their mental health during the pandemic. In England, Baxter *et al.* (2023b) sought to understand the impact of waiting for psychological therapies during the pandemic and again participants were able to identify strategies which allowed then to 'cope' with the extended wait times. Coping strategies were both internal and external, however, a limit to these strategies was also expressed.

Neutral Impacts of COVID-19 Associated Restrictions on Mental Health

Two studies within this review presented that there had been no impact to mental health among, at least some, of the participants within their studies during the pandemic (Hartley *et al.* 2022, Baxter *et al.* 2023b). Baxter *et al.* (2023b) explored the impact of 'waiting' for psychological therapies which had been impacted due to a move to remote appointments thus resulting in increased wait times for face-to-face consultations. Participants had to wait for longer than the 18-week target set out by the NHS. Although the wait was captured under the theme of the wait being 'painful', most participants did not report a deterioration in their mental health and were understanding of the reasons for why the wait was required. Hartley *et al.* (2022) also found that there was a portion of participants within their study that identified that the restrictions related to COVID-19 had no impact on their mental health. Many participants (62%, 106/171) reported no change in irritability, 43% experienced no global change in anxiety, and 46% reported no change in mood (happiness vs. sadness).

Research Objective 2

Research objective 2 - To identify resources that were lost and/or gained during the pandemic and were associated with any noted changes in mental health among adults with an intellectual disability. Table 2.5 presents the PEOS framework for this research objective. All fifteen studies included in this scoping review describe resources that were lost and/or gained during the pandemic which may have been associated with changes in the mental health of adults with an intellectual disability.

To identify resources that were lost and/or gained during the pandemic and were associated with any noted changes in mental health among adults with an intellectual disability.	
Participants	Adults (over the age of eighteen years) with an intellectual disability
Exposure	COVID-19 associated restrictions
Outcomes	Mental health
Study type	All study types are included

Table 2.5 Study selection criteria for Research Objective 2

Loss of Day Services, Work or Vocational Training

Being engaged in activities during the day such as employment, voluntary roles, or day services, and/ or the loss of such services may have been considered a factor in how individuals with intellectual disabilities were impacted during COVID-19. A factor linked to this was the level of engagement that these services maintained with individuals during the lockdown period. In the study by Embregts *et al.* (2020a) all participants were in employment or had voluntary roles pre-COVID-19. Due to closure of these services, they experienced loss of social contacts and expressed that this had a negative impact on mental health during the initial lockdown. The participants in this study had either moderate or mild intellectual disabilities. As a result, findings from this study may not represent the experiences of all individuals with intellectual disabilities, such as those with more severe and profound disabilities and those who do not use verbal communication or have a lower level of expressive communication. Not being able to take part in usual activities was the greatest cause of stress/anxiety in the study by McCarron *et al.* (2020). One participant in the study by Embregts *et al.* (2020a) described that although they had the opportunity to work remotely during the lockdown that they found it hard to focus and to create structure.

Stress, anxiety, and worry were three of the prominent impacts participants in the Kim *et al.* (2021b) study noted. They reported that one of the causes of worry was that they might forget the training and learning that had taken place at their vocational training programme, and the impact this would have on future job opportunities. Participants felt that going to the welfare centre (where they attended day services) was their only outing, and nothing could replace that. This loss of routine, which was often associated with closure of day services, vocational training and working in voluntary roles was echoed throughout several of the included studies (Embregts *et al.* 2020a, McCarron *et al.* 2020, Lake *et al.* 2021, Peacock-Brennan *et al.* 2021). In one study, participants discussed financial hardships because of not being able to work (Kim *et al.* 2021b). From several studies in the initial review, there were some positives identified by participants because of closure of services. Some people felt that they received more person-centred services which were more focussed on the individual and that they received more help from staff. They also enjoyed the more relaxed atmosphere, having 'a lie-in' in the morning, and engaging in new activities and hobbies (Peacock-Brennan *et al.* 2021). Similarly, in the study by McCarron *et al.* (2020), 58.3% of participants identified positive aspects during the pandemic. These included new/more activities (41.2%), more rest/relaxation (36%), and better relations with staff (26%).

From the nine studies included in the updated review, there were also noted impacts to mental health associated with loss of day services, work, or vocational training. Changes in day service/programme attendance or employment because of COVID-19 related restrictions were reported to be 'slightly' to 'moderately' stressful for participants in the study by Hartley *et al.* (2022). However, one in five (20%) found this loss of service to be 'very' to 'extremely' stressful. In Germany, results from an online survey of 848 caregiver proxy respondents reported, in the free comments section of the survey, that 'missing the daily structure of work, school, or other outpatient participation services' was one of the most commonly cited experiences of individuals with intellectual disabilities (Bösebeck *et al.* 2023). In Ireland, not being able to take part in 'usual activities' was the greatest cause of subjective stress/anxiety during the pandemic, and this was reported by 55.7% of participants. Within the same study, 65.5% of participants experienced a change to work or day service. For 45.1% of these participants, this change caused 'a little stress', and for 29% this loss of service caused 'a lot' of stress (McCausland *et al.* 2021a).

Smith *et al.* (2023) reported a variety of issues related to disruptions associated with changes in the provision of day programmes for participants within their study. These included implications and opportunities which presented, including both positives and negatives, one was transition of services from face-to-face to online services. One participant described how life was boring when the day service was closed, however, despite the day service reopening, this participant was unable to return for a further six months due to ongoing staff shortages, with additional issues relating to his motorised wheelchair. Other participants within this study cited additional issues with staffing, both in day services and in their homes which were related to COVID-19 and caused upset and frustration. In New Zealand, 40 self-advocates who had Down syndrome reported high levels of loss/reduction in day service/work hours during the pandemic. Prior to COVID-19, 62.5% engaged in work, either paid, voluntary, or work experience. Of these, 88% did not continue to work during lockdown. For many participants of this study, this was one of the difficulties and frustrations of lockdown and they missed both work and work colleagues (Vaccarino *et al.* 2023). From qualitative interviews in a study by Voermans *et al.* (2023) significant isolation and loneliness were associated with a lack of access to work activities. Six of the eight participants interviewed stated that social connections were significantly impacted because of loss of work activities due to COVID-19. Loss of meaning in life, fears of returning to day services/work due to concerns of infection, and fears related to quarantining, if infected, were all factors that had implications for mental health that were associated with changes in day service or work. Participants described being deprived of new opportunities to learn new things, being unable to make a difference in the lives of customers, and not having the opportunities to develop 'as a person'. Compared to the original scoping review, in the earlier stages of the pandemic, these concerns about infection risks due to returning to services were new and reflected changes in experiences impacting mental health as the pandemic persisted.

Loss of Social Connection / Relationships with Family and Friends

Throughout the studies in this review, participants expressed missing friends, family, and social connections. Whether participants missed family or friends was often dependent on their living circumstances. For some living with family, they valued the new time that they got to spend with them (Peacock-Brennan *et al.* 2021). For others, this extra time with family resulted in conflict (Kim *et al.* 2021b). This is described in greater detail in the section below on living circumstances. Participants missed friends, social activities, going to the hairdressers and going out for a cup of tea (Peacock-Brennan *et al.* 2021). One of the themes which emerged from a study in the Netherlands was 'missing social contact' and having people close by (Embregts *et al.* 2020a). Participants also described not inviting friends over to their house because they were afraid that they may risk the spread of infection to their families. McCarron *et al.* (2020) also reported that one of the greatest causes of stress/anxiety for participants over the age of 40 years in Ireland was not being able to see family and friends. In a study conducted in South Korea, participants describe being unable to connect socially with friends, and how family did not understand what they were going through. They described feeling ‘shy’ and being uncomfortable reaching out to friends using technology, and some had no cell phones (Kim *et al.* 2021b).

Unsurprisingly, as the pandemic progressed, loss of social connection and relationships continued to be reported as an impact on mental health. The link between loss of work activities and loss of social connection was evident in several studies included in the updated review (Vaccarino *et al.* 2023, Voermans *et al.* 2023). As reported by Voermans *et al.* (2023) loss of social connections was a significant determinant on mental health and wellbeing. For some, this lack of connection with others led them to focus more on themselves resulting in emotional and relational imbalance and struggles around their own position in society. Engagement in social meetings and activities outside the home were described as a distraction from negative thoughts. Similarly, not being able to see friends, parents and family were the most noted consequence of lockdown (Vaccarino *et al.* 2023). In Ireland, as a result of the pandemic, prominent causes of stress were ‘change in frequency of visits’ (69.2%) and loss of leisure time activities (68.8%), this was measured using the Life Events Scale (Hermans & Evenhuis 2012). These caused ‘a little’ to ‘a lot’ of stress for 78.6% and 82% respectively (McCausland *et al.* 2021a). Hartley *et al.* (2022) reported that changes in family, staff, or household contacts due to the pandemic was ‘slightly’ or ‘moderately’ stressful for 94/171 (54%) adults with Down syndrome and ‘very’ to ‘extremely’ stressful for 27/171 (16%) of the participants in the study.

In the United States, during interviews, participants spoke about not being able to see family due to COVID-19 positive infections, and fear of infection, and this led to feelings of loneliness, fear, and isolation. Even for individuals that were not avid socialisers, or who were happy living alone prior to the pandemic, feelings of isolation were expressed (Dodds & Maurer 2023). Bösebeck *et al.* (2023) found that caregiver responses under the domain of ‘social interactions’ included determinants which worsened during the pandemic such as problems with motivation and co-operation, self-confidence, and social affinity/making contacts. Some studies described the experience of bereavement during the pandemic among participants. McCausland *et al.* (2021a) reported that 142/682 (20.8%) of participants experienced the death of a family member/friend during the pandemic. Using the Life Events Scale (Hermans & Evenhuis 2012), for those who experienced death of a sibling, 65% reported that this caused them ‘a lot’ of stress. For those who lost a parent, this caused ‘a lot’ of stress to 61.5%. Smith *et al.* (2023) also reported that half (3/6) of the participants in their study experienced bereavement during the pandemic. One participant in their study lost their mother due to COVID-19. This participant distressingly described how they contemplated taking their own life, due to not only the loss, but also the lack of support from staff and housemates. There were also negative feelings described by this participant related to lack of adherence by others to public health measures following the loss.

Use of Technology

While the use of technology increased among many participants, and 13.6% identified using technology to communicate as a positive aspect of the pandemic (McCarron *et al.* 2020), not all participants in the study found it positive. For some, they found it helpful to connect socially, creating vlogs and chatting with friends and family (Embregts *et al.* 2020a, Peacock-Brennan *et al.* 2021). For others using videocalls made them feel insecure. One participant explained that they felt much more comfortable talking to someone face-to-face than when you can only see someone on a screen (Embregts *et al.* 2020a). Whenever participants referenced the use of technology as a positive, it was often followed up by comments related to how it was not a substitute for actual physical contact with others.

From the early stages of the pandemic, the use of technology to reduce face to face contacts was incorporated into the lives of many in society. As already reported, from a low level of use of technology among those with intellectual disabilities prior to the pandemic (McCarron *et al.* 2014, McCarron *et al.* 2017a, Boot *et al.* 2020), COVID-19 accelerated access to and use of technology among this population (McCausland *et al.* 2021c). The updated scoping review identified studies that continued to report on the mental health implications associated with technology access and use during COVID-19 among those with intellectual disabilities. Despite the reported increase in use of technology, Dodds & Maurer (2023) reported that only half of the participants within their study which included 14 participants between the ages of 23-56 years, 10 of which had a mild intellectual disability, had an email address. Additionally, most participants opted to be interviewed over the phone compared to video calling. Challenges such as the internet getting cut-off were cited. Even participants who were competent in the use of technology felt isolated despite talking to friends on Zoom. Another participant spoke about started his own YouTube channel promoting ‘staying safe’, and described how this helped his anxiety (Dodds & Maurer 2023).

A surprising finding by McCausland *et al.* (2023b) was that although there was a 50% increase in use of technology to remain in contact with family and friends during the pandemic, this increase was associated with greater stress/anxiety among participants. In the study by Smith *et al.* (2023), one participant described technology as the key to her ability to cope during the pandemic. They were supported by their employer to purchase a laptop and to continue to work remotely, and to deliver training programs. This greatly increased their sense of pride. Another participant joined a remote bible study group improving their spirituality (Smith *et al.* 2023). To address isolation during the pandemic, Vaccarino *et al.* (2023) reported that most of the participants in their study embraced the use of technology to remain in contact with family and friends, and to attend meetings with clubs and networks. Thirty three of the forty participants (82.5%) used Zoom, with many expressing satisfaction with using it as an alternative during restrictions. However, it was noted that participants still missed seeing people face to face. A participant in the study by Voermans *et al.* (2023) also noted that online contact via WhatsApp was not sufficient to experience the close connection that is achieved through physical contact.

Accessing Mental Health Supports

Rosencrans *et al.* (2021) reported on participants levels of satisfaction of mental health supports provided during the pandemic. While there was a 41% increase in mental health problems in the United States sample and 51.6% in Chilean sample, less than half (42%) and one quarter (25%) accessed mental health supports in each country, respectively. Within the sample from the United States, the following levels of satisfaction with mental health supports were reported; great 10%, good 61%, fair 23%, and poor 6%. The following was reported in Chile: 12.5% great, 68.8% good, and 18.8% fair. Bivariate analysis within this study found that loss of disability service and negative mental health symptoms were significant ($p \leq 001$), as was an increase in physical health problems and experiencing 5+ mental health symptoms. Participants who reported daily difficulties due to disability status were more likely to report more mental health symptoms ($p < .012$). There were significant associations between living arrangements and mental health symptoms ($p < 0.039$).

From a study conducted later in the pandemic, Baxter *et al.* (2023b) explored the impact on mental health of ‘waiting’ for face-to-face appointments for psychological services during COVID-19 restrictions. Six of the seven participants reported negative impacts of the pandemic, such as, being unable to engage in usual activities and not seeing family and friends. However, most participants did not identify that waiting for services resulted in a deterioration of their mental health conditions. There were additional stressors identified by participants that impacted on their mental health, these included physical health, housing, and social care. Participants described coping strategies they used and support that they received from Learning Disability Teams. In Ireland, McCausland *et al.* (2023b) reported a reduction in access to in-person modes of support for mental health among participants. However, there was an increase in use of technology to utilise health services. Regarding ‘in-person’ healthcare utilisation, reductions in psychiatry was 200%, and clinical psychology was 101% when compared to prior to the pandemic. There was an increase in remote appointments for psychiatry by 120% and in clinical psychology by 148%. Psychiatry had the greatest in-person decrease (70%) when compared to pre-pandemic utilisation. Whilst findings from this study reported that increased healthcare utilisation using technology was strongly associated with positive experiences, the specific benefits of these supports regarding mental health are not reported on (McCausland *et al.* 2023b).

Living Circumstances

Researchers found a higher percentage of participants who experienced 3+ mental health symptoms was found among the United States sample, in those living with non-family (46%), group homes (40%), or living alone (38.6%), than in those living with family (31.4%) (Rosencrans *et al.* 2021). No significant associations were found between age or sex with mental health symptoms. There was no significant difference in mental health problems across these demographic variables in the Chilean sample. Villani *et al.* (2020) conducted a clinical study involving 46 adults with Down syndrome, using the interRAI-ID which evaluates psychosocial, cognitive, and functional wellbeing. Mixed linear regression models were used to analyse the data. Whilst there was a decrease in aggression scores, one explanation provided is that there was reduced societal pressures because of the lockdown, and the increased closeness within the home/family unit may have reduced external causes of annoyance. However, this suggestion is anecdotal and was not investigated further within the study.

Interestingly, participants within another study spoke of how increased time at home with family resulted in conflict, with some describing how they were 'not allowed' to go outside by parents who were trying to protect them from the virus. Within the same study other participants spoke of great joy derived from doing chores around the home, and as this being their way of showing appreciation to family members for taking care of them during the pandemic (Kim *et al.* 2021b). McCarron *et al.* (2020) conducted a COVID-19 survey among 710 individuals over the age of 40 years with intellectual disabilities in Ireland and findings were supplemented by longitudinal data from the IDS-TILDA study Wave 4. Individuals living in residential care settings were more likely to miss their family, with 44% of participants reporting this as a cause of stress/anxiety in comparison to those living with family. 28% reported that not seeing their family impacted on their mental health. However, for those living with family or independently, not getting to see friends was a source of stress/anxiety (61%). Participants with all levels of intellectual disability were represented within the study (McCarron *et al.* 2020).

Changes in living circumstances that were brought about because of COVID-19 related restrictions meant that for some they had to move from their usual residence into alternative homes. Studies from the updated scoping review reported on the impact of these changes. In New Zealand, among a sample of 40 people with Down syndrome, 17.5% had to move from their usual home and, for most, this was back to their parental home (Vaccarino *et al.* 2023). However, the majority of participants described that returning to the family home was a positive experience, with new skills being learned and enjoyed spending time with families. Hartley *et al.* (2022) also reported on changes in living circumstances for people with Down syndrome, and 17% had living circumstances altered. Among these, 8% moved back to family homes, 9% experienced changes within their home such as a change in residents, and 83% did not experience any change in residence. From this study, participants reported that 'a change in family, staff, or household contacts' during COVID-19 was 'slightly' or 'moderately' stressful for 94/171 (54%) and 'very' to 'extremely' stressful for 27/171 (16%).

For some people living in residential settings, there were negative experiences reported. There were lockdowns within homes because of positive COVID-19 infections and this resulted in much time being isolated in own bedrooms to avoid infection (Smith *et al.* 2023). However, for two participants within the same study, the pandemic in part, accelerated moves to new homes. Both participants described this as a strong positive consequence of the pandemic, and they were much happier as a result. In Germany, a study exploring impacts among people with intellectual disabilities living in institutions was conducted (Bösebeck *et al.* 2023). Respondents were proxy caregivers and during the period of data collection there were no visitors permitted in the facility. Residents were only allowed to leave in certain conditions, primarily for health reasons. Reporting on the consequences of pandemic related risk of infection restrictions within residential facilities, respondents reported that 'most of the measures' were appropriate, but the adverse psychological and/or health effects of the restrictions were more dominant in 58% of participants (Bösebeck *et al.* 2023).

Physical Health

In Korea, participants described decreased physical activity and changes in their eating habits with increased consumption of junk foods and skipping meals. They attributed this to boredom and changes in their daily routines. Although these participants did not feel that this was a problem, family members had spoken to them about this being problematic. Some participants said that they increased engagement in walking (Kim *et al.* 2021b). In the United States and Chile, researchers found that there was a significant ($p \leq 0.05$) association between increased physical health problems and 5+ mental health symptoms experienced over the pandemic. Poor sleeping patterns emerged as a result of loss of routine among a number of participants in the study conducted by Kim *et al.* (2021b).

McCausland *et al.* (2021a) found that the most stressful life event experienced by participants was a major illness or injury during the pandemic. Within the same study, 58.2% spent more time sitting down or being sedentary, 53.7% engaged in less physical activity or exercise, and 23.3% reported an increase in health problems which were not related to COVID-19. However, data was not analysed to explore the associations between these physical health implications and mental health. Similarly, Bösebeck *et al.* (2023) reported a 21% weight increase among participants, however, this finding is not considered regarding impacts on mental health.

Understanding Restrictions and Public Health Measures

In the Netherlands, there were difficulties reported with shopping and keeping safe distances described by people with intellectual disabilities. One reason cited was because of the regular changes and updates to public health measures. One participant describing a negative interaction with a member of the public because the participant had not been clear on what constituted safe distance while in public spaces (Embregts *et al.* 2020a). Participants in Jersey and Guernsey (Peacock-Brennan *et al.* 2021) also expressed frustration regarding the consistency of information on public health measures.

The updated scoping review, which was conducted as the pandemic progressed, suggested a strong understanding and awareness among people with intellectual disabilities of both their own responsibilities and those of others in adhering to the measures. There was complex decision making surrounding this described by participants in the study by Voermans *et al.* (2023). One participant understood their heightened risk due to having lung disease and made the decision not to return to work. Although they missed contact with others at their workplace, and technology was not providing them with the close connection they needed, they perceived the risk of infection to be greater than the negative impact of feeling lonely/isolated. Similarly, for another participant who also missed their job in a nursing home, they would rather continue to miss this social connectedness, than risk contracting the virus and feel lonely during quarantining (Voermans *et al.* 2023). Participants within this study, appeared to have a strong understanding of the public health measures and how they impacted on their mental health. They made their decisions based on good understanding and awareness of public health measures. Vaccarino *et al.* (2023) also reported that participants within their study had a good understanding of the virus and the restrictions, with more than three-quarters (77.5%) receiving the information from their family.

In the study by Smith *et al.* (2023), participants described how staff took the necessary precautions and how they understood that occasionally there was a risk that staff would contract the virus. However, one participant described that although they were personally very aware of the precautions that were required, staff and fellow residents within their home did not adhere to measures such as social distancing and wearing masks. This resulted in this participant feeling uncomfortable and scared. Within the same study, most participants reported that they learned about COVID-19 and public health measures from staff. One participant learned about it from TV, and they wished that staff had explained it to them instead, because not understanding it fully was scary. No participants reported that they received information regarding risks specific to people living in group settings, such as the risk of contracting the virus from staff, and they found this lack of information frustrating and wanted more honesty from staff (Smith *et al.* 2023).

There was stress and frustration expressed by participants regarding the quality of the information received about COVID-19 in the study by Dodds & Maurer (2023). Participants suggested that most of the information received was through the news and media, with some feeling that the news sometimes exaggerated how bad things were. There were also issues related to being able to trust reports on vaccines in the media. Bösebeck *et al.* (2023) reported that there was an acceptance by respondents that the infection prevention and control measures within residential facilities was either 'appropriate' or 'predominantly appropriate'. Although they acknowledged that the measures restricted the freedom rights of residents. Significantly, these were the responses of caregivers, and as noted by authors of this study, this may be related to employee's personal fear of health risks associated with the pandemic. However, as already stated, adverse psychological and/or health effects of restrictions were more dominant in 58% of participants (Bösebeck *et al.* 2023). Baxter *et al.* (2023b) presents one of the themes from their study as 'I understand why I'm waiting' for psychological therapy. These extended wait times were due to limited options for face-to-face appointments during the pandemic. However, this is not elaborated on within this paper, and it is not clear if this acceptance of wait times was because of explanations or information related COVID-19 public health measures.

Gains in Resources Associated with Mental Health Outcomes

In Korea, engaging in new hobbies and going for walks were identified by participants as activities that they took part in during lockdowns. They also expressed joy at becoming more involved in household chores and explained that this was a way of showing appreciation to their families for taking care of them (Kim *et al.* 2021b). Within the same study, some participants said that they felt more relaxed not having to adhere to a busy schedule. In Jersey and Guernsey, participants also expressed the importance of relationships, valued the time spent at home with their families and enjoyed the opportunity to 'lie-in' and found it peaceful. The value of connection with both friends and with service providers were identified by participants. In addition those that continued to receive services found that they were more person centred and focussed on the individual during the pandemic (Peacock-Brennan *et al.* 2021). In the Netherlands, participants had different perceptions of using videocalls to remain in contact with friends, but, for some, they enjoyed interacting in this way in the absence of not being able to physically meet up (Embregts *et al.* 2020a). Using technology to communicate with family and friends was also identified as a positive among adults over the age of 40 years in Ireland (McCarron *et al.* 2020). Other positive aspects recognised by these participants were engaging in new/more activities, more relaxation and better time spent with staff.

From studies in the updated review, there were similarities in the positive aspects of the pandemic identified previously. Whilst several studies within this review present positive engagement in new or alternative activities during the pandemic, for the most part, these did not overcome or negate the overall negative impacts that were felt during implementation of restrictive public health measures. Dodds & Maurer (2023) describes how participants engaged in spiritual practices, physical fitness, and creative activities during lockdowns and how these activities aided with their ability to cope. As already highlighted increased use of technology was reported to be a helpful tool to remain in contact, or to access healthcare remotely (McCausland *et al.* 2023b). Technology was used to engage in drama and dancing groups via Zoom (Vaccarino *et al.* 2023), and to remain socially connected (McCausland *et al.* 2021a, Baxter *et al.* 2023b, Dodds & Maurer 2023, McCausland *et al.* 2023b). But other interests included taking up Tai Chi, painting, and learning how to cook (Dodds & Maurer 2023). Engagement in new hobbies, having increased opportunities for rest and relaxation, and developing better relationships with staff/support people was found by McCausland *et al.* (2021a).

When coping with waiting times for psychological therapy, the support of the Learning Disability Team was reported as a helpful resource (Baxter *et al.* 2023b). Although the pandemic resulted in changes in living circumstances for some people with intellectual disabilities, for others it provided an opportunity to move to a much more suitable home for their own needs (Smith *et al.* 2023). Others engaged in new hobbies including setting up a radio station with a friend and one individual learned English on an app, this increased the participants feeling of pride. Helping with housework and making a difference in the lives of others was reported as being important to some participants (Voermans *et al.* 2023).

Demographic Characteristics of Adults with Intellectual Disabilities and Mental Health.

Many of the studies did not explore associations related to level of intellectual disability of participants and determinants of mental health impacts, but they do acknowledge shortfalls in the representativeness of samples. One study found that level of intellectual disability appeared to be a determinant on the levels of stress/anxiety experienced by participant (mild 63.9%, moderate 59.8%, severe/profound 36.8) (McCarron *et al.* 2020). Sex was not found to play a significant role on mental health outcomes, in either the United States or Chilean samples, where this was tested for using statistical analysis (Rosencrans *et al.* 2021). However, McCarron *et al.* (2020) reported that females experienced higher rates of stress/anxiety, as did those between 40-50 years when compared to other age categories.

In Ireland, demographic characteristics were tested for associations with general mental health measures. There was no statistical significance found across gender, age categories, level of intellectual disability or residence type. Women were more likely to report loneliness than men (63.1% compared to 47.7%) (McCausland *et al.* 2021a). Interestingly, although all studies included in the review gathered some demographic details of participants, there are very limited reports on how these demographic characteristics may or may not have been significant on mental health during the pandemic.

2.13.6 Limitations

There are several key areas within this scoping review where limitations have been identified. There is a scarcity of high-quality evidence available regarding the impact on mental health due to the COVID-19 pandemic on adults with an intellectual disability. There is greater research attention required for individuals with severe and profound intellectual disabilities, as the ability to engage verbally, access technology and have mild or moderate levels of disability were prominent attributes of participants within the included studies. McCallion (2020) highlights the need for individuals with intellectual disabilities to be consulted and to act as co-researchers in identifying incidence and experience and documenting the successes and failures that have taken place in response to this unprecedented pandemic. It is encouraging to find that most of the studies included in the review sought the perspectives directly from people with intellectual disabilities to inform their studies. Involvement as co-producers/co-researchers was only found in two of the six studies in the initial review, however, this approach was incorporated into five of the nine studies in the updated review. From the six studies included in the original review, all data, with the exception of interviews by Kim *et al.* (2021b) was collected either via phone or video call. This was necessary due to the COVID-19 restrictions which were in place and may have had an impact on the data depending on the level of comfort with such technologies. As the pandemic progressed and restrictions were eased, data collection returned to face-to-face, and for the qualitative studies from the final review, the majority of the interviews were carried out in person. While the stringency of lockdown measures differed from country to country, and the studies included in this review were carried out at varying points during these measures, further research is required to establish if the level of lockdown at the time of data collection impacted on the findings.

2.13.7 Conclusions of Scoping Review

This section sought to conduct systematic scoping review of the literature in respect of the impact of COVID-19 on the mental health of adults with an intellectual disability. This was carried out using two research objectives: to identify the impact that COVID-19 has had on the mental health of this population and secondly to identify losses and/or gains in resources associated with any noted or potential change in mental health during the COVID-19 pandemic.

From the fifteen studies which were included, the evidence base remains limited at this time. This is despite there being a considerable amount of perspective and descriptive pieces available calling for an increase in research attention in the area, particularly from early in the pandemic. This review may be regarded as a starting point to build and expand upon to explore and understand the mental health impact experienced during COVID-19 associated restrictions; and to work towards identifying gains and/or loss of resources associated with such impacts among this population. Many of the impacts on mental health are similar to those experienced within the general population. However, there is a need for evidence to understand impacts which may be specific to people with intellectual disabilities.

The decision to include all study types was because of an initial scoping review yielding limited research available to answer the research question. However, the inclusion of all study types resulted in a lack of heterogeneity within the data and therefore the review did not include a meta-analysis. The researcher also notes that the implementation of public health measures was applied in countries based on the trajectory of the virus at that time in each country. It should, therefore, be considered that, in relation to mental health, people in different countries were experiencing different levels of lockdown throughout the timeframe of this scoping review.

2.14 Theoretical Framework

This researcher conducted an extensive review of the literature pertaining to stress and coping to source a theoretical framework that aligned with both the study aim and objectives, and with the researcher's own background as a Registered Nurse in Intellectual Disabilities with experience in supporting people with intellectual disabilities who also had mental health conditions. The Hobfoll's COR theory provided the opportunity to frame the study using a stress theory which went beyond the Transactional Stress Model was one important aspect for the researcher. The emphasis on the individual's appraisal of the stressful event is central to Lazarus and Folkman's theory (Lazarus & Folkman 1984), that the event must occur for the person to appraise it as such. In addition, the sole responsibility for an individual feeling stress is the responsibility of the individual and of their appraisal, however, this does not necessarily take account of the social and environmental context in which the individual exists. The COR theory is based on the acquisition and conservation of resources, described within the theory under four categories: personal characteristic, condition resources, object resources and energy resources. By applying such a categorisation of resources, Hobfoll emphasises that resources may be both internal and external. This theory states that people use key resources in order to respond to stress, and that they also sustain and build reservoirs of resources which may be used in times of future need (Hobfoll *et al.* 2018b). Hobfoll *et al.* (2018b) describe the COR theory as a motivational theory, based on humans' evolutionary need to acquire and conserve resources for survival. Table 2.6 presents a list of 74 potential resources identified by Hobfoll as being important resources within people's lives (Hobfoll 1998, p. 71). This study explores many of these resources and the impact of their loss and/or gain during the COVID-19 pandemic and presents a unique opportunity to understand the experience of stressful circumstances beyond the individual's own cognitive appraisal of how stressful the pandemic and associated restrictions were.

Personal transportation	Money for transportation	Help with tasks at home
Necessary home appliances	Housing that suits my needs	Adequate home furnishings
Adequate clothing	Adequate food	Money for advancement or self-improvement (education, starting a business)
Financial stability	Retirement security (financial)	Financial assets (stocks, property, etc)
Financial help if needed	Savings / emergency money	Money for extras
Adequate financial credit	Good relationships with my children	Children's health
Extras for children	Help with childcare	Providing children's essentials

Good marriage	Intimacy with spouse / partner	Spouse / partners health
Intimacy with one or more family members	Family stability	Affection from others
Feeling valuable to others	Time with loved ones	Intimacy with at least one friend
Loyalty of friends	Support from co-workers	Companionship
Stable employment	Adequate income	Time for work
Necessary tools for work	Status / seniority at work	Understanding from my boss / employer
Advancement in education / job training	Help with tasks at work	Free time
Time for adequate sleep	Personal health	Health of family / close friends
Medical insurance	Ability to organise tasks	Feeling that I am successful
Ability to communicate well	People I can learn from	Feeling independent
Hope	Feeling that I am accomplishing my goals	Feeling that my future success depends on me
Sense of pride in myself	Stamina / endurance	Positively changing routine
Sense of optimism	Role as a leader	Self-discipline
Feeling that my life has meaning / purpose	Feeling that my life is peaceful	Motivation to get things done
Sense of humour	Acknowledgement of my accomplishments	Feeling that I know who I am
Feeling of control over my life	Feeling positive about myself	
Involvement with church, synagogues, etc.	Sense of commitment	Involvement in organisations with others who have similar interests
Knowing where I am going with my life	*Larger home than I need	*More clothing than I need

Table 2.6 Conservation of Resources theory, examples of resources (Hobfoll 1998)

Hobfoll's COR theory provides an alternative to the seeking out of reinforcers and avoidance of punishment introduced to psychology by Pavlov and Skinner. Hobfoll suggests that human beings are not in pursuit of reinforcers, or avoiding punishment, but rather that they are motivated to construct and preserve the conditions that will allow us to do so. This theory is important because it emphasises the process as opposed to the outcome solely. The central tenet of Hobfoll's theory is that people work to obtain resources they do not have, work to retain the resources that they do possess, protect their resources when they are threatened and foster resources by positioning themselves so that resources can be put to best use (Hobfoll 1998). The theory suggests that people preserve and enhance their average outcome over time, as opposed to a single outcome following an event, as with Pavlov's dogs or Skinner's rats.

The COVID-19 pandemic may reasonably be considered as a major life stressor. The unprecedented nature of the pandemic and the global response in terms of public health measures and restrictions impacted the way in which people usually lived their lives. People were required to adapt their normal routines and behaviours to reduce the spread of the virus. Public health measures included social distancing, restrictions in movement, reductions in physical contact with family, friends, and people in general, all of which may have posed threats to the resources which people possessed. However, Hobfoll also indicates that minor bothersome events collectively may reduce people's ability to grow and protect resources, and that even in the event of no stress, that people are directed to cultivate resources. This may be relevant for some people who did not identify the restrictions associated with the pandemic as being an overall stressful event, but the accumulation of what may be perceived as minor irritating events, such as not being able to go to out for coffee, may impact on resources over time. Hobfoll (1998) elaborates on his earlier definition of stress and states that:

Stress occurs in circumstances that represent a threat of loss or actual loss of the resources required to sustain the individual-nested-in family-nested-in social organisation. Furthermore, because people will invest in what they value to gain further, stress is predicted to occur when individuals do not receive reasonable gain following investment, this being an instance of loss (Hobfoll 1998, p. 55)

Therefore, Hobfoll (1998) explains that stress occurs when:

(1) resources are threatened with loss

(2) resources are lost, or

(3) there is a failure to adequately gain resources following significant resource investment.

In addition, Hobfoll affirms that there is no organisation or family without the people, and that individuals must rely on social attachments for wellbeing, self-esteem, and survival. Individuals exist within a social network of family, friends, and organisations. Object resources have a physical presence for example a home or a car. Personal resources may be about skills and traits. Personal skills resources may include both skills such as occupational skills, self-confidence, and leadership ability, whereas personal trait resources may include self-esteem, optimism, and hope. Condition resources include being healthy, employment and marriage. Energy resources include money, credit, and knowledge. It must also be acknowledged that within this classification of resources there are resources which may cross categories, for example, is health a condition resource or a personal resource. This thesis embraces the recognition that there are many facets to the lives of people with intellectual disabilities that have the potential to impact either, or both, positively and/or negatively on their mental health. Using Hobfoll's theory, combined with the breadth of data available from the IDS-TILDA study, provided a unique opportunity to explore many resources which may have been lost or gained and the impact of these on mental health.

The first principle of the COR theory is that resource loss is disproportionately more salient than resource gain. It is this principle that the researcher has focussed on within this study. Hobfoll explains that when an individual experiences resource loss that this has much greater impact than when resources are gained. COR theory states that loss, and the threat of loss, principally defines stress. In testing his theory, Hobfoll hypothesised that resource loss was strongly related to both greater depression and anger, and that resource gain, in contrast, was marginally related to lower depression, but unrelated to anger, suggesting that positive change is not stressful and that it moderately limits stress (Hobfoll 1998).

The second principle states that people must invest in resources to protect against resource loss, recover from resource losses, and gain resources. The ways in which resources may be invested include several mechanisms such as outright expenditure of a resource, for example when time or money is invested into something to prevent other resource loss. Resource investment may involve risking the resource, such as placing trust in another, or self-esteem, if one disagrees with a colleague and being proven wrong. Resource investment may also occur through substitution or direct investment – resource for resource. This may occur when one loses the ability to physically see a family member; this may be substituted by placing greater resources towards developing a friendship with someone they live with. Investing in resources comes at a price or a potential price to resources. There is an alternative to invest in resources and this is non-action - to do nothing in response to an event. This has been described as a potential favoured option in the event of an individual being in low resource conditions. This may also be an attempt by the individual to conserve resources for everyday challenges or in the event of future stress circumstances (Schönpflug 1985). There was evidence to suggest that investment in resources became an important feature of the lives of people with an intellectual disability during the pandemic, with participants in a number of studies reporting positive aspects such as partaking in new hobbies, improved relationships with staff and appreciation of free time and time to relax (McCarron *et al.* 2020, Murphy *et al.* 2020).

Throughout the course of the COVID-19 pandemic, a number of researchers applied the COR theory to understand the impact of resource loss and gain and the subsequent impact to mental health. COR theory has been supported as a beneficial theory to understand changes in mental health associated with a global pandemic (Egozi Farkash *et al.* 2022, Yu *et al.* 2023).

Limitations of Conservation of Resources theory

As discussed, the COR theory is an alternative to appraisal-based stress and coping theories. It offers a view which extends beyond the individual's self-appraisal of a stressful situation at the time at which it occurs. Hobfoll (2001) emphasised that this theory does not disregard the idea or importance of 'appraisal'. Rather, that the individuals reserve of personal, social, economic, and environmental resources, when faced with stress, are the determinants of the response to stress and the eventual outcome. Given the presence of communication difficulties which are characteristics of having an intellectual disability, the ability to explore or measure the extent that one's self-appraisal of a stressful event may contribute towards coping, within this population, has difficulties.

Research on older people with intellectual disabilities highlights poorer physical and mental health, smaller social circles, lower rates of paid employment, marriage and having children (McCarron *et al.* 2014, McCarron *et al.* 2017a, McMahon *et al.* 2019), it may be the case that resources are already limited and they may be less likely to engage in resource investment outside of being subject to an environmental stressor. The list of 74 resources which were found to be key resources by Hobfoll (1998), among community samples, may not account for the differences that exist within the lives of many older adults with intellectual disabilities when compared to the general population. Resources identified by Hobfoll (1998) such as 'good marriage, 'spouse/partners health', 'children's health', 'help with childcare', and 'good relationships with children' are unlikely to apply to those with intellectual disabilities. Similarly, resources related to employment such as: 'status/seniority at work', 'stable employment', and 'understanding from my boss/employer' are resources which may not be directly relatable to those with intellectual disabilities, based on lower rates of paid employment within this population. To address this limitation within the current study the researcher employed several strategies. These are described within the methodology section of this thesis (section 3.14).

The COVID-19 pandemic and associated restrictions presented the global population with both loss and threatened loss of resources across many aspects of life. Among older adults with intellectual disabilities 'stay at home' policies resulted in both losses and gains of resources. For example, loss incurred because of not seeing family members for those living in residential settings. However, to maintain these relationships, there was increased use of videocall and technology. Although gains in this resource (increased use of technology) was experienced and was regarded as positive, the loss which occurred because of not being able to physical meet with family, according to COR theory, is likely to have a greater impact on negative mental health outcomes. From the available literature, people with intellectual disabilities, as well as people within the general population identified some positive aspects of the pandemic such as new hobbies, more relaxation and free time. However, to measure the impact that such gains may have resulted in poses challenges, as according to the COR theory, losses will always be more impactful when resources are being lost or threatened with loss. Nonetheless, identification of the resources that were important and were gained during the pandemic provide a foundation for understanding the resources which may contribute towards resiliency among older adults with intellectual disabilities. The concept of resilience is addressed by Hobfoll in recent writings and he emphasises that resilience is greatly undermined in individuals who are from resource poor environments (Hobfoll *et al.* 2015), which may account for many people with intellectual disabilities, based on the disparities which are well documented.

Hobfoll's theory has developed and refined over many years, as outlined, there are principles and associated corollaries which contribute towards the overall theory. To apply every aspect of this theory within this thesis was not feasible. Therefore, the central tenant and principles provided a framework to direct and guide this study. One of the notable concepts surrounding resource gain is the construct of 'gain cycles'. In the wake of significant losses of resources, people may enact these gain strategies which may be employed in the future (Hobfoll 1998). For individuals with intellectual disabilities, they may have to apply these gain cycles repeatedly to achieve benefits, such as improved resilience and coping strategies. Due to the time constraints of this study, the actual benefits from gains may only present in the aftermath of the pandemic and into the future. However, according to COR theory, this can only occur if gains are continually built upon.

2.15 Chapter Conclusion

This chapter has presented a background and context on the COVID-19 pandemic and associated restrictions that are pertinent within the context of this thesis. It has set out the policy context and the trajectory of the COVID-19 pandemic and how this related to people with intellectual disabilities. Due to the extraordinary occurrence of a global pandemic, there was a lack of well-developed research on the potential impacts for people with an intellectual disability. For this reason, the available research was presented as an overall review of the available literature comparable to the general population. A scoping review to bring together, appraise, and summarise the relevant research in the area was presented. The chapter concluded with an overview of the theoretical framework for this study.

Chapter 3 Methodology

Introduction

This chapter presents the methodological approach that was used in this study. Firstly, the research question and the research objectives of the study are clearly set out. This is followed by details of the primary data source, sampling information, ethical considerations, the measures used within the study, data collection methods, followed by data cleaning and analysis methods. Following this, an overview of how the dependent variables within this study and details on how predictor variables were constructed based on the study's theoretical framework is presented and how this guided the structure and analysis of the data to answer the research question.

3.1 Research Questions and Objectives

The primary research question in this study is: What impact have personal and social resources had on the mental health of older adults with an intellectual disability in Ireland in the context of the COVID-19 pandemic?

Within the overall research question there are three specific research objectives:

1. To identify factors associated with mental health outcomes for this population during the COVID-19 associated restrictions.
2. To measure how resource loss which occurred during the pandemic impacted on mental health.
3. To measure how resources gained during the pandemic impacted on mental health.

As a result of a review of the literature and the gaps in knowledge which were subsequently identified, these research objectives will uniquely contribute towards understanding the personal and social resources associated with mental health outcomes for older adults with and intellectual disability in the context of the COVID-19 pandemic. In addition, they will provide evidence to inform those planning services and policy makers on the promotion of mental health in the aftermath of COVID-19, and in the event of further pandemics or public health emergencies.

3.2 IDS-TILDA Background

IDS-TILDA is a longitudinal study on ageing in Ireland focussing on individuals with an intellectual disability over the age of 40 years. The study commenced in 2008 with the report for Wave 1 published in 2011 (McCarron *et al.* 2011). The study has conducted subsequent waves every three years (McCarron *et al.* 2014, McCarron *et al.* 2017a, McCarron *et al.* 2020), with a supplementary report being published in 2021, which reported on the continuing impact of the COVID-19 pandemic (McCausland *et al.* 2021a). This researcher co-authored the Wave 4 report and the supplemental report in 2021, focussing on the mental health aspect of these reports. IDS-TILDA is the first study of its kind in Europe and is the only study which directly compares ageing in those with intellectual disability and their non-intellectually disabled peers. The underpinning values of IDS-TILDA are inclusion, choice, empowerment, person centred, the promotion of people with intellectual disability, the promotion of best practice and to contribute to the lives of people with intellectual disability. The overall aim of the study is to identify the principal influences on successful ageing in persons with intellectual disability, and then determine if they are the same or different from the influences for the general population. IDS-TILDA is a supplemental study to TILDA. Participants within TILDA are 50 years and over and it is a large scale nationally representative study of more than 8000 participants, with data collection taking place in waves every three years. Information is collected on all aspects of health, economic and social circumstances and is unique amongst longitudinal studies in the breadth of physical, mental health and cognitive measures collected (Kenny *et al.* 2010).

3.3 IDS-TILDA Dataset

The primary data for this study is drawn from IDS-TILDA. This longitudinal study has been collected over four previous waves commencing in 2008 and the Wave 5 report will be published in late 2023. Data collection was underway for Wave 4 of the study when the COVID-19 pandemic emerged in March 2020. A total of 739 participants were enrolled in Wave 4. At that time data collection was paused due to restrictions implemented nationally because of the pandemic. This presented the opportunity to understand how the COVID-19 pandemic and associated restrictions were experienced by older adults with an intellectual disability in Ireland. This researcher identified this as a unique opportunity to conduct a study into the impact on mental health and so, in conjunction with the Principal Investigator of IDS-TILDA and the research team, the mental health element of a COVID-19 survey was developed. This would be administered to all participants enrolled in Wave 4, findings from which report were published in December 2020 (McCarron *et al.* 2020).

At the time there was no certainty regarding how long the pandemic was likely to continue. In early 2021, a further opportunity emerged during which the ongoing impact of the pandemic on older adults with an intellectual disability could be studied. A further COVID-19 (phase 2) survey was developed, again with this researcher heavily involved, a more comprehensive set of measurements were added to the mental health section. The protocol, of which this researcher was a co-author, has been published and peer reviewed (McCarron *et al.* 2021). The breadth of data collected in the COVID-19 (phase 2) was well positioned to apply to the theoretical framework of this study to understand the implication of resources including personal, social, and material and those which were both lost and gained during the pandemic, and how these relationships impacted on the mental health of older adults with an intellectual disability in Ireland. In addition to the dataset from the COVID-19 (Phase 2) survey, longitudinal data from Wave 4 is also applied through research objectives 1-3. The breadth of data within the IDS-TILDA Conceptual Framework (McCarron *et al.* 2020) is illustrated in Figure 3.

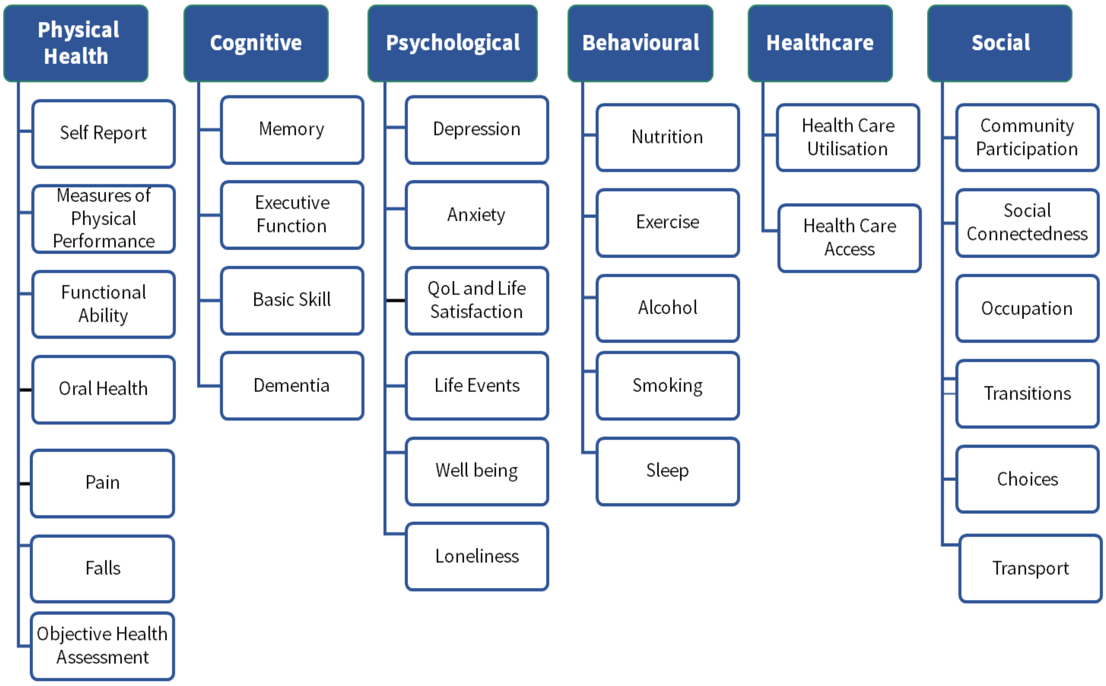


Figure 3.1 Conceptual Framework of IDS-TILDA (McCarron *et al.* 2020)

The protocol for the COVID-19 (phase 2) survey included measures across all domains of the conceptual framing. It allowed for this study to explore the relationships across a wide array of resources which had the potential to impact both positively and negatively on the mental health of participants in the Wave 4 population.

3.4 Sampling Frame

Ireland is uniquely positioned internationally in that there is a national database of people with an intellectual disability who access or who have applied to access disability services in the Republic of Ireland. The National Ability Supports System (NASS) (previously the National Intellectual Disability Database (NIDD)) captures information about disability services and individuals which is then used to assist in the planning, development, and organisation of disability services in Ireland (Casey *et al.* 2021).The original sample for the IDS-TILDA study was drawn from the NIDD. The database is managed by the Health Research Board and collects information on all people with an intellectual disability in the Republic of Ireland who are either in receipt of services or eligible to receive services in the disability sector. At the commencement of the IDS-TILDA study there were 26,066 people registered on the database (Kelly *et al.* 2010). Every person on the register is assigned a Personal Identification Number (PIN). Staff at the NASS randomly selected 1,800 PIN's using inclusion / exclusion criteria. With an anticipated 50% response rate, recruitment of 750-800 participants aged over 40 years and across Ireland was anticipated (McCarron *et al.* 2011). The regional disability database administrator (RDDA) was provided with the PINs of potential participants who confirmed that details were correct. To preserve the confidentiality of the potential participants the RDDA was provided with invitation packs by the IDS-TILDA team. They subsequently addressed and posted the pack to the person associated with each PIN received. Members of the IDS-TILDA team were also meeting with services, and providing information about the study, and services involved were also encouraged to identify a link person to support in the planning of interviews.

