An Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing

2014

Advancing Years, Different Challenges: Wave 2 IDS-TILDA

Findings on the ageing of people with an Intellectual Disability

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September 2014

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ISBN: 978-1-907894-05-3

Acknowledgements

The Wave 2 IDS-TILDA study would not be possible without the support and commitment of a large number of people, groups, bodies and organisations across Ireland, all of whom have played critical roles in making this study a success. Most importantly, we would like to thank our participants, people with an intellectual disability who participated in the second wave of this study. Their willingness to participate exceeded all expectations. Special thanks also to their family members, staff and service providers, who gave their time so willingly to support the study.

The ongoing support of Prof. Rose Anne Kenny, the TILDA team and the staff at the National Intellectual Disability Database (NIDD) at the Health Research Board is gratefully acknowledged.

We also express our thanks to the International Scientific Advisory Committee, who have and continue to play a key role in the study.

We would also like to thank Ms. Anne Shinnors and Steps Advocacy Group, Ms. Margaret Whitehead, Ms. Laura Hunt and the Seasamh Advocacy Group, Ms Mary Lucey and the contribution of the ladies from the CRC, Daughters of Charity and Ms. Lorraine Keating for their contribution in assisting with the review of questionnaires and development of supplementary materials used in Wave 2 of the study.

We would like to thank the researchers and field researchers: Liza Kelly, Patricia Armstrong, Laura Burke Hurley, Gillian Spiller, Sheila Byrne, Andrew Wormwald, Gavin Crilly, Marianne Griffiths, Martin McLaughlin, Máire O'Dwyer, Kathleen Byrnes, Lucy-Anne Foley, Ruben Keane, Evelyn Reilly, Karina O'Sullivan, Darren McCausland, Eimear McGlinchey, Eimear Cleary, Louise McCarron, Mary Ann O'Donovan, Antoinette Hughes, Vicky Andrews, Janet O'Farrell, Eilish Burke, Cathal McCarron, Stephen Burke and Tabitha Carlson.

We would like to acknowledge the contribution of Mr. Michael Keenan for his invaluable IT support and expertise, Ms. Annabel Walsh, Ms. Lisa Fitzgerald, Ms. Jenifer Ryan and Ms. Madeline Smyth for their technical and administrative support.

We would like to thank the National Federation of Voluntary Bodies and Inclusion Ireland for their ongoing support, and the intellectual disability nursing team at the School of Nursing & Midwifery, Trinity College Dublin.

Finally, we would like to acknowledge the funders, the Health Research Board and the Department of Health.

Contents

List of Tables

2. Social Participation for Older Adults with Intellectual Disability

Appendix 2A: Social Participation for Older Adults with Intellectual Disability

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

Appendix 3A: Changes in Physical and Behavioural Health of Adults with an Intellectual Disability Ageing in Ireland

4. Appendix 4A: Mental Health, Well-being and Cognitive Function in Older Adults with an Intellectual Disability

5. Healthcare Utilisation among Older Adults with an Intellectual Disability

6. Methodology

List of Figures

1. Introduction

2. Social Participation for Older Adults with Intellectual Disability

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

4. Mental Health, Well-being and Cognitive Function in Older Adults with an Intellectual Disability

5. Healthcare Utilisation among Older Adults with an Intellectual Disability

6. Methodology

Executive Summary

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 time. At Wave 1, the National Intellectual Disability Database (NIDD) provided the sampling frame for the study and a nationally representative group of 753 respondents with an ID over the age of 40 years were successfully enrolled in the study. At Wave 2, all living Wave 1 respondents were invited to complete a pre-interview questionnaire (PIQ) and also undertake an extensive face-to-face computer assisted personal interview (CAPI). The overall response rate to Wave 2 of the study was 94%. Of those not participating 34 had died. Two new data collection elements were added to Wave 2 consisting of a health assessment and an end of life (EoL) interview conducted with carers of Wave 1 participants who had died. Strategic harmonisation of questions with The Irish Longitudinal Study on Ageing have ensured that there are opportunities to compare the experiences of people with ID with experiences of the general population as they too age.

IDS-TILDA has become a rich data source for the study of the complex interrelationship between pre-existing impairment, physical, psychosocial and environmental factors that affect healthy ageing in persons with ID. 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. As Ireland launches its health reform policy agenda its key policy documents including the *Healthy Ireland – A Framework for Improved Health and Well-Being 2013-2015*, and the National Positive Ageing Strategy (2013) and have set forth opportunities and challenges associated with ageing, particularly ageing for people with an intellectual disability. Just as *The Irish Longitudinal Study on Ageing* (TILDA) is addressing this need for the general population, so too IDS-TILDA is ensuring that there is high quality data on people with an intellectual disability to assist our understanding and support both the implementation and evaluation on the important goals set out in these documents. The data available will also support the integration of this population group into future national health and social care policies and services, better ensuring a healthy and happy life span for all people in Ireland.

In this second summary report we document on how the lives of people with an intellectual disability over 40 years in Ireland has changed over this intervening period, document the point prevalence and incidence of health conditions and compare their ageing to that of the general population with data yielded by TILDA (Nolan *et al.,* 2014). The report will focus particularly on physical and behavioural health, mental health, social participation and connectedness, health care utilisation including the transitions of people into more community based settings. A more detailed and in-depth analysis of all these areas will be dealt with in forthcoming reports, paper's and PhD thesis from members of the research team. Other domains not discussed here such as family caregiving and dealing with chronic illness, and end of life will be expounded in forthcoming PhD thesis reports and publications.

Social Participation and Social Connectedness

The TILDA study of the general older population in Ireland found that engagement in each area of social participation measured (intimate social relationships, formal activity outside work, active and social leisure, passive and solitary leisure) was associated with better quality of life. Similarly, for people aged over 65 years, quality of life was highest for those who were 'most integrated' in terms of social networks and lowest for those 'most isolated' (Nolan *et al,* 2014). For people with an ID current policy in Ireland addresses social and community participation by emphasising deinstitutionalisation and the movement of people with ID into community group homes and more independent settings (Department of the Environment, Community and Local Government, 2011; HSE, 2011). This follows on similar policy and practice in several other countries including Australia, Canada, Sweden, the UK and USA. A specific aim of current policy in Ireland is to move all of the people with ID that currently reside in congregated settings (i.e. in units of 10 or more people, or in clustered campus arrangements) into ordinary housing dispersed amongst the general population. The 'vision' is that people with ID "will be actively and effectively supported to live full inclusive lives at the heart of family, community and society" (HSE, 2011: 25).

Key Findings

- Family networks of older people with ID in Ireland looked very different to that of the general population, insofar as older people with ID are generally single/unmarried and without any children or grandchildren. As such, they were far more reliant on siblings and extended family to provide family networks, especially as they age and parents pass away.
- Most family members of older people with ID lived in different neighbourhoods than their relative with ID; this is very different than that reported by TILDA for the general population and highlights the difficulty in maintaining family connections for older people with ID.
- There was a trend of reduced rates of regular contact with family between Wave 1 and Wave 2. In addition, only a little more than half of all respondents (56.6%) said that they had friends outside their own home. For respondents with severe-profound ID the rate was even lower with less than one third having contact with family. Trends here from Wave 1 to Wave 2 were for a reduction in the number of outside friend contacts and for there to be little difference between experiences in community group homes and residential settings.
- Other social partners appear more critical in the lives of older people with ID, including paid staff, which remained the highest (75.4%), friends with whom people live with (53.4%), and family members (32.0%). Paid staff remained the most likely confidant for respondents in Wave 2; but siblings were more likely to be chosen by people living in independent/family residences.
- While self-reported feelings of social exclusion (loneliness, feeling left out and finding it difficult to make friends) have reduced slightly since Wave 1, women were more likely to feel excluded than men; and people living in institutional settings (on all levels) and in community group homes (in terms of loneliness and difficulty making friends) were more likely to feel excluded than those living in independent/family residences.
- Purposeful contact with neighbours, friends and family was greatly impacted by level of ID, type of residence and age; with those with severe and profound ID, those living in institutional residences and the oldest group much less likely to engage in this type of social participation. Again, the experiences of those in community group homes were closer to those in residential setting than those living in independent/family residences.

- There has been an overall decline in the rate of engagement in social activities between Waves 1 and 2, as well as a decline in participation in voluntary organisations; people with severe/profound ID, those living in institutional environments, those aged 65 years and over, and men were all more likely not to be a member of any voluntary organisation. For the general population, TILDA reported a direct link between such participation and overall quality of life.
- People with severe-profound ID, those aged 65 years and over, and those living in institutional settings were also at much greater risk of being unable to travel around their local communities. However, the experience of those in community group homes was not substantially different with most participants requiring assistance to get around their community.
- Despite often serving a higher functioning and younger population, community group home experiences in terms of community engagement resembled institutional settings; a renewed effort is needed to ensure that community group homes are organised to support greater levels of genuine integration. These findings raise concerns for the planned movement from congregated settings of often older adults with severe and profound ID and higher levels of ill-health.
- There was very little improvement in employment status for respondents between Wave 1 and Wave 2, with dramatically lower levels of employment compared to what TILDA has reported for the general population.
- Respondents who were employed spent an average of 3.3 days a week in work over an average of 15.7 hours a week for an average wage of €72.66
- Two thirds (66.3%) of respondents reported having trouble with reading, writing, numeracy and money management; while very few currently benefit from access and use of communication technologies.
- Four out of five people attended a day service at Wave 2. The majority of these said that they choose their day service activities; and the vast majority said they were very satisfied (59%) or satisfied (36.4%) with their day service.

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

Persons with an intellectual disability (ID) are increasingly living to old age (Kelly & Kelly, 2011) which means that understanding the association between chronic disease and increased age has become an important issue in the care of adults with an ID (Haveman *et al.,* 2010). People ageing with ID are a diverse group with some experiencing age related health conditions relatively early however holding strong positive perceptions of ageing influences not only how older age is approached but also how these health conditions are faced (Burke *et al.,* 2014).

For people with Down syndrome there is higher prevalence and earlier onset of age related sensory and musculoskeletal disorders, and an exceptional risk of developing dementia both of which may result in additional disabilities (McCarron *et al.,* 2014). Additional health needs for people with a range of ID also stem from the interaction of ageing and secondary conditions associated with their impairment, its progression, or as the consequence of long term poor quality health care (Haveman *et al.,* 2009). Many people with cerebral palsy as they age, for example, report reduced mobility, increased pain, and bowel and bladder problems, probably a result of the long term effects of muscle tone abnormalities, and overuse of some joints and immobility of others (Bigby, *et al.,* 2014). Immobility, small body size, poor diet and prolonged use of anti-convulsant drugs may also contribute to early and increased risk of osteoporosis, falls and fractures (Foran *et al.,* 2013). Multi-morbidity is high in this population and prevalence figures in younger age groups are similar to those reported for the oldest old in the general population but with somewhat different disease patterns (McCarron *et al.,* 2013). A large US study of medical records reported that the frequency of cardiovascular, musculoskeletal and respiratory conditions and sensory impairments increased with age, while neurological, endocrine and mental health problems declined with age and that, despite high levels of risk factors such as obesity, heart related diseases did not appear as prevalent in people with ID as reported in the general population (Janicki *et al.,* 2002). However, most of this insight has been gleaned from small scale, local, clinical and cross sectional samples. The tracking of prevalence and incidence of disease and behavioral health contributors over time as is possible through IDS-TILDA and comparisons with general population TILDA data offer a unique opportunity to better understand changes in the physical and behavioural health of people with ID as they age and their implications for their longevity and quality of life.

Key Findings

- Approximately 46% of participants rated their health as excellent or very good which was comparable to the rates reported by TILDA for the general population and to Wave 1 findings.
- Rates of hypertension were more than 50% lower for people with ID (17.5%) than for the general population (37%).
- There was little difference in diagnosed and measured hypertension except among those with severe and profound ID where the measured rate was 50% higher than doctors' diagnoses.
- Myocardial Infarction (heart attack) was 5 times lower in people with intellectual disability than that reported by TILDA for the general population
- Based on WHO risk classification for cardiometabolic disease, 64.6% of IDS-TILDA participants were at substantially increased risk compared to 53% in TILDA with an even greater risk for women with ID, 78.4% versus 56% in TILDA.
- Reported rates of osteoporosis (16.4%) among people with ID had doubled by Wave 2, but more dramatically measurement found that 70% of people with ID indicated osteoporosis or osteopenia.
- 60% described their weight as normal but 66% had measured overweight and obesity, a serious health risk. However, underweight was rarely found in doctor's report or in objective measurement.
- Over 70% engaged in only low levels of physical activity, i.e., in levels of activity not likely to result in health benefits.
- There was a doubling from Wave 1 of rates of cataracts and of macular degeneration and higher incidence for these conditions, as compared to the general population.
- Almost 50% of those aged 65+ reported chronic constipation as did one third of those aged 40-49 years.
- The prevalence of epilepsy increased from 30.5% in Wave 1 to 35.9% in Wave 2 and from 19.2% to 27.9% for those with Down syndrome.
- Arthritis, osteoporosis and cataracts had the highest three-year incidence rates.
- Positive findings are the relatively low levels of fast food consumption, as well as levels of smoking and alcohol use which continued to remain significantly lower than for the general population.

Mental Health, Well-being and Cognitive Function in Older Adults with an Intellectual Disability.

Prevalence and incidence rates of mental health disorders may vary due to different populations, survey methods and diagnostic criteria. Similar methodological issues apply to studies in populations with ID, with the added complexity of aetiology and phenotype differences. Smiley *et al.,* (2007), reported a 2 year mental ill-health incidence rate of 12.6% when problem behaviours were excluded from the analysis. The 2 year incidence rate in those with Down syndrome is reported to be between 3.7% and 14.9% depending on the criteria used (Mantry *et al.,* 2008). Point prevalence rates of major depression (7.6%) and anxiety disorder (4.4%) have been reported from an older ID population with a higher rate of symptomatology of (16.8%) and (16.3%) respectively (Hermans *et al.,* 2013).

In addition to revisiting the measures used in Wave 1 to assess levels of mental ill-health, in Wave 2 additional items enquiring into vitality and life events were added. Identifying the preliminary estimates on the incidence of some disorders was also possible.

Key Findings

- Emotional, nervous or psychiatric disorders continued to be prevalent, nearly 60% of respondents reported receiving such a diagnosis from their doctor.
- The prevalence of reported mental health problems was higher in females and increased with age and level of disability.
- The mean annual incidence of receiving a diagnosis of mental ill health between Wave 1 and Wave 2 was 3.1% overall, 4.2% for anxiety and 2.8% for depressive disorder.
- The prevalence of mental health disorder reported by those with Down Syndrome (DS) was 33.6% which is almost 50% lower than that reported for the non-DS population at 65.8%.
- 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 84.1% and 67.8% respectively.
- The mean annual depreciation in the perception of positive mental health is 5.1% in the group as a whole.
- 14.6% of those completing the CESD reported case level depressive symptomatology with a further 30.5% reporting sub-threshold symptom burden.
- The point prevalence of case level depressive symptomatology increased by 3% since Wave 1
- The mean score on the Energy and Vitality Index (EVI) was 67.2. This compares favourably with the reported national average of 68 for individuals without an intellectual disability.

- Males, those in the youngest age cohort and those living independently reported the highest EVI scores.
- Two-thirds of respondents had experienced at least one significant life event in the previous year. Nearly one third experienced a change of staff and one in five had a change of key-worker in the previous year.
- At Wave 1, 15.8% of participants with Down syndrome reported a diagnosis of dementia which increased to 29.9% by the Wave 2. This group that are at most risk from dementia had a mean incidence of 4.7% per annum.
- Dementia screening for those with Down syndrome improved between Wave 1 and Wave 2. Over half (51.2%) of this cohort had memory screening in the previous 2 years, a considerable improvement from the 32.9% noted in Wave 1.

Health Care Utilisation among older Adults with an Intellectual Disability

Independent, successful ageing and retirement for the general population is usually supported by pensions, other financial resources, social networks and family supports and by good health and health care (McCallion, *et al.,* 2013). Van Schrojenstein Lantaman-De Valk *et al.* (2000) previously compared 318 people with ID 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. Also, Bhaumik *et al.,* (2008) have highlighted higher psychiatric morbidity among elderly (compared with younger) adults with ID. These same researchers and others (for a review, see Haveman, *et al.,* 2009) also found that such physical and mental health conditions and good health in general are highly influenced by the level of and appropriateness of health care access.

Findings in Wave 1 were of a group of people with ID who were satisfied with the healthcare they received and who accessed healthcare services on a regular basis with levels of health care and utilisation similar to general population reports except for higher rates of hospitalisation. There were also high levels of utilisation of social care services (McCarron *et al.,* 2011). Given austerity issues during the last few years there was interest in Wave 2 in exploring the extent to which levels of utilisation may have changed. Also, with increased interest in moving persons with ID out of congregated settings Wave 2 offers an opportunity to take a first look at how movement to different settings influences utilisation of health and social care services.

Key Findings

- There was little change between Wave 1 and Wave 2 in the use of health, specialist health and social care services and medications for people with ID as they age. Those rates of usage remained higher than what is being reported for the general ageing population
- Between Wave 1 and Wave 2, 120 participants changed where they lived and those changes were lateral (61) to more restrictive settings (15) and to less restrictive settings (31) with the remainder (13) in more temporary settings.
- Most individuals with ID reported not participating in choosing the new location to live and that they were not part of the decision to move.
- Participants who moved to more restrictive settings were more likely to use occupational and physiotherapy, social work, psychological/counselling, dental, neurological, geriatrician and palliative services. It will require further investigation to understand if the need for such services necessitated the move to more restrictive settings.
- On a positive note there is clearly a greater effort for people with ID to prevent influenza with vaccination levels at over 90% compared to 57% found for TILDA participants.

Methodology

This is the first report to document changes over time in the IDS-TILDA population. However, changes presented in this report are over a relatively short period of three years and for many measures and questions it was recognised that this may not have been a long enough period to observe substantive change. Nevertheless, specific steps were taken to (1) ensure continuing consistency and quality in data collection; (2) make appropriate adjustments to questions and protocols, (3) track response rates and (4) consider the value of weighting and other adjustments at this stage in the study.

Key Findings

- At Wave 1, the National Intellectual Disability Database (NIDD) provided the sampling frame for the study and a nationally representative group of 753 respondents with an ID over the age of 40 years were successfully enrolled in the study.
- At Wave 2, all living Wave 1 respondents were invited to complete a pre-interview questionnaire (PIQ) and also undertake an extensive face-to-face computer assisted personal interview (CAPI).

- The overall response rate to Wave 2 of the study was 94%. Of those not participating 34 had died. It was determined that weighting to ensure continued representativeness was not necessary for this Wave.
- Two new data collection elements were added to Wave 2 consisting of a health assessment and an end of life (EoL) interview conducted with carers of Wave 1 participants who had died.
- Strategic harmonisation of questions with The Irish Longitudinal Study on Ageing (TILDA) have ensured that there are opportunities to compare the experiences of people with ID with experiences of the general population.
- Attention to key policy documents in Ireland have ensured that there are questions and data available to assess how the implementation of key policies is influencing over time the ageing experience of people with ID.

The additional objective measures of health introduced in Wave 2 have enhanced the opportunities to better understand health status and to gather data that will better respond to the *Healthy Ireland* policy. As the study matures and the numbers of Waves increases, the opportunities to compare with TILDA will be sustained and key policy concerns will continue to be tracked. With the methodological steps taken, change will be measured more and more precisely, enabling a greater understanding of the key determinants of health and well-being of older adults with an intellectual disability in Ireland.

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1

Introduction

Mary McCarron and Philip McCallion

Contents

1 Introduction

1.1 Introduction

In September 2011, a summary report on initial findings from a major landmark study, the *"Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing"* (IDS-TILDA) was published. This study was not only the first of its kind in Europe but it was also the only study with potential to compare the ageing of people with intellectual disability directly with the general ageing population.

1.2 Rationale for an Intellectual Disability Supplement

Ageing in ID is a relatively new phenomenon and there is a substantial gap in our knowledge as to how this increasingly at risk and vulnerable population age (McCarron *et al.,* 2011). International cross-sectional studies do provide some clues and suggest that as a group, individuals with intellectual disabilities (ID) have a greater variety and number of health care needs compared to those of the same age and gender in the general population (see Haveman *et al.,* 2010 for a detailed review). The Haveman *et al.,* review (2010) also draws attention to the lack of longitudinal and incidence studies on the health of elderly people with ID. Reasons cited include difficulties in securing the needed financial resources to conduct studies, difficulty in securing needed samples sizes, recruitment and retention challenges and consent and ethical issues. Yet, similar to the general population, longitudinal studies are likely a critical element in the evidence base for understanding the key determinants of health and well being of people with an ID as they age (McCarron & McCallion, 2007). They have a particular advantage in their ability to examine multiple exposures, determinants and outcomes, and to measure relationships between variables over time.

One solution would be to ensure the inclusion of people with ID in general population longitudinal studies but there is a dearth of examples where this has occurred. Often the sampling frame or the mechanisms for data collection reduce the likelihood of such inclusion, but a question arises is the issue simply a lack of attention. *The Irish Longitudinal Study on Ageing in Ireland* (TILDA) (Kenny *et al.,* 2010) recognised that inclusion of a supplement which would purposefully include persons with an ID would not only improve understanding of how people with an ID age in their own right but support direct comparison with data from other groups of older adults to understand differences in ageing experiences. A supplement would also help illuminate the roles of disability, education, lifestyle, living situations, social networks, health concerns, health service utilisation and environmental factors in supporting or thwarting successful ageing for people with ID. The Intellectual Disability Supplement to TILDA (McCarron *et al.,* 2011) closely harmonised questions with the general ageing study TILDA to ensure that (1) differences and similarities between the population groups would be systematically ascertained, and (2) data collected inform the development of future policies, services, and resources that better address the needs of both groups as they age in Ireland.

IDS-TILDA was also designed to explore unique issues for people with ID, e.g., their ageing profile, health, health service needs, psychological health, social networks, living situations and community participation including employment. In addition the experience of family carers has been captured.

In the general ageing field there is a long-standing awareness that longitudinal studies have played a major role in understanding many health concerns in older adults, their natural history and the complex interplay between biological, genetic, environmental, psychological and social factors on health and well-being (Newman, 2010, Stanziano *et al.,* 2010). Despite this awareness, we have little understanding of similar or different interplays of these factors on health and well-being of persons with ID as they age. The Intellectual Disability Supplement to TILDA has been launched as a program of research and a platform to investigate risk and protective factors, and increase our understanding of the trajectories of healthy ageing in persons with ID as compared to those for the general population.

1.3 First Wave Findings

First wave data was collected on a random sample of 753 people with ID aged 40 years and over, drawn from Ireland's National Intellectual Disability Database (Kelly *et al.,* 2010). Preliminary results from Wave I highlighted the reality of health disparities for people with intellectual disability as they age (McCarron *et al.,* 2011), including higher levels of mental health problems, increased risk factors for cardiovascular disease, obesity and polypharmacy, coupled with lower levels of physical activity, access to health information, and health care screenings. Additional findings that people with intellectual disability were also usually unemployed, had lower levels of education and access to life-long learning, and had more limited social networks and friendships and high levels of loneliness further highlighted their difficulties in accessing community supports, integrating within their communities and perhaps placed them at greater vulnerability in terms of the social determinants of health as one ages. A particular concern from the data was that despite decades of efforts to move people with an ID from segregated into community-based accommodation, some still lived in large segregated settings and many living at addresses in the community continued to remain poorly connected with those communities.

1.4 Understanding the link to public policy

The pursuit of longitudinal answers to ageing questions for people with intellectual disability at a research level is similar to the same questions within the general population and must now be mirrored in policy responses to the data gathered. As Rimmer (2011) suggests, inclusion 'merely gives us (people with ID and their advocates) entrance into the vast 'mall' of public health; ... Getting into the mall is one thing, getting into the reports, documents and policy recommendations is a totally different thing'. As a supplement to mainstream efforts to understand ageing, IDS-TILDA is intended to promote such inclusion and not separate consideration of older adults with ID. There is little to be gained for people with ID if they, their families and their advocates discuss these issues only with each other; policy makers and health professionals with an interest in ageing but limited knowledge of intellectual disability must be reached to ensure that issues for persons with ID are at the table when policies are formulated on health care reform, health promotion, the built environment, combating obesity, and strategies to prevent the development of additional secondary disability.

As Ireland launches its health reform policy agenda, its key policy documents including the *Healthy Ireland – A Framework for Improved Health and Well-Being 2013-2025* and *Move from Congregated Settings* (DoH, 2013; HSE 2011) have set forth opportunities and challenges associated with ageing, particularly ageing for people with an ID (see *figure 1.1*). Just as *The Irish Longitudinal Study on Ageing* (TILDA) is gathering and presenting general population data to inform these efforts, so too IDS-TILDA is ensuring that there is high quality data on people with an ID to assist our understanding and support both the implementation and evaluation of the important goals set out in these documents. The data available will also support the integration of this population group into future national health and social care policies, and services, better ensuring a healthy and happy life span for all people in Ireland. Perhaps, however, the most important role for IDS-TILDA is to be a launching pad to raise visibility of the needs and experiences of persons with ID as they age and to encourage the cross-walking of that information between specialised ID services and general public health environments.

