

**Social Participation for Older People with an Intellectual
Disability in Ireland**

**A thesis submitted to the University of Dublin, Trinity College, for the
Degree of Doctor of Philosophy**

Darren McCausland

School of Nursing & Midwifery

Faculty of Health Sciences

University of Dublin, Trinity College

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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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Summary

Background

Social participation is beneficial to quality of life and other outcomes. However, the available literature suggests that people with intellectual disabilities (ID) fare worse than others in various aspects of social participation. Rates of social participation are mitigated by a range of factors for people with ID including age. However, little is known about the social participation of older people with ID in Ireland, or the specific factors that shape their outcomes in this area. Furthermore, there has been little consensus or consistency in the ID field about the definition and measurement of participation, and the literature has focused predominantly on objective measures of participation, to the exclusion of subjective individual outcomes.

Aim & Objectives

The main aim of the study was to examine the rates and outcomes of social participation for older people with ID in Ireland. Within this, the key study objectives were to: (i) Measure rates of social participation among this population using the WHO's *International Classification of Functioning, Disability and Health* (ICF) as a valid theoretical framework for the study of participation; (ii) Identify factors associated with differences in rates of social participation for this population; and (iii) Examine associations between objective measures of social participation and subjective outcomes for individuals.

Methods

Study objectives 1-3 examined cross-sectional quantitative data from wave 2 of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), based on a representative sample of 701 people with ID aged 43 years and above in the Republic of Ireland.

Results

Rates of social participation for older people with ID in Ireland were lower than comparable rates for the general older population across a number of areas of participation, including: social functioning; human rights and citizenship; education, training and occupation; social activities; local community interaction; and interpersonal relationships. Multiple factors are associated with differences in rates of participation amongst this population, including demographic factors (age; gender; and residence type), personal ability (level of ID; and functioning in ADLs, IADLs, communication and literacy), physical and mental health, and social support (family contact; family proximity; and having friends).

The importance of these factors varies between different aspects of participation. Furthermore, all forms of social participation measured were positively associated with better subjective outcomes within the sample; and the majority of positive associations were statistically significant.

Conclusions

Older people with ID in Ireland are at risk of worse quality of life and health-related outcomes than the general older population due to lower rates of social participation. The concept of social participation is broad and the adoption of a valid theoretical framework such as the ICF provides the basis for a comprehensive and more systematic and consistent study of this complex area. The complexity of social participation is emphasised by the multifactorial influences shaping rates and outcomes for this population. This requires a sophisticated approach to policy and practice in the area of social and community participation for older people with ID, which is rooted in principles of individualisation and person-centredness.

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Abbreviations

AAIDD	American Association on Intellectual and Developmental Disabilities
ADHD	Attention Deficit Hyperactivity Disorder
ADL	Activity of Daily Living
AMD	Age Related Macular Disease
CAPI	Computer Assisted Personal Interview
CGH	Community Group Home
CI	Confidence Interval
CRPD	Convention on the Rights of People with Disabilities
DSP	Department of Social Protection
ELSA	English Longitudinal Study on Ageing
EPSEN	Education for Persons with Special Educational Needs
EU	European Union
HRB	Health Research Board
HRS	Health and Retirement Study
HSE	Health Service Executive
IADL	Instrumental Activity of Daily Living
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual Disability
IDS-TILDA	Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

NIDD	National Intellectual Disability Database
NDS	National Disability Strategy
OR	Odds Ratio
PI	Principal Investigator
PIN	Personal Identification Number
PIQ	Pre-Interview Questionnaire
PVN	Private Virtual Network
SEN	Special Educational Needs
SHARE	Survey of Health and Retirement in Europe
SPSS	Statistical Package for the Social Sciences
SR	Self-Reported
TCD	Trinity College Dublin
TILDA	The Irish Longitudinal Study on Ageing
UCLA	University of California, Los Angeles
UDHR	Universal Declaration of Human Rights
UN	United Nations
UPIAS	Union of Physically Impaired Against Segregation
VIF	Variance of Inflation Factor
WHO	World Health Organisation

Section A: Introduction & Context

Chapter 1. Introduction

1.1 Introduction to the Study

Increased social participation is associated with better outcomes including quality of life for both the general population (McCrary et al. 2014, Ahnquist et al. 2012, Tay et al. 2013) and people with intellectual disabilities (Schalock et al. 2002, Schalock et al. 2007b, Emerson 2004, Brown et al. 2013). However, the research literature suggests that people with intellectual disabilities fare worse than people who don't have an intellectual disability in various different aspects of social participation, including intimate relationships (McCausland et al. 2014, Umb-Carlsson and Sonnander 2006), family contacts (McCausland et al. 2016) or engagement in their local community (Verdonschot et al. 2009). Furthermore, there is evidence of decreased participation in older age for this population (McCarron et al. 2011). Therefore, older people with intellectual disabilities may be poorly positioned to benefit from the potential outcomes of social participation.

The aim of this study is to apply a valid theoretical framework to an examination of social participation for older people with an intellectual disability in Ireland. The description and measurement of the social domain of life for people with an intellectual disability, including aspects of community inclusion or participation, has been inconsistent and conceptually underdeveloped (Verdonschot et al. 2009, Martin and Cobigo 2011, Cobigo et al. 2012, Amado et al. 2013). As such, the application of a comprehensive and theoretically underpinned approach to research of the social domain for this population has been a significant shortcoming of the literature. The current study aims to address this gap in the literature by applying the theoretical framework of the World Health Organisation's (WHO) *International Classification of Functioning, Disability and Health* (ICF) to the study of social participation for older people with an intellectual disability in Ireland.

1.2 Research Aim and Objectives

The main research question in the study is: *What are the rates and outcomes of social participation for older people with an intellectual disability in Ireland?*

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

1. Measure rates of social participation amongst older people with an intellectual disability in Ireland using the WHO ICF as a valid theoretical framework of participation;
2. Identify factors associated with differences in rates of social participation for this population;
3. Examine associations between objective measures of social participation and subjective outcomes for individuals.

Objectives 1-3 will be addressed through the analysis of cross-sectional quantitative data from wave two of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA).

1.3 Study Definitions

This section clarifies the meaning of a number of key terms as used in the context of the study, including *social participation*, *intellectual disability* and *ageing or older*.

1.3.1 Definition of Social Participation

Within the research literature there is no clear consensus on definitions of social participation or closely related concepts such as social inclusion (Cobigo et al. 2012, Amado et al. 2013). The adoption of a valid theoretical framework of social participation is central to the uniqueness of this study, and the working definition of social participation is shaped by the ICF theoretical framework used. This is outlined in greater depth later in section 2.4, from which it is clear that the concept of social

participation is broad and does not easily lend itself to simple definitions. In the context of the ICF, the WHO define *participation* as “a person’s involvement in a life situation. It represents the societal perspective of functioning.” (World Health Organization 2001c). The United Nation’s (UN) *Convention on the Rights of People with Disabilities* (CRPD) calls for “full and effective participation and inclusion in society” (United Nations 2006). While both of these statements are quite broad and somewhat vague taken out of context, they give an indication of the potential scope of the concept of participation and the fact that it is necessarily broad, as well as the difficulty in providing a succinct yet specific definition. However, a working definition will help to shape an understanding of the aims and scope of the current study. As such, social participation in the context of this study and the theoretical framework may be understood as the following:

Social participation is a person’s involvement in activities of a social nature, or in activities that may support such activities.

Where, in this working definition, *social* is understood simply as involvement with other people; in the dictionary definition this may relate to the human need for companionship, to people meeting for pleasure, or to society generally¹. This working definition also includes activities which support social activities; therefore, it includes some activities that may be individual or solitary within themselves, but which support involvement in a broader social context. For example, it includes activities of daily living (ADLs) and instrumental activities of daily living (IADLs), which may be performed as solitary activities but which also support independent living within society.

The precise content of this, or what is included in ‘social participation’ in the study, is shaped by the theoretical framework of the ICF *Activities & Participation* domain. This

¹ <http://www.oxforddictionaries.com/definition/english/social>

theoretical framework includes the nine areas outlined in Figure 1.1 below, which define the scope of social participation within the study.

Figure 1.1. Theoretical framework for social participation – ICF Activities & Participation domain



Source: World Health Organization (2001b)

The ICF framework is discussed in detail in chapter 2 of the thesis (section 2.4); and Appendix 1 also provides an outline of the ICF structure.

1.3.2 Definition of Intellectual Disability

Definition of intellectual disability (ID) in the current study is based on the definition used for inclusion within the main data source, the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). IDS-TILDA used the sampling frame of the National Intellectual Disability Database (NIDD) in Ireland to recruit its sample. Therefore, the definition of intellectual disability for the current study is based on that which is used by the NIDD. The NIDD takes its definition from the WHO

Classification of Mental and Behavioural Disorders (ICD-10). This defined *mental retardation* (coded F70-F79) (now called *intellectual disability*) as:

“a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities.”

Diagnosis is based on standardised IQ score of below 70, and classified in a range of: mild (IQ score in the range 50-69); moderate (IQ score in the range 35-49); severe (IQ score in the range 20-34); or profound (IQ score estimated less than 20). Furthermore, the presence of an intellectual disability will also result in impairment of adaptive behaviour (World Health Organization 1996). The American Association on Intellectual and Developmental Disabilities (AAIDD) has a similar focus but incorporates adaptive behaviour into its definition rather than being an associated outcome, and notes origin before the age of 18; thus defining *intellectual disability* as:

“a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18.” (AAIDD 2013)

1.3.3 Definition of Ageing and Older People

As a study on ageing amongst people with intellectual disabilities, IDS-TILDA included people aged 40 years and above when it recruited its sample for wave one. Since the original sample was not refreshed at wave two (on which the current study is based), this means that people aged 43 years and above are included in the current study. The inclusion criterion of age for IDS-TILDA differs to that of studies of ageing amongst the general population, such as The Irish Longitudinal Study on Ageing (TILDA), on which IDS-TILDA is based. TILDA includes people from the general population who are aged

50 years and above (see section 3.3). The reason for the difference in age criteria is that people with intellectual disability tend to present with signs of ageing at an earlier stage than people without intellectual disability (Lifshitz and Merrick 2004, Wong 2011, Ruiz et al. 2012). Other studies of ageing also reflect this essential difference. For example, whereas Janicki et al. (2002) included people with intellectual disabilities aged 40 years and above, international longitudinal studies on ageing amongst the general population tend to include people aged 50 years and above. This includes the Survey of Health, Ageing and Retirement in Europe (SHARE) (Börsch-Supan et al. 2013), the Health and Retirement Study (HRS) in the USA (HRS 2016), and the English Longitudinal Study on Ageing (ELSA) (Banks et al. 2012); all of which include members of the general population aged 50 years and above. Therefore, the understanding of *ageing* and *older* can differ depending on the population in question. However, for the current study, *older people with intellectual disability* will refer to people aged 43 years and above.

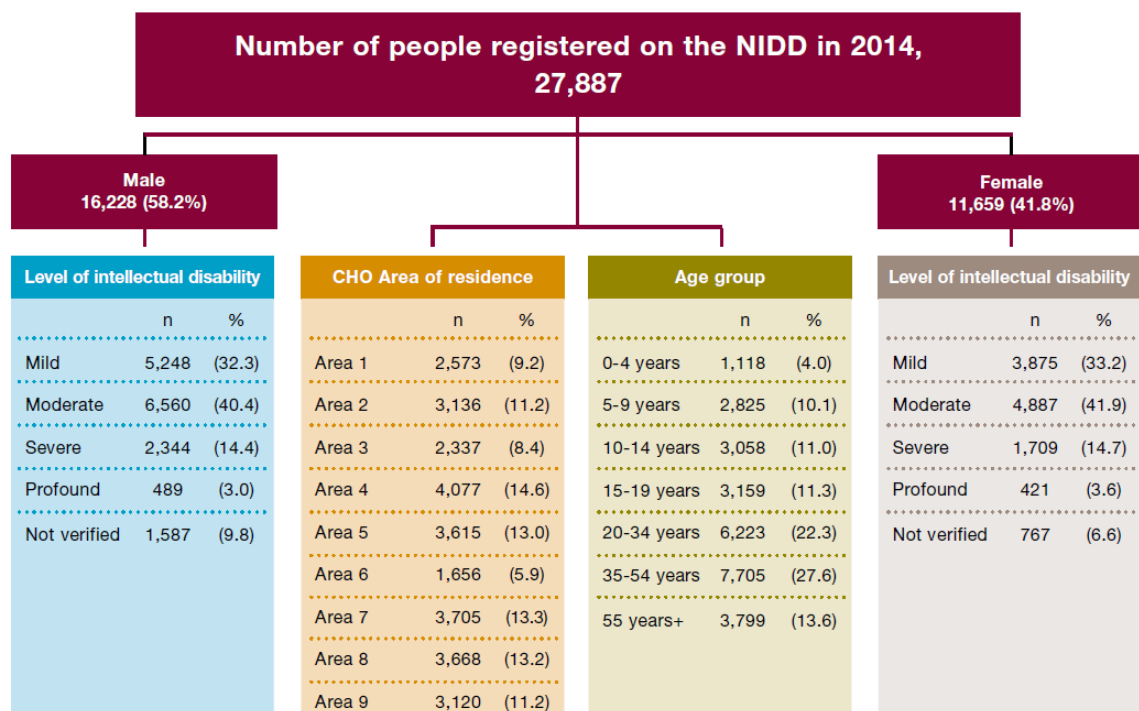
1.4 People with Intellectual Disability in Ireland

The most recent figures from the National Intellectual Disability Database (NIDD) estimate there are 27,887 people with an intellectual disability in the Republic of Ireland (Kelly 2015). However, prevalence figures from the National Disability Survey, conducted by the Central Statistics Office (CSO) in 2006, suggested there were 50,400 people with an intellectual disability (Central Statistics Office 2008). While there is a substantial gap between the estimates of the NIDD and the CSO, Kelly et al. (2013) proposed three reasons for this disparity: a difference in the definition of intellectual disability; a difference in data collection methods (the NIDD is based on multidisciplinary assessment and diagnosis, whereas the CSO relied on self/proxy reports); and the fact that the NIDD includes only those people with a diagnosis who are in receipt or in need of specialised services. Hence, there is a suggestion that the

NIDD may underestimate prevalence by omitting some people with mild ID who do not avail of specialised services, while the CSO may overestimate prevalence by including self/proxy reports of intellectual disability for people who reported having a different 'main disability' (e.g. dyslexia or specific learning difficulty, attention deficit disorder, or acquired brain injury) (Kelly et al. 2013). This should be borne in mind when considering the representativeness of the current study of the population of older people with intellectual disability in Ireland (see section 3.3.2 for further details regarding the study sample).

Notwithstanding these potential limitations in prevalence estimates, Figure 1.2 below outlines the profile of the population on the NIDD. This shows a majority of people with ID in Ireland are male (58.2%); that almost two-thirds of people with a verified level of ID have a moderate, severe or profound level; and over 40% are aged 35 years or older, which reflects a pattern in recent decades of increased longevity amongst this population (Kelly 2015).

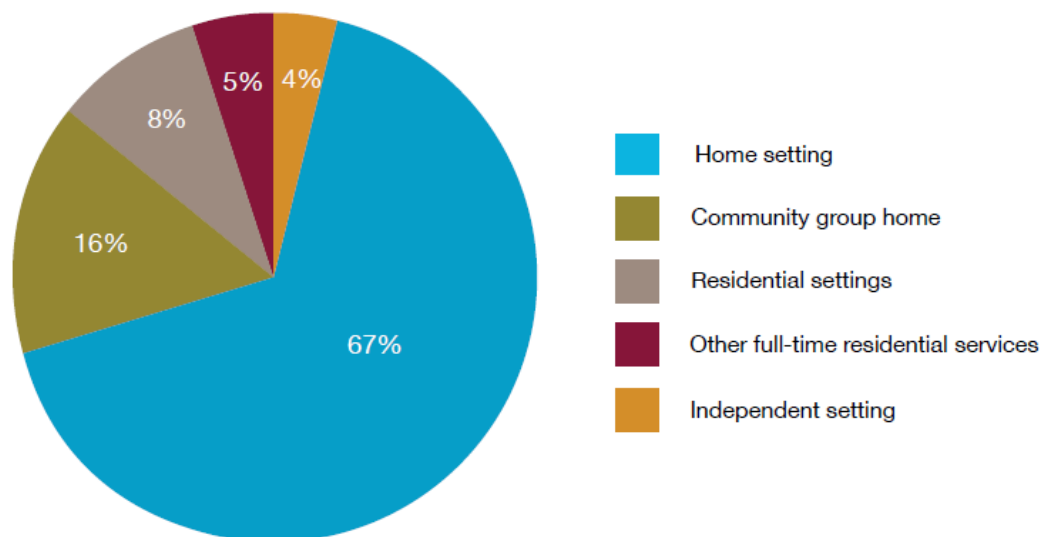
Figure 1.2. Profile of NIDD population of people with an Intellectual Disability in Ireland



Source: Kelly (2015)

Figure 1.3 below shows that the majority of people with an intellectual disability in Ireland live at home with family (67%). Deinstitutionalisation policy may be reflected in the fact that, for the eleventh consecutive year, more people live in group homes in the community (16%) than in residential settings (i.e. within segregated ID service settings) (8%). However, there is a significant effect from level of ID and age, whereby the large majority of people in full-time residential care had a moderate, severe or profound ID (82%), and were aged 35 years or older (84%) (Kelly 2015).

Figure 1.3. Residential location of People with Intellectual Disability in Ireland

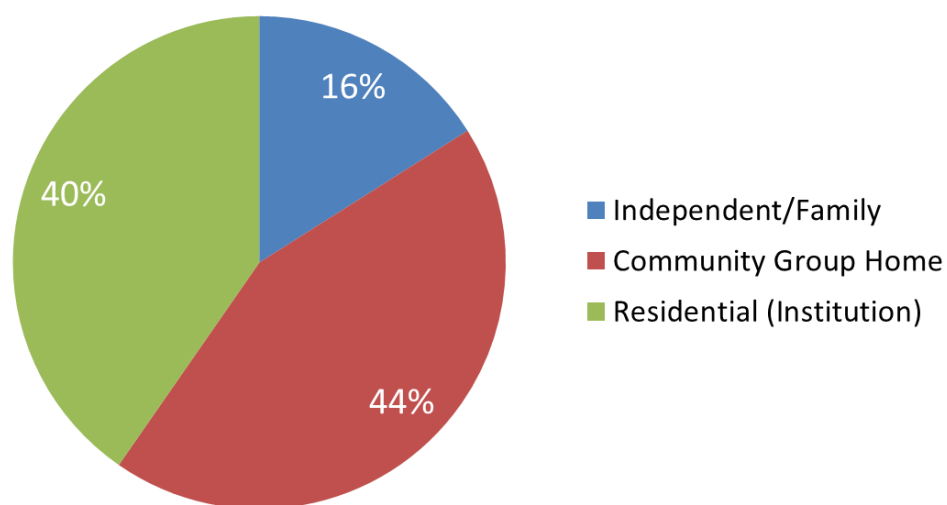


Source: Kelly (2015)

The effect of age and ID level evident in the NIDD was also apparent in a census of (segregated) residential settings for the Health Service Executive (HSE) policy document *Time to Move on from Congregated Settings*. This census identified that the majority of existing residents were aged 40 years and above (72%), and that nine out of ten residents had a severe-profound ID (58%) or moderate ID (34%) (Health Service Executive 2011). And this is also reflected in how the residential profile of the IDS-TILDA wave 2 sample (on which the current study is based) differs from the residential

profile of all people with ID; this is illustrated in Figure 1.4 below. This shows that, whereas more than 7 in 10 of the total ID population (NIDD) live either in the family home or independently, less than 2 in 10 of the older ID population (IDS-TILDA) live in these same settings. By contrast, more than 8 out of 10 of this older ID population live either in institutional settings (44%) or else in group homes based in the local community (40%).

Figure 1.4. Residential location of Older People with ID in Ireland (IDS-TILDA wave 2 sample)



Patterns of increased longevity amongst this population in Ireland, noted above, have also been reported elsewhere in the literature (McCarron et al. 2011, Burke et al. 2014, McCallion et al. 2014). With it, this also brings challenges of policy responses to social and health related issues. In terms of health, increased longevity is associated with specific issues such as an increased risk of dementia for people with intellectual disability (McCallion and McCarron 2004), musculoskeletal and age-related eye conditions (Burke et al. 2014), patterns of increased multimorbidity (McCarron et al. 2013) and related rates of polypharmacy far in excess of the general population (O'Dwyer 2015). Overall, the international literature recognises a disparity in health

outcomes for people with intellectual disability compared to the general population (Emerson et al. 2016, Krahn and Fox 2014, Anderson et al. 2013). Recent Irish data from IDS-TILDA suggests that different challenges exist for people with intellectual disability as they age compared to the general population; and there is a clear need for specific health education, promotion and management strategies for their unique health issues (McCarron et al. 2014).

From a social policy perspective, the main focus in recent years in Ireland has been the policy of deinstitutionalisation and community living, expressed through the HSE *Congregated Settings* report and the *National Housing Strategy for People with a Disability 2011-2016* (Department of the Environment Community & Local Government 2011). These documents pursue a policy of deinstitutionalisation, community living and integration for people with intellectual disabilities that has been preceded in several other countries in recent decades. This issue is explored in greater depth later in the thesis, both from a policy perspective (section 2.2) and from a conceptual and ideological perspective (section 2.5). However, it is to this element of the policy landscape that the current study is of particular relevance. A key goal of the current policy is the residential location of all people with intellectual disabilities in their local community, with the aim to “*live full, inclusive lives at the heart of family, community and society*”, and to achieve “*enhanced quality of life through maximum community participation*” (Health Service Executive 2011). As such, a critical aspect of assessing the relevance and success of the stated policy goal is to examine outcomes of social participation (including community participation) for the group of people most likely to be impacted by current policy; namely, older people with intellectual disabilities in Ireland.

1.5 Position of the Study

This study comes from the sociological and social policy perspective in which the researcher is grounded. Within this, and in response to an identified gap in the literature, social participation is conceptually framed by the WHO's ICF, which is a *biopsychosocial* model of disability positioned between the dialectically opposed medical and social models that have dominated disability discourse in recent decades. The “*intentionally neutral*” ICF model (Bickenbach 2014) provides a theoretical framework within which participation may be interrogated (see section 2.4.1).

Therefore, the study aims to bring a systematic and universal approach to the study of social participation for older people with intellectual disabilities.

However, notwithstanding this aim, the current study is also driven by the same values that underpin the IDS-TILDA study (see section 3.3.1). In particular, it is motivated by the promotion of people with intellectual disability and making a positive contribution to their lives; which is grounded in a commitment to person-centeredness, empowerment, choice and inclusion. The aim is to achieve this by contributing to the development of knowledge and research practice on social participation and community from a sociological and social policy perspective.

1.6 Layout of the Thesis

The thesis is laid out in three sections as follows:

A. Introduction & Context

- Chapter 1: Introduction
- Chapter 2: Literature Review
- Chapter 3: Methodology

B. Findings

- Chapter 4: Social Functioning for Older People with Intellectual Disability

- Chapter 5: Participation in Human Rights and Citizenship
- Chapter 6: Participation in Education, Training and Occupation
- Chapter 7: Participation in Social Activities
- Chapter 8: Participation in Local Community
- Chapter 9: Participation in Interpersonal Relationships
- Chapter 10: Subjective Outcomes of Social Participation

C. Discussion & Conclusions

- Chapter 11: Discussion
- Chapter 12: Conclusions & Recommendations

Chapter 2 reviews the literature relevant to the study. It begins by outlining the methods used for the different aspects of the literature review. Following this, it reviews the policy context; an overarching summary of the social participation literature is provided (these literature are examined in greater detail later in the thesis, in the specific contexts of chapters 4-9); the WHO ICF is then outlined and critiqued; and finally an examination of the concept of community is introduced.

Following this, chapter 3 outlines the methodology used in addressing the three research objectives. Like chapter 2, this provides an overarching outline of the study methodology, which is later complemented with further details of specific measures and procedures used in each of the findings chapters throughout Section B of the thesis.

The findings laid out in Section B of the thesis (chapters 4-10) address each of the three study objectives. Chapters 4-9 present analyses of the different elements of social participation examined; these chapters address research objectives 1 and 2.

Chapter 10 examines associations between objective measures of social participation and subjective outcomes for individuals; this addresses objective 3 of the study.

Finally, in Section C of the thesis, chapter 11 presents a discussion of the findings in the context of current policy and the research literature, and identifies overarching issues emerging for research, policy and practice; while chapter 12 presents a number of conclusions and recommendations for future research, policy and practice.

Chapter 2. Literature Review

2.1 Introduction

This chapter reviews the literature on social participation relevant to the aim of the study, including:

- First, an overview of the policy related to social participation and community in Ireland and internationally is provided (section 2.2).
- Secondly, the literature related to social participation is examined; section 2.3 briefly summarises key findings of the literature under thematic headings within the social participation literature; these literature are examined in more detail later on in the relevant findings chapters throughout section B of the thesis.
- Third, the ICF theoretical framework applied to social participation in the study is described and critiqued in section 2.4.
- Following this, the concept of community is explored in section 2.5 as a central element of social participation. The current interpretation of community in the ID field is outlined and a more expansive understanding of the concept of community is introduced.

Finally, section 2.6 draws a number of conclusions based on the literature reviewed for social participation and community, looking at how this relates to existing policy, and how it informed the research objectives for the study. The remainder of this section will firstly outline the methods used in the literature review.

2.1.1 Literature Review Methods

The review of literature involved three different elements: the policy context of the study; social participation; and the concept of community. The methodological approach used in each instance is outlined below.

2.1.1.1 Policy Context

Initially a number of relevant dimensions to the policy context were identified, including:

- a) Specific policy measures related to disability and intellectual disability;
- b) Broader policy measures related to social participation for older people with intellectual disabilities;
- c) Policy relevant to the integral issue of community and deinstitutionalisation.

Legislation and policy at national and international level was included in the scope of the review. This included legislation and related instruments at EU and international level, including the United Nation's *Convention on the Rights of Persons with Disabilities* (CRPD). Finally, where identified, other policies were added to the study context as they emerged in the review and in the broader review of social participation literature. The researcher's background in sociology and social policy, and experience working in a policy-related research environment (with the National Disability Authority, the Health Research Board and IDS-TILDA), initially provided a basis of knowledge of the policy context for this study. The researcher's supervisory team added to the knowledge base on policy for the study.

No specific timeframe was applied as an inclusion criterion for policy; alternatively, the period of review was framed by the inclusion of key policies (e.g. the UN CRPD and the Health Service Executive's (2011) report *Time to move on from Congregated Settings*), and by influential precedents. As such, policy was analysed in terms of content and process of development to provide context for the current study; however, a full policy analysis of impact and outcomes was outside the scope of the current study. Therefore, the focus was primarily on outlining policy aims and recommendations as a context for social participation, other than where evidence of the impact of policy emerged from particular studies within the broader literature review.

2.1.1.2 Social Participation Literature

The breadth of literature within a broad understanding of social participation meant that a systematic review was not feasible. Instead, systematic approaches were applied to the literature review while allowing scope to include other emergent issues and themes from within this broad and complex literature. Search strategies used:

- Academic databases (Web of Science Core Collection; PsychINFO);
- Trinity College online and library collections; and
- Google Scholar (primarily as a source of referencing and accessing full texts online).

Key search terms used included: intellectual/learning disability and participation, inclusion, community, deinstitutionalisation, integration, cohesion, exclusion, and social capital. In addition, more specific search terms were used for the different aspects of social participation, including: ADLs/IADLs, mobility, communication, literacy, choice, self-determination, advocacy, voting, education, occupation, employment, social/recreation/leisure activities, community activities, membership, family, friends and relationships.

Email alerts were also established in Web of Science and PsychINFO to capture emerging literature using the keywords: intellectual disability and (1) social participation, (2) social inclusion, (3) community.

With such a broad literature, an effort was made in the first place to include reviews of key aspects of the literature, and then to include the most relevant and recent studies in the field, while trying to ensure representation of contrary viewpoints where they emerged. Elements of the grey literature and personal communication with experts in particular fields were also included. Within this general review of social participation

literature, the potential for the ICF theoretical framework emerged and this was further explored through a combination of database searches (Web of Science and PsychINFO) and snowballing of emergent literature (Greenhalgh and Peacock 2005).

2.1.1.3 Community Literature

Systematic approaches were also used in the review of literature on community. An initial search on the Sociological Abstracts academic database was undertaken to identify sources from the general sociological and community studies literature and related fields since 2000, using the key search terms: community; community integration; community participation; community structure; social cohesion; social inclusion/exclusion; and social capital. Other key texts were also included as they emerged in the review process, or on advice from the supervision team. As identified above, email alerts for intellectual/learning disability and community were also set up on Web of Science and PsychINFO.

2.2 Policy Context

Within policy and the research literature on intellectual disability, social participation and community are inextricably linked. This is perhaps the legacy of a history of segregated institutionalisation for people with intellectual disabilities and its reversal in recent years. The modern literature in this regard is associated with the policies of deinstitutionalisation that took hold from the 1970s and developed in places such as Australia, Britain, New Zealand, Scandinavia and the USA (Mansell 2006, Amado et al. 2013). This was influenced by theories of *Normalization*, and later *Social Role Valorisation* (Wolfensberger 1970, Wolfensberger 1992, Wolfensberger and Nirje 1972, Cummins and Kim 2015), which proposed that people with disability could and should be included in the mainstream of everyday living through access to the same experiences and roles, the same societal and cultural norms, as everybody else (Nirje 1999, Thomas and Wolfensberger 1999). These theories laid the foundation for change in how services were provided for people with intellectual disability in the USA (Kozleski and Sands 1992) and the UK (Pilling 1995), influencing the transition from institutional living to living within local community and wider society (Ellis 1990, Heal 1988, Trainor and Boydell 1986). Internationally, their legacy was seen in the UN *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations 1994), and the WHO's ICF (World Health Organization 2001a) (Flynn and Lemay 1999); during a period which also marked a shift in thinking on disability from a charity to a rights perspective (Quinn et al. 2002).

This culminated in the UN *Convention on Rights of Persons with Disabilities* (CRPD) calling for “*full and effective participation and inclusion in society*”. In addition to establishing basic rights in relation to issues such as equality and non-discrimination (Article 5), accessibility (Article 9), and legal equality (Article 12, 13), the CRPD also made provisions for specific elements of social participation such as personal

relationships (Article 23), education (Article 24), work and employment (Article 27), political and public participation (Article 29) and participation in cultural, recreational, leisure and sports activities (Article 29). Furthermore, Article 19 of the CRPD stated specifically with regard to *'Living independently and being included in the community'* that countries would:

"recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community" (United Nations 2006)

At European Union (EU) level, Article 26 of the *'Charter of Fundamental Rights of the European Union'* sets out the right to live independently for people with disabilities, as well as rights to participate in the life of the community; a stated goal of the *'European Disability Strategy 2010-2020'* is the achievement of full participation in society for people with disabilities; and the Council of Europe's revised *'European Social Charter'* sets out *"the right of people with disabilities to independence, social integration and participation in the life of the community"* (European Expert Group on the Transition from Institutional to Community-based Care, 2012).

In Irish policy this found expression through the *'National Housing Strategy for People with a Disability 2011 – 2016'* (Department of the Environment Community & Local Government 2011), and the Health Service Executive's (HSE) 2011 report *'Time to Move on from Congregated settings: A Strategy for Community Inclusion'* (Health Service Executive 2011). The HSE's report stated specifically that people with intellectual disability *"will be actively and effectively supported to live full, inclusive lives at the heart of family, community and society"* (2001:25). The report provided a detailed framework and plan for the movement of up to 4,000 people with intellectual disability who were living in 'congregated' settings at the time (defined as residential units in

which 10 or more people lived, or else smaller units in clustered arrangements within ID service campuses). The report recommended the movement of all people with intellectual disability, irrespective of level of ID or age, to ordinary accommodation dispersed amongst the general community. While a number of different arrangements were outlined, no individual dwelling should house more than four people with intellectual disability (Health Service Executive 2011).

In the absence of a ratified UN CRPD in Ireland, a complex range of legislation supports existing policy related to disability; this is centred around the National Disability Strategy (NDS) 2004 (see chapter 5), although key elements remain to be fully commenced several years later (Inclusion Ireland 2013). A new NDS *Implementation Plan 2013-2015* re-stated the aim to promote “*an inclusive Irish society where people with disabilities can reach their full potential and participate in the every day life of the community*”; and set out four high-level goals of (1) Equal citizens, (2) Independence and choice, (3) Participation, and (4) Maximise potential (NDS Implementation Group 2013). A number of other existing policies are also relevant to social participation for people with intellectual disabilities, including the following:

- The HSE report *New Directions* set out a policy for day services in Ireland that envisages a move away from segregated day programmes for large groups of people with intellectual disabilities towards options that are more individualised and mainstreamed, with a focus on personal outcomes and the goal to be “*active, independent members of their community and society*” (Health Service Executive 2012). See chapter 6 for further details.
- The *Value for Money and Policy Review of Disability Services in Ireland* (Department of Health 2012) re-iterated the policy vision: “*To contribute to the realisation of a society where people with disabilities are supported, as*

far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being.”

- The *Value for Money* report was underpinned by policy recommendations made in the *Report of Disability Policy Review* (Department of Health 2011), which was undertaken by the Expert Reference Group on Disability Policy. The review recommended a re-framing of provision for people with disabilities to individualised supports, with a supports model that extends out from the individual to encompass natural supports, informal supports and formal supports. See chapter 9 for further details.
- The current *Programme for Government* (Department of the Taoiseach 2011) and social partnership agreement *Towards 2016* (Department of the Taoiseach 2006) both contain a number of commitments to improve the lives of people with disabilities, including improved participation across a range of social and community issues (Inclusion Ireland 2013).

2.2.1 Summary

This overview of policy relevant to the study has identified a somewhat fragmented and piecemeal approach to policy and legislation in Ireland. In the absence of a ratified UN CRPD, a coherent framework for policy in the intellectual disability field is absent from the Irish context. This has the potential to lead to disjunction in accessing rights (Edwards et al. 2012) and to gaps in the provision of adequate support services, such as advocacy, and other rights (Inclusion Ireland 2013). And while Fyson and Cromby (2013) noted that violation of rights under the CRPD provides no legal mechanisms for redress, many see that ratification will provide the required framework for comprehensive rights and policy in Ireland. Ratification will commit Ireland in

international law to a number of fundamental general principles across specific policy areas, yet experience in other countries suggests a lack of political will to commit to timeframes for implementation (Mittler 2016). For the current study, however, the policy of deinstitutionalisation, community living and integration of people with ID is of particular relevance. A key goal of current policy is the residential location of all people with intellectual disabilities in their local community, with the aim to “*live full, inclusive lives at the heart of family, community and society*”, and to achieve “*enhanced quality of life through maximum community participation*” (Health Service Executive 2011). Therefore, a critical aspect of assessing the relevance and success of the stated policy goal is to examine outcomes of social participation (including community participation) for older people with intellectual disabilities, which is the group most likely to be affected by these policies.

2.3 Social Participation

There is no clear consensus in the intellectual disability literature about the precise meanings of, and specific differences between, a range of terms used to describe the social domain of life; where terms such as *participation, inclusion, integration* and *belonging* are often used to describe the same thing or different aspects of a broader social phenomenon (Amado et al. 2013). However, what is clear is that this phenomenon, described here as social participation, is very important to well-being and quality of life. Different elements of social participation have been linked to better outcomes including quality of life for both the general population (McCrorry et al. 2014, Ahnquist et al. 2012, Tay et al. 2013) and people with intellectual disabilities (Schalock et al. 2002, Schalock et al. 2007a, Emerson 2004, Brown et al. 2013). In the following sections, the key points that have emerged in the review of the social participation literature are summarised thematically – these summaries are elaborated upon in detail in chapters 4-9 later, where full references are also provided.

2.3.1 Social Functioning

In this study 'social functioning' includes a number of functions that are relevant to social participation. It examines issues that constitute elements of social participation within themselves, but which also provide a foundation for participation in other dimensions of life. In many ways, therefore, this group of functional items provide the basis for social participation; thus they have been termed 'social functioning' in this study. Included within this are: Activities of Daily Living (ADLs); Instrumental Activities of Daily Living (IADLs); physical abilities related to mobility, movement and positioning; functional literacy; and aspects of communication. The literature in these areas has associated functional decline in ADLs and IADLs with ageing in both the general and intellectual disability populations; with increased risk of I/ADL dysfunction for people with intellectual disability living in institutional settings and those with more severe levels of intellectual disability. Age also impacts upon communication while level of intellectual disability is associated with higher risk of literacy and communication difficulties. Higher rates of difficulty across all functional areas are experienced by the older ID population compared to the older general population; and there is some evidence of a cumulative negative impact on social participation from these increasing difficulties. See section 4.1 for a more detailed examination of this literature.

2.3.2 Human Rights & Citizenship

A paradigm shift in disability, from charity to rights, preceded the UN Convention on the Rights of People with Disabilities (CRPD). The CRPD frames rights for people with disabilities internationally across a range of areas including several aspects of social participation. While the CRPD is yet to be ratified in Ireland, a range of legislation and policy provides the basis for a range of rights, centred around the National Disability Strategy (NDS). However, this complex range of provision may result in disjunction in securing rights and some areas are inadequately provided for and difficult to access in

practice. The literature suggests a complex range of factors may influence the self-determination of people with intellectual disabilities, with choice-making often limited to more mundane everyday choices. Advocacy provision in Ireland appears to be fragmented and underfunded. People with intellectual disabilities may have much lower rates of political participation than the general population and other people with disabilities; and rates are further challenged by more severe intellectual disability and institutional residence. See section 5.1 for a more detailed examination of the human rights literature.

2.3.3 Education, Training & Occupation

Policy provides for individualised education for students with special educational needs (SEN) in mainstream and specialised settings. While the majority of children with disabilities attend mainstream schools today, students with intellectual disabilities are more likely to be in a special provision setting. Older people with intellectual disabilities have very poor educational attainment and students today continue to struggle with poor outcomes; these are linked to poor outcomes in later life including low rates of employment, low incomes and dependency on welfare transfers. Students with disabilities also have difficulties socially in school. Lower rates of employment have been associated with level of ID while there is some conflicting evidence in the literature regarding type of residence and employment. A recent policy shift in Ireland towards individualisation in training provision has yet to yield any substantial change. Section 6.1 outlines the literature on education, training and occupation in greater detail.

2.3.4 Social Activities

The literature on social activities for people with intellectual disabilities primarily focuses on social activities performed in the context of the local community or mainstream settings; and in most cases conflates social activity with social activity

performed in ‘the community’ (i.e. in local community or mainstream settings). Under this assumption, the literature outlines that community residence is much more supportive of social activity than institutional residence; but a range of other factors are also important, including active support and staffing arrangements as well as personal characteristics such as level of ID, adaptive behaviour, level of need and social competence. A focus on the subjective experience of social activity, including individual preferences and constraints, may provide an alternative to normative assessments of what properly constitutes social activity and its related outcomes. This literature is examined in more detail in section 7.1.

2.3.5 Interaction with Local Community

This aspect of social participation includes activities by people with intellectual disability in their local community or the general community; it includes social and leisure activities performed within such contexts, use of local community amenities and involvement in community-based groups. As such there is significant overlap with the social activities literature reported above. The question of ‘what is community?’ is also pertinent in this context, and this is explored later in section 2.5. However, on the basis of an assumption of a spatial conception of community (where people with ID are physically present in their local community), the literature indicates that residential location in the community is a strong factor in determining engagement in community activities, interaction with the general community and use of community-based services and amenities. There is, however, evidence of factors which mitigate this experience including personal and support-related factors; and studies suggest that people with ID remain less involved in community than the general population even when living in community-based locations. Section 8.1 examines this literature in more detail.

2.3.6 Interpersonal Interactions & Relationships

While approaches to measurement and resulting estimates vary, the literature is clear that people with intellectual disabilities have smaller and less diverse social networks than their counterparts in the general population. A wide range of factors have been found to influence size of social network and frequency of social contact, including community versus institutional residence, size of residence, staffing and active support, proximity to family and personal characteristics such as ability and age. Few people with intellectual disability marry or have children, and many rely on family and paid support staff as their social support; however, the experience of intimate relationships appears to be strongly mitigated by level of ability. Evidence suggests that people with intellectual disabilities have few deep friendships, and that relationships with people who don't have an intellectual disability tend to be superficial or non-existent; yet reciprocity, understanding and the potential for true friendship have been identified as important in relationships for people with intellectual disabilities. Section 9.1 explores the literature on interpersonal relationships in greater depth.

2.3.7 Summary

This section has provided brief summaries of the social participation literature, which will be elaborated upon (and fully referenced) later throughout chapters 4-9. The broad scope of literature relevant to a broad conceptualisation of social participation means that there are no easy summaries or very dominant factors to point to. Across the different elements of social participation there is at least some conflicting evidence of the importance of contributory factors. When combined, these paint a complex picture that show how factors of personal characteristics, demographic characteristics, environmental influences, and structural and cultural issues related to services and support, all merge to create a different experience for individuals depending on where they sit in this configuration. This is perhaps the main overall finding of the literature review of social participation: that this complex phenomenon *is* complex and cannot be

reduced down to specific individual dominant factors such as age, level of intellectual disability or type of residence. While these are indeed strong factors in determining how social participation is experienced for people with intellectual disabilities, the literature shows that their influence varies between different aspects of social participation and between different studies; and importantly reveals a wide range of other factors that should not be diminished or overlooked. The current study attempts to put a shape on this complexity by using the WHO ICF as a valid theoretical framework to define the scope of the phenomenon. It also aims to add to the current limited knowledge of social participation for the population of older people with ID in Ireland; and in doing so will demonstrate the usefulness of applying an internationally recognised framework to the comprehensive and systematic study of this area in future research. The ICF model and its application as a theoretical framework is explored in the next section.

2.4 The WHO ICF

The *Activities & Participation* domain of the WHO's ICF was used as a theoretical framework for the investigation of social participation in this study. This section outlines the ICF framework and the rationale for applying it to the study.

2.4.1 Background to the ICF

Description and measurement of the social domain of life for people with intellectual disability have been inconsistent and conceptually underdeveloped (Verdonschot et al. 2009, Martin and Cobigo 2011, Cobigo et al. 2012, Amado et al. 2013). This has been challenged recently by developments in the area of social inclusion which have sought to offer conceptual clarity using a multidimensional approach informed by people's experiences and including subjective experience (Cobigo et al. 2012, Overmars-Marx et al. 2014); or by adopting an ecological approach to explaining the interpersonal

relationships and community participation that comprise inclusion (Simplican et al. 2015). While these developments in the field are welcome, this study has sought to develop the recommendation by Verdonschot et al. (2009) of applying a valid theoretical framework to the study of participation; where the authors recommended applying specific parts of the *Activities & Participation* domain of the WHO's ICF to the study of 'community participation', the current study broadens the scope to apply the full ICF domain to the study of social participation.

The ICF originated from the WHO's *International Classification of Impairments, Disabilities and Diseases* (ICIDH) (World Health Organization 1980), which related to the WHO's mandate to provide statistical and epidemiological reports. Acting as a complement to the *International Classification of Diseases* (ICD-10), the ICIDH aimed to fill the gap in statistics related to non-fatal health outcomes, namely functioning and disability across all life areas. Following widespread calls for an updated version an international revision process resulted in the ICF in 2001 (Üstün et al. 2003). Throughout its development the ICF was intended as a multi-purpose classification for use in a wide range of different areas. It is a classification of health and health-related domains, which aim to facilitate the description of changes in body function and structure, in what a person with a health condition can do in a 'standard environment' (i.e. their level of capacity), and what they actually do in their usual environment (i.e. their level of performance) (World Health Organization 2002).

The ICF has been applied and used extensively in a broad range of sectors internationally. It has been accepted and adopted worldwide as a classification system for describing and researching disability (Cerniauskaite et al. 2011), including the National Disability Survey in Ireland (Central Statistics Office 2008). ICF applications and core sets have been developed in a diverse range of areas including chronic health conditions (Cieza et al. 2004), disability assessment in social security (Brage et

al. 2008) and education (Hollenweger 2011), cancer treatment (Tschiesner et al. 2010), rehabilitative medicine (Stucki et al. 2002), multiple sclerosis (Coenen et al. 2011) and childhood disability (Simeonsson et al. 2003). Furthermore, the summary assessment tool based on the *Activities and Participation* domain of the ICF, the *World Health Organization Disability Assessment Schedule* (WHODAS), has been validated as a reliable assessment of disability (as expressed through activities and participation) amongst general populations (Von Korff et al. 2008), and in relation to chronic pain (Chwastiak and Von Korff 2003), depression (Luciano et al. 2010), dementia (Sousa et al. 2010), hearing loss (Chisolm et al. 2005), stroke (Schlote et al. 2009), osteoarthritis (Kutlay et al. 2011) and chronic diseases (Garin et al. 2010). In Ireland, the Health Research Board (HRB) uses the WHODAS in its measure of activity and participation for the National Physical and Sensory Disability Database (Carew and Doyle 2014).