From the original sample of 1,800 randomly selected PINs, 1,600 of these were provided with invitation packs and asked to take part in the study. Written consent was obtained from 753 individuals, which represented a response rate of 46%. This equated to 8.9% of the total eligible population at that time. The sample was 45% male and 55% female; aged 41 to 90 years (mean age 54.7 years); 24% had a mild intellectual disability, 46% moderate intellectual disability, 24% severe intellectual disability, and 5% profound intellectual disability (with 5% unverified). Around 40% lived in 52-week residential care centres, with a further 5.3% in other residential centres (i.e. 45.3% in 'institutional' or 'congregated' residential care settings); around one-third (34.1%) lived in community group homes with other individuals with an intellectual disability; 5% lived independently and 54 semi-independently; and 11% lived at home with their families (McCarron *et al.* 2011).

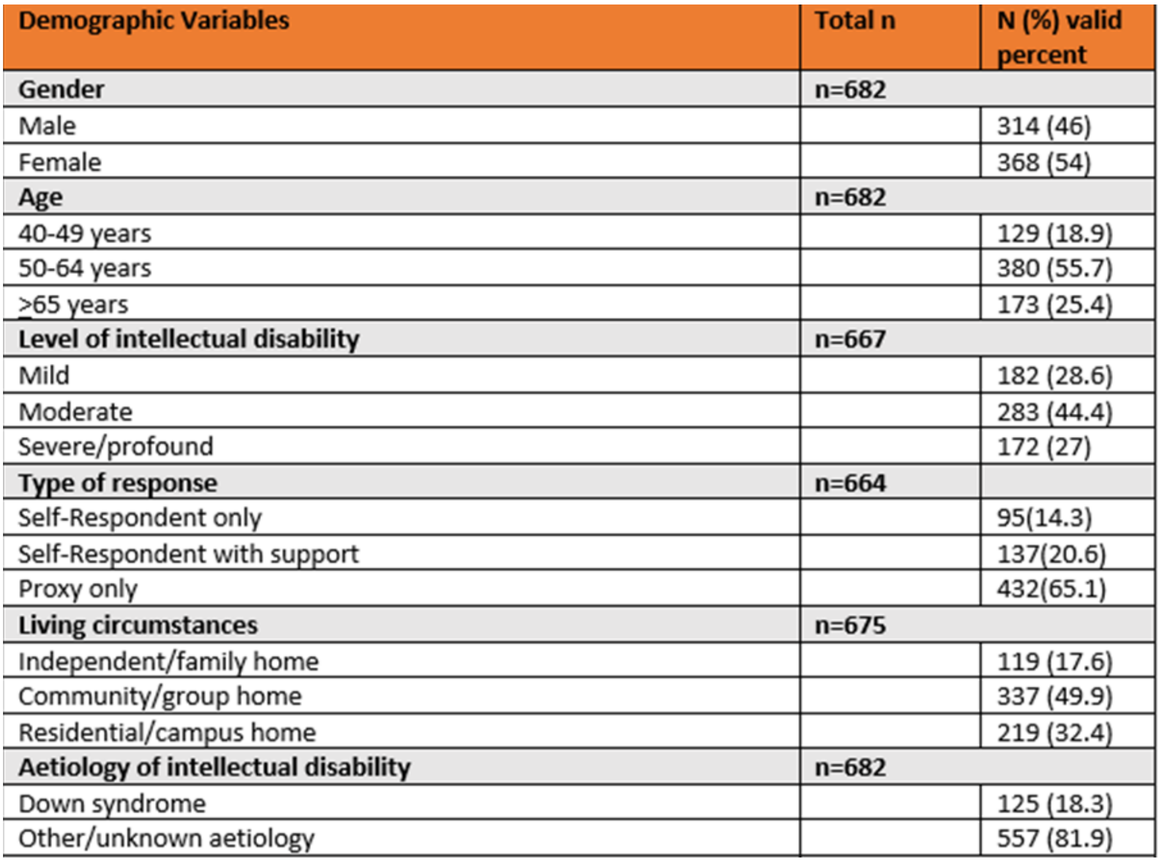
Data collection for Wave 2 commenced in 2013 and of the original 753 participants from Wave 1, 719 participants completed at least one element of Wave 2, this represented a response rate of 94%. The reasons for non-participation in Wave 2 was that 34 participants were deceased and 11 refused to take part. Due to non-replenishment of the same at this wave there was an increase in the mean age of participants. However, the sample remained largely representative. The average age had risen to 56.6 years (SD=9.313, 95% CI=55.90, 57.29). Males accounted for 44% of the participants and females for 56% of participants - 22% had a mild intellectual disability, 43% had a moderate intellectual disability, 27% a severe or profound intellectual disability, whilst 8% were either unknown or not verified (McCarron *et al.* 2014).

Wave 3 data collection began in 2016 and there was a retention rate of 86%, with 609 participants completing at least one element of Wave 3. Seventy-one percent of attrition was due to the death of participants. Among the 638 Wave 2 respondents who were alive at Wave 3, the response rate was 95.5% (609/638). Response rates for Wave 3, based on the 708 Wave 2 participants, were not significantly different for men and women: 86.2% (269/312) versus 85.9% (340/396) respectively. However, there was a significant decrease in response rates according to age group (McCarron *et al.* 2017a).

Between Wave 3 and Wave 4 a further 67 participants had died (total deceased participants since Wave 1=105), and due to participants ageing, the sample for the study was refreshed at Wave 4. To maintain the statistical power required for in-depth analysis, and to address any concerns that might arise for the continued representativeness of the sample, a refreshment of the sample was planned in Wave 4. The refreshment addressed losses likely to impact the representativeness of the sample and to replace the age 40-50 years cohort who by Wave 4 had aged to greater than 50 years. As in Wave 1, the Health Research Board (HRB) supported use of the NASS to anonymously recruit enough new participants to restore the sample to its Wave 1 size and representativeness. Recruitment for the wave resulted in an additional 233 participants which replenished the sample to 739 participants, with 135 new participants in the 40-49 years old cohort from which original participants had aged out of (McCarron *et al.* 2020).

For Wave 4 a total of 739 Computer Assisted Personal Interviews (CAPIs) were completed. During Wave 4 data collection, on the 11th of March 2020, COVID-19 was declared a global pandemic. The Government of Ireland implemented unprecedented closures across a range of public and private services, and a national 'lockdown' came into effect on March 13th, 2020. As a result, data collection for Wave 4 was paused. Prior to commencement of lockdown, 559 CAPIs were completed and on resumption of data collection (May-September 2020) a further 180 CAPIs were undertaken by participants. During the period when data collection was paused (March-May 2020), the opportunity to develop an additional survey which could be administered to IDS-TILDA participants was realised, and the COVID-19 survey (phase 1) was created. Once resumption of data collection took place, this survey was conducted with participants (n=559) that had completed CAPI prior to March 13th, 2020, and the remainder of participants (n=180) were administered their CAPI and the COVID-19 (phase one) survey simultaneously. In total 710 participants completed the COVID-19 (phase 1) survey (McCarron *et al.* 2020).

As the pandemic progressed into 2021 with lockdowns continuing in response to public health, the opportunity to further understand the impacts that these restrictions were having on the lives of older adults with an intellectual disability in Ireland was taken and a follow-up COVID-19 (phase 2) was developed. This survey was informed by a review of the literature and the findings of the COVID-19 (phase 1) survey and employed a greater level of detail in terms of exploring the impact of COVID-19 and the associated restrictions on older adults with an intellectual disability in Ireland. In total, a final sample of 682 individuals participated in the study. This gave a response rate of 94.5% (682/722) among surviving Wave 4 participants. Of the participants that completed the COVID-19 (phase 2) survey 46% (314/682) were males, 54% female (368/682); 18.9% (129/682) were 40-49 years old, 55.7% were 50-64 years old (380/682) and 25.4% (173/682) were over the age of 65 years. Table 3.1 shows the demographic profile of participants from the COVID-19 (phase2) survey.



Demographic Variables	Total n	N (%) valid percent
Gender	**n=682**	
Male		314 (46)
Female		368 (54)
Age	**n=682**	
40-49 years		129 (18.9)
50-64 years		380 (55.7)
≥65 years		173 (25.4)
Level of intellectual disability	**n=667**	
Mild		182 (28.6)
Moderate		283 (44.4)
Severe/profound		172 (27)
Type of response	**n=664**	
Self-Respondent only		95(14.3)
Self-Respondent with support		137(20.6)
Proxy only		432(65.1)
Living circumstances	**n=675**	
Independent/family home		119 (17.6)
Community/group home		337 (49.9)
Residential/campus home		219 (32.4)
Aetiology of intellectual disability	**n=682**	
Down syndrome		125 (18.3)
Other/unknown aetiology		557 (81.9)

Table 3.1 Demographic profile of participants that completed COVID-19 (phase 2) survey.

3.5 Ethics

Ethical approval for IDS-TILDA at Wave 4, as with all previous waves, was approved at four different levels, with additional approval requirements at Wave 4. In 2018, several new ethical requirements were added by the Health Research Board and the General Data Protection Regulations (GDPR) were also introduced. These included the development of a Data Protection

Impact Assessment (DPIA) and an application to the Health Research Consent Declaration Committee (HRCDC) for a Consent Declaration, which would provide ethical approval for the inclusion of some participants with intellectual disability who lacked the capacity to provide consent directly. An amended Wave 4 ethics application to include the first COVID-19 survey was approved by Trinity College REC and by the National Research Ethics Committee (NREC) COVID-19 in May 2020. This approval related to conducting CAPI interviews remotely instead of in person, and the process around reaffirming consent remotely. An additional amendment request for the second COVID-19 survey was granted by the NREC COVID-19 in April 2021.

For Wave 4, ethical approval was as follows:

- Ethical approval for the study was granted by TCD Faculty of Health Sciences Research Ethics Committee (Appendix 4)
- All participating service providers granted approval to commence data collection within their services (138)
- The HRCDC granted a full Consent Declaration for the study in December 2019, facilitating the inclusion of proxy-consented participants (Appendix 5)
- Ethical approval by the NREC to include first COVID survey (Appendix 6)
- Ethical Approval by the NREC for to include first COVID survey – phase 2 (Appendix 7)

Informed consent was sought directly in writing from those randomly selected individuals in for their participation in the study (Appendix 8). Information packs were sent to participants which contained the consent form and the Participant Information Booklet (Appendix 9). Also included in the packs was a family/guardian information leaflet (Appendix 10). Where individuals were unable to provide consent directly, it was requested that a family member/representative would review the study information and provide proxy consent for participation in the study. A system of process consent was used during the CAPI interviews. Participants were provided with information both verbally and in accessible formats and the person’s right to withdraw at any stage was reiterated.

As a Registered Nurse in Intellectual Disabilities (RNID), throughout this study the researcher adhered to the ethical principles as outlined by the Nursing and Midwifery Board of Ireland (Nursing and Midwifery Board of Ireland 2015) ensuring the principles of respect for Persons/Autonomy, Beneficence and Non-maleficence, Justice, Veracity, Fidelity, and Confidentiality. IDS-TILDA is guided by the four ethical principles of: beneficence, nonmaleficence, autonomy, and justice. Respect and autonomy of participants are central to IDS-TILDA and every opportunity to ensure that these are upheld are incorporated into the study protocol. Self-determination is a key element for individuals regarding autonomy and respect, participants are ensured right to withdraw at any stage, and the inclusion of accessible materials and no use of deception is guaranteed. Beneficence in research means to do good and to positively help a person according to Treacy & Hyde (1999). Research should benefit participants and contribute to their welfare. This study aims to increase knowledge on the impact of COVID-19 on the mental health of older adults with an intellectual disability in Ireland, and to provide evidence to inform practice and policy within this context. It is anticipated that this, in turn, will result in an overall benefit to participants in this study.

The principle of nonmaleficence states that there is an obligation not to inflict harm on others. This is closely associated with the maxim *primum non nocere* (first do no harm) (Jahn 2011). Measures used within the study were reviewed and adapted to remove any possible harm. Interviews were administered using CAPI with a view to reduce the burden of paperwork on participants. The researcher attended an intensive three-day training programme and has over twenty years' experience working with individuals with intellectual disabilities. The researcher constantly monitored for any signs of discomfort or distress in participants during the interview process. Participants were supported to take breaks, offered interviews that could be broken down into shorter sessions, and throughout the process the right to withdraw, and the system of process consent was upheld. Finally, the principle of justice is synonymous with fairness and equity and the researcher ensured that participants were treated fairly and with equity before, during and after the research study. Every attempt was made to uphold this principle within the study, participants were provided with aids to communication in the form of accessible or picture-based cards, and language and prompts used within the interview were simplified to promote maximum understanding.

3.6 Data Protection and Confidentiality

To ensure that confidentiality and protection of participants' data was protected at all stages during the study, the researcher implemented a range of systems and procedures set out by the IDS-TILDA study protocol. Individuals registered on the NASS were all assigned a PIN to protect anonymity of service users. Personal information was only distinguishable via this PIN. A pseudonymised study case number was generated for each participant to reversibly anonymise their data. This was referred to as the participant's Unique Identifier (UI). All information in relation to each participant was only referred to using this UI.

The only exception was a hard copy containing information that was provided to the researcher by the IDS-TILDA co-ordinator in advance of the interview which contained information that ensured that the correct participant was interviewed. The systems and procedures around this information were strict and the document was stored securely and locked away in a separate location to all other information. The researcher signed a confidentiality agreement to ensure the protection of all personal information of participants and those involved in the study. The researcher's computer and all computers used in relation to the study are encrypted and data uploaded by the researcher was connected using the college's Virtual Private Network (VPN) which ensured that sensitive data was safely transmitted. No copies of data were permitted on any external media. Participant consent forms were kept in a securely locked filing cabinet in the IDS-TILDA office and accessed separately from anonymised data.

3.7 Field Researcher Training

The researcher and all field researchers recruited to be involved in data collection attended an intensive three-day training session which consisted of the following fieldwork procedures, managing your caseload, making contact with participants, introducing yourself to the study, arranging appointments, notifying the IDS-TILDA co-ordinator in order to send out appointment cards, providing information and answering questions, obtaining consent and consent procedures, carrying out the interview, collecting the completed Pre-Interview Questionnaire (PIQ), uploading completed interviews and returning hard copy documents, and maintaining contact with the IDT-TILDA office. The comprehensive content of this field researcher training ensures a uniform approach among fieldworker completion of data collection and provides researchers with clarity on their key roles and responsibilities. On completion of the three-day training, the readiness of field researchers is assessed by several participants of IDS-TILDA and members of the PPI panel of the study.

Following the pause in data collection due to the COVID-19 pandemic and the additional ethical approval sought to recommence data collection remotely, changes were required regarding conducting CAPI interviews remotely and re-affirming consent remotely. This researcher, along with members of the IDS-TILDA team developed guidelines and delivered training online for a team of nine experienced Wave 4 field researchers to conduct the remaining interviews remotely. In advance of this training, a pilot of the adapted methods and new questions with 40 individuals with an intellectual disability from five service providers highlighted a general preference by participants with intellectual disability for video over phone interviews. There were no issues of concern identified with the new methods and questions.

3.8 Consent and Recruitment Process

For Wave 1 of the IDS-TILDA study invitation packs were sent to the participants whose PINs had been randomly selected by the RDDA to maintain the anonymity of those selected. Participant consent to take part was dependent on their capacity to consent. Participants received the invitation packs, which contained information about the study in both written and easy to read formats and two consent forms. One consent form was for individual consent and the other was a family agreement form. If the participant had the capacity to consent, they completed the consent form and returned it in a stamped addressed envelope to the IDS-TILDA office. Where an individual, their family member, or keyworker felt that they did not have the capacity to consent, then a family information pack which included a family agreement form was forwarded to the family. From consent forms received at Wave 1, 285 participants self-consented and for 486 participants a family agreement form was received. Following this recruitment approach, on receipt of all consent forms, and after participants were contacted by phone to thank them for participation, the actual recruited complete sample was 753 people.

Consent for participation in this multi-wave longitudinal study was obtained through this process: prior to the commencement of each subsequent wave of the study, every three years, participants were sent a pack which contained an information booklet reminding them of the details and purpose of the study. All 138 service providers were informed in writing that data collection would commence in the near future. A system of process consent is central to the IDS-TILDA study, and where consent had been obtained, this consent is reaffirmed prior to their participation in the CAPI main interview in person and throughout the interview process. Participant's right to withdraw at any stage is reiterated to participants and all field researchers receive in-depth training prior to commencement of data collection at each wave. The IDS-TILDA study since inception has employed a 'keep in touch' strategy, which is seen as essential to retain participants in longitudinal studies. This approach involves the development of and sending reports of key findings to all participants on publication of reports. Regular updates on the study are sent in the form of newsletters, this researcher has been involved in many aspects of supporting this strategy since commencement of the study. Art competitions are held before Easter and Christmas, and winning entries are printed on cards which are sent to all participants. Accessible formats such as videos are developed, including dramatized scenes of key findings which are made available online, and participants are invited to be the actors in the videos. Finally, roadshows and seminars are presented around Ireland by members of the IDS-TILDA team to increase awareness and report on findings of the study.

3.9 Data Collection for the IDS-TILDA Study

There are several components to data collection within the IDS-TILDA study overall. There are five different elements of data collection, which are as follows:

1. The Pre-Interview Questionnaire (PIQ), this is a self-completed questionnaire which is sent to participants in advance of the main interview. PIQs are collected from participants by the fieldworker following the main interview and any supports that participants may require in relation to the PIQ are facilitated by the researcher at that time.

2. The interview in which the main questionnaire is completed. This interview is conducted using a Computer Assisted Personal Interview (CAPI). It is completed in this format to reduce the burden of paperwork on participants.

The third element of data collection involves participants who are living at home with a family carer.

3. The IDS-TILDA Carers' Questionnaire: This is normally sent out to family members in advance of the main interview and is then collected by the fieldworkers after conducting the CAPI with participants.

The fourth and fifth element of the IDS-TILDA study are managed by separate members of the IDS-TILDA team and are as follows:

4. The IDS-TILDA Health Fair, which is a collection of objective health measures and assessments that are carried out by a team of Registered Nurses in Intellectual Disabilities specifically recruited on to the IDS-TILDA team. The Health Fair took place in Waves 2 and Wave 4 but was ceased because of COVID-19 in Wave 4. For this reason, the Health Fair will take place again in Wave 5. The researcher was one of the RNIDs on the team for data collection during Wave 4.

5. The IDS-TILDA End-of-Life Study: this is a questionnaire that is completed by carers and support workers of IDS-TILDA participants who have passed away since the previous wave of data collection.

In response to the COVID-19 pandemic, there were an additional two surveys developed and completed by IDS-TILDA participants at two time points during the pandemic. These were the COVID-19 (phase 1) survey and the COVID-19 (phase 2) survey.

Data for this study included data collected from elements 1 and 2 above, in addition to the data collected from the COVID-19 (phase 2) survey, detailed in section 3.3. Figure 3.2 presents the timeline for Wave 4 data collection, including the incorporation of two COVID-19 surveys (phase

1 and phase 2) into the study. The sources of data used within this study are in bold and highlighted in red in Figure 3.2. A total of 710 CAPI and PIQ were completed by IDS-TILDA participants in Wave 4 and of these, 682 participants completed the supplemental COVID-19 (phase 2) survey. Data from Wave 4 (CAPI and PIQ) and the COVID-19 (phase 2) survey were the primary data sources used within this study.

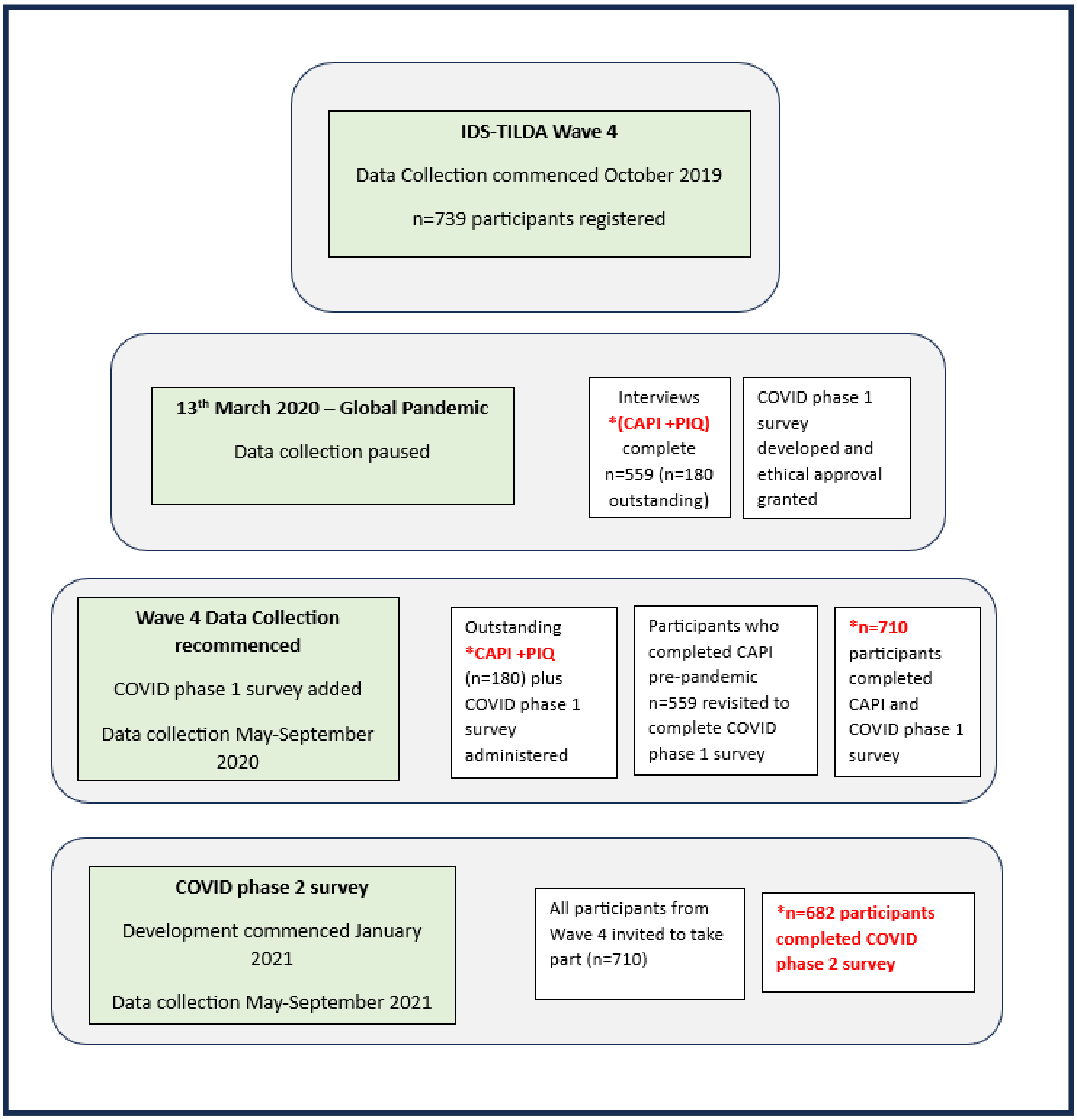


Figure 3.2 Timeline for data collection during Wave 4 IDS-TILDA including COVID-19 surveys.

3.10 Researcher Procedures in the Field

The researcher was entirely responsible for managing a caseload of 100 individual participants during Wave 4 of data collection, in addition to 70 COVID-19 (phase 1) surveys and 100 COVID-19 (phase 2) surveys. This required strict adherence to all IDS-TILDA procedures including ethical considerations, adherence to data protection and confidentiality, and ensuring the wellbeing of participants throughout their involvement in the data collection process. It also included the non-disclosure of any information regarding participants, other than with those whom access had been permitted, strict safeguarding of all documentation at every stage of the process and the use of an encrypted laptop and Virtual Private Network (VPN) when transferring sensitive data. Procedures the researcher employed in the field are outlined below.

3.10.1 Managing Caseload and Arranging Appointments for Main Interview

On receipt of the caseload via a password protected excel spreadsheet, the spreadsheet was downloaded, printed off and the original file deleted from the computer. The hard copy spreadsheet was held in a locked press in the researcher's home and only the details required for each interview were accessed prior to appointments.

In the first instance, the researcher contacted participants, or if this was not possible their keyworker/family carer, to introduce themselves, remind participants of study details where required, arrange an interview appointment which was at the participant's convenience and location of their choosing. During this phone call the field researcher also explained to the participant that they would receive an appointment card along with the PIQ which they had to complete in advance of the main interview for which the appointment had been arranged. Once the details of the interview had been confirmed with the participant, the field researcher provided these details to the IDS-TILDA co-ordinator who sent out an appointment card, which also contained a photograph of the field researcher who would be completing the interview with the participant. The pack also contained an information booklet, and an accessible consent form. The researcher also contacted the participant 24hours prior to the arranged interview via phone call to confirm appointment and to answer any questions in advance.

3.10.2 Consent and Conducting the Main Interview

For Wave 4 prior to the pandemic, and when interviews were conducted in person, upon arrival in the agreed location for the main interview, the researcher introduced themselves and presented participants with their IDS-TILDA photo identification. The study information was then presented to the participant and any questions which may have arisen were answered. The researcher then asked the participant, their keyworker, or carer to complete the accessible consent form which was sent in advance. The researcher used their experience as an RNID while communicating with the participant regarding information on the study and on the consent process. The researcher made every effort to provide the necessary information to the participant in the first instance, and with respect for the participant's level of intellectual disability. This was important to the study and the researcher, as opposed to relying solely on a support person or proxy. Participant's consent was reaffirmed as per study protocol at the beginning, during and at the end of the interview and if the participant appeared uncomfortable or expressed unease during the interview or in response to questions, their right to withdraw or to refuse to answer questions was reiterated.

It was imperative to the researcher that every effort was made to ensure the participant's comfort and wellbeing throughout the interview, and that they were informed, and process consent reaffirmed during the interview. Building trust and rapport from the time of arrival was central to the successful engagement and comprehensive data, and this was very important from the researcher's perspective. To achieve this significant emphasis was placed on sincere and genuine introductions and exchanges with the participant always in the first instance. Friendliness and chatting about the day, or introductions to other members of the household often took place and put participants, their support person, or carer at ease. During the interview, the researcher constantly observed for any signs of tiring or discomfort. If these were observed the participant was invited to take a break if they wished, or to get a beverage/snack or stretch their legs. On several occasions, the interview was held during two appointments after participants became too tired or lacked concentration. On a few occasions, proxy, or support persons were required reminding of their role in the context of the study. Proxy respondents were required to have known participants for a minimum of six months prior to the interview and understood that they were answering questions on behalf of the participant, based on their knowledge of the person, and that answers should not reflect proxies' personal views.

Following the introduction of public health measures, the process of data collection moved from face-to-face interviews to either telephone or videocall based interviews. The process remained largely the same, with a few adaptations; ethical approval for this change has been detailed. These included the completion of the consent form by both the participant and the field researcher, both of which were sent to the study co-ordinator. The PIQ was sent directly from the participant to the IDS-TILDA offices instead of being collected by the field researcher. The processes around introductions, presenting information, answering questions, observing for any signs of unease, reaffirming consent and right to withdraw were all always adhered to.

3.11 Data Cleaning

Following completion of the main interview, the researcher requested the completed PIQ form from the participant and checked the contents for completeness, clarified any anomalies, and made any necessary corrections with the participant or support person. As the main interview was already collected in electronic format, the researcher reviewed the information recorded, corrected spelling mistakes, and removed any potential identifying information. Following this review, the interview was saved and uploaded to the software package, ASKIA, which converted data to an SPSS file for statistical analysis.

3.12 Measures

This section describes the instruments/measures used as dependent variables, and the independent variables which were used within this study. Broadly speaking, the measures that are used in the IDS-TILDA study are designed to be comparable to those used in the TILDA study on the general population of ageing adults in Ireland. Where required the necessary adaptations are made to reflect the needs and abilities of people with an intellectual disability such as wording of questions and prompts suggested to aid understanding. However, there are additional measures included in the IDS-TILDA protocol which reflect the specific features of ageing in Ireland with an intellectual disability. Whilst there are multiple measures available for mental health of adults with intellectual disabilities, there exists a paucity of psychometrically robust measures (Patel et al. 2023). Hatton & Taylor (2013) recognised that there was no 'gold standard' for such measures, nor was there consistency of use of any set of measures within the research. To measure the impact on mental health within this study, the dependent variables are measured using the Generalised Anxiety Disorder-7 (GAD-7), the Patient Health Questionnaire-9 (PHQ-9), a question on loneliness, and a self-rated mental health question. This researcher and the research team of IDS-TILDA were cognisant during survey development of the challenging circumstances surrounding living with the COVID-19 associated restrictions that had been in place for more than twelve months at the time that the COVID-19 (phase 2) survey would be administered. Consideration was given to the duration of the entire survey and the length of measures included. These considerations were balanced with the psychometric properties of mental health measures available for use among the population for this study. Predictor variables comprised of demographic questions, and a large number of single variables (sixty in total) were used to create summary variables which represent resources were lost/gained during the pandemic.

3.13 Dependent Variables

3.13.1 Patient Health Questionnaire (PHQ-9)

The Patient Health Questionnaire (PHQ-9) is a nine-item depression module, which scores each of the nine DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) criteria as '0'(not at all) to '3' (nearly every day) with summed scores ranging from '0' (no depressive symptoms) to

27 (all symptoms occurring daily). The PHQ-9 questionnaire is presented in Table 3.2. The PHQ-9 has been used to make criteria-based diagnosis of depressive disorders and is also a reliable and valid measure of severity of depression (Kroenke *et al.* 2001). This questionnaire may be self-reported, with or without support, or answered by a proxy. The PHQ-9 has been used extensively to screen for psychological wellbeing across diverse populations including caregivers of adults with an intellectual disability (Lin *et al.* 2014), young people with autism (Pilunthanakul *et al.* 2021), people with traumatic brain injury (Lequerica *et al.* 2022), anti-natal depressive symptoms (Murray *et al.* 2022) and in individuals with an intellectual disability (Jenkins 2021).

One of the benefits of the measure is its brevity and ease of use. However, research has been conducted regarding the appropriate use of cut-off scores. A meta-analysis conducted to explore the optimal cut off score when using the PHQ-9 for diagnosing depression identified eighteen studies conducted across a variety of clinical settings were cut off scores ranging from 7-15 were reported. No substantial differences were identified in sensitivity and specificity for cut-off scores between 8-10 (Manea *et al.* 2012). Validity of the PHQ-9 as a brief measure for severity of depression was explored by Kroenke *et al.* (2001) and data from their studies provided strong evidence for the validity of the PHQ-9 as a brief measure for severity of symptoms of depression across two studies involving 6,000 participants. The authors reported that the measure had high internal consistency and produced Cronbach alphas of .86. Sensitivity and specificity were both reported at 88% for major depressive disorder when the score was greater than 10. However, for individuals scoring $\leq$4 they had less than a one in twenty-five chance of having depression (Kroenke *et al.* 2001). This is relative within the context of this study which used the cut-off score of $\geq$5 for mild depression. Yu *et al.* (2023) explored the reliability and validity of the tool among patients with neurological disorders; when the cut-off score was equal to 5, the values of sensitivity and specificity were 91.2% and 76.6% respectively. The authors of the study concluded good reliability and validity among the study population. Arnold *et al.* (2020) found good convergent validity with two measures for psychological wellbeing and the PHQ-9 among participants with autism.

Within the current study the decision to report PHQ-9 score was divided into two categories. Instead of reporting on increasing severity, the decision was made to report on whether participants reported any symptoms of depression. Studies conducted examining the cut off scores as originally suggested (5, 10, 15, 20+) have found that the cut-off score of 5 for mild depression had sensitivity and specificity values of 84.62 and 70.18 respectively, suggesting that use of categories of depression severity are successful in screening for depression (Ghazisaeedi *et al.* 2022). Snijkers *et al.* (2021) report that the choice of cut-off value may have a substantial impact on the sensitivity and specificity of the measure and is dependent on the population, setting and purpose.

The methodological approach to use ≥5 to capture 'any' symptoms of depression, including minimal symptoms using a binary response (having symptoms vs no symptoms) was a pragmatic approach. This is supported by the evidence that measures for screening or measuring mental health conditions among individuals with an intellectual disability, and in particular for those in the severe/profound category, has a range of difficulties (Flynn *et al.* 2017). By including scores which represented even mild symptoms within this study it provided an opportunity to understand the potential impacts that the restrictions may have had on this population. As recognised by O'Regan *et al.* (2011), categorisation of specific subtypes and severity of depression is important for diagnostic purposes in older adults. However, it is also important to recognise any depressive symptoms that may impair daily activities of living, health, or cognition. For people that may have impaired cognitive or functional abilities, depressive symptoms may have significant impact on quality of life. This is particularly relevant through the lens of the COVID-19 pandemic, the unprecedented nature of the lockdowns, and the absence of any previous research from prior pandemics for mental health and individuals with an intellectual disability. This approach was considered as an appropriate way to address the research aim and objectives of this study, which was not to understand the severity of mental health impacts but rather to understand what resources were lost and gained during the pandemic and associated restrictions and mental health impacts.

Over the **last two weeks**, how often have you been bothered by any of the following:		Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)
1.	Little interest or pleasure in doing things?				
2.	Feeling down, depressed, or hopeless?				
3.	Trouble falling asleep or staying asleep, or sleeping too much?				
4.	Feeling tired or having little energy?				
5.	Poor appetite or overeating?				
6.	Feeling bad about yourself – or that you are a failure or have let yourself or family down?				
7.	Trouble concentrating on things, such as reading the newspaper or watching TV?				

8.	Moving or speaking so slowly that other people would have noticed? Or the opposite, being so fidgety or restless that you have been moving around a lot more than usual?				
9.	Thoughts that you would be better off dead or of hurting yourself in some way?				

Table 3.2 PHQ-9 Questionnaire

3.13.2 The General Anxiety Disorder-7 (GAD-7)

The General Anxiety Disorder-7 (GAD-7) is a seven-item anxiety scale in which scores range from 0-21, The GAD-7 is presented in Table 3.3. The first three items on the scale capture the two core criteria of the DSM-IV definition of General Anxiety Disorder (GAD) and enquires about symptoms experienced in the past two weeks. Completion of the GAD-7 requires participants to have the ability to self-report feelings related to anxiety. The GAD-7 has strong criterion validity for identifying probable cases of GAD, and increasing scores on the scale were strongly associated with multiple domains of functional impairment (Spitzer *et al.* 2006). Cut-off scores of 5, 10, 15, and 20 represent categories of mild, moderate, and severe levels of anxiety. Like the PHQ-9, this survey has been used across a variety of clinical and non-clinical settings and has been found to demonstrate good psychometric properties among people with Traumatic Brain Injury (Teymoori *et al.* 2020). It has been used across several studies exploring the impacts of the COVID-19 pandemic for people with disabilities, including intellectual disabilities (Necho *et al.* 2020, Gacek & Krzywoszanski 2021, Skoda *et al.* 2021). For criterion and construct validity, the GAD-7 was examined for associations with self-reported functional impairment by participants and compared with independent diagnosis made by mental health professionals. Increasing scores in the GAD-7 were strongly associated with multiple domains of functional impairment, the GAD-7 was concluded to have good reliability and validity among adult patients attending primary care in the United States with a Cronbach's α score of 0.92 reported (Spitzer *et al.* 2006).

A similar methodological approach is used here as with the PHQ-9, described in the previous section. A score of $\geq$5 to captured 'any' symptoms of anxiety, including minimal symptoms, using a binary response (having symptoms vs no symptoms). This is supported by the evidence that measures for screening or measuring mental health conditions among individuals with an intellectual disability has a range of difficulties (Flynn *et al.* 2017, Patel *et al.* 2023). Including scores which represented even mild symptoms within this study through a binary response provided an opportunity to understand the potential impacts that the restrictions may have had on this population. This is particularly relevant through the lens of the COVID-19 pandemic and the unprecedented nature of the lockdowns and the absence of any previous research from prior pandemics for mental health and individuals with an intellectual disability.

Over the **last two weeks**, how often have you been bothered by the following problems?		Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)
1	Feeling nervous, anxious or on edge				
2	Not being able to stop or control worrying				
3	Worrying too much about different things				
4	Trouble relaxing				
5	Being so restless that it is hard to sit still				
6	Becoming easily annoyed or irritable				
7	Feeling afraid that something awful might happen				

Table 3.3 GAD-7 Questionnaire

3.13.3 Loneliness Question

A scale that is commonly used to measure loneliness is the UCLA loneliness scale. This is a self-reported scale and has undergone several revisions since it was originally designed by Russell et al. (1978). It was originally a 20-item scale designed to measure subjective feelings of loneliness as well as social isolation. The IDS-TILDA study has contained questions on loneliness from Wave 1, originally asking two questions from the three-item loneliness scale and one self-labelling loneliness item. The scale used within the COVID-19 (phase 2) survey consisted of eight questions based on a revision of the scale, made up of four questions divided into two parts. The first question asks ‘do you ever feel…’ with a yes/no response. The second part of the questions asks ‘how often’ with a three-item response: hardly ever, some of the time, most of the time. Scores range from a minimum score of 4 to a maximum score of 12. During analysis of the scale, distribution of responses was positively skewed. Using the Kolmogorov-Smirnov test for normality the result was p<.001 indicating that the distribution of scores is significantly non-normal. Based on these analyses, the measure used for loneliness within the current study was one question deconstructed in two separate parts, this question is presented in Table 3.4.

<table>
<tr><th colspan="7">Since the start of the first lockdown in March 2020, have you ever felt lonely?</th></tr>
<tr><td>Yes</td><td>No</td><td>Unable to answer</td><td>Unclear response</td><td>Don’t know</td><td colspan="2">Refused to answer</td></tr>
<tr><th colspan="7">Since the start of the first lockdown in March 2020, how often have you felt lonely?</th></tr>
<tr><td>Most of the time</td><td>Some of the time</td><td>Hardly ever/never</td><td>Unable to answer</td><td>Unclear response</td><td>Don’t know</td><td>Refused to answer</td></tr>
</table>

Table 3.4 Loneliness Question

Dividing the question into two parts made it simpler for participants to understand. The first part had a lead in of "Do you ever feel….." with a yes/no response. The second part of the question asked, "how often do you feel….." with a three-point response set. Firstly, the participant was asked 'Since the start of the first lockdown in March 2020, have you ever felt lonely'? Where participants answered yes to this question a follow up question was asked: 'Since the start of the first lockdown in March 2020, how often have you felt lonely'? There were three potential responses: 'most of the time', 'some of the time', or 'hardly ever/never'. Responses were categorised as either 'lonely' or 'not lonely'. Responses of 'some of the time' or 'most of the time' were categorised as 'lonely'. Responses where participants answered 'no' to the first question, or 'hardly ever'/'never' to the second question, were categorised as 'not lonely'. This approach has been used successfully across many studies including several longitudinal studies that have examined the impact of the COVID-19 pandemic mental health and wellbeing including loneliness (Ward *et al.* 2019a, Kotwal *et al.* 2022).

There are potential problems for people with intellectual disabilities answering questions related to subjective experiences, such as loneliness. However, McVilly *et al.* (2006), using an adapted loneliness measure, provided evidence that this population are capable of doing so. They administered the questions to 52 participants aged 16-52 years. They cross checked participants scores with a proxy assessment of loneliness and found good consistency of responses. They found that participants were competent in answering questions on loneliness; using test-retest reliability, respondents demonstrated consistency. Findings such as these demonstrate that people with intellectual disabilities have the ability to understand the concept of loneliness. Likewise, Foran *et al.* (2013) tested interrater reliability and test-retest reliability of measures investigating fear of falling among older adults with intellectual disabilities. Although there was less agreement between self-reporting participants and proxies on subjective measures compared to objective measures, their findings highlighted the importance of proxies being carefully selected. Those with the most day-to-day contact and familiar relationship with the individual should be nominated. As a result of potential issues related to reliability, proxy responses were not sought for the loneliness question in this study.

Findings from several longitudinal studies among the general population have reported the implications of loneliness on increased mortality and morbidity, links with cardiovascular risk factors, heart attack and coronary death (Eaker *et al.* 1992, Caspi *et al.* 2006) and that loneliness is associated with increased mortality (Penninx *et al.* 1997). Hawkley & Cacioppo (2010) suggest that the links between physical health and loneliness reflect the 'social essence of our species'. The role that loneliness plays in mental health and wellbeing has been studied, and associations between feelings of social isolation and cognitive decline and dementia (Gow *et al.* 2007) are particularly concerning, especially for those with Down syndrome who experience Alzheimer's Disease and dementia at a higher rate than those without Down syndrome. In Italy, (Gerino *et al.* 2017) conducted a study exploring the mediation effects of mental health and resilience to explain the relationship between mental and physical quality of life and loneliness in old age. They found that loneliness highly influences psychophysical quality of life and is mediated by both mental health and by resilience. Participants within the study were split into two age groups (65-74 years and >74 years) and The UCLA Loneliness Scale (version 3) was used to assess loneliness (Russell 1996).

The experience of loneliness among people with an intellectual disability has received research attention over the past number of years. Findings suggest that people with an intellectual disability experience loneliness at a higher prevalence than the general population. However, there was no research found from previous pandemics which reported on the experiences of loneliness, or any other mental health impact during implemented public health measures in response to these pandemics. Research studies conducted among the general population report anxiety, depression, isolation, and PTSD as impacts felt during these pandemics and in their aftermath (Park *et al.* 2020, Ahn *et al.* 2022, Delanerolle *et al.* 2022). Ernst *et al.* (2022) carried out a systematic review of the literature exploring loneliness before and after the COVID-19 pandemic; most of the studies (n=8) found an increase in loneliness, eight reported no change and one reported a decrease in loneliness.

3.13.4 Self-Rated Mental Health

Self-rated health was assessed using a single item from the RAND 36-item health survey (version 1.0) developed as part of the Medical Outcomes Study (Ware & Sherbourne, 1992). The self-rated mental health question asked all participants 'How has your mood and emotional or mental health been during the COVID-19 pandemic? Has it been …? The respondent is provided with five possible answers: excellent, very good, good, fair, or poor. The use of a self-rated tool to measure mental health has been found to be useful for monitoring a population's general mental health. It was adapted from other longitudinal studies such as TILDA (Ward *et al.* 2019b), (The English Longitudinal Study of Aging (ELSA) (Gupta *et al.* 2020), and Health and Retirement Study (HRS) (Wallace & Herzog 1995) and provides an opportunity for comparability of responses with the general population. Since the first wave of the IDS-TILDA study (McCarron *et al.* 2011), self/proxy rated mental health using a 5-point Likert scale, which was derived from the RAND-36 item survey, has been administered to participants of the study. Although there has consistently been a high prevalence of mental health conditions reported among the participants of the study, as well as in various other studies involving individuals with an intellectual disability, there has been a relatively good level of mental health reported. From Wave 3, of the n=592 valid responses obtained, more than three quarters rated their mental health as either excellent/very good (33.3%), or good (44.3%). It has been noted throughout the IDS-TILDA study that self-reporting participants rate their mental health higher than those that either self-report with support or proxy response only. When compared to the self-rated mental health of the comparable group within the general population in Ireland, participants rate mental health as excellent (25%), very good (35%) or good (30%) (O'Regan, Cronin & Kenny 2011). This represents 77.6% among those with an intellectual disability compared to 90% in the general population.

The use of self-rated mental health tools has also been used in response to the COVID-19 pandemic and the impact that it has had on mental health, with higher levels of mental health problems and poorer mental health related quality of life (Leaune *et al.* 2022). It has also been found to be a useful measure when exploring the experiences of people with an intellectual disability (McCarron *et al.* 2014, McCarron *et al.* 2017a, McConkey *et al.* 2018). Bailey *et al.* (2022) used a phenomenology approach in a study carried out with eight adults with intellectual disabilities on their perception of positive mental health. Findings suggest that understanding varied among participants but for many positive mental health and health were synonymous. Bailey *et al.* (2022) suggest that this may be due to a greater understanding of the concept of 'health' being more concrete. However, some individuals were clear on their understanding that healthy eating and engaging in exercise contributed to overall positive mental health. Exploring the resources, which are captured within the independent variables that were associated with self-rated mental health, contributes to the objectives of this thesis, and further aids the understanding of the resources that were associated with mental health outcomes among older adults with an intellectual disability in Ireland during the pandemic. Again, the large scope of the study and the considerable breadth of personal and social resources that were included within the COVID-19 (phase 2) survey allowed for a comprehensive exploration of variables which may have impacted on mental health.

3.14 Predictor variables

The IDS-TILDA study collects a considerable range of data across all aspects of the lives of individuals with an intellectual disability. It has learned and built upon what is important and significant in people's lives, which may at times differ from persons without an intellectual disability. Development of the COVID-19 (phase 2) survey was underpinned by the longitudinal data from the IDS-TILDA study and this study was uniquely positioned to gather data which was informed by this knowledge.

Additionally, a review of the available research at the time of the unprecedented and ongoing pandemic was undertaken. Several important areas that had the potential to impact on mental health in the lives of older adults with an intellectual disability were identified. A list of 'resources' were developed, consistent with the COR theory. Resources had the potential to be either, or both losses and gains. To ensure the greatest opportunity to explore the resources which were lost and gained during the COVID-19 lockdowns, a total of 60 single items from the COVID-19 (phase 2) survey were used to create predictor variables. These included six demographic variables. These were: age, sex, level of intellectual disability, type of response to survey, aetiology of intellectual disability, and living circumstances. Inclusion of demographic variables provides opportunity to identify factors associated with mental health outcomes. It also allows for comparison with the general population and with similar studies. Furthermore, research by Baksh et al. (2023) found that identification of specific subgroups based on common features within the intellectual disability population may improve development of more tailored interventions for mental health.

It was crucial to ensure that the resources used within this study were appropriate and relevant to the lives of older adults with an intellectual disability in Ireland. Consultation with the PPI panel of IDS-TILDA regarding the resources which had been constructed from the broad literature review and the scoping review to inform this study was ensured. In advance of this meeting, the researcher had been heavily involved in data collection with participants during Wave 4 and the COVID-19 (phase 1) survey and had opportunity to listen to participants experiences of the restrictions and the losses and gains that were experienced by many older adults with intellectual disabilities across Ireland. This also provided an insight and an understanding of the impacts that the pandemic was having on people's lives. As COVID-19 restrictions were in place at that time, the researcher met with PPI panel members via videoconferencing and presented the proposed resources for consultation. The PPI panel approved of the resources presented and although members had each experienced differences in terms of losses and gains within the resources, they agreed that personal circumstances such as where one resided resulted in differences in perspectives of the resources that were important. This important observation strengthened the rationale for inclusion of demographic variables within this study, as there is clearly heterogeneity within this population. It is critically important to ensure that people with intellectual disabilities are on advisory groups, are co-producers and co-researchers when research, service planning and policy are related to their lives. As highlighted by Hobfoll *et al.* (2018a) it is very difficult for a study to successfully illustrate every resource which could potentially affect an individual in a given environment, and that resources at times may be difficult to define as they can have a very individualised meaning. Therefore, in the context of research involving people with intellectual disabilities, ensuring that there is consultation and a disability inclusive approach when considering resources within the lives of people with intellectual disability was paramount.

The resources of; diagnosed mental health disorders, medication prescribed for mental health, reduction in day service/work hours, and access to mental health supports were single items from the survey. The remaining variables were summary variables, these were: physical health, physical distancing/infection history, social activities and engaging in alternative activities, relationships, illness and bereavement, stress/anxiety, and resilience. Summary variables were created by writing a syntax in SPSS whereby if participants answered 'yes' to any of the single variables contained under the resource heading, this was labelled as a 'yes' response to the summary variable. If participants answered 'no' to all the single items, this equated to a no response for the summary variable. The single item variables which were included within each summary variable are presented in detail in this chapter, section 3.14.11 - 3.14.16. Table 3.4 and Table 3.5 presents the resources which were included within this thesis as predictor variables.

Resource Loss	
• Mental health disorder	• Physical distancing and infection history
• Use of medication related to mental health	• Social activities
• Access to mental health supports	• Relationships
• Reduced work/day services hours	• Illness and bereavement
• Physical health	• Stress/anxiety

Table 3.4 Resources lost during the pandemic by older adults with an intellectual disability.

Resource Gain	
• Mental Health Disorder	• Physical Health
• Use of medication related to mental health	• Engaging in alternative activities
• Access to mental health supports	• Relationships
• Resilience	

Table 3.5 Resources gained during the pandemic by older adults with an intellectual disability.

Predictor variables are described here in greater detail. A complete list of predictor variables is provided in Appendix 11.

3.14.1 Sex

Participants' information on sex was collected at the stage where participants joined the IDS-TILDA study and is fed forward and rechecked for accuracy at commencement of each wave of data collection, specifically at the CAPI stage. There are currently two categories of response for this variable, male or female.

