Engagement in Daily Life Activities of Adults Ageing with an Intellectual Disability

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

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Eilish King

B.Sc. OT

Supervisory Team: Prof Mary McCarron, Prof Philip McCallion, Ms Joan Brangan & Dr. Mary-Ann O'Donovan

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Declaration

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

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Student Name: Eilish King

Student Number: 15340112

Date: _____

Summary

This study sought to examine engagement in daily life activities of adults growing older with intellectual disabilities, and to examine factors which influenced engagement in daily life for this population. Occupational therapists view occupation as activities that are personally meaningful, or fulfil a valued social role (Hinojosa *et al*. 2003). An occupational perspective of health posits that engagement in occupations is essential for health, quality of life and well-being (Wilcock 2006b). Occupational therapists consider personal, environmental and occupational factors that can influence engagement in meaningful daily activities, or occupations. Polatajko *et al*. 2007b). The present study applied a modified occupational perspective to investigate engagement in self-care, productivity and leisure activities of adults ageing with an intellectual disability in Ireland.

Data from wave two of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) was analysed in order to explore factors that influence engagement in self-care, productivity and leisure activities of people ageing with an intellectual disability.

Cross tabulations, chi square tests for independence, independent samples t tests, ANOVA, logistic and linear regression techniques were used to analyse the IDS-TILDA wave two data. Findings of analysis indicated that difficulty getting around the physical environment of the

home and community, and poor physical health were the strongest predictors of preclusion from engagement in self-care, productivity and leisure activities. In addition, older age, severe/profound level of ID, and living in a residential setting were significant predictors of preclusion from engagement in two out of the three domains of activity examined in the study.

These findings have important implications for occupational therapists, policy makers and people ageing with ID, in order to support creation of environments that are supportive of engagement in daily life, and promote health, well-being and quality of life for people ageing with an intellectual disability.

List of Abbreviations

AAIDD	American Association of Intellectual and Developmental Disabilities
ADL	Activities of Daily Living
ANOVA	Analysis of Variance
AOTI	Association of Occupational Therapists of Ireland
CAOT	Canadian Association of Occupational Therapists
CAPI	Computer Assisted Personal Interview
CI	Confidence Interval
CMOP-E Engagement	Canadian Model of Occupational Performance &
DoH	Department of Health
HRB	Health Research Board
HSE	Health Service Executive
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning
ID	Intellectual Disability
IDS-TILDA	Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
LAI	Leisure Assessment Inventory
NIDD	National Intellectual Disability Database
NORC	Naturally Occurring Retirement Community
OR	Odds Ratio
OT	Occupational Therapy
TCD	Trinity College Dublin, the University of Dublin
TILDA	The Irish Longitudinal Study on Ageing

PIN	Personal Identification Number
PIQ	Pre-Interview Questionnaire
SD	Standard Deviation
SPSS	Statistical Package for the Social Sciences
UN	United Nations
UN CRPD	United Nations Convention on the Rights of People with Disabilities
VIF	Variance Inflation Factor
WFOT	World Federation of Occupational Therapists
WHO	World Health Organisation

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Preface

This study has its roots in my time as an undergraduate occupational therapy student in a disability support service. My caseload was predominantly working with adults and older adults with an intellectual disability. It was during this placement that I first had the opportunity to work with people with intellectual disabilities. This placement held so many fantastic learning opportunities for me, and I really enjoyed it. I began to get a feel for the scope of occupational therapy in working with people with intellectual disabilities, and particularly so for people with ID as they grow older. As a student, I had the luxury of a reduced caseload and being able to spend time really getting to work collaboratively with people.

I found this area to be absolutely fascinating, and could see the potential breadth of occupational therapy practice in working with this population. However, I could also see that the current scope of occupational therapy practice was restricted by the limited staffing resources and financial constraints. I could see that this disparity was not due to lack of skill on the part of the therapists, but due to resource constraints, the time and type of interventions that could be facilitated with people in order to facilitate a truly occupational perspective in their work with people were limited.

As a student, I was required to complete a number of assignments based on the client group that I was working with. I found that there was a dearth of research related to ageing and intellectual disability from an occupational perspective. I believed that the lack of research served as an additional barrier to expanding the scope of occupational therapy practice in this area.

I was lucky enough to have the opportunity to be involved in a research project being undertaken within the disability support service during my placement. This project was guided by one of my supervisors for the current study, Prof Mary McCarron. This experience really opened my eyes to the exciting world of research, and the potential role of an occupational therapy perspective in research with people with intellectual disabilities. Shortly afterwards, the opportunity arose for me to the first occupational therapist to work with the IDS-TILDA team, and it was a fantastic experience.

As an occupational therapist, I was excited to work with the IDS-TILDA team. As a large quantitative study with a nationally representative sample of people ageing with an intellectual disability, I was eager to explore the relevance of this data for occupational therapy. I was aware that this data hadn't been explored with an occupational perspective, and I was excited to explore the possibilities within this data set.

The process was exciting and challenging, particularly when attempting to apply occupational concepts to a quantitative dataset, but I believe

there was huge value in the process in terms of my own learning, and it led to some interesting reflections on the data and on occupational concepts. Overall, it reinforced for me the breadth of occupational therapy, and the potential contribution that an occupational perspective could make to research, policy and practice with people with intellectual disabilities.

Introduction

This chapter provides an overview of the study, including the background to and rationale for the study, and sets out the main research question, aims and objectives of the study. Key concepts related to the study are presented, followed by definitions of important terms and the structure of the thesis.

1.1 Background

In recent years, the population of people ageing with intellectual disability (ID) has grown dramatically (McCallion & McCarron 2004). While this is certainly welcomed, strategies to promote best possible ageing experiences for people with ID are needed in order to ensure good quality of life and wellbeing as people grow older (McCarron *et al.* 2011, McCallion *et al*. 2013).

The general population in Ireland is also ageing, and there is ongoing debate about how services will be provided for the growing population of older people in the future (Kenny & Nolan, 2014). There is increased focus on the provision of services within the community through Primary Care (Primary Care: A New Direction) (Department of Health and Children, 2001). Primary care is said to be the cornerstone of health service provision (Department of Health and Children 2001). This shift to primary care has occurred in tandem with a focus on active ageing and promoting active engagement within the community as

people age, reflected in national policy documents such as the National Positive Ageing Strategy (Department of Health, 2013a), and Healthy Ireland (Department of Health, 2013b).

Implementation of deinstitutionalisation from congregated setting to facilities based within the community is also ongoing (Department of Health, 2011). While the benefits of community-based living are numerous, transition from congregated settings for people with ID who may have spent large portions of their life there may be a significant life event that requires careful planning and supports before, during and after transition (McDonnell 2007, King *et al*. 2016). Sustained positive outcomes of deinstitutionalisation are not automatic but requires the appropriate supports for people with ID and their support staff/family are in place (Bigby & Fyffe 2006). With changing age demographics and greater numbers of older people with ID living in the community, increased emphasis on primary preventative and secondary preventive approaches will be necessary in order to support people with ID to live full and active lives within the community with a focus on participation, empowerment and citizenship (Lewis 2003, McIntyre & Bryant, 2005). Primary preventive approaches refers to interventions that prevent or reduce incidence of ill health, while secondary interventions aim to minimise the impact that poor health has on the person's ability to engage in daily life through promotion of positive health changes (Padilla & Byers-Cannon, 2012). This is particularly relevant for people ageing with an ID due to the increased

rates of multimorbidities and prevalence of osteoporosis, dementia and sensory issues amongst the population of people ageing with ID (Janicki *et al.* 2002, McCarron *et al.* 2013, McCarron *et al.* 2014). Campbell & Herge (2000), and Bigby (2002) have written about the challenges faced by services in identifying the best way of providing supports required for people with ID to age successfully within the community. Limited evidence exists for the use of health promotion approaches to ageing and wellbeing for people with ID.

As engagement in meaningful activities, or occupations is essential for maintenance of health and well-being (Wilcock 2006a), more knowledge is required regarding the current levels of engagement in daily life for people ageing with ID.

1.1.2 The Role of Occupational Therapy and Occupation

In occupational therapy (OT), the importance of promoting health and well-being through engagement in meaningful occupation is recognised (Wilcock 2006a). Occupation is generally defined as referring to paid employment (Jarman 2011), but in occupational therapy, occupation is a much broader concept that is viewed as essential for life, that can involve daily life tasks, and brings meaning to life (Hinojosa *et al.* 2003).

Occupational therapists define “occupation” as activities that are meaningful on a personal, societal or cultural level, or that fulfil a valued social role (Hinojosa *et al.* 2003). The aim of occupational

therapy is to work in collaboration with the person to promote engagement in identified occupations with the ultimate goal to promote health, well-being and quality of life (Townsend & Polatajko 2007).

Occupation is a multifaceted concept that extends beyond the functional ability of completing everyday activities, to include the meaning the task holds for the person (Hasselkus 2002). In this way, the experience of occupation is subjective and individual to each person (Pierce 2003). OT theory draws from a number of fields across psychology, anatomy, physiology, philosophy and social policy as well as occupational science to develop perspectives on engagement in meaningful and purposeful activity and its relationship to health and well-being. There are many definitions of occupation across the OT literature, the definition of the Canadian Association of Occupational Therapists (CAOT) (Law *et al.* 2002) is given below:

"Occupation refers to groups of activities and everyday life, named, organised and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity)". (p. 34).

As shown above, definitions of occupation vary across the occupational therapy literature, but core shared elements of definitions of occupation including personal meaningfulness of the occupation, and the essential nature of occupation, remain constant across definitions

Adults with ID may experience barriers to engagement in meaningful occupation due to barriers within the physical, social, cultural or institutional environment, or personal factors that affect ability to engage in occupation. This means that adults ageing with ID may require additional supports for engagement in occupation.

In this way, the experience of occupation is subjective and individual to each person (Pierce 2003). Occupational therapists believe that people are occupational beings, that engaging in activities that are meaningful to the person promotes health and well-being, and that meaningful occupation is essential for quality of life (Wilcock 2006a). Occupational therapists also maintain that occupation is empowering, and that this experience adds meaning to everyday life (Hasselkus 2002). The aim of OT is to work in collaboration with the person to promote engagement in occupation to promote health, well-being and quality of life (Polatajko *et al.* 2007).

Outside of occupational therapy, this is being increasingly recognised with developments such as the International Classification of Functioning, Disability and Health (ICF). The ICF includes participation as a key determinant of health (World Health Organization 2001). Health promotion, through OT led programmes to promote successful ageing have been proven to be highly successful in the general population of ageing adults (Jackson *et al.* 1998, Lewis 2003). The focus of these programmes include education, empowerment and prevention of age-related difficulties in everyday living as a means of

promoting successful ageing and increased quality of life (Jackson *et al.* 1998).

The occupational science literature emphasises the personal, subjective aspects of engagement in daily life, and the implications that engagement in these occupations has for personal identity, and meaningfulness. It also highlights the role of subjective cultural and institutional environmental factors on engagement in occupation. This data can only be gathered accurately from self-reported data. As the data used in this study is gathered objectively, and used multiple reporting methods including proxy respondents, a modified occupational perspective was required that focused instead on objective aspects of engagement in daily life.

It is important to acknowledge that the perspective taken in this study doesn't constitute true "occupation" as per occupational science literature, but instead should be viewed as one aspect of engagement in occupation- that related to the types of activities that people engage in, and how frequently people engage in these activities.

It is not possible to assess the personal meaningfulness of these activities, or the impact that engagement in these activities can have for a person's identity from the objective data used in the present study. However, it is hoped that the current study could be viewed as a first step towards building a picture of engagement in daily life for adults ageing with intellectual disabilities.

The perspective taken in this study is based on the Person/Environment/Occupation perspective, which is an overarching perspective in occupational therapy. It emphasises that occupational therapists must consider personal, environmental and factors within the occupation itself when working with people to promote participation in daily life (Reed & Nelson Sanderson 1999).

Therefore the current study focuses on the types, and frequency of engagement in daily life activities only as this can be gathered objectively. This should be viewed as one component of occupational engagement, with opportunities to build on this picture in future research possible using mixed methods.

1.1.3 Occupational Justice

Occupational justice is an important overarching concept in the current study. It is an occupational therapy concept that promotes justice, enablement and empowerment so that people can have equality of access to engagement in meaningful occupations (Stadnyk *et al.* 2011). Occupational justice as defined by Wilcock & Hocking (2015) involves:

"the promotion of just socioeconomic and political conditions to increase population and political awareness, resources, and opportunity for people to be, belong and become healthy through engagement in occupations that meet the prerequisites of health and each person's and community's different natures, capacities and needs" (p.404).

Occupational justice advocates for the active engagement of the person in their everyday occupations, and to work in collaboration with

the person and the community to remove barriers to engagement (Bryant *et al.* 2004). It has the potential to inform strategies to promote greater and more meaningful engagement in occupation for adults ageing with ID. Recent social and policy changes, such as the development of international covenants such as the United Nations Convention on the Rights of People with Disabilities (UN CRPD) (UN Enable 2006), and the rise of the rights-based approach to disability services means that the emergence of an occupational justice perspective is timely (Quinn & Bruce 2004). An occupational justice perspective may be useful in order to inform strategies that will facilitate engagement in daily life activities of people with ID in Ireland now and in the future.

In recent years, the occupational justice perspective has been used to highlight occupational injustices affecting marginalised groups in society such as people who are homeless, those experiencing poverty, refugees and those living in crisis situations (Simo-Algado *et al.* 2002, Kronenberg *et al.* 2005). This approach is being increasingly used in other areas of OT practice, such as with people using assistive technology, those with dementia, and in vocational rehabilitation (Arthanat *et al.* 2012, O'Sullivan & Hocking 2013). In this way, occupational justice is highlighting new areas of practice for occupational therapists. Though an occupational justice perspective for people ageing with ID is beginning to emerge, in studies such as Kahlin

et al. (2016) and King *et al.* (2016) a dearth of literature exists on the use of this perspective with people ageing with ID.

Historically, many people with ID were physically secluded from wider society in institutions (McCormack 2004), and afforded little opportunities for meaningful occupational engagement or opportunities for autonomy and self-determination (McDonnell 2007). In this way, people with ID could be said to be occupationally alienated, marginalised and deprived.

As engagement in meaningful occupation is essential for health, good quality of life and well-being, occupational justice would appear to be a useful framework to assist in informing strategies for facilitating people with ID to age well.

1.2 Rationale for current study

As noted above, engagement in meaningful activities is an important determinants of health and well-being (Wilcock 2006a).

Engagement and active participation in daily life is becoming increasingly emphasised through models such as the International Classification of Functioning or ICF (World Health Organization 2001) and models of successful and active ageing (Rowe & Kahn 1997). However, there is a dearth of evidence examining engagement in daily life activities for adults ageing with ID. There is also limited evidence investigating the usefulness of models of successful ageing and

occupational perspectives in supporting adults with ID to engage in daily life. More research is needed in order to inform evidence based strategies to support engagement in daily life activities for people ageing with ID.

In addition, emerging perspectives of occupational justice which advocate for removal of barriers to engagement in daily life herald a number of exciting opportunities for occupational therapists to collaborate with multidisciplinary team members, people with ID and caregivers to support engagement in daily life (Kronenberg *et al.* 2005, Wilcock 2006c).

With a focus on engagement in daily life, a key determinant of health and well-being, and consideration of the personal, environmental and occupational factors this study will bring a unique perspective to engagement in daily life for adults ageing with ID. The modified occupational perspective provides a framework for the exploration of factors influencing engagement in daily life of people ageing with ID in Ireland, and to inform recommendations to enable people ageing with ID to continue to engage in daily life as they grow older.

1.3 Research Aim

The main aim of the study was to investigate the engagement in daily life activities of people ageing with ID in Ireland, and to analyse the key factors that relate to engagement in daily life activities.

This study aimed to investigate the use of an occupational perspective on a secondary dataset and explore the implications for research, policy and practice for people ageing with an ID.

1.4 Main research question

The overall research question is “to what extent are people with intellectual disability engaged in daily life activities in terms of self-care, productivity and leisure activities?” In addition to this broad research question, the study sought to investigate the main factors influencing engagement in daily life activities, including self-care, productivity and leisure activities for people ageing with ID.

1.5 Research Objectives

- To investigate the usefulness of a modified occupational perspective as a guiding perspective to investigate daily life activities of adults ageing with ID.
- To undertake a review of the literature on engagement in daily life activities of adults with ID.
- To identify elements that influence engagement in daily life activities of adults with ID as they age including the role of demographic variables and factors within the person, environment and activity. This will involve the following:
    - Variables related to daily life activities, in terms of self-care, productivity and leisure will be analysed in order to

investigate the levels of engagement in daily life activities of adults currently ageing with ID in Ireland.

- Objectively measurable key indicators of other personal or environmental factors, including physical, cognitive, affective, physical environmental, and social environmental factors, will be examined in relation to self-care, productivity and leisure in order to determine the predictors of engagement in daily life activities of adults ageing with ID in Ireland.
- Demographic factors such as age, gender, level of ID, and living situation will be examined in relation to self-care, productivity, and leisure activities in order to determine the predictors of engagement in daily life activities of adults ageing with ID in Ireland.

1.6 Definition of key terms

1.6.1 Intellectual disability

There are a variety of definitions of intellectual disability in the literature. The classification system used by the National Intellectual Disability Database (NIDD) in Ireland is the International Classification of and Related Health Problems 10th Revision (ICD-10) (Kelly et al. 2016). The ICD 10 (World Health Organization 2016b) classifies intellectual disability as:

"A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition"

In this study, intellectual disability is defined by the American Association of Intellectual and Developmental Disabilities (AAIDD) as "characterised by significant limitation in both intellectual functioning and in adaptive behaviour…originates before the age of 18" ((AAIDD) 2013). The World Health Organization (2016a) definition of ID also acknowledges that "disability depends not only on a child's health conditions...but also and crucially the extent to which environmental factors support the child's full participation and inclusion in society".

1.6.2 Occupation

The guiding definition of occupation in the current study is given by the Canadian Association of Occupational Therapists, as outlined below*:*

*"*Occupation refers to groups of activities and everyday life, named, organised and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity*)".*

(Law et al., 2002 p. 34)

1.6.3 Occupational Therapy

In this study, the CAOT definition of occupational therapy is used.

"Occupational therapy is the art and science of enabling engagement in everyday living, through occupation; of enabling people to perform the occupations that foster health and well-being; and of enabling a just and inclusive society so that all people may participate to their potential in the daily occupations of life".

(Townsend & Polatajko 2007) p. 372

1.7 Thesis Structure

Chapter one introduces the thesis and provides and overview of the study.

Chapter two presents a critical review of the literature examining engagement of adults ageing with ID in self-care, productivity and leisure activities, and identifies important factors that influence engagement in these activities.

Chapter three presents the methodology of the study, including the study design, participant recruitment processes, researcher involvement, ethical considerations and variables included in data analysis based on the modified occupational perspective.

Chapter four presents the main findings of the study conducted on wave 2 of IDS-TILDA data examining factors that influence engagement in self-care, productivity and leisure activities of adults ageing with ID.

The implications of the findings, reflections on the study process, as well as directions for future research, implications for occupational therapists, and policy makers, and limitations of the current study are discussed in **Chapter five.**

Literature Review

2.1 Introduction

This chapter will undertake a review of literature pertaining to current evidence available investigating engagement in daily life activities of adults with ID, focusing on self-care, productivity and leisure activities of adults ageing with ID.

2.1.1 Research Aim

The main aim of the study was to investigate the engagement in daily life activities of people ageing with ID in Ireland, and to analyse the key factors that relate to engagement in daily life activities.

This study aimed to investigate the use of an occupational perspective on a secondary dataset and explore the implications for research, policy and practice for people ageing with an ID.

2.1.2 Main research question

The overall research question is "to what extent are people with intellectual disability engaged in daily life activities in terms of self-care, productivity and leisure activities? In addition to this broad research question, the study sought to investigate the main factors influencing engagement in daily life activities, including self-care, productivity and leisure activities for people ageing with ID.

2.1.3 Research Objectives

- To investigate the usefulness of a modified occupational perspective as a guiding perspective to investigate daily life

activities of adults ageing with ID.

- To undertake a review of the literature on occupational engagement in daily life of adults with ID focusing on engagement in daily life activities (self-care, productivity and leisure).
- To identify elements that influence engagement in daily life activities of adults with ID as they age including the role of demographic variables and factors within the person, environment and activity. This will involve the following:
    - Variables related to daily life activities, in terms of self-care, productivity and leisure will be analysed in order to investigate the levels of engagement in daily life activities of adults currently ageing with ID in Ireland.
    - Objectively measurable key indicators of other personal or environmental factors, including physical, cognitive, affective, physical environmental, and social environmental factors, will be examined in relation to self-care, productivity and leisure in order to determine the predictors of engagement in daily life activities of adults ageing with ID in Ireland.
    - Demographic factors such as age, gender, level of ID, and living situation will be examined in relation to self-care, productivity, and leisure activities in order to determine the predictors of engagement in daily life activities of adults ageing with ID in Ireland.

2.2 Background

In recent years, life expectancy has been increasing in the population of people ageing with intellectual disability (ID) (Janicki *et al.* 1999, McCallion *et al.* 2013), and while this is certainly to be celebrated, increased attention is also needed to inform the provision of services and strategies to support people with ID to continue to be actively engaged in daily life as they grow older.

Intellectual disability is defined by the American Association of Intellectual and Developmental Disabilities (AAIDD) as "characterised by significant limitation in both intellectual functioning and in adaptive behaviour…originates before the age of 18" (AAIDD 2013). The World Health Organisation (World Health Organization 2016a) definition of ID also acknowledges that "disability depends not only on a child's health conditions...but also and crucially the extent to which environmental factors support the child's full participation and inclusion in society". The WHO (2000) identified a number of key areas of importance related to ageing and people with ID, including access to health supports and services, changes required in public attitudes, and other health inequalities that people ageing with ID may experience. Increased attention to issues related to ageing and ID is needed in order to effectively support this growing population to age well.

2.2.1 Ageing from the perspective of people ageing with ID

Understanding the process of ageing from the perspective of people ageing with ID is in line with the person-centred perspective of

occupational therapy, and should assist in understanding the needs of people with ID as they grow older. People ageing with ID themselves have described the process of ageing as a time of changes in health, participation and self-identity, associated with decline in physical health, and an opportunity to develop knowledge and wisdom (Kahlin *et al.* 2013, Kåhlin *et al.* 2015). Maintaining health, relationships, having a home, having opportunities to engage in meaningful activities and having choice and control were all associated with a positive ageing experience by Wark *et al.* (2015a). Similar findings were reported by Haigh *et al.* (2013), who also identified that supportive staff and family were key in supporting well-being as people with ID grow older.

A number of barriers to positive ageing experiences were also identified, including limited service options and lack of meaningful choice based on geographical location, separate funding systems for aged care and disability support services, lack of options for living situations, and structurally enforced retirement from productivity roles as well as lack of transport and finance (Haigh *et al.* 2013, Wark *et al.* 2015a). Staff supporting people with ID who are ageing have described the ageing process in mainly negative terms, relating to physical health decline and need for increased medical care (Kahlin *et al.* 2016).

2.2.2 Active Ageing

Conceptualisations of successful or active ageing provides a strengths-based approach that views people with ID as capable of active

engagement in daily life as they grow older. An occupational justice perspective promotes a viewpoint that considers the person's right to continue to engage in daily life as they grow older, and to work to remove barriers such as negative attitudes regarding the potential of people ageing with ID (O'Sullivan & Hocking 2013, Wilcock & Hocking 2015).

Active ageing has been defined as "a process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age" (World Health Organization 2002) (p.12). The World Health Organization (2000) highlighted a number of issues related to ageing with ID, and areas of focus on policy and practice using an active ageing framework. Areas of focus included promotion of equality of access for health services for older people with ID, opportunities for training for general healthcare staff/services to meet the needs of populations ageing with ID, building supportive communities for ageing in place, and promotion of mental health and women's health issues in particular.

However, Buys *et al.* (2012) and Foster & Boxall (2015) found that people with ID were largely absent from the discourse on active ageing. They identified a number of ways in which this literature would potentially be useful for people ageing with ID.

Some limitations of active ageing have also been acknowledged, including that active ageing places too much emphasis on employment and maintaining employment as a means of promoting continued

quality of life. This may not be relevant for some people with ID, who may not have had the opportunity to engage in paid employment (Foster & Boxall 2015).

2.2.3 Successful ageing

LaPlante (2014) reported that conceptualisations of successful ageing aim to promote positive health behaviours to optimise health across the lifespan. Rowe & Kahn (1997) conceptualised successful ageing as composed of three parts, high physical and cognitive functional capacity, low risk of ill health, and active engagement in life. It promotes the viewpoint that people can continue to engage in daily life as they grow older. This is a viewpoint shared by occupational therapists, who view engagement in meaningful self-care, productivity and leisure activities to be essential for health, well-being and quality of life (Wilcock 2006a). Other factors including social engagement, functional capacity, education, and self-efficacy also influence engagement in later life, according to Rowe & Kahn (1997). Successful ageing has also been criticised for a lack of consideration to spirituality, meaning and identity (Crowther *et al.* 2002).

2.2.4 An occupational perspective

Jonsson (2011) reports that engagement in meaningful occupation was one of the main predictors of positive experiences of retirement and later life for older adults in the general population. Similar findings were reported for people ageing with ID, as exemplified by the findings of Haigh *et al.* (2013), Burke *et al.* (2014), and Iriarte *et al*. (2014), and

who report that engagement in meaningful activities was a key element of positive experiencing of growing older.

Both the perspectives of people with ID, and theories of ageing appear to show how engagement in meaningful daily activities is an important component of positive ageing experiences for people ageing with ID, and in the general population. All of this supports the potential usefulness of an occupational perspective on ageing and ID.

2.3 Occupational engagement and people with intellectual disability

As outlined in chapter one, occupational therapists utilise a broad perspective on occupation, defining "occupation" as activities that are personally meaningful, or form part of a valued social role (Hinojosa *et al.* 2003).

The guiding definition of occupation in this study is the Canadian Association of Occupational Therapists (CAOT) definition of occupation (Law *et al*. 2002), in line with the guiding conceptual model of the study.

"Occupation refers to groups of activities and everyday life, named, organised and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity)" (p. 34).

Occupational engagement refers to the experience of being engaged in a meaningful occupation within a specific context, and the domains of occupation include self-care, productivity and leisure (Polatajko *et al*. 2007). Occupational engagement refers to the person's level of involvement in the occupation, encompassing factors such as identity, intensity, competency of performance (Polatajko *et al.* 2007). It is important to note that the current study explores the degree to which a person in involved in a specific meaningful activity (self-care, productivity and leisure activities) by gathering information about the type and frequency of engagement in a daily life activity, as this data could be gathered objectively. Subjective and personal factors related to implications for identity or sense or competency were not possible to capture in the current study design.

The Occupational Therapy (OT) literature views engagement as a complex and dynamic process where personal, environmental and occupational factors interact to influence engagement in meaningful occupation (Kielhofner 2008). People with ID may experience a variety of barriers to occupational engagement. Channon (2013) reports that an occupational perspective may offer new insights into everyday engagement of adults with ID. A scoping literature review to found low levels of activity generally, and very little literature relating to an occupational perspective utilised with people with ID (Channon 2013). Overall, there appears to be a lack of consensus of what is meant by "engagement" in the current literature. Many studies have highlighted

the critical role that staff play in supporting people to engage in occupation, such as Qian *et al.* (2015), who found that people with ID benefit from staff support to engage in meaningful activities, particularly for those with severe/profound level of ID. Qian *et al.* (2015) investigated engagement levels of 78 people with ID living in community group homes, with 174 direct support staff and 21 supervisors through use of direct observation methods. In their study, engagement was defined as the degree to which a person is actively participating in daily activities or social interactions. They found that people with profound ID were engaged in non-social activities 21% of the observed time, and engaged in social interaction only 3% of the observed time. Individuals with higher levels of adaptive behaviour, who were supported by more competent staff were more likely to have higher levels of social engagement compared to people with lower levels of adaptive behaviour, supported by less competent staff. In another study, Mahoney *et al.* (2016) carried out a qualitative phenomenological study to investigate levels of engagement in day programmes for people with ID. They concluded that the majority of participants required assistance to engage in activities, meaning they were highly dependent on staffing levels and staff availability.

Crowe *et al.* (2015) in an observational study found that people with ID spent about half of a two day period of observation in passive or sedentary activities. Crowe *et al.* (2015) highlighted a number of potential environmental factors that may influence engagement

including availability of staff, physical environment accessibility and community mobility. This study design involved direct observation & recording of passive (e.g. watching television), social/participation (e.g. interactions with family, friends and staff), rest/sleep and active recreation (e.g. sports, attending outings) activities of 15 adults with ID living in community group homes.

Taken together, the studies cited would appear to identify low levels of active engagement in activities related to social interaction and physical activity. It was not possible to identify in those studies whether engagement in self-care, or productivity activities were considered when examining engagement in daily life. The present study therefore seeks to examine a wider perspective on engagement in daily life activities using a modified occupational perspective focusing on self-care, productivity and leisure activities.

Many studies examining the lives of people with ID before and after moving from large congregated settings to community-based living situations have reported improvements in quality of life, but stated that relocation to community living did not always result in increased engagement in daily activities, often influenced by staff or other resources and sources of support (Cooper & Picton 2000, Bigby 2005). Cooper & Picton (2000) completed a comparative pre and post deinstitutionalisation (transition from congregated setting to community-based supports) study of 45 people with ID and also found that people with ID did not engage to a greater extent in independent

community living skills, and self-care activities including ADLs (activities of daily living) and IADLs (instrumental activities of daily living) following transition to community living, although the new environment of smaller community residential units was hypothesised to be a facilitator to completion of such ADL and IADL activities. ADLs refer to personal care tasks, while IADLs include more complex activities that are needed in order to look after oneself (Lawton & Brody 1969, Law *et al.* 2002).

It is important to consider engagement in daily life as the environment of the person changes. Emerson & Hatton (1994), for example, reported on data gathered from 26 direct observational studies of levels of engagement for people with ID in the United Kingdom. Categories of engagement in this study were defined differently to the definition of engagement in the current study, to include performance of non-social activities such as leisure activities, ADLs, IADLs, engagement in formal programmes, and social interactions. Other activities not classified as engagement included passive, non-purposeful activities, smoking or inappropriate behaviour (Emerson & Hatton, 1994). Emerson & Hatton (1994) found that the extent of engagement in activities varied greatly within different living situations. It was found that those living in traditional congregated settings experienced significantly lower levels of engagement in activities when compared to community based houses. These findings would appear to show how the physical, social and institutional environment can

influence engagement in daily life. There are similar results by King *et al.* (2016), which suggest that performance of all ADLs and IADLs was strongly related to type of living situation for those living independently/with family, in community group homes and in residential settings.

Together, these studies appear to show that broader factors within the physical, social and institutional environment in which the person lives play an important role in supporting or hindering engagement in daily life. The current study seeks to identify factors that influence engagement in self-care, productivity and leisure activities within the person, and the physical and social environment.

There appears to be a dearth of evidence related to engagement in daily life activities utilising an occupational perspective. Articles offering current available evidence for people with ID vary greatly in definitions of engagement and study design (e.g. Emerson & Hatton 1994, (Emerson & Hatton 1994, Qian *et al.* 2015, Mahoney *et al.* 2016). Current studies mainly focus on performance of various activities in isolation. An occupational perspective, such as the modified perspective taken in this study, considers personal factors, environmental factors and factors within the activity itself together, in order to examine engagement in daily life for adults ageing with ID. The current study examines one aspect of occupational engagement-related to the type and frequency of engagement in activities, with personal and environmental factors considered where they can be

objectively measured in accordance with the study design. As meaningful engagement provides a number of benefits for health, well-being, and quality of life (Wilcock 2006a), more information is needed regarding engagement in specific meaningful occupations such as self-care, productivity and leisure occupations.

The available evidence also highlights the important role of support staff in facilitating meaningful occupation with people with ID, particularly for those with severe or profound ID who may require greater assistance to initiate, sustain and maintain meaningful engagement in daily life. A number of studies report low levels of engagement in activities, with a milieu of studies reporting higher levels of engagement in passive occupations or non-purposeful activities (e.g. (Emerson & Hatton 1994, Crowe *et al.* 2015). However, further investigation is needed into other factors that influence engagement in meaningful occupation within the person, environment or occupation in order to gain a broader understanding of occupational engagement of people ageing with ID. Other studies appear to show that although changing environment may be facilitative of engagement, if appropriate supports are not in place, then gains in engagement may not follow. It is clear that support staff and carers play a critical role in promoting occupational engagement of people with ID as they age (Bigby & Fyffe 2006).

2.4 Self-Care

Self-care occupations encompass important everyday activities essential for maintenance of health and well-being. Self-care activities include all activities involved in personal care, dressing, bathing, hygiene, functional mobility, transfers indoors and outdoors and community management, transportation, shopping and finances (Law *et al.* 2002). Activities of daily living (ADL) and Instrumental Activities of Daily Living (IADL) are terms often used to describe self-care activities. ADLs include the basic activities involved in looking after oneself, such as washing, dressing, toileting, feeding, drinking, taking medication and mobilising. IADLs are more complex tasks that are also essential for self-care, including grocery shopping, meal preparation, management of finances, use of telephone, and domestic tasks (Lawton & Brody 1969). Consideration of self-care activities is important as they form an essential aspect of daily life and attention to both ADLs and IADLs is required, as both are important components of self-care activities (Hilgenkamp *et al.* 2011).

2.4.1 Engagement in self-care activities

Hallgren & Kottorp (2005) maintain that facilitating people with ID to perform ADLs with greater independence is a means of promoting greater participation in daily life, an important predictor of health and well-being. Kottorp *et al.* (2003) report that promoting independence in completion of ADL tasks can also promote autonomy for people with

ID, and that ADLs offer an arena in which to promote empowerment, and self-determination in daily life.

Level of ID, age, and mobility have been shown to be significant predictors of performance of self-care activities for adults with ID (Henderson *et al.* 2009, Hilgenkamp *et al.* 2011). Mobility and level of ID were found to be important predictors of ADL and IADL performance by Hilgenkamp *et al.* (2011). In their study, level of ID was more influential on ADL performance, and mobility was found to be more influential on IADL ability in a cross-sectional study of 989 adults aged 50 years and older with ID using the Barthel Index and Lawton IADL scale (Hilgenkamp *et al.* 2011). Henderson *et al.* (2009) also found that level of ID was a significant predictor of performance of ADLs in a cohort study of 1,371 adults ageing with ID using a proxy-completed Rochester Health Status Survey.

Belva & Matson (2013) found that many people with profound ID needed maximum support for IADLs in their study of 202 residents of residential settings in the USA, and that people with profound ID performed better in ADLs when compared to IADLs. Kottorp *et al.* (2003) had more mixed results, concluding that overall, people with moderate ID had greater difficulty with ADL performance, but that in some aspects of ADL performance (such as co-ordination, calibration, endurance and manipulation of objects) they performed equally as well as adults with mild ID in their study of 348 adults with mild and moderate ID. Similarly, Lifshitz *et al.* (2008) concluded that level of ID

was the main predictor of ADL performance in their study of 202 people with ID living in community and in residential centres. This study included people with mild, moderate, and severe levels of ID, and no significant association was found between factors such as place of residence, age, health status or gender and ADL performance. This is further reflected in the findings of Umb-Carlsson & Sonnander (2006), who found that level of ID was a more significant predictor of living conditions than gender.

Overall, level of ID consistently appears as a predictor of engagement in self-care activities in the literature, but the extent of influence appears to vary across the literature.

Presence of impairments resulting from illness has also been cited as a possible predictor of reduced ADL and IADL performance by Henderson *et al.* (2009), who found that as health issues increase for people ageing with ID, ADL ability declines. In contrast, Lifshitz *et al.* (2008) conclude that health status of adults ageing with ID is not associated with decreased ADL and IADL performance, but that level of ID was associated with ADL and IADL performance.

In the general ageing population, some ADLs were found to be predictors of self-rated physical health (Gama *et al*. 2000). Ability to mobilise around the home and transfers were strongly associated with positive self-rated health. Ability to mobilise around the community was also found to be an important predictor of ADL and IADL performance in the general ageing population (Gama *et al*. 2000).

Results from the Irish Longitudinal Study on Ageing in the general ageing population (TILDA) show that performance in ADLs and IADL decreases with age. In this study, significant decreases in ADL and IADL ability were found in those aged over 80 years (Nolan *et al.* 2014).

There appears to be different factors influencing ADL and IADL performance between people with ID and people in the general population. Level of ID appears to be the strongest predictor of engagement in self-care activities in populations of people with ID, whereas age, quality of physical health, and ability to mobilise around the home and community appears to be the main predictor of ADL and IADL performance of the general ageing population (Henderson *et al.* 2009, Hilgenkamp *et al.* 2011, Nolan *et al.* 2014).

The findings of these studies show that a multitude of factors may facilitate engagement in self-care activities across the general ageing population and those ageing with ID. These studies examine performance levels of ADLs and IADLs only, and some haven't included people with profound level of ID, and don't include a broader consideration of occupational engagement with influencing factors beyond the person, such as the physical, social, and institutional environment. An occupational perspective may offer a more rounded insight into factors affecting engagement in self-care activities. More information is needed regarding what factors are most influential on engagement in self-care activities in order to identify strategies to promote greater engagement in these activities. Consideration of

barriers and enablers within the environment to inform supports required to complete these tasks, as in the current study, may provide a broader insight into the engagement of adults with ID in self-care activities. The literature shows that greater attention to supports and training of support staff and carers for people with ID is needed to optimise engagement in self-care activities.

2.5 Productivity

From an occupational perspective, productivity encompasses any meaningful productive role that contributes to the community or society. Engagement in occupations related to productivity has positive implications for self-esteem, sense of purpose, identity and autonomy through active contribution to the community and sense of belonging. Productivity activities can vary greatly from paid employment, unpaid work and social roles such as parent, friend or volunteer (Law *et al.* 2002). This review will focus on the areas of supported employment, sheltered workshops and day service provision, as well as retirement as these areas relate strongly to people with intellectual disability. Although traditional day services would not usually be considered in the same domain as employment, McGlinchey *et al.* (2013) found that people with ID perceived themselves to be employed when attending a day service. It was also stated that those in perceived employment reported similar benefits for health and well-being as those in paid employment. It may be that people attending day services had roles within these day services that contribute to the running of activities,

assisting with domestic tasks or mealtimes or other roles that contribute to the community within the day service.

Productivity roles and retirement options may differ for people with ID compared with those in the general population. Many people with ID have attended day services or other programs rather than competitive employment for most of their lives (Bigby 2005). Opportunities for engagement in productivity roles are varied, but in Ireland, traditional models of day service remain the most commonly utilised services relating to productivity for people with ID (Doyle & Carew 2016). Day services have been shown to provide important opportunities for forming and maintaining relationships and engagement in activity by Campbell (2012), although around half of respondents indicated that models of day service delivery were in need of review. Consideration of the wishes of people with ID, and those who support them is essential so that the quality of these services can be enhanced to incorporate greater focus on meaningfulness of activities, and community inclusion (Campbell 2012).

Much has been written about the potential benefits of employment for people with ID, including reduction in poverty, greater social and community integration, and opportunities for meaningful engagement (Lysaght 2010). Alternative models such as supported employment are also coming to the fore, and are being implemented successfully (Suibhne & Finnerty 2014). Current policies promoting inclusion, and community integration of people with ID would appear to support

schemes such as supported employment over traditional day services or segregated sheltered workshops (e.g. New Directions (Health Service Executive 2012), Time to Move on from Congregated Settings (Health Service Executive 2011). Eggleton *et al.* (1999) report additional benefits of employment of people with ID to include increased autonomy, competency, self-esteem, sense of purpose, skills, well-being and financial benefit. The literature also appears to show that supported employment has a number of benefits over day services or sheltered workshops in the areas of autonomy, quality of life and financial matters. In some countries, more formal programmes for engagement in meaningful activities for people with ID as they grow older are emerging, including development of specialised day services with a focus on meeting the changing needs of people with ID as they age for people with ID post-retirement (Bigby *et al.* 2004, Stancliffe *et al.* 2015).

