

Growing Older with an Intellectual Disability in Ireland 2011

First results from The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

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

The Intellectual Disability Supplement to TILDA
School of Nursing & Midwifery
The University of Dublin, Trinity College
24 D'Olier Street
Dublin 2
Ireland

Tel: +353 1 896 3186 / +353 1 896 2692
Email: idstotilda@tcd.ie / mccarrm@tcd.ie

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Executive Summary

Introduction

The increased life expectancy of people with an intellectual disability is an incredible success story and one to be celebrated, but it also poses tremendous challenges as we know little about this population group in Ireland or indeed internationally. The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), designed to better understand these challenges, is a large scale nationally representative study of people with an intellectual disability aged 40 years and over in Ireland. This study is the first of its kind in Europe, and the only study with the potential of comparing the ageing of people with intellectual disability directly with the general ageing population.

Close harmonisation between the Intellectual Disability Supplement and TILDA (The Irish Longitudinal Study on Ageing) questions was designed to ensure that differences and similarities between the population groups would be systematically ascertained and findings would offer appropriate information to help in the design of future policies, services, and resources to better address the needs of both groups as they age in Ireland.

IDS-TILDA is also designed to explore unique and different issues for people with an ID in their ageing profile, health, health services needs, psychological health, social networks, living situations and community participation including employment. A total of 753 people with ID representing 8.9% of the ID population over the age of 40 years consented to take part in the study and preliminary descriptive findings on this group is reported here. The exploration of causal associations will be facilitated by considering this first wave baseline of data against future waves of this study, and by the tracking over time of incidence of disease as opposed to prevalence. Also we will peruse more formal comparisons with general population data gathered by TILDA. Information (although not reported here) has also been gathered on the experience of family carers.

The significance of ageing and its implications across a broad range of policy areas is being considered but has yet to be fully appreciated across EU member states. The launch of both TILDA and this unique Supplement on Intellectual Disability has highlighted Ireland's position as a leader in the development of cutting edge research in ageing and its growing readiness for the formulation of evidence-based policies, planning, service provision and design to address its own future needs; approaches that are also likely to be of influence beyond its borders.

Socio-Demographic Characteristics of Older People with an Intellectual Disability in Ireland

It is increasingly recognised that adults with an intellectual disability (ID) constitute a growing population and, similar to the general population, are experiencing increased longevity. Over the next 10-15 years, the largest proportion of adults with ID in Ireland will be aged 50 years and over. The IDS-TILDA sample successfully recruited is primarily aged 50-64 years but has participants of all ages, male and female, and includes all levels of intellectual disability and living arrangements. This is largely an unmarried group that do not have children, most are unemployed and are living in out of home placements with 63% having access to 24 hour support and the majority attend a day programme.

Key findings

- In the population with ID aged 40 years and over 45% were male and 55% were female.
- The age of respondents ranged from 41– 90 years, with an average age of 54.7 years. Similar to the general population the biggest proportion of participants (46%) fell within the 50-64 years age group.
- Unlike the general population the majority of adults with intellectual disability (ID) were not married/partnered and did not have children.
- All levels of ID were represented in the sample, with the highest number of participants (44%) falling within the moderate range of ID.
- One third had no formal education, approximately half completed some or all of their primary education and only three respondents reported having completed secondary level education. In contrast most older adults (62%) in the general population have achieved at least secondary education.
- Most participants lived in out-of-home placements; those living with families and in the community tended to be younger, with a mild/ moderate range of intellectual disability; those living in residential type accommodation tended to be older with more severe to profound levels of ID. However, there were still a substantial number of people in the younger age cohorts living in residential type centres.
- Twenty-seven percent of participants had lived in their current residence for less than five years, but 41% had lived there for more than 20 years.
- Over half of the population reported having access to 24 hour support, with some reporting that they were not in receipt of any paid support day or night.

Adults with an Intellectual Disability Ageing in Ireland as Members of their Families and Communities

Since the 1970s, there has been a concentrated effort to move people with an intellectual disability (ID) from segregated institutional type settings into community-based accommodation. Ireland has made considerable progress but there are individuals who continue to live in large segregated settings and there are concerns in Ireland and elsewhere that those living in the community continue to remain poorly connected with their communities.

The findings here support international concerns that societies have done a better job of increasing the community presence of people with an ID than facilitating opportunities to actually live within the community. Given that those currently living in community settings tend to be younger, this does not bode well for community participation as people age and experience health decline. There is an urgent need to develop sound policies and practices to better facilitate the participation of people with an ID in the life of their communities.

On a more optimistic note in terms of day-to-day life, most adults with an ID had a hobby, went on holidays or day trips, engaged in regular daytime activity and leisure pursuits and had social contacts with others. However, adults with an ID reported that they seldom engaged in social activities with friends outside their home and that families had limited roles in their lives.

Key findings

- People with an intellectual disability (ID) living in community settings participated in their local communities more than people living in residential centres. However, regardless of residential circumstances, adults with an ID in Ireland were not actively engaged with their communities and community presence was not actually equated with 'living' in the community. Given that those currently living in community settings tend to be younger, this does not bode well for community participation as they age and experience health decline.
- The majority of adults had some level of contact with at least one family member. However, approximately one in four adults reported meeting their family once a year or less. Frequency of contact declined with increasing age and was also less for those with a severe to profound ID.
- Over three quarters of adults with an ID reported that they never wrote, texted, emailed or used social media tools such as Facebook to contact their family or friends. Moreover, less than 60% used the telephone to make such contacts. Adults with an ID were less likely to own a mobile phone than other adults in the Irish population.
- Older age and more severe levels of ID often meant having fewer members in one's social network and this appeared to be associated with greater risk for social isolation. Where people lived also influenced the size of social networks, with those living in residential centres at greater risk of isolation.

- Fifty percent of those self-reporting stated that they sometimes felt lonely and one in three people who reported experiencing loneliness found it difficult to make friends.
- Most adults with an ID had a hobby, engaged in daytime activity and leisure pursuits on a regular basis, and had social contacts with others.
- However, adults with an ID seldom engaged in social activities with friends outside their home.
- The majority of adults with an ID were dependent upon others for transportation and other assistance to access community options. Participants reported that their need for such assistance was the greatest barrier to successfully participating in social activities.
- Three quarters of adults with an ID reported going on a holiday last year, with 17% going abroad on holiday. People with a more severe ID were less likely to go on holiday and more often went on day trips.
- Approximately 70% of adults with an ID in Ireland did not vote in the last general election.
- In comparison to the general population, adults with an ID had limited involvement in civic activities, such as retirement clubs, evening classes or residents associations within their communities. The Special Olympics was the highest ranked organisation in this regard.
- The majority of adults with an ID engaged regularly in a range of social activities; eating out, attending church, shopping, going to the hairdresser and cinema were all frequently cited. However, they mainly engaged in these activities with staff or peers in their group home.
- The following factors were rarely reported as concerns by adults with an ID: growing older, not having enough money, and unfriendly or negative attitudes held by other people.
- Accessibility in the community was a difficulty for many adults with an ID. Footpath design, surfaces and building accessibility posed the greatest challenges for persons with a more severe ID, and street signage and feeling unsafe posed the most difficulty for persons with a mild to moderate ID.

Physical and Behavioural Health of Older Irish Adults with an Intellectual Disability

International studies provide clues that individuals with an intellectual disability (ID) have a greater variety of health care needs compared to those of the same age and gender in the general population (US Department of Health and Human Services, 2002; Haveman, *et al.*, 2009).

Many in the IDS-TILDA sample, particularly those in the younger age cohorts, reported experiencing good health but there were significant concerns in terms of

cardiac issues (including risk factors), epilepsy, constipation, arthritis, osteoporosis, urinary incontinence, falls, cancer, and thyroid disease.

Younger adults with an ID also had a much higher incidence of disease and identifiable risk factors for conditions such as coronary artery disease and stroke, than same age and older cohorts in the general population. The high prevalence of falls in the younger age cohorts, compared to the general population, was also of concern.

Women with ID had higher risks for many diseases, both when compared to men with ID and to women in the general population. While health checks were high overall, access to screenings for cancers was of concern and access to all screening was lower for people with severe to profound ID. Conversely, screening for cholesterol was high and there appeared to be good access to physicians and dentists. Despite such apparent access to health professionals, one in three adults with an ID reported that they found it difficult to make themselves understood when speaking with health professionals.

It will be of interest, in further waves of data collection, to identify factors that pre-dispose and protect people with an ID from particular conditions. It will also be important to explore how well screenings, treatments, exercise, nutrition and physician/dentist access prevent and manage conditions, as well as the impact of disease conditions on the quality of life and longevity of people with an ID.

Finally, the prevalence figures reported here for hypertension, osteoporosis and arthritis among people with an ID need to be considered with great caution. TILDA (Cronin *et al.*, 2011), for example, found marked differences in the general Irish population between respondent reported and objectively measured rates of these conditions. Such apparent evidence of general under-reporting and differences in findings reported here for people with an ID both support continued following of this issue. They also support the addition of objective measures in subsequent waves of IDS-TILDA.

Key findings

- Cardiovascular risk factors were high among people with an intellectual disability (ID), with a marked gender difference; women were at greater risk. Prevalence increased with age.
- TILDA (2011) reported that angina, heart attack and heart failure had the highest prevalence among the general older population. By contrast, the most commonly reported heart conditions among older people with ID were heart murmur, abnormal heart rhythm and congestive heart failure.
- Lower rates of hypertension were found among those with Down syndrome, despite findings that one third of this population had high cholesterol and three quarters were overweight or obese.
- The prevalence of diabetes was similar to the TILDA general population finding but the gender difference was reversed, with diabetes more common in females than males; specifically, women within the mild to moderate range of ID were found to be at double the risk faced by men and risk increased with age.

- Epilepsy was the most common type of non-cardiovascular disease found among adults with ID; the overall prevalence was lower among those with Down syndrome, but for this subgroup incidence increased with the onset of dementia.
- Chronic constipation was a prevalent condition among adults with an ID.
- Reported levels of smoking and alcohol consumption were lower for people with ID compared to that reported by TILDA (2011) for the general Irish population.
- Sixty one percent of Irish adults with ID are overweight or obese, based on self-reported height and weight data.
- Thyroid disease was a reported health problem for 14.4% of the IDS-TILDA sample.
- Overall prevalence of reported osteoporosis is slightly lower among people with ID than that reported by TILDA (2011) for the general population, but marked gender and age differences were detected.
- The reported prevalence of cancer diagnosis was slightly lower among people with ID than reported by TILDA (2011) for the general Irish adult population. However, some similar findings were found, namely higher reported levels of cancer among women, breast cancer being the most commonly reported cancer in women and prostate cancer being most common among men. Previous reports found similar or lower levels of cancer among people with ID, with most prevalent cancers being stomach and colorectal.
- Nine out of 10 participants (91%) were taking at least one (prescription or non-prescription), medicine.
- Polypharmacy (defined as taking more than five medications (prescription and non-prescription) was observed in 59.1% of the sample, almost three times the level (21%) found for the general Irish population (TILDA, 2011).
- Polypharmacy was higher for those living in residential centres compared to those living in community, independently or with family.
- One third of people with ID reported being often troubled by pain, a concern that was more common among women than men. Moreover, one fifth reported pain to be severe. Actual prevalence is probably higher given problems in communication; this increases the likelihood that people with ID are at risk of unrecognised and untreated pain.
- The prevalence of sensory impairment among adults with ID was high; adults with ID were twice as likely to have significant visual problems and at a much younger age than the general population.
- Persons within the severe to profound range of ID were less likely to have had an eyesight test, with 30% reporting (or having proxies report for them) an eye test in the past year versus 70% of those with the mild to moderate range of ID.
- Overall, Irish adults with an ID reported that they hardly ever engaged in vigorous physical activity. Those who did engage tended to be men in the younger age groups. However, 80% did engage in some form of physical activity, at least once a week.

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- A substantial proportion of adults with ID experienced major difficulties with mobility and this increased with age.
 - Adults with ID reported a higher prevalence of at least one fall than that found among the general Irish population.
 - The prevalence rate of falls reported among younger adults with ID aged 40-49 years, at 24.5%, was comparable to fall rates reported for those in the general population aged 75 years and older.
 - One in three adults with ID reported that they found it difficult to make themselves understood when speaking with health professionals.
 - Difficulty with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) was most notable in older age.
 - The majority of adults with ID living in residential type centres, and over three quarters of those living in community settings, reported that they were unable to make a hot meal or manage their money.
 - Half of those living in the community were unable to make a phone call and one out of three was unable to shop for groceries or manage household chores. A majority of those living in residential settings reported that they were unable to do any of these same activities.
 - While those living with family and independently reported fewer difficulties, almost half could not manage their money or make a hot meal, and almost one third were unable to shop for groceries or make a phone call.

Mental Health and Cognitive Function of Older Irish Adults with an Intellectual Disability

Rates of psychopathology are reported as considerably higher in individuals with an intellectual disability (ID) compared to the general population (Fletcher *et al.*, 2007) with a constellation of associated and risk factors identified. Largely un-investigated is the role of ageing (Torr and Davis, 2007) .

Similarly, persons with ID are at least at the same risk of dementia symptoms as they grow older as the general population with the risk higher for people with Down syndrome. The development of appropriate assessments and of support and services requires that the onset of cognitive concerns in persons with ID age be systematically considered as well as the extent to which services and health systems are becoming more responsive.

Mental health issues were found to be common among those with an ID, with nearly half reporting a diagnosis of an emotional or psychiatric problem. A reported doctor's diagnosis of depression in older adults with ID was more than three times higher than that reported by TILDA for the general Irish population. Prevalence of depressive symptomatology was higher among women. It also increased with age, level of ID, sensory loss, reported experience of loneliness and living in a residential centre.

Data on cognitive function, including testing data from the TSI, will be more fully explored in future waves of this study. Here, the reported prevalence of memory impairment for those with Down syndrome was 15.8%, which was higher than the 3.6% reported for those with an ID from other aetiologies.

Key findings

- The prevalence of mental health and emotional problems is greater among persons with an intellectual disability (ID) than in the general population.
- In total, 47.5% of Irish adults with an ID aged 40 and over reported that a doctor had told them that they had an emotional, nervous or psychiatric condition.
- Almost one fifth (18.5%) of Irish adults with an ID reported that they had previously received a diagnosis of depression; this was considerably higher than the 5% reported in the general population.
- Over one fifth (21.1%) of people with an ID living independently or with family reported an emotional or mental health problem. This prevalence increases to 45.1% for those living in a community group home and 58.9% for those in a residential centre.
- Among those who self-reported, over 11% had measured case-level depressive symptoms, similar to the 10% reported for the general population. An additional 27.1% reported a sub-threshold level of depressive symptoms.
- 34.6% of those reporting a high level of depressive symptomatology have received a doctor's diagnosis of depression.
- Those who also reported feeling lonely were more likely to have a doctor's diagnosis of depression and to show a higher level of depressive symptom burden.
- Self-reported symptoms of depression were more prevalent among females, and among those who were older.
- Over one quarter (26%) of individuals with visual impairment reported case-levels of depressive symptoms and an additional 8.2% reported sub-threshold burden.
- Of those that reported a mental health diagnosis, 90.5% were in receipt of psychiatric support.
- Individuals with Down syndrome (24.1%) were less likely to report that they had an emotional or mental health disorder, other than dementia, compared with those with an ID from other causes (53.3%).
- Similar to reports for the general Irish population, nearly 90% of participants had a positive view of their mental and emotional health.
- Memory impairment was reported by 15.8% of respondents with Down syndrome; this is considerably higher than the 3.6% prevalence reported for individuals with an ID from other causes.

Health and Social Care Utilisation of Adults with an Intellectual Disability Ageing in Ireland

Key determinants of continued good health include healthcare access and healthcare utilisation. Compared to the general population, people with an ID were found to be more likely to have a long-standing relationship with their primary doctor and other healthcare professionals probably because of their life-long disability and their greater likelihood of having spent adult years in services, including residential care. Access to medical cards was also likely of influence.

Those in older age groups (who were more likely to be in residential care) had lower numbers of hospital admissions. Living in residential centres often means greater access to doctors and other healthcare professionals, and the impact of this aspect of residential care on hospitalisations needs further investigation.

Regardless of setting, extremely high levels of access to a GP suggest that opportunities exist for the coordination of care.

Increasing age and reductions in availability of services given healthcare cutbacks will pose challenges for people with an ID in the years ahead. Future waves of data collection for IDS-TILDA will closely monitor changes in healthcare access and utilisation for adults who are ageing with an ID.

Key findings

- In general, people with an intellectual disability (ID) accessed healthcare services on a regular basis and levels of health utilisation were similar to those reported in the general population except for higher rates of hospitalisation.
- More than half (56.5%) of participants reported they had never received easy to read leaflets on keeping healthy and three quarters said they had never received easy to read information leaflets on healthcare services.
- The general practitioner (GP) was the most frequently accessed healthcare service.
- There is evidence that dental service usage for people with an ID declines with age, whereas it is reported to increase in the general population.
- People living in a residential centre reported receiving services more frequently than their counterparts in community settings or living independently or with family.
- People in the severe to profound range of ID had higher levels of reported health services utilisation than those with a mild to moderate ID level.
- Despite higher levels of chronic illness and disability, older adults with an ID were less likely than other older adults in the general population to be admitted to a general hospital. Most older adults with an ID lived in residential type centres; further investigation is needed of the extent to which the availability of increased nursing and medical care in those settings influenced the need for hospitalisations.
- Overall, people with an ID reported being satisfied with their healthcare.

Employment, Retirement, Day Services and Lifelong Learning

Many of the key issues that concern the general population are also relevant to the lives of adults with an ID. They include work, work programmes, retirement, life-long learning and expenses, such as rent and day-to-day living costs. However, most people with an ID seem to have a more limited range of opportunities than the rest of the population, including choosing the activities in which they participate.

There was a high level of attendance at day programmes rather than engagement in paid employment. The current economic recession will make it difficult to increase the proportion of respondents who were in actual employment (6.6%). For this reason, it will be important for IDS-TILDA to monitor in subsequent waves changes in levels regarding both employment and access to programmes that adults with an ID themselves find meaningful.

Regardless of level of ID, the majority of people with an ID were reliant on staff to access programmes or employment. This raises questions about what happens to these opportunities if economic cutbacks reduce the number of staff available to escort.

The levels of income secured through wages and disability allowances by people with an ID would be equated with poverty by other Irish citizens. Many people with an ID did not know how much money they had available, did not collect those funds for themselves and relied upon service providers' central funds to manage the dispersing and use of these resources. This is of concern. Quality of life in retirement for most Irish citizens is enhanced by the use of savings and other resources, yet people with an ID have fewer such resources and less access to what little they have available. A need emerges for savings, pensions and other sources of income to be made available to people with an ID, if their experience of retirement is to be similar to that of the general population.

Key findings

- Overall, 6.6% ($n=50$) of Irish adults with an intellectual disability (ID) were in paid employment. It was reported that 37.6% ($n=283$) were unable to work due to permanent disability or sickness and 6.1% ($n=46$) were retired.
- Of those in paid employment, 44% ($n=22$) received less than the minimum wage.
- Over half of respondents did not know how much money they received on a weekly/monthly basis.
- The majority of those who worked travelled there by bus, and the average journey time was between 10 and 30 minutes.
- The majority of adults with an ID (79.4%) attended a day service, with 43.5% reporting they had choices in their activities there and 32.7% reporting that they rarely or never had such choices.
- Just over one third (66.8%) reported that they received assistance going to and from their day service.

-
- The average age of retirement was 62 years; however, a number of participants indicated they did not want to retire as long as their health permitted.
 - Positive social consequences of attending programmes or employment included retaining contact with staff and friends, and having somewhere to go during the day. These were reported as important factors in deciding not to retire: *'he goes to the centre to see his girlfriend and listen to music and seems to spend a lot of time in [named centre] where he clearly knows a lot of people and has the craic'*.
 - A total of 15.6%, most of whom were aged 40-49 years, indicated that they were currently engaged in further education.
 - For those who expressed a desire to engage in further education, computer and literacy classes were most frequently cited courses.
 - Over four fifths (82%) were in receipt of the disability allowance.
 - The majority (78%) paid rent, at an average of €100.58 per week.

Personal Choice, Planning for Daily Life and Beliefs About Ageing

Beliefs and experiences about happiness, choice and ageing were examined. The experience of happiness, pleasure and enjoyment of life for people with an ID was comparable to reports for the general population. Happiness was often linked to family relationships and simple aspects of life that were valued by participants including the importance respondents placed on choosing the food they ate, the clothes they wore, and what they did in their free time. It was of concern that participants enjoyed less autonomy and choice regarding more significant matters, such as where they lived, who they lived with and how they spent their money.

A high proportion of respondents also reported having IPPs; however, as these plans were not reviewed, it is not possible to gauge the extent to which they reflect person-centred principles. Future waves of data collection will seek this additional information.

People with ID also had a positive outlook on ageing. Respondents equally imparted a realistic understanding of the ageing process and associated losses of family and friends, increased dependence and death.

Key findings

- Many people with an intellectual disability (ID) reported accessing a great deal of support in making personal choices in their lives.
- Overall, adults with an ID reported having a good level of choice in relation to basic day-to-day issues in their lives, such as the food they eat, clothes they wear, and how they spent their free time.

- Nonetheless, the majority of adults with an ID reported that they had limited choice in relation to how they lived their lives. Three quarters (75.4%) reported having no choice in relation to where they lived and 85.5% reported that they had no choice in relation to who they lived with. Almost half of respondents said they had no choice in relation to the time at which they went to bed.
- Most people with ID reported having an individual personal plan (IPP). A majority also said that they were included in decisions made about their lives, and that they received good support from key workers in pursuing those IPPs. However, it should be noted that there was no means of knowing if those respondents whose responses were made by proxy shared this view of their involvement in an IPP. The contents of these IPPs were not reviewed to establish the extent to which they were person-centred.
- Those living independently or with family were slightly less likely to report having a key worker or an IPP than those living in a community setting or residential centre.
- Only a small number of respondents had accessed an independent advocacy service. However, the majority of people with an ID, particularly those with a mild to moderate ID, reported having access to an advocacy service.
- The experience of happiness, pleasure and enjoyment of life for people with an ID was comparable to that of the general population, as reported by McGee *et al.* (2011).
- Happiness among people with an ID was linked with family and simple life values; as one respondent succinctly described it, '*happiness in my life at the moment is living with my family*'.
- People with an ID reported feeling younger than their actual age and this was more likely to be the case for men.
- Adults with an ID reported a positive outlook on ageing, with 63% indicating that older people could do most things younger people could do and for 65%, older people were a source of good support.
- Adults with an ID expressed typical concerns associated with advancing years, the main issues here being loss of family and friends, increased dependence and fear of death.

1

Introduction

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1

Introduction

1.1 Introduction

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) is a large-scale, nationally representative study of people aged 40 years and over with an intellectual disability (ID) in Ireland. It is the most comprehensive study on ageing in persons with intellectual disability ever carried out in Ireland, and the first of its kind internationally, to be conducted in tandem with a national population study on ageing. IDS-TILDA will provide much needed data on the health, social, economic and environmental circumstances of 753 people as they grow older and on how their circumstances change over a 10 year period. IDS-TILDA is also designed to maximise the comparability of such data with TILDA and other well established international longitudinal studies of ageing, for example, in the United States (HRS) and the United Kingdom (ELSA). Such access to comprehensive data on ageing over time will assist national and local policy makers and services providers in planning and providing for the needs of this population group as they age.

1.2 Ageing in Ireland

In a recent report, the first wave findings of The Irish Longitudinal Study on Ageing have documented in a representative sample of 8,178 adults in Ireland aged 50 and over an overall high quality of life, with many older adults enjoying life and continuing to make significant contributions to their families and communities. However, there were also findings that self-perceived health declines with age, and that the objective burden of chronic illness increases as adults get older. Lower levels of wealth and education were also associated with declining health. Women as they age were less likely to have pensions and other financial resources, comparison of self reports with standardized psychosocial and physical measures found high levels of under-diagnosed depression, hypertension and osteoporosis and use of GP and other health services was often influenced by the availability of a medical card (Barrett *et al.*, 2011).

These are important findings capturing the experiences of ageing but also helping to explain Ireland's poor ranking (#22) in a WHO healthy life expectancy survey of 23 countries (WHO, 2001). They are also important because it is anticipated that the understanding of ageing that will result from this and subsequent waves of TILDA will influence the design and redesign of policy, health care and service provision for persons who are ageing in Ireland.

However, the sampling frame for TILDA, the Irish Geodirectory, unintentionally precludes many people with intellectual disability from participating. The ageing of this group and the need to ensure policy responses address their ageing is important too.

1.3 Ageing demographics of persons with an intellectual disability in Ireland

A steady increase in the proportion of persons aged 35 years or over has been observed in each iteration of Ireland's Health Research Board maintained National Intellectual Disability Database (NIDD) from 37.9% in 1996 to 48.6% in the 2009 dataset. Additionally, by 2009 almost half of people with a moderate, severe, or profound intellectual disability were aged 35 years or over (Kelly *et al.*, 2010). These trends can be expected to continue in the years ahead.

A review of the 2010 National Disability Database Report (NIDD) (Kelly *et al.*, 2010) points out that age is already a factor for the population of people living in full-time residential services. A review of NIDD reports over the last six years documents an overall trend for decreases in the numbers in full-time residential services, but this is true more for younger than older age cohorts. By 2009 2.9% of all 0–19-year-olds were in receipt of full-time residential services, compared with 24.8% of 20–34-year-olds, 53.7% of 35–54-year-olds, and 75.3% of those aged 55 years or over. In addition, more than one in four people with a moderate, severe, or profound intellectual disability aged 35 years or over continued to live with their families. Current and future changes in the age profile of people with ID therefore has major implications for service planning, potentially increasing demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with ID. Specific concerns include:

- Independent, successful ageing and retirement for the general population is usually supported by pensions, other financial resources, good health and health care, social networks and family supports (McCallion, *et al.*, in press). Such resources are not as available to people with ID.
- As the carers of adults with ID themselves age beyond their caring capacity, additional formal supervised living arrangements will be needed.
- Improved life expectancy among adults with a more severe intellectual disability is placing an increased demand on health services.
- Increased longevity means that fewer residential places are becoming free over time, a higher degree of support within day and residential services is required, and specific support services for older people with ID are needed.

- After several decades of efforts to either maintain or return people with ID to the community and an emphasis on person-centred planning, self-determination and promoting choice some argue that it is unclear the extent to which people with ID live lives connected to the community as opposed to being simply physically present in communities (Cummins and Lau, 2003).
- Planning for the future lives of adults with ID is of critical importance in Ireland and policy needs to be informed by an understanding of the ageing, needs, supports and life experiences of people with intellectual disability as they age.

A recent paper summarizing the scientific literature over the past fifteen years on the topic of health risks associated with ageing in people with intellectual disability, draws attention to the lack of longitudinal and incidence studies addressing health issues of elderly people with intellectual disability (Haveman *et al.*, 2009). Given the financial resources needed to conduct this type of research and the challenges in recruiting and retaining the sample sizes required and in addressing consent and ethical issues, it is perhaps understandable that researchers have instead relied upon cross-sectional studies. However, similar to the general population, longitudinal studies are a critical contributor to the evidence base for understanding key determinants of health and well-being for people with intellectual disability as they age.

To address their unintended exclusion from TILDA and the more general issues in the absence of longitudinal studies, this Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) is designed to meet this critical need, and to collect primary data to more fully understand the health consequences and mortality risks associated with ageing in persons with intellectual disability (McCarron and McCallion, 2007). A representative sample of 1,800 people with intellectual disability was drawn from the National Intellectual Disability Database (NIDD). Close harmonisation between The Intellectual Disability Supplement and TILDA questions ensured that the differences and similarities between the population groups would be systematically ascertained, so that future policies, services, and resources would have appropriate information to help better address the needs of both groups as they age in Ireland. IDS-TILDA is also designed to explore unique issues for people with ID arising from differences from the general population in their ageing profile, health, health services needs, psychological health, social networks, living situations and community participation including employment. In addition the experience of family carers has also been captured.

1.4 Ageing experiences of people with intellectual disability

Similar to the general population, marked changes in the life expectancy of persons with intellectual disability have occurred among all age cohorts but in particular, among those aged 55 years and over (Kelly *et al.*, 2010). Additionally, almost half of people with a moderate, severe, or profound intellectual disability are aged 35 years or over. These trends can be expected to continue in the years ahead. However, the life expectancy of persons with intellectual disability in Ireland remains less than that of the general population, with the average age of death in an Irish population with ID reported at 46 years (Lavin *et al.*, 2006). Longevity in Ireland is also less compared to cohorts of persons with ID identified in international reports, e.g., 66 years for New York State, (Janicki *et al.*, 1999) and 58 to 74 years depending on level of disability in the UK (Bittles, 2002). Given a dearth of social, psychological and health information on older persons with ID, the possible explanations for mortality differences have not been well investigated and cross sectional conclusions in the literature (for a review see for example, Haveman, *et al.*, 2009) drawn from small, often less than representative samples need to be tested with representative samples and supported longitudinally.

These are important concerns; as is true for the general population, there is a great need to ensure that future planning, policies, services, support and allocation of resources are sufficient to meet the changing needs of persons who are ageing with an intellectual disability. Key areas for understanding the ageing of persons with intellectual disability suggested by the international literature include: (1) their physical and psychological health status, (2) their use of health services, (3) their social networks and supports including living arrangements and income available, and (4) their experience of personally defined quality of life.

1.5 Health status

With little specific Irish data, international studies do provide some clues and suggest that as a group, individuals with intellectual disabilities have a greater variety of health care needs compared to those of the same age and gender in the general population (U.S. Department of Health and Human Services, 2002). Also that health problem experiences may vary by level of disability (Moss *et al.*, 1993). Van Schrojenstein Lantaman-De Valk *et al.* (2000) compared 318 people with intellectual disability within a general practice with others and found that people with learning (intellectual) disabilities had 2.5 times the health problems of those without such life-long disabilities. These same researchers and others (for a review, see Haveman, *et al.*, 2009) also found that some conditions seemed highly influenced by external circumstances, such as lack of information, lack of exercise, poor mobility, poor eating habits, and medication use. Given the complexity of influences on health, an intellectual disability-specific exploration of the experience and history of health conditions and the environmental and health practice factors that may be of influence appears warranted.

1.6 Health service needs

There has been controversial evidence in other countries that the experience of poor health and early mortality among people with intellectual disability may be related to the location and to the types and quality of health care services people with intellectual disability receive (see for example Strauss *et al.*, 1998). It has also been reported that:

- People with intellectual disability are more likely to lead unhealthy lifestyles which contribute to the development of physical ailments in later life (Evenhuis *et al.*, 2001; WHO, 2001).
- Health problems of persons with intellectual disability are not being recognised (Merrick, *et al.*, 2002; Cooper *et al.*, 2004).
- There is a lack of specialist knowledge and training amongst multidisciplinary team members (Gilbert *et al.*, 1998; Kerr *et al.*; 1996; Singh, 1997).
- People with intellectual disability do not access health promotion and health screening services to the same extent as peers without disability (DoHC, 2001; Kerr *et al.*, 1996; Jones and Kerr, 1997; Iacono and Sutherland, 2006).
- Health promotion programmes are seldom targeted at people with ID yet they have been shown to increase disease prevention and case finding (Cooper *et al.*, 2006; Lennox *et al.*, 2007).

- Given that people with intellectual disability are often reliant on health management by proxy, this increases both access barriers and the likelihood that health needs identified at screening are not subsequently met (Cooper *et al.*, 2006).
- Gathering information on barriers to accessing healthcare and understanding efforts toward the promotion of health for people with intellectual disability as has been undertaken in IDS-TILDA may help improve understanding of these issues in an Irish context.

1.7 Psychological health

Among the population of adults with intellectual disability, there is a reported high point prevalence (more than one third) rate of mental health problems (Cooper *et al.*, 2007). In a review of available studies, Parry (2002) reported that depending on the instruments and definitions of old age used, 20-40% of older persons with intellectual disability have a mental health problem. More recently, Bhaumik *et al.* (2008a) also highlighted higher psychiatric morbidity among elderly (compared with younger) adults with intellectual disability. Social, cultural, environmental and developmental factors (Hastings *et al.*, 2004; Day and Jancar, 1994), the consequences of polypharmacy and inadequate medication review (Mikklesen, 2007) are reported to have significant impact on the expression of both psychiatric and behavioural disorders in older people with intellectual disability. Once again these are largely findings from cross-sectional studies with samples where representativeness has not been established. The initiation of a longitudinal study of a nationally representative sample of adults with intellectual disability will help confirm these findings, add more detail and potentially identify and measure the contribution of risk and protective factors.

1.8 Social networks and supports

Community living and integration for people with an intellectual disability is a relatively new phenomenon but does date to the movement to deinstitutionalize people with intellectual disabilities which began in the 1960's and 1970's and was influenced by ideas of Normalization (Nirje, 1969; Wolfensberger 1970), and later, Social Role Valorization (Wolfensberger, 1992). Contemporary service policy and provision in Ireland and elsewhere continues to be committed to ensuring the movement of people from institutional, congregated settings into the community (HSE, 2011). Yet, recent reports from the National Intellectual Disability Database (NIDD) (Kelly *et al.*, 2010) document that there are many people with ID who are moving to institutional settings as they age, despite reports that people with ID living in community settings display increased adaptive behaviour (Felce and Emerson, 2001; Felce *et al.*, 1998), better health as compared to those living in nursing homes (Heller *et al.*, 1998), and improved quality of life when they move from large group homes with institutional features to community settings (Howard and Spencer, 1997). Living with

family has also been reported (Webb and Rogers, 1999) to offer a more community based lifestyle, natural social networks, continuity and constancy, environmental familiarity, and greater acceptance and respect. However, there are also reports that community presence is easier to achieve than community integration, and although movement of people with ID into the community has successfully occurred, achieving actual integration in those communities has been much slower to achieve (Verdonschot *et al.*, 2009).

The TILDA report (Barrett *et al.*, 2011) describes an Ireland where adults and older adults are active members of families and communities and offers concrete examples of their integration. The likelihood that adults with ID do not have spouses and children challenges the opportunity but does not mean that it is not possible to experience the same kinds of integration, however the published data has yet to answer such questions. Studies to date on community participation of persons with an ID are reported to have methodological and other concerns including that criteria for community participation are poorly defined, there are unrepresentative samples, studies seldom use a theoretical framework, and studies have mainly included people who are younger and with a mild ID (Verdonschot *et al.*, 2009). The concept of community integration of adults with ID in Ireland and indeed elsewhere is poorly understood, and deserves to be considered in a manner similar to that of the general population.

Placing value on relationships with families, and peers, exploring the 'sense of community' for people with ID and utilizing the linkage of IDS-TILDA to TILDA to explore similar quality of life and community linkage issues all offer an opportunity to address past methodological limitations and explore the sense of personal well being and self worth for people with ID as they age as well as the relationship between community integration, family, and friends and optimal health. Highly influenced by quality of life perspectives, the recommendations within the Council of Europe Disability Action Plan 2006-2015 (Council of Europe, 2006) argue that governmental policies on health and social care should be most influenced by the needs of the individual with a disability. Insights and improved understanding of health, social care and quality of life issues should therefore inform improved policy and practice approaches for this current and future generations of older people with ID in Ireland.

Against the backdrop of these cross-sectional and international findings, and recognizing that to date there have been few efforts to jointly look at general population and intellectual disability issues, the research team has been focused upon (1) building cross sectional health status and daily living data on adults with intellectual disability gathered in ways that are comparable to those for the general population, (2) building models of potential risk and protective factors for health and quality of life as people with intellectual disability age and (3) comparing the resulting findings with those yielded by TILDA for the general population. The data gathered is intended to provide the first wave baseline data and a framework that will seed a longer term longitudinal follow-up of this population.

1.9 Specific aim

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. A second aim is to develop a first wave baseline picture of ageing among persons with intellectual disability and a cohort of subjects that may then be followed longitudinally.

1.10 Objectives

1. To understand the health characteristics and status of persons with intellectual disability as they age
2. To examine the service needs and health service utilization of older persons with intellectual disability as compared to the general population
3. To identify disparities in the health status of older persons with intellectual disability as compared to findings yielded by TILDA for the general population
4. In preparation for longitudinal follow-up, to determine potential
 - Risk factors for ill health
 - Facilitators of good health and longevity
 - Biological and environmental components of successful ageing

Underlying Hypothesis: The contributors to successful ageing, health and quality of life will be the same for persons with ID compared to those identified by TILDA for persons in the general population.

The study has begun a process of advancing our knowledge of the health-related attributes of the population of older adults with an intellectual disability and their distinctive health risks, including those linked to aetiologies. On a practical level the supplement will help to ensure that the ageing of persons with intellectual disability will receive fuller consideration, the collaboration with TILDA is likely to benefit the potential for understanding of ageing of all persons in Ireland and this successful completion of data collection for the first wave of IDS-TILDA makes more feasible the continued collection of data and the building of a longitudinal dataset.

2

Socio-Demographic Characteristics of Adults with an Intellectual Disability Ageing in Ireland

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2

Socio-Demographic Characteristics of Adults with an Intellectual Disability Ageing in Ireland

2.1 Key findings

- Forty-five percent were male and 55% were female.
- The age of respondents ranged from 41– 90 years, with an average age of 54.7 years. Thirty-six percent of participants were aged between 40-49 years and 18% were 65 years or over and like the general population the biggest proportion of participants (46%) fell within the 50-64 years age group. However, 48% of this IDS-TILDA group were female and 43% male compared to 60.9% of males and 56% of females in the TILDA sample (2011).
- Unlike the general population the majority of adults with intellectual disability (ID) were not married/partnered and did not have children.
- All levels of ID were represented in the sample, with the highest number of participants (44%) falling within the moderate range of ID.
- One third had no formal education, approximately half completed some or all of their primary education and only three respondents reported having completed secondary level education.
- Most participants lived in out-of-home placements; those living with families and in the community tended to be younger, with a mild/moderate range of intellectual disability; those living in residential type accommodation tended to be older with more severe to profound levels of ID. However, there were still a substantial number of people in the younger age cohorts living in residential type centres.
- Twenty-seven percent of participants had lived in their current residence for less than five years, but 41% had lived there for more than 20 years.
- Over half of the population reported having access to 24 hour support, with some reporting that they were not in receipt of any paid support day or night.
- Most adults with ID reported having a religion with the majority 57% attending religious service at least once a week, which is comparable to reports for the general population (TILDA, 2011).

2.2 Introduction

It is increasingly recognised that adults with an intellectual disability (ID) constitute a growing population and, similar to the general population, are experiencing increased longevity. Over the next 10-15 years, the largest proportion of adults with ID in Ireland will be aged 50 years and over. Moreover, and for the first time in history, it can be expected that the cohort aged 70 years and over will also comprise a large segment of the ID population.