3.14.2 Age Category

Age within the IDS-TILDA study is divided into three categories as follows; less than 50 years (<50 years) refers to participants that are between the age of 40 and 49 years, between 50-64 years (50-64 years), and older than 65 years (65 years+). Based on the longitudinal data collected by the IDS-TILDA study, this categorisation of age groups presents accurate points at which participants experience various age-related conditions, experiences, and opportunities than are comparable with the general population.

3.14.3 Level of Intellectual Disability

Intellectual disability categorisation has been discussed in the study definitions in Chapter 1 (1.3.1) based on DSM IV criteria. Within this study there are three categories. This is due to the smaller numbers of people that are categorised as having severe or profound intellectual disabilities; these two categories are combined. Therefore, the three categories within this thesis are mild, moderate, and severe/ profound intellectual disability.

3.14.4. Living Circumstances

There are three types of 'living arrangements' that are options for selection by participants. These are:

1. Independent/family: this refers to where a participant is living either independently, this may be on their own or in a house with others but requires limited support or living with a family member.

2. Community/group home: this is related to when an individual is living in a house which is based anywhere in a community setting (i.e., not on the grounds of an old institutional setting) and is supported by staff, usually living either alone or with other people with an intellectual disability.

3. Residential/campus: this setting refers to people that are living in houses/homes that are on the grounds of the old institutional buildings, or purpose built in clusters by services providers where there are numbers of people with intellectual disabilities living together and in close proximity to each other.

3.14.5 Response Type

Due to communication difficulties which are a feature of intellectual disabilities there are people that require support with expressive and receptive communication. For this reason and to encourage participation from the greatest numbers of people with intellectual disabilities within this study, three response types are available. For the first two categories, there are several measures within the survey that can only be answered by either the person themselves, or by the person with support, but not by a proxy respondent. The rationale for this is that there are some feelings, emotions, and perceptions that are too subjective and personal to an individual and it would not be appropriate or ethical to report on a proxy's interpretation of such personal issues. The three categories of response are:

1. Self-report, this refers to where the participant answers the survey independently and without assistance from another person, the person may opt to have either a family member, friend or support worker remain with them in a supportive capacity during the interview, but the individual themselves answers the questions.

2. Self-report with proxy support, this is when an individual has a person of their choosing attend the interview with them and this person may help to either explain, or to convey the participants answers verbally where the participants may have difficultly doing so, or where the interviewer may have difficulty understanding the participants form of communication.

3. Proxy response, this is where a person that is well known to the participant (longer than six months) answers the survey to the best of their knowledge on the participants experiences and situation. Many participants will remain present during the interview with the interviewer and proxy, and some will choose to not attend. There is also the option throughout the interview to move between response types, where a participant may prefer to answer some questions independently and may then opt to have a support person answer some of the other questions.

3.14.6 Aetiology of Intellectual Disability

There are two categories within this variable, have a diagnosis of Down syndrome or other/unknown cause of intellectual disability. Although there are many diagnoses which people may have in terms of the cause of an intellectual disability, within the IDS-TILDA study this is the current data that is being collected. Over the course of the IDS-TILDA study, it has been found that there are differences in the findings between people who have Down syndrome and for individuals who do not.

3.14.7 Reduction in Day Service/Work Hours

The question asked in the survey related directly to Day Services/Work was, as below:

Reduced work / Day service – Resource loss			
Participants were asked, for each of the following, please indicate whether the pandemic has affected [you/Rname] in the way described - Reduced work hours/hours of day service.			
The following answers could be recorded:	Yes	No	N/A, unable to understand, unclear response, don't know, refused to answer

This question was used as a single variable and not combined with any others. According to the NASS (Casey *et al.* 2021) in 2020, figures regarding occupational status for people with intellectual disabilities over the age of 18 years, were as follows: 20.1% (n=3, 534/17,541) were attending a training/day service programme, 1.2% were students, and 5.2% in paid employment. Day services provide programmes to assist people in making choices and plans and to be an active, independent member of the community (HSE 2017). There are very low numbers of people with an intellectual disability in paid employment. McCausland *et al.* (2020) suggests that the presence of a day service provides an occupational activity for individuals with an intellectual disability and that this activity was associated with better mental health outcomes. However, all these services were closed in line with public health measures on March 13th, 2020, and many remained closed for up to and exceeding a year in some cases. Given the potential for socialisation, meeting friends, and completion of training or educational programmes which may be factors or enjoyable aspects of attendance at day services, this was an important variable for inclusion within this study. Findings from the scoping review also provided evidence which reflects the impacts that closure of services, training, and work placements of people with intellectual disabilities had during the pandemic (Kim *et al.* 2021b, Lake *et al.* 2021, Peacock-Brennan *et al.* 2021).

3.14.8 Mental Health Disorder

Respondents who reported a mental health disorder in previous wave of the IDS-TILDA study are asked during their CAPI interview if they still have the previously stated mental health disorder and for confirmation that they had received this diagnosis from a doctor. Participants were also asked if they had received a new diagnosis since the previous interview. The following list of disorders is provided, with the option to identify any disorder not on the list under ‘something else’ where the answer can be recorded in free text.

- Hallucinations
- Anxiety
- Depression
- Emotional problems
- Schizophrenia
- Psychosis
- Mood swings
- Manic depression/Bi-polar
- Post-Traumatic Stress Disorder (PTSD)
- Something else

3.14.9 Access to Mental Health Supports

The question directly related to mental health supports in the survey was as below:

Access to mental health supports – gain and/or loss			
If [you/Rname] felt anxious, lonely, or depressed, were/was [you/Rname] able to access supports for [your/his/her] mental health (e.g., counselling/seeing a psychologist/seeing a nurse or doctor)?			
The following answers could be recorded:	Yes	No	N/A, unable to understand, unclear response, don't know, refused to answer
If "yes", what support did [you/Rname] receive:			

National mental health policy in Ireland (DOH 2020) is recovery focussed and highlights the importance of talk therapies. It also cautions on an over-reliance on the use of pharmacology to treat mental health conditions. This is particularly relevant among the intellectual disability population where there is excessive pharmacology and polypharmacy reported (O'Dwyer *et al.* 2019). Based on findings from the literature review conducted within this study, it was evident that this was an important resource to gain an understanding on and any potential association that access to mental health supports may have had during the COVID-19 related restrictions. Health disparities among people with intellectual disabilities and the general population are well documented; however, further disparities related to healthcare utilisation and in particular access to psychiatric health care have been highlighted by Ahlström *et al.* (2020).

3.14.10 Medication Prescribed for Mental Health Disorder

Data related to medication usage for IDS-TILDA participants was collected in the PIQ which was sent to participants in advance of the Wave 4 CAPI. Further details have been provided in Chapter 3 (3.9). This was to allow adequate time to be assigned to completion of the information by the participant. Data was collected relating to all medicine groups. However, for inclusion within the analysis of this thesis specific data on anxiolytics, anti-depressant and anti-psychotic medication was analysed. There are high rates of polypharmacy (usually defined as 5 or more drugs) within the intellectually disabled populations, and these include medicines related to mental health (O'Dwyer *et al.* 2019, McMahon *et al.* 2020, Lonchampt *et al.* 2021). There is limited data related to the use of medication among people with disabilities in the context of the COVID-19 pandemic. Based on the impacts on mental health which are evidenced in the literature, this researcher took the opportunity to explore any associations or relationships which may exist between mental health impacts when medication related to mental health was a variable.

3.14.11 Physical health

Participants were asked several questions related to physical health and these were combined to create a summary variable ‘physical health’. Although the inclusion/exclusion of some single variables within this summary variable may be argued such as ‘more time in nature/outdoors’, or ‘getting less medical care than usual’, the researcher has provided transparency on the included variables and has provided evidence to support their inclusion within the summary variable. Description of how summary variables were created is provided in section 3.12.

The five variables within ‘physical health’ which represented loss of resources were:

Physical Health – Resource loss			
For each of the following, please indicate whether the pandemic has affected [you/Rname] in the way described. Since the coronavirus disease pandemic began in March 2020, what has changed for [you/him/her]? 1. Increase in health problems not related to this disease (COVID-19) 2. Less physical activity or exercise 3. Overeating or eating more unhealthy foods (e.g., junk foods) 4. More time sitting down or being sedentary 5. Got less medical care than usual			
The following answers could be recorded:	Yes	No	N/A, unable to understand, unclear response, don’t know, refused to answer

The three variables within ‘physical health’ which represented gain of resources were:

Physical Health – Resource gain	
If there were good things during the COVID-19 period, what were they? 1. Increase in exercise or physical activity 2. More time in nature or outdoors 3. Paid more attention to personal health	
The following answers could be recorded:	Yes - Please tick all that apply

As the health services were placed under serious pressure due to rates of coronavirus infections, some services were cancelled, postponed, or rescheduled. Access to out-patients’ appointments was impacted as well as scheduled or non-emergency surgeries. For a population with significant healthcare needs, access to healthcare services were likely to be reduced or lost in some instances. On the 18th October 2021, the Department of Health and the HSE published a document indicating that, at that time and as a result of the COVID-19 pandemic, there were 653,524 patients waiting for a first hospital outpatient consultation with a further 74,869 patients waiting for an appointment for their inpatient or day case treatment, 32,001 patients were waiting to receive an appointment for a GI Endoscopy (DoH 2021).

The pandemic also forced people to find new ways in which to spend their time when many public and private business were closed. The combination of more time spent at home and restrictions on the distances that people could travel from their homes provided opportunities for novel and alternative ways in which to spend their time. This may have resulted in some people having a new interest in their personal health or realising the importance of engaging in physical activity or personal care. Brand *et al.* (2020) found that in the period between March and May 2020, using a sample of 16,137 participants across 99 countries, there was a slight increase in exercise frequency during this stage of the pandemic. They report that that two-thirds of those that never or rarely exercised might adopt or increase their exercise frequency. In a study conducted among college students (n=206) in the United States, there were opposing findings regarding exercise. While many (n=103) reported more positive relationships with exercise and movement others did not and exercised less (n=78), while 35 participants were neutral towards the statement 'I exercise more during the pandemic (Yon *et al.* 2022).

For people with an intellectual disability the opportunity to engage in exercise and in new behaviours related to physical activity was a potential positive that they experienced and gained resources as a result. However, if people had been used to attending the gym or benefitted from taking part in team-based activities, for example, they may have experienced losses in terms of resources. Similarly, if there was a deficit in accessing healthcare services which were required to diagnose, treat, or maintain health conditions for individuals, they may have experienced decline or losses in their physical health, such as for chronic health conditions.

3.14.12 Physical Distancing and Infection History

Description of how this summary variable was created is provided in section 3.12. The four variables within 'physical distancing and infection history' which represented loss of resources were:

Physical Distancing and Infection History – Resource loss			
1. Since the coronavirus disease pandemic began, has [your/Rname's] entire household been quarantined for a week or longer? 2. Since the coronavirus disease pandemic began, [have/has] [you/Rname] limited physical closeness with a loved one due to concerns of infection? 3. If [you/Rname] were/was tested, please indicate if the test was positive (+) or negative (-) 4. If [you/Rname] tested positive, and/or had symptoms of COVID-19, [were/was] [you/Rname] hospitalised?			
The following answers could be recorded:	Yes	No	N/A, unable to understand, unclear response, don't know, refused to answer

Strict isolation and quarantining measures were implemented to curb the spread of the coronavirus. These measures were different depending on the point in time, the rate of spread of the infection, the vaccination roll out programme, and other factors. Infected people and close contacts, such as people living in the same home were required to isolate for a period of up to 14 days at some points during the pandemic. From previous pandemics, isolation and fear were several of the consequences that were felt by those that were impacted. The above variables were included under the domain 'physical distancing and infection history' to capture participants who were impacted by isolation, quarantining, and by being infected with the disease. Where people required hospitalisation because of more severe infections, this may have resulted in considerable loss of resources beyond the physical illness, such as limited supports while in hospital due to restrictions and difficulties with communication.

Measures in Ireland included a two-metre distance to be maintained between people in social and public settings, restrictions on visitors in homes and gardens, closure of services, schools and colleges, restrictions in travel distance from homes, as well as hygiene practices. Although there were resources circulated to communicate these measures to all, including booklets prepared on behalf of the Government of Ireland and the HSE, delivered to all homes with accessible versions created, there were still difficulties for many in understanding and adhering to these unprecedented measures. Early studies found that difficulties understanding public health measures was an area of concern for individuals with an intellectual disability (Inclusion Ireland 2020, Murphy *et al.* 2020) with some citing negative experiences involving members of the public when measures were not fully understood and adhered to. These changes in 'normal social behaviours' presented as a potential loss of resources for individuals with an intellectual disability in terms of knowledge, understanding, and ability to conduct oneself in a manner that is 'socially acceptable' as this concept had been critically adjusted because of the COVID-19 pandemic.

There were no positives identified which fit under this domain and, therefore, experiences by participants were considered losses in resources. While the IDS-TILDA study did collect data related to the COVID-19 vaccine including uptake, side-effects, and participants' opinions on receiving it, this was not included within this study. As the roll out of the vaccine was ongoing at the time of data collection it was not possible to capture if there was any impact on mental health before and after receiving it. Participants provided their answers to the question 'what did getting the vaccine mean to you?' and the responses were resoundingly positive (McCausland *et al.* 2021a).

3.14.13 Social Activities and Engaging in Alternative Activities

Description of how this summary variable was created is provided in section 3.12. The five variables within ‘social activities’ which represented loss of resources were as follows.

Social Activities – Resource loss			
For each of the following, please indicate whether the pandemic has affected [you/Rname] in the way described. 1. Family celebrations cancelled or restricted 2. Planned travel or vacation cancelled 3. Religious or spiritual activities cancelled or restricted 4. Unable to participate in social clubs, sports teams, or volunteer activities 5. Unable to do enjoyable activities or hobbies			
The following answers could be recorded:	Yes	No	N/A, unable to understand, unclear response, don’t know, refused to answer

The four variables within ‘engaging in alternative activities’ which represented gain of resources were:

Engaging in Alternative Activities – Resource gain	
If there were good things during the COVID-19 period, what were they? 1. Developed new hobbies or activities 2. More rest/relaxation 3. More free time 4. Saved money	
The following answers could be recorded:	Yes - Please tick all that apply

Opportunities to engage in social activities were severely impacted because of the COVID-19 pandemic and associated restrictions. Closure of restaurants, bars, cinemas, and cancellation of concerts and shows greatly reduced people’s ability to socialise, in addition to the restrictions on the numbers of people that were permitted to come together in groups both inside and outside their homes. As already described, for people with an intellectual disability living in long term residential facilities and those that relied on caregivers who were ‘cocooning’ to support them while outside of their homes, the restrictions created additional obstacles to socialising. McCarron *et al.* (2020) found that in response to a question asking participants ‘what were they most looking forward to after the pandemic’ most participants expressed a desire to get back to normal, to return to eating out, attending shows and concerts, and having a few drinks. However, in a survey conducted between May and September 2020 following the first COVID-19 lockdown in Ireland, 38% of participants reported positive aspects of the lockdown including: engaging in new or alternative activities such as having more free time, being able to have a lie in, and 41% took the opportunity to engage in new activities or hobbies. Where participants identified ‘loss’ regarding socialisation and ‘gains’ in terms of free time and new hobbies, these changes in resources are explored to understand potential impacts on participants mental health that concurrently experienced losses and/or gains may have had.

3.14.14 Relationships

Description of how this summary variable was created is provided in section 3.12. The five variables within 'relationships' which represented loss of resources were:

Relationships – Resource loss			
For each of the following, please indicate whether the pandemic has affected [you/Rname] in the way described. 1. Separated from family or close friends 2. Did not have the ability or resources to talk to family or friends while separated 3. Unable to visit loved one in a care facility (e.g., nursing home) 4. Increase in verbal arguments or conflict with others in the home 5.Increase in physical conflict with others in the home			
The following answers could be recorded:	Yes	No	N/A, unable to understand, unclear response, don't know, refused to answer

The six variables within 'relationships' which represented gain of resources were:

Relationships – Resource gain	
If there were good things during the COVID-19 period, what were they? 1. Spending more time at home/with family 2. Improved relationships with family or friends 3. New connections made with supportive people 4. More time/better time with staff 5. Using technology to communicate 6. Less doing things that challenge people close to me	
The following answers could be recorded:	Yes - Please tick all that apply

Research studies report that people with an intellectual disability have more restricted social networks and fewer friends outside their family and paid support staff (Emerson & McVilly 2004, Amado 2014). Using data from a nationally representative sample of adults over the age of 40 years, McCausland *et al.* (2021d) reported that 62.5% of participants expressed that friendships with staff were important. While Sigstad (2016) recognises the importance of friendship for adolescents with an intellectual disability, from a parental viewpoint sustaining meaningful friendship among this population requires considerable effort on behalf of their parents when compared with their non-disabled peers. As discussed in the previous section (4.1.2), in response to the COVID-19 pandemic, there were forced changes to how disability services adapted in order to comply with public health measures. This involved movement and redeployment of staff within services and dealing with staff absences because of contracting the virus. These changes had the potential to impact on the relationships between individuals with an intellectual disability and the staff with which they were familiar. There were initial reports from several small-scale Irish studies that these impacts were felt significantly by individuals who were no longer attending day services and there were reports that communication and contact had reduced and/or broken down due to these closures. However, for some there were positive reports regarding adaptations and changes that were made to their services which maintained good levels of contact (Inclusion Ireland 2020, Murphy *et al.* 2020). McCarron *et al.* (2020) reports similar positive experiences from participants over the age of 40 years following the first wave of the COVID-19 pandemic. 55% of respondents from a sample of 710 participants reported positive aspects of the lockdown; of these respondents 26% cited better relationship and connections with support staff. The literature reflects that there was a potential for both loss and gains in the staffing changes that occurred during public health measures. Individuals with an intellectual disability may have been negatively impacted as a result of staff being redeployed away from service users to other areas or as a result of staff absences. However, the closure of some services may have provided opportunities for people to spend more time together and build relationships while not focussed on task-based activities such as travelling to and from services or accessing services within the community.

Personal resources including family and friendship and ability to meet and engage with those closest to us provides opportunities for sharing, physical contact, and socialising. As already highlighted, individuals with an intellectual disability tend to have smaller social networks than their non-disabled peers. The restrictions imposed as a result of the COVID-19 pandemic significantly limited peoples' ability to see family and friends with whom they did not live or to take part in socialisation outside of the home during the most severe of restrictions. McCarron *et al.* (2020) found that people's living circumstances had an impact on how individuals with an intellectual disability experienced missing family and friends due to the pandemic. Those living independently or with their families missed friends more than those living in residential or community-based settings; for those in residential and community-based settings, they missed their family to a greater extent. For people with an intellectual disability there were additional restrictions which they were exposed to both directly and indirectly. For 63% of people with an intellectual disability in Ireland, they live in the family home (NASS 2020) with ageing caregivers, and many of these caregivers were required to 'cocoon' or remain in their homes for prolonged periods due to public health measures. For their adult child with an intellectual disability living with them, this also resulted in them having to remain in the home despite not being of an age where cocooning was required, particularly if they required support to leave the home and access their community. In addition to this, there are 7,601 people with an intellectual disability living in residential service settings and 26,644 people with an intellectual disability using day services (NASS 2020). For all these people their ability to see family, friends and to engage in social activities was severely limited.

There have been barriers reported in the use of assistive technology by individuals with an intellectual disability (Boot *et al.* 2017, Boot *et al.* 2020). There are also studies that report a significant underuse of what many consider day to day technologies such as mobile phones, the internet and social media, with less than a quarter of respondents owning a mobile phone and less than one in twenty being able to send a text (McCarron *et al.* 2014), with only slight increases three years later in the longitudinal study. McCarron *et al.* (2017a) reported just above a quarter (26.2%) owning a mobile phone with 16.7% of these saying that they do not actually use it. 34.9% reported that they had access to the internet via phone, a laptop, or tablet, however, use of these technologies was infrequent. As a result of the COVID-19 pandemic and associated restrictions in movement, many had to adapt to new ways of staying in contact with family and friends and working remotely. There is some evidence to suggest that this forced change in circumstances has accelerated the availability and use of technology among individuals with an intellectual disability (McCausland *et al.* 2021b). While some found the use of Zoom and Skype helpful to stay in contact with their day service, family and friends, others found it very difficult to engage through such a medium, and certainly did not see it as a replacement for face to face interactions (Murphy *et al.* 2020). The changes in use of technology by participants within this study may been considered a gain in resources; this is explored further in the analysis.

3.14.15 Illness and Bereavement

Description of how this summary variable was created is provided in section 3.12. The five variables within 'illness and bereavement' which represented loss of resources were:

<table>
<tr><th colspan="4">Illness and bereavement – Resource loss</th></tr>
<tr><td colspan="4">For each of the following, please indicate whether the pandemic has affected [you/Rname] in the way described.
1. Unable to be with a close family member in critical condition
2. Unable to attend in-person funeral or religious services for a family member or friend who died</td></tr>
<tr><td>The following answers could be recorded:</td><td>Yes</td><td>No</td><td>N/A, unable to understand, unclear response, don't know, refused to answer</td></tr>
</table>

Please indicate if [you/Rname] [have/has] gone through any of the following during the pandemic. 3. Death of a parent 4. Death of a sibling 5. Death of another relative 6. Death of a friend 7. Death of a significant other 8. Death of a pet	
The following answers could be recorded:	Yes - Please tick all that apply

Since the beginning of the COVID-19 pandemic there have been in excess of 695,189,446 infections and 6,914,967 deaths worldwide (Worldometer 2023). This has resulted in many people all over the world experiencing death and illness of family and friends due to COVID-19. For individuals with an intellectual disability, studies report that multiple and negative life events are experienced at a greater frequency and burden than the general population (Bond *et al.* 2019). Included in Life Events (Hermans & Evenhuis 2012) are bereavement of a parent, sibling, other relations, friends, and pets. As previously discussed the majority of people with an intellectual disability in Ireland reside with family members and in many cases ageing care givers (McConkey & Craig 2018). Given the risk factors presented for adverse outcomes in the event of contracting the coronavirus, older people, those with underlying health conditions, many caregivers were at greater risk of mortality because of the virus.

The demands put upon many family caregivers of adult children with an intellectual disability are high, and the supports that they provide are significant to maintain the individual's ability to continue to live in the family home. The lack of residential services for these people means that, for many, a residential placement is only provided when there is a crisis in the family home, such as the death or serious illness of a caregiver. For any person with an intellectual disability who experiences such a crisis the loss of resources spans many areas of their life, including living arrangements, family supports and relationships, mental and emotional health and much more. Illness of a loved one may result in additional demands upon the person with an intellectual disability where they themselves may acquire the caregiver role or responsibilities within the home. In Ireland people with an intellectual disability were categorised as high risk in respect of contracting the disease, and if contracted at risk of more adverse consequences (HSE 2020a). Internationally there were different approaches taken regarding specific public health guidance for people with an intellectual disability. In the United Kingdom, initially they were not categorised at greater risk. However, this guidance was reviewed and adjusted as the pandemic progressed and greater numbers of people contracted the virus and died (Williamson *et al.* 2021). Higher death rates for people with an intellectual disability have also been reported in the United States (Landes *et al.* 2020) and in Wales (Watkins 2020). Due to the high numbers of deaths reported internationally of people with an intellectual disability, this study also includes bereavement due to loss of friends with intellectual disabilities.

3.14.16 Stress/Anxiety and Resilience

Description of how this summary variable was created is provided in section 3.12. The eight variables within 'stress/anxiety' which represented loss of resources were:

Stress/Anxiety – resource loss	
Have/has [you/Rname] felt stressed/anxious about any of the following during the COVID-19 period? 1. Fear of getting COVID-19 2. Fear of peers/friends getting COVID-19 3. Fear of family members getting COVID-19 4. Isolation 5. Not being able to do usual activities 6. Not seeing friends 7. Not seeing family 8. Change in staff	
The following answers could be recorded:	Yes - Please tick all that apply

The two variables under 'Resilience' which represented gain of resources were:

Resilience – resource gain	
If there were good things during the COVID-19 period, what were they? 1. Being resilient/mentally tough 2. More appreciative of things usually taken for granted	
The following answers could be recorded:	Yes - Please tick all that apply

When the COVID-19 (phase 1) survey was developed the protocol included the question 'If you did feel stress/anxious about the COVID-19, what was the reason?' Participants were provided with the following list of options: fear of getting COVID-19; fear of peers/friends getting COVID-19; fear of family members getting COVID-19; isolation; feeling lonely; not being able to do usual activities; not seeing friends; not seeing family; change in staff; not being in own room; and other. Based on the findings from the first survey, this question was repeated in the second survey and is captured within the resilience summary variable. Similar to the first COVID-19 survey, participants were asked about being resilient or mentally tough, and having more appreciation for things that they may have taken for granted. Participants indicated that these were feelings that they had experienced during the initial stages of the pandemic both within the survey and in free-text answers. This was repeated in the COVID-19 (phase 2) survey. As resilience is an under studied concept within the lives of people with intellectual disabilities (Scheffers *et al.* 2021) and as participants had identified this as a positive aspect of the pandemic, this was considered an important variable to include. Acknowledging that this is a complex construct to quantify and measure, there are clear associations with resilience and gratitude noted in the literature (Lasota *et al.* 2022, Manuel 2022). The resource was titled 'resilience resource gain', this is not to imply that the concept of resilience was explored beyond the two single items that are presented.

3.15 Data Analysis

The SPSS package (version 27) was used to perform statistical analyses of IDS-TILDA data. The researcher undertook their own analysis of Wave 4 data and data from the COVID-19 (phase 2) survey in adherence with the overall data management protocols of the IDS-TILDA study. A range of descriptive, bivariate, and multivariate analyses were performed to address the research objectives of the current study.

3.15.1 Descriptive Statistics

Chapters 5 – 8 each address a different dependent variable – PHQ-9, GAD-7, loneliness question, and self-rated mental health. For each of these dependent variables, the same group of participants and independent variables were used for analysis. Basic descriptive data are presented, frequencies and percentages are provided which are the appropriate descriptive statistics for categorical data, as is the case with all data used in this study. Cases with any missing data were excluded from the relevant analysis.

3.15.2 Pearson's Chi-square

The appropriate non-parametric test to explore the relationship between two categorical variables is the Pearson's chi-square test. It compares the observed frequencies or proportion of cases in each category with the values that one would expect if there were no association between the two variables (Pallant 2010). A chi-square test was carried out between each independent variable and each dependent variable to establish if a relationship existed between mental health outcomes and independent variables, including demographic data related to participants. On a few occasions, the sample size of responses was small, and the Fishers exact test was the appropriated statistical test for use in analysis. The use of Fishers exact test was determined when more than 20% of cells had expected frequencies <5.

3.15.3 Logistic Regression

Logistic regression was used in the current study to test models to predict categorical outcomes with two or more categories. Within the current study, a binary logistic regression was the appropriate approach when all predictors were dichotomous, that was the PHQ-9, the GAD-7, the loneliness question and for the self-rated mental health measure.

The demographic variables of: age, gender, living circumstance, level of intellectual disability, survey response type, and aetiology of intellectual disability were controlled for across all four binary logistic regression models. The backward selection option in the regression model was the method selected for this study based on a range of factors. This included trial and testing of alternative options by the researcher, and consultation with the literature. To test the type of modelling which had the best ‘fit’ the AIC of models using the forward and backwards selection approach was carried out; the model with the lowest AIC was the backwards stepwise approach. The use of a backward stepwise approach is considered appropriate unless the number of candidate variables are greater than the sample size (Choueiry & Salameh 2019, Choueiry 2023), which is not the case within the current study. Following univariate testing, all variables with significance of $p \leq 0.05$ were entered into the full model.

3.15.4 Exp(B), or the Odds Ratio and Corresponding 95% Confidence Intervals (CI)

An odds ratio (OR) is a measure of association between an exposure and an outcome. The OR represents the odds that an outcome will occur given a particular exposure, compared to the odds of the outcome occurring in the absence of that exposure (Bannon 2013). The CI is the range of values that we can be 95% confident encompasses the true value of the odds ratio.

3.15.5 Statistical Power (sample size)

Statistical power in a study depends on the types of analysis to be performed in a study. Consideration regarding the size and nature of the sample for this study was required to use logistic regression. Initially there were many independent variables which had the possibility of having an impact on the mental health of participants during the study period. This was addressed through the development of summary variables which incorporated these single items into summary variables. A widely accepted general rule of thumb to determine adequate power in the regression analyses in this study was $N \geq 50 + 8m$, where m is the number of predictor variables (Green 1991). The largest number of predictor variables in any of the regression models throughout chapters 5-8 was 13, requiring a minimum sample size of 154 (50 + 8 x 13) for adequate power. The smallest sample size in these models was n=160, the largest was n=674. Therefore, the sample size used in the study was more than adequate for the regression models carried out within this study. A backward selection process was employed within the regression model and had the advantage of considering all variables simultaneously. Following the evidence to select the best approach, it is recommended that unless the number of candidate variables is greater than the sample size, a backward stepwise approach should be used (Choueiry & Salameh 2019, Choueiry 2023).

3.15.6 Multicollinearity

To have confidence in the results of the study, an assessment was conducted to evidence that there was not a problematic degree of multicollinearity between predictor variables in each model. Multicollinearity occurs when a strong correlation exists between two or more of the predictor variables in the regression. Problems with the models may include increased standard errors which makes it difficult to distinguish between the importance of predictors and limiting the size of the variance accounted for in the model (Field 2013). To test for multicollinearity, two approaches were employed in this study. Firstly, a Pearson's correlation test was conducted using SPSS IBM version 27. The correlation coefficient called Pearson's r becomes problematic when the correlation coefficient reaches the .80 or .90 level (Bannon 2013).

Secondly, collinearity diagnostics were carried out in the regression model; the two of these which are widely used are VIF and the tolerance statistic. VIF indicates that a predictor has a strong correlation with other predictors in the regression model and although there is no universally accepted value signifying concern, a VIF value of larger than 10.0 is indicative of a problem (Bowerman & O'Connell 1990). James (2013) states that a VIF less than 5 indicates a low correlation of that predictor with other predictors. A value between 5 and 10 indicates a moderate correlation, while VIF values larger than 10 are a sign for high, not tolerable correlation of model predictors. However, there are more rigorous cut offs for these values in the literature, including no VIF values in a regression model greater than 2.5 or 3.0 (Allison 1999). A tolerance statistic which is the reciprocal of the VIF, of less than .20 indicates a problem, and a value of less than .10 indicates a serious problem (Bannon 2013). Within this study the following standard cut off points were used to ensure that there was no risk of multicollinearity.

- No bivariate correlations >0.6
- No VIF values >10
- No tolerance values <0.2

Testing for multicollinearity was conducted for each regression model in this study, findings are reported within each chapter (5-8) are presented.

3.15.7 Test Assumptions

Logistic regression does not assume a linear relationship between the dependent and independent variables. The independent variables do not need to be interval, normally distributed, linearly related or of equal variance within each group. The error terms (residuals) do not need to be normally distributed. The dependent variable must be dichotomous. The categories (groups) as a dependent variable must be mutually exclusive and exhaustive; a case can only be in one group and every case must be a member of one of the groups (Field 2013).

Chapter 4 Descriptive Analyses of Predictor Variables

Introduction

This chapter examines participant resources which were lost and/or gained during the COVID-19 pandemic and associated restrictions which potentially impacted on mental health for IDS-TILDA participants. It is underpinned by the principles of the COR theory that loss of resources may lead to psychological distress, while gains in resources may assist in adjustment and recovery from stressful experiences. The breadth of the IDS-TILDA framework provided an opportunity to investigate a broad range of areas of people's lives where losses and gains in resources may have been experienced by participants within this study.

4.1 Descriptive Analysis of Predictor Variables

This section relates to the predictor variables used within this study and findings from descriptive analyses are presented. Firstly, the variables which capture demographic data for participants within the study include: age; sex; level of intellectual disability; response type; living circumstances; and aetiology of intellectual disability. Secondly, variables which were single items asked within the survey, and include: mental health disorder; access to mental health supports; prescribed medication for a mental health disorder; and reduced day service/work hours. Finally, the summary variables that were created consist of several single items from the survey. They were: physical health (resource loss and gain); physical distancing/infection history; social activities (resource loss); and engaging in alternative activities (resource gain), relationships (resource loss and gains), illness and bereavement (resource loss), stress/anxiety resource (resource loss) and resilience (resource gains). Table 4.1 presents the overall descriptive analysis of the predictor variables for the total study population of this thesis including numbers of responses and valid percentages.

Independent Variables	Total n	N (%) valid percent
Sex	**n=682**	
Male		314 (46)
Female		368 (54)
Age	**n=682**	
40-49 years		129 (18.9)
50-64 years		380 (55.7)
≥65 years		173 (25.4)
Level of intellectual disability	**n=667**	
Mild		182 (28.6)
Moderate		283 (44.4)
Severe/profound		172 (27)
Type of response	**n=664**	
Self-Respondent only		95(14.3)

Self-Respondent with support		137(20.6)
Proxy only		432(65.1)
Living circumstances	**n=675**	
Independent/family home		119 (17.6)
Community/group home		337 (49.9)
Residential/campus home		219 (32.4)
Aetiology of intellectual disability	**n=682**	
Down syndrome		125 (18.3)
Other/unknown aetiology		557 (81.9)
Mental health disorder	**n-682**	
Yes		325 (47.7)
No		357 (52.3)
Pharmacology		
Prescribed anti-depressants	**n=665**	
Yes		213 (32)
No		452 (68)
Prescribed anti-psychotics	**n=665**	
Yes		267 (40.2)
No		398 (59.8)
Prescribed anxiolytics	**n=665**	
Yes		95 (14.3)
No		570 (85.7)
Access to mental health supports	**n=464**	
Yes		327 (70.5)
No		137 (29.5)
Physical health loss of resources	**n=682**	
Yes		541 (79.3)
No		141 (20.7)
Physical health gain of resources	**n=682**	
Yes		334 (49)
No		348 (51)
Reduced work/day service hours	**n=682**	
Yes		474 (69.5)
No		208 (30.5)
Physical distancing and infection history resource loss	**n=682**	
Yes		587 (86.1)
No		95 (13.9)
Social activities resource loss	**n=682**	
Yes		656 (96.2)
No		26 (3.8)
Engaging in alternative activities resource gain	**n=682**	
Yes		529 (77.6)
No		153 (22.4)
Relationships resource loss	**n=682**	
Yes		598 (87.7)
No		84 (12.3)
Relationships resource gain	**n=682**	
Yes		535 (78.4)
No		147 (21.6)
Illness and bereavement resource loss	**n=682**	

Yes		202 (29.6)
No		480 (70.4)
Stress/anxiety resource loss	**n=682**	
Yes		468 (68.6)
No		214 (31.4)
Resilience resource gain	**n=682**	
Yes		197 (28.9)
No		485 (71.1)

Table 4.1 Results of descriptive analysis of predictor variables for total study population within this thesis

4.1.1 Demographic Variables

The sample of study participants (n=682) was divided with slightly more female (n=368, 54%) participants than male (n=314, 46%). There were 129 (18.9%) participants in the <50 years category, 173 (25.4%) in the 65 years+ age category, with participants in the middle age category of 50-64 years representing the highest number of participants (n=380, 55.7%). Data was missing for 30/682 participants relating to level of intellectual disability, and participants with moderate intellectual disabilities had the greatest numbers of participants (n=283, 44.4%) within the sample. There were 182 participants (28.6%) in the mild category and 172 (27%) participants in the severe/profound category for level of intellectual disability. Surveys were completed under three different types of response, these were self-report, self-report with support, and proxy only. The majority were answered by a proxy respondent (n=432, 65.1%). There were 95 participants (14.3%) in the self-report group and 137 (20.6%) who self-reported with support. Half of the participants (n=337, 49.9%) were living in community or group homes. 119 (17.6%) participants were living either independently or with family. Almost a third of participants (n=219, 32.4%) lived in residential/campus type settings. The aetiology of intellectual disability is captured by Down syndrome or other/unknown cause; 125/682 (18.3%) confirmed having Down syndrome. The results from descriptive analysis of demographic variables of the total study population (n=682) within this study is presented in percentages in Figure 4.1.

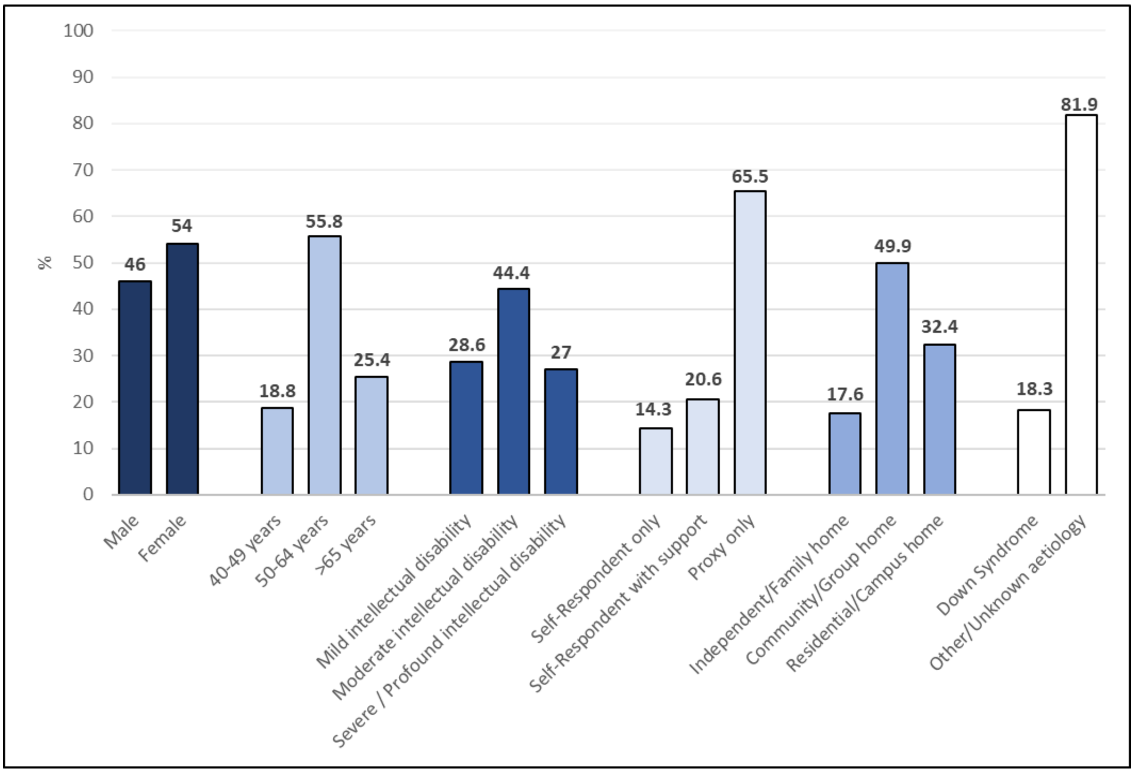


Figure 4.1 Descriptive analysis of demographic variables for the total study population (%)

4.1.2 Mental Health Disorders

The presence of a doctor's diagnosis of a mental health disorder was confirmed with participants during the Wave 4 CAPI interview which was collected between September 2019 and September 2020. As in previous waves of IDS-TILDA data, prevalence of a doctor's diagnosis of mental health disorders was very high with almost half (325/682, 47.7%) of participants with a confirmed diagnosis. Data collected included specific mental health disorder diagnosis. Table 4.2 presents the frequencies for each of the conditions experienced by participants, participants may present with a combination of disorders. The most prevalent conditions were: anxiety 26.1% (178/682); emotional problems 16% (109/682); mood swings 15.8% (108/682); and depression 12.8% (87/682).

Mental Health Disorder Diagnosis	N (%)
Hallucinations	16 (2.3)
Anxiety	178 (26.1)
Depression	87 (12.8)
Emotional problems	109 (16)
Schizophrenia	19 (2.8)
Psychosis	19 (2.8)
Mood swings	108 (15.8)
Manic depression/Bi-polar	27 (4%)
Post-Traumatic Stress Disorder (PTSD)	1 (.1)
Something else	66 (9.7)

Table 4.2 Mental health disorder diagnosis Wave 4 IDS-TILDA

In the ‘something else’ option, 10% of participants reported a combination of: obsessive compulsive disorder (OCD) (n=14); and challenging behaviour/self-injuries behaviour (n=20); low moods; and autism. One participant had a diagnosis of PTSD. Within this study the decision was made to combine all mental health disorder diagnoses into one variable referred to as ‘mental health disorders’ to capture any association with mental health impacts due to the presence of a diagnosed mental health condition.

4.1.3 Pharmacology

Regarding the use of medications prescribed for mental health disorders, the following frequencies were found within the total population (n=682): anti-depressants (n=213, 32%); anti-psychotic medication (n=267, 40.2%); and anxiolytics (n=95, 14.3%).

4.1.4 Access to Mental Health Supports

Participants were asked ‘If you felt anxious, lonely, or depressed, were you able to access supports for [your/his/her] mental health (e.g., counselling/seeing psychologist/seeing a nurse or doctor)?’. If participants answered ‘yes’ to this question, a follow-up question asked: If ‘yes’, what support did [you/Rname] receive: (an open-ended text box was provided). Of the n=464 participants that responded to the question 137 answered ‘no’ and 327 answered ‘yes’. From participants who answered ‘yes’, Table 4.3 presents supports provided by participants in the follow up question.

Mental Health Supports Identified by Participants	**n=**
Staff only	69
Friends and Family only	8
Combination of Family, Friends, and staff	19
*Psychiatry only	76
*Psychology only	40
*GP only	18
*Behaviour specialist only	11
*MHID, MDT, combination mental health professionals	76
*Bereavement support	1
*Counsellor	3
*Memory clinic	1
Referred and awaiting appointment	5
Total	**327**

(*may include support from staff/family)

Table 4.3 Mental health supports identified by participants.

4.1.5 Reduction in day service/work hours

The question asked in the survey was ‘For each of the following, please indicate whether the pandemic has affected you in the way described - Reduced work hours or hours of day service’. Regarding a reduction in day service or work hours 474/682 (69.5%) answered ‘yes’.

4.1.6 Physical Health

In terms of physical health almost 80% (n=541) reported resource loss in this area. The variable with the greatest number of responses regarding loss of resources in term of physical health was ‘more time sitting down or being sedentary’ with 58.2% of participants answering yes to this question. This was closely followed by ‘less physical activity or exercise’ at 53.7%. Among the variables where there were lower numbers of responses, there was still approximately a quarter of participants that felt that they had been eating more unhealthy foods, had an increase in health problems not related to COVID-19, and were in receipt of less medical care than usual. Table 4.4 presents the frequencies for responses related to physical health resource loss.

Physical health resource loss n=682	**Yes N (%)**	**No N (%)**
Increase in health problems not related to this disease	159 (23.3)	523 (76.7)
Less physical activity or exercise	366 (53.7)	316 (46.3)
Overeating or eating more unhealthy foods (e.g., junk foods)	157 (23)	525 (77)
More time sitting down or being sedentary	397 (58.2)	285 (41.8)
Got less medical care than usual	170 (24.9)	512 (75.1)
Physical health – any loss of resources	**541 (79.3)**	**141 (20.7)**

Table 4.4 Frequency of independent variables under physical health losses

Physical health resource gain n=682	**Yes N (%)**	**No N (%)**
Increase in exercise or physical activity	165 (24.2)	517 (75.8)
Paid more attention to personal health	95 (13.9)	587 (86.1)
More time in nature or outdoors	299 (43.8)	383 (56.2)
Physical health – any gain in resources	**334 (49)**	**348 (51)**

Table 4.5 Frequency of independent variables under physical health gains

When participants were asked about what they viewed as positives during the pandemic, almost a quarter (24.4%) reported an increase in exercise or physical activity, and many (43.8%) had spent more time in nature or outdoors. The frequencies for these results are shown in Table 4.5.

4.1.7 Social Activities (loss) and Engaging in Alternative Activities (gain)

There were also losses and gains reported under social activities and engaging in alternative activities. Almost all participants (96.2%) experienced losses. Table 4.6 presents the frequencies for responses to variables plus the overall frequencies for the resource heading. A high majority (83.9%) identified ‘unable to do enjoyable activities or hobbies’ as where they experienced the greatest loss. The importance of religious or spiritual activities was the second highest responses in this domain with 428/682 (62.8%) of participants being impacted. Missing holidays and family celebrations were also experienced by high numbers of participants 58.4% and 62.2% respectively. As seen from Table 4.7, the highest number of responses related to engaging in alternative activities as a result of the pandemic was for more time for rest and relaxation (63%).

‘More free time’ was cited by half of participants. Many participants reported developing new hobbies or activities (n=301, 44.1%). Another positive was for almost a half (45.5%) of participants was ‘saving money’.

Social activities resource loss n=682	**Yes N (%)**	**No N (%)**
Family celebrations cancelled or restricted	424 (62.2)	258 (37.8)
Planned travel or vacation cancelled	398 (58.4)	284 (41.6)
Religious or spiritual activities cancelled or restricted	428 (62.8)	254 (37.2)
Unable to participate in social clubs, sports teams, or volunteer activities	397 (58.2)	285 (41.8)
Unable to do enjoyable activities or hobbies	572 (83.9)	110 (16.1)
Social activities – any loss of resources	**656 (96.2)**	**26 (3.8)**

Table 4.6 Frequency of independent variables under social activity resource losses

Engaging in alternative activities resource gain n=682	**Yes N (%)**	**No N (%)**
Developed new hobbies or activities	301 (44.1)	381 (55.9)
More rest/relaxation	430 (63)	252 (37)
More free time	347 (50.9)	335 (49.1)
Saved money	310 (45.5)	372 (54.5)
Engaging in alternative activities – any gain of resources	**529 (77.6)**	**153 (22.4)**

Table 4.7 Frequency of independent variables under engaging in alternative activities resource gain.

4.1.8 Relationships

Resource loss in this area is presented in Table 4.8. Being separated from family or close friends was experienced by almost 80% (n=544) of participants. One fifth of participants experienced increased verbal arguments within their homes. For 4.8% (n=33) there was an increase in physical conflict within the home. Almost half (49.4%, n=337) of participants expressed that one positive from the pandemic was using technology to communicate. However, 18.9% (n=129) indicated that they did not have the ability or resources to talk to family or friends while separated due to public health measures. In Table 4.9, it can be seen that the most prominent positive relational aspect of the pandemic was spending more or better time with staff (60.6%, n=413). Making new connections with support people was reported by just above one fifth of participants (22.1%, n=151).

Relationships resource loss n=682	**Yes N (%)**	**No N (%)**
Separated from family or close friends	544 (79.8)	138 (20.2)
Did not have the ability or resources to talk to family or friends while separated	129 (18.9)	553 (81.1)
Unable to visit loved one in a care facility (e.g., nursing home)	76 (11.1)	606 (88.9)
Increase in verbal arguments or conflict with others in the home	147 (21.6)	535 (78.4)
Increase in physical conflict with others in the home	33 (4.8)	649 (95.2)
Relationships – any loss of resources	**598 (87.7)**	**84 (12.3)**

Table 4.8 Frequency of independent variables under relationship resource loss

Relationships resource gain n=682	**Yes N (%)**	**No N (%)**
Spending more time at home/with family	56 (8.2)	626 (91.8)
Improved relationships with family or friends	74 (10.9)	608 (89.1)
New connections made with support people	151 (22.1)	531 (77.9)
More time/better time with staff	413 (60.6)	269 (39.4)
Using technology to communicate	337 (49.4)	345 (50.6)
Less doing things that challenge people close to me	43 (6.3)	639 (93.7)
Relationships – any gain of resources	**535 (78.4)**	**147 (21.6)**

Table 4.9 Frequency of independent variables under relationship resource gains

4.1.9 Illness and Bereavement

Table 4.10 illustrates that 175 participants within the study had experienced a bereavement. The vast majority of these (120/175) had been unable to attend the funeral or religious service. Inclusion of the variable ‘unable to be with a close family member in critical condition’ was considered appropriate under this domain and was experienced by a small percentage (6.9%) of participants.

Illness and bereavement resource loss n=682	**Yes N (%)**	**No N (%)**
Unable to be with a close family member in critical condition	47(6.9)	635 (93.1)
Unable to attend in-person funeral or religious services for a family member or friend who died	120 (17.6)	562 (82.4)
Life event during pandemic - Death of a parent	26 (3.8)	656 (96.2)
Life event during pandemic - Death of a sibling	20 (2.9)	662 (97.1)
Life event during pandemic - Death of another relative	44 (6.5)	638 (93.5)
Life event during pandemic - Death of a friend	70 (10.3)	612 (89.7)
Life event during pandemic - Death of a significant other	12 (1.8)	670 (98.2)
Life event during pandemic - Death of a pet	3 (.4)	679 (99.6)
Illness and bereavement – any loss of resources	**202 (29.6)**	**480 (70.4)**

Table 4.10 Frequency of independent variables under illness and bereavement resource loss

4.1.10 Physical distancing and Infection History

The implementation of public health measures and the advice regarding keeping a 2-metre distance from others was experienced by many participants during the pandemic (n=556, 84.4%). In Ireland, measures were implemented quickly for people living in residential facilities amid concerns around risk. However, among IDS-TILDA participants 9.2% (n=63) tested positive for the disease, with 12 people hospitalised. Public health measures required people in homes to quarantine when other occupants were infected or suspected of being infected, and one third of participants lived in homes where they were quarantined for one week or longer during the pandemic. Table 4.11 presents frequencies of responses for each variable and for the overall resource.