The range of employment options for people with ID in Ireland has also expanded in recent years (Health Service Executive 2012). Please see Appendix 1 for summary table of productivity roles for people with ID in Ireland.

2.5.1 Day Services

The majority of people ageing with ID in Ireland attend day service programmes (Doyle & Carew 2016). Hartnett *et al.* (2008) reported that priorities for staff and parents included social interaction, choice, development of skills and happiness in provision of day services in their

small mixed methods study on quality of life of four people with severe ID moving to a community-based day service from traditional congregated setting day-service.

Recent studies have examined the content and quality of day service programmes, and have found that drinking coffee and tea was the most frequently occurring common activity across day centres, with some day centres also facilitating physically oriented, artistic and creative activities (Vlaskamp *et al.* 2007b). A study examining content of activities for 33 people with severe or profound level of ID attending day services in the Netherlands, found that the average individual activity time was 25 minutes over a period of seven hours, with most time focussed on personal care (Hiemstra *et al.* 2007). These conclusions support previous findings of low levels of engagement in activities for people with ID who attend day services (Channon 2013).

It is recognised that people with severe/profound level of ID will likely require assistance to engage in a range of activities, and productivity roles. Staff in Vlaskamp *et al*. (2007a) reported in order to better facilitate meaningful activities with people with ID they would benefit from increased knowledge of the person's functional abilities (Vlaskamp *et al.* 2007a). Staff working with people with severe/profound level of ID may benefit from more training on supporting facilitation of meaningful activities and engagement in meaningful productivity roles for people with ID. An occupational perspective may be useful to highlight factors within the environment,

occupation or the person that promote meaningful engagement with people with profound level of intellectual ID.

2.5.2 Sheltered Workshops

Much debate has taken place with regards to the suitability of sheltered workshops for people with ID. In Ireland, The New Directions (Health Service Executive 2012) report, states that 5,614 adults with disabilities are attending sheltered workshop programmes in Ireland, which represents 22% of the total 25,302 service users attending formal programmes to support productivity in Ireland.

More detail regarding the personal and environmental factors surrounding engagement in productivity occupations is needed in order to ensure best possible outcomes for provision of opportunities for engagement in productivity activities for people ageing with ID.

2.5.3 Supported employment

Supported employment has been growing as a means of enabling people with ID to gain competitive employment and engage in productivity roles in Ireland. This has resulted in an increase in employers offering supported employment from 238 to 429 employers, 78 extra jobs and 2165 jobs shadows between 2008 and 2014 (Suibhne & Finnerty 2014). Jobs shadows are part of the supported employment process, and involve a person being shown how to do a particular job by a current employee (Suibhne & Finnerty 2014). Recent research has shown a number of benefits of supported employment for people with

ID including increased quality of life (Jahoda *et al.* 2008). Many policies are promoting supported employment as a means of fostering social inclusion and community integration of people with ID. In a case control design of 50 matched pairs of people with ID to investigate the impact of employment on quality of life for people with ID, participants with ID who engaged in supported employment reported significantly higher quality of life scores compared to those attending sheltered workshops, and those who remained at home (Eggleton *et al.* 1999). This may be related to the benefits for health and well-being that engagement in productivity roles can bring. Engagement in supported employment was found by Cimera (2011) to be preferential in terms of financial benefits and community participation for people with ID. Cimera (2011) completed a large comparative study of 9808 participants that examined competitive employment outcomes following attendance at sheltered workshops versus supported employment programmes. The study involved 4904 people with ID preparing to enter supported employment who had previously attended sheltered workshops, and 4904 people with ID who had not previously attended sheltered workshops, who were then matched on primary diagnosis and gender. No differences were found between rates of employment. This study showed that people who had previously been attending sheltered workshops worked less hours, and earned less wages, and that sheltered workshops were more costly to run than supported employment programmes.

Dague (2012) found that people reported a fear of the unknown when faced with transition to community-based supported employment, and that sheltered workshops provided consistency and safety. Those in community-based supported employment reported increased job satisfaction, skills and interests. Dague's (2012) qualitative study explored the perspectives of 12 people with ID and family members of people with ID with regards to community-based supported employment or traditional sheltered workshops through semi-structured interview, observation and archival review. These perspectives were gathered from 5 people currently working in a sheltered workshop, 4 people currently working in community-based supported employment, and 3 family members of people with ID. This small qualitative study may not be generalizable to a wider population due to small sample size, but it does raise the important point that although transition from sheltered workshops to community-based supported employment can be a daunting experience, it can also be highly rewarding for people with ID (Dague 2012).

Jahoda *et al.* (2008) found that those in supported employment consistently reported higher quality of life than those attending sheltered workshops, or those who are unemployed in their review of case-control studies of people with ID in supported employment.

Supported employment has also been reported as a means of growing social networks but no significant difference was found for social belonging or community integration (Jahoda *et al.* 2008). For example,

Forrester-Jones *et al.* (2004) mapped the social networks of 20 people with ID before and after entering supported employment. This small study found that the size of people's social networks increased significantly after entering supported employment, which had positive implications for quality of life. It appears that supported employment may offer important opportunities for engagement in productivity roles for people with ID, with associated benefits for quality of life.

However, careful consideration should be given to the supports required in order to promote best possible outcomes for employee and employer. Flores *et al.* (2011) completed a cross sectional study with 507 participants using semi-structured interviews to investigate quality of working life for people with ID who are currently in supported employment, and found that increased job demands and limited resources can negatively influence quality of working life for people with ID. Jahoda *et al.* (2008) also highlighted that work can be stressful at times. Job demands and the impact of resources should be considered in facilitating appropriate supports in order to maintain job satisfaction and quality of working life for people with ID engaged in supported employment. Butterworth *et al.* (2012) in their small study of 33 employment specialists also recommended training for employment specialists as a means of improving supported employment outcomes for people with ID.

While much has been written regarding the benefits of supported employment for people with ID from service provider and employer

perspectives, it is important to consider the perspective of the person with ID themselves. Migliore *et al.* (2007) gathered the perspectives of 617 people with ID, their families and support staff with regards to preferences for sheltered workshop or supported employment. They found that people with ID preferred supported employment. Family members and staff supporting people with ID also reported preference for supported employment. Factors associated with positive views of supported employment included previous paid work experience within the community, and younger age. The majority of people with ID, their families and staff were optimistic that people with ID could perform and succeed in community employment with support.

Many of the studies examining supported employment of people with ID to date have focused on personal factors that influence employment and may not have given due consideration to broader environmental factors which may support or hinder supported employment opportunities and outcomes for people with ID (Jahoda *et al.* 2008). However, Ellenkamp *et al.* (2016) examined work environmental factors that influence likelihood of attaining and maintaining supported employment for people with ID and reported that supports such as careful job matching, training and self-advocacy were important factors to ensure successful supported employment in a systematic review.

Supported employment has been demonstrated to have positive impact on quality of life, autonomy and community integration (Lysaght 2010). The evidence appears to show that supported

employment can be a successful means of enabling people with ID to engage in community-based employment, and engaging in productivity roles within the wider community. However, as found with self-care activities, planning and appropriate supports are required to ensure the success of supported employment, particularly as people with ID transition from segregated services to community-based supported employment.

Research on engagement of people with ID in productivity roles such as supported employment and day services may also require a greater focus on environmental factors that influence opportunities to engage in these productivity roles.

2.5.4 Retirement

Retirement represents a major occupational transition, bringing significant changes to autonomy in daily routines, opportunities for engagement in leisure and social interaction (Jonsson *et al.* 2000). For many in the general population, retirement represents a time of change in productivity roles, where the role of worker or employee changes, and people may take on more informal roles related to productivity such as volunteer, carer, member of local community organisations to name a few (Cole 2011, Jonsson 2011). Just as with the general population, retirement can present challenges as people with ID transition from previously valued productive roles related to working life (Cole 2011, Burke *et al.* 2014). The New Directions (Health Service

Executive 2012) report found that greater consideration was needed in terms of service planning to changing needs of people with ID as they age, particularly when they reach 65 years and older. Some challenges to continued participation in day programmes included transport costs, financial issues, decreased staffing levels, ageing carers, mobility difficulties and greater need for medical care (Bigby *et al.* 2004, McDermott & Edwards 2012).

As people with ID grow older, they may retire from supported employment, sheltered workshops or day services. There are also growing numbers of people who are choosing not to retire, and it is important that those who wish to continue working are supported to do so, both in ID and general ageing populations (Evans *et al.* 2008).

In a sample of 76 people with ID and service providers the majority of people with ID reported they did not wish to retire as work (sheltered workshop or day services) provided meaningful social and engagement opportunities (McDermott & Edwards 2012). People ageing with ID believe they can actively engage in meaningful activities as they grow older (Burke *et al.* 2014), which should be considered, as well as personal, occupational and environmental factors, in service planning for adults ageing with ID.

Bigby *et al.* (2004) reported that concerns were highlighted by people with ID about potential loss of income, social contact and status associated with employment when they were faced with retirement. Many people also report a lack of choice regarding retirement

(McDermott & Edwards 2012). People with ID were found to continue to value active engagement and participation in employment or day programmes. Many of these people reported that retirement from employment or day programmes was a time associated with lack of meaningful engagement (McDermott & Edwards 2012). Alternatively, this could be viewed as disengagement from a previously valued productivity role as people with ID reach retirement age. Given the benefits of meaningful occupational engagement for sense of identity, purpose, self-esteem and well-being (Wilcock 2006b), adaptations to existing programmes through greater flexibility, re-structuring of the tasks and environment would be useful in facilitating opportunities for engagement in productivity roles (Bigby *et al.* 2004).

More options for retirement and specialist aged services for people with ID are becoming available. In countries such as Australia, specialist services for ageing people with ID are emerging. Bigby (2005) reviewed 7 specialist services for people ageing with ID in Australia. These programmes were designed specifically to meet the changing needs of adults with ID as they grow older. Key programme areas included choice, supporting social networks, supporting participation, self-expression, and choice and health. It is interesting to note that Bigby (2005) found there was limited focus on healthy ageing and skills in these specialised programmes.

Lysaght (2010) highlighted that there is no single way to ensure meaningful productive roles for people with ID, and that diverse and

creative opportunities should be facilitated to ensure individualised meaningful engagement in productivity activities for people with ID throughout their lives. This is particularly relevant as people with ID grow older, and may require alternative options for engagement in meaningful productive roles. Careful consideration should also be given to the tasks and activities involved in engagement in each productivity role, and how these can be adapted to best meet the needs of people with ID as they age. More information is needed on specific factors influencing engagement in productivity roles, so that supports can be optimised to promote continued engagement in productivity activities throughout life.

2.6 Leisure

2.6.1 Definition

Leisure is diverse, including personal and social activities that are freely chosen, are personally fulfilling, contribute to self-expression or identity, and are enjoyable (Fullagar & Owler 1998, Rogers *et al.* 1998, Badia *et al.* 2013a, Badia *et al.* 2013b). Major occupational transitions such as retirement, loss of income, bereavement, and caregiving roles can both positively and negatively influence opportunities for leisure engagement in older adults in both the population ageing with ID and within the general populations (McIntyre & Bryant 2005).

Leisure is an important domain of occupation for people with ID as it provides opportunities for enjoyment, social interaction, personal

meaning, and fulfilment (Reynolds 2002). Positive outcomes of meaningful leisure engagement can include increased self-esteem, social interaction, skill development and promotion of positive public perception (Beart *et al.* 2001). Badia *et al.* (2013a) also maintained that leisure engagement is an important means of facilitating enhanced community participation. Dusseljee *et al.* (2011) have also highlighted the importance of leisure engagement within the community as a means of enhancing social interaction.

Leisure is becoming increasingly recognised as an important predictor of quality of life, a major outcome area for service provision for people with ID (Felce *et al.* 2011, Badia *et al.* 2013a). Similar results were reported by Rogers *et al.* (1998) and Badia *et al.* (2013b), who found that older adults with ID who have greater levels of engagement in their preferred leisure activities have higher levels of satisfaction with life. Consideration of leisure becomes increasingly important as adults with ID approach retirement and when investigating suitable options for engagement in meaningful productive and leisure activities as people with ID grow older (Rogers *et al.* 1998, Cole 2011).

2.6.2 Leisure Engagement

A number of studies report that levels of engagement in leisure activities are lower in people with ID than in the general population (Duvdevany 2002). Zijlstra & Vlaskamp (2005a) highlighted low levels of engagement in leisure activities for 164 people with profound ID they

studied, especially at weekends. They also found high numbers of passive leisure activities such as watching television.

Badia *et al.* (2013a) surveyed 237 adults with mild and moderate level of ID, aged between 17 and 65 years to capture their current participation and preferences in leisure activities using the Leisure Assessment Inventory (LAI). They found that people with ID engaged mostly in social activities such as hanging out with friends, celebrations, shopping, eating out, travelling, dancing, outings, religious activities and visiting museums. In terms of leisure activities completed at home people primarily engaged in watching television, resting, listening to music, speaking on the telephone, playing board games, singing, and painting. Low levels of physical leisure activities such as walking, cycling, and sports were reported by Badia *et al.* (2013b). Similar results were found in the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) data, with the majority of respondents indicating they engaged in low levels of physical activity (McCarron *et al.* 2014). Reynolds (2002) gathered information from surveys of 34 community group homes to explore current leisure engagement of adults with ID. The main available creative leisure pursuits included music, art, dance, needlecraft, and to some extent, drama. Reynolds (2002) found that people with ID mostly accessed creative leisure activities within segregated ID settings rather than utilising community resources. It is difficult to gauge from these

studies how frequently these activities were facilitated for people with ID.

Neumayer & Bleasdale (1996) in semi-structured interviews with 30 people with mild and moderate level of ID aged between 20 and 73 years found that people with ID reported helping others in the community, music, television, knitting, dance, computers, sports and driving as their preferred leisure activities in semi-structured interviews. Similar to Reynolds (2002), broader factors within the environment relating to engagement in these activities were not explored. Future studies would benefit greatly from consideration of environmental and personal factors, in order to better capture engagement in leisure activities for adults with ID of all abilities.

It is important to note that overall, there appears to be a dearth of evidence investigating the leisure pursuits of people with severe and profound level of ID. Lack of support for staff or lack of training for staff can have a major impact on facilitation of meaningful leisure activities for people with ID. Zijlstra & Vlaskamp (2005a) investigated facilitation of leisure activities focusing on 164 people with profound level of ID living in residential facilities. It was found that people with profound level of ID spent just 3.8 hours on in leisure activities on average per weekend. Most of these activities were passive, such as watching television, and mostly took place within residential centres. The need for training that focuses on personalising and adapting factors within the environment or the activity itself to enable people ageing with ID to

engage in leisure activities that are personally meaningful was highlighted (Zijlstra & Vlaskamp 2005b).

Given the potential of meaningful leisure engagement to promote quality of life and well-being, greater attention should be given to the engagement in leisure activities, leisure preferences and pursuits of people with severe/profound level of ID of all ages. As with self-care and productivity activities, a broader consideration of environmental and occupational factors are essential in order to facilitate meaningful leisure activities with people ageing with ID.

2.6.3 Factors influencing leisure engagement

A wide variety of factors can impact engagement in leisure activities. Gender, age, type of residence, and attendance at a mainstream school can influence the types of leisure activities that people with ID engage in (Badia *et al.* 2013a). Gender was also found to be an important predictor of leisure engagement by Dusseljee *et al.* (2011) who found that males had a greater variety of leisure activities. Type of residence was also found to be a predictor of leisure engagement by Felce *et al.* (2011), who investigated the leisure activities of adults with ID living at home with family. Highest levels of engagement were reported by those living at home, followed by those living in supported accommodation. Emerson (2004) completed a large deinstitutionalisation study across 10 residential service sites in the United Kingdom, and found that those living in cluster-style housing were more restricted in leisure activities than people living in dispersed

housing. The factors influencing leisure engagement were not further investigated, but participants in this study who were living in cluster housing were also reported to lead more sedentary, restricted lifestyles, with less support staff.

A number of studies have also found that age is an important factor affecting engagement in leisure. Older participants expressed less desire to try new leisure activities compared to the younger participants in focus groups conducted by Beart *et al.* (2001). Dusseljee *et al.* (2011) investigated community participation of adults with ID in the Netherlands. They reported that those aged over 50 years had fewer daytime activities, and decreased social contacts with informal supports. Zijlstra & Vlaskamp (2005a) also found reduced facilitation and engagement of people with profound level of ID living in residential facilities as they grow older. Consideration of the changing requirements of people as they grow older is needed, as well as a change of focus from general group activities to personalised, meaningful activities.

More subtle factors within the social, cultural and institutional environment may impact on opportunities for engagement in meaningful leisure activities. In a smaller qualitative study, Rogers *et al.* (1998) completed unstructured interviews with 29 older adults with ID to gather their perspectives on the nature of leisure with age, and perceived barriers and enablers to accessing meaningful leisure opportunities. Participants in this study reported that selection of

leisure activities was controlled by service providers, were often passive in nature and often did not reflect individual interests or wishes of participants. Similarly, Rossow-Kimball & Goodwin (2009) found that levels of self-determination and leisure engagement were highly influenced by support staff and organisational structure in qualitative ethnographic case studies to examine leisure and self-determination of 5 women with ID living in community group homes.

People with ID can face a number of barriers to engagement in meaningful leisure activities. As with the findings of Rossow-Kimball & Goodwin (2009), this may be indicative of institutional factors that aren't attuned to what is personally meaningful for the people engaging in this service. Beart *et al.* (2001) identified lack of support, lack of availability of transport and to a lesser extent money as the main perceived barriers to meaningful leisure engagement in their study gathering the perspectives of 29 people with ID. Rogers *et al.* (1998) also report staffing restrictions and limited availability of transport to be the main barriers to accessing meaningful leisure opportunities. Participants in this study also reported that family also played a role in controlling leisure opportunities for participants living at home.

The literature illustrates that leisure is a vitally important aspect of occupational engagement, adding greatly to quality of life (McColl 2010). However, it has traditionally been given less attention in service provision than development of daily living skills. The literature shows

that meaningful leisure engagement can offer a springboard for greater social interaction, community integration, self-determination, self-expression and growth. However, it would appear that adults ageing with ID are at an increased risk of preclusion from engagement in meaningful leisure activities. Services should prioritise removal of barriers to meaningful, individualised leisure engagement such as limitations in staff resources, time and availability of transport in order to optimise quality of life for adults ageing with ID. Greater attention to environmental and occupational factors influencing engagement in these activities may serve to facilitate increased opportunities for engagement in leisure activities for people growing older with ID. Greater focus on adaptation of the occupation or environment can promote engagement as people grow and develop across the lifespan. In addition, increased focus on person-centredness and the meaningfulness of the leisure activity for the person is essential in order for the person to benefit from the well-being associated with engagement in leisure occupations.

2.7 Strategies to increase engagement in self-care, productivity and leisure activities

A variety of factors that influence engagement in self-care, productivity and leisure activities have been identified from the literature, including level of ID, age and institutional or environmental factors. However, overall, little focus has been paid to how environmental factors and factors within the person or activity itself can be considered to

promote engagement in daily life activities for people ageing with an intellectual disability.

2.7.1 Ageing in place

In the literature, there appears to be a dearth of research investigating the influence of environmental factors and how these factors can support or hinder engagement in daily life. This is interesting given recent emphasis on ageing in place for adults in the general population as a means of enabling adults to age well, and continue to be actively engaged in daily life. Bigby (2008) defines ageing in place as the facilitation of the person to remain in their chosen living situation for as long as possible. McCallion (2014) asserts that communities should become more aware of and promote opportunities to facilitate ageing in place. Provision of healthcare and other supports within the wider community aligns with policies such as New Directions (Health Service Executive 2012) and "Time to Move On" (Health Service Executive 2011), promoting community integration of people with ID.

In the general population, McCallion (2014) reports that people may experience a variety of barriers to ageing in place, including changes in family structure, household structure and caregiving responsibilities. Factors such as emigration and economic factors may also affect the person's ability to age in place (McCallion 2014). Campbell & Herge (2000) outlined challenges that people with ID may face with regards to ageing in place, particularly given the tendency for some people with ID to experience age-associated conditions, such as dementia, earlier

than in the general population (Janicki & Dalton 2000). Campbell & Herge (2000) outlined how families who support people with ID to live at home may face increasing challenges as parents/caregivers themselves grow older.

Policies such as those found in the "Time to Move On" (Health Service Executive 2011) report are particularly interesting, given previous findings which have highlighted how changing ageing demographics, with increased number of older people both in the general population, and those ageing with ID will increase need for residential supports (Kelly & McConkey 2012). People with ID may end up living in unsuitable settings due to lack of options (Bigby 2008, Kelly & McConkey 2012). From an occupational justice perspective, this could be viewed as occupational alienation, which involves preclusion of engagement in occupation through lack of options (Durocher et al. 2013a).

In the general ageing population, a variety of options are growing to support people to age in place, such as independent living, multigenerational households, naturally occurring retirement communities (NORC), age-integrated multifamily housing, assisted living, retirement communities, and shared housing intermediate care or transitional care settings, which have been shown to reduce incidence of admission to long-term residential care settings (Parsons *et al.* 2012, McCallion 2014). In recent years, increased attention has been drawn to creation of age-friendly environments, and Ireland is no

exception. Age-friendly Ireland has been involved in research to develop guidelines for provision of environments that can support older people to age in place (Age Friendly Ireland 2015). However, consideration of the needs of people ageing with ID are required in order to promote these policies for a truly inclusive society that facilitates accessibility and promotes the abilities of all people to actively engage in daily life. Age-friendly projects incorporate strategies on preparing the wider community for an ageing population (Age Friendly Ireland 2015), and this approach could be utilised for people ageing with ID.

In the general ageing population, Chippendale & Bear-Lehman (2010) have illuminated the importance of physical home adaptation to support the changing needs to support people to continue to live in their preferred home environment as they grow older. Campbell & Herge (2000) describe how therapists such as occupational therapists and physiotherapists, can assess the person's current abilities and areas of need, and work on building skills with the person, their caregivers and modifying the environment to support greater engagement and integration within the community and ageing in place.

Jokinen *et al*. (2013) provided guidelines on structuring community-based supports for people with ID and dementia. These included use of a person-centred approach focused on strengths and abilities, utilising social supports, proactive and early planning, providing training and knowledge for staff, and facilitation of safe environments that offer

opportunities for meaningful engagement in daily life. There is great potential for principles of Universal Design to be implemented when planning creation of physical environments within home and community, both for people with ID, and those in the general population. Universal design is a way of creating environments to be as accessible as possible for as many people as possible, focusing on equity of use, simplicity and intuitiveness, flexibility and minimisation of risk (Joines 2009). In addition, assistive technologies have been used with people with disabilities to support engagement in meaningful occupations (Arthanat *et al.* 2012). There is great potential for "smart" and other assistive technologies may be useful for people ageing with ID in order to support continued engagement in daily life, and ageing in place.

Throughout the literature, planning for ageing early in order to ensure preparedness and minimise difficulties to ageing in place is emphasised as a key facilitator of ageing in place, both in the general ageing population, and for those ageing with ID. Kahlin *et al*. (2016) advocated the use of an occupational justice approach to support engagement in daily life for people with ID across the lifespan, with appropriate planning for ageing supports to enable people with ID to engage in daily life as they grow older. Hogg *et al*. (2001) also promoted early planning as a means of improving best possible outcomes in ageing for people with ID.

The literature shows how proactive planning, and the creation of physical environments that can support people to engage in self-care, productivity and leisure activities as they age are essential.

2.7.2 Active Support and staff training

The current literature shows that support from family and staff has a critical role in supporting people with ID to engage in daily activities, particularly leisure activities. Jones *et al*. (1999), Mansell *et al*. (2002), and Renblad (2002) reported that informal carers such as family or formal supports such as paid support staff often play a vital role in facilitating people with ID to perform daily activities. Staff or other sources of social support such as family, friends and advocates can also promote empowerment, autonomy and choice in daily lives of people with ID. Several studies have highlighted that training and education is required for staff to be able to support people with ID to engage in self-care, productivity and leisure activities that are personally meaningful (Vlaskamp *et al.* 2007a). This training would benefit from an occupational perspective, and focus on development of strategies for support staff to increase attention to factors such as the person's motivation to engage in the occupation, adaptations to the broader physical or social environment, or to the occupation itself in order to build opportunities for engagement in meaningful occupation.

Active Support is one strategy that has showed promising results for enabling greater independence in people with ID in daily activities (Totsika *et al.* 2010). Active Support is a staff facilitated intervention

that involves creation of an individualised activities schedule for people with ID and advice on grading assistance to support optimal engagement in activities (Graham *et al.* 2013). The individualised focus of Active Support means that the level of meaning of the activity can be considered, and it can be adapted to the needs and preferences of the person, in line with an occupational perspective. Jones *et al*. (1999) completed a randomised controlled trial of Active Support for 19 people with ID living in 5 community group homes. They found that participants spent more time engaged in activity, social engagement in domestic activities increased, and it was an efficient use of staff time. Similar findings were reported by Bradshaw *et al*. (2004) who found that Active Support resulted in increased service user engagement in activities in their study of 3 community group homes involving 12 service users with severe level of ID with data collected from proxy reports. Positive reports have also been gathered from service users, family, and staff who are involved in implementing and utilising Active Support (Graham *et al.* 2013).

2.7.3 Health promotion

In the current literature, physical health was not commonly identified as a predictor of engagement in activities for adults ageing with ID. However, the relationship between health and engagement in occupation is emphasised by occupational therapists and occupational therapy has played an active role in health promotion in the general population (Wilcock & Hocking 2015). The Well-Elderly (Jackson *et al.*

1998) and the Lifestyle Matters (Mountain *et al.* 2008) programmes are occupational therapy-led programmes that focus on promoting good health through engagement in occupations that support health and well-being for people as they grow older. The benefits of these programmes include both promotion of good health, while supporting engagement in occupation as people grow older. This may also be a useful approach when working with people ageing with ID.

A number of health promotion programmes for people with ID are emerging in the literature. The types of programmes offered, aims and means of implementation vary greatly across the literature. Heller *et al*. (2014) reviewed interventions to support adults with ID to maintain health and well-being, including interventions focused on exercise and physical fitness, multi-factorial interventions incorporating healthy diet, activity and other lifestyle factors. The importance of support from staff was highlighted, as was the importance of providing services based within the community that are culturally sensitive, focus on self-determination and are specific to the needs of people with ID.

The "Health Matters" programme included topics such as physical activity, diet, healthy habits, making and implementing changes. Significant improvements were found in perceived general health, knowledge & skills, health behaviours, fitness, and social-environmental supports (Marks *et al.* 2013). Llewellyn *et al*. (2004) also piloted a health promotion programme for people ageing with ID. They advocated an individualised approach with planning earlier in life to

facilitate easier transitions in retirement, and community engagement. Aranow (2005) piloted a health promotion programme for people ageing with ID. This programme was facilitated by clinical nurse specialists, and considered physical, social, mental health and economic factors of ageing with ID. Following assessment, participants were referred for recommended services and follow up.

The aims and outcomes of these health promotion programmes appear to vary greatly across the literature. Utilisation of an occupational perspective, with a health promotion programme that promotes active engagement to support positive health habits may be beneficial for people ageing with ID. Topics from the Well-Elderly study (Jackson *et al.* 1998) or Lifestyle Matters (Mountain *et al.* 2008) programmes focused on the needs of people ageing with ID would be useful as the focus on practical tasks to support learning, and emphasis on building self-efficacy is congruent with values of empowerment and self-determination in disability support services.

2.8 Conclusions

The body of evidence presented shows that a variety of factors influence engagement in self-care, productivity and leisure activities for people with ID as they grow older. Personal factors such as level of ID may have significant influence on engagement in self-care and leisure activities, whereas organisational structure, staff knowledge/training and availability of support staff has been shown to have significant influence on availability of productivity roles, access to leisure and

other daily activities. This serves to highlight the usefulness of an occupational perspective that considers personal, environmental and occupational factors when examining engagement in daily life activities of adults with ID, and the potential benefits of incorporating this perspective in training of support staff and carers of people with ID.

The current evidence supports the assumption in OT literature that occupational performance occurs as a result of interaction of factors between the person, their environment and the activity itself (Reed & Nelson Sanderson 1999). This perspective offers a structure in which to examine engagement in daily life.

Much of the current literature to date has focused on performance in self-care, productivity and leisure activities. As people with ID grow older and may experience changes in their functional abilities and needs for support, broader contextual factors related to occupational engagement are also essential areas to consider to support continued engagement in meaningful daily activities, with associated benefits for health and well-being. An occupational perspective may better ensure that all factors related to engagement are considered. The current study focuses on one aspect of occupational engagement, related to type and frequency of engagement in daily life activities, with consideration to personal, environmental and occupational factors where possible.

Although it has been highlighted that engagement in daily life is influenced by a multitude of factors, it remains unclear to what extent

each of the individual factors influences engagement, and what implications this may have for the health and well-being of adults ageing with ID. Further investigation is required to examine the extent of influence of factors within the person and environment, which will assist in informing strategies to support continued engagement in daily life activities and well-being for adults ageing with ID.

Methodology

3.1 Introduction

This chapter gives details on the methodology of the current study, including study design, ethical considerations including confidentiality, consent, data quality procedures, and statistical analysis. This chapter also explores the variables chosen from the IDS-TILDA dataset to complete statistical analyses.

3.1.1 Research Aim

The main aim of the study was to investigate the engagement in daily life activities of people ageing with ID in Ireland, and to analyse the key factors that relate to engagement in daily life activities.

This study aimed to investigate the use of an occupational perspective on a secondary dataset and explore the implications for research, policy and practice for people ageing with an ID.

3.1.2 Main research question

The overall research question is “to what extent are people with intellectual disability engaged in daily life activities in terms of self-care, productivity and leisure activities? In addition to this broad research question, the study sought to investigate the main factors influencing engagement in daily life activities, including self-care, productivity and leisure activities for people ageing with ID.

3.1.3 Research Objectives

- To investigate the usefulness of a modified occupational perspective as a guiding perspective to investigate daily life activities of adults ageing with ID.
- To undertake a review of the literature on occupational engagement in daily life of adults with ID focusing on engagement in daily life activities (self-care, productivity and leisure).
- To identify elements that influence engagement in daily life activities of adults with ID as they age including the role of demographic variables and factors within the person, environment and activity. This will involve the following:
    - Variables related to daily life activities, in terms of self-care, productivity and leisure will be analysed in order to investigate the levels of engagement in daily life activities of adults currently ageing with ID in Ireland.
    - Objectively measurable key indicators of other personal or environmental factors, including physical, cognitive, affective, physical environmental, and social environmental factors, will be examined in relation to self-care, productivity and leisure in order to determine the predictors of engagement in daily life activities of adults ageing with ID in Ireland.
    - Demographic factors such as age, gender, level of ID, and living situation will be examined in relation to self-

care, productivity, and leisure activities in order to determine the predictors of engagement in daily life activities of adults ageing with ID in Ireland.

3.2 Study Design

The main aim of this study was to explore engagement in daily life activities of adults with intellectual disability (ID) who are ageing in terms of self-care, productivity and leisure, and to explore key factors which influence engagement in these activities. In order to answer this question, a quantitative design was considered to capture the breadth of engagement in self-care, productivity and leisure activities from a nationally representative sample of people ageing with ID in Ireland, of varying abilities, living circumstances, gender, and geographical location. This study utilised data from the second wave of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS TILDA), collected between April 2013 and February 2014. IDS-TILDA is a prospective longitudinal study examining the experience of ageing with an ID. IDS-TILDA gathers a vast array of data across a wide variety of domains including physical, behavioural and mental health, social participation and connectedness, and other areas related to health, well-being and quality of life of adults ageing with ID in Ireland. The strong quantitative design, representativeness of the sample and focus on ageing with ID meant that IDS-TILDA was the best available data for examining engagement of daily life activities of adults ageing with ID. The range of topics collected in IDS-TILDA meant

it was possible to examine some elements of engagement in daily life activities of adults ageing with ID of all abilities in order to address the research question.

The primary aim of IDS-TILDA is to identify principal influences on successful ageing in persons with ID, and to determine if they are the same as the general population (McCarron *et al*. 2011). The IDS-TILDA data collection instruments, protocol, Pre-Interview Questionnaire (PIQ) and Computer Assisted Personal Interview (CAPI) were developed in consultation with a national Steering and International Scientific Advisory Committees, self-advocacy groups of people with ID and experts in the field of intellectual disability. These groups were involved throughout the piloting, design and evaluation of IDS-TILDA questionnaires and study processes. This helped to ensure greater accessibility and quality of data collection processes for participants and researchers (McCarron *et al.* 2011).

3.2.1 Participant Involvement

IDS-TILDA aims to promote inclusion of people ageing with ID in policy and practice by highlighting issues related to ageing for people with ID, and ensuring these are included in mainstream policy agendas. Core values of IDS-TILDA include promotion of people with ID, inclusion, promotion of best practice, empowerment and consultation with people with ID, which is reflected in the study design, data collection and consultation processes (O'Donovan 2016). IDS-TILDA shares core

values with occupational therapy (OT), including empowerment and collaboration (Reed & Nelson Sanderson 1999, Polatajko *et al.* 2007, McCarron *et al.* 2011, McCarron *et al.* 2014).

People with ID were involved at all stages in planning, preparation, piloting, data gathering and dissemination of IDS-TILDA. Consultation workshops with advocacy groups of people with ID took place when planning for next wave of data collection. These workshops took place around the country in disability services. During these workshops, people with ID were able to identify issues they believed were important to include in the next wave of data collection, and to give their thoughts about proposed new topics to be included in the new questionnaire.

People with ID were also involved in the piloting of new questions for wave three of data collection. Feedback was sought from each participant about the new questions, including the relevance and usefulness of the questions. This ensured that people with ID were involved in the planning of the main questionnaire.

People with ID were involved in training of researchers for data collection of IDS-TILDA data. All researchers were assessed following data collection training by a self-advocate with an ID.

Participants with ID were involved in the recruitment processes as well. In recruitment, researchers spoke directly with participants, and with support people as needed. Each participant gave informed consent,

and process consent was used throughout the interview. In addition, feedback was sought on the interview following completion of the interview, including how the participant would like the findings to be disseminated.

People with ID were also involved in dissemination of the findings of IDS-TILDA wave two. Many participants reported they would like findings reported in DVD format- people with ID in conjunction with the IDS-TILDA team worked together to make DVDs of the main findings of the study- short DVDs of different topics- e.g. day activity, transport.

3.3 Sample Profile

The IDS-TILDA sample was drawn from the National Intellectual Disability Database (NIDD). The NIDD is a large administrative service planning database that gathers information on people with ID accessing specialised health services in Ireland to provide for future planning of these services (Kelly *et al.* 2013).

Inclusion criteria for IDS-TILDA included:

- Registered with NIDD
- Aged 40 years or older with ID
- Provided consent to participate (written where possible)
- Provided family/guardian written agreement (where required)

The IDS-TILDA included people aged 40 years and older with all levels of ID, and a range of living situations. The process of recruitment of participants is detailed in section 3.3.I. The IDS-TILDA wave one sample was 753 persons, which represented 46% of the sample drawn from the NIDD, comprising 8.9% of those registered on the NIDD who were 40 years and older (McCarron *et al.* 2011). Participants were distributed across all areas of Ireland, across full range of living situations, gender and level of ID. Characteristics of the sample are given in Table 3.1 below. Retention of participants between wave one and wave two of IDS-TILDA was high, with 94% retention rate in wave two, and was determined to be representative of the NIDD sample (McCarron *et al.* 2014). The overall number of participants in wave two was 701 (McCarron *et al.* 2014).

Table 3.1: IDS-TILDA population Wave 2 Demographic Information

	Frequency (N=699)*	%
Age		
44-49 years	187	28.7
50-64 years	333	51.1
65+ years	132	20.2
Gender		
Male	313	44.2
Female	386	55.8
Marital Status		
Single	640	98.6
Other	9	1.4
Level of ID		
Mild	153	23.7
Moderate	300	46.5
Severe/Profound	192	29.8
Living Situation		
Independent/Family	112	16
Community-based	305	43.6
Residential	282	40.3

* While the overall number of participants for Wave 2 was N=701, 2 of these participants only completed the Pre-Interview Questionnaire (PIQ), which did not

allow for accurate data analysis for the present analysis. Therefore these cases were excluded from analysis, with an overall number of participants for this study being N=699.

3.3.1 Process of Participant Recruitment

3.3.1.1 Wave 1 participant recruitment

For initial participant recruitment at wave one, staff at the Health Research Board (HRB) randomly selected 1800 personal identification numbers (PINS) from the NIDD.

The IDS-TILDA team sent information packs to Regional Disability Database managers in ten health regions. Information packs contained:

- Letter of support from respective ID service organisation
- Accessible invitation and information booklet
- Consent form and stamped addressed envelope
- Family/guardian pack (letter of support, briefing letter, information leaflet, agreement form and stamped addressed envelope)

The Regional Disability Database Managers matched the PINS to people in their area, and issued information packs to potential participants. Consent forms were returned by people with ID and families/guardians where applicable. IDS-TILDA team members also conducted

information sessions with service providers, advocacy organisations to provide further information about IDS-TILDA.

3.3.1.2 Wave 2 participant recruitment

For wave two IDS-TILDA data collection, researchers contacted those who had completed Wave one (719 individuals living at time of wave two participant recruitment), and invited participants to take part in wave two. Participants who agreed to take part in IDS-TILDA wave two data collection included 699 people (McCarron *et al.* 2014).

3.4 Data collection

Data was collected for wave two by 24 field researchers, who were either paid data collectors or postgraduate students who were using IDS-TILDA data in their postgraduate studies between April 2013 and February 2014. All field researchers completing interviews with participants had experience of working with people with ID and attended a 3 day standardised training course in preparation for data collection (McCarron *et al.* 2014). Topics covered on this course included ethical considerations, data protection, interviewing techniques, data input and Computer Assisted Personal Interview (CAPI) (O'Donovan 2016). Data was collected from all 26 counties in the Republic of Ireland. Interviews were completed at the individual's place of residence or day service. Please see Appendix 2 for details of the IDS-TILDA conceptual framework, and Appendix 3 for a list of variables from IDS-TILDA wave 2.

Data collection involved completion of computer assisted personal interviews (CAPI), completed by self-report respondents, self-report respondents in collaboration with a support person, and respondents who completed the questionnaire by proxy only. Please see Table 3.2 for details of reporting methods for IDS-TILDA wave two.

3.4.1 Reporting Methods

IDS-TILDA utilised data collection by respondents who self-reported the data, respondents who self-reported with a support person present, and by proxy respondent. Table 3.2 details the respondent rate by proxy.

Table 3.2 Reporting methods for IDS-TILDA wave 2

Reporting Method for IDS-TILDA wave 2	**N=**	**%**
Self-Report	175	25
Self-Report with support person	210	30
Proxy Respondent	314	45

The majority of participants in IDS-TILDA wave 2 responded via self-report, or self-report with a support person present (55% overall). Participants who self-reported answered the questions independently, and those who self-reported with a support person were able to nominate a person to be present to help them understand and answer the questions in the study. Collecting data from self-reporting respondents has been shown to be the preferred means of data

collection, as it promotes collaborative approaches, and acknowledges that participants are experts in their personal experiences (Perkins 2007). As detailed in Section 3.2.1, people with ID were involved at all stages of IDS-TILDA processes, from planning to data collection to dissemination. The use of first person self-reporting was encouraged wherever possible and supported through the use of visual aids and interviewer training. However, some limitations to this method have also been acknowledged, such as acquiescence or recency bias (Finlay & Lyons 2002). Consideration of inclusive and appropriate questionnaires and study design has been shown to improve accuracy of responses (Schmidt *et al.* 2010). Careful attention has been paid to the design of the questionnaire and interviewer training to promote accurate data collection in the present study. As detailed in Section 3.2.1, people with ID were involved in the proposal of topics to be included and piloting of questions to ensure the accuracy of data collected in the study.