As a model and classification tool for describing and measuring disability based on functioning, the ICF provides an internationally accepted schema for disability, which “is scientifically validated, peer reviewed and objective” (Shakespeare et al. 2016). It has provided

“a new foundation for our understanding of health, functioning, and disability. The ICF represents an advance that is both deeply conceptual and practically significant. It offers a universal framework and a classification system to comprehensively describe human experience in relation to functioning and disability. Avoiding both sociological and biomedical reductionism, the ICF gives us a starting point for a comprehensive and integrative understanding of the universal human experiences of functioning and disability” (Cieza et al. 2008).

The ‘biopsychosocial’ model of the ICF provided a synthesis of opposing understandings of disability, which has been expressed in the dialectic of ‘medical model’ versus ‘social model’. In doing so, the ICF attempted to integrate the impairment

basis of the medical model with the environmental determinants of the social model; the resulting model incorporates the biological, individual and social perspectives (World Health Organization 2001b). The social model was first articulated in the UK by the Union of the Physically Impaired Against Segregation (UPIAS) as a reaction to the dominant medical model which explained disability as impairments or defects within individuals; instead, UPIAS claimed that

“it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society” (UPIAS 1975)

This understanding gained prominence and was given academic credibility through the work of authors such as Finklestein (1980, 1981), Barnes (1991) and Oliver (1990, 1996); and became the *“ideological litmus test”* for progressive thinking on disability (Shakespeare and Watson 2001). However, critics noted that a hard-line approach to the social model failed to adequately capture the lived experience of impairment and the complexities of the body, health and disability (Kelly and Field 1996, Shilling 1997, Benson 1997, Bickenbach et al. 1999, Shakespeare and Watson 2001, Imrie 2004), and that it offered little by means of policy development or practical outcomes (Shakespeare 2006, Samaha 2007). By steering a middle course between the medical and social models, the ICF sought to move beyond the unequivocal messages of these dominant discourses in an attempt to better represent a more complex reality; and to present disability as a ‘relational phenomenon’ in which the functional limitations of impairments become disabilities as a result of each individual’s specific context (i.e. their personal and environmental factors) (Imrie 2004). The biopsychosocial model also presented disability as a *“universal human phenomenon”* rather than a concern of minority groups or civil rights campaigns presented by social model advocates (Bickenbach et al. 1999).

Imrie (2004) noted that, while social and environmental factors influence the meaning of impairment, the ICF contains a 'materialist ontology' which presents the body as a biological fact and impairment as 'pre-social'; whereas this view remains contested (Grosz 1994, Shildrick 1997, Thomas 1998, Pfeiffer 2000). Alternatively, the ICF position may simply be a 'realist' perspective of impairment (Imrie 2004), one which accepts that the materiality of the body and related aspects such as pain are more than simply socially constructed (Kelly and Field 1996, Bury 1997); hence the ICF may need to be more assertive and explicit about its materialist ontology; however, it remains underdeveloped theoretically and requires further development and elaboration (Imrie 2004).

As an alternative model, the capabilities framework provides a general theoretical framework in which to locate the social model of disability without compromising its central tenets (Burchardt 2004). Sen (1979) proposed that capabilities be used instead of utility as the object of value in measuring social phenomena such as equality. Capabilities are the opportunities to undertake certain activities or achieve particular states; and a person's capability set is the range of these activities or states that they could achieve if they wished to do so; the person has everything needed to achieve these (both the required internal and external circumstances) if that is what they wish to do (Sen 1985). Sen's approach relates capability to 'practical opportunity', and disability may be understood as the deprivation of a person's capability or functioning arising from the interaction of the person's personal characteristics, their resources and their environmental context; thus is similar in ways to the ICF, and the ICF framework is the closest to a definition of disability found under the capability approach (Mitra 2006). In common with the disability movement, autonomy and freedom to choose are strong themes in the work of capability theorists such as Sen and Nussbaum (Burchardt 2004, citing Nussbaum and Sen 1993, Sen 1999). However, a problem exists within this

insofar as the question of *who* decides on which set of capabilities are important (for measurement across populations and the provision of services, for example) remains unresolved in a context where individual autonomy is critical; as such, a tension exists between individual autonomy in determining the value of capabilities and the need to identify priorities for policy and services; thus a valid criticism of the approach is that, in attributing value autonomously, it is too individualistic and is difficult to operationalise (Deneulin and Mella 2002, Burchardt 2004, Mitra 2006). A difficulty that remains with the capability approach is that, for large-scale operationalisation, the identification of a set of capabilities that may apply to groups of people is contrary to the central tenets of autonomy and choice as the determinants of value. Therefore, to operationalise, it remains necessary to identify a normative set of capabilities. Nussbaum (2000) was criticised when proposing a set of 10 capabilities, while Sen left the proposition open by not identifying a particular set (Burchardt 2004, Mitra 2006).

Bickenbach (2014) proposed a reconciliation of the ICF and capability approach, in that the 'intentionally neutral' classification system that is the ICF may be used as the framework for descriptive measurement, and the capability approach then used to build a narrative of social justice on the basis of this scientific measurement. Previously, Chapiro and Colvez (1998) asserted that a conceptual framework is meant only for description and should not encompass strategy for reducing disablement; that strategies, such as health care or social change, can be adopted once appropriate description has been made. Mitra (2006) identified similarities between the ICF and capability approach in terms of their understanding of disability, yet claimed the ICF had been primarily used as a health classification that did not take into account individual and socioeconomic barriers that disable. In response to Bickenbach's proposition of reconciliation, Mitra (2014) claimed that the capability approach is an "*open-ended holistic framework*" which is more holistic than the ICF insofar as it

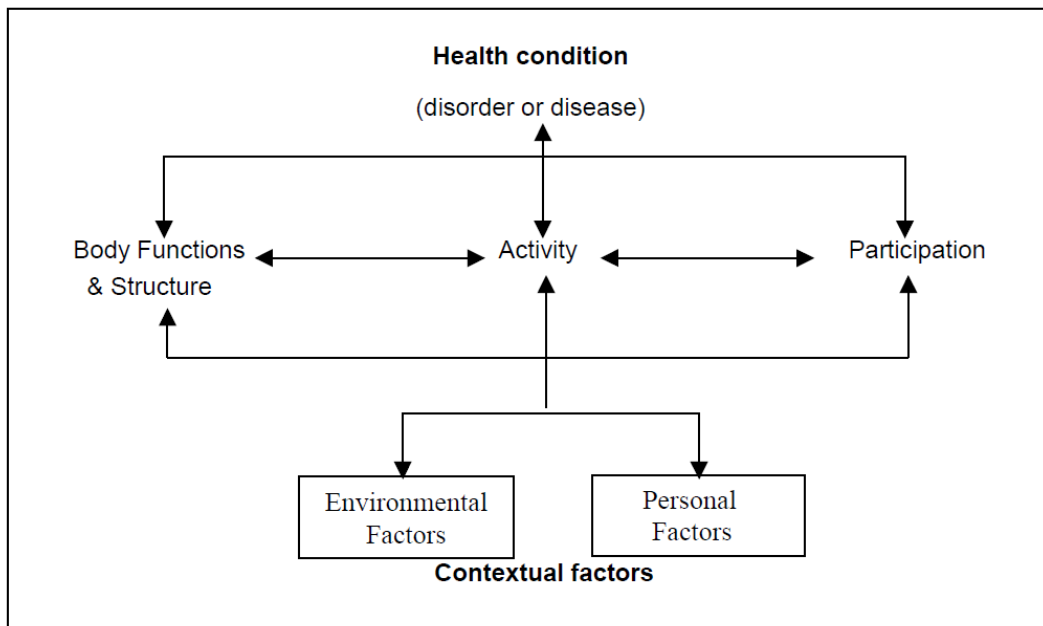
includes aspects of the lived experience, namely resources and choice, that are left out of the ICF; she noted that the ICF could be extended to include such elements; and while agreeing that there may be potential synergy between the two approaches, she rejected the idea that the ICF is the only tool available to operationalise the capability approach.

However, in the context of this study, the fundamental shortcomings of the capability approach with regard to operationalisation, and Mitra's (2014) failure to identify an alternative to the ICF to achieve this, lead to agreement with Bickenbach's claim: "*Capability Approach does not provide a feasible data collection framework... For better or worse, ICF is the international standard for disability and functioning data collection: it is the only game in town*" (Bickenbach 2014). Therefore, in the absence of a perfect and universally accepted model, which is probably unachievable, the ICF appears to be the best and most widely-accepted framework at present; and therefore represents the best available foundation on which to base a large-scale population study of this nature.

2.4.2 The ICF Framework

Use of the ICF as a theoretical framework necessitates a broad understanding of participation within an overall 'biopsychosocial' model of disability that incorporates aspects of the biological, individual and social.

Figure 2.1. The ICF Model of Disability



Source: World Health Organization (2002)

Figure 2.1 shows that, within the ICF, disability is seen as the outcome of interactions between 'health conditions' (e.g. diseases, disorders and injuries) and 'contextual factors' (including 'environmental factors' such as social attitudes, legal and social structures; and 'personal factors' such as age, gender, education, social class). In between are the three levels of human functioning: functioning of body or body part; the whole person; and the whole person in a social context. Disability is therefore experienced as dysfunction at one or more of these levels, and described as: impairments; activity limitations; and participation restrictions (World Health Organization 2002) (see Appendix 2 for definitions of the different components of the ICF model). The ICF contains four specific domains of classification and measurement: body functions; body structures; activities and participation; and environmental factors. Each of these contains a number of 'chapters' that classify and measure more specific components (see Figure 2.2).

Within the overall ICF model, social participation is most obviously expressed in terms of the *Activities & Participation* domain, but should also consider *Body Structures*, *Body Functions* and *Environmental Factors* as contextual determinants of how aspects of activities and participation are performed. The *Activities & Participation* domain is operationalised by a *performance qualifier* and a *capacity qualifier*. The performance qualifier describes what a person does in his/her own environment, and is understood in terms of 'the lived experience'; while the capacity qualifier describes the person's ability to perform a task or action within a 'standardized environment' (World Health Organization 2001b). Following this, the current study focuses on the 'activity limitations' and 'participation restrictions' that arise as a result of body structures, body functions and environmental factors. As such, the study focuses primarily on the *expression* of social participation rather than impairments that may underlie or the environmental factors that shape the experience. Therefore, the *Activities and Participation* domain provides the theoretical framework for social participation within the current study.

Figure 2.2. ICF Domains and Chapters

Body	
Function: Mental Functions Sensory Functions and Pain Voice and Speech Functions Functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems Functions of the Digestive, Metabolic, Endocrine Systems Genitourinary and Reproductive Functions Neuromusculoskeletal and Movement-Related Functions Functions of the Skin and Related Structures	Structure: Structure of the Nervous System The Eye, Ear and Related Structures Structures Involved in Voice and Speech Structure of the Cardiovascular, Immunological and Respiratory Systems Structures Related to the Digestive, Metabolic and Endocrine Systems Structure Related to Genitourinary and Reproductive Systems Structure Related to Movement Skin and Related Structures
Activities and Participation	
Learning and Applying Knowledge General Tasks and Demands Communication Mobility Self Care Domestic Life Interpersonal Interactions and Relationships Major Life Areas Community, Social and Civic Life	
Environmental Factors	
Products and Technology Natural Environment and Human-Made Changes to Environment Support and Relationships Attitudes Services, Systems and Policies	

Source: World Health Organization (2002)

2.4.3 Conclusion

Variations in the definition and classification of disability have resulted in widespread difficulties in documenting disability and of consequently providing appropriate services (Simeonsson et al. 2000). Similar variation was noted at the start of this section in the definition and measurement of the social domain of life for people with an intellectual disability. The ICF is not perfect and not without criticism; however, it has been widely adopted worldwide and offers the best fit available for the large scale assessment of disability, and as applied as a theoretical framework for social participation within a population. Other models and explanations are emerging but none provide the same

sound basis for study as the ICF. In applying this framework and mapping IDS-TILDA measures across each element, this study aims to achieve the first systematic measure of social participation for the population of older people with an intellectual disability in Ireland.

2.5 What is Community?

The UN Convention on the Rights of Persons with Disabilities (CRPD) Article 19 requires that each state will *“recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community”* (United Nations 2006).

While the CRPD places great emphasis on the importance of community for people with disabilities, it fails to define what is meant by ‘community’. Similarly, the key policy document in Ireland, the HSE’s *Congregated Settings* report, sets out policy on community transition and community living for people with intellectual disabilities without defining ‘community’ (Health Service Executive 2011). In fact, across the intellectual disability literature it is rare for authors to offer a definition of ‘community’ (Cummins and Kim 2015). Limitations of the current understanding of community may stem from the debate being hitherto focused on deinstitutionalisation and therefore not fully exploring the broader elements of community (Piggott 2013); while the focus on a dichotomy of ‘institution versus community’ distracts from the fact that deinstitutionalisation is only one factor and understanding community should not just be about the physical environment (Parker 2013). The lack of conceptual clarity has the potential to leave the meaning of community open to different interpretations and manifestations (Greig 2015). However, there appears instead to be a widespread assumption that ‘community’ refers to the general population within a specific location

(usually one's local community) and community inclusion/participation is achieved through access to a normatively prescribed life, measured by objective outcomes. For people with intellectual disabilities it implies their physical location 'in the community', where they live alongside people who do not have intellectual disabilities; living in the same types of houses, using the same local amenities, and doing the same things.

Based on this understanding of community, the literature has been largely positive about outcomes for people with intellectual disability living 'in the community' (Emerson and Hatton 1994, Heller et al. 1998, Young et al. 2004, Kozma et al. 2009, Mansell and Beadle-Brown 2009a, Chowdhury and Benson 2011). However, some have noted a bias towards objective over subjective measures of community living (Cummins and Lau 2003); while others reported variations in outcomes depending on a range of personal and other factors (Emerson and Hatton 1994, Young et al. 2004, Kozma et al. 2009, Mansell and Beadle-Brown 2009a, Chowdhury and Benson 2011), and a situation where, although people with intellectual disabilities are more connected than those who remain in institutional settings, they still remain poorly connected within these wider communities (McCarron et al. 2011) For example, social connections that people with intellectual disabilities have within the general population are reported as either superficial or non-existent (see section 9.1).

Scoring highly on objective measures of community involvement yet remaining 'unconnected' within the wider community may signal a shortcoming in how community has been conceptualised in intellectual disability; where the focus on living 'in the community' just like everybody else (an understandable focus following a recent history of institutionalisation) has resulted in a lack of development of ideas about what community really means and how people with intellectual disabilities experience community. It thus could be argued that the focus on location has overlooked the true

essence of community. But this approach to community is not unique to the intellectual disability field. In community development, for example, definitions have tended to be vague and to conflate place with community (Bhattacharyya 2004); while the key aims of community development, namely to (re-)build the structures and processes which facilitate community work and community-based service provision (Tesoriero 2010), are nonetheless based upon a spatial conception of community that is encapsulated by the geographically-bounded idea of local community. However, if a broader understanding of community, such as solidarity, is applied to the community development field (Bhattacharyya 2004); and the goal of development understood to be agency, or freedom (Sen 1999); then the purpose of community development may be understood as the positive response to reaffirm agency and solidarity (Bhattacharyya 2004).

While some recent studies in the intellectual disability field have examined how community participation is conceptualised (Verdonschot et al. 2009), or have considered the different contexts or settings in which social inclusion for people with intellectual disability may occur (Simplican et al. 2015), these nonetheless continue to view community primarily in terms of location and thereafter consider participation or inclusion within or outside of that entity. As such, there appears to have been a dearth of intellectual disability literature which explored what community means and what its defining features are. However, a small number of studies that challenge the dominant spatial conception and explore the meaning of community have begun to emerge. Cummins and Lau (2003) proposed that social rather than physical integration benefitted quality of life, and urged a refocus on subjective outcomes and a sense of belonging. Ben-Moshe (2011) questioned whether community living as a policy approach is entirely separate from institutional living, as the effects of the latter are still present in the former. She distinguished between two broad understandings of

community. On one hand is community viewed as the binary opposite of institution (and therefore related to locale); which is deemed inaccurate and insufficient, although it also implies integration with the locale and the use of 'community services', which may be better termed 'local services'. On the other hand is community as the building of human relationships, although this conceptualisation has not been widely adopted in the field. The author also notes that while ideas of community may be contested, similarly the meaning of institution may be likewise; for instance some may view group homes as mini institutions while others see them as community living (Ben-Moshe 2011).

Elsewhere, Greig (2015) recognised relationships and a sense of belonging as central to different understandings of community, including those based on place, on shared interest or identity, and on shared experiences and feelings; yet subsequently presents an analysis of inclusion based on normative standards of the general community, which relies primarily on a spatial conception of community. Working from a similar perspective of inclusion within the mainstream of the general population, Jarrett (2015) stated that inclusion and community acceptance were normative in pre-industrial times and it was the period from the asylum in the mid-nineteenth century until recent deinstitutionalisation policies that was anomalous. Cummins and Kim (2015) noted that in common understanding a distinction exists between the distant 'society' and more proximate 'community' (citing Zambianchi and Bitti 2014); the dictionary definition of community refers to a group of individuals linked by common interest, shared characteristic or a shared policy; and definitions within sociology and psychology overlap strongly, with an emphasis on feelings of connectedness to the group, reciprocity and interdependency. The authors note associations made within the literature between 'community' and 'inclusion'; but highlight also the gap between a Normalization-driven focus on physical integration and social integration with the

general population, presenting evidence that in measures of subjective quality of life the vast majority of the effect comes from satisfaction with money, meaningful activity and intimate relationships, while 'community' has a relatively weak influence. They conclude by highlighting the centrality of shared interests to the meaning of community; how, following Normalization, people with intellectual disabilities have been discouraged from finding their own community; and that "*the general population is not a community*" (Cummins and Kim 2015).

Some writers have presented alternative approaches to community and inclusion based on the somewhat controversial approaches of 'intentional communities' (Cushing 2015, Lyons 2015); controversial because, in opposition to Normalization, the CRPD and policy internationally, they present a form of living and community that is segregated from the mainstream of the general community. Cushing (2015) identified a definition of community based on a feeling of belonging towards a group, which stems from something the members have in common (whether these are real, imagined or digital), with a mutual recognition and shared responsibility. She criticised the dominant narrow understanding of community and inclusion, which has been based on a number of stories or meta-narratives containing a vision of inclusion of people with intellectual disability into the mainstream environment of the general population. An alternative approach is offered by 'intentional life-sharing communities' such as L'Arche, Camphill and Center for Discovery, and fits within the broader definition of community; and while these are based upon a segregated form of community, the latter also has the explicit goal of active integration with the broader community (Cushing 2015). Lyons (2015), meanwhile, criticised policy rhetoric about 'personalization' which at the same time maintains a preferred outcome of Normalization based upon a narrow understanding of integration with the general population, even though the logic of personalization should not pre-empt the outcome for individuals; whereas intentional communities offer the

opportunity to pursue a meaningful existence through personalization in its true sense (Lyons 2015).

Notwithstanding these welcome additions to a broader discussion on community, throughout the intellectual disability literature and policy there remains a widespread assumption that community means the general population or wider society, and the residential location of people with ID therein, in 'integrated' as opposed to segregated settings. This implies that a spatial concept of community dominates the intellectual disability field. In this context, despite policies of movement to and living in 'the community', there remains uncertainty about what 'community' means beyond deinstitutionalisation and geographic location amongst the general population. While outside the scope of the current study, the development of an alternative model of community for people with ID would appear warranted from the gaps evident in the literature.

2.6 Literature Review: Conclusions

The social dimension of life has been defined and described by several overlapping terms and concepts, including social or community participation, social inclusion and exclusion, social or community integration, social or community involvement, social capital, social cohesion and social solidarity. In studies of people with intellectual disability this has seen little consensus on approaches to the study of social phenomena (Amado et al. 2013) and a lack of consistency and systematic approach (Verdonschot et al. 2009). Internationally, policy and the research literature relating to social participation or social inclusion has been inextricably linked with aspects of community for people with intellectual disabilities; and the specific context of moving from institutionalisation to deinstitutionalisation and community living has resulted in an inadequate exploration in the field of the concept of community and, consequently, an

underdeveloped understanding of community rooted in a spatial conception. At the same time, inclusion and participation has been promoted and pursued on the basis of the achievement of a normatively-prescribed set of objective outcomes rooted in theories of Normalization and Social Role Valorisation.

A broad and holistic study of social participation, informed by an ICF theoretical framework, requires investigation across a wide range of themes that make up this broad understanding. This includes aspects of: social functioning; human rights and citizenship; education and occupation; social activities; engagement with local community; and interpersonal relationships and interactions. Within this literature there are significant gaps in knowledge about the specific circumstances of the older ID population in Ireland; while across these thematic areas the literature reports that a wide range of factors combine differently to influence social participation for people with ID, depending upon which aspect of participation is examined. However, the literature reveals at least some conflicting evidence of the importance of contributory factors to these different aspects of social participation. When taken together as a single holistic phenomenon it reveals a complex picture that shows how factors of personal characteristics, demographic characteristics, environmental influences, as well as structural and cultural aspects of services and support, all merge to create a different experience of social participation for individuals depending upon their unique makeup. As such, the application of a valid theoretical framework will help to achieve a more consistent, comprehensive and systematic approach to the field. A developing literature also places subjective experience and outcomes at the heart of any measure of social inclusion or participation, alongside (and not in place of) the objective measures that currently dominate the literature.

As with the approach to applying a sound theoretical framework to the study of social participation, the review also identifies a need to explore and clarify the concept of community. Community has been conceptually underexplored within the ID field during a period when there has been significant focus on community for people with ID and their inclusion within the community. This has been expressed in a relatively narrow way within ID policy and research, based primarily upon a spatial conception that equates community for people with ID with geographic location amongst the general population. An emerging literature in the ID field suggests that community is about much more than geographic location and, while outside the scope of the current study, this is an area that needs further exploration in the future to create the basis for a fuller understanding of community for people with ID.

Chapter 3. Methodology

3.1. Introduction

Following on from the literature review, this chapter presents the methodological approach used in the study (apart from the literature review methods, which were outlined in chapter 2). It first sets out the research question and key study objectives. Then an outline of the primary data source is presented, with details of the sampling procedures and sample profile, ethical considerations, measures used, and procedures around the collection, cleaning and analysis of data. This is followed by an overview of how the ICF framework relates to the thematic presentation of social participation findings within the thesis – the mapping of measures to the ICF framework is outlined in more detail later in each thematic findings chapter.

3.2 Research Question and Objectives

The main research question in the study is: What are the rates and outcomes of social participation for older people with an intellectual disability in Ireland?

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

1. Measure rates of social participation amongst older people with an intellectual disability in Ireland using the WHO ICF as a valid theoretical framework of participation;
2. Identify factors associated with differences in rates of social participation for this population;
3. Examine associations between objective measures of social participation and subjective outcomes for individuals.

Arising from the literature review and the gaps in knowledge identified therein, these objectives will provide a basis of knowledge about social participation for people with ID as they age at a particularly opportune time in Ireland. Internationally, people with ID

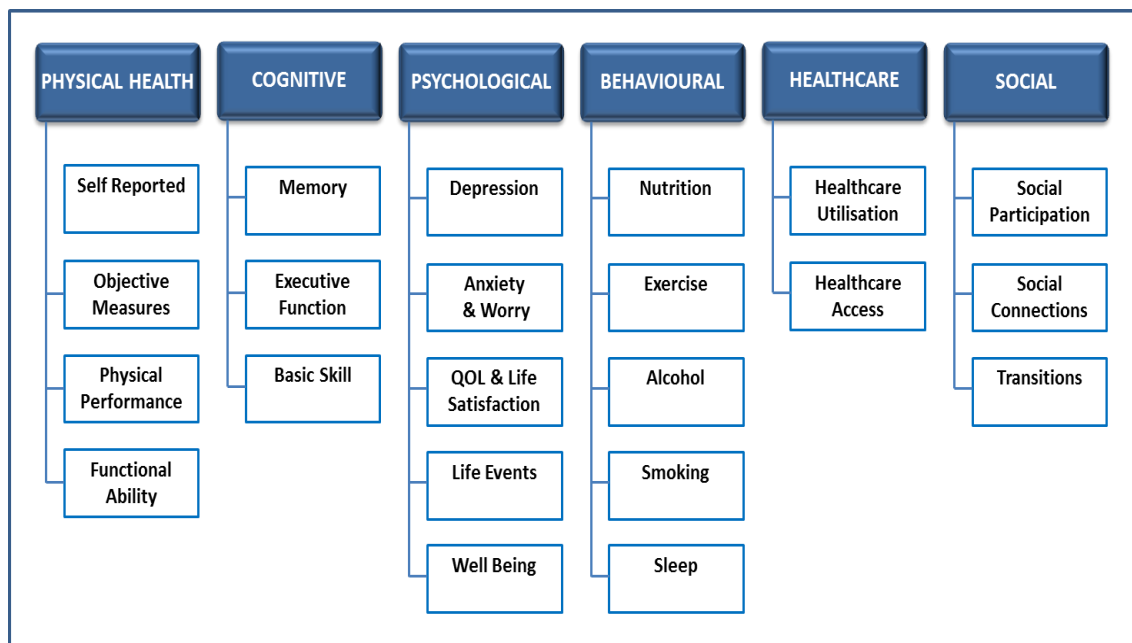
are now living to a much older age than they have historically (P. Janicki 1999) and in Ireland we now have the first generation of older people with ID (McCarron et al. 2011). This also coincides with ageing populations worldwide and in Ireland (Nolan et al. 2014) and a policy context which has responded to these changing demographics (Department of Health 2013). In the past 10 years in Ireland, TILDA changed the discourse on ageing generally and developed discussion through its research around quality of life of life and social participation issues (McCrory et al. 2014). This has identified risks of social isolation and threats to quality of life amongst the general population, as suggested by social disengagement theory (Cumming and Henry 1961); yet has yet has framed the discussion with a more positive perspective on ageing, as proposed by critics of disengagement theory (Hochschild 1975, Cornwell et al. 2008).

Where these risks of disengagement or isolation exist for the general population as they age, the available literature suggests that there are even greater risks for people with ID as they age due to poorer health and more limited social supports. As such, the current study, guided by the above research objectives, will help to illuminate the experience of social participation for people with ID as they age, particularly at such a critical time of flux within policy and provision for this population.

3.3 IDS-TILDA Dataset

Primary data used in the study is from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). This data is used to address study objectives 1-3. While IDS-TILDA is a longitudinal study, which began with wave one in 2009 and will commence its third wave of data collection in 2016, the current study only uses data from wave two in a cross-sectional analysis of social participation. The rationale for using IDS-TILDA as the primary data source was based on the fit between the broad definition of social participation used within the study, informed by the ICF theoretical framework, and the breadth of data within the IDS-TILDA dataset. The breadth of data within IDS-TILDA is illustrated by the conceptual framework of the longitudinal study in Figure 3.1 below.

Figure 3.1. IDS-TILDA Conceptual Frame



Source: McCarron (2015)

This breadth of data provided a unique opportunity within the field to undertake a holistic and systematic assessment of social participation for older people with an intellectual disability, framed by the ICF.

3.3.1 Background to IDS-TILDA

IDS-TILDA is a longitudinal study of ageing amongst older people with an intellectual disability in the Republic of Ireland. Data collection for wave one of IDS-TILDA was undertaken in 2009-10, reported by McCarron et al. (2011); wave two data was collected in 2013, reported by Burke et al. (2014); and data collection for the third wave commences in 2016. The overall aim of IDS-TILDA is:

“To identify the principal influences on successful ageing in persons with intellectual disability, and then determine if they are the same or different from the influences for the general population.” (McCarron et al. 2011)

In addition, the study is underpinned by the values of inclusion, empowerment, choice, person centeredness, the promotion of best practice, the promotion of people with intellectual disability and making a contribution to their lives. IDS-TILDA is unique worldwide in being the only longitudinal study on ageing amongst the intellectual disability population that is being implemented parallel to a study of ageing amongst the general population (McCarron 2014).

IDS-TILDA is a supplement to The Irish Longitudinal Study on Ageing (TILDA), which is a study of ageing amongst the general population in Ireland aged 50 years and above. TILDA is a large-scale, nationally representative study of ageing involving more than 8,000 people. It is a multidisciplinary study which aims to develop the scientific knowledge of ageing in Ireland and highlight the impact of public policy on all domains of older peoples' lives (Barrett et al. 2011).

3.3.2 Sampling Frame and Procedures

Whereas the main TILDA study includes members of the general population aged 50 and above, IDS-TILDA included people with intellectual disability aged 40 years and above at wave 1. The reason for this is that people with intellectual disability tend to

present with signs of ageing at an earlier stage than people without intellectual disability (Lifshitz and Merrick 2004, Wong 2011, Ruiz et al. 2012). The IDS-TILDA sample was drawn randomly from the population of adults aged 40 years and above on the National Intellectual Disability Database (NIDD). The NIDD is an administrative database managed by the Health Research Board (HRB) and contains information on people with an intellectual disability in the Republic of Ireland who are registered with a service provider. The NIDD dataset currently contains information on 27,887 individuals (Kelly 2015) – the potential limitations of the database and its representativeness of the total population of people with ID in Ireland were discussed earlier in section 1.4. For recruitment of the original sample at wave one the dataset contained 26,066 individuals (Kelly et al. 2010). From this, the inclusion criterion of being aged 40 years and above was applied and 1,800 individuals were randomly selected by NIDD staff; just over 1,600 of these were provided information and asked to participate in the study. This part of the selection process was completed with the assistance of NIDD staff, to ensure the anonymity of individuals until consent was granted. Written consent was obtained from 753 individuals (a 46% response rate), either directly by self-consenting individuals (38%, n=285) or by a family member or guardian for those who were unable to self-consent (62%, n=468).

The final wave one sample was demographically and geographically representative of the target population within the NIDD; it equated to 8.9% of the total eligible population at the time. The sample was 45% male and 55% female; aged 41 to 90 years (mean age 54.7 years); 24% had a mild ID, 46% moderate ID, 24% severe ID, and 5% profound ID (with 5% unverified). Around 40% lived in 52-week residential care centres, with a further 5.3% in other residential centres (i.e. 45.3% in 'institutional' or 'congregated' residential care settings); around one-third (34.1%) lived in community group homes with other individuals with intellectual disability; 5% lived independently or

semi-independently; and 11% lived at home with their families (McCarron et al. 2011). The retention rate for wave two of IDS-TILDA was 94%, with a final sample of 708 completing at least one element of the study. No new participants were recruited at wave two; however, the geographic and demographic representativeness of the sample in relation to the eligible NIDD population was maintained. The elements from which data for the present study are drawn, the Pre-Interview Questionnaire (PIQ) and the Computer Assisted Personal Interview (CAPI) were completed by 701 individuals in wave two (Carroll et al. 2014).

3.3.3 Ethical Considerations

3.3.3.1 *Consent Process*

For wave one of IDS-TILDA, approval and consent for the longitudinal study was sought at four different levels:

1. Ethical approval was obtained from the Faculty of Health Sciences Ethics Committee at Trinity College Dublin;
2. Approval was then sought from local and regional ethical committees attached to the 138 services who support the individuals who would be invited to participate in the study;
3. Informed consent was sought directly from individuals in writing for their participation in the study; family packs were included among the accessible information sent to individuals which, in cases where individuals were unable to provide consent directly, requested that a family member/guardian would review the study information and provide proxy consent for their family member's participation;
4. Finally, where consent was obtained for individuals to participate, a system of process consent was used whereby each individual's consent was reaffirmed at

the time of their main interview; both verbal and accessible written information was provided and the person's right to withdraw at any stage was reiterated.

Consent for the multi-wave longitudinal study was obtained through this process. Prior to the commencement of wave two interviews, all participants were sent an information booklet to remind them about the purpose and nature of the study. The 138 services were informed in writing of the pending data collection, and step four in the above process was repeated with individuals prior to their main interview to ensure their willingness to continue in the study. Between waves one and two the IDS-TILDA project team, including the researcher, also employed a 'Keeping in Touch' strategy to maintain communication with participants, families and services. This involved the regular production of study newsletters as well as Easter and Christmas cards. Through this process participants were kept up-to-date on progress with the study and were notified in advance that they would be contacted for wave two interviews from May 2013.

3.3.3.2 Confidentiality and Data Protection

IDS-TILDA has implemented a range of systems and procedures to protect the confidentiality and data of participants at all times. Each participant was given an anonymised personal identification number (PIN) that was generated for the study and randomly assigned. All personal information is distinguished only by the PIN numbers, with the exception of a hard copy 'Preload' document, which was completed on site by fieldworkers prior to the main interview. This document was used to ensure that the right person was being interviewed, as well as confirming date of birth and contact details. These documents are stored separately from all other information in a securely locked storage area. Access to these documents is restricted to the Principal Investigator (PI) and project manager. All fieldworkers and project personnel signed a confidentiality agreement for the protection of personal information of participants,

families and services. All computers used in the study were encrypted and the upload of data from fieldworkers was operated through a secure Private Virtual Network (PVN) developed by Trinity College IT Services specifically for the project. Data analysis was only permitted on files within the IDS-TILDA network and no copies of data were permitted on hard drives, USB devices or other external media.

3.3.3.3 Participant Well-being

A number of measures were taken to ensure the well-being of participants throughout the data collection process:

1. Every effort was made to arrange an interview time that was most suitable to the participant and/or proxy respondent;
2. It was particularly important that respondents with intellectual disability were in a familiar environment in which they felt comfortable; as such, all interviews took place in a location of their choosing, most often their own home;
3. If the participant and/or proxy respondent found the interview to be too long they were offered the option of taking breaks and/or to return on another occasion to complete the interview; these options were outlined to respondents at the start of the interview;
4. Every effort was made by interviewers to explain the questions clearly to respondents with intellectual disability, sometimes by using show cards if required;
5. Respondents were told at the start of the interview that if there were any questions that they were not comfortable with, and didn't wish to answer, they could do so without any explanation.
6. Respondents were also told at the outset that they could stop the interview at any time if they wished.

3.3.3.4 *Ethics in the Field*

The researcher was solely responsible for managing a caseload of 62 individual IDS-TILDA participants. With regard to ethical considerations, this entailed ensuring that the correct procedures were adhered to in relation to confidentiality and data protection in the field, and for the well-being of these participants throughout their involvement in the data collection process. Procedures in the field to safeguard confidentiality and data protection included:

- Non-disclosure by the researcher of information regarding the participants' involvement in IDS-TILDA, other than to individuals with whom access was negotiated;
- Careful safeguarding of any documentation relating to participants' involvement in the study, including keeping PIQs and others documents in my possession at all times during data collection, and their removal from my car at the end of each data collection day.
- Strict non-disclosure of any personal information provided by the participant or supports and proxies to any third parties – procedures were in place to deal with disclosure of abuse or risk, but nothing of this nature arose in the researcher's time in the field;
- Use of an encrypted laptop computer for the main CAPI interview for all participants

In addition to the measures previously described to ensure the well-being of participants during their interview and entire data collection involvement, a number of specific issues emerged throughout the data collection process that the researcher needed to manage. These included:

- Negotiating consent with participants – every effort was made to obtain consent directly from participants in the first instance; the researcher was able to use his experience of working with people with intellectual disabilities to assess each individual's ability and level of comprehension in the initial introductions and informal exchanges upon arrival at each interview location (usually their home); this was considered in tandem with prior knowledge of the participant (e.g. regarding level of ID and communication), and used to determine an individual's ability to provide consent themselves – rather than simply relying on a supporter or proxy.
- Ensuring the comfort and happiness of the participant with the interview situation – from the researcher's perspective, the most important factor in a completing successful interview was to ensure that the participant was happy and comfortable with the situation, with the level of support as required and, crucially, with the researcher as interviewer; accordingly, great importance was placed upon the arrival, introductions and early exchanges with the participant; these were kept as informal and friendly as possible while also, after an initial settling period, going through the procedures required for the interview (e.g. consent) in a methodical yet friendly manner.
- Concerns of proxy interviewees and supporters – a number of proxy interviewees and supporters who were staff members in particular services required reassurance as to permissions granted for the conduct of the interview, and of theirs and the participant's involvement in the study. The main concern in this regard was that staff were reluctant to grant access and/or consent at local level without having the authority to do so; in all cases staff were reassured when the researcher informed them that consent was previously obtained at service management level and from the participant or his/her family for the

duration of the IDS-TILDA study; the option was given to staff to double-check with their superiors as to the authenticity of these assertions, but was not necessary in any of my cases.

- Clarity in the roles of proxies and supporters – it was necessary on a number of occasions to reiterate with proxy or support interviewees the specific nature of their roles – in that they were there to provide information as to the best of their knowledge regarding the participant, even where they were answering all questions on their behalf; as such, the researcher noted on a number of occasions that it was not their role to second-guess the participant, and also reminded the proxy respondents that it was the participant’s experience and not their own that they were being asked to provide.

3.3.4 Measures

Measures used in IDS-TILDA are designed to be comparable, in so far as possible, to measures of the general older population by TILDA; while changes are made to suit the intellectual disability population (such as changes to wording) and some alternative measures used. However, broadly speaking, the measures used in IDS-TILDA reflect those used in TILDA and the scope of these are outlined in the theoretical frame of IDS-TILDA (Figure 3.1 above). Within the current study, the measures used are examined thematically throughout Section B of the thesis under the headings of: social functioning (chapter 4); human rights and citizenship (chapter 5); education, training and occupation (chapter 6); social activities (chapter 7); local community interaction (chapter 8); and interpersonal relationships (chapter 9). How these themes relate to the ICF framework is outlined in section 3.4 below; with greater detail provided in each thematic findings chapter later. Chapter 10 uses a self/proxy-rated measure of emotional or mental health to examine possible associations between objective measures of social participation and individual subjective outcomes. All of the specific

IDS-TILDA measures utilised in the current study are outlined in greater detail throughout the relevant findings chapter in Section B of the thesis (see also Appendix 3).

3.3.5 Data Collection

The IDS-TILDA study comprised two main data collection components in wave one: the Pre-Interview Questionnaire (PIQ) and a Computer Assisted Personal Interview (CAPI), which was the main face-to-face interview. An objective health assessment was added in wave two; however this was not a feature of data collection for the current study. Each fieldworker was given a caseload with contact details of participants to manage and complete. The main elements of the data collection process were as follows:

- Fieldworker training was provided over three days in March 2013, covering: the study aims and objectives; questions and variables in the PIQ and main questionnaire; caseload management and fieldworker responsibilities; ethical procedures; use of the CAPI; run-through of the data collection process; practice of each element of the process; procedures for data entry of PIQ and uploading of data. Along with data cleaning and validation approaches (see 3.3.6 below), the systematic fieldworker training process aimed to ensure a high degree of consistency between interviewers.
- Following training, individual fieldworkers made contact with each person in their caseload to introduce themselves and to arrange a suitable time and place to conduct the interview; participants were also notified at this time that they would be sent the PIQ, which should be completed by them (with assistance if required) and then collected by the fieldworker when they called out for the interview; a period of approximately two weeks was left

before the interview to allow time for the PIQ to be posted out and completed prior to the interview.

- On the day of the interview, upon arrival at the designated place, the fieldworker introduced himself, went through the study information and consent procedures, checked the PIQ for completion, and then conducted the main interview.
- The main interview was usually conducted (directly, supported or by proxy) in one visit but some required additional visits to complete, depending on each individual participant; breaks were taken as directed by the wishes of the participant; additional follow-up was also required at times to obtain PIQs that were not completed on the day of the interview.
- Once all elements were completed, fieldworkers manually entered data from the PIQ into SPSS and uploaded this with the main interview file to the project VPN.

The current study uses data from the entire wave two sample of 701 participants; which includes data collected by the researcher and by the other fieldworkers. Of these, the researcher completed data collection (PIQs and CAPI) for 62 individual cases between May and December 2013. This included collection of information across the entire range IDS-TILDA study variables for the 62 cases. There was a roughly even three-way split in these 62 cases between direct one-to-one interviews, supported interviews and proxy interviews. The vast majority of these took place in the person's home, with just two taking place in a day service setting.

While the data collection process was the most enjoyable element of the study, one of the most challenging aspects of the data collection process was the logistical effort of

arranging interviews. Quite often the contact details for support people or key workers were out of date or the person had moved on in their three year period since the previous interview. This often necessitated several phone calls and follow-ups to find the correct support person and then to agree a time and place for interview. The researcher quickly realised that staff were extremely busy and it was always better to follow up with another call rather than wait for a staff member with several higher priorities to return a call.

In some instances, support people contacted by phone didn't have any knowledge of IDS-TILDA and were wary about granting access to the participant. Usually staff were reassured once informed about the study in general, on the participant's involvement in it – and indeed of the importance of the participant's continued involvement in the study. In a few instances, support staff indicated that the participant's health had deteriorated since their previous interview (e.g. through dementia) and either would not be up to an interview or not be able to provide the same level of information as they had before. In these cases, the researcher noted the even greater importance that this gave to the participant's involvement, since changes in status of this nature were exactly the thing we were attempting to capture in the longitudinal study; while the different interview options were outlined for involvement (i.e. support or proxy).

Some challenges also arose during the interviewing process that the researcher needed to negotiate. In two particular supported interviews the participants became upset and anxious, triggered by specific questions related to family. In one case, the person was very agitated to begin with and then became verbally aggressive as he became more anxious through the early stages of the interview. He indicated on a number of occasions that he wanted to participate, yet it appeared that he was unable to continue without becoming more and more agitated. It was eventually agreed with the participant and supporter not to continue with the participant present as it was too

upsetting, and to complete the interview with the supporter as proxy. The researcher was satisfied that the participant was happy with this arrangement; and indeed the participant later returned to apologise and to informally speak with the researcher.

On another occasion, a participant in a supported interview was taking part and answering questions very happily until we started into the social connectedness module, and specifically the questions about family and family contacts. At this point he became withdrawn and reticent. The researcher reminded the participant he didn't have to answer any questions he didn't want to, and that he could take a break or end the interview at any time. In the end it was agreed to take a break and return to complete the interview on another occasion. When a second visit was arranged the participant indicated that he didn't wish to take part himself, but was happy for his keyworker to complete the interview as a proxy on his behalf.

Apart from these specific instances, no major instances arose during the data collection process. On a few occasions, the researcher proposed a break and return for a second visit after noticing that participants were becoming tired and didn't have the energy to continue. In a small number of other instances, the proxy respondents sometimes veered off the course of the interview, either becoming focused on their own situation or else on a service-related issue that didn't specifically relate to the participant. In these instances it was the role of the researcher to subtly steer the focus back to the participant and the specific questions at hand. However, the vast majority of supporters and proxies maintained the correct focus and were genuinely interested in representing their participants' views and experiences to the best of their ability; and in general the data collection process was a hugely positive and rewarding experience for the this researcher.

The inclusion of different types of responses to questionnaire items in IDS-TILDA may potentially lead to an inconsistency in responses, depending on whether responses are

from a direct, supported or proxy interview; however, research on the consistency of responses in this regard has been inconclusive (Perry 2004, Stancliffe 2000). Some studies have identified inconsistency (Stancliffe 1995, Rapley et al. 1998); whereas others have found consistency (Schalock and Keith 1993, Stancliffe 1999); while others have noted more consistency in objective measures (Perry and Felce 2002). However, studies need to make a judgement on whether it is better to omit proxy responses completely, and therefore exclude people who are unable to answer for themselves, or to accept possible limitations of proxies and include them (Perry 2004). In the current study, it was considered the better option to include the full sample rather than limit the analysis to the direct responses of the most able within the sample. To maintain a high standard of response in supported and proxy interviews, only people who knew the participant for a minimum of six months qualified to provide support or proxy responses for the participant; and in reality the vast majority of supporters and proxies had long-term relationships with the participant that far exceeded this minimum standard.

3.3.6 Data Cleaning and Validation

A process for data cleaning and validation was established within the structures of the IDS-TILDA project to ensure the quality of the data collected. This was led by the project manager with individual responsibilities for the research team including fieldworkers. Data cleaning and validation involved the following procedures:

- Each fieldworker, including the researcher, checked the hard copy of each PIQ for completeness; when this was input to SPSS a separate member of the research team checked this against the hard copy.
- Where any systematic errors arose, these were reported to the project manager and then relayed to the researcher(s) in question to eradicate repeat of such errors in future cases.
- The main interviews were conducted using the CAPI system, thereby reducing the scope for input error.
- Once individual case files were uploaded they were merged by a member of the research team into a master data file; a structured cleaning and cross-validation process of the master file was then performed by the research team including the researcher, involving:
 - Running and checking descriptive statistics to ensure logic in filter questions and related responses in the CAPI data;
 - Manual sorting and checking of cases;
 - Independent checking of PIQ hard copy and entered data using an algorithm that determined the correct entry for each item

- Any errors or inconsistencies identified through this process were reviewed and corrected by the research team

3.3.7 Data Analysis

The SPSS package was used to perform statistical analyses of IDS-TILDA data. The researcher undertook his own analysis of wave two data within the overall data management protocols of the IDS-TILDA study. A range of descriptive, bivariate and multivariate analyses were performed to address the objectives of the current study. The measures used are described in each thematic findings chapter in Section B of the thesis, along with the analytical procedures used; while all of the measures used are outlined in Appendix 3. Briefly, data analysis procedures included:

- Descriptive frequencies expressed in percentages of the population;
- Cross-tabulations for bivariate associations between variables, using the chi-square (χ^2) test to establish significance of association;
- Binary and multinomial logistic regression models to explore factors associated with different aspects of social participation, reporting adjusted Odds Ratios (OR) and corresponding 95% Confidence Intervals (CI);
- The alpha level (α) for the study was set at 0.05, or $p < 0.05$ for statistical significance.