Physical distancing & infection history resource loss n=682	**Yes N (%)**	**No N (%)**
Since the coronavirus disease pandemic began, has your entire household been quarantined for a week or longer? (n=671)	223 (33.2)	448 (66.8)
Limit physical closeness due to concerns of infection (n=659)	556 (84.4)	103 (15.6)
Tested positive (any time)	63(9.2)	619(90.8)
If you tested positive, and/or had symptoms of COVID-19, were you hospitalised? (n=682)	13 (12)	669 (88)
Physical distancing/infection history – any loss of resources	**587 (86.1)**	**95 (13.9)**

Table 4.11 Frequency of physical distancing and infection history resource loss

4.1.11 Stress/Anxiety and Resilience

In the first IDS-TILDA COVID-19 survey, participants identified aspects of the pandemic which resulted in stress/anxiety. These questions were replicated in the COVID-19 (phase 2) survey. Table 4.12 presents the response frequencies for individual variables which were then brought together to create the variable ‘stress/anxiety loss of resources’. Positives experiences were captured using ‘resilience gain of resources’. The greatest cause of stress/anxiety was not being able to do usual activities (n=380, 55.7%), followed by not being able to see family (n=327, 47.9%) and friends (n=239, 35%). Causes of stress/anxiety with similar response frequencies included fear of getting COVID-19 (n=96, 14.1%), fear of family members getting COVID-19 (14.5%). 89 (13%) participants identified changes in staff as being a cause of stress/anxiety. Participants were asked: ‘Have you felt stressed/anxious about any of the following during the COVID-19 period….?

Stress/anxiety resources loss n=682	**Yes N (%)**	**No N (%)**
Fear of getting COVID-19	96 (14.1)	586 (85.9)
Fear of peers/friends getting COVID-19	82 (12)	600 (88)
Fear of family members getting COVID-19	99 (14.5)	583 (85.5)
Isolation	221 (32.4)	461 (67.6)
Not being able to do usual activities	380 (55.7)	302 (44.3)
Not seeing friends	239 (35)	443(65)
Not seeing family	327 (47.9)	355 (52.1)
Change in staff	89 (13)	593 (87)
Stress/anxiety – any loss of resources	**468 (68.6)**	**214 (31.4)**

Table 4.12 Frequency of independent variables under stress/anxiety resource loss

When participants were asked about positive aspects during the pandemic, a quarter (25.5%, n=174) of participants identified being resilient; or this was paraphrased as ‘being mentally tough’. More than one in ten (13%, n=89) felt that they were more appreciative of things they had previously taken for granted. Frequency of responses for resource gains related to resilience are presented in Table 4.13.

Resilience resource gain n=682	Yes N (%)	No N (%)
Being resilient/mentally tough	174 (25.5)	508 (74.5)
More appreciative of things usually taken for granted	89 (13)	593 (87)
Resilience resource gain	**197(28.9)**	**485(71.1)**

Table 4.13 Frequency of independent variables under resilience resource gain

4.2 Summary of Findings for Descriptive Analysis of Predictor Variables

Figure 4.2 presents the overall percentages of yes/no responses for each of the remaining (non-demographic) predictor variables for the total study population within this thesis. The total number of responses and number of participants that responded to each variable have been presented in Tables 4.4-4.13. High percentages were found in relation to loss of social activities (n=656, 96.2%), loss of resources related to relationships (n=598, 87.7%), and losses related to physical distancing and infection history (n=587, 86.1%). Findings related to gains in resources also presented with some high percentages, such as relationship gains (n=535, 78.4%) and engaging in alternative activities (n=529, 77.6%). Participants reported that 70.5% had access to mental health supports if they required them. Finally, there was a high prevalence of mental health disorders among participants. This has been a consistent finding over previous waves of IDS-TILDA.

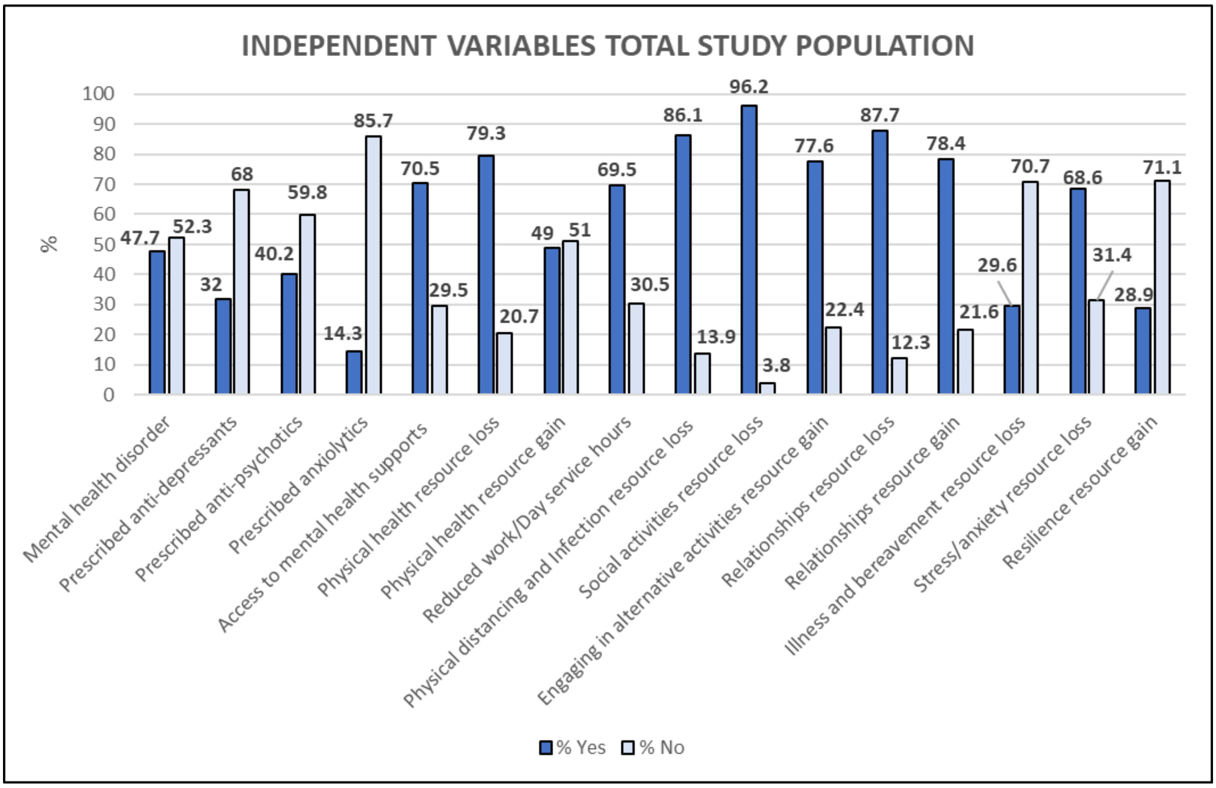


Figure 4.2 Descriptive analysis of independent variables of total study sample

4.3 Chapter Conclusion

Chapter 4 has set out the descriptive statistics for the total study population of this study (n=682). The independent variables that were used within each of the analyses reported hereafter (Chapter 5-8) have been described, including demographic variables, and all other predictor variables, single item, and summary variables.

Chapter 5 – Mental Health Impacts – Symptoms of Depression

Introduction

This chapter examines resources that participants within the study may have lost or gained because of the public health measures that were implemented in response to the COVID-19 pandemic, and the possible impact that these may have had on participants experiencing symptoms of depression or not. Depression was measured using the PHQ-9, the scoring for which was then converted into a binary response indicating symptoms of depression or no symptoms. A binary logistic regression model was then used to explore the variables with the most statistically significant association with depression when demographic data such as sex, age, living circumstances and response type to the survey was controlled for. Findings from the analysis are presented followed by a summary of the findings.

5.1 Methods

This chapter builds on the methodological approach outlined in Chapter 2 of this thesis and provides additional details on the specific measures and procedures used. The independent variables, including demographic data and resources that are relevant to participants' experience of depressive symptoms using the PHQ-9, during the COVID-19 lockdown period are examined within this chapter.

5.1.1 Measures

As outlined in the methodology section, the measure used for symptoms of depression was the PHQ-9 (Kroenke *et al.* 2001). It was used within this study to understand resource loss and gain in participants who experienced symptoms of depression versus no symptoms of depression. In total 545/682 participants answered the PHQ-9. There were three types of responses for this measure; participants self-responded, responded with support, or by proxy only.

The independent variables which were used within this study have already been explained in greater detail in Chapter 3. These variables were: sex; age (categorical); level of intellectual disability (mild, moderate, severe/profound); living arrangements (independent/family); community/group homes, residential/campus homes); response type (self, self with support, proxy); and aetiology of intellectual disability (Down syndrome or other/unknown cause). Also included were independent variables: mental health disorders; medication prescribed for mental health disorders (anxiolytics, anti-depressant, anti-psychotic); and reduction in day service or work hours. In addition to these measures, the summary variables, details of which are provided in Chapter 3, were also included in analysis: physical health (losses and gains); physical distancing and infection history; social activities and engaging in alternative activities resource (losses and gains); relationships resource (losses and gains); illness and bereavement; stress/anxiety resource loss; and resilience resource gains.

5.2 Analysis

Data analysis was conducted in three phases. The data was analysed descriptively using univariate analysis. Secondly, the relationship was tested between the dependent variable, depressive symptoms and all independent variables using bivariate analysis. Predictor variables associated with the dependent variable at a statistically significant level ($p \leq .05$) were subsequently entered into the full binary logistic regression model. Within the model, the dependent variable had two potential outcomes; participants that scored below the cut-off of 5 were the reference group (no symptoms), and those that scored at equal to or above 5 were the target group (had symptoms). Bivariate tests were carried out across all independent variables and the binary outcome for depressive symptoms using the PHQ-9 with a cut off ≥ 5. As both sets of data were categorical a chi-square test was completed. In instances where numbers were not adequate for a chi-square test, Fishers exact test was carried out. The result of this test for associations is presented in Table 5.1.

A binary logistic regression model then explored both losses and gains of resources during the pandemic and associated restrictions and their association with symptoms of depression. Predictor variables were coded yes/no, and summary variables were used as described in Chapter 4. Firstly, demographic variables: sex; age; living circumstances; level of intellectual disability; response type; and aetiology were controlled for, they were entered into block 1 of the model, regardless of statistical significance, using the enter selection method. This was followed by a backward selection entry of all statistically significant variables into block 2 of the model. The results of the correlation matrix conducted to examine the potential for multicollinearity between independent variables are presented in Appendix 11 and no statistically significant correlations (>0.6) were found. The highest correlation was between level of intellectual disability and response type for the survey (0.483), and the second highest correlation was between living circumstance and level of intellectual disability (0.396). The significant associations ($p \leq 0.05$) in the multivariate analyses were expressed as an odds ratio (OR) with corresponding 95% confidence intervals (CI).

	Tolerance	VIF
Sex	.949	1.054
Aetiology	.845	1.183
Level of intellectual disability	.756	1.322
Type of response to survey	.787	1.270
Living arrangements	.788	1.269
Age Categorical	.831	1.203
Access to mental health supports	.823	1.215
Physical health resource loss	.935	1.069
Stress/anxiety resource loss	.832	1.202
Resilience resource gains	.898	1.113

Table 5.1 Results of collinearity test between independent variables in full model – PHQ-9

5.3 Results

5.3.1 Descriptive/Univariate Results

A total of n=545 participants completed the PHQ-9 (complete cases only); of these slightly over half were female (53.2%). Over half (55.4%) of the sample was represented in the 50-64 years age category, and slightly less than half had a moderate level of intellectual disability (47.2%). Data for all respondent types were analysed within this study with nearly a quarter being self-response with support (22.7%). The largest response type was by proxy (61%). More than half of participants lived in community/group homes with the second highest group living in residential/campus-based homes (27.5%). One fifth (21%) of participants had Down syndrome and the remainder had other/unknown cause of intellectual disability. Figure 5.1 presents the demographic variables presented as percentages for the total study population who responded to the PHQ-9, with further detail including numbers of responses for each variable presented in Table 5.2.

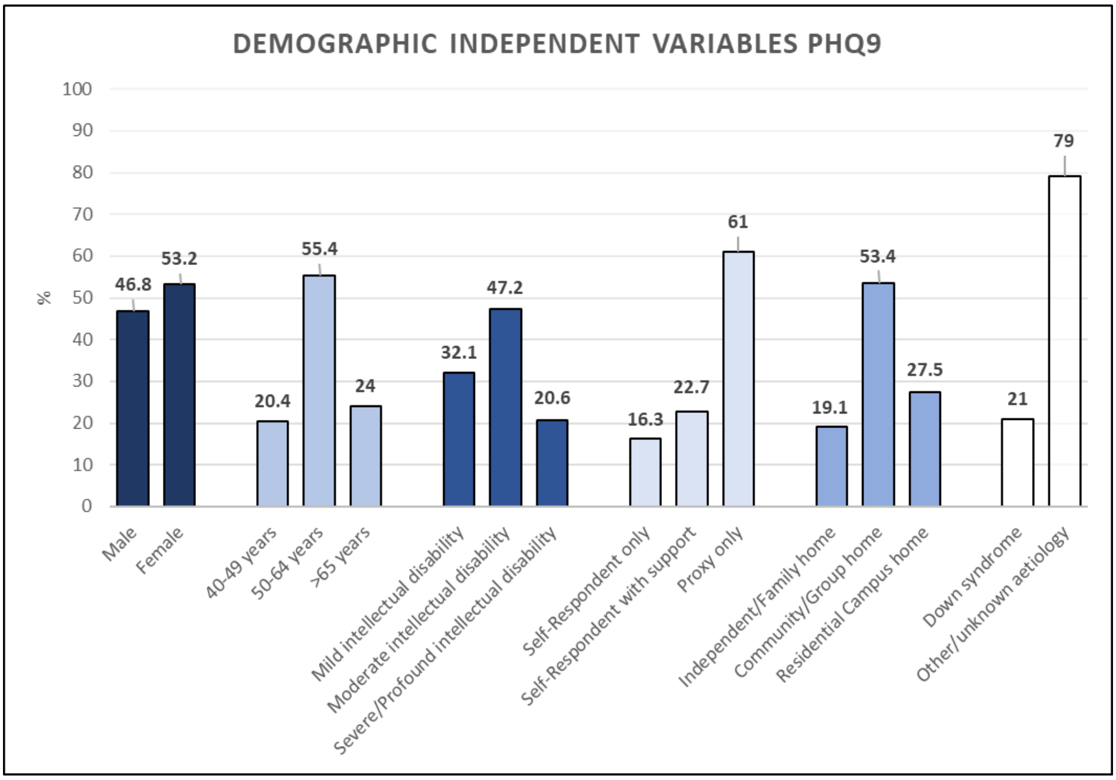


Figure 5.1 Univariate/descriptive analysis of demographics for PHQ-9 respondents.

Within the variable 'mental health disorder', there were 250 (45.9%) participants who had a doctor's diagnosis. Prescribed medication for mental health disorders was highest in the anti-psychotic (39.3%) group, followed by antidepressants (32.7%), and 13% taking anxiolytic medication. Almost one third (32.4%) of participants who answered the PHQ-9 had no access to mental health supports if they required them. There was a high number of participants who experienced physical health resource loss (421/545) and similarly high numbers had their day service or work hours reduced (396/545). Half of participants (50.8%) felt that they had experienced some gains regarding their physical health. Public health measures related to physical distancing and coronavirus infections impacted 86.2% of participants. Almost all (96.5%) experienced losses in related social activities, but a high number also experienced gains from engaging in alternative activities such as new hobbies, more relaxation and free time (80%). While there was loss of relationship resources (89.4%), there were gains in other relationships (80%). Illness and bereavement impacted 165/545 of participants. More than two thirds (68.8%) experienced losses related to stress/anxiety and 29.2% of participants experienced resilience resource gains. Figure 5.2 presents the percentages of yes/no responses from the total number of participants across all independent (non-demographic) variables. Further detail including numbers of responses for each variable is presented in Table 5.2.

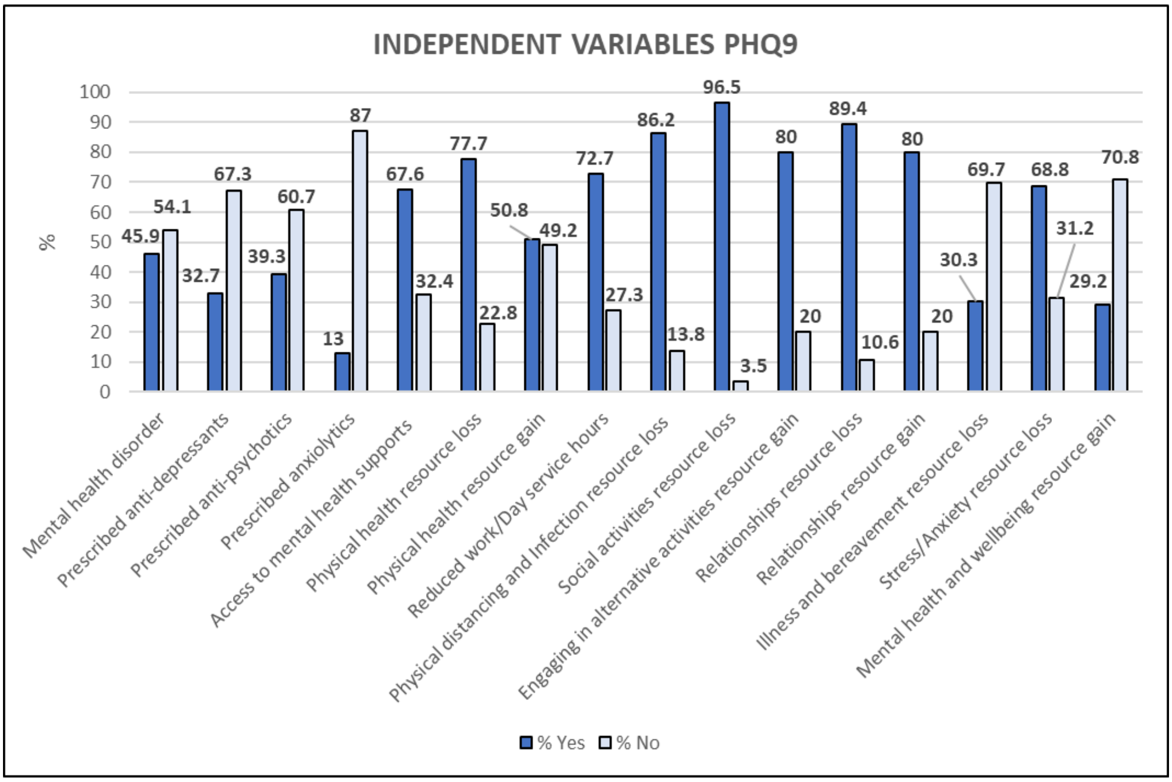


Figure 5.2 Univariate/descriptive analysis of independent variables PHQ9

5.3.2 Bivariate Results

Table 5.2 presents a descriptive and bivariate analysis of the predictor study variables explored when considering depressive symptoms using the PHQ-9 as the dependent variable within this study. Among the n=682 participants that completed the COVID-19 (phase 2) survey, n=545 completed the PHQ-9, Using the cut off score of ≥5 a total of 74/545 (13.6%) participants were included in the analysis as having symptoms of depression. There were more female (15.2%) than male (11.8%) participants reporting symptoms of depression, and there were almost equal percentages of participants in each age category with depressive symptoms. More participants with a mild intellectual disability (19.1%) reported depressive symptoms than those with moderate intellectual disabilities (12.6%), with the lowest percentage was in the severe/profound category (8.7%). Higher percentages of people living independently or with their family scored above the cut-off (17.5%) when compared to those living in community/group homes (12.8%) and in residential/campus-based homes (12.2%).

Predictor Variables	**<5 No symptoms of depression**	**≥5 Have symptoms of depression**	**n (%) Total PHQ-9 study population**	**P value**
PHQ-9 Total	**n=471 (86.5%)**	**n=74 (13.6%)**	**n=545**	
Sex			545	0.247
Male	225 (88.2)	30 (11.8)	255 (46.8)	

Female	246 (84.8)	44 (15.2)	290 (53.2)	
Age			545	0.998
40-49 years	96 (86.5)	15 (13.5)	111 (20.4)	
50-64 years	262 (86.5)	41 (13.5)	303 (55.4)	
≥65 years	113 (86.3)	18 (13.7)	131 (24)	
Level of intellectual disability			504	**0.040**
Mild	131 (80.9)	31 (19.1)	162 (32.1)	
Moderate	208 (87.4)	30 (12.6)	238 (47.2)	
Severe/profound	95 (91.3)	9 (8.7)	104 (20.6)	
Living circumstances			528	0.423
Independently / family	85 (82.5)	18 (17.5)	103 (19.1)	
Community / group home	251 (87.2)	37 (12.8)	288 (53.4)	
Residential / campus type setting	130 (87.8)	18 (12.2)	148 (27.5)	
Type of response			539	**0.005**
Self-Respondent only	69 (80.2)	17 (19.8)	86 (16.3)	
Self-Respondent with support	96 (80)	24 (20)	120 (22.7)	
Proxy only	290 (90.1)	32 (9.9)	322 (61)	
Aetiology of intellectual disability			477	0.109
Down syndrome	81 (81)	19 (19)	100 (21)	
Other/unknown aetiology	329 (87.3)	48 (12.7)	377 (79)	
Mental health disorder			545	0.205
Yes	211 (84.4)	39 (15.6)	250 (45.9)	
No	260 (88.1)	35 (11.9)	295 (54.1)	
Prescribed anti-depressants			529	0.976
Yes	150 (86.7)	23 (13.3)	173 (32.7)	
No	309 (86.8)	47 (13.2)	356 (67.3)	
Prescribed anti-psychotics			529	0.891
Yes	181 (87)	27 (13)	208 (39.3)	
No	278 (86.6)	43 (13.4)	321 (60.7)	
Prescribed anxiolytics			529	0.233
Yes	63 (91.3)	6 (8.7)	69 (13)	
No	396 (86.1)	64 (13.9)	460 (87)	
Access to mental health supports			374	**0.008**
Yes	200 (79.1)	53 (20.9)	253 (67.6)	
No	109 (90.1)	12 (9.9)	121 (32.4)	
Physical health loss of resources			545	**≤0.001**
Yes	352 (83.6)	69 (16.4)	421 (77.7)	
No	119 (96)	5 (14)	124 (22.8)	
Physical health gain of resources			545	0.249
Yes	244 (88.1)	33 (11.9)	277 (50.8)	
No	227 (84.7)	41 (15.3)	268 (49.2)	
Reduced work/day service hours			545	0.531
Yes	340 (85.9)	56 (14.1)	396 (72.7)	
No	131 (87.9)	18 (12.1)	149 (27.3)	
Physical distancing & Infection history resource loss			545	0.667
Yes	405 (86.2)	65 (13.8)	469 (86.2)	
No	66 (88)	9 (12)	75 (13.8)	
Social activities resource loss			545	0.489
Yes	455 (86.5)	71 (13.5)	526 (96.5)	

No	16 (84.5)	3 (15.8)	19 (3.5)	
Engaging in alternative activities resource gain			545	0.492
Yes	379 (86.9)	57 (13.1)	436 (80)	
No	92 (84.4)	17 (15.6)	109 (20)	
Relationships resource loss			545	0.447
Yes	419 (86)	68 (14)	487 (89.4)	
No	52 (89.7)	6 (10.3)	58 (10.6)	
Relationships resource gain			545	0.189
Yes	381 (87.4)	55 (12.6)	436 (80)	
No	90 (82.6)	19 (17.4)	109 (20)	
Illness and bereavement		**Total=74**	545	0.211
Yes	138 (83.6)	27 (16.4)	165 (30.3)	
No	333 (87.6)	47 (12.4)	380 (69.7)	
Stress/anxiety resource loss		**Total=74**	545	**0.006**
Yes	314 (83.7)	61 (16.3)	375 (68.8)	
No	157 (92.4)	13 (7.6)	170 (31.2)	
Resilience resource gain		**Total=74**	545	**0.010**
Yes	128 (80.5)	31 (19.5)	159 (29.2)	
No	343 (88.9)	43 (11.1)	386 (70.8)	

Table 5.2 Frequencies and bivariate analysis results PHQ-9 study population.

A greater percentage of participants with a mental health disorder had depressive symptoms (15.6%) than those without a diagnosis (11.9%). Furthermore, a greater percentage (13.9%) of participants who were not taking anxiolytic medication had symptoms of depression than those who were taking anxiolytics (8.7%). When bivariate testing using the Pearson's chi-square was carried out on demographic variables, those that were significant ($p \leq 0.05$) were level of intellectual disability (0.040), and type of response to survey (0.005). For the remaining independent variables, the following were significant: access to mental health supports (0.008); physical health resource loss (<0.001); stress/anxiety resources loss (0.006); and resilience gain (0.010). The independent variables included in the full regression model, along with their p-values, are presented in Table 5.3. These were: sex; age; level of intellectual disability (mild, moderate, severe/profound); aetiology (Down syndrome or other/unknown cause); living arrangements (independent/family, community group home, residential/campus home); and response type (self, self with support, proxy). Although none of the demographic variables were statistically significant, they were controlled for in the full model as described in data analysis. Access to mental health supports; physical health resource loss; stress/anxiety loss; and resilience gains were all statistically significant and included in the full model.

Independent Variables	p-value
Sex	0.247
Age	0.998
Level of Intellectual Disability	***0.040**
Living Circumstances	0.423
Aetiology	0.109
Type of response	***0.005**
Access to mental health supports	***0.008**
Physical health resource loss	***≤0.001**
Stress/anxiety resource loss	***0.006**
Resilience resource gains	***0.010**

Table 5.3 Variables in the full binary logistic model PHQ9 (*statistically significant)

5.3.3 Multivariate Analyses Results

When all the above variables were included in the model, there were four variables that remained statistically significant in the reduced model: aetiology (Down syndrome), access to mental health supports, resilience gains, and physical health resource loss. The full model for depression explained between 13.1% (Cox and Snell R Squared) and 21.3% (Nagelkerke R Squared) of the variance in the depression and associated resources model. The classification table for the full model had an overall percentage of 83%. Results from the regression model indicated that participants who had Down syndrome had almost two and a half times greater odds of having symptoms of depression than participants that did not have Down syndrome (0.032 OR 2.463 CI 1.081, 5.610).

Having access to mental health supports during the pandemic was statistically significant (0.011) and positively associated with having symptoms of depression (OR 3.078 CI 1.300, 7.289). Gains in resilience were found to be statistically significant (0.013) and positively associated with having symptoms of depression, with those participants having more than two times greater odds of having depression symptoms when compared to those who did not experience mental health gains (OR 2.368 CI 1.203, 4.662). Physical health loss was statistically significant (0.044) and positively associated with symptoms of depression. Participants that experienced loss of resources with their physical health had more than two and a half times greater odds (OR 2.829) to score $\geq$5 on the PHQ-9 than those who did not have physical health losses. Table 5.4 presents the results from the reduced binary logistic regression model with significant ($p \leq 0.05$) variables highlighted and in bold.

	B	Sig.	Exp(B)	95% C.I.for EXP(B)	
				Lower	Upper
Sex female	.029	.931	1.030	.534	1.986
Aetiology Down syndrome	**.901**	**.032***	**2.463**	**1.081**	**5.610**
Level of intellectual disability (mild)		.601			
Level of intellectual disability (moderate)	-.387	.317	.679	.318	1.448
Level of intellectual disability (severe/profound)	-.323	.555	.724	.248	2.116
Type of response to survey (self)		.057			
Type of response to survey (self with support)	.198	.692	1.219	.457	3.250
Type of response to survey (proxy)	-.704	.141	.495	.194	1.262
Living arrangements (independent/family)		.227			
Living arrangements (community/group)	-.769	.085	.464	.193	1.112
Living arrangements (residential/campus setting)	-.635	.243	.530	.183	1.538
Age Categorical (40-49 years)		.455			
Age Categorical (50-64 years)	.651	.210	1.917	.693	5.303
Age Categorical (65 years +)	.562	.361	1.754	.526	5.851
Access to mental health supports	**1.124**	**.011***	**3.078**	**1.300**	**7.289**
Physical health resource loss	**1.040**	**.044***	**2.829**	**1.028**	**7.785**
Resilience resource gain	**.862**	**.013***	**2.368**	**1.203**	**4.662**

Table 5.4 Reduced Regression Model PHQ-9

5.4 Summary of Findings

This aspect of the study found that 13.57% of participants had symptoms of depression. Older adults with a mild intellectual disability reported higher rates of depressive symptoms during bivariate analysis than those with moderate and severe/profound intellectual disabilities. However, this was not statistically significant in the regression analyses. Those living either independently or with family had higher levels of depressive symptoms than either those living in community/group homes or those in residential homes in campus settings. Results from the regression model indicated that participants who had Down syndrome had more than two and a half times greater odds (OR 2.463, CI 1.081-5.610) of having symptoms of depression than participants that did not have Downs syndrome. Having access to mental health supports during the pandemic was statistically significant (0.011) and positively associated with having symptoms of depression. Physical health resource loss was statistically significant (0.044) and positively associated with symptoms of depression (OR 2.829, CI 1.028-7.785). Overall, from the study sample 83.6% of participants experienced losses related to physical health resources. There was a positive and statistically significant (0.013) association between depressive symptoms and gains in resilience in the binary logistic regression model.

5.5 Chapter Conclusion

This study examined a comprehensive set of variables which were important resources within the lives of older adults with an intellectual disability in the context of the COVID-19 pandemic, and how gains or losses in these resources may have impacted on whether participants experienced symptoms of depression. In bivariate testing, statistically significant ($p \leq 0.05$) associations were found between having symptoms of depression and level of intellectual disability, response type, access to mental health supports, physical health loss, resilience resource gain, and stress/anxiety resource loss. All the above variables were entered into the full regression model including demographic variables: sex; age; level of intellectual disability; living circumstances; and aetiology. On completion of all steps, the reduced model found statistically significant results across access to mental health supports, physical health resource loss, and resilience resource gain. These were all positively associated with symptoms of depression. Participants with Down syndrome had greater odds of being lonely than participants without Down syndrome.

Chapter 6 Mental Health Impacts – Symptoms of Generalised Anxiety Disorder

Introduction

This chapter examines the impacts of resources on participants' experiences of symptoms of anxiety during the COVID-19 pandemic. Again, the breadth of data collected within the IDS-TILDA study afforded the researcher the opportunity to explore the variety of potential resources which may have been present and impacted on symptoms of anxiety. The independent variables that were presented in the methodology chapter are the same predictors used in this chapter, including the demographic variables and other key variables.

6.1 Methods

The overall study methodology has already been outlined in Chapter 3 of this thesis. As already detailed, the independent variables which represent the resources that participants may have lost or gained during the COVID-19 associated lockdowns are the predictors that are consistent across chapters 5-8 in this thesis. This section provides additional detail on the measure used for anxiety, the Generalised Anxiety Disorder Assessment (GAD-7).

6.1.1 Measures

Generalised Anxiety Disorder Assessment (GAD-7) scores used to create a binary response to indicate 'having symptoms' versus 'no symptoms' is the dependent variable. There were two types of responses for this measure, participants self-responded, or responded with support. Proxy responses were not included. Excluding missing cases 163/232 participants completed the GAD-7 assessment.

The independent variables used in these analyses, which are explained in greater detail in Chapter 3, were: sex; age (categorical); level of intellectual disability (mild, moderate); living arrangements (independent/family, community/group homes, residential/campus homes); response type (self or self with support); and aetiology of intellectual disability (Down syndrome or other/unknown cause). Also included were: mental health disorder; use of medication related to mental health disorders (anxiolytics, anti-depressant, anti-psychotic); reduction in day service or work hours; physical health (resource loss and gains), physical distancing and infection history; social activities and engaging in alternative activities (resource loss and gains); relationships (resource loss and gains); illness and bereavement; stress/anxiety resource loss; and resilience resource gains.

6.2 Analysis

Statistical analyses were performed using SPSS version 27.0. Data analysis was conducted in three phases - univariate, bivariate, and multivariate. Bivariate tests of all independent variables and the dependent variable categorical data used a chi-square test and where numbers were not adequate for a chi-square test, Fisher's exact test was conducted. Demographic variables, and all variables that were statistically significant were entered into the full binary logistic regression model. Firstly, demographic variables: sex; age; living circumstances; level of intellectual disability; response type; and aetiology were controlled for, they were entered into block 1 of the model, regardless of statistical significance, using the enter selection method. This was followed by a backward selection entry of all statistically significant variables into block 2 of the model.

The dependent variable had two potential outcomes; participants that scored below the cut-off of 5 were the reference group (no symptoms) and those that scored ≥ 5 was the target group (had symptoms). Backward selection was the chosen approach in the regression model, which allowed for a larger number of independent variables to be analysed. Starting with the full model has the advantage of considering the effects of all variables simultaneously. Choueiry (2023) recommends that unless the number of variables is greater than the sample size, a backward stepwise approach should be used. The significant associations ($p \leq 0.05$) in the multivariate analyses were expressed as an odds ratio (OR) with corresponding 95% confidence intervals (CI).

Testing was carried out across independent variables in advance of performing the regression model for multicollinearity and there was no strong correlation between predictor variables in the regression model. The results of the collinearity testing are presented in Table 6.1 where the Variance Inflation Factor (VIF) did not exceed 1.353 and the reciprocal tolerance was 0.739, i.e., figures were well below the rigorous cut-off set within this thesis. A correlation matrix was also performed which tested for bivariate correlations between all statistically significant independent variables prior to completing the binary logistic regression model (see Appendix 12)**.** The strongest correlation between independent variables was level of intellectual disability and response type for survey (0.483). Another high correlation was between living arrangements and level of intellectual disability (0.396) which may be attributed to people with more complex needs living in residential campus-based settings.

	Tolerance	VIF
Sex	.945	1.058
Aetiology	.762	1.312
Level of intellectual disability	.906	1.104
Type of response to survey	.843	1.187
Living arrangements	.771	1.297
Age Categorical	.739	1.353
Access to mental health supports	.852	1.174
Physical distancing/infection history	.778	1.286
Stress/anxiety resource loss	.788	1.269
Resilience resource gain	.907	1.102

Table 6.1 Results for tests for collinearity between independent variables GAD-7

6.3 Results

6.3.1 Descriptive/Univariate Analysis Results

Only measures which were answered by self-report or self-report with support were included, and incomplete cases were excluded. More females (n=91, 55.8%) than males (n=72, 44.4%) completed the GAD-7. Almost one third who completed it (n=52, 31.9%) were from within the youngest age category (40-49 years), 60.3% (n=91) had a mild intellectual disability, and 46.6% completed it independently without support. Above half (n=88, 54.3%) resided in community/group homes with the next highest living circumstance being independently or with family (n=55, 34%). 18.4% (n=30) of participants who answered the GAD-7 had Down syndrome. Figure 6.1 presents the demographic variables represented as percentages for the total study population who responded to the GAD-7. Further detail including numbers of responses for each variable is presented in Table 6.2.

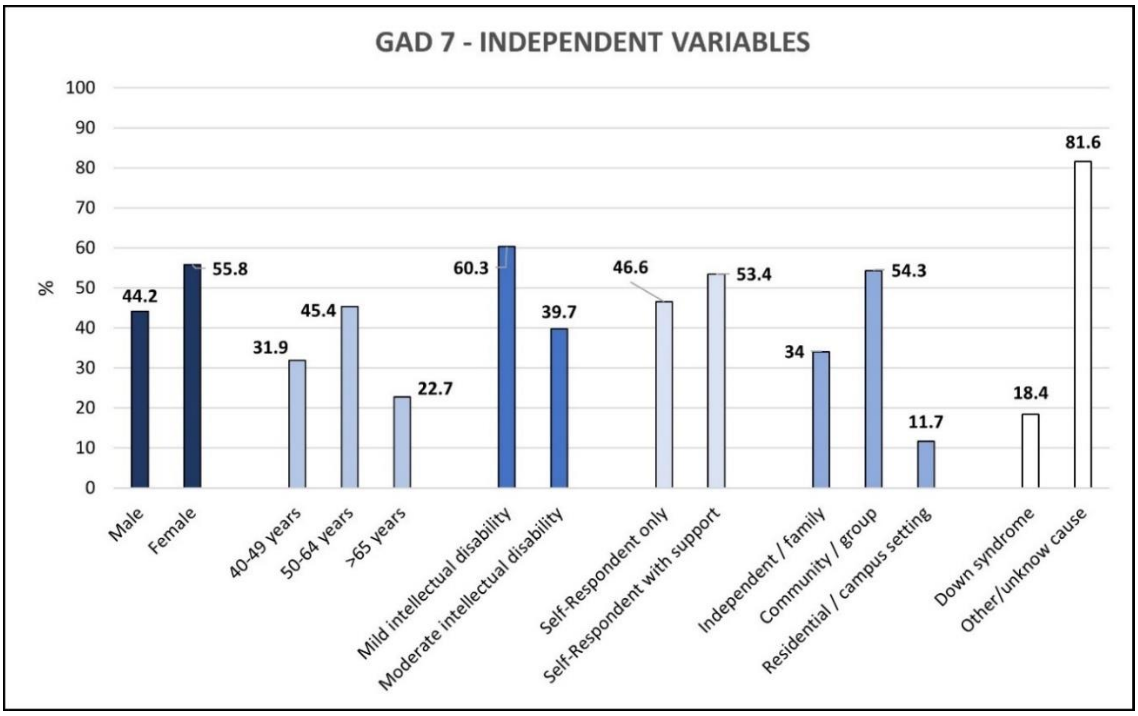


Figure 6.1 Descriptive Analysis of demographics for GAD-7 Respondents.

For other independent variables, 35.6% had a diagnosed mental health disorder and equal percentages were prescribed antidepressant and antipsychotic medication (n=43, 27.2%). Nine participants (5.7%) were taking anxiolytics. Almost three quarters (n=87, 73.7%) of those who completed the GAD-7 reported that they had access to mental health supports if required. There were a high number of participants who experienced physical health loss of resources (134/163) and 62% (n=101) who felt they experienced gains in their physical health. Within the variable for reduced day service/work hours, there were a high percentage of participants who were impacted (n=135, 82.8%), with a similarly high number being impacted by physical distancing and infection (n=137, 84%). Almost all (98.2%) had losses in social activities, but 83.4% identified gains via engaging in alternative activities (136/163). Illness and bereavement of family/friends was experienced by 71 participants (43.6%). Three quarters experienced stress/anxiety losses (124/163) with more than two thirds (39.9%) having experienced gains in resilience. Figure 6.2 presents the percentages of yes/no responses from the total number of participants who responded to the GAD-7, across all independent (non-demographic) variables. Further detail including numbers of responses for each variable is presented in Table 6.2.

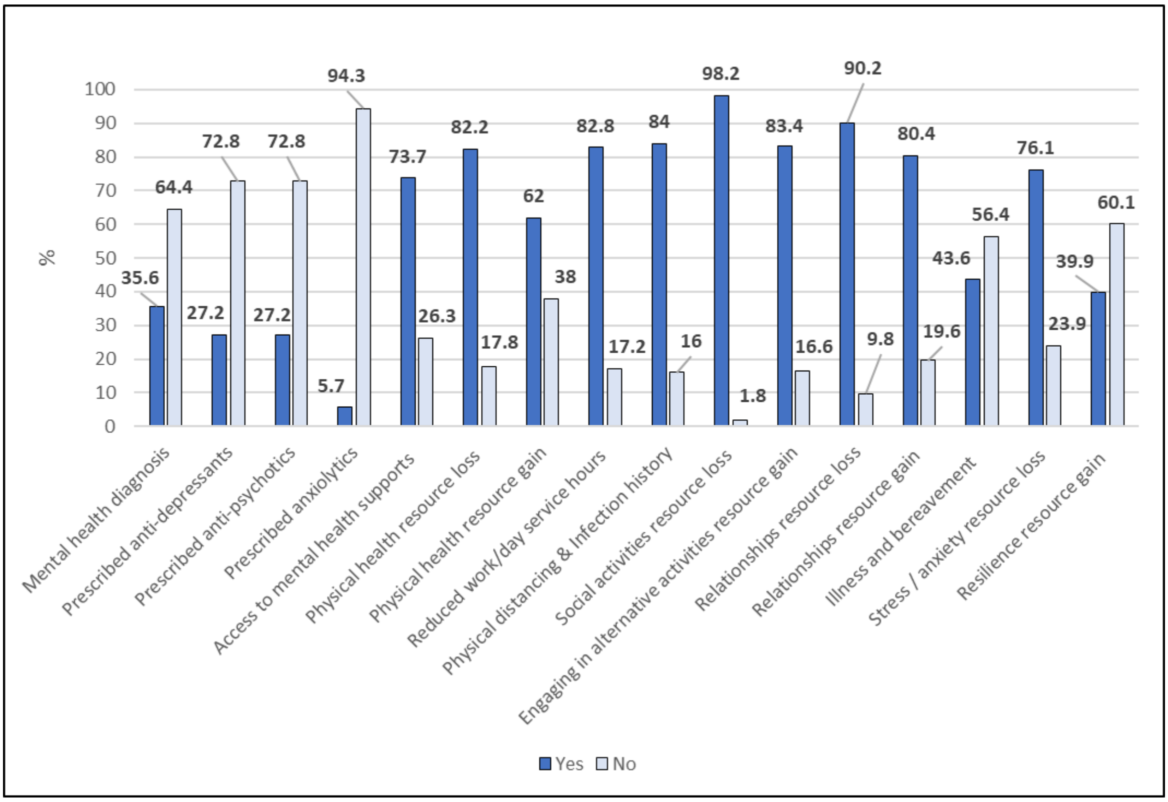


Figure 6.2 Univariate/descriptive analysis of independent variables and GAD-7 respondents.

6.3.2 Bivariate Analysis Results

Among the 682 participants that took part in the overall COVID-19 (phase 2) survey, 242 were self-report (46.6%) or self-report with support (53.4%). When incomplete cases were excluded (where participants did not answer all seven questions in the GAD-7) there were 163 cases analysed. Results from univariate analysis found that where participants completed the GAD-7, there were slightly more male (22.2%) than female participants (20.9%) with symptoms of anxiety. There was a lower percentage (n=6, 16.2%) of participants in the oldest age category (65 years+) with symptoms when compared to the other two categories. Equal percentages were observed in the other two age groups scoring over the cut-off for symptoms of anxiety (23%). There were no differences in the type of living arrangements or aetiology of intellectual disability between those that scored ≥5, with one in five in each group reporting symptoms of anxiety. More people with a moderate intellectual disability (23.3%) had symptoms than those with a mild intellectual disability (19.8%). For participants that responded independently without support 27.6% reported symptoms, compared with 16.1% of those that responded with support. There was little difference between participants that had Down syndrome when compared to those with other/unknown causes of intellectual disability.

From the non-demographic variables, access to mental health supports was available to the majority (30/34) of participants that had symptoms of anxiety if they felt they needed them. Where participants had a mental health disorder, they had higher reported symptoms of anxiety than those without a diagnosis (25.9% vs. 19%). For results related to use of medications used to treat mental health disorders, there was a higher percentage of participants prescribed anti-psychotic and anxiolytic medication that had symptoms of anxiety than those that were not prescribed these medications. For those taking antipsychotic medicines they were more likely to have symptoms of anxiety (23.3%) than those not taking antipsychotic medication (20%).

There was a high frequency of symptoms of anxiety (34/35) in participants that experienced loss within the variable physical distancing and infection history that had symptoms of anxiety. All participants that scored above the cut-off of 5 experienced losses related to social activities. Participants that had a loss of resources related to relationships over the pandemic had a percentage two times higher than those that did not experience loss in that resource. Almost three quarters of participants (73.4%) that experienced stress/anxiety resources loss did not have symptoms of anxiety. A similar percentage (70.8%) also reported positive aspects to resilience over the pandemic and they also did not show anxiety symptoms.

Independent Variables GAD7=	**≤5 No symptoms of anxiety**	**≥5 Have symptoms of anxiety**	**n (%) Total GAD-7 study population**	**p-value**
GAD7 Total	**128 (78.5)**	**35 (21.5)**	**N=163**	
Sex			163	0.836
Male	56 (77.8)	16 (22.2)	72 (44.2)	
Female	72 (79.1)	19 (20.9)	91 (55.8)	
Age			163	0.676
40-49 years	40 (76.9)	12 (23.1)	52 (31.9)	
50-64 years	57 (77)	17 (23)	74 (45.5)	
≥65 years	31 (83.8)	6 (16.2)	37(22.7)	
Level of intellectual disability			151	0.601
Mild	73 (80.2)	18 (19.8)	91 (60.3)	
Moderate/other	46 (76.7)	14 (23.3)	60 (39.7)	
Type of response			163	0.073
Self-Respondent only	55 (72.4)	21 (27.6)	76 (46.6)	
Self-Respondent with support	73 (83.9)	14 (16.1)	87 (53.4)	
Living circumstances			162	0.974
Independent/family home	44 (80)	11 (20)	55 (34)	
Community/group home	69 (78.4)	19 (21.6)	88 (54.3)	

Residential/campus home	15 (78.9)	4 (21.1)	19 (11.7)	
Aetiology of intellectual disability			163	0.828
Down syndrome	24 (80)	6 (20)	30 (18.4)	
Other/unknown aetiology	104 (78.2)	29 (21.8)	133 (81.6)	
Mental health disorder			163	0.310
Yes	43 (74.1)	15 (25.9)	58 (35.6)	
No	85 (81)	20 (19)	105 (64.4)	
Prescribed anti-psychotic medication			158	0.654
Yes	33 (76.7)	10 (23.3)	43 (27.2)	
No	93 (80)	23 (20)	115 (72.8)	
Prescribed anxiolytic medication			158	0.596
Yes	7 (77.8)	2 (22.2)	9 (5.7)	
No	118 (79.2)	31 (20.8)	149 (94.3)	
Prescribed anti-depressant medication			158	0.973
Yes	34 (79.1)	9 (20.9)	43 (27.2)	
No	91 (79.1)	24 (20.9)	115 (72.8)	
Access to mental health supports			118	**0.023**
Yes	57 (65.5)	30 (34.5)	87 (73.7)	
No	27 (87.1)	4 (12.9)	31 (26.3)	
Physical health loss of resources			163	0.267
Yes	103 (76.9)	31 (23.1)	134 (82.2)	
No	25 (86.2)	4 (13.8)	29 (17.8)	
Physical health gain of resources			163	0.902
Yes	79 (78.2)	22 (21.8)	101 (62)	
No	49 (79)	13 (21)	62 (38)	
Reduced work/day service hours			163	0.995
Yes	106 (78.5)	29 (21.5)	135 (82.8)	
No	22 (78.6)	6 (21.4)	28 (17.2)	
Physical distancing and Infection history resource loss			163	**0.017**
Yes	103 (75.2)	34 (24.8)	137 (84)	
No	25 (96.2)	1 (3.8)	26 (16)	
Social activities resource loss			163	0.482
Yes	125 (78.1)	35 (21.9)	160 (98.2)	
No	3 (100)	0	3 (1.8)	
Engaging in alternative activities resource gain			163	0.682
Yes	106 (77.9)	30 (22.1)	136 (83.4)	
No	22 (81.5)	5 (18.5)	27 (16.6)	
Relationships resource loss			163	0.287
Yes	114 (77.6)	33 (22.4)	147 (90.2)	
No	14 (87.5)	2 (12.5)	16 (9.8)	
Relationships resource gain			163	0.951
Yes	103 (78.6)	28 (21.4)	131 (80.4)	
No	25 (78.1)	7 (21.9)	32 (19.6)	
Illness and bereavement resource loss			163	0.500
Yes	54 (76.1)	17 (23.9)	71 (43.6)	
No	74 (80.4)	18 (19.6)	92 (56.4)	
Stress/anxiety resource loss			**163**	**0.004**
Yes	91 (73.4)	33 (26.6)	124 (76.1)	

No	37 (94.9)	2 (5.1)	39 (23.9)	
Resilience resource gain				**0.049**
Yes	46 (70.8)	19 (29.2)	65 (39.9)	
No	82 (83.7)	16 (16.3)	98 (60.1)	

Table 6.2 Frequencies and bivariate analysis results GAD-7 study population.