The population of people ageing with an ID is diverse and it was important to be able to capture this diversity in the study. 45% of the study population responded by proxy report. It is widely reported that people with ID may experience communication difficulties, particularly those with severe or profound intellectual disabilities (Finlay & Lyons 2001) and so it was important to facilitate means of promoting these people to participate in IDS-TILDA.

The use of proxy respondents was necessary in order to include people with ID of all abilities, as some people with ID may experience communication difficulties (Sexton *et al.* 2016). Proxy responses have been shown to be reliable for objective measurement, but sometimes less so for subjective measures (Perkins 2007). In IDS-TILDA, proxy respondents were not included for subjective questions, such as self-rated happiness or loneliness. Therefore, proxy respondents were included for objective questions only to ensure accurate data analysis. Proxy respondents were required to have known the person for at least six months prior to interview, as the selection of proxy respondents with a good level of knowledge of the person have been found to increase accuracy of responses for people with ID (Schmidt *et al.* 2010, Foran *et al.* 2013). Field researchers met with participants and all participants were invited to be present during interview, regardless of whether interview was self-report, supported self-report of proxy format.

3.5 Ethical Considerations

IDS TILDA has received ethical approval from the Trinity College Faculty of Health Sciences Ethics Committee, and from the 138 intellectual disability service providers involved in recruitment of participants for IDS-TILDA for both wave one and wave two (McCarron 2011, McCarron *et al.* 2014). Please see Appendix 4 for Trinity College Dublin Faculty of Health Sciences Ethics Committee letter of approval.

The Health Research Board (HRB) and Department of Health (DoH) have provided funding for IDS-TILDA.

All field researchers undertaking data collection with IDS-TILDA were Garda vetted, and completed a standardised training course to ensure best possible interview experience for participants.

3.5.1 Consent

3.5.1.1 Wave 1 consent

The process of obtaining informed consent from participants was of paramount importance to the study. The importance of gaining informed consent has been highlighted in the Declaration of Helsinki, which provides guidelines for conducting ethical research (World Medical Association 2001). At wave one, each participant in the study received invitation packs including an information leaflet, and consent form.

A period of seven days minimum was allowed between receipt of information pack, and follow up phone call by the field researcher. This ensured the participants could seek advice and be supported by a family member/guardian/support worker in order to consider participation in the study. At the follow up phone call with the field researcher, interviews were scheduled with participants who agreed to participate in the study. Written consent was obtained at time of interview. Please see Appendix 5 for a copy of the consent form used in

IDS-TILDA Wave 2. A system of process consent was also used, which is detailed in section 3.5.1.2.

3.5.1.2 Wave 2 consent

At the time of wave two data collection, field researchers contacted participants from wave one and invited them to participate in wave two of data collection. Once interviews were scheduled, participant packs were posted, including the pre-interview questionnaire, consent forms and information regarding the study.

A system of process consent was also used, with consent and right to withdraw from the study reaffirmed during the interview. Process consent is a means of promoting informed consent throughout the interview. It involves ongoing negotiation of subjects discussed and consent to participate in the study, throughout the data collection process, and has been used successfully in collaborative research processes with people with ID (Knox *et al.* 2000, Knox & Hickson 2001). Participants were informed that they could complete the interview in a number of sessions over a number of days, take a break during the interview, and that participants could choose not to answer any questions at any time.

3.5.2 Confidentiality

IDS-TILDA has a comprehensive data protection protocol in place in order to ensure confidentiality for participants. Please see Appendix 6

for a copy of this protocol. Each participant has a unique IDS TILDA identification number to ensure confidentiality in data analysis.

Measures in place to ensure data security and confidentiality included:

- Generation of personal identification numbers (PINs) in order to anonymise participant's names during data analysis.
- Only one document (Personal Information Form) used for interview scheduling purposes, contains the person's name and PIN together. These are stored securely in a locked filing cabinet on site and are accessed separately from the anonymised data. Access to this information is restricted to the Principal Investigator, Project Manager, and the interviewer conducting that particular interview. It is password protected from all others.
- All service providers remained anonymous and no identifying features are used in any reports.
- Hard copy records (e.g. Pre-Interview Questionnaire) are stored in a locked cabinet on site, with restricted access.
- All computerised data are stored on password locked systems on encrypted laptops with restricted access.
- Specific variables from IDS-TILDA data are requested by the researcher from the Data manager, and all data analysis is completed within IDS TILDA offices and held on secure servers.

- Laptops used to collect data used password protection and encryption. Data is held securely for a five year period (McCarron *et al.* 2011).

3.5.3 Data Quality procedures

Missing data is a common difficulty in longitudinal studies (Newman 2010). In IDS-TILDA, a keeping in touch strategy is in place, with participants receiving an accessible report, DVD of results and other innovative knowledge dissemination projects such as a Roadshow, as well as regular newsletters, cards and website. Please see Appendix 7 for further information on the IDS-TILDA keeping in touch strategy. This aims to ensure inclusion, collaboration and to encourage continued participation in the study. Potential for missing data was also minimised through use of CAPI to ensure maximum possible information was collected, through reminders and prompts in the CAPI programme (O'Donovan 2016).

At wave two, hard copy data inputted from Pre-Interview Questionnaires was cross checked by two members of the IDS-TILDA research team. The data manager merged all data collected onto a master file to facilitate structured data cleaning and cross validation.

3.6 Researcher Role

All researchers accessing IDS-TILDA data must contribute to the study process. The researcher was involved in numerous pre-data collection processes. This assisted with development of data collection skills, as

well as informing the current study and future studies. The researcher was involved in consultation workshops with people with intellectual disabilities. These workshops were an excellent learning opportunity for the researcher, as people with intellectual disabilities were able to identify topics to be included in future waves of IDS-TILDA. Topics discussed ranged from spirituality, sense of community to making decisions about healthcare. The researcher was involved with facilitating these workshops, and gathering the thoughts and opinions of people with ID in relation to the importance of these topics to be included in IDS-TILDA. These workshops took place in conjunction with the project manager, and workshops took place in many different disability support services across the country.

The researcher received training in data collection and was involved with the piloting of new questions for wave three data collection. The questions were piloted with a range of people with intellectual disabilities across Ireland, in different disability support services. Piloting of new questions for data collection involved completion of pilot interviews, as well as gathering feedback on the data collection process with pilot interviewees.

The researcher completed 3 days of standardised training in preparation for data collection for Wave 3 of IDS-TILDA. The researcher engaged in the data collection process for wave three of IDS-TILDA data collection, with a caseload of 25 interviews completed, with a range of people with intellectual disabilities in various disability support services

and locations across Ireland. In addition, the researcher also engaged in the IDS-TILDA keeping in touch strategy through preparation of Christmas and Easter cards for participants (See Appendix 7 for details of the IDS-TILDA Keeping In Touch Strategy). The researcher also assisted with dissemination of IDS-TILDA data through preparation for the launch of DVD findings of the study and poster presentations.

3.7 Data Analysis

3.7.1 Selection of variables for analysis to reflect occupational constructs

The current study is guided by a modified occupational perspective. As the research question focuses on factors that influence engagement in self-care, productivity and leisure activities, the review of the literature and data analysis focused on the types and frequency of engagement in self-care, productivity and leisure activities. This study examines one aspect of occupational engagement, related to the types of activity that people engage in, and the frequency in which people ageing with ID engage in these activities. Personal and environmental key indicators were used where objectively measurable variables could be used.

The researcher wished to ensure that a person/environment/occupation perspective was adhered to as closely as possible in analysis of IDS-TILDA data.

As may be seen in Table 3.3 below, IDS-TILDA variables were matched to person/environment/occupation constructs where possible.

Table 3.3: Self Care variables

Self-Care activities: Element Captured	Related IDS-TILDA Variables	Answer options
Utilisation of social supports for ADLs and IADLs were the main variables considered in the present study as supports received to complete ADLs and IADLs will better capture the level of involvement of the person in completing ADL and IADL tasks. Those who were independent in ADL and IADL tasks were excluded from further analysis due to small group size (N=7).	Social support required for ADL tasks (dressing, bathing/showering, toileting, feeding, mobilising, bed mobility, oral care)	(a.) Support required for engagement in EITHER ADL or IADL tasks (b.) Support required for engagement in BOTH ADL and IADL tasks
	Social support required for IADL tasks (meal preparation, laundry, telephone use, money management)	
	Social support required for ADL or IADL tasks	
	Social support required for both ADL and IADL tasks	

Table 3.4: Productivity variable

Productivity: Element Captured	**Related IDS-TILDA Variables**	**Answer options**
Responses were grouped into 2 groups, those who were currently engaged in a productivity role, and those who are not. Those included in a productivity role included those who were employed, self-employed, attending sheltered workshop, day service, voluntary work, education/training or looking after home and family. Those not currently engaged in a productivity role included those who reported to be unable to work, those who were unemployed, and those who were retired.	Attendance at: Employment Self-employment Sheltered workshop Day service Education/training Looking after home & family Voluntary work Retirement Unemployed/ seeking work Unable to work due to illness or disability Currently engaged in productivity role Not currently engaged in productivity role	(a.) Currently engaged in productivity role (b.) Not currently engaged in productivity role

Leisure: Element Captured	**Related IDS-TILDA Variables**	**Answer options**
Responses for frequency of engagement in leisure activities were reverse coded and summed to create a continuous leisure variable capturing both number of leisure activities that people engaged in, and frequency of engagement in these leisure activities.	Frequency of engagement (daily, weekly, monthly, less frequently) in: Education/training Going for coffee/tea Attending sports events Participating in sports events Attending religious services Engaging in local arts groups/choirs Visiting art galleries Going to cinema Hobbies/creative activities Visiting family/friends Speaking with family/friends on the telephone Going to hairdresser Other social activities Going to the pub	Continuous variable with responses from 0 (doesn't engage in leisure activities) to 70.

	Shopping	
	Going to the library	
	Going to social clubs	
	Eating out	

Table 3.5: Leisure variable

3.7.2 Key Indicators

In order to effectively address the main research question "to what extent are people with intellectual disability engaged in daily life activities in terms of self-care, productivity and leisure activities" and to investigate the factors that influence engagement in these activities, it was necessary to identify key indicators of factors within the environment and the person. The aim of capturing key indicators was to choose variables that best reflected personal and environmental factors that influence engagement in daily activities in line with the modified occupational perspective of the study. In order to facilitate statistical analysis, it was necessary to choose variables that were could be measured objectively, and were an indicator that a factor that may influence engagement in self-care, productivity and leisure activities. It was not possible within the current study design to examine these aspects of the person or environment in depth. Table 3.6 below details the IDS-TILDA key indicators used in this study.

Table 3.6 Personal Factors Key Indicators

Person Factors	**IDS-TILDA Indicator and answer options:**	**Rationale:**
Physical	Self-rated physical health (a.) Good self-rated physical health (b.) Poor self-rated physical health	Self-rated physical health gives an indication of the respondent's perception of their physical health for engagement in meaningful occupation, this has been shown to be an important component and sometimes under-represented aspect of quality of life measurement (Ruddick & Oliver 2005). It is also important in order to facilitate a person-centred approach.
Cognitive	Level of ID (a.) Mild level of ID (b.) Moderate level of ID (c.) Severe/profound level of ID	Level of ID may provide a broad overview of cognitive ability of people ageing with ID. It is a widely used indicator in research literature.

Affective	Self-rated mental health (a.) Good self-rated mental health (b.) Poor self-rated mental health	Self-rated mental health gives an indication of the respondent's perception of their emotional well-being for engagement in meaningful occupation. (Bouras *et al.* 1998) found that gathering information from people with ID themselves regarding their mental health was important.

Table 3.7

Environmental Factors Key Indicators

Factor:	**IDS-TILDA Indicator and answer options:**	**Rationale:**
Physical Environment	Level of difficulty mobilising around home environment (a.) Difficulty mobilising around home environment (b.) No difficulty mobilising around home environment (c.) Difficulty travelling around local community, or does not travel around local community (d.) No difficulty travelling	The home is a key element of the physical environment encountered in daily life. Physical environmental factors such as size, physical layout, and type of home environment have been found to impact on levels of community integration of adults with ID (Heller *et al.* 1998). Level of difficulty mobilising around home environment may provide an indicator of the physical environment as an enabler or barrier to participation in valued activities. The local community also forms an important part of the physical environment surrounding the person, and therefore may

	around local community	promote or be a barrier to engagement in community life.
Social Environment	Presence of friends outside the home (a.) Friends outside the home (b.) No friends outside the home	Social networks and relationships are important for good quality of life, particularly as the person grows older. However, (McCausland *et al.* 2015) have found that frequency of contact with friends and family varies greatly for people ageing with ID. Presence of friends outside the home gives an indicator of social networks of people with ID.
Living Situation	Living Situation (a.) Independent/ with family (b.) Community group home (c.) Residential setting	It is challenging to capture the influence of the institutional environment on daily life, as influence is often indirect and subtle. Deinstitutionalisation studies aim to capture how people's lives change as they relocate from traditional residential settings to community-based settings e.g.(Cooper & Picton 2000). This could also be viewed as gauging one aspect of the impact of the institutional environment as policy changes directly impact on living situation.

3.8 Statistical Analysis

IDS TILDA wave 2 data was analysed quantitatively using Statistical Package for Social Sciences (SPSS Version 21.0).

Descriptive statistics were completed to investigate the demographic profile of IDS-TILDA respondents and to examine current performance and frequency of engagement in self-care, productivity and leisure activities. Key elements of self-care,

productivity and leisure activities were identified in order to create summary groups for self-care, productivity and leisure.

3.8.1 Inferential statistics

Chi-square tests of independence for self-care, productivity and leisure variables based on key indicators, IDS-TILDA demographic information and review of the literature were completed in order to identify preliminary factors that influence engagement in self-care, productivity and leisure activities.

A cut off point of P<=0.05 was used for all analyses.

Binary logistic regression and linear regression analyses were completed based on results of the chi-square tests. Variables that were found to be significant in chi square tests for independence were included in binary logistic regression model for self-care, productivity and leisure variables. Odds ratios are presented in order to show strength and magnitude of associations between variables. Tabachnick & Fidell (2007), as cited in Pallant (2010) defined odds ratios as "the change in odds of being in one of the categories of outcome when the value of a predictor increases by one unit" (p. 461). A higher odds ratio indicates stronger likelihood of an event occurring, and a lower odds ratio indicates lower likelihood of an event occurring. Confidence intervals give an indication of the accuracy of the odds ratios presented, with narrower confidence intervals indicating greater accuracy of the odds ratios (Pallant 2010).

3.9 Limitations

The methodology of the current study has some limitations. As the sampling frame for IDS-TILDA is drawn from the NIDD, there may possibly be an under-representation of those ageing with ID who were not currently registered with health and social care providers. However, the NIDD database is representative of the population of people with ID in Ireland (Kelly 2012). The IDS-TILDA sample is representative of those registered on the NIDD (McCarron *et al.* 2011).

This study utilises objective data from multiple reporting methods, including self-report, self-report with a support person, and proxy data collection. As detailed in section 3.4.1, this ensured that all people ageing with an ID could be represented in the current study. The current study did not facilitate collection of subjective data related to occupation in terms of spiritual, cultural or institutional factors, personal meaningfulness of an activity, implications for identity and self-efficacy as these factors are subjectively experienced, it was not possible to accurately gather data from proxy respondents, and so these views could not be accurately represented in wave two data collection (Unruh *et al.* 2002).This would be required of an occupational perspective. However, the design of the current study does facilitate exploration of what people ageing with intellectual disability are doing in their everyday lives, and factors that might influence engagement in these activities at a population level. In this

way, the current study examines one aspect of engagement in occupation, in terms of frequency of engagement in daily activities.

However, for wave three of IDS-TILDA data collection, questions relating to spirituality were included for self-reporting participants in the study.

Findings

4.1 Introduction

This chapter will present results of the main findings from the analysis of self-care, productivity and leisure variables in the IDS-TILDA wave two dataset, in line with the research question, aims and objectives.

4.1.1 Research Aim

The main aim of the study was to investigate the engagement in daily life activities of people ageing with ID in Ireland, and to analyse the key factors that relate to engagement in daily life activities.

4.1.2 Main research question

The overall research question is "to what extent are people with intellectual disability engaged in daily life activities in terms of self-care, productivity and leisure activities? In addition to this broad research question, the study sought to investigate the main factors influencing engagement in daily life activities, including self-care, productivity and leisure activities for people ageing with ID.

4.1.3 Research Objectives

- To investigate the usefulness of a modified occupational perspective as a guiding perspective to investigate daily life activities of adults ageing with ID.
- To undertake a review of the literature on occupational engagement in daily life of adults with ID focusing on engagement in daily life activities (self-care, productivity and

leisure).

- To identify elements that influence engagement in daily life activities of adults with ID as they age including the role of demographic variables and factors within the person, environment and activity. This will involve the following:
- Variables related to daily life activities, in terms of self-care, productivity and leisure will be analysed in order to investigate the levels of engagement in daily life activities of adults currently ageing with ID in Ireland.
- Objectively measurable key indicators of other personal or environmental factors, including physical, cognitive, affective, physical environmental, and social environmental factors, will be examined in relation to self-care, productivity and leisure in order to determine the predictors of engagement in daily life activities of adults ageing with ID in Ireland.
- Demographic factors such as age, gender, level of ID, and living situation will be examined in relation to self-care, productivity, and leisure activities in order to determine the predictors of engagement in daily life activities of adults ageing with ID in Ireland.

Prior to conducting data analysis, frequency analysis was completed in order to identify missing data and outliers. Valid percentages only are reported throughout this chapter, with considerations for missing data. A cut off point of $p<.05$ was used to indicate statistical significance for

all analyses. The results of analyses are presented in terms of those who engaged in self-care, productivity and leisure activities in the IDS-TILDA wave 2 data.

4.2 Self-care

As activities related to self-care are essential in order to maintain health and wellbeing, it was expected that all respondents would engage in self-care activities. The self-care variable was composed of two mutually exclusive groups. The first group included those who required support for EITHER ADLs or IADLs, and those who required support for BOTH ADLs and IADLs.

Table 4.1 presents findings of those who required support for EITHER ADLs or IADLs, and those who required support for BOTH ADLs and IADLs. The first group who required support for EITHER ADLs or IADLs was much smaller (N=103, representing 15.3%) than the group who required support for BOTH ADL and IADLs, (N=569) which accounted for 81.4% of this population. The remaining 3.9% (N=27) was missing data. Participants in the smaller group were more likely to be male (15.8%), aged between 50-64 years (19%), reported good physical (17.9%) and mental health (17.5%), and had mild level of ID (34.1%). In addition, respondents in this group were more likely to live independently/ with family (34.3%), be engaged in a productivity role (16.9%), and have friends outside of the home (19.2%) than those who

required support for BOTH ADLs and IADLs. The majority of participants in the group who required support for EITHER ADLs or IADLs reported no difficulty in travelling around their local community (26.2%), and all respondents in this group reported no difficulty navigating their home environment (18.6%).

Table 4.1 also presents findings from those who required support for BOTH ADLs and IADLs. Differing trends were observed in this group when compared to those who required support for EITHER ADLs or IADLs. Participants who required support for BOTH ADLs and IADLs were more likely to be older (aged 65 years and older) accounting for 90.3% of this group, have poor self-rated physical (97.1%) and mental health (89.4%), have severe/profound level of ID (98.4%), and were less likely to have friends outside the home (89.2%), and more likely to live in residential settings (94.9%) when compared to those who required support for EITHER ADLs or IADLs. The majority (90.4%) of respondents in the group who required support for BOTH ADLs and IADLs had difficulty getting around their local community, and all of the participants who required support for BOTH ADLs and IADLs had difficulty getting around their home environment.

Table 4.1: Cross tabulation and Chi Square test for independence for self- care variable

Self-Care:	**Support for EITHER ADL or IADL (N=103, 15.3%)**	**%**	**Support for BOTH ADL and IADL (N=569, 81.4%)**	**%**	**Chi Square P=**
Gender					.833
Female	56	14.9	319	85.1	
Male	47	15.8	250	84.2	
Age					.580
40-49 years	25	13	167	87	
50-64 years	64	19	272	81	
65+ years	14	9.7	130	90.3	
Self-rated physical health					*<.001
Good	100	17.9	460	82.1	
Poor	3	2.9	101	97.1	
Self-rated mental health					*.044
Good	85	17.5	400	82.5	
Poor	18	10.6	152	89.4	
Level of ID					*<.001
Mild	47	34.1	91	65.9	
Moderate	39	13.2	257	86.8	
Severe/Profound	3	1.6	183	98.4	
Physical Environment (Home)					*<.001
No difficulty navigating home environment	103	18.6	451	81.4	
Difficulty navigating home environment	0	0	118	100	

Self-Care	Support for EITHER ADL or IADL (N=103, 15.3%)	%	Support for BOTH ADL and IADL (N=569, 81.4%)	%	Chi Square P=
Physical Environment (Community):					*<.001
No difficulty accessing local community	60	26.2	169	73.8	
Difficulty/does not access local community	42	9.6	396	90.4	
Social Environment:					*.004
Friends outside home	71	19.2	299	80.8	
No friends outside home	32	10.8	265	89.2	
Living situation:					*<.001
Independent/Family	35	34.3	67	65.7	
Community group home	54	18.3	241	81.7	
Residential	14	5.1	261	94.9	
Productivity:					*.009
Engaged in productivity role	97	16.9	476	83.1	
Not currently engaged in productivity role	6	6.1	93	93.9	

*Indicates significance (P<0.05)

Linear by linear chi square values are reported for variables with three groups (level of ID, age and living situation). No significant differences in gender and age were observed between the two self-care groups. Significant differences between the two self-care groups were found for many of the key indicators. Highly significant differences (at P<.001 level) were found between physical health, level of ID, physical environment (as indicated by difficulty mobilising around home and community), presence of friends outside the home, and living situation between the group who required

support for EITHER ADLS or IADLS, and those who required support for BOTH ADLs and IADLs. Significant differences between the two groups were also noted for mental health, and engagement in a productivity role.

4.2.1 Logistic Regression with crude odds ratio

Logistic regression was completed to identify predictors of engagement in self-care activities, and to provide more information on what factors influence amount of support required for engagement in self-care activities. Crude odds ratios are presented in order to examine the size and magnitude of associations between the two self-care groups.

Results of binary logistic regression with crude odds ratio are presented in Table 5.2 below. Factors that were identified as having significant differences between the two self-care groups in the chi square tests for independence were included in the logistic regression. These factors were physical health, mental health, level of ID, physical environment (home and community), presence of friends outside the home, type of living situation and engagement in productivity role. Additional demographic variables (age and gender) were also included in binary logistic regression.

Binary logistic regression was not completed on the physical environment (home) variable as there were 0% (N=0) respondents in the group who required support with EITHER ADLs or IADLs, so logistic regression analysis was not possible for this variable.

Level of ID was found to be a highly significant predictor at p<.001 of support required for in self-care activities. Those with severe/profound level of ID were found to be 31.5 times (9.6-103.7, 95% confidence interval) more likely to require support for BOTH ADLs and IADLs than those with mild level of ID. The wide confidence interval (C.I.) reported for this analysis is likely due to the fact that only 1.6% (N=3) of the population with severe/profound level of ID were in the group that required support for EITHER ADLs or IADLs.

Type of living situation was also found to be highly significant predictor of the amount of support required for engagement in self-care activities. There was a highly significant difference (P<.001) between support required for self-care activities between those with living independently or with family, and those living in residential settings in particular, with those living in residential 9.7 times (95% C.I. 4.9-19.1) more likely to require support for BOTH ADLs and IADLs than those living independently or with family. There was also significant difference between those living independently, and those living in community group homes for level of support required for self-care activities.

Those who reported to be in poor physical health were 7.3 times (95% C.I. 2.3-23.6) more likely to require support for BOTH ADLs and IADLs than those who reported good physical health. Those who reported difficulty getting around their local community were over 3.3 times (95% C.I. 2.2-3.1) more likely to require support for BOTH ADLs and

IADLs. Those who reported that they didn't have friends outside the home were 2 times (95% C.I. 1.3-3.1) more likely to require support for BOTH ADLs and IADLs than those who reported to have friends outside the home.

Table 4.2: Logistic Regression Self-Care variable with crude odds ratio

	P Value	Crude Odds Ratio	95% Confidence Interval	
Age:				
● Age 40-49 (Ref. group)	*.02			
● Age 50-64	.08	.64	.39	1.05
● Age 65+ (Ref. group)	.35	1.39	.7	2.78
Gender:				
● Gender: Female	.75	1.07	.70	1.63
Level of ID:				
● Level of ID: Mild (Ref. group)	*<.001			
● Level of ID: Moderate	*<.001	3.40	2.09	5.54
● Level of ID: Severe/profound	*<.001	31.5	9.55	103.7
Living Situation:				
● Independent/with family (Ref group)	*<.001			
● Community group home	*.001	2.33	1.41	3.86
● Residential setting	*<.001	9.74	4.96	19.14
Physical Health				
● Poor physical health	*.001	7.32	2.28	23.55
Mental Health:				
● Poor mental health	*.034	1.79	1.04	3.09
Physical Environment: Community:				
● Difficulty mobilising around local community	*<.001	3.35	2.17	5.16
Friends outside home:				
● No friends outside home	*.003	1.97	1.26	3.08
Productivity:				
● Not engaged in productivity role	*.008	3.16	1.35	7.42

*indicates significance, p<.05

4.2.2 Logistic Regression with adjusted odds ratio

Binary logistic regression with adjusted odds was completed in order to identify predictors of engagement in self-care activities, while controlling for impact of demographic factors such as age, gender, and for other factors identified as significant by the chi square test for independence. It aims to isolate the impact of specific variables such as level of ID, type of living situation, physical health, mental health, physical environment and social environment on engagement in self-care activities. Results of binary logistic regression analysis are presented in Table 4.3 below. There were 10 independent variables included in the model. The full model containing all independent variables was statistically significant, (N=593, P<.001) indicating that the model was able to determine participants who required more or less support for self-care activities. The model explained between 17.3% (Cox & Snell R Square) and 30.4% (Nagelkerke R square) of variance in support required for self-care activities, and classified 85.2% of cases correctly.

Level of ID was identified as a significant predictor of support required for self-care activities as an isolated variable in the crude odds ratio. When controlling for demographic variables such as age, gender, and other variables identified as significant in chi square test for independence, level of ID continued to be the strongest predictor of support required for self-care activities, regardless of all other variables in the model. Those with severe/profound level of ID were 19.5 times

(95% C.I. 5.6-67.5) more likely to require support for BOTH ADLs or IADLs compared to those with mild level of ID, regardless of any other factor in the model. This high adjusted odds value of 19.5 and wide 95% confidence interval of 5.6-67.5 are due to the small numbers in the group who require support for EITHER ADLs or IADLS (1.6%, N=3). Those with moderate level of ID were 2.4 times (95% C.I. 1.6-4.7) more likely to require more support compared to those with mild level of ID.

Type of living situation was also identified as a significant predictor of support required for self-care activities in the crude odds ratio. When adjusting for all other variables in the model, type of living situation was the second strongest predictor of support required for self-care activities, with those living in residential settings 3.9 times more likely to require increased support for self-care activities compared to those living independently/with family (95% C.I. 1.7-8.7). However, there was no significant difference between those living independently, and those living in community group homes with regards to level of support required for self-care activities when controlling for other variables.

Poor physical health continued to be a significant predictor of support required for self-care activities when adjusting for all other variables, as well as in the crude odds ratio. Those reporting poor physical health were 4.6 times more likely to require increased support for self-care activities (95% C.I. 1.3-15.9).

In addition, those reporting difficulty getting around their local community were also 1.9 times (95% C.I. 1.1-3.3) more likely to require

support for BOTH ADLs and IADLs when adjusting for all other variables in the model, as well as in the crude odds ratio.

Age, mental health, presence of friends outside the home, gender and engagement in productivity roles were not found to be significant predictors of engagement in self-care activities when adjusting for demographic and other significant variables.

Table 4.3: Logistic Regression Self-Care variable with adjusted odds ratio

Logistic Regression Self-Care	P Value	Adjusted Odds Ratio	95% Confidence Interval	
Age:				
• Age 40-49 (Ref. group)	.073			
• Age 50-64	.104	.61	.33	1.11
• Age 65+	.569	1.28	.55	2.99
Gender:				
• Gender: Male	.849	.95	.57	1.6
Level of ID:				
• Level of ID: Mild (Ref. group)	*<.001			
• Level of ID: Moderate	*<.001	2.37	1.58	4.71
• Level of ID: Severe/profound	*<.001	19.45	5.61	67.49
Living Situation:				
• Independent/with family (Ref group)	*.003			
• Community group home	.211	1.51	.79	2.87
• Residential setting	*.001	3.86	1.71	8.72
Physical Health				
• Poor physical health	*.016	4.61	1.33	15.89
Mental Health:				
• Poor mental health	.763	1.11	.57	2.13
Physical Environment: Community:				
• Difficulty mobilising around local community	*.032	1.86	1.06	3.26
Friends Outside the Home:				
• No friends outside home	.237	.71	.4	1.26
Productivity:				
• Not engaged in productivity role	.750	1.18	.44	3.17

4.3 Productivity

In this study, an occupational perspective of productivity was utilised. Engagement in a productivity role encompassed engagement in employment, sheltered workshops, day services, voluntary work, education or looking after family. Prevalence of engagement in productivity roles was high, the majority (85.4%, N=597) of respondents reported to be engaged in a productivity role. Results of cross tabulations and chi square tests for independence are presented in Table 4.4 below. Higher percentages were reported for those who were female (85.5%), in the younger age range (40-49 years) (90.4%), reported good physical (89.1%) and mental health (88.8%), had moderate level of ID (87%), had friends outside the home (90.1%), reported no difficulty getting around their home (90.1%) or community (95.2%), and lived independently or with family (96.5%). Higher percentages were also observed for those who required support for EITHER ADLs or IADLs (94.2%).

The group who weren't currently engaged in a productivity role, comprised 14.6% (N=102) of the IDS-TILDA sample. Conversely to the group who were engaged in a productivity role, higher percentages were noted for those who were male, aged 65 years and older, reported poor physical and mental health, had severe/profound level of ID, had difficulty getting around their home or local community, had

no friends outside the home, lived in residential settings, and required increased support for self-care activities.

Linear by linear chi square values are reported for variables with three groups (level of ID, age and living situation). Highly significant differences ($P<.001$) between those who were and were not currently engaged in a productivity role were found for age, physical and mental health, physical environment (getting around home and local community), presence of friends outside the home, and type of living situation. Level of ID and level of support required for self-care activities were also significant according to chi-square test for independence. No significant differences between groups were noted for gender.

Table 4.4: Crosstabulation and Chi Square test for independence for productivity variable

Productivity:	**Engaged in productivity role (N=597, 85.4%)**	**%**	**Chi Square P=**
Gender			>.999
Female	335	85.5	
Male	262	85.3	
Age			*<.001
40-49 years	179	90.4	
50-64 years	311	88.1	
65+ years	107	72.3	
Self-rated physical health			*<.001
Good	517	89.1	
Poor	72	66.7	
Self-rated mental health			*<.001
Good	446	88.8	
Poor	137	77.4	
Level of ID			*.03
Mild	135	88.2	
Moderate	261	87	
Severe/Profound	151	78.6	
Physical Environment (Home)			*<.001
No difficulty navigating home environment	518	90.1	
Difficulty navigating home environment	76	63.9	
Physical Environment (Community)			*<.001
No difficulty accessing local community	236	95.2	
Difficulty/does not access local community	354	79.7	

* Indicates significance (P<.05)

4.3.1 Logistic Regression with crude odds ratio

Logistic regression was completed to identify predictors of engagement in a productivity role, with crude odds ratios to examine the strength and magnitude of associations between significant personal and environmental key indicators and engagement in a productivity role. Table 4.5 presents results of binary logistic regression with crude odds ratio. Factors that were identified as having significant differences between the 2 groups in the chi square test for independence were included in the logistic regression. These factors were physical health, mental health, level of ID, physical environment (home and community), presence of friends outside the home, living situation and engagement in productivity role. Additional demographic variables (age and gender) were also included in binary logistic regression.

The strongest predictor of preclusion from engagement in a productivity role was difficulty getting around the home environment in the current study. Those who reported to have difficulty getting around their home environment were 5.1 times more likely not to be engaged in a productivity role (95% C.I. 3.2-8.17). This was closely followed by those who reported difficulty getting around the home environment, who were 5 times less likely to be engaged in a productivity role than those who didn't experience difficulty getting around their home environment (95% C.I. 2.6-9.3).

Those in poor physical health (as defined by self-reported physical health) were also 4.1 times less likely to be engaged in a productivity role than those who report to be in good physical health (95% C.I. 2.5-6.6). Participants who required support for BOTH ADLs and IADLs were also 3.2 times less likely to be engaged in a productivity role (95% C.I. 1.35-7.4) than those who required support for EITHER ADLs or IADLs.

Participants who were living in a residential setting were 6.6 times less likely to be engaged in a productivity role than those living independently or with family (95% C.I. 2.3-18.6). Type of residence was a significant predictor of engagement in productivity role, with those living in residential settings being the least likely to be engaged in a productivity role compared to those living independently/with family, or in community group homes. However, there were also significant differences between those living independently/with family, and those living in community group homes. Having severe/profound level of ID was a significant predictor of engagement in a productivity role, with those with severe/profound level of ID 2 times less likely to be engaged in a productivity role compared to those with mild level of ID (95% C.I. 1.1-3.6). However, no significant differences were found between those with mild level of ID and those with moderate level of ID for engagement in productivity roles.

Mental health was also a significant predictor of engagement in a productivity role, with those who reported poor mental health as defined by self-reported mental health 2.3 times less likely to be

engaged in a productivity role compared to those reporting good mental health (95% C.I. 1.5-3.6).

Participants who reported to have with no friends outside the home were 2.4 times less likely to be engaged in a productivity role than those with friends outside the home (95% C.I. 1.5-3.6). Age was also a significant predictor of engagement in a productivity role, with those aged 65 years and older 3.6 times less likely to be engaged in a productivity role than those aged between 40-49 years (95% C.I. 2-6.5). However, no significant difference was found between those in the younger 40-49 year group, and the middle age group of 50-64 years for engagement in a productivity role.

Table 4.5: Logistic Regression Productivity variable with crude odds ratio

Logistic Regression Productivity	P Value	Crude Odds Ratio	95% Confidence Interval	
Age:				
• Age 40-49 (Ref. group)	*<.001			
• Age 50-64	.409	1.27	.72	2.26
• Age 65+	*<.001	3.61	1.99	6.54
Gender:				
• Gender: Female	.965	.99	.65	1.51
Level of ID:				
• Level of ID: Mild (Ref group)	*.028			
• Level of ID: Moderate	.708	1.12	.62	2.03
• Level of ID: Severe/profound	*.027	1.97	1.08	3.61
Living Situation:				
• Independent/with family (Ref group)	*.001			
• Community group home	*.005	4.51	1.58	12.86
• Residential setting	*<.001	6.57	2.32	18.6
Physical Health:				
• Physical health: Poor	*<.001	4.1	2.54	6.62
Mental Health:				
• Mental health: Poor	*<.001	2.33	1.49	3.64
Physical Environment (Home):				
• Difficulty getting around physical home environment	*<.001	5.14	3.24	8.17
Physical Environment (Community):				
• Difficulty getting around local community	*<.001	5	2.68	9.34

Logistic Regression Productivity	P Value	Crude Odds Ratio	95% Confidence Interval	
Friends outside the home:				
• No friends outside home	*<.001	2.35	1.52	3.62
Self-Care activities:				
• Support needed for both ADL & IADL	*.008	3.16	1.35	7.42

*Indicates significance, p<.05

4.3.2 Logistic regression with adjusted odds ratio

Binary logistic regression was also completed with adjustment for other variables that were identified as significant from the chi square test for independence. These variables included age, level of ID, living situation, physical health, mental health, physical environment (home and community), friends outside the home and support required self-care activities. Gender was also included in the regression, as it was a demographic variable. Results of binary logistic regression with adjusted odds ratio are presented in Table 4.6 below. There were 10 independent variables included in the model. The full model containing all independent variables was statistically significant, (N=593, p<.001) indicating that the model was able to determine engagement in a productivity role. The model explained between 14.3% (Cox & Snell R

Square) and 25.2% (Nagelkerke R square) of variance in engagement in a productivity role, and classified 86.2% of cases correctly.

Difficulty getting around the home environment was identified as a significant predictor of engagement in a productivity role in the crude odds ratios. When controlling for all other variables, difficulty getting around the home environment remained the strongest predictor of engagement in a productivity role. Those who reported difficulty getting around their home environment were 3.5 times less likely (95% C.I. 1.9-6.2) to be engaged in a productivity role compared to those who had no difficulty getting around their home.

In a similar manner, difficulty getting around the local community remained a significant predictor of engagement in a productivity role when controlling for all other variables in the regression model. Those who had difficulty getting around the local community were 3.6 times (95% C.I. 1.6-7.9) less likely to be engaged in a productivity role than those who had no difficulty getting around the local community. Participants who reported to be in poor physical health were 1.9 times (95% C.I. 1-3.4) less likely to be engaged in a productivity role than those who reported to be in good physical health.

Age continued to be a significant predictor of engagement in a productivity role when controlling for all other variables in the regression model, with significant differences found between the youngest (40-49 years) and oldest (65 years +) age groups. Those aged 65 years and over were 2.8 times (95% C.I. 1.3-5.7) less likely to be

engaged in a productivity role, compared to those in the younger 40-49 years group. However, no significant differences were found between those in the youngest (40-49 years) and middle age (50-64 years) group.

Gender, living situation, mental health, support required for self-care activities and friends outside the home were not found to be significant predictors of engagement in productivity when adjusting for other variables.

Table 4.6 Logistic Regression with Adjusted Odds Ratio for Productivity Variable

Logistic Regression Productivity	P Value	Adjusted Odds Ratio	95% Confidence Interval	
Age:				
• Age 40-49 (Ref. group)	*.006			
• Age 50-64	.585	1.2	.62	2.32
• Age 65+	*.005	2.79	1.36	5.72
Gender:				
• Gender: Female	.723	.91	.54	1.53
Level of ID:				
• Level of ID: Mild (Ref group)	.257			
• Level of ID: Moderate	.181	.6	.28	1.27
• Level of ID: Severe/profound	.763	.88	.39	1.99
Living Situation:				
• Independent/with family (Ref group)	.293			
• Community group home	.176	2.39	.68	8.44
• Residential setting	.368	1.81	.5	6.56
Physical Health:				
• Physical health: Poor	*.04	1.89	1.03	3.46
Mental Health:				
• Mental health: Poor	.18	1.46	.84	2.53
Physical Environment (Home):				
• Difficulty getting around physical home environment	*<.001	3.51	1.98	6.24
Physical Environment (Community):				
• Difficulty getting around local community	*.002	3.57	1.6	7.96

Logistic Regression Productivity	P Value	Adjusted Odds Ratio	95% Confidence Interval	
Friends outside the home				
No friends outside home	.157	1.48	.86	2.55
Self-Care activities:				
Support needed for both ADL & IADL	.831	1.12	.41	3.02

*indicates significance (P<.05)

4.4 Leisure

A continuous variable of leisure engagement was constructed based on the number of leisure activities that a person engages in, and how frequently a person engages in these activities. Analysis of leisure engagement was based on this continuous variable. Those who engaged in a wider variety of leisure activities on a more regular basis received higher leisure engagement scores than those who engage in less leisure activities on a less regular basis. Tests for normality of distribution were completed on the leisure engagement variable. The Kolmogorov-Smirnov test was completed with a significant of value of .064 was found, indicating normality of distribution of values. Please see Appendix 8 for histogram of leisure engagement, which shows that the distribution of values follows a fairly normal distribution, as evidenced by the tendency of the values to fall close to the normal curve.