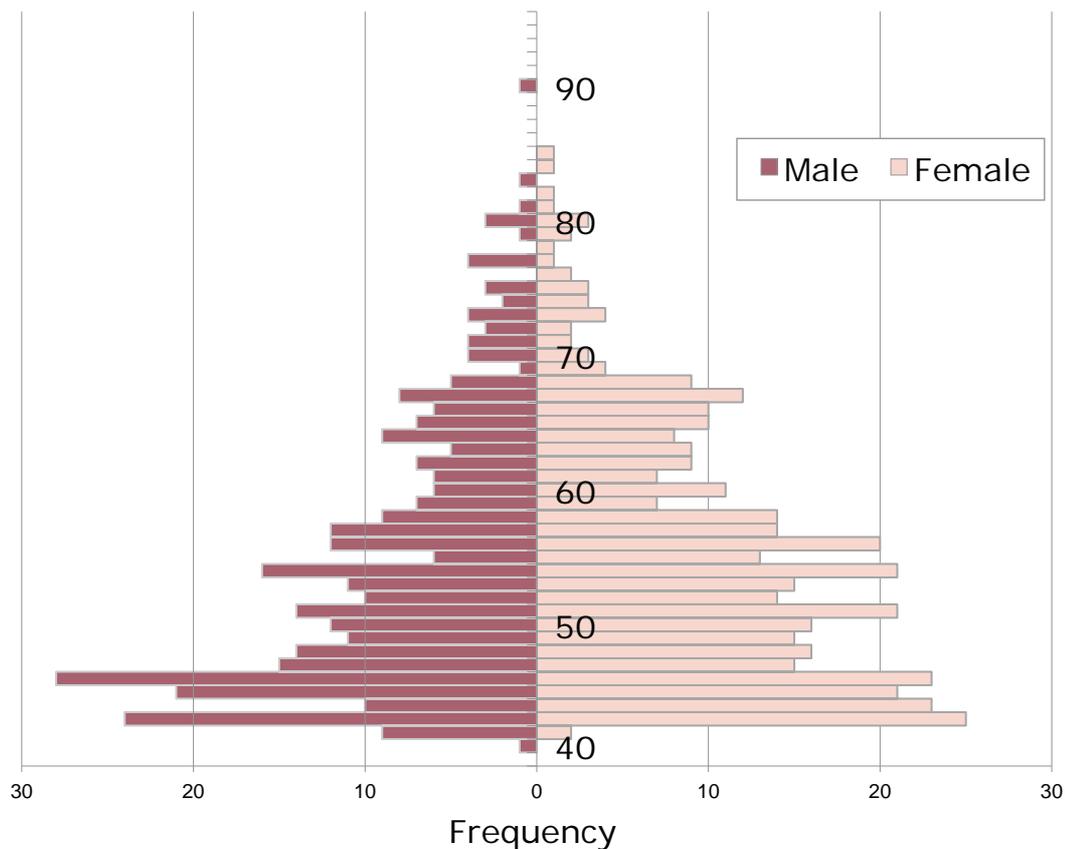
This chapter provides a picture of adults with an ID as they age in Ireland, in terms of age groups, gender, marital status, level of ID, religion, living circumstances, education, and employment history. Results are reported for the total sample. In presenting these findings, attention is drawn to differences regarding levels of ID and living arrangements. It is likely that an examination of these factors will improve our understanding of some differences in the lives of people with ID as they age.

2.3 Age and gender

The youngest participant was aged 41 years and the oldest was 90 years. The highest proportion of participants (46%) were aged between 50-64 years, with 36% falling within the 40-49 age group. A further 18% were aged 65 years and over. This is comparable to data from the National Intellectual Disability Database (NIDD) (HRB, 2011), except that NIDD reports approximately 45% in the 40-49 years group and fewer aged 65 years and over. In the general population TILDA report the largest proportion of participants was also in the 50-64 year old age group accounting for 58.3% of the population (Kamiya and Sofroniou, 2011). However, given pre-mature ageing and early mortality in persons with ID particularly those with Down syndrome it was considered important to track key determinants of health and well being in people with ID at a younger age hence overall the population is younger when compared to TILDA.

Figure 2.1 portrays the sample's overall age and gender distribution. The NIDD 2010 data reports that the population of people with ID over 40 years is 51% male and 49% female (HRB, 2011). However, in this sample, 45% of participants were male and 55% were female. In the general population 47.9% were male and 52.1% were female (Kamiya and Sofroniou, 2011). There was a noted gender and age difference. In the younger age group 40-49 years males with ID outnumbered females at 39.8% versus 33.7% respectively. Similar to the general Irish population the largest proportion of the IDS-TILDA sample was in the 50-64 age group; unlike the general population where males in this age cohort outnumbered females at 60.9% versus 56%; in the ID population females represented the largest group at 48% versus 43% for males.

Figure 2.1: Age and gender distribution the sample



2.4 Marital status

It has recently been reported that in the general Irish population, most men and women over the age of 50 years are married (Kamiya and Sofroniou, 2011). Conversely, the majority of participants in IDS-TILDA (99%) reported they were not married. Previous studies have also reported that people with severe ID are less likely to marry, however rates among people with mild ID have been reported as high as 73% (see Hall *et al.*, 2005).

One IDS-TILDA participant was married, another was living with a partner, a further two participants reported having a partner but not co-habiting and three participants reported that they were separated. A larger, but still small, number ($n=16$, or 2%) reported having given birth to a child. This contrasts with the mean number of 1.84 children born per woman over 50 years in the TILDA sample (Kamiya and Sofroniou, 2011).

Spouses, other partners, and children are frequent sources of caring support for older adults living in the community. The partnering and birth rates found for the IDS-TILDA sample suggest that this important support will not be available for people with ID as they age.

The lack of partners and children among people with ID reflects attitudes and the historical development of services for people with ID in Ireland and elsewhere that is being increasingly challenged. A strong international consensus currently exists to support rights-based policies and approaches regarding relationship and sexual health for persons with ID (Foley and Kelly, 2009). Indeed, a number of participants expressed that they would love to have a partner to grow old with; for example one participant stated, *‘I would like a companion okay, to walk around and do things with and talk to if I had my own companion I could stay as long as I want out.’* Another stated that he has a very good friend, noting *‘she is a very good buddy, I know I’ll never be married but I love her’.*

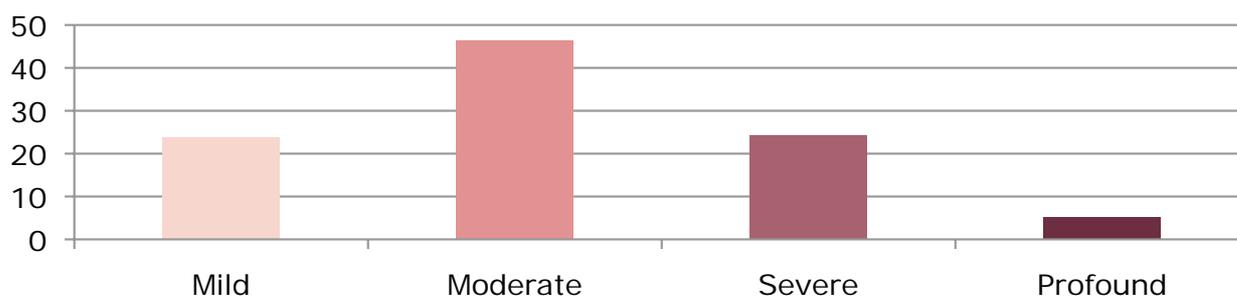
Longitudinally, it will be interesting to explore if greater openness by society, families and services to such relationships will translate into trends for increased partnering among people with ID.

2.5 Level and cause of intellectual disability

2.5.1 Level of intellectual disability

All levels of ID are represented in IDS-TILDA. The sample proved to be largely representative of the total population aged 40 years and over registered on the National Intellectual Disability Database (NIDD) (Kelly *et al.*, 2010). This belied two concerns expressed at the beginning of the study: that people with mild ID would be difficult to locate and recruit as they may be less known to services, and that it would be difficult to collect data from people with severe and profound ID. As can be seen in Figure 2.2, 24% of the sample have a mild level of ID, 46% have a moderate level, 24% have a severe level and 5% ($n=37$) have a profound level of ID. For approximately 5% of the sample, their level of ID was not verified.

Figure 2.2: Level of intellectual disability



Note: N=695: Missing obs = 58; Not verified included in missing obs (n=19)

2.5.2 Causes of intellectual disability

Participants and/or their proxies were asked to indicate the cause of their ID. For 50%, the cause was unknown. A further 20% reported Down syndrome, and 17.3% cited a range of other causes, including birth trauma, Cerebral Palsy, Autism and road traffic accidents. A remaining 12.7% responded 'don't know'.

2.6 Level of education

Education may influence the options and choices in a person's life. Higher levels of education earlier in life are associated with increased attention to good health practices, and health service access and usage (WHO, 2008). In this sample, 31% indicated they had engaged in some years of primary education. An additional 23% completed their primary education and 1.6% ($n=10$) reached Junior Certificate level in terms of secondary education. A further three participants completed their Leaving Certificate. Finally, 11% identified other educational experiences, usually a special needs school (See Table 2.1). These findings concur with previous studies such as Hall *et al.* (2005) where less than 5% of adults with ID were found to have achieved a formal education by the age of 35 years. It is very different from the reported 62% of people over 50 years in Ireland who have completed secondary education (Kamiya and Sofroniou, 2011). Of even more concern was the fact that 32% of participants reported having had no education whatsoever.

On a more hopeful note, perhaps reflecting changing trends and opportunities, this study identified two individuals who had achieved a primary degree and four who had completed a diploma or certificate. A number of participants (19%) indicated an interest in participating in educational and lifelong learning opportunities. Recently, there have been expansions in educational resources and a growing movement towards supporting persons with ID to participate in mainstream education and vocational opportunities. Longitudinal follow-up of this sample will offer opportunities to determine the actual extent to which educational opportunities increase and are accessed.

Table 2.1: Levels of education attained by participants

Levels of Education	Frequency	%
No Education	205	32.0
Some primary education	198	30.8
Primary education	148	23
Junior Certificate level	10	1.6
Leaving Certificate level	3	0.5
Diploma/Certificate	4	0.6
Degree	2	0.3
Other	72	11.2

2.7 Residence arrangements and concerns

One of the main challenges for ID services is the large number of people still living in congregate settings. The report of the working group on congregated settings, *Time to move on from Congregated Settings – A Strategy for Community Inclusion*, identified 4,000 adults with ID who continued to live in large congregated settings (HSE, 2011). The NIDD 2010 data (HRB, 2011) shows that for people with ID aged 40 years and over, 23.5% ($n=2097$) live in residential centres; 16.3% ($n=343$) of this population participated in IDS-TILDA. As the public debate moves in the direction of reducing reliance on congregate residential arrangements, the IDS-TILDA sample offers an important opportunity to follow people with ID in such settings as they are moved to more community-based options.

2.7.1 Residential circumstances of participants

Table 2.2 presents the wide range of residential circumstances among participants. Three participants lived in a psychiatric hospital or nursing home. Two fifths (40.2%) lived in 52 week residential centre, while a further 5.3% lived either in a five day a week residential centre or a residential centre that involved two weeks or more holidays per year. One third (34.1%) lived in community group homes. Five percent lived independently or semi-independently and the remaining 11% lived at home, supported by their family. Of the family supported group, 32 resided with a sibling or other relative and 51 lived with one or both parents. This final cohort will be particularly interesting to follow over time, to see how ageing impacts the family's ability and willingness to continue to provide support at home.

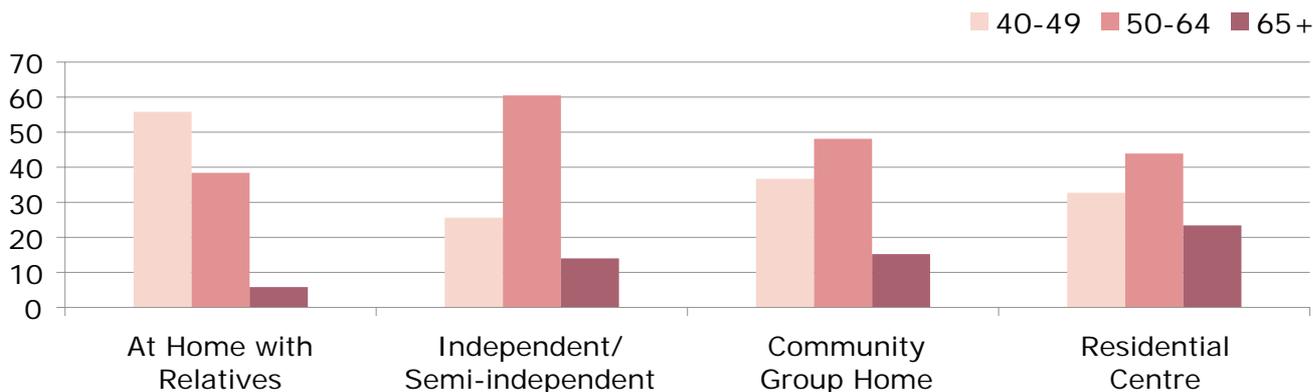
Table 2.2: Residential circumstances of participants

Type of residence	Frequency	%
At home with both parents	20	2.7
At home with one parent	31	4.1
At home with sibling	31	4.1
At home with other relative	1	0.1
Living independently	20	2.7
Living semi-independently	18	2.4
5-day community group home	15	2.0
7-day community group home (48 weeks – goes home for holidays)	58	7.7
7-day community group home (52 weeks)	184	24.4
5-day residential centre	7	0.9
7-day residential centre (48 weeks – goes home for holidays)	33	4.4
7-day residential centre	303	40.2
Nursing home	2	0.3
Psychiatric hospital	1	0.1
Intensive placement (challenging behaviour)	4	0.5
Other	23	3.1
Don't know	1	0.3

2.7.2 Living arrangements across the age groups

TILDA (Kamiya and Sofroniou, 2011) reported that the dominant living arrangements among adults in Ireland were living alone or as a couple. As the majority of people with ID (99%) are unmarried, the option of living with a spouse is negated. Only 38 people live independently or semi-independently. Figure 2.3 portrays the living arrangements for three age groups: 40-49 years, 50-64 years and 65+ years. In this sample at least, it emerged that younger participants were more likely to live with family and that the oldest age category were in more residential type settings. However, there were a substantial number of people in the younger age cohorts living in residential type centres. There are trends in the NIDD data which suggest that people as they age are more likely to be found in residential care settings (NIDD, 2010). In its subsequent waves, this study has the potential to identify over time the barriers and facilitators for continued community living for people with ID as they age.

Figure 2.3 Living arrangements across the age groups



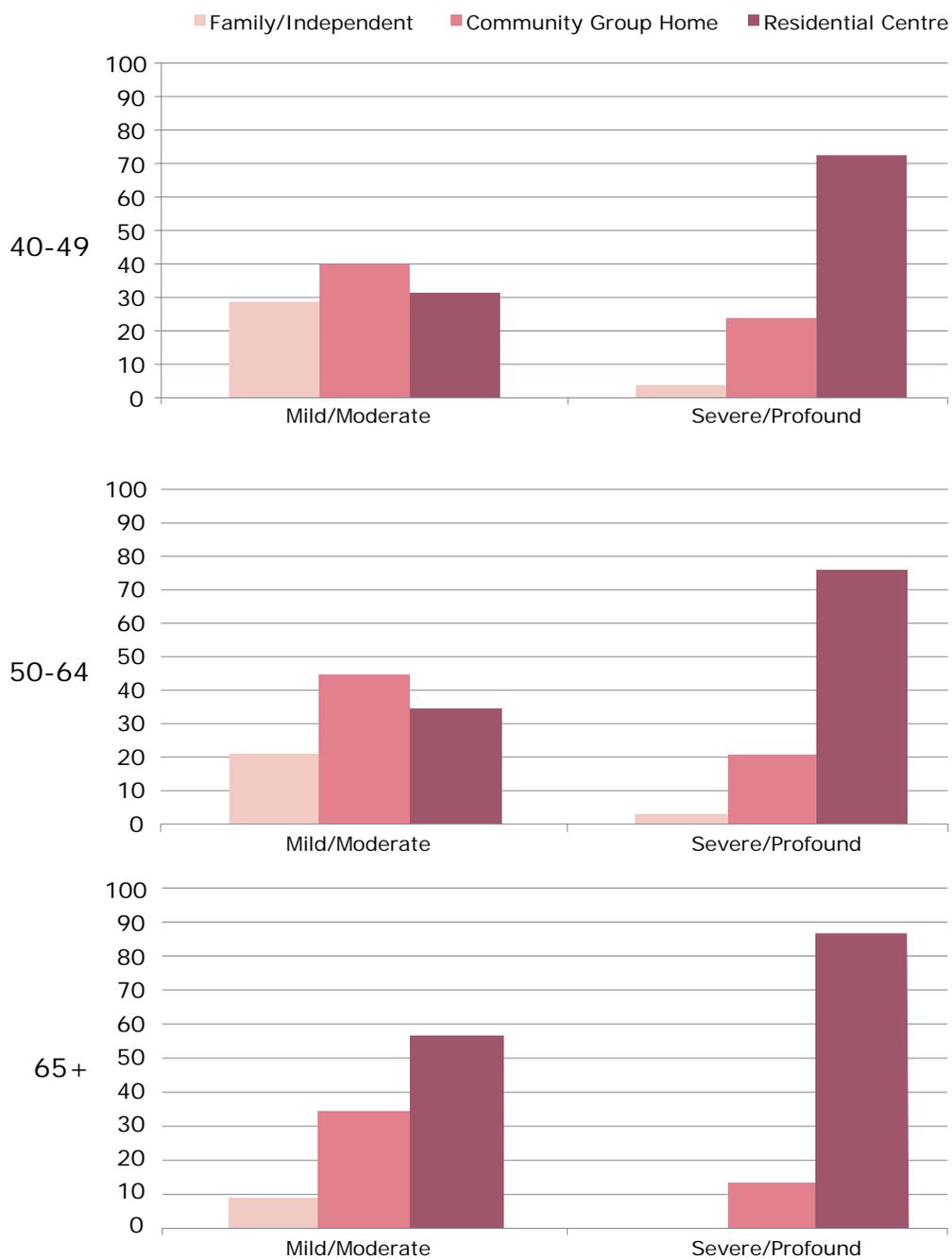
Note: N=752; Missing Obs = 1

2.7.3 Living circumstances associated with level of ID and age

As can be seen in Figure 2.4, the level of ID was strongly associated with type of residence. Adults whose ID was within the severe and profound range were more likely to reside in a residential setting. The proportion of participants in residential settings also increased with age. Conversely, 28.7% of those with mild or moderate ID aged between 40 and 49 years lived with family or independently, but this number decreased with age. Twenty-one percent of those with mild or moderate ID aged between 50 and 64 years lived with their family or independently. This fell to only 8.9% of those aged 65+ with a mild or moderate ID residing at home.

Subsequent chapters will also systematically consider differences in participants' health, health service access and social needs, across the different types of residence.

Figure 2.4: Levels of ID, age and associated living circumstance



Note: N=748; Missing Obs = 5

2.7.4 Types of support

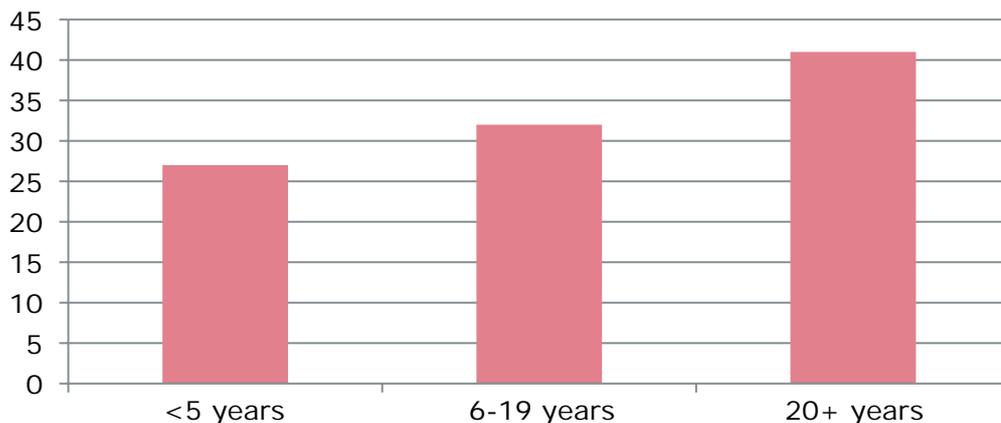
Thirteen percent of participants indicated that they were not in receipt of paid support from any support/nursing staff. These individuals were usually living independently or with family. Of the 63% who reported that they received 24 hour support¹, 17% were within the mild range of ID, 42% fell within the moderate range of ID and 41% were within the severe to profound range. Twenty-four hour support was primarily associated with those living in residential type accommodation, namely, those who were older and had a more severe level of ID (see Figure 2.4); only 32% of those living in community settings received 24 hour support. For those in receipt of 24 hour support, 44% had nursing staff as part of their support team. The linkage between levels of physical and mental health needs and the type of support received, across different residential settings, will be explored further in subsequent chapters.

2.7.5 Permanence

Immigration is not really a factor within the ID population. The vast majority of participants (96%) were born and have always resided in the Republic of Ireland. Four percent identified the United Kingdom as their place of origin and two participants reported the United States as their country of birth. Participants were asked how long they had lived in their current residence and many respondents reported living there for a considerable period of time, with 41% of participants reporting that they had been living in their current place of residence for more than 20 years. A further 32% had been living in their place of residence for between six and nineteen years and 27% had been there for less than five years. Approximately 6% indicated they had lived for over 60 years in their current residence. Figure 2.5 portrays the length of time people had resided in their current place of residence. This issue will be interesting to follow longitudinally, considering the ongoing changes in social policy relating to this field.

¹ Twenty-four hour support represents both waking staff and/or sleep over situations.

Figure 2.5: Length of stay in residence



Note: N=690; Missing Obs = 63

2.7.6 Physical environment

Participants were asked to identify their type of living accommodation. The majority, 60%, reported living in a bungalow/one storey house. However a further 30% lived in a house with two or more storeys, and 13 people (2%) said they lived in a flat or apartment.

The majority of participants in the study (75%) indicated they had their own room. Among the remaining participants, 19% shared a room with one person only (with 6% not responding to this item). Among those who shared a room, 44% indicated they would prefer a room of their own.

Almost all of the participants (80%) had access to a bathroom, bedroom and kitchen, all on the same level. A majority of 85% stated they had no difficulty getting around their home. However, 60 people (8%) had some difficulty in this regard and 52 people (7%) said they had a lot of difficulty here or even that they could not get around their home independently. Wheelchair use (35%, $n=39$) and diminished mobility due to unsteady gait (20%, $n=22$) were some of the most common challenges identified. An additional 11 people reported visual impairment as their key concern. Several identified stairs as posing the greatest barrier to independent mobility in their home. One participant described the impact this has on their life by stating:

'I can't manage stairs, so I stay downstairs'. Staff also expressed this concern; as one stated:

'...he/she has recently begun to have difficulty climbing stairs in this house, this is getting worse with time and he/she will need to move house before long because of this, as the bedroom is currently upstairs.'

Another reported that, '*...the living room is on the first floor and therefore he/she will not be going up there at all from now on*'.

Other identified challenges were mainly associated with medical conditions such as uncontrolled epilepsy, hemi-plegia, anxiety associated with increased fear of falling or Alzheimer dementia. All of these issues are relevant to an ageing population that is likely to experience increasing health concerns. They will be further explored within Chapters 4 and 5.

As can be seen in Table 2.3, those with the greatest difficulties in getting around the home fell within the severe and profound range of ID.

Table 2.3: Levels of difficulty getting around the home associated with level of ID

Variable	Mild/Moderate	Severe/ Profound
	%	%
No difficulty	75.8	24.2
Some Difficulty	40.7	59.3
A lot of Difficulty	53.8	46.2
Cannot do at all	29.2	70.8

Seventy-seven percent of participants indicated that no modifications were needed to their home, however 5% ($n=41$) did highlight such a need (see Table 2.4). Given the relatively small numbers presenting here and the nature of identified challenges, it appears that low cost interventions would alleviate concerns. Indeed, many participants (17%, $n=125$) reported that modifications had been made to their home. Examples included 'grab rails in the bathroom' (51%, $n=85$), 'ramps on street level entrances' (35%, $n=58$) and 'widened doorways or hallways' (26%, $n=43$). Longitudinal follow-up will assess the extent to which environmental concerns are being addressed, recognising too that with increasing age, the challenges posed by a lack of modifications are likely to increase.

Table 2.4: Level of modifications

Have modifications been made to your home?	Frequency	%
Yes	125	17
No but modifications are needed	41	5
No and modifications are not needed	583	77
Don't know	4	0.5

2.8 Employment situation

Although every citizen of Ireland has a right to employment, it is generally recognised that relatively few people with ID are employed. In this study only 6.6% ($n=50$) of participants reported that they were in paid employment. For many, employment was often of a short duration, for example, a couple of hours to one day a week, and in addition many also associated employment with attendance at a day service. This picture of employment, while very different to that reported by TILDA (Kamiya and Sofroniou, 2011) for the general population, is comparable to other reports in the field of ID. For example, Verdonschot *et al.* (2009) concluded that adults with ID were three to four times less often employed than people without disabilities and were more likely to be employed in segregated settings such as sheltered workshops. Both employment status and day service provision and access will be addressed in more detail in Chapter 7.

2.9 Religious participation

Respondents were asked to state the religion they identified with; how often they attended religious services and for those who could self-report how important religion was in their lives.

Similar to the general population most participants were Roman Catholic (96%), with 15 participants identified as Church of Ireland/Anglican, Methodist or Presbyterian. Ten participants responded as 'other' here and eight participants stated they had no religion. The majority (57%, $n=422$) attended service at least once a week, which was similar to that reported by TILDA (Timonen *et al.*, 2011) for the general population; 14% ($n=106$) attended less frequently and 13% ($n=94$) never or almost never attended. Weekly attendance was highest in those aged 50-64 years at 56.4%; with 47% of those aged 40-49 years, and 65 years and over attending mass on a weekly basis.

The survey included several perception questions on religious practice for those who self-reported ($n=470$). Thirty-five percent said they got comfort and strength from their religion, with a further 41% stating it was an important part of their lives. An additional 16% stated that religion was not that important and 12% never found comfort from religion. Those aged 50-64 years reported that they got more strength and comfort from their religion than those in the older age group 65 years and over at 69% versus 57% respectively. In the general population TILDA reported that religious importance increased with age (Timonen *et al.*, 2011). However, this needs to be interpreted with caution given the lower numbers in the older age group in the ID population.

2.10 Conclusion

The IDS-TILDA sample successfully recruited is primarily aged 50-64 years, but has participants of all ages, male and female, and includes all levels of intellectual disability and living arrangements. This is largely an unmarried group that do not have children, most are unemployed and are living in out of home placements with 63% having access to 24 hour support and the majority attend a day program.

The reported lower longevity for people with ID raises concerns about the ability to pursue longitudinal studies to examine ageing in this population. For this reason the sample is aged 40 and above rather than 50 and above as in the TILDA study. This strategy has produced a sample with 82% aged 40-65 years. This age profile bodes well for the tracking ageing processes over several waves of data intended in this study.

The size and representativeness of this sample are not the only relevant factors. Both the likelihood of increased longevity among people with ID and the breadth of data reported in subsequent chapters highlight the value of continued study of this group. This opportunity may lead to valuable insights into the determinants and mediators of ageing, good health and quality of life. Furthermore, from a public policy perspective, it is relevant that the sample includes people living in large congregate settings. Re-interviewing these participants in subsequent waves will lead to additional insights, over time, on ways to improve the quality of life of those living in or moving from congregate settings.

3

Adults with an Intellectual Disability Ageing in Ireland as Members of their Families and Communities

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3

Adults with an Intellectual Disability Ageing in Ireland as Members of their Families and Communities

3.1 Key findings

- People with an intellectual disability (ID) living in community settings participated in their local communities more than people living in residential centres. However, regardless of residential circumstances, adults with an ID in Ireland were not actively engaged with their communities and community presence was not actually equated with 'living' in the community. Given that those currently living in community settings tend to be younger, this does not bode well for community participation as they age and experience health decline.
- The majority of adults had some level of contact with at least one family member. However, approximately one in four adults reported meeting their family once a year or less. Frequency of contact declined with increasing age and was also less for those with a severe to profound ID.
- Over three quarters of adults with an ID reported that they never wrote, texted, emailed or used social media tools such as Facebook to contact their family or friends. Moreover, less than 60% used the telephone to make such contacts. Adults with an ID were less likely to own a mobile phone than other adults in the Irish population.
- Older age and more severe levels of ID often meant having fewer members in one's social network and this appeared to be associated with greater risk for social isolation. Where people lived also influenced the size of social networks, with those living in residential centres at greater risk of isolation.
- Fifty percent of those self-reporting stated that they sometimes felt lonely and one in three people who reported experiencing loneliness found it difficult to make friends.
- The majority of adults with an ID had someone to confide in; however three quarters reported that their confidant was a key worker/support person.
- Most adults with an ID had a hobby, engaged in daytime activity and leisure pursuits on a regular basis, and had social contacts with others.
- However, adults with an ID seldom engaged in social activities with friends outside their home.
- The majority of adults with an ID were dependent upon others for transportation and other assistance to access community options. Participants reported that their need for such assistance was the greatest barrier to successfully participating in social activities.

- Three quarters of adults with an ID reported going on a holiday last year, with 17% going abroad on holiday. People with a more severe ID were less likely to go on holiday and more often went on day trips.
- Approximately 70% of adults with an ID in Ireland did not vote in the last general election.
- Overall, 14.7% of people with an ID reported receiving help from their neighbour and 13.1% said they helped their neighbour. The majority of those engaging in this type of activity lived in community settings and reported this to be a positive experience.
- In comparison to the general population, adults with an ID had limited involvement in civic activities, such as retirement clubs, evening classes or residents associations within their communities. The Special Olympics was the highest ranked organisation in this regard.
- The majority of adults with an ID engaged regularly in a range of social activities; eating out, attending church, shopping, going to the hairdresser and cinema were all frequently cited. However, they mainly engaged in these activities with staff or peers in their group home.
- The following factors were rarely reported as concerns by adults with an ID: growing older, not having enough money, and unfriendly or negative attitudes held by other people.
- Accessibility in the community was a difficulty for many adults with an ID. Footpath design, surfaces and building accessibility posed the greatest challenges for persons with a more severe ID, and street signage and feeling unsafe posed the most difficulty for persons with a mild to moderate ID.
- Most adults with an ID seldom used public transport.

3.2 Introduction

Since the 1970s, there has been a concentrated effort to move people with an intellectual disability (ID) from segregated institutional type settings into community-based accommodation. Central to this move was the belief that this would promote community integration and enable people with an ID to live as equal and valued members of their communities. Ireland has made considerable progress in moving services in this direction, although there are individuals who continue to live in large segregated settings (HSE, 2011). The benefits of community living with respect to improved quality of life for people with an ID is well documented (see for example, Heller *et al.*, 1998) United Nations and other declarations (UN, 2006) exist on the rights of all adults, regardless of level of disability, to have the opportunity to participate in their communities. Despite this however, the social engagement of adults with an ID in the community remains poorly understood. Verdonschot *et al.* (2009), in a review of studies published 1996 to 2006, suggest that those studies provide a poor definition of community participation, lack a solid theoretical framework, mainly include people with a mild ID and are limited to a few areas of community participation. However, both this review and another one on

moves from campus to community settings (Kozma *et al.*, 2009) share an overall conclusion: that while people with an ID who have moved from segregated settings into the community are more connected than people who remain in more segregated settings, those living in the community continue to remain poorly connected with their communities.

This chapter is organised into two major sections: social connectedness and social engagement of Irish adults with an ID.

3.3 Social connectedness

Informal social networks that support people with an ID are likely to be an important prerequisite for maintaining optimal health and wellbeing as they age. In the general population, children and siblings play an important role in supporting ageing family members and parents. There is less understanding of the role of families in supporting ageing persons with an ID, and little data on the role of persons with an ID themselves in supporting ageing parents and family members. It is known that in Ireland, several critical factors are to be considered. These are summarised below.

1. The historical development of ID services in Ireland has resulted in very often large geographical distance between adults with an ID and their families, which often made regular contact difficult to sustain.
2. Services organisations traditionally assumed the role of families and parents, acting 'in locus parentis' and with many families relinquishing their care-giving role. There is now a challenge for both services and families to rebuild some of the role of 'family' in people's lives as they age, roles that must be more actively considered for future generation of people with an ID. The various waves proposed for this study offer an opportunity to observe how these issues are addressed.
3. Many parents and families who continue to support adults with an ID as they age are themselves growing older and are likely to be dealing with their own age-related health concerns.
4. As documented elsewhere in this report, many older adults with an ID have minimal income, assets or pensions to support their older age.
5. Unlike the general population, the vast majority of this current generation of adults with an ID are not married and do not have children to support them as they age.

As the general population ages, its members turn to a combination of public and informal family supports to maintain quality of life and community living. Personal assets and pensions also help to supplement this care. Such supports and financial assets are rarely available to people with an ID. Economic pressures are discouraging exclusive reliance on public resources for all persons who are ageing. In this current fiscal environment, a key policy question for the ID sector presents: how will persons with an ID be supported in old age so that they may experience a good quality of life and continued community living when children and other family supports are not available?

In this section, under 'social networks', types of relationships, and frequency of contact of adults with an ID with their family members will be described and social inclusion and experiences of loneliness will also be discussed. Patterns and variants of social connectedness by age, gender, level of an ID and residential circumstances will also be presented.

3.4 Social networks

3.4.1 Meeting family members

Respondents in this study were asked to identify how often they made social contact with their family, either through arrangement or by chance, not counting family members they lived with. Three areas were considered: meeting their family socially, speaking to them on the phone and written communication, which included social multimedia formats such as Facebook or texting.

The most striking findings were that approximately one in four adults with an ID (27.7%) reported meeting their family once a year or less and that 8% reported that they never meet family members. Persons with a mild to moderate ID (53%) tended to meet their family on a more regular basis (three to four times per week, weekly or monthly) than those with a severe to profound ID (40.8%). Those in the younger age groups (53%) were more likely to have frequent contact than those in the older age groups (47% of those aged 50-64 years and 33% of those aged 65 years and older). Although the wording of the measures are not exactly the same, findings in IDS-TILDA differed from the general Irish population where three quarters of older adults whose parents were still alive reported seeing their parents frequently (daily, weekly or several times per month) (Kamiya and Timonen, 2011). Table 3.1 presents frequency of contact between study participants and their families.

Table 3.1: Social meetings with family

Meeting with family	%	Frequency
Three or more times a week	3.6	24
Once or twice a week	16.9	113
Once or twice a month	29.1	195
Every few months	22.7	152
Twice a year or less	19.7	132
Never	5.6	42
Not applicable	2.1	14
Don't know/Unclear response	0.4	3

3.4.2 Speaking to family on the phone

A large number of respondents (42.5%) had no phone contact with their family, with 9% of this group indicating that this question was not relevant, perhaps because they did not own a phone or lacked the skills to use one, or that they did not have family members to contact or that they had communication difficulties. When people did have phone contact with family (34%; $n=255$) it was usually on a weekly basis or more; 18% ($n=131$) had this contact on a monthly basis, and 5.5% ($n=41$) had it on a less frequent basis. Overall, the use of the telephone by adults with an ID as a means to sustain relationships and family connections was low. Even among those with a mild to moderate ID, almost half (46%) seldom, if ever, used the phone to contact family members. When considered alongside data reported earlier on low levels of mobile and internet access among people with an ID, there appears to be strong evidence of people with an ID living outside of technologies that appear to drive communication for other adults in Ireland. This presents a challenge for ID services to consider how to address this communication technology divide. The success or lack of success of those efforts will be tracked in subsequent waves of this study.

3.4.3 Written communication with family

Eleven percent of respondents ($n=86$) had written contact with family twice a year or less, 11.6% ($n=87$) had this on a monthly basis or less and a further 2% ($n=14$) had at least weekly written contact. This means that three quarters of adults with an ID (75%) reported that they never wrote, texted, emailed or used social media such as Facebook to contact their family; this is despite the fact that 64% of respondents were within the mild to moderate level of ID. Given that Ireland is considered a country with high usage of text messaging, email and social media (CSO, 2009), such findings further emphasise an important divide between adults with an ID and others. Low incidence of written communication may reflect the low education and poor literacy levels in adults with an ID already reported, further compounded by the identified lack of adult learning opportunities.

3.4.4 Meeting friends

With regards friendships, people were also asked to identify how often they made social contact with their friends, either by arrangement or by chance (not counting friends who resided in their home). The same three areas were considered for friends as for family (socially meeting their friends, speaking to them on the phone and making some form of written communication including use of social media). Of great concern was the finding that 37% of adults with an ID in Ireland reported never meeting their friends; among this subgroup, 50% were within the mild to moderate ID levels. Contact also varied by residential circumstances: 72% ($n=42$) of those without contact lived in a residential setting, 22% ($n=13$) in a community setting and 6% ($n=3$) were living independently or with their family. There did appear to be a relationship between community living and social contact with friends, a relationship which will be explored further in future waves of data collection.

Of those who reported meeting friends, almost half (48%, $n=286$) met on a regular basis (weekly or more). However, reports of frequent contact (meeting regularly) was lower among those aged 65 years and over, at 25% ($n=33$); compared to 39% ($n=105$) of those aged 40-49 years, and 43% ($n=148$) of those aged 50-64 years. A further 19% ($n=143$) met with their friends on a monthly basis or less. Table 3.2 presents the frequency of social contact with friends across age categories.

Table 3.2: Social contact with friends

Meeting up with friends	Age categories					
	40-49 years		50-64 years		65+ years	
	frequency	%	frequency	%	frequency	%
> once a week	105	39	148	43	33	25
< once a month	46	17	65	19	32	24
Twice a year or less	95	35	105	31	56	44

3.4.5 Speaking to friends on the phone and written communication with friends

The majority of participants indicated that they never spoke on the telephone (58%, $n=432$) or wrote (73%, $n=548$) to their friends. Others indicated that these questions were not applicable – 14% ($n=104$) and 16% ($n=120$) respectively. Of those responding that speaking on the telephone to friends was not applicable, 55% had a mild to moderate level of ID and 45% were within the severe/profound level of ID. A further 36% lived in a community setting, (25% in a community group home and 11% living independently or with their family) but most (64%) lived in a residential setting.

For the 16% ($n=120$) of people who indicated that writing to their friends was not applicable, 63% were within the mild to moderate range of ID and 37% within the severe/profound range. The majority of these participants (65%) lived in a residential setting, with 22% living in the community and 13% living independently or with family.

It would not be unexpected that those with severe/profound levels of ID would face greater communication challenges and risk of social exclusion. Social exclusion is never justified for anyone but it is particularly concerning that so many people with a mild to moderate ID fell within the not applicable group.

Nevertheless, levels of social contact with family and friends appeared high for many respondents. Future waves will explore who those 'friend' contacts are and the extensiveness of social networks. There are reports in the literature that as people with an ID age, their social networks shrink (Bigby, 2008). For all adults with an ID, staff carers have long been identified as primary and sometimes the exclusive members of their friendship networks (Amado, 1993). Data here already supports the view that social networks and associated communication may be influenced by residence and level of ID; this will also be investigated further.

3.5 Loneliness and inclusion

3.5.1 Experience of loneliness

Loneliness is a personal concept. It is not necessarily synonymous with actual circumstances but is more a feeling resulting from deficiency in social relationships; a person can be alone but not lonely or in company and feel lonely (Shiovitz-Ezra and Leitsch, 2010). During their engagement in the development of the research protocol, persons with an ID in the consultative groups talked extensively about loneliness being a concern in their lives and recommended strongly that a measure of loneliness be included in the protocol.

This study examined the experience of loneliness in people with an ID utilising a modified version of UCLA loneliness scale (Russell, 1996). High levels of education, good economic circumstance, and greater functional independence have been reported as directly associated with absence of loneliness (Newell *et al.*, 2009) and these associations were confirmed by TILDA (Timonen *et al.*, 2011) for the general Irish population. For people with an ID, such protective factors are less likely to be present and data reported in the demographics chapter confirms this for the IDS-TILDA sample. Given a paucity of protective resources and the desire expressed by people with an ID themselves to explore this issue, in this study respondents who were able to self-report were asked:

- if they ever felt lonely, and if so, whether this was most of the time, sometimes or rarely;
- if they ever felt left out;
- if they found it difficult to make friends.