Bivariate analysis was conducted across all independent variables, presented in Table 6.2 including p-values. Those found to be statistically significant ($p \leq 0.05$) were: access to mental health supports (0.023), physical distancing and infection history resource loss (0.017), stress/anxiety loss of resources (0.004), and resilience resources gains (0.049). In addition to the statistically significant variables, the demographic variables of sex, age, level of intellectual disability, living circumstances, type of response, and aetiology were included in the full model.

Independent Variables	p-value
Sex	0.836
Age	0.676
Level of Intellectual Disability	0.601
Living Circumstances	0.974
Aetiology	0.828
Type of response	0.073
Access to mental health supports	***0.023**
Physical distancing and infection history	***0.017**
Stress/anxiety resource loss	***0.004**
Resilience resource gains	***0.049**

Table 6.3 Variables in the full binary logistic regression model GAD-7 (*statistically significant)

6.3.3 Multivariate Analyses Results

The full model for anxiety explained between 17.3% (Cox and Snell R Squared) and 24.8% (Nagelkerke R Squared) of the variance in the anxiety and associated resources model. The classification table for the full model has an overall percentage of 71.7%. The binary logistic regression model was completed with all the variables set out in Table 6.3; however, the variable of physical distancing/infection history had an extremely large beta coefficient (20.530) and a p-value of 0.998. The model was completed again entering each variable manually to understand which variable was affecting physical distancing/infection history. When living arrangements was included the beta increased to 20.530. The full model was completed a final time with the variable physical distancing/infection history removed. This was justified due to its non-significance and confounding effect on the model. The researcher concluded that removing living arrangements instead would be inconsistent with the approach across all four studies which allows for comparability across findings in this thesis. The second reduced model with physical distancing/infection history removed is presented in Table 6.4 with significant ($p \leq 0.05$) variables highlighted and in bold. This iteration of the reduced model has two statistically significant variables remaining which were access to mental health supports which was negatively associated (0.026) with symptoms of anxiety, (coding was changed to present this finding as a positive beta coefficient, as presented in table 6.4) and resilience resource gains which was positively associated with having symptoms of anxiety (0.009 OR 3.774 CI 1.385, 10.283).

				95% C.I.for EXP(B)	
	B	Sig.	Exp(B)	Lower	Upper
Sex (male)	-.356	.464	.700	.270	1.817
Level of intellectual disability (moderate)	.299	.555	1.349	.499	3.647
Response to survey (self with report)	-.389	.463	.678	.240	1.915
Living arrangements (independent/family)		.736			
Living arrangements (community/group home)	-.261	.655	.770	.245	2.421
Living arrangements (residential/campus setting)	.292	.723	1.339	.266	6.741
Age (<50 years)		.267			
Age (50-64 years))	-.037	.949	.964	.314	2.964
Age (65 years +)	-1.116	.153	.327	.071	1.512
Aetiology (Down syndrome)	.226	.754	1.254	.304	5.165
No access to mental health supports	**1.518**	**.026***	**4.563**	**1.201**	**17.340**
Resilience resource gains (yes)	**1.328**	**.009***	**3.774**	**1.385**	**10.283**

Table 6.4 Reduced binary logistic regression model GAD-7

6.4 Summary of Findings

This chapter has examined a range of resources that may have been lost or gained by older adults with an intellectual disability in Ireland during the COVID-19 associated restrictions, and explored the associations that these losses or gains may have had on people's experience of anxiety over this period. Overall, the number of participants that presented as having symptoms of general anxiety disorder were 35/163 (21.5%).

Participants within this study either self-reported or self-reported with support. It must, therefore, be acknowledged that this study does not capture the experience of those with severe and profound intellectual disabilities or those with significant communication difficulties. The reduced binary regression model contained two variables which remained statistically significant. Firstly, participants that had no access to mental health supports had greater odds of having symptoms than those that had access to mental health supports (OR 4.563). Secondly, participants that experienced resilience resource gains had greater odds of having symptoms of anxiety than those who did not experience gains within this variable (OR 3.774 CI 1.385, 10.283). There were no significant findings related to demographic variables.

6.5 Chapter Conclusion

The experience of anxiety related to public health measures being implemented has been widely reported. However, the empirical research on the topic among people with intellectual disability is considerably lacking. This chapter highlights the mental health impacts specifically related to symptoms of anxiety among older adults with intellectual disabilities during public health measures and the COVID-19 pandemic. Among those that completed the GAD-7, 21.47% (35/163) of participants had symptoms of anxiety. The resources which were statistically significant in bivariate testing were access to mental health supports, physical distancing/infection history, resilience resource gain and stress/anxiety related resource loss. These variables as well as demographic variables of age, sex, level of intellectual disability, living arrangements, and aetiology were all included in the full binary logistic regression model. In the final reduced model, the variables that remained statistically significant were access to mental health supports, and gains in resilience resources. Although physical distancing/infection history was not included in the reduced model, it was significant in bivariate analysis. The discussion chapter presents these findings with a focus on the relevant literature within the context of resources that were lost and gained during the COVID-19 pandemic and the impacts that this had on older adults with an intellectual disability.

Chapter 7 Mental Health Impact - Loneliness

Introduction

The analyses reported in this chapter took the opportunity to explore the potential associations between loneliness and the losses and/or gains of resources experienced by older adults with an intellectual disability over the course of the pandemic. The independent variables that were presented in the methodology chapter are the same predictors used in this chapter, including the demographic variables and other key variables.

7.1 Methods

Details of the overall study methodology were outlined earlier in Chapter 2. This section provides additional detail on the specific measure of loneliness used and the procedures used to examine the factors associated with loneliness in the context of the COVID-19 pandemic and associated lockdowns. There were two types of responses for this measure, participants self-responded, or responded with support. Proxy responses were not included. Excluding missing cases 160/232 participants completed the loneliness question.

7.1.1 Measures

The dependent variable within this chapter is loneliness and the measure used was the loneliness question which has already been described in the methodology chapter and is one question deconstructed into two parts. This measure is presented using a binary outcome and identifies participants who experienced feeling lonely versus not lonely.

The independent variables used to examine the resources associated with participants' feelings of loneliness during the COVID-19 pandemic and associated restrictions were demographic variables: sex; age (categorical); response type (self-report or self-report with support); level of intellectual disability (mild, moderate/other); living arrangements (independent/family, community/group homes, residential/campus homes); and aetiology of intellectual disability (Down syndrome or other/unknown cause). Additional variables were: mental health disorders; access to mental health supports; use of medication related to mental health disorders (anxiolytics, anti-depressant, anti-psychotic); reduction in day service or work hours; physical health resource (losses and gains); physical distancing/infection history; social activities resource loss and engaging in alternative activities resource gain; relationships (resource loss and gains); illness and bereavement; stress/anxiety (losses); and resilience (gains).

7.2 Analysis

Statistical analyses were performed using SPSS version 27.0. Analysis was carried out in three stages, using descriptive/univariate, bivariate and multivariate analyses. Predictor variables used either two or three item response categories and the dependent variable on loneliness was a two-category response item. Therefore, Pearson's chi-square test was used to measure associations for all independent variables and the dependent variable, unless numbers were smaller than permitted in which case a Fisher's exact test was performed. Correlations between statistically significant variables were checked for collinearity. No correlations existed which exceeded the limits set out within the methodology section of this thesis which were no bivariate correlations >0.6, no VIF values >10, and no tolerance values <0.2. Table 7.1 presents the results of the collinearity statistics conducted between variables included in the full binary logistic regression model. The correlation matrix performed for the variables included in the full model are presented in Appendix 13.

The dependent variable loneliness had two outcomes, either lonely or not lonely. The participants that reported not being lonely were the reference category. Firstly, demographic variables: sex; age; living circumstances; level of intellectual disability; response type; and aetiology were controlled for, they were entered into block 1 of the model, regardless of statistical significance, using the enter selection method. This was followed by a backward selection entry of all statistically significant variables into block 2 of the model. Backward selection was used within the model to start with the full model and then remove the least significant variables one after another until the overall prediction of the model does not deteriorate (Ranganathan *et al.* 2017). The significant associations ($p \leq 0.05$) in the multivariate analyses were expressed as an odds ratio (OR) with corresponding 95% confidence intervals (CI).

	Tolerance	VIF
Sex	.940	1.064
Aetiology	.707	1.414
Level of intellectual disability	.881	1.135
Type of response to survey	.842	1.187
Living arrangements	.791	1.264
Age Categorical	.717	1.394
Mental health disorder	.818	1.222
Taking antidepressants	.953	1.049
Physical health resource loss	.913	1.095
Stress/anxiety resource loss	.939	1.065

Table 7.1 Results of test for collinearity between independent variables.

7.3 Results

7.3.1 Descriptive/Univariate Analysis Results

The total study population that responded to the loneliness question (complete cases only) was n=160, which consists of participants who self-reported or self-reported with support. More females than males answered the loneliness question (n=90, 56.3%). 45% of those that responded were in the middle age category of 50-64 years, with 31.9% in the younger age category. There was a higher percentage of respondents that had a mild intellectual disability compared to moderate intellectual disability (60.8% vs. 39.2%). There were slightly fewer (47.5%) self-report participants compared with self-report with support (52.5%). Only 11.9% (n=19) of participants were living in residential/campus-based homes with the highest numbers living in community/group homes (54.7%). There were 27/160 participants that had Down syndrome which was 16.9% of the total study population. Figure 7.1 presents the demographic variables represented as percentages for the total study population who responded to the loneliness question. Further detail including numbers of responses for each variable is presented in Table 7.2.

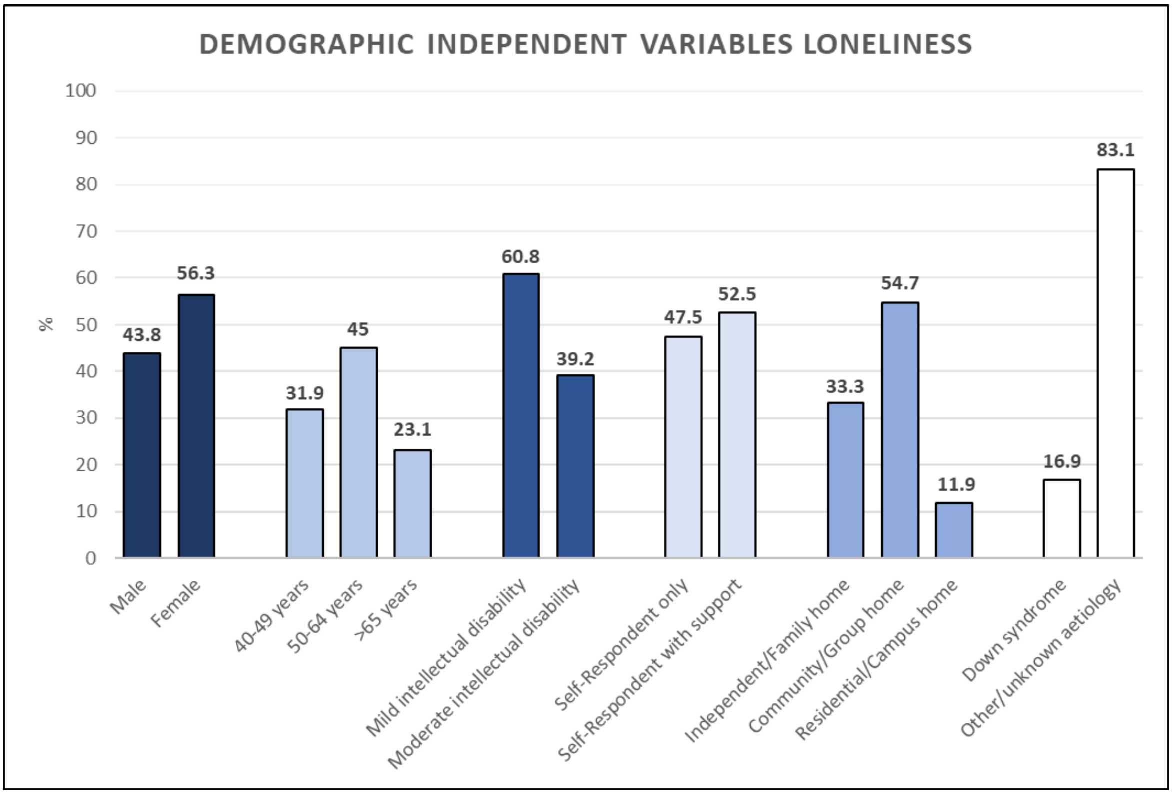


Figure 7.1 Descriptive analysis of predictor demographic variables for respondents to the loneliness question.

From the non-demographic independent variables, which are presented in Figure 7.2, 63.7% had no mental health disorder. Although there was a small number prescribed anxiolytic medication (n=9, 5.8%), more than a quarter were prescribed anti-psychotic and anti-depressant medication. Nearly three-quarters (73.7%) felt that they had no access to mental health supports if they needed them. Many of those that answered the loneliness question (81.9%) had losses relating to physical health and a high percentage were impacted by physical distancing and infection history (84.4%). Many participants experienced reduced day service/work hours n=132/160 (82.5%). High numbers had losses related to social activities resources (158/160), but there was also a high number (134/160) that found positives through engaging in alternative activities. High numbers of participants identified losses in terms of relationships (90.6%). However, there was also a high percentage that identified gains within this resource (80.6%) from other types of relationships. More than three quarters experienced stress/anxiety resource loss (76.3%). There were also resilience resource gains identified by participants that answered the loneliness question, with 40% reporting these. Figure 7.2 presents the percentages of yes/no responses from the total number of participants across all independent (non-demographic) variables. Further detail including numbers of responses for each variable is presented in Table 7.2.

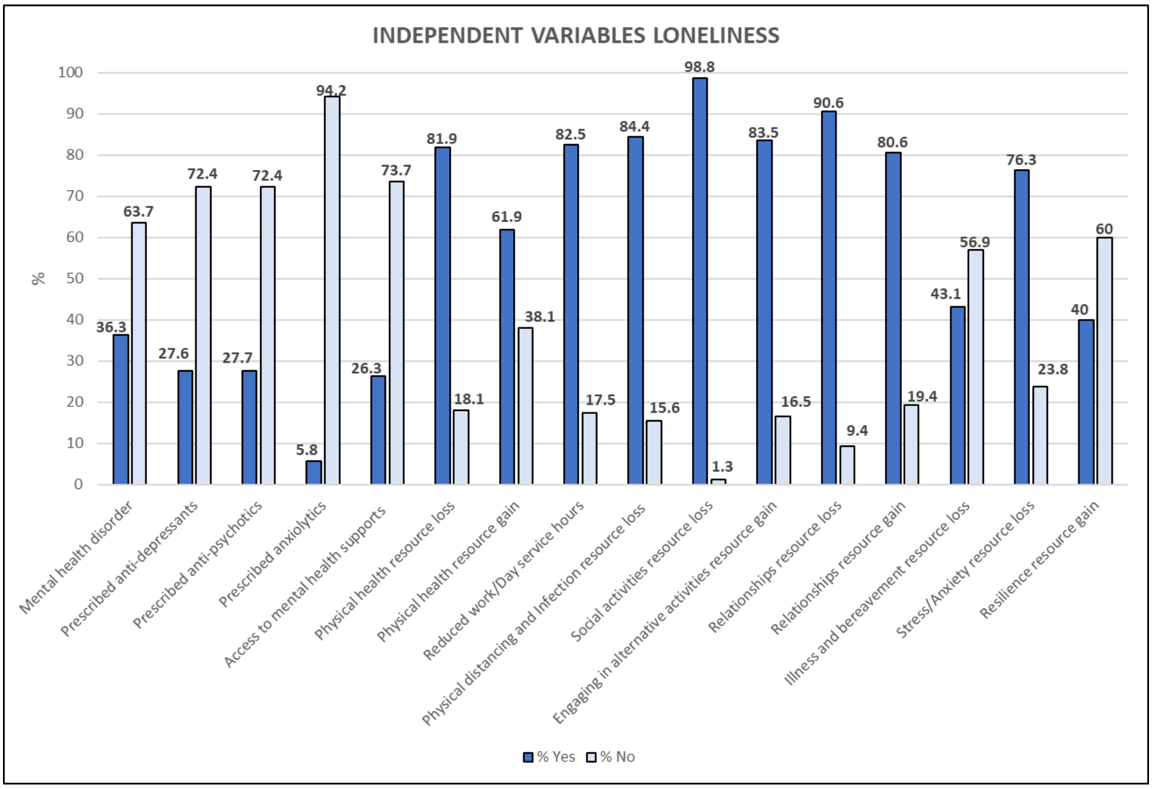


Figure 7.2 Descriptives analysis of predictor variables for respondents to the loneliness question.

7.3.2 Bivariate Analysis Results

Frequencies and bivariate association were carried out. Results are presented in Table 7.2. Of the 160 participants that answered the loneliness question 60% (n=96) were categorised as lonely and 40% (n=64) as not lonely. There was a lower percentage of participants with mild intellectual disability (n=51, 56.7%) reporting loneliness when compared to those with moderate/other intellectual disability (n=38, 65.5%). The reason for 'other,' is because a small number (n=7) of participants who were categorised as severe/profound level of intellectual disability responded to the loneliness question with support, these were included. From participants in the 50-64 years age category, 58.3% (n=42) reported loneliness compared with higher percentages in the youngest participants (60.8%) and the oldest participants (n=23, 62.2%) who reported as the loneliest age category. There was a largely similar level of loneliness between those who self-reported and those who reported with support (59.2% and 60.7% respectively). 65.5% (n=57) of those living in community/group homes were lonely compared to 50.9% (n=27) who were living independently or with family. A higher percentage of people with Down syndrome reported being lonely compared to those with other/unknown causes of intellectual disability (63% vs. 59.4%).

Independent Variables	**Lonely n=96 (60%)**	**Not lonely N=64 (40%)**	**N (%) Total loneliness study population**	**p-value**
Sex			**N=160**	**.051**
Male	36 (51.4)	34 (48.6)	70 (43.8)	
Female	60 (66.7)	30 (33.3)	90 (56.3)	
Age			160	.919
40-49 years	31 (60.8)	20 (39.2)	51 (31.9)	
50-64 years	42 (58.3)	30 (41.7)	72 (45)	
≥65 years	23 (62.2)	14 (37.8)	37 (23.1)	
Level of intellectual disability			148	.283
Mild	51 (56.7)	39 (43.3)	90 (60.8)	
Moderate/other	38 (65.5)	20 (34.5)	58 (39.2)	
Type of response			160	.846
Self-Respondent only	45 (59.2)	31 (40.8)	76 (47.5)	
Self-Respondent with support	51 (60.7)	33 (39.3)	84 (52.5)	
Living circumstances			159	.230
Independent/family home	27 (50.9)	26 (49.1)	53 (33.3)	
Community/group home	57 (65.5)	30 (34.5)	87 (54.7)	
Residential/campus home	11 (57.9)	8 (42.1)	19 (11.9)	
Aetiology of intellectual disability			160	.730
Down syndrome	17 (63)	10 (37)	27 (16.9)	
Other/unknown aetiology	79 (59.4)	54 (40.6)	133 (83.1)	
Mental health disorder			**160**	**.037**
Yes	55 (53.9)	47 (46.1)	102 (36.3)	

No	41 (70.7)	17 (29.3)	58 (63.7)	
Anti-depressants			109	.091
Yes	30 (69.8)	13 (30.2)	43 (27.7)	
No	61 (54.5)	51 (45.5)	66 (72.4)	
Anti-psychotics			155	.815
Yes	26 (60.5)	17 (39.5)	43 (27.7)	
No	65 (58)	47 (42)	112 (72.3)	
Anxiolytics			155	.083
Yes	7 (77.8)	2 (22.2)	9 (5.8)	
No	84 (57.5)	62 (42.5)	146 (94.2)	
Access to mental health supports			118	.760
Yes	19 (61.3)	12 (38.7)	31 (26.3)	
No	56 (64.4)	31 (35.6)	87 (73.7)	
Physical health loss of resources			**160**	**.002**
Yes	86 (65.6)	45 (34.4)	131 (81.9)	
No	10 (34.5)	19 (65.5)	29 (18.1)	
Physical health gain of resources			160	.595
Yes	61 (61.6)	38 (38.4)	99 (61.9)	
No	35 (57.4)	26 (42.6)	61 (38.1)	
Reduced work/day service hours			160	.107
Yes	83 (62.9)	49 (37.1)	132 (82.5)	
No	13 (46.4)	15 (53.6)	28 (17.5)	
Physical distancing & Infection history resource loss			160	.374
Yes	83 (61.5)	52 (38.5)	135 (84.4)	
No	13 (52)	12 (48)	25 (15.6)	
Social activities resource loss			160	.158
Yes	96 (60.8)	62 (39.2)	158 (98.8)	
No	0	2 (100)	2 (1.3)	
Engaging in alternative activities resource gain			160	.861
Yes	80 (59.7)	54 (40.3)	134 (83.5)	
No	16 (61.5)	10 (38.5)	26 (16.5)	
Relationships resource loss			160	.580
Yes	88 (60.7)	57 (39.3)	145 (90.6)	
No	8 (53.3)	7 (46.7)	15 (9.4)	
Relationships resource gain			160	.514
Yes	79 (61.2)	50 (38.8)	129 (80.6)	
No	17 (54.8)	14 (45.2)	31 (19.4)	
Illness and bereavement			160	.241
Yes	45 (65.2)	24 (34.8)	69 (43.1)	
No	51 (56)	40 (44)	91 (56.9)	
Stress/anxiety resource loss			160	**.003**
Yes	81 (66.4)	41 (33.6)	122 (76.3)	
No	15 (39.5)	23 (60.5)	38 (23.8)	
Resilience resource gain			160	.843
Yes	39 (60.9)	25 (39.1)	64 (40)	
No	57 (59.4)	39 (40.6)	96 (60)	

Table 7.2 Frequencies and bivariate results for loneliness question

For participants with a mental health disorder, 55 (53.9%) were lonely. Among lonely participants 56 (64.4%) felt that they did not have access to mental health supports. Where participants were taking anxiolytic medication, 77.8% were lonely compared to 22% being not lonely. In relation to physical health, 86/96 of these participants experienced physical health resource losses and 61/96 experienced gains. There was more loneliness among participants that had reduced hours of work or days service (62.9%) compared to those that did not have loss in this resource (46.6%). The majority (88/96) of participants that were lonely, experienced relationship loss. The experience of loss related to stress/anxiety was related to 66.4% (n=81) being lonely compared with 33.6% (n=41) who did not feel lonely. All lonely participants answered yes to experiencing loss in social activities.

Sex approached statistical significance (0.051) with more females experiencing loneliness than males. No other significant associations with demographic variable were found. From the other independent variables, having a mental health disorder was significantly associated with feeling lonely (0.037). Physical health resource loss and stress/anxiety resource loss both had highly significant associations at .002 and .003 respectively and were included in the full binary logistic regression model. Table 7.3 presents the variables (and their p-values) which were included in the full binary logistic regression for loneliness.

Independent Variables	**p-value**
Sex	***0.051**
Age	0.919
Level of Intellectual Disability	0.283
Living Circumstances	0.230
Aetiology	0.730
Type of response	0.846
Mental health disorder	***0.037**
Physical health resource loss	***0.002**
Stress/anxiety resource loss	***0.003**

Table 7.3 Independent variables entered in the full model (*statistically significant)

7.3.3 Multivariate Analysis Results

The full model for loneliness explained between 15.9% (Cox and Snell R Squared) and 21.5% (Nagelkerke R Squared) of the variance in the loneliness and associated resources model. The classification table for the model had an overall percentage of 70.7%. Table 7.4 presents the results of the reduced model of the binary logistic regression model with significant ($p \leq 0.05$) variables highlighted and in bold. The strongest association when controlling for demographics was stress/anxiety resource loss (0.003). Participants that experienced stress/anxiety resource loss had almost four times higher odds to be lonely than those that did not experience mental health losses (OR 3.979 CI 1.616, 9.795). Females had more than two times greater odds than males to be lonely (OR 2.250 CI 1.063, 4.762) and participants that had physical health resource loss had three times higher odds than those that did not report related to physical health resources (OR 3.148 CI 1.242, 7.983). In addition, to sex, the model was adjusted for level of intellectual disability, response type, living arrangements, age, and aetiology. However, these were not statistically significant in bivariate or multivariate analyses.

				95% C.I.for EXP(B)	
	B	Sig.	Exp(B)	Lower	Upper
Sex (females)	**.811**	**.034***	**2.250**	**1.063**	**4.762**
Level of intellectual disability (moderate)	.386	.331	1.471	.675	3.207
Type of response to survey (self with support)	-.286	.487	.751	.336	1.682
Living arrangements (independent/family)		.821			
Living arrangements (community/group))	.083	.852	1.086	.455	2.595
Living arrangements (residential/campus setting)	.434	.537	1.543	.390	6.103
Age Categorical (40-49 years)		.950			
Age Categorical (50-64 years)	.001	.998	1.001	.423	2.373
Age Categorical (65 years +)	-.152	.786	.859	.287	2.575
Aetiology (Down syndrome)	-.234	.648	.791	.289	2.164
Physical health resource loss	**1.147**	**.016***	**3.148**	**1.242**	**7.983**
Stress/anxiety resource loss	**1.381**	**.003***	**3.979**	**1.616**	**9.795**

Table 7.4 Reduced regression model for loneliness

7.4 Summary of Findings

Females were found to have over two times greater odds than males to be lonely (OR 2.250 CI 1.063- 4.762). None of the remaining demographic variables were significant in regression analysis. Reported physical health resources loss was significant and positively associated with symptoms of loneliness (0.016). Overall, 81.9% of participants in this study reported losses related to physical health and these participants had over three times greater odds (OR 3.148, CI 1.242-7.983) of feeling lonely than those that did not. The presence of a mental health disorder was statistically significant (0.037) in bivariate analysis. However, it was not sustained in the reduced regression model. Loss of stress/anxiety resources was significantly associated with loneliness (0.003). Participants who experienced stress/anxiety related loss had almost four times greater odds of being lonely compared to those who did not report this loss (OR 3.979, CI 1.616-9.795).

7.5 Chapter Conclusion

This study has examined resources that may be present in the lives of older adults with an intellectual disability in Ireland and how the loss and/or gain of these resources during the COVID-19 pandemic and associated restrictions may have impacted on participants' subjective experience of loneliness. It is important to note that this study does not include the experiences of participants that did not self-report. Results must be considered with this in mind. Findings from this study have been presented in terms of bivariate and multivariate analysis using a binary logistic regression model. The discussion chapter presents these findings in the context of the current literature on COVID-19 and loneliness. Much of this literature is focussed on the general population, with smaller numbers of studies focussing on people with an intellectual disability. This further highlights the importance of the current study in contributing important research in understanding the impacts of the pandemic both for the present time and in the event of future pandemics or public health emergencies.

Chapter 8 Mental health impacts – Self-Rated Mental Health

Introduction

This chapter utilised a single item measure of self-rated mental health to further aid understanding of the resources that were associated with mental health outcomes among older adults with an intellectual disability in Ireland during the pandemic.

8.1 Methods

The overall study methodology has already been outlined in Chapter 3 of this thesis. As occurred in prior chapters the same independent variables were the predictors utilised.

8.1.1 Measures

The self-rated mental health question had response options on a 5-point Likert scale ranging from excellent, very good, good, fair, poor. The question was asked as follows: How has [your/his/her] mood and emotional or mental health been during the COVID-19 pandemic? Has it been…? There were three types of responses for this measure, participants could self-report, respond with support, or by proxy only. In total 674/682 participants answered the self-rated mental health question.

The independent variables which were used within this study and have already been explained in greater detail in chapter 3 were the demographic variables of: sex; age (categorical); level of intellectual disability (mild, moderate, severe/profound); living arrangements (independent/family, community/group homes, residential/campus homes); response type (self or self with support, proxy); and aetiology of intellectual disability (Down syndrome or other/unknown cause). Also included were single item independent variables: the presence mental health disorder; use of medication related to mental health disorders (anxiolytics, anti-depressant, anti-psychotic); access to mental health supports and reduction in day service/work hours. Summary predictor variables were also used: physical health (resource loss and gains); physical distancing/infection history; social activities and engaging in alternative activities (resource loss and gains); relationships (resource loss and gains); illness and bereavement; stress/anxiety resource loss; and resilience resource gains.

8.2 Analysis

Statistical analyses were performed using SPSS version 27.0. Independent variable frequencies and bivariate associations with the dependent variable were initially examined. Self-rated mental health was adjusted to a binary response where participants fell into either ‘excellent, very good, good’ or ‘fair or poor’ self-rated mental health. Originally, the researcher had intended to conduct a multinomial logistic regression using the 5-item response or a 3-item response where the responses were collapsed into ‘excellent/very good/good’, and ‘fair/poor’. However, low frequencies within some results categories meant the accuracy and fit of the models was improved by conducting a binary logistic regression.

All independent variables were either two or three category responses. Therefore, Pearson’s chi-square test was conducted between all independent and the dependent variables, unless numbers were smaller than permitted in which case a Fisher’s exact test was performed. A binary logistic regression was performed to identify the factors associated with how participants perceived their mental health (excellent/very good/good or fair/poor) during COVID-19 and the related public health measures. Firstly, demographic variables: sex; age; living circumstances; level of intellectual disability; response type; and aetiology were controlled for, they were entered into block 1 of the model, regardless of statistical significance, using the enter selection method. This was followed by a backward selection entry of all statistically significant variables into block 2 of the model. Prior to conducting the regression model, all the above variables were tested for multicollinearity using collinearity statistics VIF, tolerance (Table 8.1) and bivariate correlations, see Appendix 14 for full correlation matrix. No correlations exceeded the limits set out within the methodology section of this thesis which were no bivariate correlations >0.6, no VIF values >10, and no tolerance values <0.2.

	Tolerance	VIF
Sex	.968	1.033
Aetiology	.809	1.235
Level of intellectual disability	.682	1.466
Type of response to survey	.751	1.332
Living arrangements	.680	1.471
Age Categorical	.813	1.229
Mental health disorders	.831	1.203
Access to mental health supports	.787	1.271
Physical health resource loss	.921	1.085
Physical health resource gain	.753	1.328
Engaging in alternative activity resource gain	.817	1.225
Stress/anxiety resource loss	.876	1.142

Table 8.1 Results of test for collinearity between independent variables – self rated mental health

8.3 Results

8.3.1 Descriptive/Univariate Analyses Results

A total of 674 participants completed the self-rated mental health measure. There were more females (n=364, 54%) compared with males (n=310, 46%) who completed the question. One quarter (n=171, 25.4%) of the participants were over the age of 65 years and 55.8% (n=376) were in the 50-64 years category. Regarding level of intellectual disability, the largest number was in the moderate category (278/674). The greatest number of responses was provided by proxy respondents (n=424, 64.6%). Half of the participants (n=335, 50.2%) lived in community/group homes and one in five participants (20.3%) had Down syndrome. Figure 8.1 presents the demographic variables represented as percentages for the total study population who responded to the self-rated mental health question. Further detail including numbers of responses for each variable, is presented in Table 8.2.

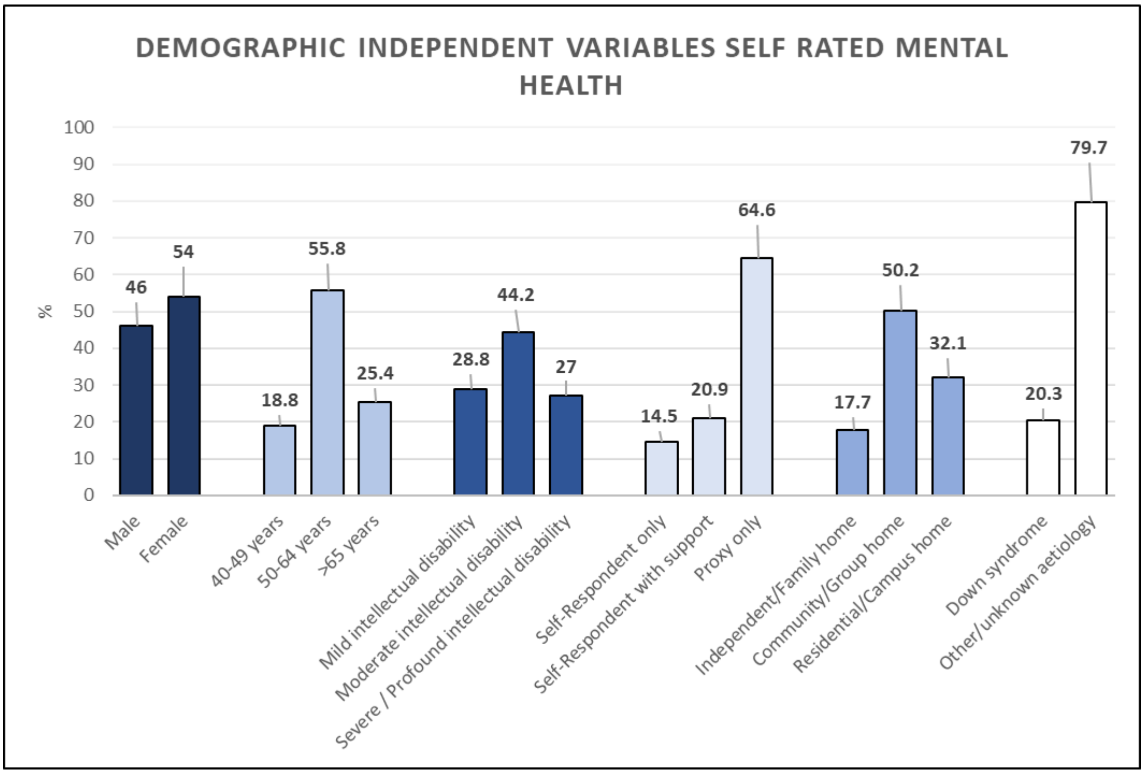


Figure 8.1 Descriptive analysis of predictor demographic variables for self-rated mental health question respondents.

Figure 8.2 presents the percentages of yes/no responses from the total number of participants across all independent (non-demographic) variables. Further detail including numbers of responses for each variable, is presented in Table 8.2. Of those that responded, almost half (n=320, 47.5%) had a diagnosed mental health disorder, and one third (n=212, 32.3%) were taking antidepressant medication. Antipsychotic medication was prescribed to 40.2% (n=264). Most participants (368/674) felt that they had access to mental health support if it was required. 79.2% (n=534) of participants had loss of physical health resources and slightly over half (51%) had no gains in physical health. Two thirds (469/674) experienced reduced work/day service hours. Most participants (n=579, 85.9%) experienced losses related to physical distancing and infection history. Almost all (96.1%) had losses related to social activities and 77.7% (n=524) felt that they experienced gains through engaging in alternative activities. There was both relationship losses and gains experienced by many participants (88% and 78.3% respectively). Almost one third (29.5%, n=199) were impacted by bereavement or illness of someone close to them. While 68.8% (n=464) experienced stress/anxiety resource loss during the pandemic, 28.9% (n=195) experienced resilience resource gain.

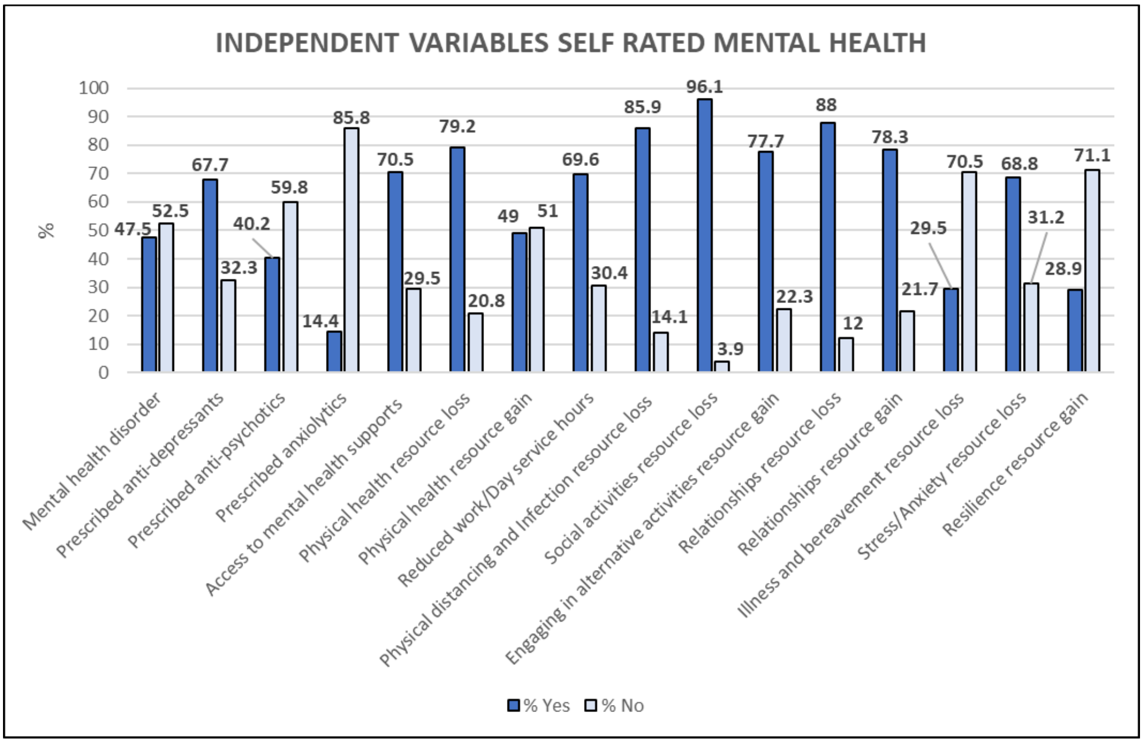


Figure 8.2 Descriptive analysis of predictor independent variables for self-rated mental health question respondents.

8.3.2 Bivariate Analysis Results

There was a total of 674 valid responses to the self-rated mental health question. Excellent, very good or good was reported by 73% (492/674) of participants and 27% (182/674) reported fair or poor. Results from univariate and bivariate analysis are outlined in Table 8.2 which was carried out, in the first instance for all independent variables and secondly, between all independent variables and self-rated mental health. Males reported slightly better mental health than females, with 74.2% (n=230) of males reporting excellent/very good/good mental health in comparison to 72% (n=262) of females. Self-reported mental health was similar across each of the age categories with results between 72.4% and 73.4%. Among levels of intellectual disability, those with moderate intellectual disability reported higher percentages (30.9%, n=86)) of fair/poor mental health compared with those with severe/profound intellectual disabilities (27.6%, n=47). The lowest fair/poor mental health was reported in those with mild intellectual disabilities (23.2%, n=42). Those living independently or with family reported the highest rated mental health (n=139, 76.3%), with lowest ratings of excellent/very good/good mental health in community/group homes (n=241, 71.9%) and residential/campus homes (n=154, 72%). Participants with mild intellectual disability had higher rated mental health (76.8%) than those with moderate (69.2%) or severe/profound disabilities (72.4%). Where the scale was answered by a proxy respondent there were lower ratings of good mental health (70.3%, n298) when compared to those that self-reported or self-reported with support (77.9% and 78.1% respectively). Regarding poorer mental health ratings, proxy respondents had the highest percentages (29.7%) compared to those who self-reported and reported with support (22.1% and 21.9% respectively). People with Down syndrome had lower ratings (68%) of excellent/very good/good mental health than people with other/unknown causes (73.4%). For participants that had a mental health disorder, they had poorer mental health ratings than those that had no diagnosis (32% vs 23.4%).

For participants taking antidepressant medication, the self-rated mental health response was almost identical between groups. Whether taking medicines or not 73% rated mental health excellent/very good/good. Results were almost the same for use of antipsychotic medication. Within the variable for prescribed anxiolytic medicines, those taking anxiolytics had a higher percentage (30.1%, n=28) of fair/poor mental health compared with those not taking the medication (26.6%, n=150). Participants that had access to mental health supports, if they required it, had higher ratings for fair/poor mental health than those that did not have access to supports (n=107, 33.1% vs. n=33, 24.4%). Participants that experienced physical health resource loss had poorer rated mental health than those who had no loss (30.7% vs. 12.9%). Where gains related to physical health were experienced, self-rated mental health was higher (77.3% vs 68.9%). Only 4 participants (15.4%) who rated mental health as poor/fair had experienced no loss of social activity resources. Participants that experienced relationship resource gains during the pandemic rated their mental health as excellent/very good/good (n=405, 76.7%) compared to those that experienced no gains in this area (n=87, 59.6%). Among those who experienced stress/anxiety resource loss 157 participants (33.8%) rated mental health as fair/poor compared to the 25 participants (11.9%) who experienced no loss within this resource. However, among participants who reported fair/poor rated mental health, 25.1% (n=49) reported gains in resilience compared with 27.8% (n=133) of participants who did not report any gains in resilience.

Independent Variables	**Excellent/ Very good/ Good**	**Fair/ Poor**	**n (%) self-rated mental health study population**	**Total n=**	**p-value**
	n=492 (73%)	**n=182 (27%)**		**n=674**	
Sex				674	.518
Male	230 (74.2)	80 (25.8)	310 (46)		
Female	262 (72)	102 (28)	364 (54)		
Age				674	.965
40-49 years	92 (72.4)	35 (27.6)	127(18.8)		
50-64 years	276 (73.4)	100 (26.6)	376 (55.8)		
≥65 years	124 (72.5)	47 (27.5)	171 (25.4)		
Level of intellectual disability				629	.195
Mild intellectual disability	139 (76.8)	42 (23.2)	181 (28.8)		
Moderate intellectual disability	192 (69.2)	86 (30.9)	278 (44.2)		
Severe/profound intellectual disability	123 (72.4)	47 (27.6)	170 (27)		
Living Circumstances				667	.633
Independent/family home	90 (76.3)	28 (23.7)	118 (17.7)		
Community/group home	241 (71.9)	94 (28.1)	335 (50.2)		
Residential/campus home	154 (72)	60 (28)	214 (32.1)		
Type of Response				656	.103
Self-report	74 (77.9)	21 (22.1)	95 (14.5)		
Self-report with support	107 (78.1)	30 (21.9)	137 (20.9)		
Proxy	298 (70.3)	126 (29.7)	424 (64.6)		
Aetiology of intellectual disability				600	.234
Down syndrome	83 (68)	39 (32)	122 (20.3)		
Other/unknown aetiology	351 (73.4)	127 (26.6)	478 (79.7)		
Mental health disorder				674	**0.029**
Yes	221 (69.1)	99 (30.9)	320 (47.5)		
No	271 (76.6)	83 (23.4)	354 (52.5)		
Prescribed Anti-depressants				674	.916
Yes	154 (72.6)	58 (27.4)	212 (32.3)		
No	325 (73)	120 (27)	445 (67.7)		
Prescribed Anti-psychotics				674	.932
Yes	192 (72.7)	72 (27.3)	264 (40.2)		
No	287 (73)	106 (27)	393 (59.8)		
Prescribed Anxiolytics				674	.480
Yes	65 (69.9)	28 (30.1)	93 (14.4)		
No	414 (73.4)	150 (26.6)	564 (85.8)		
Access to mental health supports				**458**	**.066**
Yes	216 (66.9)	107 (33.1)	368 (70.5)		
No	102 (75.6)	33 (24.4)	135 (29.5)		
Physical health resource loss				**674**	**<0.001**
Yes	370 (69.3)	164 (30.7)	534 (79.2)		
No	122 (87.1)	18 (12.9)	140 (20.8)		
Physical health resource gain				**674**	**0.014**

Yes	255 (77.3)	75 (22.7)	330 (49)		
No	237 (68.9)	107 (31.1)	344 (51)		
Reduced work/day service hours				674	.287
Yes	348 (74.2)	121 (25.8)	469 (69.6)		
No	144 (70.2)	61 (29.8)	205 (30.4)		
Physical distancing/Infection history resource loss				674	.246
Yes	418 (72.2)	161 (27.8)	579 (85.9)		
No	74 (77.9)	21 (22.1)	95 (14.1)		
Social activities resource loss				674	.174
Yes	470 (72.5)	178 (27.5)	648 (96.1)		
No	22 (84.6)	4 (15.4)	26 (3.9)		
Engaging in alternative activities resource gain				**674**	**0.009**
Yes	395 (75.4)	129 (24.6)	524 (77.7)		
No	97 (64.7)	53 (35.3)	150 (22.3)		
Relationships resource loss				674	.117
Yes	427 (72)	166 (28)	593 (88)		
No	65 (80.2)	16 (19.8)	81 (12)		
Relationships resource gain				**674**	**<0.001**
Yes	405 (76.7)	123 (23.3)	528 (78.3)		
No	87 (59.6)	59 (40.4)	146 (21.7)		
Illness and bereavement				674	.477
Yes	149 (74.9)	50 (25.1)	199 (29.5)		
No	343 (72.2)	132 (27.8)	475 (70.5)		
Stress/anxiety resource loss				**674**	**<0.001**
Yes	307 (66.2)	157 (33.8)	464 (68.8)		
No	185 (88.1)	25 (11.9)	210 (31.2)		
Resilience resource gain				674	.484
Yes	146 (74.9)	49 (25.1)	195 (28.9)		
No	346 (72.2)	133 (27.8)	479 (71.1)		

Table 8.2 Frequencies and bivariate results self-rated mental health study population

None of the demographic variables were found to be significant in the reduced regression model. Having a mental health disorder was statistically significant (0.029) and access to mental health supports was also close to significant (0.066). Both were therefore included in the full model. The greatest level of significance was found between self-reported mental health and physical health resource loss (<0.001), relationships with others (<0.001), and where participants experienced stress/anxiety resource loss (<0.001). The other independent variables where significant associations where found were in engaging alternative activities resource gain (0.009) and physical health resource gain (0.014). Table 8.3 presents the variables that were included in the full mode with p-values.

Independent Variables	p-value
Sex	0.518
Age	0.965
Level of Intellectual Disability	0.195
Living Circumstances	0.633
Aetiology	0.234
Type of response	0.103
Access to mental health supports	***0.066**
Mental health disorder	***0.029**
Physical health resource loss	***<0.001**
Physical health resource gain	***0.014**
Engaging in alternative activities resource gain	***0.009**
Relationship resource gain	***<0.001**
Stress/anxiety resource loss	***<0.001**

Table 8.3 Variables in full model for self-rated mental health (*statistically significant)

8.3.3 Multivariate Analysis Results

The full model for self-rated mental health explained between 17.2% (Cox and Snell R Squared) and 24.1% (Nagelkerke R Squared) of the variance in self-rated mental health and associated resources model. The classification table for the model had an overall percentage of 71.9%. The reduced model is presented in Table 8.4 with significant ($p \leq 0.05$) variables highlighted and in bold. Response type was significant and positively related to participants reporting either fair or poor mental health when compared to those that self-reported. Proxy responses had OR 3.834 times greater odds than self-response participants to reported fair/poor mental health. Those with mental health disorders were twice as likely to report poor mental health than those without a diagnosis (OR 2.060 CI 1.199, 3.542). Stress/anxiety resource loss and physical health resource loss were significant, and positively associated with poorer report mental health. Participants that had physical health resource loss had odds four times greater than those that had no loss (OR 4.102 CI 1.938, 8.685) to report poorer mental health. For those with stress/anxiety resource loss they were also more than four times more likely (OR 4.125 CI 2.077, 8.195) to report either fair or poor mental health than those that did not report losses in these areas. The final predictor variable in the model to remain statistically significant and was also associated with poorer rated mental health was for participants that did not experience relationships resource gains over the pandemic period. As ‘no’ was the indicator responses in the model, this response was recoded to produce a positive beta coefficient. There were more than two and a half times (OR 2.541 CI 1.397, 4.622) greater odds that these participants would report their mental health as fair or poor than those who experienced resource gain in relationships.

	B	Sig.	Exp(B)	95% C.I.for EXP(B)	
				Lower	Upper
Sex (female)	-.082	.746	.922	.563	1.510
Aetiology (other/unknown)	-.379	.264	.684	.352	1.331
Level of intellectual disability (moderate)	.268	.398	1.308	.702	2.438
Level of intellectual disability (severe/profound)	-.139	.731	.870	.394	1.924
Response type (self with support)	.869	.081	2.385	.899	6.326
Response type (proxy)	**1.344**	**.003**	**3.834**	**1.574**	**9.341**
Living arrangements (community/group)	-.079	.842	.924	.425	2.012
Living arrangements (residential/campus)	-.452	.328	.637	.258	1.573
Age (50-64 years)	-.454	.228	.635	.303	1.329
Age (65 years+)	-.513	.244	.599	.253	1.418
Mental health disorder	**.723**	**.009***	**2.060**	**1.199**	**3.542**
Physical health resource loss	**1.412**	**<.001***	**4.102**	**1.938**	**8.685**
Relationship resource gain (no)	**.933**	**.002***	**2.541**	**1.397**	**4.622**
Stress/anxiety resource loss	**1.417**	**<.001***	**4.125**	**2.077**	**8.195**

Table 8.4 Reduced binary logistic regression model - self rated mental health.