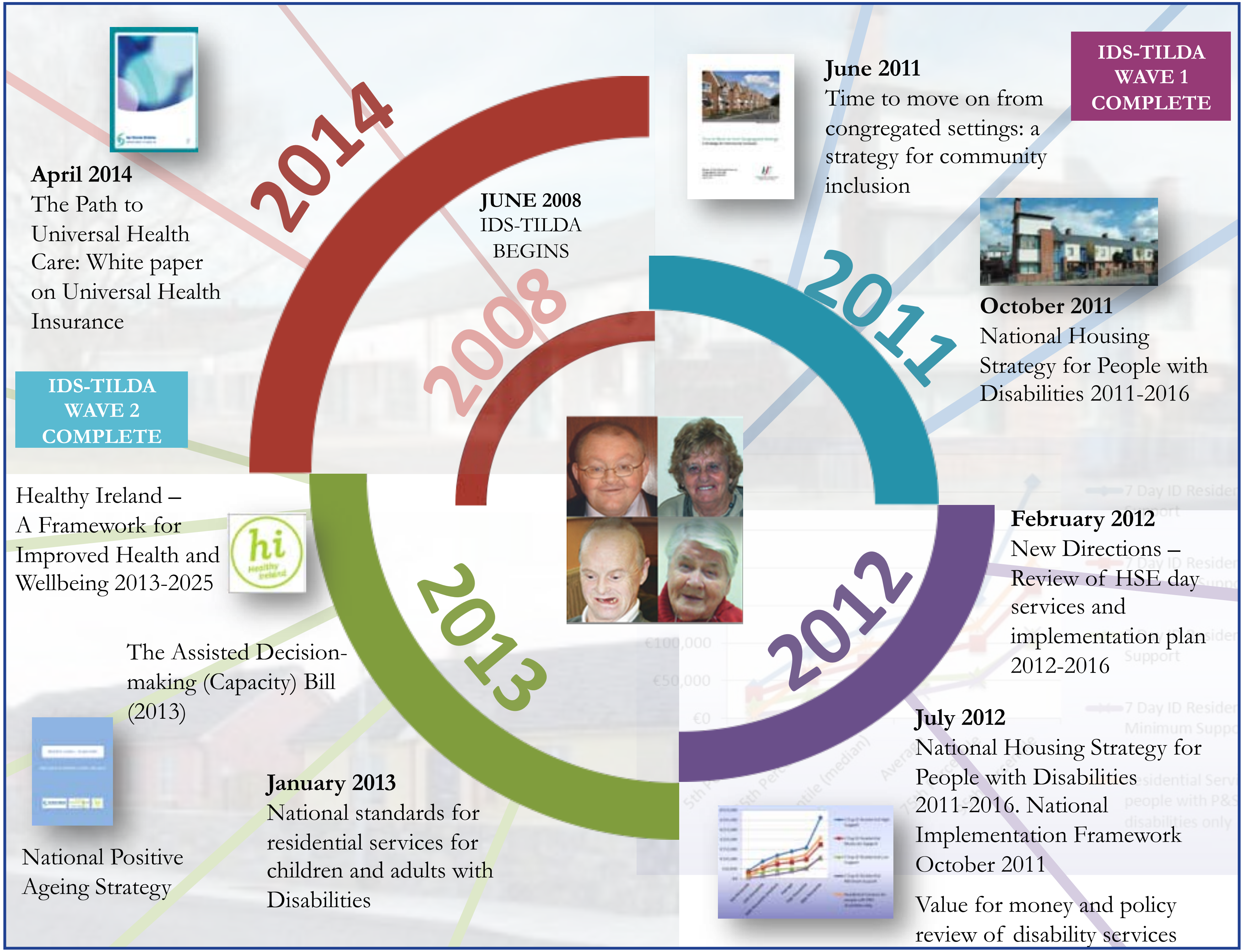
There are also ID-specific issues and over time IDS-TILDA will assist in identifying key issues in the prevention of disease and secondary disability in people with ID and improve understanding of the roles of pre-existing disability, social and living circumstances, education, wealth and social connectedness. There is also a need for similar intellectual disability supplements to longitudinal studies in other countries which will only occur when there are ID researcher advocates and openness by other researchers, funders and governments to support them. Such a commitment will 'bear fruit' in the implementation of evidence based policies that not only 'add years to life, but life to years' for people with intellectual disability as they age.

1.5 Wave 2 of The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA).

IDS-TILDA is now ready to report the results of its second wave of data collection. As can been seen in *figure 1.1* the period since IDS-TILDA began in 2008 has seen considerable social and economic change. In this second summary report, we document how the lives of people with an intellectual disability over 40 years in Ireland has changed over this intervening period, document the point prevalence and incidence of health conditions, and compare their ageing to that of the general population as documented in data yielded by TILDA (Nolan *et al.,* 2014). The report will focus particularly on physical and behavioural health, mental health, social participation and connectedness, and health care utilisation including the transitions of people into more community based settings. A more detailed and in-depth analysis of all these areas will be dealt with in forthcoming reports, papers and PhD theses from members of the research team. Additional domains not discussed here such as family caregiving, dealing with chronic illness and end of life will be addressed in forthcoming PhD thesis reports and publications.

Details of IDS-TILDA methodology, sampling and study population are described in the Wave I summary report (McCarron *et al.,* 2011). Chapter 6 of this report contains a detailed description of methodology for Wave 2 including a summary of amendments to the original protocol from Wave 1 and a detailed description of objective measures. The recruitment and data collection approaches for Wave 2 are illustrated in *figure 1.2.*

Figure 1.1 Positioning IDS-TILDA among the policy change affecting the field of intellectual disability in Ireland 2008 – 2013.



JUNE 2008
IDS-TILDA
BEGINS

IDS-TILDA
WAVE 1
COMPLETE

June 2011
Time to move on from congregated settings: a strategy for community inclusion

October 2011
National Housing Strategy for People with Disabilities 2011-2016

February 2012
New Directions – Review of HSE day services and implementation plan 2012-2016

July 2012
National Housing Strategy for People with Disabilities 2011-2016. National Implementation Framework October 2011

Value for money and policy review of disability services

January 2013
National standards for residential services for children and adults with Disabilities

National Positive Ageing Strategy

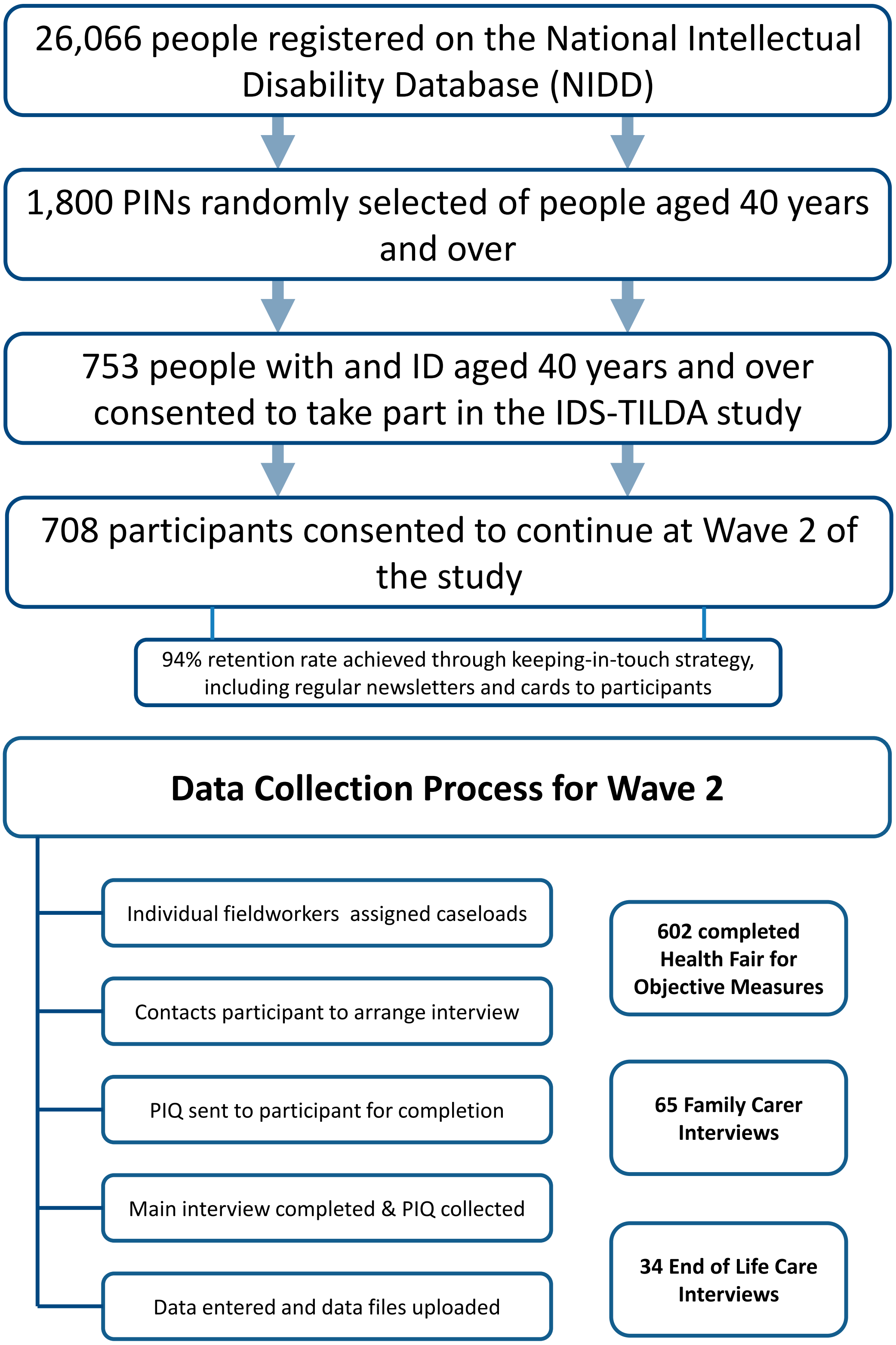
The Assisted Decision-making (Capacity) Bill (2013)

Healthy Ireland – A Framework for Improved Health and Wellbeing 2013-2025

IDS-TILDA
WAVE 2
COMPLETE

April 2014
The Path to Universal Health Care: White paper on Universal Health Insurance

Figure 1.2: Recruitment and data collection process for IDS-TILDA



1.6 Key Aspects of Wave 2

- At Wave 1, the National Intellectual Disability Database (NIDD) provided the sampling frame for the study and a nationally representative group of 753 respondents with an ID over the age of 40 years were successfully enrolled in the study.
- At Wave 2, all living Wave 1 respondents were invited to complete a pre-interview questionnaire (PIQ) and also undertake an extensive face-to-face computer assisted personal interview (CAPI).
- The overall response rate to Wave 2 of the study was 94%. Of those not participating 34 had died.
- Two new data collection elements were added to Wave 2 consisting of a health assessment and an end of life (EoL) interview conducted with carers of Wave 1 participants who had died.
- Strategic harmonisation of questions with The Irish Longitudinal Study on Ageing (TILDA) have ensured that there are opportunities to compare the experiences of people with ID with experiences of the general population as they too age.
- Attention to key policy documents in Ireland have ensured that there are questions and data available to assess how the implementation of key policies are influencing over time the ageing experience of people with ID.

1.7 Structure of the Report

We begin in Chapter 2 by describing how social participation and social connectedness changes over time by comparing relevant data from Wave 1 to Wave 2. We examine levels and types of social connections, engagement in social life, facilitators and barriers of social participation, and changes in residential status since Wave 1. Where possible comparisons will be made with the general population with data yielded from TILDA and/other identified sources. This descriptive and comparative approach is repeated in chapter 3 through 5. Chapter 3 focuses on the changes in physical and behavioural health. Point prevalence and incidence of health conditions will be presented and comparisons will be shown with the general population using reported data from TILDA (Finucane *et al.,* 2014; Leahy *et al.,* 2014). Chapter 4 focuses on changes in mental health including consideration of cognitive decline and the impact of life events. Chapter 5 focuses on health care utilisation and how it changes as people with ID move between living situations. Finally, Chapter 6 documents the methodological approach utilised for Wave 2 of IDS-TILDA, and describes the sample and new elements of data collection.

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Appendix 1: IDS-TILDA Reports and Publication

IDS-TILDA Reports and Accessible Material

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1. Burke, E., McCarron, M., Carroll, R., McGlinchey, E. & McCallion, P. (2014)What it’s like to grow older: The aging perceptions of people with an intellectual disability in Ireland. *Intellectual and Developmental Disabilities,52*(3), 205 – 219.
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2. McCausland D., McCallion P., McCarron M. Social Connections for Older People with Intellectual Disability in Ireland: Results from Wave One of IDS-TILDA. *Journal of Applied Research in Intellectual Disability.*

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1. Burke E., McCallion, P., Walsh JB., and McCarron M. Structured Feedback from Older Adults with an Intellectual Disability on their Experience of Attending for a Health Assessment – Results from a Feasibility Study.
2. Burke E., McCarron M., Walsh JB., and McCallion, P. Osteoporosis and People with Down Syndrome; A preliminary Descriptive Examination of the IDS-TILDA Wave 1 Results.
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Ms. Janet Swinburne*: Feasibility of Anthropometric Measurements for Large-scale Application in the Irish Longitudinal Study on Ageing among People with an Intellectual Disability (IDS-TILDA): An Exploratory Study. Trinity College Dublin 2014.

Ms. Sinead Foran: The prevalence and predictors of falls and falls related injuries in older adults with intellectual disabilities in Ireland.

Dr. Niamh Mulryan (MD student): Mental health and associated factors in a national sample of persons with an intellectual disability aged 40 and over.

Ms. Maire O'Dwyer: Prevalence, Patterns and Indications for Medicine Use in an Ageing Population with Intellectual Disability.

Ms. Ann Belton: Changing patterns of medication use in an ageing population with an intellectual disability.

Ms. Mary Ann O'Donovan: Changes in living arrangements in later life: implications for health services and the health of the older person with an intellectual disability.

Ms. Marianne Griffiths: An exploratory study measuring changing experiences of carers of older people with an Intellectual Disability and investigating their support service requirements in the context of continued caregiving.

Mr. Darren McCausland: A study of social participation for older people with intellectual disabilities.

Ms. Janet Clare O'Farrell: Understanding equality and inclusion in Palliative Care: Identifying and addressing the needs of people with an Intellectual Disability.

Ms. Eilish Burke: An exploratory study to measure bone health and the prevalence of osteoporosis in older people with an intellectual disability in Ireland.

2

Social Participation for Older People with Intellectual Disability

Darren McCausland, Philip McCallion, Rachael Carroll, MaryAnn O'Donovan, Eimear McGlinchey, Carolyn Shivers, Eilish Burke and Mary McCarron.

Contents

An Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing

2

Social Participation for Older People with Intellectual Disability

2.1 Key Findings

- Family networks of older people with ID in Ireland looked very different to that of the general population, insofar as older people with ID are generally single/unmarried and without any children or grandchildren. As such, they were far more reliant on siblings and extended family to provide family networks, especially as they age and parents pass away.
- Most family members of older people with ID lived in different neighbourhoods than their relative with ID; this is very different than that reported by TILDA for the general population and highlights the difficulty in maintaining family connections for older people with ID.
- There was a trend of reduced rates of regular contact with family between Wave 1 and Wave 2. In addition, only a little more than half of all respondents (56.6%) said that they had friends outside their own home. For respondents with severe-profound ID the rate was even lower with less than one third having contact with family. Trends here from Wave 1 to Wave 2 were for a reduction in the number of outside friend contacts and for there to be little difference between experiences in community group homes and institutional settings.
- Other social partners appear more critical in the lives of older people with ID, including paid staff which remained the highest (75.4%), friends with whom people live with (53.4%), and family members (32.0%). Paid staff remained the most likely confidant for respondents in Wave 2; but siblings were more likely to be chosen by people living in independent/family residences.
- While self-reported feelings of social exclusion (loneliness, feeling left out, and finding it difficult to make friends) have reduced slightly since Wave 1, women were more likely to feel excluded than men; and people living in institutional settings (on all levels) and in community group homes (in terms of loneliness and difficulty making friends) were more likely to feel excluded than those living in independent/family residences.
- Purposeful contact with neighbours, friends and family was greatly impacted by level of ID, type of residence and age; with those with severe and profound ID, those

living in institutional residences, and the oldest group much less likely to engage in this type of social participation. Again, the experiences of those in community group homes were closer to those in institutional settings than those living in independent/ family residences.

- There has been an overall decline in the rate of engagement in social activities between Waves 1 and 2, as well as a decline in participation in voluntary organisations; people with severe/profound ID, those living in institutional environments, those aged 65 years and over, and men were all more likely not to be a member of any voluntary organisation. For the general population, TILDA reported a direct link between such participation and overall quality of life.
- People with severe-profound ID, those aged 65 years and over, and those living in institutional settings were also at much greater risk of being unable to travel around their local communities. However, the experience of those in community group homes was not substantially different, with most participants requiring assistance to get around their community.
- Despite often serving a higher functioning and younger population, community group home experiences in terms of community engagement resembled institutional settings; a renewed effort is needed to ensure that community group homes are organised to support greater levels of genuine integration. These findings raise concerns for the planned movement from congregated settings of often older adults with severe and profound ID and higher levels of ill-health.
- There was very little improvement in employment status for respondents between Wave 1 and Wave 2, with dramatically lower levels of employment compared to those which TILDA has reported for the general population.
- Respondents who were employed spent an average of 3.3 days a week in work, over an average of 15.7 hours a week, for an average wage of €72.66.
- Two thirds (66.3%) of respondents reported having trouble with reading, writing, numeracy and money management; while very few currently benefit from access and use of communication technologies.
- Four out of five people attended a day service at Wave 2. The majority of these said that they choose their day service activities; and the vast majority said they were very satisfied (59%) or satisfied (36.4%) with their day service.

2.2 Context: Social Participation and Intellectual Disability

The TILDA study of the general older population in Ireland found that engagement in each area of social participation measured (intimate social relationships, formal activity outside work, active and social leisure, and passive and solitary leisure) was associated with better quality of life. Similarly, for people aged over 65 years, quality of life was highest for those who were 'most integrated' in terms of social networks, and lowest for those 'most isolated' (Nolan *et al.,* 2014).

For people with an ID current policy in Ireland addresses social and community participation by emphasising deinstitutionalisation and the movement of people with ID into community group homes and more independent settings (Department of the Environment, Community and Local Government, 2011; HSE, 2011). This follows on similar policy and practice in several other countries including Australia, Canada, Sweden, the UK and USA. A specific aim of current policy in Ireland is to move all of the people with ID that currently reside in congregated settings (i.e. in units of 10 or more people, or in clustered campus arrangements) into ordinary housing dispersed amongst the general population. The 'vision' is that people with ID *"will be actively and effectively supported to live full, inclusive lives at the heart of family, community and society"* (HSE, 2011: 25).

In the research literature, Mansell and Beadle Brown (2009) noted general findings that community-based service models achieve better outcomes for people with ID than institutions, with some variation reflective of individual characteristics and range of abilities, characteristics of service design and, most importantly, differences in staff performance; Emerson and Hatton (1994) found that a majority of transition studies in the UK and Ireland showed positive impacts across five of six outcome measures (including community participation); Young *et al.,* (1998) reported that a majority of similar studies in Australia showed positive impacts across six of nine outcome measures (including community participation and contact with family/ friends); and in the USA, Heller *et al.,* (1998) found that people moving out of a nursing home found more positive community functioning. Participation increased from close to no activities to activities one to three times per month. Activities usually consisted of talking with family and friends and visiting friends. However, the actual day to day differences in people's lives were limited. Findings by Emerson and McVilly (2004) raised concerns in that they found that people with ID living in community settings had low levels of friendship activities over a four-week period, with a median of two friendship activities with friends who also had an ID, and a median of zero friendship activities with people who didn't have an ID.

Similarly, Robertson *et al.,* (2001) reported low levels of social connectedness amongst people with ID living in community residences with an average social network size of just two people (excluding staff). Finally, Cummins and Lau (2003) concluded their review of community participation research by criticising what they saw as a 'heavily biased' literature misrepresenting community integration as physical presence when it should be about personal experiences and a sense of belonging to community. Similarly, Verdonschot *et al.,* (2009) noted that, while people with ID living in community settings participated more in the community than those in segregated dwellings, their level of participation remained much lower than for people with other disabilities or for those without an identified disability.

These are important concerns and challenges as Ireland moves an increasing number of people with ID into the community. In Wave 1 of IDS-TILDA community settings were found to offer more opportunities, but overall people with ID still often have low levels of connectedness with family and friends and small social networks outside of staff and the other people with ID with whom they live – relationships whose importance nonetheless also needs to be recognised (Novak Amado *et al.,* 2013). Even where improvements are reported, people with ID appeared to start from such a low baseline that improvements still leave them less connected than the general population and/or people with other types of disabilities. The initial findings presented in this chapter, along with more in-depth analyses of Wave 2 data later on, will add to our understanding of social participation for older people with ID and how it is influenced by where people live.

2.3 Social & Community Engagement. Results & Comparison Wave 1 to Wave 2

Findings from Wave 2 of IDS-TILDA are outlined in this section. These are drawn mainly from the Social Participation and Social Connectedness, Occupation and Lifelong Learning modules of the main questionnaire. Changes over time are outlined by comparing relevant data from Wave 1. Comparisons between older people with ID with the general Irish population are made where possible using data reported from Wave 2 of TILDA and other identified sources. Findings in this section will look at results for social connections, engagement in social life, facilitators and barriers of social participation, and a range of different aspects related to occupation and lifelong learning.

2.3.1 Social Connections for People with Intellectual Disability

As in Wave 1, respondents were asked about the type and frequency of contacts that they had with family and friends who they were not living with. New to Wave 2, respondents were also asked to identify the members in their family network, and their proximity to those family members.

2.3.1.1 Connections with Family

As noted in Wave 1, in contrast to the general population the vast majority of older people with ID were not married and had no children. Without the network provided by partners, children and grandchildren, older people with ID are more reliant on parents, siblings and extended family. This is reflected in table 2.1 below, which shows that sisters (77.0%, *n*=538) and brothers (70.4%, *n*=492) are the most common family members, followed by niece/nephew (53.2%, *n*=372), cousins (25.3%, *n*=177) and mothers (24.6%, *n*=172). Those over 65 are the group most likely to report having no family at all (8.8%).

Table 2.1: Family of Older People with ID

Family Member	Gender		Age			Level of ID			Type of Residence			Total	
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe-Profound	Independent / Family	Community Group Home	Institution	*n*	%
Sister	73.1	80.1	84.2	77.2	66.9	68.0	77.0	82.3	86.7	78.2	71.7	538	77.0
Brother	68.5	71.9	75.5	73.5	56.1	73.2	69.0	69.8	81.4	70.3	66.1	492	70.4
Niece/Nephew	51.6	54.5	57.7	52.7	48.6	51.6	61.7	39.6	74.3	54.1	43.8	372	53.2
Cousin	24.4	26.1	29.1	26.5	17.6	33.3	26.3	16.7	38.1	27.1	18.4	177	25.3
Mother	26.0	23.5	47.4	21.1	2.7	24.2	23.0	25.5	39.8	23.1	20.1	172	24.6
Aunt/Uncle	14.6	16.9	24.5	15.2	6.1	24.8	17.0	7.8	32.7	15.5	9.5	111	15.9
Father	9.7	9.0	22.4	5.6	0.7	9.2	7.0	13.5	18.6	7.3	7.8	65	9.3
Spouse/Partner	1.0	0.8	1.0	1.1	0.0	1.3	0.7	0.0	2.7	0.7	0.4	6	0.9
Other	3.6	2.3	2.6	2.8	3.4	3.3	2.0	3.1	7.1	2.0	2.1	20	2.9
No family	3.9	3.6	2.0	2.5	8.8	4.6	4.0	2.6	0.0	3.6	5.3	26	3.7
Total	308	391	196	355	148	153	300	192	113	303	283	699	

Where respondents indicated that they did have family members, they were then asked to identify where those family lived in relation to them. With the exception of cousins (52.6%, *n*=91), the majority of family members lived outside the respondent's own neighbourhood (see table 2.2 below). However, with approximately 40% additionally having family members who live in the same county, there is perhaps the potential to improve the social connectedness for older people with ID by utilising this relatively untapped social resource. As we will see below, less than a third of respondents currently do social activities with family.

Table 2.2: Proximity of family members

Proximity	Spouse/ Partner	Mother	Father	Brother	Sister	Aunt/ Uncle	Niece/ Nephew	Cousin	Other
Lives with me	33.3	19.8	21.5	4.5	5.1	0.9	2.5	6.9	26.3
In same building	0.0	0.6	3.1	1.4	0.9	0.0	0.5	0.0	0.0
In same neighbourhood	16.7	7.6	7.7	9.6	7.9	11.0	9.0	45.7	10.5
In same county	16.7	40.1	38.5	43.4	45.6	44.0	46.9	0.0	42.1
In different county	33.3	30.8	29.2	32.6	34.2	38.5	35.1	38.7	15.8
In different country	0.0	1.2	0.0	8.4	6.2	5.5	6.0	8.7	5.3
n	*6*	*172*	*65*	*488*	*531*	*109*	*367*	*173*	*19*

Respondents were asked about the frequency of face-to-face, phone and written contact they had with family members who they were not living with. *Figures 2.1 and 2.2* below show the changes in face-to-face and written contact between Waves 1 and 2. While the number of people who never have contact with their family has fallen slightly, there were also fewer people with regular contact (i.e. at least monthly) at Wave 2 compared to Wave 1. Regular/monthly face-to-face contact has fallen from 53.5% (*n*=394) in Wave 1 to 52.3% (*n*=348) in Wave 2. Whereas regular telephone contact has fallen from 49.7% (*n*=336) in Wave 1 to 46.6% (*n*=298) in Wave 2. Written contact remains very low, with just 4.2% (*n*=25) having such contact at least once a month (down slightly from 4.8%, *n*=31, in Wave 1). For further details see Appendix Tables 2.A.1, 2.A.2, 2.A.3.