More than 50% ($n=393$) of the sample self-reported on these items, and one in every two of those reporting stated they had experienced loneliness. Of those who reported loneliness, 15% ($n=29$) reported feeling lonely most of the time, a majority of 74% ($n=142$) felt lonely sometimes, and a further 10% ($n=20$) said they occasionally felt lonely. These figures are comparable to those reported in studies of general populations. For example, Wenger and Burholt (2004) reported that 20-40% of older adults expressed feeling moderate to severe loneliness, and in Ireland, the National Survey of Lifestyle, Attitudes and Nutrition concluded that 17% of respondents aged 65 and over reported being often lonely (Slán, 2007). Data from TILDA, which used the same measure of loneliness as IDS-TILDA, is just beginning to be reported but it does appear that for the TILDA sample, a relationship existed between health, education and socio-economic circumstances. There will be opportunities to further explore loneliness, as well as these and other risk and protective factors for people with an ID.

As was also found by TILDA (Timonen *et al.*, 2011), women with an ID were more likely to report loneliness (55%). Levels of reported chronic loneliness were low and also appeared comparable to the general population. However, for adults with an ID in Ireland, some level of loneliness was a common experience. One participant captures this when they reported, *'I'd love to have a friend that I could go out for tea with or something like that'*.

An interesting picture emerged with respect to a sense of loneliness in general and its relationship to residential circumstances and age. Those living in community-based settings including group homes, independent living and with families were more likely to report experiencing at least some loneliness (see Table 3.3). This was particularly the case among those in the younger age groups. Among those aged 40-49 years who self-reported and lived in the community, 51% ($n=38$) reported feeling lonely, as did 50% ($n=25$) of those who lived independently or with their family and 39% ($n=12$) of those who lived in a residential setting. Among those aged 50-64 years, 64.6% ($n=31$) of those living in residential settings reported feelings of loneliness, as did 46.9% ($n=23$) of those living independently or with their family and 43.8% ($n=39$) of those living in the community. Among those living in the community who were 65 years or older, a small majority of 58.1% ($n=18$) reported being lonely, as did 46.7% ($n=7$) of those living in a residential setting and 36.4% ($n=4$) of those living independently or with family. These findings are summarised in Table 3.3 but should be viewed with caution, given the small numbers in some of the grouping and the fact that the measurement related to any level of loneliness, not just chronic loneliness.

Table 3.3: Frequency of people who are lonely in relation to their living circumstances

Residential circumstance	Age categories					
	40-49 years		50-64 years		65+ years	
	frequency	%	frequency	%	frequency	%
Independent/living with family	25	50	23	46.9	4	36.4
Living in the community	38	51.1	39	43.8	18	58.1
Living in residential centre	12	38.7	31	64.6	7	46.7

Further examination of the experience of loneliness by age and level of ID revealed that 48.4% ($n=62$) of those between 40-49 years with a mild to moderate ID reported feeling lonely compared to 62.5% ($n=5$) of those with a severe/profound ID. Furthermore, 52.2% ($n=84$) of those with a mild to moderate ID aged 50-64 years reported loneliness, compared to 42.9% ($n=3$) of those in the same age group with a severe/profound ID. Finally, 56.8% ($n=25$) of those with a mild to moderate ID and aged 65 years and over reported loneliness, compared to 25% ($n=1$) of those aged 65 years and over with severe/profound ID. Again, caution is needed here in interpreting these findings, given the small numbers.

Despite this need for caution and the fact that these data do not include the experiences of potentially the most isolated group, those not able to report for themselves, some interesting differences emerged here. Such variations may speak to both efforts to foster community involvement and the extensiveness of individuals' social networks. These findings offer data that will support a fuller consideration in the future regarding the risk and protective factors that influence loneliness among adults with an ID.

3.5.2 Experience of inclusion

A sense of exclusion may negatively impact need for belonging, as well as health, wellbeing and feelings of self-worth. Self-reporting participants were asked if they ever felt left out, and approximately one third 34% ($n=140$) reported experiences of feeling left out most of the time (12%; $n=16$) sometimes (74%; $n=103$) and rarely (14%; $n=19$). One participant captured it this way: *'I feel left out of family occasions especially at holiday times like Christmas and Easter.'*

3.5.3 Making friends

Participants were asked if they found it difficult to make friends and one in three (32%; $n=132$) reported such difficulty. A factor that was less understood, and to be explored in future waves of data collection, was the extent to which such difficulty emerged from lack of opportunity and autonomy to make one's own decisions. Relevant issues here could include financial freedom and living arrangements.

3.5.4 Do you have someone in whom you can confide?

People with an ID rarely have the two main sources of informal support that the majority of adults rely on: a partner/spouse and children. However, 68% ($n=506$) of people with an ID confirmed that they did have someone they felt they could talk with about private matters. A further 3% ($n=25$) felt they had no one in whom they could confide and 28% ($n=210$) were reported as completely dependent on others to interpret their needs and wants. On further examination of those who had someone to talk to, 75% ($n=377$) stated their confidant was their key worker or support person (i.e., a paid staff member), 23% ($n=116$) identified a sibling, 11% ($n=57$) identified a friend and 10% ($n=52$) stated their parent played this role. Small numbers of respondents identified other relatives ($n=14$), neighbours ($n=5$), and advocates ($n=4$) in this regard.

3.6 Social engagement

Reflecting the approach taken by TILDA (Timonen *et al.*, 2011), participation will be described across a range of leisure activities and categorised into four groupings:

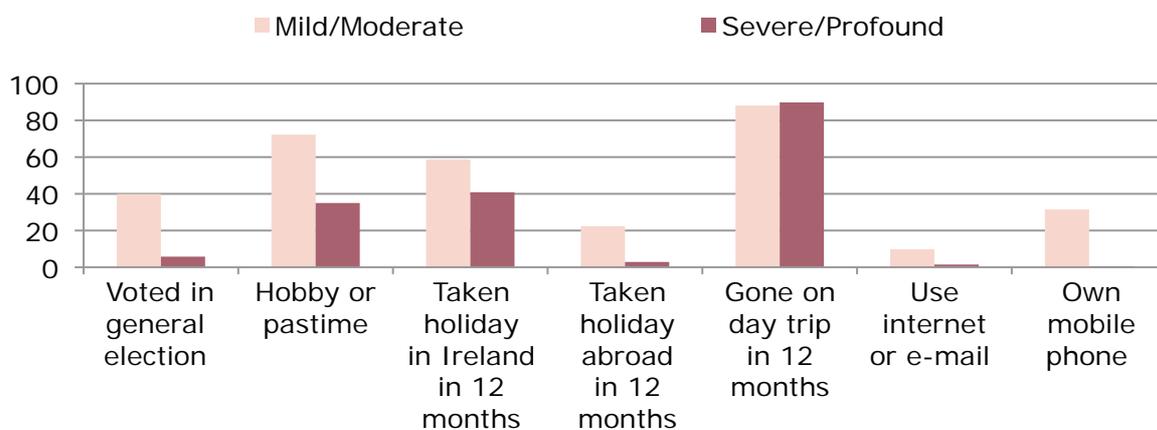
- 1) intimate social relationships, i.e., family and friends, with a particular focus on engagement with friends outside the home;
- 2) formal engagement with organisations including church or religious services, Arch Clubs, tenants groups, Special Olympics and other community-based groups;
- 3) leisure activities, including those with whom respondents engage in these activities;
- 4) passive or solitary activities including watching TV, listening to music, reading, etc. Volunteering and a picture of transport use are also presented here.

The next section describes the patterns and variants of social engagement and social connection by age, gender, level of ID and living circumstances.

3.7 General activities

Community participation among people with an ID not only includes their physical presence in the community but, more critically, their active participation in activities within their communities. In order to develop a picture of participation in their local community, study respondents were asked a broad variety of questions. Initially, people were asked general questions about their lives, such as whether they voted, went on holiday, used the internet, had a hobby or owned their own mobile phone. Figure 3.1 presents participation in general activities by level of ID.

Figure 3.1: Participation in general activities, by level of ID



Note: N=695; Missing Obs = 58

3.7.1 Voting

Almost three quarters of adults with an ID in Ireland did not vote in the last general election. Of those who voted ($n=233$), the majority had a mild to moderate ID. The greatest proportion of voters were aged between 40 and 49 years; 33.2% of this subgroup voted. A similar proportion (32.8%) of those aged 50-64 years also voted, but this dropped to 21.6% for those aged 65 years and over. Those living at home or independently were more likely to vote than those living in a community group home, or in a residential centre, at 61.2%, 41.4% and 12.1% respectively. This last finding may reflect the fact that those living in residential centres were more likely to have severe to profound levels of ID than others and therefore have less ability to participate in voting. Nevertheless, voting figures for those with a mild to moderate levels of ID, at less than 40%, were lower than those reported for the general Irish population, which was approximately 80%. Opportunities for political participation represent one of the markers of citizenship; future waves of data collection will look to further explore the barriers and facilitators in Ireland to voting experienced by people with an ID.

3.7.2 Holidays

With regards holidays, 53% reported that they went on holidays in Ireland in the last year and 17% reported they holidayed abroad. Those aged 50-64 years are most likely to holiday in Ireland, with 57.8% ($n=199$) of that age group doing so. Of those aged 40-49 years, 54.4% ($n=149$) holidayed in Ireland, as did 38.8% ($n=52$) of those aged 65 years and over. Of those taking a holiday abroad, 18.6% ($n=51$) are in the 40-49 year age category, 18.3% ($n=63$) are aged 50-64 years and just 11.2% ($n=15$) are 65 years and over. The opportunity to take holidays appeared to decline with age. Foreign holidays were clearly less common for all, although age did not seem to influence this. By contrast, the person's place of residence did appear to influence access to holidays. People living in a community group home (66%, $n=177$) were more likely to holiday in Ireland than those living independently (57.4%, $n=74$) or within a residential centre (41.9%, $n=149$). However, people who lived independently or with their family (36.4%, $n=47$) were more likely to go on a foreign holiday than those living in a community setting (23.5%, $n=63$) or in a residential centre (5.3%, $n=19$). There are probably a multitude of reasons for these differences, ranging from opportunity, financial means and support for physical or health problems; level of ID also appeared to be of influence. People with a more severe/profound level of ID were less likely to holiday in Ireland (41%), or abroad (2.9%), than those in the mild to moderate category, among whom 58.7% holidayed in Ireland and 22.3% holidayed abroad. It was encouraging to see that 88% of people reported they had gone on a day trip in the last year. Moreover, the proportion of those in the severe/profound category who did so (90%, $n=185$) was similar to that found among those in the mild to moderate category (88%, $n=431$). Neither did place of residence seem to influence access; 89% of those living in community setting or residential centre and 84% of those living independently or at home went on day trips.

3.7.3 Internet access

The Central Statistics Office data (CSO, 2009) documented use of the internet in 63% of Irish households. By contrast, and regardless of residential circumstances, internet use amongst Irish adults with an ID was low. Overall, 7.3% ($n=55$) reported that they had used the internet in the last year and of those who had, the majority ($n=48$) were within the mild to moderate range; 15 lived independently or at home, 25 lived in a community setting and 15 living in a residential centre. In addition, 23% ($n=172$) of people reported that they owned their own mobile phone, which is low by general Irish standards (CSO, 2009). The majority of those who reported owning a mobile phone had a mild to moderate ID, with just one person within the severe/profound category owning their own mobile. As internet use, mobile phone access and social media participation continue to increase in Ireland (CSO, 2009), low levels of access and use appear to place people with an ID at a distinct disadvantage in terms of community participation. This will be an important issue to track in subsequent waves of IDS-TILDA.

3.7.4 Hobbies and activities

With regards hobbies or past-times, 61% of participants reported having a hobby. By far, most of those who reported having a hobby were within the mild to moderate range of ID.

3.7.5 Watching television

In this study respondents were asked to identify and report the amount of TV/DVD they had watched on a daily basis in the last month. Reports for the general Irish population were that 98% watched TV at least once a week (Timonen *et al.*, 2011) and 81.5% of adults with an ID were similarly engaged. Overall, 40% reported watching TV/DVD for an average of one to three hours a day, 16% reported watching between three and five hours per day and a further 7% reported watching TV for more than five hours per day. However, 18% reported they did not watch any TV and almost 19% reported watching TV for less than one hour per day.

3.8 Engaging in community life

People must have a sense of belonging to their community, if they are to experience the true sense of community participation. To that end, this study considered people's engagement through clubs and leisure activities, the difficulties people faced when participating in activities outside the home, in getting around their community and accessing transportation.

3.8.1 Neighbours and community inclusion

A neighbour can be defined as a person who resides nearby. However, being a neighbour entails more than just a passive acquaintance; it includes friendship and willingness to give a helping hand. In this study, 14.7% ($n=111$) received help from their neighbour over the past two years. Of these people, 20.4% ($n=22$) received help on a daily basis, 34.3% ($n=37$) received help on a weekly basis and 19.4% ($n=21$) received monthly help, with 25.9% ($n=28$) receiving help less often. Of those who received help, 40.5% ($n=45$) lived at home or independently, 31.5% ($n=35$) lived in a community setting and 27.9% ($n=31$) were in a residential centre.

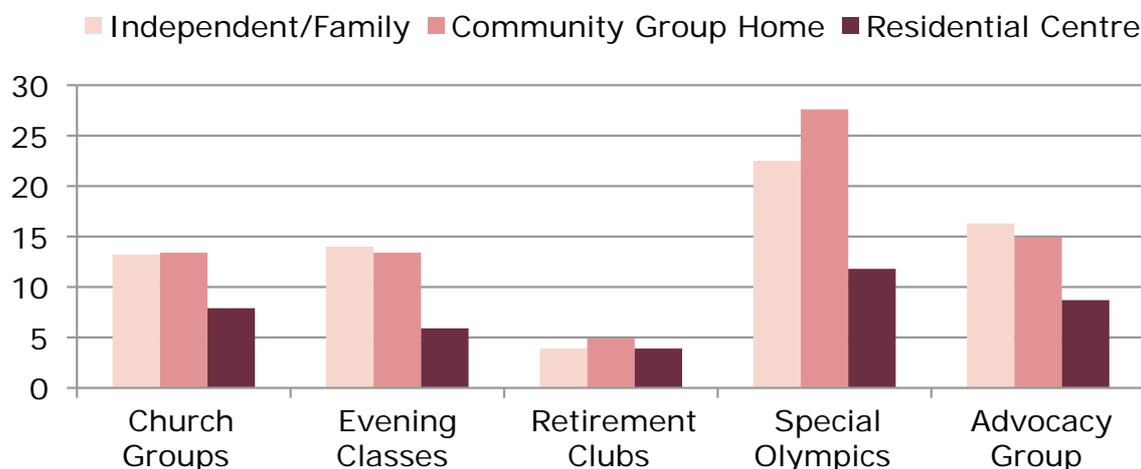
A total of 13.1% ($n=97$) gave help to their neighbours. Among this group, 44.3% ($n=43$) lived at home or independently, 33% ($n=32$) lived in a community setting and 22.7% ($n=22$) lived in a residential setting. People gave some examples of what they did for neighbours. One participant stated, '*I go shopping for my neighbour*'. A support worker explained (the person with an ID), '*supports neighbours by doing heavier jobs like cutting grass, carrying shopping in, going shopping with neighbours especially helping with carrying items and supporting older people*'. Another participant stated, '*the neighbour comes over to visit but I have not gone over to him I would have to ask*

... but it'd be nice to help out'. Neighbourliness appeared valued; however, the small number reporting neighbourly exchanges may reflect societal trends whereby many people, with and without disability, do not know their neighbours.

3.8.2 Member of an organisation or club

Respondents were asked to identify, from a list of options, the clubs, societies or organisations to which they belonged. Special Olympics ranked the highest, reported by 19% ($n=145$). Advocacy groups were next at 12% ($n=92$), followed by church/religious groups at 11% ($n=81$). Respondents were less likely to report engaging in education/music or evening classes (10%, $n=75$), or retirement clubs (4.2%, $n=32$) with very few (2.3%, $n=17$) reporting they were members of tenants or residents associations. A number of respondents (4.1%, $n=31$) reported being a member of the Arch Club, eleven were members of a charitable association and three were members of a political party. Club or organisation participation usually took place in community settings (see Figure 3.2). Overall however, the level of involvement in organisations and clubs was much lower than the approximate 80% of adults over 50 years within the general population, as reported by TILDA (Timonen *et al.*, 2011).

Figure 3.2: Membership of an organisation or club, by living circumstances



Note: N=753

For Irish adults with an ID, popular social activities reported included eating out (88%); going out for coffee (86%); going shopping (84%) and going to church (78%), with performing in the local arts group (8.8%) going to the library (21.1%) and attending social clubs (21.9%) amongst the less popular activities (See Table 3.4). Visiting family and friends (86%) and reading (73%) were among the most popular leisure activities reported by TILDA (Timonen *et al.*, 2011), and these were also

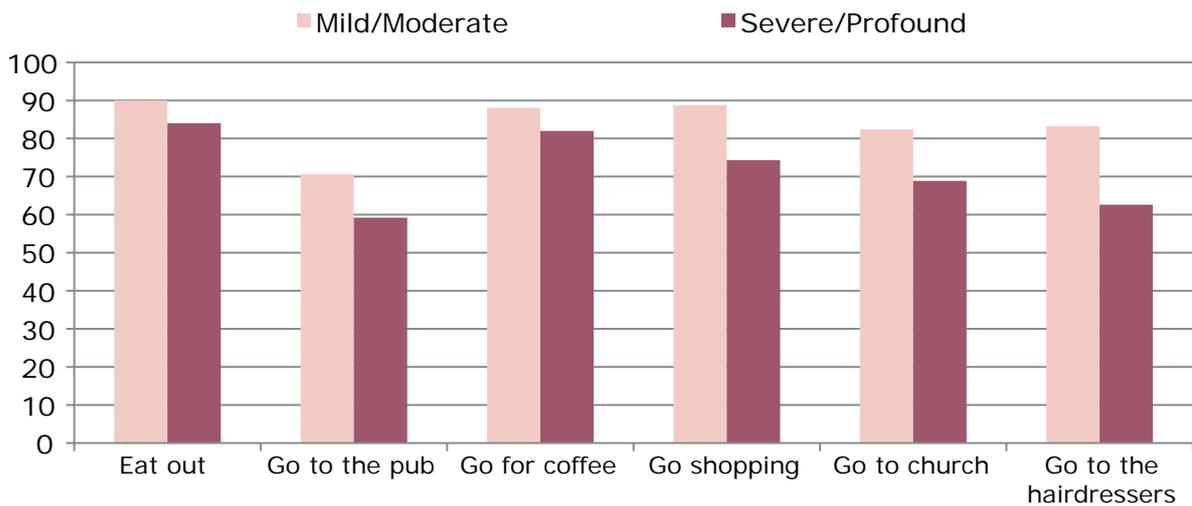
reported by people with an ID but at lower rates - 66% reported visiting family and friends, and 21% reported going to the library. Table 3.4 presents, in order of reported preference, the leisure activities engaged in by adults with an ID.

Table 3.4: Engaging in community life – leisure activities in rank order

Rank order	Leisure activity	%	frequency
1	Eat out	87.8	661
2	Going out for coffee	85.8	646
3	Going shopping	83.9	632
4	Going to church/worship	78.0	587
5	Hairdresser	77.0	580
6	Going to the pub for a drink	67.5	508
7	Visit family and friends in their home	66.3	499
8	Go to the cinema	62.2	468
9	Go to the theatre, a concert or an opera	54.1	407
10	Spend time on hobbies	51.7	389
11	Go to sports events	29.5	222
12	Go to an art gallery or museum	22.4	169
13	Go to social clubs (e.g. bingo)	21.9	165
14	Go to the library	21.1	159
15	Perform in the local arts group/choir	8.8	66

It is evident that age group, level of ID and living circumstances all have some influence on the person’s engagement in leisure activities. People aged between 50-64 years were more likely to eat out (90%), go for coffee (88%) or go to the pub (70%), whereas for people aged 40-49 years, going shopping (86%) was the most commonly engaged in activity. For people aged 65 years and over, going to church (80.6%) and to the hairdressers (81.3%) were the most popular activities. People with a mild to moderate ID engaged more frequently in the six most popular leisure activities than those in the severe/profound range (see Figure 3.3). Living circumstances had a lower influence here, but those people living in a residential centre (83%) were less likely to eat out than people in community settings or those living at home or independently (88%). Figure 3.3 presents the most popular leisure activities by level of ID.

Figure 3.3: Most popular leisure activities, by level of ID



Note: N=695; Missing Obs = 68; NV included in missing obs (n=19)

Respondents were also asked to identify who they primarily involved in their social activities: family, friends within your house, friends outside your house, or key worker/support staff. The majority of respondents (79%) identified their key worker/support staff as the main person with whom they engaged in leisure activities. In addition, a further 57% reported engaging in these activities with friends within their house, and 34% reported engaging in these activities with their family. Overall, only 30% reported engaging in these activities with friends outside the house. Respondents reporting that they engaged in leisure activities with friends outside the house tended to have a mild to moderate ID; 35% of this group reported this, compared with only 16.4% of those with a more severe/profound ID. Respondents were also asked to identify how often they engaged in these leisure activities with others. Overall, respondents reported quite regular engagement, with 80.8% reporting going out to the cinema every few months or more, 52.1% going shopping at least once a week and 46.2% going to the pub for a drink once a week or less. Table 3.5 presents leisure activities by frequency of engagement.

Table 3.5: Frequency people engaged in their leisure activities

Variable	Once a week/ more		Twice a month /less		Twice a year / less	
	frequency	%	frequency	%	frequency	%
Eat out	49.6	323	47.6	310	2.8	18
Going out for coffee	66.4	426	31.3	303	1.7	11
Going shopping	52.1	326	41.4	259	6.5	41
Going to church/ worship	68.9	401	27.8	162	3.3	19
Hairdresser	2.2	12	96.3	557	1.6	9
Going to the pub for a drink	46.2	231	46.8	234	7.0	35
Visit family/friends in their home	33.2	164	51.5	254	15.2	75
Go to the cinema	6.7	31	80.8	373	12.6	58
Go to the theatre/ concert/opera	1.0	4	45.3	184	53.7	218
Spend time on hobbies	95.1	365	4.7	18	0.3	1
Go to sports events	16.4	35	51.9	111	31.8	68
Go to an art gallery or museum	5.4	1	37.0	69	57.6	95
Go to social clubs (e.g. bingo)	44.3	88	41.3	67	4.3	7
Go to the library	29.1	45	54.9	85	16.1	25
Perform in the local arts group/choir	35.5	22	22.6	14	41.9	26

Respondents were also asked if there were any particular activities they would like to engage in more often. Over 60% expressed a wish to do more activities, particularly gardening, boating, bowling or keeping fit. Other responses focused on finding new companions for activities and engaging more with family and friends. As one participant said, *'I'd like to learn to read and write better, see my friends more, visit church more, none of the people I live with are able to do the same things as me which means I have to do everything on my own or with staff.'* Overall, a concern emerges that participation in social activities does not necessarily equate with high interaction within the community or in community life, a concept that will be explored further in future waves.

3.8.3 Difficulties participating in social activities outside the home

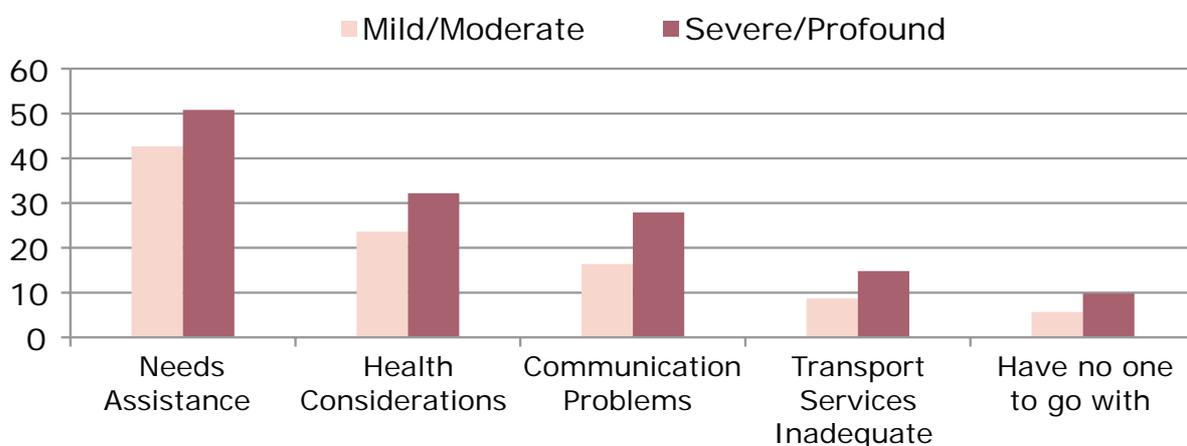
This study was also interested in understanding potential difficulties for adults with an ID in engaging in social activities outside the home; a series of questions attempted to elicit such barriers. Over 50% of adults with an ID reported having difficulty in participating in social activities outside their home, with greatest difficulties being the need to have someone's assistance (44.2%) and health considerations (26%). Interestingly, factors such as getting too old, not having enough money, facilities not being accessible and unfriendly or negative attitude by people were rarely reported as concerns by the adults with an ID. Table 3.6 presents the difficulties reported.

Table 3.6: Difficulties in participating in social activities outside the home, in rank order (n=382, 52%)

Rank order	Leisure activity	%	frequency
1	Needing assistance	44.2	246
2	Health consideration/physically unable	25.9	144
3	Communication/language problems	19.6	109
4	Transport services are inadequate or not accessible	10.6	59
5	Having no one to go with	7.2	40
6	Needing specialist aids or equipment that you do not have	6.3	35
7	Don't like social activities	4.5	25
8	Lack of local facilities or suitable activities	3.6	20
9	Service facilities are not accessible	2.9	16
10	Don't have enough time	2.7	15
11	You are self-conscious of your intellectual disability	1.8	10
12	Unfriendly or negative attitudes towards you	1.6	9
13	Don't have enough money	1.3	7
13	Family and friends residence is not accessible	1.3	7
15	Getting too old	1.1	6
16	Not allowed to go	0.7	4

It was also evident that people in the older categories experience more difficulty than the younger age groups; 47.8% of those aged 40-49 years reported experiencing difficulty, compared to 52% in those aged 50-64 years, and 58.3% of those aged 65 years and over. People with a more severe/profound ID reported greater difficulty in social participation than people with a mild to moderate ID, at 71.4% and 43.6% respectively. Generally, people living independently/with their family (30.4%) or in a community setting (43.3%) reported less difficulty than those living in a residential centre (65.3%). Figure 3.4 presents the difficulties people experienced by level of ID.

Figure 3.4: Difficulties in participating in social activities, by level of ID



3.8.4 Difficulties getting around the community

Although a sizable proportion of respondents (42.1%, $n=313$), reported they did not experience any difficulty getting around their community, almost 60% did; 38.2% ($n=284$) reported a lot of difficulty here and a further 19.7% ($n=147$) reported that this was not applicable to them, because they did not travel around their community. Of those aged 65 years and over, 67.3% ($n=66$) experienced the greatest level of difficulty, compared to 49.3% ($n=140$) of those aged 50-64 years and 49.8% ($n=107$) of those aged 40-49 years. A total of 74.5% ($n=105$) of those within the severe/profound category reported experiencing greater difficulty, compared with 46.4% ($n=191$) of people with a mild to moderate ID.

Footpath design was identified as causing the greatest difficulty. One staff presented the difficulties succinctly when they stated, *'he/she has severe unsteady gait exacerbated by not concentrating, making walking around outside the house hazardous, so he/she is always in a wheelchair. Complete re-design of recreational areas and additional crossings and sloped pavements (removal of pot holes) would help a lot'*. In terms of specific problems, 10% of respondents ($n=76$) cited street signage, 9% ($n=68$) reported safety as the issue, a further 9% ($n=65$) reported a lack of street crossings and 4% ($n=34$) cited getting access to recreational areas.

See Table 3.7 for the rank order of difficulties experienced by adults with an ID in accessing their community.

Table 3.7: Difficulties experienced by adults with an ID getting around the community, in rank order

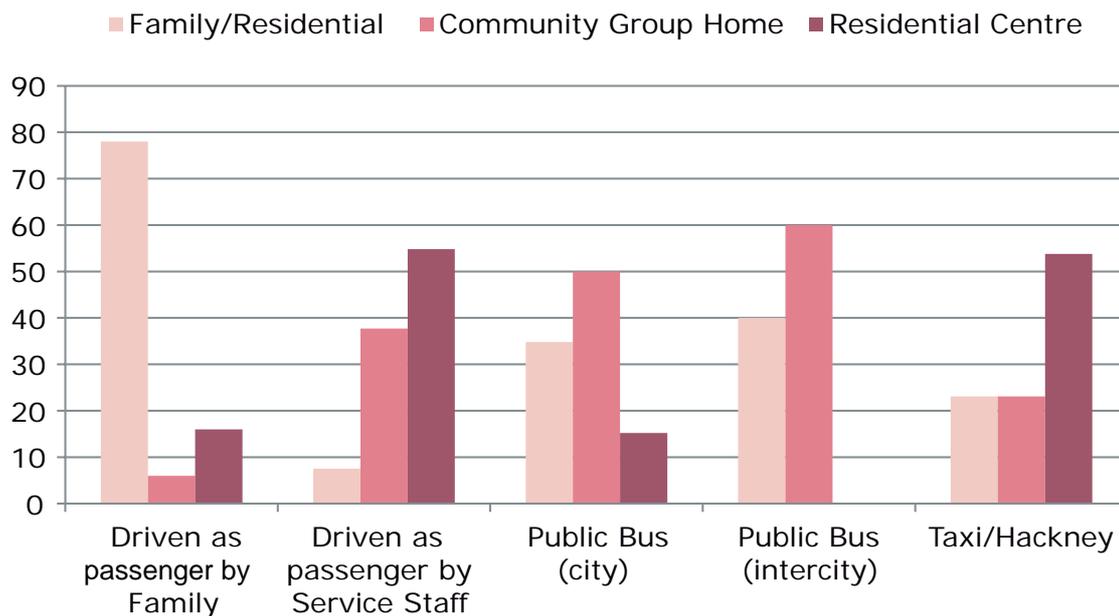
Rank order	Difficulties experienced	%	frequency
1	Footpath design and surfaces	29.4	92
2	Problems with signs (e.g. size and colour)	24.3	76
3	Feeling unsafe	21.7	68
4	Lack of street crossings	20.8	65
5	Getting access to recreational areas	10.9	34

Further examination identified that those living in a community setting experienced the greatest level of difficulty; with 22.3% ($n=25$) having difficulty due to a lack of street crossings, 33% ($n=37$) had problems with signage, and a further 29.5% ($n=33$) felt unsafe. In contrast 30.6% ($n=53$) of people living in a residential setting had difficulty with footpath design and surfaces. Finally, 14.3% ($n=4$) people living independently experienced the greatest level of difficulty in accessing recreational areas. Some of these setting-based differences are likely to occur, because those living in community settings have greater access to the community and are encouraged to make greater use of community resources. In turn, they encounter greater difficulties when the resources themselves have access and safety issues. These findings highlight that if we are placing adults with an ID in the community, a societal responsibility exists to address access and safety issues in community resources.

3.8.5 Transportation

People were asked to identify the means of transport they utilised within the past year. The majority of people (90%, $n=678$) identified being driven as a passenger by service staff as the means of transport they used most often. This comprised 75% of those aged 40-49 years, 75% of those aged 50-64 years and 87% of those who were 65 years and over. The majority (89.7%) were living in a residential setting and 89.1% were within the severe/profound range of ID. Taxi/hackney use ranked second (46.3%; $n=349$) and being driven as a passenger by a family member (38.5%, $n=270$) ranked third. The general population reports indicate that 76% of people drive themselves, with 14% reporting being driven by a family member (Timonen *et al.*, 2011). Such a contrast highlights the different level of support people with an ID require to truly engage in their community (Brady and Gates, 2003). Figure 3.5 presents the findings of transportation usage by living circumstances.

Figure 3.5: Transport usage, by living circumstances



Note: N= 743; Missing Obs: 10

Although public transport is free in Ireland for people with an ID, regardless of setting (community or residential), use of public transport was not common. In total, 20.6% ($n=155$) reported using the public bus, and 2.8% ($n=21$) used the public bus in rural settings. Table 3.8 presents, in rank order, overall transportation usage and types utilised.

Table 3.8: Types of transport most used, in rank order

Rank order	Type of transportation	%	frequency
1	Driven as a passenger by service staff	90.0	678
2	Taxi/hackney	46.3	349
3	Driven as a passenger by family	38.5	290
4	Public bus	20.6	155
5	Train (intercity)	12.4	93
6	Dart/Luas	12.1	91
7	Train (commuter)	11.7	88
8	Driven as a passenger by friends	9.2	69
9	Public bus (intercity)	5.7	43
10	Public bus (rural)	2.8	21
=11	Bicycle/motorbike	1.1	8
=11	Bus (Rural Transportation Scheme)	1.1	8
13	Drive myself	0.3	2

When asked how often they used public transportation, 12.9% ($n=95$) of respondents reported that they used it every week or more, 29.8% ($n=220$) used it on a monthly basis or less and 57.3% ($n=422$) never used public transportation. An equal percentage (14%) of people aged 40-49 years and 50-64 years used public transport on a weekly basis while for the older cohort, only 8.5% did so. People with a mild to moderate ID (16.2%, $n=78$) were more likely than people with a severe/profound ID (2.5%, $n=5$) to utilise public transportation on a weekly or more basis. Of those living independently, 27.5% ($n=35$) utilised public transport on a weekly basis or more, as did 18.4% ($n=48$) of those living in a community setting and 3.5% ($n=12$) of those in a residential centre. When asked if they would like to use public transport more often, 32.7% ($n=201$) responded positively. Among these respondents, 36.3% ($n=143$) had a mild to moderate ID and 45.5% ($n=40$) lived at home or independently. When probed as to why they did not use public transport more, the majority (76.1%) cited transport provided by their service provider as the main reason. The high usage of service provided transportation effectively equates with the high reliance on private cars reported by TILDA (Timonen *et al.*, 2011) for the general Irish population.

Needing assistance was the second most reported reason for why people with an ID did not use public transport (29.5%; $n=199$). This was followed by people having private transport provided by their families (17.2%, $n=116$), communication and language problems (12.8%; $n=86$) of those who responded, public transport being too infrequent (2.8%; $n=19$) and, for four participants, having one's own car. See Table 3.9 for the rank ordering of reasons why people in this study did not use public transport more often.

Table 3.9: Why people do not use public transportation more often – in rank order

Rank order	Why don't you use public transport more often?	%	frequency
1	Private transport provided by ID service provider	76.1	513
2	Need someone's assistance	29.5	199
3	Private transport provided by family	17.2	116
4	Communication/language problems	12.8	86
5	Not convenient	8.5	57
6	No public transport available	8.3	56
7	Transport facilities are not accessible	7.9	53
8	Your health prevents you	7.0	47
9	Public transport available does not take you where you want to go.	6.1	41
10	Prefer to walk	5.0	34
11	Private transport provided by friends	3.9	26
12	All amenities local, so don't need any transport	3.1	21
13	Infrequent	2.8	19
14	Too expensive	2.2	15
15	Unfriendly or negative attitudes toward you	1.6	11
16	Fear of crime	1.2	8
=17	You are self conscious	0.6	4
=17	Use your own car	0.6	4
19	Too dirty	0.4	3

Given that mobility often plays an essential role in access and meaningful engagement in a community, another important finding was that 37.7% ($n=244$) of participants reported a lack of transportation within their community. Within this group, 37 respondents (15%) felt that lack of transportation affected their lifestyle a great deal, 39.2% ($n=94$) reported that this affected them to some extent, and 45.4% ($n=109$) felt that there were no ill effects. When asked to identify the most important improvements that could be made to the transportation options available, replies overwhelmingly identified improved frequency or the establishment of a bus service. As one participant summed it up, *'more buses that come out to here because if I miss one bus then I could wait another hour for the next one, especially don't like waiting for a bus when there is no shelter'*. People also identified accessibility problems: *'the bus is in the local town which is a 20 minute walk with a wheelchair which can be difficult – more accessible transport. Also accessibility of the train – depends which side you come in on the platform, you need to ring ahead so that the wheelchair can be taken off'*. Future waves of data collection plan to consider in more detail the impact of transportation barriers, including reliance on buses provided by services.

3.9 Voluntary work

Volunteering involves helping others and having an impact on community life. There is evidence both in the generic literature (Haski-Leventhal, 2009; Lurn and Lightfoot, 2005) and in recent studies within the field of ID (Tang, 2009; Kim and Pai, 2010) that volunteering promotes improved health and wellbeing and may reduce incidence of depression, especially among older adults. In this study, people were asked if they did any voluntary work and to identify the factors that most motivated them to engage in these activities.

TILDA reported that 15% of the general Irish population of adults over age 50 volunteered (Timonen *et al.*, 2011). Numbers volunteering (7.7%; $n=58$) were smaller for adults with an ID, with the majority (63.2%, $n=36$) doing so twice a month or more. Reasons why people with an ID volunteered (see Table 3.10) included enjoyment (8.5%, $n=35$), contributing something useful (7.9%, $n=33$), meeting other people (6.0%, $n=25$) and a sense of achievement and feeling needed (4.1%; $n=17$). One participant captures these sentiments stating, *'I play the piano for an hour a week in the local nursing home, I enjoy it because they really enjoy it and they clap me. Then I sit and have a chat ...'*

As with TILDA (2011), very little difference was found regarding frequency of volunteering between the two genders; 8.7% of males volunteered, as did 7% of females. The majority of respondents who volunteered were within the mild to moderate range of ID. Higher levels of volunteering (10.6%) were found in IDS-TILDA among those aged 40-49 years, whereas in the general Irish population, the older age group (65-74 years) were more likely to volunteer frequently.

Table 3.10: Reasons for volunteering, by rank order

Rank order	Reason for volunteering	%	frequency
1	Because I enjoy it	8.4	35
2	To contribute something useful	7.9	33
3	To meet other people	6.0	25
4	Because I'm needed	4.1	17
5	To use my skills	3.9	16
6	For personal achievement	3.6	15
=7	For work experience	2.2	9
=7	To learn particular skills	2.2	9
9	To keep fit	1.7	7
10	Because I feel obliged to do it	0.2	1

3.10 Conclusion

Overall, people with an ID living in community settings were more likely to participate in their community than were people living in residential centres. However, low levels of engagement in communities were found for adults with an ID, regardless of residential circumstances. This suggests that society has done a better job of increasing the community presence of people with an ID than facilitating them to actually live within the community. This finding is not unique to Ireland but is consistently reported in studies published in this field. Given that those currently living in community settings tend to be younger, this does not bode well for community participation as people age and experience health decline. Consequently, as we move people to more community-based accommodation it is not good enough to be simply happy with a 'presence'. Instead, there is an urgent need to develop sound policies and to support actions to facilitate people with an ID to participate in the life of their communities.

In terms of day-to-day life, it was encouraging to find that most adults with an ID had a hobby, went on holidays or day trips, engaged in regular daytime activity and leisure pursuits and had social contacts with others. However, adults with an ID reported that they seldom engaged in social activities with friends outside their home; almost 80% of respondents relied on staff support and companionship when it came to social activities and a majority reported being dependent upon others for transportation and other assistance to access community options. It is of particular concern that older people with severe levels of ID appeared to have increased risk for social isolation.

Additionally, and in contrast to the general population, a range of findings related to both social connectedness and social participation by adults with an ID. They included the following:

- one in four adults reported meeting their family once a year or less;
- over three quarters of adults with an ID reported that they never wrote, texted, emailed or used multimedia such as Facebook to contact their family or friends;
- less than 60% used the telephone to make such contact;
- most adults with an ID identified a staff member as their confidant and their principal source of social interactions.

These findings highlight the growing challenges faced by people with an ID in making connections with others. They also show that opportunities for social networks can shrink as people with an ID age. In particular, the very limited role of families in the lives of many adults with an ID is of concern. This is especially so when we consider that, for the general population, family represents both a central source of social engagement and an important provider of support for adults as they age.