8.4 Summary of Findings

Following completion of the binary logistic regression model with self-rated mental health as the dependent variable, the variables that remained significant were: type of survey response; mental health disorder; physical health resource loss; relationship resource gains; and stress/anxiety resource loss. When adjusting for demographic and statistically significant variables within the model, when the self-rated mental health question was answered by a proxy only, participants had greater odds of having fair or poor rated mental health.

As presented earlier in this thesis the most prominent mental health disorders among IDS-TILDA participants were: anxiety 26.1% (178/682); emotional problems 16% (109/682); mood swings 15.8% (108/682); and depression 12.8% (87/682). In the reduced regression model, participants with mental health disorders had two times greater odds of having fair or poor mental health than those with no diagnosed mental health disorder (OR 2.060 CI 1.199, 3.542). Among participants in this study related to self-rated mental health, 32.3% are prescribed antidepressant medication, 14.4% (n=93) are prescribed anxiolytics and 40.2% (n=264) are prescribed antipsychotic medication. One quarter (29.5%) of the participants within this study felt that they had received less medical care than usual during the pandemic period.

For those that felt they experienced no gains within relationship resources they had almost two and a half times greater odds of having fair/poor rated mental health. Within the summary relationship resources variable, the two variables with the greatest frequencies were more time/better time with staff (60.6%) and using technology to communicate (49.4%). The summary variable of stress/anxiety resource losses had a statistically significant (<.001) and positive association with a fair/poor response to the self-rated mental health question in the COVID-19 (phase 2) survey. Those that answered yes to having experienced any of the variables which comprised of the summary variable had above four times greater odds of having fair/poor mental health than those that answered no to these questions (OR 4.125 CI 2.077, 8.195).

8.5 Chapter Conclusion

Chapter 8 examined the resources which may have had an impact on self-rated mental health for older adults with an intellectual disability in Ireland during the COVID-19 pandemic and associated lockdowns. Statistically significant associations were found between ‘fair/poor’ rated mental health and seven independent variables: mental health disorders; access to mental health supports; physical health resource loss; physical health resource gain; engaging in alternative activity resource gain; relationship resource gain; and stress/anxiety resource loss. Following these being entered into the full binary logistic regression model and adjusting for demographic variables, the statistically significant variables that remained were response type, mental health disorders, physical health resource loss, relationship resource gain and stress/anxiety resource loss. These findings are discussed within the discussion chapter in the context of the literature and aligned with the research objectives of the overall study.

Chapter 9 Discussion

Introduction

This chapter revisits the findings from the four studies described within this thesis (chapters 5-8) and considers these in the context of current literature and policy on mental health, in what is now, the aftermath of the COVID-19 pandemic. Findings are presented within the framework of the COR theory, using the resources that where lost and/or gained during the pandemic to guide the discussion. As society moves from the response phase of the public health emergency into the recovery phase, there is a necessity to ensure that resumption of services does not leave older adults with an intellectual disability behind. The Government recognised early in the pandemic that the social implications of the COVID-19 pandemic needed to be planned for, and recognised the implications that the pandemic would have in several areas. These included mental health and the impact that restrictions related to sports and exercise could have on social isolation and mental health (Government of Ireland 2020a). This study found that these areas for concern were realised as significant impacts experienced by older adults with an intellectual disability. It is essential that learnings from the pandemic are incorporated into recovery and preparedness planning to mitigate risks for this population. Policy introduced in the aftermath of the COVID-19 pandemic aimed at building back better and reforming services in the field of mental health have urged governments to place mental health at the core of COVID-19 recovery plans. The findings from this study support this need.

The National Service Plan (HSE 2023b) sets out the priorities and activities for the Government in order to achieve equity in the health system and to address long-standing challenges, some of which may have been compounded by the pandemic. Governments across the globe have commenced inquiries to examine their countries’ response to the pandemic, the impact that it had on their populations, and identify lessons that can be learned for the future. As recognised in the COR theory, one’s social environment is a key determinant of health status and comprises of many resources which were both lost and gained during the pandemic. As such, plans for COVID recovery must consider these determinants when planning health services, and this is recognised in the national service plan (HSE 2023b). This study provides evidence across a wide variety of aspects of the lives of older adults with an intellectual disability in Ireland which were impacted. This new evidence will help to inform the discussion towards any revised implementation plans for national policies, including Transforming Lives, Sharing the Vision, Sláintecare, and Healthy Ireland (HSE 2015a, 2017, Oireachtas Committee on the Future of Healthcare 2017, DoH 2020).

9.1 Principal Study Findings

During the COVID-19 pandemic this study found that women were lonelier than men and that people with Down syndrome reported more symptoms of depression than those without Down syndrome. Other demographic variables were not statistically significant within the study. Recovery and future planning should consider these two groups as being at greater risk of poorer mental health outcomes.

The loss of physical health resources was found to be one of the major contributors towards poorer mental health outcomes and presents as a particular area of importance when planning for recovery and any future pandemics. The disparities which already existed in terms of poorer physical health in older adults with intellectual disabilities in comparison to the general population, were further compounded by an association with poorer mental health during COVID. Participants reported lower engagement in exercise, higher levels of sedentary behaviours and unhealthy diets during the pandemic. All of these are important determinations of physical and mental health outcomes, and supporting older adults with intellectual disabilities to rebuild their lives and address these issues post the pandemic is critical, and it will be important to monitor this in future waves of IDS-TILDA.

The provision of mental health supports which are appropriate and effective to support the needs of older adults with an intellectual disability has been presented within this study as an area of critical importance. An important finding in this study was that mental health supports were available for many participants, however, further analysis of these results found that many supports were being provided by staff, friends, and family. Access to mental health supports was positively associated with symptoms of depression. For those who did not have access to supports there was higher rates of anxiety. The evidence also supported previous research which suggested that those with pre-existing mental health difficulties were more at risk of poorer mental health outcomes.

Although participants within this study identified a variety of positive aspects of the COVID-19 pandemic, these did not result in improved mental health outcomes. The COR theory states that in times of resource loss that resource gain becomes more important, and that these gains may assist in adjustment and recovery. This is supported by the findings of this study and highlights the success of use of this framework when exploring the impacts of COVID-19 on the mental health of this population. It provides evidence that this is a beneficial and useful framework and provides an opportunity to explore the resources that are relevant and are centrally valued among people with intellectual disabilities.

This study presents evidence on several areas that were anticipated as potential risks or areas for concern for older adults with intellectual disabilities. However, some of these were not found to be statistically significant. Most notably, the reduction in day service/work hours, social activities, relationships, and living in congregated settings.

The three research objectives of this study were:

1. To identify factors associated with mental health outcomes for this population during the COVID-19 associated restrictions.
2. To measure how resource loss which occurred during the pandemic impacted on mental health.
3. To measure how resources gained during the pandemic impacted on mental health.

9.2 Research Objective 1

1. To identify factors associated with mental health outcomes for this population during the COVID-19 associated restrictions.

Older adults with intellectual disabilities do not represent a homogenous group within society. There are varying degrees of intellectual disability which may also present with mental, physical, and sensory impairments. To conduct research within this population without adjusting for demographic information would not capture their unique experiences. This study sought to achieve this through the consistent inclusion of six demographic variables across the four mental health measures that were explored.

9.2.1 Sex

In relation to the COVID-19 pandemic period, females were found to have over two times greater odds than males to be lonely. This is consistent with findings from TILDA, where females were also found to score higher on the UCLA loneliness scale than males (Ward *et al.* 2021b). From both the IDS-TILDA study and the TILDA study there were also significant overall increases in the numbers of participants experiencing loneliness when compared with before the COVID-19 pandemic. In Germany, prior to the pandemic, a longitudinal study explored the differences in loneliness among those with and without disabilities. Researchers found that males reported lower levels of loneliness than females using the 3-item UCLA loneliness scale. For females with severe disabilities, loneliness increased with age, particularly for those over the age of 66 years. Pagan (2020) also found that people with disabilities experienced greater levels of loneliness than their non-disabled peers during initial lockdowns. Longitudinal data from the IDS-TILDA study also found that levels of loneliness were associated with functional limitations that left people with intellectual disabilities more exposed to precipitating variables for loneliness. These included access to education, transportation, pain and emotional health (Wormald *et al.* 2019).

Findings from the current study show much higher levels of loneliness in females (66.7%) when compared to males (51.4%) during the COVID-19 restrictions. This compares to much lower rates of loneliness among the general population over the pandemic period (Ward *et al.* 2020). Findings from this thesis shows that older women with intellectual disabilities have experienced loneliness at a higher rate than men but also when compared to their non-disabled female peers. Planning for both disability services and mental health services in the aftermath of the pandemic for this specific group has not distinguished between the needs of men and women with intellectual disabilities.

There were vast differences between the marital and parental status of participants of the IDS-TILDA population and that of the general population. From Wave 3 of the study, 0.5% (n=3) reported having a spouse/partner, and 0.02% (n=1) had a child (McCarron *et al.* 2017a). For men in the general population, protective factors from depressive symptoms included spousal support, less strain from spouse, and better social network integration. For both men and women social support from friends and children were protective factors. Depressive symptoms in women were positively associated with strain from children (Santini *et al.* 2016). The findings from this study suggest a greater need for further research to be undertaken to explore this phenomenon among older women with intellectual disabilities and to plan services and policy appropriately. The demographic variable of sex was not statistically associated with the other dependent variables in this study.

9.2.2 Age

Age was not found to be statistically significant in bivariate or multivariate analysis across all four studies within this thesis. This was an interesting finding as the age categories represent three generally distinct times throughout the life span. The overall levels of loneliness from this study were high with 60% of participants identifying that they felt lonely during the pandemic. Prior to the COVID-19 pandemic, for older adults among the general population in Ireland, loneliness did not increase linearly with age; it decreased from 50-67 years, and then increased again in older age. Moderate loneliness was more common in those over 75 years than in younger participants in the study (50 years+) (Ward *et al.* 2019a). Findings from the current study also found slightly higher reported loneliness within those aged 65 years at 62.2% (23/37). However, this was only marginally higher when compared to those aged 40-49 years at 60.8% (31/51) and in those aged between 50-64 years at 58.3% (42/72). In the United States, researchers compared emotional, physical, and overall wellbeing, related to the social restrictions during the pandemic between older and younger cohorts. They found that older adults (aged 60-72 years) reported greater health and wellbeing than younger adults, and suggest that older adults may be more resilient to the impacts of the pandemic (Feliciano *et al.* 2022). As people with an intellectual disability continue to experience greater longevity, and where there are more people living into old age, it is important that age categorisation continues to be included in studies to understand changing experiences across the life span.

9.2.3 Level of Intellectual disability

Level of intellectual disability was found to be significant in bivariate analysis for symptoms of depression (0.040). However, when the binary logistic regression model was complete this variable was not sustained. Level of intellectual disability was not statistically significant in bivariate or multivariate analyses among the other three studies within this thesis. The variances among the different categorisations of intellectual disability may have suggested that there would have been some distinctions between levels of intellectual disability and mental health impacts within this study, but that was not supported by the findings.

9.2.4 Type of Response

There was a statistically significant association between symptoms of depression and type of response in bivariate analysis, but it was not sustained in the reduced regression model. Regarding self-rated mental health, where surveys were completed by proxy respondents, this was positively associated with fair/poor reported mental health in the reduced regression model. Type of survey response was not statistically significant at either level of analysis for loneliness. From bivariate analysis, type of survey response and symptoms of anxiety, the p-value approached statistical significance (0.073) and was included in the full regression model. This was consistent with the inclusion of demographic variables in each model, but it did not remain in the reduced model. Lower levels of mental health ratings among proxy respondents are consistent with findings from previous waves of the IDS-TILDA study and do suggest that response type may contribute towards findings related to mental health and wellbeing (McCarron *et al.* 2014, McCarron *et al.* 2017a). Research conducted by Foran *et al.* (2013) explored the inter rated agreement between self-reporting people with intellectual disabilities and nominated proxies in relation to fear of falling and found good consistency and reliability in proxy responses. However, the study highlighted the importance of choosing the correct proxy and suggests that those with the most frequent day-today contact, such as keyworkers are the most appropriate proxies. Within the current study, proxy respondents were required to have known the participants for a minimum of six months. Many proxies were keyworkers, or family members who knew the participant very well.

It is acknowledged within the methodology chapter of this study that proxy ratings may have difficulties, especially when related to subjective experiences, and for this reason proxy responses were excluded from the subjective measurements of loneliness and anxiety. However, they were included for symptoms of depression and self-rated mental health, which have more observable presentations such as showing less interest in previously enjoyed activities, poorer appetite, and speaking more slowly or not being able to concentrate.

9.2.5 Living Circumstances

The predictor variable of living circumstances was not significantly associated in bivariate or multivariate analysis with symptoms of depression or anxiety, loneliness, or self-rated mental health. In the landscape of current national policy (HSE 2011) related to housing for people with an intellectual disability and the slow progression from congregated settings to homes within the community (HSE 2017), this was considered to be an important variable for inclusion within this study. Within the context of the COVID-19 pandemic and in the interest of public health measures to protect those most at risk, the HSE (HSE 2020b) issued guidelines specific to people living in these settings, referred to as 'residential care facilities' within the guidance. There were strict bans on visiting, closures of group-based day and respite services and redeployment of staff from these services into residential settings. The guidance also related to advance care directives, transfer to hospital, and infection prevention and control measures. These guidelines were continually reviewed over the following two years, but for the most part more stringent restrictions and guidance were in place for people living in these homes than in the general population. However, the swift implementation of these measures in Ireland, and the adherence to these measures by individuals with intellectual disabilities, staff and family members appear to support low rates of excess mortality and morbidity related to the coronavirus.

Despite the challenges that were present for older adults with intellectual disabilities, and that may have been different depending on their living arrangements, in the context of mental health through the lens of COVID, living circumstances were not associated with any of the mental health outcomes in this study.

9.2.6 Aetiology of Intellectual Disability

Within the current study, 18.3% of participants had Down syndrome and 81.9% had other/unknown aetiology for intellectual disability. In the study where the dependent variable was symptoms of depression, having Down syndrome was statistically significant in the regression model. These participants had almost two and a half times greater odds of having symptoms of depression than those with other/unknown cause of intellectual disability.

Aetiology was not statistically significant at any level of analyses with symptoms of anxiety, loneliness, or self-rated mental health. The IDS-TILDA study has collected data specific to those with a diagnosis of Down syndrome since the study commenced at Wave 1 (McCarron *et al.* 2011). Findings have indicated lower levels of mental health conditions (26.2%) among participants with Down syndrome when compared to those without (51.9%). However, consistent with the current study, Villani *et al.* (2020) also found increased depressive burden among adults with Down syndrome in their study in Italy conducted using the interRAI assessment following the first COVID-19 lockdown. This increase in symptoms also impacted on participants experience of social withdrawal.

Within the current study, one in five participants with Down syndrome reported symptoms of anxiety, which was similar to the overall prevalence of anxiety in the study population. This is contrary to findings from Sideropoulos *et al.* (2023) who report that individuals with Down syndrome had lower levels of anxiety related to the COVID-19 pandemic when compared to those with other causes of intellectual disabilities. However, authors found that having an existing diagnosis of an anxiety disorder was a strong predictor of anxiety related to the pandemic for people with Down syndrome. From the onset of the pandemic, it was widely recognised that people with Down syndrome were at a higher risk of more adverse consequences if they contracted the virus due to their predisposition to respiratory illness. In Spain, research was conducted on mortality among adults with Down syndrome pre and post COVID pandemic and despite an expected increase in mortality, this did not present within the findings of the study. Authors acknowledge that vaccination was a strong protective factor against COVID related death for this group, and the importance of prioritising people with Down syndrome in future immunisation campaigns was highlighted (Sánchez Moreno *et al.* 2023).

Research early in the pandemic reported very worrying outcomes in terms of mortality and morbidity for those with Down syndrome. Research from the United Kingdom reported a fourfold increased risk of hospitalisation and a tenfold increased risk of COVID-related death with findings adjusted for cardiovascular and pulmonary disease, and care home residence (Clift *et al.* 2021). In the United States, there was also evidence that those with Down syndrome had a threefold increase for more severe outcomes associated with COVID following hospitalisation. However, risks of more serious outcomes were greater in those over the age of 40 years (Huls *et al.* 2021). One possible explanation for the increased depressive symptoms among those with Down syndrome was the widespread emphasis on the increased risks and vulnerability of this group, particularly in the early stages of the pandemic prior to vaccination programmes. Specific planning of mental health services for people with intellectual disabilities does not distinguish between those with Down syndrome and those without. This study presents evidence that those with Down syndrome may require specific supports to assist with mental health during pandemics.

9.3 Research Objective 2 and 3

2. To measure how resource loss which occurred during the pandemic impacted on mental health.

3. To measure how resources gained during the pandemic impacted on mental health.

9.3.1 Mental Health Disorder

There is a greater prevalence of mental health conditions among people with an intellectual disability. The presence of conditions such as depression, anxiety, mood disorders and the presence of loneliness among this population are presented within the literature (Cooper *et al.* 2007, Cooper *et al.* 2015, Bond *et al.* 2019). Findings from a study conducted by the World Health Organisation (WHO 2020b) highlighted how those with intellectual disabilities were at considerable risk of inequities in mental health care and treatment during the COVID-19 pandemic. From the onset of the pandemic, researchers, service providers, healthcare professionals, and people with intellectual disabilities and their families/support workers raised concerns related to the mental health and wellbeing of those with an intellectual disability (Tromans *et al.* 2020b). For these reasons, this was a key variable for inclusion within this study and is consistent with the resource of personal health in the COR theory. Mental health service delivery in the recovery phase of the COVID-19 pandemic, which is guided by implementation of current mental health policy (DoH 2020), may be required to a greater extent post-pandemic by older adults with intellectual disabilities. This is based on the increased mental health impacts reported within this study, and particularly among those with a pre-existing mental health diagnosis. While the policy recognised the challenges and deficits which existed prior to the pandemic, the negative impacts on mental health experienced during the COVID-19 pandemic may result in greater demand on services which were already under-resourced. The National Service Plan (HSE 2023b) sets out the plans for healthcare in the recovery phase of the pandemic and emphasises the importance of fully implementing 'Sharing the Vision', but there are no provisions made for increased need following the pandemic.

9.3.2 Pharmacology

Polypharmacy and excessive pharmacology are common place for older adults with an intellectual disability in Ireland (O'Dwyer *et al.* 2016), with the highest group of medications prescribed being anti-psychotic medication. (43.2%, 319/736). From the overall population within the current study (n=682) there was also high prescribing of medications related to mental health: anti-depressants (n=213, 32%); anti-psychotic medication (n=267, 40.2%); and anxiolytics (n=95, 14.3%). As each of the above three medication groups are prescribed to treat mental health disorders, and due to prescribing rates being high among this population, the inclusion of this variable was deemed by the researcher to be a significant resource to consider within this study. Mental health policy is largely dominated by a recovery orientated approach among the general population. Such an approach, however, is not well documented within the mental health and intellectual disability literature and was not evident, based on the high prescribing rates presented. In the United Kingdom, the STOMP project (stopping over-medication of people with a learning disability, autism or both, with psychotropic medicines) was initiated due to the high levels of prescribing of psychotropic medication among people with intellectual disabilities. Branford & Shankar (2022) explored the benefits or problems which may have been associated with the implementation of the STOMP project in the United Kingdom. They found that although the deprescribing of antipsychotic medication began initially, this coincided with an increase in the prescribing of antidepressant medication and, most concerningly, the prescribing of antidepressants for those without an active diagnosis of depression rose by 13.5% between 2016, when the STOMP project commenced, and 2020.

Despite the high rates of prescribing and contrary to the researchers' expectations, there were no statistically significant associations found between these medication groups and mental health impacts within this study. The researcher suggests further investigation is needed to explore the potential protective or risk factors associated with these groups of medication and mental health outcomes. Any interventions to address prescribing of such medications should apply learning from the United Kingdom context.

9.3.3 Access to Mental Health Supports

At the core of mental health policy in Ireland is to provide mental health services to support tangible changes in the lives of those accessing mental health services. The policy focusses on enabling recovery supported by a person-centred approach, where there is an emphasis on personal decision making supported by clinical best practice (HSE 2022). The Government's national health strategy for the aftermath of the COVID-19 pandemic commits to implementation of all reform and developments set out in the national mental health policy.

There are recognised challenges present in mental health and disability services. Particularly challenging are issues related to resourcing specialist mental health intellectual disability teams (HSE 2023b). The need for full implementation of specialist MHID teams across the country are a crucial component of the mental health strategy. However, findings from this study suggest that mental health supports which were available to participants during the pandemic did not result in improved mental health outcomes for those experiencing symptoms of depression. For those who did not have access to supports, there was increased symptoms of anxiety.

In bivariate analysis, access to mental health supports was found to have statistical significance with symptoms of depression (0.008), symptoms of anxiety (0.023), and approached significance with self-rated mental health (0.066). In the reduced regression model for symptoms of anxiety, where participants identified that they had no access to mental health supports, there was higher rates of anxiety. From the regression model with depression, access to mental health supports remained statistically significant and positively associated with symptoms of depression. This finding may suggest that supports were not effective for participants experiencing depressive symptoms. However, it may also be considered that people experiencing depressive symptoms were more likely to be accessing mental health supports.

When analysing results from the question related to access to mental health, there was several sources of supports that were identified by participants. These supports have been presented in Chapter 4. From the findings it was concerning to observe that a high percentage (29%, n=96) of those who identified receiving mental health supports, these were not provided by mental health care professionals. Mental health supports identified included staff, such as care staff, social care workers, and day services staff; family members; and friends. This is a relevant finding in the context of COVID-19, and in supporting the mental health of older adults with intellectual disabilities within the broader context. Consideration for training and education, and the burden that this places on these staff, family, and friends, requires further research attention and action.

Psychiatrists were identified as supports by 76 participants, psychologists by 40 participants, GP by 18 participants, and specialists in behaviour were identified by 11 participants. With each of these the support of family and friends was also acknowledged by many participants. However, national mental health policy presents the need for a combination of specialist mental health professionals, trained and skilled in supporting the mental health needs of adults with intellectual disabilities. For 76 participants, they were receiving supports from a team of mental health professionals; these were referred to as mental health teams, MHID, and multi-disciplinary teams. Only one participant was in receipt of bereavement support. This appears low when considering that among participants in this study 175 were bereaved during the pandemic. These findings are important in the context of this study when discussing the associations between access to mental health supports and the outcome variables of anxiety and depression. It is also important to consider that less than one quarter (76/327, n=23.2%) of participants were in receipt of mental health services as set out in mental health policy.

From previous pandemics, studies within the general population suggest that mental health impacts may continue for periods of months to years following the event (Jeong *et al.* 2016, Torales *et al.* 2020, Delanerolle *et al.* 2022). Lunsky *et al.* (2022) conducted a review of the literature in respect of mental health services and needs among people with an intellectual disability, specifically focused on the first six months of the pandemic internationally. They highlight the importance of understanding the mental health needs of this population and how these needs have evolved over the course of the pandemic and associated restrictions. Tromans *et al.* (2020a) reports a significant reduction in referrals to intellectual disability mental health services, from 539 pre-lockdown to 308 referrals during the first lockdown period. One worrying explanation for this reduction in referrals was that people were reluctant to try to access healthcare services unless it was perceived as an 'emergency' because many people were shielding at home and/or living at home with aging family members. Tromans *et al.* (2020a) suggested that there is a risk that mental health difficulties were not seen as an emergency, and there was greater fear around being in hospital and contracting the virus.

The need for education and training among people with disabilities, their families and carers/support workers in recognising symptoms of mental health conditions is crucial for preparedness in the event of future public health emergencies. Public health measures must provide clarity on what is deemed an emergency to provide people with the confidence to seek supports when needed. Prior to the pandemic, Whittle *et al.* (2017) identified several enablers and barriers to the ability of people with intellectual disabilities to access mental health services. One challenge that is widely documented, and continues to persist, is the lack of availability of specialists in mental health and intellectual disability to provide services to this population. To address the resource issues, there may be opportunities for some supports to be provided by non-mental health professionals, such as low intensity interventions. However, if strategies such as these are to be effective, high-quality training and education must be provided and monitored.

Possibly of more concern when considering the findings of the current study is the increased depressive symptoms among those that felt that they had access to mental health services. Walton *et al.* (2022) conducted a systematic review and found there was evidence to suggest that access to mental health services was not an indicator of improved mental health outcomes. These findings were related to those who accessed both specialist intellectual disability services and general mental health services. There is a recognised shortage of specialist mental health and intellectual disability professionals, there remains a question as to the types of interventions and strategies which may result in the most successful outcomes for this population. Although the research on non-pharmacological interventions is growing with a range of interventions being studied. Interventions include: Cognitive Behavioural Therapy (CBT) (Graser et al. 2022, Fynn et al. 2023), bright light therapy (Hamers et al. 2020), digital mental health interventions (Cooney et al. 2018, MacHale et al. 2023), and Eye Movement Desensitization and Reprocessing (EMDR) for trauma and PTSD (Quevedo et al. 2021, Unwin et al. 2023). Despite the growing research evidence, the prominence of recovery focussed and non-pharmacology interventions in modern mental health models appears to be less prevalent in intellectual disability mental health services.

In one of the few studies on recovery in people with intellectual disabilities, Trustam *et al.* (2022) conducted qualitative interviews with this cohort. Researchers explored their experiences of recovery to help inform recovery focussed recommendations for practice. These recommendations included issues around entry to services, valuing information, and managing expectations. Regarding valuing information, participants explained that there was an oversimplification of their feelings; for example, being described as ‘upset’, and not being treated like an adult. Participants emphasised the importance of information to understand their mental health, to learn coping strategies and seek advice. Findings from studies such as this may provide useful evidence to developing mental health services to support people in the aftermath of the COVID-19 pandemic. They can provide strategies and interventions which support self-determination and encourage adults with an intellectual disability to take ownership of their own mental health. The importance of mental health promotion and recovery focussed interventions, which is fundamental to the provision of mental health services, should become an area of priority in the delivery of services and will enhance preparedness in the event of future pandemics.

The implications of changes in delivery of mental health services in response to the COVID-19 pandemic must be considered in the context of intellectual disability services. The Government response plan (Government of Ireland 2020a) invested €1.1 million into online mental health supports to help people manage their mental health during and following the pandemic. While mental health services may have remained available, however, most moved from face-to-face towards remote consultations via video or phone. The mode of delivery of such services may have impacted on their effectiveness both positively and/or negatively. Provision of services remotely have been reported as both barriers and facilitators to accessing a mental healthcare professional. Barriers identified by both service users and practitioners include poor access, connectivity issues, and technology literacy, and these were worsened where there were pre-existing inequalities, and concerns about reduced therapeutic alliance (Witteveen *et al.* 2022). Positives include cost effectiveness and convenient access to services. Transport or physical difficulties did not inhibit attendance at appointments (Maleka & Matli 2022).

The presence of COVID-19 and the associated restrictions provided an opportunity to develop capacity among healthcare professionals, disability services, and the public in general to engage in telemedicine. Delivery of healthcare in this way was expediated at a much greater rate than could ever have occurred outside of a global health emergency and may have provided opportunity to explore options for people with intellectual disabilities and mental health difficulties. From data collected for this study, half (49.4%) of the participants (337/682) identified that increased use of technology was a positive aspect of the COVID-19 pandemic. This started from a very low base in terms of use of technology among individuals with an intellectual disability in the IDS-TILDA study. Technology use at previous waves was low, with only 26.2% owning a mobile phone, with 16.7% of these saying that they do not actually use it, and only 34.9% of participants reporting that they had access to a computer/internet (McCarron *et al.* 2017a). These numbers had only marginally improved from the previous two waves of the study.

Increased use of technology among this population could be further developed to improve access to specialised mental health services via telemedicine. It may be a useful approach to address resource issues, such as geographical barriers and transport issues, but must take account of individuals' preference and ability to engage. Geographical barriers which caused disparities for people with intellectual disabilities accessing mental health services in Ireland were reported prior to the pandemic (Ramsay *et al.* 2016, Ramsay & Dodd 2018). However, if this is to be considered as a viable and effective option to remove barriers to access then there are measures which must be implemented to facilitate and evaluate services. An individualised approach to all aspects of mental health supports is essential and, therefore, may include additional training and education such as how to use technology to avail of such services, support to communicate, and strategies to prepare for appointments. Any such changes to

MHID teams need to be addressed within the current mental health policy if this is to affect the proposed numbers of MHID teams across the country. Moreover, it must be on an individualised, needs based approach so that the individual in receipt of the service can successfully engage with it. Challenges that have been identified during the pandemic could provide valuable learning to address challenges prior to telemedicine being fully implemented into mental health services (Geraldina et *al.* 2023, Lind et *al*. 2023).

In recognising the increased need for remote interactions for mental health supports during the pandemic, Great Ormond Street Hospital in the United Kingdom (Batchelor *et al.* 2020) delivered training on low intensity therapy to staff providing mental health support to children and adolescents. Low intensity therapy may be provided by a non-specialist who has been trained by specialists, and involves supporting self-guided therapy, group interventions, help to build mental health and wellbeing skills, and how to access resources. This approach may be considered for those experiencing mild to moderate depression or anxiety. Benefits of online training in low intensity interventions were evaluated from the perspective of staff attending the training, and responses were positive. There has been research into the delivery of low intensity psychosocial interventions by staff, over the past number of years; however, is not specific to those with an intellectual disability (Bennett-Levy *et al.* 2010, Sijbrandij *et al.* 2020). This may be beneficial in terms of addressing reduced specialist resources, and increasing availability of supports to those with mild/moderate depression and anxiety. This additional task shifting onto frontline staff, however, may stretch the resources of frontline staff even further. As research found that staff were under considerable pressures related to both personal and work life during the COVID-19 pandemic (Sheerin *et al.* 2019, Sheehan *et al.* 2021, Chen *et al.* 2022). It should not be considered a replacement for specialised mental health supports, rather a supplemental resource to both staff and individuals in supporting and promoting mental health and wellbeing among older adults with intellectual disabilities.

9.3.4 Physical Health Resources

One of the essential and most prevalent resources that was lost by participants during COVID-19 was that of physical health which included: increase in health problems not related to COVID-19; less physical activity, or exercise; overeating, or eating more unhealthy foods; more time sitting down or being sedentary; and getting less medical care than usual. From the regression models, it was positively associated with symptoms of depression, loneliness, and with poorer self-rated mental health. Research prior to the pandemic indicated that people with an intellectual disability already engaged in less physical activity and in more sedentary behaviours than the general population (Lynch *et al.* 2022). There is also ample evidence to suggest that this population experience greater health disparities when compared to the general population (Krahn & Fox 2014, Hatton & Emerson 2015, Videlefsky *et al.* 2019), have high incidence of co-morbidities and multi-morbidities (McCarron *et al.* 2013, Tyrer *et al.* 2019), and die up to twenty years earlier than those without an intellectual disability (Lauer & McCallion 2015, McCarron *et al.* 2015, Hosking *et al.* 2016, Doyle *et al.* 2021). Burke *et al.* (2019) highlighted the complex health needs of people with intellectual disabilities as well as a range of issues such as obesity, osteoporosis, falls and fractures, oral health problems, and polypharmacy which further compromises the health and wellbeing of this population. Increased incidence of chronic health disease in Ireland has been addressed in the HSE's National Service plan (HSE 2023b). The findings of this study suggest that this prevalence may increase even further. Findings from this study also presents evidence that these physical health losses are associated with mental health impacts following the COVID-19 pandemic, and this two-way relationship represents a worrying outlook for older adults with an intellectual disability in Ireland in the recovery phase of the pandemic and into the future.

Marconcin *et al.* (2022) conducted a systematic review during the first year of the pandemic and found that higher rates of physical activity were associated with wellbeing, quality of life, and lower depressive symptoms within several groups including older adults. In studies investigating sedentary behaviours among those with intellectual disabilities, high rates of such behaviours and inadequate physical activity have been found consistently (Melville *et al.* 2017). Harris *et al.* (2018) conducted an analysis of secondary data and found that people with intellectual disabilities were sedentary for over 70% of the day, prior to the pandemic. Taking this into consideration, it is important and concerning to recognise that the COVID-19 pandemic and associated restrictions may have decreased physical activity and increased sedentary behaviours even further.

Public health measures included strict restrictions on exercise distance for one's home (2km and 5km) during the pandemic. Being required to 'stay at home' and closures of gyms and swimming pools may have increased sedentary behaviours even further. In the context of COVID-19, Looze & McDowell (2021) report that among older adults from the general population in Ireland, participants who reported low levels of physical exercise were more likely to be in the severe category for anxiety when compared to those with high levels of physical activity. However, losses in physical health resources were associated with depression, loneliness, and self-rated mental health, but not with anxiety in the current study. Despite this, there were similarities between older adults both with and without intellectual disability in terms of reduced physical activity, and with this being associated with negative mental health impacts. Regarding preparedness in the event of future public health emergencies, the findings of this study provide strong evidence that there is a critical need for public health measures to include strategies to encourage older adults to remain active and to reduce sedentary behaviours. The importance of health promotion and how to ensure nutritious, healthy diets should be a priority. Proactive measures can be implemented to improve health promotion and inclusion of older adults with intellectual disabilities aligned with national policy to promote physical activity in Ireland. Such as ‘Get Ireland Active - The National Physical Activity Plan’ within the Healthy Ireland Framework (DoH 2013).

Participants that experienced physical health losses had over three times greater odds of feeling lonely than those that did not experience losses related to their physical health. In the United States, Hawkley *et al.* (2009) also reported associations between loneliness and physical activity, and found that loneliness was associated with a significantly reduced odds of physical activity (OR 0.65) among 229 participants aged between 50-68 years. Among the older population in Ireland, loneliness is associated with both self-rated physical health and self-rated mental health. Findings from TILDA suggest that increased loneliness and social isolation which occurred due to the COVID-19 associated restrictions will result in negative consequences for both the physical and mental wellbeing of older adults (Ward *et al.* 2021b). Authors of a longitudinal study monitoring population health in Wales, that randomly selected 600 adults, found that people reporting any level of loneliness had greater odds of increased weight during the pandemic (Allen *et al.* 2022). From the current study, although weight increase was not explored, almost a quarter (23%) of participants reported overeating or eating more junk foods, and more than half (53.7%) reported less physical activity/exercise. These results may suggest that weight increase may also have been a concern for this population who already experience overweight and obesity at a greater prevalence than the general population (Ryan *et al.* 2021).

Ward *et al.* (2020) reports a concerning finding among those over the age of 70 years within the general population in Ireland. Participants were found to have not presented for medical treatment or examination, such as after experiencing falls, to comply with ‘stay safe’ measures. Within this thesis, participants report both receiving less medical care (24.9%) and an increase in medical problems not related to COVID (23.3%). The impacts of resource loss in terms of physical health have statistically significant and positive associations with having fair or poor mental health, depressive symptoms, and loneliness during the COVID-19 pandemic. There are studies which have found significant links between self-rated mental health and mortality, health care utilisation and morbidity. Vasiliadis *et al.* (2005) found that in a large national survey conducted in Canada, apart from the presence of a mental disorder, participants’ self-evaluation of their mental health was a strong predictor in whether they accessed healthcare services for their mental health. Miilunpalo *et al.* (1997) investigated mortality among a working age population in Finland and found that participants subjective evaluation of their mental health was a predictor of health status and physician contacts per year.

Preparedness and planning in the event of future pandemics should include strategies to remove barriers for older adults with an intellectual disability accessing healthcare while adhering to public health measures. When comparing the impacts on mental health between the findings of this study and other studies exploring physical health losses among the general population, there are areas where losses and impacts have been similar. These findings emphasise the need for national policy in recovery and preparedness to develop disability inclusive policy which applies to all people. For policy to be inclusive policy makers must consult those with disabilities and remove the barriers for inclusion.

9.3.5 Reduced Day Service/Work Hours

The rights of people with disabilities to work on an equal basis with others is included in the UN Convention of Rights of People with Disabilities (CRPD, article 27) (UN 2006). However, for many people with an intellectual disability there are limited opportunities or access to paid employment, with numbers as low as 6.6% among older adults with intellectual disabilities (McGlinchey *et al.* 2013). McCausland *et al.* (2020) reiterates the small numbers of older adults with intellectual disabilities within paid employment in Ireland. But presents research on their involvement in occupational activities, which for the most part represent attendance at day services provided by disability service providers. Research conducted with people with intellectual disabilities in the early stages of the COVID-19 pandemic found that one of the most difficult aspects of the lockdown for participants was not being able to attend day services, but this was inextricably linked with not being able to see friends, within the qualitative interviews that were carried out (Murphy *et al.* 2020). Stable employment is one of the resources in the COR theory. For many with an intellectual disability, accessing occupational activity may be an alternative resource in the lives of those with disabilities who do not engage in or have access to paid employment. In the absence of occupation for financial gain, there may be other resource gains that attending day services provide for older adults with an intellectual disability, such as socialisation, meeting with friends, and engaging in training or activities.

Bivariate analyses were carried out between the variable ‘reduced day service/work hours’ and each of the dependent variables within this thesis, and contrary to the researcher’s expectations, there was no statistically significant associations found across symptoms of depression, symptoms of anxiety, loneliness, or self-rated mental health. Responses from other questions within the survey point towards alternative options to how some people with intellectual disabilities preferred to spend their day. Participants reported that having more free time, better time with staff, and new hobbies, as positives during the initial lockdowns (McCarron *et al.* 2020). Day service centres were closed, and staff were redeployed to people's homes. There is anecdotal evidence that for many who had to get up early and take bus rides to and from day services, this was a welcome adjustment. The current national policy on day service provision to people with an intellectual disability in Ireland, New Directions (HSE 2015), proposes a move away from predominantly group-based activities and focusses on a more person-centred service of the person's choosing. A further document, the Transforming Lives programme, was produced by the HSE to provide a framework for the implementation of this policy (HSE 2017).

Implementation of this policy had been underway for five years prior to the pandemic, and COVID-19 related public health measures may have accelerated the implementation of these programmes. The non-significant association with day service closure and mental health impacts within this study may provide evidence to support the principles of 'New Directions' and may be the preferred option for many with an intellectual disability. The National Service Plan (HSE 2023b) aims to continue to deliver on implementation of New Directions (HSE 2015b). As full implementation of this policy is realised there may be reduced impact on day services in the event of future pandemics or public health emergencies because older adults with an intellectual disability will not be gathering in group-based activities, but rather receiving more individualised supports of their choosing, thus reducing the risk of spreading infection.

9.3.6 Physical Distancing and Infection History

Given the strict implementation of public health measures that were in place during the COVID-19 pandemic, this study found limited evidence that these measures impacted directly on the mental health of older adults with an intellectual disability in Ireland. In bivariate analysis with this variable and symptoms of anxiety there was a significant association. However, as reported in Chapter 5 (5.3), this variable was removed from the full regression model in multivariate analysis. There were significant differences reported internationally on the prevalence of coronavirus infections and associated death among people with intellectual disabilities. In the United States, people with an intellectual disability were reported to be more likely to die if infected with COVID-19 than those without intellectual disabilities (8.2% vs. 3.8%) (Gleason *et al.* 2021). In Wales, Watkins (2020) reported three to eight times higher mortality among people with intellectual disabilities and COVID. Within the current study, 9.2% (63/682) of participants tested positive for the coronavirus and 13 (12%) participants were hospitalised. Between the period of March 2020-September 2021, there were three participants of the IDS-TILDA study that died while having a COVID-19 infection; this was not, however, confirmed as cause of death in any of these cases (McCausland *et al.* 2021a).

As the pandemic was an unprecedented global health emergency, the importance of physical health was given priority. In Ireland, there was swift and targeted action taken to reduce the risk of people with intellectual disabilities contracting the disease and spreading the virus. The HSE (HSE 2020b) promptly issued guidelines for those over the age of 65 years, those with underlying medical conditions, and for people living and working in residential care facilities regarding PPE, IPC, and care planning. Closure of disability services, such as day and respite services and redeployment of staff, may have had a role to play in the numbers of infections and mortality rates in Ireland being lower than those reported elsewhere. From the current study 33.2% of participants had their entire household quarantined for a week or longer during the pandemic, and 84.4% of those surveyed had to limit physical closeness with a loved one due to concerns of infection. Adherence to promptly issued guidelines appear to have improved the mortality and morbidity of people with intellectual disabilities and based on the findings of this study, may also have been a factor in the lack of significant associations between COVID-19 associated restrictions and mental health impacts. Additionally, following representations to Government from the disability sector, people with intellectual disabilities were included in priority groups for initial COVID-19 vaccination in Spring 2021. This may be another contributing factor towards non-significance of this variable in the study. There were also much lower rates of mortality and morbidity among those with intellectual disabilities in Ireland when compared to older adults living in nursing homes despite similarities in health risk profile (McCausland *et al.* 2021a). According to the Central Statistics Office almost 30% of COVID-19 deaths occurred in nursing homes in Ireland (CSO 2022).

Further research on how these findings may be beneficial for planning in the event of future public health emergencies is required, and there may be learning that can be applied from those with intellectual disabilities in Ireland, where physical distancing and infection history was not associated with mental health impacts.

9.3.7 Social Activities and Engaging in Alternative Activities Resources

Loss of social activity resources was analysed for statistically significant associations through bivariate analysis with the four measures, symptoms of depression and anxiety, loneliness, and self-rated mental health. Despite the high frequency of responses within the social activities resource loss variable, no statistical significance was found throughout regression models. Although social activity losses were experienced by many participants, they were also experienced by most groups within society, and although these restrictions on normal lives were unexpected, inconvenient, and difficult at times, they may not have reached the extent to where they resulted in negative impacts on mental health. It may be the case that negative impacts may have decreased overtime, and this suggestion is supported by findings from Yu *et al.* (2023). Within their study, researchers applied the COR theory to the experience of resource loss among a population of Chinese adults during the COVID-19 pandemic and found that depressive symptoms increased initially and were associated with losses incurred due to restrictions. However, these impacts lessened over a twelve-month period, as the vaccination programme was implemented, and quarantining was reduced i.e., resource loss was lessened.

Based on the findings of the scoping review conducted within this thesis, positive determinants of mental health during the pandemic were predominantly related to connections with others. For people living at home there was joy expressed at being able to help out around the house to show appreciation to their families, and others enjoyed having the opportunity to spend more time with their families in the absence of busy schedules (Kim *et al.* 2021b, Peacock-Brennan *et al.* 2021). From included studies there was recognition by adults with intellectual disabilities that they had more time to relax, have lie-ins and have some peace, with time away from busy schedules associated with services (McCarron *et al.* 2020, Peacock-Brennan *et al.* 2021). Findings from this thesis related to resource loss and gain in this area may be explained by the COR theory, where in times of stress when resources have been lost, resource gain becomes more salient. The non-significant association between this resource and mental health outcomes supports the COR theory that resource gain (new hobbies, free time, rest and relaxation) may increase in value in the face of loss, and that the ability to gain resources becomes increasingly important (Egozi-Farkash *et al.* 2022). From descriptive analyses, frequencies were high across both losses and gains of this resource, gains may have aided in adjustment from losses experienced. Although the non-significant finding related to social activities was an unexpected finding for this researcher, it is supported by the theoretical framework of this study. However, while participants appear to have adapted during the pandemic, and gained resources while others were lost, these gains may not be the preference in the recovery phase as life returns to normal. The importance of the resource of engaging in social activities is reasonably expected to return to being an important and significant aspect of the lives of older adults with an intellectual disability, as was the case for society as a whole.

9.3.8 Relationship Resources

Within the current study, bivariate analyses found no statistically significant associations between relationship resource loss and the dependent variables of symptoms of depression or anxiety, or loneliness. Statistical significance was found with self-rated mental health (<0.001). In the regression model for self-rated mental health, where participants identified that they did not experience relationship resource gain, this was positively associated with fair/poor rated mental health. This finding suggests that where participants did not have the opportunity to build new relationships that this had a negative impact on mental health. Building relationships may have been dependent on where the participant lived; for example, those living with families may have seen friends less and vice versa. The ability to build relationships may have been impacted by communication, or access to resources such as technology or transport. One aspect of gains in resources related to relationships which could be considered further is access to technology to communicate with friends/family. For 50.6% of participants from the overall population of this study this was not experienced or viewed as a positive aspect of the pandemic.

As already discussed, access to technology started from a very low base among individuals with an intellectual disability. For participants of the IDS-TILDA, there were low numbers owning and using mobile phones, and only three in ten participants having access to the internet (McCarron *et al.* 2017a); these numbers had only marginally improved from previous waves of the study. Spassiani *et al.* (2023) found that digital connection assisted with feeling connected to others and that this had a positive impact on mental health for people with disabilities within the context of the pandemic. Once the appropriate supports were in place to assist those with intellectual disabilities to overcome technological barriers they found it easy to remain socially connected. McCausland *et al.* (2023a) reported that during the COVID-19 pandemic, technology use increased among people with intellectual disabilities, with highest rates in community group homes and lowest rates among those living independently or with family.

Among the general population in Ireland, there was also an increased use of technology due to necessity during the pandemic. Older people used technology to stay connected with family and friends while cocooning and complying with public health measures. However, there remain considerable numbers who still do not have access to the internet. 74% of those aged 50 years and older living in urban areas have home internet access, compared to 67% in rural areas (Doody *et al.* 2020). While it is certainly a positive that there has been an acceleration in the use of technology among older adults with an intellectual disability, and that this helped to maintain communication and interactions with people that they could not see face to face over the pandemic, this did not improve mental health outcomes, nor did it make up for the loss of in person care or connection (McCausland *et al.* 2023a).

The high numbers of participants that identified both gains and loss related to relationships over the pandemic, and the non-statistically significant association with mental health outcomes, may further support suggestion earlier in this chapter related to ‘social activities resource loss’ and ‘engaging in alternative activities resource gain’. Whereby resource gain became very important when relationship resources were threatened with being lost, or actually lost, as supported by the COR theory. For example, participants may have lost relationships with friends who they met while attending day services but may have improved relationships with staff in their homes. This balancing or adapting to the restrictive measures during COVID-19 by gaining new relationships may have contributed towards mental wellbeing among older adults with an intellectual disability. However, findings from this study reported that for those who did not achieve relationship gains there was poorer rated mental health, and this is a concerning finding for this group of participants. Further research to explore any similarities or common factors, such as communication difficulties, self-esteem or difficulties adapting to public health measures, may assist in supporting this group and planning in the event of future restrictions.

9.3.9 Illness and Bereavement

There were no statistically significant bivariate associations found between the summary variable of illness and bereavement and dependent variables. The summary variable comprised of the following single items: unable to visit a family member in critical condition, being unable to attend the funeral of a family member/friend, or of having a bereavement during the pandemic. Despite evidence to suggest that bereavement and loss can have effects on mental health such as depression and anxiety, behaviour, and the emotional lives of people with intellectual disabilities (Dodd *et al.* 2005), this was not evident at the time data was collected for this study. As life returns to normality and older adults with an intellectual disability come to the realisation that their loved one or friend is no longer coming to visit or meet for social activities, the impacts of the past loss may present. Research suggests that there is a tendency among support staff and family members to either protect people from the loss or to underestimate their understanding of loss and bereavement. However, studies have found that people with intellectual disabilities can present with atypical signs of grief, or complex grief, and individualised approaches are required (Irwin *et al.* 2020). Gray & Abendroth (2015) report there is little understanding reported among staff that behaviours which may be considered maladaptive may be a symptom of coming to terms with, or coping with, their loss and this may be misinterpreted due to the time that has elapsed since the death. This researcher suggests that the impacts of loss and bereavement among older people with an intellectual disability may not present until the aftermath of the COVID-19 pandemic, and that both typical and atypical symptoms of grief should be observed for and supported through individualised and therapeutic interventions.

9.3.10 Stress/Anxiety Resource Loss and Resilience Resource Gain

In bivariate analysis the resource stress/anxiety (resource loss) and resilience (resource gain) were analysed for statistical significance with the four mental health impacts. Stress/anxiety resource loss was significant across all four studies of symptoms of depression and anxiety, loneliness, and self-rated mental health. It remained significant in regression models for loneliness and self-rated mental health and was positively associated with poorer outcomes. Resilience resource gains were positively associated with symptoms of depression and symptoms of anxiety. This positive association between resilience resource gains and poorer mental health outcomes may initially present as a juxtaposition. However, consistent with the COR theory, gains in resources during stressful circumstances may support in adjustment and recovery after the event, but may not improve psychological distress at the time of the event (Hobfoll 1998). In their study which applied the COR theory to explore the impacts of resource loss during stressful events, Rhodes *et al.* (2010) found that resource loss is a stronger predictor of psychological outcomes than resource gains in study sample groups such as survivors of Hurricane Katrina (Rhodes *et al.* 2010), and inner city women (Hobfoll *et al.* 2003).

Findings from the current study have reported on the resources that were both lost and gained during public health measures and the impacts of these on mental health during the pandemic, but the implications of these losses and gains may continue to have an effect in its aftermath. Hobfoll *et al.* (2015) state that it is important to understand that resilience is not a static phenomenon. It is dynamic and is something that can be built or diminished over time. Understanding the concept of resilience is crucial to understanding the stress process. One reasonable suggestion from the findings related to gains in resilience resources is, despite participants feeling negative impacts associated with the public health restrictions, one quarter of the population recognised their own strengths and abilities within the situation that they had been faced with.