Figure 2.1: Face-to-face contact with family

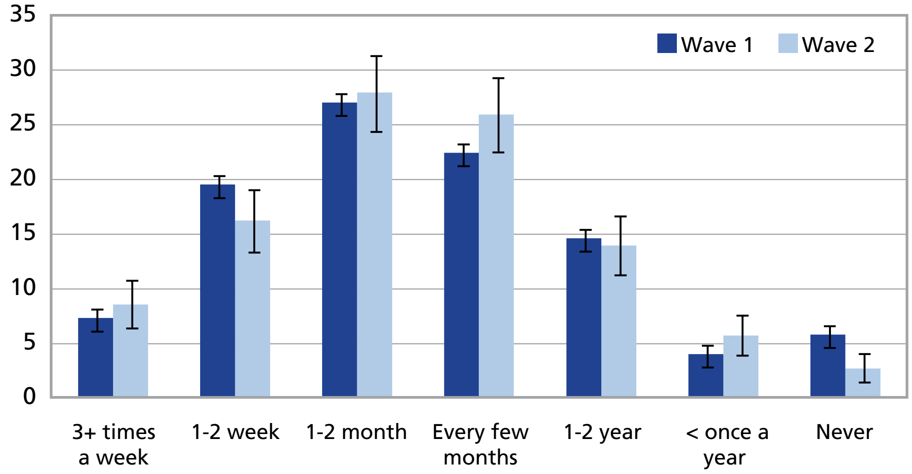
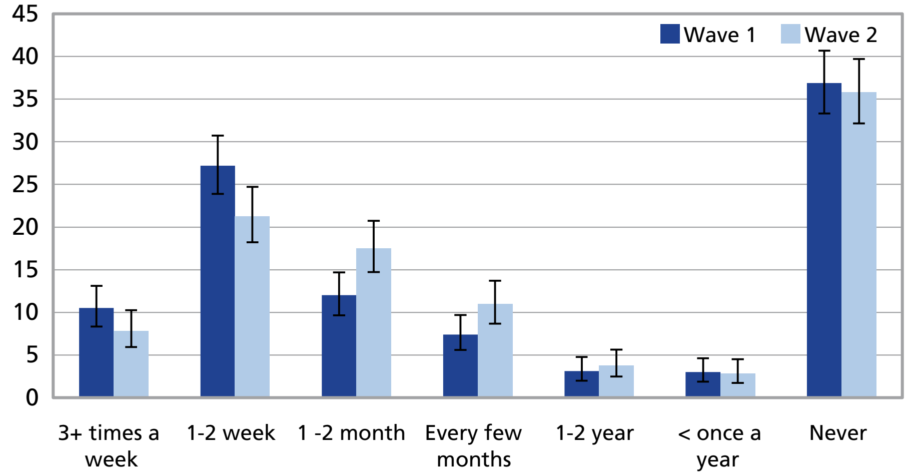


Figure 2.2: Telephone contact with family



2.3.1.2 Connections with Friends

In Wave 2 respondents were first asked to indicate whether or not they had any friends outside their own home and then to report on the type and frequency of such social contacts. As may be seen in table 2.3 below almost half of respondents (43.4% *n*=301) had no friends outside their own home; the numbers and percentages were lower for respondents with severe-profound ID (34.4%, *n*=65); those living in independent/family residences were more likely to have friends outside their own home (86.7%, *n*=98) compared to those living in community group homes (59.5%, *n*=179) or institutional settings (41.2%, *n*=115). While the importance of friends who participants lived with should not be underestimated, these results are nonetheless indicative of particularly limited social networks for all people with ID. Those with the most severe disabilities and living in institutional settings are at greatest risk, with concerns remaining for those in community group homes.

Table 2.3: Do you have friends outside your home?

	Wave 2		Number in sample
	%	95% CI	
Gender:			
Male	52.5	46.7 – 58.16	305
Female	59.8	54.71 -64.67	388
Age:			
43-49	59.2	51.93 – 66.06	196
50-64	57.8	52.46 – 63.02	351
65+	50.0	41.66-58.34	146
Level of ID:			
Mild	77.1	69.5-83.35	153
Moderate	57.9	52.06-63.55	297
Severe/Profound	34.4	27.74-41.68	189
Type of Residence:			
Independent/Family	86.7	78.74-92.14	113
Community Group Home	59.5	53.67-65.02	301
Institutional	41.2	35.43-47.26	279
Total	**56.6**	**52.78-60.29**	**693**

For respondents who said they had friends outside their own home, the majority (82.3%, *n*=320) had face-to-face contact with those friends at least once a month. Men (84.9%) had slightly more regular/monthly contact than women (80.4%); regular contact decreased with increasing age; and those living in independent/family residences (87.7%) reported more regular contact than those in community group homes (83.0%) or institutional settings (76.5%) (See Appendix Table 2.A.4).

In relation to telephone contact with non-resident friends, the overall rate was much lower than face-to-face contact at 22.1% (*n*=82). Respondents with mild ID (36.9%, *n*=42) had the highest rates of regular/monthly telephone contact; compared to 16.6% (*n*=31) of those with moderate ID, and just 3.6% (*n*=2) of respondents with severe-profound ID (see Appendix Table 2.A.5). Similar to that reported for family contact, overall rates of written contact with friends was also very low with only 4.4% (*n*=15) having regular contact, highlighting the reliance upon and importance of face-to-face contact for people with the most severe disabilities (see Appendix Table 2.A.6).

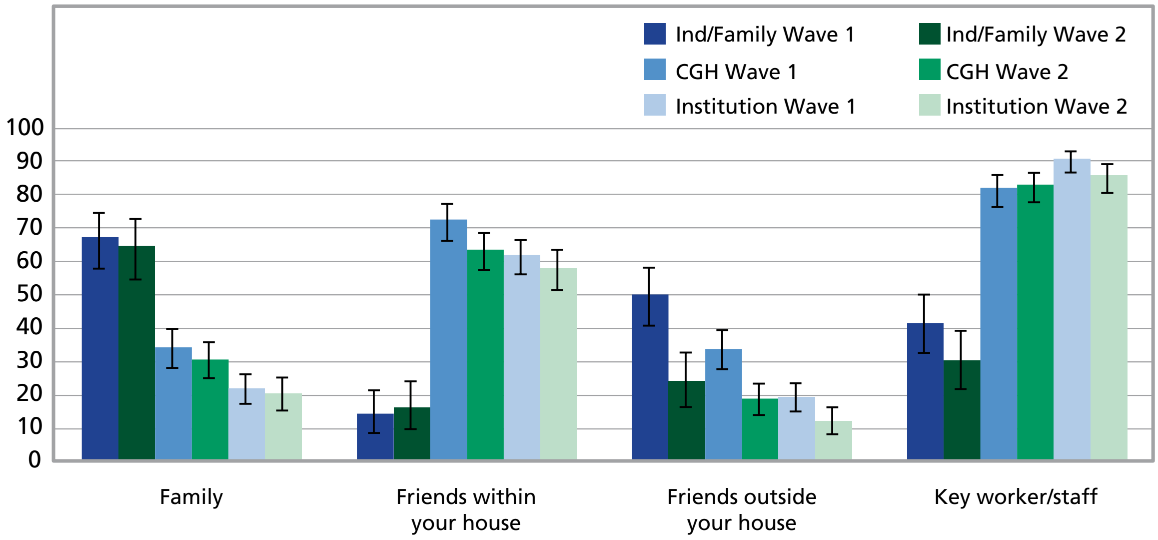
Respondents in Wave 2 were also asked about who participated in their main social activities. As shown in table 2.4, regardless of age over 70% of respondents participated in social activities with staff, with those with moderate to severe ID, regardless of whether the lived in the community or an institutional setting being heavily dependent on paid staff. Movement to a community group home does not appear to change the central social role that staff play in the lives of older adults with ID.

Table 2.4: People who respondents do their main social activities with

Family Member	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe-Profound	Independent / Family	Community Group Home	Institution	
Key worker/ support staff	76.8	74.2	73.3	75.8	77.1	56.2	74.5	91.1	30.1	83.1	85.9	75.4
Friends within your house	53.7	53.2	46.6	54.8	59.3	52.9	57.1	49.2	15.9	63.5	58.0	53.4
Family	33.6	30.8	44.5	32.3	14.3	37.9	32.7	21.2	64.6	30.4	20.1	32.0
Friends outside your house	13.1	19.7	17.8	17.3	14.3	23.5	17.0	10.1	23.9	18.6	11.9	16.8
Other	2.7	2.4	3.7	2.6	0.7	4.6	2.4	0.0	8.0	2.7	0.0	2.5
Total	298	380	191	347	140	153	294	179	113	296	269	678

Looking at changes in activity participation by type of residence, there is a general decline across settings in respondents socialising with friends outside their own homes, and little difference between community group homes and institutional settings in relation to the numbers who socialise mainly with staff and those who socialise mainly with friends within their home (see *figure 2.3*).

Figure 2.3: People with whom respondents do their main social activities with by type of residence

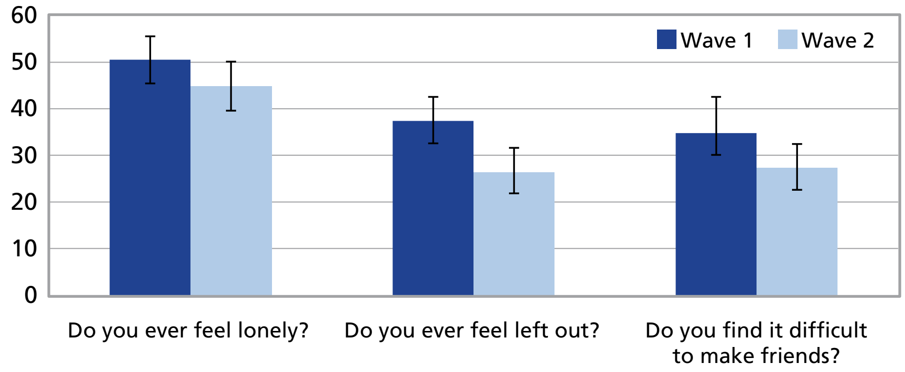


Note: CGH: Community group home
Ind.: Independent Living

2.3.1.3 Social Inclusion & Exclusion

In Wave 2 respondents were again asked a number of questions about feelings of loneliness and other aspects of social inclusion. *Figure 2.4* below shows that, between Waves 1 and 2, less people reported feeling lonely, feeling left out or finding it difficult to make friends.

Figure 2.4: Self-reported feelings of social inclusion/exclusion



While overall feelings of exclusion have fallen there were notable differences in relation to gender and type of residence. Women were more likely than men to report feeling lonely (52.7%, *n*=168, versus 34.2%, *n*=98), feel left out (28.4%, *n*=55, versus 23.7%, *n*=32) and having difficulty making friends (27.6%, *n*=53, versus 26.8%, *n*=36). Respondents living in institutional residences were much more likely than those living in independent/family residences to report feeling lonely (48.2%, *n*=41, versus 35.9%, *n*=33), feel left out (33.8%, *n*=25, versus 23.1%, *n*=21) and having difficulty making friends (32.9%, *n*=24, versus 18.9%, *n*=17). Those in community group homes reported similar levels to institutional residences in terms of feeling lonely (47.8%, *n*=85) and difficulty making friends (29.3%, *n*=49) but had lower levels for feeling left out (23.1%) (See Appendices, Table 2.A.7 and Table 2.A.8).

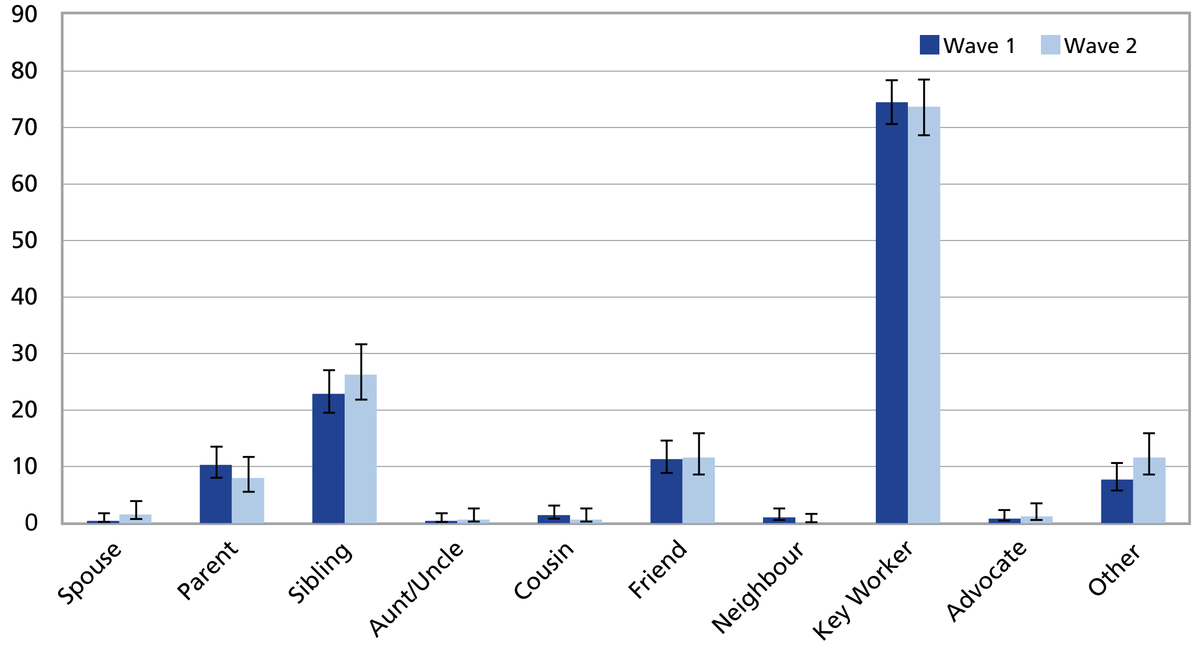
Respondents were again asked in Wave 2 if they had someone in whom they could confide, or talk to about private matters. While a change in the format of the question means a direct comparison of the overall figure is not possible, an analysis of the people who respondents confide in shows that paid staff remain the most likely confidant (73.7%, *n*=241), well ahead of siblings (26.3%, *n*=86) and friends (11.6%, *n*=38) (see table 2.5 below).

Table 2.5: People who respondents confide in.

Person confides in	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe-Profound	Independent / Family	Community Group Home	Institution	
Keyworker/Staff	76.6	71.6	64.1	75.0	84.1	69.8	77.3	93.3	43.8	87.7	78.7	73.7
Sibling	28.5	24.7	27.2	26.2	25.4	27.8	22.7	33.3	41.6	20.9	20.0	26.3
Friend	7.3	14.7	9.8	12.2	12.7	15.9	8.4	0.0	11.2	11.0	13.3	11.6
Parent	11.7	5.3	15.2	6.4	1.6	6.3	9.1	6.7	15.7	6.1	2.7	8.0
Spouse/partner	1.5	1.6	3.3	1.2	0.0	2.4	1.3	0.0	1.1	2.5	0.0	1.5
Advocate	2.2	0.5	1.1	1.7	0.0	0.8	1.9	0.0	1.1	1.8	0.0	1.2
Cousin	0.7	0.5	0.0	1.2	0.0	1.6	0.0	0.0	1.1	0.0	1.3	0.6
Aunt/uncle	0.0	1.1	1.1	0.6	0.0	0.8	0.6	0.0	1.1	0.0	1.3	0.6
Other	12.4	11.1	12.0	13.4	6.3	13.5	8.4	0.0	19.1	7.4	12.0	11.6
n	137	190	92	172	63	126	154	15	89	163	75	327

As shown in *figure 2.5* the most notable change by Wave 2 was an increase in the rate of siblings as confidants, from 22.9% in Wave 1 to 26.3% in Wave 2. A fall in the rate of parents as confidants, from 10.3% (*n*=52) to 8.0% (*n*=26), might be expected with an ageing sample.

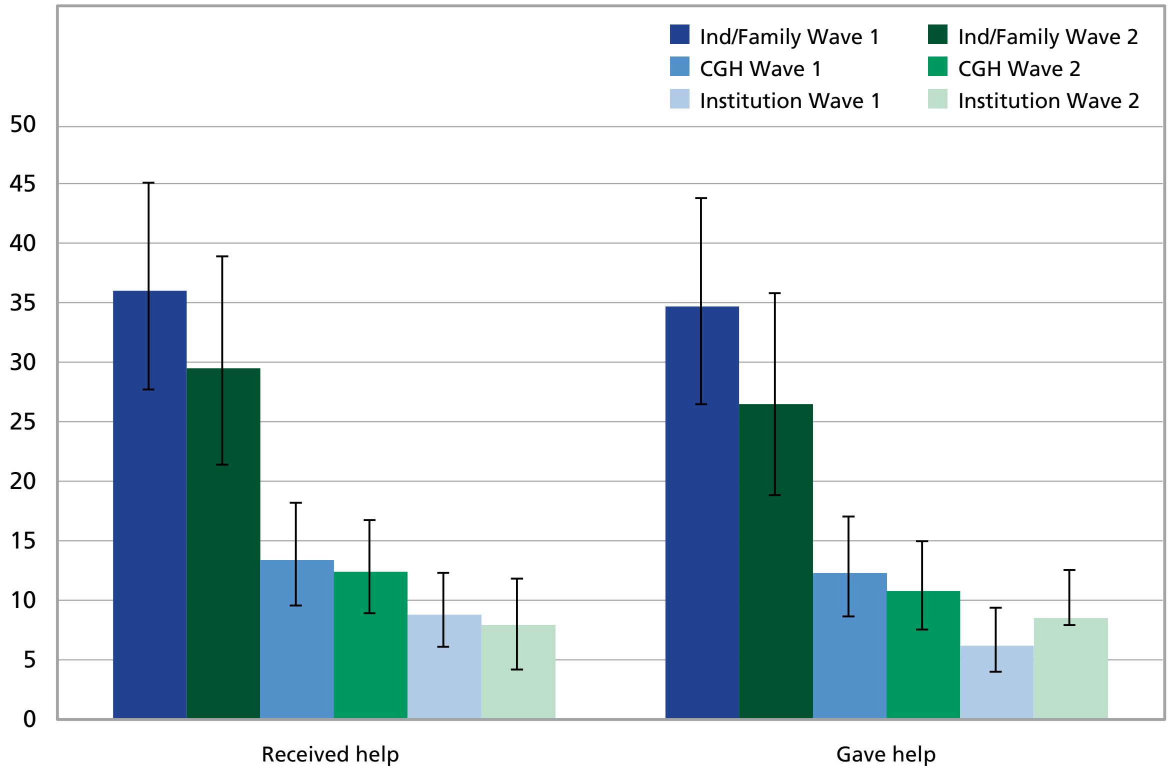
Figure 2.5: People confided in by respondents who said they had confidants.



Purposeful contact with neighbours and friends is another important element of social inclusion and participation in community. As in Wave 1, respondents were asked in Wave 2 if they had given or received any help to/from neighbours or friends in the previous two years. Results show an overall decline in both the level of help given (12.4%, *n*=86) and received (13.3%, *n*=92) since Wave 1.

Within these figures the rates of giving and receiving help has dropped for men (respectively down from 16.3% [*n*=54] to 14.1% [*n*=43]; and from 18.6% [*n*=62] to 13.2% [*n*=40]) while increasing slightly for women (up from 10.5% [*n*=43] to 11.1% [*n*=43]; and from 12.0% [*n*=49] to 13.4% [*n*=52]). Figures for Wave 2 continued to highlight a large gap between rates of giving and receiving help for people with severe-profound ID (2.1% [*n*=4] and 4.2% [*n*=8]) compared to those with mild ID (27.5% [*n*=41] and 29.5% [*n*=44]) (see Appendix Table 2.A.9). There were also significant gaps depending on type of residence, as shown in *figure 2.6* below. While rates declined for people living in independent/family residences, they remain much more likely to give and receive help compared to people living in both community group homes and institutional settings.

Figure 2.6: Help received from/given to neighbours or friends by type of residence



Note: CGH: Community group home
Ind.: Independent Living

Respondents were also asked if they provided any support/help to family. Table 2.6 shows that, regardless of gender, age, level of ID or type of residence, most support was provided to siblings and parents, with the number helping parents declining with respondent age.

Table 2.6: Family members to whom respondents provide support/help

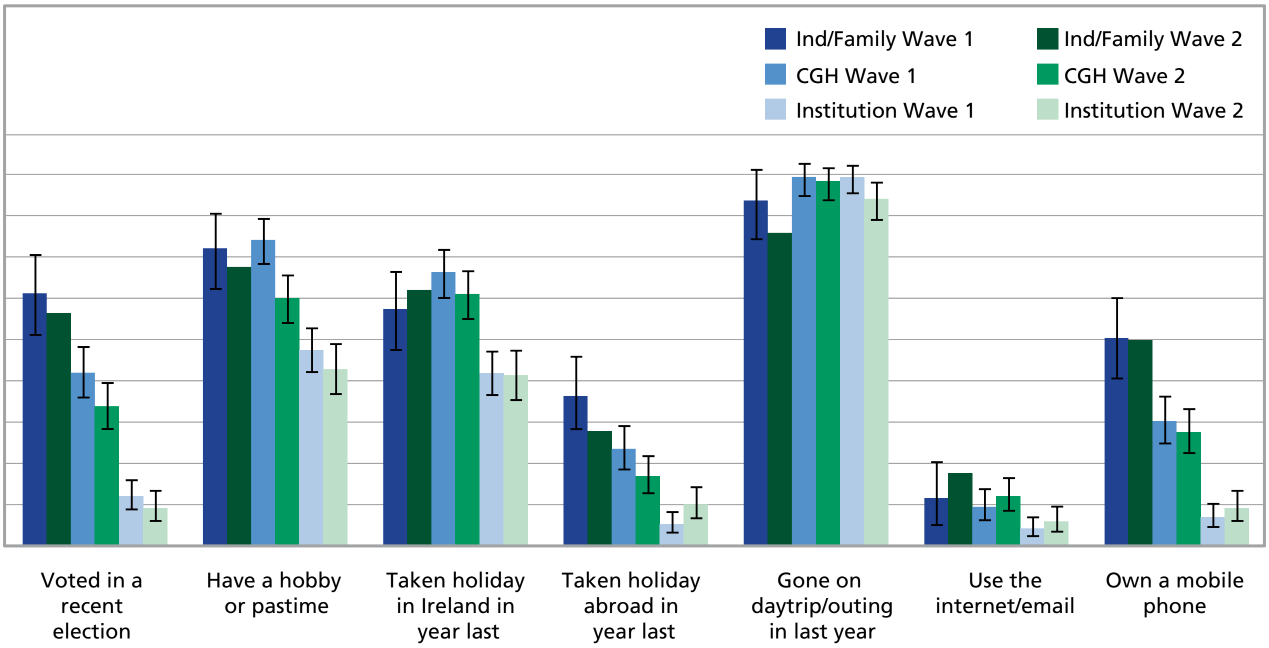
Person confides in	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe-Profound	Independent /Family	Community Group Home	Institution	
Sibling	67.9	50.8	50.9	61.1	88.9	66.7	51.0	66.7	58.2	64.1	41.7	58.5
Mother	34.0	46.2	50.9	37.0	0.0	39.6	40.8	33.3	47.8	30.8	33.3	40.7
Father	13.2	12.3	21.8	5.6	0.0	8.3	22.4	0.0	17.9	5.1	8.3	12.7
Aunt/Uncle	0.0	1.5	1.8	0.0	0.0	0.0	2.0	0.0	1.5	0.0	0.0	0.8
Cousin	0.0	1.5	0.0	1.9	0.0	0.0	2.0	0.0	0.0	2.6	0.0	0.8
Other	17.0	9.2	5.5	18.5	22.2	12.5	12.2	0.0	13.4	10.3	16.7	12.7
n	53	65	55	54	9	48	49	6	67	39	12	118

The rates of family support/help given were far lower than those for the general population in Ireland. TILDA initially reported that older people in the general population provide a broad range of support to family: 36% provided non-financial support to non-resident children; 47% provided care to grandchildren; and among the 50-64 year-olds 50% provided non-personal care, and 28% provided personal care to parents (Barrett *et al.,* 2011). TILDA's Wave 2 quality of life analysis also identified that those who were 'most integrated' socially had significantly higher quality of life scores than those who were 'least integrated' (McCrory *et al.,* 2014). That this is an important area in social participation in which most older people with ID are losing out is reinforced by the findings that 100% of IDS-TILDA respondents in Wave 2 who said they provided support/help to a family member also spoke of the satisfaction they experienced from providing such support and help.