Figure 3.2 below outlines the analysis plan for the study.

Figure 3.2: Study Analysis Plan

Study Objective	Methods	Chapter
Objective 1: <i>Measure rates of social participation amongst older people with an intellectual disability in Ireland</i>	<ul style="list-style-type: none"> • Descriptive statistics of rates of participation in % of the sample. • Scope of social participation defined by ICF theoretical framework. 	4 – 9
Objective 2: <i>Identify factors associated with differences in rates of social participation</i>	<ul style="list-style-type: none"> • Bivariate statistics using cross-tabulations and chi-square tests. • Multivariate statistics using binary and multinomial logistic regression models, adjusted Odds Ratios and 95% Confidence Intervals 	4 - 9
Objective 3: <i>Examine associations between objective measures of social participation and subjective outcomes for individuals</i>	<ul style="list-style-type: none"> • Bivariate statistics using cross-tabulations and chi-square tests. • Multivariate statistics using binary logistic regression, adjusted Odds Ratios and 95% Confidence Intervals. 	10

3.3.7.1 Sample Size and Power

Statistical power within a study depends upon the individual types of analyses performed. In the present study, sample size and power was an important consideration when performing chi-square tests and regression analyses. Goodness-of-fit tests that compare observed and expected frequencies in cells that combine discrete variables, such as chi-square, could have little power if expected frequencies are too small; and ideally, all expected frequencies would be greater than 1 and no more than 20% less than 5 (Tabachnick and Fidell 2013); this standard was adhered to in the study. With regression analysis, the ratio of cases to independent variables (IVs) in the model must be substantial or else the outcome will be meaningless (Tabachnick and Fidell 2013). A widely-accepted general rule of thumb to determine adequate power in the regression analyses in this study was $N \geq 50 + 8m$, where m is the number of predictor

variables (Green 1991). The largest number of predictor variables in any of the regression models throughout chapters 4-9 was 13, requiring a minimum sample size of 154 ($50 + 8 \times 13$) for adequate power. The smallest sample size in these models was 458. The regression model in chapter 10 included 15 predictor variables, thereby requiring a minimum sample of 170 ($50 + 8 \times 15$); whereas the sample included in this model was 439. Thus, the sample size used in the study was more than adequate for the analyses performed.

3.3.7.2 Multicollinearity

Testing for multicollinearity between independent variables was also undertaken prior to regression modelling. Multicollinearity arises when there is a strong correlation between two or more of the predictor variables in a regression, and may cause problems with the model including increased standard errors, limiting the size of the variance accounted for in the model and making it difficult to distinguish the individual importance of a predictor variable (Field 2013). Testing for multicollinearity in the current study employed two approaches, both performed using SPSS. These assessed: (1) the Variance of Inflation Factor (VIF) and tolerance for each variable; and (2) the pairwise correlation coefficients between variables using Spearman's correlation coefficient. VIF indicates whether a predictor variable has a strong linear relationship with other predictor variables in a regression model; it is related to 'tolerance', which is reciprocal ($1/VIF$) (Field 2013). While there is no one universally accepted measure that is indicative of multicollinearity, a number of guidelines exist: VIF values > 2 (Kutner et al. 2004); a largest VIF value greater than 10 (Bowerman and O'Connell 1990, Myers 1990); average VIF substantially greater than 1 (Bowerman and O'Connell 1990); and tolerance value below 0.2 (Menard 1995).

Correlation coefficients greater than 0.8 or 0.9 may give another indication of multicollinearity in the regression model (Farrar and Glauber 1967, Tabachnick and Fidell 2013, Field 2013). To ensure no risk of multicollinearity this study employed a cut-off standard of:

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

Testing for multicollinearity for regression models in chapters 4-9 raised no concerns in line with these standards, and all VIF values were well below the upper limit. However, some relatively high bivariate correlations emerged in the analysis of subjective outcomes, and a decision was made to exclude two independent variables from the regression model (see chapter 10 for details). Further details of measures and data analysis procedures used in the study are outlined in the thematic chapters throughout Section B of the thesis.

3.4 Mapping IDS-TILDA Measures to the ICF Framework

With the ICF theoretical framework for social participation established in chapter 2, we can identify the IDS-TILDA measures used to address objectives 1 and 2 of the study, and the corresponding parts of the ICF that these are mapped to. This is set out in two ways in the thesis. Firstly, Figure 3.3 below outlines the nine high-level parts of the ICF *Activities & Participation* domain alongside the thematic chapters presented in the thesis findings. Secondly, within each of the findings chapters in Section B of the thesis, the IDS-TILDA measures used in the study are outlined in detail and mapped to a specific part of the ICF (see also Appendix 3 where all of the measures are brought together). This will show that the study has achieved good coverage across the nine

main elements of the ICF theoretical framework that define the scope of social participation.

Figure 3.3. ICF Framework and Corresponding Thesis Chapters

ICF Activities & Participation Domain	Thesis Chapter
D1. Learning and applying knowledge	Chapter 4 – Social Functioning Chapter 6 – Education, Training & Occupation
D2. General tasks and demands	Chapter 4 – Social Functioning
D3. Communication	Chapter 4 – Social Functioning
D4. Mobility	Chapter 4 – Social Functioning
D5. Self-care	Chapter 4 – Social Functioning Chapter 5 – Human Rights & Citizenship
D6. Domestic life	Chapter 4 – Social Functioning Chapter 5 – Human Rights & Citizenship Chapter 9 – Interpersonal Relationships
D7. Interpersonal interactions and relationships	Chapter 4 – Social Functioning Chapter 5 – Human Rights & Citizenship Chapter 9 - Interpersonal Relationships
D8. Major life areas	Chapter 4 – Social Functioning Chapter 5 – Human Rights & Citizenship Chapter 6 – Education, Training & Occupation
D9. Community, social and civic life	Chapter 4 – Social Functioning Chapter 5 – Human Rights & Citizenship Chapter 7 – Social Activities Chapter 8 – Interactions with Local Community

Section B of the thesis will next outline the study findings. This includes the above scope of social participation throughout chapters 4-9, addressing objectives 1 and 2 of the research; and also includes findings for objective 3 (chapter 10) of the study.

Section B: Findings

Having established the context, scope, objectives and methods for the study in Section A of the thesis, Section B now presents the main research findings. This will, throughout chapters 4-10, outline measures and associated factors of social participation for older people with intellectual disability in Ireland (objectives 1 and 2) and examine their relationship with individual subjective outcomes (objective 3). Each findings chapter is also set within the context of the research literature pertaining to the specific theme examined (elaborating on summaries in chapter 2); specific measures and analyses are outlined (building on chapter 3); and an initial discussion of the findings for each specific issue is provided (ahead of the overall discussion in chapter 11 of the thesis). Section B is set out as follows:

- Chapter 4. Social Functioning for Older People with Intellectual Disability
- Chapter 5. Participation in Human Rights & Citizenship
- Chapter 6. Participation in Education, Training & Occupation
- Chapter 7. Participation in Social Activities
- Chapter 8. Participation in Local Community
- Chapter 9. Participation in Interpersonal Relationships
- Chapter 10. Subjective Outcomes of Social Participation

Chapter 4. Social Functioning for Older People with Intellectual Disabilities

4.1 Introduction

This chapter examines a number of functional areas that are relevant to social participation, including:

- Activities of Daily Living (ADLs);
- Instrumental Activities of Daily Living (IADLs);
- Communication;
- Functional literacy; and
- Physical abilities related to mobility, movement and positioning.

The chapter explores factors that are associated with limitations in these areas and compares levels of functional limitation with the general older population in Ireland. Within the overall study and thesis, this examination of social functioning is relevant to all of the main parts the ICF theoretical framework (see section 3.4). It looks at issues that constitute elements of social participation within themselves (e.g. domestic participation), but which also provide the basis for participation in other dimensions of life (e.g. how aspects of literacy impact on participation in education, or how communication impacts on participation in interpersonal relationships). In many ways, therefore, this group of functional items provide the basis for social participation; thus they have been termed 'social functioning' in this study.

The chapter begins by examining the literature on each of the areas examined. It then outlines the specific methods used in more detail (building on chapter 2), presents the findings regarding these aspects of participation, and discusses these in context of the literature and underpinning policy. The broader impact of functioning on other aspects of social participation is also examined in the subsequent findings chapters of the thesis, where summary measures of social functioning are included in bivariate and multivariate analyses.

4.1.1 Activities of Daily Living

In the literature, functional decline in both ADLs and IADLs is associated with growing older (Hébert 1997). Activities and instrumental activities of daily living are often used to assess disability in older age through measuring increases in functional difficulty in performing the everyday activities that help people to live independently and integrate within their environment (Millán-Calenti et al. 2010). A distinction is drawn between the basic ADL and the more complex IADL, whereby ADLs are activities essential to independent living while IADLs require a higher degree of personal autonomy (World Health Organization 2001a). Limitations with IADLs normally precede those with ADLs because IADLs require greater capacity to make decisions and to interact with one's environment (Judge et al. 1996). However, both potentially contribute to the changes that compromise continued independence (McCallion 2014).

A study of 8,178 people aged 50 years and over in the general Irish population found a steady increase in limitations of ADLs and IADLs as people got older, with 28% of those aged 75 years and older having 'disabilities' in ADL and/or IADL compared to just 8% of the 50-64 years group (Normand et al. 2011). Another study of 3,215 older people aged 75-98 years in the general German population found increased age to be associated with IADL impairment (Koehler et al. 2011). For people with ID, studies have similarly found age to be a factor in decreased functioning in ADLs (Maaskant et al. 1996, Janicki and Jacobson 1986). Amongst the general population, declines in cognitive ability have also been found to be associated with functional impairment in IADLs (Koehler et al. 2011). Within the ID population, level of ID has been negatively associated with longevity (Bittles et al. 2002, Patja et al. 2000). People with mild ID experience less functional limitations and are more independent than those with moderate or severe ID (McCarron et al. 2011, Lifshitz et al. 2008). Therefore the linkage between ADL and IADLs and increased functional decline in older age is more complex for people with ID.

With regard to gender, Normand et al. (2011) found that women over 50 in the general Irish population had higher levels of disability as defined by overall dysfunction of either ADLs or IADLs; but women had lower ADL disability and higher IADL disability than men. Koehler et al. (2011) on the other hand found that being male was associated with loss of functioning in IADLs amongst the general population. Amongst people with ID, McCarron et al. (2011) found that while older women with ID in Ireland reported higher limitations in ADL functioning, men had higher limitations in IADL functioning. Some have also argued that findings of higher dysfunction with IADLs in men may be attributable to a gender bias in the construction of IADL measures, with a focus on traditionally female roles (Ward et al. 1998).

People with ID living in institutional residences were found to have higher dysfunction in ADLs and IADLs than those living in community group homes, while those living in independent or family residences had the lowest level of dysfunction; although this is partly explained by findings that those living in institutional residences tend to be older, with more severe levels of ID and greater social and health related needs than those living in the general community (McCarron et al. 2011).

Other studies have indicated that environment itself can influence I/ADL functioning of adults with ID. Young et al. (1998) reported that studies in Australia had found that placement in the community was associated with increased adaptive behaviour. Kim et al. (2001) identified similar findings in studies in the U.S., whereby people with ID moving from institutions to community settings demonstrated improved adaptive behaviour skills. This influence of environment and the changeability of I/ADL skills is also reflected in studies which found that, because ADLs and IADLs are influenced by physical and cognitive capacity, they may also be improved to some extent through training or supports (Hilgenkamp et al. 2011, Daniels et al. 2008, Gama et al. 2000). This follows Deeg's (1993) distinction between functional and situational disability relating to IADL; whereby

situational IADL disability is attributable to non-health factors and is often more modifiable than functional IADL disability. Improvement in adaptive behaviour, therefore, may be related to the situational increased opportunity associated with less restrictive environments. For example, people with ID living in community settings have more opportunities than people in institutional settings to practice the basic and instrumental activities that support daily living and greater independence (Spreat and Conroy 2001).

4.1.2 Communication & Sensory Difficulties

Finucane et al. (2014) found significant increases in eye conditions with age amongst the general older population in Ireland, including cataracts, glaucoma and age related macular disease (AMD). McCarron et al. (2014) noted that sensory impairment was an issue of serious concern for older people with ID, with particularly high rates of chronic eye diseases such as cataracts compared to the general population. Janicki and Jacobson's (1986) study of 10,532 older people with ID over a span of almost fifty years (1890-1939) had previously identified an association between age and decreased sensory ability. More recent data in Ireland highlighted that, in patterns of multimorbidity among people with ID, eye disease combined with neurological conditions or mental health difficulties was highly influential in predicting secondary health problems (McCarron et al. 2013). Cronin et al. (2011) reported a deterioration in hearing as people in the general population get older, with older adults twice as likely to rate their hearing as poor than those younger. Amongst older people with ID, rates of hearing difficulties have been reported at 11.6%, which includes those who rated their hearing as fair to poor or who were legally deaf (McCarron et al. 2014). Haveman et al. (2011) also reported an 11.9% prevalence of hearing problems among adults with ID aged over 65 years. Taken together, sensory impairments appear to be an important variable to consider in any examination of functioning in older age.

Koehler et al. (2011) found that poor performance in verbal fluency and delayed recall of words increased the risk of functional impairment in IADLs amongst the general population. This was supported by O'Regan et al. (2011), who noted that *“the association between IADL disability and poor verbal fluency is especially striking”* (2011: 179). McCarron et al. (2011) found that a third of older people with ID had at least some difficulty in making themselves understood when communicating with professionals and service providers; almost a quarter had at least some difficulty communicating with friends, while one in six also reported difficulty communicating with their family. Belva et al. (2012) found that adults with profound ID displayed significantly more receptive than expressive communication skills, and significantly more receptive and expressive communication skills than written communication skills; suggesting that people with profound ID understand more than they can communicate in return, either physically, verbally or in writing. Here again, verbal fluency appears to be an important variable to consider in any examination of functioning in older age and in particular for people with ID the influence of a focus by carers and others upon expressive rather than receptive communication skills may magnify fluency's impact.

4.1.3 Literacy Difficulties

People with ID historically have not engaged in education; for example, McCarron et al. (2011) reported that almost two-thirds of older people with ID in Ireland had not completed primary education, with 32% receiving no education at all. McCausland et al. (2014) reported that around four in five older people with ID had difficulty with reading, writing, numeracy and understanding money. This not only excludes people with ID from valued social roles within society, but also places them at a disadvantage, and possibly risk, of lacking the skills required to negotiate community and society (Morgan et al. 2011, Forts and Luckasson 2011, McCausland et al. 2014). Abbott and McConkey (2006) identified a lack of literacy and numeracy skills, as well as little knowledge of one's local area, as a barrier to social inclusion for people with intellectual disability.

4.1.4 Impact on Social Participation

Some studies have identified level of ID and associated adaptive behaviour skills as significant factors in determining different aspects of social participation for people with ID (McCausland et al. 2016, Kozma et al. 2009, Baker 2007, McConkey et al. 2007). Outcomes for people with ID moving to and living in community-based residences have been found to vary depending upon a number of key factors including personal characteristics and adaptive behaviour (Mansell and Beadle-Brown 2009a, Felce and Emerson 2001). Hébert (1997) noted that functional decline has a negative impact on quality of life. This was supported by McCrory et al. (2014), who identified an association between having a 'disability' (defined by having a restriction in at least one ADL) and decreased quality of life in older age in the general Irish population. Previously, McCarron et al. (2011) noted a much higher rate of dysfunction in ADLs and IADLs for older people with ID in Ireland, especially for those aged 65 and over; therefore an equivalent detrimental impact on quality of life for this group may be surmised but remains to be investigated.

Gilmore and Cuskelly (2014) identified functional difficulties associated with ID as well as individual skills deficits such as communication skills as part of an explanatory model for loneliness in people with intellectual disability. Communication difficulties have also been identified as underlying other difficulties for people with ID that negatively impact potential for social participation, such as exhibiting challenging behaviours (Belva et al. 2012, Matson et al. 2011, Ringdahl et al. 2008, Paclawskyj et al. 2000). Communication/language problems were identified as creating difficulties for participating in social activities outside the home by more than a quarter of older people with ID in Ireland (McCausland et al. 2014). McCarron et al. (2011) reported that older people with ID had difficulty communicating with family, friends and other people generally. McCarron et al. (2014) also highlighted the concern that some people with ID may be unable to self-report symptoms of certain health conditions, such as arthritis or pain in general, due to an

inability to communicate, thus impacting greatly on their quality of life; this especially impacts on people with more severe ID.

4.1.5 Conclusion

Overall the literature points to increased functional difficulties with ADLs and IADLs, as well as increased problems with communication, vision and hearing as people get older. This is true of both the general older population and older people with ID. There are also some indications of a cumulative negative impact from these increasing difficulties on social participation. Within the Irish policy context we also know that the majority of people remaining in congregated settings are older and have a higher level of support needs (Health Service Executive 2011). Holistic assessment of social participation should, in line with the ICF theoretical framework of participation, include assessments of these aspects of functioning. Not only do they impact directly on key aspects of participation such as domestic participation and independent living, but may also impact on other aspects of participation such as relationships, social activity, and engagement in community and civic life. While these secondary influences are examined in subsequent findings chapters, this chapter focuses on the primary impact of five specific areas of functioning and on factors associated with levels of limitation for older people with ID in Ireland.

4.2 Methods

This section builds on the methodological approach outlined in chapter 2 of the thesis. It provides additional details about the specific measures and procedures used for this part of the study.

4.2.1 Measures

This chapter examines ADLs, IADLs, physical ability, and difficulties related to communication (eyesight, hearing, speaking and writing notes) and to functional literacy (reading, writing, numbers and computers). Demographic variables used in the analyses include gender, age, level of ID (mild; moderate; severe-profound), and type of residence

(independent/family; community group home (CGH); institutional). Other variables used in the analyses include self-reported physical health (good-excellent; fair-poor); proximity to family (same neighbourhood; different neighbourhood); contact with family (weekly; monthly; less than monthly); and whether or not participants had any non-resident friends.

Figures 4.1, 4.2 and 4.3 outline the measures of social functioning used in this chapter; with each variable mapped to a specific part of the ICF's *Activities & Participation* domain. For each of the ADLs, IADLs and physical abilities (Figure 4.1), respondents indicated what degree of difficulty they had with each item: no difficulty; some difficulty; a lot of difficulty; or cannot do at all.

Figure 4.1. Measures used: ADLs, IADLs and physical abilities

Activities of Daily Living	ICF Reference¹
<i>Please indicate the level of difficulty, if any, you have with...</i>	
Dressing, including putting on shoes or socks	d540
Walking across a room	d450-469
Getting around inside your home	d450-469
Bathing or showering	d510
Cleaning your teeth / taking care of your dentures	d520
Eating	d550
Getting in or out of bed	d410/420
Using the toilet, including getting up or down	d530
Taking medication	d598/d570
Instrumental Activities of Daily Living	ICF Reference²
<i>Please indicate the level of difficulty, if any, you have with...</i>	
Preparing a hot meal	d630
Shopping for groceries	d620/d860
Making telephone calls (including hearing)	d729/d9205
Managing money (e.g. paying bills, tracking expenses)	d620/d860
Doing household chores (e.g. laundry, cleaning)	d640
Physical Abilities	ICF Reference
<i>Please indicate the level of difficulty, if any, you have with...</i>	
Walking 100 yards	d450-469
Sitting for about two hours	d415
Getting up from a chair after sitting for long periods	d410/420
Climbing one flight of stairs without resting	d450-469
Stooping, kneeling or crouching	d410/d415
Reaching or extending your arms above shoulder level	d445
Pulling or pushing large objects like a living room chair	d449
Lifting/carrying weights over 10lbs/5kgs (e.g. heavy bag of groceries)	d430
Picking up a small coin from a table	d440
¹ In addition to specific references, ADLs and IADLs also map generally to chapter D2, <i>General Tasks & Demands</i> (parts d210, d220 and d230).	
² In addition, IADLs also map to chapter D1, <i>Learning & Applying Knowledge</i> (parts d155, d160, d163, d175 and d177).	

Four items were used to measure difficulties related to communication (Figure 4.2).

Self/proxy-rated eyesight was rated: excellent, very good, good, fair, poor, or legally blind.

Difficulty hearing a conversation and speaking/making yourself understood when speaking were rated: no difficulty, some difficulty, a lot of difficulty, or cannot do at all. Ability to write notes and messages was rated: yes, without assistance; yes, with assistance; no/cannot do.

Figure 4.2. Measures used: communication difficulties

Question	ICF Reference
[How] is your eyesight (using glasses or lenses if you use them)?	d115/d310
Can you follow a conversation with one person?	d330/d350/d355
Do you have any difficulty speaking or making yourself understood?	d345
[Can you] write notes and messages?	d110/d315/d320/d325

Four items measured literacy difficulties ('functional literacy') (Figure 4.3). Participants responded yes or no when asked if they had any difficulty with reading, writing, numbers or using computers.

Figure 4.3. Measures used: functional literacy

Question	ICF Reference
Do you have any difficulty with reading?	d140/d166
Do you have any difficulty with writing?	d145/d170/d345
Do you have any difficulty with numbers?	d150/d172
Do you have any difficulty with computers?	d130-159/d155/ d160-179

4.2.2 Analysis

Rates of difficulty and associations with key demographic covariates were initially characterised for each variable. Summary variables were then derived for the five groups of items described in figures 4.1-4.3 above. An average level of difficulty was calculated for ADLs, IADLs and physical ability. Responses were recoded (no difficulty=0; some difficulty=1; a lot of difficulty=2; cannot do=3), then summed and divided by the number of

input variables; where an average of zero indicated no difficulty and an average of three indicated complete difficulty (unable to do any functions). Cases with any missing responses were excluded from the relevant computation. Summed levels of difficulty were derived for communication and literacy; where individual items were recoded as binary outcomes of 'no difficulty' (0) or 'difficulty' (1); with summed scores of 0-4 reflecting the number of difficulties reported. Again, any cases with missing responses were excluded from the sum.

The summed scores for all five functional areas were recoded into binary outcome variables (lower difficulty; higher difficulty) for further analysis; and these were treated differently depending on the composition of the summed variable and/or the distribution of scores amongst respondents for the specific measures. Where a very small proportion of respondents scored highly or lowly for a particular measure, the binary cut-off levels were adjusted to ensure enough cases in each category for multivariate analysis. As such, the five summed binary outcomes (higher/lower) are not directly-comparable absolute values; instead they facilitate comparison of individuals within the sample for each specific item (i.e. whether they have a higher or lower level of difficulty in comparison to other respondents for that item). Logistic regressions were then performed to identify predictors of functional limitation/difficulty with ADLs, IADLs, physical abilities, communication and functional literacy. Independent variables added to the models were: gender; age; level of ID; type of residence; self/proxy rated physical health; proximity of nearest family member; frequency of social contact (meet or phone) with family; and whether or not respondents had friends outside their own home.

4.3 Results

4.3.1 Frequencies and Covariates

Frequencies and bivariate analyses for the five summary variables of social functioning are outlined below (Table 4.1). A large majority of respondents reported having some level

of difficulty with ADLs; and while most were at the lower end of the range of difficulty, women were more likely to report difficulties at the higher end, as were people aged over 65, and particularly people with severe-profound ID and those living in institutional residences. Average difficulty with IADLs for more than half of respondents was high, with just one-fifth reporting none or low level of difficulty. There were acute differences in relation to level of ID, with more than nine out of ten people with severe-profound ID reporting a high average difficulty (score 2.1-3), compared to less than one in five for those with mild ID. People in institutional settings, those aged over 65, and men were also more likely to report a high average level of IADL difficulty. Physical Abilities (PAs) presented a similar pattern to ADLs, with women, people aged over 65, those with severe-profound ID and those living in institutional residences more likely to have a high average level of difficulty in performing these activities.

Eight out of ten respondents reported difficulty with at least one measure of communication. Over half reported difficulties with at least two of the communication functions measured. This was exacerbated particularly for people with severe-profound ID, with more than nine out of 10 reporting at least two communication difficulties, compared to less than a quarter of people with mild ID. More than three-quarters of institutional residents reported at least two communication difficulties, compared to about half of those in community group homes and less than a third in independent/family residences. With regard to functional literacy, more than two-thirds of all respondents reported having difficulty with all four aspects measured. There were significant differences in relation to level of ID and type of residence, where again people with severe-profound ID and those living in institutional settings had the highest levels of difficulty.

Table 4.1. Frequencies & covariates: five summary variables of social functioning

	Gender		Age			Level of ID			Type of Residence			
	Total	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe- Profound	Independent /Family	CGH	Institution
Average ADLs Difficulty (0-3)	n=645	(n=645, p<0.05)		(n=645, p<0.01)			(n=596, p<0.001)			(n=645, p<0.01)		
Zero	17.2	18.7	16.1	12.3	22.5	10.6	35.3	17.0	1.6	40.4	20.6	5.9
0.1 - 1	57.1	58.8	55.7	62.6	55.6	53.9	56.8	65.7	44.6	52.8	63.4	51.7
1.1 - 2	14.3	15.5	13.3	14.6	12.9	17.0	5.8	9.2	29.6	3.4	9.8	22.7
2.1 - 3	11.5	7.0	15.0	10.5	9.0	18.4	2.2	8.1	24.2	3.4	6.3	19.7
Average IADLs Difficulty (0-3)	n=666	(n=666, p<0.05)		(n=666, p<0.001)			(n=613, p<0.001)			(n=666, p<0.001)		
Zero	2.1	0.3	3.5	2.7	2.4	0.7	8.3	0.3	0.0	10.0	0.7	0.4
0.1 - 1	18.2	15.5	20.2	19.1	21.1	9.9	42.8	15.0	0.6	34.5	20.8	8.4
1.1 - 2	24.3	26.6	22.6	19.1	29.5	19.0	29.7	31.7	6.6	29.1	32.1	13.7
2.1 - 3	55.4	57.6	53.7	59.0	47.0	70.4	19.3	53.0	92.8	26.4	46.4	77.6
Average PAs Difficulty (0-3)	n=628	(n=628, p<0.01)		(n=628, p<0.001)			(n=577, p<0.001)			(n=628, p<0.001)		
Zero	29.3	33.5	26.1	33.5	32.9	14.2	42.2	29.5	14.2	42.6	33.3	18.7
0.1 - 1	43.3	46.2	41.1	47.2	42.8	39.4	42.9	48.7	32.9	47.2	49.1	34.9
1.1 - 2	17.7	14.5	20.1	10.2	16.6	30.7	9.5	15.3	31.6	6.5	11.1	30.3
2.1 - 3	9.7	5.8	12.7	9.1	7.7	15.7	5.4	6.5	21.3	3.7	6.5	16.2
Communication Difficulties (No.)	n=660	(n=660, not significant)		(n=660, not significant)			(n=608, p<0.001)			(n=660, p<0.001)		
Zero	20.6	15.8	24.5	16.8	25.9	13.0	49.0	16.3	0.6	41.8	20.8	11.5
One	22.7	25.0	20.9	24.2	21.1	24.6	27.5	27.7	11.0	30.0	29.1	12.6
Two	35.2	37.7	33.2	36.3	33.1	38.4	17.4	37.0	51.2	23.6	30.4	45.2
Three	16.5	16.1	16.8	15.8	16.0	18.8	4.7	16.3	30.0	3.6	14.5	24.1
Four	5.0	5.5	4.6	6.8	3.9	5.1	1.3	2.8	11.8	0.9	5.2	6.5
Literacy Difficulties (No.)	n=666	(n=666, not significant)		(n=666, not significant)			(n=615, p<0.001)			(n=666, p<0.001)		
Zero	4.1	2.7	5.1	5.2	4.5	1.5	11.4	2.7	0.0	7.3	3.4	3.4
One	7.7	6.8	8.4	7.8	9.5	2.9	18.6	6.2	0.5	19.3	7.9	2.6
Medium	5.7	5.1	6.2	6.7	6.2	2.9	9.3	6.2	0.5	8.3	6.5	3.8
Three	14.1	14.9	13.5	14.5	14.6	12.4	19.3	15.5	8.7	23.9	12.7	11.7
Four	68.5	70.6	66.8	65.8	65.2	80.3	41.4	69.4	90.2	41.3	69.5	78.5

4.3.2 Factors Associated with Functional Difficulty

Tables 4.2 to 4.5 present results from the binary logistic regressions performed to predict difficulty in each of the five functional areas measured. Table 4.2 presents results of the (separate) models for average difficulty with ADLs and IADLs. The ADLs model explained 41% (Nagelkerke r^2) of the variance in average ADL difficulty. Level of ID was the strongest predictor when controlling for the other variables in the model; with people with severe-profound ID over seven times more likely to have higher ADL difficulty than people with mild ID. Respondents reporting fair-poor physical health (OR=6.70), those living in institutional residences (OR=4.76), those aged over 65 years (OR=1.92), and women (OR=1.7) were also more likely to have a higher level of difficulty with ADLs.

The IADLs model in Table 4.2 explained 55% (Nagelkerke r^2) of the variance in average IADL difficulty. Level of ID was by far the strongest predictor of IADL difficulty when controlling for other factors in the model; where people with severe-profound ID were over 26 times more likely than people with mild ID to have a higher level of difficulty, and those with moderate ID were more than three times more likely. Following ID level, having fair-poor physical health (OR=4.38), living in institutional residence (OR=4.24), having less than monthly contact with family (OR=4.02), having no friends outside your house (OR=2.66) and being 65 years or older (OR=1.99) significantly predicted greater IADL difficulty.

Table 4.2. Factors associated with ADL (n=558) and IADL (n= 572) difficulty

	Higher Average ADL Difficulty ¹		Higher Average IADL Difficulty ²	
	OR (95% CI)	p-value	OR (95% CI)	p-value
Gender				
Male	1.0		1.0	
Female	1.7 (1.08-2.81)	0.02	1.09 (0.69-1.71)	0.72
Age				
< 65 years	1.0		1.0	
65+ years	1.92 (1.10-3.34)	0.02	1.99 (1.11-3.58)	0.02
Level of ID				
Mild	1.0		1.0	
Moderate	1.36 (0.62-3.0)	0.44	3.22 (1.86-5.59)	<0.001
Severe-Profound	7.59 (3.40-16.95)	<0.001	26.38 (12.15-57.30)	<0.001
Type of Residence				
Independent/Family	1.0		1.0	
Community Group Home	1.55 (0.46-5.23)	0.48	1.59 (0.69-3.67)	0.27
Institutional	4.76 (1.43-15.84)	0.01	4.24 (1.77-10.19)	0.001
Physical Health				
Very Good-Excellent	1.0		1.0	
Good	1.91 (1.13-3.25)	0.02	1.06 (0.65-1.72)	0.81
Fair-Poor	6.70 (3.50-12.85)	<0.001	4.38 (2.10-9.12)	<0.001
Proximity to Family				
Same neighbourhood	1.0		1.0	
Outside neighbourhood	1.13 (0.51-2.48)	0.76	0.60 (0.29-1.27)	0.18
Contact with Family				
At least weekly	1.0		1.0	
At least monthly	1.74 (0.90-3.36)	0.10	1.62 (0.92-2.85)	0.09
Less than monthly	1.49 (0.81-2.76)	0.20	4.02 (2.31-6.97)	<0.001
Have Friends Outside				
Yes	1.0		1.0	
No	1.10 (0.68-1.80)	0.69	2.66 (1.65-4.27)	<0.001

¹ Higher ADL Difficulty (score >1); reference category is Lower ADL Difficulty (score 0-1).

Nagelkerke $r^2=0.41$

² Higher IADL Difficulty (score >2); reference category is Lower ADL Difficulty (score 0-2).

Nagelkerke $r^2=0.55$

$p<0.05$ is significant. All significant factors in bold.

The model for average difficulty with physical abilities is presented in Table 4.3. The model explained 37% (Nagelkerke r^2) of the variance in the outcome variable. Physical health was the strongest predictor variable in the model, where respondents who reported fair-poor health were over six times more likely to have higher average difficulty than those with very good-excellent health. People living in institutional settings (OR=3.96), those with severe-profound ID (OR=3.64), those aged 65 year and

older (OR=3.29) and women (OR=2.29) were also more likely to have higher functional difficulty with these physical abilities.

Table 4.3. Factors associated with difficulty with physical abilities (n=538)

	Higher Average Functional Difficulty ¹	
	OR (95% CI)	p-value
Gender		
Male	1.0	
Female	2.29 (1.43-3.68)	0.001
Age		
< 65 years	1.0	
65+ years	3.29 (1.90-5.69)	<0.001
Level of ID		
Mild	1.0	
Moderate	0.95 (0.51-1.78)	0.95
Severe-Profound	3.64 (1.83-7.22)	<0.001
Type of Residence		
Independent/Family	1.0	
Community Group Home	1.11 (0.44-2.79)	0.82
Institutional	3.96 (1.56-10.04)	0.004
Physical Health		
Very Good-Excellent	1.0	
Good	1.73 (1.05-2.86)	0.03
Fair-Poor	6.39 (3.43-11.88)	<0.001
Proximity to Family		
Same Neighbourhood	1.0	
Outside neighbourhood	0.99 (0.49-2.01)	0.98
Contact with Family		
At least weekly	1.0	
At least monthly	1.25 (0.69-2.30)	0.46
Less than monthly	1.05 (0.60-1.86)	0.86
Have Friends Outside		
Yes	1.0	
No	0.81 (0.50-1.31)	0.39

¹ Higher Difficulty (average score >1); reference category is Lower Difficulty (score 0-1). Nagelkerke $r^2=0.37$
 $p<0.05$ is significant. All significant factors in bold.

Table 4.4 presents two separate regression models for the summed variables of communication difficulty (Nagelkerke $r^2 = 44\%$) and literacy difficulty (Nagelkerke $r^2 = 37\%$). Level of ID was by far the strongest predictor of difficulty in the communication model, where people with severe-profound ID were 25 times more likely than those with mild ID to have a higher level of difficulty, and those with moderate ID were 3.55 times more likely. Next, fair-poor physical health (OR=3.20), institutional residence

(OR=3.03), less than monthly contact with family (OR=2.63) and not having any friends outside your house (OR=1.52) all significantly predicted a higher level of communication difficulty. For the functional literacy model, level of ID was again by far the strongest predictor of difficulty level. People with severe-profound ID were more than 35 times more likely, and people with moderate ID three times more likely, than those with mild ID to report a higher level of literacy difficulty. Having no friends outside your own home (OR=3.30) and being aged 65 years and older (OR=3.18) were also significant predictors of a higher level of literacy difficulty in the model.

Table 4.4. Factors associated with communication (n=567) and literacy difficulty (n= 573)

	Higher Communication Difficulty ¹		Higher Literacy Difficulty ²	
	OR (95% CI)	p-value	OR (95% CI)	p-value
Gender				
Male	1.0		1.0	
Female	0.79 (0.52-1.21)	0.28	0.85 (0.51-1.44)	0.55
Age				
< 65 years	1.0		1.0	
65+ years	0.98 (0.57-1.68)	0.94	3.18 (1.35-7.47)	0.008
Level of ID				
Mild	1.0		1.0	
Moderate	3.55 (2.14-5.89)	<0.001	3.04 (1.79-5.15)	<0.001
Severe-Profound	25.03 (11.81-53.08)	<0.001	35.21 (8.0-154.93)	<0.001
Type of Residence				
Independent/Family	1.0		1.0	
Community Group Home	1.67 (0.79-3.56)	0.18	1.26 (0.58-2.73)	0.55
Institutional	3.03 (1.36-6.73)	0.006	1.30 (0.55-3.08)	0.56
Physical Health				
Very Good-Excellent	1.0		1.0	
Good	1.0 (0.64-1.56)	0.99	1.22 (0.71-2.09)	0.48
Fair-Poor	3.20 (1.62-6.32)	<0.001	2.03 (0.81-5.08)	0.13
Proximity to Family				
Same Neighbourhood	1.0		1.0	
Outside neighbourhood	0.64 (0.32-1.26)	0.20	0.78 (0.37-1.66)	0.52
Contact with Family				
At least weekly	1.0		1.0	
At least monthly	1.46 (0.86-2.50)	0.16	1.77 (0.90-3.45)	0.10
Less than monthly	2.63 (1.58-4.36)	<0.001	1.37 (0.73-2.60)	0.33
Have Friends Outside				
Yes	1.0		1.0	
No	1.52 (0.97-2.37)	0.07	3.30 (1.72-6.35)	<0.001

¹ Higher Communication Difficulty (score 2-4); reference category is Lower Communication Difficulty (score 0-1). Nagelkerke $r^2=0.44$

² Higher Literacy Difficulty (score 3-4); reference category is Lower Literacy Difficulty (score 0-2). Nagelkerke $r^2=0.37$

$p<0.05$ is significant. All significant factors in bold.

4.4 Discussion

This chapter examined specific measures of functioning which in themselves are forms of social participation, and which also impact on other forms of social participation. These included ADLs, IADLs, physical abilities (related to mobility, movement and positioning), communication and literacy. It was found that large majorities of older people with ID (between 70.3% and 97.9%) reported at least some level of difficulty across the five areas of functionality examined. This can be compared to the general

older population in Ireland with data from TILDA, which reported that 88% of the population over 50 had neither ADL nor IADL difficulty – 3% had ADL only, 5% had IADL only, and 5% had both ADL and IADL difficulty (Murphy et al. 2014). Therefore, older people with ID in Ireland experience much higher rates of functional limitation than the general older population. The regression models for each of the five functional areas revealed that level of ID was by far the strongest predictor of a higher level of functional limitation in four of the five areas (ADLs, IADLs, communication and functional literacy), and remained a significant predictor behind physical health in the model for physical abilities. Controlling for other factors in these models, having a severe-profound level of ID strongly predicted higher functional limitation compared to having a mild level of ID, followed by reporting fair-poor physical health, living in an institutional setting (compared to living independently or with family) and being aged 65 years and older. Being a woman predicted higher limitation in two of the models (ADLs and physical abilities), but otherwise gender was not significant. Of the factors of social support added to the models, having less than monthly contact with family predicted greater difficulty with IADLs and communication, while having no friends outside your own home predicted greater difficulty with IADLs and functional literacy.

The analysis supports previous findings from both the older general population (Normand et al. 2011, Koehler et al. 2011, Hébert 1997) and ID population (Maaskant et al. 1996, Janicki and Jacobson 1986) that functional limitations in ADLs and IADLs increase with age. However, it also shows the disparity between the general population and ID population; while 88% of the older general population had no limitation to either ADL or IADL, 97.8% of the older ID population had IADL limitation and 82.8% had ADL limitation. The results also add weight to previous findings linking I/ADL functional decline with increased severity of ID and with institutional residence (McCarron et al. 2011, Lifshitz et al. 2008, Bittles et al. 2002, Patja et al. 2000) and there being a

relationship with gender (McCarron et al. 2011, Koehler et al. 2011). Findings that while older women with ID had greater ADL dysfunction, men had higher rates of IADL dysfunction, are the opposite to findings for the general Irish population (Normand et al. 2011), supporting a need for further research on gender differences in ID. That absence of social support was a significant predictor of IADL difficulty suggests that better family contact and non-resident friends may be important to continued independent living.

The impact of these factors on other elements of social participation will be explored in the chapters which follow, where it will be demonstrated that limitations of social functioning are associated with and may influence many other aspects of social participation. Within the context of this chapter, that will reinforce and support the need to adopt a broad understanding of social participation (which includes these factors to begin with). It is in-keeping with findings by Mansell and Beadle-Brown (2009), who identified the potential for variation in outcomes of community living due to personal characteristics, service design and staff performance. Furthermore, this supports also the consideration of the *Environmental Factors* of the ICF model as influential contextual factors that shape the experience of participation. While the specific measurement of environmental factors is outside the scope of the current study, we know from the literature that they are important factors. They include: products and technology; natural and built environment; supports and relationships; attitudes; and services, systems and policies. It is recommended that future research not only adopts a broad theoretical framework of social participation that includes factors of functioning, but also includes assessment of these environmental factors. The findings encourage a nuanced and personalised approach to the provision of accommodation and supports for older people with intellectual disabilities. Changing locations is not enough to achieve public policy social participation goals; policy makers must also consider the

fuller range of relevant factors found here. Nothing here contradicts prior findings of increased ADL/IADL performance where individuals are given more opportunities to practice these skills and their relationship to being in community, family and independent living situations. However, the majority of people remaining in congregated settings are older and have a greater level of support needs (Health Service Executive 2011). Policy makers and service providers must be cognisant that the same support needs persist regardless of living situation; that those with the most severe disabilities, the most physically unwell, and the oldest of people with intellectual disabilities experience the greatest challenges to their social participation, and as such will continue to need the greatest level of support, whether living in congregated, clustered, dispersed or other residential settings. These points are further discussed in chapter 11 later in the thesis.

Chapter 5. Participation in Human Rights & Citizenship

5.1 Introduction

This chapter focuses on measures of participation related to human rights and citizenship, which are located in the ICF part d9, *Community, Social and Civic Life* (see Appendix 1). It examines a number of aspects of participation in this area, including voting, choice and advocacy for older people with ID in Ireland. The chapter begins by examining the literature relevant to human rights and people with intellectual disability. It then outlines the specific methodological dimensions for the chapter, building on the main Methodology chapter. The results of bivariate and multivariate analyses are then reported; and finally these are discussed in the context of current policy and research.

5.1.1 Background: Human Rights and Intellectual Disability

Human rights are the rights a person has because they are human (Donnelly 2013). They are, following the *Universal Declaration of Human Rights* (UDHR) (United Nations 1948), and the *Vienna Declaration* (United Nations 1993), considered universal, indivisible and interdependent; meaning that there is a functional relationship between rights, and that a life of dignity is not possible without having close to the full range of internationally recognised rights (Donnelly 2013). Quinn et al. (2002) identified the process that took place in the late twentieth and early twenty-first centuries in which perspectives on disability shifted from charity to rights; where people with disabilities came to be viewed as subjects rather than objects; as holders of rights rather than problems. The disability rights debate was about the effective enjoyment of all rights rather than specific ones; and the process was inspired by the values that underpin human rights, namely:

“...the inestimable dignity of each and every human being, the concept of autonomy or self-determination that demands that the person be placed at the centre of all decisions affecting him/her, the inherent equality of all regardless of difference, and the ethic of solidarity that requires society to sustain the freedom of the person with appropriate social supports.” (Quinn et al 2002: 1)

The movement towards the recognition of human rights within the broader disability field culminated in the UN *Convention on the Rights of Persons with Disabilities* (CRPD) (United Nations 2006), which expresses the key tenets of the disability human rights agenda in its general principles, emphasising autonomy, choice, independence, equality and participation for individuals (Figure 5.1). Since the Netherlands ratified the CRPD in January 2016, Ireland is now one of just two EU member states (along with Finland) who have yet to ratify the Convention (European Union Agency for Fundamental Rights 2014b).

Figure 5.1. General principles of the UN Convention on the Rights of People with Disabilities

- a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- b. Non-discrimination;
- c. Full and effective participation and inclusion in society;
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- e. Equality of opportunity;
- f. Accessibility;
- g. Equality between men and women;
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

In the absence of the ratified CRPD, the legislation and policy landscape in Ireland concerning disability is complex. Disability legislation in recent years came under the umbrella of the National Disability Strategy 2004, which included provision for the Education for People with Special Educational Needs (EPSEN) Act 2004, the Disability Act 2005, and the Citizens Information Act 2007 (Inclusion Ireland 2014). The Equality Act 2000-2008 provides protection against discrimination and for measures of affirmative action, while the Health Act 2007 also provides protection against abuse (Edwards et al. 2012). However, legislation in Ireland has fallen short of the comprehensive rights-based

legislation that people with disabilities and advocates previously campaigned for (Inclusion Ireland 2013); and some provision that was legislated for, such as assessment of need, supports for special educational needs, and advocacy, have been difficult to access in practice (National Disability Authority 2011, Inclusion Ireland 2013).

Edwards et al. (2012) identified structural, procedural, attitudinal and accessibility barriers to people with disabilities accessing the criminal justice system. In an Irish context the authors also highlighted an absence of data regarding people with disabilities and crime and their experiences accessing the criminal justice system; and noted a complex and conflicting range of policy and legislation that shape the experiences of people with disabilities – including extra ‘protection’ in criminal law, special measures in giving evidence as a ‘vulnerable witness’, anti-discrimination legislation and affirmative action measures, legislation relating to capacity to make decisions, and legislation safeguarding against abuse; a complex situation that results in disjunction for people with disabilities in relation to the criminal justice system (Edwards et al. 2012).

Choice and autonomy are key tenets of human rights, articulated in Article 12 of the CRPD, which for people with ID and other disabilities have been compromised by outdated legal capacity systems in the majority of European countries including Ireland (Commissioner for Human Rights 2012). However, some have also noted that the provisions in the CRPD on legal capacity and supported decision-making are sparse and leave broad scope for state interpretation with the possibility of stricter regulation (Lord et al. 2010). Others have argued that human rights instruments such as the CRPD and UDHR presume capacities of reason and conscience underpin autonomous decision-making, which is removed from the reality for some people with intellectual disability; and that this pursues independence for people when in fact every person is relational and interdependent (Fyson and Cromby 2013).