There is very little research into the concept of resilience among individuals with an intellectual disability. In a literature review on resilience among adults with an intellectual disability, Scheffers *et al.* (2020) found six papers on the topic. Studies differentiated between internal and external sources of resilience. Internal sources were closely linked to wellbeing, self-acceptance, and physical health. External sources were supportive social networks and daily activities. The positive association between resilience resource gains and symptoms of depression and anxiety also cautions against the idea that gains in resources should equate to positives in mental health outcomes, especially in the short term. However, the implication of this finding requires further exploration during the recovery phase of COVID-19 to understand if these gains aided in adjustment and recovery for participants.

Prior to the COVID pandemic, the absence of strong social supports was found to be harmful to wellbeing, and social isolation was associated with depressive symptomatology, functional limitations and with poorer rated health among older adults in the general population in Ireland (Ward et al. 2019). In the Netherlands, researchers found that for older adults, although loneliness increased during the pandemic that mental health remained stable, with loss of social contact, worries about the pandemic, and a decline in trust associated with societal institutions, resulting in increased loneliness and mental health problems (van Tilburg *et al.* 2020). Similarly, Heinze *et al.* (2021) also found relatively stable incidence of loneliness among the non-disabled population in their study, which collected data over two time points during the pandemic. In their systematic review of the literature in the general population, there was a consensus that the COVID-19 pandemic impacted on loneliness and that it was positively associated with symptomatology of mental illness (Pai & Vella 2021).

In Finland, a study comparing psychological distress between those with intellectual disabilities and without during the pandemic found the odds of psychological distress persisting was more common (OR 6.00, 95% CI 3.53, 10.12) among people with disability (65.7%) than among those without (24.9%). This was also higher in those that had a poor baseline quality of life measurement prior to the pandemic (Holm *et al.* 2023). Among participants in the IDS-TILDA study that were surveyed in the early stages of the COVID-19 pandemic, 26.9% reported that loneliness was one of the main causes of feeling stressed or anxious, preceded only by not being able to do usual activities and not being able to see family and friends (McCarron *et al.* 2020). However, as the pandemic continued the levels of loneliness among the same study sample increased to 60%, as reported within the current study. It is known from previous pandemics that fear and isolation are prominent feelings experienced in response to public health measures and restrictions (Yoon *et al.* 2016). However, as there was no research located on the experience of people with intellectual disabilities during previous pandemics such as MERS, SARS or Ebola, this study provides strong evidence that COVID-19 related stress/anxiety is a particular area of concern for the study population. An understanding of contributory factors may provide evidence for strategies to be implemented to reduce the experience of negative mental health impacts during public health related restrictions.

Chapter 10 – Conclusions and Recommendations

Introduction

This final chapter synthesises research findings and the implications of these findings for the overall aims and objectives of this research study. The key messages which have emerged from the study will be presented in the context of how they contribute to the field of mental health for older adults with an intellectual disability as relates to the recovery phase of the pandemic and preparedness for future pandemics. The limitations of this study are also identified. The study's findings are also applied to recommendations for research, policy, and practice.

10.1 Contributions to the Field

This study has made the following contributions to the field of research.

1. The emergence of the COVID-19 pandemic caused widespread concern and this researcher recognised the gap in the literature regarding the implications on mental health for older adults with an intellectual disability, both during and in the aftermath of public health emergencies. Providing evidence from a large nationally representative population of older adults with an intellectual disability is one of the greatest strengths of this study.
2. Through the application of a theoretical framework which recognises the important resources that were either lost and/or gained during the pandemic, service providers and policy makers now have evidence to understand the broad range of resources which may be targeted to improve mental health for older adults with an intellectual disability. Such an approach may provide a framework to inform disability service provision, and assessment and planning for mental health services.
3. This study has demonstrated that older adults with an intellectual disability have the ability and desire to contribute to research that impacts on their lives. Participants were willing to engage at one of the most challenging times for global public health within our lifetime. The co-production and consultation with individuals with intellectual disabilities was core to every aspect of this study and provides evidence that this is a beneficial model for research.

10.2 Key Study Implications and Recommendations for Policy

1. Findings from this study show that differences exist within the population of older adults with intellectual disabilities, and that they are not a homogenous group. People with Down syndrome and women were found to have greater mental health impacts. Current policy related to COVID-19 recovery, does not take account of the differences in experiences among those with intellectual disabilities. The HSE's National Plan (HSE 2023b) refers more generally to 'people with a disability'. The findings of this study highlight the need for

recognising the individualised experiences and service needs of this population during the pandemic.

2. Findings from this study have highlighted loss of physical health resources as a major contributor towards poorer mental health outcomes during the pandemic. Risks related to physical health resource loss may also increase in the aftermath of the pandemic. Health promotion for older adults with intellectual disabilities, their families, and staff requires the availability of high-quality information.
3. Based on the similarities which exist with older adults in the general population, general sources of information could be targeted to include people who have compromised abilities to engage in some mainstream exercise such as wheelchair users and those experiencing frailty.
4. HSE guidance related specifically to people living in residential care facilities was swiftly implemented. The results of high levels of adherence to the measures by people with intellectual disabilities, their families, staff, and service providers appeared to result in relatively low rates of excess mortality and morbidity as reported within the current study population. These strict measures were not found to be associated with negative mental health outcomes within this study and may have been mitigated through gains in resources. The government's COVID-19 response inquiry (date of commencement not available at time of writing) will provide accurate excess morbidity and mortality numbers for people with intellectual disabilities. However, the evidence suggests that swift action taken resulted in much lower incidence of mortality than was seen in other countries. Prioritisation for vaccination, and measures to reduce the spread of infection in Residential Care Facilities, should inform preparedness planning for future emergencies, but should also include strategies and interventions to reduce the loss of resources and encourage gains identified within this study.
5. There is an urgent need to involve older adults with intellectual disabilities in policy consultation and research in recovery and preparedness planning, with an emphasis on supporting individuals to take ownership of their mental health, including health promotion, how to access appropriate supports and with a recovery focussed approach.
6. Non-significant findings from this study suggest that the policy set out for more individualised, non-group-based day services is beneficial. There is now an opportunity to re-engage and consult with people with intellectual disabilities, their families and support workers to inform any revisions to day services policy.

10.3 Key Study Implications and Recommendations for Practice

1. While there is now evidence to suggest that individuals, staff, and family members should be aware of increased loneliness and depressive symptoms among women and people with Down syndrome respectively, proactive measures such as mental health promotion and possible strategies to reduce loneliness may be assessed for and implemented with each individual as the decision maker.
2. Innovative approaches exist such as accessible and easy-read materials delivered online to support older adults with an intellectual disability to become educated and take ownership of their own health and wellbeing and become health savvy and should be more widely used. Such approaches should be extended to include mental health.
3. Findings related to the sources of mental health supports identified that almost one third of respondents were receiving supports from family, friends, and staff. There may be scope to train staff in providing 'low intensity' psychosocial interventions which may address some of the present need.
4. There now exists clear evidence that there may be increased need for mental health supports in the recovery phase and in preparing for future public health emergencies. Incorporation of training specific to supporting the intellectual disability population for all healthcare professionals would enhance services received. This is particularly relevant for those with mild intellectual disabilities for whom mental health services are provided by general adult psychiatry services.

10.4 Key Study Implications and Recommendations for Research

1. Further research specific to women and people with Down syndrome is required to understand the determinants and risk factors for poorer mental health outcomes during the pandemic, particularly as many of the determinants which are reported among the general population are not present in the lives of people with intellectual disabilities, such as spousal support, and protective factors such as children.
2. Inter-rater reliability should be carried out to explore the reasons for poorer rated mental health among self-reporters and proxy respondents.
3. Further research is required to compare the mental health impacts, and the losses and gains of resources that occurred during the COVID-19 pandemic, among older adults with intellectual disabilities with older adults in the general population.
4. Further research is needed among people with intellectual disabilities, staff, and family members to identify the barriers to promoting movement and making healthy food choices during and after the pandemic.

5. Patel *et al.* (2023) conducted a systematic review of studies exploring the psychometric properties of measures used to assess common mental health problems among adults with intellectual disabilities. The authors of the study reported a paucity of robust measures. This researcher recognised the difficulties in measuring mental health outcomes among older adults with an intellectual disability and utilised four different measures to explore the greatest number of mental health impacts. Measures which caused the least burden on participants were chosen. The approach within this thesis provided the greatest opportunity to identify symptoms of mental health impacts irrespective of severity. Within the measures used only complete cases were analysed. There were several questions within the instruments that had greater frequencies of unanswered responses. These incomplete responses may provide useful information and may further point to the need for greater development of measures which are usable for both participants and researchers. Analysis strategies must also be considered that make use of incomplete data such as machine learning and other approaches that impute a greater percentage of missing data. Findings from this study provides opportunity to build further research, which should include the qualitative experiences of participants during and in the aftermath of COVID.
6. Half of the participants within this study reported using technology to stay in contact with family and friends. This was a vast increase in technology use compared to prior to the pandemic. The COVID-19 pandemic hastened the use of technology among older adults with intellectual disabilities and investigation is needed on how to sustain this momentum that will contribute towards independent health, living, education, and employment. Research is required to gain the perspectives of older adults with intellectual disabilities on the delivery of mental health services through virtual appointments/telemedicine. Research into the concept of coping, resilience, and adjustment among older adults with intellectual disabilities, both in general terms and in the aftermath of the pandemic, will provide additional understanding related to the gains in resources that were identified by participants. Appropriate measures for resilience among older adults with intellectual disabilities must be identified, adapted, or developed. Findings were supported by the theoretical framework of this study. Further research is required, however, to understand if these positives may have supported recovery and adjustment following the COVID-19 pandemic.

10.5 Study Limitations

1. Due to the unprecedented nature of the pandemic, there were time constraints on the development and inclusion of variables in the protocol. There were opportunities which

may have been missed, the most notable of these being understanding participants' feelings and experience of the use of masks when communicating.

2. Data collection took place between March-September 2021. The level of public health measures, based on the national framework for living with COVID (Department of Health 2020) that were in place at the time of the interview, may have had an impact on the participants' mental health. There may have been more optimism towards the end of data collection when restrictions were being removed as opposed to when public health measures were more restrictive earlier in the pandemic.
3. The sample for the IDS-TILDA study is taken from the NASS, this database includes all those accessing or that are registered to access disability services in Ireland. However, people with a mild intellectual disability who are not accessing any disability services and were therefore not available to sample, may have unique or additional experiences.
4. The experiences of loneliness and anxiety was not captured for people who have significant communication impairments, who are often those with severe/profound intellectual disabilities. While the utilisation of four measures provided opportunity for capturing responses across a variety of mental health impacts, this did result in smaller response numbers for some measures. The additional challenge of interviews being carried out remotely required reasonable adjustments being made to ensure quality data. This may have been more difficult for some participants compared to face-to-face interviews.

10.6 Conclusions

This study sought to identify factors associated with mental health outcomes for older adults with an intellectual disability through the lens of the COVID-19 pandemic and in doing so provided evidence to show that older adults with an intellectual disability are not a homogenous group. This study utilised the study sample from the IDS-TILDA study, a longitudinal study on ageing in Ireland, and therefore accessed a large nationally representative population of older adults with an intellectual disability and gained insight into their experiences on the cusp of a global pandemic. In using key demographic variables when exploring the complex area of mental health, the differences, and similarities across a number of these variables were identified. This demographic information provided opportunities for comparisons with the general population. The broad range of variables which were included in this study were drawn from all aspects of the lives of participants. While applying a theoretical framework which produced findings not only on losses of these resources but also on the positives. These were explored across a range of mental health outcomes to capture the impacts on mental health that occurred during the pandemic and associated restrictions. The findings of this study have provided strong and comprehensive evidence to inform research, policy, and practice as society emerges from the pandemic to inform responses to building back better in the aftermath of COVID-19 and preparedness in the event of future pandemics or public health emergencies.

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Appendix 1 Categorisation of Level of Intellectual Development

The World Health Organisation (WHO 2019/2020) categorisation of level of intellectual development are presented as follows.

6A00.0 Mild Disorder of Intellectual Development

- In Mild Disorder of Intellectual Development, intellectual functioning and adaptive behaviour are found to be approximately 2 to 3 standard deviations below the mean (approximately 0.1 – 2.3 percentile), based on appropriately normed, individually administered standardized tests. Where standardized tests are not available, assessment of intellectual functioning and adaptive behaviour requires greater reliance on clinical judgment, which may include the use of behavioural indicators provided in Tables 6.1 through 6.4. Persons with a Mild Disorder of Intellectual Development often exhibit difficulties in the acquisition and comprehension of complex language concepts and academic skills. Most master basic self-care, domestic, and practical activities. Affected persons can generally achieve relatively independent living and employment as adults but may require appropriate support.

6A00.1 Moderate Disorder of Intellectual Development

- In Moderate Disorder of Intellectual Development, intellectual functioning and adaptive behaviour are found to be approximately 3 to 4 standard deviations below the mean (approximately 0.003 – 0.1 percentile), based on appropriately normed, individually administered standardized tests. Where standardized tests are not available, assessment of intellectual functioning and adaptive behaviour requires greater reliance on clinical judgment, which may include the use of behavioural indicators provided in Tables 6.1 through 6.4. Language and capacity for acquisition of academic skills of persons affected by a Moderate Disorder of Intellectual Development vary but are generally limited to basic skills. Some may master basic self-care, domestic, and practical activities. Most affected persons require considerable and consistent support to achieve independent living and employment as adults.

6A00.2 Severe Disorder of Intellectual Development

- In Severe Disorder of Intellectual Development, intellectual functioning and adaptive behaviour are found to be approximately 4 or more standard deviations below the mean (less than approximately the 0.003rd percentile), based on appropriately normed, individually administered standardized tests. Where standardized tests are not available, assessment of intellectual functioning and adaptive behaviour requires greater reliance on clinical judgment, which may include the use of behavioural indicators provided in Tables 6.1 through 6.4. Persons affected by a Severe Disorder of Intellectual Development exhibit very limited language and capacity for acquisition of academic skills. They may also have motor impairments and typically require daily support in a supervised environment for adequate care but may acquire basic self-care skills with intensive training. Severe and Profound Disorders of Intellectual Development are differentiated exclusively based on adaptive behaviour differences because existing standardized tests of intelligence cannot reliably or validly distinguish among individuals with intellectual functioning below the 0.003rd percentile.

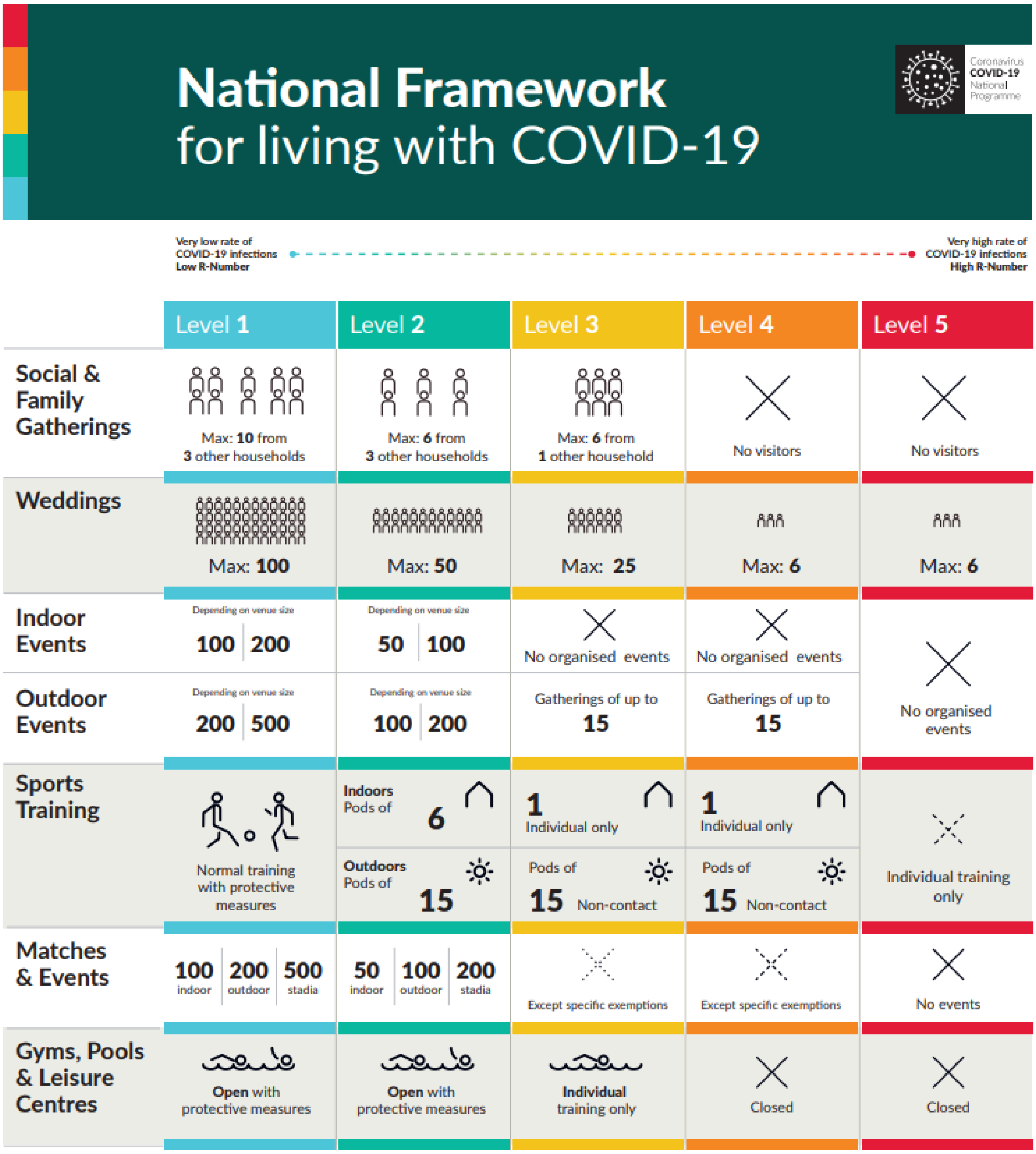
6A00.3 Profound Disorder of Intellectual Development

- In Profound Disorder of Intellectual Development, intellectual functioning and adaptive behaviour are found to be approximately 4 or more standard deviations below the mean (approximately less than the 0.003rd percentile), based on individually administered appropriately normed, standardized tests. Where standardized tests are not available, assessment of intellectual functioning and adaptive behaviour requires greater reliance on clinical judgment, which may include the use of behavioural indicators provided in Tables 6.1 through 6.4. Persons affected by a Profound Disorder of Intellectual Development possess very limited communication abilities and capacity for acquisition of academic skills is restricted to basic concrete skills. They may also have co-occurring motor and sensory impairments and typically require daily support in a supervised environment for adequate care. Severe and Profound Disorders of Intellectual Development are differentiated exclusively based on adaptive behaviour differences because existing standardized tests of intelligence cannot reliably or validly distinguish among individuals with intellectual functioning below the 0.003rd percentile.

6A00.4 Disorder of Intellectual Development, Provisional

- Disorder of Intellectual Development, Provisional is assigned when there is evidence of a Disorder of Intellectual Development, but the individual is an infant or child under the age of four, making it difficult to ascertain whether the observed impairments represent a transient delay. Disorder of Intellectual Development, Provisional in this context is sometimes referred to as Global Developmental Delay. The diagnosis can also be assigned in individuals 4 years of age of older when evidence is suggestive of a Disorder of Intellectual Development but it is not possible to conduct a valid assessment of intellectual functioning and adaptive behaviour because of sensory or physical impairments (e.g., blindness, pre-lingual deafness), motor or communication impairments, severe problem behaviours, or symptoms of another Mental, Behavioural, or Neurodevelopmental Disorder that interfere with assessment.

Appendix 2 National Framework for living with COVID-19

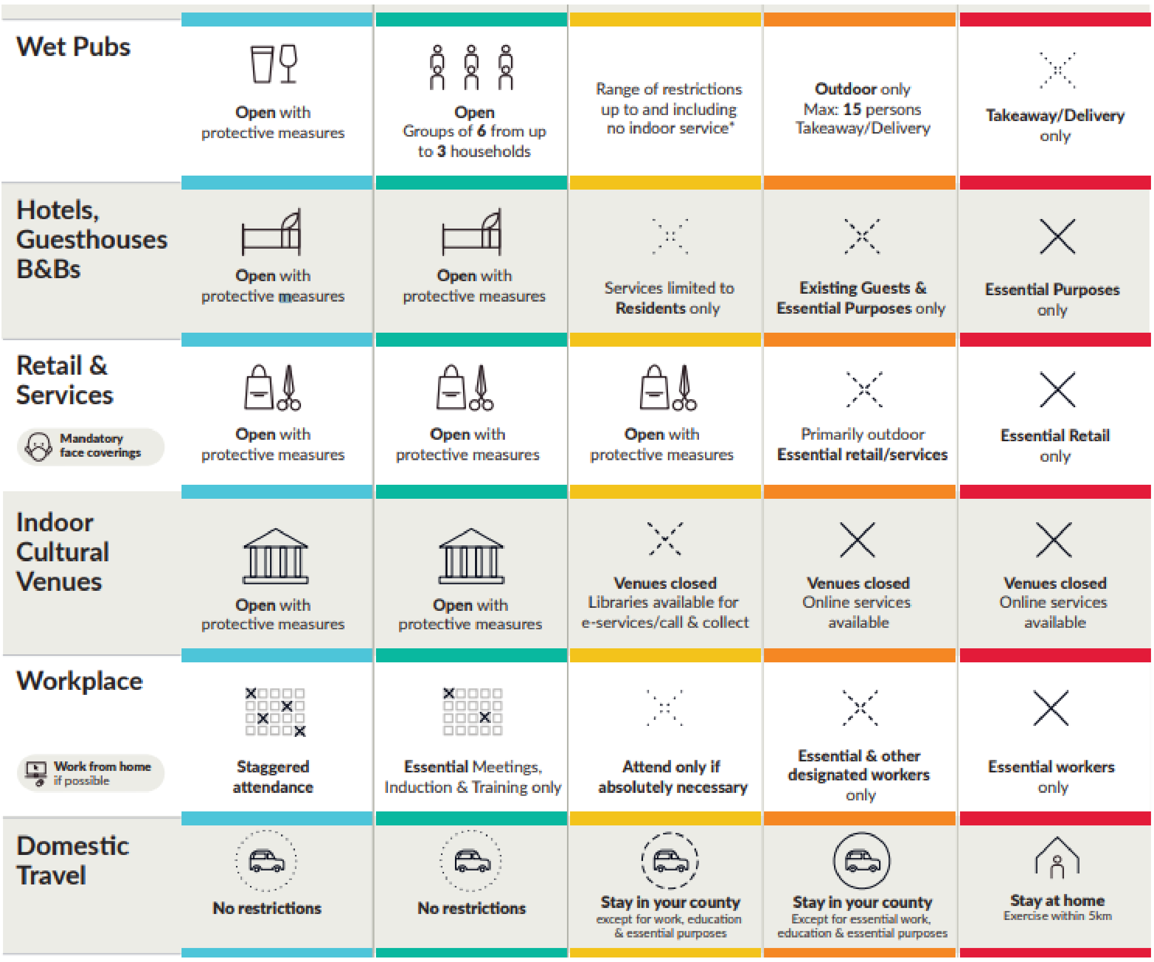


National Framework for living with COVID-19

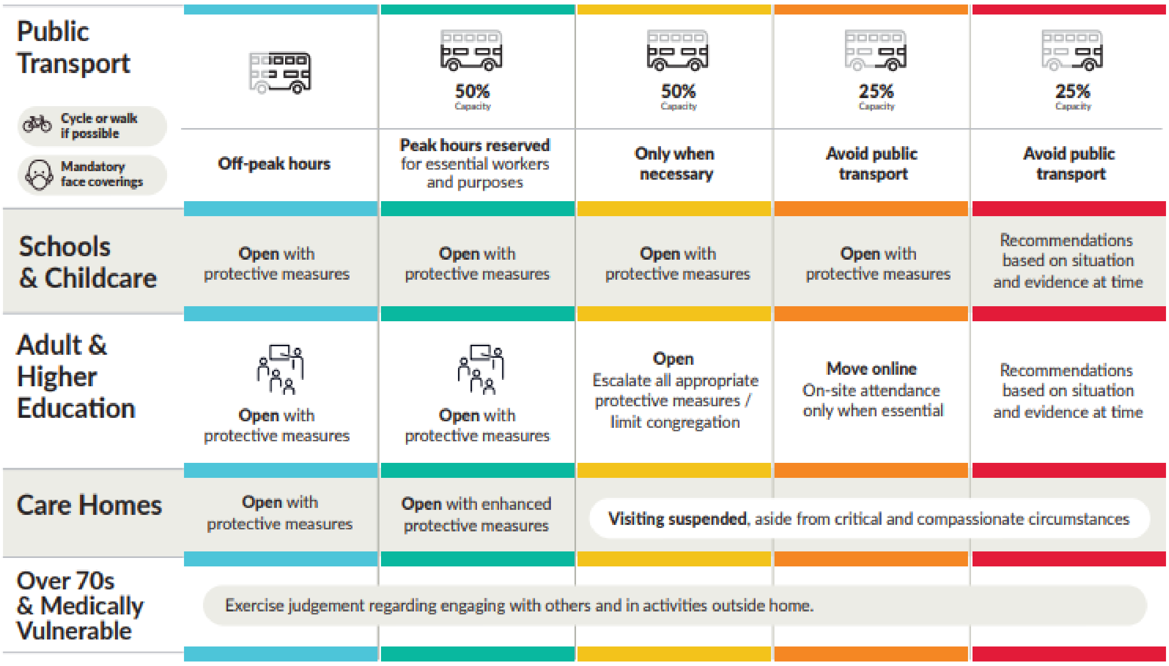
Coronavirus COVID-19 National Programme

Very low rate of COVID-19 infections **Low R-Number** → Very high rate of COVID-19 infections **High R-Number**

	Level 1	Level 2	Level 3	Level 4	Level 5
Social & Family Gatherings	Max: **10** from **3** other households	Max: **6** from **3** other households	Max: **6** from **1** other household	No visitors	No visitors
Weddings	Max: **100**	Max: **50**	Max: **25**	Max: **6**	Max: **6**
Indoor Events	Depending on venue size **100** | **200**	Depending on venue size **50** | **100**	No organised events	No organised events	No organised events
Outdoor Events	Depending on venue size **200** | **500**	Depending on venue size **100** | **200**	Gatherings of up to **15**	Gatherings of up to **15**	
Sports Training	Normal training with protective measures	**Indoors** Pods of **6** **Outdoors** Pods of **15**	**1** Individual only Pods of **15** Non-contact	**1** Individual only Pods of **15** Non-contact	Individual training only
Matches & Events	**100** indoor | **200** outdoor | **500** stadia	**50** indoor | **100** outdoor | **200** stadia	Except specific exemptions	Except specific exemptions	No events
Gyms, Pools & Leisure Centres	**Open** with protective measures	**Open** with protective measures	**Individual** training only	Closed	Closed



Wet Pubs	**Open** with protective measures	**Open** Groups of **6** from up to **3** households	Range of restrictions up to and including no indoor service*	**Outdoor** only Max: **15** persons Takeaway/Delivery	**Takeaway/Delivery** only
Hotels, Guesthouses B&Bs	**Open** with protective measures	**Open** with protective measures	Services limited to **Residents** only	**Existing Guests & Essential Purposes** only	**Essential Purposes** only
Retail & Services Mandatory face coverings	**Open** with protective measures	**Open** with protective measures	**Open** with protective measures	Primarily outdoor **Essential retail/services**	**Essential Retail** only
Indoor Cultural Venues	**Open** with protective measures	**Open** with protective measures	**Venues closed** Libraries available for e-services/call & collect	**Venues closed** Online services available	**Venues closed** Online services available
Workplace **Work from home** if possible	**Staggered attendance**	**Essential** Meetings, Induction & Training only	**Attend only if absolutely necessary**	**Essential & other designated workers** only	**Essential workers** only
Domestic Travel	**No restrictions**	**No restrictions**	**Stay in your county** except for work, education & essential purposes	**Stay in your county** Except for essential work, education & essential purposes	**Stay at home** Exercise within 5km



Public Transport Cycle or walk if possible Mandatory face coverings	**Off-peak hours**	**50%** Capacity **Peak hours reserved** for essential workers and purposes	**50%** Capacity **Only when necessary**	**25%** Capacity **Avoid public transport**	**25%** Capacity **Avoid public transport**
Schools & Childcare	**Open** with protective measures	**Open** with protective measures	**Open** with protective measures	**Open** with protective measures	Recommendations based on situation and evidence at time
Adult & Higher Education	**Open** with protective measures	**Open** with protective measures	**Open** Escalate all appropriate protective measures / limit congregation	**Move online** On-site attendance only when essential	Recommendations based on situation and evidence at time
Care Homes	**Open** with protective measures	**Open** with enhanced protective measures	**Visiting suspended**, aside from critical and compassionate circumstances		
Over 70s & Medically Vulnerable	Exercise judgement regarding engaging with others and in activities outside home.				

*Pubs currently remain closed in Dublin

Appendix 3 Timeline of Restrictions from March 2020-February 2022

Date	Public Health Measures Ireland 2020
11th March	WHO declared a global pandemic. First confirmed COVID death in Ireland.
12th March	Close non-essential outlets and services, this included Day Services and Respite Services in the disability sector.
24th March	Close non-essential outlets and services, cancel all events. Restrict home visits and limitations on outdoor social gatherings, and advice to work from home.
27th March	'Stay at Home' unless necessary for work or essential shopping. Cocooning Exercise permitted within 2kms of home. Until May 2020
1st May	A roadmap for reopening society and business was publish by Government. Extension of the 2km limit to 5km and guidance to enable those cocooning to take exercise in their local area.
May 2020	Framework for the Resumption of Adult Disability published by the new direction's subgroup, HSE Reshaping Disability Services From 2020 and beyond in line with COVID-19 restrictions HSE Version 2 29 May 2020
18th May	Reopening phase 1: outdoor working e.g. construction. Some retail e.g. hardware, garden centres. Outdoor amenities e.g. beaches, golf courses. Small outdoor gatherings – groups of 4 within a 5km radius to your home.
8th June	Reopening phase 2: 'Stay Local' - All retail outlets open, travel within your own county, or up to 20kms, playgrounds and commercially serviced outdoor amenities, indoor / outdoor gatherings – meet up to 6 people from outside your own household
25th June	Masks on public transport
29th June	Reopening phase 3: Wellbeing / personal services open. Cultural outlets e.g. galleries, museums. Indoor / outdoor home visits – six people from 3 households, no travel restrictions, childcare opened, Churches, hospitality – cafes, restaurants, hotels, pubs serving food. Sporting activities recommence.
15th July	Postponement of move to Phase 4 Face coverings must be worn in all shops and shopping centres. Pubs, hotel bars, nightclubs and casinos would remain closed until 10 August. Pubs currently serving food can remain open. Social visits to people's homes should be limited to a maximum of ten people from no more than four different households. Current restrictions of 50 people in indoor gatherings, 200 at outdoor gatherings would be extended until 10 August
4th August	Government announced that planned to ease of restriction on the 10th of August would not proceed Pubs, bars, hotel bars, nightclubs and casinos would remain closed. Restaurants and pubs serving food would have to close by 11pm, but takeaways and deliveries could remain open after that time. Face coverings would be mandatory in all shops and shopping centres from 10 August.

8-22nd August	High level restrictions implemented in Laois, Kildare, and Offaly due to large outbreak
10 August	Face coverings were made mandatory in all shops, shopping centres, libraries, cinemas, museums, nail salons, hairdressers, dry cleaners, betting stores, tattooists, and travel agent
18thAugust	All outdoor events would be limited to 15 people. All indoor events would be limited to 6 people, except for religious services, weddings, and businesses, such as shops and restaurants. Gardaí would be given new powers to enforce rules around social gatherings in restaurants and bars serving food, and in private homes. Restaurants and cafés could remain open with closing times of 11.30pm People would be advised to work from home and to avoid using public transport, unless absolutely necessary. Sports events and matches would revert to behind closed doors with strict avoidance of social gatherings before and after events. Additional restrictions to remain for 2 more weeks in Kildare
9thSeptember	Government announces that measures announced on the 18th August 2020 would be extended until 15th September 2020
14 September	The self-isolation period for patients who test positive for COVID-19 was reduced from 14 days to 10 days
15th September	Resilience and Recovery 2020-2021: Plan for Living with COVID-19 published – include a colour-coded, five-level system to indicate what public health measures were in place in different areas of the country at any given time. See Appendix 5 for the National Framework for living with COVID-19.
21st September	Level 3 in Dublin, reopening of wet pubs outside of Dublin
5th October 2020	Level 3 measures implemented nationally
19th October	Level 5 measures implemented nationally – 6-week period including national ban on household visits **(as the country tackled a second epidemic wave)** Under Level 5 restrictions: • People must stay at home. • People would be permitted to exercise within a radius of 5 km of their home. • Non-essential businesses and services would close. • Public transport would operate at 25% capacity for the purposes of allowing those providing essential services to get to work. • Pubs, cafés, and restaurants may provide takeaway and delivery services only. • Schools, early learning, and childcare services would continue to remain open. • There should be no organised indoor or outdoor events.
1st December	All non-essential retail shops, hair and beauty providers, gyms and leisure centres, cinemas, museums, and galleries reopened after six weeks of closure
4th December	Thousands of restaurants, cafés, gastropubs, and hotel restaurants reopened after six weeks of closure.
22nd December	The entire country to Level 5 lockdown restrictions with a number of adjustments from Christmas Eve until 12 January 2021 at the earliest Under Level 5 restrictions: Restaurants and gastro-pubs must close at 3pm on 24 December (Christmas Eve). Hotels may provide food and bar services to guests only after 3pm on Christmas Eve. Hotels may only open to guests for essential purposes after 26 December. Up until 26 December (St Stephen's Day)

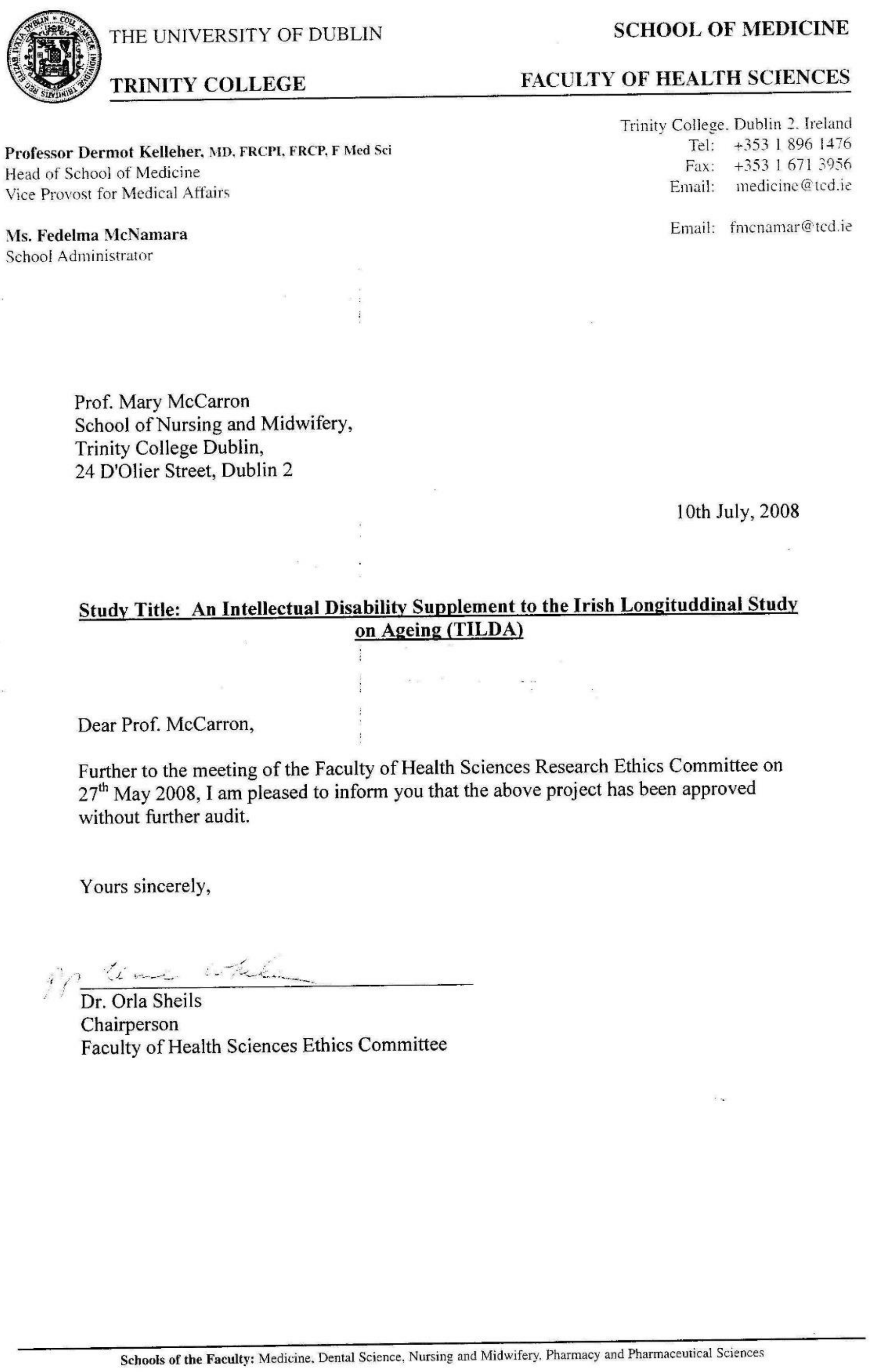
	Visits from up to two other households will be permitted. Household visits would be reduced to one other household from 27 December. From 1 January, no household mixing would be allowed except for compassionate, care or childcare reasons. Non-essential retail would remain open, but shops would be requested to defer January sales events. No new inter-county travel would be allowed after 26 December. Personal services, including hairdressers and barbers must close. Gyms, leisure centres and swimming pools would remain open for individual training only
29th December	Ireland's COVID-19 vaccination programme commenced. (Pfizer/BioNtech COVID-19 vaccine)
30th December	entire country to full Level 5 lockdown restrictions from midnight until the revised date of 31 January 2021 at the earliest Under additional Level 5 restrictions: All schools to remain closed after the Christmas break until 11 January 2021. Childcare facilities and crèches to remain open. All non-essential retail and services must close from 6pm on 31 December. People must stay at home except for work, education, or other essential purposes, and will be allowed to exercise within 5 km of home

Date	**Public Health Measures Ireland 2021**
6th January	New lockdown measures including the closure of all schools until February with Leaving Certificate students allowed to attend school for three days a week (this was abandoned the following day and LC students would not return until February), the closure of all non-essential construction sites with certain exceptions
7th January	The rollout of the Pfizer–BioNTech COVID-19 vaccine in private and voluntary nursing homes began nationwide, with 22 nursing homes of 3,000 residents and staff to be vaccinated
11 January	Figures revealed by the Our World in Data organisation showed that Ireland had the highest daily number of new confirmed COVID-19 cases in the world for every million people
12th January	The first shipment of the Moderna vaccine arrived in the Republic of Ireland
26 January	The government announced the extension of the Level 5 lockdown restrictions until 5th of March. Mandatory 14-day quarantine period for all people travelling into the country without a negative COVID-19 test
23 February	Extension of Level 5 lockdown restrictions for another six weeks until 5 April at the earliest The government published its new revised Living with COVID-19 plan called "The Path Ahead"
1 March	Over 320,000 junior primary school pupils and Leaving Certificate students nationwide returned to school for the first time since Christmas
6 March	Ireland had reached the milestone of half a million COVID-19 vaccines administered
23 March	Mandatory hotel quarantine in Ireland opened for those arriving into the country from Friday 26 March, with a 12-night stay for passengers arriving from high risk countries
12 April	The phased easing of Level 5 restrictions began with the 5 km travel limit lifted, the resumption of all residential construction work, two households could meet up outdoors and the full reopening of all schools.

15 April	Over 26,000 people registered for a COVID-19 vaccination after the online portal for 69-year-olds went live.
4 May	The COVID-19 vaccine registration portal opened to people aged between 50 and 59 on a phased basis, starting with people aged 59
10 May	Further easing of Level 5 restrictions- all hairdressers, barbers, beauticians, galleries, museums, libraries, and other cultural attractions reopening. resumption of non-essential retail on a phased basis inter-county travel and in-person religious services Three households (or six people) from individual households to meet outdoors.
17 May	Further easing of Level 5 restrictions came into effect with the reopening of all non-essential retail for the first time in over four months
19 May	The COVID-19 vaccine registration portal opened to people aged between 45 and 49 on a phased basis, starting with people aged 49
2 June	The COVID-19 vaccine registration portal opened to people aged between 40 and 44 on a phased basis, starting with people aged 44
7 June	The gradual easing of COVID-19 restrictions continued with the reopening of all bars, restaurants and cafés for outdoor service, gyms, swimming pools, leisure centres, cinemas and theatres, the partial resumption of driver theory test services, and the allowance of an unvaccinated household to visit another unvaccinated household indoors
20 June	The COVID-19 vaccine registration portal opened to people aged between 35 and 39 on a phased basis, starting with people aged 39
29 June	Due to the rapidly increasing incidence of the Delta variant, the government announced that the planned reopening of indoor dining and drinking in restaurants and pubs on 5 July would be delayed until at least 19 July when a system to verify vaccination or immunity would be implemented, while 50 guests would be permitted to attend wedding celebrations as an exception from July
1 July	Fourth wave of COVID-19 was beginning in Ireland (Delta)
7 July	The COVID-19 vaccine registration portal opened to people aged between 30 and 34 on a phased basis, starting with people aged 34
12 July	Fully vaccinated people began receiving their EU Digital COVID Certificate via email or post. The government approved legislation for the resumption of indoor hospitality, with proofs of vaccination needed for those who were vaccinated or recovered from COVID-19, while those under 18 would be required to be accompanied by a fully vaccinated person
16 July	The COVID-19 vaccine registration portal opened to people aged between 25 and 29 on a phased basis, starting with people aged 29
19 July	The COVID-19 vaccine registration portal opened to people aged between 18 and 24 for the AstraZeneca vaccine on a phased basis, starting with people aged 24
26 July	Restaurants, cafés, and bars reopened for indoor dining and drinking for the first time since December 2020, operating under strict new public health regulations
27 July	After the COVID-19 vaccine registration portal opened to people aged 16 and 17 for the Pfizer or Moderna vaccines.
5 August	Numbers allowed at weddings increased to 50
11 August	The COVID-19 vaccine registration portal opened to people aged 12 to 15 for the Pfizer or Moderna vaccines
31 August	The government announced a further reopening plan for the country, with all remaining COVID-19 restrictions to be eased by 22 October, including the two-metre social distancing rule depending on the requirement of individual sectors,

	while masks would still be required in the health and retail sectors and on public transport
1 September	Public transport began operating at 100% capacity across the country
10 September	Latest figures showed that 90% of adults in Ireland were fully vaccinated against COVID-19, while the seven-millionth dose was administered the highest rate in the European Union
20 September	Thousands of workers across the country began returning to their offices and places of work. Rules around organised indoor group activities being relaxed and limits on outdoor group activities for participants being removed
29 September	Ireland's COVID-19 booster vaccination campaign commenced
22 October	Nightclubs and late venues reopened after almost 600 days of closure
6 November	The Government announced a series of measures in a bid to curb the spread of COVID-19, with a closing time for bars, restaurants, and nightclubs to be midnight, household contacts of a person with COVID-19 to restrict movements for five days and take three antigen tests, people required to work from home where possible and vaccination certificates required for cinemas and theatres
1 December	First case of new variant of the coronavirus – Omicron detected in Ireland
7 December	Nightclubs to close, bars and restaurants to revert to six adults per table and no multiple table bookings allowed, indoor cultural and sporting events to operate at 50% capacity, a maximum of four households allowed to meet indoors
20 December	To curb the spread of COVID-19 over the Christmas period, the Government announced an 8pm closing time for bars, restaurants, live events, cinemas, and theatres that would remain in place to 30 January
Date	**Public Health Measures Ireland 2022**
22nd January	Announced the easing of almost all COVID-19 restrictions from 6am on 22 January, with the requirements of vaccine certificates and social distancing to end, restrictions on household visits and capacity limits for indoor and outdoor events to end, nightclubs to reopen and pubs and restaurants to resume normal trading times, while rules on isolation and the wearing of masks would remain
22 February	The Government agreed to end almost all remaining COVID-19 restrictions from 28 February, with mask wearing in schools, indoor retail settings and on public transport to be voluntary, restrictions in schools to end and testing to be scaled back

Appendix 4 Ethical approval Wave 1 (July 2008) and reaffirmed Wave 4 (January 2019)



THE UNIVERSITY OF DUBLIN
TRINITY COLLEGE

SCHOOL OF MEDICINE
FACULTY OF HEALTH SCIENCES

Trinity College, Dublin 2, Ireland
Tel: +353 1 896 1476
Fax: +353 1 671 3956
Email: medicine@tcd.ie

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

Ms. Fedelma McNamara
School Administrator

Email: fmcnamar@tcd.ie

Prof. Mary McCarron
School of Nursing and Midwifery,
Trinity College Dublin,
24 D'Olier Street, Dublin 2

10th July, 2008

Study Title: An Intellectual Disability Supplement to the Irish Longituddinal Study on Ageing (TILDA)

Dear Prof. McCarron,

Further to the meeting of the Faculty of Health Sciences Research Ethics Committee on 27th May 2008, I am pleased to inform you that the above project has been approved without further audit.

Yours sincerely,

Dr. Orla Sheils
Chairperson
Faculty of Health Sciences Ethics Committee

Schools of the Faculty: Medicine, Dental Science, Nursing and Midwifery, Pharmacy and Pharmaceutical Sciences

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

IDS-TILDA,
School of Nursing & Midwifery,
Trinity College,
2 Clare Street,
Dublin 2

23rd January 2019

Ref: 181210

Title of Study: An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (hereafter IDS-TILDA)

Dear Prof McCarron,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in December 2018. We are pleased to inform you that the above project has ethical approval to proceed.

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

Prof. Brian O'Connell
Chairperson
Faculty Research Ethics Committee

Dámh na nEolaíochtaí Sláinte
Foirgneamh na Ceimice,
Coláiste na Tríonóide,
Ollscoil Átha Cliath,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences
Chemistry Building,
Trinity College Dublin,
The University of Dublin,
Dublin 2, Ireland.

www.healthsciences.tcd.ie

Appendix 5 HRCDC Full consent declaration acknowledgement letter (December 2019)

HRCDC
Health Research Consent
Declaration Committee

Teach Grattan
67-72 Sráid an Mhóta Íochtarach
Baile Átha Cliath 2
D02 H638
Éire

Grattan House
67-72 Lower Mount Street
Dublin 2
D02 H638
Ireland

T: 353 1 234 5000
F: 353 1 661 2335
E: info@hrcdc.ie

www.hrcdc.ie

PRIVATE AND CONFIDENTIAL

Professor Mary McCarron,
Director of the Trinity Centre for Ageing and Intellectual Disability,
Trinity College Dublin,
Dublin 2,
D02 DK07

20th December 2019

Dear Mary,

RE: **Application:** "Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)"
Reference ID: 19-015-AF2
Data Controller(s): Trinity College Dublin
Decision: Conditional Declaration

The HRCDC convened on December 16th, 2019 and reviewed the letter dated December 4th 2019, which outlined responses to the conditions attached to the declaration made by the HRCDC.

The HRCDC welcomed and were satisfied with the responses provided and the conditions attached to the declaration are now deemed to have been met.

In this regard, a full declaration is now in place.