2.3.2 Engagement in Social Life

At Wave 2 respondents were again asked a range of questions regarding their participation in general and social activities. The small decline noted in the level of social activity and in engagement in voluntary organisations may reflect the impact on services to support social participation, resulting from the economic recession experienced in Ireland. As may be seen in *Figure 2.7* by Wave 2 people in independent/family settings remained far more likely to vote and own a mobile phone compared to those in community group homes and institutions, with people in community settings were more likely to have a hobby or pastime and to go on a holiday.

Figure 2.7: Participation in general activities by type of residence – Wave 1 and 2



Note: CGH: Community group home
Ind.: Independent Living

Overall the number of voters dropped between waves from 30.9% (*n*=233) to (27.5%, *n*=184) and remained significantly lower than the 80% voting rate found amongst the general older population (Barrett *et al.,* 2011).

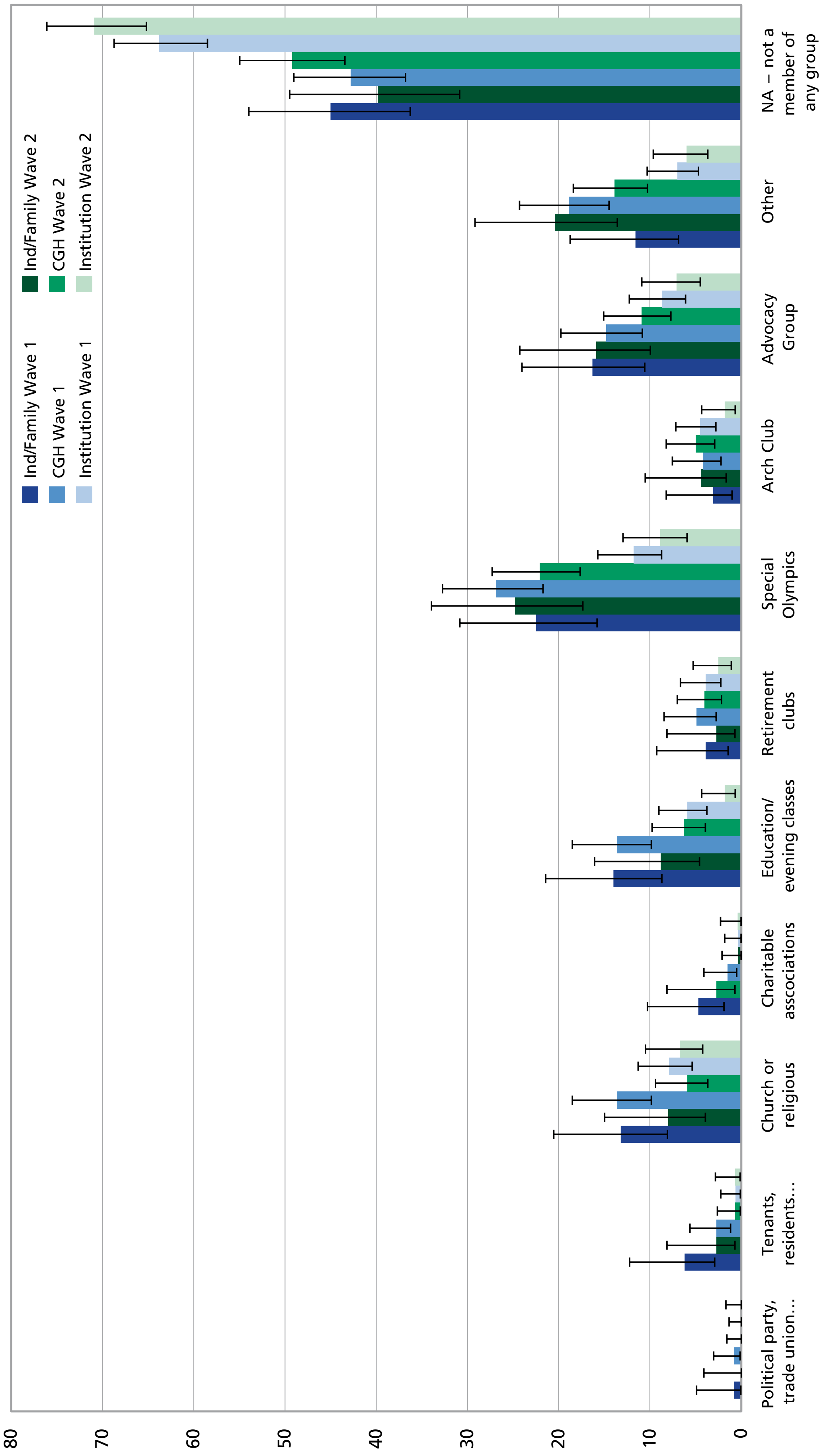
2.3.2.1 Internet and Mobile Phone

There was a small increase with internet use from 7.3% (*n*=55) to 10.5% (*n*=70). However, this remains far below the usage rates among the general population of 77% (CSO, 2012). Ownership of mobile phones remained essentially the same (23.8% as compared to 22.8% and continues to compare poorly with mobile phone ownership figures nationally of 120% (Central Bank of Ireland, 2013).

2.3.2.2 Membership of Clubs, Organisations and Societies

Involvement in voluntary clubs, organisations and societies declined from 47% to 43%. Men (58.8%, *n*=181) were a little more likely not to be a member of any voluntary organisation than women (54.6%, *n*=213) and membership levels were lower for people with severe-profound ID (75.0%, *n*=144), people living in institutional settings (70.9%, *n*=200), and people aged 65 years and over (65.5%, *n*=97). For those who were members, Special Olympics remained the most popular organisation, followed by Advocacy and Church/Religious Groups. As may be seen in *figure 2.8* there was little difference between independent/family residences and community group homes, but those in institutional settings had substantially lower membership of voluntary organisations. Regardless of setting, level of ID or age, membership in organizations by people with ID were substantially less than the 64.1% reported by TILDA for the general population (Nolan *et al.,* 2014: 171) (see Appendix Table 2.A.10).

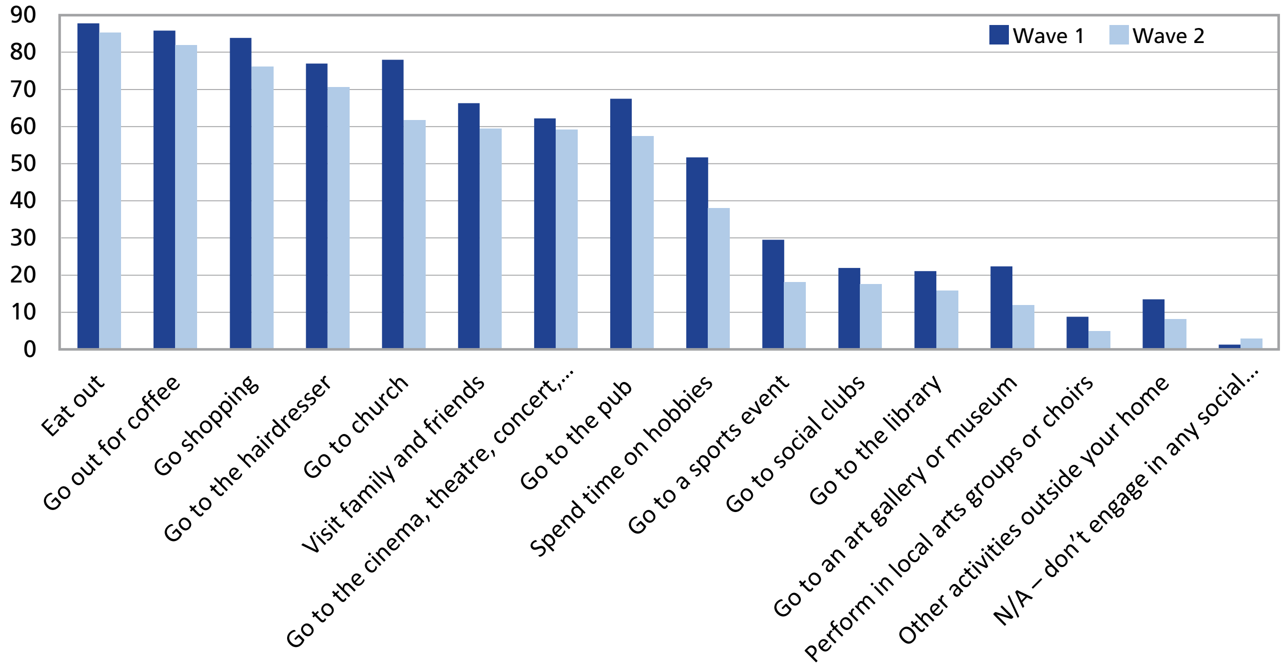
Figure 2.8: Membership of clubs, organisations and societies by type of residence



2.3.2.3 Social Activities

Although there were some declines it is still impressive the number of activities in which people with ID are involved as are the very high number participating in activities like eating out/going for coffee; shopping and going to the hairdresser; and going to church, visiting friends and going to the cinema *(figure 2.9)*.

Figure 2.9: Social activities in Wave 1 and Wave 2



Respondents aged 65 years and over had lower activity rates than other age groups; people with mild disabilities had the highest participation rates across all activities while those with severe-profound had the lowest; and with regard to type of residence, people living in institutional settings had the lowest participation rates across the majority of social activities (see Appendices, Table 2.A.11 and Table 2.A.12).

2.3.3 Facilitators & barriers of social participation

In Wave 2 respondents were asked about the difficulties they experienced in getting out of their home to engage in social activities. People were also asked about difficulties experienced getting around their community, about transport options available and any transportation difficulties experienced.

2.3.3.1 Difficulties participating in social activities outside the Home

Just over half (52.4%, *n*=356) of respondents in Wave 2 said they experienced difficulties participating in social activities outside their homes, which is similar to the rate reported in Wave 1 (51.6%, *n*=382) (see Appendix Table 2.A.13). More women (55.4%, *n*=211) experienced these difficulties than men (48.5%, *n*=145). The over-65 age group (59.4%, *n*=85) also experienced these difficulties more than either the under-50 group (50.3%, *n*=98) or the 50-64 group (50.6%, *n*=173). However, the biggest differences related to level of ID and type of residence. More than three-quarters of people with severe-profound ID (78.3%, *n*=148) experienced such difficulties, compared to 30.7% (*n*=46) of people with mild ID, and 47.7% (*n*=137) of people with moderate ID. Just over a quarter of people living in independent/family homes (26.5%, *n*=30) experienced these difficulties, compared with almost half (48.3%, *n*=144) of people living in community group homes, and more than two-thirds (67.7%, *n*=182) of people living in institutional settings. *Figure 2.10* below also highlights that difficulties for community group home and institutional respondents have increased compared to those in independent/family residences.

Figure 2.10: Difficulties participating in social activities outside the home by type of residence – Waves 1 and 2

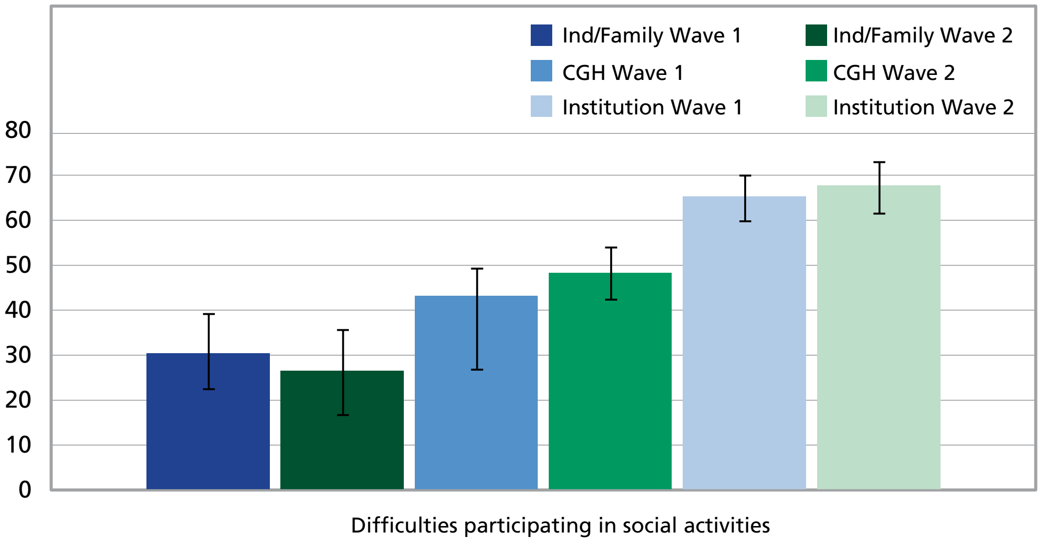
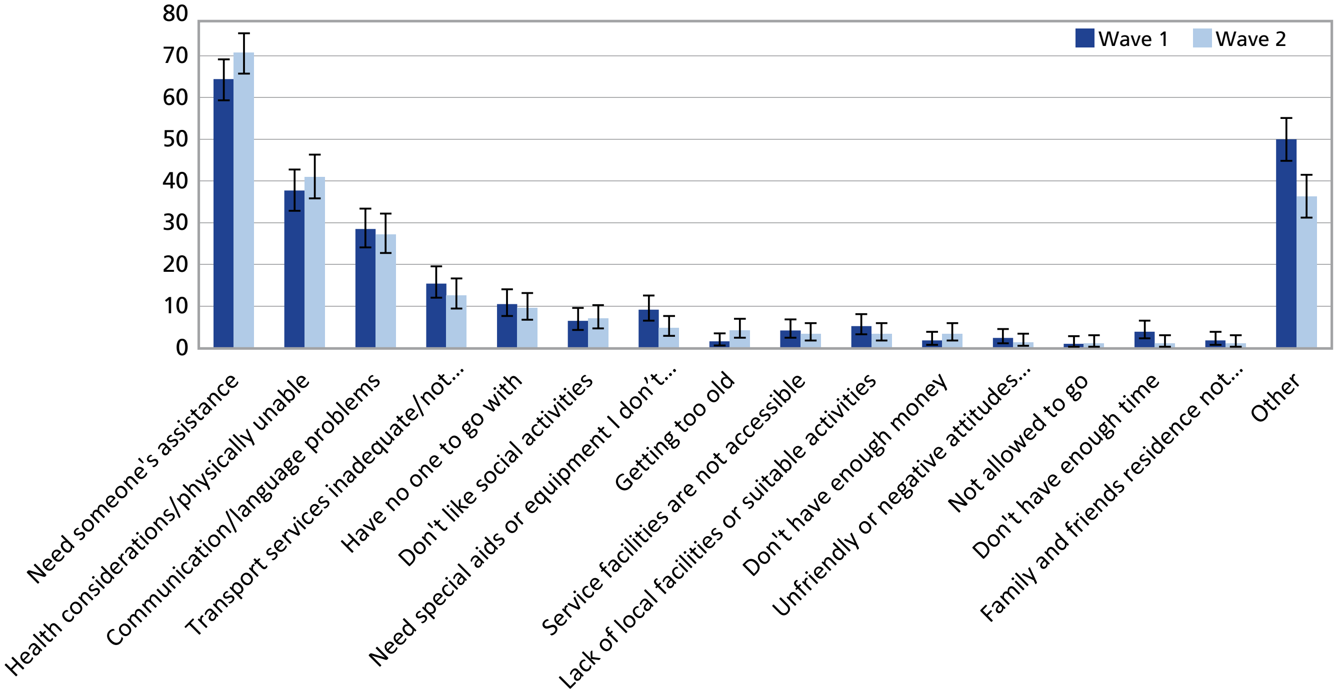


Figure 2.11 highlights that needing someone's assistance not only continued to be the most frequently reported difficulty (70.8%, *n*=252), followed by *health considerations or physically unable* (41.0%, *n*=146), but the percentage experiencing these two difficulties increased.

Figure 2.11: Difficulties experienced participating in social activities outside the home – change since

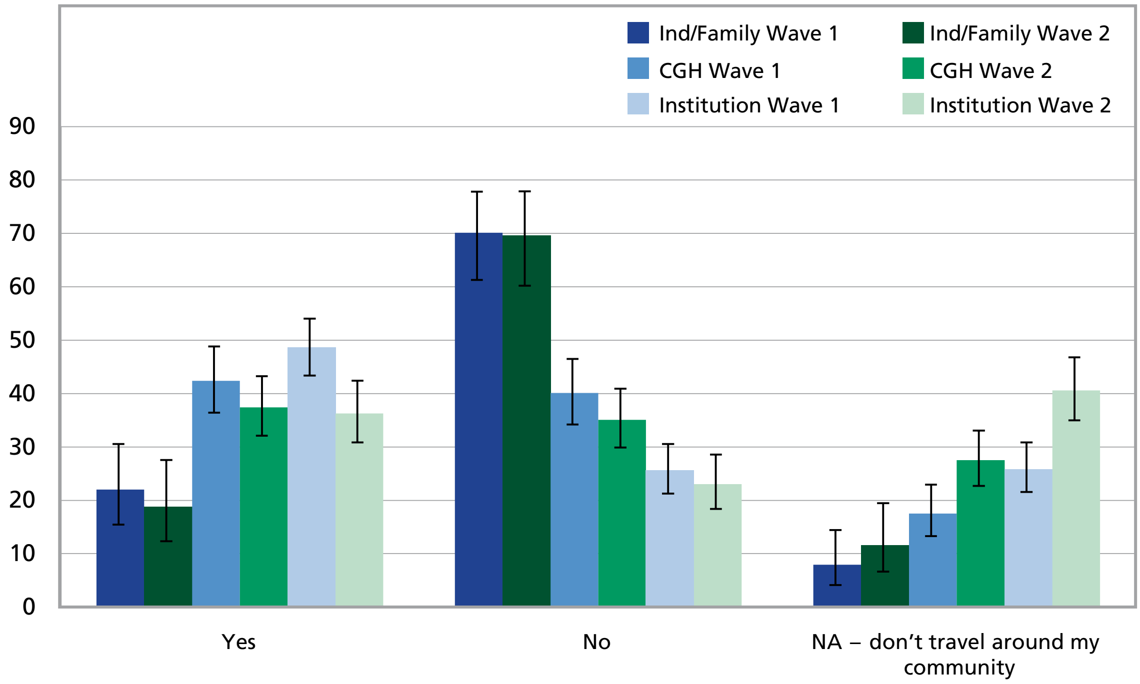


2.3.3.2 Difficulties getting around the community

An initial appearance that there was a reduction between Waves from 42% to 34% in people experiencing any difficulties getting around their community, must be balanced with a larger increase in the number of people who said that they don't travel around their community at all, from 19.8% in Wave 1 to 30% in Wave 2. Taken together, this means that almost two-thirds (64.2%, *n*=444) either experience difficulty or else do not travel around their community at all, an increase of 2.3% since Wave 1.

While more men (35.7%, *n*=109) than women (32.6%, *n*=126) reported difficulties getting around their community, more women (31.3%, n =121) than men (28.9%, *n*=82), people aged 65 years and older (42.5%, *n*=62), and people living in institutional residences (40.6%, *n*=113) were much more likely than others to report that they didn't travel around their community at all (see Appendix Table 2.A.14). *Figure 2.12* below shows that, while there has been little change for people living in independent / family settings, those living in community group homes and institutional settings had higher rates of difficulties.

Figure 2.12: Difficulties experienced getting around your community by type of residence – Wave 1 and 2

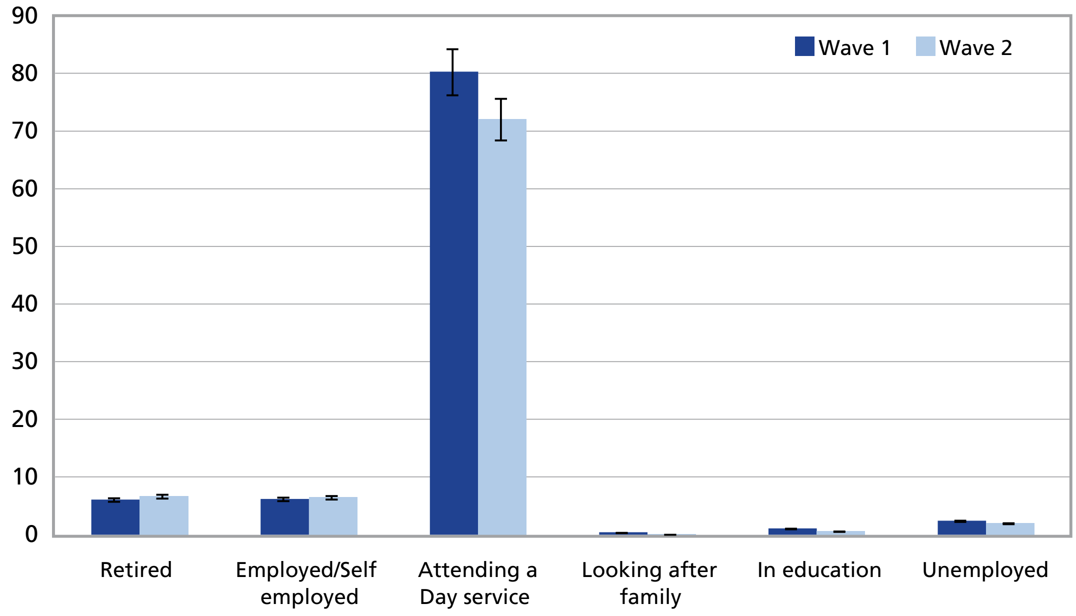


Note: CGH: Community group home
Ind.: Independent Living

2.3.4 Employment Changes from Wave 1

As may be seen in *figure 2.13*, in Wave 2 6.5% were in regular paid employment/self-employed, 11.6% were attending a sheltered workshop, and a further 80.3% were attending a day service. These findings are very similar to the employment status identified in Wave 1 IDS-TILDA but were significantly different from the picture for TILDA, where 33% were employed (Hudson *et al.,* 2014). There was a small increase in retirees from 6.1% to 6.7%. This compares to 40% of TILDA participants being retired. Less than 1% of IDS-TILDA participants looked after the home whereas this was true of 16% of TILDA participants (Hudson *et al.,* 2014).

Figure 2.13 Occupational status comparisons between Wave 1 and Wave 2



2.3.4.1 Labour Market Movement between Wave 1 and Wave 2

There was very little movement observed in the labour market between Wave 1 and Wave 2. Of the 44 who were employed in Wave 1, 65.9% were still in employment in Wave 2. Of the 14 respondents who no longer indicated that they were employed, 8 moved to a day service, two moved to sheltered employment and two indicated that they were unable to work due to being permanently sick or disabled.

The small number of individuals in open paid employment spent an average of 3.3 days a week in work, over an average of 15.7 hours a week, for an average wage of €72.66. The industries in which people were most commonly involved were the food and drink industry (28.9%, *n*=11), retail (26.3%, *n*=10), cleaning/maintenance industry (15.8% *n*=6), office work (*n*=3), banking (*n*=1) and other services (*n*=2).

2.3.5 Day Services

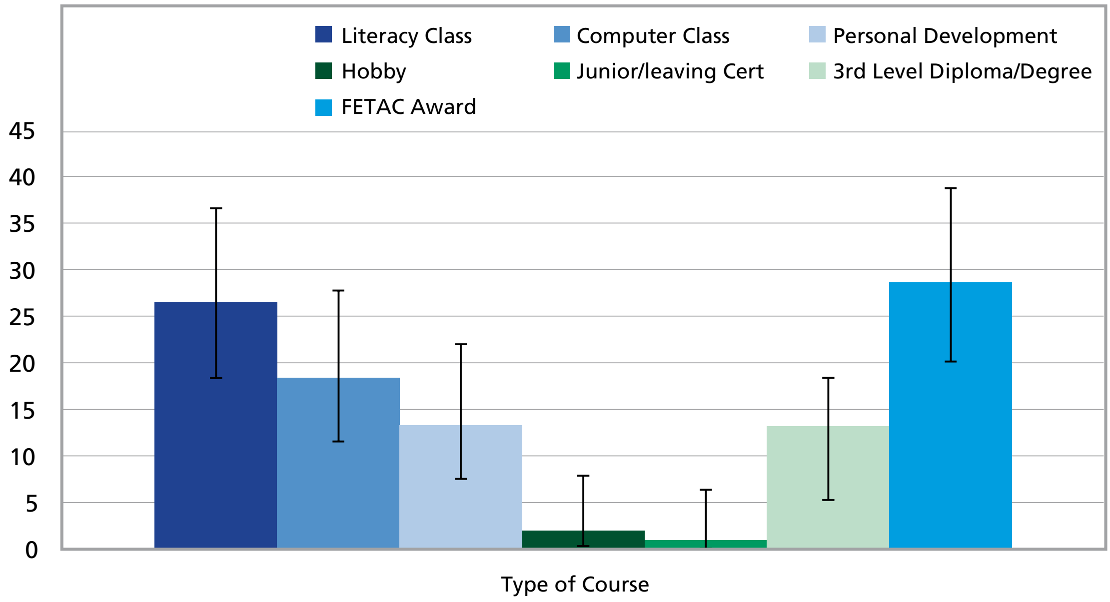
Just over 80% of people were attending a day service in Wave 2. Similar to findings in Wave 1, arts & crafts (72.9%), and music (69.3%) were the most frequent activities. The majority (51.4%, n = 228) chose their activities most of the time, while 18.6% (*n*=83) said that they rarely or never chose their activities. Individuals attended the day service on average 4.3 days a week, for 21.8 hours a week. Fifty nine percent of those attending a day service were very satisfied and a further 36.4% were satisfied. Four percent indicated that they were dissatisfied with the day service.