The Irish Law Reform Commission made a series of recommendations on legal capacity, including: an emphasis on capacity rather than a lack of capacity, with the assumption in the first place of the capacity of adults to make decisions about their lives; an enabling rather than restrictive approach; an appropriate balance between autonomy and protection by promoting the interests of vulnerable adults; and a functional approach to legal capacity that considers a person's capacity in relation to a particular decision at the time it is being made (Law Reform Commission 2005). Bach and Kerzner (2010) supported the distinction drawn between legal capacity and mental capacity in the CRPD. They expressed the principle of equal recognition of legal capacity as:

“People enjoy and exercise their right to legal capacity differently depending on a person's unique characteristics. A person's autonomy and legal capacity is maximized equally to the extent that they access the supports and accommodations they need to exercise their legal capacity; and to the extent that supports and accommodations adapt to each person's evolving decision-making abilities and capabilities.” (2010: 159)

Within this principle, the authors identified 'decision-making capability' as the capability people have to make decisions about their own life through a combination of their 'decision-making ability' and the 'decision-making supports' and 'decision-making accommodations' made available to them. A minimum threshold for decision-making ability was proposed:

“To act in a way that at least one other person who has personal knowledge of an individual can reasonably ascribe to that individual's actions: personal intention or will; memory; coherence of the person's identity through time; and communicative abilities to that effect.” (Bach and Kerzner 2010: 159)

Three decision-making statuses were proposed as an outcome of the process, under the guidance of the CRPD: (1) Legally independent decision-making status (i.e. can

understand and appreciate); (2) Supported decision-making status (i.e. can express and represent themselves to a third party); and (3) Facilitated decision-making status (i.e. for those who do not meet the previous two standards). Overall, the aim is to develop legislation that can maintain a balance between the right to autonomy while at the same time safeguarding those who may be vulnerable to abuse and neglect (Bach and Kerzner 2010). Some argue that in practice there is a tension in this area between 'permissive rights' (which highlight choice) and 'protective rights' (which safeguard) for people with intellectual disabilities (Fyson and Cromby 2013). Alternatively, the emphasis within the CRPD on independence and autonomy of people with disabilities should not be interpreted as undermining care and rehabilitation services, which are also protected (Hendricks 2007). Regardless, legislative reform on the Assisted Decision-Making (Capacity) Bill 2013 in Ireland was finally enacted and signed into law in December 2015; a welcome change that updates the Lunacy Regulation (Ireland) Act 1871, enshrines in law the ability of people with ID to make decisions for themselves, and removes a significant barrier to the ratification of the CRPD (Inclusion Ireland 2015b).

Ratification of the CRPD is seen as a legislative panacea by some, but it remains the case that violation of rights under the CRPD provides no legal mechanisms for redress, which depend on the system and provisions within each country (Fyson and Cromby 2013). Others have been critical of the process behind the CRPD, which has left some gaps. Kayess and French (2008) note that the CRPD was a high watermark for disability rights and human rights law and offered potential to transform the lives of people with disabilities, but was compromised by an uncritical and populist adoption of the social model of disability in which impairment has no underlying reality; whereas the social model has become heavily nuanced and impairment has been re-established as a fundamental aspect of the lived experience of disability; as such the transformative potential of the CRPD will rely on interpretation and implementation that embraces a more sophisticated understanding of the place of impairment in disability. Lord et al. (2010) also

identified an unresolved tension between the medical model and social construction of disability which, coming from a negotiated process that resulted in a compromised text, represented a missed opportunity to address some salient health issues for people with disabilities such as bioethics and compulsory treatment.

5.1.2 Self-Determination and Choice

Self-determination and choice is influenced by a range of different factors. Type of disability is a significant influence, where people with less cognitive capacity tend to have reduced levels of self-determination (Shogren et al. 2007, Wehmeyer et al. 2012, Wehmeyer et al. 2013, McCarron et al. 2011). Family factors have been associated with level of self-determination (Zhang 2005, Carter et al. 2013); as have social skills (Nota et al. 2007) and levels of social capital (Walker et al. 2011); while opportunities for self-determination (Shogren et al. 2007, Branding et al. 2009), community living (Emerson and Hatton 1996, Stancliffe 2001, Kozma et al. 2009, Walsh et al. 2010) and community support (Carter et al. 2009, Dattilo and Rusch 2012) may also be influential. Using an ecological approach consistent with the ICF's biopsychosocial conceptualisation, Shogren (2013) concluded that a complex range of factors across multiple levels impact upon the development and expression of an individual's self-determination; these include factors at the microsystem (individual factors such as age, disability, gender, and social networks) , the mesosystem (including services and community factors), and the macrosystem (including policy and cultural norms). Studies have also shown, however, that people with intellectual disabilities tend to be included more in choices about the more mundane everyday aspects of life (such as what to eat, what to watch on TV) while being excluded from the bigger decisions (such as where to live and who to live with) (Emerson and Hatton 1996, Fyson et al. 2007, Antaki et al. 2009, McCarron et al. 2011).

5.1.3 Advocacy

Access to advocacy is increasingly important as models of personalised and individualised supports are developed (Tatlow-Golden et al. 2014). While they may not name it, families often engage in advocacy activities in supporting and fighting for their family members with ID (Chadwick et al. 2013). People with disabilities value independence in advocacy (MacCann 2009); and advocacy has been identified as an essential support for people with intellectual disability in planning for their lives (Health Service Executive 2011) and critical for people with disabilities enjoying protection and fulfilment of their human rights (Inclusion Ireland 2015c).

There are various different models of advocacy, although they tend to operate along a continuum rather than being very separate (Tatlow-Golden et al. 2014). Four basic principles of advocacy are empowerment, autonomy, inclusion, and citizenship; while the main forms of advocacy include self-advocacy (where people are empowered to speak for themselves), peer advocacy (where someone with similar experience advocates for another), family advocacy (by a family member), group advocacy (where individuals work together towards a shared goal), citizen advocacy (by volunteers), and professional advocacy (by a paid advocate) (Citizens Information Board 2010). However, advocacy services remain relatively underdeveloped (Tatlow-Golden et al. 2014), and in Ireland a lack of service coordination alongside funding cutbacks for voluntary providers has left the advocacy sector under-resourced and fragmented (Inclusion Ireland 2015c). McCarron et al. (2011) reported that almost three-quarters of older people with intellectual disabilities in Ireland did not have an independent advocate; while residential location in an institution was associated with lower rates of advocacy and living in independent/family homes was associated with higher rates.

5.1.4 Political Participation

The right to political participation is firmly established in international law and human rights instruments, including primary and secondary legislation of the EU (European Union Agency for Fundamental Rights 2014a). Article 29 of the CRPD requires that states will ensure the same political rights and opportunities as all other citizens (United Nations 2006). Irish law on voting is based primarily on the Electoral Act 1992, and the Electoral (Amendment) Act 1996. The Electoral Act is premised on the assumption that a person with a mental disability lacks capacity to perform as a member of the Irish parliament; it also gives certain powers to Presiding Officers which may impact on the right of certain persons to vote; this law will be amended prior to ratification of the UN CRPD (Winters 2015).

McCarron et al. (2011) reported that around seven out of ten older people with intellectual disability did not vote in the previous general election; voting rates decreased with increasing age and severity of ID, and those living in community locations, especially those in independent/family residences, were much more likely to vote than people living in institutional settings. These rates compare unfavourably with participation amongst the general older population, which was reported at around 80% (Barrett et al. 2011); and the age trend for people with intellectual disabilities appears the reverse of the general population, where higher voting rates and other political participation are found in older age groups (European Union Agency for Fundamental Rights 2014a). When looking at people with disabilities in general (all types of disability), the rates reported across European countries are actually slightly higher than the general population, which is explained by the higher proportion of older people who have a disability and the fact that older people are more likely to vote; and this trend also applies to membership of political parties and to being politically active in general (e.g. attending a meeting or demonstration) (European Union Agency for Fundamental Rights 2014a). Rates of voting for people with intellectual disabilities in the UK again contrast with the general population

and with other people with disabilities. Just 16.5% of people with intellectual disabilities voted compared to 60.8% for the general population, from 66.1% of people with intellectual disabilities who were registered to vote compared with 95% of the general population; while adults with ID living in supported accommodation were more likely than those in private accommodation to be registered to vote, but less likely to actually use their vote; meaning that overall a larger proportion of people in private households (19.7%) than those in supported accommodation (12.8%) used their vote (Keeley et al. 2008).

Within the overall context of social participation this chapter aims to examine in greater detail the experience of participation related to human rights and citizenship for older people with intellectual disabilities in Ireland, and to explore factors associated with varying degrees of participation amongst this population.

5.2 Methods

Details of the methods used in the overall study were previously outlined in chapter 3. This section provides additional detail on the measures used that relate specifically to human rights and citizenship, and the procedures used to examine these aspects of participation.

5.2.1 Measures

The measures used in this chapter are outlined in Figure 5.2 below, which also maps each measure to a specific part of the ICF. Participants responded yes or no to whether or not they voted in any recent election and whether or not they had an independent advocate. Responses to the choice questions indicated that each choice was made by the respondent (self-choice or supported choice) or by someone else (relative, friend, or support staff).

Analyses also included a range of demographic and personal characteristics: gender; age; level of ID (mild, moderate, or severe-profound); type of residence (independent/family,

community group home, or institutional/congregated); self/proxy-rated physical and mental health (very good-excellent, good, or fair-poor); difficulty with ADLs, IADLs, communication and literacy (each categorised as lower/higher level of difficulty); family proximity (living in same neighbourhood, or outside neighbourhood); family contact (frequency of face-to-face or phone contact categorised as: weekly; monthly; less than monthly); and having non-resident friends (yes/no).

Figure 5.2. Measures used: human rights & citizenship

Question	ICF Reference
Have you voted in any recent election?	d950
In general who chooses:	
<i>The food you eat?</i>	d940/d5/d6
<i>What food is cooked in your home?</i>	d940/d5/d6
<i>The clothes you wear?</i>	d940/d5/d6
<i>Who you spend your free time with?</i>	d940/d5/d9
<i>Where you go in your free time?</i>	d940/d5/d9
<i>How you spend your money?</i>	d940/d870
<i>Where you keep you money?</i>	d940/d870
<i>What time you go to bed?</i>	d940/
<i>What job you have?</i>	d940/d840-589
<i>Where you live?</i>	d940/d610
<i>Who you live with?</i>	d940/d610/d7
<i>What support you may receive?</i>	d940/e3/e5
<i>What TV shows you watch?</i>	d940/d920
<i>How you decorate your room?</i>	d940/d6
Do you have an independent advocate?	d940/e3

5.2.2 Analysis

A new summary variable called *level of choice* was derived from the 14 choice questions. Each item was recoded and scored according to level of choice exercised by the individual (self-choice=2; supported choice=1; someone else chooses or not applicable = 0). Scores were summed, averaged and categorised as: low choice (average score <1), medium choice (average score 1-1.5), and high choice (average score >1.5). Bivariate

analyses explored relationships between demographic and personal characteristics and three variables: *voted*; *level of choice*; and *independent advocate*. Level of choice was then recoded into a binary response outcome categorised as: lower choice (<1); and higher choice (≥ 1). A logistic regression analysis was performed to explore factors associated with this binary outcome variable; independent variables added to the model included those demographic and personal variables outlined above.

5.3 Results

Rates of choice, voting and advocacy are outlined in Table 5.1 below, along with bivariate associations with a range of demographic, personal and social factors. Level of choice was significantly associated with all measures apart from gender. Level of choice was significantly higher for respondents aged less than 65 years, those with less severe ID, with better physical and mental health, with less ADL and IADL limitations, and with less difficulty with communication and literacy. With regard to residence, people living independent/family homes had the highest levels of choice, while those in community group homes had more choice than people in institutions. Factors of social support were also significantly associated with level of choice; whereby people with more frequent family contact, those living closer to family, and those with friends outside their own home exercised more choice than others. With regard to voting, almost three-quarters of all respondents reported not voting in a recent election. As with choice, rates of voting were higher for respondents with better social support through family contact, family proximity and non-resident friends. It was also lowest for those with greater challenges to personal ability including ADL and IADL limitations, difficulties with communication and literacy, worse physical and mental health, and more severe ID levels. People living in institutions had by far the lowest rates of voting in comparison to community-based settings, while those in independent/family settings voted more than those in group homes; and respondents aged under 65 years voted more than the over-65s.

A somewhat more complicated picture emerged regarding having an independent advocate. More frequent family contact and having non-residents friends were associated with having an independent advocate; however, people living closer to family had lower rates of advocacy. People with less IADL limitations had higher rates of advocacy, as did people with less ADL limitations, although the latter was not significant. Having less difficulty with both communication and literacy was also associated with higher rates of advocacy, but again these differences were not significant in the bivariate analyses.

Results of the binary logistic regression to explore factors associated with the level of choice exercised by individuals are presented in Table 5.2. The model explained 57% (Nagelkerke r^2) of the variance in level of choice. Type of residence was the strongest predictor of level of choice when all other variables in the model were controlled for; people living in institutions were over eight times more likely than people in independent/family homes to exercise a lower level of choice (OR=8.39), while those living in group homes were almost seven times more likely to have less choice (OR=6.75). After residence, people with a severe-profound level of ID were almost four times more likely to exercise less choice than people with mild ID (OR=3.97). Factors of social support were significant in the model; people with less than monthly contact (OR=3.11) and those with monthly contact (OR=2.14) had less choice than people with weekly family contact; while people who had no friends outside their home had lower levels of choice (OR=2.78). Finally, people with greater IADL limitations exercised less choice than people with fewer limitations (OR=2.7).

Table 5.1. Rates and bivariate associations for human rights and citizenship

	Level of Choice			Voted		Independent Advocate	
	Low	Medium	High	Yes	No	Yes	No
Gender	(n=647, p=0.13)			(n=669, p=0.60)		(n=663, p=0.008)	
Male	53.8	34.6	11.5	28.5	71.5	17.3	82.7
Female	51.5	31.3	17.2	26.7	73.3	25.8	74.2
Age	(n=647, p=0.007)			(n=669, p=0.03)		(n=663, p=0.91)	
< 65 years	49.8	33.7	16.5	29.4	70.6	22.1	77.9
65+ years	63.2	29.3	7.5	20.1	79.9	21.7	78.3
Level of ID	(n=596, p<0.001)			(n=617, p<0.001)		(n=612, p=0.05)	
Mild	20.7	42.1	37.1	56.5	43.5	19.3	80.7
Moderate	48.5	41.5	9.9	26.4	73.6	25.4	74.6
Severe-Profound	86.4	13.0	0.5	3.8	96.2	16.4	83.6
Type of Residence	(n=647, p<0.001)			(n=669, p<0.001)		(n=663, p=0.17)	
Independent/Family	13.8	42.2	44.0	57.0	43.0	16.0	84.0
Community Group Home	48.8	38.4	12.8	33.6	66.4	24.7	75.3
Institutional	73.2	22.6	4.3	9.3	90.7	21.4	78.6
Physical Health	(n=640, p<0.001)			(n=661, p=0.001)		(n=656, p=0.54)	
Very Good-Excellent	45.1	37.3	17.6	33.2	66.8	23.9	76.1
Good	55.5	29.4	15.1	25.6	74.4	21.2	78.8
Fair-Poor	70.0	26.0	4.0	14.4	85.6	19.0	81.0
Mental Health	(n=633, p=0.002)			(n=652, p<0.001)		(n=650, p=0.32)	
Very Good-Excellent	44.4	33.8	21.7	35.7	64.3	22.0	78.0
Good	52.3	33.6	14.1	28.1	71.9	24.6	75.4
Fair-Poor	61.0	31.1	7.9	17.2	82.8	18.5	81.5
Communication Difficulty	(n=613, p<0.001)			(n=633, p<0.001)		(n=626, p=0.05)	
Lower	26.6	42.5	30.9	49.1	50.9	26.1	73.9
Higher	70.1	26.6	3.4	12.8	87.2	19.6	80.4
Literacy Difficulty	(n=621, p<0.001)			(n=638, p<0.001)		(n=636, p=0.06)	
Lower	16.7	40.7	42.6	59.3	40.7	29.2	70.8
Higher	59.8	31.2	9.0	20.4	79.6	20.9	79.1
ADLs Limitation	(n=600, p<0.001)			(n=620, p<0.001)		(n=616, p=0.54)	
Lower	43.3	38.6	18.1	34.4	65.6	23.3	76.7
Higher	85.4	14.6	0.0	4.3	95.7	21.0	79.0
IADLs Limitation	(n=617, p<0.001)			(n=639, p<0.001)		(n=635, p=0.04)	
Lower	22.1	47.1	30.8	48.8	51.2	26.1	73.9
Higher	76.8	21.4	1.8	10.2	89.8	19.3	80.7
Proximity to Family	(n=623, p<0.001)			(n=642, p<0.001)		(n=636, p=0.02)	
Same Neighbourhood	34.3	36.6	29.1	43.7	56.3	14.2	85.8
Outside Neighbourhood	57.1	31.9	11.0	23.1	76.9	23.9	76.1
Contact with Family	(n=619, p<0.001)			(n=640, p<0.001)		(n=632, p=0.04)	
At least weekly	33.3	41.8	24.9	39.5	60.5	26.9	73.1
At least monthly	54.5	35.9	9.7	28.5	71.5	20.0	80.0
Less than monthly	71.6	21.3	7.1	12.4	87.6	17.6	82.4
Friends Outside	(n=645, p<0.001)			(n=663, p<0.001)		(n=657, p=0.004)	
Yes	36.1	39.9	24.0	39.4	60.6	26.2	73.8
No	73.8	23.4	2.8	12.2	87.8	16.9	83.1
Total	52.6	32.8	14.7	27.5	72.5	22.0	78.0

Table 5.2. Factors associated with level of choice (n=456)

	Lower Level of Choice ¹	
	Odds Ratio (95% CI)	p-value
Gender		
Male	1.0	
Female	0.75 (0.45-1.27)	0.29
Age		
< 65 years	1.0	
65+ years	0.74 (0.38-1.42)	0.36
Level of ID		
Mild	1.0	
Moderate	1.87 (0.93-3.76)	0.08
Severe-Profound	3.97 (1.64-9.64)	0.002
Type of Residence		
Independent/Family	1.0	
Community Group Home	6.75 (1.81-25.11)	0.004
Institutional	8.39 (2.19-32.19)	0.002
Physical Health		
Very Good-Excellent	1.0	
Good	0.97 (0.54-1.75)	0.92
Fair-Poor	1.28 (0.57-2.87)	0.54
Mental Health		
Very Good-Excellent	1.0	
Good	0.81 (0.43-1.59)	0.54
Fair-Poor	0.82 (0.40-1.67)	0.58
Communication Difficulty		
Lower	1.0	
Higher	1.33 (0.72-2.46)	0.36
Literacy Difficulty		
Lower	1.0	
Higher	1.97 (0.84-4.63)	0.12
ADLs Limitation		
Lower	1.0	
Higher	1.92 (0.93-3.93)	0.08
IADLs Limitation		
Lower	1.0	
Higher	2.70 (1.45-5.04)	0.002
Contact with Family		
At least weekly	1.0	
At least monthly	2.14 (1.11-4.12)	0.02
Less than monthly	3.11 (1.63-5.91)	0.001
Proximity to Family		
Same Neighbourhood	1.0	
Outside Neighbourhood	0.81 (0.34-1.95)	0.64
Friends Outside Home		
Yes	1.0	
No	2.78 (1.63-4.74)	<0.001

¹ Reference category: Higher Level of Choice.

Nagelkerke $r^2=0.57$

$p<0.05$ is significant. All significant factors in bold.

5.4 Discussion

Under the heading of human rights and citizenship, this chapter has examined choice, voting and advocacy for older people with ID in Ireland. These factors of participation relate to sections d940 (human rights) and d950 (political life and citizenship) of the ICF theoretical framework (see Appendix 1). Findings here regarding choice support previous findings in the literature that a wide range of factors are associated with self-determination for people with intellectual disabilities (Shogren 2013). This included factors related to personal characteristics and ability, demographic factors including residence, and factors of social support, all of which (apart from gender) were significant in the bivariate analyses. The regression analysis for level of choice-making maintained this multi-factorial influence behind rates of choice for this population, with again elements of demographic (residence), personal (level of ID, IADLs, ADLs) and social support (family contact, friends outside one's home) all predicting choice. The strongest predictor, in a model which explained over half of the variance in level of choice, was type of residential setting. That residence in an independent/family setting was far more likely to result in higher choice, when all other factors were controlled for, supports the idea that opportunity to make choice in such settings increases the probability of making choice. Provided that the required supports are available to address needs related to personal ability, policies which support people with intellectual disability to live independently and within their family residences, allied to social supports outside the home, should be pursued to provide the best environment for self-determination for this population.

Low rates of independent advocacy found in this study perhaps reflect the under-developed, under-resourced and fragmented state of advocacy services in Ireland identified in the literature (Tatlow-Golden et al. 2014, Inclusion Ireland 2015c). Rates here were even lower than reported by McCarron et al. (2011) and found the reverse with regard to residential location – i.e. living in independent/family homes was associated with

lower rates of advocacy (although differences were not statistically significant). Better social support in the form of frequent family contact and having non-resident friends, was significantly associated with higher rates of advocacy; however proximity to family was actually associated with lower rates. This may be partially explained by people living independently or in family homes have less need for an independent advocate (due to higher personal ability), or that they did not view family as fulfilling such a role even when they did. This latter effect was identified previously, where advocacy may not be named or recognised in family settings even where it is taking place (Chadwick et al. 2013). This highlights a need for greater awareness of the role of advocacy amongst individuals with intellectual disability and their family members and supporters; while the low rates overall support calls for greater coherence and funding (Inclusion Ireland 2015c) for a sector that provides what has been described in policy as an 'essential' support for greater independence for people with intellectual disability (Health Service Executive 2011).

Finally, findings here regarding voting confirm previous findings of very low rates of political participation for this population in Ireland, especially when compared to the large majority of the general older population who vote. Crucially, findings also identify an inconsistency with age-related trends internationally amongst the general population; this sees people with intellectual disability lose the boost in voting participation related to ageing, which both the general older population and older people with other types of disabilities benefit from. The analyses here suggest once again that a range of different variables related to personal ability, demographic and social factors may combine to exclude this population. Research from the UK suggests that people with intellectual disabilities need more support in registering to vote, but also support in using their vote once registered. More research to better understand this phenomenon is needed so that older people with intellectual disability can be supported to participate more as voting citizens with a political voice. These points are explored further in the overall discussion in chapter 11 of the thesis.

Chapter 6. Participation in Education, Training & Occupation

6.1 Introduction

This chapter examines a number of aspects of participation in education, training and occupation for older people with ID in Ireland. Within the theoretical framework, these measures relate to the ICF sections *Learning and applying knowledge* (d1) and *Major life areas* (education, work and employment; economic life) (d8) (see Appendix 1). More specific ICF references are detailed in Figure 6.1 below.

6.1.1 Background

Education for people with intellectual disability and other special educational needs (SEN) is guided internationally by the provisions of Article 24 of the UN CRPD, which asserts the right to inclusive education at all levels (United Nations 2006). While Ireland has yet to sign the Convention, provision for SEN in Ireland is guided by the Education for Persons with Special Educational Needs (EPSEN) Act 2004, providing a right to inclusive education and a process of individualised provision (Government of Ireland 2004). Estimates of SEN internationally vary widely due to different interpretations and definitions, from less than 1% in some countries to more than 20% in others; while recent figures for Ireland show that the proportion of all children who attended special education (i.e. a special school or special class) was under 5%, but prevalence of SEN (including all special need categories) may be around 25% (Banks and McCoy 2011) or as high as 27.8% in total with 4.8% accounting for general learning disability, which may have included some children with mild ID who had not been diagnosed (Cosgrove et al. 2014). This compares with rates of 2.7% of pupils with intensive SEN support needs and 18.2% with less intensive support needs in the UK (Ofsted 2010). Analysis of the National Disability Survey in Ireland found that 72% of children with disabilities attended mainstream education, 13% went to special classes within mainstream school, and 15% attend special schools; while children with intellectual disabilities are

far more likely to be placed in special settings than children with learning difficulties such as ADHD or dyslexia (Banks et al. 2015).

Historically, people with intellectual disability have not engaged in formal education; McCarron et al. (2011) found that nearly two-thirds of older people with intellectual disability in Ireland had not completed a primary level of education; while 32% had no education at all. In terms of contemporary educational outcomes, children with intellectual disability and other SEN are at far greater risk of poorer academic outcomes (Humphrey et al. 2013). They have considerably lower test scores in mathematics and reading than children without SEN (Cosgrove et al. 2014). Rose et al. (2012) found that pupils with special educational need in Irish schools had persistent difficulties in academic attainment. A review in the UK found that no one particular model of provision (inclusive or segregated provision) was better for achievement outcomes for pupils with SEN (Ofsted 2010).

Students with special educational needs tend to have more social difficulties than other students. A study of social participation for students with SEN in Belgium, Norway and the Netherlands found that, across different education systems, students with SEN experienced more social difficulties compared to other students; and that this was as much the case in the more inclusive Norwegian system as in the Dutch and Belgian systems (Bossaert et al. 2015). Previous studies found that students with SEN had fewer social interactions with their peers, were less popular and were neglected or rejected more often (Bossaert et al. 2013); students with SEN had fewer friends, had lower levels of social self-concept and perceptions of self in relation to their own social inclusion compared to others (Pijl et al. 2010, Schwab et al. 2015), were less independent and were at greater risk of being bullied (Cosgrove et al. 2014).

McCausland et al. (2014) found that four out of five older people with intellectual disability had difficulty with reading, writing, numeracy and understanding money.

These disadvantages not only exclude people with intellectual disability from taking up valued social roles within society, but also mean they are lacking the fundamental skills required to negotiate community and society (Morgan et al. 2011, Forts and Luckasson 2011, McCausland et al. 2014). Furthermore, a lack of literacy and numeracy skills, in addition to having little knowledge of one's local area, is an acknowledged barrier to social inclusion for people with intellectual disability (Abbott and McConkey 2006).

Being in employment has been associated with a range of benefits for people with intellectual disabilities as well as the general population; including perceived greater purpose in life and social status (Jahoda et al. 2009), better physical and mental health (Butterworth et al. 2011, McGlinchey et al. 2013), and better subjective quality of life (McCrory et al. 2014). Meanwhile, a positive yet relatively weak relationship between level of pay and job and pay satisfaction suggest that other factors of work are highly valued in addition to wages (Judge et al. 2010). Education is recognised as a key influence on later life including prospects of employment, earnings and exposure to poverty; and the long term impact of poor performance and attainment in education for students with special needs is potentially a dependence on social transfers and increased risk of poverty (Watson et al. 2015). People with disability suffer a double disadvantage, whereby their long-term prospects are impacted by their disability status and also by poor educational attainment (National Disability Authority 2012). People with intellectual disabilities face a range of barriers to employment, including internal barriers such as low self-confidence, poor literacy and numeracy skills (Winn and Hay 2009), and difficulties understanding rules of the workplace (Jahoda et al. 2009); while also facing external barriers of stigmatisation and discrimination (Winn and Hay 2009, McGlinchey et al. 2013). Watson and Nolan (2011) identified flexible working arrangements, modified job tasks and a wage subsidy as factors that could facilitate greater inclusion in employment for people with disabilities; while many aspects of

accessibility also present potential barriers, such as transport and parking, accessible workplaces and workstations, toilets, and communication (Watson et al. 2015).

Analysis of the labour market in Ireland since the late 1990s shows that the rate of unemployment fell from 15.7% in 1998 to around 4% in 2000, and low rates were sustained until 2008 when the rate tripled from 5% in the first quarter of 2008 and peaked at 15% in the third quarter of 2011. In that time, the probability of becoming unemployed varied considerably according to educational attainment; and those with the lowest level of education were at the greatest risk, while those with third-level education were at the lowest risk (Conefrey et al. 2015). Within the same period, rates of long-term unemployment rose from 1.5% in 2006 to 9.2% in 2012 (Kelly et al. 2015). Considering their low educational attainment, these macro level trends in open labour market unemployment might be expected to impact most of all on people with intellectual disabilities; however, specific data is not available as it is not routinely collected by disability status (Kelly et al. 2015).

Employment rates for the general older population in Ireland (aged 50+) are 36%; for the 50-64 year-old group the employment rate is 54%, in which 62% of men and 46% of women are employed; while rates drop off considerably after the age of 65, to 16% for 65-74 year-olds and 11% for those aged 75 and older (Mosca and Barrett 2011). For older people of working age (50-64 years), this compares to similar rates of 62% for men and 43% for women across other European countries (Barnay and Debrand 2006). Rates of employment for older people with intellectual disability are considerably lower, reported as just 6.6% for people with ID aged 40-64 years in Ireland (McGlinchey et al. 2013). Elsewhere, employment rates for adults with ID (aged 21-64 years) in the USA were reported at 26.1%, which were significantly lower than rates for all people with disabilities (41.1%) and people with no disability (79.1%) (Brault 2012). Bouck (2012) found that secondary students with moderate-severe intellectual disability

had low rates of post-school outcomes including employment, post-secondary education, and independent living. There is little evidence of differences in employment outcomes based on type of residence (Walsh et al. 2010, Tatlow-Golden et al. 2014). However, McGlinchey et al. (2013) found that community residence was associated with increased employment for older people with intellectual disabilities; and increased rates of employment was also associated with educational attainment, level of intellectual disability, self-reported health and depression in this population.

The treatment of people with intellectual disability within the labour market also raises questions about employment and unemployment in comparison to people who do not have a disability, and the motivation to create employment opportunities for the former. For example, people who are unemployed in Ireland typically receive either 'Jobseekers Allowance' (JA) or 'Jobseeker's Benefit' (JB); conditions of which include that the recipient must be able to work and be actively seeking work (and be able to prove this). Receipt of these payments is also conditional on engagement with 'activation' policies which are "*engagement with jobseekers to support them back into employment*", and include education and training schemes, employment support schemes, internships and other measures (Citizens Information Board 2015). On the other hand, people with disabilities not in work typically receive 'Disability Allowance', for which they must be 'substantially restricted' in being able to undertake work; and for which, unlike JA/JB payments, there is no requirement to engage in activation measures; those in receipt are able to do 'rehabilitative work' without their payments being affected and are also eligible for the JobBridge internship programme, although not required to engage (Department of Social Protection 2016). Thus, these different approaches suggest an expectation that adults with intellectual disabilities will be passive recipients of welfare supports rather than actively engaged in education, training or work.

A parallel may also be seen with regard to differences in approaches to training for people with and without disability. Non-disabled people in receipt of job-seeker payments are obliged to engage with the *Intreo* service within the Department of Social Protection (DSP). This provides an active focus on attaining or returning to employment, with personalised supports and routes to further vocational education and training, engaging with *Solas*, the national body with responsibility for further education and training. By contrast, people with intellectual disabilities engage in a wide variety of activities that may or may not have an educational or vocational focus to them. The Working Group for *New Directions Review of HSE Day Services* revealed a wide variety of provision for over 25,000 people with disabilities (13,720 of whom had an intellectual disability) by 81 different organisations (90% of which were voluntary organisations) in 817 locations nationwide (Health Service Executive 2012). A census of existing provision identified 13 different types of service, ranging from day care programmes to supported employment to voluntary work (see Appendix 4), which were poorly defined and lacking in clarity and consistency (Health Service Executive 2012). The proposed new approach identified a suite of 12 personalised supports from which providers must deliver their services (see Appendix 4) (Tatlow-Golden et al. 2014); some of which are vocationally-orientated, others which are not; but with an overarching focus on moving away from group programmes provided in segregated settings, to individualised approaches in local community settings (Health Service Executive 2012). However, a recent study suggested that little has changed in practice to date other than a re-branding of services (Fleming et al. 2016). Whilst issues of employment and training for people with ID are complex and require deeper investigation beyond the scope of the current study, it is important to highlight these different approaches and treatment for people with ID compared to the general population.

Overall, the available literature highlights poorer levels of educational and occupational participation for people with intellectual disabilities, in comparison to both the general population and other people with disabilities. However, little is known about the specific educational, training and employment outcomes for older people with intellectual disability in Ireland, within the broader context of social participation, and the factors influencing these outcomes. This chapter aims to add to that knowledge by examining specific aspects of education, training and occupation and exploring factors influencing these experiences for individuals.

6.2. Methods

Details of the overall study methods were outlined in the main Methodology chapter. This section provides additional detail on the measures used that relate specifically to education, training and occupation, and the procedures used to examine these aspects of participation.

6.2.1 Measures

The measures used are outlined in Figure 6.1 below, which also maps each measure to a specific part of the ICF theoretical framework. Highest level of education completed was taken from the wave 1 IDS-TILDA dataset, which recorded: some primary (not complete); primary or equivalent; intermediate/junior/group certificate or equivalent; leaving certificate or equivalent; diploma/certificate; primary degree; postgraduate/ higher degree; other; none; don't know. Respondents answered yes or no to attending a training course, to having ever done paid work and to doing voluntary work. For current occupational situation, respondents could select multiple responses from the options given.

Figure 6.1. Measures used – education, training & occupation

Question	ICF Reference
What is the highest level of education you have completed?	d810-839/ d130-159
Are you currently attending or did you participate in any courses or any other education and training in the last year? (Yes/No)	d810-839/ d130-159
Have you ever done paid work? (Yes/No)	d850
Which of these would you say describes your current situation? <i>Employed; self-employed; in a sheltered workshop; attending a day service; unemployed or looking for work; retired; unable to work due to being permanently sick or disabled; looking after home or family; in education or training; other</i>	d840-859/ d810-839
Do you do any voluntary work? (Yes/No)	d855

The bivariate and regression analyses included measures of: gender; age; level of ID (mild, moderate, or severe-profound); type of residence (independent/family, community group home, or institutional/congregated); self/proxy-rated physical and mental health (very good-excellent, good, or fair-poor); difficulty with ADLs, IADLs, communication and literacy (each categorised as lower/higher level of difficulty); family proximity (living in same neighbourhood, or outside neighbourhood); family contact (frequency of face-to-face or phone contact categorised as: weekly; monthly; less than monthly); and having non-resident friends (yes/no).

6.2.2. Analysis

Bivariate analyses explored relationships between the above range of demographic, personal and social factors and: education level; ever done paid work; occupational situation; doing a training course; and voluntary work. Educational Level (attainment) was regrouped into three categories: none (no education); some primary (incomplete) (which included those who attended a special school); and primary or more (complete primary or higher). For Occupational Situation, four categories were created: not occupied (unemployed or looking for work; unable to work due to being permanently sick or disabled; and retired); home based (respondents who received some form of

day programme within their home, recoded from 'other'); occupied (sheltered workshop; day service; in education or training; unpaid work); and employed (employed; self-employed).

Two regression models explored multivariate relationships. First, the Occupational Situation variable was collapsed into a binary response and called *Type of Occupational Status*: active (occupied, employed); and non-active (not occupied, home based). A bivariate logistic regression was performed to explore factors associated with Type of Occupational Status. Secondly, a new variable was derived called *Education/Occupation Activity*. This aimed to measure how active respondents currently were in activity related to education, training and occupation; it was coded active and non-active. Within this, three binary variables were scored one or zero and summed to give a score for Education/Occupation Activity: Type of Occupational Status (active=1, non-active=0); Voluntary Work (yes=1, no=0); and Training Course (attending currently or in the past year) (yes=1, no=0). Summed scores were grouped as low (0), medium (1) and high (2-3) to represent varying levels of Education/Occupation Activity. A multinomial regression was performed to explore the relationship of the independent variables with this outcome variable. Testing for multicollinearity among the interdependent variables was performed prior to regression analyses and no such concerns emerged.

6.3. Results

The rates of educational and occupational status and activity were produced, along with analysis of bivariate relationships with a range of factors. Table 6.1 shows that a third of all respondents had no education at all; while just over a quarter had completed primary level or higher. Level of education was significantly associated with level of ID, residence type, difficulty with communication and literacy, ADL and IADL limitation, family contact and having non-resident friends. Seven out of ten respondents reported

that they had never done paid work. Whether or not respondents ever did paid work was significantly associated with all variables apart from gender, age and physical and mental health; and increased rates were associated with less severe levels of ID, fewer challenges to ability and functioning, and better social support.

Occupational situation was significantly associated with all variables in the bivariate analyses apart from gender. While just 6.6% (n=45) of all respondents were employed, a further 72.5 % (n=495) were occupied (e.g. attending a day programme); but more than one in five respondents were either not occupied at all (14.1%, n=96) or in receipt of day activation within their home (6.9%, n=47). Younger respondents had lower rates of the more inactive statuses (i.e. 'not occupied' and 'home-based') and higher rates of the more active statuses (i.e. 'occupied' and 'employed'). Similarly, respondents with less severe levels of ID had far higher rates of occupied/employed statuses than those with severe-profound ID; while the trend in relation to type of residence saw rates of activity increase substantially from institutions to community group homes and independent/family settings. More active occupational situations were also associated with better physical and mental health, with less challenges to ability and functioning, and with having better social supports.

Among all respondents, only one in seven (14.3%, n=99) were currently or had in the past year engaged in a training course. Training activity was significantly associated with all variables apart from gender. Younger respondents and those with less severe levels of ID participated more in training; as did people with better physical and mental health, people with less difficulties with ADLs, IADLs, communication and literacy, and those with better social support in the form of closer proximity to family, weekly contact with family, and having friends outside one's home. The rate of participation in training for people in group homes was more than double that of people living in institutions; but the rate for those living independently or with family was in turn almost double the rate

of people in group homes. Only one in 17 respondents (5.9%, n=41) reported that they engaged in voluntary work. Rates of volunteering were higher among younger respondents, people with mild ID levels, people living in independent/family homes, those with less difficulty with communication and literacy, with less limitation of ADLs and IADLs, and was also higher for those who had friends outside their own home and who saw family more frequently.

Table 6.1. Rates and bivariate associations for education, training and occupation

	Education Level			Paid Work		Occupational Situation			Training Course		Voluntary Work		
	None	Some Primary	Primary or more	Yes	No	Not Occupied	Home Based	Occupied	Employed	Yes	No	Yes	No
Gender	(n=586, p=0.90)			(n=686, p=0.34)		(n=683, p=0.66)			(n=693, p=0.35)		(n=693, p=0.53)		
Male	33.3	41.5	25.2	31.5	68.5	14.0	8.0	70.8	7.3	15.7	84.3	6.6	93.4
Female	32.9	40.2	26.8	28.1	71.9	14.1	6.0	73.8	6.0	13.2	86.8	5.4	94.6
Age	(n=586, p=0.92)			(n=686, p=0.17)		(n=683, p<0.001)			(n=693, p=0.001)		(n=693, p=0.01)		
< 65 years	33.5	40.7	25.8	30.8	69.2	11.1	7.4	73.4	8.1	16.7	83.3	7.1	92.9
65+ years	31.6	41.2	27.2	25.0	75.0	25.5	5.0	68.8	0.7	5.4	94.6	1.4	98.6
Level of ID	(n=540, p<0.001)			(n=635, p<0.001)		(n=629, p<0.001)			(n=640, p<0.001)		(n=640, p<0.001)		
Mild	5.0	45.7	49.3	51.0	49.0	12.2	2.7	69.6	15.5	25.0	75.0	11.8	88.2
Moderate	26.2	48.9	24.9	28.7	71.3	12.2	1.4	81.6	4.8	13.8	86.2	3.0	97.0
Severe-Profound	71.2	22.7	6.1	6.9	93.1	19.8	20.3	59.9	0.0	4.2	95.8	3.7	96.3
Type of Residence	(n=586, p<0.001)			(n=686, p<0.001)		(n=683, p<0.001)			(n=693, p<0.001)		(n=693, p<0.001)		
Independent/Family	18.1	47.6	34.3	41.1	58.9	6.3	0.9	80.2	12.6	30.6	69.4	18.0	82.0
CGH	24.7	42.4	32.9	33.4	66.6	12.9	1.4	77.9	7.8	15.9	84.1	5.6	94.4
Institutional	49.6	35.8	14.6	20.7	79.3	18.3	15.1	63.7	2.9	6.1	93.9	1.4	98.6
Physical Health	(n=576, p=0.07)			(n=675, p=0.12)		(n=674, p<0.001)			(n=684, p=0.003)		(n=684, p=0.07)		
Very Good-Excellent	29.6	42.7	27.7	33.4	66.6	8.0	9.2	74.5	8.3	16.7	83.3	8.2	91.8
Good	32.3	42.3	25.5	26.4	73.6	13.7	5.9	73.8	6.6	15.5	84.5	4.6	95.4
Fair-Poor	46.1	31.5	22.5	26.0	74.0	33.7	2.9	63.5	0.0	3.7	96.3	2.8	97.2
Mental Health	(n=569, p=0.05)			(n=669, p=0.06)		(n=654, p=0.02)			(n=675, p=0.002)		(n=674, p=0.10)		
Very Good-Excellent	25.0	46.3	28.7	35.1	64.9	10.2	8.3	72.7	8.8	20.4	79.6	6.3	93.7
Good	35.6	39.7	24.7	29.7	70.3	11.9	5.8	75.1	7.2	13.7	86.3	7.9	92.1
Fair-Poor	39.4	34.5	26.1	24.1	75.9	21.1	7.0	68.4	3.5	8.0	92.0	2.9	97.1

Table 6.1. Rates and bivariate associations for education, training and occupation (continued)

	Education Level			Paid Work		Occupational Situation			Training Course		Voluntary Work		
	None	Some Primary	Primary or more	Yes	No	Not Occupied	Home Based	Occupied	Employed	Yes	No	Yes	No
Communication Difficulty	(n=551, p<0.001)			(n=649,p<0.001)		(n=645, p<0.001)			(n=656, p<0.001)		(n=656, p=0.004)		
Lower	12.5	48.8	38.7	45.2	54.8	8.9	2.8	76.6	11.7	25.4	74.6	9.2	90.8
Higher	48.5	34.3	17.2	18.9	81.1	18.2	9.4	69.4	3.0	7.0	93.0	3.8	96.2
Literacy Difficulty	(n=556, p<0.001)			(n=657,p<0.001)		(n=651, p<0.001)			(n=663, p<0.001)		(n=662, p<0.001)		
Lower	10.4	42.5	47.2	60.3	39.7	6.1	0.0	75.4	18.4	30.2	69.8	13.9	86.1
Higher	38.4	40.2	21.3	22.9	77.1	15.8	8.4	71.9	3.9	11.2	88.8	4.2	95.8
ADLs Limitation	(n=535, p<0.001)			(n=632,p<0.001)		(n=633, p<0.001)			(n=640, p<0.001)		(n=640, p=0.01)		
Lower	22.2	47.0	30.8	35.1	64.9	10.2	4.7	77.3	7.9	16.8	83.2	7.2	92.8
Higher	67.6	20.1	12.2	11.1	88.9	25.9	15.4	58.6	0.0	2.4	97.6	1.8	98.2
IADLs Limitation	(n=562, p<0.001)			(n=654,p<0.001)		(n=650, p<0.001)			(n=662, p<0.001)		(n=663, p<0.001)		
Lower	13.5	47.9	38.6	48.5	51.5	7.6	1.7	76.1	14.5	25.9	74.1	11.9	88.1
Higher	50.2	34.3	15.5	12.5	87.5	19.4	10.2	70.1	0.3	4.1	95.9	1.6	98.4
Proximity to Family	(n=560, p=0.12)			(n=658,p=0.01)		(n=654, p=0.048)			(n=664, p<0.001)		(n=664, p=0.18)		
Same Neighbourhood	26.2	43.1	30.8	38.1	61.9	10.7	2.9	76.4	10.0	24.5	75.5	8.6	91.4
Outside Neighbourhood	35.6	39.5	24.9	26.8	73.2	14.4	7.8	71.8	6.0	11.8	88.2	5.5	94.5
Contact with Family	(n=557, p<0.001)			(n=655,p<0.001)		(n=651, p<0.001)			(n=661, p<0.001)		(n=661, p=0.001)		
At least weekly	23.7	44.4	31.9	40.1	59.9	11.5	1.5	76.5	10.4	26.2	73.8	10.3	89.7
At least monthly	29.0	42.8	28.3	27.7	72.3	14.7	6.4	73.1	5.8	5.8	94.2	5.8	94.2
Less than monthly	49.2	33.2	17.6	18.5	81.5	15.7	12.8	68.1	3.4	7.0	93.0	2.1	97.9
Friends Outside	(n=583, p<0.001)			(n=680,p<0.001)		(n=678, p<0.001)			(n=687, p<0.001)		(n=687, p<0.001)		
Yes	24.9	41.5	33.5	40.0	60.0	9.7	4.2	76.0	10.2	22.3	77.7	10.1	89.9
No	44.3	39.4	16.3	16.3	83.7	20.0	9.8	68.5	1.7	4.3	95.7	0.7	99.3
Total	33.1	40.8	26.1	29.6	70.4	14.1	6.9	72.5	6.6	14.3	85.7	5.9	94.1

A binomial logistic regression to explore factors associated with type of occupational status is reported in Table 6.2. For this analysis, the *Occupational Situation* variable was collapsed into a binary response: active (occupied, employed); and non-active (not occupied, home based). All independent variables that were significantly associated to the four-category Occupational Situation variable remained significant associated with the new binary outcome. The regression model examined factors that predicted an active or non-active status amongst respondents, and explained 24% (Nagelkerke r^2) of the variance in status. The only statistically significant factor in the model when all other independent variables were controlled for was ADLs limitation. People with greater limitation with ADLs were more than twice as likely as those with less limitation to have an inactive occupational status (OR=2.07).