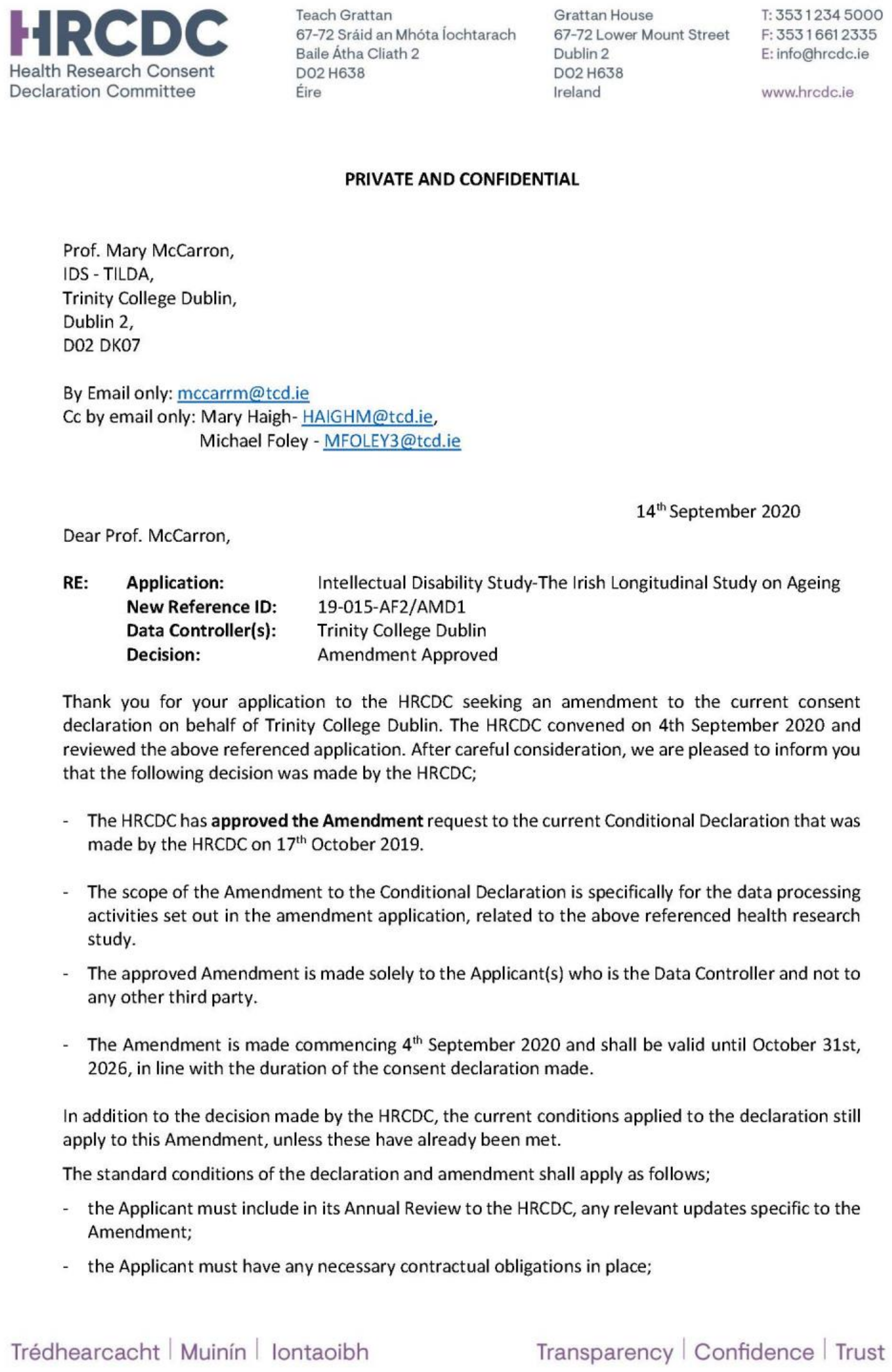
On behalf of the HRCDC and Secretariat, we wish you the very best of luck with the research study.

Kind regards,

Emily Vereker, PhD
Programme Manager, Secretariat
Health Research Consent Declaration Committee

Trédhearcacht | Muinín | Iontaoibh　　Transparency | Confidence | Trust

Appendix 6 HRCDC Amendment to Wave 4 approval (September 2020)



HRCDC
Health Research Consent
Declaration Committee

Teach Grattan
67-72 Sráid an Mhóta Íochtarach
Baile Átha Cliath 2
D02 H638
Éire

Grattan House
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T: 353 1 234 5000
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E: info@hrcdc.ie

www.hrcdc.ie

PRIVATE AND CONFIDENTIAL

Prof. Mary McCarron,
IDS - TILDA,
Trinity College Dublin,
Dublin 2,
D02 DK07

By Email only: mccarrm@tcd.ie
Cc by email only: Mary Haigh- HAIGHM@tcd.ie,
Michael Foley - MFOLEY3@tcd.ie

14th September 2020

Dear Prof. McCarron,

RE:	**Application:**	Intellectual Disability Study-The Irish Longitudinal Study on Ageing
	New Reference ID:	19-015-AF2/AMD1
	Data Controller(s):	Trinity College Dublin
	Decision:	Amendment Approved

Thank you for your application to the HRCDC seeking an amendment to the current consent declaration on behalf of Trinity College Dublin. The HRCDC convened on 4th September 2020 and reviewed the above referenced application. After careful consideration, we are pleased to inform you that the following decision was made by the HRCDC;

- The HRCDC has **approved the Amendment** request to the current Conditional Declaration that was made by the HRCDC on 17th October 2019.
- The scope of the Amendment to the Conditional Declaration is specifically for the data processing activities set out in the amendment application, related to the above referenced health research study.
- The approved Amendment is made solely to the Applicant(s) who is the Data Controller and not to any other third party.
- The Amendment is made commencing 4th September 2020 and shall be valid until October 31st, 2026, in line with the duration of the consent declaration made.

In addition to the decision made by the HRCDC, the current conditions applied to the declaration still apply to this Amendment, unless these have already been met.

The standard conditions of the declaration and amendment shall apply as follows;

- the Applicant must include in its Annual Review to the HRCDC, any relevant updates specific to the Amendment;
- the Applicant must have any necessary contractual obligations in place;

3

2

- all activities being carried out are in compliance with the General Data Protection Regulations, the Data Protection Act 2018 and Health Research Regulations, for the duration of the Declaration;
- any breaches that occur that affect the integrity of the Declaration and Amendment and the protection of data subjects, must be reported to the HRCDC;
- the health research must be conducted lawfully and ethically.

Please confirm acceptance of the decision of the HRCDC within 30 working days of receipt of this letter, or the Amendment will lapse.

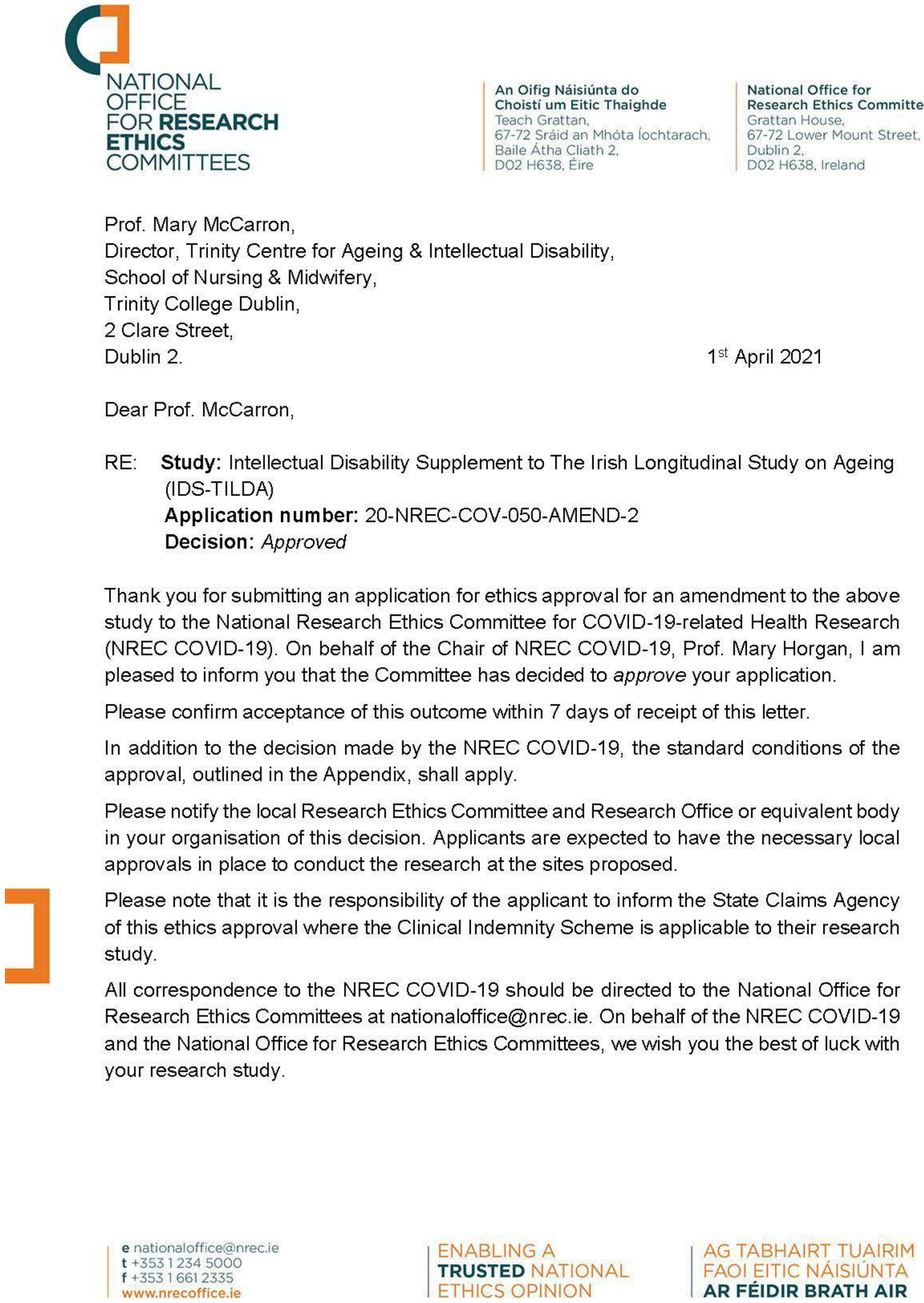
Please notify your Data Protection Officer or equivalent authority within your organisation of this decision.

On behalf of the HRCDC and Secretariat, we wish you the very best of luck with the research study.

Kind regards,

Emily Vereker, PhD
Programme Manager, Secretariat
Health Research Consent Declaration Committee

Appendix 7 NREC Amendment to ethics approval letter COVID phase 2 survey (April 2021)



NATIONAL
OFFICE
FOR **RESEARCH**
ETHICS
COMMITTEES

An Oifig Náisiúnta do
Choistí um Eitic Thaighde
Teach Grattan,
67-72 Sráid an Mhóta Íochtarach,
Baile Átha Cliath 2,
D02 H638, Éire

National Office for
Research Ethics Committees
Grattan House,
67-72 Lower Mount Street,
Dublin 2,
D02 H638, Ireland

Prof. Mary McCarron,
Director, Trinity Centre for Ageing & Intellectual Disability,
School of Nursing & Midwifery,
Trinity College Dublin,
2 Clare Street,
Dublin 2.

1st April 2021

Dear Prof. McCarron,

RE: **Study:** Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)
Application number: 20-NREC-COV-050-AMEND-2
Decision: *Approved*

Thank you for submitting an application for ethics approval for an amendment to the above study to the National Research Ethics Committee for COVID-19-related Health Research (NREC COVID-19). On behalf of the Chair of NREC COVID-19, Prof. Mary Horgan, I am pleased to inform you that the Committee has decided to *approve* your application.

Please confirm acceptance of this outcome within 7 days of receipt of this letter.

In addition to the decision made by the NREC COVID-19, the standard conditions of the approval, outlined in the Appendix, shall apply.

Please notify the local Research Ethics Committee and Research Office or equivalent body in your organisation of this decision. Applicants are expected to have the necessary local approvals in place to conduct the research at the sites proposed.

Please note that it is the responsibility of the applicant to inform the State Claims Agency of this ethics approval where the Clinical Indemnity Scheme is applicable to their research study.

All correspondence to the NREC COVID-19 should be directed to the National Office for Research Ethics Committees at nationaloffice@nrec.ie. On behalf of the NREC COVID-19 and the National Office for Research Ethics Committees, we wish you the best of luck with your research study.

e nationaloffice@nrec.ie
t +353 1 234 5000
f +353 1 661 2335
www.nrecoffice.ie

ENABLING A
TRUSTED NATIONAL
ETHICS OPINION

AG TABHAIRT TUAIRIM
FAOI EITIC NÁISIÚNTA
AR FÉIDIR BRATH AIR

NATIONAL
OFFICE
FOR **RESEARCH**
ETHICS
COMMITTEES

Kind regards,

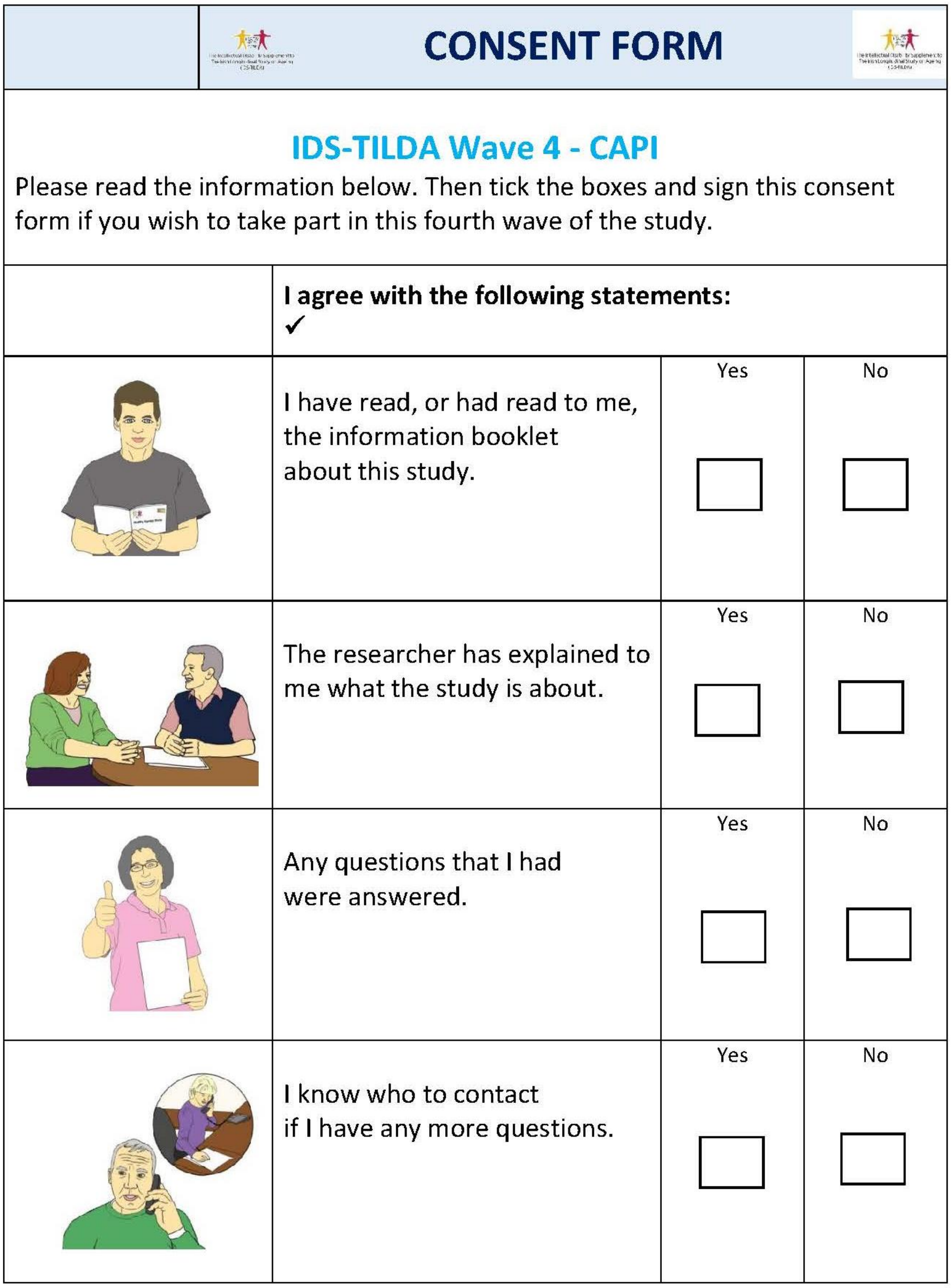
Aileen Sheehy
Programme Manager, National Office for Research Ethics Committees

Dr Jennifer Ralph James
Head, National Office for Research Ethics Committees

Appendix: Conditions of Research Ethics Approval by NREC COVID-19

- the Applicant must complete an Annual Report to the NREC COVID-19 on the anniversary date of this decision letter and for every year thereafter for the duration of the study, in addition to a Final Report on its completion (templates to be provided);
- the Applicant must have any necessary contractual obligations in place;
- all activities being carried out relating to the study must be in compliance with the General Data Protection Regulations, the Data Protection Act 2018 and Health Research Regulations 2018the Applicant must seek prior approval from NREC COVID-19 for any changes or amendments to the study protocol[1];
- the health research must be conducted lawfully and ethically, including in accordance with ethical principles outlined in the Declaration of Helsinki and Good Clinical Practice. Please note NREC COVID-19 have reviewed this study from an ethical perspective only;
- where the study encompasses a Clinical Trial of Investigational Medicinal Product (CTIMP), the Applicant must fulfil the regulatory reporting requirements[2] for safety including reporting to NREC COVID-19 as the relevant ethics committee;
- where the study does not encompass a CTIMP, the Applicant must report any serious or unexpected adverse reactions, or unforeseen events that might affect the benefits/risks ratio of the study, to the NREC COVID-19 as soon as possible but not later than 7 days of becoming aware of the event;
- where the study does not encompass a CTIMP and is prematurely suspended or terminated, the Applicant should inform the NREC COVID-19 in writing, including the underpinning reasons and a summary of results to that point, within 15 days of the date of suspension or termination;
- where the study encompasses a CTIMP, the applicant should fulfil the regulatory reporting requirements[2] for study suspension or termination, including reporting to NREC COVID-19 as the relevant ethics committee.

Appendix 8 Consent Form for Wave 4 CAPI

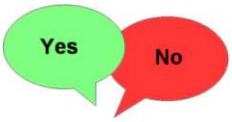


CONSENT FORM

IDS-TILDA Wave 4 - CAPI

Please read the information below. Then tick the boxes and sign this consent form if you wish to take part in this fourth wave of the study.

	I agree with the following statements: ✓		
	I have read, or had read to me, the information booklet about this study.	Yes ☐	No ☐
	The researcher has explained to me what the study is about.	Yes ☐	No ☐
	Any questions that I had were answered.	Yes ☐	No ☐
	I know who to contact if I have any more questions.	Yes ☐	No ☐

	I understand that I will be asked questions about my: • life • health • work • friends, and • things I like to do	Yes ☐	No ☐
	I know that I will be asked questions about Coronavirus.	Yes ☐	No ☐
	I know that it is my choice to take part in this study.	Yes ☐	No ☐
	I know that I do not have to answer questions I do not feel happy with.	Yes ☐	No ☐
	The researcher can ask the HSE what medicine I take.	Yes ☐	No ☐
	I know that I can stop taking part in this study when I want to. I do not have to give a reason.	Yes ☐	No ☐

	I understand that all information I give during this study will be kept safe and private.	Yes ☐	No ☐
	I know that I will not be named in any reports.	Yes ☐	No ☐
	I know that there are no known risks with this study. And that there are no direct benefits to me from this study.	Yes ☐	No ☐
Trinity College Dublin The University of Dublin	I know this study will continue and I will be contacted again in three years about consenting to take part in the next Wave.	Yes ☐	No ☐
	I am happy to take part in this study.	Yes ☐	No ☐

Your Consent

Your name: ____

Your phone number: ______________________________________

Your address: ____

____

____

Please sign your name: __________________________________

Date: ____

THE PERSON SUPPORTING YOU

I have supported the person named above to fill out this form. I believe they understand the information and have freely agreed to take part in this study.

Print name: ____

Relationship to the person named above: _________________

Phone number: ____

Signature: ____

Date: ____

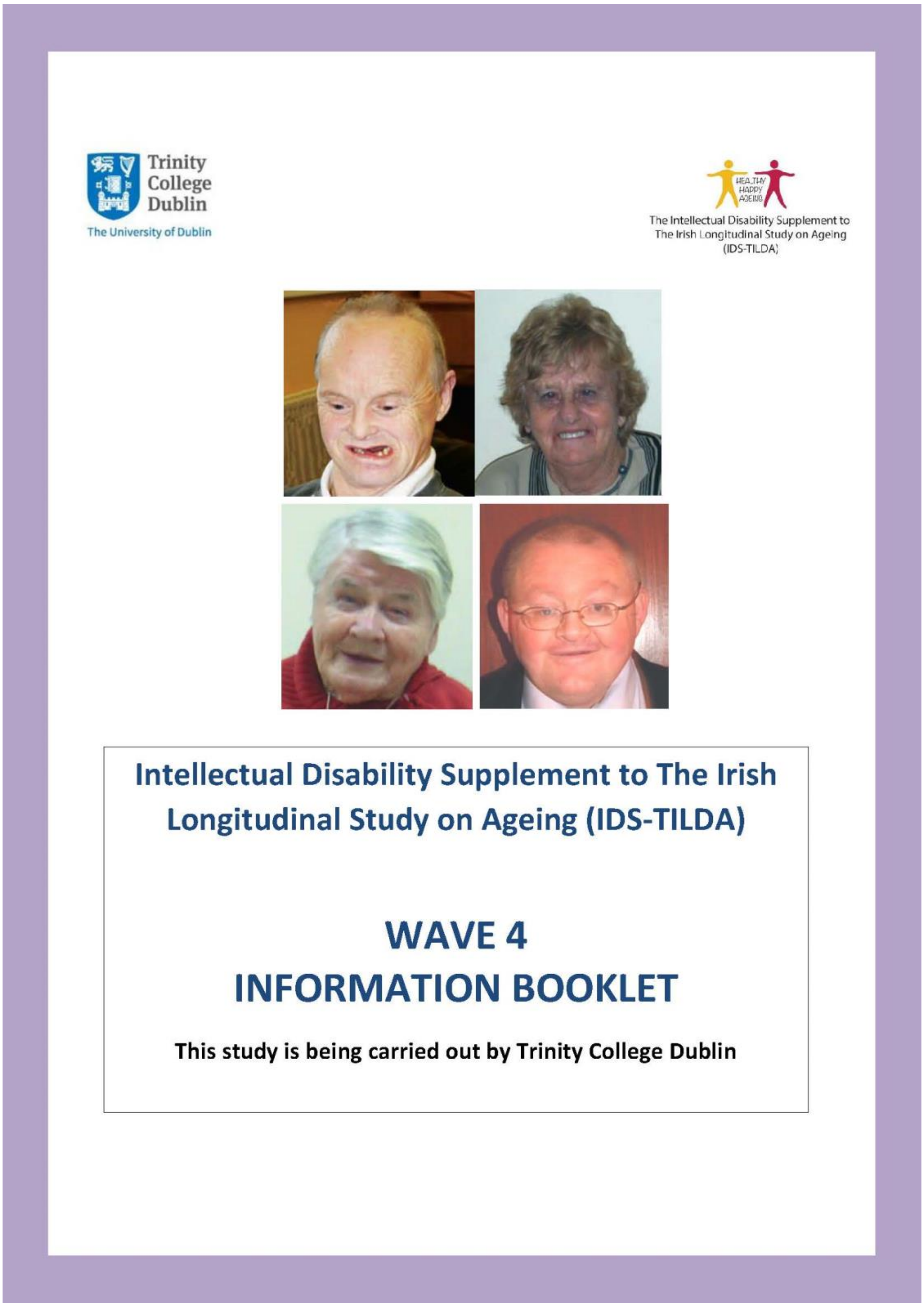
OFFICE USE ONLY

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

RESEARCHER'S SIGNATURE ___________________________________

Date: ____

Appendix 9 Wave 4 Participant Information Booklet



Trinity
College
Dublin
The University of Dublin

HEALTHY
HAPPY
AGEING
The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

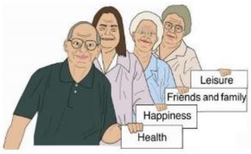
WAVE 4
INFORMATION BOOKLET

This study is being carried out by Trinity College Dublin

Dear Participant (and/or support person),

We are currently phoning people to collect their information for the IDS-TILDA study.

This booklet tells you all about IDS-TILDA and what will happen if you decide to take part.

1. What is this study about?	
	This study is about growing older with an intellectual disability in Ireland. Trinity College Dublin is doing this study.
	This study will help us to understand what is important to people with an intellectual disability.
	It will help us to learn about the • health • well-being • and lifestyles of people as they get older.

2. Who is taking part in the study?	
	People with an intellectual disability aged 40 years and over.
	People from all over Ireland are taking part in the study. You were one of the people selected for the study. We hope you decide to take part in the study. We may not be able to include everybody in all parts of the study. But we will be in touch to explain what you will do.

3. What are the different parts to the study?	
There are two main parts to the study:	
	1. First you fill in a **survey** that we send out to you. This is a booklet with questions about your health. You can ask someone to help you fill in the survey.
	2. Next, you do an **interview**. A researcher calls you on the telephone to do this with you. You can ask someone to support you for this.

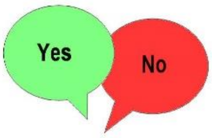
4. What may you be asked about?	
You may be asked questions about:	
	Activities you do everyday
	Your health and well-being
	Your friends
	Your family
	Interests and hobbies

	Work and retirement
	Your home and if you have moved recently
	Coronavirus
You can choose someone to help you answer questions	

6. If you are selected, who will call you?	
Trinity College Dublin The University of Dublin	A researcher from Trinity College will call you on the telephone to speak to you.

7. How will they collect the information?	
	The researcher will put your answers into a computer.
🔒	All of your information will be kept safe and private.

8. If you are selected, how long will it take?	
	The interview will last for around an hour and a half.
	If the interview is too long, you can take a break.
	The researcher can also ring you back a second time to finish the interview.

9. Do you have to take part?	
	No. It is your choice to take part in the study. You can also change your mind and stop taking part at any time. Your decision will not affect the support you receive.

10. Are there any risks or benefits involved?	
	We do not know of any risks to you being involved in this study. There are no direct personal benefits to taking part in the study.

11. Will anyone else know what you tell us?	
	No. We will keep all your personal information private. Your name will not be in any report.

12. What should you do next?	
	If you want to take part you should: ✓ Sign the consent form ✓ Send it back to us using the envelope in the pack

	After that, a researcher will contact you to explain how you will take part in the study.

13. Who do you contact if you have any questions?	
?	If you have any questions, please contact:
	Margaret Haigh IDS-TILDA Project Manager Phone: 01 – 896 3187 Email: haighm@tcd.ie
	Or write to us at: IDS-TILDA Trinity College 2 Clare Street, Dublin 2

Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College,
Trinity Centre for Ageing and Intellectual Disability
2 Clare Street,
Dublin 2.

Phone: (01) 896 3186 or (01) 896 3187
Fax: (01) 896 3001
Email: idstilda@tcd.ie

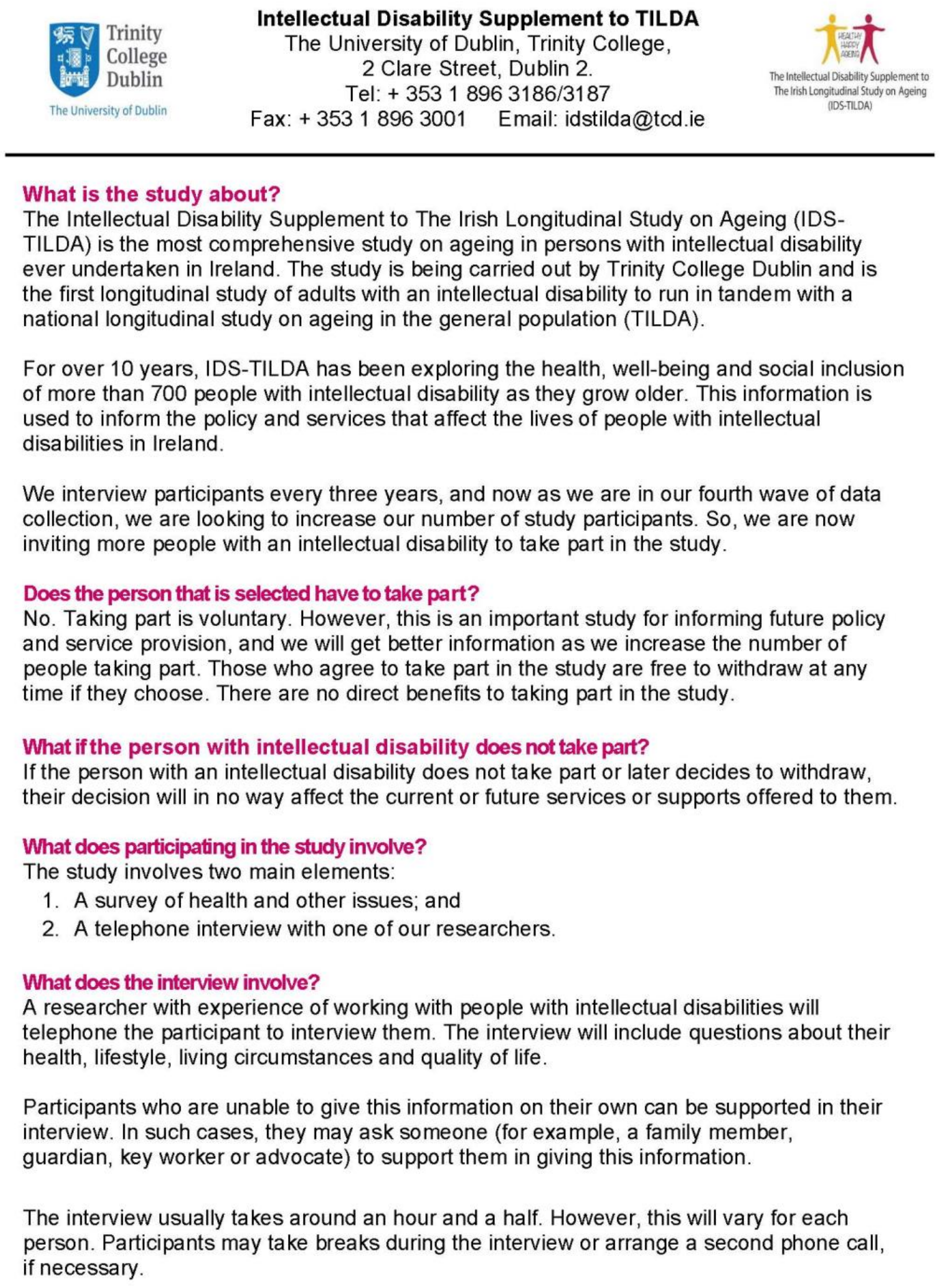
The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing is funded by the Health Research Board and the Department of Health

An Roinn Sláinte
DEPARTMENT OF HEALTH

HRB Health Research Board

Trinity College Dublin
The University of Dublin

Appendix 10 Family/Guardian Information Leaflet



Trinity College Dublin
The University of Dublin

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2 Clare Street, Dublin 2.
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The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

What is the study about?

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) is the most comprehensive study on ageing in persons with intellectual disability ever undertaken in Ireland. The study is being carried out by Trinity College Dublin and is the first longitudinal study of adults with an intellectual disability to run in tandem with a national longitudinal study on ageing in the general population (TILDA).

For over 10 years, IDS-TILDA has been exploring the health, well-being and social inclusion of more than 700 people with intellectual disability as they grow older. This information is used to inform the policy and services that affect the lives of people with intellectual disabilities in Ireland.

We interview participants every three years, and now as we are in our fourth wave of data collection, we are looking to increase our number of study participants. So, we are now inviting more people with an intellectual disability to take part in the study.

Does the person that is selected have to take part?

No. Taking part is voluntary. However, this is an important study for informing future policy and service provision, and we will get better information as we increase the number of people taking part. Those who agree to take part in the study are free to withdraw at any time if they choose. There are no direct benefits to taking part in the study.

What if the person with intellectual disability does not take part?

If the person with an intellectual disability does not take part or later decides to withdraw, their decision will in no way affect the current or future services or supports offered to them.

What does participating in the study involve?

The study involves two main elements:

1. A survey of health and other issues; and
2. A telephone interview with one of our researchers.

What does the interview involve?

A researcher with experience of working with people with intellectual disabilities will telephone the participant to interview them. The interview will include questions about their health, lifestyle, living circumstances and quality of life.

Participants who are unable to give this information on their own can be supported in their interview. In such cases, they may ask someone (for example, a family member, guardian, key worker or advocate) to support them in giving this information.

The interview usually takes around an hour and a half. However, this will vary for each person. Participants may take breaks during the interview or arrange a second phone call, if necessary.

Are there any risks involved?

There are no known risks involved in this study. We will explain each stage of the study to the person with intellectual disability using accessible materials. At all times, the well-being of participants will take priority over research activities. If the person with an intellectual disability tells us or indicates that they do not want to take part, or decides to withdraw, we will fully respect their decision.

Is the study confidential?

Yes. We will treat all information as strictly confidential and we will not publish the name of the participant or pass it on to anyone outside of the research team. The Faculty of Health Sciences Research Ethics Committee, of Trinity College Dublin, approved this study and ensured that proper safeguards are in place.

Who is involved in the study?

This study has been set up by a team who have a lot of experience working with people with intellectual disability. The advisory team includes family members, researchers, nurses, doctors, psychologists, psychiatrists, and service providers.

People with intellectual disabilities also play an important role in our advisory team through participation in consultative workshops, which are run throughout the country.

Where can I get more information?

If you would like to know more about the study, please contact:

Margaret Haigh
Project Manager
Phone: 01- 896 3186/3187
Email: haighm@tcd.ie

Or write to:

IDS-TILDA
Trinity College Dublin
Trinity Centre for Ageing and Intellectual Disability
2 Clare Street
Dublin 2

The Intellectual Disability Supplement to TILDA is funded by the Health Research Board.

Appendix 11 – Correlation Matrix for model 1 – Depression symptoms

Correlations

		Sex	Aetiology	Level of intellectual disability	Response type	Living arrangements	Age Categorical	Access to mental health supports	Mental health losses	Mental Health gains	Physical health loss
Sex	Pearson Correlation	1	.053	-.049	-.003	.013	.134**	.102*	.060	.076*	.081*
	Sig. (2-tailed)		.193	.216	.941	.744	.000	.027	.117	.047	.036
	N	682	608	637	664	675	682	464	682	682	682
Aetiology	Pearson Correlation	.053	1	.052	-.025	.167**	.364**	.130**	.005	-.045	-.049
	Sig. (2-tailed)	.193		.209	.543	.000	.000	.008	.904	.266	.225
	N	608	608	582	592	602	608	411	608	608	608
Level of intellectual disability	Pearson Correlation	-.049	.052	1	.483**	.396**	-.004	.017	-.174**	-.177**	.025
	Sig. (2-tailed)	.216	.209		.000	.000	.914	.723	.000	.000	.529
	N	637	582	637	620	631	637	432	637	637	637
Response type	Pearson Correlation	-.003	-.025	.483**	1	.327**	.110**	-.017	-.068	-.123**	-.023
	Sig. (2-tailed)	.941	.543	.000		.000	.004	.712	.079	.002	.559
	N	664	592	620	664	657	664	454	664	664	664
Living arrangements	Pearson Correlation	.013	.167**	.396**	.327**	1	.276**	.156**	-.041	-.107**	.030
	Sig. (2-tailed)	.744	.000	.000	.000		.000	.001	.286	.005	.442
	N	675	602	631	657	675	675	458	675	675	675

Age Categorical	Pearson Correlation	.134**	.364**	-.004	.110**	.276**	1	.141**	-.001	.011	.044
	Sig. (2-tailed)	.000	.000	.914	.004	.000		.002	.981	.771	.248
	N	682	608	637	664	675	682	464	682	682	682
Access to mental health supports	Pearson Correlation	.102*	.130**	.017	-.017	.156**	.141**	1	.307**	.128**	.156**
	Sig. (2-tailed)	.027	.008	.723	.712	.001	.002		.000	.006	.001
	N	464	411	432	454	458	464	464	464	464	464
Mental health losses	Pearson Correlation	.060	.005	-.174**	-.068	-.041	-.001	.307**	1	.215**	.107**
	Sig. (2-tailed)	.117	.904	.000	.079	.286	.981	.000		.000	.005
	N	682	608	637	664	675	682	464	682	682	682
Mental health gains	Pearson Correlation	.076*	-.045	-.177**	-.123**	-.107**	.011	.128**	.215**	1	.046
	Sig. (2-tailed)	.047	.266	.000	.002	.005	.771	.006	.000		.233
	N	682	608	637	664	675	682	464	682	682	682
Physical health loss	Pearson Correlation	.081*	-.049	.025	-.023	.030	.044	.156**	.107**	.046	1
	Sig. (2-tailed)	.036	.225	.529	.559	.442	.248	.001	.005	.233	
	N	682	608	637	664	675	682	464	682	682	682

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Appendix 12 – Correlation Matrix for model 2 – Generalised Anxiety Disorder symptoms

Correlations

		Sex	Aetiology	Level of intellectual disability	Response type	Living arrangements	Age Categorical	Access to mental health supports	Physical distancing / infection history	Relationship loss	Mental health losses	Mental Health Gains
Sex	Pearson Correlation	1	.053	-.049	-.003	.013	.134**	.102*	.036	.021	.060	.076*
	Sig. (2-tailed)		.193	.216	.941	.744	.000	.027	.345	.587	.117	.047
	N	682	608	637	664	675	682	464	682	682	682	682
Aetiology	Pearson Correlation	.053	1	.052	-.025	.167**	.364**	.130**	-.010	-.025	.005	-.045
	Sig. (2-tailed)	.193		.209	.543	.000	.000	.008	.801	.542	.904	.266
	N	608	608	582	592	602	608	411	608	608	608	608
Level of intellectual disability	Pearson Correlation	-.049	.052	1	.483**	.396**	-.004	.017	.047	-.027	-.174**	-.177**
	Sig. (2-tailed)	.216	.209		.000	.000	.914	.723	.235	.495	.000	.000
	N	637	582	637	620	631	637	432	637	637	637	637
Response type	Pearson Correlation	-.003	-.025	.483**	1	.327**	.110**	-.017	.040	-.055	-.068	-.123**
	Sig. (2-tailed)	.941	.543	.000		.000	.004	.712	.305	.155	.079	.002
	N	664	592	620	664	657	664	454	664	664	664	664
Living arrangements	Pearson Correlation	.013	.167**	.396**	.327**	1	.276**	.156**	.197**	-.023	-.041	-.107**
	Sig. (2-tailed)	.744	.000	.000	.000		.000	.001	.000	.550	.286	.005
	N	675	602	631	657	675	675	458	675	675	675	675
Age Categorical	Pearson Correlation	.134**	.364**	-.004	.110**	.276**	1	.141**	.007	-.078*	-.001	.011
	Sig. (2-tailed)	.000	.000	.914	.004	.000		.002	.851	.042	.981	.771
	N	682	608	637	664	675	682	464	682	682	682	682
Access to mental health supports	Pearson Correlation	.102*	.130**	.017	-.017	.156**	.141**	1	.061	.029	.307**	.128**
	Sig. (2-tailed)	.027	.008	.723	.712	.001	.002		.192	.529	.000	.006

	N	464	411	432	454	458	464	464	464	464	464	464
Physical distancing / infection history	Pearson Correlation	.036	-.010	.047	.040	.197**	.007	.061	1	.274**	.148**	.079*
	Sig. (2-tailed)	.345	.801	.235	.305	.000	.851	.192		.000	.000	.039
	N	682	608	637	664	675	682	464	682	682	682	682
Relationship loss	Pearson Correlation	.021	-.025	-.027	-.055	-.023	-.078*	.029	.274**	1	.266**	.140**
	Sig. (2-tailed)	.587	.542	.495	.155	.550	.042	.529	.000		.000	.000
	N	682	608	637	664	675	682	464	682	682	682	682
Mental health losses	Pearson Correlation	.060	.005	-.174**	-.068	-.041	-.001	.307**	.148**	.266**	1	.215**
	Sig. (2-tailed)	.117	.904	.000	.079	.286	.981	.000	.000	.000		.000
	N	682	608	637	664	675	682	464	682	682	682	682
Mental Health gains	Pearson Correlation	.076*	-.045	-.177**	-.123**	-.107**	.011	.128**	.079*	.140**	.215**	1
	Sig. (2-tailed)	.047	.266	.000	.002	.005	.771	.006	.039	.000	.000	
	N	682	608	637	664	675	682	464	682	682	682	682

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Appendix 13 – Correlation Matrix for model 3 – Loneliness

Correlations

		Sex	Aetiology	Level of intellectual disability	Response type	Living arrangements	Age Categorical	Prescribed antidepressant	Mental health diagnosis	Physical health loss	Mental Health Gains
Sex	Pearson Correlation	1	.053	-.049	-.003	.013	.134**	-.041	-.032	.081*	.076*
	Sig. (2-tailed)		.193	.216	.941	.744	.000	.290	.410	.036	.047
	N	682	608	637	664	675	682	682	682	682	682
Aetiology	Pearson Correlation	.053	1	.052	-.025	.167**	.364**	-.012	.286**	-.049	-.045
	Sig. (2-tailed)	.193		.209	.543	.000	.000	.762	.000	.225	.266
	N	608	608	582	592	602	608	608	608	608	608
Level of intellectual disability	Pearson Correlation	-.049	.052	1	.483**	.396**	-.004	-.030	.168**	.025	-.177**
	Sig. (2-tailed)	.216	.209		.000	.000	.914	.455	.000	.529	.000
	N	637	582	637	620	631	637	637	637	637	637
Response type	Pearson Correlation	-.003	-.025	.483**	1	.327**	.110**	-.060	.112**	-.023	-.123**
	Sig. (2-tailed)	.941	.543	.000		.000	.004	.121	.004	.559	.002
	N	664	592	620	664	657	664	664	664	664	664
Living arrangements	Pearson Correlation	.013	.167**	.396**	.327**	1	.276**	-.021	.263**	.030	-.107**
	Sig. (2-tailed)	.744	.000	.000	.000		.000	.595	.000	.442	.005
	N	675	602	631	657	675	675	675	675	675	675
Age Categorical	Pearson Correlation	.134**	.364**	-.004	.110**	.276**	1	-.086*	.164**	.044	.011
	Sig. (2-tailed)	.000	.000	.914	.004	.000		.024	.000	.248	.771
	N	682	608	637	664	675	682	682	682	682	682
Prescribed antidepressant	Pearson Correlation	-.041	-.012	-.030	-.060	-.021	-.086*	1	-.039	-.034	.002

	Sig. (2-tailed)	.290	.762	.455	.121	.595	.024		.315	.369	.962
	N	682	608	637	664	675	682	682	682	682	682
Mental health diagnosis	Pearson Correlation	-.032	.286**	.168**	.112**	.263**	.164**	-.039	1	-.013	-.064
	Sig. (2-tailed)	.410	.000	.000	.004	.000	.000	.315		.733	.095
	N	682	608	637	664	675	682	682	682	682	682
Physical health loss	Pearson Correlation	.081*	-.049	.025	-.023	.030	.044	-.034	-.013	1	.046
	Sig. (2-tailed)	.036	.225	.529	.559	.442	.248	.369	.733		.233
	N	682	608	637	664	675	682	682	682	682	682
Mental Health Gains	Pearson Correlation	.076*	-.045	-.177**	-.123**	-.107**	.011	.002	-.064	.046	1
	Sig. (2-tailed)	.047	.266	.000	.002	.005	.771	.962	.095	.233	
	N	682	608	637	664	675	682	682	682	682	682

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Appendix 14 – Correlation Matrix for Model 4 – Self Rated Mental Health

		Sex	Aetiology	Level of intellectual disability	Response type	Living arrangements	Age Categorical	Mental health diagnosis	Access to mental health supports	Physical health loss	Physical health gains	Social activity gains	Mental health losses
Sex	Pearson Correlation	1	.057	-.043	-.002	.013	.132**	-.029	.107*	.085*	-.023	-.050	.061
	Sig. (2-tailed)		.160	.281	.954	.733	.001	.457	.022	.027	.560	.193	.117
	N	674	600	629	656	667	674	674	458	674	674	674	674
Aetiology	Pearson Correlation	.057	1	.052	-.022	.170**	.364**	.285**	.137**	-.055	-.006	.020	.007
	Sig. (2-tailed)	.160		.217	.600	.000	.000	.000	.006	.177	.877	.618	.862
	N	600	600	574	584	594	600	600	405	600	600	600	600
Level of intellectual disability	Pearson Correlation	-.043	.052	1	.485**	.395**	-.004	.167**	.013	.024	.156**	.079*	-.173**
	Sig. (2-tailed)	.281	.217		.000	.000	.919	.000	.785	.547	.000	.048	.000
	N	629	574	629	612	623	629	629	426	629	629	629	629
Response type	Pearson Correlation	-.002	-.022	.485**	1	.326**	.112**	.110**	-.017	-.025	.089*	.014	-.066
	Sig. (2-tailed)	.954	.600	.000		.000	.004	.005	.724	.530	.022	.723	.093
	N	656	584	612	656	649	656	656	448	656	656	656	656
Living arrangements	Pearson Correlation	.013	.170**	.395**	.326**	1	.271**	.263**	.157**	.031	.138**	.040	-.035
	Sig. (2-tailed)	.733	.000	.000	.000		.000	.000	.001	.418	.000	.300	.373
	N	667	594	623	649	667	667	667	452	667	667	667	667
Age Categorical	Pearson Correlation	.132**	.364**	-.004	.112**	.271**	1	.167**	.149**	.045	-.007	.007	.008

	Sig. (2-tailed)	.001	.000	.919	.004	.000		.000	.001	.243	.866	.866	.830
	N	674	600	629	656	667	674	674	458	674	674	674	674
Mental health diagnosis	Pearson Correlation	-.029	.285**	.167**	.110**	.263**	.167**	1	.197**	-.011	.069	.020	.024
	Sig. (2-tailed)	.457	.000	.000	.005	.000	.000		.000	.771	.072	.606	.538
	N	674	600	629	656	667	674	674	458	674	674	674	674
Access to mental health supports	Pearson Correlation	.107*	.137**	.013	-.017	.157**	.149**	.197**	1	.158**	-.222**	-.101*	.305**
	Sig. (2-tailed)	.022	.006	.785	.724	.001	.001	.000		.001	.000	.031	.000
	N	458	405	426	448	452	458	458	458	458	458	458	458
Physical health loss	Pearson Correlation	.085*	-.055	.024	-.025	.031	.045	-.011	.158**	1	.040	-.060	.114**
	Sig. (2-tailed)	.027	.177	.547	.530	.418	.243	.771	.001		.301	.119	.003
	N	674	600	629	656	667	674	674	458	674	674	674	674
Physical health gains	Pearson Correlation	-.023	-.006	.156**	.089*	.138**	-.007	.069	-.222**	.040	1	.403**	-.153**
	Sig. (2-tailed)	.560	.877	.000	.022	.000	.866	.072	.000	.301		.000	.000
	N	674	600	629	656	667	674	674	458	674	674	674	674
Social activity gains	Pearson Correlation	-.050	.020	.079*	.014	.040	.007	.020	-.101*	-.060	.403**	1	-.033
	Sig. (2-tailed)	.193	.618	.048	.723	.300	.866	.606	.031	.119	.000		.395
	N	674	600	629	656	667	674	674	458	674	674	674	674
Mental health losses	Pearson Correlation	.061	.007	-.173**	-.066	-.035	.008	.024	.305**	.114**	-.153**	-.033	1
	Sig. (2-tailed)	.117	.862	.000	.093	.373	.830	.538	.000	.003	.000	.395	
	N	674	600	629	656	667	674	674	458	674	674	674	674

Research Contributions

McCarron M., McCausland D., Allen A.P., Luus R., Sheerin F., Burke E., McGlinchey E., Flannery F. & McCallion P. (2020) Understanding the impact of COVID-19 on the health and well-being of older adults with an intellectual disability in Ireland. Findings from Wave 4 of The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). Trinity College Dublin, Dublin

McCarron M., Allen A., McCausland D., Haigh M., Luus R., Bavussantakath F., Sheerin F., Mulryan N., Burke E., McGlinchey E., Flannery F. & McCallion P. (2021) The impact of COVID-19 on people ageing with an intellectual disability in Ireland: Protocol for a follow-up survey [version 2; peer review: 2 approved]. *HRB open research* **4**(95).

McCausland D., Allen A.P., Haigh M., Sheerin F., Burke E., McGlinchey E., FLannery F., Mulryan N., McCallion P. & M. M. (2021) *Overcoming Adversity: The Continuing Impact of COVID-19 on People Ageing with an Intellectual Disability in Ireland*. The University of Dublin, Trinity College, Dublin.

Conference Presentations

Flannery, F., Sheerin, F., Eustace-Cook, J., McCarron M., McCausland D., McCallion, P. (2020) The Impact of COVID-19 on the Mental Health of Adults with an Intellectual Disability. Trinity Health & Education International Research Conference. Integrated Healthcare: Developing Person-Centred Health Systems. March 4th and 5th 2020, Dublin, Ireland.

Flannery, F., Sheerin, F., Eustace-Cook, J., McCarron M., McCausland D., McCallion, P. (2021) The Impact of COVID-19 on the Mental Health of Adults with an Intellectual Disability. International Association for the Scientific Study of Intellectual and Developmental (virtual) Europe Congress. Value Diversity. July 6th & 8th 2021.