2.3.6 Education and Life Long learning

There is a clear link between educational level and employment, spending power, health and well-being and further education has been linked to better health behaviours, improved cognitive ability and engagement in preventative healthcare (Lochner, 2011; Grundy & Holt 2001). However as was seen in Wave 1 of IDS-TILDA, educational levels were low with 32% noting they had never attended an education programme (McCarron *et al.,* 2011).

In Wave 2 we further explored educational experiences by asking people to identify if they had engaged in any further education. The majority (85.7%) of adults with an ID were not currently engaged in further education. The 14.3% who did attend represents a slight decline from Wave 1 (15.4%). Of this 14.3%, the majority (28.6%) were attending a FETAC level course, with 26.5% engaging in literacy classes (see *figure 2.14*). Of the courses attended, 21.6% reported was organised by a training centre, 11.3% by a local community programme, and 9.3% by and Institute of Technology.

Figure 2.14 Types of engagement in further education

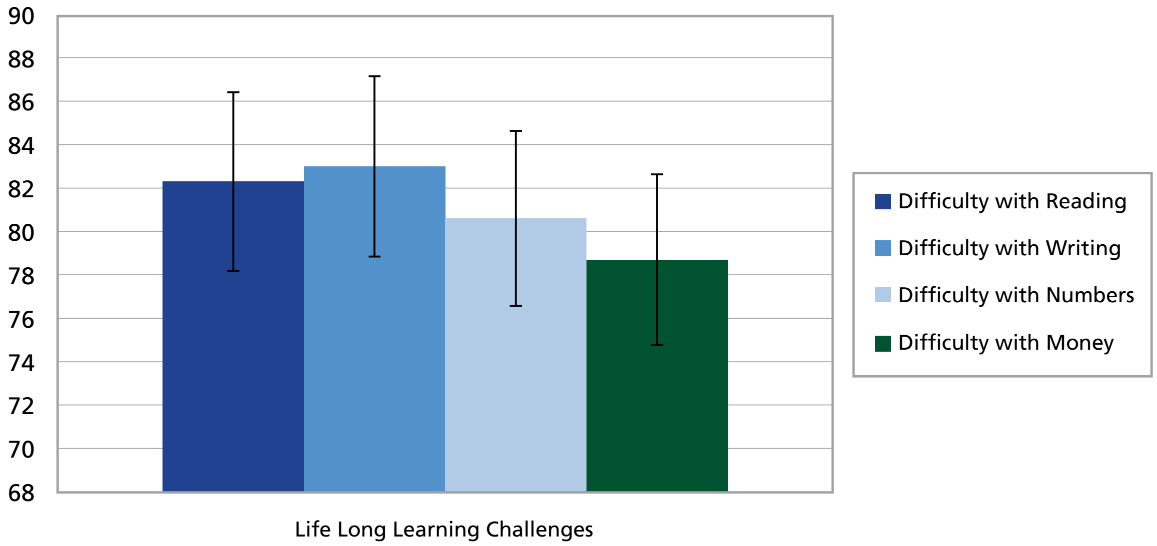


Of the 85.7% who were not engaged in further education, 83 (11.9%) expressed interest in attending courses, with the most preferred courses being reading/ writing and computers. This level of interest declined from Wave 1, when 32.2% of respondents reported a desire to attend courses.

2.3.7 Prevalence of difficulties engaging in further education

Additional questions in the Wave 2 interview examined issues of numeracy and literacy. As shown in *figure 2.15*, 82.3% identified difficulties with reading, 83% with writing, 80.6% with number identification and 78.7% with understanding money and monetary transactions.

Figure 2.15 Challenges engaging with lifelong learning.



Overall, only 8.5% of the participants reported that they had no trouble with any of the described tasks; both males and females noted high levels of difficulty with approximately 5% more females reporting concerns; difficulties increased with age and by level of ID with those within the severe-profound category presenting with the greatest difficulties (see Appendix Table 2.A.15).

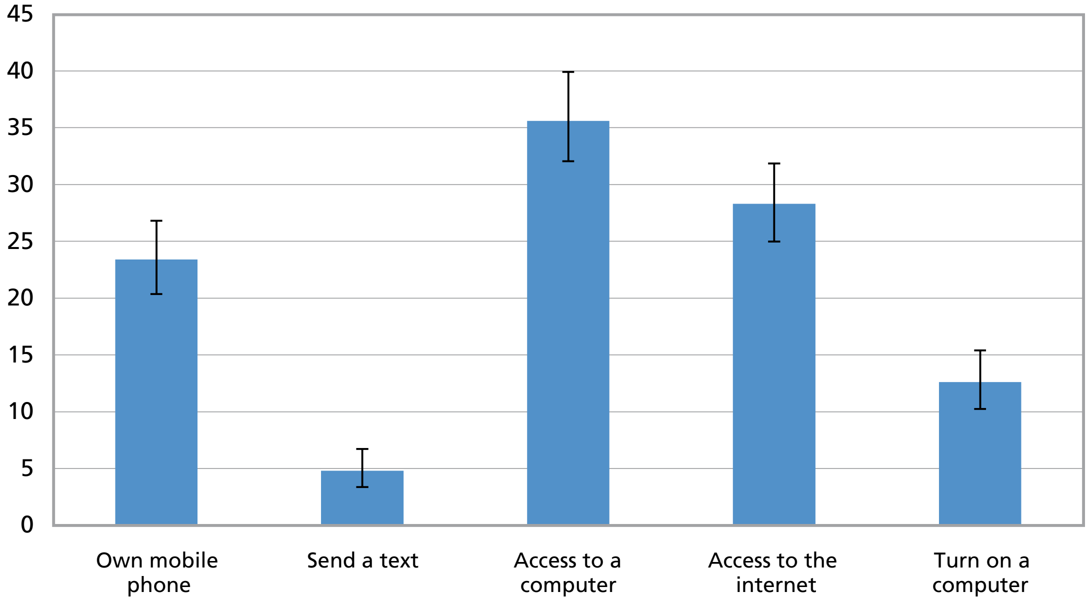
Among community survival knowledge, often identified as in signing one's own name, recognising numbers and being able to know what change you get from purchases, there were additional concerns. Just 29.4% of people reported they could read their own name without assistance with a further 7.9% indicating they would require assistance however the majority, 62.7% reported they were unable to read their own name. The majority of people (93.9%) reported being unable to complete forms such as a bank deposit slip and just 1.1% reported being able to use a calculator. Approximately 15% reported they could identify the differences between currency notes however 89.9% said they would not be able to recognise if change was due when making a purchase (see Appendices, Table 2.A.16a, Table 2.A.16b).

Considering the policy changes that have occurred in recent years within the field of ID in Ireland with greater emphasis on engaging in the community lack of education and basic literacy skills among a group of people with ID who are now ageing represents a major barrier to successful community participation. To some extent greater educational efforts will be helpful but of more concern is the need for concentrated efforts using technology and other aides to compensate for these literacy barriers so that day to day participation in community life becomes more feasible.

2.3.8 Access and engagement with technology

The growth in technologies and social media in recent years has the potential to offer older people with ID greater opportunities for social engagement. However, findings from Wave 2 show this population continues to be behind the general population with regard to having access to and being able to use information and communication technology (ICT). *Figure 2.16* below shows that less than a quarter of respondents owned a mobile phone, while less than one in 20 could send a text message. Just over a third of respondents (35.6%) said that they had access to a computer, and only 28.3% had internet access. However, just 12.6% said that they were able to turn on a computer (7.9% with assistance only). As such, we can see that currently in Ireland ICTs are not being utilised to anywhere near their potential for this already marginalised group of people (see Appendix Table 2.A.17).

Figure 2.16: Access and Engagement with Technology



2.4 Conclusion

Concern that placement in the community does not necessarily mean living in the community on the same terms as other community members continue to be well founded for older people with ID. On the one hand there is the reality of more limited social networks because so few people with ID have spouses and children. On the other hand low levels of social activities, reliance on staff, low levels of employment and survival literacy challenges make successful community engagement more difficult. There are additional concerns that the IDS-TILDA group of respondents have at best sustained a low level of community engagement and in some areas have seen declines in access and participation. Of most concern is that a primary mechanism of community integration and engagement, movement to community group homes, in many areas more resembles experiences in institutional settings rather than other community-based living situations such as family care and independent living. To some extent lower levels of community participation noted are attributable to differences in levels of intellectual disability. However, family and independent living situations already represent substantially less community engagement than experienced by the general population. It is of concern that community group homes are not yet matching family/independent settings when this represents just a first step in offering people with ID community experiences similar to the general population.

That those living in community group homes tend to be younger, higher functioning and experience less health problems than those currently living in institutional settings heightens the concern that physical location in the community does not appear to be translating to the espoused community living benefits in terms of friendships, employment, and engagement in neighbourhoods. A renewed effort is needed to ensure that community group homes are organised to support greater levels of genuine integration; it is also a responsibility for day and employment programmes to see as a critical role the facilitation of opportunities for friendships and community engagement. Finally, there remain questions that if, for the highest functioning and supported persons with ID, community group homes are not yet fully supporting the transition to community life, what additional steps will be needed to support the movement from congregated settings of those with greater needs and barriers to integration. As others have noted movement must not simply be about a change of address.

Also of concern is the continuing low level of employment opportunities for people with ID, coupled with low levels of reading, writing, numeracy and money management capacity which, individually and collectively, further disadvantage the community integration of people with ID. Again, community placement alone is not sufficient; there is a need for interventions and wider use of technology to compensate for these disadvantages, increase the likelihood of employment and offer tools for greater community involvement.

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Appendix 2A: Tables on Social Participation of Older Adults with an Intellectual Disability

Table 2.A.1. Frequency of contact with family with whom respondents do not live: meeting up

Meet up	Spouse/ Partner	Mother	Father	Brother	Sister	Aunt/Uncle	Niece/ Nephew	Cousin	Other
3+ times a week	75.0	3.6	5.9	6.0	5.5	3.7	4.5	1.2	6.7
Once or twice a week	0.0	24.6	29.4	9.2	13.1	0.9	6.7	3.5	6.7
Once or twice a month	0.0	30.4	11.8	22.5	25.7	13.1	19.4	5.8	26.7
Every few months	0.0	16.7	17.6	23.8	26.1	18.7	28.9	22.7	40.0
Once or twice a year	0.0	12.3	15.7	18.5	15.5	26.2	19.7	22.1	20.0
Less than once a year	0.0	6.5	7.8	12.7	9.2	17.8	11.0	20.3	0.0
Never	25.0	5.8	11.8	7.3	4.9	19.6	9.8	24.4	0.0
n	4	138	51	466	510	107	356	172	15

Table2.A.2: Frequency of contact with family with whom respondents do not live: telephone

Meet up	Spouse/ Partner	Mother	Father	Brother	Sister	Aunt/Uncle	Niece/ Nephew	Cousin	Other
3+ times a week	50.0	7.6	8.5	4.7	6.1	1.9	2.1	0.6	7.7
Once or twice a week	25.0	23.5	17.0	11.0	17.7	3.9	3.8	1.2	23.1
Once or twice a month	0.0	11.4	6.4	14.5	16.9	5.8	7.1	4.7	15.4
Every few months	0.0	9.8	6.4	10.5	12.7	10.7	12.6	8.3	0.0
Once or twice a year	0.0	1.5	4.3	5.6	4.2	4.9	3.8	8.9	0.0
Less than once a year	0.0	2.3	2.1	4.0	3.1	4.9	3.5	2.4	0.0
Never	25.0	43.9	55.3	49.7	39.2	68.0	67.1	74.0	53.8
n	4	132	47	447	479	103	340	169	13

Table 2.A.3. Frequency of contact with family with whom respondents do not live: written contact

Meet up	Spouse/ Partner	Mother	Father	Brother	Sister	Aunt/Uncle	Niece/ Nephew	Cousin	Other
3+ times a week	0.0	0.0	0.0	0.0	0.5	0.0	1.0	1.3	0.0
Once or twice a week	0.0	1.7	4.4	0.5	0.5	0.0	0.0	0.7	8.3
Once or twice a month	25.0	0.8	2.2	1.0	2.6	0.0	0.0	0.7	8.3
Every few months	0.0	5.8	2.2	4.3	6.5	0.0	3.6	0.7	8.3
Once or twice a year	0.0	8.3	2.2	10.3	11.1	5.4	4.9	5.3	0.0
Less than once a year	0.0	0.8	2.2	3.8	3.0	4.3	1.9	2.7	8.3
Never	75.0	82.5	86.7	80.2	75.9	90.2	88.6	88.7	66.7
n	4	120	51	398	431	92	308	150	12

Table 2.A.4. Frequency of contact with friends with whom respondents do not live: meeting up

Meet up	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe-Profound	Independent /Family	Community Group Home	Institution	
3+ times a week	50.3	44.3	56.9	43.3	40.3	46.1	48.3	47.7	62.2	43.2	39.1	46.8
Once or twice a week	23.3	24.8	27.6	24.4	18.1	28.7	22.7	18.5	20.4	27.3	22.6	24.2
Once or twice a month	11.3	11.3	8.6	12.4	12.5	10.4	11.6	13.8	5.1	12.5	14.8	11.3
Every few months	7.5	8.3	5.2	9.5	8.3	7.0	7.6	9.2	8.2	6.3	10.4	8.0
Once or twice a year	3.1	4.3	0.0	4.0	9.7	3.5	3.5	3.1	0.0	4.0	7.0	3.9
Less than once a year	3.1	1.3	0.9	1.0	6.9	0.9	3.5	0.0	1.0	2.8	1.7	2.1
Never	1.3	5.7	0.9	5.5	4.2	3.5	2.9	7.7	3.1	4.0	4.3	3.9
n	159	230	116	201	72	115	172	65	98	176	115	389

Table 2.5 Frequency of contact with friends with whom respondents do not live: telephone

Meet up	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe-Profound	Independent /Family	Community Group Home	Institution	
3+ times a week	3.4	4.9	2.8	6.2	1.4	7.9	1.8	1.8	8.4	3.0	2.8	4.3
Once or twice a week	8.7	13.5	15.6	12.4	2.9	20.2	9.6	1.8	14.7	13.1	6.4	11.6
Once or twice a month	5.4	6.7	6.4	5.7	7.2	8.8	7.2	0.0	7.4	6.5	4.6	6.2
Every few months	6.0	4.0	6.4	4.1	4.3	7.9	3.6	1.8	8.4	4.2	2.8	4.8
Once or twice a year	2.0	3.1	0.9	2.6	5.8	1.8	2.4	0.0	2.1	4.2	0.9	2.7
Less than once a year	1.3	2.7	0.9	2.6	2.9	3.5	2.4	0.0	2.1	3.6	0.0	2.2
Never	73.2	65.0	67.0	66.5	75.4	50.0	73.1	94.5	56.8	65.5	82.6	68.3
n	149	223	109	194	69	114	167	55	95	168	109	372

Table 2.A.6. Frequency of contact with friends with whom respondents do not live: written contact

Meet up	**Gender**		**Age**			**Level of ID**			**Type of Residence**			**Total**
	Male	**Female**	**43-49**	**50-64**	**65+**	**Mild**	**Moderate**	**Severe-Profound**	**Independent /Family**	**Community Group Home**	**Institution**	
3+ times a week	1.4	0.0	0.9	0.6	0.0	1.9	0.0	0.0	1.1	0.0	1.0	0.6
Once or twice a week	0.7	3.5	3.8	1.8	1.5	4.6	2.0	0.0	3.3	2.6	1.0	2.3
Once or twice a month	0.7	2.0	1.9	1.2	1.5	2.8	1.4	0.0	1.1	1.3	2.0	1.5
Every few months	0.7	1.0	1.9	0.0	1.5	0.0	2.0	0.0	0.0	1.3	1.0	0.9
Once or twice a year	1.4	4.5	2.8	3.5	3.1	2.8	2.7	7.8	0.0	3.3	6.1	3.2
Less than once a year	1.4	2.0	0.9	2.9	0.0	3.7	1.4	0.0	0.0	2.6	2.0	1.8
Never	93.6	87.0	87.7	90.0	92.3	84.3	90.5	92.2	94.6	88.7	86.7	89.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
n	141	200	106	170	65	108	148	51	92	151	98	341

Table 2.A.7. Self-reported feelings of social exclusion

		Do you ever feel lonely?						Do you ever feel left out?					
		Wave 1			Wave 2			Wave 1			Wave 2		
		%	95% CI	n	%	95% CI	n	%	95% CI	n	%	95% CI	*n*
Gender	Male	44.4	36.91-52.22	171	34.2	26.84-42.4	152	36.2	28.93-44.14	163	23.7	16.99-31.93	135
	Female	55.3	48.4-61.91	219	52.7	45.61-59.7	203	38.4	31.87-45.35	211	28.4	22.24-35.33	194
Age	43-49	51.3	43.12-59.45	152	41.7	31.83-52.18	96	38.7	30.94-46.99	150	30.8	21.75-41.44	91
	50-64	52.7	45.28-59.93	188	48.1	40.82-55.52	187	38.5	31.47-46.13	179	26.4	20.22-33.62	178
	65+	40.0	26.73-54.8	50	40.3	29.09-52.51	71	28.9	16.84-44.52	45	20.0	11.19-32.7	60
ID Level	Mild	53.1	44.66-61.37	145	50.4	41.3-59.49	123	34.3	26.61-42.85	140	28.1	20.49-37.12	121
	Moderate	50.5	43.15-57.9	186	40.4	33.25-48.07	178	38.3	31.28-45.86	180	24.5	18.22-32.1	159
	Severe-Profound	50.0	26.77-73.23	18	52.6	29.49-74.79	19	29.4	11.38-55.95	17	33.3	20.14-79.86	15
Residence	Independent /Family	47.7	38.13-57.45	109	35.9	26.33-46.61	92	42.6	33.24-52.47	108	23.1	15.16-33.31	91
	Community Group Home	50.5	43.15-57.9	186	47.8	40.26-55.33	178	35.6	28.68-43.07	180	25.0	18.72-32.47	164
	Institution	53.8	43.16-64.05	93	48.2	37.37-59.27	85	33.3	23.65-44.55	84	33.8	23.45-45.81	74
Total		50.5	45.44-55.57	390	44.8	39.56-50.13	355	37.4	32.55-42.57	374	26.4	21.82-31.62	329

Table 2.A.8. Self-reported feelings of social inclusion

		Do you find it difficult to make friends?						Do you have someone to confide in?					
		Wave 1			Wave 2			Wave 1			Wave 2		
		%	95% CI	n	%	95% CI	n	%	95% CI	n	%	95% CI	*n*
Gender	Male	34.6	27.39-42.49	162	26.8	19.8-35.14	138	65.9	60.4-70.92	328	81.1	74.18-86.52	169
	Female	35.0	28.77-41.81	217	27.6	21.53-34.59	192	70.2	65.51-74.54	413	86.0	80.52-90.13	221
Age	43-49	37.0	29.27-45.41	146	20.2	12.73-30.33	89	67.3	61.41-72.61	284	85.2	76.76-91.04	108
	50-64	34.9	28.21-42.32	186	31.8	25.2-39.27	179	70.0	64.78-74.76	340	85.1	79.32-89.61	202
	65+	27.7	16.09-42.87	47	24.2	14.6-37.02	62	65.8	56.4-74.17	117	78.8	67.89-86.79	80
ID Level	Mild	30.7	23.35-39.15	140	28.1	20.49-37.12	121	93.2	87.8-96.37	161	97.7	92.83-99.4	129
	Moderate	37.2	30.23-44.64	183	27.8	21.18-35.46	162	78.8	7.379-83.09	316	83.2	76.9-88.16	185
	Severe-Profound	43.8	20.75-69.45	16	21.4	5.71-51.59	14	31.1	24.92-37.94	206	38.5	23.81-55.34	39
Residence	Independent/ Family	27.1	19.17-36.7	107	18.9	11.7-28.8	90	90.5	83.62-94.77	126	97.8	91.53-99.62	91
	Community Group Home	35.9	29.02-43.41	181	29.3	22.69-36.96	167	80.5	75.06-85.09	257	82.3	76.13-87.22	198
	Institution	41.1	31-51.99	90	32.9	22.6-44.98	73	51.4	46.08-56.71	354	74.3	64.43-82.21	101
Total		34.8	30.08-39.89	379	27.3	22.61-32.47	330	68.3	64.78-71.6	741	83.8	79.73-87.28	390

Table 2.A.9: Help received from/given to neighbours or friends in the last 2 years

		Help received from neighbours/friends						Help given to neighbours/friends					
		Wave 1			Wave 2			Wave 1			Wave 2		
		%	95% CI	n	%	95% CI	n	%	95% CI	n	%	95% CI	*n*
Gender	Male	18.6	14.62-23.24	334	13.2	9.7-17.66	303	16.3	12.59-20.84	331	14.1	10.5-18.63	305
	Female	12.0	9.05-15.58	410	13.4	10.28-17.34	387	10.5	7.78-13.94	410	11.1	8.38-14.81	386
Age	43-49	16.5	12.48-21.43	285	9.3	5.75-14.49	194	17	12.88-21.96	283	11.9	7.82-17.46	194
	50-64	14.4	10.94-18.7	340	16.9	13.17-21.29	350	12.4	9.14-16.44	340	14.6	11.13-18.84	350
	65+	12.6	7.47-20.25	119	10.3	6.06-16.66	146	5.9	2.62-12.27	118	8.2	4.48-14.13	147
ID Level	Mild	27.7	21.19-35.28	166	29.5	22.49-37.64	149	28.9	22.29-36.55	166	27.5	20.68-35.54	149
	Moderate	12.9	9.48-17.14	319	10.8	7.62-15.05	296	10.4	7.38-14.44	317	10.5	7.33-14.67	296
	Severe-Profound	6.9	3.97-11.54	203	4.2	01.96-8.38	191	3.9	1.84-7.9	203	2.1	0.67-5.59	192
Residence	Independent /Family	36	27.75-45.12	125	29.5	21.42-38.94	112	34.7	26.51-43.82	124	26.5	18.89-35.83	113
	Community Group Home	13.4	9.6-18.23	262	12.4	8.96-16.77	299	12.3	8.69-17.08	260	10.8	7.59-15	297
	Institution	8.8	6.14-12.35	322	7.9	5.12-11.86	279	6.2	4.04-9.42	353	8.5	5.66-12.0	281
Total		14.9	12.48-17.73	744	13.3	10.93-16.15	690	13.1	10.79-15.78	741	12.4	10.13-15.2	691

Table 2.A.10: Membership of organisations, clubs and societies by gender, age and level of ID

Club, Organisation or Society	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe-Profound	Independent /Family	Community Group Home	Institution	
Special Olympics	16.9	17.4	19.4	19.5	8.8	21.6	19.7	9.4	24.8	22.1	8.9	17.2
Advocacy Group	10.4	10.0	11.2	11.0	6.8	6.5	14.0	5.2	15.9	10.9	7.1	10.2
Church/ Religious	3.6	9.0	6.1	6.8	6.8	7.2	6.7	7.3	8.0	5.9	6.7	6.6
Education, Arts, Music or Evening Class	6.2	3.8	4.6	5.6	3.4	7.8	6.4	0.5	8.8	6.3	1.8	4.9
Arch Club	4.9	2.6	5.6	3.1	2.0	5.2	3.7	2.6	4.4	5.0	1.8	3.6
Retirement Club	3.2	3.1	0.0	2.5	8.8	6.5	2.7	1.0	2.7	4.0	2.5	3.2
Tenants, Residents, Neighbourhood Watch	1.0	1.0	0.5	1.7	0.0	1.3	1.3	0.0	2.7	0.7	0.7	1.0
Charitable Association	0.3	1.0	1.0	0.8	0.0	2.0	0.0	0.0	2.7	0.3	0.4	0.7
Political, Trade Union, Environmental	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Other Group	10.4	12.8	12.8	13.0	7.4	19.6	12.4	4.7	20.4	13.9	6.0	11.7
Not a member of any group	58.8	54.6	55.6	53.1	65.5	43.1	51.5	75.0	39.8	49.2	70.9	56.4
n	308	390	196	354	148	153	299	192	113	303	282	698

Table 2.A.11: Social activities in Wave 1 and Wave 2

Social Activity	Wave 1			Wave 2			Change
	n	%	95% CI	n	%	95% CI	%
Eat out	753	87.8	85.18-89.99	698	85.2	82.42-87.74	-2.6
Go out for coffee	753	85.8	83.04-88.16	697	81.9	78.81-84.67	-3.9
Go shopping	753	83.9	81.07-86.44	698	76.1	72.69-79.16	-7.8
Go to the hairdresser	753	77.0	73.82-79.96	698	70.6	67.07-73.96	-6.4
Go to church/place of worship	753	78.0	74.78-80.83	698	61.7	58.02-65.35	-16.3
Visit family and friends in their home	753	66.3	62.75-69.62	698	59.5	55.7-63.11	-6.8
Go to the cinema, theatre, concert, opera	753	72.2	68.87-75.38	698	59.2	55.41-62.83	-3.0
Go to the pub for a drink	753	67.5	63.96-70.77	698	57.4	53.68-61.14	-10.1
Talk to family or friends on the phone	n/a	n/a	n/a	698	46.6	42.82-50.34	n/a
Spend time on hobbies/creative activities	753	51.7	48.03-55.28	698	38	34.37-41.70	-13.7
Go to a sports event	753	29.5	26.27-32.9	698	18.1	15.31-21.14	-11.4
Participate in sports activities/events	n/a	n/a	n/a	698	17.5	14.78-20.55	n/a
Go to social clubs (e.g. bingo, cards)	753	21.9	19.04-25.07	698	17.6	14.91-20.7	-4.3
Go to the library	753	21.1	18.29-24.25	698	15.8	13.18-18.73	-5.3
Go to an art gallery or museum	753	22.4	19.54-25.62	698	11.9	9.63-14.58	-10.5
Perform in local arts groups or choirs	753	8.8	6.89-11.07	698	4.9	3.45-6.81	-3.9
Other activities outside your home	753	13.5	11.23-16.25	698	8.2	6.3-10.52	-5.3
N/A – don’t engage in any social activities	753	1.3	0.68-2.51	698	2.9	1.81-4.48	+1.6