Prevalence of engagement in leisure activities was high, the majority (96.9%, N=677) of the IDS-TILDA population engaged in at least one leisure activity once or twice per year. The analysis shows 3.2% (N=22) of the IDS-TILDA population did not engage in leisure activities at all.

A high proportion of participants who engaged in leisure activities were female (56.1%), aged between 50-64 years (50.5%), reported good physical (83%) and mental health (71.8%). In addition, participants who engaged in leisure activities were more likely to have moderate level of ID (42.9%), have no difficulty getting around home (82.3%) and experience no difficulty getting around the local community (64.2%). They were also more likely to have friends outside the home (56.1%), live in community group homes (42.2%), require support for both ADLs and IADLs, and be engaged in a productivity role (85.4%).

Independent samples t tests and one way between groups ANOVA were used to determine significant differences between groups, as presented in Table 4.7 below. Highly significant differences at $p<.001$ level were found for all key indicators, including physical health, mental health, ability to mobilise around physical environment of home and community, level of ID, type of living situation, and presence of friends outside the home. Highly significant differences were also found one of the demographic variable of age, at $p<.001$ level. Gender was the only variable that was not found to significantly influence engagement in leisure activities from independent samples t test and ANOVA.

Table 4.7: Independent samples t test and one way between groups ANOVA for engagement in leisure activities

Leisure	Leisure N=699	%	t	Df	Mean	T-test or ANOVA p
Gender			-.522	697		.602
Female	392	56.1			26.4	
Male	307	43.9			26.93	
Age				2		*<.001
40-49 years	198	28.3			28.87	
50-64 years	353	50.5			27.3	
65+ years	148	21.2			22.05	
Self-rated physical health			-7.22	686		*<.001
Good	580	83			28.19	
Poor	108	15.5			18.4	
Self-rated mental health			-4.07	677		*<.001
Good	502	71.8			28.09	
Poor	177	25.3			23.37	
Level of ID				2		*<.001
Mild	153	21.9			32.92	
Moderate	300	42.9			27.18	
Severe/Profound	192	27.5			20.5	
Physical Environment (Home)			-8.84	692		*<.001
No difficulty navigating home environment	575	82.3			28.67	
Difficulty navigating home environment	119	17			17.35	

Leisure	Leisure N=699	%	t	df	Mean	T-test or ANOVA p
Physical Environment (Community)			-6.67	690		*<.001
No difficulty accessing local community	248	35.8			31.16	
Difficulty/does not access local community	444	64.2			24.26	
Friends outside home			8.4	691		*<.001
Friends outside home	392	56.1			30.29	
No friends outside home	301	43.1			22.01	
Living situation				2		*<.001
Independent/Family	113	16.2			31.18	
Community group home	295	42.2			29.8	
Residential	283	40.5			26.63	
Self-Care activities			-6.95	670		*<.001
Support for either ADL or IADL	103	14.7			34.75	
Support for both ADL & IADL	569	81.4			25.13	
Productivity activities			-9.18	697		*<.001
Engages in productivity role	597	85.4			28.46	
Not currently engaged in productivity role	102	14.6			15.93	

4.4.1 Simple Linear Regression

Linear regression was completed to examine the strength and magnitude of associations between factors identified as significant from independent samples t tests, and ANOVA analysis, including physical and mental health, presence of difficulty mobilising around home and local community, and presence of friends outside the home. Demographic variables such as age, gender, level of ID and living

situation were also included. Results of linear regression analysis are presented in Table 4.8 below.

Level of ID, physical and mental health, ability to get around home and community environment, presence of friends outside the home, engagement in productivity role and support required for self-care activities were all highly significant predictors of engagement in leisure activities at P<.001 level.

Other significant predictors of engagement in leisure activities included type of living situation. Highly significant differences for engagement in leisure activities were found between those living independently/with family and those living in residential settings, but there was no significant difference between those living independently/with family, and those living in community group homes.

In a similar manner, age was also a significant predictor of engagement in leisure activities, and highly significant differences were observed between the youngest (40-49 years) and oldest (65+ years) groups. No significant difference was found between the youngest and middle (50-64 years) groups.

Gender was the only variable found not to be a significant predictor of engagement in leisure activities.

Table 4.8: Linear regression for engagement in leisure variable

Leisure	Coefficient	P	R^2	E(Y)	95% Confidence Intervals	
Gender						
• Male	26.932		<.001	26.4	25.42	28.44
• Female	-.536	.602		26.4	-2.56	1.49
Age						
• 40-49	28.87	*<.001	.034	28.87	27.02	30.72
• 50-64	-1.57	.183		27.3	-3.89	.742
• 65+	-6.821	*<.001		22.05	-9.65	-3.99
Level of ID						
• Level of ID Mild	32.92	*<.001	.117	32.92	30.93	34.91
• Level of ID Moderate	-5.742	*<.001		27.18	-15.09	-9.75
• Level of ID severe/profound	-12.42	*<.001		20.5	-8.19	-3.29
Type of living situation						
• Independent/family	31.18	*<.001	.074	31.18	28.78	33.58
• Community group home	-2.17	.131		29.01	-4.98	.644
• Residential care	-8.91	*<.001		22.27	-11.75	-6.07
Physical health						
• Good physical health	-9.87		.071	28.19	-12.45	-7.12
• Poor physical health	28.19	*<.001		18.41	27.13	29.25

Logistic Regression Leisure	Coefficient	P	R^2	E(Y)	95% Confidence Intervals	
Mental health						
• Good mental health	-4.71		.024	28.09	-6.99	-2.44
• Poor mental health	28.09	*<.001		23.38	26.92	29.25
Physical environment (home)						
• No difficulty	-11.32		.102	28.67	-13.83	-8.81
• Difficulty	28.67	*<.001		17.35	27.63	29.71
Physical environment (community)						
• No difficulty	-6.89		.061	31.16	-8.92	-4.87
• Difficulty	31.16	*<.001		24.26	29.53	32.78
Friends outside home						
• Friends outside home	-8.278		.091	30.29	-10.21	-6.34
• No friends outside home	30.29	*<.001		22.01	29.01	31.56
Self-care activities						
• Support required for ADL or IADL	-9.62		.067	34.75	-12.34	-6.90
• Support required for both ADL and IADL	34.75	*<.001		25.13	32.25	37.25
Productivity activities						
• Engaged in productivity role	-12.53		.108	28.46	-15.21	-9.85
• Not currently engaged in productivity role	28.46	*<.001		15.93	27.44	29.49

* Indicates significance, p<.05

4.4.2 Multiple linear regression

A multiple linear regression was calculated to predict leisure engagement based on demographic variables, and variables found to be significant from independent samples t tests and ANOVA including age, gender, level of ID, living situation, physical health, mental health, physical environment (home and community), friends outside the home and support required for self-care activities. Results of multiple linear regression are presented in Table 4.9 below.

There were 11 independent variables included in the model. The full model containing all independent variables was statistically significant, (P<.001) indicating that the model was able to identify predictors of engagement in leisure activities. The R Square value indicated that the model explained 31.6% of variance in leisure engagement.

Dummy variables were created for categorical variables that include 3 or more categories including: age, level of ID, and type of living situation. Initially, mild level of ID and independent/family living situation were used as reference groups for the regression analysis. However, when this was completed, the overall model showed signs of multicollinearity. In order to address this, the groups with the largest number of respondents were selected as reference groups for level of ID and type of residence dummy variables in order to reduce possibility of multicollinearity as per guidelines from Wisseman *et al.* (2007). The new model showed some multicollinearity between type of living situation (community group home) and type of living situation

(residential care) at .721 level, but no evidence of multicollinearity was evident in collinearity diagnostics, Variance Inflation Factors were all <1.5, and tolerance values all <1, indicating multicollinearity was not impacting on the overall regression model.

While the simple linear regression showed that engagement in a productivity role was a predictor of engagement in leisure activities, the multiple linear regression showed that the strongest predictor of engagement in leisure activities was engagement in a productivity role, when adjusting for all other variables in the regression model. Those who were not currently engaged in a productivity role were 7.2 times less likely to be engage in leisure activities compared to those who were engaged in a productivity role.

Difficulty getting around the home environment was identified as a predictor of engagement in leisure activities in the simple linear regression. In the multiple linear regression, those who reported difficulty getting around their home environments were 4.7 times less likely to engage in leisure activities, compared to those with no difficulty getting around their home when adjusting for all other variables in the model.

This was closely followed by those who reported that they did not have friends outside the home, who were 4.4 times less likely to engage in leisure activities than those who did have friends outside the home in the multiple regression, as well as being identified as a predictor of leisure engagement in the simple linear regression.

Level of ID was found to be a significant predictor of leisure engagement in the simple linear regression. When adjusting for all other variables in the regression model, participants who had severe/profound level of ID were 4 times less likely than those with moderate level of ID to engage in leisure activities, and those with mild level of ID were also 2.9 times less likely to engage in leisure activities than those with moderate level of ID.

Having been identified as a significant predictor of leisure engagement in the simple linear regression, participants who reported poor physical health were 3.4 times less likely than those in good physical health to engage in leisure activities when controlling for all other variables.

Requiring support for BOTH ADLs and IADLs was found to be a predictor of leisure engagement in the simple linear regression. This was shown to continue to be a predictor of leisure engagement when controlling for all other variables in the multiple linear regression. Those who required support for BOTH ADLs and IADLS were 3.3 times less likely than those who required support for either ADLs or IADLs to be engaged in leisure activities.

Age was shown to be a significant predictor of leisure engagement in the simple linear regression. When controlling for other variables in the model, participants who were aged 65 years and older were 3 times less likely than those aged 40-49 years to be engaged in leisure activities. There was no significant difference between the youngest (40-49 years) and middle age (50-64 years) groups.

Type of living situation was identified as a significant predictor of leisure engagement in the simple linear regression. When controlling for all other variables in the model, type of living situation was also a significant predictor of leisure engagement, with those in residential settings 2.5 times less likely than those in community group homes to be engaged in leisure activities. Those living independently or with family were also 3 times less likely to engage in leisure activities than those living in community group homes.

Gender, level of difficulty getting around community environment, and mental health were not found to be significant predictors of leisure engagement when adjusting for other variables in the model.

Table 4.9: Linear Regression for leisure variable adjusting for other variables

Leisure	Unstandardised Coefficient (B)	P	Beta	95% Confidence Intervals	
Gender					
• Female	-.83	.375	-.031	-2.67	1.01
Age					
• 50-64	-1.07	.322	-.041	-3.19	1.05
• 65+	-3.04	*.026	-.093	-5.7	-.37
Level of ID					
• Level of ID Mild	2.9	*.020	.091	.45	5.34
• Level of ID severe/profound	-4	*<.001	-.139	-6.22	-1.79
Type of living situation					
• Independent/family	-3	*.043	-.079	-5.9	-.1
• Residential care	-2.45	*.018	-.091	-4.47	-.43
Physical health					
• Poor physical health	-3.42	*.012	-.094	-6.1	-.74
Mental health					
• Poor mental health	-2.06	.061	-.068	-4.2	.09
Physical environment (home)					
• Difficulty	-4.68	*<.001	-.135	-7.28	-2.08
Physical environment (community)					
• Difficulty	-1.5	.170	-.053	-3.64	.65
Friends outside home					
• No friends outside home	-4.35	*<.001	-.164	-6.31	-2.38
Self-care activities					
• Support required for both ADL and IADL	-3.27	*.021	-.088	-6.04	-.49

Leisure	Unstandardised Coefficient (B)	P	Beta	95% Confidence Intervals	
Productivity					
Not currently engaged in productivity role	-7.16	*<.001	-.192	-9.91	-4.4

* Indicates significance, p<.05

4.5 Conclusion

The findings demonstrate that a variety of factors influence engagement in self-care, productivity and leisure activities. It appears that factors within the person, including physical health, mental health, level of ID, and factors within the environment, such as physical environment, presence of friends, and living situation can predict engagement in self-care, productivity and leisure activities.

Overall, difficulty getting around home and community environment, and poor physical health were the strongest predictors of preclusion from engagement in all three domains of self-care, productivity and leisure activities.

Residential living situation, severe/profound level of ID, and 65+ age group were found to be predictors of engagement in two out of three domains of activity.

Other factors were only found to be significant for preclusion from engagement in leisure activities only, including: not engaged in a productivity role, no friends outside the home, mild level of ID, support required for BOTH ADLs and IADLs, and independent/family living situation.

Discussion

5.1 Introduction

This chapter discusses the implications of the findings from the analysis in the context of current literature and policy. It also discusses the implications of the findings for occupational therapy practice, service planning and policy for people ageing with ID. The findings of the study indicated that a number of factors may influence engagement in self-care, productivity and leisure activities. In particular, factors within the physical environment, and physical health were found to impact on engagement across all three domains of self-care, productivity and leisure activities. Ability to get around the home and the local community, and physical health were the strongest predictors of engagement in the current study. Residential living situation, severe/profound level of ID and older age (65+ years) were found to have significant influence on two out of the three domains of activities examined. These findings have a number of important implications for policy and practice with people growing older with ID.

5.1.1 Research Aim

The main aim of the study was to investigate the engagement in daily life activities of people ageing with ID in Ireland, and to analyse the key factors that relate to engagement in daily life activities.

5.1.2 Main research question

The overall research question is “to what extent are people with intellectual disability engaged in daily life activities in terms of self-care, productivity and leisure activities? In addition to this broad research question, the study sought to investigate the main factors influencing engagement in daily life activities, including self-care, productivity and leisure activities for people ageing with ID.

5.1.3 Research Objectives

- To investigate the usefulness of a modified occupational perspective as a guiding perspective to investigate daily life activities of adults ageing with ID.
- To undertake a review of the literature on occupational engagement in daily life of adults with ID focusing on engagement in daily life activities (self-care, productivity and leisure).
- To identify elements that influence engagement in daily life activities of adults with ID as they age including the role of demographic variables and factors within the person, environment and activity. This will involve the following:
- Variables related to daily life activities, in terms of self-care, productivity and leisure will be analysed in order to investigate the levels of engagement in daily life activities of adults currently ageing with ID in Ireland.
- Objectively measurable key indicators of other personal or

environmental factors, including physical, cognitive, affective, physical environmental, and social environmental factors, will be examined in relation to self-care, productivity and leisure in order to determine the predictors of engagement in daily life activities of adults ageing with ID in Ireland.

- Demographic factors such as age, gender, level of ID, and living situation will be examined in relation to self-care, productivity, and leisure activities in order to determine the predictors of engagement in daily life activities of adults ageing with ID in Ireland.

5.2 Environmental Factors and Ageing in Place

5.2.1 The physical environment

In this study, the physical environment was defined as physical natural and built factors that surround the person in their daily life (Law *et al*. 2002). Seventeen percent (N=119) of the sample reported difficulty getting around their home environment. Those who reported difficulty getting around the physical environment of their home or local community were significantly less likely to engage across all domains of self-care, productivity and leisure activities. This illustrates the role of the physical environment in supporting engagement in daily life. These findings also support the concept of occupational deprivation within an occupational justice perspective, which posits the view that factors

within the environment, that are outside the control of the person can hinder engagement in occupation (Whiteford 2010).

It is important to note that the interaction between the person/environment/occupation is dynamic and can have dramatic effects on the ability to engage in an occupation (Christiansen *et al.* 2005). Chippendale & Bear-Lehman (2010) outlined how age-related changes in sensory function and mobility can cause once easily accessible environments to become prohibitive of engagement in daily life activities. The current study supports the idea that physical environment in which an individual lives has a significant influence on engagement in daily life. Following on from this line of thinking, it should be possible to promote engagement in meaningful occupation through creation of environments that are supportive of engagement.

Kahlin *et al.* (2016) report that as people with ID grow older, they may engage less in community life and spend more time at home. Current Irish policy is promoting closure of traditional day services in favour of "day activation" at home through increased community engagement (Health Service Executive 2012). This means that as people with ID age, they may spend more time at home, which further increases the potential of the home environment to support or hinder engagement in daily life. This is a particularly important consideration for the group who report difficulty getting around their home environment, which make up 17% of the sample in the current study. Some studies, such as that of Kahlin *et al.* (2016) found that not all residents of community

group homes were able to access all areas of their home, there was a lack of accessibility features, and no evidence of adaptations to the environment to support cognition (e.g. signage, labelling) that people may need as they grow older. Other factors such as nursing style uniforms, segregated staff spaces, and scheduled mealtimes also impacted on the person's engagement in daily life (Kahlin *et al.* 2016). Although the current study focused on a broad overview of factors influencing engagement in daily life rather than examining specific features of the physical environment that support or hinder engagement, the findings of Kahlin *et al.* (2016) are concurrent with the findings of the present study, which indicate that difficulties getting around the home environment may be a factor hindering engagement in self-care, productivity and leisure activities. An occupational justice perspective would advocate for the modification and adaptation to the home environment to support engagement in meaningful occupation, a core occupational right (Whalley Hammell & Iwama 2012). The current study provided a first insight into possible factors influencing engagement in daily life activities for people ageing with an ID at a population level. Future studies would benefit from examination of the impact of the physical environment on engagement in daily life in greater depth.

In the general ageing population, Chippendale & Bear-Lehman (2010) have illuminated the importance of physical home adaptation to support the changing needs to support people to continue to live in

their preferred home environment as they grow older. Campbell & Herge (2000) describe how therapists, such as occupational therapists and physiotherapists can assess the person's current abilities and areas of need, and work on building skills with the person, their caregivers and modifying the environment to support greater engagement and integration within the community and ageing in place. In many cases, adaptations can be made to the physical environment to support continued engagement in meaningful daily activities for people with ID as they age.

The physical environment of the local community was also an important area of consideration in the current study. Prevalence of difficulty getting around the local community was high, with the majority 64.2% (N=444) of participants reporting that they have difficulty getting around their local community, or that they do not travel around their local community at all. This was also reflected in the findings of regression analysis which showed that difficulty getting around the local community was a predictor of preclusion from engagement in self-care, productivity and leisure activities for people ageing with ID. Chippendale & Bear-Lehman (2010) have outlined factors within the environment of the local community which can impact on engagement in daily life for older adults in the general population. They found design of footpaths, poor signage, obstacles, traffic safety, and geographical proximity may support or hinder the person's ability to access their local community. This may also be true

for people ageing with ID. Cramm *et al.* (2016) have highlighted how people may become increasingly dependent on supports within the local community as mobility status declines in order to facilitate ageing in place. An occupational perspective would also emphasise the need to consider more subjective factors within the cultural and institutional environment that may influence engagement in daily life activities, however, this was beyond the scope of the current study, which focussed on gathering objectively measurable data. However, the influence of cultural and institutional environmental factors deserves further investigation in future research.

5.2.2 Ageing in Place

The current study shows how the physical environment may be a predictor of engagement in self-care, productivity and leisure activities for people ageing with ID. It is important to consider how this environment can be maintained as people grow older. In recent years, increased attention has been given to models that support a person to grow old in their preferred living environment, often known as "ageing in place". This is reflected in policies such as the National Positive Ageing Strategy (Department of Health 2013b), and Age Friendly initiatives (Age Friendly Ireland 2015). The majority of older adults in the general population prefer to age in place (McCallion 2014). Literature regarding ageing in place for people with ID is emerging, and appears to indicate that people with ID also prefer to age in place (Bigby 2008, Shaw *et al.* 2011).

This study found that difficulty getting around the physical environment of home and community was a predictor of preclusion from engagement in self-care, productivity and leisure activities. Following on from this idea, creation of a supportive physical environment should facilitate engagement in daily life as people with ID grow older. However, Maes & Van Puyenbroeck (2008) found that the types of physical home environments provided for people with ID in Belgium were not adapted to meet the changing needs of an ageing population.

As experts in enabling meaningful engagement in daily life through creation of supportive environments, occupational therapists need to advocate as a profession to be included in planning for creation of age-friendly environments, particularly for those ageing with ID. Within an occupational justice perspective, it is not sufficient to provide modifications to the environment at an individual level without consideration to the broader institutional factors influencing engagement in daily life (Wilcock & Hocking 2015). The modified occupational perspective was useful to highlight objectively measurable elements within the physical and social environment that may influence engagement in daily life activities. However, further investigation is needed to more subjective factors within the cultural and institutional environment, with a focus on personal meaningfulness of the activities, and spiritual factors that may influence engagement in daily life activities.

However, the present study does provide some support for the concept of the unique perspective of occupational therapy, including consideration of occupational, personal and environmental factors to broaden the understanding of ageing in place and how the environment can be adapted to support engagement, a key determinant of ageing well for people with ID. This study provides information at a population-based level, and supports the idea that personal, environmental and occupational factors influence engagement in daily life. The literature shows how consideration is needed primarily to the physical environment, but also to the social and institutional environments of people ageing with ID, in order to support creation of environments that support people of diverse abilities to engage in daily activities, and maintain the social connections that enable people to age in place. This further emphasises the need for additional research focused on subjective aspects of occupation, including attention to institutional, social, cultural and spiritual factors that may influence engagement in daily life activities.

5.2.2.1 Social Environment

In the current study, presence of friends outside the home was used as a key indicator of the social environment of people ageing with ID. Those who reported that they did not have friends outside the home were significantly less likely to engage in leisure activities. This is an interesting finding that may allude to the role that leisure activities play

in supporting social networks of people ageing with ID, and deserves further investigation in future research.

It is also an interesting finding given that Chippendale & Bear-Lehman (2010) and McCallion (2014) argue that the primary factors that enable people to age in place are the social networks and support resources that surround people ageing with ID, as well as the level of accessibility provided by the physical environment. This is also supported by the findings of Cramm *et al.* (2016). As the majority of opportunities for social connections happen within the community, working to promote community accessibility will also be a crucial factor in supporting people with ID to age in place.

People ageing with ID may be at risk of decreased social networks and supports, particularly as they grow older (McCausland *et al.* 2015). Furthermore, the findings of the current study show that older age was a significant predictor of preclusion from engagement in productivity roles within employment, day services, or voluntary work. Engagement in these productivity roles has been shown to be an important source of social networks and friends (Jahoda *et al.* 2008, Campbell 2012). This means that adults growing older with ID are at an even greater risk of reduced social networks as they age, therefore supporting engagement in social activities is even more important.

The importance of social supports from staff to enable people with ID to engage in daily life has been highlighted by Mahoney *et al.* (2016). Future studies would also benefit from greater attention to the social

environment, including family, friends, partners, and support staff and how this may influence the person's ability to engage in daily life. The current study utilised a key indicator of an individual's social environment, and it is clear from the literature that the social environment can be a vitally important resource for people ageing with an ID, and warrants greater exploration in future research.

5.2.2.2 Institutional Environment

In the occupational therapy literature, the institutional environment refers to socio-economic, political and legal factors that influence engagement in daily life (Law *et al*. 2002). Although the influence of the institutional environment is broad, far-reaching, subjective, and often difficult to observe in concrete terms, direct impact of policies such as the "Time to Move On" (Health Service Executive 2011) can be viewed in types of living situation availed of by people with ID, and how this impacts on engagement in self-care, productivity and leisure activities. The present study found that living in a residential setting was a significant predictor of preclusion from engagement in leisure activities, and a predictor of requiring increased support for self-care activities. Consideration of how a person's current living situation may facilitate or hinder engagement in self-care, productivity and leisure activities is particularly pertinent in the current context of deinstitutionalisation. The benefits of community-based living are numerous and well-documented, e.g. (Emerson & Hatton 1994, Bigby 2005) but Bigby & Fyffe (2006) found that although often promoted as

a person-centred approach, deinstitutionalisation processes were often more determined by organisational factors, with standardised house design that may limit potential for adaptations to support the person, accommodation of residents based on similarity of needs rather than personal preferences, and timing of transitions influenced by organisational timelines rather than preparation. Similar findings were reported by Thompson *et al.* (2004) in their UK-based study. Overall, Bigby & Fyffe (2006) emphasise that deinstitutionalisation is much more than a geographical relocation to community, and that much work remains to actively support people with ID to engage in community life. They argue that more work is needed on developing equality of access at a community level, to prepare communities for deinstitutionalisation as well as people with ID. This demonstrates the need for creation of environments that can meet the needs of people with ID as they grow older. This will require careful planning, and education for those in both disability support and care of the older person sectors in order to best meet the needs of this growing population.

It is also important to note that residential living situation was not the only type of residence found to be a predictor of preclusion from engagement in leisure activities in this study. Those living independently or with family were also found to be significantly less likely to engage in leisure activities when compared to those living in community group homes. This deserves further investigation, as it may

be an indicator of lack of supports for those based in the community without strong links to disability support services. Future research may also benefit from examination of engagement in daily life as implementation of these policies continues, in order to investigate the changes that these policies may bring to the lives of people ageing with ID.

It is also important to note that the institutional environment is complex and multifaceted, and often subjectively experienced. Future research should focus on examining the influence of the institutional environment in greater depth for the population of people ageing with an ID.

5.2.3 Strategies to support ageing in place for people with ID

The National Positive Ageing Strategy (Department of Health 2013b) appears to advocate active engagement in daily life to promote health and well-being, through facilitation of opportunities for meaningful engagement and promotion of strategies to maintain health and well-being. The main goals of this policy include removal of barriers to engagement in daily life at home and within the community, promotion of health and well-being, ageing in place and evidence-based approaches to positive ageing (Department of Health 2013b). While this policy doesn't focus on ageing with ID (O'Donovan *et al.* 2017), the overall goals of the policy match well with the aims of promoting engagement in daily life for people with ID as they grow older. Taking an occupational justice perspective, it would seem that greater

awareness of people with ID is needed within policy to ensure the needs of this population are met, particularly as they grow older, to create a more inclusive society with equality of access in home and community (O'Donovan *et al.* 2017).

5.2.3 Summary

In summary, this study supports the view that for people ageing with ID, the physical environment within the home and local community has a significant influence on the person's ability to engage in self-care, productivity and leisure activities in daily life. The literature demonstrates how factors within the physical and home environment can be modified to support engagement in daily life. This is beginning to take place within age-friendly communities within the general ageing population. However, greater consideration needs to be given to inclusion of people ageing with ID as part of the ageing population living within the community.

Utilising a modified occupational perspective (through consideration of personal, environmental and occupational factors that influence engagement in daily life) in this study has shown how occupational therapists have a valuable contribution to make in the process of integrating people ageing with ID with the general ageing population in terms of creation of environments that support engagement in daily life, with an understanding of the dynamic relationships between the person, the environment, and their daily meaningful activities. There are opportunities to further develop the role of occupational therapy in

working with policy-makers, local authorities, service-planners and developers to inform evidence-based recommendations to promote creation of inclusive home and community environments.

In this study, objectively measureable key indicators of social networks and types of living situation were shown to have an influence on engagement in self-care, productivity and leisure activities, and had emphasised the need for further exploration of the social, cultural and institutional environments in greater depth for the population of people ageing with an ID. The literature has demonstrated how proactive planning for ageing is a crucial part of enabling ageing in place and optimal outcomes for people ageing with ID.

5.3 Health and Ageing

5.3.1 Physical health and people ageing with ID

In the present study, information was gathered regarding participant's self-reported physical health, and categorised as either "good physical health" or "poor physical health" for the purposes of analysis. Poor physical health was found to be a significant predictor of preclusion from engagement across all three domains of self-care, productivity and leisure activities. Physical health is a key determinant of ability to engage in daily life, and an important component of well-being (Wilcock 2006a). This is particularly important given that people ageing with ID are at increased risk of diseases associated with ageing earlier than the general population (Bershadsky *et al.* 2012).

Attention to physical health factors is essential, as a number of studies have identified higher rates of physical health conditions amongst populations of people ageing with ID, including high rates of osteoporosis, osteopenia, thyroid difficulties, dementia, and sensory difficulties, eye related conditions such as macular degeneration and cataracts, constipation, as well decreased incidences of cardiovascular conditions and diabetes compared to the general ageing population (Janicki *et al.* 2002, Coppus 2013, McCarron *et al.* 2014). Perkins & Moran (2010) and McCarron *et al.* (2013) have also identified higher rates of multimorbidities amongst a population of people ageing with ID compared to the general ageing population. Other research conducted by McCarron *et al.* (2005) indicated that rates of co-morbidities (particularly for lung disease, gastric issues and decreased mobility) were higher for those ageing with ID and dementia. Given the high rates of multimorbidities amongst this population, Goddard *et al*. (2008) argue for greater inclusion of people with ID in policies and service provision for long-term and chronic health conditions. In tandem with increased rates of multimorbidities, lifestyle factors must be considered when examining physical health of people ageing with ID. Bodde & Seo (2009) and Coppus (2013) report that people with ID tend to lead more sedentary lifestyles, with decreased physical activity compared to the general population, and increased risk of obesity.

The current study found that 15.7% (N=108) respondents reported poor physical health, which appears to be relatively low in light of the

literature exploring health issues for people ageing with ID. However, poor physical health was found to be a predictor of preclusion from engagement across all three domains of self-care, productivity and leisure activities in this study. Haveman *et al.* (2010) outlined that maintaining or preventing deterioration in physical status, good oral health, good nutrition, engagement in physical activities and reduced incidence of polypharmacy were primary outcome areas for maintenance of good physical health for people ageing with ID. Given the potential of poor physical health to negatively influence engagement in daily life, it is essential to consider how to prevent or minimise barriers to engagement caused by poor health. Preventive health measures may be a valuable means of preventing onset of health conditions.

Preventive health measure and health promotion approaches are increasingly recognised in Irish national policy, such as Healthy Ireland (Department of Health 2013a) as a key tenet of maintaining a healthy population. Though this policy doesn't consider the particular needs of people ageing with ID (O'Donovan *et al.* 2017), the underlying principles of health promotion are very relevant to this population. Future policies should be more inclusive of people with ID, in order to promote sustainable communities that can effectively support people to maintain health, and engage in daily life.

5.3.1.1 Preventive health measures

Given that the findings of this study show that poor health can be a barrier to engagement in self-care, productivity and leisure activities, ways of overcoming or minimising the effects of poor health should be explored. This aligns with an occupational justice perspective to remove barriers to engagement in order to support active engagement in daily life. Preventive health measures and health promotion approaches involve intervention at early stages to minimise effects of ill health. Primary preventive approaches refer to interventions that prevent or reduce incidence of ill health, (Byers-Connon *et al.* 2012). However, some studies report that adults ageing with ID are at increased risk of health conditions associated with ageing (such as sensory function, mobility and cognition changes) as such changes may not be detected due to lack of preventive health measures, or skills on part of caregivers or staff to assess and address these issues (Janicki *et al.* 2002, Martinez-Leal *et al.* 2011). The literature shows that support staff are critical supports for people with ID to access health services and other supports, but are not always well equipped to support the changing health needs of people with ID as they age (Bowers *et al.* 2014, Wark *et al.* 2015b, Mahoney *et al.* 2016). It would appear that utilisation of preventive health measures is lower amongst the population of people ageing with ID, when compared to the general ageing population.

5.3.1.2 Health Promotion Programmes

This study shows that poor health is a predictor of preclusion from engagement in self-care, productivity and leisure activities for people ageing with ID. The literature demonstrates how a number of health promotion programmes are emerging for people with ID (Llewellyn *et al.* 2004, Aranow 2005, Marks *et al.* 2013). Given the relationship between health and engagement in occupation, promotion of good health is essential in order to facilitate engagement in occupation, which is in turn supportive of health and wellbeing (Wilcock 2006a). In the general ageing population, secondary health promotion programmes have been found to have very positive outcomes in terms of self-efficacy and positive health changes (Jackson *et al.* 1998, Mountain *et al.* 2008). Given the detrimental impact of poor physical health on engagement in self-care, productivity and leisure activities that people ageing with ID may experience as found in this study, people ageing with ID may also benefit from secondary preventive programmes with an occupation-focused mix of education and practical tasks, with adaptation to meet the specific health needs of a population of people ageing with ID. This is supported by the findings of Hogg *et al.* (2001) and Martinez-Leal *et al.* (2011).

5.3.2 Ageing, retirement and people with ID

In this study, increasing age was identified as a significant predictor of engagement in productivity and leisure activities, with those aged 65 years and older significantly less likely to be engaged in productivity

and leisure activities than those who were younger (aged 40-49 years). There were no significant differences between those in the youngest age group (40-49 years) and the middle age group (50-64 years). This is interesting, given the tendency of people in the general ageing population to retire from employment at around 65 years of age.

However, people with ID may not necessarily wish to retire at this age. In fact, the literature shows that many people growing older with ID have expressed apprehension when faced with retirement (Bigby *et al.* 2011), as engagement in that productivity role provided important meaningful engagement opportunities and social connections. Many people also expressed fear regarding lack of resources and availability of services post retirement (Bigby *et al*. 2011). People with ID wish to continue to be actively engaged as they grow older (McDermott & Edwards 2012, Burke *et al.* 2014). Thorpe *et al.* (2001) report that people ageing with ID may experience difficulties as they age, but that this shouldn't be a barrier to active engagement in life, as other issues such as physical illness or conditions should be treated separately.

Planning for retirement has been found to be an important factor in positive transition to retirement in the general population (Llewellyn *et al.* 2004). Innovative options for retirement for people with ID are developing, as evidenced by Stancliffe *et al*. (2015), who reported positive outcomes in terms of social inclusion from their study trialling a transition to a retirement lifestyle through engagement in community

groups in Australia. Similar programmes could be of benefit to those ageing with ID in Ireland.

Given the findings of this study which show that older age may be a predictor of preclusion from engagement in productivity and leisure activities, there is need for services that can meet the changing needs of this population. An occupational justice approach supports the need for development of options for engagement in productivity roles for older people with ID are required in order to promote and maintain quality of life and well-being as people grow older. This is especially relevant in light of current policy promoting closure of traditional day services and replacement with community-based supports (Health Service Executive 2012). It is essential that opportunities for engagement in productivity and leisure activities are facilitated for people with ID as they grow older, in order to promote optimal engagement in daily life.

5.3.3 Strategies to implement positive ageing approaches with people with ID

Through identification of physical health as a predictor of engagement in self-care, productivity and leisure activities, this study supports the idea that promotion of good physical health for people ageing with ID is essential in order to support engagement in daily life. This is also supported by the current literature, and theories of ageing.

Theories of ageing such as successful or active ageing which support engagement in daily life as a mediator of health are relevant for people with ID, and people with ID should be included in policies such as Healthy Ireland (Department of Health 2013a), which are underpinned by these theories. The current study supports the occupational therapy concept that health and engagement in activities are intertwined, with poor health being a predictor of preclusion from engagement in self-care, productivity and leisure activities, and engagement in occupation has been shown to be beneficial for health and wellbeing in the literature (Reed & Nelson Sanderson 1999, Wilcock 2006a). Greater collaboration between disability support services and healthcare providers could promote creation of primary and secondary health promotion programmes that would enable people ageing with ID to optimise their physical health and support engagement in self-care, productivity and leisure activities as they grow older.

This study also found that people with ID may be at risk from preclusion from engagement in productivity and leisure activities as they age over 65 years. The literature appears to show that people ageing with ID continue to value engagement in productivity and leisure activities as they grow older, so there is need for development of opportunities to support engagement in productivity and leisure activities as people with ID age. This is particularly pertinent in the current context of changing policies on day services, which were the most common productivity role for participants in the current study.

The current study focussed on a broad overview of what people ageing with an ID are doing in their everyday lives, and what factors may potential influence engagement in these activities, using a modified occupational perspective focusing on objectively measurable factors. This study has highlighted the potential influence of factors within the person and the environment that require more in-depth exploration using an occupational perspective in future research.

5.3.4 Summary

Good physical health is a key determinant of well-being, and an important factor influencing engagement in self-care, productivity and leisure activities. Adults ageing with ID may be at increased risk of poor health for a variety of reasons, so it is even more important to promote preventive health strategies such as regular health checks, screening for common chronic health conditions, and vaccinations.

In addition, the literature shows the role of health promotion as a means of enhancing health and well-being for people ageing with ID. Occupation-based approaches that target self-efficacy, empowerment and health behaviours may be beneficial for people ageing with ID. Focus is needed on specific health issues of people ageing with ID, with consideration to the usefulness of a practical, occupation-focused programme that builds self-efficacy and positive health behaviours.

Increasing age was found to be predictor of preclusion from engagement in productivity and leisure activities in the current study.

The literature shows that people with ID value continued engagement in productivity and leisure activities as they age. This means that opportunities for meaningful leisure and productivity activities should be facilitated for people with ID.

5.4 Reflections on the Modified Occupational Perspective

5.4.1 Activity vs. Occupation

This study is primarily concerned with engagement in daily life activities guided by a modified occupational perspective. This study attempted to utilise a version of the personal/environmental/occupational perspective guiding occupational therapy, and apply this to a large quantitative dataset. As the current study sought to examine engagement in daily activities for a population of people ageing with ID as a whole, it was deemed more suitable to focus on a broad overview of objectively measurable potential factors influencing engagement in daily life, rather than considering individual factors within the person and environment in-depth.

In order to be able to include all participants from IDS-TILDA wave two, it was necessary to utilise objectively measurable data, which included the use of proxy respondents for those who had difficulties with verbal language. Proxy respondents cannot accurately report on the subjective experiences of meaning, identity and spirituality and so

these factors couldn't be considered in the design of the current study (Perkins 2007).

Subjective factors related to the personal meaningfulness of an activity, sense of competence, associated implications for identity, spirituality and more subtle factors related to the influence of the cultural and institutional environment could not be considered in this study. As a result, this study could not capture a true experience of occupation, as defined by occupational science literature. Central to the concept of occupation is the level of meaning that an activity holds for a person (Hasselkus 2002). In addition, Pierce (2003) maintains that occupation is subjectively experienced.

The current study considered what the population of people ageing with an ID do in their daily lives, and identified broad factors that may influence an individual's ability to engage in these daily life activities. This facilitated the use of robust statistical analysis techniques in order to consider the needs of the population of people ageing with ID as part of the nationally representative sample in the IDS-TILDA study. However, it is interesting to consider the Canadian Association of Occupational Therapists (CAOT) definition of occupational engagement in light of this, which focuses on level of involvement, meaningfulness, satisfaction, sense of competency and implications for identity that engagement in meaningful occupation can bring in addition to performance of the occupation (Polatajko *et al*. 2007).

The CAOT literature utilises a broad definition of the concept of occupational engagement, emphasising the doing of the activity within a specific sociocultural context and considering the level of meaning that the task holds for the person. As discussed in Chapter 1, this perspective is potentially very useful when considering the population of people ageing with an ID.

In this way, the current study focuses on one facet of occupational engagement only- relating to performance of activities in daily lives of people ageing with an ID in Ireland. This gave many interesting and fresh insights into the important of engagement in daily life as a component of health and well-being. However, it has also emphasised the need for greater exploration of subjective aspects of occupation and occupational engagement, related to cultural, spiritual and institutional factors that influence engagement in meaningful occupation, as well as consideration of supports available to the individual. Wave three of IDS-TILDA included questions related to spirituality and meaning for the population of people ageing with an ID.

The current study could be viewed as a first step towards building understanding of occupational engagement for people ageing with an ID in Ireland. It is clear that much more information is needed in order to build a picture of the experience of meaningful occupation for people ageing with an ID. Future studies focusing on self-reported data investigating the experience of meaningful occupation are needed in order to add to the current data and explore the implications of

occupational engagement for the health and well-being of people ageing with an intellectual disability in Ireland.

5.4.2 The Potential of an Occupational Perspective

Adapting occupational concepts for analysis of IDS-TILDA data highlighted for me the unique perspective of occupational therapy, considering personal, environmental and occupational factors. Though much information has been gathered in relation to what people do, lots more information is needed in order to examine true occupation, and occupational engagement, particularly in relation to factors related to the subjective meaningfulness of a particular activity, and the influence of cultural and institutional factors that influence engagement in meaningful occupation. More information is needed in relation to the supports required by the person.