Adults with an ID reported difficulties in getting around in their communities. Relevant issues here included their need for and reliance on others for transport, lower use of public transport than was true for other adults and streetscapes that were difficult to use, or were unsafe. Those living in community settings, who had the most opportunities to access their community, in some ways reported the highest levels of dependence on others and difficulties with their surrounding communities.

Increasing infirmity and dependence in older age may add to concerns that older age will mean less community participation for people with an ID. Proactive steps, at the levels of policy and service planning, are required to increase access and reduce barriers in this field. Subsequent waves of data collection will measure the extent to which such policies and practices are realised. It will be even more difficult, but equally important, to measure increases in family and friend contact, building of a sense of neighbourhood and neighbourliness, as well as levels of civic engagement and volunteering that are likely to have beneficial effects on health and wellbeing.

4

Physical and Behavioural Health of Adults with an Intellectual Disability Ageing in Ireland

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4

Physical and Behavioural Health of Adults with an Intellectual Disability Ageing in Ireland

4.1 Key findings

- Cardiovascular risk factors were high among people with an intellectual disability (ID), with a marked gender difference; women were at greater risk. Prevalence increased with age.
- TILDA (2011) reported that angina, heart attack and heart failure had the highest prevalence among the general older population. By contrast, the most commonly reported heart conditions among older people with ID were heart murmur, abnormal heart rhythm and congestive heart failure.
- Lower rates of hypertension were found among those with Down syndrome, despite findings that one third of this population had high cholesterol and three quarters were overweight or obese.
- The prevalence of diabetes was similar to the TILDA general population finding but the gender difference was reversed, with diabetes more common in females than males; specifically, women within the mild to moderate range of ID were found to be at double the risk faced by men and risk increased with age.
- Epilepsy was the most common type of non-cardiovascular disease found among adults with ID; the overall prevalence was lower among those with Down syndrome, but for this subgroup incidence increased with the onset of dementia.
- Chronic constipation was a prevalent condition among adults with an ID.
- Reported levels of smoking and alcohol consumption were lower for people with ID compared to that reported by TILDA (2011) for the general Irish population.
- Sixty one percent of Irish adults with ID are overweight or obese, based on self-reported height and weight data.
- Thyroid disease was a reported health problem for 14.4% of the IDS-TILDA sample.
- Overall prevalence of reported osteoporosis is slightly lower among people with ID than that reported by TILDA (2011) for the general population, but marked gender and age differences were detected.

- The reported prevalence of cancer diagnosis was slightly lower among people with ID than reported by TILDA (2011) for the general Irish adult population. However, some similar findings were found, namely higher reported levels of cancer among women, breast cancer being the most commonly reported cancer in women and prostate cancer being most common among men. Previous reports found similar or lower levels of cancer among people with ID, with most prevalent cancers being stomach and colorectal.
- Nine out of 10 participants (91%) were taking at least one (prescription or non-prescription), medicine.
- Polypharmacy (defined as taking more than five medications (prescription and non-prescription) was observed in 59.1% of the sample, almost three times the level (21%) found for the general Irish population (TILDA, 2011).
- Polypharmacy was higher for those living in residential centres compared to those living in community, independently or with family.
- One third of people with ID reported being often troubled by pain, a concern that was more common among women than men. Moreover, one fifth reported pain to be severe. Actual prevalence is probably higher given problems in communication; this increases the likelihood that people with ID are at risk of unrecognised and untreated pain.
- The prevalence of sensory impairment among adults with ID was high; adults with ID were twice as likely to have significant visual problems and at a much younger age than the general population.
- Persons within the severe to profound range of ID were less likely to have had an eyesight test, with 30% reporting (or having proxies report for them) an eye test in the past year versus 70% of those with the mild to moderate range of ID.
- Overall, Irish adults with an ID reported that they hardly ever engaged in vigorous physical activity. Those who did engage tended to be men in the younger age groups. However, 80% did engage in some form of physical activity, at least once a week.
- A substantial proportion of adults with ID experienced major difficulties with mobility and this increased with age.
- Adults with ID reported a higher prevalence of at least one fall than that found among the general Irish population.
- The prevalence rate of falls reported among younger adults with ID aged 40-49 years, at 24.5%, was comparable to fall rates reported for those in the general population aged 75 years and older.
- One in three adults with ID reported that they found it difficult to make themselves understood when speaking with health professionals.

- Difficulty with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) was most notable in older age.
- The majority of adults with ID living in residential type centres, and over three quarters of those living in community settings, reported that they were unable to make a hot meal or manage their money.
- Half of those living in the community were unable to make a phone call and one out of three was unable to shop for groceries or manage household chores. A majority of those living in residential settings reported that they were unable to do any of these same activities.
- While those living with family and independently reported fewer difficulties, almost half could not manage their money or make a hot meal, and almost one third were unable to shop for groceries or make a phone call.

4.2 Introduction

International studies provide clues that individuals with intellectual disability (ID) have a greater variety of health care needs compared to those of the same age and gender in the general population (US Department of Health and Human Services, 2002; Haveman, *et al.*, 2010). It has been reported that health problems vary by level of disability (Moss *et al.*, 1993) and that people with ID have 2.5 times the health problems of those without ID (Van Schrojenstein Lantaman-De Valk *et al.*, 2000). When syndrome-specific health problems are examined, in particular for persons with Down syndrome, a distinct set of co-morbidity conditions become evident, as does a different pattern of ageing. In addition, central nervous system compromise, which has resulted in the underlying ID (for example in epilepsy or cerebral palsy), may present additional health risks. It is also recognised that other potential health determinants need to be investigated. Examples include access to health care, lifestyle, health promotion practices and environmental issues, all of which may directly cause, or interact with hereditary factors. This is required in order to protect against or confer specific health risks (Davidson *et al.*, 2003).

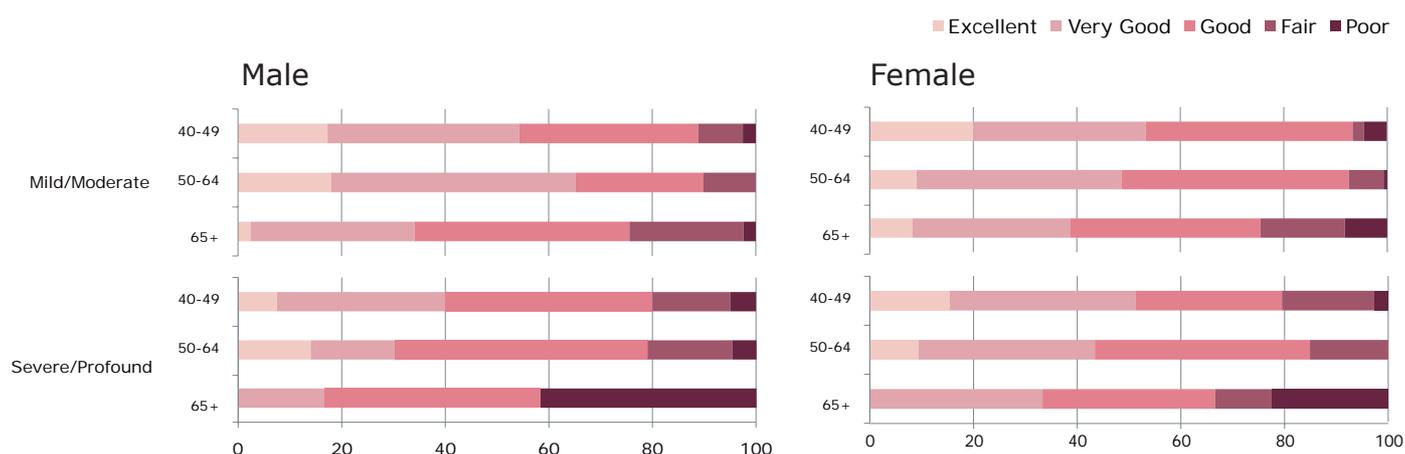
This chapter presents the prevalence of chronic diseases among people with ID as they age. It also examines variations in prevalence associated with age, gender, level of ID and living circumstances. It compares the prevalence and patterns of these diseases to those found by TILDA in the general Irish population. Health behaviours are discussed, including smoking, alcohol consumption, physical activity and engagement with preventative health screening. Patterns of medication use are described and specific co-morbid conditions which result in different patterns of ageing in persons with Down syndrome are presented.

4.3 Self-rated health

Despite the limitations inherent in the use of self and/or proxy reported health status as a measure of health, an association has been shown between perceived health and future mortality in both ageing and middle aged populations (Miilunpalo *et al.*, 1997). In IDS-TILDA, participants or proxies were asked to appraise the individual's general health using the global rating scale of excellent, very good, good, fair and poor. A total of 12% of participants rated their health as excellent, 36% as very good, 37% as good, 11% as fair, while 4% described their health as poor. In order to check the validity of proxy responses, the reports of 147 self-reporting participants were compared with those of the total group. Among the former, 92% reported their health was excellent, very good or good, as did 85% of the total group. This is a high level of concordance and differences suggest that proxy reporters were a little more conservative in their appraisal.

In the general population TILDA (Cronin *et al.*, 2011) used the same measure and identified that self-rated health declined with age for both genders, with their 'oldest old' less likely to report excellent, very good or good health (see Figure 4.1). TILDA presented 'good health' as a combination of ratings of excellent, very good and good; adopting this strategy, IDS-TILDA (2011) found that 73% of participants aged 65 years and over reported having good health. This reflected the TILDA findings that 72% of those aged 65–74 years and 66% of those aged 75 years and over reported good health. However, 89% of IDS-TILDA participants aged 50-64 years reported having 'good health' compared to 79% of TILDA participants in this age group. Among IDS-TILDA participants aged 40–49 years, 88% assessed their health within the good health range (this was not measured for this age group in TILDA). For IDS-TILDA then, ratings of health status were positive and younger participants were more likely to rate their health as good.

Figure 4.1: Self-rated health by age, gender and level of ID



Note: N=745; Missing Obs = 8

When adults with ID were asked how their health compared with other people their own age, their outlook remained positive: 17% perceived their health as excellent, 41% as very good, 36% as good and 6% as fair or poor, as compared to others of a similar age. Actual data on health status shows that many participants were relatively disease free (see Table 4.1). However, significant concerns emerged in terms of cardiac concerns, epilepsy, constipation, arthritis, osteoporosis, cancer, and thyroid disease.

Table 4.1: General and age-specific prevalence rates of health problems

Health problems	40-49 years (n=274)		50-64 years (n=344)		65 years + (n=134)	
	%	Frequency	%	Frequency	%	Frequency
Abnormal heart rhythm	4.4	12	2.9	10	3.7	5
Age related macular degeneration	1.1	3	3.8	13	3.8	5
Angina	0.4	1	0.9	3	2.2	3
Angioplasty/Stent	0.4	1	0.3	1	-	-
Arthritis	7.0	19	11.7	40	16.4	22
Asthma	3.6	10	5.2	18	7.5	10
Cancer	1.8	5	4.1	14	9.9	13
Cataracts	11.4	31	12.0	41	19.4	26
Cerebral palsy	7.3	20	5.2	18	3.7	5
Chronic constipation	13.5	37	17.7	61	23.9	32
Chronic lung disease	4.1	11	1.5	5	8.2	11
Cirrhosis/chronic liver disease	0.7	2	0.6	2	-	-
Coeliac disease	2.2	6	2.3	8	1.5	2
Congestive heart failure	0.7	2	0.3	1	6.8	9
Diabetes	3.3	9	10.5	36	12.2	16
Epilepsy	32.7	89	30.7	105	26.1	35
Gastroesophageal reflux disease	5.8	16	7.8	27	11.9	16
Glaucoma	-	-	1.8	6	3.0	4
Heart attack	0.4	1	0.9	3	3.0	4
Heart murmur	6.2	17	4.7	16	3.0	4
High cholesterol	24.2	66	32.9	113	43.3	58
Hypertension	7.3	20	17.4	59	27.6	37
Multiple sclerosis	0.4	1	0.3	1	-	-
Muscular dystrophy	0.4	1	0.3	1	-	-
Open heart surgery	0.7	2	0.6	2	-	-
Osteoporosis	2.9	8	9.0	31	16.4	22
Parkinson's disease	-	-	-	-	5.3	7
PKU	1.8	5	1.5	5	-	-
Scoliosis	6.9	19	4.4	15	3.0	4
Spina bifida	1.1	3	0.3	1	0.7	1

Stomach ulcer	4.0	11	4.7	16	4.5	6
Stroke	0.7	2	0.9	3	3.0	4
Thyroid disease (hyper/hypo)	13.9	38	17.2	59	9.7	13
Transient ischaemic attack	0.7	2	1.7	6	7.5	10
Varicose ulcers	0.7	2	2.6	9	4.5	6

4.4 Cardiovascular disease

In Ireland, cardiovascular disease remains the foremost cause of death, accounting for 35% of all deaths (Central Statistics Office, 2011). Haveman *et al.* (2009) conducted a comprehensive review of the scientific literature over the past fifteen years on health risks associated with ageing in people with ID. They reported:

'No indications of excess mortality or morbidity due to cardiovascular disease in older persons with intellectual disability, with lower rates of hypertension, high cholesterol and diabetes' (2009, p.39).

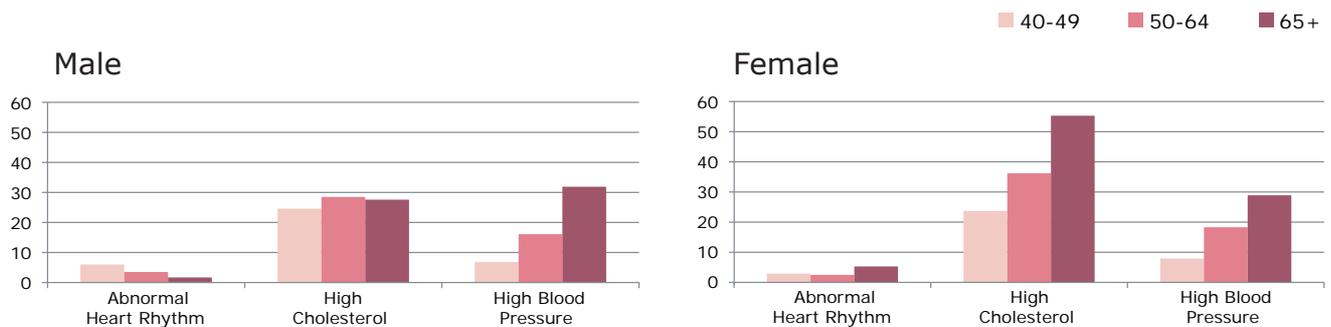
To understand cardiovascular risk factors for people with ID in Ireland, participants were asked if they had ever been told by a doctor that they had any of the following conditions: high cholesterol, high blood pressure, angina, heart attack (myocardial infarction), congestive cardiac failure, stroke, abnormal heart rhythm, heart murmur or any other heart condition. To facilitate comparisons with TILDA data, prevalence of reported diagnosis of diabetes is also included here.

4.5 Cardiovascular risk factors by age and gender

4.5.1 High cholesterol

A common risk factor frequently associated with a subsequent cardiac event is high cholesterol. Screening rates were high; 83% of participants, regardless of residential circumstance, reported they had their cholesterol level checked within the last two years. Similar to TILDA (Cronin *et al.*, 2011) findings, one in three adults with ID (32%) reported a doctor diagnosis of high cholesterol and 65% of those with a reported diagnosis were on cholesterol lowering medication.

Figure 4.2 Prevalence of cardio risk factors by age and gender



Note: N= 752; Missing obs = 1

The prevalence in the IDS-TILDA sample of reported high cholesterol increased with age; it rose from 24.2% in persons between the age of 40-49 years, to 32.9% in those aged 50-64 years, to 43.3% in those aged 65 years and over (see Figure 4.2). This is similar to, though slightly lower than, reports for the general population, as presented in TILDA (Cronin *et al.*, 2011). The relationship between heightened cholesterol levels and use of cholesterol lowering medications, and actual incidence of heart disease needs to be more specifically explored with the longitudinal tracking of new cases. IDS-TILDA offers the opportunity to do this. The collection of data on actual cholesterol levels, which is being considered for Wave 2 of IDS-TILDA, will also help improve knowledge of heart disease and cholesterol in people with ID.

A higher proportion of women with ID reported high cholesterol than men, at 35.5% versus 26.8% respectively. While a gender difference also emerged within the general population (Cronin *et al.*, 2011), it was not of this magnitude; here, a higher proportion of men (35.5%) reported having high cholesterol. High cholesterol among persons with ID has not been studied or reported to the same extent as the general population. Even less is known about gender-based health differences for people with ID. A gender-based difference of this magnitude has not been previously reported in people with ID and this will also benefit from further investigation. Moreover, the healthcare system should be made aware of these initial findings, which suggest strongly that people with ID should be specifically targeted in all cardiac-related education and health promotion efforts.

Weight is another important risk factor for high cholesterol. In this study, a large proportion of those with high cholesterol were overweight or obese (calculated from self-reported weight and height data); 28% were overweight, and a further 38% were obese. However, these self-report estimates may be lower than those based on measured data. A recent systematic review of the literature substantiated the existence of a bias associated with self-reported weight and height data (Connor Gorber *et al.*, 2007), with many studies finding that self-reports underestimate weight and overestimate height (Shields *et al.*, 2008). This leads to consequential underestimates of body mass. For this reason, higher levels of overweight and obesity may exist among those with

reported high cholesterol in this study, and across this population group. The inclusion of objective measurements such as height, weight, waist and hip circumference will be an important consideration in future waves of this study.

4.5.2 Hypertension

Bhaumik *et al.* (2008) report older adults with ID have a more significant risk of developing hypertension. This is due to the presence of lifestyle risk factors such as inactivity and obesity. One in six IDS-TILDA participants (16%) reported a diagnosis of hypertension. This was lower than that reported for the general population, in which one in three people had this diagnosis, representing 29.7% of those aged 50-64 years and 53.7% in those aged 75 years and over (Cronin *et al.*, 2011). As with the general population, the incidence of high blood pressure among IDS-TILDA participants increased with age, growing from 7.35% of those aged 40 to 49 years, to 17.4% of those aged 50 -64 years, to 27.6% of those aged 65 years and over (see Figure 4.2). Overall, levels were lower than those reported for the general population across all age groups, but were akin to previous reports on high blood pressure in the ID population (Haveman *et al.*, 2011). Women with ID reported higher levels of high blood pressure than men, at 16.7% and 14.1% respectively; a gender difference was also reported in TILDA (Cronin *et al.*, 2011) for the general population.

These first wave results need to be interpreted with caution given that a relatively small number of people with ID were in the older age category. It is likely that subsequent waves of the study will provide opportunities to explore the increasing incidence and prevalence of hypertension with age, and its relationship to lifestyle factors such as overweight and obesity and levels of physical activity.

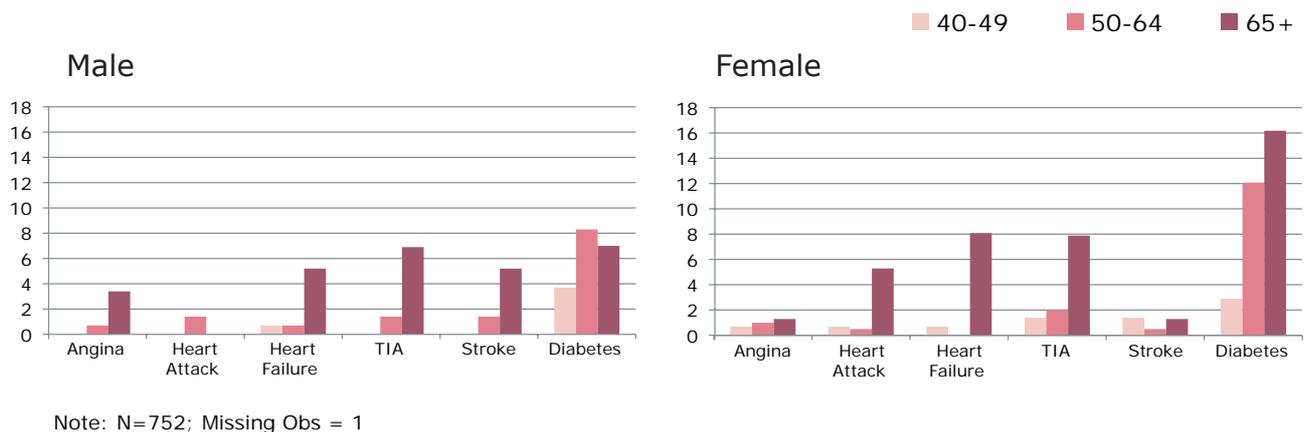
It is notable that only a small cohort of eight individuals with a diagnosis of high blood pressure also had Down syndrome (about 5% of this group). This is in keeping with international research that reports significantly lower rates of hypertension among this population (Kapell *et al.*, 1998), despite the fact that 32% of those with Down syndrome had high cholesterol and 68.7% ($n=79$) were reported to be overweight or obese.

4.6 Cardiovascular disease

TILDA (Cronin *et al.*, 2011) reported that angina, heart attack and heart failure were among the highest cardiovascular conditions experienced by older people. However, in IDS-TILDA, heart murmur, abnormal heart rhythm, transient ischaemic attack (TIA) and congestive heart failure were most frequently cited. Five percent ($n=37$) of individuals reported a heart murmur, 20 of whom also had Down syndrome. A further 27 participants reported an abnormal heart rhythm and 26 people reported congestive heart failure, two of whom also had Down syndrome.

Figure 4.3 below offers additional data by displaying the prevalence of cardiovascular disease by age and gender.

Figure 4.3 Prevalence of cardiovascular disease by age and gender



Although TILDA (Cronin *et al.*, 2011) reported that one in 20 older Irish adults present with angina or a previous myocardial infarction, IDS-TILDA identified this condition among only one in 50 of people with ID. A further seven people reported having angina, eight had experienced a heart attack, nine reported having had a stroke; 18 reported a TIA and 61 reported having diabetes.

Two other differences emerged for people with ID. Firstly, the TILDA data appears to support the view that cardiac conditions increase with age. However, while this study found that cardiac conditions for people with ID initially increase with age, rates then appeared to decrease among those aged 65 years and over: of those who reported these cardiovascular diseases, 14.1% were aged 40-49 years, 49.5% were aged 50 -64 years and 36.4% were aged 65 years and over. Secondly, the prevalence of congestive heart failure, at 3% ($n=26$), was greater than that reported for the general population (1.1%).

Comparisons need to be interpreted with caution, given the smaller numbers in the ID cohort. Longitudinal investigation in future waves will help confirm or offer an alternative explanation for the cross-sectional findings presented here. It will be of interest to explore:

- whether low prevalence rates are more related to poor surveillance, and an inability by many to self-report than to actual prevalence;
- the apparent higher prevalence of congestive heart failure among people with ID;
- the impact of policies for active health screening, facilitated access to health and nursing care, and low levels of smoking;

- the apparent lack of impact of low levels of education and wealth which TILDA reported as protective for the general Irish population;
- whether objective screenings that are being considered for Wave 2 will discover similar discrepancies between self-reported and objective measures of disease as found for the general Irish population in which, for example, 58% of men and 49% of women presented with objective evidence of undiagnosed hypertension (Cronin *et al.*, 2011);
- if low levels of reported hypertension found for people with Down syndrome represent under-reporting or pose an interesting question about uniqueness in Down syndrome that is protective against cardiac disease.

In order for answers to be found, it will be critical that objective measures of disease are included and explored in future IDS-TILDA waves.

4.7 Diabetes

Diabetes is a rapidly growing health concern with dramatic rises being reported and anticipated for older adults (Sloan *et al.*, 2008). Similar to TILDA (Cronin *et al.*, 2011) findings for the Irish population, 8.2% of adults with ID reported a doctor's diagnosis of diabetes. In the TILDA sample, more men than women presented with the condition, at 9.6% versus 6.5% respectively. In addition, the prevalence increased with age, rising from 6% among those aged 50-64 years to 11.1% of those aged 75 years and over (Cronin *et al.*, 2011). A somewhat different picture was found in adults with ID. In this population, diabetes was more common among women than men, at 9.7% and 6.3% respectively. Women within the mild to moderate range of ID also emerged more at risk with a prevalence of 11.7% versus 5.2% among men in this category. A higher prevalence of diabetes for women with increasing age was also of concern, with reported rates of 12.1% among those age 50-64 years, increasing to 16.2% among those aged 65 years and over; this contrasts with 8.3% and 7% in men of the same age cohorts.

A major risk factor for type 2 diabetes is obesity and in this study 26% of those with diabetes were overweight with a further 43% obese. Another major contributory factor is lack of physical activity, which will be examined in further detail in this chapter. Again the gender variation that differs from that found in the general population in Ireland needs to be followed up and better understood. The tracking of growing trends in incidence and prevalence of diabetes is of worldwide concern and this is also true for people with ID. As with cardiac conditions previously reported, there is also a need to examine the gender differences and the apparent higher risk of diabetes among older age groups.

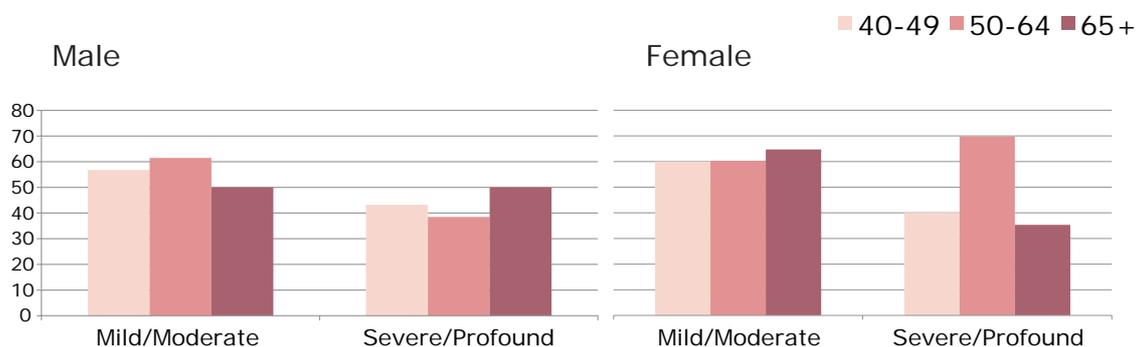
4.8 Other non-cardiac health conditions

IDS –TILDA respondents were asked if their doctor had ever told them that they had been diagnosed with any of the following health conditions: epilepsy, chronic lung disease, chronic constipation, thyroid disease, arthritis, osteoporosis and fractures, sensory impairments, foot health, oral health, stomach ulcers, gastroesophageal disease, pain and cancer (see Table 4.1).

4.8.1 Epilepsy

Epilepsy's approximate annual incidence rate is 40–70 per 100,000 in industrialized countries and prevalence is highest among young children and those over 65 years (Sander, 2003). For people with ID, however, rates are reported to be higher. In a cross-sectional study involving 1,253 adults aged 19 years and over across 14 European countries, Haveman *et al.* (2011) reported an overall prevalence of 28%, with an inverse relationship with increasing age. In this study, epilepsy proved the most common type of non-cardiovascular disease, with 31% ($n=229$) of respondents reporting a diagnosis of this condition; incidence decreased with increasing age. See Figure 4.4.

Figure 4.4: Prevalence of epilepsy by age, gender and level of ID



Note: N=752; Missing Obs = 1

Prevalence of epilepsy was lower among those with Down syndrome than those with ID from other aetiologies, at 12.6% and 87.4% respectively. The mean age of those with Down syndrome and epilepsy was 52 years, with a range of 43-56 years. Of those with Down syndrome and epilepsy, 28.6% had dementia. For this subgroup at least, epilepsy incidence did appear to increase with age.

The most common type of seizure (53%) was tonic-clonic seizures. Of those who reported seizures, 81.5% kept a record of their seizure activity, and 43.4% ($n=89$) reported no seizure activity within the past two years. A total of 28.8% ($n=59$) reported having seizures less than once a month, 9% ($n=18$) experienced a seizure on a weekly basis, 13% ($n=27$) did so more than once a month and 2% ($n=4$) reported having a seizure daily. Sixty-three percent of people with epilepsy attended an epilepsy clinic; for the majority of them, their epilepsy was reviewed in the last year. Epilepsy was more prevalent in women (59%) than men (41%).

4.8.2 Constipation

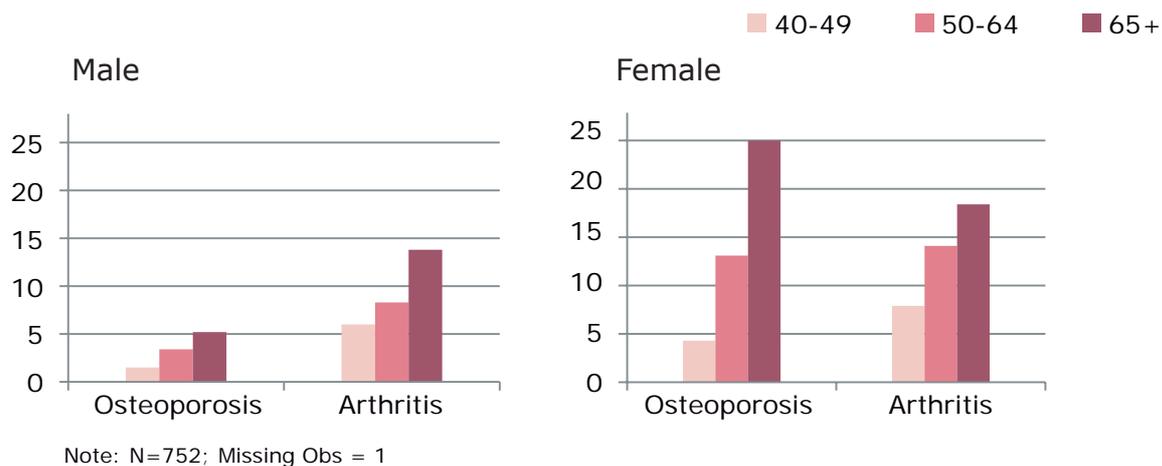
Chronic constipation is a major concern for people with ID, with Haveman *et al.* (2011) reporting a prevalence rate of 26.6%. However, research literature indicates that constipation was not correlated with age; instead, other risk factors such as immobility, specific drugs, physical inactivity and neurological conditions were reported (Haveman *et al.*, 2011; Haveman *et al.*, 2009; Morad *et al.*, 2007). In the IDS-TILDA sample, 17.3% reported that they suffered with chronic constipation and, similar to previous studies, this did not appear age related.

4.8.3 Arthritis, osteoporosis and fractures

A number of studies report that osteoporosis and associated fractures are more common in people with ID than in the general population (see, for example, van Schronjenstein–Lantman-deValk *et al.*, 2000 and Leslie *et al.*, 2008). A number of predisposing factors, as summarised by Haveman *et al.* (2009), include small body size, hypogonadism, Down syndrome, oestrogen deficiency, polypharmacy (particularly high levels of anti-epileptic medication), and lack of exercise.

The overall prevalence of reported osteoporosis in the IDS-TILDA sample was 8.1% which is similar but slightly lower than that reported by TILDA (Cronin *et al.*, 2011) for the general population (9.3%). The prevalence of osteoporosis was higher (9%) at a younger age in people with ID in those aged 50-64 years; this compares with 7% identified in the same age cohort among the general Irish population (Cronin *et al.*, 2011). Additionally, 3% of those with ID aged 40-49 years reported a diagnosis of osteoporosis. See Figure 4.5.

Figure 4.5: Prevalence of osteoporosis and arthritis by age and gender



Marked gender and age differences emerged: 13.1% of women with ID aged 50-64 years and 25% of those age 65+ years reported a diagnosis of osteoporosis, compared with 3.4% and 5.2% of men in these respective age cohorts (see Figure 4.5). Regarding those aged 50-64 years, TILDA reported a similar rate of 12.5% among women in the general Irish population (Cronin *et al.*, 2011). However, women with ID aged 65+ years reported a higher prevalence rate, at 25% compared to 19.1% of the general female population.

Respondents were also asked if they were ever told by a doctor that they had arthritis and, if so, to identify which types of arthritis they were told they had, including osteoarthritis/ rheumatoid arthritis. They were also asked if they had sustained a fracture and to identify which bone (for example, hip, wrist, ankle, shoulder or knee) was involved.

A total of 10.8% reported that they had a doctor’s diagnosis of arthritis, with osteoarthritis being the most common type at 54.1%. The overall prevalence of arthritis found in people with ID (10.8%) was much lower than that reported by TILDA for the general Irish population, where one in four (or 27.6%) of those aged 50 years and over had arthritis. Again a discernable gender and age gradient emerged. Among women with ID aged 40-49 years, 7.9% had arthritis; this rose to 14.1% among those aged 50-64 years and 18.4% among those aged 65 years and over. See Figure 4.5.

These prevalence figures for osteoporosis and arthritis among people with ID need to be considered with great caution. A total of 76.2% of people with ID reported never having a bone density scan, and many of this population were not able to verbally report symptoms and lacked the language to communicate body changes and pain sensation. It is therefore very possible that prevalence figures are underestimated here. In the general Irish population, marked differences arose between respondent reported and objectively measured rates of osteoporosis. Only 34% of women with objective evidence of osteoporosis reported a doctor’s diagnosis and, of even more concern, 100% of men with objective evidence of osteoporosis did not report a doctor’s diagnosis’

(Cronin *et al.*, 2011). This evidence of under-reporting and differences in findings for people with ID both highlight the value of following this issue, as well as the addition of objective measures in subsequent waves.

4.8.4 Fractures

A total of 20.5% of older adults with ID reported having a fracture. Ankle fractures were most commonly identified, occurring in 6.6% of the population; 6.1 % reported a wrist fracture; 4.1 % a hip fracture and 1.7% a knee fracture. The overall prevalence of hip fractures in people with ID was higher than that reported for the general population at 4.1% versus 3.6%; 9.2% of those with ID under the age of 65 years reported having fractured their hip, versus 2.8% of those aged under 65 years in the general population (Cronin *et al.*, 2011). No gender difference emerged with respect to the prevalence of overall fractures, however; as with the general population, hip fractures among those with ID were more common among men and those aged 65 and older (although low numbers encourages caution with this conclusion). Future waves of data collection and longitudinal follow-up may help establish whether the high prevalence of fractures in the younger age groups increases risks of morbidity and mortality.

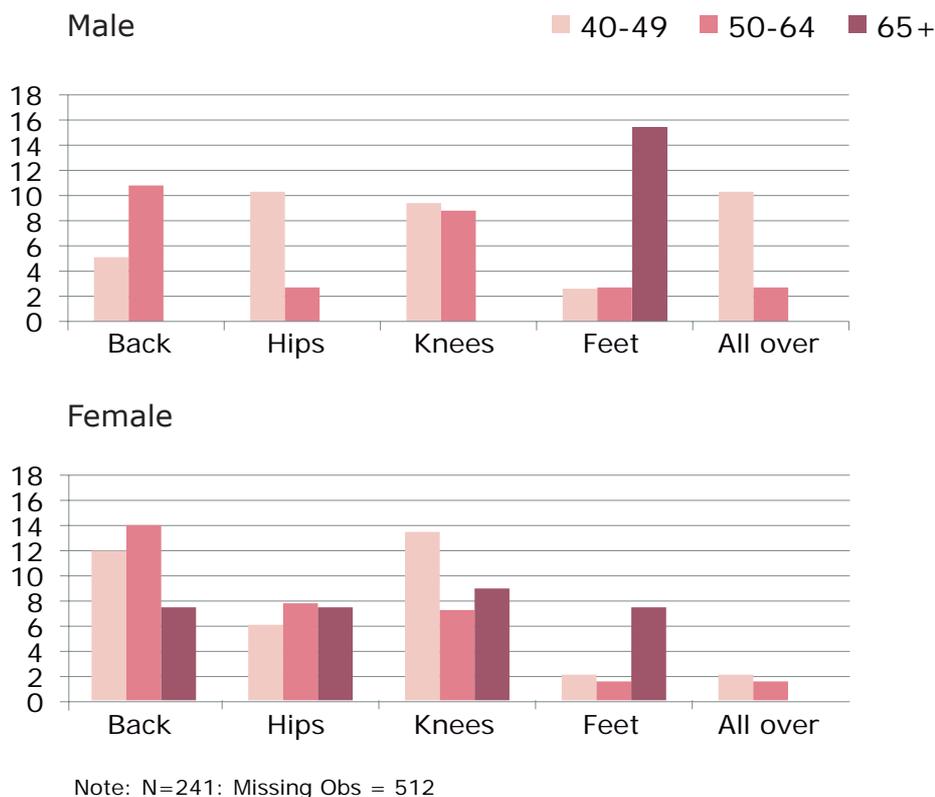
4.8.5 Pain

It has been increasingly recognised that pain in people with ID is often unrecognised and poorly treated, and that many people with ID have significant problems in reporting and explaining their pain. Moreover, the incidence of many conditions, such as arthritis and osteoporosis, which predispose one to pain increase with age. Given that people with ID are experiencing increased longevity, their risk of these conditions also increases.

Participants in this study were asked to report if they were often troubled by pain and, if so, to identify the part of the body that was in the most pain. Overall, one third (33.2%) of people with ID reported being often troubled by pain, with 39.3% of these reporting that pain was moderate, and 20.1% reporting pain to be severe. Reported pain was more prevalent among women with ID than men (62.8% versus 36.7% respectively), which is similar to the general population. However, men aged 40-49 years reported a higher prevalence of pain than women in the same cohort (10.3% versus 1.9% respectively). Findings regarding back pain were also similar to the TILDA findings for the general Irish population (Cronin *et al.*, 2011); it was the most common type of reported pain, at 47%, and it was twice as often reported by women than men, at 31% versus 16% respectively. Knee pain was the second commonest type of pain reported in people with ID at 45.7%, and again was more common among women than men, at 27.5% versus 18.2% respectively. Hip and foot pain were also common, at 32.7% and 30.9% respectively, with foot pain being more commonly reported by men than women, at 20.7% versus 10.2%. (See Figure 4.6). Almost half of the population (45%) said that pain did make it difficult to do usual chores, work or leisure activities.

The majority of those who experienced pain (79%) reported taking medications for pain relief, with almost all (98.4%) reporting that medication controlled the pain.

Figure 4.6: Prevalence of pain by site, age and gender



Only 20% of the population were able to complete the total research interview independently and to self-report on all items including pain, with the remaining 80% receiving some or total assistance from proxy. In light of this, it is likely that those who were not able to self-report are at risk here and are likely to suffer from untreated pain.

4.8.6 Falls

While there is a wealth of empirical knowledge highlighting the effect of falls on the health and wellbeing of older people in the general population (Bloem *et al.*, 2003), limited research has been conducted around the issue of falls experienced by people with ID. Despite high co-morbidity and the increased risk factors for falls, such as balance and gait disorders, visual impairment, epilepsy and use of psychotropic medication, to date no studies have systematically investigated the prevalence and risk factors for falls in an Irish population of older people with ID. International studies suggest that falls for people with ID are a significant cause of injury and morbidity

(Lohiya *et al.*, 1999, Hsieh *et al.*, 2001, Sherrard *et al.*, 2001 and Schrage *et al.*, 2007). A Scottish study by Finlayson *et al.* (2010) found that 40.1% of adults with ID reported at least one fall, with 12.1% of the study sample reporting an injurious fall. Cox *et al.* (2010) also reported high rates of falls among adults with ID; 34% of their study sample reported at least one fall in the previous 12 months.

In this study, the definition of falls developed by Brady and Lamb (2008) was used. This defines a fall, 'as an unexpected event in which the participant comes to rest on the ground, floor or lower level'. Recognising the potential for problems with recall, respondents were asked firstly to recall 'in the past month if you have had a fall including a slip or trip in which you lost your balance and landed on the floor or ground at a lower level'. They were then asked the same question in relation to the past year.