Table 2.A.12: Social activities by gender, age, level of ID and type of residence

Social Activity	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe-Profound	Independent /Family	Community Group Home	Institution	
Eat out	85.1	85.4	88.3	87.3	76.4	91.5	88.3	77.6	83.2	89.4	81.6	85.2
Go out for coffee	77.9	85.1	85.2	82.4	76.4	85.0	82.6	81.8	79.6	84.1	80.5	81.9
Go shopping	70.5	80.5	78.1	78.8	66.9	87.6	76.9	67.7	77.0	81.5	69.9	76.1
Go to the hairdresser	59.7	79.2	67.3	74.6	65.5	82.4	71.2	62.5	74.3	75.6	63.8	70.6
Go to church/place of worship	60.7	62.6	62.8	63.0	57.4	68.6	61.2	57.8	68.1	61.7	59.2	61.7
Visit family and friends in their home	60.7	58.5	74.0	59.6	39.9	75.2	63.9	39.6	83.2	67.3	41.5	59.5
Go to the cinema/ theatre/concert/opera	56.8	61.0	65.3	61.9	44.6	66.0	61.9	49.5	61.9	61.1	56.0	59.2
Go to the pub for a drink	66.6	50.3	61.7	61.0	43.2	64.7	59.9	47.4	60.2	64.7	48.6	57.4
Talk to family or friends on the phone	46.4	46.7	53.6	49.2	31.1	71.9	54.2	13.5	68.1	53.8	30.1	46.6
Spend time on hobbies/ creative activities	37.3	38.5	41.3	36.7	36.5	52.3	36.1	28.1	41.6	41.3	33.0	38.0
Go to a sports event	26.6	11.3	21.4	19.2	10.8	22.2	17.7	13.0	27.4	19.5	12.8	18.1
Participate in sports activities/events	20.8	14.9	21.4	18.9	8.8	24.2	17.7	10.4	23.0	18.5	14.2	17.5
Go to social clubs (e.g. bingo, cards)	15.3	19.5	17.3	18.9	14.9	22.9	18.7	12.0	20.4	18.5	15.6	17.6
Go to the library	15.3	16.2	17.9	17.8	8.1	24.8	14.4	10.9	22.1	17.8	11.0	15.8
Go to an art gallery or museum	12.0	11.8	13.8	13.3	6.1	11.8	10.4	12.5	8.0	13.5	11.7	11.9
Perform in local arts groups or choirs	4.9	4.9	7.7	4.5	2.0	6.5	5.4	3.1	9.7	4.3	3.5	4.9
Other activities outside your home	10.4	6.4	9.7	7.9	6.8	5.2	9.4	8.3	13.3	8.3	6.0	8.2
N/A – don't engage in any social activities	3.2	2.6	2.6	2.0	5.4	0.0	1.7	6.8	0.0	2.3	4.6	2.9
n	308	390	196	354	148	153	299	192	113	303	282	698

Table 2.A.13. Difficulties experienced participating in social activities outside the home – change since Wave 1

Difficulty experienced	Wave 1 (*n*=382)		Wave 2 (*n*=356)		Change
	%	95% CI	%	95% CI	%
Need someone's assistance	64.4	59.34-69.16	70.8	65.72-75.40	+6.4
Health considerations or physically unable	37.7	32.86-42.79	41.0	35.89-46.33	+3.3
Communication/language problems	28.5	24.11-33.39	27.2	22.75-32.25	-1.3
Not able to read signs and timetables	n/a	n/a	19.7	15.74-24.25	n/a
Transport services inadequate/not accessible	15.4	12.05-19.56	12.6	9.46-16.65	-2.8
Have no one to go with	10.5	7.67-14.09	9.6	6.8-13.21	-0.9
Don't like social activities	6.5	4.36-9.63	7.0	4.68-10.32	+0.5
Need special aids or equipment I don't have	9.2	6.55-12.62	4.8	2.9-7.69	-4.4
Getting too old	1.6	0.64-3.56	4.2	2.46-7.0	+2.6
Service facilities are not accessible	4.2	2.5-6.85	3.4	1.84-5.97	-0.8
Lack of local facilities or suitable activities	5.2	3.31-8.11	3.4	1.84-5.97	-1.8
Don't have enough money	1.8	0.8-3.9	3.4	1.84-5.97	1.6
Unfriendly or negative attitudes towards you	2.4	1.16-4.59	1.4	0.52-3.43	-1.0
Not allowed to go	1.0	0.34-2.85	1.1	0.36-3.05	+0.1
Don't have enough time	3.9	2.3-6.54	1.1	0.36-3.05	-2.8
Family and friends residence not accessible	1.8	0.8-3.9	1.1	0.36-3.05	-0.7
You are self-conscious of your ID	n/a	n/a	0.6	0.1-2.24	n/a
Other	50.0	44.88-55.12	36.2	31.28-41.5	-13.8

Table 2.A.14 Difficulties experienced getting around your community – change since Wave 1

	Wave 1							Wave 2						
	Yes		No		NA			Yes		No		NA		
	%	95% CI	%	95% CI	%	95% CI	n	%	95% CI	%	95% CI	%	95% CI	*n*
Gender:														
Male	41.7	36.42-47.25	40.2	34.97-45.74	18.0	14.13-22.67	333	35.7	30.41-41.43	35.4	30.1-41.1	28.9	23.9-34.34	305
Female	42.3	37.54-47.29	36.5	31.87-41.38	21.2	17.38-25.51	411	32.6	27.96-37.51	36.2	31.43-41.21	31.3	26.73-36.19	387
Age:														
43-49	41.1	35.37-47.13	39.4	33.67-45.35	19.5	15.41-24.71	282	32.7	26.24-39.76	40.3	33.45-47.56	27.0	21.08-33.92	196
50-64	41.1	35.89-46.53	41.1	35.89-46.53	17.8	13.97-22.33	343	36.3	31.29-41.6	36.9	31.84-42.18	26.9	22.35-31.89	350
65+	47.1	37.92-56.39	26.9	19.37-35.93	26.1	18.63-35.04	119	30.1	22.97-38.37	27.4	20.51-35.5	42.5	34.42-50.92	146
Level of ID:														
Mild	26.2	19.81-33.76	65.2	57.37-72.39	8.5	4.92-14.18	164	27.2	20.39-35.09	62.3	53.97-69.9	10.6	6.37-16.91	151
Moderate	46.7	41.12-52.35	36.0	30.72-41.54	17.4	13.44-22.07	317	37.8	32.34-43.66	29.1	24.01-34.64	33.1	27.84-38.83	296
Severe-Profound	51.0	43.95-57.95	17.5	12.69-23.51	31.6	25.37-38.44	206	36.1	29.41-43.42	20.9	15.54-27.54	42.9	35.87-50.28	191
Type of Residence:														
Independent/ Family	22.0	15.38-30.45	70.1	61.21-77.71	7.9	4.05-14.36	127	18.8	12.23-27.46	69.6	60.13-77.78	11.6	6.57-19.38	112
Community Group Home	42.4	36.34-48.72	40.1	34.09-46.37	17.5	13.18-22.84	257	37.4	31.99-43.17	35.1	29.78-40.81	27.5	22.6-32.95	302
Institutional	48.6	43.31-53.92	25.6	21.18-30.48	25.8	21.44-30.78	356	36.3	30.73-42.32	23.0	18.3-28.51	40.6	34.87-46.69	278
Total	42.1	38.51-45.72	38.2	34.68-41.78	19.8	16.99-22.84	744	34.0	30.46-37.64	35.8	32.28-39.56	30.2	26.83-33.8	692

Table 2.A.15: Prevalence of level of difficulty in reading, writing, numeracy and money recognition by gender age and level of ID.

	Difficulty Reading			Difficulty Writing			Difficulty with number			Difficulty with money		
	%	95% CI	Number in sample	%	95% CI	Number in sample	%	95% CI	Number in sample	%	95% CI	Number in sample
Gender:												
Male	84.6	79.93-88.35	305	85.9	81.37-89.5	305	83.2	78.43-87.15	304	81.6	76.73-85.73	305
Female	80.4	76.01-84.2	383	80.8	76.41-84.52	385	78.5	74-82.47	382	76.3	71.66-80.4	384
Age:												
43-49	80.5	74.11-85.68	195	82.1	75.78-87.02	195	79.8	73.29-85.08	193	78.5	71.89-83.88	195
50-64	80.5	75.89-84.46	349	80.9	76.32-84.81	351	77	72.16-81.25	348	76	71.11-80.31	350
65+	88.9	82.31-93.32	144	89.6	83.11-93.85	144	90.3	84.03-94.42	145	85.4	78.35-90.55	144
Level of ID:												
Mild	61.6	53.3-69.28	151	59.2	95.78-99.81	152	56.4	48.02-64.4	149	50.7	42.47-58.81	152
Moderate	84.8	80.14-88.63	297	86.5	81.99-90.1	297	83.8	78.97-87.69	296	83.4	78.61-87.4	296
Severe/Profound	98.9	95.78-99.81	187	97.9	94.29-99.31	188	97.3	93.57-99.02	188	96.3	92.22-98.37	189
Residence:												
Indep/Family	65.2	55.53-73.77	112	69	59.54-77.21	113	60.2	50.52-69.14	113	58	48.34-67.18	112
CGH*	81.8	76.87-85.88	302	82.1	77.22-86.18	302	80.1	75.01-84.34	301	76.5	71.22-81.07	302
Residential	89.8	85.42-92.99	274	89.8	85.47-93.01	275	89.7	85.32-92.94	272	89.5	85.05-92.71	275
Total	82.3	79.16-85.01	688	83	79.98-85.72	690	80.6	77.41-83.46	686	78.7	75.37-81.62	689

Table 2.A.16a: Participant's ability to engage in foundational skills of education – reading and writing ability

Reading Skills	Yes, without assistance	95% CI	Yes, with assistance	95% CI	No	95% CI	No. in sample
I can read my own name	29.4	25.63-33.26	7.9	5.87-10.49	62.7	58.68-66.76	570
I can identify most letters of the alphabet	16.6	13.59-19.85	10.9	8.5-13.8	72.5	68.74-76.21	570
I can read name of own street or town	11.6	8.97-14.37	4.6	3.06-6.7	83.9	80.71-86.9	570
I can read easy to read material	8.4	6.18-10.9	7.5	5.57-10.1	84.1	80.89-87.05	570
I can read common environmental words in context	14.4	11.67-17.6	5.6	3.93-7.91	80.0	76.43-83.16	570
I can read basic large print book	5.3	3.67-7.53	6.7	4.8-9.14	88.0	85.03-90.54	569
I can read instructions, such as those on a medicine bottle	1.4	0.66-2.87	4.6	3.07-6.71	94.0	91.66-95.76	596
I can read instructions on packaged goods in shops or supermarkets	1.4	0.66-2.87	4.6	3.07-6.71	94.0	91.66-95.76	596
I can read information from government agencies, businesses, or other institutions	0.7	0.22-1.91	3.7	2.36-5.68	95.6	93.5-97.08	596
I can read newspaper articles	1.8	0.9-3.32	4.0	2.64-6.09	94.2	91.87-95.91	569
Writing Skills							
I can write most of the letters of the alphabet	13.2	10.62-16.33	13.7	11.09-16.89	73.0	69.18-76.59	575
I can write my own name	26.4	22.91-30.27	8.7	6.59-11.38	64.9	60.79-68.75	575
I can write notes and letters (e.g. birthday or Christmas cards)	5.2	3.61-7.45	14.4	11.71-17.63	80.3	76.81-83.47	575
I can fill out forms such as applications or bank deposit slips	0.7	0.23-1.9	5.2	3.61-7.45	94.1	91.75-95.81	575

Table 2.A.16b: Participant's ability to engage in foundational skills of education – numeracy and money ability

Numeracy Skills	Yes, without assistance	95% CI	Yes, with assistance	95% CI	No	95% CI	No. in sample
I can recognise numbers 1-10	24.7	21.21-28.52	10.6	8.19-13.47	64.8	60.62-68.69	559
I can recognize and locate numbers on phone or ATM or Post office machine	9.8	7.56-12.69	7.9	5.84-10.5	82.3	78.81-85.31	559
I can dial numbers on phone	10.9	8.51-13.86	8.6	6.46-11.3	80.5	76.92-83.65	559
I understand more-less relationships e.g. If I have 10 apples I have less than someone who has 20 apples	7.0	5.07-9.5	5.9	4.16-8.27	87.1	83.99-89.73	559
I can do simple sums – that is add and subtract	4.1	2.68-6.2	5.0	3.42-7.25	90.9	88.11-93.07	559
I can tell time on a clock or watch	16.1	13.2-19.47	3.4	2.12-5.36	80.5	76.92-83.65	559
I can use a calculator of simple sums	1.1	0.43-2.44	3.2	1.98-5.14	95.7	93.59-97.17	559

Money Skills							
I can identify €5, €10, and €20 notes	15.0	12.21-18.39	7.7	5.68-10.36	77.2	73.45-80.66	545
I can identify coins: 1¢, 2¢, 5¢, 10¢, 20¢, 50¢	11.7	9.22-14.81	9.2	6.94-11.99	79.1	75.37-82.37	545
I can arrange coins in order of value	5.7	3.96-8.07	7.0	5.04-9.53	87.3	84.18-89.96	545
I can arrange notes in order of value	5.5	3.8-7.85	7.5	5.51-10.15	87.0	83.78-89.62	545
I can understand more or less applied to money: can attempt to identify from price of an item whether change is due from note or coin handed in	4.6	3.05-6.79	5.5	3.8-7.85	89.9	86.99-92.25	545

Table 2.A.17: Prevalence of computer skills and social networking

Computer skills and Social Networking	Yes, without assistance	95% CI	Yes, with assistance	95% CI	No	95% CI	No. in sample
I can type my own name on a keyboard	10.5	8.27-13.33	9.2	7.1-11.89	80.2	76.79-83.28	607
I can type a letter	4.8	3.28-6.88	6.8	4.94-9.12	88.5	85.59-90.85	607
I can turn on a computer	6.8	4.91-9.12	7.9	5.95-10.42	85.3	82.22-88.01	607
I can send an email	0.5	0.13-1.56	5.4	3.83-7.63	94.1	91.81-95.76	607
I can look up topics of interest on Google	1.2	0.5-2.47	5.9	4.24-8.19	92.9	90.51-94.77	607
I can use social media sites such as Facebook, Twitter, etc	0.3	0.06-1.32	2.5	1.44-4.14	97.2	95.46-98.31	607

3

Changes in Physical and Behavioural Health of Older Adults with Intellectual Disability

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Contents

3

Changes in Physical and Behavioural Health of Older Adults with Intellectual Disability

3.1 Key Findings

- Approximately 46% of participants rated their health as excellent or very good which was comparable to the rates reported by TILDA for the general population and to Wave 1 findings.
- Rates of hypertension were more than 50% lower for people with ID (17.5%) than for the general population (37%).
- There was little difference in diagnosed and measured hypertension except among those with severe and profound ID where the measured rate was 50% higher than doctors' diagnoses.
- Myocardial Infarction (heart attack) was 5 times lower in people with intellectual disability than that reported by TILDA for the general population.
- Based on WHO risk classification for cardio metabolic disease, 64.6% of IDS-TILDA participants were at substantially increased risk compared to 53% in TILDA with an even greater risk for women with ID of 78.4% versus 56% in TILDA.
- Reported rates of osteoporosis (16.4%) among people with ID had doubled by Wave 2, but objective measurement found that 70% of people with ID had osteoporosis or osteopenia.
- 60% described their weight as normal but 66% had measured overweight and obesity, a serious health risk. However, underweight was rarely found in doctor's report or in objective measurement.
- Over 70% engaged in only low levels of physical activity, i.e., in levels of activity not likely to result in health benefits.
- There was a doubling from Wave 1 of rates of cataracts and of macular degeneration and higher incidence for these conditions, as compared to the general population.
- Almost 50% of those aged 65+ reported chronic constipation, as did one third of those aged 40-49 years.

- The prevalence of epilepsy increased from 30.5% in Wave 1 to 35.9% in Wave 2 and from 19.2% to 27.9% for those with Down syndrome.
- Arthritis, osteoporosis and cataracts had the highest three-year incidence rates.
- Positive findings are relatively low levels of fast food consumption, as well as levels of smoking and alcohol use which continued to remain significantly lower than for the general population.

3.2 Introduction

Persons with an intellectual disability (ID) are increasingly living to old age (Kelly & Kelly, 2011) which means that understanding the association between chronic disease and increased age has become an important issue in the care of adults with an ID (Haveman *et al.,* 2010). People ageing with ID are a diverse group with some experiencing age related health conditions relatively early, however holding strong positive perceptions of ageing influences, not only how older age is approached but also how these health conditions are faced (Burke *et al.,* 2014). For people with Down syndrome there is higher prevalence and earlier onset of age related sensory and musculoskeletal disorders, and an exceptional risk of developing dementia, both of which may result in additional disabilities (McCarron *et al.,* 2014). Additional health needs for people with a range of ID also stem from the interaction of ageing and secondary conditions associated with their impairment, its progression, or as the consequence of long term poor quality health care (Haveman *et al.,* 2009).

Many people with cerebral palsy as they age, for example, report reduced mobility, increased pain, and bowel and bladder problems, probably a result of the long term effects of muscle tone abnormalities, and overuse of some joints and immobility of others (Bigby *et al.,* 2014). Immobility, small body size, poor diet and prolonged use of anti-convulsant drugs may also contribute to early and increased risk of osteoporosis, falls and fractures (Foran *et al.,* 2013). Multi-morbidity is high in this population and prevalence figures in younger age groups are similar to those reported for the oldest old in the general population but with somewhat different disease patterns (McCarron *et al.,* 2013). A large US study of medical records reported that the frequency of cardiovascular, musculoskeletal and respiratory conditions and sensory impairments increased with age, while neurological, endocrine and mental health problems declined with age and that, despite high levels of risk factors such as obesity, heart related diseases did not appear as prevalent in people with ID as reported in the general population (Janicki *et al.,* 2002). However, most of this insight has been gleaned from small scale, local, clinical and cross sectional samples. The tracking of prevalence and incidence of disease and behavioral health contributors over time, as is possible through IDS-TILDA, and comparisons with general population TILDA data offer a unique opportunity to better understand changes in the physical and behavioral health of people with ID as they age and their implications for their longevity and quality of life.

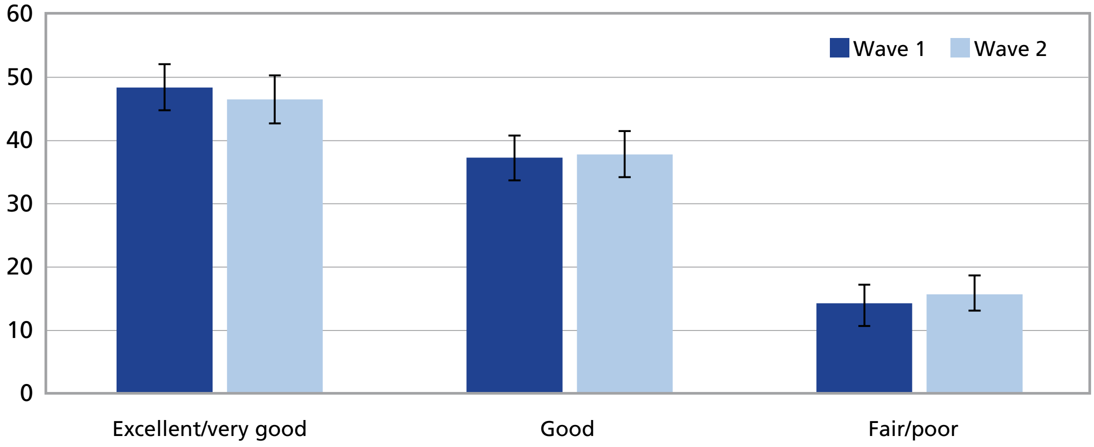
3.3 Key Methodological Considerations

As the overall sample was not refreshed for Wave 2 of the survey, the youngest participant was aged 43 years. Only people who participated in both Wave 1 and Wave 2 were included in Wave 2 analyses. Incidence was calculated as the number of new cases of each health condition reported among people who were free of that condition in Wave 1. Point prevalence and incidence data were stratified by age and gender and where appropriate by level of ID. Comparisons were drawn with the general population using reported data from TILDA (Finucane *et al.,* 2014; Leahy *et al.,* 2014). In those comparisons it should be noted that TILDA data was for people aged 52 and older while IDS-TILDA data in Wave 2 was for individuals aged 43 and older. On some occasions, noted as such in the text of this chapter, the more direct comparison of those 50 and older in both groups will be reported. Finally, for the comparison with TILDA data it was not possible to calculate confidence intervals and so all highlighting of differences is presented with the caution that significance of differences has not yet been assessed.

3.4 Changes in Self-Rated Health

An individual's perception and appraisal of their own health has been shown to be a strong predictor of future morbidity and mortality (Idler & Benyamini, 1997; Riise, Riise, Natvig, & Daltveit, 2014). Similar to Wave 1, self-rated health in Wave 2 was measured on a five point Likert scale from excellent to poor but for the purposes of reporting was grouped into excellent/very good, good and fair/poor.

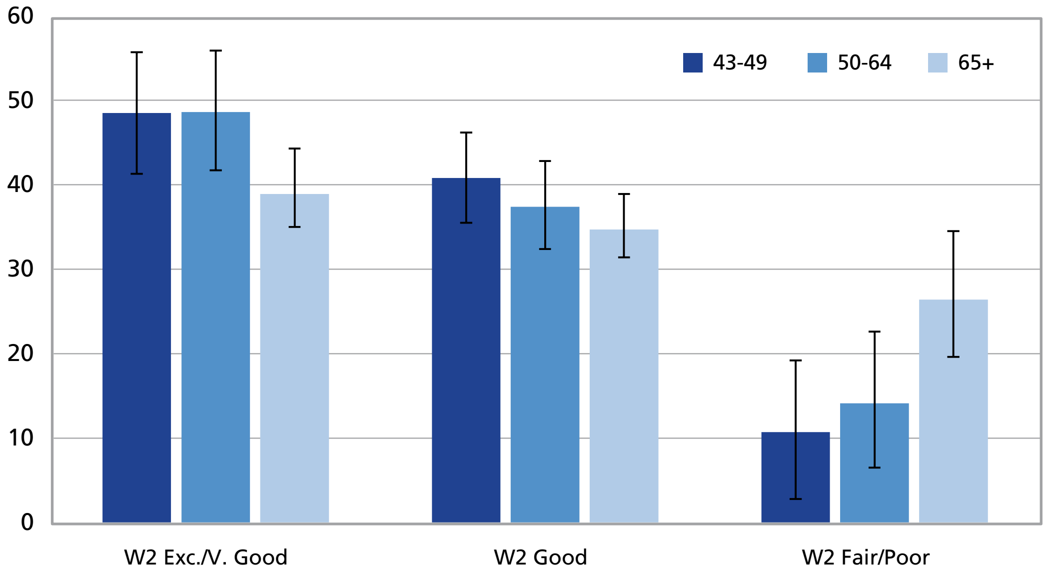
Figure 3.1: Distribution of self-rated health



There was little change observed overall in self-reported health between Wave 1 and Wave 2 (See *figure 3.1*). Of the Wave 2 participants, 46.5% reported having excellent or very good health compared with 50.5% of the same population at Wave 1. This is comparable to the general population (TILDA) report of 44% rating their health as excellent or very good health (Finucane *et al.,* 2014).

Overall older people rated their health within the fair-poor category by comparison to other age groups (see figure 3.2) However the majority of participants across all age categories who reported their health as excellent to very good in Wave 1 continued to do so in Wave 2. The greatest difference was among the middle age group (50 – 64 years) where 47.4% (*n*=65) who reported their health as good in Wave 1 now considered it to be excellent to very good, and a further 62% (*n*= 23) who considered their health as poor in Wave 1 now rated themselves within the good and very good/ excellent categories. Considering level of ID, in Wave 2 those within the mild category were more inclined to rate their health as excellent or very good (51.3%). Conversely higher numbers of those within severe/profound category rated their health as poor, 21.2% versus 11.3% within the mild category and 15.2% within the moderate category (Appendix table 3.A.1)

Figure 3.2: Self-rated health at Wave 2 by age.