The modified occupational perspective would appear to be a useful framework from which to examine engagement in daily life activities, as all of the key indicators of personal and environmental factors were found to be significant at differing stages of the regression analyses. Strength of influence varied across the type of activity, but all were found to be significant in regression analysis.

This study has illuminated the importance that environmental factors within the home environment and local community have as a strong predictor of engagement across self-care, productivity and leisure activities. The majority of the literature on engagement with

consideration of the environment of people ageing with ID refers to type of residence, or support staff available in isolation. The present study was able to take key indicators of the physical and social environments into account, thereby offering a broader insight into engagement in daily life activities. The modified occupational perspective demonstrated support for further investigation into the influence of personal, environmental and occupational factors in greater depth for the population of people ageing with an intellectual disability.

Both the literature review and the findings of the analysis showed how people ageing with ID may require support to perform self-care, productivity and leisure activities. The literature supports the idea that people ageing with ID can be actively involved in the activity and reap the associated benefits for health and well-being (Kjellberg 2002).

The literature showed how previous studies of engagement provide a variety of definitions of engagement. Using an occupational perspective in future studies has the potential to provide clear definitions of engagement, and highlight important factors to consider within the person, environment and occupation.

Other conceptualisations relevant to people with ID, such as ageing in place tend to consider interactions between personal and environmental factors (McCallion 2014). The modified occupational

perspective also considered activity as a key component of engagement in daily life.

An occupational perspective would be useful to outline important domains of concern for research, and practice with people ageing with ID. The underpinning values of the occupational perspective including empowerment, enablement and justice align well both with rights based approaches to disability support services (UN Enable 2006), and theories of ageing such as successful ageing (Rowe & Kahn 1997, Polatajko *et al.* 2007).

Engagement is daily life is increasingly recognised as an important factor influencing quality of life and health, both of which are important outcome areas for disability support services, and healthcare services. By its nature, a focus on occupational engagement works to promote engagement in community life to promote health and wellbeing, which is congruent with both disability and healthcare sectors. An occupational engagement focus may be ideal to bridge these two sectors to support the needs of adults ageing with ID.

5.4.3 Occupational Justice

Occupational justice is an occupational therapy concept that promotes a vision for a society where all members have the opportunity to participate in meaningful occupation (Wilcock 2006c, Wilcock & Hocking 2015). An occupational justice perspective on OT practice challenges occupational therapists to work not just with individuals but with communities, to promote removal of barriers to participation in

meaningful occupations for populations as well as individuals. In this way, occupational justice is forging a new vision of OT practice. It focuses on enablement, empowerment and social inclusion of those who are generally excluded from society (Nilsson & Townsend 2010). Definitions of these concepts as per the occupational science literature can be viewed in Appendix 9.

Key elements of this perspective promote the use of collaborative, empowering approaches, raising awareness of existing occupational injustices and respect for diversity (Wilcock & Hocking 2015). This is highly congruent with the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), which is underpinned by the values of inclusion, choice, person centeredness and empowerment (McCarron *et al.* 2011).

Occupational justice was an important guiding concept in the current study. The idea of occupational justice and working beyond the level of the individual to promote equitable access to meaningful occupation was a motivating factor in choosing to utilise IDS-TILDA data for the current study. The IDS-TILDA data provided high quality, robust quantitative data into a nationally representative sample of people ageing with an intellectual disability in Ireland. IDS-TILDA engages with individuals, service providers and government to promote best policy and practice for people ageing with an intellectual disability.

Enablement, empowerment and justice have been defined as the "pillars" underpinning OT practice (Townsend & Whiteford 2010).

Definitions of these concepts are available in Appendix 10.

Occupational justice serves to promote health and well-being so that people's physical, emotional and social needs are met through occupation (Durocher *et al.* 2014b). It also includes exerting citizen empowerment, choice and control (Durocher *et al.* 2014a).

Occupational justice provided important insights into recommendations for research, policy and practice for adults ageing with ID. Occupational justice concepts such as occupational rights and occupational marginalisation lend a language in which to frame important issues relating to engagement in daily life for people with ID. It provided a framework for recommendations, and rationale for new and exciting opportunities for occupational therapists utilising this perspective. Occupational justice also has important implications for service planning and provision of supports for people ageing with ID now and in the future.

Using occupational justice in OT practice means that occupational therapists will have to give greater consideration to environmental barriers that may hinder engagement in occupations, in order to promote engagement in meaningful occupation, and optimal health and quality of life with clients (Wolf *et al.* 2010). In particular, occupational justice has served to illuminate the role of the occupational therapist in supporting adults ageing with ID to engage in daily life through collaboration with policy makers, local authorities and service planners, as well as people ageing with ID and their caregivers

in order to promote equality of access to services, and increased opportunities for meaningful engagement as people with ID grow older.

The occupational justice perspective also served to highlight the unique contribution that occupational therapy can make as part of a multidisciplinary team supporting people ageing with ID through removal of barriers to engagement in daily life. This approach means that OT is aligning with human rights, social justice, empowerment and changing definitions of health and well-being, as well as moving away from a biomedical model (Kronenberg & Pollard 2006).

Occupational justice concepts are congruent with the ideals of a rights-based approach to disability supports, incorporating ideas of empowerment, self-determination and justice in an OT practice approach. It also supports theories of gerontology including successful or active ageing, health promotion and ageing in place, and provides an insight into how OT can play a role in supporting implementation of these concepts in practice. In this way, occupational justice provides a common ground for disability support and care of the older person services, highlighting how occupational therapy can be useful across multiple sectors.

5.5 Limitations and directions for future research

The current study had a number of limitations. It is important to note that while the use of logistic regression and linear regression techniques was useful to identify predictors of engagement in self-care, productivity and leisure activities of people ageing with ID, these findings cannot imply causation, as they are based on one wave of data. Future research would benefit from longitudinal examination of patterns of engagement in daily life activities over time, in order to inform how ageing processes, changing temporal environments and implementation of policies influence engagement in daily life. It would also facilitate identification of potential causal barriers and facilitators of engagement in daily life for people ageing with ID.

As discussed in section 5.4, an important limitation of the current study was the inability to consider the influence of subjective factors such as spirituality cultural environment, institutional environment and personal meaningfulness of the activities considered in the current study. Spirituality as defined by the occupational science literature is an important component of occupational engagement encompassing factors related to meaning, identity and spirit, which was not possible to capture in the present study (Law *et al*. 2002). It was also not possible to capture the influence of the cultural environment on engagement in daily life, as there were no relevant questions in the

IDS-TILDA data. As the influence of the cultural environment and spirituality are hard to define in concrete quantifiable terms, it was not possible to capture the influence of these factors in a quantitative study design as in the IDS-TILDA study. It would be essential that factors relating to personal meaning, and identity be gathered from the person themselves, which means that those who cannot self-report would have to be excluded, which would result in unfair representation of the population of the study. Future waves of IDS-TILDA data now include questions relating to spirituality and hope for people with ID, gathered in self-report data. Future studies examining engagement in daily life for adults ageing with ID would also benefit from consideration of these factors.

In addition, the current study focused on one aspect of occupational engagement, related to performance of daily life activities. Occupational engagement is more complex, including level of meaning of the activity, competence, satisfaction and implications for identity (Polatajko *et al.* 2007). The current study should therefore be viewed as a first step towards building a picture of occupational engagement of people ageing with an intellectual disability in Ireland. Future studies would benefit from increased gathering of self-reported data with a focus on spirituality, meaning and subjective factors related to occupational engagement as well as performance of these activities. More information is also required in relation to supports available to people ageing with an intellectual disability.

The current study focused on gathering objectively measurable data related to engagement in daily life activities for a population of people ageing with an intellectual disability in Ireland. Key indicators of personal and environmental factors were considered, where objectively measurable data was available. It was not possible to examine the influence of these factors in depth within the current study design. The findings of the current study identified that personal and environmental factors (particularly those related to the physical environment and physical health) have a significant influence on engagement in daily life activities. However, this analysis was completed at a very broad level and deeper exploration of these factors is required in order to build a picture of engagement in daily life activities for people ageing with an ID. Future research would benefit from a more in-depth exploration of the personal, environmental and occupational factors in order to provide a greater insight into the experience of ageing with ID, and inform strategies to remove barriers to engagement, and promote greater engagement in daily life for adults ageing with ID.

5.6 Conclusions

The aim of the present study was to examine objectively measurable factors that influence engagement in self-care, productivity and leisure activities of people ageing with ID. Factors within the physical environment of the home and community, and physical health, were found to be the strongest predictors of engagement in self-care, productivity and leisure activities of people ageing with ID in Ireland using IDS-TILDA wave two data. This study facilitated a broad view of

engagement, with consideration to factors within the person, their environment, and activity, and facilitated identification of some of the objective factors that are most influential on engagement in daily life activities.

The current study utilised a modified occupational perspective, considering objective personal, environmental and activity-related factors to examine engagement in daily life activities. This led to some very interesting insights into the role of the physical environment, health, and age on engagement in daily activities. However, the occupational science literature has emphasised the need for future research considering more subtle, subjective aspects of engagement in daily life activities with consideration needed to spiritual, cultural and institutional factors that influence engagement in daily life. The current study could be viewed as a first step towards building a picture of occupational engagement of people ageing with an intellectual disability in Ireland.

This study emphasises the current and potential role of the occupational therapist in supporting engagement of people ageing with ID. Occupational therapists are skilled in both the areas of environmental adaptation and health promotion which this study highlights may be very relevant for people ageing with ID. This study also illuminates the potential of occupational therapy to directly influence quality of life through supporting engagement in daily life.

The occupational justice approach utilised in this study shows how an occupational perspective on engagement in daily life is congruent with emerging disability policies and right-based approaches promoting empowerment and self-determination for people with ID, and equality of access to services within the community. The pragmatic nature of occupational therapy practice offers the potential to take practical steps to implement policies of inclusion, citizenship, self-determination and equality through use of an occupational justice perspective.

This study offers a unique perspective on engagement in daily life for people ageing with ID, utilising a modified occupational perspective to inform strategies to enable people with ID to age well. This study provides a greater insight into factors that affect engagement in daily life, an important determinant of health and well-being that is not given adequate consideration.

5.7 Summary of recommendations

A summary of recommendations for research, occupational therapy, service provision and policy makers based on the findings of the current study and the literature are outlined below.

5.7.1 Research

- Future research should utilise an occupational perspective and consider investigation of occupational engagement, focusing on supports available to the person, as well as subjective factors associated with occupational engagement, including

competence, satisfaction, meaning and identity in daily occupations. Consideration of mixed methods research designs may be useful as self-reported data will be essential in order to accurately gather this information.

- Future research should investigate environmental and personal factors that influence engagement in self-care, productivity and leisure occupations in greater detail in order to inform strategies to remove barriers to engagement in daily life for people ageing with ID.
- Future research should utilise longitudinal research methods to consider how patterns of engagement change over time, and investigate factors that influence changing patterns of engagement.
- Future research should consider the nature of engagement in occupations in more depth, such as types of leisure occupations, and whether occupations are undertaken by personal choice, or as part of habits or routines. Greater consideration of cultural and institutional environmental factors is required.

5.7.2 Occupational Therapy

- Occupational therapists should use an occupational justice perspective to develop and expand their role working with adults ageing with ID to incorporate collaboration with policy-makers, service planners and local authorities to provide

recommendations in creation of environments to support engagement for people of diverse abilities.

- Occupational therapists should work to develop and adapt occupation-focused health promotion programmes to meet the needs of people ageing with ID, as part of a multi-disciplinary team, focused on a person-centred approach.
- Occupational therapists should work as part of a multidisciplinary team to integrate theories of gerontology with a rights-based approaches to best meet the needs of people ageing with ID

5.7.3 Policy makers and service planners

- Greater attention should be given to engagement in daily life activities as a key determinant of successful ageing, health and well-being in theories of ageing, policies and practice with adults ageing with ID.
- Timely planning for ageing processes is essential in order to enable ageing in place and for people with ID.
- Greater utilisation of preventive health measures and health promotion approaches, such as health screenings and vaccinations is needed to promote positive health outcomes for people ageing with ID.
- Policy-makers and local authorities should be more inclusive of people ageing with ID in developing national policies and age-friendly initiatives.

- Those working in disability support sectors and care of the older person need to collaborate and learn from each other in order to provide best possible outcomes for people ageing with ID.
- There is need for development of opportunities to support engagement in productivity and leisure occupations for people with ID as they grow older, and to emphasise preparation of community-based supports to enable people to engage in meaningful productivity and leisure occupations as they grow older.

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Appendices

Productivity Role:	**Brief description:**
Supported Employment	Supported employment aims to support people with ID to seek, obtain and maintain paid employment in the general workforce (Nic Suibne & Finnerty, 2014). People with ID are supported in the process of job selection, skills development and maintaining employment.
Sheltered Workshop	Sheltered workshops are more traditional segregated employment schemes for people with ID, often run by disability support services (Dague, 2012). People employed in sheltered workshops typically receive support to complete task, and generally receive lower wages than those in competitive community-based employment (Cimera, 2011). Work may be completed for therapeutic or commercial purposes, the types of work completed are varied, and workers may or may not receive payment for their work. (New Directions, 2012).
Day Services	There is a lack of clarity regarding definitions of day services (New Directions, 2012). Day programmes generally aim to support people in engagement in activities and development of skills, and therapy or health supports (New Directions, 2012). Day services may be facilitated

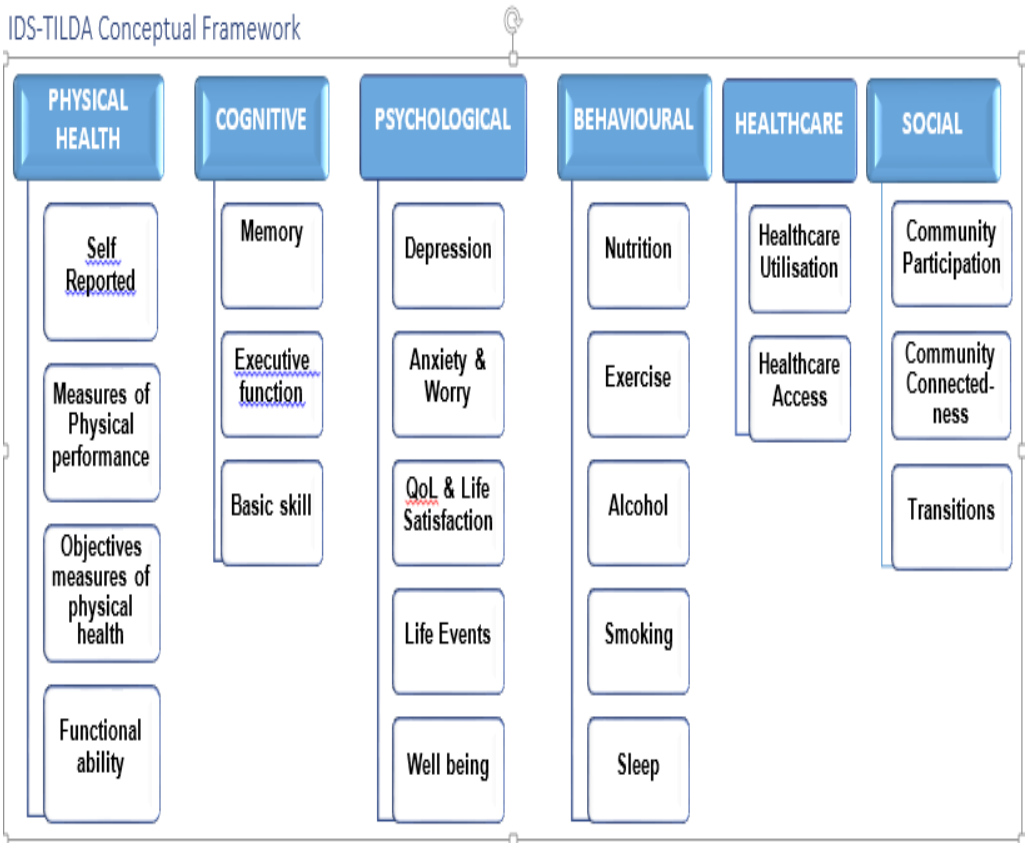
	within a segregated service provider setting, or within the community (New Directions, 2012).

Appendix 1
Types of Productivity

Roles for People

Ageing with an Intellectual Disability

Appendix 2
IDS-TILDA Conceptual Framework



Appendix 3

List of Variables in IDS-TILDA Wave 2:

Main Questionnaire	
Variable Name:	**Description:**
Respondent ID	ID
DataCollection_InterviewerID	Who interviewed this respondent?
DataCollection_StartTime	At what time did this interview start?
DataCollection_FinishTime	At what time did this interview finish?
DataCollection_BatchID	System generated unique batch identifier
DataCollection_BatchName	What name do you want to assign to this batch?
DataCollection_DataEntryMode	What is the data entry mode of this respondent?
DataCollection_Removed	Is the data of this respondent removed?
RespID	Respondent ID
Interviewer	Researcher ID
SectionQ	Please choose the Section that you will next complete:
Section 1: Coverscreen & Demographics	
CS_1	Now I would like to ask some questions about where you live. We have asked this question of you before but we are interested in finding out if many people

	have moved house since their last interview. Where do you live now?
CS_1_Other_Other	
CS_2	Is this the residence in which you were living at the time of the last interview?
CS_3	How many times have you moved since your last interview?
CS_4	What residence were you living in before current residence?
CS_4_Other_Other	
	What were the reasons for the move?
CS_501	• Physical health changes/change in health status
CS_502	• Loss of primary carer e.g. death of a parent
CS_503	• Change in Service Policy
CS_504	• Moved to accommodate service
CS_505	• Not happy where I was living
CS_506	• Funding Shortages/Staff Shortage
CS_507	• Lack of accessibility within the home/Home not accessible for my changing needs. (e.g. no downstairs facilities)
CS_508	• Lack of Nursing Support
CS_509	• Lack of 24hr care
CS_510	• As part of the transition process
CS_511	• Personal choice
CS_512	• I don't know the reason for the move
CS_513	• Other, please tell us

CS_5_Other	
CS_6	Now, thinking about the reason(s) you chose, what was the most important reason for this move?
CS_6_Other_Other	
	Who was involved in choosing new home
CS_71	• Myself
CS_72	• Family
CS_73	• Key Worker
CS_74	• The Staff
CS_75	• The Service
CS_76	• Other, please tell us
CS_7_Other	**When did you move?**
CS_8_date1_Month	(MM/YYYY) : Month: (MM)
CS_8_date1_Month_Codes	(MM/YYYY) : Codes
CS_8_date1_Year	(MM/YYYY) : Year: (YYYY)
CS_8_date1_Year_Codes	(MM/YYYY) : Codes
CS_8A	
CS_9_date1_Month	(MM/YYYY) : Month: (MM)
CS_9_date1_Month_Codes	(MM/YYYY) : Codes
CS_9_date1_Year	(MM/YYYY) : Year: (YYYY)
CS_9_date1_Year_Codes	(MM/YYYY) : Codes
CS_9A	
CS_10	Did you view any alternative accommodation options? (e.g. bungalow, independent living house or flat, nursing home)?
CS_11	Did you want to move?

CS_12	Are you happy with your new home?
CS_13	Is this the only move you made since your last interview?
CS_14	What residence were you living in before this move?
CS_14_Other_Other	
	What was the reason for the move?
CS_1501	• Physical health changes/change in health status
CS_1502	• Loss of primary carer e.g. death of a parent
CS_1503	• Change in Service Policy
CS_1504	• Moved to accommodate service
CS_1505	• Not happy where I was living
CS_1506	• Funding Shortages/Staff Shortage
CS_1507	• Lack of accessibility within the home/Home not accessible for my changing needs. (e.g. no downstairs facilities)
CS_1508	• Lack of Nursing Support
CS_1509	• Lack of 24hr care
CS_1510	• As part of the transition process
CS_1511	• Personal choice
CS_1512	• I don't know the reason for the move
CS_1513	• Other (please specify)
CS_15_Oth	• Please tell us
CS_16A	Did you move more than twice since your last interview?
CS_16	What residence were you living in before this move

CS_16_Other_Other	
CS_1701	• Physical health changes/change in health status
CS_1702	• Loss of primary carer e.g. death of a parent
CS_1703	• Change in Service Policy
CS_1704	• Moved to accommodate service
CS_1705	• Not happy where I was living
CS_1706	• Funding Shortages/Staff Shortage
CS_1707	• Lack of accessibility within the home/Home not accessible for my changing needs. (e.g. no downstairs facilities)
CS_1708	• Lack of Nursing Support
CS_1709	• Lack of 24hr care
CS_1710	• As part of the transition process
CS_1711	• Personal choice
CS_1712	• I don't know the reason for the move
CS_1713	• Other (please specify)
CS_17_Oth	• Please tell us
CS_18A	Did you move more than 3 times since your last interview
CS_18	What residence were you living in before this move?
CS_18_Other_Other	
CS_1901	• Physical health changes/change in health status
CS_1902	• Loss of primary carer e.g. death of a parent
CS_1903	• Change in Service Policy
CS_1904	• Moved to accommodate service

CS_1905	• Not happy where I was living
CS_1906	• Funding Shortages/Staff Shortage
CS_1907	• Lack of accessibility within the home/Home not accessible for my changing needs. (e.g. no downstairs facilities)
CS_1908	• Lack of Nursing Support
CS_1909	• Lack of 24hr care
CS_1910	• As part of the transition process
CS_1911	• Personal choice
CS_1912	• I don't know the reason for the move
CS_1913	Other,
CS_19_Oth	Please tell us
CS_20A	Did you move more than 4 times since your last interview
CS_20	What residence were you living in before this move
CS_20_Other_Other	
CS_2101	• Physical health changes/change in health status
CS_2102	• Loss of primary carer e.g. death of a parent
CS_2103	• Change in Service Policy
CS_2104	• Moved to accommodate service
CS_2105	• Not happy where I was living
CS_2106	• Funding Shortages/Staff Shortage
CS_2107	• Lack of accessibility within the home/Home not accessible for my changing needs. (e.g. no downstairs facilities)
CS_2108	• Lack of Nursing Support

CS_2109	• Lack of 24hr care
CS_2110	• As part of the transition process
CS_2111	• Personal choice
CS_2112	• I don't know the reason for the move
CS_2113	• Other,
CS_21_Oth	• Please tell us
CS_22	How many people live where you live (who live under the same roof as you)? By live we mean people who are NOT paid staff and who reside at this residence for the majority of the week (e.g. family members, other)
CS_22_Codes	Codes
CS_23	Do you have your own bedroom for yourself?
CS_24	How many people do you share a bedroom with? (other than with a partner
CS_24_Codes	Codes
CS_25	Would you prefer to have your own bedroom?
CS_26	Do you receive support from nursing staff in your residence?
CS_26_Other_Other	
CS_27	Do you receive support from other staff (e.g. key worker, support worker) in your residence (excluding nursing staff)...?
CS_27_Other_Other	
CS_28	Is your residence...? **(Type of building)**
CS_28_Other_Oth	

CS_29	Does your residence have a bathroom, bedroom and kitchen all on the same floor or level?
CS_30	About how often do you go to religious services?
CS_31	SELF-REPORT ONLY How important would you say religion is in your life?
CS_32	Do you find that you get comfort and strength from religion or not?
CS_33	Any Other Information (Religion)

Section 2: Cognitive Health	
CH_0	Only the SR can answer the questions in this section. It cannot be completed by a proxy. Part of this study is concerned with people's day-to-day memory. In this section, we will do some memory and concentration tasks. Some of them may seem rather easy and
CH_1	How would you rate your day to day memory at the present time? Would you say it is….?
CH_2	Can you tell me what year it is?
CH_3	Can you tell me what month it is?
CH_4	Can you tell me what day of the week it is?
CH_5	Can you tell me what today's date is?
CH_6	Any Other Information (Memory)
CH_7	Show me how you would use this comb.
CH_8	Can you put the top on the pen?
CH_9	Write your name
CH_10	TOTAL MOTOR PERFORMANCE (Max = 3)
CH_11	Point to your ear.
CH_12	Close your eyes.
CH_13	Show me the red pen
CH_14	Show me the green pen.

CH_15	TOTAL LANGUAGE-COMPREHENSION (Max=4)
CH_16	What is this called? Point to your nose.
CH_17	What colour is this pen?
CH_18	What colour is this pen?
CH_19	What is this called? Show the SR the key.
CH_20	TOTAL LANGUAGE PRODUCTION (Max = 4)
CH_21	Hold hands out with open hands. Which hand is the clip in?
CH_22	With hands closed. Which hand is the clip in?
CH_23	With hands behind back. Which hand/side is the clip in/on?
CH_24	TOTAL MEMORY IMMEDIATE (Max = 3)
CH_25	How many ears do I have?
CH_26	Count my fingers and thumbs
CH_27	How many weeks are in a year?
CH_28	I am going to sing a song. If you know the words I want you to sing along with me.
CH_29	TOTAL GENERAL KNOWLEDGE (Max = 4)
CH_30	Which of these is different?
CH_31	Place one red and one green pen down and hand SR the other red pen.

CH_32	Watch me move the paper clip, which hand will I move it to next?
CH_33	Now which hand will I put it in next?
CH_34	TOTAL CONCEPTUALISATION (Max = 4)
CH_35	Which of these have we not worked with already?
CH_36	TOTAL MEMORY DELAYED (Max = 1)
CH_37	Extend hand to shake hands
CH_38	TOTAL MOTOR PERFORMANCE (Max = 1)
CH_39	TOTAL TSI Score (Max = 24)
CH_40	Any Other Information (Cognitive Domains):

Section 3: Social Participation	
SP_101	Have voted in any recent election
SP_102	Have a hobby or pastime
SP_103	Have taken a holiday in Ireland in the last 12 months
SP_104	Have taken a holiday abroad in the last 12 months
SP_105	Have gone on a day trip or outing in the last 12 months
SP_106	Use the internet and/or email
SP_107	Own a mobile phone
SP_108	Not applicable - none of these statements apply to me
SP_109	Unclear response
SP_110	Don't know
SP_111	Refused to answer
SP_2	Over the past 30 days, on average, how many hours per day did you sit and watch TV or videos? Would you say ...?
	Are you a member of any of these groups, frequency of attendance, setting
SP_301	• Political party, trade union or environmental groups
SP_302	• Tenants groups, resident groups, Neighbourhood Watch
SP_303	• Church or religious groups
SP_304	• Charitable associations (e.g. St Vincent De Paul's)
SP_305	• Education, arts or music groups or evening classes
SP_306	• Retirement clubs

SP_307	• Special Olympics Network
SP_308	• Arch Club
SP_309	• Advocacy Group
SP_310	• Other (please specify)
SP_311	• Not applicable - You are not a member of any organisation, club or society
SP_312	• Unclear response
SP_313	• Don't know
SP_314	• Refused to answer
SP_3_Other_Other	
	Frequency attending group & setting in which it takes place
SP_3A_Political_SP3AQ	• 'Political party, trade union or environmental groups'
SP_3A_Tenants_SP3AQ	• 'Tenants groups, resident groups, Neighbourhood Watch'
SP_3A_Church_SP3AQ	• Church or religious groups
SP_3A_Charity_SP3AQ	• Charitable associations (e.g. St Vincent De Paul's)
SP_3A_Education_SP3AQ	• 'Education, arts or music groups or evening classes'
SP_3A_Retirement_SP3AQ	• Retirement clubs
SP_3A_SO_SP3AQ	• Special Olympics Network
SP_3A_Arch_SP3AQ	• Arch Club
SP_3A_Advocacy_SP3AQ	• Advocacy Group
SP_3A_Oth_SP3AQ	• Other
SP_4	• Any Other Information (General Activities)
	Do you do any of the following?

SP_501	• Go to the cinema theatre, concert or the opera
SP_502	• Eat out
SP_503	• Go to an art gallery or museum
SP_504	• Go to church or other place of worship
SP_505	• Go to the pub for a drink
SP_506	• Go to a coffee shop for light refreshments
SP_507	• Go shopping
SP_508	• Go to sports events
SP_509	• Participate in sports activities/events
SP_510	• Go to library
SP_511	• Go to social clubs (e.g. bingo, play cards)
SP_512	• Go to the hairdressers
SP_513	• Perform in local arts groups and choirs
SP_514	• Spend time on hobbies or creative activities
SP_515	• Visit family and friends in their home
SP_516	• Talk to family or friends on the telephone
SP_517	• Other activities outside of your home (please specify)
SP_518	• Unclear response
SP_519	• Don't know
SP_520	• Refused to answer

SP_521	• Non applicable - don't engage in any social activities
SP_5_Other_Other	
	Frequency of engagement in activities
SP_5A_Cinema_SP5	• 'Go to the cinema theatre, concert or the opera'
SP_5A_Eat_SP5	• Eat out
SP_5A_Art_SP5	• Go to an art gallery or museum
SP_5A_Church_SP5	• Go to church or other place of worship
SP_5A_Pub_SP5	• Go to the pub for a drink
SP_5A_Coffee_SP5	• Go to a coffee shop for light refreshments
SP_5A_Shopping_SP5	• Go shopping
SP_5A_Sports_SP5	• Go to sports events :
SP_5A_Participate_SP5	• Participate in sports activities/events
SP_5A_Library_SP5	• Go to library
SP_5A_Social_SP5	• 'Go to social clubs (e.g. bingo, play cards)'
SP_5A_Hair_SP5	• Go to the hairdressers
SP_5A_Choirs_SP5	• Perform in local arts groups and choirs
SP_5A_Hobbies_SP5	• Spend time on hobbies or creative activities
SP_5A_Family_SP5	• Visit family and friends in their home
SP_5A_Telephone_SP5	• Talk to family or friends on the telephone
SP_5A_Oth_SP5	• Other activities outside of your home
	Setting in which these activities take place
SP_5A_Cinema_SP5A	• 'Go to the cinema theatre, concert or the opera'
SP_5A_Eat_SP5A	• Eat out

SP_5A_Art_SP5A	• Go to an art gallery or museum
SP_5A_Church_SP5A	• Go to church or other place of worship
SP_5A_Pub_SP5A	• Go to the pub for a drink
SP_5A_Coffee_SP5A	• Go to a coffee shop for light refreshments
SP_5A_Shopping_SP5A	• Go shopping
SP_5A_Sports_SP5A	• Go to sports events
SP_5A_Participate_SP5A	• Participate in sports activities/events
SP_5A_Library_SP5A	• Go to library
SP_5A_Social_SP5A	• 'Go to social clubs (e.g. bingo, play cards)'
SP_5A_Hair_SP5A	• Go to the hairdressers
SP_5A_Choirs_SP5A	• Perform in local arts groups and choirs
SP_5A_Hobbies_SP5A	• Spend time on hobbies or creative activities
SP_5A_Family_SP5A	• Visit family and friends in their home
SP_5A_Telephone_SP5A	• Talk to family or friends on the telephone
SP_5A_Oth_SP5A	• Other activities outside of your home
	Who do you do these activities with?
SP_61	• Family
SP_62	• Friends within your house
SP_63	• Friends outside the house
SP_64	• Key worker/support staff
SP_65	• Other (please specify)
SP_66	• Unclear response
SP_67	• Don't know
SP_68	• Refused to answer
SP_6_Other_Other	

SP_7	Are there particular activities you would like to do more?
SP_8	What activities would you like to do?
SP_8_Codes	Codes
SP_9	Do you experience any difficulties participating in social activities outside your home?
	Reasons for difficulty:
SP_1001	• Health considerations or physically unable
SP_1002	• Need someone's assistance
SP_1003	• Need specialised aids or equipment that you do not have
SP_1004	• Transport services are inadequate or not accessible
SP_1005	• Service facilities are not accessible
SP_1006	• Not able to read signs and timetables
SP_1007	• Not allowed to go
SP_1008	• Have no one to go with
SP_1009	• Lack of local facilities or suitable activities
SP_1010	• Unfriendly or negative attitude towards you
SP_1011	• You are self-conscious of your intellectual disability
SP_1012	• Don't have enough money
SP_1013	• Don't have enough time
SP_1014	• Don't like social activities
SP_1015	• Getting too old
SP_1016	• Family and friends' residence not accessible to you
SP_1017	• Communication/language problems

SP_1018	• Other (please specify)
SP_1019	• Unclear response
SP_1020	• Don't know
SP_1021	• Refused to answer
SP_10_Other_Other	
SP_11	Do you experience any difficulty getting around your community (e.g. using zebra crossings, using traffic lights etc)?
	Reasons for difficulty
SP_121	• Footpaths design and surfaces
SP_122	• Lack of street crossings
SP_123	• Problems with signs (e.g. size and colour)
SP_124	• Getting access to recreational areas
SP_125	• Feeling unsafe
SP_126	• Other (please specify)
SP_127	• Unclear response
SP_128	• Don't know
SP_129	• Refused to answer
SP_12_Other_Other	
SP_13	Any Other Information (Social Activities):
Section 3b:	**Means of transport (last year)**
DR_101	• Bicycle/motorbike
DR_102	• Drive myself
DR_103	• Driven as a passenger by family
DR_104	• Driven as a passenger by friends
DR_105	• Driven as a passenger by service staff
DR_106	• Public bus (city or urban)

DR_107	• Public bus (intercity)
DR_108	• Public bus (rural)
DR_109	• Taxi/hackney
DR_110	• DART/Luas
DR_111	• Train (commuter)
DR_112	• Train (intercity)
DR_113	• Bus operating as part of a rural transport scheme
DR_114	• Other (please specify)
DR_115	• Not applicable - haven't used any forms of transport in the last year
DR_116	• Unclear response
DR_117	• Don't know
DR_118	• Refused to answer
DR_1_Other_Other	
DR_2	Which of these methods of transport do you use the most often?
DR_2_Other_Oth	
DR_3	How would you rate overall private transport options in your neighbourhood such as taxis and hackneys?
DR_4	How would you rate overall public transport options in your neighbourhood such as trains, public buses and community buses?
DR_5	How often do you use public transport? (e.g. the bus or train)
	Why don't you use public transport more often?
DR_601	• Private transport provided by intellectual disability service provider

DR_602	• Private transport provided by family
DR_603	• Private transport provided by friends
DR_604	• Use your own car
DR_605	• No public transport available
DR_606	• Public transport available does not take you where you want to go
DR_607	• Transport facilities are not accessible
DR_608	• Not able to read signs and timetables
DR_609	• Need someone's assistance
DR_610	• Your health prevents you
DR_611	• Fear of crime
DR_612	• Too dirty
DR_613	• Not convenient
DR_614	• Prefer to walk
DR_615	• Too expensive
DR_616	• Infrequent
DR_617	• You are self-conscious of your intellectual disability
DR_618	• Unfriendly or negative attitudes towards you
DR_619	• Communication/Language problems
DR_620	• All amenities are local, so don't need any transport
DR_621	• Other (please specify)
DR_622	• Unclear response
DR_623	• Don't know
DR_624	• Refused to answer
DR_6_Other_Other	
DR_7	Would you like to use more public transport?

DR_8	Do you feel there is a lack of transport facilities in your area?
DR_9	Does the lack of transport facilities in your area affect your lifestyle?
DR_10	What would you consider are the <u>most important improvements</u> that could be made to the transport options available to you?
DR_10_Codes	Codes
DR_11	Any Other Information (Transport):

Section : Social Connectedness	
	Do you have family?
SC_101	• Spouse/Partner
SC_102	• Mother
SC_103	• Father
SC_104	• Brother(s)
SC_105	• Sister(s)
SC_106	• Aunt/Uncle
SC_107	• Nieces/Nephews
SC_108	• Cousin
SC_109	• Not Applicable, I don't have any family
SC_110	• Other
SC_111	• Unclear response
SC_112	• Don't know
SC_113	• Refused to answer
	Where do they live in relation to you?
SC_2_Spouse_SC2AQ	• Spouse/Partner
SC_2_Mother_SC2AQ	• Mother
SC_2_Father_SC2AQ	• Father
SC_2_Brother_SC2AQ	• Brother(s)
SC_2_Sister_SC2AQ	• Sister(s)
SC_2_Aunt_SC2AQ	• Aunt/Uncle
SC_2_Niece_SC2AQ	• Nieces/Nephews
SC_2_Cousin_SC2AQ	• Cousin
SC_2_Oth_SC2AQ	• Other
	How often do you (a) meet up, (b) speak on the

	phone, (c) write, text, email or facebook
SC3_SpousSC3Suba_Meeup_botarrangeandchancmeetinSinglResponQuesti	Spouse/Partner, a) Meet up (both arranged and chance meeting)
SC_3_Spouse_SC_3Sub_b_Speak_on_the_phone_SingleResponseQuestion	Spouse/Partner, b) Speak on the phone
SC_3Spouse_SC3Sub_cWrite_textemailor_facebookSinglResponsQuestio	Spouse/Partner, 'c) Write, text, email or facebook'
SC3_MotheSC3Suba_Meeup_botarrangeandchancmeetinSinglResponQuesti	Mother, a) Meet up (both arranged and chance meeting)
SC_3_Mother_SC_3Sub_b_Speak_on_the_phone_SingleResponseQuestion	Mother, b) Speak on the phone
SC_3Mother_SC3Sub_cWrite_textemailor_facebookSinglResponsQuestio	Mother, 'c) Write, text, email or facebook'
SC3_FatheSC3Suba_Meeup_botarrangeandchancmeetinSinglResponQuesti	Father, a) Meet up (both arranged and chance meeting)
SC_3_Father_SC_3Sub_b_Speak_on_the_phone_SingleResponseQuestion	Father, b) Speak on the phone
SC_3Father_SC3Sub_cWrite_textemailor_facebookSinglResponsQuestio	Father, 'c) Write, text, email or facebook'
SC3_BrotheSC3SubaMeetupbotharrangandchancemeetinSingResponQuesti	Brother(s), a) Meet up (both arranged and chance meeting)
SC_3_Brother_SC_3Sub_b_Speak_on_the_phone_SingleResponseQuestion	Brother(s), b) Speak on the phone
SC_3BrotherSC_3Subc_Writetextemail_orfacebookSinglResponsQuestio	Brother(s), 'c) Write, text, email or facebook'
SC3_SisteSC3Suba_Meeup_botarrangeandchancmeetinSinglResponQuesti	Sister(s), a) Meet up (both arranged and chance meeting)
SC_3_Sister_SC_3Sub_b_Speak_on_the_phone_SingleResponseQuestion	Sister(s), b) Speak on the phone
SC_3Sister_SC3Sub_cWrite_textemailor_facebookSinglResponsQuestio	Sister(s), 'c) Write, text, email or facebook'

SC3_AuntSC3SubaMeetup_botarrangeandchancemeetinSinglResponQuesti	Aunt/Uncle, a) Meet up (both arranged and chance meeting)
SC_3_Aunt_SC_3Sub_b_Speak_on_the_phone_SingleResponseQuestion	Aunt/Uncle, b) Speak on the phone
SC_3_AuntSC_3Subc_Writetext_emailor_facebookSingleResponsQuestio	Aunt/Uncle, 'c) Write, text, email or facebook'
SC3_NiecSC_Suba_Meetupbotharrangeandchancmeetin SinglResponQuesti	Nieces/Nephews, a) Meet up (both arranged and chance meeting)
SC_3_Niece_SC_3Sub_b_Speak_on_the_phone_SingleResponseQuestion	Nieces/Nephews, b) Speak on the phone
SC_3Niece_SC3Sub_c_Writetextemail_orfacebookSingleResponsQuestio	Nieces/Nephews, 'c) Write, text, email or facebook'
SC3_CousiSC3Suba_Meeup_botarrangeandchancmeetinSinglResponQuesti	Cousin, a) Meet up (both arranged and chance meeting)
SC_3_Cousin_SC_3Sub_b_Speak_on_the_phone_SingleResponseQuestion	Cousin, b) Speak on the phone
SC_3Cousin_SC3Sub_cWrite_textemailor_facebookSinglResponsQuestio	Cousin, 'c) Write, text, email or facebook'
SC3_OthSC3Suba_Meetupbotharrangeandchancemeetin SinglResponQuesti	Other, a) Meet up (both arranged and chance meeting)
SC_3_Oth_SC_3Sub_b_Speak_on_the_phone_SingleResponseQuestion	Other, b) Speak on the phone
SC_3_OthSC_3Sub_cWrite_textemail_or_facebookSinglResponseQuestio	Other, 'c) Write, text, email or facebook' :
SC_4	Do you have friends outside your home
	How often do you
SC_5_aMeet_up_botharranged_andchance_meetingSinglResponseQuestio	a) Meet up (both arranged and chance meeting)
SC_5_b_Speak_on_the_phone_SingleResponseQuestion	b) Speak on the phone

SC_5_c_Write_text_email_or_facebook _SingleResponseQuestion	'c) Write, text, email or facebook'
SC_6	Now I would like to ask you some questions about happiness. Most of the time do you feel happy?
SC_7	What makes you happy?
SC_7_Codes1	• Unable to understand the question
SC_7_Codes2	• Unclear response
SC_7_Codes3	• Don't know
SC_7_Codes4	• Refused to answer
SC_7_Codes5	• SR not present/proxy unable to complete
SC_8	The next few questions are about how people sometimes feel. Do you ever feel lonely?
SC_9	How often do you feel lonely? Would you say.....?
SC_10	Do you ever feel left out?
SC_11	How often do you feel left out? Would you say...?
SC_12	Do you find it difficult to make friends?
SC_13	How often do you feel you lack friendship/friends?
SC_14	Do you ever feel isolated? (Never asked out to socialise e.g. out for coffee, I live very far away from other people)
SC_15	Do you have someone with whom you can

	confide? (e.g. someone that you feel at ease with, can talk to about private matters, and can call on for help)
SC_1601	• Spouse/Partner/Boyfriend/Girlfriend
SC_1602	• Parent
SC_1603	• Sibling
SC_1604	• Grandparent
SC_1605	• Aunt/Uncle
SC_1606	• Cousin
SC_1607	• Friend
SC_1608	• Neighbour
SC_1609	• Key worker/Support worker
SC_1610	• Advocate
SC_1611	• Other (please specify)
SC_1612	• Unclear response
SC_1613	• Don't know
SC_1614	• Refused to answer
SC_16_Other_Other	
SC_17	Do you have a pet?
SC_18	In the last 2 years, did your neighbours or friends give you any kind of help, such as:
SC_18a	Please record any narrative information below
SC_19	About how much help did you receive from friends and neighbours over the last two years?