Overall 26.7% of adults with ID sustained a fall in the past year and of those who fell, 7% reported having had two or more falls. This prevalence is higher than that reported for the general Irish population, but lower than previous studies within the field of ID (Finlayson *et al.*, 2010). In the general population, 19% of adults had a fall in the past year, with 7% reporting two or more falls (Cronin *et al.*, 2011). The prevalence of falls reported among younger adults with ID aged 40-49 years, at 24.5%, was comparable to fall rates reported for those in the general population who were aged 75 years and older.

Given the higher number of falls overall and the potential for poor recall of multiple incidents among people with ID, the use of falls diaries and other measures will be considered for subsequent waves of data collection.

4.8.7 Cancer

In general, the incidence of cancer among people with ID has not been widely studied. However, it is considered akin to the general population with risk increasing with age (Haveman, *et al.*, 2009; Hogg and Tuffrey-Wijne, 2008). It has been previously suggested that people with ID suffer from different cancers than the general population, with some of these genetically linked. For example, leukaemia is associated with Down syndrome, men with ID have an increased risk of brain and stomach cancers but a reduced risk of prostate cancers and women have an increased risk for corpus uteri and colorectal cancers (Sullivan *et al.*, 2004, Patja *et al.*, 2001).

The prevalence of reported cancer in this study (4.3%) is slightly lower than the TILDA reported prevalence of 6.1%. However, women with ID presented more frequently with cancer than men, at 59% versus 41%, and breast cancer was their most common type of cancer reported. Both of these findings reflected those from the TILDA study of the general population; among women who reported having cancer, for example, 30% of women in the general TILDA population and 29% of women in the IDS-TILDA sample cited breast cancer. However, a difference did emerge regarding the second highest reported form of cancer; while for the general population this was bowel cancer, for women in IDS-TILDA sample, cervical cancer rated second, at 13% of all

cited cancers. Prostate cancer was the highest report form of cancer among men with ID; this was also the case for the general male population. However, prevalence (16%) was lower than the 29% reported for the general population (Cronin *et al.*, 2011). Lung cancer also featured nationally among the top three cancers for both men and women; however, within the ID population, lung cancer did not feature prominently. This may be due to the reported lower smoking rates discussed later in this chapter. Among the population with Down syndrome ($n=147$), two reported having had a diagnosis of cancer, which is in keeping with international research documenting the low incidence of cancer in this subgroup (Yang *et al.*, 2002).

The findings on cancer need to be interpreted with caution given that the prevalence numbers here are very small. Nevertheless, improving understanding of types of cancers, active health promotion campaigns and uptake of cancer screening for people with ID will all be increasingly important as this population ages and risks of cancers increase. It is critical that health awareness and educational programmes targeted at the general population are made accessible. Whereas in Ireland the national BreastCheck campaign (NCCS, 2008) reports an uptake of 75%, this study documents that only 48% of adults over 40 years with ID are being reached by this campaign. Moreover, the findings show that the greater the severity of a woman's ID, the less likely she was to have availed of breast screening. Of those who did attend breast screenings, 30.4% had a mild ID, 48.4% had a moderate ID, 19.9% had a severe ID, and two individuals had a profound ID.

4.8.8 Thyroid disease

Thyroid disease is another commonly reported health problem for people with ID, with 14.4% of the IDS-TILDA sample reporting this diagnosis. This is higher than previous reports of thyroid disease in this population at 8% (Janicki *et al.*, 2002, Haveman *et al.*, 2011). Of those with thyroid disease, 50.9% had a diagnosis of Down syndrome. The prevalence of thyroid disease was age related; it increased from 34.5% among those aged 40-49 years to 53.6% in those aged 50 - 64 years, and then dropped to 11.8% for those aged 65 years and older. This reduced prevalence for older people with Down syndrome was not reported in prior studies (see, for example, Kappell *et al.*, 1998). In total, 73.3% had had a thyroid screen within the past two years, a further 31.1% went for screening over two years ago and 15% have not had a thyroid screen (the remainder responded 'don't know' or no response was given).

4.8.9 Sensory health

Sensory decline appears to be a common problem as people age (Cronin *et al.*, 2011). In 2009, Haveman *et al.* conducted a comprehensive review of the scientific literature conducted over the past fifteen years on visual impairment in people with ID. They concluded that there are both age and cause-specific differences in the rates of vision impairment in people with ID compared to the general population.

In this study, respondents were asked 'to rate their eyesight using the following response options: 'excellent, very good, good, fair and poor'. (A 'not applicable' option was also available in the event that a participant was legally blind). In addition, participants were asked if their doctor had ever told them they had age related macular degeneration, glaucoma, cataracts, or any other eye disease.

4.8.10 Vision

Consistent with findings from previous studies of sensory impairment in people with ID, prevalence was high. Over 40% of participants were prescribed and regularly wore glasses or contact lenses for reduced vision. This is likely to be an underestimation, given that some people with ID may have difficulty in wearing prescribed aids such as glasses. Moreover, accurately screening for visual and hearing impairments, particularly among those with severe and profound ID, is fraught with difficulties; many may not be able to understand and co-operate with these tests. However, when participants were asked to appraise their vision 73% of them, across all age groups, reported their eyesight as being very good or good, with a further 8.1% rating their eyesight as excellent. However, 15.3%, even with the use of glasses or lens, reported their eyesight as fair to poor and a further 3.6% were registered as legally blind.

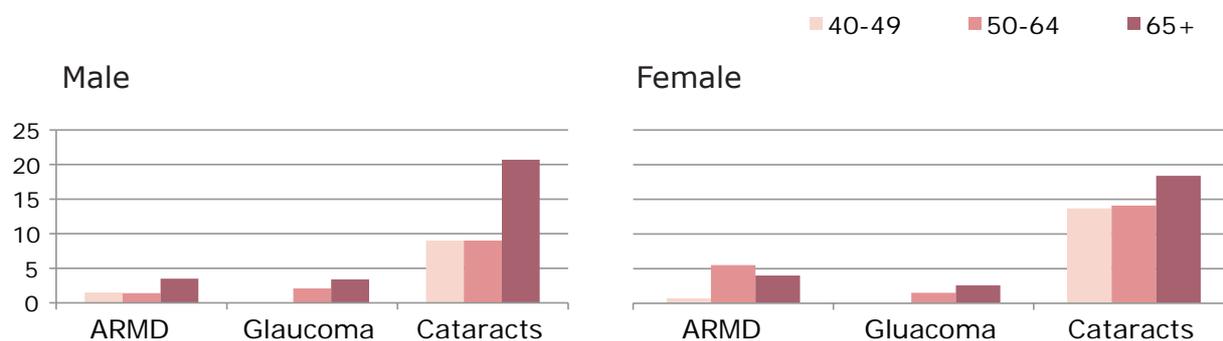
Among adults with ID, 19% had significant visual problems. However, unlike reports for the general population (Cronin *et al.*, 2011), these did not appear to be age related. People with ID aged under 65 years were twice as likely to have visual problems as those in the general population aged 75 years and over (Cronin *et al.*, 2011). Examining these figures with regards the persons' residential circumstances, 83% of people living at home or independently rated their eyesight as being within the 'good health range' as did 85% of those living in community group homes. However, 77% of those living within residential type settings, a group who were older and more likely to be in the severe/profound range of ID, rated their eyesight within the 'good health range'.

In relation to the promotion of eye health, over half of participants (55%) had been for an eye exam in the previous year, and a further 27% attended one within the last one to three years. Another 10% of people had their eye exam more than three years ago, while 8% had never gone for an eye exam. Persons within the severe to profound range of ID were less likely to have had an eyesight test; 30% of this group reported (or had proxies report for them) that they had an eye test in the past year, compared with 70% of those within the mild to moderate range of ID. This finding may highlight the challenges faced by those who support people with severe to profound ID.

As with the general population, the prevalence of age related macular degeneration, cataracts and glaucoma increased with age and was more common in females than in males (see Figure 4.7). The overall prevalence of cataracts was 13.1%, which was higher than that reported for the general population at 11.3%. A clear age gradient was observed, with 11.4% of those aged 40-49 years reporting cataracts;

12% of those aged 50-64 years and 19.4% of those aged 65 years and older. An overall prevalence of 1.3% reported glaucoma and 2.8% reported age related macular degeneration. Prevalence of glaucoma was lower than that reported for the general population, at 2.4%. Age related macular degeneration was higher, with a reported prevalence rate at 1.7% for the general population (Cronin *et al.*, 2011).

Figure 4.7: Prevalence of eye disease by age and gender



Note: N=752; Missing Obs = 1

4.8.11 Hearing

An overall prevalence rate of 3.2% for hearing problems among Irish adults with ID is 50% lower than that reported in previous studies involving this cohort (Haveman *et al.*, 2011). The prevalence in this sample of reported hearing problems rose from 2.2% for those aged 40-49 years to 4.1% of those age 50-64 years. It then decreased to 3% among those aged 65 years and over. Previous studies in ID reported a prevalence of 11.9% regarding hearing problems among those aged 65 years and older (Haveman *et al.*, 2011).

In relation to screening for hearing difficulties, 46% reported that they never had a hearing test. A further 19.9% had a hearing test in the last year, 17.2% reported they had one between one and three years ago, and a further 17% had one more than three years ago. Of those who had never had a hearing test, 47.5% lived in residential care, 28.9% lived in a community group home and 23.6% were living with relatives. Clearly, further investigation of hearing issues is warranted.

4.8.12 Urinary and bowel incontinence

Incontinence is often a problem for people with ID and is sometimes associated with levels of pre-existing intellectual impairment and/or impoverished care environments. In the general population, the development of urinary incontinence with increasing age is often associated with increased social isolation and depression (Nitti, 2001).

In the general Irish population, TILDA (Cronin *et al.*, 2011) reported that prevalence of urinary incontinence increased from 9% of those aged 50-64 years to 19% of those aged 75 years and older. In adults with ID, a very different picture of incontinence emerges. Here, an overall reported prevalence rate for urinary incontinence emerged at 27.6%, and for faecal incontinence at 15.7%. Over 80% of these participants also reported having mentioned this problem to a doctor or health professional. For 7.5% of the sample, this question was not relevant as they were never continent or only continent with assistance from staff. The prevalence rate reported for people with ID in the 50-64 years age group, at 26%, was three times higher than that reported in the general population (9%). For those with an ID who were aged 65 and over, the prevalence rate was 37.3%. Again, this warrants further investigation.

4.8.13 General communication

In this study, participants were asked if they had difficulty in speaking or making themselves understood when speaking. Overall, 83.5% stated that they could make themselves completely understood when talking to family, 12.8% said that they could be partially understood and for 3.65%, the participant or proxy reported that they could not be understood at all. Communication with friends appeared easier; 73.9% said that they could be understood completely by their friends, 21.9% felt they were partially understood, while 4.2% reported that they could not make themselves understood at all. Of most concern was the fact that one in three adults with an ID reported that they found it difficult to make themselves understood when speaking with professionals. When so much care in chronic illness in later life is dependent upon communication with health professionals, such a perceived lack of success in communication does not bode well for people with ID.

4.9 Behavioural health

It is increasingly recognised that health behaviours such as smoking, drinking and physical exercise are linked to health outcomes (Davidson *et al.*, 2003). With the exception of those with mild ID, it is generally reported that people with ID have lower levels of smoking and alcohol use as compared to the general population. For example, Haveman *et al.* (2011) reported 6% of people with ID as daily smokers versus 28% in the general population, with those in the 65 years and older age group reporting higher levels of smoking, at 10.9%. Reported use of alcohol was somewhat higher, at 35.1%, and those in older age groups were more likely to use alcohol. On the other hand, the levels of overweight and obesity in people with ID is recognised as a major health concern by many researchers (e.g. Janicki *et al.*, 2002; Traci *et al.*, 2002; Haveman *et al.*, 2011).

For the IDS-TILDA sample, data was gathered on smoking, alcohol consumption, nutritional health, physical activity, sleep and participation in preventative health screening. Variations were explored in relation to age, level of ID and living circumstances. Prevalence rates were also compared to those reported for the general population in TILDA (Cronin *et al.*, 2011).

4.9.1 Smoking

In this study respondents were asked if they had ever smoked cigarettes, cigars, cigarillos or a pipe for a period of at least one year. They were also asked if they were smoking at the present time, and, if so, how many smokes they had per day. Overall, the prevalence of smoking among older Irish adults with ID was low, at 8.1% compared to a prevalence of 19% reported for the general Irish population in TILDA (Cronin *et al.*, 2011). Indeed, 84.6% indicated that they never had smoked. Out of those who did smoke, the majority (93.1%) smoke cigarettes, on average 11 cigarettes per day. Unlike reports for the general Irish population, there was a noted gender difference with men with ID (64%) more likely to smoke than women (36%). Smoking was also more common among those with mild to moderate ID. Higher rates of smoking were found among those aged 50–64 years (47.5%) and the lowest rate was found in the 40-49 age groups (21.3%). A higher rate of smoking was also reported in the 50-64 years age group in the general Irish population (Cronin *et al.*, 2011).

4.9.2 Alcohol consumption

Ireland is reported to have the highest levels of alcohol consumption amongst member states in the European Union (Hope, 2008). Haveman *et al.* (2011), in a cross-sectional study across 14 European member states, reported modest levels of alcohol consumption among people with ID, with 64.9% not drinking alcohol and 30.6% consuming an average of one to two glasses per day. In this study, respondents were asked if they had drunk alcohol anytime within the past six months. The frequency and quantity of their alcohol consumption was also recorded.

Alcohol consumption among older Irish adults with ID could be considered modest, with 60% of this population reporting that they did not drink alcohol in the past six months. Of those who did drink alcohol, over 50% of them drank once or twice a month or less. The number of drinks consumed was equally modest; approximately 80% reported having had no more than two drinks in a single day. A further 9.2% reported having two to three drinks once or twice a month and 8.3% said they had two drinks once or twice a week. Some gender and age specific differences were observed; more males (55.4%) than females (44.6%) reported alcohol consumption, and 42% of those aged 50-64 years did so, compared with 20% of those aged 65 years and over. Of those who consumed alcohol, 75.7% had a mild or moderate level of ID. However, it is not known whether alcohol consumption was a positive personal/ supported choice for people with ID, or whether it was in fact a forced choice with limited opportunities and lack of access. Although overall reported rates of alcohol consumption were low, the circumstances in which alcohol was consumed were not explored and should be addressed in subsequent waves of the study.

4.9.3 Nutritional Health

Nutritional wellbeing plays a key role in optimising the ageing process, and assists in preventing the development of many age-related diseases, such as diabetes and vascular diseases, with potentially life changing consequences for individuals (Vellas, 2009). In this study, participants or proxies were asked to appraise the healthfulness of the individual's overall diet using the global 5-point rating scale of excellent, very good, good, fair and poor. A total of 14% rated their overall diet as excellent, 50% as very good, 30% as good, 4% as fair, while 2% described their diet as poor. Despite the positive appraisal of their overall diet, Body Mass Index (BMI) scores, based on self-reported height and weight data ($n=584$), revealed that 31% of participants scored in the obese category, 30% fell into the overweight category, while 37% and 2% respectively, were in the normal and underweight category. Compared to the general population, these estimates are not starkly different, with three quarters of older Irish adults overweight (44%) or obese (34%) (Cronin *et al.*, 2011). However, a difference in gender was noted between the population groups in the obese category, with higher rates of obesity seen in women with intellectual disability compared to TILDA, which seen higher rates of men in this BMI category (Cronin *et al.*, 2011), and warrants further investigation. Within the population group, the finding that women were more likely to be obese than men with ID is in keeping with international research (e.g., Melville *et al.*, 2008; Stedman & Leland, 2010).

The prevalence estimates of body mass and the comparisons made with TILDA need to be interpreted with caution, as the figures reported by TILDA are based on objective measurements, so the prevalence of overweight and obesity may be higher in older adults with ID, if objective measurements were also taken. The collection of similar objective measurements to TILDA will be an important consideration in future waves of this study. Other nutritional related topics discussed in the interview included the perception of weight status; prevalence of special diets and types; unintentional weight loss or gain in the last three months; daily food intake routine; and the frequency of consumption of the main food groups. An analysis of these topics along with a more in-depth review of body mass across all the relevant variables, such as, the demographics and physical health parameters of this population, and any differences between self and proxy responses, will be completed and available in later publications.

4.9.4 Activity levels

There is evidence that people with ID seldom engage in regular physical exercise and that they are a population that has high levels of obesity and mental health problems (Emerson, 2005; Haveman *et al.*, 2009). Haveman *et al.* (2011) recently reported that more than 50% of the populations they studied engaged in no or few physical activities, with the remainder engaged in only light activities for approximately four hours per week. In this study, respondents were asked to record how often they took part in activities of a vigorous, mild or moderate nature. Vigorous activity was defined as one that lasts for 10-20 minutes, and which causes heavy sweating or a large increase in breathing or heart rate; examples include activities like running, cycling,

tennis, or swimming. Moderate activity was defined as an activity that lasts for 10-20 minutes, and which causes light sweating or a moderate increase in breathing or heart rate; examples here included walking at a moderate pace, dancing, swimming or cycling. Mild activity was defined as an activity that lasts for 10-20 minutes, causing minimal or no sweating or a mild increase in breathing or heart rate; examples included bowls, golf, laundry or home repairs. Overall, 84.5% of Irish adults with an ID reported hardly ever doing vigorous physical activity, and those who did engage, tended to be men in the younger age groups (40-49 years). This is a different picture to that reported for the general population where one third (34%) reported having engaged in vigorous physical activity.

Almost half of the population with ID (46%) reported having engaged in physical activity of a moderate nature and the majority (80%) reported engaging in mild physical activities once a week or more. However, 16% reported hardly ever engaging in physical activity of even a mild nature, with a further 3.2% reporting engagement in mild physical activity only one to three times per month. By contrast, in the general population, two thirds of the population 66% reported having engaged in physical activity of a moderate nature (Cronin *et al.*, 2011).

For people with ID, overall level of activity appeared to decrease with age, going from 35.5% among those aged 40-49 years, to 28.9% among those aged 50-64 years, to 17.2% of those aged 65 and over. Men in the older age groups were more regularly engaged in moderate physical activity than women; 28.3% of men aged 50-64 years and 20.7% in those aged 65 years regularly engaged, versus 24.1% and 14.5% of women in the same age cohorts. Regardless of age, level of physical activity also appeared related to level of pre-existing intellectual impairment; those in the mild to moderate range of ID were twice as likely to engage regularly in physical activity of a moderate nature (33%) compared to those with severe to profound ID (16%). Mobility problems and lack of stamina may provide some explanations for low participation but low numbers engaged in vigorous physical activity even in the younger aged group poses some concerns. Then again, 66% of the general Irish population was also reported to not engage in vigorous physical activities necessary to accrue health benefits; for both populations, the factors involved require further investigation.

Respondents were also asked what difficulties might stop them from doing physical activities; interestingly, 32.1% reported having no difficulties with one fifth instead reporting that they did not like exercise. A further 37.3% reported health considerations, 8.4% reported that they required assistance and that it was not available and 11.3% identified being in a wheelchair as a difficulty. The following factors were generally not reported as barriers here: lack of money, being self-conscious, service facilities not being accessible, not being allowed to go, lack of transport, and negative or unfriendly attitudes.

4.9.5 Mobility limitations

Due to pre-existing intellectual impairment, people with ID often have mobility problems, and these are likely to increase as they age. Respondents in this study were asked to rate the level of difficulty they had with walking across a room, walking 100 yards, and running or jogging 1.5 kilometres. The level of difficulty was rated using a four point Likert scale ranging from no difficulty, some difficulty, a lot of difficulty and cannot do it at all. Data was also captured on the use of aids and appliances to assist with mobility.

A proportion of adults with ID reported experiencing difficulty with mobility: 8.3% could not walk at all, 3.5% experienced a lot of difficulty, with a further 6.1% reporting that they experienced some difficulty. Difficulty with walking appeared to increase with age, with 9.5% those aged 40-49 years experiencing significant difficulties or not being able to walk at all; this rose to 11.4% of those aged 50-64 years and 16.5% of those aged 65 years and older. Among those who experienced difficulty, 55.1% used some form of equipment or device, the most common being a wheelchair (73.6%) with a further 35.5% reporting use of a walking frame. Regarding running or jogging 1.5 meters, 83.1% reported a lot of difficulty or that they could not do it at all, 5.2% reported having some difficulty and 11.3% reported that they had no difficulty. Again, experience of difficulty increased with age, with 77% of those aged 40-49 years experiencing a lot of difficulty or not being able to do at all; this rose to 84.5% of those aged 50-64 years and 92.2% of those aged 65 years and over.

4.9.6 Oral health

The oral health status of adults with an ID is an area of increasing concern, with periodontal disease among the top ten secondary conditions which has a negative impact on the quality of life for people with ID (Traci *et al.*, 2002). Moreover, some studies reported a higher rate of missing and decayed teeth among people with ID compared to the general population (Skymana *et al.*, 2001). In this study, people were asked a number of questions in relation to oral health status, oral hygiene practices and dental health screening. Overall, 64.4% of adults with ID reported that they had their own teeth, with some missing but no dentures. A further 19% reported having dentures (either full or some). Almost all respondents (93.1%) reported brushing their teeth (independently or with assistance) at least once per day and visits to the dentist appeared to be regular, with 72.4% having visited their dentist within the past year, 14.2% having visited within the last one to two years, 11.7% reporting it was more than two years, and 1.8% never having visited.

Of concern was the large number of older adults with ID (16.5%) that reported having no teeth or dentures; this comprised 8.8% of those aged 40-49 years; 16.3% of those aged 50-64 years, and 33% of those aged 65 and over. People with severe to profound levels of ID were also more than twice as likely to have had their teeth removed and not wear dentures than those with mild to moderate levels of ID (27.2% versus 12.5% respectively). This may reflect older approaches to dental care.

Given current regular attendance to dental care and services reported here, it will be interesting to follow this over time, to see if patterns change and translate into better oral health and more active interventions, such as restorations for dental problems rather than tooth extractions.

4.9.7 Foot health

The majority of adults with ID were happy with their foot health with 14.1% reporting it was excellent and a further 33.1% and 37.6% reporting their foot health was very good and good, respectively. Reports of poor foot health varied by age: 14.3% of those aged 40-49 years reported their foot health as being fair to poor, as did 14.8% of those aged 50-64 years and 18.4% of those aged 65 years and older. Of those who reported experiencing foot pain, mainly associated with bunions, corns and the build-up of callus, 16.5% reported that this pain limited their walking quite a bit or extremely. Many of these foot conditions reported by adults with ID were amenable to treatment but were not always treated; failure to recognise and treat these problems will have a negative impact on the quality of life for people with ID as they age.

4.10 Medication, supplement use and polypharmacy

Safe and effective pharmacotherapy is a major challenge for older adults. Elderly patients often suffer from several chronic disorders and consequently use more medicines than any other age group. The diminished physiological reserve associated with ageing can be further depleted by effects of medicines and acute or chronic disease states (Jackson, 2009).

The presence of multiple and long-standing chronic conditions is likely to encourage the use of multiple medications; this also raises concerns about the monitoring of their use and associated interactions and side effects. This is a particular concern for people with ID given reduced ability to notice and report side effects. The term 'polypharmacy' is generally used to refer to the concurrent use of multiple medications (prescription and non-prescription) by a patient. Consistent with the approach taken by TILDA (Cronin *et al.*, 2011), it is defined here as using five or more medicines and supplements.

Information on medications (prescription and non-prescription) taken on a regular basis (every day or every week) were recorded on the pre-interview questionnaire. They were then crosschecked by the interviewer at the time of the interview. Such verification, based on an in-home inventory of medication obtained by direct observation, is reported to be more reliable than self-report recall methods (Qato *et al.*, 2009).

Nine out of 10 participants (91%) were taking at least one (prescription or non-prescription), medicine, compared with seven out of 10 (72%) reported by TILDA (Cronin *et al.*, 2011) for the general population. Approximately four out of 10 (39%) took at least one dietary supplement; as found in TILDA (Cronin *et al.*, 2011), medication usage did increase with age but it was much higher in persons with ID at a younger age.

The number of medications taken was, on average, higher for the IDS-TILDA sample than the general Irish population. However, it was found that for people with ID there was minimal use of non-prescription/OTC medications (they too tended to be covered by prescriptions). This would suggest that a more complete listing of all medications resulted for this group.

Six out of 10 (61%) IDS-TILDA participants were not taking any dietary supplements (vitamins, mineral preparations or medical food) but were using on average 4.6 medications. For those taking dietary supplements, the average number of medications was 7.77, or 9.24 when the supplements were included. Supplement use among people with ID appeared to correlate with higher medicine use and supplement users were also generally older than non-supplement users. For four out of 10 participants, laxatives were used; this was consistent with the reported high levels of constipation.

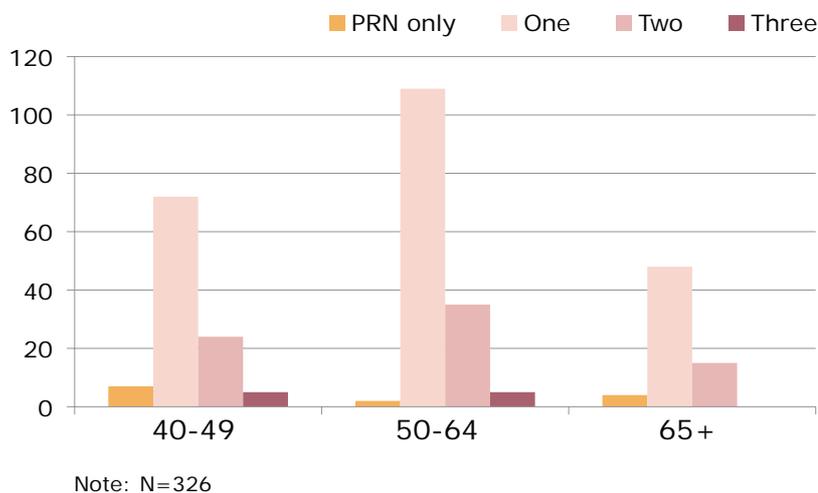
Polypharmacy was observed in 445 participants or in 59.1% of the sample, almost three times the level (21%) found for the general Irish population (Cronin *et al.*, 2011). Level of polypharmacy also appeared to increase with age; from 50.4% of those aged 40-49 to 57.8% among the 50-64 age group and to 80.6% among those 65 years and older. Polypharmacy was identified for 24% of those living independently or with family, 51.5% of those living in the community and 77.8% of those living in residential centres. Polypharmacy was also highest (81%) among individuals with a diagnosis of depression, manic depression, Alzheimer's disease, dementia, organic brain syndrome or senility, serious memory impairment or epilepsy and this population were more likely to be living in residential centres. See Chapter 5 for a further discussion on the mental and cognitive health profile of adults with ID.

There are widespread concerns about the linkage between polypharmacy and increases in falls and mortality and declines in ADLs and IADLs (Jyrkka *et al.*, 2009). However, the data here also links polypharmacy to significant health concerns, suggesting that pharmacotherapy may also play a very important role in health management for people with ID. Further investigation of the risks and benefits of polypharmacy will require a more elaborate approach than simply tracking incidence and prevalence, an approach which will inform the development of medication-related data collections and analyses in subsequent waves of IDS-TILDA.

Looking more specifically at the medications used, antipsychotics and antiepileptic medications, were the most commonly used prescription medicines; this is consistent with findings of higher levels of psychiatric and epilepsy concerns among people with ID. As can be seen in Figure 4.8 and Figure 4.9, 50% used one of these types of medications and 30% used medications from both medication groups.

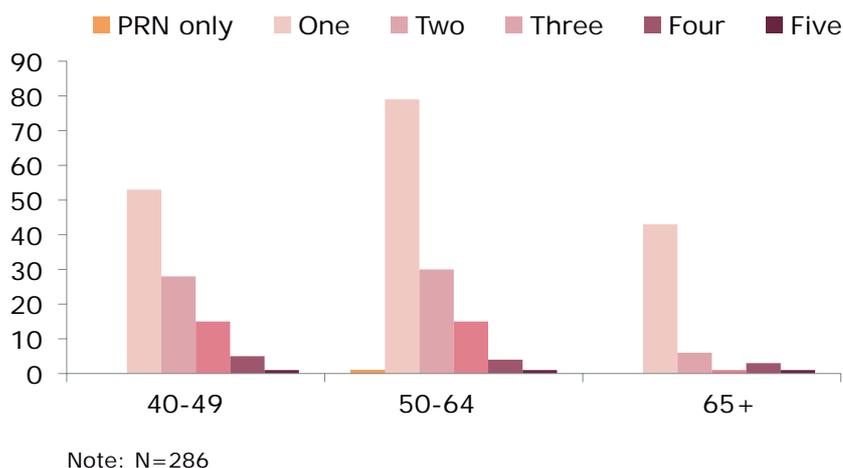
Second generation antipsychotics (AP) were mostly used by all age groups (33-39% of each group), but first generation AP were more likely to be used among those aged 65 years and over. A few APs were used only pro re nata (as needed).

Figure 4.8: Use of antipsychotic medicines across the age groups



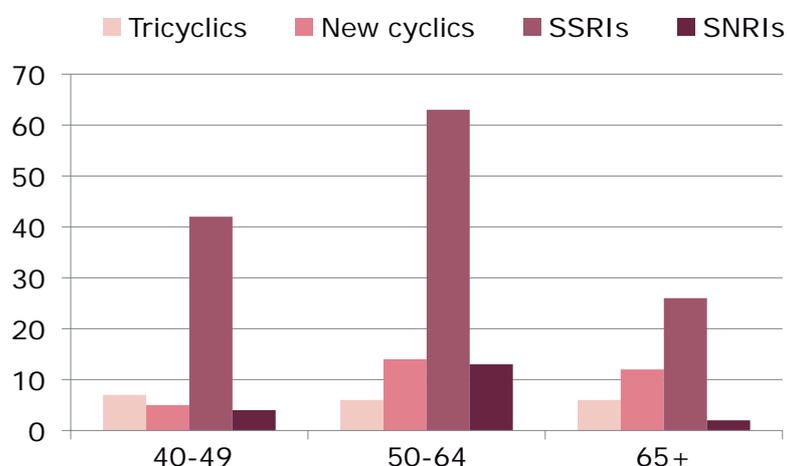
Thirty-eight percent reported using at least one antiepileptic on regular basis (in one case an 'as needed' supplemented a regularly used antiepileptic). As can be seen in Figure 4.9, in this group some participants were using up to five medicines just from this group.

Figure 4.9: Antiepileptic use according to age groups and number of medications



Anxiolytics (which includes benzodiazepines) and antidepressants were another frequently used group of medications. Anxiolytics were used by one out of every four respondents, as were medication in the antidepressant group. However, as can be seen in Figure 4.10, there was higher use in older participants; 32% in oldest group (65+ years), as compared to 26% in the 50-64 group and 21% in the 40-49 years group. Characteristics of used antidepressants are presented in Figure 4.10.

Figure 4.10: Characteristics of used antidepressants



Note: N=191

Antipsychotics, antidepressants and anxiolytics are among those medicines with the highest cognitive impairment side effects. This effect is more powerful when a combination of those medicines is used. Table 4.2 includes the frequencies of combination use found.

Table 4.2: Combined use of antipsychotics, antidepressants and anxiolytics

Age group	All three	Antipsychotics and AD	Antipsychotics and ANX	AD and ANX
40-49	5.5%	13.1%	15.0%	8.0%
50-64	9.0%	19.5%	18.0%	9.0%
65+	5.2%	20.9%	14.9%	9.0%
All	7.0%	17.4%	16.4%	8.6%

Further studies are needed to estimate the anticholinergic and sedative impact on cognitive function for people with ID. Additional research is also required to examine the impact of the levels of use of hypnotics; 20% of persons reported use of at least one hypnotic and 13% reported use of two or more hypnotics concurrently.

4.11 Functional limitations, activities of daily living and instrumental activities of daily living

People with ID require assistance, support and encouragement to attain and maximise their potential. By definition, intellectual disability is characterised by impairment in intellectual functioning and in adaptive behaviour, and these limitations impinge on everyday conceptual, practical and social skills (AAIDD, 2011). People with an ID therefore have a higher need for support and assistance. The need for assistance also appears to increase with age and for the general Irish population. TILDA (Normand *et al.*, 2011) reported that 12% of men and 14% of women over the age of 50 years had at least one disability, leading to increased difficulty with functional limitations, daily activities of living (ADLs) or instrumental activities of daily living (IADLs).

In this study, a series of items addressed levels of difficulty experienced with functional limitations, ADLs and IADLs. Respondents were asked to rate their level of difficulty using the following response options: no difficulty, some difficulty, a lot of difficulty or cannot do at all. In the presentation of these findings below, responses of 'a lot of difficulty' and 'cannot do at all' have been combined into the category of 'a lot of difficulty'. Variations in difficulties experienced are also described with respect to age, gender, level of ID and residential circumstances.

4.11.1 Gender differences

Women with ID reported greater difficulty with functional limitations and ADLs than men, a finding similar to that reported by TILDA (Normand *et al.*, 2011) for the general Irish population. For example, 31% of women with ID reported having a lot of difficulty in carrying a weight in excess of five kilograms, compared to 24.1% of men. A total of 49.8% of women reported having a lot of difficulty in climbing several flights of stairs, compared to 33.1% of men and 24.1% of women reported difficulties with dressing (an ADL) compared with 18.3% of men. However, when examining IADLs, 67.4% of men reported having a lot of difficulty in making a phone call compared with 57.2% of women and 70.4% of men had a lot of difficulty with shopping for groceries, compared to 63.6% of women.

Table 4.3 presents the difficulties experienced in ADLs and IADLs, by gender.

4.11.2 Age, level of ID and living circumstances

Similar to reports for the general population (Normand *et al.*, 2011), adults with ID aged 65 years and over were more likely to have a lot of difficulty with all functional limitations, ADLs and IADLs. For example, 32.4% of those aged 40-49 years reported having a lot of difficulty or could not climb several flights of stairs without resting, and 42.1% of those aged 50-64 years reported similar difficulty. However, level of difficulty was 62.8% among those aged 65 years and over. Similarly, regarding ADLs, 45.1% of those aged 65 years and over had a lot of difficulty in bathing or showering compared to 35.4% of those aged 50-64 years and 34.5% of those aged 40-49 years.

Regardless of age or residential circumstances, adults with ID reported major problems in carrying out IADLs. The vast majority (95%) of those living in residential type centres and 75-79% of those living in community settings reported that they were unable to make a hot meal or manage their money. Additionally, half of those living in the community were unable to make a phone call and one out of every three was unable to shop for groceries or manage household chores. For those living in residential settings, the majority reported that they were unable to do any of these same activities. While those living with family and independently appeared to have fewer difficulties, nonetheless almost half could not manage their money or make a hot meal, and almost one third were unable to shop for groceries or make a phone call.

For all items relating to functional limitation, ADL and IADL, those living in residential centres scored lower than those in any other type of accommodation. To some extent this is explained by the greater prevalence of severe and profound ID and chronic illness in this group, as well as higher levels of functional limitation; all of these are likely to lead to greater difficulty in ADLs and IADLs. While for some people, the difficulty can be attributed to pre-existing level of intellectual impairment, for others, regardless of setting, it is more often associated with lack of opportunity and barriers in the living environment. This is evident from the following quotes by study respondents: '*nobody ever taught me how to cook*'; '*it is policy that clients are not allowed near the cooker or kettle*'. A support worker, when asked to identify the main obstacles reported, stated, '*the ID and education also until recently they would not have had access to money*'.

In the general population, declines in ability regarding IADLs and ADLs often suggest increased frailty (Vermeulen *et al.*, 2011). However, the relationship between ADL difficulty and frailty is more complex among people with ID. Many have experienced a life-long inability to complete such activities. Others have not had the opportunity to do so; in some cases, this is caused by an unwillingness among families and/or services providers to take the risks associated with challenging people with ID to assume greater responsibility, particularly the completion of IADLs. Providing adults with ID with the opportunity to develop independence and to take risks is both critical and possible. Knowledge brings skills, skills bring confidence.

More people with ID within residential centres in Ireland are likely to move to community settings in the future (HSE, 2011). In light of this, future waves of data collection, recognising that will bring an opportunity to follow the impact of this development on functional ability, ADL and IADL difficulty, particularly as ageing increases challenges in these areas.

Tables 4.2 – 4.10 provide a summary of the Functional Limitations, ADLs and IADLs findings.