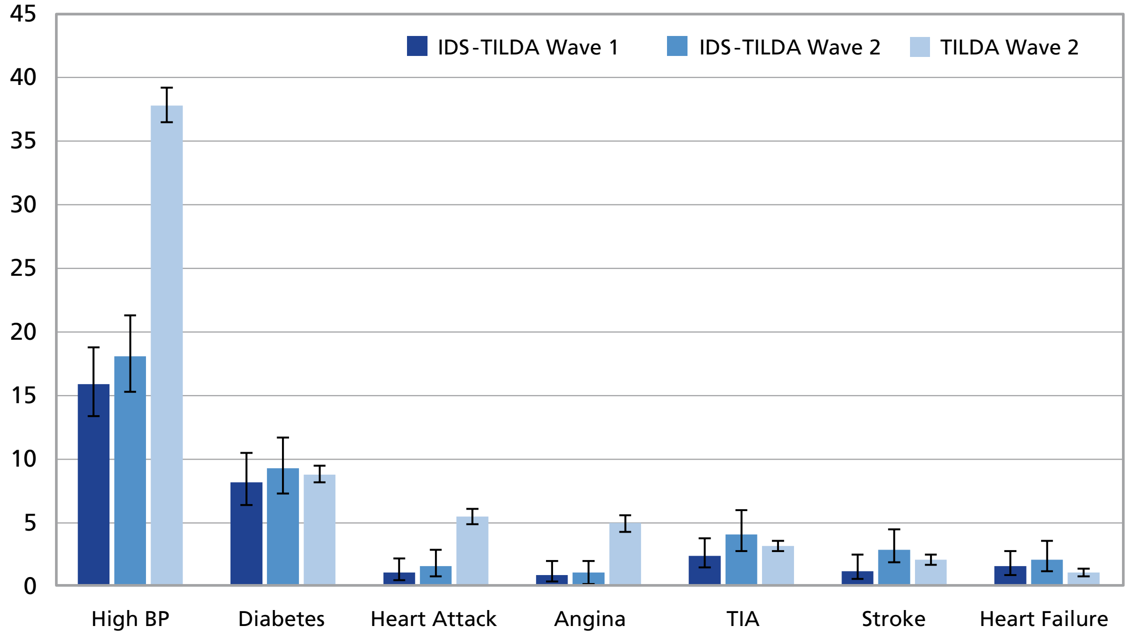
3.5 Prevalence and Incidence of Cardiovascular Disease (CVD)

There are a number of reports that CVD is lower among people with ID than the general population despite increased risk factors such as overweight, obesity and inactivity (Haveman *et al.,* 2009). More recent work by McCarron *et al.,* (2013) has highlighted that the pathways of disease and disease pairs are different for older adults with ID compared to the general population, and also supports that the cardiovascular picture may be different.

3.5.1 Changes in prevalence of cardiovascular conditions

Prevalence of cardiovascular conditions was measured by asking participants if they had a previous doctor's diagnosis of cardiovascular conditions including hypertension, myocardial infarction, diabetes, stroke and angina. *Figure 3.3* shows the changes in the point prevalence of cardiovascular conditions between Wave 1 and Wave 2 and compares the point prevalence rates at Wave 2 for both IDS-TILDA and TILDA (Finucane *et al.,* 2014). Prevalence of hypertension in IDS-TILDA participants increased between Wave 1 and Wave 2 from 15.9% to 18.1%. Of most interest was the finding that rates of hypertension among people with ID were 50% lower than the reported general population rate of 37.2% (Finucane *et al.,* 2014).

Figure 3.3: Prevalence of cardiovascular conditions.

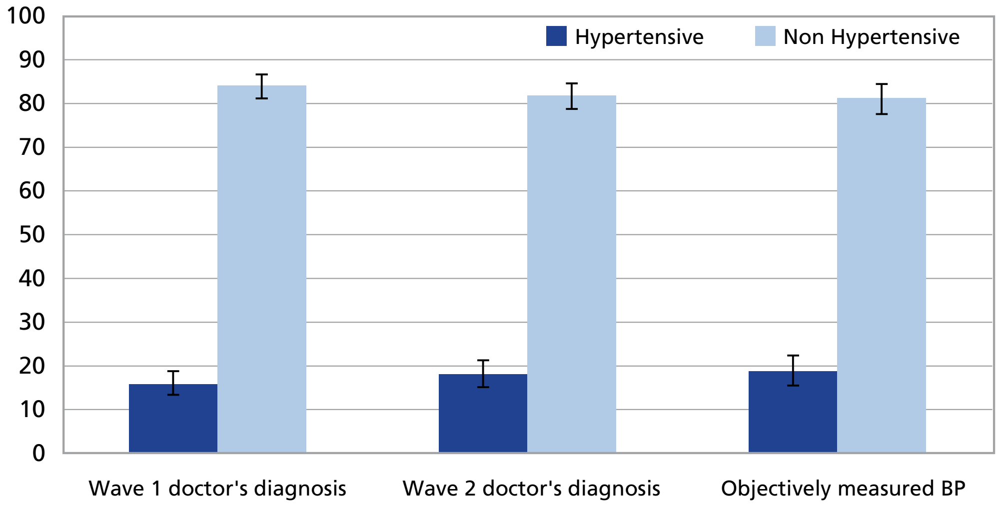


In TILDA Wave 1 a significant difference was identified between self-reported hypertension and objectively measured rates, with 58% of men and 49% of women having undiagnosed hypertension despite measured symptoms (Cronin *et al.,* 2011). Mindful of this, IDS-TILDA introduced objective measurement of blood pressure in Wave 2.

3.5.2 Doctor’s diagnosis verses objectively measured hypertension

In contrast to the general population, as can be seen from *figure 3.4,* there is very little difference between the doctor’s diagnosis and objectively measured hypertension in people with ID at 17.5% versus 18.1% on objective measurement. The minimal difference may be reflective of most people with ID having regular access through their service provider to their GP and/or to nursing services and their blood pressure is regularly checked.

Figure 3.4: Comparison of doctor's diagnosis of hypertension verses objectively measured hypertension



Looking at differences between doctor's diagnosis and objectively measured blood pressure with regards to age, gender and level of ID (Appendix table 3.A.2), what is notable is that under diagnosis of elevated blood pressure was higher among the younger cohort (40-49 years) with 5.5% reporting a doctor's diagnosis compared to 12.3% meeting criteria for hypertension on objective measurement. This was reversed amongst the older aged cohort 65+ years with 30.8% reporting a doctor's diagnosis compared to 23.4% objectively measured. For the older group this difference may reflect active efforts to manage previously identified hypertension. Although, rates of hypertension among the general population reported by TILDA were twice as high as those reported for the ID population the underlying trends were similar.

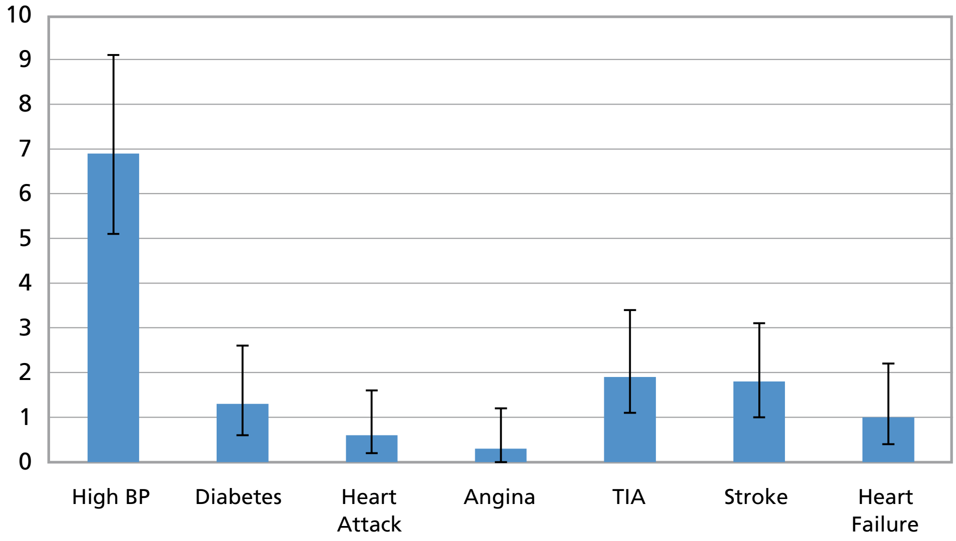
Examining gender, women had higher levels of doctor's diagnosis than objectively measured hypertension (17.8% versus 15.8%) whereas men's rates of diagnosis were less than measured hypertension (18.5% versus 22.7%). Regarding level of ID, of concern was the under diagnosis of hypertension in people with severe to profound ID with 11.8% reporting a doctor's diagnosis, versus 17.5% meeting criteria for hypertension on objective measurement.

3.5.3 Three-year incidence of cardiovascular conditions

As may be seen in *figure 3.5* three-year incidence of cardiovascular conditions in Wave 2 was highest in terms of hypertension (6.9%), TIA (2%) and stroke (1.8%). The incidence of hypertension was similar to the two-year incidence reported for TILDA at (6.5%), however TIA was double the reported TILDA incidence (0.9%) and stroke had more than four times the incidence reported by TILDA (0.4%) (See Appendix table 3.A.3).

The incidence of diabetes among the IDS-TILDA population (1.3%) was lower than the incidence reported by TILDA (2.0%). The incidence of heart failure, heart attack and angina was 1% or lower.

Figure 3.5: Three-year incidence of cardiovascular conditions



3.5.4 Changes in the point prevalence of other cardiovascular conditions

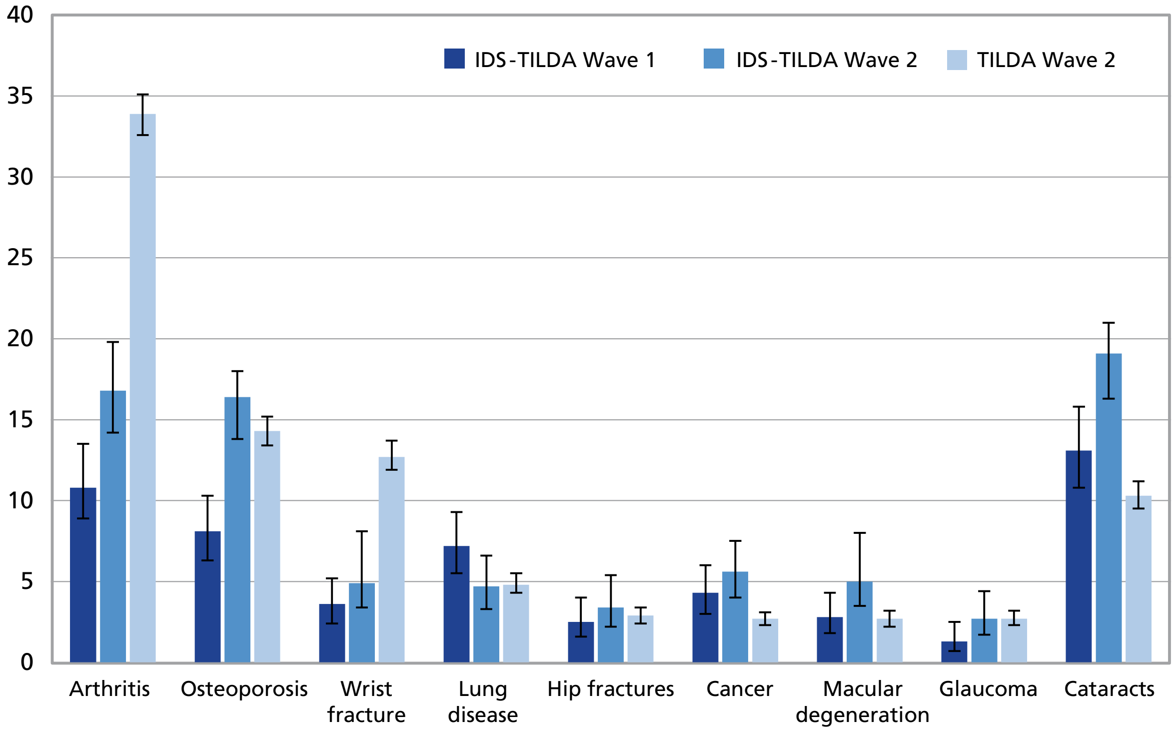
Trans-ischemic attack (TIA) and stroke almost doubled from Wave 1 to Wave 2 and there was slightly higher prevalence of diabetes (9.3%), stroke (2.9%), and TIA (4.1%) among people with ID than among the TILDA population at 8.8%, 2.1%, and 3.2% respectively (Finucane *et al.,* 2014). The picture is reversed when considering angina and myocardial infarction with prevalence of these conditions almost five times greater in the general population than among adults with ID in this study. The prevalence of myocardial infarction was 1.6% in IDS-TILDA Wave 2 compared with 5.5% among the TILDA population Wave 2. The prevalence of angina was also higher among the TILDA population (5.0%) compared with the IDS-TILDA in Wave 2 (1.1%). These comparisons can be observed in *figure 3.3*.

Prevalence rates of cardiovascular conditions by gender, age and level of ID in Wave 2 IDS-TILDA are shown in Appendix table 3.A.4. For example more females present with diabetes (11.1%), angina (1.3%), TIA (4.6%) and stroke (3.1%), whereas more males present with myocardial infarction (heart attack, 1.6%), hypertension (18.5%) or heart failure (2.3%). Age gradient increases are evident across all conditions and higher prevalence of most conditions are noted among those within the mild or moderate categories of ID, apart from TIA and stroke where there are higher prevalence among those within the severe/profound category.

3.6 Changes in Point Prevalence of Chronic Conditions (Non-Cardiovascular)

Data was collected on a range of non-cardiovascular conditions including muscular skeletal and sensory conditions. *Figure 3.6* documents the increases in point prevalence for these conditions from Wave 1 to Wave 2 and compares this data with the prevalence rates reported by TILDA for the general population (Finucane *et al.,* 2014). For both the general population and IDS-TILDA prevalence increased most significantly for osteoporosis, arthritis and cataracts, with the point prevalences for cancers, cataracts and macular degeneration higher for people with ID than that reported for the general population.

Figure 3.6: Point prevalence of chronic conditions (non-cardiovascular)



3.6.1 Muscular skeletal conditions

Muscular skeletal conditions pose a major and pervasive burden on individuals, service providers and health care systems (Hoy *et al.,* 2014). TILDA have identified increased rates of arthritis especially among their oldest population (Finucane *et al.,* 2014). In IDS-TILDA the prevalence of arthritis has more than doubled from 8.1% in Wave 1 to 16.8% in Wave 2, however this rate is approximately 50% lower than the 33.9% reported for the general population. Such a finding needs to be interpreted with caution given that diagnosis of arthritis relies heavily upon self-report of symptoms and many people with ID have significant difficulty identifying and communicating their health needs and concerns.

3.6.2 Osteoporosis

The prevalence of doctor's diagnosis of osteoporosis for people with ID doubled from Wave 1 to Wave 2, from 8.1% to 16.4% respectively, which is higher than that reported for the general population at 14.3% (Finucane *et al.,* 2014). Doctor's diagnosis of osteoporosis was three times higher in females than males at 23.5% versus 7.4% respectively, and doctor's diagnosis of osteoporosis increased fivefold with age from 5.6% (40 – 49 years) to 29.7% (65 years+). There was very little difference attributable to level of ID with doctor's diagnosis of osteoporosis at 13% among the mild category, 17.3% in the mild category and 17.2% within the severe/ profound category.

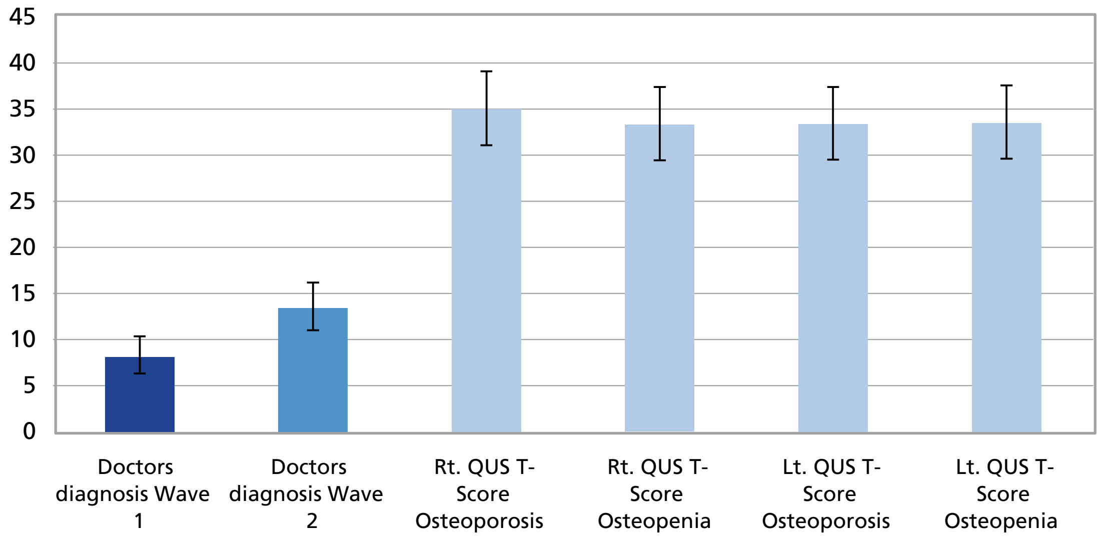
3.6.3 Objective measurement of bone status

In Wave 1 TILDA objectively measured bone status and found a significant discrepancy between a doctor's diagnosis and objectively measured osteoporosis. Among those objectively measured as having osteoporosis, 66% of females and all the men (100%) did not report a doctor's diagnosis of this debilitating condition (Cronin *et al.,* 2011). For Wave 2, IDS-TILDA introduced objective bone status measurement using measures from the validated GE Lunar Achilles Insight Express II (see methodology chapter 6; section 6.7).

Given difficulties with identification of foot dominance for persons with ID, bone status was evaluated for both feet. As may be seen in *figure 3.7*, on the right foot the overall prevalence of osteoporosis was 34% and 36% for the left foot, with a further 34% meeting criteria for osteopenia with no difference between left and right foot.

Overall the point prevalence of osteoporosis for people with ID was higher than for the general population at 35% versus 28% respectively. Of specific concern was that the prevalence of osteoporosis in women with ID in the 50 – 64 years age group (36.8%) was almost 5 times higher than the 8% reported for the similarly aged female general population (Cronin *et al.,* 2011). Of further concern is that the prevalence of osteopenia was more than double that of the general population at 37% versus 14%, equating to almost seven out of ten people with ID having either osteoporosis or osteopenia.

Figure 3.7: Doctor's diagnosis versus objectively measured bone health



Considering level of ID, those within the mild category were objectively measured at 23.2% (left foot) and 17.9% (right foot), as meeting criteria for osteoporosis, and those with moderate level of ID were measured at 27% for both feet. Of most concern was that those within the severe to profound range of ID presented with 59.7% (left foot) and 58% (right foot), over four times higher than the doctor's reported diagnosis of osteoporosis for this group (14.8%) and almost double that of their peers with moderate ID (see Appendix table 3.A.5). Possible explanations are that this group presents with greater mobility challenges, and have higher rates of morbidity and health challenges. Despite these increased related health concerns, the group would also be more likely to have greater communication difficulties and to be less likely to express their experience of pain for example. In light of these findings it would be prudent to further investigate and monitor for increased risk for fragility fracture and their consequences among people with severe/profound ID.

IDS-TILDA in its Wave 1 report noted lower rates of fracture between its cohort and the general population. There are some changes to this picture by Wave 2. A rise in prevalence of wrist fracture from 2.7% to 4.8% by Wave 2 in IDS-TILDA contrasts with a rate of 12.7% in TILDA and supports continuation of lower rates of fracture. However, a rise in hip fracture from 2.5% in Wave 1 to 3.4% in Wave 2 for IDS-TILDA when compared to a decline from 3.6% to 2.9% in the general population at Wave 2 means hip fracture is now slightly higher among IDS-TILDA participants. The lower rates of wrist fracture may reflect that people with an ID when they fall may be less likely than the general population of older adults to reach and try to break that fall, with the unintended consequence of wrist fractures.

3.6.4 Sensory impairment

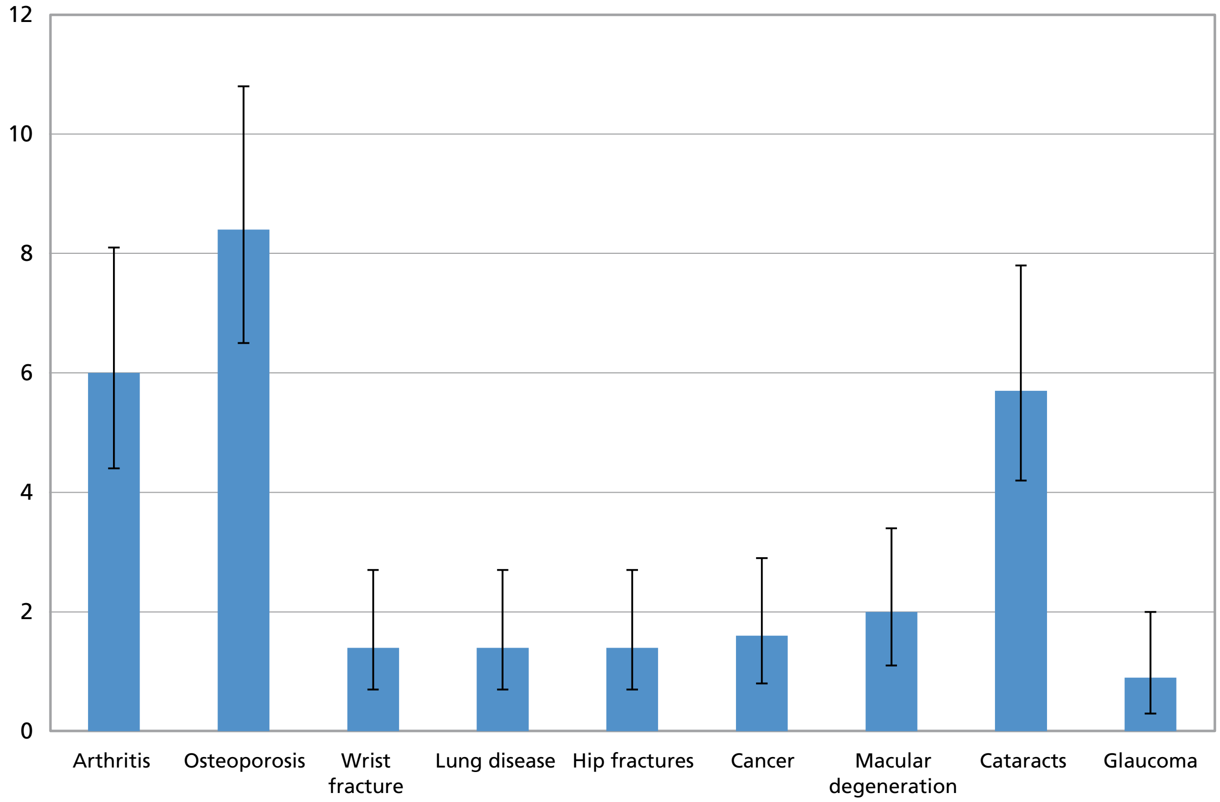
Sensory impairment continues to emerge as an issue of serious concern among adults with ID. Sensory impairment was noted in Wave 1 as significant and although their point prevalence held steady for the general population, vision and hearing difficulties in IDS-TILDA have almost doubled by Wave 2. As shown in *figure 3.8* the point prevalence of cataracts in Wave 2 has increased by 6 percentage points (a 46% increase) to 19.1% compared with 13.1% at Wave 1, macular degeneration has almost doubled to 5.0% from 2.8%, and glaucoma prevalence doubled to 2.6% from 1.3%. Overall, more women than men presented with higher rates across all eye conditions with almost twice as many women than men presenting with macular degeneration at 5.9% versus 3.9%, in the middle age group (50 – 64 years) and falling within the moderate level of ID (6.3%). Chronic eye diseases such as cataracts are noted to be particularly high among people with ID. Recently, McCarron *et al.,* (2013) highlighted that in multimorbidity among people with ID eye disease combining with mental health or neurological conditions was among the most influential conditions for secondary ill health. Although there are many challenges that surround assessment and amelioration of these conditions, the limitations these conditions may impose on a person's daily living activities and quality of life suggest it would be prudent to address these issues further.

The prevalence of hearing difficulties was unchanged with 11.6% of people reporting their hearing as fair to poor or as legally deaf in Wave 1 and 11.4% prevalence in Wave 2. Prevalence of non-cardiovascular conditions by gender, age and level of ID can be observed in Appendix table 3.A.6.

3.6.5 Three-year incidence of chronic conditions (non-cardiovascular)

Similar to the TILDA reports for the general population, the highest incidence rates of non-cardiovascular chronic conditions (by doctor's diagnosis) in IDS-TILDA were osteoporosis (8.5%) arthritis (6.0%) and cataracts (5.9%). By Wave 2 the greatest increase in incidence was of eye disease, particularly cataract disease at 5.9% and macular degeneration at 2.1% (see *figure 3.8*).

Figure 3.8: Three-year incidence of chronic conditions.



All other chronic conditions have an incidence rate of below 2%. It should be noted that the incidence period was two years for TILDA and three years for IDS-TILDA, meaning the overall incidence difference between the two groups could possibly be greater (see Appendix table 3.A.7).