Table 6.2. Factors associated with type of occupational status (n=477)

	Non-Active Occupational Status ¹	
	Odds Ratio (95% CI)	p-value
Gender		
Male	1.0	
Female	0.70 (0.48-1.15)	0.16
Age		
< 65 years	1.0	
65+ years	1.57 (0.88-2.82)	0.18
Level of ID		
Mild	1.0	
Moderate	0.55 (0.25-1.22)	0.14
Severe-Profound	1.27 (0.52-3.14)	0.60
Type of Residence		
Independent/Family	1.0	
Community Group Home	0.97 (0.32-3.02)	0.98
Institutional	1.38 (0.43-4.41)	0.58
Physical Health		
Very Good-Excellent	1.0	
Good	0.93 (0.52-1.68)	0.81
Fair-Poor	1.86 (0.93-3.71)	0.08
Mental Health		
Very Good-Excellent	1.0	
Good	0.92 (0.49-1.75)	0.81
Fair-Poor	1.47 (0.75-2.87)	0.26
Communication Difficulty		
Lower	1.0	
Higher	0.57 (0.29-1.15)	0.12
Literacy Difficulty		
Lower	1.0	
Higher	2.05 (0.70-5.99)	0.19
ADLs Limitation		
Lower	1.0	
Higher	2.07 (1.15-3.73)	0.01
IADLs Limitation		
Lower	1.0	
Higher	1.80 (0.84-3.87)	0.13
Contact with Family		
At least weekly	1.0	
At least monthly	1.44 (0.72-2.87)	0.31
Less than monthly	1.66 (0.85-3.25)	0.14
Proximity to Family		
Same Neighbourhood	1.0	
Outside Neighbourhood	0.93 (0.42-2.02)	0.85
Friends Outside Home		
Yes	1.0	
No	1.60 (0.94-2.72)	0.08

¹ Reference category: Active Occupational Status.

Nagelkerke $r^2=0.24$

$p<0.05$ is significant. All significant factors in bold.

A multinomial regression examined factors associated with how active respondents were in relation to current education, training and occupation activities (Table 6.3). This model predicted 42% (Nagelkerke r^2) of the variance in this type of activity. Two variables of social support, having non-resident friends and level of family contact, were the strongest predictors of being highly active. People who had non-resident friends were over six times more likely than people who didn't to be highly active in relation to education, training and occupation (OR=6.63); while people with weekly family contact were more than five times more likely than those who had less-than-monthly contact (OR=5.70). Following these, IADLs limitation and type of residence also significantly predicted activity; people with lower IADLs difficulty were more likely to be highly active than those with greater difficulties (OR=3.89), and people living in community group homes were more likely than people living in institutions to be highly active (OR=2.62). Lower IADLs limitation (OR=2.29), having a moderate level of ID compared to severe-profound level (OR=2.23) and being female (OR=1.75) also predicted a medium level of activity (compared to a low level).

Table 6.3. Factors associated with education/occupation activity (n=472)

	LEVEL OF EDUCATION/OCCUPATION ACTIVITY ¹			
	Medium Activity		High Activity	
	OR (95% CI)	p-value	OR (95% CI)	p-value
Gender				
Male	1.0		1.0	
Female	1.75 (1.04-2.96)	0.03	0.77 (0.35-1.69)	0.51
Age				
65+ years	1.0		1.0	
< 65 years	1.24 (0.67-2.28)	0.49	2.72 (0.83-8.91)	0.10
Level of ID				
Severe-Profound	1.0		1.0	
Moderate	2.23 (1.19-4.19)	0.01	1.06 (0.40-3.32)	0.92
Mild	1.23 (0.46-3.25)	0.31	0.76 (0.18-3.20)	0.70
Type of Residence				
Institutional	1.0		1.0	
Community Group Home	1.54 (0.87-2.73)	0.14	2.62 (1.04-6.65)	0.04
Independent/Family	1.65 (0.42-6.39)	0.47	4.59 (0.89-23.55)	0.07
Physical Health				
Fair-Poor	1.0		1.0	
Good	1.77 (0.88-3.56)	0.11	3.02 (0.72-12.56)	0.13
Very Good-Excellent	1.74 (0.84-3.58)	0.13	3.30 (0.78-13.93)	0.10
Mental Health				
Fair-Poor	1.0		1.0	
Good	1.40 (0.76-2.60)	0.28	1.84 (0.65-5.26)	0.25
Very Good-Excellent	1.20 (0.60-2.40)	0.61	1.30 (0.42-4.02)	0.65
Communication Difficulty				
Higher	1.0		1.0	
Lower	0.64 (0.31-1.32)	0.22	0.82 (0.30-2.25)	0.70
Literacy Difficulty				
Higher	1.0		1.0	
Lower	2.66 (0.71-10.04)	0.15	3.92 (0.93-16.54)	0.06
ADLs Limitation				
Higher	1.0		1.0	
Lower	2.29 (1.26-4.19)	0.007	2.23 (0.63-7.87)	0.21
IADLs Limitation				
Higher	1.0		1.0	
Lower	1.60 (0.70-3.63)	0.26	3.89 (1.25-12.13)	0.02
Contact with Family				
Less than monthly	1.0		1.0	
At least monthly	1.65 (0.85-3.20)	0.14	0.74 (0.20-2.74)	0.65
At least weekly	1.36 (0.68-2.72)	0.39	5.70 (2.0-16.23)	0.001
Proximity to Family				
Outside Neighbourhood	1.0		1.0	
Same neighbourhood	0.85 (0.37-1.94)	0.70	0.63 (0.19-2.08)	0.44
Friends Outside Home				
No	1.0		1.0	
Yes	1.58 (0.91-2.74)	0.10	6.63 (2.49-17.68)	<0.001

¹Reference category is low level of Education/Occupation Activity.
Nagelkerke $r^2=0.42$
 $p<0.05$ is significant. All significant factors in bold

6.4. Discussion

This chapter examined elements of participation related to education, training and occupation for older people with ID in Ireland; which relate to the ICF sections of *Learning and applying knowledge* (d1) and *Major life areas* (d8) (education, work and employment; economic life) (see Appendix 1). The study found very low participation rates for education and employment for older people with intellectual disabilities; and with disability benefit rates of 84.4% (n=580), supports the literature which portrays how people with special educational needs fare much worse in relation to educational outcomes than the general population; how these educational outcomes also lead to poor rates of employment and economic outcomes later in life (Watson et al. 2015); and how people with intellectual disability fare worse in comparison with people with other disabilities as well as the general population (Brault 2012). That less than one in ten was in paid employment, and that seven out of ten had never done any paid work, highlights how, when compared to rates internationally for the older general population, this population is missing out on the quality of life and other benefits that have been associated with employment. Furthermore, these disadvantages in education and employment are exacerbated for the oldest, the most severely disabled (both physically and cognitively), for those in the poorest health, those living in institutional settings and those with the most limited social supports of family and friends.

Alongside low employment rates, however, the study also found that the majority of older people with intellectual disabilities were involved in some kind of regular occupational activity, most likely a day programme. Recent research suggests that involvement in regular structured activity such as a day programme, volunteering, supported or paid employment is associated with better quality of life outcomes (Bigby et al. 2015). Policy in Ireland is to move away from segregated day programmes for large groups of people with intellectual disabilities towards options that are more

individualised and mainstreamed (Health Service Executive 2012). Emerging anecdotal evidence suggests day programmes within services are being closed and people are instead being 'activated' at home. This bears up in the data where 6.9% (n=47) reported they were receiving some form of home-based day programme or activation. Very little is known about these approaches at present, and the overall benefit to individuals of this or more traditional approaches to day programmes requires further investigation; while recent research noted that these programmes lack definition (Fleming et al. 2016). Further research is required to monitor the impact of the new policy approach over time, and also to understand the impact in terms of outcomes for individuals whether they are in new forms of mainstream day programme, home activation or another form of individualised programme; or indeed if they still attend more traditional forms of day programmes within intellectual disability services.

While education is an undoubted influence on employment status, the regression analysis examining other factors associated with whether people have an inactive occupational status (i.e. were either non-occupied or home-based) identified ADL limitations as the only significant predictor when other factors were controlled for; suggesting that physical ability plays a significant role in determining how active individuals may be in this regard (i.e. being active in employment, day service, sheltered workshop, etc.) regardless of cognitive ability, type of residence, or aspects of social support. This should serve as a reminder, in light of current policies for day services and community living (Health Service Executive 2011, Health Service Executive 2012), of the ongoing support requirements needed to facilitate greater participation for people in these areas regardless of residential location or level of intellectual disability.

The regression analysis exploring level of educational and occupational activity (incorporating type of occupational status, involvement in training courses and

involvement in voluntary work) revealed a range of associated factors. That the strongest predictors of being more active in this regard were factors of social support (having non-resident friends and frequent family contact) supports findings elsewhere in this study that informal natural supports can play a huge role in facilitating participation for older people with intellectual disabilities. These types of support have been identified in policy as a means of supporting people with intellectual disability to participate more in community life (Department of Health 2011, Tatlow-Golden et al. 2014); however, while the scope for natural supports for people with intellectual disabilities is limited (Duggan and Linehan 2013) there also remains a significant role for formal supports (e.g. paid staff) in supporting participation in these areas.

Finally, the potential for improving participation in voluntary work is high when rates of just 5.9% (n=41) are compared to 46% of the general older population in Ireland who volunteer; while the potential rewards for this type of participation have been identified in terms of improved quality of life (McCrory et al. 2014). This aspect of participation, alongside activities such as providing support to family, may also be important in a broader understanding of community (see section 2.5). Interdependent and reciprocal relationships appear to be important in such an understanding, and it is through activities such as volunteering and supporting family where people with intellectual disabilities may be supported to give something of themselves, and thus begin to create the important bonds of community, rather than being seen as passive recipients of care and support.

Chapter 7. Participation in Social Activities

7.1 Introduction

This chapter examines participation in social activities for older people with an intellectual disability in Ireland. Social activities here are activities that people do for recreation, leisure or similar purposes (e.g. spiritual or cultural activities); and may include activities that are done in a social context with other people, but may also include some solitary recreational activities (e.g. creative hobbies). In this context, this paper will examine participation in specific recreation and leisure activities, holidays, attendance of religious services, and active membership of organisations and clubs. Within the ICF theoretical framework this relates to chapter d9, *Community, social and civic life* (see Appendix 1). More specific ICF references are detailed in Figure 7.1 below. The chapter begins by reviewing the relevant literature on social activities; this is followed with an outline of the specific methods used in this part of the study (building on chapter 3); results are then presented, followed by an initial discussion within the context of the literature, relevant policy and the overall study.

7.1.1 Social Activity for People with Intellectual Disability

The literature on social activity for people with intellectual disabilities is dominated by deinstitutionalisation studies and comparisons of social engagement on the basis of residential setting – i.e. living in community (including group homes located within the general community) versus congregated or institutional settings (including clustered campus arrangements) (e.g. Emerson, 2004; Walsh et al., 2010; Chowdhury and Benson, 2011). This approach usually equates activities that take place within the general community as social activity or engagement *per se*; where social activity is defined in terms of engagement within general community/mainstream, and activity that takes place in segregated or non-mainstream environments (for example attending the showing of a film or the birthday party of a peer with ID within a service campus) is often not counted as social activity.

The ideological and policy context for this approach to social activity is influenced by *Normalisation* ideas (Wolfensberger 1970, Wolfensberger and Nirje 1972), by a spatial conceptualisation of community that equates community with physical location amongst the general population (see section 2.5), and by the assertion that ‘community living’ is a human right (European Union 2010, Health Service Executive 2011, United Nations 2006). As a result, literature on levels of social activity for people with ID *without* regard for the location of where that activity takes place (i.e. whether in ‘the community’ or not) is scant. Where activity is examined free of this requirement of a general population/wider community context, it is usually focused on physical activity and health issues rather than social activity (e.g. Haveman et al. (2011)).

Social activity as an outcome in the literature is therefore inextricably linked with residential situation and engagement within the general community, with acknowledgement that other factors such as personal characteristics and abilities, service design and staff also have a significant bearing on outcomes (Mansell and Beadle-Brown 2009a). For example, recent studies in Ireland found variation in activity levels according to age, level of disability as well as type of living arrangement; where being older, having severe-profound ID and living in more restrictive institutional settings suggested lower activity (McCausland et al. 2014, McCarron et al. 2011). It should be noted, however, that these variables are not independent of each other; in Ireland the least able, the oldest and those with more severe ID are over-represented amongst those who remain in institutional settings (Health Service Executive 2011).

Previously, Emerson (2004) reported that people living in clustered housing arrangements participated in fewer and a more restricted range of leisure and social activities and generally led more sedentary lives than people in dispersed accommodation in the general community; supporting prior studies that associated deinstitutionalisation with *“increased participation in community-based activities”*

(Emerson and Hatton 1994, Emerson and Hatton 1996, Kim et al. 2001, Young et al. 1998). Among the deinstitutionalisation studies examined in their review, Walsh et al. (2010) found “*consistent evidence of greater participation in community-based activities in community-based settings*” and “*consistent evidence that greater participation in community-based activities occurs in smaller, less institutional settings*” in the post-deinstitutionalisation studies examined (2010: 141). Kozma et al. (2009) reported that studies they examined found greater participation in activities outside the home for people living in smaller community living arrangements; but also found increased participation was associated with adaptive behaviour, level and complexity of need and individuals’ social competence, and that use of community amenities did not guarantee better outcomes. Verdonschot et al. (2009) found that the leisure activities of people with intellectual disability are mostly solitary and passive in nature, often accompanied by support staff and/or co-resident peers. A comprehensive review by Mansell and Beadle-Brown (2009b) found that campus or clustered settings were superior to dispersed housing in terms of actual number of hours of recreational activity; however, the authors noted that this was mainly confined to village campuses, and they concluded generally that dispersed housing was better. Taken together these studies suggest that understanding social activity for people with intellectual disability requires consideration of a greater complexity of factors than might be initially thought.

Other studies have also identified that different types of factors influence social activity. A recent study in Spain found that material, emotional and physical well-being were most closely related to leisure participation; while gender, age, level of intellectual disability or type of residence had no significant effect on participation in activities or quality of life. Furthermore, while quality of life was not related to objective measures of leisure participation (i.e. number of leisure activities), it was related to subjective measures including leisure activity preferences and constraints (Badia et al. 2013).

This supported previous findings of Hammel et al. (2008) and reflects claims that engagement in more community activities does not alone guarantee any subjective sense of belonging to a community (Amado et al. 2013). The subjective element in these findings also reflects calls for a more subjective consideration of living and support outcomes (Cummins and Lau 2003) and of what constitutes social inclusion for people with ID (Hall 2009, Cobigo et al. 2012, Overmars-Marx et al. 2014).

In summary, normative assumptions of what constitutes social activity tend to equate community-based social activity with social activity *per se*. This potentially overlooks the importance of other elements of social activity, and may bias the assessment of social activity because it omits activity that doesn't take place in the general or local community. Our understanding of social activity and its implications for the lives of people with ID may be enhanced by a broader understanding. Therefore, the approach in this chapter is to move away from these assumptions to examine social activities regardless of where the activity took place, or whether the activity was with members of the general community, with other people with ID or with support staff. The aim here is to assess levels of engagement by older people with ID in Ireland in a number of specific social activities, to examine factors associated with differences in levels of engagement, and to explore predictors of varying rates of participation.

7.2. Methods

Details of the overall study methodology were outlined earlier in chapter 2. This section provides additional detail on the specific measures of social activity used here and the procedures used to examine this aspect of participation.

7.2.1 Measures

A number of items measured specific recreation and leisure activities; membership of organisations, clubs or societies; and attendance of religious services (Figure 7.1). Each variable was mapped to a specific part of the ICF *Activities & Participation* framework. Respondents answered yes/no to having taken a holiday in Ireland or abroad. Respondents also answered yes/no to membership of various types of organisation, club or society. For each recreation and leisure activity, respondents first answered yes/no to each activity and then provided information on frequency: daily/almost daily; once a week or more; twice a month or more; about once a month; every few months; about once or twice a year. Finally, participants were asked to specify the frequency of their attendance of religious services, responding: no religion; never/almost never; about once or twice a year; every few months; about once a month; twice a month; about once a week; more than once a week. Bivariate and regression analyses included measures of: gender; age; level of ID (mild, moderate, or severe-profound); type of residence (independent/family, community group home, or institutional); self/proxy-rated physical and mental health (very good-excellent, good, or fair-poor); summary measures of difficulty with communication, literacy, ADLs and IADLs (all grouped as lower or higher level of difficulty); family proximity (living in same neighbourhood, or outside neighbourhood); family contact (frequency of face-to-face or phone contact grouped as: weekly; monthly; less than monthly); and having non-resident friends (yes/no).

Figure 7.1. Measures used – social activities

Question	ICF Reference
Have you taken a holiday in Ireland in the last 12 months?	d9208
Have you taken a holiday abroad in the last 12 months?	d9208
Are you a member of any of these organisations, clubs or societies? <i>Political party, trade union or environmental groups / Tenants groups, resident groups, Neighbourhood Watch / Church or religious groups / Charitable associations (e.g. St Vincent De Paul's) / Education, arts or music groups or evening classes / Retirement clubs / Special Olympics Network / Arch Club / Advocacy Group / Other</i>	d9205/d950
Do you do any of the following activities? <i>Go to the cinema, theatre, concert or the opera / Eat out / Go to an art gallery or museum / Go to church or other place of worship / Go to the pub for a drink / Go to a coffee shop for light refreshments / Go shopping / Go to sports events / Participate in sports activities/events / Go to library / Go to social clubs (e.g. bingo, play cards) / Go to the hairdressers / Perform in local arts groups and choirs / Spend time on hobbies or creative activities / Visit family and friends in their home / Other</i>	d9200 / d9201 / d9202 / d9203 / d9204 / d9205
How often do you go to religious services?	d9300

7.2.2 Analysis

Statistical analyses were performed using SPSS version 22.0. Frequencies and bivariate associations were initially examined. The two holiday questions were combined to assess whether respondents had taken any holiday in the last 12 months (yes to either). Membership of organisations, clubs or societies was recoded, summed and categorised: member of zero; member of one; member of two or more. The 17 individual recreational and leisure activities were recoded and summed based upon frequency of activity participation (never = 0; once or twice a year = 1; every few months = 2; once a month = 3; twice a month = 4; once a week = 5; daily/almost daily = 6). Summed responses were then categorised as: Lower (level of activity) (score 0-20); Medium (21-32); Higher (>32). Attendance of religious services was recoded and categorised as: weekly; less than weekly.

A multinomial regression was then performed to identify factors contributing to level of engagement in the 17 recreational and leisure activities, using the three levels of outcome: lower; medium; higher (level of activity). Independent variables added to the model included: gender; age (under 65; 65+); level of ID (mild; moderate; severe-profound); type of residence (independent/family; community group home (CGH); institutional/congregated); self/proxy rated physical health (very good-excellent; good; fair-poor); self/proxy rated mental health (very good-excellent; good; fair-poor); level of communication difficulties (lower; higher); level of literacy difficulties (lower; higher); level of limitation with ADLs (lower; higher); level of limitation with IADLs (lower; higher); frequency of contact with non-resident family (at least weekly; at least monthly; less than monthly); proximity of nearest family member (same neighbourhood; outside neighbourhood); and whether or not respondents had any non-resident friends (yes; no).

7.3. Results

Frequencies and bivariate associations are outlined in Table 7.1. Included are associations of social activities with key demographic variables including gender, age, and type of residence; individual characteristics such as level of ID, physical and mental health, ADL and IADL limitation and difficulty with communication and literacy; as well as aspects of social support such as family proximity, family contact and having non-resident friends. All of the variables outlined, apart from gender, were significantly associated with one or more of the social activities included. Activity decreased with increased age for holidays and recreational and leisure activities; but the reverse was the case for weekly attendance of religious services, consistent with a general decline in religious attendance amongst younger groups nationally (Central Statistics Office 2012). Type of residence was significantly associated with all types of activity, with activity declining from independent/family residences to community group homes to

institutional settings. For religious attendance, however, there were similar rates between independent/family and institutional settings, and poorer attendance for those in community group homes. Level of ID, physical and mental health and ADL/IADL limitation were significantly associated with all four measures of social activity. Those with less severe ID, those in better health, and those with the least limitation in ADLs and IADLs, all demonstrated higher rates of social activity than those with more severe disability, worse health, and greater ADL/IADL limitation. Higher communication difficulty was associated with significantly lower rates of activity, as was higher literacy difficulty; while having friends outside one's own home and more frequent contact with family was associated with increased rates of activity. Living in the same neighbourhood as family was also associated with increased membership of organisations.

The multinomial logistic regression explained 42% (Nagelkerke r^2) of the variance in level of recreation and leisure activity (Table 7.2). The strongest predictor in the model when controlling for other factors was frequency of contact with family. People who had contact with family less than once a month were six times more likely to have less social activity (OR = 5.98); while those with monthly family contact also had less social activity than those with weekly family contact (OR = 2.97). After family contact, having worse mental health (OR = 4.27), higher ADL limitation (OR = 3.77), worse physical health (OR = 3.0), higher IADL limitation (OR = 2.94), and having no friends outside one's own home (OR = 2.72), were all associated with engaging in less social activity. Being aged over 65 years and having severe-profound ID predicted less activity but these factors fell outside statistical significance ($p=0.07$). Family contact, mental health and difficulty with literacy also predicted a medium level of activity (i.e. less social activity for those with less family contact, worse mental health and greater difficulty with

literacy). Factors of residence type, proximity to family and communication difficulty were not significant in the model when other factors were controlled for.

Table 7.1. Bivariate associations with social activities

	Taken a Holiday		Religious Services		Member of Organisations			Recreation & Leisure Activities		
	Yes	No	Week	<Week	0	1	2+	Lower	Medium	Higher
Gender	(n=669, p=0.76)		(n=689, p=0.09)		(n=698, p=0.34)			(n=664, p=0.55)		
Male	57.0	43.0	44.7	55.3	60.4	26.6	13.0	31.6	33.0	35.4
Female	58.2	41.8	51.2	48.8	55.4	31.5	13.1	33.2	35.4	31.4
Age	(n=669, p<0.001)		(n=689, p=0.05)		(n=698, p=0.07)			(n=664, p=0.001)		
43-49	65.2	34.8	41.0	59.0	56.9	30.5	12.7	28.6	33.9	37.6
50-64	59.5	40.5	50.6	49.4	53.8	31.2	15.0	28.7	35.6	35.6
65+	43.2	56.8	52.7	47.3	67.6	23.6	8.8	46.5	31.9	21.5
Level of ID	(n=617, p<0.001)		(n=637, p=0.01)		(n=644, p<0.001)			(n=613, p<0.001)		
Mild	72.1	27.9	53.3	46.7	43.8	38.6	17.6	12.9	37.4	49.7
Moderate	62.3	37.7	52.6	47.4	52.8	32.1	15.1	30.2	33.1	36.7
Severe-Profound	37.6	62.4	39.6	60.4	75.5	19.8	4.7	50.5	35.6	13.8
Residence	(n=669, p<0.001)		(n=689, p=0.001)		(n=698, p<0.001)			(n=664, p<0.001)		
Ind/Family	72.0	28.0	56.8	43.2	41.1	34.8	24.1	17.9	36.8	45.3
CGH	64.7	35.3	40.4	59.6	50.8	33.1	16.1	24.9	34.9	40.1
Institution	44.4	55.6	53.6	46.4	71.5	23.1	5.3	46.5	32.7	20.8
Physical Health	(n=661, p<0.001)		(n=678, p=0.05)		(n=688, p<0.001)			(n=655, p<0.001)		
VG-Excellent	68.7	31.3	52.7	47.3	49.7	36.2	14.1	22.9	35.6	41.5
Good	56.0	44.0	44.9	55.1	58.8	26.5	14.6	34.0	35.2	30.7
Fair-Poor	28.8	71.2	41.1	58.9	76.9	15.7	7.4	57.1	29.5	13.3
Mental Health	(n=652, p<0.001)		(n=669, p=0.03)		(n=679, p=0.004)			(n=647, p<0.001)		
VG-Excellent	69.0	31.0	49.1	50.9	50.0	37.4	12.6	21.5	32.7	45.8
Good	55.2	44.8	53.0	47.0	56.8	27.9	15.4	34.7	34.3	30.9
Fair-Poor	47.9	52.1	40.1	59.9	67.2	22.6	10.2	41.7	36.3	22.0
Communication Difficulty	(n=633, p<0.001)		(n=650, p=0.08)		(n=660, p<0.001)			(n=626, p<0.001)		
Lower	71.4	28.6	52.9	47.1	45.1	37.1	17.8	17.9	35.9	46.2
Higher	49.2	50.8	45.9	54.1	65.0	24.6	10.4	41.8	33.2	25.0
Literacy Difficulty	(n=638, p=0.04)		(n=657, p=0.95)		(n=665, p<0.001)			(n=634, p<0.001)		
Lower	66.4	33.6	48.7	51.3	35.3	42.2	22.4	19.4	23.1	57.4
Higher	55.6	44.4	48.3	51.7	61.7	27.3	10.9	35.4	36.1	28.5
ADLs Limitation	(n=620, p<0.001)		(n=636, p<0.001)		(n=645, p<0.001)			(n=613, p<0.001)		
Lower	64.5	35.5	53.9	46.1	51.8	32.8	15.4	21.6	38.2	40.2
Higher	32.9	67.1	34.3	65.7	76.5	18.7	4.8	61.3	28.8	9.8
IADLs Limitation	(n=639, p<0.001)		(n=658, p=0.02)		(n=666, p<0.001)			(n=635, p<0.001)		
Lower	74.7	25.3	52.9	47.1	41.4	37.4	21.2	15.2	32.2	52.5
Higher	43.5	56.5	43.9	56.1	71.8	22.0	6.2	46.2	36.5	17.3
Family Proximity	(n=642, p<0.11)		(n=661, p=0.18)		(n=669, p=0.03)			(n=636, p=0.08)		
Same N'hood	63.7	36.3	54.0	46.0	47.5	35.5	17.0	24.2	40.2	35.6
Outside N'hood	56.0	44.0	47.5	52.5	60.0	28.0	11.9	34.1	32.9	32.9
Family Contact	(n=640, p<0.001)		(n=658, p=0.46)		(n=666, p=0.001)			(n=632, p<0.001)		
Weekly	66.8	33.2	51.3	48.7	49.4	34.7	15.8	20.6	27.8	51.6
Monthly	64.2	35.8	49.7	50.3	54.8	33.1	12.1	29.1	40.5	30.4
<Monthly	42.5	57.5	45.9	54.1	68.0	21.7	10.2	46.2	37.3	16.5
Friends Outside	(n=663, p<0.001)		(n=683, p=0.004)		(n=692, p<0.001)			(n=658, p<0.001)		
Yes	66.2	33.8	53.1	46.9	45.7	35.7	18.6	21.0	36.0	43.1
No	47.0	53.0	42.1	57.9	72.7	21.3	6.0	46.4	32.6	21.0
Total	57.7	42.3	48.3	51.7	57.6	29.4	13.0	32.5	34.3	33.1

Table 7.2. Factors associated with recreation & leisure activity (n=463)

	RATE OF RECREATION & LEISURE ACTIVITY ¹			
	Medium Rate of Activity		Lower Rate of Activity	
	OR (95% CI)	p-value	OR (95% CI)	p-value
Gender				
Male	1.0		1.0	
Female	1.56 (0.93-2.60)	0.09	1.63 (0.89-2.96)	0.11
Age				
< 65 years	1.0		1.0	
65+ years	1.49 (0.76-2.95)	0.25	2.03 (0.95-4.33)	0.07
Level of ID				
Mild	1.0		1.0	
Moderate	0.74 (0.40-1.37)	0.34	1.40 (0.58-3.39)	0.45
Severe-Profound	1.89 (0.79-4.55)	0.15	2.76 (0.92-8.25)	0.07
Type of Residence				
Independent/Family	1.0		1.0	
Community Group Home	0.75 (0.32-1.74)	0.51	0.69 (0.20-2.38)	0.56
Institutional	0.84 (0.33-2.11)	0.71	1.01 (0.28-3.63)	0.99
Physical Health				
Very Good-Excellent	1.0		1.0	
Good	0.99 (0.56-1.74)	0.97	1.23 (0.63-2.39)	0.54
Fair-Poor	1.91 (0.80-4.55)	0.15	3.00 (1.18-7.64)	0.02
Mental Health				
Very Good-Excellent	1.0		1.0	
Good	1.68 (0.91-3.10)	0.10	3.39 (1.56-7.37)	0.002
Fair-Poor	2.24 (1.10-4.56)	0.03	4.27 (1.84-9.91)	0.001
Communication Difficulty				
Lower	1.0		1.0	
Higher	0.61 (0.33-1.14)	0.12	0.75 (0.35-1.63)	0.47
Literacy Difficulty				
Lower	1.0		1.0	
Higher	2.40 (1.15-4.99)	0.02	0.94 (0.35-2.55)	0.91
ADLs Limitation				
Lower	1.0		1.0	
Higher	1.58 (0.70-3.58)	0.27	3.77 (1.64-8.66)	0.002
IADLs Limitation				
Lower	1.0		1.0	
Higher	1.35 (0.71-2.57)	0.36	2.94 (1.31-6.62)	0.01
Proximity to Family				
Same Neighbourhood	1.0		1.0	
Outside neighbourhood	0.53 (0.25-1.14)	0.11	0.63 (0.25-1.61)	0.33
Contact with Family				
At least weekly	1.0		1.0	
At least monthly	3.16 (1.68-5.96)	<0.001	2.97 (1.34-6.58)	0.01
Less than monthly	4.65 (2.39-9.07)	<0.001	5.98 (2.77-12.93)	<0.001
Friends Outside Home				
Yes	1.0		1.0	
No	1.32 (0.75-2.33)	0.34	2.72 (1.43-5.18)	0.002

¹Reference category is Higher Rate of Recreation & Leisure Activity

Nagelkerke $r^2=0.42$

$p<0.05$ is significant. All significant factors in bold

7.4. Discussion

This chapter has examined rates of engagement in a range of social activities by older people with ID in Ireland, and factors associated with different rates of engagement. The approach taken challenges how social activity for people with ID is both conceptualised and measured, with regard to the assumption that activities performed in the general community are better *per se* than those performed in other settings. Looking at actual activities rather than community location, no significant difference was found in rates of social activity based on type of residence when other factors were controlled for. In the regression analysis, level of social support (contact with family; having non-resident friends) as well personal characteristics such as mental and physical health, ADL and IADL limitation and literacy were more significantly related to rate of social activity. Those with lower levels of social support, in particular family contact, and with greater challenges in terms of health and personal ability, had lower rates of social activity.

The finding that contact with family was the strongest predictor of social activity was striking and raises of the potential that either direct support or advocacy by family may lead to greater social activity regardless of living situation. In situations where people with ID were living with family or independently, the influence of family in encouraging and supporting activity may be more direct. However, in situations where people with ID are living in community group homes or institutional settings there may be an added advocacy or oversight dimension to increased family contact. Regardless, while further investigation of the potential benefits of increased family contact for social activity is needed, the findings here suggest such involvement should be promoted and facilitated.

In recent Irish policy on community living for people with intellectual disability (Health Service Executive 2011), 'natural supports' (including family) have been identified as a key support to enable people to live independently and participate more in the general community (Tatlow-Golden et al. 2014, Department of Health 2011). However, where the scope for natural supports is limited (Duggan and Linehan 2013) there is potential that social activity will be more limited. As such, while interventions to improve the range of informal supports available are required, there is continued need for formal supports of social activity, especially where family contact is restricted or even absent. This is further highlighted by findings elsewhere in this study that many older people with ID rely on support staff as a primary source of social support (see chapter 9).

The intentional decision to not place any prior judgement on which setting is better or worse for social activity appears more consistent with the core principles for quality of life outlined by Schalock et al. (2002) – to measure the meaningful life experiences which are *valued by people with intellectual disabilities*, and contribute to a life that *they value and enjoy*, within environments that are most important *to them* (my italics). However, this would require that the freedom to choose activities is equal across settings, which may not be the case (Emerson 2004, McCarron et al. 2011). Nonetheless, this observation is reinforced by findings which linked quality of life with activity preferences and constraints rather than simply with objective measures of activities done (Badia et al. 2013). Notwithstanding issues over choice, findings here question predominant literature and policy understandings equating community living with increased engagement in social activities (Tatlow-Golden et al. 2014) and instead highlight the challenges of social support, health status, level of ID and I/ADL limitation that must be addressed even for those living in what are seen as more activity-beneficial environments such as community group homes. These issues are further explored in the main discussion later in chapter 11.

Chapter 8. Participation in Local Community

8.1 Introduction

This chapter examines participation in local community by older people with intellectual disability in Ireland. It looks specifically at membership of community-based organisations, engagement in social activities in a local community context, and difficulty participating in the local community. Within the theoretical framework, these measures relate to the ICF section *Community, Social & Civic Life* (d9) (see Appendix 1). More specific ICF references are detailed in Figure 8.1 below. Social activities are defined similarly to those in chapter 7 (see section 7.1), except here we consider those that take place within the local community context. Differences in participation are examined on the basis of a number of demographic and personal variables; and factors that predict different rates of membership, activity and difficulty for people in their local community are explored. The chapter begins by reviewing the relevant literature. It then outlines specific methodological aspects to this part of the study (building on chapter 3); results are then presented and these are discussed within the context of the literature and prevailing policy.

8.1.1 People with Intellectual Disability and Community

Prior to the asylum period of the mid-nineteenth century, the presence and inclusion of people with intellectual disabilities in local community was a normative part of pre-industrial society (Jarrett 2015). While the origins of formal community-based supports for people with intellectual disabilities can be traced back to the 1950s, the modern literature on people with intellectual disability in the general community is associated with the policies of deinstitutionalisation that took hold from the 1970s and developed in places such as Australia, Britain, New Zealand, Scandinavia and the USA (Mansell 2006, Amado et al. 2013). As previously suggested (see section 2.2), this was influenced by Nirje and Wolfensberger's theories of *Normalization*, and later *Social Role Valorisation* (Wolfensberger 1970, Wolfensberger 1992, Wolfensberger and Nirje

1972), which proposed that people with disability could and should be included in the mainstream of everyday living through access to the same experiences and roles, the same societal and cultural norms, as everybody else (Nirje 1999, Thomas and Wolfensberger 1999). These theories laid the foundation for change in how services were provided for people with ID in the USA (Kozleski and Sands 1992) and the UK (Pilling 1995), influencing the transition of people with ID from institutional living to living within their local communities and wider society (Ellis 1990, Heal 1988, Trainor and Boydell 1986). Internationally their legacy is seen in in the UN *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations 1994), and the WHO's ICF (World Health Organization 2001a) (Flynn and Lemay 1999). It culminated in Article 19 of the UN's *Convention on Rights of Persons with Disabilities*, which relates specifically to *Living independently and being included in the community*, and declares that states:

“recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community” (United Nations 2006).

In Irish policy this was expressed in the 2011 report *‘Time to Move on from Congregated Settings: A Strategy for Community Inclusion’*, which stated that people with intellectual disability would be *“actively and effectively supported to live full, inclusive lives at the heart of family, community and society”* (Health Service Executive 2011).

The research literature is largely positive about outcomes for people with intellectual disability living ‘in the community’ (Emerson and Hatton 1994, Heller et al. 1998, Young et al. 2004, Kozma et al. 2009, Mansell and Beadle-Brown 2009a, Walsh et al. 2010, Chowdhury and Benson 2011, Tatlow-Golden et al. 2014). However, some

commentary has noted a bias in favour of objective over subjective measures of community living (Cummins and Lau 2003), an inconsistency in outcomes depending on a range of personal and service-related factors (Emerson and Hatton 1994, Young et al. 2004, Kozma et al. 2009, Mansell and Beadle-Brown 2009b, Chowdhury and Benson 2011), and a situation where, although people with ID living in community settings participate more in the community are more connected than those living in institutional settings, they participate far less than other groups and remain poorly connected within these wider communities (Verdonschot et al. 2009, McCarron et al. 2011, Tatlow-Golden et al. 2014).

8.1.2 What Community?

In the context of this chapter, it is important to consider what exactly is meant by reference to *community* or *the community* in policy and research, and in the general discourse around intellectual disability and community. As noted in section 2.5 of the thesis, the concept of community has been underdeveloped in the ID field. Some recent studies have examined how community participation is conceptualised (Verdonschot et al. 2009), or have considered the different contexts or settings in which social inclusion for people with ID may occur (Simplican et al. 2015); however, these have nonetheless viewed community primarily in terms of location and thereafter considered participation or inclusion within or outside of that space. A small number of studies in the field have explored the deeper meaning of community (Cummins and Lau 2003, Ben-Moshe 2011, Cummins and Kim 2015, Greig 2015, Cushing 2015, Lyons 2015), but to date these remain the exception. Consequently, throughout the literature there is a widespread assumption that community (or ‘the community’) means the general non-disabled community or wider society and the residential location of people with ID therein – in ‘integrated’ as opposed to segregated settings. This implies that a spatial concept of community predominates the ID field, whereby community is

equated primarily with physical/geographical location within the general non-disabled community. Elsewhere, the general sociological literature on community identifies a more complex concept that is defined more by reciprocity and bonding between individuals and having a sense of belonging, and which may be based upon influences such as common interests or shared identity rather than, or alongside, physical proximity or location (Anderson 1983, Cohen 1985, Delanty 2003, Crow and Maclean 2006). There are some recent examples in the literature on social inclusion for people with ID which complement and provide parallels to these ideas of reciprocity and belonging (Hammel et al. 2008, Hall 2009, Overmars-Marx et al. 2014, Simpican et al. 2015) but they have yet to challenge the predominant conceptualisation of community as being first and foremost about location within the general community. The quantitative data within the current study relates to 'local community', and as such is also based on the spatial conception of community as place; however, given the evident gaps in knowledge about the concept of community in the ID field, further research to explore this concept is required.

8.2 Methods

Details of the overall study methodology were previously outlined in chapter 3. This section provides additional detail on the measures that relate specifically to participation in the local community, and the procedures used to examine these aspects of participation.

8.2.1 Measures

Measures of participation in local community are outlined and mapped to the ICF theoretical framework in Figure 8.1 below. Respondents answered yes/no to whether they were members of a range of specific organisations, clubs or societies; and for each membership indicated whether this was in a local community and/or ID service setting. Respondents answered yes/no to whether or not they engaged in a range of social activities; and identified how often they did these activities (daily/almost daily; once a week or more; twice a month or more; about once a month; every few months; about once or twice a year), and whether they did these activities in a local community and/or ID service setting. Participants were asked if they experienced any difficulties participating in social activities outside their home (yes/no). Participants were also asked if they experienced any difficulty getting around their local community, responding: yes; no; not applicable – I don't travel around my local community. Bivariate and regression analyses included measures of: gender; age; level of ID (mild, moderate, or severe-profound); type of residence (independent/family, community group home, or institutional/congregated); self/proxy-rated physical and mental health (very good-excellent, good, or fair-poor); difficulty with ADLs, IADLs, communication and literacy (each categorised as lower/higher level of difficulty); family proximity (living in same neighbourhood, or outside neighbourhood); family contact (frequency of face-to-face or phone contact categorised as: weekly; monthly; less than monthly); and having non-resident friends (yes/no).

Figure 8.1. Measures used – participation in local community

Question	ICF Reference
Are you a member of any of these organisations, clubs or societies? <i>Political party, trade union or environmental groups / Tenants groups, resident groups, Neighbourhood Watch / Church or religious groups / Charitable associations (e.g. St Vincent De Paul's) / Education, arts or music groups or evening classes / Retirement clubs / Special Olympics Network / Arch Club / Advocacy Group / Other</i>	d9205/d950
Do these activities happen within a local community setting, an ID service setting or both?	d9100/1
Do you do any of the following activities? (If yes, how often?) <i>Go to the cinema, theatre, concert or the opera / Eat out / Go to an art gallery or museum / Go to church or other place of worship / Go to the pub for a drink / Go to a coffee shop for light refreshments / Go shopping / Go to sports events / Participate in sports activities/events / Go to library / Go to social clubs (e.g. bingo, play cards) / Go to the hairdressers / Perform in local arts groups and choirs / Other</i>	d9200 / d9201 / d9202 / d9203 / d9204 / d9205
Do these activities happen within a local community setting, an ID service setting or both?	d9109
Do you experience any difficulties participating in social activities outside your home?	d999
Do you experience any difficulty getting around your community?	d999

8.2.2 Analysis

Frequencies and bivariate associations were initially examined. Membership of organisations, clubs or societies within local community was recoded as a binary outcome variable: *member* (a member of one or more community-based groups); or *non-member* (not a member of any community based groups). Activities done in the local community were recoded based on frequency and the number of activities done at least once a month was summed and then categorised as *lower* (0-4 monthly community-based activities) and *higher* (five or more monthly community-based activities). The approach to recoding and analysing social activities here differs to the approach in chapter 7 (see section 7.2.2) because here the analysis focused on the number of activities (within a baseline frequency); whereas the previous chapter

focused more on the rate or level of activity generally. Difficulty participating in social activities outside the home and difficulty getting around the local community were combined to create a new variable, difficulty interacting with local community, coded as: difficulty (has difficulty with at least one); no difficulty (difficulty with neither). Binary logistic regressions were performed to explore associations with (1) membership of groups (organisations, clubs and societies) in local community, (2) social activity in local community, and (3) difficulty participating in local community. Independent variables added to the models are outlined in *Measures* above.

8.3 Results

8.3.1 Membership of Groups in Local Community

In the bivariate analysis, all of the variables examined apart from gender were significantly associated with membership of community-based groups (Table 8.1). Membership was positively associated with being younger, having a less severe level of ID, living in community-based residences, having better physical and mental health, having less difficulty with ADLs, IADLs, communication and literacy, living close to family, having more frequent family contact, and having friends outside one's own home. The regression model explained 27% (Nagelkerke r^2) of the variance in membership of local community groups (Table 8.2). Having less limitation with IADLs (OR=2.81) was the strongest predictor of membership when other variables in the model were controlled for. Following this, people living in community group homes were 2.7 times more likely than people living in institutional residences to be a member (while independent/family residence was not statistically significant). People with less literacy difficulty were more than twice as likely (OR=2.05) to be a member than people with greater difficulty. And people who reported having friends outside their own home were almost twice as likely (OR=1.90) to be a member than those who had no friends outside their home.

Table 8.1. Bivariate associations with membership of groups in local community

	Member of Groups in Local Community	
	Member	Non-Member
Gender	(n=690, p=0.63)	
Male	25.1	74.9
Female	23.5	76.5
Age	(n=690, p=0.004)	
43-64	26.6	73.4
65+	15.2	84.8
Level of ID	(n=638, p<0.001)	
Mild	40.1	59.9
Moderate	24.7	75.3
Severe-Profound	12.0	88.0
Type of Residence	(n=690, p<0.001)	
Independent /Family	36.0	64.0
Community Group Home	31.0	69.0
Institution	12.2	87.8
Physical Health	(n=682, p<0.001)	
Very Good-Excellent	30.3	69.7
Good	22.2	77.8
Fair-Poor	11.1	88.9
Mental Health	(n=672, p=0.01)	
Very Good-Excellent	28.6	71.4
Good	26.5	73.5
Fair-Poor	15.8	84.2
Communication Difficulty	(n=654, p<0.001)	
Lower	33.0	67.0
Higher	18.3	81.7
Literacy Difficulty	(n=658, p<0.001)	
Lower	43.5	56.5
Higher	20.3	79.7
ADLs Limitation	(n=638, p<0.001)	
Lower	29.0	71.0
Higher	8.4	91.6
IADLs Limitation	(n=658, p<0.001)	
Lower	39.2	60.8
Higher	11.5	88.5
Family Proximity	(n=661, p=0.04)	
Same Neighbourhood	30.9	69.1
Outside Neighbourhood	22.6	77.4
Family Contact	(n=658, p<0.001)	
Weekly	31.6	68.4
Monthly	25.8	74.2
<Monthly	15.4	84.6
Friends Outside Home	(n=686, p<0.001)	
Yes	33.2	66.8
No	12.4	87.6
Total (n=690)	24.2	75.8

Table 8.2. Factors associated with membership of groups in local community (n=485)

	Member of Local Community Groups ¹	
	Odds Ratio (95% CI)	p-value
Gender		
Female	1.0	
Male	0.99 (0.61-1.61)	0.97
Age		
65+ years	1.0	
< 65 years	1.35 (0.69-2.67)	0.38
Level of ID		
Severe-Profound	1.0	
Moderate	1.26 (0.61-2.60)	0.53
Mild	0.94 (0.40-2.23)	0.89
Type of Residence		
Institutional	1.0	
Community Group Home	2.70 (1.50-4.86)	0.001
Independent/Family	1.68 (0.70-4.05)	0.25
Physical Health		
Fair-Poor	1.0	
Good	0.83 (0.36-1.91)	0.67
Very Good-Excellent	1.38 (0.62-3.07)	0.43
Mental Health		
Fair-Poor	1.0	
Good	1.90 (0.99-3.63)	0.053
Very Good-Excellent	1.25 (0.62-2.52)	0.52
Communication Difficulty		
Higher	1.0	
Lower	0.75 (0.41-1.37)	0.35
Literacy Difficulty		
Higher	1.0	
Lower	2.05 (1.10-3.83)	0.02
ADLs Limitation		
Higher	1.0	
Lower	1.23 (0.55-2.79)	0.61
IADLs Limitation		
Higher	1.0	
Lower	2.81 (1.46-5.40)	0.002
Proximity to Family		
Outside Neighbourhood	1.0	
Same Neighbourhood	1.43 (0.70-2.93)	0.33
Contact with Family		
Less than monthly	1.0	
At least monthly	1.68 (0.85-3.29)	0.13
At least weekly	1.28 (0.67-2.45)	
Friends Outside		
No	1.0	
Yes	1.90 (1.09-3.33)	0.02

¹ Reference category: Not a member of local community groups.