Table 4.3: Overall difficulty in ADLs and IADLs by gender

ADLs & IADLs	Male					Female				
	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	n	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	n
	%	%	%	%		%	%	%	%	
Walking 100 Yards	74.0	10.7	8.1	7.2	335	69.6	11.1	5.8	13.5	415
Run/Jog a mile	15.8	5.7	8.3	70.5	315	7.9	5.4	7.9	78.8	391
Sit for about 2 hours	87.5	6.3	3.9	2.4	336	85.1	7.7	4.3	2.9	415
Getting up after sitting for a long period	74.5	15.9	5.4	4.2	333	66.8	17.1	6.1	9.3	407
Climbing several flights of stair without resting	53.0	13.9	6.9	26.2	317	35.7	14.6	10.1	39.7	378
Climb one flight of stairs without resting	69.2	7.0	3.4	20.4	328	51.6	11.2	6.9	27.5	393
Stooping or kneeling	71.1	12.2	3.3	13.4	329	60.9	12.4	7.4	19.3	404
Reaching or extending arms	88.0	6.9	3.3	1.8	332	87.2	7.1	2.7	3.0	406
Pushing or pulling large object	83.1	3.1	3.7	10.1	326	74.0	5.4	3.7	16.8	404
Lifting or carrying weight >5kg	68.1	7.8	5.0	19.1	320	57.6	11.4	2.5	28.5	396
Picking up a small coin	85.3	7.2	2.4	5.1	334	86.7	5.7	1.0	6.7	406
Dressing	57.9	23.9	8.4	9.9	335	55.3	20.6	7.9	16.2	407
Walking across a room	84.2	8.1	3.0	4.8	336	80.6	4.6	3.6	11.2	412
Bathing/Showering	33.1	29.6	17.0	20.3	335	32.0	31.5	12.1	24.4	406
Cleaning teeth/dentures	56.8	15.9	6.6	20.7	333	54.5	12.7	7.8	24.9	409
Eating	62.3	24.0	6.9	6.9	334	53.7	26.5	9.3	10.5	405
Getting in & out of bed	86.6	4.5	3.6	5.4	335	78.0	7.3	3.7	11.0	401
Using toilet & getting up and down	82.3	7.2	3.3	7.2	334	77.5	6.7	3.0	12.8	399
Preparing a hot meal	7.6	12.1	10.3	70.0	330	10.7	14.2	11.5	63.6	400
Shopping for groceries	14.7	15.0	19.6	50.8	327	17.3	19.0	15.0	48.6	401
Making phone calls	21.1	11.5	11.5	55.9	322	27.6	15.3	10.8	46.4	406
Managing money	4.8	11.8	7.9	75.5	330	7.8	12.5	10.5	69.3	400
Doing Household chores	28.0	21.0	16.4	34.7	329	35.4	16.5	14.7	33.4	401

Table 4.4: Functional Limitations according to age category

Functional Limitations	Age Range											
	40-49				50-64				65+			
	No difficulty	Some difficulty	A lot/ cannot do at all	n	No difficulty	Some difficulty	A lot/ cannot do at all	n	No difficulty	Some difficulty	A lot/ cannot do at all	n
Walking 100 yards	76.9	8.4	14.7	273	70.3	11.9	17.7	344	63.9	13.5	22.5	133
Run/jog one mile	15.2	7.8	77.0	256	9.9	5.6	84.5	323	7.1	0.8	86.1	127
Sit for about 2 hours	85.3	7.3	7.3	273	87.5	6.1	6.4	344	84.3	9.0	6.7	134
Getting up after sitting for a long period	75.5	15.2	9.2	269	68.9	17.5	13.6	338	63.2	18.8	18.0	133
Climbing several flights of stairs	52.3	15.2	32.4	256	42.1	15.7	42.1	318	28.9	8.3	62.8	121
Climbing one flight of stairs without resting	69.8	7.1	23.1	268	60.4	10.4	29.3	328	44.8	11.2	44.0	125
Stooping, kneeling or crouching	72.1	10.9	17.0	265	65.9	11.3	22.8	337	51.1	17.6	31.3	131
Reaching or extending arms	90.3	5.6	4.1	268	87.6	6.8	5.7	338	81.8	10.6	7.6	132
Pulling or pushing large object	82.2	3.0	14.9	269	78.3	3.9	17.8	332	69.0	8.5	22.5	129
Lifting or carrying weight >5kg	70.1	8.3	21.6	264	61.0	11.1	27.9	323	49.6	9.3	41.1	129
Picking up small coin	86.5	6.0	7.5	267	84.7	6.8	8.6	340	88.7	6.0	5.3	133

Table 4.5: Level of difficulty with Activities of Daily Living according to age category

ADLS	Age Range											
	40-49				50-64				65+			
	No difficulty %	Some difficulty %	A lot/ cannot do at all %	n	No difficulty %	Some difficulty %	A lot/ cannot do at all %	n	No difficulty %	Some difficulty %	A lot/ cannot do at all %	n
Dressing including shoes and socks	57.6	21.2	21.2	229	58.8	20.3	20.8	340	48.1	28.6	23.3	133
Walking across a room	85.3	5.1	9.5	272	83	5.6	11.4	342	73.7	9.8	16.5	133
Bathing or showering	36.1	29.4	34.5	269	35.7	28.9	35.4	339	17.3	37.6	45.1	133
Cleaning your teeth/ dentures	55.9	13.7	30.3	270	57.9	13.5	28.5	340	48.5	16.7	34.8	132
Eating/cutting up your food	57.2	15.6	15.6	238	60.4	23.2	16.4	341	50.8	27.3	22.0	132
Getting in and out of bed	87.4	3.3	9.3	269	80.4	7	12.6	341	74.6	9.0	16.4	134
Using the toilet including getting up and down	82.1	6.7	11.2	248	80.5	7.1	12.5	338	72.9	6.8	20.3	133

Table 4.6: Level of difficulty with Instrumental Activities of Daily Living (IADLs) according to age category

IADLs	Age Range											
	40-49				50-64				65+			
	No difficulty	Some difficulty	A lot/ cannot do at all	n	No difficulty	Some difficulty	A lot/ cannot do at all	n	No difficulty	Some difficulty	A lot/ cannot do at all	n
Making a hot meal	10.5	13.9	73.7	267	10.1	15.8	74.1	336	4.7	5.5	89.8	128
Shopping for Groceries	16.5	18.0	65.6	271	19.1	18.2	63.8	330	7.8	13.2	79.0	129
Making a phone call	26.2	15.0	58.9	260	28.4	14.1	57.5	334	11.8	9.4	78.8	127
Managing money	6.4	12.5	81.1	265	7.2	14.7	78.2	334	4.6	5.3	90.1	131
Household chores	34.7	15.5	49.8	265	34.1	21.1	44.8	337	21.1	18.0	60.9	128

Table 4.7: Functional Limitations according to living circumstances

Functional Limitations	Living Circumstances											
	Independent/Family				Community Group Home				Residential Centre			
	No difficulty	Some difficulty	A lot/ cannot do at all	n	No difficulty	Some difficulty	A lot/ cannot do at all	n	No difficulty	Some difficulty	A lot/ cannot do at all	n
Walking 100 yards	86.0	7.8	6.2	129	84.2	9.8	6.1	266	56.7	12.9	30.4	356
Run/jog one mile	16.8	14.3	68.9	119	13.7	5.6	80.7	249	7.7	2.4	89.9	339
Sit for about 2 hours	92.2	5.4	2.4	129	86.5	9.0	4.5	262	83.7	6.2	10.1	356
Getting up after sitting for a long period	77.8	17.5	4.8	126	81.7	14.5	3.8	247	58.9	18.7	22.3	353
Climbing several flights of stairs	66.1	12.1	21.8	124	51.0	17.4	31.6	247	29.2	12.6	58.2	325
Climbing one flight of stairs without resting	82.5	4.0	13.5	127	73.4	12.0	14.6	259	43.6	9.2	47.1	337
Stooping, kneeling or crouching	78.7	11.0	10.2	127	76.5	12.7	10.7	260	52.2	12.7	35.1	347
Reaching or extending arms	92.9	3.9	3.2	127	92.7	5.7	1.6	262	81.4	9.4	9.1	350
Pulling or pushing large object	86.6	5.5	7.8	127	85.5	4.2	10.3	262	69.0	4.1	26.9	342
Lifting or carrying weight >5kg	80.2	8.7	11.1	126	72.3	10.7	17.0	253	47.9	9.5	42.6	338
Picking up small coin	95.3	0.8	4.0	127	93.2	5.3	1.6	264	77.4	9.1	13.4	350

Table 4.8: Level of difficulty with Activities of Daily Living according to living circumstances

ADLS	Living Circumstances											
	Independent/Family				Community Group Home				Residential Centre			
	No difficulty %	Some difficulty %	A lot/ cannot do at all %	n	No difficulty %	Some difficulty %	A lot/ cannot do at all %	n	No difficulty %	Some difficulty %	A lot/ cannot do at all %	n
Dressing including shoes and socks	83.5	9.4	7.0	127	75.8	15.8	8.5	260	32.6	31.2	36.3	356
Walking across a room	93.0	3.1	3.9	128	93.6	3.4	3.0	267	69.4	9.3	21.3	353
Bathing or showering	74.2	14.1	11.8	128	41.7	37.1	21.3	259	10.7	31.8	57.5	355
Cleaning your teeth/dentures	86.7	7.0	6.2	128	70.6	14.0	15.5	265	32.6	16.9	50.6	350
Eating/cutting up your food	83.6	10.9	5.4	128	69.7	20.1	10.2	264	38.7	34.5	26.8	351
Getting in and out of bed	95.3	1.6	3.2	127	91.6	5.7	2.6	262	69.7	7.9	22.5	356
Using the toilet including getting up and down	94.5	3.1	2.4	127	93.1	3.5	3.4	260	64.3	10.8	25.0	353

Table 4.9: Level of difficulty with Instrumental Activities of Daily Living (IADLs) according to living circumstances

IADLs	Living Circumstances											
	Independent/Family			Community Group Home			Residential Centre					
	No difficulty %	Some difficulty %	A lot/ cannot do at all %	No difficulty %	Some difficulty %	A lot/ cannot do at all %	No difficulty %	Some difficulty %	A lot/ cannot do at all %	n	n	
Making a hot meal	31.2	26.4	42.4	8.9	19.1	72.0	1.7	4.3	94.0	125	257	350
Shopping for Groceries	45.2	21.0	33.9	17.9	26.8	55.3	17.9	8.7	87.0	124	257	377
Making a phone call	59.5	11.1	29.3	33.2	17.9	49.6	5.8	11.8	82.4	126	250	346
Managing money	23.8	27.0	49.2	5.5	15.1	79.4	0.9	4.0	95.1	126	254	351
Household chores	63.7	16.9	19.4	41.6	26.5	31.9	13.7	13.1	73.1	124	257	350

Table 4.10: Level of difficulty in FLs, ADLs and IADLs according to level of ID

Functional Limitations, ADLs & IADLs	Mild/Moderate						Severe/Profound					
	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	n		No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	n	
	%	%	%	%		%	%	%	%			
Walking 100 yards	78.5	11.5	5.7	4.3	488	54.1	9.8	9.8	26.3	205		
Run/Jog one mile	14.4	5.9	10.7	69.1	459	4.1	3.1	3.1	89.8	196		
Sit for about 2 hours	89.2	6.7	2.2	1.8	489	79.5	6.3	8.8	5.4	205		
Getting up after sitting for a long period	75.5	17.2	4.8	2.5	482	56.4	17.8	6.4	19.3	202		
Climbing several flights of stairs without resting	49.5	16.3	9.2	25.1	455	25.1	9.8	8.2	56.8	183		
Climb one flight of stairs without resting	69.4	9.2	4.5	16.9	467	39.6	9.1	7.1	44.2	197		
Stooping, kneeling or crouching	71.1	12.7	5.4	10.8	467	49.2	12.3	5.6	32.8	197		
Reaching or extending arms	91.7	6.7	1.5	0.2	481	77.6	8.0	6.5	8.0	195		
Pulling or pushing large object	82.8	4.8	4.0	8.4	477	65.5	3.6	3.0	27.9	197		
Lifting or carrying weight >5kgs	71.9	9.0	3.4	15.8	469	39.1	9.9	3.6	47.4	192		
Picking up small coin	93.6	4.3	1.2	0.8	485	66.3	11.6	2.5	19.5	199		
Dressing including shoes and socks	71.3	18.5	4.6	5.6	480	17.1	31.7	16.6	34.6	205		
Walking across a room	89.3	4.3	2.7	3.7	488	64.9	9.4	4.5	21.3	202		
Bathing/Showering	42.9	33.8	12.9	10.4	480	4.4	22.5	17.6	55.4	204		
Cleaning your teeth/dentures	70.0	16.3	4.3	9.5	486	13.9	10.9	14.4	60.7	201		
Eating	71.3	20.2	5.2	3.3	485	18.0	40.5	16.5	25.0	200		
Getting in & out of bed	88.0	5.8	2.9	3.3	483	64.4	7.3	5.9	22.4	205		
Using the toilet + getting up and down	89.0	5.6	1.9	3.5	480	55.0	9.9	6.9	28.2	202		
Preparing a hot meal	12.4	17.9	13.3	56.4	475	1.0	1.0	2.5	95.5	200		
Shopping for groceries	21.3	23.0	18.5	37.2	470	1.5	3.5	12.6	82.4	199		
Making phone calls	32.7	18.3	13.5	35.5	465	2.5	3.0	4.5	90.0	200		
Managing money	8.0	16.1	12.7	63.2	473	1.0	0.5	1.0	97.5	201		
Doing household chores	42.6	21.3	15.8	20.3	474	7.0	9.0	15.1	68.8	199		

4.12 Conclusion

This chapter presented cross-sectional variations in risk for disease, disease prevalence and health behaviours in people with ID as they age. It also highlights variations in prevalence associated with age, gender, level of ID and living circumstances. Findings on prevalence and patterns of self-rated health and reported disease were compared to those found by TILDA (Cronin *et al.*, 2011) regarding the general Irish population. In addition, specific co-morbid conditions that result in different patterns of ageing in persons with Down syndrome were identified.

The prevalence of disease among people with ID as they age has been investigated previously. However, those studies have tended to be cross-sectional and the samples have been small, geographically anchored in one region or facility and were rarely representative of a range of ID, ages and aetiologies. The sample accumulated here offers an opportunity to more systematically consider these issues and to compare experiences with a general sample (TILDA) gathered at the same time and in the same communities. Many in the IDS-TILDA sample, particularly those in the younger age cohorts, experienced good health but there were significant concerns in terms of cardiac issues (including risk factors), epilepsy, constipation, arthritis, osteoporosis, urinary incontinence, falls, cancer, and thyroid disease. The fact that the risk for these conditions increases with age is also of concern. Younger adults with an ID had a much higher incidence of disease and identifiable risk factors for developing conditions, such as coronary artery disease and stroke, than those in the general population. The high prevalence of falls in the younger age cohorts, compared to the general population, is also of concern. Women with ID had higher risks for many diseases, both when compared to men with ID and to women in the general population. While health checks were high overall, access to screenings for cancers was of concern and access to all screening was lower for people with severe to profound ID. Conversely, screening for cholesterol was high and there appeared to be good access to physicians and dentists.

Despite apparent access to health professionals, one in three adults with an ID reported that they found it difficult to make themselves understood when speaking with health professionals. When so much care in chronic illness in later life is dependent upon communication with health professionals, such a perceived lack of success in communication is of concern. Difficulties in communication also raise concerns about the high levels of medication use. Nine out of 10 participants (91%) reported taking at least one (prescription or non-prescription) medication and over 59% reported taking five or more medications. This means an increased potential for drug interactions and a higher need for monitoring side effects and medication effectiveness and usefulness. However, the ability of people to self-report concerns or to have their concerns heard is diminished for people with ID. The need to review medication use, relate it to diseases to be treated and to monitor medication use against evidence-based best practices becomes more critical. Additional gathering and analysis of data in subsequent waves of IDS-TILDA has the potential to greatly assist such reviews.

The high levels of physical inactivity, and the high level of obesity and proportion of people who were overweight, suggest that people with ID and their carers need to be more aware of the health risks associated with obesity and lack of physical exercise. The surveillance of nutritional health longitudinally may also improve our understanding of the prevalence and distribution of underweight, overweight and obesity in Irish adults with intellectual disability as they age and its impact on health. Regardless, the findings in all of these areas highlight that people with ID need to be better included in all health promotion activities targeted at the general population.

It will be of interest, in further waves of data collection, to identify factors that pre-dispose and protect people with an ID from particular conditions. It will also be important to explore how well screenings, treatments, exercise, nutrition and physician/dentist access prevent and manage conditions, as well as the impact of disease conditions on the quality of life and longevity of people with ID. The low levels identified of people with an ID being able to complete ADL and IADL tasks without difficulty add to these concerns. When half of those living in the community were unable to make a phone call and one out of three was unable to shop for groceries or manage household chores and the majority of those living in residential settings were unable to do any of these same activities, the associated sedentary lifestyles and dependence on others for support increase the challenges for quality of life and longevity of people with ID. Additional waves of data collection will hopefully help to better explain the challenges and monitor the extent to which increased placement in the community improves independence and reduces difficulty and monitor the impact of such challenges over time.

The prevalence figures reported here for hypertension, osteoporosis and arthritis among people with ID need to be considered with great caution. This is because TILDA (Cronin *et al.*, 2011) found marked differences in the general Irish population between respondent reported and objectively measured rates of these conditions. Such apparent evidence of general under-reporting and differences in findings reported here for people with ID both support continued following of this issue. They also support the addition of objective measures in subsequent waves of IDS-TILDA.

The first wave of data collection, the results of which are reported here, are essentially cross-sectional. While it is therefore possible to draw some associations between different domains, it would be incorrect and inappropriate to draw conclusions regarding causality. The exploration of causal associations will be facilitated by considering this first wave baseline of data against future waves of this study, and by the tracking over time of incidence of disease as opposed to prevalence. For the first time, this will offer insights into the key determinants of health and wellbeing for people with an ID in Ireland. Indeed, such findings would also have international implications.

5

Mental Health and Cognitive Function of Older Irish Adults with an Intellectual Disability

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5

Mental Health and Cognitive Function of Older Irish Adults with an Intellectual Disability

5.1 Key findings

- The prevalence of mental health and emotional problems is greater among persons with an intellectual disability (ID) than in the general population.
- In total, 47.5% of Irish adults with an ID aged 40 and over reported that a doctor had told them that they had an emotional, nervous or psychiatric condition.
- Almost one fifth (18.5%) of Irish adults with an ID reported that they had previously received a diagnosis of depression; this was considerably higher than the 5% reported in the general population.
- Over one fifth (21.1%) of people with an ID living independently or with family reported an emotional or mental health problem. This prevalence increases to 45.1% for those living in a community group home and 58.9% for those in a residential centre.
- Among those who self-reported, over 11% had measured case-level depressive symptoms, similar to the 10% reported for the general population. An additional 27.1% reported a sub-threshold level of depressive symptoms.
- 34.6% of those reporting a high level of depressive symptomatology have received a doctor's diagnosis of depression.
- Those who also reported feeling lonely were more likely to have a doctor's diagnosis of depression and to show a higher level of depressive symptom burden.
- Self-reported symptoms of depression were more prevalent among females, and among those who were older.
- Over one quarter (26%) of individuals with visual impairment reported case-levels of depressive symptoms and an additional 8.2% reported sub-threshold burden.
- Of those that reported a mental health diagnosis, 90.5% were in receipt of psychiatric support.
- Individuals with Down syndrome (24.1%) were less likely to report that they had an emotional or mental health disorder, other than dementia, compared with those with an ID from other causes (53.3%).
- Similar to reports for the general Irish population, nearly 90% of participants had a positive view of their mental and emotional health.

- Memory impairment was reported by 15.8% of respondents with Down syndrome; this is considerably higher than the 3.6% prevalence reported for individuals with an ID from other causes.

5.2 Introduction

Mental health is a state of wellbeing in which every individual realises their own potential, enabling them to cope with the normal stresses of life, work productively and contribute to their community (WHO, 2007). Rates of psychopathology are considerably higher in individuals with an intellectual disability (ID) compared to the general population (Fletcher *et al.*, 2007); a constellation of associated and risk factors including genetics, preceding life events and level of disability have been reported to be possible reasons for the noted higher prevalence. Other issues which further complicate our understanding of mental health within this population include:

- Standard assessment measures are challenging to implement with people with an ID and often staff have not been trained in appropriate interview techniques or to differentiate characteristics of the underlying ID from potential mental health symptoms (Hurley, 2008);
- Individuals with Down syndrome have a lower incidence of mental health problems overall, however, they are at particular risk of developing dementia as they age (Tyrrell *et al.*, 2001; Coppus *et al.*, 2006; Mantry *et al.*, 2008);
- Despite the increasing life expectancy of people with an ID few studies have investigated the role of ageing in the incidence of mental ill-health (Torr and Davis, 2007).

Similarly, persons with ID are at least at the same risk of dementia symptoms as they grow older as the general population with the risk higher for people with Down syndrome. This reality is seriously challenging the ID service system placing demands for increased services, questioning programming philosophies and risking reversals of achievements in moving people with ID into community settings (McCallion and McCarron, 2004). Many services are unprepared to address dementia care concerns and front line staff/family are often unable to recognise dementia type changes. There is a lack of staff training in dementia care approaches, and lack of skills and competence both in ID and general services in dementia assessment and diagnosis in persons with an ID is an increasing challenge.

Assessment of cognitive symptoms has been a critical concern; assessment instruments used with the general population are rarely effective when there is an intellectual disability (Aylward *et al.*, 1997) and the absence of treatment alternatives and the potential for diagnosis to result in transfer to other placements is seen as discouraging rigorous assessment (Janicki *et al.*, 2002). Yet the development of appropriate assessments and of support and services requires that the onset of cognitive concerns as persons with ID age be systematically considered as well as the extent to which services and health systems are becoming more responsive.

This chapter presents the prevalence of mental health and cognitive problems in people with an ID in three age cohorts, as well as variations in prevalence associated with age, gender, level of ID and living circumstances. Several useful comparisons are also provided with the reported prevalence and patterns of mental health problems found by TILDA (2011) in the general Irish population.

5.3 Mental health issues in adults with ID

A more comprehensive understanding of the influence of ageing on mental illness in those with an ID is required. This would include further elucidation of the factors influencing prevalence in an ageing population and the relationship of risk and environmental factors to the onset of symptoms. Such research is necessary to better inform policy and to increase the provision of appropriate services that are sensitive to the special issues and profiles of those in need.

5.4 Mental health measures

5.4.1 Reported diagnosis

Respondents were asked if they had been told by their doctor that they had an emotional, nervous or psychiatric condition. A number of possible diagnoses were offered and the respondent was asked to indicate any and all that applied. If they had received treatment, respondents were also asked to specify the type of professional that provided their care.

5.4.2 Self/proxy rated emotional and mental health

Respondents and/or their carers were asked to rate their perception of the respondent's mental and emotional health on a five point scale with measures ranging from excellent to poor.

5.4.3 The Center for Epidemiological Studies Depression Scale (CES-D)

The CES-D is a self-report scale specifically devised for assessing depressive symptomatology in epidemiological studies (Radloff, 1977). The scale consists of 20 items with four answer options; this facilitates its use by lay interviewers and makes it acceptable to respondents. Items are scored from zero to three. Four of the statements are positively framed, in which case the scoring approach is reversed. The maximum score is 60. Over the past few decades its use has been widely reported and the scale has been validated in many different populations. However, despite this widespread use, the instrument has rarely been applied to people with an ID (Maiano, 2011). The CES-D was administered using CAPI and a cut off score (≥ 16) was applied to indicate that the individual had a significant level of depressive

symptomatology. Similar to TILDA (2011), sub-threshold scores of 8-15 were also reported, and in this way those who may have functional impairment even with a low level of discrete depressive symptoms were identified. Given the potential comprehension difficulties in this population, a score was considered valid if the scale was completed entirely. For 61 respondents, one or two items were incomplete. Here, personal mean scores were imputed (Bono *et al.*, 2007) for the missing items which helped increase the number of included respondents to 225. The data reported are the same as those for the generic TILDA study; this allows for direct comparison between the groups (O'Regan *et al.*, 2011). The CES-D instrument was completed when the survey respondent was able to self-report and demonstrated an ability to comprehend the statements.

5.4.4 Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD)

If an individual was unable to complete the CES-D, the Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD) Checklist questionnaire (Moss *et al.*, 1998) was completed by a supporting carer or relative. Ongoing work by IDS-TILDA aims to reach an understanding of the presentation of mental ill-health among those with ID who are unable to self-report. This will be explored further in subsequent waves of IDS-TILDA.

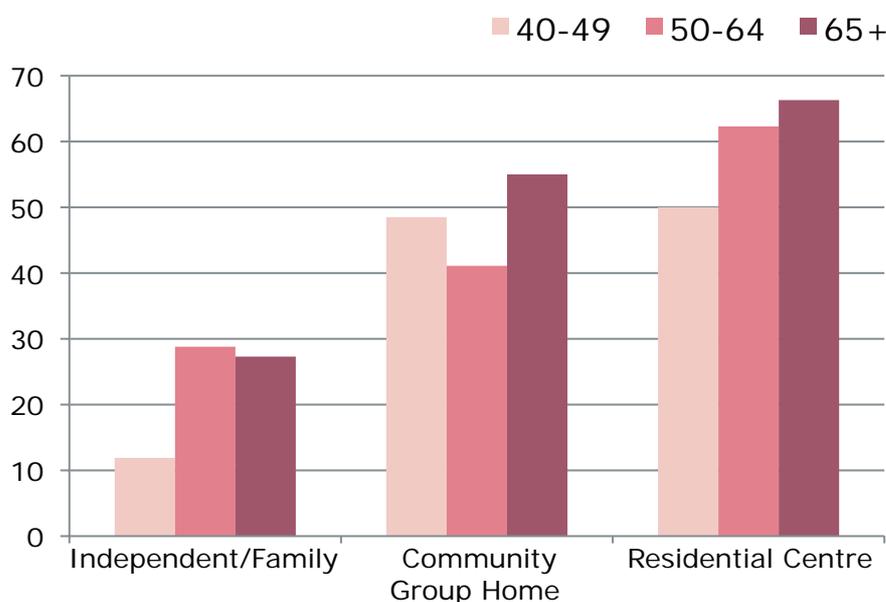
5.5 Prevalence of mental health problems

The prevalence of mental health problems among respondents was high, with 47.5% ($n=355$) reporting that a doctor had told them that they had an emotional, nervous or psychiatric condition (see Figure 5.1). This figure is comparable to, if somewhat higher than, that reported in other prevalence studies within the field of ID. For example, Cooper *et al.* (2007) reported a point prevalence of 40.9% in a UK study and there have been similar findings reported in Australia (31.7%) (Morgan *et al.*, 2008) and Canada (31-44%) (Bielska, 2009). Of note, only 5% of respondents in TILDA (2011) reported a diagnosis of depression, a figure considerably less than the 18.5% reported by respondents to IDS-TILDA.

Mental health problems were more common in females, at 49%, than in males, at 45%. Ageing also appeared to be associated with increased reporting of such problems; 40.8% of those aged 40-49, 48.1% of those aged 50-64 years and 59.7% of those aged 65 years and over reported mental health problems. People with a mild to moderate level of ID reported less emotional or psychiatric conditions (46%) than those with a severe to profound ID (53.7%). As can be seen in Figure 5.1, people living in residential settings were twice as likely to report a mental health diagnosis as those living independently or with family.

Adults with ID in the younger age group of 40-49 years who were living in community settings reported similar levels of mental health problems to those living in residential centres at 48.5% and 49.1% respectively. However, in the older age groups there was a strong association with mental health problems and residential circumstances with a stepwise increase with age. In the 50-64 year old age group, 62.3% of those living in residential centres had a mental health problem, versus 39.5% of those living in the community. This increased to 66.3 % and 55 % respectively among those age 65 years and over.

Figure 5.1: Prevalence of reported mental health diagnosis by age and living circumstances



Note: N=750; Missing Obs = 3

Of note, and consistent with the literature (Coppus, 2006; Mantry *et al.*, 2008), persons with Down syndrome were less likely to report a diagnosis of emotional or mental health disorder (24.1%) when compared to adults with an ID from other aetiologies (53.3%).

Among those who stated that they had been diagnosed with a mental health problem, 90.5% ($n=325$) reported that they were receiving psychiatric treatment. This treatment was provided by a psychiatrist (96.3%), GP (29.6%) or other person such as a nurse (3.1%). Over half of those with a diagnosis were receiving psychological treatment (55%) from a psychologist, counsellor or nurse specialist.

5.5.1 Self/proxy rated emotional or mental health

Respondents and/or their carers were asked to rate their perception of the respondent’s emotional or mental health on a five point scale ranging from excellent to poor. Of the 733 individuals who responded, 139 entirely self-reported, 262 had proxy only ratings and the remainder ($n=332$) self-reported with some support. Despite the relatively high levels of reported mental health problems, the majority rated their overall mental health favourably (see Figure 5.2).

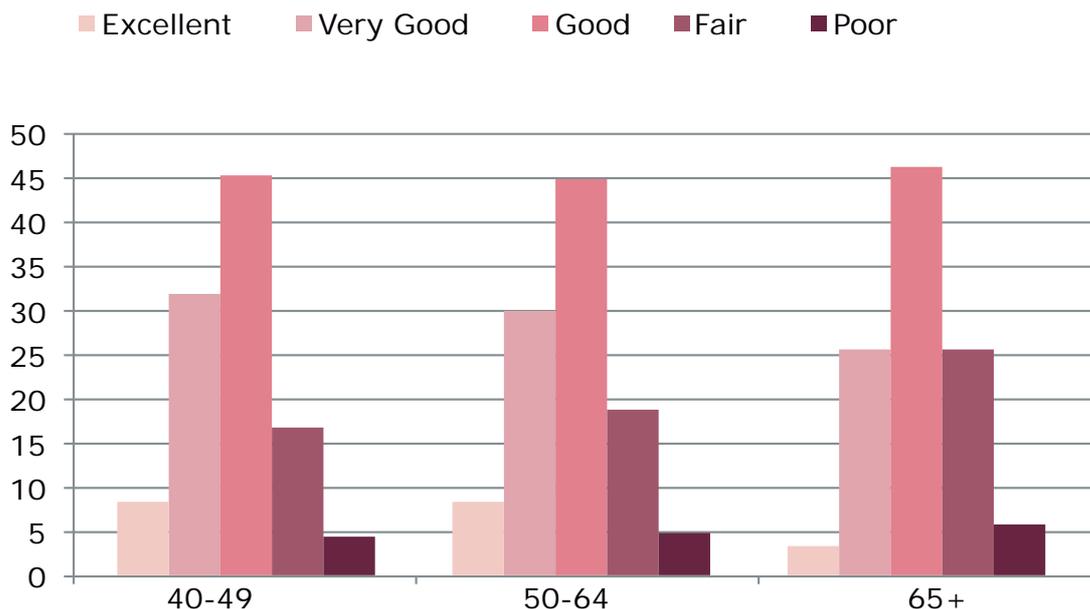
Those participants who self-reported were more likely to rate their emotional or mental health as excellent, very good or good than those who had proxy only replies, at 89.2% and 68.3% respectively. Interestingly, TILDA (2011) reported that 90% of the generic population also rated their emotional health favourably.

Figure 5.2: Self and proxy rated mental health



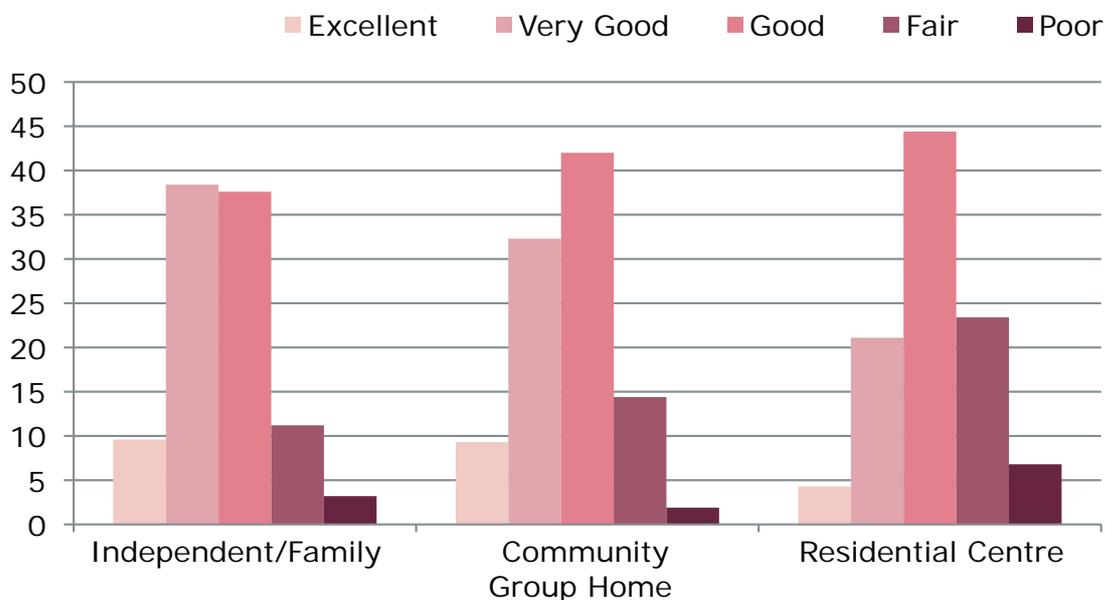
Level of ID appeared to have little influence on the rated emotional or mental health. In total, 78.7% ($n=375$) of those with a mild to moderate ID reported excellent, very good or good emotional or mental health compared to 74.6% ($n=101$) of those with a severe to profound ID. Younger respondents and those living independently or with family were also more likely to rate their mental health as excellent, very good or good. (See Figures 5.3 and 5.4).

Figure 5.3: Self/proxy rated emotional or mental health by age groups



Note: N=732; Missing Obs = 21

Figure 5.4: Self/proxy rated emotional or mental health by living circumstances



Note: N= 733; Missing Obs = 20

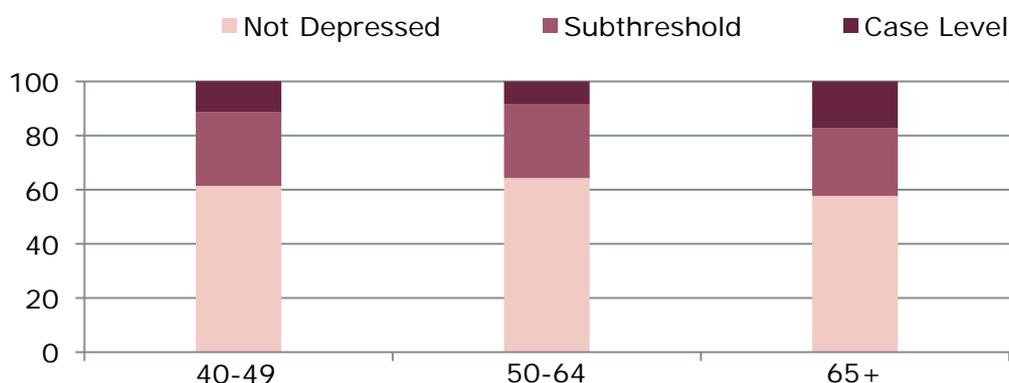
5.5.2 Depression – results of the CES-D scale

Of the 225 self-reporting respondents for whom total scores on the CES-D were generated, 11.6% scored above 16, i.e., with clinically significant depressive symptoms. This is similar to the generic population, in which 10% scored above 16, as reported in TILDA (2011). Among the individuals scoring at this level, (34.6%) also had a doctor's diagnosis of depression. For the IDS-TILDA sample, an additional (27.1%) scored at the sub-threshold depressive symptom burden level (8-15), a figure that is higher than that of 18% reported by TILDA (2011) for the general population. Of people with an ID scoring at this level, 24.6% also had a doctor's diagnosis of depression.

There was an increased prevalence of depressive symptoms among women with an ID; 13.4% ($n=19$) of women scored at case-level of depressive symptoms in comparison to 8.4% ($n=7$) of men. Sub-threshold symptoms were also more frequent, with 28.2% of women scoring at this level compared to 25.3% of men.

As can be seen in Figure 5.5, case-level symptoms of depression were higher among those aged 65 years and older.

Figure 5.5: Prevalence of depressive symptoms by age



Note: N=224; Missing Obs = 27

5.5.3 Depression and visual impairment

Visual impairment is more prevalent in adults with an intellectual disability than the general population (Van Splunder *et al.*, 2006) and this loss further impairs functioning (Evenhuis *et al.*, 2009). Of the 19% that reported visual problems in IDS-TILDA, 26% scored as having clinically significant depressive symptoms with a further 8.2% having sub-threshold symptomatology. In the general population, TILDA (2011) reported a strong association between visual impairment and depression; 32% of those with self-reported poor vision had case-level depression compared with 6% of those with excellent sight.

5.5.4 Depression and epilepsy

A recent prospective study reported an increased incidence of mental health problems among those diagnosed with epilepsy (Turky *et al.*, 2011). Initial analysis of IDS-TILDA data shows an increased prevalence of significant depressive symptoms among this group; 14.8% ($n=9$) of those with epilepsy reported mental health problems, compared with 10.4% ($n=17$) of those without this condition. However, sub-threshold symptomatology was noticeably higher among those without epilepsy, at 31.1%, ($n=51$) versus 16.4% ($n=10$) of those with epilepsy.

5.5.5 Depression and loneliness

Loneliness and its detrimental effect on physical, cognitive and mental wellbeing have been documented in the ageing general population (Hawkley and Cacioppo, 2007; O'Launigh and Lawlor, 2008; Conroy *et al.*, 2010). Slán 2007, the Irish national lifestyle survey, reported that 14% of respondents had often felt lonely in the previous four weeks (Barry *et al.*, 2009). One of the strongest predictors of loneliness was ageing, with 17% of those over the age of 65 feeling lonely in previous weeks. Overall, loneliness correlated most strongly and consistently with the mental health variables used in that study. To date, reports on loneliness in the ID domain focus on young people, work and living arrangements.

Of the 390 people who self-responded to the question 'Do you ever feel lonely?', 50% reported that they had experienced loneliness. Of this group, 19.3% ($n=38$) also reported a doctor's diagnosis of depression. Nearly half of respondents had not felt lonely and, of these, 15.5% ($n=30$) had a previous doctor's diagnosis of depression.

Looking specifically at the 220 individuals who self-reported to the question 'Do you ever feel lonely?' and who also completed the CES-D, almost half reported experiencing loneliness. Of those who reported being lonely, 17.1% scored case-level depression on the CES-D and a further 28.8% had sub-threshold symptoms. Only 6.4% of those who did not report feeling lonely scored a high level of symptomatology, with a further 24.8% reaching sub-threshold scores. For further discussion on loneliness in adults with ID, see Chapter 3.

5.6 Cognitive function

Increasing longevity for those with an ID is a great achievement. However, it also exposes those individuals to the ageing process and all that this entails, including the onset of age-associated chronic illness such as dementia. In addition, people with Down syndrome may show early ageing and are at increased risk of developing Alzheimer-type dementia decades before the general population. Assessment at a single point in time is of little value; serial measurements for an individual are more likely to identify change over time. Inherent difficulties in measuring memory loss and diagnosing dementia in this population has led to agreed international consensus on this issue: people with Down syndrome over the age of 35 years and those with ID from other aetiologies over 50 years should have an annual assessment. This should identify changes in memory, cognition and functional skills (Alyward *et al.*, 1997) with a view to active management.

Cognitive function is the intellectual process by which an individual perceives and understands concepts. It has many constituent elements including thinking, reasoning and remembering, each of which can be measured at different points in time. A person with an ID often begins life with diminished cognitive function, which varies depending on their level of ID. This variation means that standard measures and screens developed for the general population, such as the Folstein Mini-Mental State Examination (Folstein *et al.*, 1975), are not useful; this is because pre-existing cognitive issues will mean low scores at baseline, rendering the instruments ineffective in identifying new changes in cognitive function over time (Deb and Braganza, 1999). In addition, those with a mild ID may demonstrate a ceiling effect regarding measures designed for use in those with a more severe disability. Yet the likelihood of age-related cognitive concern means that measurement of potential decline is important. For this reason, a range of tools must be employed to allow for accurate, serial assessment.

5.7 Cognitive measures

Cognitive assessment was addressed using four measures; these are outlined below.

5.7.1 Reported diagnosis of memory disorder

Respondents were asked if they had ever been told by a doctor that they had a memory disorder, Alzheimer-type dementia, dementia or serious memory impairment. Respondents were also asked whether they had been screened or assessed for a memory impairment/dementia within the previous two years or prior to that.

5.7.2 Self-rated memory

Those who could self-report were asked to rate their memory on a five point scale ranging from excellent to poor.

5.7.3 Orientation in time

This was assessed by asking the respondents to state the year, month, day and date.

5.7.4 Test for Severe Impairment (TSI)

The TSI was developed by Albert and Choen (1992) to provide an objective measure of cognitive function for people with severe cognitive impairment. It has been validated for use in people with ID (Cosgrave *et al.*, 1998). The TSI was administered to all individuals who were able to complete the items ($n=498$). Analysis of the findings for the TSI is continuing and will not be reported here.

5.8 Cognitive findings

5.8.1 Reported memory impairment

Overall, 5.8% of the 753 survey participants said they had been told that they had a memory impairment such as Alzheimer-type dementia, another form of dementia or a serious memory impairment. Reports were considerably higher among those with Down syndrome, at 15.8% ($n=23$), compared to 3.6% for those with an ID from other causes. Almost one third (32.9%) of those with Down syndrome had had their memory status assessed within the previous two years and a further 8.2% had been last assessed more than two years prior to their survey interview. For those with an ID from other aetiologies, 9.9% had had their memory screened during the previous two years and 2.6% had such a screening more than two years prior to their interview.

5.8.2 Self-rated memory

In total, 86.8% ($n=362$) reported their memory as excellent, very good or good, while 13.2% ($n=55$) perceived their memory to be fair or poor. These figures compare favourably with reports of the general Irish population, where 82% perceived their memory to be excellent, very good or good (TILDA, 2011). Within the IDS-TILDA sample, positive perceptions of memory varied slightly by gender, at 87.4% for females and 86.1% for males. It also varied by level of ID, at 88.7% for those with a mild to moderate 88.7% disability compared with 80.7% for those at a severe or profound level. Finally, age was also a relevant factor here; over 90% of those in the youngest cohort (aged 40-49 years) gave a positive report of their memory, compared to 84.9% of those aged 50-64 years and 83.9% of those aged 65 years and over.

5.8.3 Time orientation

Among those who completed this section, 83.7% correctly stated the day of the week whereas only 48.7% knew the correct date. Over future waves of this study, it will be possible to follow this cohort and assess the stability of their orientation in time.

5.9 Conclusion

This chapter reported on the mental and cognitive health of those ageing with an ID in Ireland. In addition to stating the prevalence of conditions and associated factors, data from the generic Irish population and international studies were compared to these findings. The IDS-TILDA study allows for systematic, longitudinal assessment of a large representative sample of those experiencing ageing from both subjective and objective perspectives.