SC_20	In the last 2 years, did you give any kind of help to your friends and neighbours (who did not pay you), such as: household help: help with home repairs, gardening, transportation, help with person shopping, household chores
SC_20a	Please record any narrative information below
SC_211	• Daily
SC_212	• Weekly
SC_213	• Monthly
SC_214	• Less often
SC_215	• Unclear
SC_216	• Don't know
SC_217	• Refused to answer
SC_22	Do you provide support/help to a family member?
SC_231	• Mother
SC_232	• Father
SC_233	• Sibling
SC_234	• Aunt/Uncle
SC_235	• Cousin
SC_236	• Other
SC_237	• Unclear response
SC_238	• Don't know
SC_239	• Refused to answer
SC_23_Other_Other	• Please tell us

	What kind of help do you provide?
SC_241	• Day to day support e.g. washing, dressing, cooking
SC_242	• Help with shopping
SC_243	• Help with remembering day to day items and events
SC_244	• Support with mobility e.g. going up and down stairs/from room to room
SC_245	• Emotional Support e.g. companionship
SC_246	• Financial Support
SC_247	• Full support - do everything for them
SC_248	• Other
SC_24_Other_Other	• Please tell us
SC_25	How satisfied are you with providing support/help to a family member?
SC_25a	Please tell us more about this
SC_26	Any Other Information (Social Connectedness):

Section 5: Personal Choices	**Who chooses?**
PC_1_Eat_SingleResponseQuestion	• The food you eat?
PC_1_Cooked_SingleResponseQuestion	• What food is cooked in your home?
PC_1_Clothes_SingleResponseQuestion	• The clothes you wear?
PC_1_Free_SingleResponseQuestion	• Who you spend your free time with?
PC_1_Where_fr_SingleResponseQuestion	• Where you go in your free time?
PC_1_How_Money_SingleResponseQuestion	• How you spend your money?
PC_1_Bed_SingleResponseQuestion	• What time you go to bed?
PC_1_Job_SingleResponseQuestion	• What job you have?
PC_1_Live_SingleResponseQuestion	• Where you live?
PC_1_Who_live_SingleResponseQuestion	• Who you live with?
PC_1_Support_SingleResponseQuestion	• What support you may receive?
PC_1_Shows_SingleResponseQuestion	• What TV shows you watch?
PC_1_Decorate_SingleResponseQuestion	• How you decorate your room?
PC_1_Where_money_SingleResponseQuestion	• Where you keep your money?
PC_2	Now I would like to ask you some questions about any personal plan you may have. Do you have a personal plan?
PC_3	Does your plan include what you want to do and the support you will need to do it?
PC_4	Does your plan take account of your abilities and your skills?

PC_5	Do you have a key worker?
PC_6	Does your key worker talk to you about your plan and how it is going to be achieved?
PC_7	Are you involved in your plan as much as you would like to be?
PC_8	Do you talk about your plan at least every six months?
PC_9	Do you have an independent advocate? An independent advocate is a person who assists and enables more effective communication and who is a person outside the normal services you receive.
PC_10	Do you have access to an advocacy service, if you so wished?
PC_11	Any Other Information (Personal Choices)

Section 6: Ageing Perceptions	
AP_0	Only the SR can answer the questions in this section. It cannot be completed by a proxy
AP_1	We are interested in your own personal views and experience about getting older.
AP_1_Codes	Codes
AP_2	How would you describe yourself, would you say you are a young adult, middle aged, or old?
AP_2_Other_Oth	
AP_3	Are there any good things about getting older?
AP_4	
AP_5	What would you say are the good things about getting older?
AP_5_Codes	Codes
AP_6	Do you have any concerns or worries about getting older?
AP_7	What might these concerns be?
AP_7_Codes	Codes
AP_8	Do you think older people can do most things like work, go out, play sport, use the computer etc?
AP_9	What activities do you think older people like to do?
AP_9_Codes	Codes
AP_10	Do you think that people who are older can support you?
AP_11	Any Other Information (Ageing Perceptions):

Section 7: Occupation	
OC_1	Now I would like to ask you questions about work, day service and retirement. Have you ever done paid work?
OC_201	• Employed, which includes - Open paid employment, Supported Employment Scheme, Participating in apprenticeship or employment programme - such as Community Employment
OC_202	• Self-Employed (including farming)
OC_203	• In a Sheltered Workshop
OC_204	• Attending a Day Service
OC_205	• Unemployed or Looking for work
OC_206	• Retired
OC_207	• Unable to work due to being permanently sick or disabled
OC_208	• Looking after home or family
OC_209	• In education or training
OC_210	• Other (please specify)
OC_211	• Unclear response
OC_212	• Don't know
OC_213	• Refused to answer
OC_2_Other_Other	
OC_3	On average, how many days per week do you spend at work?
OC_3_Codes	Codes
OC_4	On average, how many hours per week do you spend at work?
OC_4_Codes	Codes

OC_5	Could you please tell me if your job is...?
OC_6	How much is your typical weekly wage?
OC_6_Codes	Codes
OC_7	In what kind of business, industry or service do you work in (that is, what do they make or do at the place where you work)?
OC_7_Codes	Codes
OC_8	In general how satisfied are you with your job... ?
OC_8A	Please tell us more about this
OC_9	When you travel to work, is this mainly by:
OC_9_Other_Oth	
OC_10_time_Hrs	Hours:
OC_10_time_Hrs_Codes	Codes
OC_10_time_Mins	Minutes:
OC_10_time_Mins_Codes	Codes
OC_10A	
OC_11	Does anyone support you going to and from work?
OC_12	What support do they give you?
OC_12_Codes	Codes
OC_13	At what age do you plan to stop working?
OC_13_Codes	Codes
OC_14	Do you have any concerns about retiring/stopping work... ?
OC_14a	Please tell us

OC_15	On average, how many days per week do you spend at the Sheltered Workshop?
OC_15_Codes	Codes
OC_16	On average, how many hours per week do you spend at the Sheltered Workshop?
OC_16_Codes	Codes
OC_17	How much is your typical weekly wage?
OC_17_Codes	Codes
OC_18	What do you do or make in the Sheltered workshop?
OC_19	In general how satisfied are you with working in the Sheltered Workshop... ?
OC_19a	Please tell us
OC_20	When you travel to the Sheltered workshop, is this mainly by:
OC_20_Other_Oth	
OC_21_time_Hrs	Hours:
OC_21_time_Hrs_Codes	Codes
OC_21_time_Mins	Minutes:
OC_21_time_Mins_Codes	Codes
OC_21A	
OC_22	Does anyone support you going to and from the Sheltered Workshop?
OC_23	What support do they give you?
OC_23_Codes	Codes
OC_24	At what age do you plan to stop working in the sheltered workshop?
OC_24_Codes	Codes

OC_25	Do you have any concerns about stopping work in the sheltered workshop?
OC_25a	Please tell us
	What kind of activities do you do in the day service?
OC_2601	• Music
OC_2602	• Arts & Crafts
OC_2603	• Cooking/Baking
OC_2604	• Multisensory and other health therapies
OC_2605	• Daily living Skills Development (e.g. cooking, money management etc.)
OC_2606	• Sports (e.g. Swimming)
OC_2607	• Social Skills Development (e.g. ordering in a restaurant, booking theatre/cinema tickets etc.)
OC_2608	• Horticulture
OC_2609	• Woodwork
OC_2610	• Information Technology
OC_2611	• Other (please specify)
OC_2612	• Unclear response
OC_2613	• Don't know
OC_2614	• Refused to answer
OC_26_Other_Other	
	Where do these activities take place?
OC_26a_Music_OC_26AQ	Music
OC_26a_Arts_OC_26AQ	Arts & Crafts
OC_26a_Cooking_OC_26AQ	Cooking/Baking

OC_26a_Therapy_OC_26AQ	Multisensory and other health therapies
OC_26a_DailySkillsDev_OC_26AQ	'Daily living Skills Development (e.g. cooking, money management etc.)'
OC_26a_Sports_OC_26AQ	Sports (e.g. Swimming)
OC_26a_SocialSkillsDev_OC_26AQ	'Social Skills Development (e.g. ordering in a restaurant, booking theatre/cinema tickets etc.)'
OC_26a_Hort_OC_26AQ	Horticulture
OC_26a_Woodwork_OC_26AQ	Woodwork
OC_26a_IT_OC_26AQ	Information Technology
OC_26a_Oth_OC_26AQ	Other
OC_27	How often do you choose the activities that you do in the day service? Would you say ...?
OC_28	On average, how many days per week do you attend?
OC_28_Codes	Codes
OC_29	On average, how many hours per week do you spend at the day service?
OC_29_Codes	Codes
OC_30	When you travel to the day service, is this mainly by:
OC_30_Other_Oth	
OC_31_Time_Hrs	Hour(s)
OC_31_Time_Hrs_Codes	Codes
OC_31_Time_Mins	Mins
OC_31_Time_Mins_Codes	Codes
OC_31A	
OC_32	Does anyone support you going to and from the day service?

OC_33	What support do they give you?
OC_33_Codes	Codes
OC_34	Would you like to attend a day service outside your home/residence?
OC_35	In general how satisfied are you with the Day Service... ?
OC_35a	Please tell us
OC_37	Have you any concerns about when you stop going to the day service?
OC_36	
At what age do you plan to stop going to the day service?	
OC_36_Codes	Codes
OC_38_date1_Month	(MM/YYYY) : Month: (MM)
OC_38_date1_Month_Codes	(MM/YYYY) : Codes
OC_38_date1_Year	(MM/YYYY) : Year: (YYYY)
OC_38_date1_Year_Codes	(MM/YYYY) : Codes
OC_38A	
OC_39	Would you tell us how you became unemployed?
OC_39_Other_Oth	
OC_40	Are you looking for part-time or full-time work?
OC_41	What type of work are you looking for?
OC_41_Codes	Codes
	What are all the things you have done to find work?
OC_4201	• Not applicable - I'm not looking for work
OC_4202	• Read advertisements
OC_4203	• Attended school or received training

OC_4204	• Checked with employment agency
OC_4205	• Checked with private employment agency
OC_4206	• Visited or wrote to employer directly
OC_4207	• Asked friends or relatives
OC_4208	• Placed or answered advertisements
OC_4209	• Searched the internet
OC_4210	• Didn't do anything specific
OC_4211	• Other (please specify)
OC_4212	• Unclear response
OC_4213	• Don't know
OC_4214	• Refused to answer
OC_42_Other_Oth	
OC_43	How long have you been looking for work?
OC_44	Is someone supporting you to look for work?
OC_45_date1_Month	Month: (MM)
OC_45_date1_Month_Codes	Codes
OC_45_date1_Year	Year: (YYYY)
OC_45_date1_Year_Codes	Codes
OC_45A	
OC_46	Did you retire from... ?
OC_46_Other_Other	Please Tell us
OC_47	What would you say was the main reason why you retired?
OC_47_Other_Other	
OC_48	Did you take early retirement, that is did you retire before the normal retirement age?

	What would you say is the main reason you retired?
OC_4901	• Own ill health
OC_4902	• Ill health of a relative or friend
OC_4903	• Made redundant/dismissed/had no choice
OC_4904	• Offered early retirement incentive by employer
OC_4905	• Could not find another job
OC_4906	• To spend more time with partner/family
OC_4907	• To enjoy life while still young and fit enough
OC_4908	• Fed up with job and wanted a change
OC_4909	• To retire at the same time as husband/wife/partner
OC_4910	• To give the young generation a chance
OC_4911	• Other (please specify)
OC_4912	• Unclear response
OC_4913	• Don't know
OC_4914	• Refused to answer
OC_49_Other_Other	
OC_50	In what kind of business, industry or service did you work in (that is, what did they do or make at the place where you worked)?
OC_50_Codes	Codes
OC_51	On average, how many days per week did you spend at work?
OC_51_Codes	Codes
OC_52	On average, how many hours per week did you spend at work?
OC_52_Codes	Codes

OC_53	In general how satisfied are you with being retired?
OC_53a	Please tell us
OC_54	What activities/work does this involve... ?
OC_55	Any Other Information (Occupation):

Section8: Sources of Income	
	Did you receive any of these payments in the last year?
SI_101	• Disability Allowance
SI_102	• Mobility Allowance
SI_103	• Disability Benefit (previously known as Illness Benefit)
SI_104	• Retirement Pension from Former Employment
SI_105	• Contributory State Pension (previously known as Contributory Old Age Pension)
SI_106	• Non-Contributory State Pension (previously known as Non-Contributory Old Age Pension)
SI_107	• Transition State Pension (previously known as Retirement Pension)
SI_108	• Invalidity Pension
SI_109	• Widow's or Widower's Contributory Pension
SI_110	• Private Pension
SI_111	• Jobseeker's Allowance (previously known as Unemployment Assistance)
SI_112	• Jobseeker's Benefit (previously known as Unemployment Benefit)
SI_113	• Supplementary Welfare Allowance
SI_114	• Other (please specify)
SI_115	• Not applicable - did not receive any of these payments
SI_116	• Unclear response
SI_117	• Don't know
SI_118	• Refused to answer
SI_1_Other_Other	

SI_2	Do you control your own money?
SI_3	Have you received information and support to manage your money?
SI_4	Do you know how much money you receive?
SI_5	If SR or proxy does not know their income and expenditure [or an unclear response or refused to answer occurred in the previous question], interviewer to ask permission to gain this information from another source.
SI_6	And what is the name of the person we may ask?
SI_6A	
SI_7	Is this person available now?
SI_7A	Record any other related information below
SI_8	Payment or payments received in the last year. The sources indicated were: Thinking about the payment or payments you have received, how much money did you receive in total?
SI_8_Codes	Codes
SI_8A	
SI_8B	If the amount is from different sources, record the amount from each source below
SI_9	Do you receive money from any other sources? (not previously mentioned)
SI_10	How much money do you receive?
SI_10_Codes	Codes
SI_10A	

SI_10B	If the amount is from different sources, record the amount from each source below.
SI_10B_Codes	
SI_11	Do you know when you receive your money/allowances?
SI_12	Do you collect your money/allowances yourself from the post office or bank?
SI_13	Do you know who does collect it?
SI_14	Does some of your money go into a central fund (i.e. for mobility allowance)?
SI_15	Do you agree with this?
SI_16	Have you somewhere safe to keep your money?
SI_17	Now there are a few questions about the money you pay to live in your residence. Do you ...?
SI_18	How much rent do you pay?
SI_18_Codes	Codes
SI_18A	
SI_19	Does your rent include all charges and services, such as electricity, gas or heating?
SI_20	On average, how much do you pay for charges and services that are not included in your rent?
SI_20_Codes	Codes
SI_20A	
SI_21	Any Other Information (Sources of Income):

Section : Voluntary work	
VW_1	By voluntary work, we mean any kind of unpaid work, whether formal or informal. Do you do any voluntary work?
VW_2	How often do you do voluntary work? Is it...?
	Why do you do voluntary work?
VW_301	• To meet other people
VW_302	• To contribute something useful
VW_303	• For personal achievement
VW_304	• Because I am needed
VW_305	• Because I enjoy it
VW_306	• To use my skills
VW_307	• To keep fit
VW_308	• Because I feel obliged to do it
VW_309	• For work experience
VW_310	• To learn particular skills
VW_311	• Other (please specify)
VW_312	• Unclear response
VW_313	• Don't know
VW_314	• Refused to answer
VW_3_Other_Other	
VW_4	Any Other Information (Voluntary Work):

Section 10: Lifelong Learning	
LE_2	If the SR has attended more than one course, enquire about the activity that has led to a formal qualification or has lasted for the longer period. Was/Is the course or activity run or organised by... ?
LE_2_Other_Oth	
LE_3	What type of course was this?
LE_3_Other_Oth	
LE_4	On average, how many hours per week did (does) this course involve?
LE_4_Codes	Codes
LE_5	For how many weeks did/will this course last?
LE_5_Codes	Codes
LE_6	What was the main reason for participating in this course or activity? Job-related (professional): the SR takes part in this activity in order to obtain knowledge and/or learn new skills for a current or future.
LE_7	Would you like to participate in a course or other education and training scheme?
LE_8	What course or other education and training scheme would you like to do?
LE_8_Codes	Codes
LE_9	Now we would like to ask you some questions about reading, writing and numbers. Do you have difficulty with reading?
LE_10_Name_LE_10	• I can read my own name
LE_10_Alpha_LE_10	• I can identify most letters of the alphabet

LE_10_Street_LE_10	• I can read name of own street or town
LE_10_Easy_LE_10	• I can read easy to read material
LE_10_Environment_LE_10	• 'I can read common environmental words (Stop, Exit, Ladies, Gents) in context (i.e. recognizes them when they are in the appropriate position in the environment)'
LE_10_LargePrint_LE_10	• I can read basic large print book
LE_10_Instructions_LE_10	• 'I can read instructions, such as those on a medicine bottle'
LE_10_GoodsInstructions_LE_10	• I can read instructions on packaged goods in shops or supermarkets
LE_10_Information_LE_10	• 'I can read information from government agencies, businesses or other institutions'
LE_10_News_LE_10	• I can read newspaper articles
LE_11	Do you have any difficulty with writing?
LE_12_Alpha_LE_12	I can write most letters of the alphabet
LE_12_Name_LE_12	• I can write my own name
LE_12_Notes_LE_12	• I can write notes and letters (e.g. birthday or ~Christmas cards)
LE_12_Forms_LE_12	• I can fill out forms such as applications or bank deposit slips
LE_13	Do you have any difficulty with numbers e.g. knowing the numbers on a phone or doing simple sums?
LE_14_One_Ten_LE_14	• I can recognise numbers 1-10
LE_14_Phone_ATM_LE_14	• I can recognise and locate numbers on phone or ATM or Post office machine

LE_14_Dial_Phone_LE_14	• I can dial numbers on phone
LE_14_More_Less_LE_14	• I understand more-less relationships
LE_14_Simple_LE_14	• I can do simple sums - that is add and subtract
LE_14_Time_LE_14	• I can tell time on a clock or watch
LE_14_Calculator_LE_14	• I can use a calculator for simple sums
LE_15	Do you have any difficulty with money e.g. recognising different money values or knowing the change you should get in a shop?
LE_16_IdNotes_LE_16	• 'I can identify €5, €10, €20 notes'
LE_16_IdCoins_LE_16	• 'I can identify coins: 1c, 2c, 5c, 10c, 20c, 50c'
LE_16_ArrangeCoins_LE_16	• I can arrange coins in order of value
LE_16_ArrangeNotes_LE_16	• I can arrange notes in order of value
LE_16_Understand_LE_16	• I can understand more or less applied to money: can attempt to identify from price of an item whether change is due from note or coin handed in
LE_17	Do you own a mobile phone?
LE_18	Can you send a text message?
LE_19	Do you have access to a computer on a regular basis?
LE_20	Do you have access to the Internet?
LE_21	Do you have any difficulty with computers e.g. turning a computer on, sending an email, logging onto the internet... ?
LE_22_IdName_LE_22	• I can type my name on a keyboard
LE_22_Letter_LE_22	• I can type a letter
LE_22_TurnOn_LE_22	• I can turn on a computer

LE_22_Email_LE_22	• I can send an email
LE_22_Google_LE_22	• I can look up topics of interest on Google
LE_22_Social_LE_22	• 'I can use social media sites such as Facebook, Twitter'
LE_23	• Any Other Information (Lifelong Learning)

Section 11 : Physical Health	
PH_1	Would you say your health is ...?
PH_2	Now thinking about your physical health, which includes Physical illness and injury, how many days during the past 30 days was your physical health not good?
PH_2_Codes	Codes
PH_3	Would you say your emotional or mental health is ...?
PH_4	Now thinking about your mental health, which includes stress, depression, and problems with emotions, how many days during the past 30 days was your mental health not good?
PH_4_Codes	Codes
PH_5	During the past 30 days, approximately how many days did poor physical health or mental health keep you from doing your usual activities, such as self-care, work or recreation?
PH_5_Codes	Codes
PH_6	Do you have any long term health conditions?
PH_7	What long-term health conditions are they?
PH_7_Codes	Codes
PH_8	Do (es) these/this condition(s) limit your activities in any way?
PH_9	For the past six months or more, to what extent have you been limited because of a health condition in activities people usually do?
PH_10	Do you have any health conditions that limit the kind or

	amount of paid work you could do, should you want to?
PH_11	Is this a health condition that you expect to last less than three months?
PH_12	In general, compared to other people your age, would you say your health is...?
PH_13	Any Other Information (Overall Health and Functional Limitations):
PH_14	Is your eyesight (using glasses or contact lenses if you use them)...?
PH_15	How good is your eyesight for seeing things at a distance, like recognising a friend across the street (using glasses or corrective lens if you use them)? Would you say it is...?
PH_16	How good is your eyesight for seeing things up close, for example like reading ordinary newspaper print or looking at photographs (using glasses or corrective lens if you use them)? Would you say it is...?
PH_17	Have you been prescribed glasses or contact lenses?
PH_18	Do you usually wear ordinary glasses, bifocals or contact lenses?
PH_19	Do you usually wear your glasses or contact lenses?
PH_20	When was your last eye exam?
	Reasons that you haven't had an eye exam recently:
PH_2101	• The environment is not accessible e.g. the chair is

	too high, no wheelchair access
PH_2102	• No need
PH_2103	• I don’t get enough time at my appointment
PH_2104	• I have to wait too long in the waiting room
PH_2105	• Fear
PH_2106	• Transport
PH_2107	• Cost
PH_2108	• Other
PH_2109	• Unclear response
PH_2110	• Don't know
PH_2111	• Refused to answer
PH_21_Other_Other	
PH_22	Any Other Information (Eyesight):
PH_23	Would you say your hearing is?
PH_241	• Hearing aid (all the time)
PH_242	• Hearing aid (some of the time)
PH_243	• Phone messaging service
PH_244	• Amplifier
PH_245	• None of the above
PH_246	• Unclear response
PH_247	• Don't know
PH_248	• Refused to answer
PH_25	Is your hearing (with or without a hearing aid)...?
PH_26	Can you follow a conversation with one person (with or without a hearing aid)?

PH_27	Can you follow a conversation with four people (with or without a hearing aid)?
PH_28	When was your last hearing test?
	Reason that you haven't had a hearing test recently
PH_2901	• The environment is not accessible e.g. the chair is too high, no wheelchair access
PH_2902	• No need
PH_2903	• I don't get enough time at my appointment
PH_2904	• I have to wait too long in the waiting room
PH_2905	• Fear
PH_2906	• Transport
PH_2907	• Cost
PH_2908	• Other
PH_2909	• Unclear response
PH_2910	• Don't know
PH_2911	• Refused to answer
PH_29_Other_Other	
PH_30	Any Other Information (Hearing)
PH_31	Do you have any difficulty speaking or making yourself understood when speaking?
PH_32_Family_SingleResponseQuestion	• Members of your own family:
PH_32_Friends_SingleResponseQuestion	• Your friends
PH_32_Pros_SingleResponseQuestion	• Professionals and service providers such as doctors and home help workers
PH_32_Oth_SingleResponseQuestion	• Other people

PH_33	• Any Other Information (General Communication)
PH_34	Which best describes the teeth you have?
PH_35	Have you had dentures fitted by a dentist?
PH_36	Why do you not wear your dentures?
PH_36_Other_Other	
PH_37	Would you like to have replacement of your missing teeth?
PH_38	How often do you brush your teeth or dentures/have them brushed OR how often do you clean your mouth/have it cleaned for you?
PH_39	When was the last time you visited a dentist or dental hygienist?
	Reason for not attending dentist recently
PH_4001	• The environment is not accessible e.g. the chair is too high, no wheelchair access
PH_4002	• No need
PH_4003	• I don’t get enough time at my appointment
PH_4004	• I have to wait too long in the waiting room
PH_4005	• Fear
PH_4006	• Transport
PH_4007	• Cost
PH_4008	• Other
PH_4009	• Unclear response
PH_4010	• Don't know

PH_4011	• Refused to answer
PH_40_Other_Other	
PH_41	Do you have any obvious problems with teeth or gums? (e.g. painful or sensitive teeth, bleeding gums when you brush your teeth)
	In general are the following used to make it easier?
PH_4201	• Verbal reassurance (eg. Someone with you to tell you that you will be ok)
PH_4202	• Oral sedation
PH_4203	• Gas and air sedation
PH_4204	• IV sedation
PH_4205	• General Anaesthesia
PH_4206	• Don’t use any of these
PH_4207	• Other
PH_4208	• Unclear response
PH_4209	• Don't know
PH_4210	• Refused to answer
PH_42_Other_Other	
PH_43	Any Other Information (Oral Health)
PH_44	In general, how healthy is you overall diet? Would you say ... ?
PH_45	Do you add salt to food at the table?
PH_46	In general, would you consider yourself to be ...?
PH_47	Are you on any special diet?
	Who advised you to follow this diet?
PH_4801	• A dietician

PH_4802	• A nurse
PH_4803	• A doctor
PH_4804	• A family member
PH_4805	• A key worker/support worker
PH_4806	• Yourself
PH_4807	• Other (please specify)
PH_4808	• Unclear response
PH_4809	• Don't know
PH_4810	• Refused to answer
PH_48_Other_Other	
	Type of diet followed?
PH_4901	• Low fat/cholesterol
PH_4902	• Low sodium
PH_4903	• High calorie
PH_4904	• Gluten free
PH_4905	• Weight reducing
PH_4906	• Diabetic diet
PH_4907	• PKU
PH_4908	• Lactose intolerant
PH_4909	• Low potassium
PH_4910	• Soft/liquidised foods
PH_4911	• Thickened fluids
PH_4912	• Other (please specify)
PH_4913	• Unclear response
PH_4914	• Don't know
PH_4915	• Refused to answer
PH_49_Other_Other	
PH_50	Within the last year, have you lost or gained ten pounds (4.5 kg)

	or more in weight when you weren't trying to?
PH_51	Any Other Information (Nutritional Health)
PH_52	In general, what condition would you say your feet are in?
PH_53	Do you have any pain in your feet?
PH_54	What is the cause of this pain?
PH_54_Codes	Codes
PH_55	How much does your foot health limit you walking (e.g. because of foot pain)?
PH_56	Any Other Information (Foot Health)
PH_57	In the past month have you had any fall including a slip or trip
PH_58	How often have you fallen down in the past month?
PH_58_Other_Other	
PH_59	In general, were most of these falls...?
PH_601	• No apparent or obvious reason
PH_602	• Due to a pre-existing physical or mental health condition (e.g. epilepsy, Parkinson's disease, diabetes)
PH_603	• As a result of being pushed
PH_604	• Other (please specify)
PH_605	• Unclear response
PH_606	• Don't know
PH_607	• Refused to answer
PH_60_Other_Other	

PH_61	In the past year have you had any fall including a slip or trip in which you lost your balance and landed on the floor or ground or lower level?
PH_62	How often have you fallen down in the past year?
PH_62_Other_Other	
PH_63	In general, were most of these falls...?
PH_641	• No apparent or obvious reason
PH_642	• Due to a pre-existing physical or mental health condition (e.g. epilepsy, diabetes, Parkinson's)
PH_643	• As a result of being pushed
PH_644	• Other (please specify)
PH_645	• Unclear response
PH_646	• Don't know
PH_647	• Refused to answer
PH_64_Other_Other	
PH_65	Because of a fall, did you ever injure yourself seriously enough to need medical treatment? (i.e. At an A&E Department or visit to or by a General Practitioner or Resident Physician)
PH_661	• Bruise
PH_662	• Scratch or small cut
PH_663	• Cut that required stitches
PH_664	• Fracture/broken bone
PH_665	• Head Injury
PH_666	• Other (please specify)
PH_667	• Unclear response

PH_668	• Don't know
PH_669	• Refused to answer
PH_66_Other_Other	
PH_67	Have you ever had a blackout or fainted? (i.e. Not related to seizure type activity)
PH_68	Approximately, how many times have you blacked out or fainted in the last year?
PH_68_Codes	Codes
PH_69	Since your last interview have you attended a falls clinic?
PH_70	Any Other Information (Falls)
PH_71	Are you afraid of falling?
PH_72	Do you feel somewhat afraid or very much afraid of falling?
PH_73	Do you ever limit your activities, for example, what you do or where you go, because you are afraid of falling?
PH_74	Any Other Information (Fear of Falling)
	How steady are you when?
PH_75_Walking_SingleResponse Question	• Walking
PH_75_Standing_SingleResponse Question	• Standing
PH_75_Getup_SingleResponseQ uestion	• Getting up from a chair
PH_76	Have you ever fractured/broken a bone?
PH_7701	• Arm
PH_7702	• Leg
PH_7703	• Hip

PH_7704	• Wrist
PH_7705	• Ankle
PH_7706	• Shoulder
PH_7707	• Knee
PH_7708	• Other (please specify)
PH_7709	• Unclear response
PH_7710	• Don’t know
PH_7711	• Refused to answer
PH_77_Other_Other	
PH_78	Have you had any joint replacements?
PH_791	• Hip
PH_792	• Both hips
PH_793	• Knee
PH_794	• Both knees
PH_795	• Other (please specify)
PH_796	• Unclear response
PH_797	• Don’t know
PH_798	• Refused to answer
PH_79_Other_Other	
PH_80	Was/were the joint replacement(s) because of …?
PH_80_Other_Oth	
PH_81	Any Other Information (Steadiness and Fractures):
	Do you fear falling when?
PH_82_Dressed_PH_82	• Getting dressed or undressed
PH_82_Bath_PH_82	• Taking a bath or a shower
PH_82_Chair_PH_82	• Getting in or out of a chair

PH_82_stairs_PH_82	• Going up or down stairs
PH_82_Reach_PH_82	• Reaching for something over your head or on the ground
PH_82_Slope_PH_82	• Walking up or down a slope
PH_82_Social_PH_82	• Going out to a social event
PH_83	Are you often troubled with pain?
PH_84	How bad is the pain most of the time? Is it ... ?
PH_8501	• Back
PH_8502	• Hips
PH_8503	• Knees
PH_8504	• Feet
PH_8505	• Mouth/teeth
PH_8506	• All over
PH_8507	• Other (please specify)
PH_8508	• Unable to understand
PH_8509	• Unclear response
PH_8510	• Don't know
PH_8511	• Refused to answer
PH_8512	
PH_85_Other_Other	
PH_86	Does the pain make it difficult for you to do your usual activities such as household chores, work, social or leisure activities?
PH_87	Are you taking any medication to control the pain?
PH_88	Does this medication control your pain?
PH_89	Any Other Information (Pain):

PH_90	We are interested in finding out more about problems that affect people's quality of life. I would therefore like to ask you some questions about going to the toilet/urinary incontinence. During the last 12 months
PH_91	Did this happen more than once during a 1 month period?
PH_92	Have you ever mentioned this problem to a doctor, nurse or other health professional?
PH_93	Do you ever limit your activities, for example, what you do or where you go because of this problem?
PH_94	Any Other Information (Bladder Incontinence):
PH_95	During the last 12 months, have you lost any amount of faeces beyond your control?
PH_96	Did this happen more than once during a 1 month period?
PH_97	Have you ever mentioned this problem to a doctor, nurse or other health professional?
PH_98	Do you ever limit your activities, for example, what you do or where you go because of this problem?
PH_99	Any Other Information (Bowel Incontinence):
PH_100	Is constipation a problem for you?
PH_101	Have you ever mentioned this problem to a doctor or a nurse?
PH_102	Do you ever limit your activities, for example, what you do or

	where you go because of this problem?
PH_103	Any Other Information (Bowel Continence):
PH_104	In the pre-interview questionnaire, we asked you to record all medications that you take on a regular basis, like everyday or every week. This included prescription and non-prescription medications, over-the-counter medicines, vitamins
PH_105	Do you know what medication you take and how often you take them?
PH_106	Do you administer/take your own medication/tablets?
PH_107	Have you ever received training/instructions about taking medications?
PH_107A	Please tell us
PH_108	Do you know what your medications are for?
PH_109	Do you experience any side effects from taking any of your medications?
PH_109A	Please tell us which tablet and what side effect.
PH_110A	Is proxy present at interview?
PH_110	Do you know what medication (name) takes?
PH_111	Do you know how often (name) has to take medication?
PH_112	Have you ever received training/instructions about administering medications?
PH_112A	Please tell us.

PH_113	Do you know what the SR's medications are for?
PH_114	Do you understand the side effects of the medications?
PH_115	Any Other Information (Medication)

Section 12 : Mental Health	
MH_3	How much of the time during the past 4 weeks did you feel full of pep?
MH_4	How much of the time during the past 4 weeks did you have a lot of energy?
MH_5	How much of the time during the past 4 weeks Did you feel worn out?
MH_6	How much of the time during the past 4 weeks Did you feel tired?
MH_7	PLEASE INDICATE HOW THE VITALITY QUESTIONS (PREVIOUS FOUR QUESTIONS) WERE COMPLETED
	Have you experienced any of the following life events in the past year?
MH_801	• No significant Life Event experienced
MH_802	• Change of staff in my home where I live or day service I attend.
MH_803	• New resident moved into my home
MH_804	• Change of my key worker
MH_805	• Change at or from work or day service
MH_806	• Death of a parent
MH_807	• Death of a sibling
MH_808	• Death of other relative
MH_809	• Death of a friend
MH_810	• Death of a pet
MH_811	• Major illness of a relative , caregiver or friend
MH_812	• Death of a significant other (other than a relative or friend)
MH_813	• Moving within service organisation

MH_814	• Moving from my family home to a service supported home (community group home/residential setting)
MH_815	• Change in frequency of visits from or to family/friend
MH_816	• Major illness or injury
MH_817	• Break up of a steady relationship/ Divorce
MH_818	• Experience of crime (mugged or burgled)
MH_819	• Problems with justice and/or authorities
MH_820	• Other event or change of routine which may have caused distress, please tell us...
MH_8_Other_Other	
	Level of stress caused by particular life events
MH_8A_Staff_MH8AQ	• Change of staff in my home where I live or day service I attend.
MH_8A_Resident_MH8AQ	• New resident moved into my home
MH_8A_Key_worker_MH8AQ	• Change of my key worker
MH_8A_Day_Service_MH8AQ	• Change at or from work or day service
MH_8A_Parent_MH8AQ	• Death of a parent/sibling
MH_8A_Relative_MH8AQ	• Death of other relative
MH_8A_Friend_MH8AQ	• Death of a friend
MH_8A_Pet_MH8AQ	• Death of a pet
MH_8A_Illness_MH8AQ	• 'Major illness of a relative , caregiver or friend'
MH_8A_Partner_MH8AQ	• Death of a significant other (other than a relative or friend)
MH_8A_ServiceOrg_MH8AQ	• Moving within service organisation

MH_8A_FamilyHome_MH8AQ	• Moving from my family home to a service supported home (community group home/residential setting)
MH_8A_Visits_MH8AQ	• Change in frequency of visits from or to family/friend
MH_8A_PersonalIllness_MH8AQ	• Major illness or injury
MH_8A_Divorce_MH8AQ	• Break up of a steady relationship/ Divorce
MH_8A_Crime_MH8AQ	• Experience of crime (mugged or burgled)
MH_8A_Justice_MH8AQ	• Problems with justice and/or authorities
MH_8A_Oth_MH8AQ	• Other event or change of routine which may have caused distress
MH_9	• Any Other Information (Mental Health)

Section 13: Behavioural Health	
BH_1	Have you ever smoked cigarettes, cigars, cigarillos or a pipe daily for a period of at least one year?
BH_2	Do you smoke at the present time? Respond 'yes' if the SR has smoked anytime in the past 3 months
BH_3	How old were you when you stopped smoking?
BH_3_Codes	Codes
BH_4	For how many years have you smoked altogether?
BH_4_Codes	Codes
BH_5	Any Other Information (Smoking)
BH_6	Do you drink alcohol? Respond 'yes' if the SR has drank alcohol anytime in the last 6 month
BH_7	During the last 12 months how often have you drunk any alcoholic beverages, like beer, cider, wine, spirits or cocktails?
BH_8	During the last 12 months, how often have you had more than two drinks in a single day?
BH_9	During the last 12 months, on the days you drank alcohol, about how many drinks did you have?
BH_9_Codes	Codes
BH_10	Any Other Information (Alcohol):
	How often do you eat the following?
BH_11_Breakfast_SingleResponse Question	Breakfast

BH_11_Lunch_SingleResponseQuestion	Lunch
BH_11_Dinner_SingleResponseQuestion	Dinner
BH_11_Snacks_SingleResponseQuestion	Snacks
	How often do you eat the following?
BH_12_meat_SingleResponseQuestion	• 'meat, fish and poultry e.g. beef, pork, lamb, chicken (Serving: size of a deck of cards)'
BH_12_bread_SingleResponseQuestion	• 'bread and savoury biscuits e.g. cream crackers, Ryvita (Serving: 1 slice or biscuit)'
BH_12_cereals_SingleResponseQuestion	• 'cereals e.g. porridge, cornflakes, muesli (Serving: 1 med sized bowl)'
BH_12_potatoes_SingleResponseQuestion	• 'potatoes, rice and pasta (Serving: about a cupful)'
BH_12_dairy_SingleResponseQuestion	• 'dairy products e.g. milk, cream, cheese, butter, margarine (Serving: medium)'
BH_12_fruit_SingleResponseQuestion	• 'fruit e.g. apples, pears, oranges, bananas, tinned fruit (Serving: 1 piece of fruit)'
BH_12_veg_SingleResponseQuestion	• 'vegetables e.g. carrots, broccoli, cauliflower, baked beans (Serving: 2 tablespoons)'
BH_12_sweet_SingleResponseQuestion	• 'sweet and savoury snacks e.g. chocolates, crisps (Serving: medium)'
BH_12_fast_SingleResponseQuestion	• 'Fast food e.g. McDonalds, Chipper take away, Chinese meal, Subway etc.'
BH_13_tea_SingleResponseQuestion	• tea (Serving: one cup)

BH_13_coffee_SingleResponseQuestion	• coffee (Serving: one cup)
BH_13_water_SingleResponseQuestion	• water (Serving: one cup)
BH_13_Milk_SingleResponseQuestion	• milk (Serving: one cup)
BH_13_Low_cal_SingleResponseQuestion	• low calorie or diet soft fizzy (Serving: one glass)
BH_13_fizzy_SingleResponseQuestion	• fizzy soft drinks e.g. Cocoa Cola (Serving: one glass)
BH_13_fruit_SingleResponseQuestion	• pure fruit drinks e.g. orange juice (Serving: 1 small glass)
BH_13_squash_SingleResponseQuestion	• fruit squash (Serving: one small glass)
BH_14	• Any Other Information (Diet)
BH_15	
BH_15_Codes	Codes
BH_16	How much time (Minutes per day) did you usually spend doing vigorous physical activities on one of those days?
BH_16_Codes	Codes
BH_17	
BH_17_Codes	Codes
BH_18	How much time (Minutes per day) did you usually spend doing moderate physical activities on one of those days?
BH_18_Codes	Codes
BH_19	During the last 7 days on how many days did you do mild physical exercise
BH_19_Codes	Codes
BH_20	How much time (Minutes per day) did you usually spend doing

	mild physical activities on one of those days?
BH_20_Codes	Codes
	Types of physical activity frequently engaged in
BH_2101	• Not applicable - I don't take part in regular physical activity
BH_2102	• Bowling
BH_2103	• Swimming
BH_2104	• Walking
BH_2105	• Gym/treadmill/cycling bike
BH_2106	• Cycling
BH_2107	• Running/jogging
BH_2108	• Aerobics
BH_2109	• Golf
BH_2110	• Basketball
BH_2111	• Badminton
BH_2112	• Horseback riding
BH_2113	• Soccer/football
BH_2114	• Dancing
BH_2115	• Other (please specify)
BH_2116	• Unclear response
BH_2117	• Don't know
BH_2118	• Refused to answer
BH_21_Other_Other	
	Difficulties experienced with physical activity
BH_2201	• Not applicable - I don't experience any difficulties

BH_2202	• Health considerations or physically unable
BH_2203	• Wheelchair use
BH_2204	• Motor impairment
BH_2205	• Don't have enough money
BH_2206	• Can't get a lift
BH_2207	• Transport services are inadequate or not accessible
BH_2208	• Have no one to go with for company
BH_2209	• Not allowed to go
BH_2210	• Need someone's assistance but there is no one to help you
BH_2211	• Get too tired
BH_2212	• Don't have enough time
BH_2213	• There is nothing you can do at the leisure centre
BH_2214	• Don't like exercise
BH_2215	• Service facilities are not accessible
BH_2216	• You are self-conscious
BH_2217	• Unfriendly or negative attitudes towards you
BH_2218	• No available exercise facilities
BH_2219	• Getting too old
BH_2220	• Other reason (please specify)
BH_2221	• Unclear response
BH_2222	• Don't know
BH_2223	• Refused to answer
BH_22_Other_Other	
BH_23	Would you like to do more (or some, where applicable) physical activities?