Nagelkerke $r^2=0.27$

$p<0.05$ is significant. All significant factors in bold.

8.3.2 Social Activities in Local Community

Bivariate analyses of participants' levels of social activity in their local community are outlined in Table 8.3, which shows significant associations with all variables tested apart from family proximity. Male respondents and people aged under 65 years were more active in their local community. Activity decreased as level of disability became more severe, as physical and mental health got worse, as people experienced greater limitation with ADLs and IADLs, and greater difficulty with communication and literacy. In terms of social support, respondents who had non-resident friends and who had more frequent contact with their family also had higher levels of activity in their local community. With regard to residence type, people living in institutional settings had much lower rates than those living in community settings but, notably, respondents in community group homes had higher rates of community activity than people living either with family or independently. Table 8.4 outlines the results of the binomial logistic regression for social activity in respondents' local community. The model explained 23% (Nagelkerke r^2) of the variance in the outcome variable. In the model, contact with family was the strongest predictor of having a higher rate of activity in one's local community. People with weekly family contact were 2.78 times more likely to have a higher level of activity than those with less than monthly family contact. Following this, people with very good-excellent mental health were 2.3 times more likely to have higher social activity than people with fair-poor mental health. People residing in community group homes were almost twice as likely to have a higher level of community activity as those in institutional residences (OR=1.98). Finally, people with less difficulty with literacy were also nearly twice as likely to have a higher level of community activity as those with greater literacy difficulties.

Table 8.3. Bivariate associations with social activities in local community

	Level of Activities in Local Community	
	Higher	Lower
Gender	(n=652, p=0.02)	
Male	52.8	47.2
Female	43.8	56.3
Age	(n=652, p=0.02)	
43-64	50.0	50.0
65+	38.5	61.5
Level of ID	(n=602, p<0.001)	
Mild	61.1	38.9
Moderate	50.5	49.5
Severe-Profound	31.0	69.0
Type of Residence	(n=652, p<0.001)	
Independent /Family	52.8	47.2
Community Group Home	58.4	41.6
Institution	33.2	66.8
Physical Health	(n=642, p<0.001)	
Very Good-Excellent	53.7	46.3
Good	46.7	53.3
Fair-Poor	29.9	70.1
Mental Health	(n=635, p<0.001)	
Very Good-Excellent	59.7	40.3
Good	43.7	56.3
Fair-Poor	39.1	60.9
Communication Difficulty	(n=619, p<0.001)	
Lower	57.4	42.6
Higher	40.9	59.1
Literacy Difficulty	(n=622, p<0.001)	
Lower	64.9	35.1
Higher	43.7	56.3
ADLs Limitation	(n=603, p<0.001)	
Lower	54.1	45.9
Higher	24.1	75.9
IADLs Limitation	(n=622, p<0.001)	
Lower	61.9	38.1
Higher	33.5	66.5
Family Proximity	(n=626, p=0.47)	
Same Neighbourhood	50.4	49.6
Outside Neighbourhood	46.8	53.2
Family Contact	(n=623, p<0.001)	
Weekly	59.5	40.5
Monthly	51.0	49.0
<Monthly	31.5	68.5
Friends Outside Home	(n=646, p<0.001)	
Yes	54.3	45.7
No	39.3	60.7
Total (n=652)	47.7	52.3

Table 8.4. Factors associated with social activities in local community (n=458)

	Higher Level of Community Activities ¹	
	Odds Ratio (95% CI)	p-value
Gender		
Female	1.0	
Male	1.38 (0.91-2.10)	0.13
Age		
65+ years	1.0	
< 65 years	1.10 (0.64-1.89)	0.72
Level of ID		
Severe-Profound	1.0	
Moderate	1.38 (0.78-2.41)	0.26
Mild	1.30 (0.63-2.67)	0.47
Type of Residence		
Institutional	1.0	
Community Group Home	1.98 (1.24-3.17)	0.004
Independent/Family	0.92 (0.42-2.01)	0.83
Physical Health		
Fair-Poor	1.0	
Good	1.31 (0.67-2.58)	0.43
Very Good-Excellent	1.26 (0.65-2.46)	0.49
Mental Health		
Fair-Poor	1.0	
Good	1.29 (0.76-2.19)	0.35
Very Good-Excellent	2.30 (1.30-4.09)	0.004
Communication Difficulty		
Higher	1.0	
Lower	0.66 (0.39-1.13)	0.13
Literacy Difficulty		
Higher	1.0	
Lower	1.94 (1.03-3.65)	0.04
ADLs Limitation		
Higher	1.0	
Lower	1.73 (0.94-3.18)	0.08
IADLs Limitation		
Higher	1.0	
Lower	1.61 (0.92-2.79)	0.09
Proximity to Family		
Outside Neighbourhood	1.0	
Same Neighbourhood	1.12 (0.60-2.10)	0.73
Contact with Family		
Less than monthly	1.0	
At least monthly	1.70 (0.97-2.99)	0.06
At least weekly	2.78 (1.63-4.74)	<0.001
Friends Outside		
No	1.0	
Yes	0.95 (0.59-1.51)	0.82

¹ Reference category: Lower level of community activities.

Nagelkerke $r^2=0.23$

$p<0.05$ is significant. All significant factors in bold.

8.3.3 Difficulty Participating in Local Community

Bivariate analyses of difficulty that respondents had participating in their local community are outlined in Table 8.5, which shows significant associations with all variables tested apart from gender and age. Reported rates of no difficulty were highest for people living in independent/ family residences, compared to both community group homes and institutional settings. Rates of no difficulty were also higher for people with milder ID, for those with less literacy and communication difficulties, those with less limitation in ADLs and IADLs, with better physical and mental health, and with better social supports in terms of living closer to and having better contact with family, and also having non-resident friends. The regression model for difficulty participating in local community explained 43% (Nagelkerke r^2) of the variance in the outcome variable (Table 8.6). People living in an independent/family setting were 6.57 times more likely to have no difficulty participating than people living in institutional environments, and this was the strongest predictor in the model of having no difficulty participating in one's local community. Next, people with poor-fair physical health were much less likely to report no difficulty participating than people with very good-excellent (OR=3.99) and good physical health (OR=3.71). People with mild ID were also nearly four times more likely (OR=3.73) than people with a severe-profound level to have no difficulty participating. People with less ADL limitation were 3.5 times more likely than those with higher limitation to have no difficulty participating.

Table 8.5. Bivariate associations with difficulty participating in local community

	Difficulty Participating in Local Community	
	No Difficulty	Difficulty
Gender	(n=695, p=0.66)	
Male	25.4	74.6
Female	24.0	76.0
Age	(n=695, p=0.12)	
43-64	25.9	74.1
65+	19.7	80.3
Level of ID	(n=641, p<0.001)	
Mild	51.3	48.7
Moderate	20.5	79.5
Severe-Profound	6.8	93.2
Type of Residence	(n=695, p<0.001)	
Independent /Family	58.0	42.0
Community Group Home	24.7	75.3
Institution	11.1	88.9
Physical Health	(n=686, p<0.001)	
Very Good-Excellent	30.8	69.2
Good	25.4	74.6
Fair-Poor	5.6	94.4
Mental Health	(n=675, p<0.001)	
Very Good-Excellent	33.9	66.1
Good	25.1	74.9
Fair-Poor	13.6	86.4
Communication Difficulty	(n=658, p<0.001)	
Lower	43.7	56.3
Higher	11.8	88.2
Literacy Difficulty	(n=662, p<0.001)	
Lower	53.4	46.6
Higher	18.1	81.9
ADLs Limitation	(n=642, p<0.001)	
Lower	30.5	69.5
Higher	3.0	97.0
IADLs Limitation	(n=664, p<0.001)	
Lower	43.2	56.8
Higher	9.5	90.5
Family Proximity	(n=666, p<0.001)	
Same Neighbourhood	41.4	58.6
Outside Neighbourhood	21.1	78.9
Family Contact	(n=663, p=0.001)	
Weekly	31.9	68.1
Monthly	26.3	73.7
<Monthly	17.2	82.8
Friends Outside Home	(n=690, p<0.001)	
Yes	34.5	65.5
No	12.0	88.0
Total (n=695)	24.6	75.4

Table 8.6. Factors associated with difficulty participating in local community (n=488)

	No Difficulty Participating in Local Community ¹	
	Odds Ratio (95% CI)	p-value
Gender		
Female	1.0	
Male	1.47 (0.86-2.52)	0.16
Age		
65+ years	1.0	
< 65 years	0.73 (0.36-1.47)	0.38
Level of ID		
Severe-Profound	1.0	
Moderate	1.40 (0.59-3.29)	0.44
Mild	3.73 (1.44-9.63)	0.007
Type of Residence		
Institutional	1.0	
Community Group Home	1.41 (0.75-2.63)	0.29
Independent/Family	6.57 (2.52-17.11)	<0.001
Physical Health		
Fair-Poor	1.0	
Good	3.71 (1.20-11.50)	0.02
Very Good-Excellent	3.99 (1.32-12.09)	0.01
Mental Health		
Fair-Poor	1.0	
Good	1.81 (0.88-3.74)	0.11
Very Good-Excellent	1.97 (0.92-4.26)	0.08
Communication Difficulty		
Higher	1.0	
Lower	1.80 (0.96-3.40)	0.07
Literacy Difficulty		
Higher	1.0	
Lower	1.95 (0.95-3.84)	0.054
ADLs Limitation		
Higher	1.0	
Lower	3.54 (1.18-10.59)	0.02
IADLs Limitation		
Higher	1.0	
Lower	1.16 (0.59-2.27)	0.67
Proximity to Family		
Outside Neighbourhood	1.0	
Same Neighbourhood	1.30 (0.58-2.91)	0.53
Contact with Family		
Less than monthly	1.0	
At least monthly	1.30 (0.62-2.74)	0.49
At least weekly	0.79 (0.39-1.61)	0.53
Friends Outside		
No	1.0	
Yes	1.22 (0.67-2.24)	0.52

¹ Reference category: Difficulty participating in local community.

Nagelkerke $r^2=0.43$

$p<0.05$ is significant. All significant factors in bold.

8.4 Discussion

This chapter has examined aspects of participation that respondents had with their local community. Findings highlight the complexity of local community participation for people with ID and encourage consideration of a range of contributory factors rather than a narrow focus on single factors. It suggests that an over-focus on one particular factor may be misguided and counter-productive; and instead it encourages a very person-centred and individualised approach. This supports previous findings of multi-factorial influences on community participation (Emerson and Hatton 1994, Young et al. 2004, Kozma et al. 2009, Mansell and Beadle-Brown 2009b, Chowdhury and Benson 2011).

The findings suggest that a number of different types of factors are associated with membership of groups, social activity within the community, and with having difficulty participating outside the home. These include factors related to the personal ability or functioning of individuals, namely IADL and ADL limitation, literacy ability, mental and physical health, level of ID, and communication ability. That IADLs was the strongest predictor of membership of community groups suggests that this aspect of community participation is something that may be developed for individuals since, following Deeg's (1993) distinction of modifiable situational IADL disability, studies have found that IADL performance may be improved through training or supports (Gama et al. 2000, Daniels et al. 2008, Hilgenkamp et al. 2011). Others found that people with ID living in community settings had better opportunities to practice IADLs and ADLs (Spreat and Conroy 2001) and that community placement was associated with increased adaptive behaviour (Young et al. 1998, Kim et al. 2001). Therefore, as community placement is associated with improved adaptive behaviour through better opportunity and support, findings here suggest that this improved functioning may also lead to improved participation through memberships of clubs and organisations. As such, active support

geared towards the improvement of IADL functioning for individuals should be encouraged in community-based settings.

This is further supported by the finding that type of living arrangement was also a significant influence across the measures used; with residence in community group homes predicting greater membership and social activity in community settings (although less important than IADL functioning and family contact respectively), while residence in independent/family settings predicted less difficulty participating in community settings. This supports previous findings linking residence in smaller community-based accommodation with more activity outside the home and participation in the local community (Kozma et al. 2009, Walsh et al. 2010). Although it is interesting to note the difference with previous findings in chapter 7, where residence type was not significant in the model for all social activities (i.e. not just those performed in local community). Nonetheless, findings here for participation in the local community confirm previous research findings, that when considering objective measures of participation in local community, segregated institutional settings represent the worst accommodation option (McConkey et al. 2007). To achieve greater levels of this type of participation, therefore, this finding would support a policy of providing accommodation options in integrated settings within the general community rather than in segregated settings. In this regard, it was interesting to note that people living in group homes in the community engaged in more activities in the local community than people living independently or in family settings; however, this does not account for the quality of activities engaged in or the level of individual choice.

A third type of factor found to have significant influence on participation within local community is that of social support. While frequency of contact with family was the strongest predictor of social activity in the local community, having friends outside one's home also predicted higher levels of group membership. As such, social support

appears to have the potential to enhance participation within the local community. These results support previous findings by Bigby (2008), which suggested that the families who were most engaged with their family members with ID living in supported accommodation fulfil a role of monitoring well-being and support. Here, family contact appears to act in a supportive or oversight capacity for increased social activity in the local community, either by directly supporting activities or through an advocacy or surveillance-type role (as also noted in chapter 7). Therefore, while further research in this area is needed, services should support and facilitate greater contact with the family members of people with ID who they support. The finding which associates increased membership of community groups with having non-resident friends also encourages intervention initiatives that aim to engender and support friendships outside the home for people with ID. While there is evidence of the success of these types of 'befriending' interventions, little evaluation has been undertaken (Duggan and Linehan 2013); therefore, a more systematic approach in this regard is encouraged in future initiatives.

Several studies have noted that increased community activity or interaction doesn't necessarily guarantee better quality of life outcomes for individuals (Hammel et al. 2008, Kozma et al. 2009, Badia et al. 2013, Amado et al. 2013). This speaks to the complexity of community and social participation, which is highlighted by the multi-factorial influences identified in this study. Indeed, mention should also be given to important factors not included in the models explored here (which relate to the *Environmental Factors* highlighted in the WHO's ICF), primarily the quality of staff support and the values and culture of support services (Felce and Emerson 2001, Emerson and McVilly 2004, McConkey and Collins 2010). However, in identifying the influence of this range of factors there also remains the need to include subjective outcome measures of community living in order to truly assess the impact that

increased participation has on people's lives (Cummins and Lau 2003, Hall 2009, Cobigo et al. 2012, Overmars-Marx et al. 2014). Subjective assessment of social participation is examined in chapter 10 of the thesis.

The context of local community considered here and throughout the literature often identifies difficulties that people with ID have in participating within that environment; thereby locating the 'problem' primarily within people with intellectual disability (Bigby 2012). An approach more in keeping with the social model of disability (UPIAS 1975, Oliver 1996) and with the biopsychosocial approach of the ICF, would consider the environmental factors within this also. As such, it should consider also how the local community environment may be disabling individuals with cognitive impairments and thereby excluding them from participating. This approach would consider ways in which the local community may need to change in order to include people with intellectual disabilities, rather than the reverse. Craig and Bigby (2015) recently noted the difficulty in trying to balance the need for specific accommodations and supports to facilitate involvement by people with intellectual disabilities in local community groups, with the primary purposes of such groups and the needs of their existing members. It highlighted the potential for successful inclusion, but also the work required to achieve this and the inertia of the status quo that may exist amongst the general community in the face of difference. This is a field of enquiry that needs particular attention in future research about participation of people with intellectual disability in their local community (Amado et al. 2013).

Chapter 9. Participation in Interpersonal Relationships

9.1 Introduction

This chapter examines participation in interpersonal relationships by older people with intellectual disability, with a focus on relationships and interactions with family, friends and others including co-residents, support staff and neighbours. Within the theoretical framework, these measures relate primarily to the ICF section *Interpersonal Interactions and Relationships* (d7). In the ICF these consist of *general interpersonal interactions*, which includes basic interactions (e.g. respect, tolerance, social cues, physical contact) and complex interactions (e.g. forming and terminating relationships, social rules, maintaining social space); and also *particular interpersonal interactions*, including: relating with strangers; formal relationships (with people in authority, subordinates, and equals); informal social relationships (with friends, neighbours, acquaintances, co-inhabitants, and peers); family relationships; and intimate relationships (World Health Organization 2001b) (see Appendix 1). Within a supports model this may include: family/natural supports (extended family, friends, neighbours); informal supports (e.g. voluntary groups); and formal supports (e.g. services) (Department of Health 2011). As such, in the context of this chapter, the policy focus on 'natural supports' is of particular relevance (Tatlow-Golden et al. 2014, Department of Health 2011).

The chapter begins by reviewing the relevant literature; then the specific methods that apply to this part of the study are outlined; results are presented and then these are discussed within the literature and policy context.

9.1.1 Interpersonal Relationships for People with Intellectual Disability

Recent studies have confirmed that people with ID have smaller social networks and less engagement in interpersonal relationships than people without ID (McCarron et al. 2011, Amado et al. 2013, McCausland et al. 2016). The literature over the last 20 years

has also identified a number of factors that mitigate or exacerbate these experiences for people with ID. Living in smaller residences and/or location within the general community may be beneficial for social connectedness compared to larger institutions and congregated settings (Emerson and Hatton 1996, Young et al. 1998, Walsh et al. 2007, Emerson 2004); although very few who relocate to community settings make new friends there (Bigby 2008). Some congregated settings such as village communities have potential for better outcomes of this type (Mansell and Beadle-Brown 2009b); and social contact may be more influenced by proximity to family and other personal characteristics rather than residential setting (Kozma et al. 2009). An individual's ability and adaptive behaviour is highly influential in defining personal relationships and social contacts, whereby those with more severe disabilities have more limited networks and interactions (Mansell and Beadle-Brown 2009a, Felce and Emerson 2001); and staffing and active support also influence social networks and engagement (Kozma et al. 2009, Walsh et al. 2010, Amado et al. 2013).

9.1.1.1 The Make-up of Social Networks

There is little consistency in approaches to measuring social networks in the ID literature; and this results in a degree of variation in figures identified. When staff relationships are excluded, social networks of approximately 2-3 people are reported for people with ID (Dagnan and Ruddick 1997, Robertson et al. 2001) with size of network influenced most by level of ID. Kamstra et al. (2015) found an average informal (i.e. excluding staff) network size of 5.1 amongst people with profound intellectual and multiple disabilities (PIMD); 79.4% of contacts were family, and of the remainder 9.5% were volunteers, 2.2% were people with ID, and 8.9% were 'other' (including friends without disabilities and other contacts). However, Forrester-Jones et al. (2006) recorded an average network size of 22 when staff were included; staff represented 43% of the network, other service users with ID 25%, family members 14%, and social

acquaintances and other friends 11%. McCausland et al. (2014) found a sizeable minority of older people with ID (43.4%) had no friends outside their own home, and that for most their main social activities were with keyworker/support staff (75.4%) or friends within their house (53.4%), compared to 32% with family and 16.8% with friends outside their house. Others have also reported that staff were the main providers of emotional as well as practical support (Forrester-Jones et al. 2006). McConkey et al. (2007) found that people with ID were more likely to have friends outside their home in all other accommodation settings compared to campus-based residences, with people in clustered supported living the most likely to have such friends; while people with higher social competence and female respondents were also more likely to have non-resident friends. McVilly et al. (2006) noted that people with ID who required behavioural support had very poor or non-existent social networks outside their own immediate family and paid support staff.

The majority of studies on intimate relationships of people with ID focus on people with mild disability (Verdonschot et al. 2009). On one hand, studies report that the vast majority of people of all levels of ID are not in intimate relationships – e.g. 97% of all people with ID (Umb-Carlsson and Sonnander 2006) or 99% of older people with ID (McCausland et al. 2014) were single. On the other hand, Maughan et al. (1999) found that, at age 33, almost three-quarters of women (74.7%) and three out of five (61.8%) men with mild ID were living with a partner; and by the same age, 90.2% of women and 63.4% of men with mild ID had had a child. Hall et al. (2005) found that 73% of people with mild ID were married, but those with severe ID were unlikely to marry or have any children. By comparison, TILDA have reported that 92% of the older general Irish population were married or have been married (Nolan et al. 2014); of those who ever marry nine out of ten have children (Kamiya and Sofroniou 2011); and almost three-

quarters of older people live either very close or close proximity to their children, with 36% having co-resident children (Kamiya and Timonen 2011).

9.1.1.2 Frequency of Interactions

In a sample of 1542 adults with intellectual disability living in a range of different supported accommodation in England, Emerson and McVilly (2004) identified a median number of two friendship activities with friends with ID and zero activities with friends without ID during a four-week period, and concluded that setting characteristics were more strongly related to outcomes than personal characteristics. Living in institutional settings has also been associated by others with less frequent contacts with family than in other settings (Ashman and Suttie 1996, Spreat and Conroy 2001, McCausland et al. 2016). McConkey et al. (2007) found that people living in campus settings were the least likely to have had a visitor to their home within the previous month and the most likely to be socially isolated; people in clustered accommodation were most likely to have a visitor and least likely to be socially isolated; females and people aged under 50 were also more likely to have visitors; and people with the lowest social competence were most likely to be social isolated. The review by Mansell and Beadle-Brown (2009b) found that campus or clustered housing was superior to dispersed housing with regard to contact with family, visitors to one's home and satisfaction with relationships; however superior outcomes related primarily to village communities (which chiefly served people with less severe disabilities) rather than other campus or clustered housing. Emerson (2004) noted that while clustered housing resulted in fewer friendship activities than dispersed housing, there were no differences with regard to friendship activities with other people with ID; although previous research had found clustered housing was associated with having fewer friends with ID (Emerson et al. 2000). Kozma et al. (2009) concluded that family contact was related to distance from the family home and personal characteristics such as ability and age, rather than

residential setting. Overall, probably because of such low levels of contact and the intervening variables described, findings on the role of setting have been somewhat equivocal.

9.1.1.3 Quality of Relationships

McVilly et al. (2006) reported that people with ID identified moral character, effective communication and understanding as valued traits of a friend; friendship included joint leisure activities and both practical and emotional support. They also found that support in developing and maintaining friendships was important as was perceived similarity and equality, with people with ID noting greater 'comfort' among other people with ID and the possibility for 'true friendship' when they shared a sense of identity. Staff have been identified as the primary social companion and the biggest source of confidants for older people with ID in Ireland (McCausland et al. 2014, McCausland et al. 2016). Superficiality (or the non-existence) of relationships that people with ID had with people other than family, peers with ID or support staff has been noted (Emerson and Hatton 1996, McVilly et al. 2002). However, other studies have identified the potential of fleeting 'encounters' with members of the general public to extend social networks (Bigby 2015, Bigby and Wiesel 2011).

Simplican et al. (2015) identified reciprocity and intensity as key structural qualities of interpersonal relationships within a model of social inclusion for people with ID, alongside other qualities such as network size and frequency of contacts. For the ID and general populations, reciprocity within relationships and providing support to others has been described as central to inclusion and able to positively influence quality of life (Overmars-Marx et al. 2014, Hall 2009, Hammel et al. 2008, McCrory et al. 2014). While staff relationships can provide more support for people with ID in terms of confiding and company, and provide closer and more frequent relationships than others including with other people with ID, such relationships are less likely to be reciprocal

than those with other people with ID (Forrester-Jones et al. 2006). With regard to reciprocity in relationships with those outside the home, in a sample of older adults with ID, a minority reported either giving (13.1%) or receiving help (14.7%) to/from friends or neighbours (McCarron et al. 2011); and this was lower than rates of giving (23%) and receiving help (17%) reported amongst the general older population (Barrett et al. 2011).

There is no single clear message emerging from the literature in relation to the interpersonal interactions and relationships of people with intellectual disabilities. While several studies point to larger networks and increased social contacts for people living in smaller and community-based residences, there is also evidence of highly confounding factors related to personal ability and type of service provided. A lack of consistency in approach to the study of this area, and more broadly in the study of social participation or social inclusion (Verdonschot et al. 2009, Amado et al. 2013), also contributes to a lack of definitive conclusions in this complex area. Comparison by residence is also made difficult by the differences of populations living in different types and location of settings (Mansell and Beadle-Brown 2009b). Clearly, more work is needed to better understand these phenomena. This chapter aims to develop our understanding of interpersonal relationships of older people with ID in Ireland, and of the factors associated with this element of social participation for this population.

9.2 Methods

Details of the overall study methodology were previously outlined in chapter 3. This section provides additional detail on the measures used that relate specifically to interpersonal relationships and interactions, and the procedures used to examine these aspects of participation.

9.2.1 Measures

The measures used in this part of the study are outlined in Figure 9.1 below, along with reference to the specific part of the ICF theoretical framework to which each measure maps. Respondents identified participants in their social activities from a choice of: family; friends within your house; friends outside the house; keyworker/ support staff; other. Existing family members and their proximity were identified as: lives with me; in same building; in same neighbourhood; in different neighbourhood but same county; in different county; in different country. For each non-resident family member, frequency of face-to-face and phone contact was recorded. Participants responded yes/no to having any friends outside their own home, and frequency of face-to-face and phone contact with any non-resident friends was recorded. Regarding support to family, participants were asked if they provided support/ help to a family member (yes/no); those who said yes were asked who they supported, what type of support they provided (day to day support; shopping; remembering day to day items and events; mobility; emotional support; financial support; full support; other), and how satisfied they were providing this support (very satisfied; satisfied; not satisfied). Participants responded yes/no to whether they had given/received any help to/from friends or neighbours in the previous two years.

An additional series of self-report only questions were asked of respondents who could answer for themselves. These included four adapted items from the UCLA Loneliness scale (Russell 1996) which asked if respondents ever felt lonely, left out, isolated, or found it difficult to make friends (yes/no to each); if they had someone they could confide in (yes/no), and if so who (spouse/partner; parent; sibling; grandparent; aunt/uncle; cousin; friend; neighbour; keyworker/support worker; advocate; other).

Figure 9.1. Measures used – interpersonal interactions and relationships

Question	ICF Reference
Who are your main social activities with?	d740/d750/d760
What family do you have?	d760/d770
Where does your family live in relation to you?	d760/d770
How often do you meet up with (non-resident) family members?	d710/d720/d760
How often do you speak on the phone with (non-resident) family members?	/d770
Do you have friends outside your home?	d750
How often do you meet up with your (non-resident) friends?	d710/d720/d750
How often do you speak on the phone with your (non-resident) friends?	d710/d720/d750
Do you ever feel lonely? (SR ²)	d750/d760/d770
Do you ever feel left out? (SR)	d750/d760/d770
Do you find it difficult to make friends? (SR)	d730/750
Do you ever feel isolated? (SR)	d750/d760/d770
Do you have someone in whom you can confide? (SR)	d710/d720/750
- Who do you confide in?	/d760/d770
Do you provide support/help to a family member?	d660/d710/d720
- Who do you provide support/help to?	/760
- What support do you provide?	
- How satisfied are with providing support?	
In the last two years did your neighbours or friends give you any kind of help?	d660/d710/d720
In the last two years did you give any kind of help to your neighbours or friends?	/d730
	d750/d910

9.2.2 Analysis

Frequencies and bivariate associations were initially examined. Proximity to family was recoded as a binary variable: inside neighbourhood; outside neighbourhood. Face-to-face and phone contact were combined for contact with non-resident family and contact with non-resident friends. Frequency of both family and friends contact were recoded

² SR = self-report only question

as: at least once a week (weekly); less than once a week but at least once a month (monthly); and less often than once a month (<monthly). A binary logistic regression was used to identify factors associated with having non-resident friends. A multinomial regression was performed to identify factors that predict levels of contact with non-resident family.

Independent variables included in the bivariate and regression analyses, were: gender; age; level of ID (mild; moderate; severe-profound levels); type of residence (grouped as: independent/family; community group home; institutional); self/proxy-rated physical and mental health (excellent; very good; good; fair; poor); communication difficulty (higher; lower); literacy difficulty (higher; lower); ADL limitation and IADL limitation (higher; lower).

9.3 Results

Results are laid out according to relationships and interactions with family, then with regard to friends and other people, and then self-reported feelings of inclusion or exclusion are examined.

9.3.1 Relationships with Family

9.3.1.1 What family members

Most respondents reported having sisters (77%, n=538), brothers (70.4%, n=492) and a niece/nephew (53.2%, n=372), with a further 25.3% (n=177) reporting having cousins. Given the age profile of respondents, it was not surprising that just under a quarter reported having a mother (24.6%, n=172) and just 9.3% (n=65) had a father. A further 15.9% (n=111) had an aunt/uncle and a further 2.9% (n=20) had other family. All but 3.7% (n=26) reported having family of some kind, but in contrast with the general population less than 1% (0.9%, n=6) reported having a spouse/partner. While

the number of people who had family decreased with age, a large majority of even the oldest group (aged 65 years and older) still had some family (91.2%, n=135).

9.3.1.2 Proximity to family

Only 1 in 5 respondents lived close to family, either living with them (10.9%, n=73) or in the same neighbourhood (10.1%, n=68). The large majority of respondents lived further away from family, with their nearest family member living either in a different neighbourhood within the same county (47%, n=315) or outside the county (31.9%, n=214). In the bivariate analyses more of the youngest group, those with mild level of ID and those living in independent/family residences were living within the same neighbourhood as family. The number living in a different neighbourhood to their nearest family member increased with level of ID, from 68.8% (n=99) for mild ID to 81.6% (n=234) for moderate ID and 86.1% (n=161) for severe-profound ID. Rates of living in a different neighbourhood than family were almost identical for people living in community group homes (89.7%, n=262) and institutional residences (89.9%, n=239), compared to just 25% (n=28) for people living in independent/family residences.

9.3.1.3 Contact with non-resident family

Level of contact that respondents had with non-resident family was examined. In bivariate analyses (Table 9.1) respondents aged under 65 years, those with mild ID and those living in independent/family residences had substantially higher rates of regular family contact. Likewise, those with less difficulty with ADLs, IADLs, communication and functional literacy had higher rates of weekly contact. Some of the biggest differences in rates of weekly contact were for those living in the same neighbourhood as family (69.9%, n=95) as opposed to living outside their neighbourhood (31.95, n=169). Respondents who had friends outside their own home also had significantly higher rates of weekly family contact (47.7%, n=178) than those who had no such friends (30.2%, n=87).

A multinomial regression was also performed to identify which factors predicted level of family contact. The model explained 32% (Nagelkerke r^2) of the variance in the outcome variable. The outcome variable had three categories of contact with non-resident family: (at least) weekly; (less than weekly but at least) monthly; and less often than once a month. As Table 9.2 shows, proximity to family was the strongest predictor of both levels of family contact. After this, people with greater IADL limitation (OR=3.28), those aged 65 years and older (OR=2.83), and people with greater communication difficulty (OR=2.70) were all more likely to have the lowest level of family contact. Neither type of residence nor level of ID were significant once all other factors in the model were controlled for.

Table 9.1. Bivariate associations with level of contact with non-resident family

	Level of Family Contact		
	Weekly	Monthly	< Monthly
Gender		(n=667, p=0.72)	
Male	38.2	24.6	37.2
Female	41.2	22.7	36.1
Age		(n=667, p<0.001)	
43-64	43.2	23.6	33.2
65+	26.9	23.1	50.0
Level of ID		(n=615, p<0.001)	
Mild	56.6	22.1	21.4
Moderate	41.7	25.1	33.2
Severe-Profound	23.0	21.9	55.1
Type of Residence		(n=667, p<0.001)	
Independent /Family	68.2	14.0	17.8
Community Group Home	39.9	27.6	32.4
Institution	28.5	22.8	48.7
Physical Health		(n=656, p=0.10)	
Very Good-Excellent	41.4	26.7	31.9
Good	36.9	20.1	43.0
Fair-Poor	38.0	25.0	37.0
Mental Health		(n=647, p=0.05)	
Very Good-Excellent	46.7	24.3	29.0
Good	36.5	25.6	38.0
Fair-Poor	36.8	21.1	42.1
Communication Difficulty		(n=630, p<0.001)	
Lower	54.7	23.2	22.1
Higher	30.5	23.4	46.0
Literacy Difficulty		(n=636, p<0.001)	
Lower	60.0	18.2	21.8
Higher	36.3	24.7	39.0
ADLs Limitation		(n=618, p<0.001)	
Lower	44.3	23.2	32.5
Higher	24.2	25.5	50.3
IADLs Limitation		(n=635, p<0.001)	
Lower	57.6	23.7	18.7
Higher	25.6	24.1	50.3
Family Proximity		(n=665, p<0.001)	
Same Neighbourhood	69.9	15.4	14.7
Outside Neighbourhood	31.9	25.7	42.3
Friends Outside Home		(n=661, p<0.001)	
Yes	47.7	21.4	30.8
No	30.2	26.0	43.8
Total (n=667)	39.9	23.5	36.6

Table 9.2. Factors associated with level of contact with non-resident family (n=488)

	<u>LEVEL OF FAMILY CONTACT¹</u>			
	At least once a month		Less than once a month	
	OR (95% CI)	p-value	OR (95% CI)	p-value
Gender				
Male	1.0		1.0	
Female	0.76 (0.46-1.26)	0.29	0.86 (0.53-1.41)	0.56
Age				
< 65 years	1.0		1.0	
65+ years	1.52 (0.78-2.95)	0.21	2.83 (1.51-5.29)	0.001
Level of ID				
Mild	1.0		1.0	
Moderate	0.93 (0.49-1.75)	0.81	1.06 (0.53-2.14)	0.86
Severe-Profound	1.57 (0.66-3.70)	0.31	1.79 (0.74-4.29)	0.19
Type of Residence				
Independent/Family	1.0		1.0	
Community Group Home	1.17 (0.47-2.86)	0.74	0.77 (0.28-2.13)	0.62
Institutional	1.03 (0.39-2.71)	0.95	0.83 (0.29-2.39)	0.73
Physical Health				
Very Good-Excellent	1.0		1.0	
Good	0.69 (0.39-1.22)	0.20	1.11 (0.64-1.93)	0.71
Fair-Poor	0.73 (0.34-1.55)	0.41	0.50 (0.23-1.06)	0.07
Mental Health				
Very Good-Excellent	1.0		1.0	
Good	1.22 (0.67-2.22)	0.51	1.19 (0.65-2.19)	0.58
Fair-Poor	1.02 (0.52-2.03)	0.94	1.38 (0.70-2.70)	0.35
Communication Difficulty				
Lower	1.0		1.0	
Higher	1.23 (0.67-2.27)	0.50	2.70 (1.49-5.04)	0.002
Literacy Difficulty				
Lower	1.0		1.0	
Higher	1.51 (0.72-3.20)	0.28	0.77 (0.35-1.72)	0.53
ADLs Limitation				
Lower	1.0		1.0	
Higher	1.62 (0.79-3.34)	0.19	1.18 (0.61-2.29)	0.63
IADLs Limitation				
Lower	1.0		1.0	
Higher	1.08 (0.56-2.08)	0.82	3.28 (1.72-6.27)	<0.001
Proximity to Family				
Same Neighbourhood	1.0		1.0	
Outside neighbourhood	2.99 (1.45-6.14)	0.003	11.60 (4.82-27.95)	<0.001
Friends Outside Home				
Yes	1.0		1.0	
No	1.20 (0.69-2.07)	0.51	1.01 (0.59-1.72)	0.97

¹Reference category is contact at least once a week
Nagelkerke $r^2=0.32$

$p<0.05$ is significant. All significant factors in bold

9.3.1.4 Support to family

Less than one in five respondents (17.0%, n=118) said they supported a family member, with significant differences in rates based on age, ID level and residence ($p < 0.001$). Rates of providing support were highest for the youngest group (aged 43-49: 28.1%, n=55), compared to the middle age group (aged 50-64: 15.3%, n=54) and respondents aged 65 years and older (6.2%, n=9). There was a similar pattern regarding level of ID, from 31.4% (n=48) for people with mild ID to 16.5% (n=49) for people with moderate ID and just 3.2% (n=6) for people with severe-profound ID. As may be expected, there was a big difference in rates of supporting family between those living in independent/family settings (59.8%, n=67) and those living in community group homes (12.9%, n=39) and institutional settings (4.3%, n=12). The family member supported most often was a sibling (58.5%, n=69), followed by mother (40.7%, n=48) and father (12.7%, n=15). Day-to-day support (62.9%, n=73) was the most common type of support provided, followed by emotional support/companionship (48.3%, n=56), help with shopping (41.4%, n=48), and with remembering daily items and events (21.6%, n=25). Finally, all respondents who said they supported family (n=115) said that they were either very satisfied (73.9%) or satisfied (26.1%) with providing help/support to their family member.

9.3.2 Relationships with Friends and Others

9.3.2.1 Friends outside your own home

Just over half of respondents (56.6%, n=392) said they had friends outside their own home. People living in independent/family residences were more likely to have non-resident friends (86.6%, n=97) compared to people living in community group homes (59.7%, n=181), while those in institutional/congregated settings had the lowest rates (41.0%, n=114; $p < 0.001$). Around one-third of respondents with severe-profound ID (34.4%, n=65) had non-resident friends, increasing to over half for people with

moderate ID (57.9%, n=172) and more than three-quarters of people with mild ID (77.1%, n=118; $p < 0.001$). More women had non-resident friends (59.8%, n=232) than men (52.5%, n=160), but this difference fell just outside statistical significance ($p = 0.05$). There were no statistically significant differences based on age.

A binary logistic regression was performed to identify the factors that predict having non-resident friends. The model explained 30% (Nagelkerke r^2) of the variance in having non-resident friends (Table 9.3). Type of residence was by far the strongest factor; people living in independent/family residences were more than 17 times more likely to have non-resident friends than people living in institutional residences, while those living in community group homes were also more likely to have non-resident friends than those in institutions but to a far lesser extent (OR=1.67). People with less difficulty with literacy were more likely to have non-resident friends than those with greater difficulty (OR=2.84); as were people with a lower level of IADL limitation (OR=2.10); and people with 'good' mental health (OR=2.19). Notably, level of ID was not significant in the model when other factors were controlled for.

Table 9.3: Factors associated with having non-resident friends (n=488)

	Have Friends Outside Your Home ¹	
	Odds Ratio (95% CI)	p-value
Gender		
Female	1.0	
Male	0.73 (0.48-1.10)	0.13
Age		
65+ years	1.0	
< 65 years	0.95 (0.57-1.59)	0.84
Level of ID		
Severe-Profound	1.0	
Moderate	1.25 (0.74-2.10)	0.41
Mild	1.62 (0.77-3.41)	0.20
Type of Residence		
Institutional	1.0	
Community Group Home	1.67 (1.07-2.60)	0.02
Independent/Family	17.06 (5.05-57.64)	<0.001
Physical Health		
Fair-Poor	1.0	
Good	0.67 (0.36-1.24)	0.20
Very Good-Excellent	0.97 (0.52-1.81)	0.93
Mental Health		
Fair-Poor	1.0	
Good	2.19 (1.31-3.65)	0.003
Very Good-Excellent	1.34 (0.76-2.37)	0.31
Communication Difficulty		
Higher	1.0	
Lower	0.99 (0.58-1.71)	0.99
Literacy Difficulty		
Higher	1.0	
Lower	2.84 (1.31-6.14)	0.008
ADLs Limitation		
Higher	1.0	
Lower	0.84 (0.49-1.44)	0.53
IADLs Limitation		
Higher	1.0	
Lower	2.10 (1.19-3.69)	0.01
Proximity to Family		
Outside Neighbourhood	1.0	
Same Neighbourhood	0.83 (0.42-1.65)	0.60
Contact with Family		
Less than monthly	1.0	
At least monthly	0.82 (0.47-1.40)	0.46
At least weekly	0.98 (0.57-1.67)	0.93

¹ Reference category: Do Not Have Friends Outside Your Home.

Nagelkerke $r^2=0.30$

$p<0.05$ is significant. All significant factors in bold.

9.3.2.2 *Contact with non-resident friends*

Participants who had non-resident friends were asked about their level of contact with these friends (n=390). Bivariate analyses revealed significant differences in relation to age, physical health, ADL and IADL limitation, learning difficulty and contact with family (Table 9.4). Respondents aged under 65 years were more likely to have weekly contact with their non-resident friends (75.8%, n=241) than those aged 65 years and above (58.3%, n=42). Also, people reporting very good-excellent (75.3%, n=149) or good health (74.3%, n=104) were much more likely to have weekly contact with non-resident friends than those reporting fair-poor health (57.4%, n=27), as were people with lower levels of limitation with ADLs (75.0%, n=219) and IADLs (79.5%, n=178) compared to those with higher levels of limitation in ADLs (65.6%, n=42) and IADLs (61.9%, n=91) and people with a higher level of difficulty with functional literacy (82.8%, n=82 versus 69.7%, n=189). Finally, people with weekly family contact were also more likely to have weekly contact with non-resident friends (82.0%, n=146) compared to those with monthly (68.4%, n=54) or less than monthly family contact (64.9%, n=74).

Table 9.4. Bivariate associations with level of contact with non-resident friends

	Level of Contact		
	Weekly	Monthly	< Monthly
Gender		(n=390, p=0.34)	
Male	76.1	10.7	13.2
Female	70.1	11.3	18.6
Age		(n=390, p=0.01)	
43-64	75.8	10.1	14.2
65+	58.3	15.3	26.4
Level of ID		(n=353, p=0.57)	
Mild	78.4	8.6	12.9
Moderate	71.5	12.2	16.3
Severe-Profound	67.7	13.8	18.5
Type of Residence		(n=390, p=0.05)	
Independent /Family	83.5	6.2	10.3
Community Group Home	71.5	11.2	17.3
Institution	64.9	14.9	20.2
Physical Health		(n=385, p=0.001)	
Very Good-Excellent	75.3	13.6	11.1
Good	74.3	9.3	16.4
Fair-Poor	57.4	6.4	36.2
Mental Health		(n=382, p=0.33)	
Very Good-Excellent	76.4	12.1	11.4
Good	74.1	9.6	16.3
Fair-Poor	65.8	13.2	21.1
Communication Difficulty		(n=380, p=0.13)	
Lower	75.5	8.3	16.2
Higher	68.8	14.8	16.5
Literacy Difficulty		(n=370, p=0.04)	
Lower	82.8	6.1	11.1
Higher	69.7	13.3	17.0
ADLs Limitation		(n=356, p=0.02)	
Lower	75.0	12.0	13.0
Higher	65.6	7.8	26.6
IADLs Limitation		(n=371, p<0.001)	
Lower	79.5	10.3	10.3
Higher	61.9	12.2	25.9
Family Proximity		(n=372, p=0.17)	
Same Neighbourhood	81.0	7.0	12.0
Outside Neighbourhood	71.3	11.0	17.6
Family Contact		(n=371, p=0.01)	
Weekly	82.0	6.7	11.2
Monthly	68.4	13.9	17.7
< Monthly	64.9	12.3	22.8
Total (n=390)	72.6	11.0	16.4

9.3.2.3 Participants in social activities

When respondents were asked about the other participants in their social activities, the most frequently reported was *key worker/support staff* (75.4%, n=511), followed by *friends within my house* (53.4%, n=362), *family* (32.0%, n=217) and *friends outside my house* (16.8%, n=114). In bivariate analyses there were significant differences in rates of socialising with support staff by level of ID and type of residence ($p < 0.001$). More than nine out of ten respondents with severe-profound ID (91.1%, n=163) identified staff, compared to three-quarters of people with moderate ID (74.5%, n=219) and just over half of those with mild ID (56.2%, n=86). There were similar rates for people living in community group homes (83.2%, n=248) and institutional/ congregated settings (85.8%, n=230), with lower rates of social activity with staff among people living in independent/family residences (29.5%, n=33). Socialising with co-resident friends varied by type of residence. While just 16.1% (n=18) of respondents living in independent/family residences said they socialised with such friends, over half of people living in institutional residences (57.8%, n=155) and approaching two-thirds of people in community group homes (63.4%, n=189) did so.

Rates of social activities with family varied by age, level of ID and residence. Rates fell substantially as age increased, from 44.5% (n=85) for the 43-49 year old group, to under a third (32.3%, n=112) for the 50-64 group, and 14.3% (n=20) for the over-65 group ($p < 0.001$); and also in terms of level of ID, from 37.9% (n=58) for respondents with mild ID, to 32.7% (n=96) for moderate ID, and 21.2% (n=38) for severe-profound ID ($p = 0.003$). Differences were also large between different types of residence, at 64.3% (n=72) for people living in independent/family residences, 30.5% (n=91) in community group homes and 20.1% (n=54) in institutional settings ($p < 0.001$). Female respondents were more likely to socialise with non-resident friends (19.7%, n=75) than males (13.1%, n=39; $p = 0.022$) and rates also appeared influenced by ID level, at

23.5% (n=36) for respondents with mild ID, 17.0% (n=50) for moderate ID, and just one in ten (10.1%, n=18) for severe-profound ID (p=0.004).