Mental health issues were common among those with an ID, with nearly half reporting a diagnosis of an emotional or psychiatric problem. A reported doctor's diagnosis of depression in older adults with ID was more than three times higher than that reported by TILDA for the general Irish population, at 18.5% versus 5% respectively. However, when depressive symptoms in persons with ID were assessed using the CES-D, a similar prevalence of significant (greater than a score of 16) depressive symptoms emerged as was found among the general Irish population. Prevalence of depressive symptomatology was higher among women. It also increased with age and level of ID. Other factors that were associated with its prevalence included sensory loss, reported experience of loneliness and living in a residential centre.

Data on cognitive function, including testing data from the TSI, will be more fully explored in future waves of this study. Here, the reported prevalence of memory impairment for those with Down syndrome was 15.8%, which was higher than the 3.6% reported for those with an ID from other aetiologies.

Ageing with an ID is one of the great success stories of recent times. In Ireland, advances in care and support have ensured that more individuals with an ID are living into old age (Kelly *et al.*, 2010). Mental and cognitive health is a cornerstone of quality of life. This national, longitudinal study promises to add to our knowledge base and to support the development of interventions to better ensure that gained years are fulfilling, with an enhanced quality of life.

6

Health and Social Care Utilisation of Adults with an Intellectual Disability Ageing in Ireland

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6

Health and Social Care Utilisation of Adults with an Intellectual Disability Ageing in Ireland

6.1 Key findings

- In general, people with an intellectual disability (ID) accessed healthcare services on a regular basis and levels of health utilisation were similar to those reported in the general population except for higher rates of hospitalisation.
- More than half (56.5%) of participants reported they had never received easy to read leaflets on keeping healthy and three quarters said they had never received easy to read information leaflets on healthcare services.
- The general practitioner (GP) was the most frequently accessed healthcare service.
- There is evidence that dental service usage for people with an ID declines with age, whereas it is reported to increase in the general population.
- People living in a residential centre reported receiving services more frequently than their counterparts in community settings or living independently or with family.
- People in the severe to profound range of ID had higher levels of reported health services utilisation than those with a mild to moderate ID level.
- Despite higher levels of chronic illness and disability, older adults with an ID were less likely than other older adults in the general population to be admitted to a general hospital. Most older adults with an ID lived in residential type centres; further investigation is needed of the extent to which the availability of increased nursing and medical care in those settings influenced the need for hospitalisations.
- Overall, people with an ID reported being satisfied with their healthcare.

6.2 Introduction

Key determinants of continued good health include healthcare access and healthcare utilisation. Risk of chronic illness for persons with an intellectual disability (ID) increases with age as it does with the general population, but people with an ID also have a distinct set of co-morbidity conditions and often a different pattern of ageing. There is also likely to be a different history of service utilisation. People with an ID are more likely to have a long-standing relationship with their primary doctor as well as to a broad range of healthcare professionals; this is because of their life-long disability and their greater likelihood of having spent adult years in services, including residential care. In this chapter, patterns in the reported use of healthcare services by adults with an ID in Ireland will be presented.

6.3 Service utilisation

Respondents reported that they frequently accessed health services. In the last year, visits were made by 92% to their general practitioner (GP), 63% to their dentist, 62.2% to a chiropodist, 41.3% to an optician and 39% to psychiatry services. Approximately one fifth accessed dietician, physiotherapy and social work services. 22.1% accessed occupation therapy services and 20.9% accessed speech and language services. The least accessed services were Meals on Wheels (0.8%, $n=6$) and Home Help (3.3%, $n=25$), and very few people reported accessing the services of a geriatrician. Table 6.1 presents the findings of health service utilisation in order of most frequent usage.

Table 6.1: Rate of health service utilisation for adults with an ID

Service received	Yes		No	
	%	frequency	%	frequency
General Practitioner (GP)	92.1	692	7.8	59
Dental services	63.2	475	36.8	276
Chiropody services	62.5	469	37.5	282
Optician	41.3	310	58.7	441
Psychiatry services	39.0	293	61.0	458
Dietician services	26.5	199	73.5	552
Physiotherapy	26.2	197	73.8	554
Social work	23.0	173	77.0	578
Occupational therapy	22.1	166	77.9	585
Speech and language therapy	20.9	157	79.1	593
Psychological services/counselling	20.1	151	79.9	600
Personal care attendant	12.1	91	87.9	660
Hearing services	11.6	87	88.4	664
Public health nurse	10.7	80	89.3	671
Neurological services	9.2	69	90.8	682
Respite services	6.9	52	93.1	699
Dermatological services	4.3	32	95.7	719
Endocrinology services	4.0	30	96.0	721
Home help services	3.3	25	96.7	726
Geriatrician services	2.5	19	97.5	731
Palliative care services	1.2	9	98.8	742
Meals on Wheels	0.8	6	99.2	745
None of these services	2.5	19	97.5	732
Don't know the services received	0.8	6	99.2	745

When TILDA (2011) examined health utilisation by self-rated health, they combined ratings of excellent, very good and good into 'good health', and fair to poor health as 'poor health'. The same recoding was used here for adults with an ID. It was found that those in good health reported the same levels of GP use as general population members in good health (82.7% versus 84.6%). Those with an ID in the poorer health category visited their GP somewhat less often than general population, at 81.3% and 95.7% respectively. Regardless of health status, persons with an ID attended the accident and emergency (A&E) department somewhat more often than adults in the general population, at 15.9% versus 14.9% and had higher rates of hospital admission at 23.4% as compared to 12.9%. Table 6.2 presents the patterns of health services utilisation for older adults with an ID.

Table 6.2: Patterns of health service utilisation, by adults with an ID

Services used	IDS-TILDA 2011
	%
Good health	
GP visits	82.7
Outpatient	44.3
A&E attendance	15.9
Psychiatric hospital admission	0.8
General hospital admission	8.1
Poor health	
GP visits	81.3
Outpatient visits	56.1
A&E attendance	29.9
Psychiatric hospital admission	0.9
General hospital admission	23.4

This study also examined utilisation of health services among adults with an ID by age, level of ID and residential circumstances. As can be seen in Table 6.3, utilisation of health services generally increased with age, except for respite and dental services. Declines in dental service usage may be directly linked to the finding that 21% ($n=100$) of those aged 50 years and older reported having neither teeth nor dentures. A further 13.2% ($n=63$) reported having a full set of dentures. Within the generic population there is a steady rise in dental service usage, which only decreases marginally in the oldest age category of 80 years and over (Normand *et al.*, 2011).

The use of respite services went from 9.2% for those aged 40-49 years to 4.5% for those age 65 years and over. This is possibly attributable to the fact that the majority of people (62%) in this older age category are already living in out-of-home placements.

Interestingly, the majority (91%, $n=122$) of respondents aged 65 years and over had not seen a geriatrician in the last year. Table 6.3 presents a fuller picture of service usage by age.

Table 6.3: Percentage of adults with an ID who utilised health services according to age

Service used	40-49 years ($n=274$)	50-64 years ($n=344$)	65+ years ($n=134$)	Total ($n=753$)
	%	%	%	%
General practitioner (GP)	89.7	93.3	94	92.1
Public health nurse	8.8	11.6	11.9	10.7
Occupational therapy	20.5	20.6	29.1	22.1
Chiropody service	52.4	65.4	75.4	62.5
Physiotherapy	24.9	24.1	34.3	26.2
Social work	22	24.7	20.9	23.0
Psychological services/counselling	18.3	20.9	21.6	20.1
Home help services	3.3	3.2	3.7	3.3
Personal care attendant	11	10.8	17.9	12.1
Meals on Wheels	.7	0.9	0.7	0.8
Optician	31.9	45.6	50	41.4
Dental services	70.3	62.5	50.7	63.2
Hearing services	9.9	11	16.4	11.6
Dietician service	26	24.4	32.8	26.5
Speech and language therapy	20.1	20.4	23.9	20.9
Psychiatric services	38.1	47	47	39.0
Neurological services	9.2	11	4.5	9.2
Geriatrician services	.7	1.5	9	2.5
Endocrinology services	3.7	4.7	3	4.0
Dermatological services	3.7	4.9	3.7	4.3
Palliative care services	0	1.2	3.7	1.2

Those living in a residential centre were more likely to report receiving and accessing services and healthcare professionals than people living in any other type of living circumstance. These findings probably relate to the fact that this group are older, with a more severe ID and higher levels of health concerns. It is also likely that this group have a history of more regular nursing and medical assessments and checkups. Table 6.4 presents data on utilisation of health services by living circumstance.

Table 6.4: Healthcare utilisation according to living circumstances

Service used	Independent /family (n=129)	Community setting (n=268)	Residential centre (n=356)	Total (n=753)
	%	%	%	%
General practitioner (GP)	82.9	94	94.1	92.1
Public health nurse	17.1	16.9	3.7	10.7
Occupational therapy	13.2	12.7	32.4	22.1
Chiropody service	32.6	56.2	78	62.5
Physiotherapy	11.6	23.2	33.8	26.2
Social work	23.3	20.2	25.1	23.0
Psychological service/ counselling	10.1	19.5	24.2	20.1
Home help service	13.2	2.6	0.3	3.3
Personal care attendant	6.2	6.4	18.6	12.1
Meals on Wheels	2.3	0.7	0.3	0.8
Optician	34.9	50.9	36.6	41.4
Dental services	51.2	70	62.5	63.2
Hearing services	13.2	11.6	11	11.6
Dietician services	14.0	18.4	37.2	26.5
Speech and language therapy	6.2	11.7	35.2	20.9
Psychiatric services	10.1	35.2	52.4	39.0
Neurological services	5.4	8.2	11.3	9.2
Geriatrician services	0.8	1.9	3.7	2.5
Endocrinology services	0.0	3.0	6.2	4.0
Dermatological services	3.1	3.7	5.1	4.3
Palliative care services	0.0	0.4	2.3	1.2

There also appear to be associations between health utilisation and level of ID. Overall, utilisation of health services was higher among those with a severe/profound ID. The only exception here was regarding use of optician and auditory services, use of which was lower among this group than for persons with a mild to moderate ID. The high proportion of those with a severe/profound ID who did not access optician (70.2%, $n=144$) and auditory services (90.2%, $n=185$) is of concern, given reported high prevalence of sensory impairment among this cohort (Evenhuis *et al.*, 2001). It may suggest that some conditions are undiagnosed. The low proportion of people accessing a dietician is also notable, especially for those with a mild to moderate ID.

The findings show that 75.1% ($n=367$) of people with mild/moderate ID and 66.8% of people with a severe/profound ID do not access a dietician. Yet this study found that 28.6% ($n=110$) of those with a mild/moderate ID had a body mass index (BMI) within the overweight range and a further 39.3% ($n=151$) had one within the obese range. It also identified high levels of overweight and obesity among those with a severe/profound ID, at 33.9% ($n=56$) and 13.9% ($n=23$) respectively. In light of these findings, the low proportion of people with an ID accessing a dietician is of concern.

Lack of funds and available staff support are among the highest cited reasons reported for people not receiving services. Table 6.5 presents utilisation of services according to level of ID.

Table 6.5: Healthcare utilisation according to level of ID

Service used	Mild/ moderate ($n=489$)	Severe/ profound ($n=206$)	Total ($n=695$)
	%	%	%
General practitioner (GP)	91.6	95.6	92.1
Public health nurse	12.7	6.3	10.7
Occupational therapy	18.2	33.2	22.1
Chiropody services	58.5	76.1	62.5
Physiotherapy	22.9	38.0	26.2
Social Work	22.7	26.8	23.0
Psychological services/counselling	19.6	23.4	20.1
Home help services	4.3	1.5	3.3
Personal care attendant	9.8	19.0	12.1
Meals on Wheels	1.0	-	0.8
Optician	46.0	29.8	41.4
Dental services	63.0	63.9	63.2
Hearing services	11.9	9.8	11.6
Dietician services	24.9	33.2	26.5
Speech and language therapy	15.6	37.6	20.9
Psychiatric services	36.6	49.3	39.0
Neurological services	8.2	11.7	9.2
Geriatrician services	1.8	3.9	2.5
Endocrinology services	3.7	5.9	4.0
Dermatological services	4.3	4.9	4.3
Palliative care services	1.0	2.0	1.2

Note: Missing Obs = 58.

6.3.1 Frequency and usage of medical services

GP care was the most widely used service (92.1%, $n=692$) reported by people with an ID. Among these respondents, 83% reported visiting their GP between one and 10 times in a year, 10.2%, did so between 11 and 19 times and 2.7% accessed their GP between 20 and 30 times a year. A remaining 1.5% ($n=10$) did so over 31 times within one year. People self-reporting their health as 'good health' (86.0%, $n=533$) visited their GP once a year; this was similar to the figure reported for the generic population (84.6%) in TILDA (Normand *et al.*, 2011).

Adults with a severe/profound ID visited their GP more often than people with a mild/moderate ID at 90.3% versus 80.4% respectively. This may be indicative of more complex multiple health conditions. However, a small cohort of 5.2% ($n=34$) did not visit their GP at all. Of these, three people (3.3%) reported having poor health and never went to the GP. People living independently or with their family also visited their GP less frequently than those living in a community setting or in a residential centre. This may indicate that these people with an ID have better health than those living in the community settings or the residential centres. For those who reported visits to the GP, Table 6.6 presents the frequency of GP visits, by living circumstances.

Table 6.6: Frequency of GP visits according to living circumstances

Living circumstances	GP Visits			
	1-10 visits	11-20 visits	21-30 visits	31+ visits
Independently/Family	88.5	7.3	1.0	3.1
Community Setting	87.9	9.9	2.2	-
Residential	76.4	17.2	4.1	2.4
Total	82.5	13.0	2.9	1.6

In terms of medical cover, 96.8% ($n=720$) of people with an ID had a medical card. This figure is significantly higher than the 36% of the general population with a medical card. Moreover, only 4.9% of people with an ID reported having their own private health insurance, with a further 1.7% ($n=12$) reporting that they were named as a relative of a subscriber and one person stating they were the spouse of a subscriber. By contrast, TILDA reported that in the general population, almost 60% of people aged 50-69 years primarily relied upon private health insurance (Normand *et al.*, 2011).

6.3.2 Outpatient visits

In the previous year, 45.8% of people with an ID visited an outpatient clinic, with 96.8% of this group attending between one and 10 times. A total of seven people attended one between 11 and 19 times and three people did so over 20 times.

TILDA (2011) used slightly different age categories in presenting outpatient usage. Nonetheless, it appears that reported use of outpatient services among those with an ID is somewhat higher than that found among the general population. Among people with an ID, 46.2% aged 50-64 years and 48.5% aged 65 years and over accessed outpatient clinics. Among the general population, 35.7% of those aged 50-59 years and 43.3% of those aged 60-69 years did so. It is also of note that the proportion of people with an ID aged 40-49 years who used outpatient services, at 44.2%, was higher than that found among people aged 50-59 years in the general population.

6.3.3 Hospital admissions

Among respondents, 10.4% ($n=78$) reported being admitted in the previous year to a general hospital, for a length of time ranging from one to over 20 nights. In total, 89.7% spent between one and 10 nights in hospital and these participants were more likely to be aged between 40-49 years. This finding differs from the general population, in which older adults reported spending more days hospitalised (Normand *et al.*2011). Most older adults with an ID lived in residential centres, with high levels of nursing and medical care; further investigation is needed of the extent to which the availability of this additional nursing and medical care impacted on the need for hospitalisations.

6.3.4 Psychiatric hospital and nursing/convalescent home admission

Six individuals with an ID reported an overnight admission to a psychiatric hospital and a further 18 people were admitted to a nursing/convalescent home.

6.3.5 A&E visits

In the year prior to the survey being carried out, 18.7% of people with an ID reported using their A&E department; this was higher than the 14.9% reported for the general population. The most common reason for A&E attendance in IDS-TILDA was fracture, at 15.2%. Table 6.7 provides additional information on the reasons for A&E admission.

Table 6.7: Rank order of attendance to A&E department

Rank order	Reasons for A&E admission	%	Frequency
1	Broken or fractured bone	15.2	22
2	Cut/open wound	11.8	17
3	Strain/sprain	11.7	17
4	Bruise/scrape/blister	4.9	7
5	Pneumonia	4.2	6
6	Dislocation	1.4	2
7	Internal injury	0.7	1

6.3.6 Need for healthcare

Respondents were asked if there was ever a time when they needed healthcare and did not receive it. In answer to this question, 13 respondents reported that they were made to wait too long. A further four people felt that healthcare was not available when needed and others reported for example that when, *'X is having recurrent seizures yet the GP doesn't feel she needs to be seen by an epilepsy specialist'*. Another noted, *'At times it can be very hard to get the doctor to come to the unit when he is needed.'* Given cuts in health services that are now underway, it will be important in future waves of data collection to assess whether such difficulties in accessing services increase.

6.3.7 Other services

Eight percent of people with an ID reported receiving other services. These ranged from urology to cardiac services, from aromatherapy to Tai Chi. It was encouraging to see opportunities to access such services existed, even if this is only the case for a small proportion of people with an ID.

People also identified services they would benefit from but were not currently receiving. These included dietician, chiropody services and education. Regarding the latter, one participant's support noted, *'literacy services, he/she would love to be able to read and write, very embarrassed that he/she cannot'*. Another support person remarked on a decrease in activities for an older person with an ID:

'Maybe due to age, activities are reduced in day centres and we feel that older people with ID are not afforded the same opportunities for activities as younger people have. Older people need a lot of motivation – we feel older people have the same needs as younger people but sometimes carers in these centres decide they need less activity and this is not what we are finding to be the case'.

6.3.8 Support from other organisations

Approximately 21% ($n=151$) of participants identified receiving support from the Irish Wheelchair Association, Special Olympics, parents and friends associations and disability services. The role of such organisations in helping people with an ID live active participatory lives in their community will be followed over the lifetime of this longitudinal study.

6.3.9 Satisfaction with services

People with an ID were also asked to appraise the services they received during the previous year. Respondents were most satisfied with their GP and speech therapy; one participant noted how they loved attending their speech therapist and described its benefits: *'...because it helps to interact with people'*.

Access was the most cited cause of dissatisfaction. In addition, poor attitudes and low standards of service delivery were also a concern; as one sibling stated:

'not happy with the general hospital, x had to wait 10 hours to be seen after she had a stroke. My sister did not understand and I had to fight for the service or she would still be waiting or have had a major stroke.'

Service satisfaction and dissatisfaction warrant further exploration.

6.3.10 Health literacy

Difficulties surrounding levels of education, especially literacy issues, formed a major barrier that prevented people with an ID from engaging in and taking ownership of their own health. Over half of respondents (56.5%) reported that they had never received easy to read leaflets on keeping healthy and almost three quarters (69.1%) said they had never received easy to read information leaflets on healthcare services.

6.4 Conclusion

Given the range of chronic health conditions reported by this group, it was not surprising to see some higher levels of healthcare utilisation, when compared to the general population. It is also probable that greater access to medical cards had an impact here. However, it emerged that the most relevant factor was that of living in a residential centre.

The lower number of hospital admissions among those in the older age group is striking. People in this category are more likely to live in residential centres, where they have greater access to doctors and other healthcare professionals than is available to people in the general population, and the impact of this aspect of residential care on hospitalisations needs further investigation.

Regardless of setting, extremely high levels of access to a GP suggest that opportunities exist for the coordination of care.

More than half of participants reported they had never received easy to read leaflets on keeping healthy and three quarters said they had never received easy to read information leaflets on healthcare services. This lack of information represents a major barrier to people with an ID for engaging in and taking ownership of their own health. Plans to move people with an ID from residential centres to community settings are likely to lead to changes in the pattern of health care services. Moreover, increasing age and reductions in availability of services given healthcare cutbacks will pose challenges for people with an ID in the years ahead. Future waves of data collection for IDS-TILDA will closely monitor changes in healthcare access and utilisation for adults who are ageing with an ID.

7

Employment, Retirement, Day Services and Lifelong Learning

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7

Employment, Retirement, Day Services and Lifelong Learning

7.1 Key findings

- Overall, 6.6% ($n=50$) of Irish adults with an intellectual disability (ID) were in paid employment. It was reported that 37.6% ($n=283$) were unable to work due to permanent disability or sickness and 6.1% ($n=46$) were retired.
- Of those in paid employment, 44% ($n=22$) received less than the minimum wage.
- Over half of respondents did not know how much money they received on a weekly/monthly basis.
- The majority of those who worked travelled there by bus, and the average journey time was between 10 and 30 minutes.
- The majority of adults with an ID (79.4%) attended a day service, with 43.5% reporting they had choices in their activities there and 32.7% reporting that they rarely or never had such choices.
- Just over one third (66.8%) reported that they received assistance going to and from their day service.
- The average age of retirement was 62 years; however, a number of participants indicated they did not want to retire as long as their health permitted.
- Positive social consequences of attending programmes or employment included retaining contact with staff and friends, and having somewhere to go during the day. These were reported as important factors in deciding not to retire: *'he goes to the centre to see his girlfriend and listen to music and seems to spend a lot of time in [named centre] where he clearly knows a lot of people and has the craic'*.
- A total of 15.6%, most of whom were aged 40-49 years, indicated that they were currently engaged in further education.
- For those who expressed a desire to engage in further education, computer and literacy classes were most frequently cited courses.
- Over four fifths (82%) were in receipt of the disability allowance.
- The majority (78%) paid rent, at an average of €100.58 per week.

7.2 Introduction

Engaging in the labour market is rewarding not only from an economical perspective but also because it is usually associated with increased opportunities to develop social relationships. It is generally recognised that relatively few people with an intellectual disability (ID) are in paid employment (Haveman *et al.*, 2011), and this study's findings support this view.

For the purposes of the study, employment was defined as: paid regular employment; attending a supported employment scheme or sheltered work/workshop; participating in an apprenticeship or employment programme (Community Employment Scheme); or being temporarily away from work.

7.3 Employment status

People with an ID were less likely to be employed. Unemployment leads to difficult economic circumstances, and this increases the vulnerability of people with an ID as they age. Only 23.1% ($n=174$) of the population surveyed described themselves as being in employment and 6.1% ($n=46$) reported being retired. Table 7.1 presents the occupational status of participants.

Table 7.1: Occupational situation

Which best describes your current situation?	%
Retired	6.1
Employed (includes regular paid employment, sheltered workshop, supported employment scheme apprenticeship, temporarily away from work).	23.1*
Self-employed	0.1
Unemployed/ looking for work	2.4
Unable to work due to being permanently disabled or sick	37.6
Looking after the home or family	0.4
In education or training	1.1
Other	29.3

*See table 7.1a for breakdown of employment description.

Of those who reported themselves as employed, 50% ($n=87$) were female and 50% ($n=87$) were male. Levels of employment decreased with age; 27.8% ($n=76$) of those aged 40-49 years were employed, as were 24.4% ($n=84$) of those aged 50-64 years and 10.4% ($n=14$) of those aged 65 years and older.

A large number of respondents reported their day service or sheltered workshop as a place of employment; 33.3% ($n=58$) who described themselves as employed actually attended a day service or other kind of service and a further 37.9% ($n=66$) attended a sheltered workshop. In total, almost three quarters (71.1%) of respondents reported their participation in some form of sheltered workshop or day service as employment. In fact, adults with an ID in Ireland in paid employment could be more accurately described at 6.6% ($n=50$). It also emerged that 56% ($n=28$) of those in paid employment earned the minimum wage or above, with 44% ($n=22$) earning below the minimum wage.

Table 7.1a: Breakdown of employment description

Employment as described by participants	Total identified as employed ($n=174$)		Total ($n=753$)
	%	frequency	%
Paid employment (full/part-time, regular paid employment/self-employed)	28.7	50	6.6
Sheltered workshop	37.9	66	8.8
Other	33.3	58	7.7
Total	100	174	23.1

Work sites that participants identified included grocery stores, where they packed shelves, cafés/restaurants where they worked as a waitress or waiter, and sheltered workshop settings where they engaged in contract work such as labelling or packing envelopes:

'We put addresses on envelopes and sealing copy covers, we put five copy covers in the bag. And we do loads more, we put brochures in envelopes. And the credit union, we put the stickers on for them and the printers print them'.

Many of those involved in sheltered employment described a decrease in both the quantity and variety of available work. One respondent noted, *'usually package aeroplane bags and other orders they get in, may be changing to more therapeutic day service activities if work doesn't come in'.* Another identified how their workshop had completely changed when they said, *'don't do any of the things that we used to do here. Workshop activities have stopped. Mainly do crosswords, go shopping have coffee, sit around and chat to friends'.*

Eighteen participants indicated they were currently looking for work, eight were in further education and three reported that they were looking after a family member.

Travel to work was usually by bus (40.2%, $n=70$) and the average trip took between 10 and 30 minutes. Almost half respondents (49.1%, $n=85$) reported using a travel support companion, often so the respondent would feel safe; as one participant described it, '*[they] walk up with me to keep me safe*'.

Health status directly affects ability to engage in full employment. In total, 37.6% ($n=283$) reported being unable to work due to being permanently sick or disabled. Almost half of this group (48.0%, $n=171$) lived in a residential centre, while a further 30.6% ($n=82$) lived in a community setting and 23.3% ($n=30$) lived independently or with their family. Regardless of level of ID, there were high levels of unemployment among reported.

7.4 Day services

Overall, 79.4% ($n=597$) of respondents reported attending a day service, where the most popular activities were arts and crafts (76.7%), music (69%), and multisensory and other health therapies such as massage or occupational therapy (59.8%). See Table 7.2 for further detail.

Table 7.2: Frequency of engagement in day service activities

Day service activities engaged in	$n= 597$
	%
Arts and crafts	76.7
Music	69.0
Multisensory and other health therapies	59.8
Cooking and baking	49.6
Skills development (e.g. social skills, daily living skills)	48.4
Swimming	34.2
Horticulture	29.1
Information technology	22.8
Woodwork	7.4

Other activities reported included beauty therapy, day trips, bowling, drama, dance, table top games, watching movies and socialising. In total, 43.5% ($n=256$) reported that they were usually able to choose the activities they engaged in, and a further 23.8% ($n=140$) reported that they got this opportunity sometimes; However, not everyone was happy with their day service. Almost one third (32.7%) reported that they rarely or never had the opportunity to choose activities. One participant reported that people with an ID, *'just sit around and do nothing'*.

Respondents attended their day service approximately four days per week for an average of 23 hours. Over one quarter (27.1%) accessed their day service by bus, a further 21.6% walked, and for 10.4%, their day service was located in the centre in which they lived. The average travel time to day services was 14 minutes; however, 50 participants indicated that travel took over an hour, probably due to transport services stopping to bring multiple service users to their day service/work. A large proportion of people with an ID (66.8%) reported requiring support to go to the day service. This was the case with the majority (91.5%) of those with a severe to profound ID, as well as did three out of five of those with a mild to moderate ID. As one participant reported, *'I always need to link someone due to my sight difficulties and severe epilepsy which means I am never on my own.'* Another reported, *'staff help me get on the bus I need help getting on and off the bus'*.

7.5 Lifelong learning

The majority (84.5%) of adults with an ID were not engaged in further education, with only 15.4% ($n=116$) reporting that they had or were currently attending courses. Of those engaging in further education, 26.1% reported that their course was organised by the Vocational Education Committee (VEC), 11.3% by a training centre, and 7.8% by a local community programme.

Those engaged in further education were more likely to be aged between 40 and 64 years, to have a mild/moderate ID, and to live independently, with family, or in a community setting. Courses engaged in included subjects such as personal development (21.1%), computer skills (18.4%) and literacy (14.9%).

On average, people spent 4.95 hours per week at courses, for an average of 38.07 weeks per year. Twenty people with an ID indicated that they had achieved FETAC awards. Courses were chosen for personal or social development (85.2%, $n=98$) or for a job-related reason (14.8%, $n=17$).

Among the 32.2% ($n=222$) who were interested in attending further courses, the most preferred courses were on computers and literacy skills. One participant noted, *'computers, I know how to do the games but I'd like to be able to do the letters it's a bit hard for me. My sister has shown me how to use my own camera on the computer, my nephew is very good. I'd like to learn how to do the bit on the computer'*.

Several support workers highlighted challenges faced by people with an ID who wished to attend further education. One noted that the respondent was *'...currently ... very ill however we would like to give him the choice however health currently restricts this... level of activity is in line with current physical ability'*. Another said, *'I think that he would be interested in doing something different but there is very little opportunity in the unit.'* Overall, however, people expressed a high level of interest in engaging in further education: *'can't think of any course at the moment but I'd like to do something'*.

Classes themselves posed other challenges. One support worker commented that the respondent, *'has literacy support but it is not a formal training course, he did attend computers but the pace was too fast.'* A respondent said, *'I used to do a computer course in the centre but the lady doing it left and now it's on a Monday and Thursday and I would be working'*. Other identified difficulties included health limitations, poor concentration and the need for extra support: *'she would need a lot of support and guidance to participate [sic] in a training scheme'*. Funding reductions and cutbacks were identified in one case as causing difficulty: *'... was doing computer course but the funding was pulled and therefore there is no course anymore...'*

7.6 Retirement

The need for retirement services that meet the needs of the ageing population of people with an ID is growing. Despite this, no national policy is in place to address this issue (Lawrence and Rouse, 2008). Retirement does not simply mean no longer working for a salary, or (for most adults with an ID) no longer attending a day programme. It is also about a new stage of life. One staff reported that, *'currently a step down service/retirement service is under review and planning within the service'*. Forty-six participants, most of whom were over 65 years, reported they were retired. Among these, 26 were male and 20 were female. In terms of living circumstance, 25 lived in a residential centre, 18 in a community setting and three lived independently or at home. A total of 35 of this group had a mild to moderate ID and eight had a severe or profound ID.

The average preferred age of retirement was 62 years. Three quarters (75.4%) of those attending a day service reported they did not plan to retire from it at all and a further 12.2% of the total sample reported that they had already retired. Some respondents indicated they had no choice but to retire; as one participant reported, *'when 50 you automatically retire from the day service'*.

Generally, people agreed with the following views expressed by one participant:

'I'm not ready yet, I don't want to yet, not yet I'll keep going on I'm still young maybe in a few years time' and, *'I'm too young for that yet 66 is the time but I'd miss it I will go as long as I am healthy I might retire at 66 but I might be bored.'*

Other studies in the field of ID support this idea, namely that a lack of *'meaningful and age appropriate programmes may influence many older adults with an ID to remain in a structured work environment'* (Haveman *et al.*, 2011)

Some participants reported that the issue of retirement could also be determined by other variables beyond the person's control; as one person noted, *'retirement services are in place, a new retirement home is being developed locally, but just take things as they come, more than planning by age, the house isn't a 24 hour house so if they got sick they would be placed somewhere that is'*. The concept of retirement and planning for retirement for people with an ID are issues which will be explored in future waves of TILDA.

When retirees were asked their main reason for retiring, 34.1% ($n=14$) reported it was due to ill health, 17.1% ($n=7$) reported they were eligible for the state pension, 4.9% ($n=2$) said that they were made redundant and 39.0% ($n=16$) indicated other reasons. These included a workshop closed and one person noted, *'I was fed up and wanted to go somewhere I could get a bit of peace'*.

A large number of adults with an ID indicated that they did not want to retire. Positive social consequences, including retaining contact with staff and friends and having somewhere to go during the day, are likely to be serious considerations in people's decision not to retire. This is evidenced in some of the qualitative responses made by participants. For example, the when asked if they were planning to retire, one person noted, *'I'm not ready yet, I don't want to yet, not yet I'll keep going on I'm still young maybe in a few years time.'*

A support worker reported that one person under their care *'...doesn't mind stopping but knows that he would be bored at home and also his girlfriend would miss him at work'*. Another support worker pointed out: *'he goes to the centre to see his girlfriend and listen to music and seems to spend a lot of time in [named centre] where he clearly knows a lot of people and has the craic'*.

7.7 Sources of income

The majority of respondents reported that they were in receipt of the disability allowance, with 3.8% indicating they received the mobility allowance. A further 10.4% ($n=76$) received payments from other sources such as wages, foreign pensions or a fund set up by their family (See Table 7.3). Some respondents opted not to disclose their source of income.

Table 7.3: Distribution of income/allowances

Income/allowance	Total: 729
	%
Disability allowance	82.0
Mobility allowance	3.8
Disability benefit (previously known as illness benefit)	0.3
Retirement pension from former employer	0.1
Contributory state pension (previously known as contributory old age pension)	0.3
Non-contributory state pension (previously known as on-contributory old age pension)	8.9
Transition state pension (previously known as retirement pension)	0.3
Invalidity pension	0.8
Private pension	0.5
Supplementary welfare allowance	0.3

Note: Missing Obs = 24

People were asked if they controlled their own money, and 39.3% reported they did not; 43.2% were described by support workers as not having the capacity to do so. Over half of respondents (55.5%) did not know how much money they received on a weekly/monthly basis. People were also asked if they received information and support to manage their money, and of those who responded, 57.4% ($n=135$) said that they did.

For those who did not know the amount of money they received, permission was obtained from family or the services provider to access this information. It emerged that on average, each person received €185.15 per week.

Overall, 46.0% of respondents reported that they knew when they received their money. However, more than three quarters reported they did not collect their own money themselves and more than half of these respondents (53.8%) did not know who collected their money. In terms of what happens to their money, 45.2% indicated that some or all of their money went into a central fund and a majority (86.2%) agreed with this approach. Also, 36.7% reported not having somewhere safe to keep their money.

People were then asked about how they spent their money; 78% of respondents indicated they paid rent, which on average cost €100.58 per week. For 83.6%, these rent charges also covered utility and grocery costs. Other living expenses averaged €54.22 per week.

7.8 Conclusion

Many of the key issues that concern the general population are also relevant to the lives of adults with an ID. They include work, work programmes, retirement, life-long learning and expenses, such as rent and day-to-day living costs. However, most people with an ID seem to have a more limited range of opportunities than the rest of the population. While factors such as age, level of ID and living circumstances had some impact on this, it emerged that the majority of people with an ID have limited opportunities, including that of choosing the activities in which they participate.

There was a high level of attendance at day programmes rather than engagement in paid employment. It was of interest that a number of adults with an ID identified day programme and sheltered workshop attendance as a form of employment. This speaks of the value participants gained from attending these programmes, as did their reluctance towards the idea of retiring.

The current economic recession will make it difficult to increase the proportion of respondents who are in actual employment (6.6%). For this reason, it will be important for IDS-TILDA to monitor in subsequent waves changes in levels regarding both employment and access to programmes that adults with an ID themselves find meaningful. In particular, the statement by one participant that he was required to retire from the day programme at 50 years raises the spectre of older age being a time without meaningful engagement. This can mean giving up those things that another participant highlighted as important, namely seeing girlfriends and boyfriends, listening to music, knowing a lot of people and 'having the craic'.

Mechanisms for meaningful activities and access to both peers and to the community in general will be important if retirement is to be a stage of life rather than the end of things that are valued. One support worker indicated that, '*a step down service/retirement service is under review*' at least in one services provider. Future waves of IDS-TILDA will monitor the development of such services. However, these data also present a challenge to service planners and providers to expand options available, and to ensure that courses meet the needs and interests of adults with an ID. It is also important that budgetary cutbacks do not further limit opportunities for adults with ID.

Regardless of level of ID, the majority of people with an ID were reliant on staff to access programmes or employment. This raises questions about what happens to these opportunities if economic cutbacks reduce the number of staff available to escort. At a more fundamental level, it raises questions as to whether enough is being done to encourage and facilitate independence in adults with an ID. These will also be issues to be monitored in subsequent waves of data collection.

The levels of income secured through wages and disability allowances by people with an ID would be equated with poverty by other Irish citizens. Many people with an ID did not know how much money they had available, did not collect those funds for themselves and relied upon service providers' central funds to manage the dispersing and use of these resources. This is of concern. Quality of life in retirement for most Irish citizens is enhanced by the use of savings and other resources, yet people with an ID have fewer such resources and less access to what little they have available. A need emerges for savings, pensions and other sources of income to be made available to people with an ID, if their experience of retirement is to be similar to that of the general population.

8

Personal Choice, Planning for Daily Life and Beliefs About Ageing

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8

Personal Choice, Planning for Daily Life and Beliefs About Ageing

8.1 Key findings

- Many people with an intellectual disability (ID) reported accessing a great deal of support in making personal choices in their lives.
- Overall, adults with an ID reported having a good level of choice in relation to basic day-to-day issues in their lives, such as the food they eat, clothes they wear, and how they spent their free time.
- Nonetheless, the majority of adults with an ID reported that they had limited choice in relation to how they lived their lives. Three quarters (75.4%) reported having no choice in relation to where they lived and 85.5% reported that they had no choice in relation to who they lived with. Almost half of respondents said they had no choice in relation to the time at which they went to bed.
- Most people with ID reported having an individual personal plan (IPP). A majority also said that they were included in decisions made about their lives, and that they received good support from key workers in pursuing those IPPs. However, it should be noted that there was no means of knowing if those respondents whose responses were made by proxy shared this view of their involvement in an IPP. The contents of these IPPs were not reviewed to establish the extent to which they were person-centred.
- Those living independently or with family were slightly less likely to report having a key worker or an IPP than those living in a community setting or residential centre.
- Only a small number of respondents had accessed an independent advocacy service. However, the majority of people with an ID, particularly those with a mild to moderate ID, reported having access to an advocacy service.
- The experience of happiness, pleasure and enjoyment of life for people with an ID was comparable to that of the general population, as reported by McGee *et al.* (2011).
- Happiness among people with an ID was linked with family and simple life values; as one respondent succinctly described it, '*happiness in my life at the moment is living with my family*'.
- People with an ID reported feeling younger than their actual age and this was more likely to be the case for men.

- Adults with an ID reported a positive outlook on ageing, with 63% indicating that older people could do most things younger people could do and for 65%, older people were a source of good support.
- Adults with an ID expressed typical concerns associated with advancing years, the main issues here being loss of family and friends, increased dependence and fear of death.

8.2 Introduction

This chapter provides a descriptive account of the experience of people with an ID in Ireland regarding personal choice-making, happiness, and the development and implementation of individual personal plans (IPPs). It presents findings regarding the beliefs about ageing among this group. Variations associated with age, gender, level of intellectual disability (ID) and living circumstances are also described.

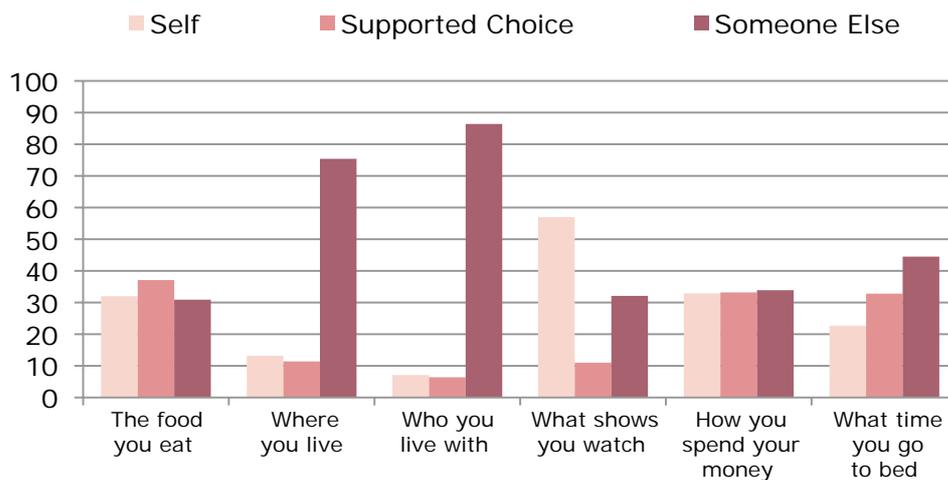
8.3 Personal choices

A key aspect of quality of life is self-determination – making one’s own personal choice and decisions. For many people with an ID, making independent decisions and choices can be a challenge and support is frequently required. Some people with ID lack such opportunities and supports. In this survey, respondents were asked a variety of questions to identify the level of independent and supported choice they experienced. Questions addressed everyday life choices such as food eaten, clothes worn, and how free time is spent. Some related to autonomy; respondents were asked where they lived, who they lived with, and how they spent their money.