BH_24	Which physical activities would you like to do more of?
BH_24_Codes	Codes
BH_25	Any Other Information (Physical Activity):
BH_26	How often do you have trouble falling asleep at night?
BH_27	For what reasons do you have trouble falling asleep at night? (e.g. sharing a room etc.)
BH_27_Codes	Codes
BH_28	Is your sleep interrupted during the night by episodes of wakefulness?
BH_29	For what reasons is your sleep disrupted? (e.g. sharing a room etc.)
BH_29_Codes	Codes
BH_30	How often do you have trouble with waking up too early and not being able to fall asleep again?
BH_31	For what reasons do you wake too early? (e.g. sharing a room etc.)
BH_31_Codes	Codes
BH_32	How likely are you to doze off and fall asleep during the day?
BH_33	Any Other Information (Sleep):

Section 14: Functional Limitations	
FL_1	Please indicate the level of difficulty you having walking 100 yards
FL_2	Please record description of the difficulty here
FL_3	Please indicate the level of difficulty, if any, you have with running or jogging about 1.5 kilometres (1 mile).
FL_4	Please record description of the difficulty here
FL_5	Please indicate the level of difficulty, if any, you have with sitting for about two hours.
FL_6	Please record description of the difficulty here
FL_7	Please indicate the level of difficulty, if any, you have getting up from a chair after sitting for long periods
FL_8	Please record description of the difficulty here
FL_9	Please indicate the level of difficulty, if any, you have with climbing several flights of stairs without resting.
FL_10	Please record description of the difficulty here
FL_11	Please indicate the level of difficulty, if any, you have with climbing one flight of stairs without resting.
FL_12	Please record description of the difficulty here
FL_13	Please indicate the level of difficulty, if any, you have with stooping, kneeling, or crouching.

FL_14	Please record description of the difficulty here
FL_15	Please indicate the level of difficulty, if any, you have with reaching or extending your arms above shoulder level.
FL_16	Please record description of the difficulty here
FL_17	Please indicate the level of difficulty, if any, you have with pulling or pushing large objects like a living room chair.
FL_18	Please record description of the difficulty here
FL_19	Please indicate the level of difficulty, if any, you have with lifting or carrying weights over 10 pounds/5 kilos, like a heavy bag of groceries.
FL_20	Please record description of the difficulty here
FL_21	Please indicate the level of difficulty, if any, you have with picking up a small coin from the table
FL_22	Please record description of the difficulty here
FL_23	Any Other Information (Functional Limitations):
FL_24	Please indicate the level of difficulty if any you have with dressing, including putting on shoe and socks
FL_25	Please record description of the difficulty here
FL_26	Do you ever use equipment or devices to help you get dressed?
FL_271	• Velcro fastenings on clothes
FL_272	• Shoe horn

FL_273	• Pick-up stick
FL_274	• Device for putting on socks
FL_275	• Other (please specify)
FL_276	• Unclear response
FL_277	• Don't know
FL_278	• Refused to answer
FL_27_Other_Other	
FL_28	Does anyone ever help you with dressing including putting on shoes and socks?
FL_29	Please indicate the level of difficulty, if any, you have with walking across a room.
FL_30	Please record description of the difficulty here
FL_31	Do you ever use equipment or devices such as a walking stick or frame when crossing a room?
FL_3201	• Walking stick
FL_3202	• Walking frame
FL_3203	• Crutches
FL_3204	• Railing
FL_3205	• Orthopaedic shoes
FL_3206	• Brace (leg or back)
FL_3207	• Limb prosthesis
FL_3208	• Oxygen/Respirator
FL_3209	• Furniture or walls
FL_3210	• Wheelchair
FL_3211	• Other (please specify)
FL_3212	• Unclear response
FL_3213	• Don't know

FL_3214	• Refused to answer
FL_32_Other_Other	
FL_33	Does anyone ever help you with walking/getting across a room?
FL_34	Do you have difficulty getting around inside your home for example, getting to and from the toilet, going from room to room, such as your bedroom to the living room?
FL_35	What do you have difficulty with (e.g. getting upstairs, no stair lift, no hoist, doorways not wide enough)?
FL_35_Codes	Codes
FL_36	Have any modifications been made to your home to help you get around?
	Types of modifications have been (or need to be) made
FL_3701	• Ramps on street level entrances
FL_3702	• Automatic or easy to open doors (includes lever handles)
FL_3703	• Widened doorways or hallways
FL_3704	• Lift device
FL_3705	• Visual alarms or audio warning devices
FL_3706	• Grab bars or a bath lift (in the bathroom)
FL_3707	• Lowered counters in the kitchen
FL_3708	• Other (please specify)
FL_3709	• Unclear Response
FL_3710	• Don't Know
FL_3711	• Refused to answer

FL_37_Other_Other	
FL_38	Please indicate the level of difficulty, if any, you have with bathing or showering.
FL_39	Please record description of the difficulty here
FL_40	Do you ever use equipment or devices such as a shower seat, grab rails, hand-held shower when bathing or showering?
	Type of equipment
FL_4101	• Shower seat
FL_4102	• Grab rails
FL_4103	• Hand-held shower
FL_4104	• Walking frame or stick
FL_4105	• Rubber mat
FL_4106	• Hoist
FL_4107	• Other (please specify)
FL_4108	• Unclear response
FL_4109	• Don't know
FL_4110	• Refused to answer
FL_41_Other_Other	
FL_42	Does anyone ever help you with bathing or showering?
FL_43	Please indicate the level of difficulty, if any, you have with cleaning your teeth/taking care of your dentures.
FL_44	Please record description of the difficulty here
FL_45	Does anyone ever help you to clean your teeth/take care of your dentures?

FL_46	Please indicate the level of difficulty, if any, you have with eating such as cutting up your food, use of utensils, drinking from a cup/glass etc?
FL_47	Please record description of the difficulty here
FL_48	Do you ever use special utensils when you eat?
	Type of Equipment
FL_491	• Beakers
FL_492	• Grip mats
FL_493	• Modified utensils e.g. spoons, forks
FL_494	• Plate guards
FL_495	• Other (please specify)
FL_496	• Unclear response
FL_497	• Don't know
FL_498	• Refused to answer
FL_49_Other_Other	
FL_50	Does anyone ever help you with eating?
FL_51	Please indicate the level of difficulty, if any, you have with getting in or out of bed.
FL_52	Please record description of the difficulty here
FL_53	Do you ever use equipment or devices such as a stick, frame or wheelchair when getting in or out of bed?
	Type of Equipment
FL_5401	• Walking stick
FL_5402	• Walking frame

FL_5403	• Bed rail
FL_5404	• Crutches
FL_5405	• Orthopaedic Shoes
FL_5406	• Brace (leg or back)
FL_5407	• Prosthesis
FL_5408	• Oxygen/Respirator
FL_5409	• Furniture/walls
FL_5410	• Wheelchair
FL_5411	• Bed lever
FL_5412	• Hoist
FL_5413	• Other (please specify)
FL_5414	• Unclear response
FL_5415	• Don't know
FL_5416	• Refused to answer
FL_54_Other_Other	
FL_55	Does anyone ever help you with getting into or out of bed?
FL_56	Please indicate the level of difficulty, if any you have with using the toilet, including getting up or down.
FL_57	Please record description of the difficulty here
FL_58	Do you ever use equipment or devices such as a raised toilet seat or portable toilet, when using the toilet?
	Type of Equipment
FL_591	• Raised toilet seat
FL_592	• Portable toilet/commode
FL_593	• Grab rails

FL_594	• Other (please specify)
FL_595	• Unclear response
FL_596	• Don't know
FL_597	• Refused to answer
FL_59_Other_Other	
FL_60	Does anyone ever help you with using the toilet, including getting on and off the toilet?
FL_61	Please indicate the level of difficulty, if any, you have with taking medication
FL_62	Does anyone help you to take your medication(s)?
FL_63	What support do they give you?
FL_63_Codes	Codes
FL_64	If you receive help with any of the activities we have just discussed (e.g. getting across a room; dressing; bathing; eating; cleaning your teeth/taking care of your dentures; getting in/out of bed; and with using the toilet) who most often supports you with these activities?
FL_64_Other_Oth	
FL_65	Let's think for a moment about the help you receive with the activities that we just talked about. During the last month, how often did you receive help from this person?
FL_66	On the days when you receive this help, about how many hours per day do they spend helping you? If more than one of activity, try to get total time of support by key worker etc.
FL_67	Any Other Information (Activities of Daily Living):

FL_68	Please indicate the level of difficulty you have if any with preparing a hot meal
FL_69	Please record description of the difficulty here
FL_70	Does anyone help you with preparing a hot meal?
FL_71	Please indicate the level of difficulty, if any, you have with shopping for groceries.
FL_72	Please record description of the difficulty here
FL_73	Does anyone help you with shopping for groceries?
FL_74	Please indicate the level of difficulty, if any, you have with making telephone calls (including hearing).
FL_75	Please record description of the difficulty here
FL_76	Does anyone help you make phone calls?
FL_77	Please indicate the level of difficulty, if any, you have with managing money, such as paying bills and keeping track of expenses
FL_78	Please record description of the difficulty here
FL_79	Does anyone help you with managing your own money?
FL_80	Please indicate the level of difficulty, if any, you have with doing household chores, such as laundry and cleaning.
FL_81	Please record description of the difficulty here
FL_82	Does anyone help you with doing household chores?

FL_83	If you receive help with any of the everyday activities we have just discussed (e.g. preparing a hot meal; shopping for groceries; making a telephone call; managing money and paying bills), who most often supports you with this activity
FL_83_Other_Oth	
FL_84	Let's think for a moment about the help you receive with the activities that we just talked about. During the last month, on about how many days did you receive help from this person?
FL_85	On the days when you receive this help, about how many hours per day do they spend helping you?
FL_86	Are there any of these activities you feel you need more help with e.g. preparing a hot meal; shopping for groceries; making a telephone call; managing money and paying bills?
FL_87	What help do you feel you need?
FL_87_Codes	Codes
FL_88	Any Other Information (Instrumental Activities of Daily Living):

Section 15: Objective Measures	
Section 16: Evaluation Questions	
EQ_1	Now I just have a few final questions before we reach the end of my visit. In general, did you find the questions in the interview easy to understand?

EQ_2	Which questions did you find most difficult to understand?
EQ_2_Codes	Codes
EQ_3	Did you find the information booklet (sent before the interview) easy to understand?
EQ_4	Which part(s) did you not find easy to understand?
EQ_4_Codes	Codes
EQ_5	Did you find the showcards useful?
EQ_6	Which part(s) did you not find useful?
EQ_6_Codes	Codes
EQ_7	Once we have spoken to everyone taking part in this study and reviewed the findings we will be writing about parts of it. Are there any particular topics that you would like to see written about and published?
EQ_8	Which topics or areas would you like to know more about or read more about?
EQ_8_Codes	Codes
EQ_9	How would you like us to present the findings from this study? Please tell us your first preference. Would you say....?
EQ_9_Other_Other	
EQ_10	Any Other Information (Evaluation):
Section 17: Final Checks	
FC_1	We are coming to the end of the interview, before we reach the final questions is there anything else you would like to tell us about

	yourself? Or the people who support you, where applicable?
FC_1_Codes	Codes
FC_2	Would you agree to us contacting you again, if needed, so we can talk about certain areas of your life in more depth, such as talking more about getting older?
FC_2A	And, where applicable talk to ... (name of SR's informal carer) about their own health?
FC_3	As I explained earlier this is a longitudinal study which means that people who take part will be visited once every three years. Are you willing to be re-contacted to participate in a similar interview in the next 3 years? Again your participation will be voluntary.
FC_4	Interviewers should make every effort to outline to the respondent of the importance of the study and the benefits to people with intellectual disability living in Ireland. Also attempt to understand reasons for not wanting to be re-contacted (where applicable) and address these i.e. give assurances on confidentiality and anonymity.
FC_5	Any Other Information (Final checks):
FS_1	TO BE COMPLETED BY THE INTERVIEWER
FS_1A	Do you wish to record the Source of Income details now?
FS_2_Visit1_SingleResponseQuestion	Visit 1 :
FS_2_Visit2_SingleResponseQuestion	Visit 2 :

FS_2_Visit3_SingleResponseQuestion	Visit 3 :
FS_2_Visit1_Oth	Visit 1 : Other (please specify)
FS_2_Visit2_Oth	Visit 2 : Other (please specify)
FS_2_Visit3_Oth	Visit 3 : Other (please specify)
FS_3	What was the SR's general communication style?
FS_3_Other_Oth	
	Types of communication style
FS_41	• Words
FS_42	• Sign
FS_43	• Vocalisations
FS_44	• Eye expressions
FS_45	• Facial expressions
FS_46	• Bodily movements
FS_47	• Gestures
FS_48	• Other (please specify)
FS_4_Other_Oth	
FS_5_Visit1_Response1	Visit 1 :
FS_5_Visit2_Response1	Visit 2 :
FS_5_Visit3_Response1	Visit 3 :
FS_5_Visit1_Response1_Codes	Visit 1 : Codes
FS_5_Visit2_Response1_Codes	Visit 2 : Codes
FS_5_Visit3_Response1_Codes	Visit 3 : Codes
FS_5_Visit1_SingleResponseQuestion	Visit 1 : Not Applicable
FS_5_Visit2_SingleResponseQuestion	Visit 2 : Not Applicable

FS_5_Visit3_SingleResponseQuestion	Visit 3 : Not Applicable
FS_5A	Did you take any breaks during the interview?
FS_5B	How many did you take?
FS_6_Preload_SingleResponseQuestion	Preload completed :
FS_6_PreInt_SingleResponseQuestion	Pre-Interview Questionnaire collected :
FS_7	Please identify if this location is in .... ?
FS_8	Please identify the Health Service Executive area or residence HSE area in which the individual lives most of the time.
FS_9	Any Other Information (Final Status):
FS_Section_Oth_Section_18_OthInfo	Section 18 - Final Status :
InterviewLength	Length of interview
InterviewLengthMINS	Length of interview in minutes
SessionStartTime	Used to calculate time after a restart

Pre-Interview Questionnaire (PIQ)	
Variable Name	**Description**
Survey_respondent_id_number	IDS-TILDA ID Number
Gender	Gender
Interview_date	Interview Date
Researcher_id_number	Interviewer ID Number
ADOB	Date of birth dd.mm.yy
BMaritalStatus	Marital status
CMovedResidence	Have you moved residence since Wave 1
DPayRent	Do you pay rent
EOtherInformation	Other Info on Rent
FType_Rental_Situation	Type of Rental Situation
GOther_Rental_Situation	Other type of rental situation
HAdapted_notAdapted	Housing Adapted/Not Adapted
ITenancyAgreement	Tenancy Agreement
Q1Age_Related_Eye_Disease	Has age related macular degeneration
Q2Glaucoma_Eye_Disease	Has glaucoma
Q3Cataract_Eye_Disease	Has cataracts
Q4Cataract_Surgery	Has had cataract surgery
Q5Other_Eye_Disease	Has other eye diseases
Q6Name_Other_Eye_Disease	Name of other eye disease

Q7HD_High_Cholestrol	Has high cholesterol
Q7HD_Heart_Murmur	Has a heart murmur
Q7HD_Abnormal_Heart_Rhythm	Has an abnormal heart rhythm
Q7HD_None_of_these_conditions	None of the these conditions
Q7HD_Dont_know	Don't know conditions relating to heart disease
Q8Tablets_high_cholesterol	Is SR taking tablets for high cholesterol
Q9High_Blood_Pressure	Has had high blood pressure
Q10Age_High_Blood_Pressure	Age told had high blood pressure (years)
Q11Angina	Has had angina
Q12Age_Angina	Age told had angina (years)
Q13Angina_Limits_Activities	Angina limits activities
Q14Heart_Attack	Has had a heart attack
Q15Age_Heart_Attack	Age told had heart attack (years)
Q16Mth_Year_Heart_Attack	Month & year of last heart attack
Q17No_of_Heart_Attacks	Number of heart attacks had
Q18Angioplasty_Stent	Have had an angioplasty or stent
Q19Mth_Year_Angio_Stent	Month & year of angioplasty of stent
Q20Open_Heart_Surgery	Have ever had open heart surgery

Q21Mth_Year_Heart_Surgery	Month & year of last open heart surgery
Q22Congestive_Heart_Failure	Has congestive heart failure
Q23Age_Congest_Heart_Failure	Age told has congestive heart failure (years)
Q24Education_Heart_Health	Education on heart health
Q25Education_Nutrition	Education on nutrition
Q26Diabetes	Has diabetes
Q27Age_Diabetes	Age told has diabetes
Q28Type_Diabetes	Type of diabetes
Q29Blood_Checked	How often blood glucose checked
Q30Medication_for_Diabetes	Take medication for diabetes
Q31Inject_Insulin_Diabetes	Take insulin injections for diabetes
Q32Leg_Ulcers_Diabetes	Has leg ulcers because of diabetes
Q32Protein_in_Urine_Diabetes	Has protein in urine because of diabetes
Q32Tingling_Legs_Feet_Diabetes	Has tingling in legs/feet because of diabetes
Q32Damage_Eye_Diabetes	Has damage to back of eye because of diabetes
Q32Damage_Kidneys_Diabetes	Has damage to kidneys because of diabetes
Q32None_of_these_diabetes_related_conditions	No conditions relating to diabetes

Q32Dont_know	Don’t know conditions relating to diabetes
Q33Education_Diabetes	Education on managing Diabetes
Q34Stroke	Has had stroke
Q35Age_Stroke	Age when first told had stroke
Q36No_of_Strokes	Number of strokes had
Q37Year_Recent_Stroke	Year of last stroke
Q38Ministroke_TIA	Has had a ministroke/TIA
Q39Age_Ministroke_TIA	Age told had ministroke/TIA
Q40No_of_Ministrokes_TIA	Number of ministrokes/TIAs had
Q41Year_Recent_MinistrokeTIA	Year of last ministroke/TIA
Q42Other_Heart_Trouble	Has other heart trouble
Q43Other_Heart_Trouble_Type	Type of other heart trouble
Q44Age_Other_Heart_Trouble	Age told had any other heart trouble
Q45ChronicCond_Asthma	Told has Asthma
Q45ChronicCond_Stomach_ulcers	Told has Stomach ulcers
Q45ChronicConditions_Varicose_ulcers	Told has Varicose ulcers
Q45ChronicCond_Liver_Damage	Told has Cirrhosis or serious liver damage
Q45ChronicCond_Constipation	Told has Chronic constipation

Q45ChronicCond_Coeliac	Told has Coeliac disease
Q45ChronicCond_PKU	Told has Phenylketonuria (PKU)
Q45ChronicCond_HypoThyroid_Disease	Told has HypoThyroid disease
Q45ChronicCond_HyperThyroid_Disease	Told has HyperThyroid disease
Q45ChronicCond_Gastro_Reflux	Told has Gastroesophageal reflux disease
Q45ChronicCond_Osteoporosis	Told has Osteoporosis/thin or brittle bones
Q45ChronicCond_MultipleSclerosis	Told has Mulitple sclerosis
Q45ChronicCond_Cerebral_palsy	Told has Cerebral palsy
Q45ChronicCond_Scoliosis	Told has Scoliosis
Q45ChronicConditions_Muscular_dystrophy	Told has Muscular dystrophy
Q45ChronicConditions_Spina_Bifida	Told has Spina bifida
Q45None_of_these	None of these chronic conditions
Q45Dont_know	Don't know of chronic conditions
Q46ChronicCond_Other	Has other chronic conditions
Q47ChronicCond_Other_Name	Name of other chronic condition
Q48Lung_Disease	Has chronic lung disease
Q49Oxygen_for_Lung_Disease	Receives oxygen for lung disease

Q50Lung_Disease_Limits_Activities	Lung disease limits activities
Q51Arthritis	Has arthritis (including osteoarthritis or rheumatism)
Q52Arthritis_Type_Osteoarthritis	Has osteoarthritis
Q52Arthritis_Type_Rheumatoid	Has Rheumatoid arthritis
Q52Arthritis_Type_Other_Kind	Has some other kind of arthritis
Q52Dont_Know_Arthritis	Dont Know type of arthritis
Q53Age_Arthritis	Age told had arthritis
Q54Arthritis_Activities_Difficult	Arthritis makes usual activities difficult
Q55Arthritis_Limit_Activities	Arthritis limit activities
Q56Arthritis_Sleep_Difficult	Arthritis makes sleeping difficult
Q57Education_Bone_Health	Received education on Bone Health
Q58Cancer	Told has cancer (including leukaemia, lymphoma)
Q59Age_Cancer	Age told when had cancer
Q60Cancer_Lung	Has/had lung cancer
Q60Cancer_Breast	Has/had breast cancer
Q60Cancer_Colon_Rectum	Has/had colon or rectum cancer
Q60Cancer_Stomach	Has/had stomach cancer
Q60Cancer_Oesophagus	Has/had oesophagus cancer

Q60Cancer_Prostate	Has/had prostate cancer
Q60Cancer_Bladder	Has/had cancer of the bladder
Q60Cancer_Liver	Has/had liver cancer
Q60Cancer_Brain	Has/had brain cancer
Q60Cancer_Ovary	Has/had ovarian cancer
Q60Cancer_Cervix	Has/had cervical cancer
Q60Cancer_Endometrium	Has/had endometrial cancer
Q60Cancer_Thyroid	Has/had thyroid cancer
Q60Cancer_Kidney	Has/had cancer of the kidney
Q60Cancer_Testicle	Has/had testicular cancer
Q60Cancer_Pancreas	Has/had cancer of the pancreas
Q60Cancer_Malignant_Melanoma	Has/had malignant melanoma (skin)
Q60Cancer_Non_Malignant_Melanoma	Has/had non-malignant melanoma
Q60Cancer_Oral_Cavity	Has/had cancer in oral cavity
Q60Cancer_Larynx	Has/had cancer of the larynx
Q60Cancer_Other_Pharynx	Has/had other pharynx cancer
Q60Cancer_Non_Hodgkins_Lymphoma	Has/had non-Hodgkin lymphoma cancer
Q60Cancer_Leukaemia	Has/had leukaemia
Q60Cancer_Other_organ	Has had cancer of another organ

Q60Dont_know_Cancer	Don’t know location of cancer
Q61Received_Treatment_Cancer	Received treatment for cancer
Q62Cancer_Treatment_Chemotherapy	Received chemotherapy for cancer
Q62Cancer_Treatment_Medication	Received medication for cancer
Q62Cancer_Treatment_Surgery	Received surgery for cancer
Q62Cancer_Treatment_Radiotherapy_Xray	Received radiotherapy/X-ray for cancer
Q62cancer_Treatment_Symptoms	Received treatment for symptoms (pain, nausea, rashes)
Q62cancer_Treatment_Biopsy	Received biopsy for cancer
Q62None_of_these_cancer_treatments	None of these treatments for cancer
Q62Dont_know_received_cancer_treatment	Don't know if treatment was received for cancer
Q63Cancer_Treatment_Other	Received other treatment for cancer
Q64Cancer_Treatment_Other_Name	Name of other treatment received for cancer
Q65Effectiveness_of_Cancer_Treatment	Effectiveness of cancer treatment
Q66Why_not_received_treatment	Why have you not received treatment
Q67Parkinsons_Disease	Has Parkinson's disease
Q68Age_Parkinsons_Disease	Age told has Parkinson's disease

Q69Emotional_Psychiatric_Cond	Has emotional, nervous or psychiatric condition
Q70Psych_Cond_Type_Hallucinations	Has hallucinations
Q70Psych_Cond_Type_Anxiety	Has anxiety condition
Q70Psych_Cond_Type_Depression	Has depression
Q70Psych_Cond_Type_Emotional_Problems	Has emotional problems
Q70Psych_Cond_Type_Schizophrenia	Has schizophrenia
Q70Psych_Cond_Type_Psychosis	Has psychosis
Q70Psych_Cond_Type_Mood_Swings	Has mood swings
Q70Psych_Cond_Type_Manic_Depression	Has manic depression
Q70None_of_these	None of these emotional/psychiatric conditions
Q70Dont_know	Don't know what type of emotional/psychiatric cond.
Q70Psych_Cond_Type_Other	Has other nervous or psychiatric condition
Q70Psy_Cond_Type_Other_Name	Name of other nervous or psychiatric condition
Q71Psychiatric_treatment	Now getting psychiatric treatment for conditions
Q72WhoGivesTreatment_Psychiatrist	Psychiatrist treats psychiatric condition
Q72Address_Psychiatrist	Address of psychiatrist
Q72WhoGivesTreatment_GP	GP treats psychiatric condition
Q72Address_GP	Address of GP

Q72WhoGivesTreatment_Other	Other person treats psychiatric condition
Q72Name_Address_Other	Name and address of other person
Q72Dont_know	Don't know who gives psychiatric treatment for condition
Q73Psychological_Treatment	Now getting psychological treatment for condition
Q74WhoGivesTreatment_Psychologist	Psychologist treating condition
Q74Address_Psychologist	Address of psychologist
Q74WhoGivesTreatment_Counsellor	Counsellor treating condition
Q74Address_Counsellor	Address of counsellor
Q74WhoGivesTreatment_CNS	CNS treating condition
Q74Address_CNS	Address of CNS
Q74WhoGivesTreatment_Other	Other person gives psychological treatment
Q74Name_Address_Other	Name and address of other
Q74Dont_know	Don't know who gives psychological treatment for condition
Q75Annoyed_Frustrated	Become Annoyed or Frustrated when things don't work out
Q76Do_Nothing	Do Nothing
Q76Scream	Scream

Q76Throw_Things	Throw Things
Q76Hit_Out	Hit Out
Q76Self_Injure	Self Injure
Q76None_of_These	None of these
Q76Other	Other
Q76Other_Named	Other Named
Q77Alzheimers_Disease	Has Alzheimer's disease
Q78Age_Alzheimers_Disease	Age told has Alzheimer's disease
Q79Dementia	Has dementia, organic brain syndrome or senility
Q80Age_Dementia	Age told has dementia, organic brain syndrome or senility
Q81Epilepsy	Has epilepsy
Q82Age_Epilepsy	Age told has Epilepsy
Q83Epilepsy_Type_Tonic_Clonic	Has tonic-clonic seizures
Q83Epilepsy_Type_Tonic	Has tonic seizures
Q83Epilepsy_Type_Atonic	Has atonic seizures
Q83Epilepsy_Type_Clonic	Has clonic seizures
Q83Epilepsy_Type_Myoclonic	Has myoclonic seizures
Q83Epilepsy_Type_Absence	Has absence seizures
Q83Epilepsy_Type_Simple	Has simple partial seizures
Q83Epilepsy_Type_Complex	Has complex partial seizures
Q83Dont_know_Type_of_Epilepsy	Don't know type of epilepsy

Q84Attend_Epilepsy_Clinic	Attend an epilepsy clinic
Q85Last_Epilepsy_Review	Last had epilepsy reviewed
Q86Epilepsy_Review_GP	General Practitioner reviewed epilepsy
Q86Epilepsy_Review_Psychiatrist	Psychiatrist reviewed epilepsy
Q86Epilepsy_Review_Neurologist	Neurologist reviewed epilepsy
Q86Epilepsy_Review_CNS	CNS reviewed epilepsy
Q86Dont_know	Don't know the practitioner
Q86Other_Review_Epilepsy	Other person review epilepsy
Q86Other_Review_Epilepsy_Name	Other person who reviewed epilepsy
Q87Epilepsy_Limit_Chores	Epilepsy limits chores
Q87Epilepsy_Limit_Work	Epilepsy limits work
Q87Epilepsy_Limit_Social_Activities	Epilepsy limits social activities
Q87Epilepsy_Limit_Sports	Epilepsy limits sports activities
Q87Epilepsy_Limit_Driving	Epilepsy limits driving
Q87Epilepsy_Limit_Going_Out_Alone	Epilepsy limits going out alone
Q87Epilepsy_Limit_None_of_Above	Epilepsy limits none of the above
Q87Epilepsy_Limit_Other	Epilepsy limits Other
Q87Epilepsy_Limit_Other_Named	Epilepsy limits Other Named
Q88Rescue_Med_Epistatus	Rescue Med Epistatus

Q88Rescue_Med_Frisium	Rescue Med Frisium
Q88Rescue_Med_Stesolid	Rescue Med Stesolid
Q88Rescue_Med_Clonazapam	Rescue Med Clonazapam
Q88Rescue_Med_Lorazepam	Rescue Med Lorazepam
Q88Rescue_Med_None	Rescue Med None
Q88Rescue_Med_Dont_Know	Rescue Med Don't Know
Q88Rescue_Med_Other	Rescue Med Other
Q88Rescue_Med_Other_Named	Rescue Med Other Named
Q89Used_Epistatus	Used Epistatus
Q89Used_Frisium	Used Frisium
Q89Used_Stesolid	Used Stesolid
Q89Used_Clonazapam	Used Clonazapam
Q89Used_Lorazepam	Used Lorazepam
Q89Used_None	Used None
Q89Used_Dont_Know	Used Don't Know
Q89Used_Other	Used Other
Q89Used_Other_Named	Used Other Named
Q90Record_of_Seizures	Keep record of seizures
Q91Frequency_of_Seizures	Frequency of seizures in last 2 years
Q92Education_Epilepsy	Education on managing Epilepsy
Q93Constipation_Straining	Have you experienced Straining
Q93Lumpy_Hard_Stool	Have you experienced Lumpy or Hard stool

Q93Incomplete_Evacuation	Have you experienced incomplete evacuation
Q93Anorectal_Obstruction	Have you experienced Anorectal Obstruction/Blockage
Q93Manual_Maneuvers	Have you experienced Manual Manoeuvres
Q93Fewer_than_3_Defecations_Weekly	Have you experienced fewer than 3 defecations per week
Q93Pain_during_defecation	Have you experienced pain during defecation
Q94Normal_Loose_Stool_Without_Laxative	Have you experienced normal or loose stool without the use of laxatives
Q95Diagnosed_IBS	Have you been diagnosed with Irritable Bowel Syndrome
Q96Encopresis	Have you experienced Encopresis
Q97Flu_Injection	Has had a flu injection
Q98HepatitisB_Vaccine	Has had a Hepatitis B vaccine
Q99Blood_Test_Cholestrol	Has had a blood test for cholesterol
Q100Blood_Pressure_Measured	Has had blood pressure measured

Q101Thyroid_Function_Test	Has had a thyroid function test
Q102Blood_Glucose_Test	Has had a blood glucose test
Q103Dementia_Assessment	Has had assessment for memory impairment/dementia
Q104Bone_Density_Test	Has had a bone density test
Q105Mother_Father_Hip_Fracture	Mother/Father had Hip Fracture
Q105Mother_Father_Colon_Cancer	Mother/Father had Colon Cancer
Q105Mother_Father_Breast_Cancer	Mother/Father had Breast Cancer
Q105Mother_Father_Dementia	Mother/Father had Dementia
Q105Mother_Father_Dont_Know	Mother/Father had Don't Know
Q106Had_CT_Brain_Scan	Had CT Brain Scan
Q106Had_CT_Scan_Other	Had Other CT Scan
Q106Other_CT_Scan_Named	Other CT Scan Named
Q106Had_MRI_Brain_Scan	Had MRI brain scan
Q106Had_MRI_Scan_Other	Had Other MRI scan
Q106Other_MRI_Scan_Named	Other MRI scan named
Q106Had_EEG_Scan	Had EEG scan
Q106Dont_Know_Tests	Don't Know what test I had
Q107Menopause	Has gone through the menopause
Q108Age_Menopause	Age the menopause started

Q109Used_Prescription_Hormone	Use of prescription hormone (HRT, oestrogen)
Q110Years_Prescription_Hormone	No. of years using prescription hormones
Q111Years_Prescription_Hormone	No. of years took prescription hormone
Q112Check_Breasts_Lumps	Check breasts for lumps regularly
Q113GP_Check_Breasts_Lumps	GP checked breasts for lumps
Q114Mammogram	Has had mammogram or x-ray to search for cancer
Q115Check_Testicles_Lumps	Check testicles for lumps regularly
Q116GP_Check_Testicles_Lumps	GP checked testicles for lumps
Q117Exam_Prostate_Cancer	Has had examination for prostate cancer
Q118Blood_Test_Prostate	Has had blood test for prostate cancer
Q119Medical_Cover	Medical cover
Q120Medical_Insurance	Medical insurance
Q121Visit_with_GP	Number of visits with GP in the last year
Q122No_visits_AandE	Number of visits to A & E in last year
Q123Not_Visit_AandE_last_year	Has not visited A & E as a patient in the last year
Q123AandE_Multiple_Injuries	Visited A & E in the last year with multiple injuries

Q123AandE_Fractured_Bones	Visited A & E in the last year with broken or fractured bone(s)
Q123AandE_Burn	Visited A & E in the last year with burn
Q123AandE_Dislocation	Visited A & E in the last year with dislocation
Q123AandE_Sprainorstrain	Visited A & E in the last year with sprain or strain
Q123AandE_Cut_Open_Wound	Visited A & E in the last year with cut (open wound)
Q123AandE_Scrape_Bruise_Blister	Visited A & E in the last year with scrape, bruise, blister
Q123AandE_Concussion_Brain_Injury	Visited A & E in the last year with concussion or other brain injury
Q123AandE_Poisoning	Visited A & E in the last year with poisoning
Q123AandE_Internal_Injury	Visited A & E in the last year with internal injury
Q123AandE_Pneumonia	Visited A & E in the last year with pneumonia
Q123AandE_Dont_know	Don't know the reason for visit to A & E
Q123AandE_Other_Treatment	Visited A & E in the last year for another reason
Q123AandE_Other_Treatment_Name	Visited A & E in the last year for another named injury

Q124Visits_to_Outpatients	No. of visits to out-patients in the last year
Q125Nights_in_General_Hosp	No. of nights spent in general hospital in the last year
Q126Nights_in_Psych_Hosp	No. of nights spent in psychiatric hospital in the last year
Q127Time_in_Nursing_Home	Time spent in a nursing/convalescent home in the last year
Q128Need_for_Healthcare	Need for healthcare in the last year, but didn't receive
Q129Healthcare_Not_Offered	Healthcare was not offered
Q129Healthcare_Not_Available	Healthcare not available in area
Q129Healthcare_Not_Avail_Time	Healthcare not available at time required
Q129Healthcare_Long_Waiting	Waiting time too long
Q129Healthcare_Service_No_Good	Felt that the service would not be good
Q129Healthcare_Too_Costly	Too costly
Q129Heathcare_Too_Busy	Too busy
Q129Healthcare_Didnt_Bother	Didn't get around to it/didn't bother
Q129Healthcare_Didnt_Know_Where	Didn't know where to go
Q129Healthcare_Transport_Problems	Problems with transport
Q129Healthcare_Language_Problems	Communication/language problems

Q129Healthcare_Family_Responsibilities	Personal or family responsibility
Q129Healthcare_Fear	Fear of healthcare and/or of treatment
Q129Healthcare_Decided_Against_care	Decided not to seek care
Q129Healthcare_Inaccessible_Materials	Information material not accessible/inadequate communication aids
Q129Healthcare_Not_Taken_Serious	Complaint was not taken seriously enough
Q129Healthcare_Negative_Attitudes	Negative attitudes of staff
Q129Healthcare_Too_Embarrassing	Too embarrassing
Q129Healthcare_Too_Much_Pain	Was in too much pain
Q129Healthcare_Forgot_Appointment	Forgot about my appointments
Q129Healthcare_Dont_know	Don't know the reasons for not getting healthcare
Q129Healthcare_Other_Reasons	Other reason for not having received healthcare
Q129Healthcare_Other_Reasons_Named	Named other reasons for not having received healthcare
Q130Type_of_Care_Physical_Health	Treatment of a physical health problem was needed
Q130Type_of_Care_Mental_Health	Treatment of an emotional or mental health problem was needed
Q130Type_of_Care_Regular_CheckUp	A regular check-up was needed

Q130Type_of_Care_of_Injury	Care of an injury was needed
Q130Dont_know	Don't know the type of care
Q130Type_Other_Care_Needed	Another type of care that was needed
Q130Type_Other_Care_Needed_Named	Named type of care that was needed
Q131Services_General_Practitioner	In last year, received services from general practitioner
Q131Services_Public_Health_Nurse	In last year, received services from public health nurse
Q131Services_Occupation_Therapy	In last year, received services from occupational therapy
Q131Services_Chiropody	In last year, received services from chiropody services
Q131Services_Physiotherapy	In last year, received services from physiotherapy
Q131Services_Social_Work	In last year, received services from social work
Q131Services_Psychological_Counselling	In last year, received services from psychological/counselling
Q131Services_HomeHelp	In last year, received services from home help
Q131Services_Personal_Care_Attendant	In last year, received services from personal care attendant