9.3.2.4 *Confidants*

A self-report only question (n=390) asked participants if they had anyone with whom they could confide in or talk to about private matters. Most of these respondents (83.8%, n=327) said that they did. Amongst those who answered, almost all respondents with mild ID (97.7%, n=126) said they had a confidant, compared to eight in ten respondents with moderate ID (82.3%, n=154), and just 38.5% (n=15) of those with severe-profound ID. With regard to residence, rates dropped from a high of 97.8% (n=89) of people living in independent/family residences to 82.3% (n=163) for community group homes and 74.3% (n=75) for institutional settings. Participants who answered yes to having a confidant were further asked who their confidant was. The most frequently cited confidant for respondents was keyworker/support staff (73.7%, n=241), followed by siblings (26.3%, n=86), friends (11.6%, n=38) and parents (8.0%, n=26).

9.3.2.5 *Help received from and given to friends and neighbours*

Just 13.3% (n=92) of respondents said that they had received help from friends or neighbours within the previous two years; and 12.4% (n=86) said they had given any such help. Help *received* was higher for people with mild ID (29.5%, n=44) compared to moderate ID (10.8%, n=32) and severe-profound ID (4.2%, n=8); and people living in independent/family residences (29.7%, n=33) had much higher rates than respondents living in either community group homes (12.3%, n=37) or institutional settings (7.9%, n=22). Similarly, help *given* to friends or neighbours was higher for people with mild ID (27.5%, n=41) compared to people with moderate ID (10.5%, n=31) and severe-profound ID (2.1%, n=4); and higher for people living in independent/family residences

(26.8%, n=30) compared to community group homes (10.7%, n=32) and institutional settings (8.6%, n=24).

9.3.3 Feelings of Exclusion

A series of questions about feelings of exclusion were asked to self-reporting respondents. Of those who answered, 44.8% (n=159) said they sometimes feel lonely, 26.4% (n=87) said they sometimes feel left out, 25.3% (n=76) said they sometimes feel isolated, and 27.3% (n=90) said they found it difficult to make friends. There were no statistically significant differences related to age, level of ID or residence, but more than half of female respondents (52.7%, n=107) said they sometimes feel lonely, compared to just over a third of males respondents (34.2%, n=52; $p=0.001$). When the four items were summed, almost six out of ten respondents had answered yes to one (27.9%, n=102) or more (31.0%, n=113) of the items. There were no significant differences between the summed items and either age, ID level or residence; while gender differences fell just outside statistical significance ($p=0.059$).

9.4 Discussion

This chapter examined a number of elements of participation that relate specifically to interpersonal interactions and relationships. A striking aspect of the findings here is the difference in the intimate social networks related to immediate family for older people with ID compared to the general population. While 92% of the general older population in Ireland are or have been married (Nolan et al. 2014), less than 1% of the older ID population reported they had a spouse/ partner, which is similar to rates reported by Umb-Carlsson and Sonnander (2006) but lower than those of people with mild ID reported elsewhere (Maughan et al. 1999, Hall et al. 2005). Additionally, just 2% of the IDS-TILDA sample reported that they had a child. Older people with ID, therefore, do not have an intimate network provided by spouses/partners, children or grandchildren,

nor the local contacts opened up through schools, sports clubs and friends that children develop; instead they are reliant on parents, siblings, nieces and nephews as their primary source of family.

More than two out of five respondents reported having no friends outside their own home. Findings here suggest that support staff and co-resident friends take the place of immediate family and other friends for older people with ID, particularly those living in institutional settings and community group homes. This raises a number of complexities that need further exploration. For example, staff are first and foremost employees who are paid to provide a support service to people with ID in these environments. While they may develop close relationships with the people they support, transfer or retirement will impact relationships in ways that 'friendships' normally don't. There may be issues of power (Cummins and Lau 2003), mutuality (Forrester-Jones et al. 2006, Simplican et al. 2015) or longevity (Bigby 2008) that impinge on these relationships, and this may extend to relationships with volunteers or professional advocates. However, along a continuum from very good to very bad experiences, the potential exists for mutually supportive relationships between people with ID and their support staff, and for some people with ID this may be the only validating relationship in their lives (Marquis and Jackson 2000). The nature and importance of these relationships requires further investigation in future research (Amado et al. 2013).

While 96% of respondents had family available, less than a third said that family members participated in their social activities. The relative importance of co-resident friends compared to other contacts may support previous findings by McVilly et al. (2006) about the importance of shared identity in forming friendships for people with ID, an idea supported in the sociological literature on community, where certain types of community develop based upon the symbolic focal point of a perceived and recognised

shared culture or shared identity (Crow and Maclean 2006, Delanty 2003, Cohen 1985, Anderson 1983) (see section 3.4). However, data here in this regard is limited and further research is required to explore the quality and importance of these relationships for this population.

Proximity to family emerged as the strongest predictor of frequency of family contact, ahead of factors related to personal ability or age, while type of residence was not significant when other factors were controlled for. This supports previous findings by Kozma et al. (2009) and when considered alongside findings of better social interactions in village communities (Mansell and Beadle-Brown 2009b) and clustered supported housing (McConkey et al. 2007) it suggests that the issue is less about accommodation and more about support solutions for people with ID when family and other natural supports are not available. This may be further reinforced by findings here which suggest that, across a range of social measures, there is not a huge difference between outcomes for people living in institutional/ settings and those living in community group homes. In measures of family proximity, family contact, having friends outside your home, socialising with staff and co-resident friends, and help from/to friends or neighbours, the findings for community group homes were much closer to those for institutions than they were for independent/family settings. This, again, suggests that outcomes may be more influenced by factors other than type or location of dwelling. It also raises the question considered by Ben-Moshe (2011) about the contested meaning of 'institution' (as well as 'community'), and how some may see community-based group homes as institutional while other see them as community.

Low rates of providing support to family, friends and neighbours in comparison with the general population mean that people with ID may be missing out on the benefits to quality of life of providing such supports (McCrary et al. 2014), as well as the type of reciprocal relationships that are important to inclusion (Overmars-Marx et al. 2014, Hall

2009, Hammel et al. 2008, Simplican et al. 2015) and which are central to a broader understanding of community (see section 2.5). In support of recent policy on community living in Ireland (Health Service Executive 2011), 'natural supports' have been identified as a means of supporting people with ID to live more independently and participate in the general community (Tatlow-Golden et al. 2014, Department of Health 2011). Findings here for an older population agree with Duggan and Linehan's (2013) conclusions that the scope of natural supports for people with ID is limited, and that this population remains largely dependent on the formal supports of service providers. Further investigation is needed on relationships that people with ID have with staff, both in terms of the type and nature of those relationships and also the degree to which staff remain a means of social support even where people live in residences within the general community. The finding of similarities between institutional and community group home settings also needs further exploration, particularly in the current Irish policy context where movement to the community is intended to build social support and engagement (Health Service Executive 2011). Finally, a broader consideration is needed about what we mean when we talk about 'community' - one which goes beyond spatial conceptions of living amongst the general community - if people with intellectual disability are to get the most from 'community living'.

Chapter 10. Subjective Outcomes of Social Participation

10.1 Introduction

The preceding findings chapters (4-9) measured the rates of social participation and their associated factors for older people with intellectual disabilities in Ireland; these addressed objectives 1 and 2 of the study. This chapter now addresses research objective 3 of the study, which is to: *Examine associations between objective measures of social participation and subjective outcomes for individuals*. In doing so it explores the potential impact or added value of social participation on the lives of individuals, beyond the objectively measured outcomes that have been examined thus far in chapters 4-9 of the thesis. This follows recommendations within the research literature that the social and community lives of people with intellectual disability should include subjective as well as objective assessment (Cummins and Lau 2003, Hammel et al. 2008, Cobigo et al. 2012, Cummins and Kim 2015).

10.2 Methods

Chapter 3 of the thesis outlined the methodology applied to the broader study, including the sampling strategy, measures used and analysis plan. This section builds on chapter 3 to outline additional aspects of the methodology that relate to the specific measures and procedures used here.

10.2.1 Measures

Data collection for this study (via IDS-TILDA) consisted of a mix of direct interviews with self-reporting participants, supported interviews where the participant was supported by another person, and proxy interviews in which someone who knew the participant answered on their behalf because they themselves were unable to (see section 3.3.5). A number of questions were self-report only (i.e. answered only by participants who could answer directly themselves); and some of these were subjective questions about how the participant felt about certain things (e.g. feelings of happiness

or loneliness) (as reported earlier in section 9.3.3). To avoid analysis being biased towards the most able in the overall sample, it was decided that the current study should exclude self-report only questions, and instead use a subjective outcome which included the full sample of respondents (i.e. which included self-report, supported and proxy responses).

Therefore, the relationship between measures of social participation and subjective outcomes for individuals reported here used '*self/proxy-rated emotional or mental health*' as the subjective outcome. The social participation measures assessed against this subjective outcome are among those that were previously identified throughout chapters 4-9 of the thesis. Figure 10.1 outlines both the subjective outcome and the social participation measures used in this chapter. Details of measures and coding for the social participation items was previously provided in the thesis section referenced in parenthesis.

Figure 10.1. Measures used – subjective outcome and social participation

Subjective Outcome Measure

- *Would you say your emotional or mental health is...?*
(Self/proxy-rated: excellent; very good; good; fair; poor)

Social Participation Measures

- ADLs Limitation – level of limitation with ADLs (see section 4.2)
 - IADLs Limitation - level of limitation with IADLs (section 4.2)
 - Communication Difficulty – level of difficulty with communication (section 4.2)
 - Literacy Difficulty – level of difficulty with functional literacy (section 4.2)
 - Level of Choice – level of choice-making in one's life (section 5.2)
 - Voted in Election – has voted in a recent election (section 5.2)
 - Independent Advocate – has an independent advocate (section 5.2)
 - Occupational Situation – active or non-active with regard to occupation (section 6.2)
 - Occupational Activity – level of occupation-related activity (section 6.2)
 - Social Activity – level of engagement in social activities (section 7.2)
 - Community Group Member – is a member of a local community group (section 8.2)
 - Community Activity - level of engagement in community-based social activities (section 8.2)
 - Community Participation – level of difficulty participating in local community (section 8.2)
 - Contact with Family – level of contact with non-resident family (section 9.2)
 - Friends Outside – has friends who live outside his/her own home (section 9.2)
 - Received Help – has received help from neighbours or friends in past 2 years (section 9.2)
 - Gave Help – has given help to neighbours or friends in past 2 years (section 9.2)
-

10.2.2 Analysis

For the purpose of analysis, the subjective outcome measure (self/proxy-rated emotional or mental health) was recoded into a binary outcome variable of: (1) good-excellent; and (2) fair-poor. Details of how the social participation measures were coded are provided in the sections referenced in Figure 10.1 above. Cross-tabulations were performed to explore the bivariate relationships between the subjective outcome measure and the objective measures of social participation, with chi-squared tests used to assess the statistical significance of the associations (where $p < 0.05$). A binary logistic regression was then performed to explore the association between the

subjective outcome and the measures of social participation, where the subjective outcome was the binary dependent variable in the model. Testing for multicollinearity between the social participation measures in Figure 10.1 was undertaken prior to running the regression model (see section 3.3.7.2 for procedures). A relatively strong correlation was found between some of these variables:

- Occupational situation and occupational activity ($r_s = 0.785$, $p < 0.001$);
- Social activity and community activity ($r_s = 0.694$, $p < 0.001$).

On this basis, two variables were excluded as independent variables in the regression model to prevent any potential problems with multicollinearity that could arise; namely, occupational activity and community activity. Therefore, the remaining 15 objective measures of social participation were added to the regression model as independent variables.

10.3 Results

Overall, almost three-quarters of respondents rated their emotional/mental health as good-excellent, and just over a quarter as only fair-poor. Table 10.1 outlines the bivariate relationships between the subjective outcome of self/proxy-rated emotional or mental health and 17 objective measures of social participation. This shows that the majority (12) of social participation measures were significantly associated with emotional or mental health. In the measures of social functioning, IADL limitation and difficulty with communication had significant differences; whereby those with lower levels of limitation/difficulty in these areas reported substantially better emotional or mental health. Two of the measures related to human rights and citizenship were statistically significant; where a higher level of choice-making and voting in elections were associated with having better emotional or mental health. Both of the measures related to education, training and occupation were also significant; with better

emotional or mental health linked to higher participation in these areas. Level of engagement in social activities was significant; with emotional or mental health improving steadily as the level of activity increased. A similar improvement was associated with higher engagement in community-based social activities. The other measures of local community engagement were also significantly associated with emotional or mental health: respondents who were members of community-based groups had substantially better emotional or mental health; as did people who reported no difficulty in engaging in their local community. Finally, two of the measures of interpersonal relationships were significantly associated with the subjective outcome. People who reported having friends outside their own home, and those who said they had received help from friends/neighbours, rated higher for emotional or mental health. People who gave help to neighbours/friends also had better emotional or mental health, but these differences fell just outside statistical significance ($p=0.06$). Overall, we can see significant differences in emotional or mental health for the majority of the objective measures examined in the bivariate analyses; suggesting that increased social participation is associated with better subjective outcomes for this population.

Table 10.2 outlines the findings of the binary logistic regression that explored relationships between self/proxy-rated emotional or mental health and a number of predictor variables of social participation. The model explained 12% of the variance (Nagelkerke r^2) in self/proxy-rated emotional or mental health. When all other independent variables were controlled for, the only significant factor in the model was having non-resident friends. People who have friends outside their own home are almost twice as likely as people who don't have such friends ($OR=1.91$) to have good-excellent emotional or mental health. Therefore, in this analysis of associations between social participation and subjective individual outcome, having friends outside one's own home is the strongest predictor of having better emotional or mental health.

Table 10.1 Bivariate associations with emotional or mental health

	Emotional or Mental Health	
	Good-Excellent	Fair-Poor
ADLs Limitation	(n=632, p=0.09)	
Lower	74.4	25.6
Higher	67.5	32.5
IADLs Limitation	(n=651, p=0.004)	
Lower	79.4	20.6
Higher	69.4	30.6
Communication Difficulty	(n=647, p<0.001)	
Lower	81.9	18.1
Higher	68.3	31.7
Literacy Difficulty	(n=651, p=0.08)	
Lower	80.9	19.1
Higher	72.9	27.1
Level of Choice	(n=633, p=0.01)	
Higher	78.9	21.1
Lower	69.6	30.4
Voted in Election	(n=652, p<0.001)	
Yes	84.0	16.0
No	70.0	30.0
Independent Advocate	(n=650, p=0.18)	
Yes	78.5	21.5
No	72.9	27.1
Occupational Situation	(n=664, p=0.005)	
Active	76.7	23.3
Non-Active	65.0	35.0
Occupational Activity	(n=658, p=0.001)	
Higher	86.7	13.3
Medium	74.0	26.0
Lower	66.4	33.6
Social Activity	(n=647, p<0.001)	
Higher	82.9	17.1
Medium	72.5	27.5
Lower	66.3	33.7
Community Group Member	(n=672, p=0.002)	
Yes	82.9	17.1
No	70.7	29.3
Community Activity	(n=635, p=0.01)	
Higher	80.0	20.0
Lower	71.2	28.8
Community Participation	(n=676, p<0.001)	
No Difficulty	85.8	14.2
Difficulty	70.0	30.0
Contact with Family	(n=647, p=0.16)	
At least weekly	75.6	24.4
At least monthly	76.8	23.2
Less than monthly	69.2	30.8
Friends Outside	(n=674, p<0.001)	
Yes	79.9	20.1
No	65.9	34.1
Received Help	(n=670, p=0.02)	
Yes	83.7	16.3
No	72.5	27.5
Gave Help	(n=671, p=0.06)	
Yes	82.6	17.4
No	73.0	27.0
Total (n=679)	73.9	26.1

Table 10.2. Factors associated with subjective emotional or mental health (n=439)

	Good-Excellent Emotional or Mental Health ¹	
	Odds Ratio (95% CI)	p-value
ADLs Limitation		
Lower	0.83 (0.46-1.52)	0.55
Higher	1.0	
IADLs Limitation		
Lower	0.63 (0.32-1.23)	0.18
Higher	1.0	
Communication Difficulty		
Lower	1.47 (0.79-2.76)	0.23
Higher	1.0	
Literacy Difficulty		
Lower	0.67 (0.31-1.46)	0.31
Higher	1.0	
Level of Choice		
Higher	0.72 (0.39-1.33)	0.30
Lower	1.0	
Voted in Election		
Yes	1.59 (0.79-3.18)	0.19
No	1.0	
Independent Advocate		
Yes	1.12 (0.63-1.99)	0.70
No	1.0	
Occupational Situation		
Active	1.52 (0.86-2.68)	0.15
Non-Active	1.0	
Social Activity		
Higher	1.80 (0.88-3.69)	0.11
Medium	1.19 (0.67-2.11)	0.55
Lower	1.0	
Community Group Member		
Yes	1.52 (0.77-3.00)	0.22
No	1.0	
Community Participation		
No Difficulty	1.84 (0.94-3.63)	0.08
Difficulty	1.0	
Contact with Family		
At least weekly	1.06 (0.60-1.89)	0.83
At least monthly	1.24 (0.66-2.31)	0.50
Less than monthly	1.0	
Friends Outside		
Yes	1.91 (1.14-3.19)	0.01
No	1.0	
Received Help		
Yes	1.36 (0.57-3.21)	0.49
No	1.0	
Gave Help		
Yes	0.80 (0.32-1.98)	0.62
No	1.0	

¹ Reference category: Fair-Poor Emotional or Mental Health.
Nagelkerke $r^2=0.12$. $p<0.05$ is significant. All significant factors in bold.

10.4 Discussion

Findings that almost three-quarters (73.9%) of older people with intellectual disability rated their emotional or mental health as good-excellent appears very positive; however, this is set in context by a substantially higher comparative rate of 90% for the general older population in Ireland (O'Regan et al. 2011). Therefore, we can say that older people with an intellectual disability have poorer overall emotional/mental health than the general older population³. From this starting point, the analysis has shown that a number of different aspects of social participation are significantly associated with this subjective outcome for older people with intellectual disabilities. This compares with similar findings that have linked better social outcomes with better subjective outcomes including quality of life in the general older population (McCrory et al. 2014) and for people with intellectual disability (Cummins and Lau 2003).

Across all 17 of the objective measures of social participation, higher participation implied better outcomes for emotional and mental health; although just 12 of these were statistically significant differences ($p < 0.05$). This significant positive association between social participation and subjective individual outcome was apparent across all of the different themes of participation presented in the thesis findings, including measures of: social functioning; human rights and citizenship; education, training and occupation; social activities; local community involvement; and interpersonal relationships. Potentially this is very positive, and suggests that improved social participation may bring with it better subjective outcomes for individuals. However, as has been highlighted in the findings of chapters 4-9, people with intellectual disability are often worse off in objective measures of social participation than people who do not have an intellectual disability. Thus, it is no surprise that older people with intellectual

³ Although a difference in the age profiles of samples should be noted here; the IDS-TILDA wave 2 sample included people with intellectual disability aged 43 years and above, while TILDA included people from the general population aged 50 years and above.

disability have worse subjectively-rated emotional or mental health than the general older population; although of course there are other factors associated with this.

In the regression analysis, the finding that having non-resident friends was the strongest predictor of emotional or mental health may be important in building upon previous studies, which identified that merely having social relationships was in itself important to quality of life (Schalock et al. 2002, Brown et al. 2013). However, measurement of subjective outcomes for human beings will invariably exclude important factors, and only a minority of the variance in the outcome variable is explained by the model. Thus, results of the regression may tell us more about the relative strengths of the predictor variables added to this particular model (in which having non-resident friends is the strongest), rather than their absolute value in the broader scheme of things. Therefore, while it is significant that having these friendships was the strongest predictor of better subjective outcome, this finding does nothing to negate previous studies which have highlighted the undoubted importance of other factors; which may include other aspects of social participation not included in the model here, and environmental factors such as service design, staffing and active support (Felce and Emerson 2001, Mansell et al. 2002, Mansell et al. 2008, Fyffe et al. 2008, Kozma et al. 2009, Walsh et al. 2010, Mansell and Beadle-Brown 2012, Amado et al. 2013); while individual preferences and constraints may also influence subjective outcomes (Badia et al. 2013). Clearly, therefore, further investigation of the subjective outcomes of social participation for this population is needed, particularly in the context of implementing research that uses a valid theoretical framework such as the ICF.

Nonetheless, this finding supports calls in recent policy for the type of inclusion supports that will allow people with intellectual disability to build relationships and develop their social networks in community settings (Health Service Executive 2011); with this expected to benefit individual wellbeing. However, it is important here to

distinguish between the ideas of simply 'exposing' people with intellectual disability to the wider community, which has shown to yield limited benefit (Emerson and Hatton 1996, McVilly et al. 2002, Cummins and Lau 2003, Bigby 2008, McCarron et al. 2011), and building friendships that impact upon people's wellbeing. Furthermore, while 'natural supports' have been identified in policy as a means of supporting greater participation in the local community (Tatlow-Golden et al. 2014, Department of Health 2011), findings noted previously in chapter 9 agreed with conclusions by Duggan and Linehan (2013), that the scope of natural supports for people with intellectual disability is limited and this population remains largely dependent on the formal supports of service providers. As such, the need remains for the provision of formal supports, including independent advocacy and person centred approaches, that may provide the platform for people with intellectual disability to develop wider friendships and improve their overall wellbeing.

Moving forward, subjective outcome measures should be included in research related to social and community participation for people with intellectual disabilities. This ties in with deeper understandings of community discussed earlier (section 2.5), where subjective feelings of bonding with other people and a sense of belonging are central to the development of community; and follows similar calls for the consideration of the subjective experience of inclusion and integration for people with intellectual disability (Cummins and Lau 2003, Hammel et al. 2008, Cobigo et al. 2012, Cummins and Kim 2015).

Research into the quality of relationships that people with intellectual disabilities have is needed to identify the deep and lasting friendships that can influence their subjective outcomes, rather than simply counting numbers of people in social networks and frequency of contacts. This should not preclude any relationships which may be valued by individuals with intellectual disability, and thus may include relationships or

friendships with co-resident peers and support staff. Findings here and previous studies have shown that these relationships remain important social outlets for older people with intellectual disabilities, and that the nature of these requires further investigation (Amado et al. 2013, McCausland et al. 2016).

Section C: Discussion & Conclusions

Chapter 11. Discussion

11.1 Introduction

This chapter draws upon the findings laid out in chapters 4-10 of the thesis, to discuss their implications in the context of current policy and the research literature. As identified in section 2.2 of the literature review, current Irish policy on deinstitutionalisation and community living is of primary relevance to the current study, as expressed through the HSE *Congregated Settings* report (Health Service Executive 2011) and the *National Housing Strategy for People with a Disability* (Department of the Environment Community & Local Government 2011). As such, this policy is of particular relevance in the following discussion, alongside other policies related to the social and community participation of older people with intellectual disabilities.

Within the relevant policy landscape, the UN CRPD also provides an obvious context piece for this discussion, particularly in light of policy gaps that have been identified and areas that need further investigation (United Nations 2006). While Ireland is committed to ratification of the CRPD and has seemingly overcome one of the final hurdles to ratification with enactment of new capacity legislation, the implications of ratification for policy remain unclear. Ratification will commit Ireland in international law to a number of fundamental general principles across specific policy areas (Mittler 2016); although violation of rights provides no legal recourse in the CRPD (Fyson and Cromby 2013). The experience in other countries suggests a lack of political will by national governments to develop a timetabled roadmap for the implementation of specific articles of the CRPD (Mittler 2016). Nonetheless, ratification of the CRPD will provide a basis on which policy formation may be assessed, at least in principle.

The layout of the discussion will be framed by the three research objectives of the study, namely:

1. Measure rates of social participation amongst older people with intellectual disability in Ireland using the WHO ICF as a valid theoretical framework of participation;

2. Identify factors associated with differences in rates of social participation for this population;
3. Examine associations between objective measures of social participation and subjective outcomes for individuals.

Objectives 1 and 2 are linked and these are discussed together. For these, the discussion is structured by the thematic approach of chapters 4-9 in the thesis findings; and, within that, reference to the relevant parts of the ICF framework is made. Objective 3 is then discussed separately. Finally, the overarching issues raised in the study and their implications for the field in terms of research, policy and practice are discussed.

11.2 Research Objectives 1 and 2

Objective 1: *Measure rates of social participation amongst older people with an intellectual disability in Ireland using the WHO ICF as a valid theoretical framework of participation.*

Objective 2: *Identify factors associated with differences in rates of social participation for this population.*

The study findings under each theme have already been considered individually in the discussions throughout chapters 4-9. Therefore, here we will briefly review the key discussion points under each theme, before looking at a number of cross-cutting themes and key issues emerging from the analyses.

11.2.1 Social functioning of older people with intellectual disabilities in Ireland

A key study finding was that almost all (97.9%) of this group experienced at least some degree of difficulty in the five functional areas examined, which contrasted with much lower rates reported for the older general population. Across the five functional areas, the regression models revealed that level of ID was the strongest predictor of functional limitation; followed by physical health, type of residential setting, and age. Being a woman predicted higher limitation in two of the models (ADLs and physical abilities). Of the factors of social support included in the models, having less than monthly contact with family predicted greater difficulty with IADLs and communication, while not having any friends outside your own home predicted greater difficulty with IADLs and functional literacy; which may support findings from the general population linking reduced functioning with poorer social support (McCorry et al. 2014).

The analysis follows previous findings that functional limitation increases with age and that associated I/ADL functional decline with severity of ID and with institutional residence. Findings regarding gender and I/ADLs are the opposite to findings for the general Irish population, indicating a need for further research on gender differences in

the older ID population. The association of social support with IADL difficulty suggests that better family contact and non-resident friends may be important to continued independent living.

The potential impact of limited social functioning on social participation is twofold, impacting in the first instance directly upon participation of the type required for independent living, while also influencing many other aspects of social participation. In each of the areas of participation examined here, all measures of social functioning included were negative covariates of social participation. Their importance as factors was also seen in the regression analyses, in which IADL limitation predicted participation across all areas examined in these chapters and was the strongest predictor of being a member of groups in the local community; ADL limitation and literacy predicted participation across the majority of areas examined; and communication was a significant factor in relation to interpersonal relationships.

What we can say from the study findings, therefore, is that older people with intellectual disabilities in Ireland experience much higher rates of limitation to social functioning, and that these may have a disproportionately negative impact on many aspects of social participation for this group. In the wider context, where the literature notes associations with quality of life outcomes and social participation (Brown et al. 2013, McCrory et al. 2014), findings here suggest that the quality of life of this population may be negatively impacted as a result of lower rates of social participation. This bears up in the examination of associations between objective measures of participation and the subjective outcome of emotional or mental health in chapter 10, where both IADL limitation and communication difficulty were significant negative covariates.

Overall, the findings regarding social functioning reinforce and support the need to adopt a broad understanding of social participation that includes these factors; and as such confirms the value of adopting the ICF as a theoretical framework for the study. In light of current policy, findings here encourage a nuanced and personalised approach

to the provision of accommodation and supports for older people with intellectual disabilities. Changing locations is not enough to achieve public policy social participation goals; policy makers must also consider the fuller range of relevant factors found here. That IADL performance was such a prominent factor across all aspects of social participation provides great hope that both of these can be positively improved for this population with the provision of the right personalised active supports (Mansell et al. 2002, Hilgenkamp et al. 2011). However, policy makers and service providers must remain cognisant that the same support needs persist regardless of living situation. Those with the most severe ID, the most physically unwell, and the oldest of people with intellectual disabilities experience the greatest challenges in functioning, and hence to their social participation; and as such will continue to need the greatest level of support, whether living in congregated, clustered, dispersed or other residential settings.

11.2.2 Participation in human rights and citizenship

The prominence of self-determination and choice-making for people with intellectual disabilities internationally (United Nations 2006) and in existing Irish policy (Health Service Executive 2011) highlights what a critical issue this is for this population. In Ireland, this was reinforced by the campaign for updated legislation in this area (Inclusion Ireland 2015a, NUI Galway 2015, Morrissey 2015), which culminated in the enactment and signing into law of the Assisted Decision-Making (Capacity) Bill in December 2015. Underpinning this is the assumption of respect for every adult's *"individual autonomy including the freedom to make one's own choices, and independence of persons"* (United Nations 2006). This is further highlighted by the centrality of self-determination in the concept of quality of life, which *"is based on individual needs, choices, and control"*, and which *"is composed of those same factors and relationships for people with intellectual disabilities that are important to those without disabilities"* (Schalock et al. 2002).

With autonomy and self-determination an assumed starting point for adults, the findings in this study that over half of older adults with intellectual disabilities in Ireland exercise a low level of choice highlights the challenge to their human rights and quality of life. For the majority, choice was exercised most often on their behalf by someone else. Therefore, the findings here highlight a low level of self-determination by older people with intellectual disabilities in Ireland, in comparison to the assumed standards of autonomy and choice contained in the principles of international human rights and quality of life.

Findings here support previous findings in the literature of a wide range of factors being associated with self-determination for people with intellectual disabilities (Shogren 2013). The current study found choice to be negatively associated with increased age, more severe ID, institutional residence, poorer physical and mental health, more limited functioning, and to lower rates of social contact with family and friends. The regression analysis for level of choice-making supported this multi-factorial influence behind rates of choice for this population, with factors of residence, personal ability and social support all predicting choice. That residence in an independent or family setting was far more likely to result in higher choice, when controlling for other factors, supports the idea that having greater opportunity to make choice in such settings increases the probability of making choice (Walsh et al. 2010, Kozma et al. 2009, Branding et al. 2009, Shogren et al. 2007). Provided that the required supports are available to address needs related to personal ability, policies which support people with intellectual disability to live independently and within their family residences, allied to social supports outside the home, appear to provide the best environment for self-determination for this population.

As a crucial support to decision-making for people with intellectual disabilities, the low rates of independent advocacy appear to confirm the under-developed, under-resourced and fragmented state of advocacy services in Ireland (Tatlow-Golden et al.

2014, Inclusion Ireland 2015c, Linehan et al. 2015). This supports calls for greater coherence and funding (Inclusion Ireland 2015c) for a sector that provides what has been described in policy as an 'essential' support for greater independence for people with ID (Health Service Executive 2011).

Rates of political participation, in the form of voting, were found to be very low amongst respondents compared to the general older population in Ireland (Barrett et al. 2011) and internationally (European Union Agency for Fundamental Rights 2014a). The analysis here supports international research (Keeley et al. 2008) that a range of different variables related to personal ability, demographic and social factors may combine to exclude this population. . Further research is needed to better understand this phenomenon so that older people with intellectual disability can be supported to participate more as voting citizens with a political voice.

11.2.3 Participation in education, training and occupation

The very low participation rates in education and paid work amongst respondents, alongside high dependency on disability benefits, support previous findings of far worse educational outcomes than the general population, and how these outcomes translate to poor rates of employment and economic outcomes later in life (Watson et al. 2015). Findings here highlight that this population is missing out on the quality of life and other benefits that have been associated with employment. Furthermore, these disadvantages are exacerbated for the oldest, the most severely disabled (both physically and cognitively), for those in the poorest health, those living in institutional settings and those with the most limited social supports of family and friends.

However, the majority of this population were involved in some kind of regular occupational activity, most likely a day programme. Recent research suggests that involvement in regular structured activity such as a day programme, volunteering, supported or paid employment is associated with better quality of life outcomes (Bigby et al. 2015). With recent changes of policy in Ireland (Health Service Executive 2012),

provision is somewhat in flux (Fleming et al. 2016). Therefore, additional research is required to monitor the impact of the new policy approach over time, and also to understand the impact in terms of outcomes for individuals, whether they are in new forms of mainstream day programme, home activation or another form of individualised programme; or indeed if they still attend more traditional forms of day programmes within intellectual disability services.

While education is an undoubted influence on employment status, the analysis suggests that physical ability plays a significant role in determining whether individuals are actively engaged in some kind of regular occupational activity. This should serve as a reminder, in light of current policies for day services and community living, of the ongoing support requirements needed to facilitate greater participation for people in these areas regardless of age, residential location or level of ID.

On a broader level of participation, being actively engaged in education, training and occupation was most significantly associated with factors of social support, lending weight to findings elsewhere in the study that natural supports can play a huge role in facilitating participation for older people with intellectual disabilities. However, while the scope for natural supports for people with intellectual disabilities is limited (Duggan and Linehan 2013), there also remains a significant role for formal supports (i.e. paid staff) in supporting participation in these areas.

Rates of participation in voluntary work were found to be much lower than the general older population; suggesting significant scope for improvement where the potential benefit to quality of life of this type of participation has been identified (McCrory et al. 2014). This aspect of participation, alongside similar activities such as providing support to family or helping friends and neighbours, may also be important within the context of a broader understanding of community, which places interdependent and reciprocal relationships at the centre of community.

11.2.4 Participation in social activities

This study departed from the conventional approach within the ID literature which conflates activities that are based in the local community with social activities *per se*; and as such included all social activities, including those which may have taken place within ID services or segregated locations. The study found that the majority of respondents were involved in regular social activities and took holidays, but most were not a member of any organisations or clubs. Several personal and social factors were associated with social activity. With regard to residence, the rate of social activity increased substantially from institutional residences, to community group homes, and were highest for people living independently or with family.

However, no significant difference was found in rates of social activity based on type of residence when other factors were controlled for in the regression analysis. Instead, the analysis found that people with lower levels of social support, in particular family contact, and with greater challenges in terms of health and personal ability, had lower rates of social activity. Family contact was the strongest predictor of social activity; which may suggest that support or advocacy by family may directly or indirectly lead to greater social activity regardless of living situation, which supports previous findings of this nature (Bigby 2008). While further investigation of the potential benefits of increased family contact for social activity is needed, findings here suggest that such involvement should be actively promoted and facilitated and that this may improve participation in social activities by older people with intellectual disabilities. However, while the extent of natural supports remains limited there is continued need for formal supports of social activity, especially where family contact is restricted or even absent. Notwithstanding issues over choice, findings here question predominant literature and policy understandings equating community living with increased engagement in social activities}. Instead, the study highlights that challenges to social support, health status,

level of ID and I/ADL limitation must be addressed even for those living in what are seen as more activity-beneficial environments such as community group homes.

11.2.5 Participation in local community

The study found that many older people with intellectual disabilities participate in their local community, but most have difficulty doing so and only a minority participate with local groups. The analysis identified a multi-factorial influence to participation in local community and suggests that an over-focus on one particular factor may be misguided and counter-productive; instead, it encourages a very person-centred and individualised approach. This supports previous findings of multi-factorial influences on community participation.

That IADLs was the strongest predictor of membership of community groups suggests that this aspect of community participation is something that may be developed for individuals through training or active support; while findings regarding residence support findings elsewhere which associated improved outcomes with smaller, community-based accommodation. Therefore, the study supports a policy of providing accommodation options in integrated settings within the general community rather than in segregated settings. In this regard, it was interesting to note that people living in group homes in the community engaged in more activities in the local community than people living independently or in family settings; however, this does not account for the quality of activities engaged in or the level of individual choice.

A third type of factor found to have significant influence on participation within local community is that of social support, including family contact and having friends outside one's home. Family contact appears to enhance social activity in the local community, either through directly supporting activities or through an advocacy or even surveillance-type role. Therefore, while further research in this area is needed, services should support and facilitate greater contact with the family members of people with ID who they provide a service to. Findings regarding friends also encourage intervention

initiatives that aim to engender and support friendships outside the home for people with intellectual disabilities (Bigby et al. 2015); however, a more systematic approach to the evaluation of these initiatives is encouraged in the future (Duggan and Linehan 2013).

Any consideration of participation in the local community should avoid locating the 'problem' within people with ID, and consider also how the environment may be disabling individuals with cognitive impairments, and ways in which the local community may need to change in order to include people with ID, rather than the reverse; a perspective lacking in the literature (Bigby 2012). This is a field of enquiry that needs particular attention in future research about participation of people with ID in their local communities (Amado et al. 2013).

Finally, while the study identified that multiple factors influence objective outcomes of participation in local community, the literature notes that this doesn't necessarily guarantee improved quality of life. As such, there remains the need to include subjective outcomes measures of community living in order to truly assess the impact that increased participation has on people's lives.

11.2.6 Participation in interpersonal relationships

The study found that respondents had almost the opposite experience as the general population with regard to immediate family, with very few marrying or having children of their own; therefore missing out on the intimate networks provided by spouses/partners, children or grandchildren; relying instead on their parents, siblings, nieces and nephews as their primary source of family contact. At the same time, more than two out of five respondents reported having no friends outside their own home. Findings suggest that support staff and co-resident friends take the place of immediate family and other friends for older people with ID, particularly those living in institutional settings and community group homes. This raises a number of complexities that need further exploration, including the social role of paid support staff and the nature of

relationships people with ID have with them. Questions about these relationships have been raised in the literature; however, along a continuum from very good to very bad experiences, the potential exists for mutually supportive relationships between people with ID and their support staff, and for some people with ID this may be the only validating relationship in their lives (Marquis and Jackson 2000). The nature and importance of these relationships requires further investigation in future research (Amado et al. 2013). The relative importance of co-resident friends may support findings elsewhere about the importance of shared identity in forming friendships for people with ID, an idea supported in the sociological literature where certain types of community develop based upon the symbolic focal point of a shared culture or shared identity. However, data here in this regard is limited and further research is required to explore the nature and quality of these relationships, as well as the question of choice for this population.

The analysis regarding family contact suggests that the issue may be less about residence than adequate support solutions when family and other natural supports are not available. This is reinforced by findings which suggest that, across a range of social measures, there is not a huge difference between outcomes for people living in institutional settings and those living in community group homes. This, again, suggests that outcomes may be more influenced by factors other than type or location of dwelling, and raises the question about how some may consider community-based group homes as institutional while others see them as community.

Low rates of providing support to family, friends and neighbours may result in this group losing potential benefits to quality of life, as well as the type of reciprocal relationships that are important to inclusion and which are important elements in a broader understanding of community (see section 2.5).

11.2.7 Cross-Cutting Themes

From the above summary and the broader analysis through chapters 4-9, a number of important cross-cutting themes may be identified. These include the following:

i. Multifactorial Complexity of Participation

Taken together, the areas of participation examined in the study consistently show the influence of different types of factors in shaping the overall experience of participation. This applies across factors related to individual ability and health, social supports and demographic factors such as residence, age and gender. On top of this, the study not only reveals the complexity of participation due to this multifactorial influence, but also shows how the importance of different factors changes depending upon which aspect of participation is examined. This finding is crucial in advocating a complex and personalised response to the social participation support needs of this population.

ii. Impact of Social Functioning

Under the ICF conceptual framework, chapter 4 illustrated the challenges to participation presented by functional limitations in a range of elements of 'social functioning'. However, the chapters that followed demonstrated how central these aspects of functioning are to all aspects of social participation, with higher functioning in ADLs, IADLs, literacy and communication frequently predicting better participation in areas such as social activity, relationships and local community interaction. This supports the application of an ICF model which includes these functional items in a framework of participation.

iii. Family Influence

The influence of family is apparent across a number of the different areas of participation examined. This associated greater family contact with increased participation in choice-making, education/occupational activity, social activities

and local community activities. The importance of family to participation supports policies and measures aimed to develop and maintain family contacts for people with ID, especially as they get older and experience greater challenges to family contact.

iv. Having Friends

The importance of social supports is also clear in how having friends outside one's home influenced higher levels of social participation for this group. This was seen through an association between having these types of friends and increased participation in choice-making, education/occupational activity and social activities.

v. Limited Natural Supports & Role of Paid Support

In light of the importance of social supports, another important cross-cutting theme was the lack or absence of natural supports, and the importance to social participation for this population of paid supports (in their place). This was seen in the relative lack of immediate family networks and friends, how these impacted on participation right across the conceptual frame, combined with the important social roles that staff play in both supporting social activity and providing more intimate friendship.

11.2.8 Conclusion: Research Objectives 1 & 2

Overall, the picture emerging from the examination of social participation rates and associated factors is highly complex. It shows generally that older people with intellectual disability experience lower rates of participation than people who do not have an intellectual disability; that there are multiple factors associated with differences amongst this group; and that the importance and potential influence of these factors varies depending upon the aspect of participation being examined. These findings support the application of the ICF as a valid and comprehensive theoretical framework

to the study of social participation amongst older people with ID, insofar as it provides a systematic framework that encompasses the breadth of the phenomenon. The ICF has been recognised as the international standard for describing disability based on functioning (Cerniauskaite et al. 2011, Bickenbach 2014). The validity of the ICF as a framework for participation among people with ID was initially identified by Verdonschot et al. (2009) to provide consistency in the study of community participation, and findings here support the broader application of the framework to the study of social participation. This validity is further enhanced by the consideration that an ICF-framed study of social participation (defined by the nine parts of the *Activities & Participation* domain and within the context of its *Environmental Factors*) also includes the key elements identified in models of social inclusion for people with ID (Hall 2009, Cobigo et al. 2012, Overmars-Marx et al. 2014, Simplican et al. 2015). Therefore, in addition to comprehensive new data on social participation for older people with ID in Ireland, objectives 1 and 2 of the study also demonstrate the value to the field of applying the ICF as a valid conceptual framework in this area of research.

11.3 Research Objective 3

Objective 3: *Examine associations between objective measures of social participation and subjective outcomes for individuals.*

In response to a growing recognition in the literature of the importance of assessing the subjective outcomes of social participation alongside the objective measures, chapter 10 of the thesis examined the association between a range of social participation measures and the subjective outcome of self/proxy-rated emotional or mental health. This addressed objective 3 of the study.

The study found that respondents had poorer rates of emotional/mental health than those reported by the general older population (O'Regan et al. 2011); and identified

that a number of different aspects of social participation are significantly associated with this subjective outcome for older people with intellectual disabilities. This supports previous findings that have linked social measures with better subjective outcomes including quality of life (McCrory et al. 2014, Cummins and Lau 2003). Across all 17 of the objective measures of social participation, higher participation implied better outcomes for emotional and mental health among the sample; with 12 of these being statistically significant differences. This significant positive association between social participation and the subjective individual outcome was apparent across all of the different themes of participation presented in the thesis findings, including measures of: social functioning; human rights and citizenship; education, training and occupation; social activities; local community involvement; and interpersonal relationships. Potentially these findings may be very positive, and suggest that improved social participation may bring with it better subjective outcomes for individuals. However, as has been highlighted in the findings of chapters 4-9, older people with intellectual disability are often worse off in objective measures of social participation than people who do not have an intellectual disability. Therefore, it is perhaps no surprise that older people with intellectual disability have worse subjectively-rated emotional or mental health than the general older population; although of course there are other factors associated with this.

In the regression analysis, the finding that having non-resident friends significantly predicted better emotional or mental health may be important in building upon previous studies, which identified that merely having social relationships was in itself important to quality of life (Schalock et al. 2002, Brown et al. 2013). However, measurement of subjective outcomes for human beings will invariably exclude important factors, and only a minority of the variance in the outcome variable is explained by the model. As such, while it is significant that having these friendships was the strongest predictor of the subjective outcome, this finding adds to rather than negates previous studies which

have highlighted the undoubted importance of other factors. These will likely include environmental factors such as service design, staffing and active support (Felce and Emerson 2001, Mansell et al. 2002, Mansell et al. 2008, Fyffe et al. 2008, Kozma et al. 2009, Walsh et al. 2010, Mansell and Beadle-Brown 2012, Amado et al. 2013); while individual preferences and constraints may also influence subjective outcomes (Badia et al. 2013). Clearly, therefore, further investigation of the subjective outcomes of social participation for this population is needed, particularly in the context of implementing research that uses a valid theoretical framework such as the ICF and the scope of social participation that this implies.

Nonetheless, this finding supports calls in recent policy for the type of inclusion supports that will allow people with intellectual disability to build relationships and develop their social networks in community settings (Health Service Executive 2011); with this expected to benefit individual wellbeing. However, it is important here to distinguish between the ideas of simply 'exposing' people with intellectual disability to the wider community, which has shown to yield limited benefit (Emerson and Hatton 1996, McVilly et al. 2002, Cummins and Lau 2003, Bigby 2008, McCarron et al. 2011), and building friendships that impact upon people's wellbeing. This is supported by contact theory, which proposes that simple, casual contact is not enough to engender positive outcomes between people, and that certain conditions of contact such as equal status or interdependence must be satisfied to reduce prejudice against marginalised groups (Allport 1954, Novak and Rogan 2010). Furthermore, as previously discussed, the scope of natural supports for people with intellectual disability is limited and this population remains largely dependent on the formal supports of service providers. As such, the need remains for the provision of formal supports, including independent advocacy and person centred approaches, that may provide the platform for people with intellectual disability to develop wider friendships and improve their overall wellbeing.

Moving forward, the study has highlighted that subjective outcome measures should be included in future research related to social and community participation for people with intellectual disabilities. This ties in with the broader understanding of community discussed earlier (section 2.5), where subjective feelings of bonding with other people and a sense of belonging are central to the development of community; and follows similar calls for the consideration of the subjective experience of inclusion and integration for people with intellectual disability (Cummins and Lau 2003, Hammel et al. 2008, Cobigo et al. 2012, Cummins and Kim 2015). Research into the quality of relationships that people with intellectual disabilities have is needed to identify the deep and lasting friendships that can influence their subjective outcomes, as a complement to examining social networks and frequency of contacts. Crucially, this should not preclude any relationships that may be valued by individuals with intellectual disability, and thus may include relationships or friendships with co-resident peers and support staff. These relationships remain important social outlets for older people with intellectual disabilities and require further investigation (Amado et al. 2013, McCausland et al. 2016).