Overall, respondents reported having a good level of choice in relation to day-to-day aspects in their lives. Almost three quarters (69.1%) of adults with an ID reported having either independent (32%) or supported choice (37.1%) with respect to the food they eat. A total of 68% reported independent (57%) or supported choice (11%) with respect to the TV programmes they watched. Almost three quarters (72.5%) reported having either independent (49%) or supported choice (23.5%) in relation to the clothes they wore. Almost two thirds (65.3%) reported that they had either independent (39.8%) or supported choice (26.5%) with respect to where they went in their free time. Similarly, 66.1% reported having either independent (32.9%) or supported choice (33.2%) regarding how they spent their money.

Not all findings were so positive, however. Just over half (55.5%) respondents reported having independent (22.7%) or supported choice (32.8%) in relation to the time they went to bed. Moreover, three quarters (75.4%) reported having no choice in relation to where they lived and 85.5% reporting having no choice in relation to who they lived with. In terms of where people lived, 18.7% reported that families made this decision on their behalf, while 78.8% said that organisations/services providers were their main decision-maker. Figure 8.1 presents the results of a selection of items on people’s personal choices.

Figure 8.1: Personal choices



Note: N=752; Missing Obs = 1

8.3.1 Personal choice and level of ID

For people with a severe or profound ID their decisions were predominantly made by someone else; this was the case regarding all listed items. People with a mild to moderate ID identified that they either made choices for themselves or were supported to make a choice, regarding seven of the 13 listed items. Those items for which people with a mild to moderate ID had the least input were: where they lived, who lived with them, what support they received and where they kept their money. Table 8.1 presents the amount of personal choice participants received, by levels of ID.

8.3.2 Personal choice and living circumstance

All people living in residential centres reported that 'someone else', usually the support staff or service administrator, was the predominant decision maker in their lives. This was the case for all items asked. Those people living independently or with family enjoyed the greatest level of personal autonomy, making their own decisions in eight out of the 13 items; the most commonly reported items here were how they spent their money (65.9%, $n=85$) and the TV shows they watched (86.0%, $n=111$). People living in community settings reported that they made their own decisions independently for five of the thirteen items and cited supported decision-making for a further four items. Decisions that were predominantly made by someone else were: where money was kept (55.1%, $n=145$), support received (74.5%, $n=196$), who respondents lived with (87.8%, $n=231$) and where they lived (67.8%, $n=179$). See Table 8.1 for information on the level of support required when making decisions, by living circumstances.

Table 8.1: Personal choices according to living circumstances and level of ID

Personal Choices	Living circumstances												Level of ID					
	Independent/with family (n=129)			Community setting (n=268)			Residential centre (n=356)			Mild/moderate (n=489)			Severe/profound (n=206)					
	self	supported choice	someone else	self	supported choice	someone else	self	supported choice	someone else	self	supported choice	someone else	self	supported choice	someone else			
The food you eat	53.5	17.8	28.7	34.9	15.5	49.6	21.3	38.5	40.2	40.6	37.9	21.5	10.2	37.4	52.4			
What food is cooked in the house	34.9	15.5	49.6	18.0	50.9	31.1	2.2	20.5	77.2	17.0	36.7	46.3	1.5	18.0	80.6			
The clothes you wear	68.2	13.2	18.6	65.3	21.6	13.1	29.8	28.7	41.6	62.8	22.1	15.1	13.1	28.2	58.7			
Where you go in your free time	85.3	4.7	10.1	81.3	10.8	7.8	61.8	14.3	23.9	82.0	9.2	8.8	50.0	17.0	33.1			
Who you spend your free time with	62.8	18.6	18.6	44.8	29.9	25.3	27.7	26.8	45.5	50.1	29.1	20.2	15.0	18.9	66.0			
How you spend your money	65.9	15.5	18.6	31.6	44.9	23.6	22.0	31.0	47.0	39.7	40.3	20.0	14.1	19.4	66.5			
What time you go to bed	49.6	26.4	24.0	28.3	43.4	28.3	8.7	27.3	63.9	30.0	40.0	30.0	1.5	17.1	81.9			
Where you live	43.4	11.6	45.0	11.0	21.2	67.8	3.7	4.0	92.3	18.2	15.3	66.5	0.5	2.9	96.6			
Who you live with	34.1	8.5	57.4	1.9	10.3	87.8	1.1	2.8	96.0	9.3	8.5	82.2	0.5	1.0	98.5			
What support you may receive	28.6	19.0	52.4	7.2	18.3	74.5	2.8	7.6	89.6	11.8	18.3	69.9	1.0	1.5	97.6			
What shows you watch on TV	86.0	5.4	8.5	69.3	12.1	18.6	37.2	12.1	50.7	71.6	11.1	17.3	20.0	10.7	69.3			
How do you decorate your room	57.8	16.4	25.8	48.1	28.8	23.1	15.3	26.8	57.9	46.4	27.5	26.1	6.3	20.9	72.8			
Where you keep your money	41.1	17.8	41.1	16.3	28.5	55.1	2.5	10.5	87.0	18.6	23.4	58.0	1.0	3.9	95.1			

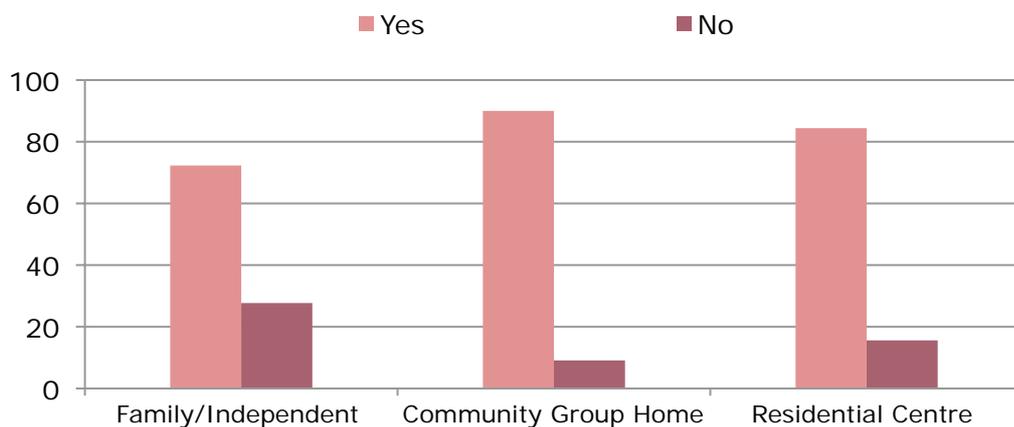
Note: 68 people could not verify or did not know their ID.

8.4 Personal planning

People with an ID often require support in order to participate in everyday life. In this study, respondents were asked a number of questions in relation to planning their life, such as whether they had an IPP and, if so, whether it included what they want to do and supports they needed, and how often the IPP was reviewed. Respondents were also asked if they had a key worker, an independent advocate or access to an advocacy service.

Most respondents (88.0%) reported that they had a key worker and 84.7% reported that they had an IPP. Little difference emerged between the proportion of those with an IPP who lived in community settings (90.4%) and those who lived in residential centres (90.9%). However, those living independently or with their family were less likely to report having an IPP, at 74.6%. Figure 8.2 presents an overview of the incidence of having an IPP by living circumstances.

Figure 8.2: Incidence of having an individual personal plan (IPP), by living circumstance



Note: N=719; Missing Obs = 34

Almost all people (95.5%) reported that their IPP included what they wanted to do and the support they needed to achieve their aims. Moreover, 89.8% reported that they talked with their key-worker about their IPP and how it was going to be achieved. A total of 85.5% reported that their IPP was discussed with them at least every six months and 92.2% said that they were involved in their IPPs as much as they would like to be.

Reports of involvement in IPPs did not appear influenced to be by ID level; 96.6% ($n=371$) of people with a mild to moderate ID and 92.6% ($n=162$) of those with a severe or profound ID reported such involvement. However, in cases where reports

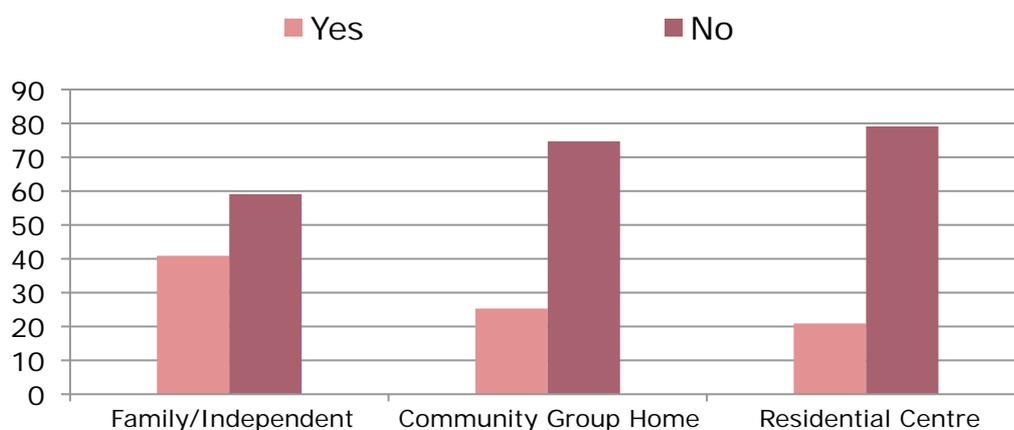
were made by a proxy, there was no means of knowing whether the person with an ID shared the presented view of their involvement in an IPP. Moreover, the contents of IPPs were not reviewed to establish the extent to which they were person-centred.

8.5 Advocacy

Inclusion Ireland, the national association for people with a disability, has shown that the opportunity to be a self-advocate or to access advocacy services increases choice and self-determination in areas such as money management, negotiating with service providers protecting privacy and securing accommodations. McCann (2009) previously reported that service users valued the independence of an advocate and preferred an advocate not to be attached to their support service. In this study however, 74.2% ($n=519$) of respondents reported not having an independent advocate. This was particularly an issue for people living in community settings (74.7%, $n=183$) or residential centres (79.1%, $n=268$). For those who lived independently or with their family, 59.1% ($n=68$), did report receiving independent advocacy. Figure 8.3 presents the utilisation of independent advocacy service according to living circumstances.

In total, 65.2% ($n=424$) of all respondents reported that they had access to an advocacy service, if they so wished. A greater proportion of those with a mild to moderate ID reported having access to advocacy services than those with service or profound ID, at 72% ($n=295$) and 48.9% ($n=93$) respectively. The concept and usage of advocacy is an important issue that will be explored in subsequent waves of IDS-TILDA.

Figure 8.3: Advocacy utilisation according to living circumstances



Note: N = 699; Missing Obs = 54

8.6 Happiness

Many factors influence a person’s quality of life, one of which is the extent to which they feel happy. In this study, respondents who were able to self-report were asked a series of question in relation to happiness. For example, they were asked whether or not they were happy (they could also respond ‘not sure’ to this question) and to identify the main issues in their lives that contributed to their experience of happiness. In-depth narrative information was also captured for each of the items in this section.

Over half of the sample (59.5%, $n=448$) self-completed some or all of the items included in the happiness section of the protocol. A sense of happiness was experienced by most people in this study. Moreover, it emerged that people with an ID have the same desires and everyday sources of pleasure as the rest of the population. Family, friends, feeling engaged in society and simple pleasure were some of the most common causes of happiness for people with ID. For example, one person stated that ‘birds singing in the morning’ made them feel happy, while another said, ‘everything [made them happy]: having my room painted and having a new TV, going home, going out with staff, making phone calls and friends and friends calling to the house’. Most people identified having family in their lives as a source of happiness; one participant succinctly stated, ‘to see my sister smile, happiness in my life at the moment is living with my family.’

Poignantly, a number of participants identified aspirations that others take for granted, like being able to cross the road or use the bus; as one respondent simply stated, ‘when everyone is nice to me I’m happy’.

Among those who responded to the question on how they feel most of the time, 84.4% ($n=403$) reported being happy and just 6.0% ($n=24$) reporting they were not happy, with 9.7% ($n=39$) saying they were not sure. This is comparable to reports of the general Irish population (McGee *et al.*, 2011). Happiness did not appear to be influenced by level of ID and, reports of happiness appeared to increase with age. Table 8.2 presents findings regarding how people feel most of the time, by age.

Table 8.2: How people feel most of the time, by age

Variable	Age categories			
	40-49 years ($n=150$)	50-64 years ($n=191$)	65+ years ($n=62$)	Total ($n=403$)
	%	%	%	%
Happy	81.3	83.2	95.2	84.4
Not happy	9.3	4.7	1.6	6.0
Not sure	9.3	12.0	3.2	9.7

8.7 Future perceptions

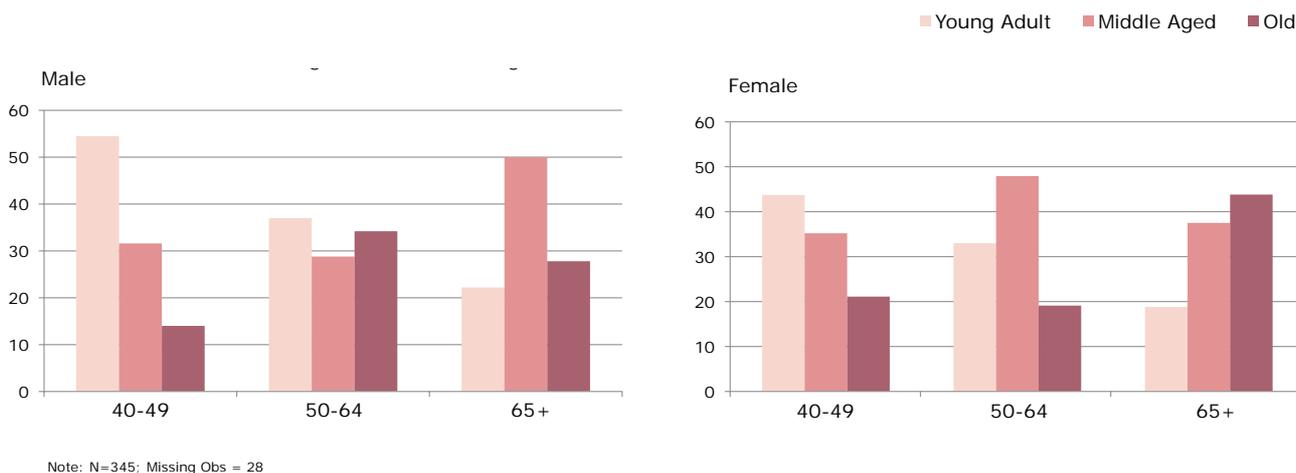
People had a strong sense of what would make them happy in the future; factors here included being with family, having a friend, and having a boyfriend or girlfriend. One person responded, *'just being with my family more'* and another stated, *'if I could have a girlfriend and I could talk to her and have a chat and have a bit of company'*. Other aspirations included getting married or having children. One participant said, *'I'd like to go to ... and be on my own with no staff and get married I would like to have two little boys'*. Having control over one's life and making one's own decisions was another concept raised here; one participant felt that *'getting a new place, a new house where I would chose to live'* would make him happy. Others sought happiness through material acquisitions and wealth gain; one participant noted here, *'to win the lotto, getting my own apartment in the future if I won the lotto'*.

8.8 Beliefs about ageing

Successful ageing is often about adapting to changes over time and having a positive view of the age at which one finds oneself. In this study, respondents were asked a series of questions in relation to their personal views and experience of getting older. When presented with the options of young, middle aged or old, similar proportions of those who self-reported (49.5%, $n=373$) described themselves as young (34.9%, $n=130$), middle aged (34.9%, $n=130$) and as older (22.8%, $n=85$). A higher proportion of men (38.8%, $n=62$) than of women (31.95%, $n=68$) believed themselves to be young. Not surprisingly, people with ID were more likely to view themselves as ageing as their age increased; 16.7% ($n=23$) of people aged 40-49 years believed they were old, compared to 24.2% ($n=43$) of people aged 50-64 years and 33.3% ($n=19$) of those aged 65 years and older.

One positive finding was that 62.6% ($n=209$) felt that older people can do most things that younger people can do, such as work, sports or using the computer. This opinion was held by both genders and among all age categories. In addition, 64.7% ($n=211$) felt that older adults could offer them support, although this view of older adults declined with age; 66.0% ($n=105$) of people aged 50-64 years felt older people could support them while just 41.7% ($n=20$) of people aged 65 years and over expressed the same opinion. Figure 8.4 presents respondents' perceptions of their own age category, by gender.

Figure 8.4: Perceptions of age, by gender



Respondents' personal views and experiences of getting older raised themes of frailty, wisdom, retirement and death. Physical descriptions were prominent; as one noted, *'you get wrinkles, getting slow in your walk, most people who are old complain of pain in their feet'*. Others described the frailty associated with ageing: *'oh getting on, get stiff, memory not as good, you might need glasses and your hearing is not as good as it was slowing down.'* Another respondent identified the anxiety that accompanies increasing dependency as one ages: *'I don't really like it much, that you're not able to look after yourself'*.

On a more positive note, some people attached value to the ageing process. For example, one person expressed their view of growing older as follows: *'it means superior and it's like teaching someone younger than myself. We can help each other, it makes me wiser'*. Others viewed ageing as a time to slow down: *'you can't work anymore, not able to walk'* and another commented that, *'you couldn't work you know, you might get the pension or something like that'*.

Death was also a theme; participants viewed death as final, and this was largely based upon their own experiences of the death of a parent: *'the time my mama was alive I helped her – she was very old she had MS, she died from that and I miss her'*. It was also based on the sense of powerlessness they experienced when faced with death: *'some people go into hospital and don't come home'*.

When asked if they felt that things got better, worse or remained the same in older age, many, regardless of age, opted for better (40.1%, $n=144$) with 34.3% ($n=123$) feeling that things stayed the same. Over one fifth (22.6%, $n=81$) felt things became worse. Table 8.3 presents people's beliefs about ageing, by age.

Table 8.3: Beliefs about ageing, by age

Variable	Age categories			
	40-49 years (n=134)	50-64 years (n=177)	65+ years (n=48)	Total (n=359)
	%	%	%	%
Better	38.1	42.9	35.4	40.1
Worse	25.4	20.9	20.8	22.6
Stay the same	33.6	34.5	35.4	34.3

Note: 3.1% (n=11) of people who self-reported were unable to complete this question

When people were asked if anything good came of growing older, 47.7% (n=143) said yes, and 47.0% (n=141) said no. Women were more likely to answer yes to this question than men, at 49.4% (n=82) and 45.5% (n=61) respectively. In addition, 53.6% (n=59) of people aged 40-49 years held positive beliefs about growing older, as did 44.6% (n=66) of people aged 50-64 years and 42.9% (n=18) of people aged 65 years and older.

Living circumstance was not of major influence here; of those living in residential centres, 46.5% believed there were good things about getting older as did 47.3% of those living in community setting and 46.5% of those living independently or with family.

Respondents identified a range of positive aspects to ageing. For example, one person identified, *'getting a home help and getting someone to do things for you and for company in the afternoon, once a week an afternoon of laughter – I like her a lot.'* Another identified, *'taking part in music and I have my own choice cause I like to play my music all day Saturday and Sunday, when I was younger I did not have that kind of choice'*. Some reflected on their lives, with one noting, *'there are good things and bad things about getting older – you have nice things and free travel but some of your family die'*.

When asked if they had any concerns or worries about getting older a majority of 71.7% (n=261) reported that they had no concerns. A slightly higher proportion of men (25.2%, n=40) than of women (24.4%, n=50) worried about getting older. Regarding age category, those in the 50-64 years age group (25.3%, n=44) were more likely to do so than those in the other age categories. Through further probing of this issue, it emerged that life changing events such as illness, change in living circumstance, family and imminent death caused most concerns. One participant stated, *'I'm nervous about [growing] really old, frightened about it, scared that I might be sick'*. A similar fear was evident when another participant said: *'if you got cancer or a stroke or a heart attack anything might happen, and if anything happened to my family I wouldn't be able to go to them any more'*.

Another noted:

"If I was an elderly person maybe if I was, I'd go into a home or something with other elderly people, I know my mother wouldn't but I would, Mam wouldn't like to go into a home but if it was me I would because I'd have nobody to look after me."

Such concerns should be investigated further.

8.9 Conclusion

The experience of happiness, pleasure and enjoyment of life for people with an ID is comparable to that of the general population, as reported by McGee *et al.* (2011). This is an important finding. Happiness was often linked to family relationships and simple aspects of life that were valued by participants. The fact that many reported feeling younger than their actual age may also be a relevant factor here. The value that respondents placed on the simple things in life was reflected in the importance they placed on choosing the food they ate, the clothes they wore, and what they did in their free time. It is of concern that participants enjoyed less autonomy regarding more significant matters, such as where they lived, who they lived with and how they spent their money.

The National Disability Authority and others (NDA, 2010) continue to emphasise the importance of increasing choices for people with an ID. They also continue to advocate person-centred planning, access to advocacy for those less able to advocate for themselves and the value of an IPP, as a means to realise such choices. Although a small proportion of respondents reported accessing independent advocacy services, the majority of people with ID, particularly those with a mild to moderate ID, did report having access to an advocacy service. A high proportion of respondents also reported having IPPs; however, as these plans were not reviewed, it is not possible to gauge the extent to which they reflect person-centred principles. Future waves of data collection will seek this additional information.

Finally, it was of interest that people with ID had a positive outlook on ageing. This finding contradicts stereotypical images of older people presented by the media. In total, 63% felt that older people could do most things that younger people could do. At the same time, respondents imparted a realistic understanding of the ageing process, sharing concerns relating to the future loss of family and friends, increased dependence and death.

9

Methodology

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9

Methodology

9.1 Summary

- The National Intellectual Disability Database (NIDD) provided the sampling frame for the study and facilitated the random selection of people with intellectual disability aged 40 years and over.
- IDS-TILDA successfully recruited a random sample of 753 participants across all the age groups, male and female, and includes all levels of intellectual disability and living arrangements.
- Ethical approval was sought from and granted by Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin.
- A total of 138 intellectual disability service providers throughout Ireland were involved in supporting people with ID to take part in this study.
- The process of gaining local ethical approval for all the services represented, both statutory and voluntary, was resource intensive. No central/regional ethics committee exists for the statutory and/or voluntary sector.
- Each participant completed, or was assisted to complete a pre-interview questionnaire, and then took part in a face to face interview. A carers' questionnaire was left to complete and return, where applicable.
- Based on the invitations released, a response rate of 46% was achieved which was consistent with expected 45-50% response rate assumed in the sampling strategy. The sample of 753 people with ID aged 40 years and over who completed all interviews represented 8.9% of the total population 40 years and over registered on the 2008 NIDD database.

9.2 Introduction

This chapter reviews the methodological approach utilised for the first wave of IDS-TILDA. The study's underlying structure assumed the following areas are key to understanding the ageing of persons with ID: (1) physical and behavioural health (2) mental and cognitive health (3) health utilization, (4) social networks and supports (5) employment, retirement, day services and lifelong learning and (6) experience of quality of life. The underpinning ethos of promoting the inclusion and participation of people with an intellectual disability (ID) guided the design of the study as did maximizing comparability with the Irish Longitudinal Study on Ageing (TILDA) and other European and international studies on ageing. In addition, the study included measures and topics that are particularly and uniquely relevant to people with ID.

The study's rigorous methodological approach cannot be fully captured in a short summary; a technical report on the IDS-TILDA design of the study, including a more in-depth discussion on each component and the rationale of the design, will be published at a later date.

9.3 IDS-TILDA design

The input of two groups was critical to the design of the study, people with ID and an international scientific committee. In pursuit of inclusion and participation people with an ID were included in every stage of the development, design, implementation and evaluation of the pilot and Wave One of the study. Their input helped in the design of pictorial explications to complement all written material increasing the accessibility of the study's questionnaires. An international scientific committee with extensive experience working with people with intellectual disability advised on the development of all protocols and provided input on both ID-specific content and advised on the opportunities for comparability with international studies. The IDS-TILDA was granted full ethical approval for Wave One by Trinity College Dublin Faculty of Health Sciences Research Ethics Committee in 2009, following the completion of an extensive pilot (McCarron *et al.*, 2010), which tested the survey instruments and fieldwork approach.

9.4 IDS-TILDA target population and sampling methods

The National Intellectual Disability Database (NIDD) collates information on all people with an ID in the Republic of Ireland who are eligible for or receive services. Currently, there are in excess of 26,066 people with an ID registered with the NIDD (Kelly *et al.*, 2010). The population includes persons at all levels of ID, and the full range of residential circumstances. Permission to use the NIDD as a sampling frame was granted after review by the National Intellectual Disability Database Committee. A nationally representative sample was then drawn of people with an intellectual disability aged 40 years and over.

Each person with an ID is assigned a personal identification number (PIN) when registered with the NIDD. Staff at NIDD, consistent with inclusion/exclusion criteria, randomly selected 1,800 'PINs'. The approach recognized that a 50% response rate or less is commonly reported in social research (O'Brien *et al.*, 2006) and so successful recruitment of 750 to 850 people with ID aged 40 years and over from across Ireland was anticipated.

NIDD released the PIN numbers of potential participants to the regional disability database administrator (RDDA) who ensured that information was correct and the person identified was still registered on the NIDD. To preserve confidentiality prior to the completion of consent, invitation packs were provided by IDS-TILDA to each RDDA and the RDDA addressed and posted the pack to the person associated with each PIN received. Invitation packs contained summaries explaining the project and consent forms, including easy read versions, directed to the person with ID and to families and support staff.

Concurrently, IDS-TILDA team members were conducting information sessions with services providers, advocacy organizations and gatherings of families and of people with ID and advertising material on the study (e.g. DVD, information leaflets, posters etc) was distributed. IDS-TILDA staff also explained the forthcoming packs and answered queries or concerns expressed by people with ID, families, staff and services. Services were also encouraged to identify a link person with whom IDS-TILDA team members would liaise in setting up interviews once consents were returned to the IDS-TILDA team.

9.5 Site and services level ethical approval

Ethical approval was sought and received from the Faculty of Health Sciences Ethics Committee at Trinity College Dublin. Individuals with an ID receiving invitation packs were linked to 138 service providers and over an 18 month period local and /or regional ethical committee approval was sought and received from each provider before invitation packs were forwarded. On receiving ethical approval from a service provider a local letter of support for the study was then requested and included in the invitation packs.

9.5.1 Consent process

A potential participant receiving an invitation pack was encouraged in the accompanying letter to read the study material and the consent materials either independently or with support from a key worker/family member and if willing to participate to then sign the consent form and return it in the stamped addressed envelope enclosed. A system of process consent was used whereby the individuals consent was reaffirmed at the time of the interview, and the person's right to withdraw from the study at any time was upheld.

It was recognized that some people with an ID would be unable to provide consent independently. Each invitation pack also included a family pack, and in such cases where the support worker/ key worker or the individual themselves perceived the person as unable to independently self consent, a family member/ guardian was requested to review the materials and to sign a letter of agreement supporting participation in the study of their family member, and to return the letter to the research team in the provided stamped addressed envelope.

A total of 285 participants (38%) self-consented and of these 103 also returned the letter of agreement confirming the family's agreement to their participation. Four hundred and sixty-eight participants (62%) were deemed unable to self consent and a letter of agreement/consent to participate was received from a family member/guardian.

On receipt of consent, the interviewer contacted the participant and/or support person (where designated) to thank them for participating and to explain next steps in the study process.

Following this recruitment approach, the actual recruited, consented and protocols completed sample was 753 people with an intellectual disability aged 40 and over, an overall response rate of 46% which represented 8.9% of the total population 40 years and over registered on the 2008 NIDD database.

9.6 Data collection process

9.6.1 Training of field staff

The fieldwork was carried out by eight research assistants, two PhD students and one MD student. All were selected because of extensive experience of interviewing and working with people with an ID. Each team member completed a structured training program in the administration of the protocol. This addressed understanding the aims and objectives of the research; key components and main purpose of each module; pertinent issues in relation to consent, confidentiality, participant wellbeing and data security; the minimisation of inconsistency and standardisation of face-to-face interviewing; and training in administering face-to-face interviews. All field staff also 'shadowed' an experienced interviewer for a minimum of one interview.

9.6.2 Data collection

A pre-interview questionnaire (PIQ) was sent to the participant approximately seven days prior to the interview. The questionnaire covered demographic information, health status, healthcare utilisation and medication usage. Sending the questionnaire was designed to increase reliability by giving respondents time to source the information; a follow-up phone call ensured receipt of the questionnaire, addressed any initial queries and confirmed the date and time for the face-to-face interview. The interviewer sent an appointment card that included details of the date, time of the scheduled interview and phone contact details. The appointment card included a picture of the interviewer. At the time of the interview, the interviewer reaffirmed willingness to participate, reviewed and collected the PIQ and then completed the computer-assisted administration of the main questionnaire.

Where applicable and with the permission of the person with ID, informal carers were also invited to complete the carer's self-completion questionnaire (carer data will be provided in a separate report).

9.7 The interview

Similar to TILDA the interview included: socio-demographic characteristics; physical health and behavioural health; mental and cognitive health, social participation and social connectedness, health care utilization, employment, income and life-long learning.

Interviews were completed at a place and time chosen by the participant and were undertaken using a computer assisted personal interview (CAPI). Participants reported that they found CAPI less intimidating than a large, paper-based questionnaire. Questionnaires included self-report items to be answered if possible only by the person with ID and other questions which could be completed by either the person or by a carer or key staff.

The respondent's level of communication and level of ID influenced the type of support required to complete the interview resulting in several styles of interview: self-reporting participants, participants supported by a proxy, or proxy interviews conducted on behalf of participants. Proxy is defined as, the 'authority given to a person to act for someone else' (Cambridge, 2011). IDS-TILDA required that proxy informants have known the person with ID for a minimum of six months, where at all possible. Table 9.1 presents frequencies of the types of interview conducted.

Table 9.1: Types of interviews conducted

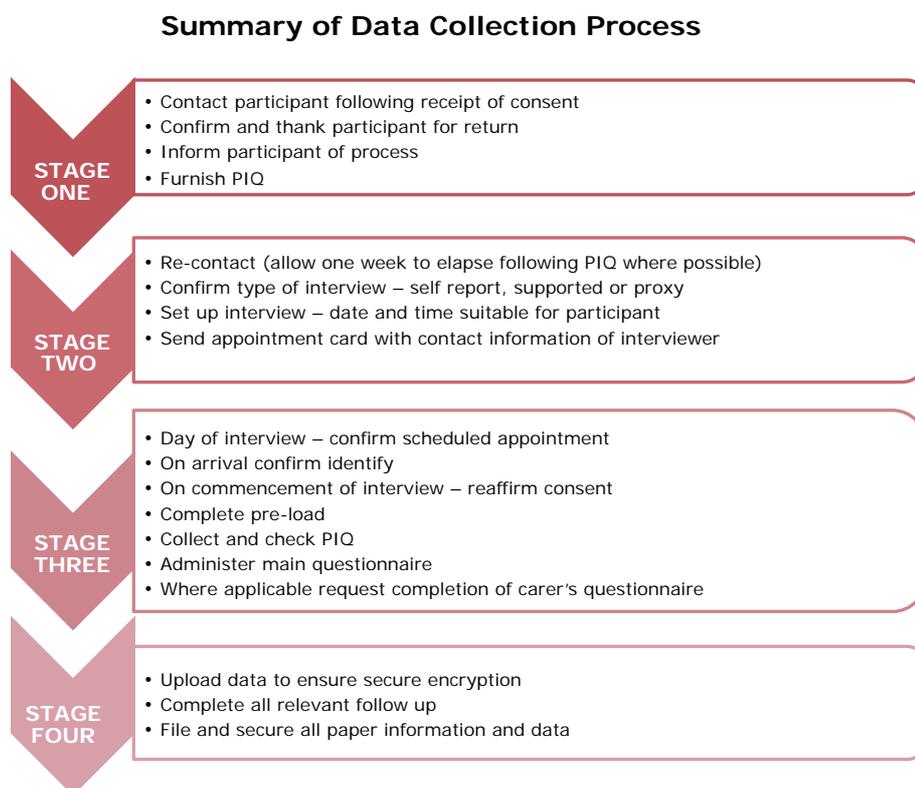
Types of interview	frequency
Direct interview with participant (SR)	147
Assisted interview – a proxy assisted the SR occasionally	157
Assisted interview – a proxy assisted the SR frequently	157
A proxy answered all questions for SR who was present.	127
Interpreted interview (answers given to proxy by the SR)	1
A proxy answered all questions for the SR who was not present	138
Other	26

9.8 Data protection

In cognisance of the Data Protection Act 1988 (amended in conjunction with EU Data Protection Directive 95/46/EC Government of Ireland 2003), all participants were made aware that all collected data for IDS-TILDA will be retained for the duration of the study and the stipulated five year period using encrypted computer storage in a locked facility. Data collected in the field using the CAPI was on password protected laptops and this data was then transferred to secure storage.

Figure 9.1 summarizes the systematic approach taken to establishing interviews collecting data and securely transferring data for storage and analysis.

Figure 9.1: Systematic approach to the data collection process.



9.9 Population distribution

Of the 753 people with an ID who consented to participate in the study; 44.8% were male and 55.2% were female. Gender breakdown by age category are provided in Table 9.2.

Table 9.2: Gender by age

Age category	Male		Female		Total	
	%	frequency	%	frequency	%	frequency
40-49 years	48.9	134	51.1	140	36.4	274
50-64 years	42.2	145	57.8	199	45.7	344
65+ years	43.3	58	56.7	76	17.8	134
Missing Obs.	0.002	1	0	0	0.001	1
Total	44.8	338	55.2	415	100	753

9.9.1 Classifications of populations

To support analysis and comparative reporting, participants were regrouped into categories often by age, gender, location, living accommodation and level of ID. Some groupings were to facilitate explicit comparisons with TILDA data as well as with other national/international reports. The most commonly used categories are summarised below.

Age and gender: respondents were grouped into age categories of 40-49 years, 50-64 years and 65 years and over. An original 'oldest old' category of those aged 75 years and over was merged with those aged 65-74 years, due to small number of participants aged 75 years and over.

Living accommodation: the original 18 categories were collapsed into three sub-groups for convenience of reporting; 'living independently or with family', 'community home' and 'residential centre'.

Level of ID: people identified their level of ID, if it was known, at the PIQ stage. For the purposes of reporting at this initial stage of the study, mild and moderate groups were collapsed together as 'mild/moderate' as were severe/profound.

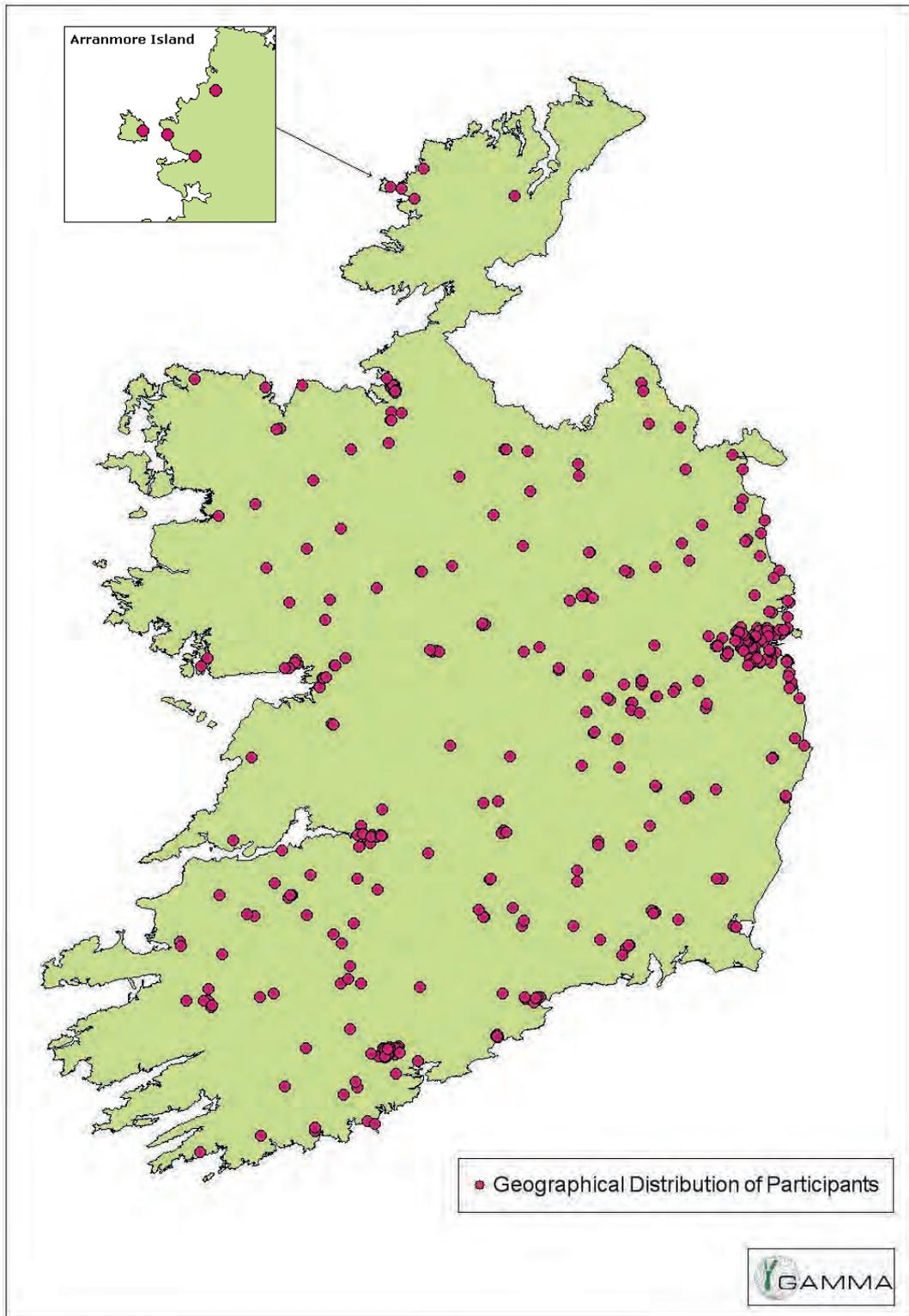
Throughout the report, the unverified/unknown ID level categories are included in analysis; however, they are not included when levels of ID are reported. This will be re-evaluated for subsequent waves and future publications.

Body Mass Index (BMI): BMI was calculated using the reported height and weight of each participant: body weight (in kilograms) by height (in meters) squared (BMI = weight/height²).

9.9.2 Population distribution

The geographic representativeness of the sample was examined (see Figure 9.2) by plotting the locations of everyone interviewed. The 753 people successfully recruited were also examined in terms of geographic subgroups: 'living in Dublin city or county' (28.1%), 'a town or city in the Republic of Ireland' (55.8%) and 'a rural area in the Republic of Ireland' (16.1%). All ten HSE areas were also found to be represented.

Figure 9.2: Geographical distribution of participants



9.10 Data analysis

For the purposes of this report only descriptive data is reported and all analyses were conducted using SPSS version 18. Other than the variables level of ID and aetiology of ID there was a small amount of item level missing data and other than those two variables little evidence that the small amount of missing data would result in differences in findings. This concern will be investigated further in subsequent analyses, including mechanisms to re-weight level of ID in particular.

9.11 Future waves of IDS-TILDA

Steps are now underway to maintain contact with this group in preparation for a second wave data collection planned now for late 2012.

9.12 Limitations and future analyses

It is acknowledged that the purpose of this report is to solely describe the current circumstances of the population; it does not explore causal relationships between factors nor are any differences described reported as statistically significant. Future analyses of data from questionnaire components including formal comparisons between sub-groups within the ID population and compared to the general population will be conducted in the near future to provide a deeper understanding of the health, social, economic, psychological and environmental circumstances of this population group now and as they age.

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