Q131Services_Meals_on_Wheels	In last year, received services from meals-on-wheels
Q131Services_Optician	In last year, received services from optician services
Q131Services_Dental	In last year, received services from dental services
Q131Services_Hearing	In last year, received services from hearing services
Q131Services_Pharmacist	In last year, received services pharmacist
Q131Services_Dietician	In last year, received services from dietician services
Q131Services_Speech_Language	In last year, received services from speech & language
Q131Services_Day_Centre	In last year, received services from day centre services
Q131Services_Respite	In last year, received services from respite services
Q131Services_Residential	In last year, received services from residential services
Q131Services_Neurological	In last year, received services from neurological services
Q131Services_Geriatician	In last year, received services from geriatrician services
Q131Services_Endocrinology	In last year, received services from endocrinology services

Q131Services_Dermatological	In last year, received services from dermatological services
Q131Services_Psychiatry	In last year, received services from psychiatry services
Q131Services_Palliative_Care	In last year, received services from palliative care services
Q131Dont_know	Don't know the services received
Q131Services_Other	Other services received in the last year (excluding services paid for)
Q131Services_Other_Named	In last year, received other services (excluding services paid for)
Q131AGeneral_Practitioner_Satisfaction	Satisfaction with GP
Q131APublic_Health_Nurse_Satisfaction	Satisfaction with Public Health Nurse
Q131AOccupational_Therapy_Satisfaction	Satisfaction with Occupational Therapy
Q131AChiropody_Satisfaction	Satisfaction with Chiropody
Q131APhysiotherapy_Satisfaction	Satisfaction with Physiotherapy
Q131ASocial_Work_Satisfaction	Satisfaction with Social Work
Q131APsychological_Satisfaction	Satisfaction with Psychological Services
Q131AHome_Help_Satisfaction	Satisfaction with Home Help

Q131APersonal_Care_Attendant_Satisfaction	Satisfaction with Personal Care Attendant
Q131AMeals_on_Wheels_Satisfaction	Satisfaction with Meals on Wheels
Q131AOptician_Satisfaction	Satisfaction with Optician
Q131ADental_Satisfaction	Satisfaction with Dental Services
Q131AHearing_Satisfaction	Satisfaction with Hearing Services
Q131APharmacist_Satisfaction	Satisfaction with Pharmacist
Q131ADietician_Satisfaction	Satisfaction with Dietician
Q131ASpeech_Language_Satisfaction	Satisfaction with Speech and Language
Q131ADay_Centre_Satisfaction	Satisfaction with Day Centre
Q131ARespite_Satisfaction	Satisfaction with Respite
Q131AResidential_Satisfaction	Satisfaction with Residential Centre
Q131ANeurological_Satisfaction	Satisfaction with Neurological Services
Q131AGeriatrician_Satisfaction	Satisfaction with Geriatrician
Q131AEndocrinology_Satisfaction	Satisfaction with Endocrinology
Q131ADermatological_Satisfaction	Satisfaction with Dermatological Services
Q131APsychiatry_Satisfaction	Satisfaction with Psychiatry
Q131APalliative_Satisfaction	Satisfaction with Palliative Care

Q131ADont_Know_Satisfaction	Satisfaction Don't Know
Q131AOther_Satisfaction	Satisfaction with Other service
Q132Reason_Not_Satisfied	Reason for Dissatisfaction
Q133General_Practioner_Setting	General Practitioner Setting
Q133Public_Health_Nurse_Setting	Public Health Nurse Setting
Q133Occupational_Therapy_Setting	Occupational Therapy Setting
Q133Chiropody_Setting	Chiropody Setting
Q133Physiotherapy_Setting	Physiotherapy Setting
Q133Social_Work_Setting	Social Work Services Setting
Q133Psychological_Setting	Psychological Services Setting
Q133Home_Help_Setting	Home Help Setting
Q133Personal_Care_Attendant_Setting	Personal Care Attendant Setting
Q133Meals_on_Wheels_Setting	Meals on Wheels Setting
Q133Optician_Setting	Optician Setting
Q133Dental_Setting	Dental Setting
Q133Hearing_Setting	Hearing Services Setting
Q133Pharmacist_Setting	Pharmacist Setting
Q133Dietician_Setting	Dietician Setting
Q133Speech_and_language_Setting	Speech and Language Setting
Q133Day_Centre_Setting	Day Centre Setting
Q133Respite_Setting	Respite Setting

Q133Residential_Setting	Residential Setting
Q133Neurological_Setting	Neurological Setting
Q133Geriatrician_Setting	Geriatrician Setting
Q133Endocrinology_Setting	Endocrinology Setting
Q133Dermatological_Setting	Dermatological Setting
Q133Psychiatry_Setting	Psychiatry Setting
Q133Palliative_Care_Setting	Palliative Care Setting
Q133Dont_Know_Setting	Don't Know Setting
Q133Other_Setting	Other Setting
Q133Other_Setting_Named	Other Setting Named
Q134Benefit_Service_Not_Receiving	Benefit from Services not receiving
Q135General_Practitioner_Not_Receiving	Not Receiving General Practitioner
Q135Public_Health_Nurse_Not_Receiving	Not Receiving Public Health Nurse
Q135Occupational_Therapy_Not_receiving	Therapy
Q135Chiropody_Not_Receiving	Not Receiving Chiropody
Q135Physiotherapy_Not_receiving	Not Receiving Physiotherapy
Q135Social_Work_Not_Receiving	Not Receiving Social Work Services
Q135Psychological_Services_Not_Receiving	Not Receiving Psychological Services
Q135Home_Help_Not_Receiving	Not Receiving Home Help Services
Q135Personal_Care_Attendant_Not_Receiving	Not Receiving Personal Care Attendant
Q135Meals_On_Wheels_Not_Receiving	Not Receiving Meals on Wheels

Q135Optician_Services_Not_Receiving	Not Receiving Optician
Q135Dental_Services_Not_Receiving	Not Receiving Dental Services
Q135Hearing_Services_Not_Receiving	Not Receiving Hearing Services
Q135Pharmacist_Not_Receiving	Not Receiving Pharmacist Services
Q135Dietician_Not_Receiving	Not Receiving Dietician Services
Q135Speech_Language_Not_Receiving	Not Receiving Speech and Language Services
Q135Day_Cantre_Not_Receiving	Not Receiving Day Centre Services
Q135Respite_Services_Not_Receiving	Not receiving Respite Services
Q135Residential_Services_Not_Receiving	Not Receiving Residential Services
Q135Neurological_Services_Not_Receiving	Not Receiving neurological Services
Q135Geriatrician_Services_Not_Receiving	Not Receiving Geriatrician Services
Q135Endocrinology_Services_Not_Receiving	Not Receiving Endocrinology Services
Q135Dermalogical_Services_Not_Receiving	Not Receiving Dermatological Services
Q135Psychiatry_Services_Not_Receiving	Not Receiving Psychiatry Services
Q135Palliative_Care_Services_Not_Receiving	Not Receiving Palliative Care Services
Q135Dont_Know_Services_Not_Receiving	Don't Know

Q135Other_Service_Not_Receiving	Not Receiving Other Services
Q135Other_Service_Not_Receiving_Named	Other Service Not receiving Named
Q136Know_How_Access_Service	Do you know how to Access this Service
Q137Main_Thing_Prevents_Access_Service	What is the main thing that prevents you from receiving this service
Q138Nights_In_Respite	In last year, nights spent in respite (excluding nursing home)
Q139Easy_Read_Info_Bone_Health	Easy Read Information on Bone Health
Q139Easy_Read_Info_Heart_Health	Easy Read Information on Heart Health
Q139Easy_Read_Info_Epilepsy	Easy Read Information on Epilepsy
Q139Easy_Read_Info_Diabetes	Easy Read Information on Diabetes
Q139Easy_Read_Info_Exercise	Easy Read Information on Exercise
Q139Easy_Read_Info_Nutrition	Easy Read Information on Nutrition
q139Easy_Read_Info_Constipation	Easy Read Information on Constipation
Q139Easy_Read_Info_None_of_Above	Easy Read Information on None of Above

Q139Easy_Read_Info_Dont_Know	Easy Read Information Don't Know
Q140Source_Easy_Read_Info_Bone_Health	Source of Easy to Read info on Bone Health
Q140Source_Easy_Read_Info_Heart_Health	Source of Easy Read Info on Heart Health
Q140Source_Easy_Read_Info_Epilepsy	Source on Easy Read Info on Epilepsy
Q140Source_Easy_Read_Info_Diabetes	Source on Easy to Read Info on Diabetes
Q140Source_Easy_Read_Info_Exercise	Source on Easy to Read Info on Exercise
Q140Source_Easy_Read_Info_Nurtition	Source on Easy to Read Info on Nutrition
Q140Source_Easy_Read_Info_Constipation	Source on Easy to Read Info on Constipation
Q140Source_Other_Information_Named	Other Information Source Easy Read Info
Q141Easy_Read_Medication	Easy Read Info on Medication
Q142Source_Easy_Read_Info_Medication_GP	Easy Read Info on Medication from GP
Q142Source_Easy_Read_Info_Medication_Pharmacist	Easy Read Info on Medication from Pharmacist
Q142Source_Easy_Read_Info_Medication_PHN	Easy Read Info on Medication from Public Health Nurse
Q142Source_Easy_Read_Info_Medication_RNID	Easy Read Info on Medication from RNID

Q142Source_Easy_Read_Info_Medication_Dont_Know	Don't Know source of Easy read info on Medication
Q142Source_Easy_read_Info_Medication_Other	Easy Read Info on Medication from Other
Q142Source_Easy_Read_Infor_Med_Other_Named	Other Source of Easy Read Info on Medication
Q143Support_from_SVDP	In last year, received support from St. Vincent de Paul
Q143Support_from_SeniorHelpline	In last year, received support from The Senior Helpline
Q143Support_from_Samaritans	In last year, received support from The Samaritans
Q143None_of_these	No support from these organisations
Q143Dont_know	Don't know if received support
Q143Support_from_Other_Organisation	In last year, receive support from other organisations
Q143Support_from_Other_Org_Named	Named organisation from which support was received
Q144Dont_Know_Medication	Don't Know What Medication I take
Q144Dont_Take_Medication	Don't Take Medication
Q144Medication_1	Name Medication 1
Q144Medication_1_Dosage	Dosage Medication 1
Q144Medication_1_Frequency	Frequency Medication 1
Q144Medication_1_Route	Route Medication 1

Q144Medication_Date_Prescribed	Date Prescribed Medication 1
Q144Medication_2	Name Medication 2
Q144Medication_2_Dosage	Dosage Medication 2
Q144Medication_2_Frequency	Frequency Medication 2
Q144Medication_2_Route	Route Medication 2
Q144Medication_2_Date_Prescribed	Date Prescribed Medication 2
Q144Medication_3	Name Medication 3
Q144Medication_3_Dosage	Dosage Medication 3
Q144Medication_3_Frequency	Frequency Medication 3
Q144Medication_3_Route	Route Medication 3
Q144Medication_3_Date_Prescribed	Date Prescribed Medication 3
Q144Medication_4	Name Medication 4
Q144Medication_4_Dosage	Dosage Medication 4
Q144Medication_4_Frequency	Frequency Medication 4
Q144Medication_4_Route	Route Medication 4
Q144Medication_4_Date_Prescribed	Date Prescribed Medication 4
Q144Medication_5	Name Medication 5
Q144Medication_5_Dosage	Dosage Medication 5
Q144Medication_5_Frequency	Frequency Medication 5
Q144Medication_5_Route	Route Medication 5
Q144Medication_5_Date_Prescribed	Date Prescribed Medication 5
Q144Medication_6	Name Medication 6
Q144Medication_6_Dosage	Dosage Medication 6

Q144Medication_6_Frequency	Frequency Medication 6
Q144Medication_6_Route	Route Medication 6
Q144Medication_6_Date_Prescribed	Date Prescribed Medication 6
Q144Medication_7	Name Medication 7
Q144Medication_7_Dosage	Dosage Medication 7
Q144Medication_7_Frequency	Frequency Medication 7
Q144Medication_7_Route	Route Medication 7
Q144Medication_7_Date_Prescribed	Date Prescribed Medication 7
Q144Medication_8	Name Medication 8
Q144Medication_8_Dosage	Dosage Medication 8
Q144Medication_8_Frequency	Frequency Medication 8
Q144Medication_8_Route	Route Medication 8
Q144Medication_8_Date_Prescribed	Date Prescribed Medication 8
Q144Medication_9	Name Medication 9
Q144Medication_9_Dosage	Dosage Medication 9
Q144Medication_9_Frequency	Frequency Medication 9
Q144Medication_9_Route	Route Medication 9
Q144Medication_9_Date_Prescribed	Date Prescribed Medication 9
Q144Medication_10	Name Medication 10
Q144Medication_10_Dosage	Dosage Medication 10
Q144Medication_10_Frequency	Frequency Medication 10
Q144Medication_10_Route	Route Medication 10

Q144Medication_10_Date_Prescribed	Date Prescribed Medication 10
Q144Medication_11	Name Medication 11
Q144Medication_11_Dosage	Dosage Medication 11
Q144Medication_11_Frequency	Frequency Medication 11
Q144Medication_11_Route	Route Medication 11
Q144Medication_11_Date_Prescribed	Date Prescribed Medication 11
Q144Medication_12	Name Medication 12
Q144Medication_12_Dosage	Dosage Medication 12
Q144Medication_12_Frequency	Frequency Medication 12
Q144Medication_12_Route	Route Medication 12
Q144Medication_12_Date_Prescribed	Date Prescribed Medication 12
Q144Medication_13	Name Medication 13
Q144Medication_13_Dosage	Dosage Medication 13
Q144Medication_13_Frequency	Frequency Medication 13
Q144Medication_13_Route	Route Medication 13
Q144Medication_13_Date_Prescribed	Date Prescribed Medication 13
Q144Medication_14	Name Medication 14
Q144Medication_14_Dosage	Dosage Medication 14
Q144Medication_14_Frequency	Frequency Medication 14
Q144Medication_14_Route	Route Medication 14
Q144Medication_14_Date_Prescribed	Date Prescribed Medication 14

Q144Medication_15	Name Medication 15
Q144Medication_15_Dosage	Dosage Medication 15
Q144Medication_15_Frequency	Frequency Medication 15
Q144Medication_15_Route	Route Medication 15
Q144Medication_15_Date_Prescribed	Date Prescribed Medication 15
Q144Medication_16	Name Medication 16
Q144Medication_16_Dosage	Dosage Medication 16
Q144Medication_16_Frequency	Frequency Medication 16
Q144Medication_16_Route	Route Medication 16
Q144Medication_16_Date_Prescribed	Date Prescribed Medication 16
Q144Medication_17	Name Medication 17
Q144Medication_17_Dosage	Dosage Medication 17
Q144Medication_17_Frequency	Frequency Medication 17
Q144Medication_17_Route	Route Medication 17
Q144Medication_17_Date_Prescribed	Date Prescribed Medication 17
Q144Medication_18	Name Medication 18
Q144Medication_18_Dosage	Dosage Medication 18
Q144Medication_18_Frequency	Frequency Medication 18
Q144Medication_18_Route	Route Medication 18
Q144Medication_18_Date_Prescribed	Date Prescribed Medication 18
Q144Medication_19	Name Medication 19

Q144Medication_19_Dosage	Dosage Medication 19
Q144Medication_19_Frequency	Frequency Medication 19
Q144Medication_19_Route	Route Medication 19
Q144Medication_19_Date_Prescribed	Date Prescribed Medication 19
Q144Medication_20	Name Medication 20
Q144Medication_20_Dosage	Dosage Medication 20
Q144Medication_20_Frequency	Frequency Medication 20
Q144Medication_20_Route	Route Medication 20
Q144Medication_20_Date_Prescribed	Date Prescribed Medication 20
Q144Medication_21	Name Medication 21
Q144Medication_21_Dosage	Dosage Medication 21
Q144Medication_21_Frequency	Frequency Medication 21
Q144Medication_21_Route	Route Medication 21
Q144Medication_21_Date_Prescribed	Date Prescribed Medication 21
Q144Medication_22	Name Medication 22
Q144Medication_22_Dosage	Dosage Medication 22
Q144Medication_22_Frequency	Frequency Medication 22
Q144Medication_22_Route	Route Medication 22
Q144Medication_22_Date_Prescribed	Date Prescribed Medication 22
Q144Medication_23	Name Medication 23
Q144Medication_23_Dosage	Dosage Medication 23

Q144Medication_23_Frequency	Frequency Medication 23
Q144Medication_23_Route	Route Medication 23
Q144Medication_23_Date_Prescribed	Date Prescribed Medication 23
Q144Medication_24	Name Medication 24
Q144Medication_24_Dosage	Dosage Medication 24
Q144Medication_24_Frequency	Frequency Medication 24
Q144Medication_24_Route	Route Medication 24
Q144Medication_24_Date_Prescribed	Date Prescribed Medication 24
Q145Did_Not_Get_Bloods_Done	Did not get bloods done last year
Q145FBC_Redblood_Number_of_Months	FBC Red blood Number of Months
Q145FBC_Redblood_Result	FBC Red blood Result
Q145FBC_Redblood_Fasting	FBC Red blood Fasting/Not Fasting
Q145FBC_Redblood_Normal_Range	FBC Red blood Normal Lab Range
Q145FBC_Whiteblood_Number_of_Months	FBC White blood Number of Months
Q145FBC_Whiteblood_Result	FBC White blood Result
Q145FBC_Whiteblood_Fasting	FBC White blood Fasting/Not Fasting
Q145FBC_Whiteblood_Normal_Range	FBC White blood Normal Lab Range
Q145FBC_Haemoglobin_Number_of_Months	FBC Haemoglobin Number of Months
Q145FBC_Haemoglobin_Result	FBC Haemoglobin Result

Q145FBC_Haemoglobin_Fasting	FBC Haemoglobin Fasting/Not Fasting
Q145FBC_Haemoglobin_Normal_Range	FBC Haemoglobin Normal Lab Range
Q145FBC_Platelets_Number_of_Months	FBC Platelets Number of Months
Q145FBC_Platelets_Result	FBC Platelets Result
Q145FBC_Platelets_Normal_Range	FBC Platelets Fasting/Not Fasting
Q145FBC_Platelets_Fasting	FBC Platelets Normal Lab Range
Q145ESR_Number_of_Months	ESR Number of Months
Q145ESR_Result	ESR Result
Q145ESR_Fasting	ESR Fasting/Not Fasting
Q145ESR_Normal_Range	ESR Normal Lab Range
Q145HbA1C_Number_of_Months	HbA1C Number of Months
Q145HbA1C_Result	HbA1C Result
Q145HbA1C_Fasting	HbA1C Fasting/Not Fasting
Q145HbA1C_Normal_Range	HbA1C Normal Lab Range
Q145BloodGlucose_Number_of_Months	Blood Glucose Number of Months
Q145BloodGlucose_Result	Blood Glucose Result
Q145BloodGlucose_Fasting	Blood Glucose Fasting/Not Fasting
Q145BloodGlucose_Normal_Range	Blood Glucose Normal Lab Range
Q145UandE_Number_of_Months	U&E Number of Months

Q145UandE_Result	U&E Result
Q145UandE_Fasting	U&E Fasting/Not Fasting
Q145UandE_Normal_Range	U&E Normal Lab Range
Q145B12_Number_of_Months	B12 Number of Months
Q145B12_Result	B12 Result
Q145B12_Fasting	B12 Fasting/Not Fasting
Q145B12_Normal_Range	B12 Normal Lab Range
Q145Folate_Number_of_Months	Folate Number of Months
Q145Folate_Result	Folate Result
Q145Folate_Fasting	Folate Fasting/Not Fasting
Q145Folate_Normal_Range	Folate Normal Lab Range
Q145LFT_Number_of_Months	LFTs Number of Months
Q145LFT_Result	LFTs Result
Q145LFT_Fasting	LFTs Fasting/Not Fasting
Q145LFT_Normal_Range	LFTs Normal Lab Range
Q145Serum_Cholesterol_Number_of_Months	Serum Cholesterol Number of Months
Q145Serum_Cholesterol_Result	Serum Cholesterol Result
Q145Serum_Cholesterol_Fasting	Serum Cholesterol Fasting/Not Fasting
Q145Serum_Cholesterol_Normal_Range	Serum Cholesterol Normal Lab Range

Q145Lipid_Profile_Number_of_Months	Lipid Profile Number of Months
Q145Lipid_Profile_Result	Lipid Profile Result
Q145Lipid_Profile_Fasting	Lipid Profile Fasting/Not Fasting
Q145Lipid_Profile_Normal_Range	Lipid Profile Normal Lab Range
Q145VitD_Number_of_Months	VitD Number of Months
Q145VitD_Results	VitD Result
Q145VitD_Fasting	VitD Fasting/Not Fasting
Q145VitD_Normal_Range	VitD Normal Lab Range
Q145HepScreen_A_Number_of_Months	Hep Screen A Number of Months
Q145HepScreen_A_Result	Hep Screen A Result
Q145HepScreen_A_Fasting	Hep Screen A Fasting/Not Fasting
Q145HepScreen_A_Normal_Range	Hep Screen A Normal Lab Range
Q145HepScreen_B_Number_of_Months	Hep Screen B Number of Months
Q145HepScreen_B_Result	Hep Screen B Result
Q145HepScreen_B_Fasting	Hep Screen B Fasting/Not Fasting
Q145HepScreen_B_Normal_Range	Hep Screen B Normal Lab Range
Q145HepScreen_C_Number_of_Months	Hep Screen C Number of Months
Q145HepScreen_C_Result	Hep Screen C Result
Q145HepScreen_C_Fasting	Hep Screen C Fasting/Not Fasting

Q145HepScreen_C_Normal_Range	Hep Screen C Normal Lab Range
Q145TFT_Number_of_Months	TFTs Number of Months
Q145TFT_Result	TFTs Result
Q145TFT_Fasting	TFTs Fasting/Not Fasting
Q145TFT_Normal_Range	TFTs Normal Lab Range
Q145Calcium_Number_of_Months	Calcium Number of Months
Q145Calcium_Result	Calcium Result
Q145Calcium_Fasting	Calcium Fasting/Not Fasting
Q145Calcium_Normal_Range	Calcium Normal Lab Range
Q145PSA_Number_of_Months	PSA Number of Months
Q145PSA_Result	PSA Result
Q145PSA_Fasting	PSA Fasting/Not Fasting
Q145PSA_Normal_Range	PSA Normal Lab Range
Q145Blood_Test_1_Name	Blood Test 1 Name
Q145Blood_Test_1_Number_of_Months	Blood Test 1 Number of Months
Q145Blood_Test_1_Result	Blood Test 1 Result
Q145Blood_Test_1_Fasting	Blood Test 1 Fasting/Not Fasting
Q145Blood_Test_1_Normal_Range	Blood Test 1 Normal Lab Range
Q145Blood_Test_2_Name	Blood Test 2 Name
Q145Blood_Test_2_Number_of_Months	Blood Test 2 Number of Months

Q145Blood_Test_2_Result	Blood Test 2 Result
Q145Blood_Test_2_Fasting	Blood Test 2 Fasting/Not Fasting
Q145Blood_Test_2_Normal_Range	Blood Test 2 Normal Lab Range
Q145Blood_Test_3_Name	Blood Test 3 Name
Q145Blood_Test_3_Number_of_Months	Blood Test 3 Number of Months
Q145Blood_Test_3_Result	Blood Test 3 Result
Q145Blood_Test_3_Fasting	Blood Test 3 Fasting/Not Fasting
Q145Blood_Test_3_Normal_Range	Blood Test 3 Normal Lab Range
Q145Blood_Test_4_Name	Blood Test 4 Name
Q145Blood_Test_4_Number_of_Months	Blood Test 4 Number of Months
Q145Bllood_Test_4_Result	Blood Test 4 Result
Q145Blood_Test_4_Fasting	Blood Test 4 Fasting/Not Fasting
Q145Blood_Test_4_Normal_Lab_Range	Blood Test 4 Normal Lab Range
Q146Time_Taken_To_Complete	Time taken to complete the questionnaire
Q147Easy_to_Understand	Easy to understand the questions
Q148Most_Difficult_Questions	Most Difficult Questions to Understand
Q149Other_Comments	Any Other Comments About the Questionnaire
Q150Supported_Fill_Questionnaire	Has been supported to fill out questionnaire

Q151Name_of_Person_Supporting_You	Name of person assisting you
Q152Same_Person_as_First_Interview	Same person as the first interview
Q153Relationship_To_Person_Supporting	Relationship of the person supporting you to you
Q153Relationship_Other_Named	Named relationship of the person supporting you
Q154Length_Time_Known_Supporter	Length of time you have known supporter

Appendix 4

Trinity College Dublin Faculty of Health Science Ethical

Approval Letter

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

Appendix 5

Consent Form for IDS-TILDA Wave 2

CONSENT FORM

IDS-TILDA PARTICIPANT ID W 2

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

I agree with the following statement

Please tick √

I have gone through the information about this study ☐

I know who to contact if I have any other questions. ☐

Any questions that I might have had were answered. ☐

I know that it is my choice to take part in this study. ☐

Trinity College Dublin

I understand this study is for ten years and I will be visited again by a researcher from Trinity College Dublin. ☐

I understand that I will be asked questions about my:

- life
- health
- work
- friends

and things I like to do.

☐

I have gone through the information about this study

☐

I understand that I do not have to answer questions I don't feel happy with.

☐

As part of the study, I know that I will be asked to try and do some things such as write my name.

☐

I do understand that I can stop taking part in this study when I want to.

I do not have to give a reason.

☐

I understand that all information I give during this study will be kept safe and private.

I will not be named in any reports.

☐

I understand that there are no known risks with this study.

☐

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: _____

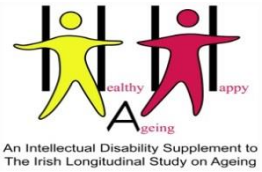
Please return this consent form to the field researcher before the interview commences.

IDS-TILDA, The University of Dublin, Trinity College, School of Nursing & Midwifery, 24 D'Olier Street, Dublin 2

Tel: +353 1 8963138/8963187 Fax: +353 1 8963001 Email: idstilda@tcd.ie

Appendix 6

Data Protection Protocol



Data Use Protocol and Procedure of the Intellectual Disability Supplement of The Irish Longitudinal Study on Ageing (IDS-TILDA)

July 2015

Intellectual Disability Supplement to TILDA,

Trinity College Dublin,The University of Dublin,

School of Nursing & Midwifery,

No. 2 Clare St,

Dublin 2,

Ireland

Telephone: (01) 896 3186 / (01) 896 3187

Fax: (01) 8963001

Email: idstilda@tcd.ie

Developed and reviewed by	**Review Date**
Prof. Mary McCarron, Prof. Philip McCallion, Eilish Burke	24/10/2011
Prof. Mary McCarron, Prof. Philip McCallion, Dr Rachael Carroll, Eilish Burke	12/03/2014
Prof. Mary McCarron, Prof. Philip McCallion, Dr Rachael Carroll, Eilish Burke	16/07/2015

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Page Number

1.0 Protocol Statement

This policy will provide guidance on the use of IDS-TILDA research project data findings and results for the IDS-TILDA research team itself, for PhD/MD students and any person with whom the PIs may collaborate in the development of peer reviewed articles, presentations or any electronic or other dissemination.

In support of fundamental research ethical principles requiring the safeguarding participant confidentiality and strict adherence to fundamental precepts of research integrity, all access to, use of and publications from IDS-TILDA data will be managed and approved by the IDS-TILDA PIs supported by the project manager and the data manager.

2.0 Background

Currently, the IDS-TILDA dataset is only available with the permission of the PIs. With suitable protection the investigators will consider to access the dataset as they recognise the criticalness that publications from IDS-TILDA data be developed including by students and collaborators to (1) increase knowledge about the ageing of people with intellectual disability across a range of disciplines, (2) support the training of researchers, (3) influence consideration of key policy concerns and (4) offer data reports likely to encourage support for subsequent waves of data collection for the benefit of people with ID.

3.0 Definition of Terms

IDS-TILDA**:** Intellectual disability supplement to the Irish longitudinal study on ageing in Ireland hereinafter referred to as the project.

Investigators or PIs: Refers to the principal investigators Professor Mary McCarron and Professor Philip McCallion.

Research team member: All staff employed in the IDS-TILDA research study project either full time, part-time or under a contract basis as well as PhD/MD students supervised by the PIs.

Collaborators: All persons invited to contribute, write and work in a joint intellectual capacity with the IDS-TILDA team and investigators.

Public Use Dataset: At a future time the IDS-TILDA team will make the IDS-TILDA dataset available in an appropriate data archive. The specific protocol for the use of such a dataset will be posted there. In the interim, there is no public use dataset.

4.0 Scope of the Protocol

The protocol applies to all uses of the data other than by the investigators and research team staff they designate. The scope of this document may be amended in light of any future developments.

5.0 Purpose of the Protocol

The purpose of this policy is to provide all IDS-TILDA research team members, PhD and masters students and collaborators clear guidance regarding the use of project data to include all analyses, publications, oral

presentations, electronic dissemination and/or other dissemination of the data.

6.0 Data User Roles and Responsibilities

All persons wishing to have access to data shall complete an IDS-TILDA Contract of Agreement and Data Access Request Form and furnish this to the investigators Prof. Mary McCarron and Prof. Philip McCallion (hardcopy and email).

Until such times as data files are posted as a public use dataset, the IDS-TILDA Contract of Agreement and Data Access Request Form must include (1) specification of a time period to access the data, (2) explanation of the research question and related analyses, (3) intended type of publication/dissemination, (4) a signed agreement that all PI stated restrictions on use will be adhered to and that a copy of the final data analysis file will be provided to the PIs for the IDS-TILDA data archive (5) acknowledgement in all products that IDS-TILDA is the source of the data, using the language provided by the investigators and (6) acknowledgement that the principal investigators will be the final arbitrator for all publication and data access related decisions.

6.1 Access to Data Concerns

Conducting research carries the responsibility to protect the confidentiality and privacy of participants. Access to data will therefore be carefully managed and granted to appropriate persons on the sole discretion and permission of the investigators. All data furnished shall be logged and

tracked by the data manager in the IDS-TILDA office. All persons wishing to access data shall do so in adherence to the IDS-TILDA Contract of Agreement and Access to Data Procedure.

6.2 Data Access and Use by Investigators, Research Team members, Designated Collaborators and Investigator – supervised MD/PhD students

In providing access to the data the investigators reserve the right to directly write articles themselves, support PhD/MD students they supervise in the development of approved theses, and work with research team members and approved collaborators on the development of additional articles.

1. After receiving signed approval for the project proposal (see Permission to Access Data Proposal form) the research team member, collaborator or supervised PhD/MD student will request the specific variables to be used in the proposed analysis.
2. Data will be accessed on secure computers located in the IDS-TILDA office.
3. Permission to access will only be for the approved variables and timeframe.
4. No data shall be removed, copied or accessed outside the IDS-TILDA office.
5. Agreement to the terms of this protocol and procedure is understood on signature of the Data Access Proposal Form.

Access to the data is granted with the additional understanding that the investigators will have the opportunity to be among the authors on all publications, determine the scope of each article, authorize order of authorship, and establish the timelines for publication. These requirements are further specified in 6.3 and 6.4.

6.3 Authorship

For PhD/MD students and research staff, the investigators shall authorise all aspects of the proposed publications. This includes the content of the

paper, early discussion of publication and authorship practice for the work, the appropriate authorship, the place of publication, the protection of intellectual property rights, and any release of results on the Internet.

An approved thesis will be the work of the PhD/MD student and will be completed within a timeline agreed with the investigators.

Articles by research team members and designated collaborators as well as articles resulting from PhD/MD theses are encouraged by the investigators and the scope, content, timeline for completion and order of authorship of articles to be completed will be negotiated in advance with the investigators. In particular, the investigators reserve the right to take back control of an article if agreed timelines are not met. This may include changing the originally agreed order of authorship.

The investigators will be the final arbitrators of all related decisions.

6.4 Criteria for authorship.

To be recognized as an author, a research team member, collaborator or PhD student shall

- Contribute substantially to the IDS-TILDA creative process within any of the following areas: generation of hypotheses, data collection, analysis or interpretation of data.
- Contribute substantially to the preparation of the article to be published either
  through preparation of drafts or through critical revision.

- Accept in writing the final draft and be prepared to take public responsibility for the content.
- Meet the specific requirements for authorship required by any journal considered for publication.
- Within reasonable limits accept responsibility for the contents of the report
  as being based on honest research.

For members of the research team, designated collaborators and/or by PhD/MD students supervised by the investigators, the investigators must have the opportunity to review and approve the final version of any article/presentation/report to be submitted for publication or other type of dissemination.

7.0 Data Access Procedure for Non-Research Team Members or Investigator supervised PhD/MD students

After receiving signed approval from the investigators for the project proposal (see Permission to Access Data Proposal form).

1. Researcher or PhD/MD student (with a co-sign by their supervisor) will complete a variable request form (approved list will be available on confirmation of proposal) and submit the form to

the data manager. Should the researcher seek variables beyond the approved list (e.g., identifiable variables such as open questions) a separate request shall be made to the investigators, cc the project and data managers.

2. The Project Manager will obtain related access permissions to the Drive on the secure IDS-TILDA server (this will require at least one week after receipt of data access approval).
3. On receipt of access permission the Data Manager will set up a secure folder with the data set requested.
4. The dataset is then available to access on a computer available in the IDS-TILDA office; the procedure for doing this will be demonstrated on the first day at the office.
5. All analysis shall be undertaken in the IDS-TILDA office, to that end approved researchers and PhD/MD students must arrange dates for 'hot desk' access (this can be arranged when requesting folder setup) by liaising with the executive officer, Ms Madeline Smyth at msmyth2@tcd.ie or idstilda@tcd.ie or through the project or data managers.
6. No data shall be removed, copied or accessed except within the assigned folder on the secure J drive.
7. No data shall be removed, copied or accessed outside the IDS-TILDA office.
8. Agreement to the terms of this protocol and procedure is understood on signature of the Data Access Proposal Form.

The investigators will be the final arbitrators of all related decisions.

References

An Bord Altranais (2007) *Guidance to Nurses and midwives regarding Ethical Conduct of Nursing and Midwifery Research*. An Bord Altranais: Dublin.

Trinity College Dublin (2009) Policy on Good Research Conduct accessed on https://www.tcd.ie/research/dean/TCDGoodResearchPractice.pdf 24.10.2011.

Appendix 7

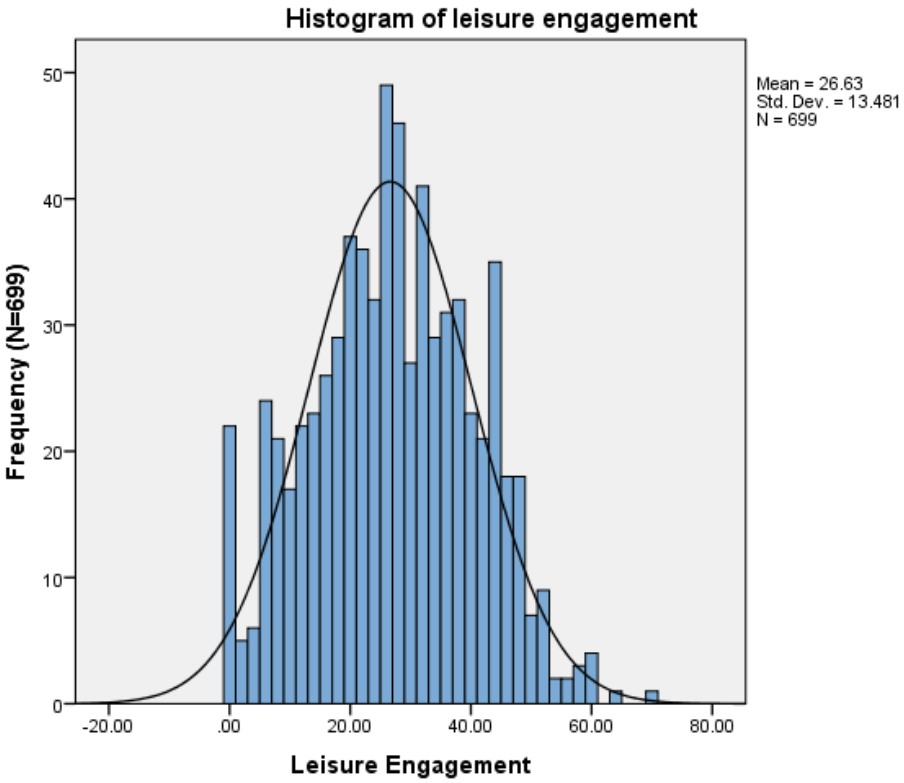
IDS-TILDA Keeping In Touch Strategy

It is imperative for longitudinal studies that a solid 'keeping in touch' strategy is employed to maintain the link with the participant community. Maintaining connectivity with participants ensures they remain central to the study, are acknowledged for their contribution and preserve study numbers. Along with hybrid publications, IDS-TILDA has created such platforms for their study participants to ensure a robust 'Keeping in touch' strategy.

WEBSITES	NEWSLETTER	PERSONAL CONTACT	ROADSHOW
Online platform that provides up to date news on IDS-TILDA activity, including reports, accessible videos and strategy actions Website is updated monthly	• Bi-annual newsletter published with up to date IDS- • Each individual participant receives a • IDS-TILDA holds competitions and events advertised through the	• Each participa receives a personalised Easter and Christmas car every year fro • Each partici receives a phone call from the s team prior to recommencen in the field • This contact is ongoing and ensures a link wi participants, anc confirmation of their address	• Ensuring participants, families and support staff realise the benefit of the research IDS-TILDA run seminars • Such events are ongoing and it is anticipated that this activity will increase as the next study wave nears. These events are imperative in disseminating results, maintaining the sample and demonstrating appreciation.

Appendix 8

Histogram of Engagement in Leisure Activities (IDS-TILDA Wave2)



Key Term:	Definition:
Occupational Injustice:	An outcome of social policies and other forms of government that structure how power is exerted to restrict participation in the everyday occupations of populations and individuals. May also be as a result of other factors that preclude engagement in meaningful occupation such as social, cultural or physical inequalities (Nilsson & Townsend, 2010).
Occupational rights:	Viewpoint that argues that people have the right to engage in purposeful and meaningful occupation, and to be active participants in their daily lives to maximise their potential (Durocher, Gibson, Rappolt, 2014). Occupational rights have been proposed as: o Right to experience occupation as meaningful and enriching o Right to develop through participation in occupations for health and social inclusion o Right to exert individual or population autonomy through choice in occupations o Right to benefit from fair privileges for diverse participation in occupations. (Townsend & Wilcock, 2004).
Occupational deprivation:	A state of prolonged preclusion from engagement in meaningful occupation due to factors outside of the person's control, including social, economic, environmental, geographic, historic, cultural or political factors (Whiteford, 2010)
Occupational alienation:	Isolation of a population from society, or a separation from those occupations that promote sense of identity or spirituality (Durocher , Gibson & Rappolt, 2014; Townsend & Wilcock, 2004).
Occupational marginalisation:	Preclusion of a population from exercising autonomy through lack of choice of occupations, often through subtle factors such as societal expectations (Nilsson & Townsend, 2010; Durocher, Gibson & Rappolt, 2014).
Occupational apartheid:	Formally institutionalised occupational injustice, where populations are systematically excluded from

	engagement in meaningful occupation (Durocher, Gibson & Rappolt, 2014).

Appendix 9
Key Definitions

Related to the Concept of Occupational Justice

Appendix 10
Definitions Related to the Concept of Occupation

Construct:	**Definition:**
Enablement	Enablement is a core skill of occupational therapy, considers collaborative approaches, power relationships, and capacity for individual and social change (Townsend & Polatajko 2007).
Client-centred enablement	Use of enablement skills to promote collaborative and empowering approaches in occupational therapy interventions.
Empowerment	Refers to personal and social processes that transform visible and invisible relationships so that power is shard more equally (p. 180 Law et al. 2002