11.4 Key Issues Emerging from the Study

This section identifies a number of key issues that have emerged from the study and which follow from the preceding discussion of the research objectives. This will consider a range of implications for research, policy and practice related to older people with intellectual disability.

12.5.1 Implications for Research

The following implications for research in the field arise from the study and the preceding discussion.

- Arising from an identified gap in the research literature (Verdonschot et al. 2009, Martin and Cobigo 2011, Cobigo et al. 2012, Amado et al. 2013), this

study used the WHO's ICF as a theoretical framework to examine social participation by older people with an intellectual disability. The study has demonstrated that the application of the ICF framework provides a valid, comprehensive and systematic approach to the study of an area that has often been undertaken inconsistently and without any theoretical underpinning across the field. It demonstrated the underlying complexity of studying this phenomenon and the multifactorial nature of influences that shape different experiences of participation for this heterogeneous group, supporting previous findings elsewhere (Kozma et al. 2009, Mansell and Beadle-Brown 2009b, Chowdhury and Benson 2011). This has identified great potential for a more consistent approach in the future based around an internationally recognised framework; one which is also capable of incorporating a more expansive understanding of community.

- The study found that the assessment of subjective outcomes of participation was useful in assessing the value of participation in real terms for individuals, as suggested in the literature (Cummins and Lau 2003, Hammel et al. 2008, Cobigo et al. 2012, Cummins and Kim 2015). It also significantly ties in with an alternative conceptualisation of community, based upon subjective feelings of bonding and a sense of belonging for individuals within their various communities. This highlights the central importance of subjective assessment in social and community research for older people with ID moving forward, as an essential complement to the continued assessment of objective measures of participation.
- While the study has identified the need for a broader understanding of community, which may provoke a re-think in the field of how community is conceptualised and measured; there remains a place for 'local community' within this, as a form of community based on location and locality. However,

assessments of community based on locality should nonetheless be undertaken alongside assessments of the subjective outcomes of this type of community participation. As such, for example, findings here that social support in the form of family contact and having non-resident friends are associated with better participation in local community, needs to consider the literature which suggests that local community participation may not necessarily lead to better quality of life and other subjective outcomes (Emerson and Hatton 1996, McVilly et al. 2002, Cummins and Lau 2003, Bigby 2008, McCarron et al. 2011). Research on local community participation, therefore, also needs to examine subjective outcomes associated with this type of community participation. This is in-keeping with an alternative understanding of community that focuses on subjective outcomes of relationships (bonding and belonging), rather than the simple existence of relationships and interactions. It also fits within the overarching ICF framework of social participation, relating to part d9 with regard to local community and part d7 with regard to relationships.

- Findings that having non-resident friends is associated with improved social participation supports a more methodical approach to 'befriending' initiatives and interventions between older people with intellectual disabilities and others, both with and without intellectual disabilities. This also supports recent recommendations in the literature for demonstration programmes to develop individualised approaches to developing and maintaining social relationships (Bigby et al. 2015). In tandem with these types of initiatives, a systematic approach to evaluation of interventions is needed (Duggan and Linehan 2013).
- Study findings of difficulties people have engaging in their local communities, alongside the environmental factors contained within the

biopsychosocial ICF model, suggest that further research is needed on how local communities may be disabling individuals with intellectual disability. This would remove the 'problem' from people with intellectual disabilities and consider ways in which local communities and their members may need to change or adapt to support and facilitate inclusion of this population; the complexity of which has recently been highlighted in the literature (Craig and Bigby 2015).

- The study has identified very particular type of social network for this population, and one which differs greatly from the typical network of the general older population, which is based around the intimate network provided by immediate family. By contrast, older people with intellectual disability remain reliant on support staff in particular as well as co-residents with ID, as their primary social supports in place of spouses, children and grandchildren. These relationships are hugely important, and further research is needed on the extent, nature and quality of these relationships in the lives of this population.
- The very particular social networks of this ageing group should also be borne in mind when moving people from institutional residences to accommodation within the local community. In particular, research on the impact of movement on existing ties and social bonds is needed, especially considering the difficulty that people with ID have in forming new relationships within the general community. As the population of people with intellectual disabilities ages, the reverse process may also be an emerging research issue in the future (O'Donovan 2016), looking at the impact on social networks and bonds of people moving from the local community to residential care in response to changing health and other needs (such as loss of primary care-giving parents).

- Interdependent and reciprocal relationships have been identified in the study as being very important to an alternative view of community, and in the literature on social inclusion (Hammel et al. 2008, Hall 2009, Cobigo et al. 2012, Overmars-Marx et al. 2014). Initial indicators in the study findings (e.g. participation in volunteering, help given to/received from friends and neighbours, or support provided to family) suggest that older people with ID currently have low rates of these types of relationships, and therefore may not be well disposed to experience community in any broader sense. Further research is needed in this area to develop indicators of interdependence and reciprocity in relationships for this group, as a basis for examining community participation in the future.
- The study proposes an alternative approach to assessing the social activities of people with intellectual disabilities, which avoids conflation of social activities based in the local community with social activities *per se*. This approach counts all types of social activity, including activities which may be performed in segregated or specialised settings away from the general community. The approach also emphasises the importance of subjective outcomes of activity for people with intellectual disabilities, which has been highlighted elsewhere (Badia et al. 2013)
- Being linked to the IDS-TILDA study, the current study is well placed to bring issues emerging here to an applied research space; and a number of the emerging issues have already been discussed and developed in this forum, including key issues of subjective outcomes, assessing belonging in considerations of community, and exploring the qualitative nature of the existing friendships and relationships of this population. These are considerations that will feed forward into the next wave of the longitudinal

study, with potential for further development in future waves and specific add-on studies of a qualitative nature.

12.5.2 Implications for Policy

Many of the issues discussed above also have significant relevance and implications for policy. The key implications for policy arising from the study are as follows.

- The application of a systematic approach to studying social participation has highlighted the complexity of the phenomenon, as previous studies have indicated (Kozma et al. 2009, Mansell and Beadle-Brown 2009b, Chowdhury and Benson 2011); the association of multiple factors across the different aspects of social participation reinforces this complexity, and the need to avoid reductive statements and policy that fail to consider the broader picture or diminish the importance of one aspect in favour of another.
- Findings that multiple factors are associated with all aspects of social participation encourage a nuanced and personalised approach to the provision of accommodation and supports for older people with intellectual disability; and discourages any blanket approach or one-size-fits-all approach to policy. While policy identifies a range of individualised approaches and supports (Health Service Executive 2011) the provision of crucial resources to underpin this appears lacking to date (Tatlow-Golden et al. 2014, Inclusion Ireland 2015c).
- Findings indicate that the same support needs persist for individuals regardless of their residential location; which is especially relevant for this older population in Ireland who have been targeted for community transition under the Congregated Settings policy. The 'essential programmes' of support identified in the policy really are essential.

- The policy focus on natural supports for people with intellectual disabilities (Department of Health 2011) is, on one hand, supported by a range of findings linking social supports with increased participation. However, on the other hand, findings here support previous research which identified that the scope of natural supports available to this population in Ireland is very limited (Duggan and Linehan 2013). Therefore, in the absence of natural supports, existing formal supports (and additional personalised supports) remain very important for this group and this should be reflected in policy considerations. These should be considered and resourced within the existing supports model.
- As previously noted, the very particular social networks of this ageing group should be borne in mind in policies of moving people from their current homes, whether from institutional residences to accommodation in the local community or vice versa. Particular vigilance should be taken when disrupting existing ties and social bonds, especially considering the difficulty that people with intellectual disabilities can have in forming new relationships and interacting within the general community (Robertson et al. 2001, Bigby 2008, Bigby and Wiesel 2011, Bigby et al. 2015); and policy should prioritise personalised approaches to planning for moves in advance.
- The study found that, in several measures of social participation, there is little difference between institutional residences and community group homes. This highlights the importance of factors other than residence type/location, noted above; but also raises the question of what counts as community and what counts as institution (Ben-Moshe 2011); and perhaps the real issue is about service culture and personalisation, as well as resources, rather than location and size of dwelling. Therefore, policy needs to be cognisant that type or location of residence may not be the most

significant factor, and that a multifactorial and individualised approach is needed.

- Family emerged as a very strong factor having a positive association with social participation for this population. Findings across a range of measures in the study suggested that family contact may have an important influence on social participation, either through direct involvement or perhaps indirectly in an advocacy or surveillance capacity. This is a crucial finding that adds to previous findings (Bigby 2008). Family should be prioritised more actively in all policy considerations for older people with intellectual disabilities, particularly for this group in terms of maintaining contact or reconnecting with family where this has been lost in situations where people with ID are not living with or in close proximity to family.
- Recognition of a broader conceptual understanding of community raises significant challenges for policy makers. It suggests a change in the way they must think about community and community participation. It opens up the possibility of community participation meaning more than just participation in one's locality. It means that people may form communities that are of importance and relevance to them based on a range of factors. Among these may be communities of people with intellectual disabilities based on the shared identity or difference of being a person with an intellectual disability. Recent research found a perception by people with ID of their being different from people without disabilities (Monteleone and Forrester-Jones 2016). Accepting this difference poses a significant ideological and intellectual challenge for policy makers in an environment which places primacy on the sameness of people with an intellectual disability to other people, or prescribes the same outcomes (Health Service Executive 2011, United Nations 2006).

- Related to the previous point, a policy which adapts to incorporate a broader understanding of community and community participation will need to be cognisant of the cognitive and social demands of interdependent and reciprocal relationships for people with an intellectual disability (Mahar et al. 2013). It is likely that, following recommendations arising from the additional research needed on this matter, specific policies and measures will need to be targeted and resourced to support people with intellectual disabilities in developing and maintaining these type of relationships.

12.5.3 Implications for Practice

Finally, there are a number of issues that arise from the research with regard to practice and the provision of support to older people with intellectual disabilities. Many of these are linked to the previous points on policy implications, with others also arising from the study findings. The key issues emerging from the study in relation to practice are as follows.

- Findings of the multifactorial nature of social participation for older people with intellectual disabilities strongly support an individualised and person-centred approach to providing support to this population. As with the point made in relation to policy, these findings encourage a nuanced and personalised approach to service provision and discourage any blanket or one-size-fits-all approaches.
- Findings that this population experience much higher rates of functional limitation than the general older population, that this directly impacts upon their social participation, and that changeable IADL functioning is prominent among these limitations, suggests that a focus on active support to develop skills in these areas should be prioritised.

- In addition to this, the opportunity to practice these skills and exercise choice at home is also an important consideration, both for service providers and for families. Findings support the literature which suggests that these opportunities may be more forthcoming in non-institutional settings (Spreat and Conroy 2001); however, there should be no reason not to increase these opportunities regardless of setting.
- Nonetheless, findings indicate that the same support needs persist for individuals regardless of their residential location. Hence, those with the highest support needs will continue to have them, even if they move to community-based locations in line with policy, and this should be planned for if individuals are to benefit from expected advantages of non-institutional residences. Again, services need to plan for this on an individual basis in any transition programmes.
- As identified in the previous section, the policy focus on natural supports is underpinned by a range of findings linking social supports with increased participation; however, the findings also identify that the scope of natural supports available to this population in Ireland is very limited (Duggan and Linehan 2013). There are two key implications for services in this regard. Firstly, there is significant scope for increased social support given the finding that nearly all respondents had at least one family member, yet only one-third said they did social activities with family. Services need to support the connection or reconnection with family members where this does not exist or has been lost. Findings show the potential importance of family contact and proximity for social participation, so this should be addressed in personalised plans. Secondly, services need at the same time to recognise the important social role that staff continue to play in the lives of older

people with intellectual disability, and to again plan for this in a personalised way.

- As with approaches at policy level, services must also be aware of the very particular social networks of this ageing group, especially in the planning of transition programmes. Particular care should be taken with existing ties and social bonds, with planning for ways to protect and maintain these, as well as seeking to develop other relationships in new environments.
- Findings that, in many measures of social participation, there is little difference between institutional residences and community group homes encourages services to consider what a move actually means. It encourages reflection on service culture (Tatlow-Golden et al. 2014, Bigby et al. 2012) and whether a change of location or environment means a significant and positive change in the lives of the people moving. Undoubtedly, the more inclusive and personalised the process, the more significant and positive the experience will be.
- A changing understanding of community and community participation may imply changing the focus of support for community participation. In particular, this may see support requirements for this population in the skills needed to develop and maintain the type of reciprocal and interdependent relationships that are at the heart of community. While, as mentioned above, further research is needed to identify specific support needs, these may tie in with the recommended befriending interventions and the demonstration programmes advocated in the literature (Bigby et al. 2015).

Chapter 12. Conclusions & Recommendations

12.1 Introduction

This final chapter attempts to synthesise the preceding consideration of the overall research approach, findings and implications, to identify the key messages emerging from the study. This will in turn identify the principal findings from the research, the key contributions that the study has made to the field, and the main recommendations for research, for policy and for practice; while the limitations of the study are also discussed.

12.2 Principal Study Findings

The principal findings emerging from the study are as follows:

- Older people with intellectual disabilities in Ireland have much lower rates of social participation than those reported by the older general population.
- Multiple factors are associated with differences in the rates of social participation for older people with intellectual disabilities, across all aspects of participation examined.
- The multifactorial nature of social participation is highlighted by the association of different types of factors across the areas examined, including demographic factors (age; residence; and gender), personal ability (level of ID; functioning in ADLs, IADLs, communication and literacy), health (physical and mental health), and social support (family contact and proximity; friends).
- Social participation in all of the areas examined (social functioning; human rights; education, training and occupation; social activities; local community; and interpersonal relationships) is positively associated with subjective outcomes for this population.

- The WHO's ICF provides a valid theoretical framework that facilitates a comprehensive approach to the study of social participation, providing a systematic framework which illustrates the complexity and multifactorial nature of this phenomenon.

12.2 Contributions to the Field

The following contributions to the field of study arise from the research:

- The cross-sectional analysis of IDS-TILDA wave 2 data provides the first comprehensive examination of social participation for this population in Ireland, and generalised findings add significantly to the body of literature in the field.
- A fundamental contribution to the field has been the innovative application of the ICF theoretical framework to the comprehensive study of social participation; the use of which has demonstrated the value to future research of using a valid theoretical framework to study this complex phenomenon.
- The study also provided a new approach to the consideration of social activities for people with intellectual disabilities; in distinguishing between social activities *per se* and those performed in a general/local community context; with a view to assessing all activities, including those performed in settings other than the general/local community.
- The study has been influential in new developments for the IDS-TILDA longitudinal study of older people with an intellectual disability in Ireland; directly influencing the development of additional measures for wave 3 data collection beginning in 2016; these additions include:

- A standardised subjective quality of life measure that may be used as a global outcome indicator across all measures within IDS-TILDA;
 - A new question to assess respondents' sense of belonging to their local community;
 - Two additional scales to assess the type and quality of friendships and relationships that older people with ID have.
- A number of papers and presentations from the study have been made to date, and dissemination of findings is expected to continue in the next year, alongside the development of additional research opportunities based on the study findings (see Appendix 5 for an outline of papers and presentations).

12.3 Key Study Recommendations

The following recommendations for research, policy and practice emerge from the study.

12.3.1 Recommendations for Research

1. Future studies examining social participation or inclusion for people with intellectual disabilities should use the ICF theoretical framework to provide a comprehensive, systematic and more consistent approach to the research; while studies looking at specific elements of participation may use the framework to identify where their focus lies and how it may be considered part of a larger phenomenon rather than just a discrete issue. Application of a consistent and comprehensive approach would address an inconsistency in the field in conceptualising and measuring social participation. This more consistent measurement would provide a more consistent knowledge base for making key policy and service decisions. The ICF provides an internationally recognised

and validated tool that has been demonstrated within the current study as providing a suitable framework that captures the full complexity of social participation.

2. The subjective outcomes of individuals should complement objective measures of social and community participation in research about the lives of this population. The literature has shown that achieving success in objective measures of participation doesn't necessarily translate to improved quality of life outcomes. This apparent disconnect may be bridged through the inclusion of subjective indicators of participation alongside objective measures. The application of a validated subjective quality of life measure may be best suited to supplement studies of participation, and may lend further weight to claims of success in intervention and evaluation studies.
3. Research that explores the social activities of people with ID should include those activities that may occur in places other than the local/general community; this may include social activities that take place within non-mainstream settings, but should also consider issues of choice, preferences, constraints and subjective outcomes. This would better represent the full range actual activities that people engage in, and reflect a more objective assessment of social activity for this population. Further, it would avoid the conflation of social activity with social activity in the local/general community. This should take a two-stage approach to establishing social activity – first by identifying the range and extent of activity, and secondly by establishing the location, context or setting of each activity. The relationships with subjective outcomes for these objective outcomes should then be assessed, and considered alongside issues of choice and any other contextual factors.
4. Programmes aimed at developing the ability of older people with ID to build and maintain reciprocal and interdependent relationships should be undertaken and

evaluated systematically. These would build on the 'befriending' initiatives reported as demonstrating success in the literature, but which under-evaluated. It also follows from study findings which associate better participation with having friends; from the identification of a lack of friends for many; and the potential importance of quality relationships to a sense of belonging within a broader understanding of community.

5. A comprehensive and systematic approach to assessing the readiness and developmental needs of local communities is required, if they are to provide a welcoming and supportive environment for older people with ID, particularly those transitioning from institutional settings. The literature previously identified a focus within the field on the individual with ID and problems they have in local communities, rather than a more balanced examination of the context of the environment, and the person within that. This is supported by the current study which identified difficulties experienced by older people with ID in participating in their local communities, which includes both personal and environmental issues. The environmental factors identified within the ICF may provide a framework for community assessments, alongside ecological views of social inclusion recently emerging in the literature. Given the immediate policy context in Ireland, where people are currently being transitioned or prepared for transition in response to the relatively new deinstitutionalisation policy; this piece of work would perhaps appear to be most urgently required, given that people are currently moving to local community environments that may be ill-prepared to receive them.
6. Additional research is needed on the nature, extent and quality of relationships that older people with ID have, including relationships with support staff and co-resident peers with ID; amongst other uses, this may inform transition programmes for services and help to direct supports to maintain existing bonds

that people have prior to moving. This emerges from the key study findings on the important social role that paid support staff play for older people with ID; but also within a context when little is known about the quality of these relationships, and indeed where such relationships remain somewhat controversial. In a context where natural supports remain limited for this population, ongoing quantitative assessment of the role played by staff is required in the context of deinstitutionalisation policies; while additional qualitative investigation is needed to consider the value of these relationships to older people with ID.

7. The study identified the need to examine in greater depth the concept of community, and to develop a theoretical model that may guide a more thoughtful consideration of community for people with ID beyond that of geographic location. In the first instance, this would identify the bonds and belonging that individuals have with other people in their lives; and from there may examine the profile, location, structures and potential overlap of the networks that are based on relationships with these qualities. On this basis, studies may look at involvement in all communities by people with ID – involvement in local community but also identifying other communities they may be part of. Examining the specific interdependent/reciprocal relationships that people with ID have may provide an objective way of measuring community under the proposed model, since these are the type of relationships that lead to or signify bonding/belonging; this may be combined with direct questions, where feasible, about subjective feelings of bonding and belonging. Further research needs to be undertaken to develop and test methods and measures for evaluating community based upon the proposed theoretical model. These approaches may help to address the discrepancy identified in the literature between community presence (i.e. local community presence) and community

inclusion (which would relate closer to bonding and belonging) and how the latter may be optimised for people with ID.

12.3.2 Recommendations for Policy

8. Policy makers should be cognisant of the breadth of issues involved in devising policy for the social and community participation of older people with ID, as demonstrated in the study by the application of the ICF theoretical framework. Furthermore, they must be cognisant of the multifactorial nature of this phenomenon; while policy and (crucially) the resources that underpin it should reflect this complexity, avoid blanket approaches, and instead direct resources towards individualised solutions.
9. Policy needs to consider a broader understanding of community; this would not preclude considerations of community and community participation based upon locality, but would at the same time open up the idea of community participation in the other types of communities to which people with ID may belong.
10. Findings that individuals will continue to have the same support needs regardless of type of dwelling or location suggest that a policy approach in which resources are linked directly to and follow the individual may be best suited to a policy of transition from institutional settings.
11. A policy focus of natural supports facilitating social and community participation must not obscure the reality that these resources are limited for older people with ID; the broader policy of a comprehensive supports model, which also incorporates the continued importance of formal supports for this population, should be adequately resourced.
12. The importance of family connections for the social and community participation of older people with ID should be reflected in policy. Measures for the maintenance and, where needed, the re-establishment of family ties should be

prioritised for this older age cohort in particular, whose family ties may have been broken or weakened through the individual histories of institutionalisation amongst this generation.

12.3.3 Recommendations for Practice

13. As with policy, findings of the multifactorial nature of social and community participation for this population encourage the further implementation of an individualised approach to service provision.
14. Services should implement programmes of staff training to facilitate active support for older individuals with intellectual disability, as a potential way to improve participation through the development of IADLs and other adaptive behaviours; this may be particularly relevant for older individuals who may have spent many years living in institutional environments that restrict opportunities to practice these skills.
15. Services too must recognise that individuals will continue to have the same support needs regardless of residence type, and must account for this on an individualised basis during transition planning.
16. Services should use the research into the nature, extent and quality of relationships that older people with ID have (recommended above) to inform transition planning and to target the supports needed to maintain existing bonds and develop new ones; this approach may also be used to enhance social relationships where people have already moved or do not plan to move from their current home.
17. The prioritising of family in policy must translate to practice, especially for this older cohort where family ties may not be as strong as for younger generations; and services should place family involvement at the centre of their support

plans, including family in person-centred planning approaches as much as possible, according to individual wishes.

18. Services need also to recognise the importance of support staff to the social participation of this older population, particularly where natural supports are diminished or non-existent; the qualitative dimension to these relationships should be recognised as well as the practical supports to engage socially, and services should reflect this through a person-centred consideration of the individual with ID; for example, including staff with close connections with the individual in the person-centred planning process, or through prior consultation with the individual in matters of staff transfer or change of keyworker.

12.4 Study Limitations

The NIDD sampling frame used by IDS-TILDA and the current study potentially underestimates the total number of people with intellectual disabilities in Ireland. As noted earlier in section 1.4 of the thesis, only those people with a diagnosed intellectual disability and who are in receipt of or registered for support services are included in the database; and this may exclude some people with mild ID who are not in receipt of any services. This may affect the representativeness of the sample of the population of older people with ID in Ireland; and it may exclude the views and experiences of people with borderline mild ID, although given that this is a particularly high functioning group their experiences may closely emulate those of the general population.

Data collection for IDS-TILDA includes a mix of self-reported, supported and proxy interviews. As discussed in section 3.3.5 of the Methodology, the literature notes that this may have the potential to cause variation in responses to measures, in particular in relation to subjective measures. However, a decision was taken in the current study that, on balance, it is better to include as many of the total sample as possible in measures reported here, rather than to exclude those individuals who are unable to communicate their own responses. In this regard, the subjective outcome selected for analysis in Chapter 10 was self/proxy-reported emotional or mental health, which contains a mix of response types. This was selected instead of other subjective measures within IDS-TILDA that only included self-reported responses, since using only the self-reported responses would have excluded nearly half of the sample, and primarily those with more severe disabilities.

Data used within the study was collected by a number of different fieldworkers, including the researcher; and this may have the potential to result in inconsistency in data collected. However, the 3-day fieldworker training course provided a comprehensive basis for the systematic approach on a consistent basis; along with procedures and systems in place to maintain data quality, including the CAPI system.

In Chapter 4, the measures of communication and literacy difficulty used were comprised of yes/no responses to having these difficulties and as such were not sensitive in capturing different levels of difficulty. Also some of the regression models produced large confidence intervals for specific factors. Testing for multicollinearity between independent variables had raised no concerns at the outset. Further exploration of the cross-tabulations showed small cell counts between some variables; whilst not ideal, small figures were to be expected in each of these instances and all chi-squared tests satisfied assumptions for cell sizes in these bivariate analyses.

In Chapters 7 and 8, the range of social activities used in the analyses was necessarily limited, being drawn from an existing IDS-TILDA dataset. It is probably an impossible task to reach consensus on a definitive set of social activities which covers all interests, but a broad range of social activities were measured, and the analysis included 'other' activities identified by the respondents. In chapter 9, contact with family and friends included contacts only with people the respondents were not living with. While it is difficult to discern incidents of social contact with co-resident family, there is no doubt that these relationships are important. Similarly, social interactions and relationships with co-resident friends are important for many people with ID, as are relationships with staff, and these are not captured in the data on frequency of contact and may therefore underestimate overall interactions and relationships for some.

In section 2.5 the study examined the concept of community and recommended further research to develop a deeper understanding of community. However, the quantitative data examined within the study was nonetheless based on this limited spatial understanding of community. This is acknowledged in the analysis which refers to participation in 'local community', with the recognition that this considers only one aspect of community for older people with ID. These reflections on the nature of community have also influenced planned data collection for wave 3 of IDS-TILDA,

which will now include additional measures of respondents' sense of belonging with community and the quality of their relationships.

Some environmental factors that may be important for social participation are not included in the analysis. For example, the influence of service culture, and the nature and quality of staffing and support, have been identified in the literature as important factors; they are also among the environmental factors recommended for consideration within the overall ICF model. However, measures of these factors were not available for the current study, which may account for part of the unexplained variance in the regression models performed in the study analyses.

12.5 Conclusion

This study sought to examine the area of social participation for older people with intellectual disabilities in Ireland, by examining rates of participation and their associated factors, and by exploring associations between measures of participation and subjective personal outcomes amongst this population. To underpin this, the study also aimed to address a particular gap in the literature related to the theoretical consideration of, and approach to researching, social participation. The study findings contribute the first comprehensive data about the social participation of this ageing population in Ireland, including associated factors and personal outcomes. Through further dissemination it is hoped that these can contribute to the knowledge base underpinning policy, practice and research in the field. With the application of the ICF theoretical framework the hope is that the study will also make a significant contribution to the field with regard to how social participation is considered and researched in the future. Ultimately, as outlined at the start of the thesis, the researcher's aim is that the study will make a positive and lasting contribution to the lives of older people with intellectual disabilities.

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Appendices

Appendix 1: Overview of the WHO ICF theoretical framework

Figure A1a. The four ICF domains



Figure A1b: The Theoretical Framework – 9 chapters of the ICF Activities & Participation domain



Figure A1c. ICF chapter D1 (Learning & Applying Knowledge)

D1. LEARNING & APPLYING KNOWLEDGE	REFERENCE
Purposeful sensory experiences	D110-129
Basic learning	D130-159
Applying knowledge	D160-179
Learning and applying knowledge, other specified / unspecified	D198/199

Figure A1d. ICF chapter D2 (General Tasks & Demands)

D2. GENERAL TASKS & DEMANDS	REFERENCE
Undertaking a single task	D210
Undertaking multiple tasks	D220
Carrying out daily routine	D230
Handling stress and other psychological demands	D240
General tasks and demands, other specified / unspecified	D298/299

Figure A1e. ICF chapter D3 (Communication)

D3. COMMUNICATION	REFERENCE
Communication – receiving	D310-329
Communication – producing	D330-349
Conversation and use of communication devices and techniques	D350-369
Communication, other specified / unspecified	D398/399

Figure A1f. ICF chapter D4 (Mobility)

D4. MOBILITY	REFERENCE
Changing and maintaining body position	D430-429
Carrying, handling and moving objects	D430-449
Walking and moving	D450-469
Moving around using transportation	D470-489
Mobility, other specified / unspecified	D498/499

Figure A1g. ICF chapter D5 (Self-Care)

D5. SELF-CARE	REFERENCE
Washing oneself	D510
Caring for body parts	D520
Toileting	D530
Dressing	D540
Eating	D550
Drinking	D560
Looking after one's health	D570
Self-care, other specified / unspecified	D598/599

Figure A1h. ICF chapter D6 (Domestic Life)

D6. DOMESTIC LIFE	REFERENCE
Acquisition of necessities	D610-629
Household tasks	D630-649
Caring for household objects and assisting others	D650-669
Domestic life, other specified / unspecified	D698/699

Figure A1i. ICF chapter D7 (Interpersonal Interactions & Relationships)

D7. INTERPERSONAL INTERACTIONS & RELATIONSHIPS	REFERENCE
General interpersonal interactions	D710-729
Basic interpersonal interactions	D710
Complex interpersonal interactions	D720
Other specified / unspecified	D729
Particular interpersonal interactions	D730-779
Relating with strangers	D730
Formal relationships	D740
Informal social relationships	D750
Family relationships	D760
Intimate relationships	D770
Other specified / unspecified	D779
Interpersonal interactions and relationships, other specified / unspecified	D798/799

Figure A1j. ICF chapter D8 (Major Life Areas)

D8. MAJOR LIFE AREAS	REFERENCE
Education	D810-839
Informal education	D810
Preschool education	D815
School education	D820
Vocational training	D825
Higher education	D830
Other specified / unspecified	D839
Work and employment	D840-859
Apprenticeship (work preparation)	D840
Acquiring, keeping and terminating a job	D845
Remunerative employment	D850
Non-remunerative employment	D855
Other specified / unspecified	D859
Economic Life	D860-879
Basic economic transactions	D860
Complex economic transactions	D865
Economic self-sufficiency	D870
Other specified / unspecified	D879
Major life areas, other specified / unspecified	D898/899

Figure A1k. ICF chapter D9 (Community, Social & Civic Life)

D9. COMMUNITY, SOCIAL & CIVIC LIFE	REFERENCE
Community life	D910
Informal associations	D9100
Formal associations	D9101
Ceremonies	D9102
Other specified / unspecified	D9109/9109
Recreation and leisure	D920
Play	D9200
Sports	D9201
Arts and culture	D9202
Crafts	D9203
Hobbies	D9204
Socialising	D9205
Other specified / unspecified	D9208/9209
Religion and spirituality	D930
Organised religion	D9300
Spirituality	D9301
Other specified / unspecified	D9308/9309
Human rights	D940
Political life and citizenship	D950
Community, social and civic life, other specified / unspecified	D998/999

Appendix 2: Definition of ICF Components

Figure A2. Definition of ICF components

Body Functions are physiological functions of body systems (including psychological functions).

Body Structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity is the execution of a task or action by an individual.

Participation is involvement in a life situation.

Activity Limitations are difficulties an individual may have in executing activities.

Participation Restrictions are problems an individual may experience in involvement in life situations.

Environmental Factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

World Health Organisation (2002: 10)

Appendix 3: Study Measures Used

Figure A3. Measures used by thesis chapter and ICF reference

THESIS CHAPTER / MEASURE USED	ICF REFERENCE
Chapter 4: Social Functioning	
<i>ADLs – Level of difficulty, if any, with the following:</i>	All ADLs: d210, d220, d230
Dressing, including putting on shoes or socks	d540
Walking across a room	d450-469
Getting around inside your home	d450-469
Bathing or showering	d510
Cleaning your teeth / taking care of your dentures	d520
Eating	d550
Getting in or out of bed	d410/420
Using the toilet, including getting up or down	d530
Taking medication	d598/d570
<i>IADLs – Level of difficulty, if any, with the following:</i>	All IADLs: d155, d160, d163, d175, d177
Preparing a hot meal	d630
Shopping for groceries	d620/d860
Making telephone calls (including hearing)	d729/d9205
Managing money (e.g. paying bills, tracking expenses)	d620/d860
Doing household chores (e.g. laundry, cleaning)	d640
<i>Physical Abilities – Level of difficulty, if any, with the following:</i>	
Walking 100 yards	d450-469
Sitting for about two hours	d415
Getting up from a chair after sitting for long periods	d410/420
Climbing one flight of stairs without resting	d450-469
Stooping, kneeling or crouching	d410/d415
Reaching or extending your arms above shoulder level	d445
Pulling or pushing large objects like a living room chair	d449
Lifting/carrying weights over 10lbs/5kgs (e.g. heavy bag of groceries)	d430
Picking up a small coin from a table	d440
<i>Communication Difficulties</i>	
[How] is your eyesight (with glasses or lenses if used)?	d115/d310
Can you follow a conversation with one person?	d330/d350/d355
Do you have any difficulty speaking or making yourself understood?	d345
[Can you] write notes and messages?	d110/d315/d320/d325
<i>Functional Literacy</i>	
Do you have any difficulty with reading?	d140/d166
Do you have any difficulty with writing?	d145/d170/d345
Do you have any difficulty with numbers?	d150/d172
Do you have any difficulty with computers?	d130-159/d155/ d160-179

THESIS CHAPTER / MEASURE USED	ICF REFERENCE
Chapter 5: Human Rights & Citizenship	
Have you voted in any recent election?	d950
<i>In general who chooses:</i>	
The food you eat?	d940/d5/d6
What food is cooked in your home?	d940/d5/d6
The clothes you wear?	d940/d5/d6
Who you spend your free time with?	d940/d7/d9
Where you go in your free time?	d940/d7/d9
How you spend your money?	d940/d870
Where you keep your money?	d940/d870
What time you go to bed?	d940
What job you have?	d940/d840-859
Where you live?	d940/d610
Who you live with?	d940/d610/d7
What support you may receive?	d940/e3/5 ⁴
What TV shows you watch?	d940/d920
How you decorate your room?	d940/d6
Do you have an independent advocate?	d940/e3

Chapter 6: Education, Training & Occupation	
What is the highest level of education you have completed?	d810-839/d130-159
Are you currently attending or did you participate in any courses or any other education and training in the last year?	d810-839/d130-159
Have you ever done paid work?	d850
Which of these would you say describes your current situation?	
Employed; self-employed; in a sheltered workshop; attending a day service; unemployed or looking for work; retired; unable to work due to being permanently sick or disabled; looking after home or family; in education or training; other	d810-839/d840-859
Do you do any voluntary work?	d855

Chapter 7: Social Activities	
Have you taken a holiday in Ireland in the last 12 months?	d9208
Have you taken a holiday abroad in the last 12 months?	d9208
Are you a member of any of these organisations, clubs or societies:	
Political party, trade union or environmental groups / Tenants groups, resident groups, Neighbourhood Watch / Church or religious groups / Charitable associations (e.g. St Vincent De Paul's) / Education, arts or music groups or evening classes / Retirement clubs / Special Olympics Network / Arch Club / Advocacy Group / Other	d9205/d950
Do you do any of the following activities:	
Go to the cinema, theatre, concert or the opera / Eat out / Go to an art gallery or museum / Go to church or other place of worship / Go to the pub for a drink / Go to a coffee shop for light refreshments / Go shopping / Go to sports events / Participate in sports activities/events / Go to library / Go to social clubs (e.g.	d9200 / d9201 / d9202 / d9203 / d9204 / d9205

⁴ Environmental Factors Domain: e3 – Supports and Relationships; e5 – Services, Systems and Policies.

THESIS CHAPTER / MEASURE USED	ICF REFERENCE
bingo, play cards) / Go to the hairdressers / Perform in local arts groups and choirs / Spend time on hobbies or creative activities / Visit family and friends in their home / Other	
How often do you go to religious services?	d9300

Chapter 8: Interaction with Local Community	
Are you a member of any of these organisations, clubs or societies:	
Political party, trade union or environmental groups / Tenants groups, resident groups, Neighbourhood Watch / Church or religious groups / Charitable associations (e.g. St Vincent De Paul's) / Education, arts or music groups or evening classes / Retirement clubs / Special Olympics Network / Arch Club / Advocacy Group / Other	d9205/d950
Do these activities happen within a local community setting, an ID service setting or both?	d9100/1
Do you do any of the following activities (If yes, how often):	
Go to the cinema, theatre, concert or the opera / Eat out / Go to an art gallery or museum / Go to church or other place of worship / Go to the pub for a drink / Go to a coffee shop for light refreshments / Go shopping / Go to sports events / Participate in sports activities/events / Go to library / Go to social clubs (e.g. bingo, play cards) / Go to the hairdressers / Perform in local arts groups and choirs / Other	d9200 / d9201 / d9202 / d9203 / d9204 / d9205
Do these activities happen within a local community setting, an ID service setting or both?	d9109
Do you experience any difficulties participating in social activities outside your home?	d999
Do you experience any difficulty getting around your community?	d999

Chapter 9: Interpersonal Relationships	
Who are your main social activities with?	d740/d750/d760
What family do you have?	d760/d770
Where does your family live in relation to you?	d760/d770
How often do you meet up with (non-resident) family?	d710/d720/d760 /d770
How often do you speak on the phone with (non-resident) family?	d710/d720/d760 /d770
Do you have friends outside your home?	d750
How often do you meet up with your (non-resident) friends?	d710/d720/d750
How often do you speak on the phone with your (non-resident) friends?	d710/d720/d750
Do you ever feel lonely? (SR ⁵)	d750/d760/d770
Do you ever feel left out? (SR)	d750/d760/d770
Do you find it difficult to make friends? (SR)	d730/750
Do you ever feel isolated? (SR)	d750/d760/d770
Do you have someone in whom you can confide? (SR) Who?	d710/d720/750 /d760/d770
Do you provide support/help to a family member?	d660/d710/d720/760
- Who do you provide support/help to?	
- What support do you provide?	

⁵ Self-Report only question.

THESIS CHAPTER / MEASURE USED	ICF REFERENCE
- How satisfied are with providing support?	
In the last two years did your neighbours or friends give you any help? In the last two years did you give any help to your neighbours or friends?	d660/d710/d720/d730 /d750/d910

Appendix 4: New Directions Programmes & Supports

Figure A4a. New Directions description of existing services

PROGRAMME DESCRIPTION	EXPLANATION
Day Care Programme	High support services primarily focused on providing a health care service to meet the specific needs of individuals.
Day Activation/Activity	A day programme which is essentially a support and therapeutic service designed to meet the needs of people through individual plans. The environment is designed to maximise the functional levels of service users. Day programmes provide a range of skills and activities such as independent living skills, personal development, education classes, social and recreational activities, and health-related and therapy supports. Day activation is essentially a programme that does not include work activity.
Active Community Participation/Inclusion	Programmes and supports specifically targeted towards the inclusion and active participation of service users in mainstream community programmes and activities. This includes participation in educational opportunities, sport and recreation involvement, social events, local partnership projects and advocacy initiatives. A range of supports that promote and facilitate inclusion are provided to individuals and groups, such as accessing services, liaison, planning, co-ordinating and supporting attendance and active participation by service users.
Sheltered Work Therapeutic	A centre-based programme designed to provide constructive occupation for an individual or group where work activity is a key element of the programme. The work is carried out in a centre or location designed for that purpose but there is no third party involvement, that is, no contract work and not open to public. Examples of this could be a day service that focuses on cooking and baking or arts and crafts. The product is consumed within the service. They may also hold coffee mornings to showcase the work and sell some of the products at nominal cost to encourage service users and prevent a build-up of stock. Service users may or may not receive allowances or discretionary top-up payments.
Sheltered Work Commercial	A day programme which consists of work activity. In these situations, the public has access to the product or service and contract work is carried out for a third party. Money is exchanged for goods or services. Service users may or may not receive allowances or discretionary top-up payments.
Sheltered Work 'Like Work'	A day programme which involves service users working within HSE or service provider organisations in what could be described as 'like work' situations. This includes service users working in kitchens, maintenance work, landscaping, office, administration, post room, catering, hospital shops, canteens, and so on. Service users receive a discretionary top-up payment. The purpose of this discretionary payment is to give the service user a sense of worth and reward and encourage him or her to continue with the activity. This payment could be argued to be an important part of the therapeutic aspect of the work done.
External Work 'Like Work' (less than minimum wage)	A day programme which involves service users working in external 'like work' situations. In most cases, the service provider sources the placement in an open employment setting as part of

PROGRAMME DESCRIPTION	EXPLANATION
	the individual's day programme. Minimum wage or Disability Allowance (DA) plus rules do not apply but the employer normally makes a discretionary top-up payment, either directly to the individual or to the service provider to allocate at its discretion. Examples include service users working in supermarkets, fast food chains, and so on. Short-term work placements that are part of a recognised training programme are not included.
Open Employment (no supports)	This is employment in the open labour market without additional supports. In some instances, a service user may be in open employment with no supports for only part of his or her week. The service provider may have helped the individual to get their job but has now withdrawn all support.
Supported Employment	Supported Employment is paid employment in the open labour market with ongoing supports. The minimum wage and full employee status applies. Service users may be participating in the FÁS-funded Supported Employment Programme or in initiatives run by service providers.
Sheltered Employment	Employment in an enterprise set up specifically to employ people with disabilities and which receives designated funding from the HSE. It refers to employment under sheltered conditions where workers have a contract of employment and are in receipt of the minimum wage.
Rehabilitative Training	Rehabilitative Training programmes are designed to equip participants with basic personal, social and work-related skills that will enable them to progress to greater levels of independence and integration in the community. These are approved programmes with 'Whole Time Equivalent' (WTE) places allocated by the national Occupational Guidance Service structure.
Education Programme	Programmes funded by the Department of Education and Skills to enhance day services.
Voluntary Work	<p>The volunteer works in the community or for the benefit of the natural environment primarily because he or she chooses to do so. A volunteer worker does not get paid or receive compensation for services rendered. Each person's motivation will be unique but will often be a combination of:</p> <ul style="list-style-type: none"> • altruism (volunteering for the benefit of others), • quality of life (serving the community because doing service makes one's own life better, for example from being with other people, staying active and having a sense of the value of themselves that may not be as clear in other areas of life), and • giving back, a sense of duty or religious conviction.

Source: Health Service Executive (2012)

Figure A4b. Personalised supports services (New Directions) (1)

1. Support for making choices and plans
2. Support for making transitions and progression
3. Support for inclusion in one's local community
4. Support for accessing education and formal learning
5. Support for maximising independence
6. Support for personal and social development
7. Support for health and wellbeing
8. Support for accessing bridging programmes to vocational training
9. Support for accessing vocational training and work opportunities
10. Support for personal expression and creativity
11. Support for having meaningful social roles
12. Support for influencing service policy and practice

Source: Health Service Executive (2012)

Figure A4c. Personalised supports services (New Directions) (2)



Source: Health Service Executive (2012)

Appendix 5: Papers and Presentations

Published Papers

- McCausland, D., McCallion, P., Cleary, E., McCarron, M. (2016) 'Social Connections for Older People with Intellectual Disability in Ireland: Results from Wave One of IDS-TILDA', *Journal of Applied Research in Intellectual Disabilities*, 29(1), 71-82.

Submitted Papers

- McCausland, D., McCallion, P., Brennan, D., McCarron, M. (Under Review) 'Social functioning of older people with intellectual disability: functional limitation within an ICF framework of participation', *Journal of Intellectual and Developmental Disabilities*
- McCausland, D., McCallion, P., Brennan, D. & McCarron, M. (Under Review) 'Interpersonal relationships of older people with intellectual disability in Ireland', *Journal of Applied Research in Intellectual Disabilities*

Unpublished Reports

- McCausland, D., McCallion, P., Carroll, R., O'Donovan, M. A., McGlinchey, E., Shivers, C., Burke, E. & McCarron, M. (2014) 'Social participation for older people with intellectual disability', in E. Burke, P. McCallion & M. McCarron (eds.) *Advancing years, different challenges: Wave 2 IDS-TILDA*. Dublin: Trinity College Dublin.

Oral Presentations

- McCausland, D., McCarron, M., Burke, E., McCallion, P. (2012) 'An exploration of the experiences of community for older people with an intellectual disability in

Ireland', TCD School of Nursing & Midwifery 13th Healthcare Interdisciplinary Research Conference, November 2012.

- McCausland, D. (2013) 'Developing an understanding of 'community' for older people with an intellectual disability: what can we learn from the sociological and equality literature?' TCD School of Nursing & Midwifery 14th Healthcare Interdisciplinary Research Conference, Student Colloquium, November 2013.
- McCausland, D. (2014) 'Social relationships and inclusion for older people with an intellectual disability', TCD School of Social Policy Seminar, *Somebody to Love*, Long Room Hub, Trinity College Dublin, April 2014.
- McCausland, D., Carroll, R., McCarron, M., McCallion, P. (2014) 'Social participation for older people with Intellectual Disability (ID) living in different residential settings in Ireland: results from wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)', International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) European Congress, Vienna, July 2014.
- McCausland, D., Carroll, R., McCarron, M., McCallion, P. (2015) 'Comparing the social networks of older people with intellectual disabilities (ID) and the general older population in Ireland', International Association of Gerontology and Geriatrics, European Region Congress, Dublin, April 2015.
- McCausland, D., Brennan, D. McCallion, P., McCarron, M. (2015) 'Challenging community policy for people with intellectual disabilities', 12th Conference of the European Sociological Association, Prague, August 2015.
- McCausland, D., Brennan, D. McCallion, P., McCarron, M. (Accepted) 'Using the WHO's ICF as a theoretical framework for the study of social participation for older people with intellectual disability', International Association for the Scientific

Study of Intellectual and Developmental Disabilities (IASSIDD) World Congress,
Melbourne, August 2016.

Poster Presentations

- McCausland, D., Burke, E., McGlinchy, E., Carroll, R., Swinburne, J., McCallion, P., McCarron, M. (2012) 'An exploration of community presence for older people with an intellectual disability', Irish Gerontological Society Scientific Meeting, September 2012.
- McCausland, D., Burke, E., McGlinchy, E., Carroll, R., Swinburne, J., McCallion, P., McCarron, M. (2013) 'Use of transport for older people with an intellectual disability', Irish Gerontological Society Scientific Meeting, September 2013.