3.7 Prevalence and Incidence of Falls

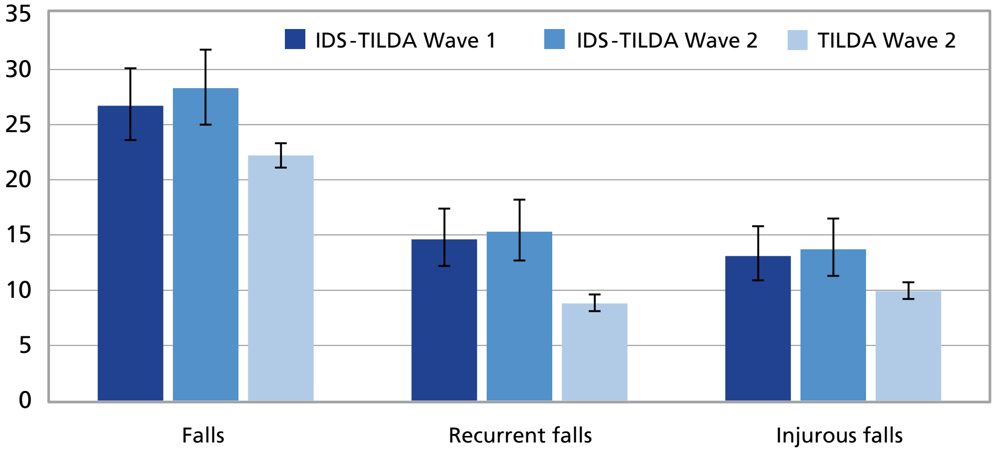
Risk of falls for older people with ID is similar to that of the older general population in terms of co-morbidity, vision impairment and gait abnormalities. However, an added loading given higher rates of these conditions, and higher levels of epilepsy and cerebral palsy further increases potential for falls in people with an ID (Cox *et al.,* 2010; Hsieh *et al.,* 2012).

Similar to Wave 1, people were asked if they experienced a fall in the past month and in the past year, which included a slip or trip in which they lost their balance and landed on the floor or ground at a lower level. For the purposes of the report and to support comparability with TILDA, people who reported one fall are classified as fallers and those who reported two or more are classified as recurrent fallers. People also reported if they sustained an injury as a result of the fall (classified as injurious falls).

3.7.1 Changes in prevalence of falls

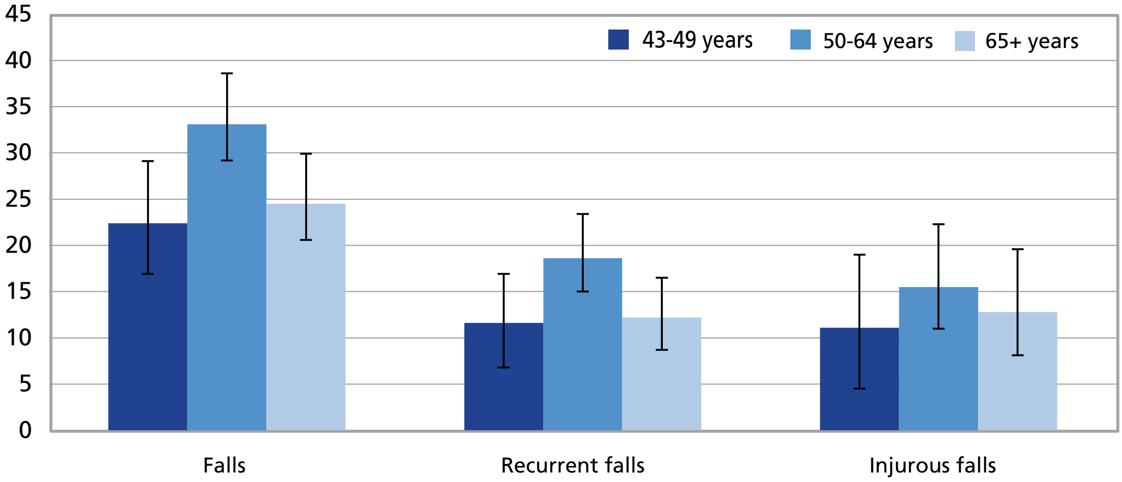
Overall, the falls picture for people with ID was similar to that reported for the general population (Finucane *et al.,* 2014). As can be seen from *figure 3.9* there is a slight increase in falls and recurrent falls from Wave 1 (26.7%) to Wave 2 (28.3%). This was a higher rate than that reported by TILDA (22.2%), with recurrent falls almost double that of the general population, 15.3% versus 8.8%. With regards to injurious falls, more people with ID appear to experience an injury from their fall than reported for the general population at 13.7% versus 9.9% respectively.

Figure 3.9: Comparison of the prevalence of falls, recurrent falls and injurious falls between IDS-TILDA and TILDA.



Of those experiencing falls, the highest prevalence of falls, recurrent falls and injurious falls is among those aged 50 – 64 years *(figure 3.10)*. However, similar to IDS-TILDA Wave 1 findings, the prevalence of falls among younger adults with ID aged 40-49 years (22.7%) is almost similar to the TILDA older age group of 75+ years (24.6%). Of great concern is that prevalence of falls in the 50 – 59 years group of people with ID (33%) was almost double that for similarly aged persons in the general population (17.6%).

Figure 3.10: Prevalence of falls, recurrent falls and injurious falls at Wave 2 by age.



3.7.2 Changes in falls prevalence between Wave 1 and Wave 2

As may be seen in Table 3.1, of those who had no falls in Wave 1, 9.8% reported a fall in Wave 2 with a further 11.2% with recurrent falls in Wave 2. Of those who reported one fall in Wave 1, 13.4% reported recurrent falls in Wave 2. Finally, from Wave 1 to Wave 2, the number of recurrent fallers reduced by almost 50%.

Table 3.1: Changes in falls prevalence between Wave 1 and Wave 2

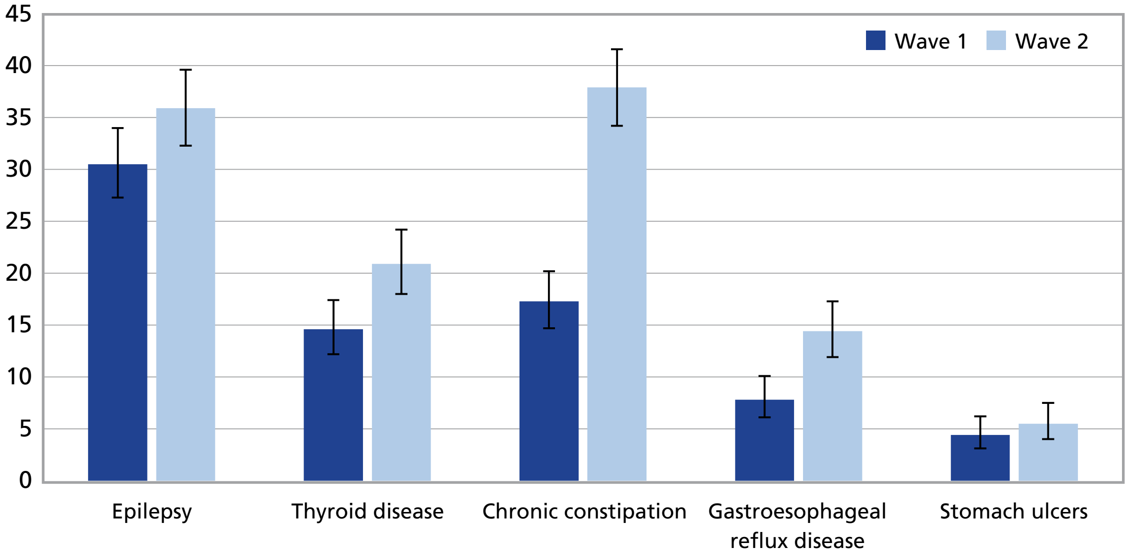
	No Falls W2 % (95% CI)	One Fall W2 % (95% CI)	Recurrent Falls W2 % (95% CI)	Total	Number in Sample
No Falls W1	79.0 (75.2 – 82.4)	9.8 (7.4 – 12.8)	11.2 (8.6 – 14.3)	100	510
One Fall W1	68.3 (57.0 – 77.9)	18.3 (10.9 – 28.7)	13.4 (7.2 – 23.1)	100	82
Recurrent Falls W1	46.1 (36.3 – 56.2)	15.7 (9.5 – 24.5)	38.2 (28.9 – 48.4)	100	102
Total	72.9 (69.4 – 76.1)	11.7 (9.4 – 14.3)	15.4 (12.9 – 18.4)	100	694

The prevalence of falls of those with mild to moderate ID was higher than for those with severe to profound ID. Given that people within the mild to moderate range of ID are more likely to be living within community/independent type settings, these results highlight the need for falls prevention programmes (see Appendix table 3.A.8).

3.8 Other Non-Cardiovascular Chronic Conditions

There were some increases at Wave 2 in the point prevalence of other non-cardiovascular chronic conditions (see *figure 3.11*).

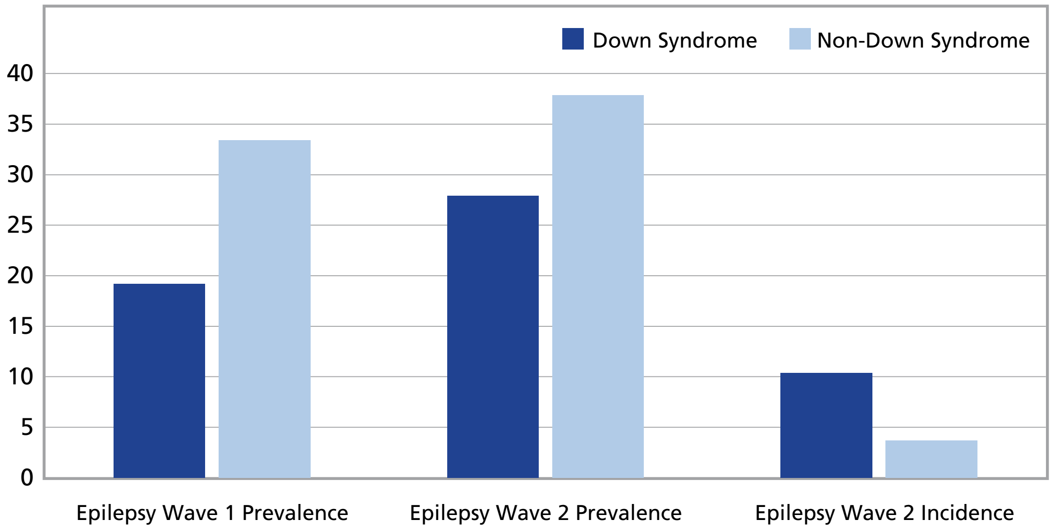
Figure 3.11: Changes in prevalence of other chronic conditions (non-cardiovascular).



The point prevalence of chronic constipation has more than doubled from Wave 1 to Wave 2, 17.3% to 38% respectively. Almost 50% of those aged 65+ reported chronic constipation as did more than one third (38.1%) of those aged 40-49 years (see Appendix table 3.A.9).

The prevalence of epilepsy increased from 30.5% in Wave 1 to 35.9% in Wave 2. The most noted increase was among people with Down syndrome, where prevalence increased from 19.2% to 27.9% and incidence of epilepsy from Wave 1 to Wave 2 in the Down syndrome population was 10.4%. (See *figure 3.12*). Epilepsy onset was strongly associated with the diagnosis of Alzheimer’s dementia.

Figure 3.12: Wave 2 Prevalence and incidence of epilepsy by aetiology.



As may be seen in table 3.2, thyroid disease continued to be a concern among older adults with ID. Females presented with a higher prevalence, 25.5% compared to 15% for males. Despite the point prevalence decline between waves for males and increase for females, there was very little difference between male and female incidence at 5.9% and 6.2% respectively. The greatest rise in prevalence was seen among females, among those of a moderate level of ID and those within the 65+ year category. Also, the highest incidence Wave 1 to Wave 2 was among those in the 65 +year age category.

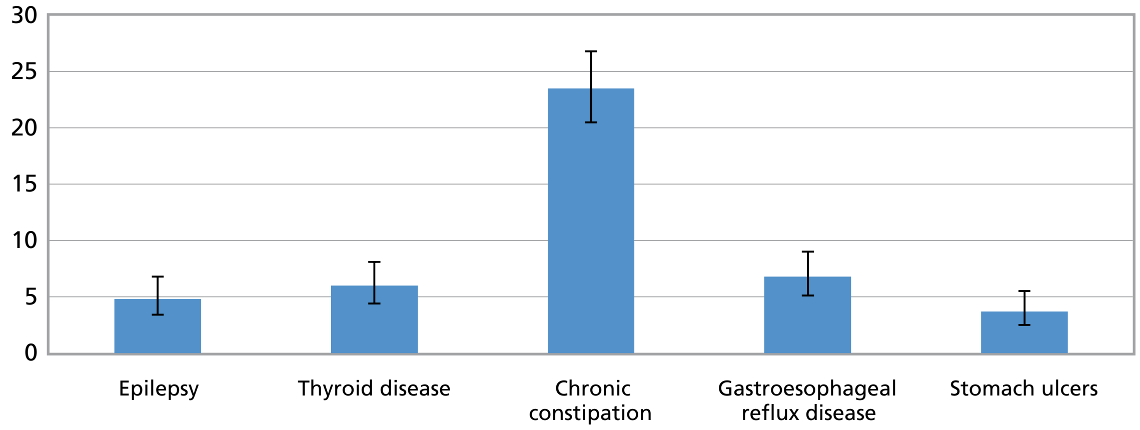
Table 3.2: Wave 1 & 2 prevalence and Wave 2 incidence of thyroid disease by age, gender and level of ID.

	Thyroid Disease W1 Prevalence% (95% CI)	Thyroid Disease W2 Prevalence % (95% CI)	Thyroid Disease W2 Incidence% (95% CI)
Gender:			
Male	19.3 (15.7 – 23.5)	15.0 (11.3 – 19.6)	5.9 (4.1 – 9.2)
Female	8.9 (6.2 – 12.6)	25.6 (21.4 – 30.3)	6.2 (3.6 – 9.3)
Age:			
43 – 49	13.9 (10.1 – 18.7)	19.6 (14.4 – 26.0)	5.2 (2.6 – 9.5)
50 – 64	17.1 (13.4 – 21.6)	21.1 (17.0 – 25.8)	5.1 (3.2 – 8.1)
≥65	9.7 (5.5 – 16.3)	22.6 (16.3 – 30.4)	9.6 (5.5 – 15.9)
Level of ID:			
Mild	9.6 (5.8 – 15.4)	13.2 (8.5 – 20.0)	3.3 (1.2 – 8.0)
Moderate	15.8 (12.1 – 20.3)	23.7 (19.1 – 29.0)	7.7 (5.0 – 11.4)
Severe/Profound	17.5 (12.7 – 23.5)	22.7 (17.1 – 29.5)	5.3 (5.3 – 9.8)

3.8.1 Three-year incidence of other chronic conditions (non-cardiovascular)

Figure 3.13 presents the overall three year incidence of non-cardiovascular chronic conditions. Incidence rates are highest for chronic constipation at 23.8%, gastroesophageal reflux at 6.9%, thyroid disease at 6.1%, epilepsy at 4.9% and stomach ulcers at 3.8% (see Appendix table 3.A.10).

Figure 3.13: Three year incidence of other chronic conditions



3.9 Pain

People were asked to report if they were often troubled by pain. There was a small drop in those reporting pain from 33.2% in Wave 1 to 30% in Wave 2, although rates remained high (see table 3.3). What was of note was that more women (33%) than men (26.3%) reported pain and, regardless of gender, pain reports were high among the older age group (65 years+). Across all levels of ID the prevalence of pain appeared to decline, but confidence intervals do not support that the declines were significant. Additionally given communication difficulties experienced by people with ID pain is likely to be under-reported particularly for those with a more severe intellectual disability.

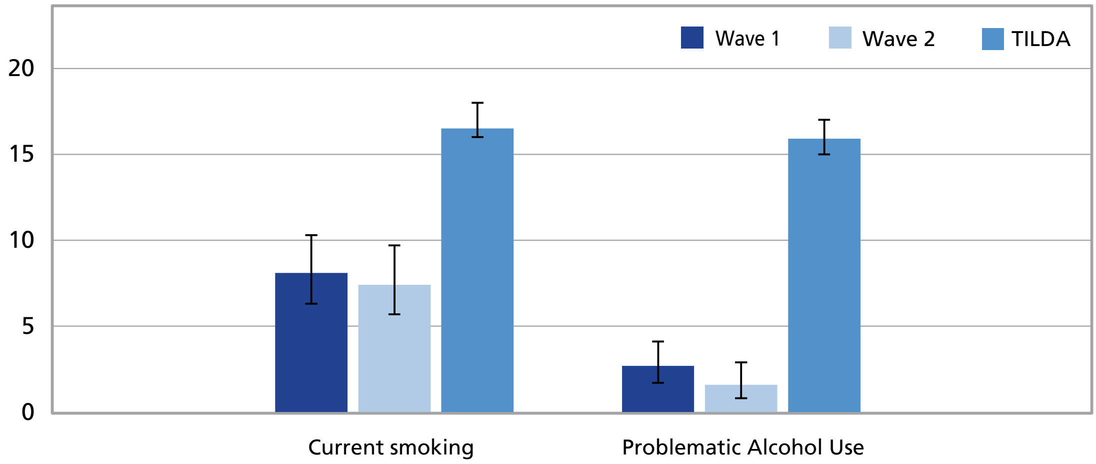
Table 3.3: Prevalence of pain Wave 1 and Wave 2 by gender, age and level of ID

	Wave 1		Wave 2	
	%	(95% CI)	%	(95% CI)
Gender:				
Male	27.7	(23.0 – 32.9)	26.3	(21.4 – 31.8)
Female	37.9	(32.8 – 42.5)	33.0	(28.3 – 38.0)
Age:				
43 – 49	35.1	(29.4 – 41.2)	22.5	(16.9 – 29.2)
50 – 64	31.6	(26.7 – 37.0)	31.8	(27.0 – 37.2)
≥65	32.6	(24.7 – 41.4)	35.7	(27.9 – 44.1)
Level of ID:				
Mild	34.5	(27.4 – 42.4)	29.1	(22.2 – 37.2)
Moderate	30.5	(25.5 – 35.9)	29.2	(24.1 – 34.9)
Severe/Profound	38.0	(31.2 – 45.3)	33.1	(26.3 – 40.7)
Total	33.1	(29.8 – 36.7)	30.0	(26.6 – 33.7)

3.10 Changes in Behavioural Health

Behavioural lifestyle patterns can have a positive or negative impact on overall health and well-being (Emerson, 2005). Engaging in negative behaviours such as smoking or alcohol abuse, the quality of nutritional choices and the levels of physical activity all influence ageing and overall health and well-being (Rizzuto *et al.,* 2012). The effects of lifestyle choice and associated increased obesity and inactivity levels may in turn increase the risk of poorer health outcomes as people age (De Winter *et al.,* 2012). Smoking and alcohol abuse were already relatively low among this population and declined further in Wave 2. There were similar trends for TILDA.

Figure 3.14: Prevalence of negative health behaviours.



Of those who smoked among the IDS-TILDA study, 67.3% (*n*=35) were male, 40% (*n*=21) were living in community group homes and 36.5% (*n*=19) were living in residential settings; and the majority 87.2% had a mild or moderate level of ID. As was found in Wave 1 of IDS-TILDA, the lowest rates of smoking were found in the younger age group; 15.4% of those who smoked were aged between 42 and 49, 46.2% were aged between 50 and 64 and 38.5% were over 65.

Levels of alcohol consumption remained stable in the IDS-TILDA population (40.4% in Wave ; 39% in Wave 2). Problematic alcohol use, defined as drinking alcohol 3 or more days per week, declined from 2.6% (*n*=18) in Wave 1 to 1.6% (*n*=11) in Wave 2 (see *figure 3.14*). By comparison TILDA noted an increase in problematic alcohol use from 12.2% in Wave 1 to 15.9% in Wave 2.

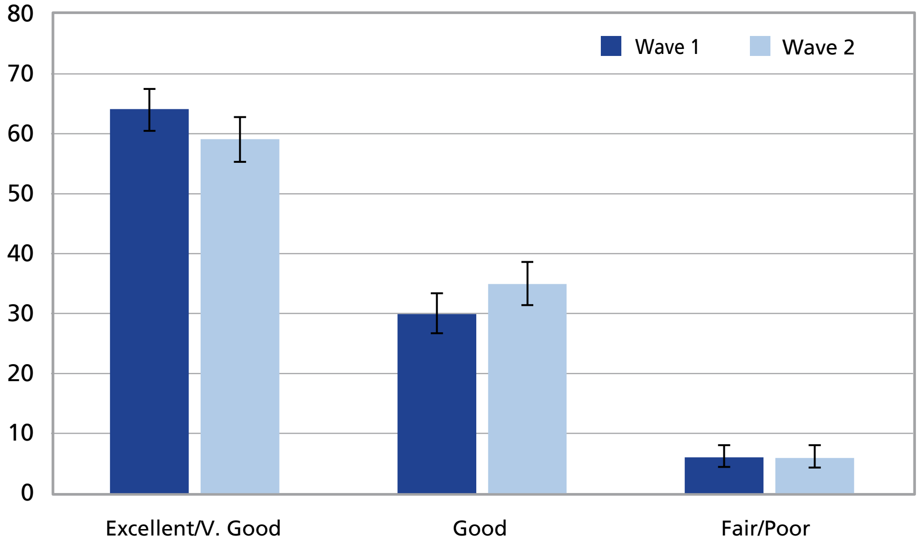
3.11 Nutritional Health and Obesity

Nutritional health is a key determinant for healthy ageing and the prevention of age-related diseases such as cardiovascular conditions, diabetes and hypertension (Södergren *et al.,* 2014).

3.11.1 Self-rated nutritional health

In Wave 2 people were asked to rate their overall diet on the 5-point global rating scale from excellent to poor. As can be seen in *figure 3.15,* there was a slight drop (5%) from Wave 1 to Wave 2 among those who previously reported excellent to very good nutritional status, with a corresponding increase in those reporting good nutritional status. There were no observed changes among those who rated their nutritional status as poor. Nor were there any additional differences across age groups or levels of ID. A trend continued of women being more inclined to rate their nutritional status at lower levels than men.

Figure 3.15: Distribution of self-rated nutritional health.

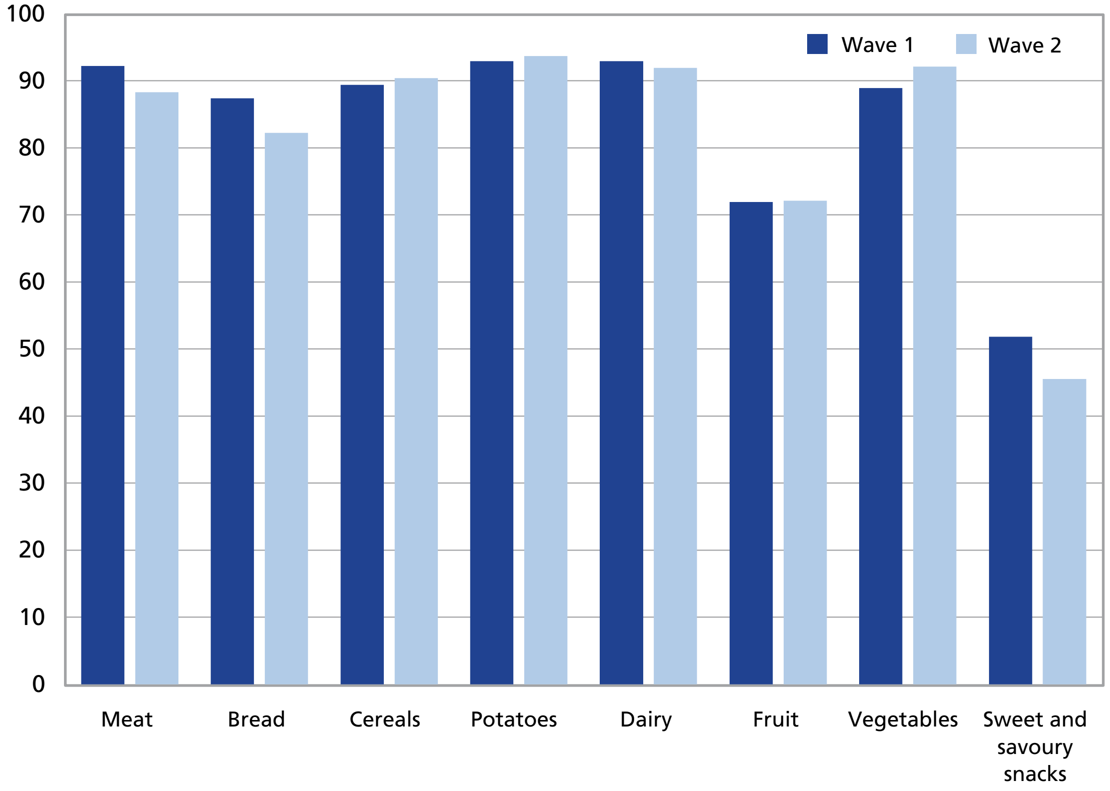


3.11.2 Dietary consumption

Utilising the SLAN instrument (Harrington *et al.,* 2008), similar to Wave 1 people identified the types of food they consumed with no notable changes from Wave 1. As may be seen in *figure 3.16* there were minor increases in vegetable intake; fruit intake remained lowest in terms of the overall food pyramid and there was almost a seven percentage point drop in the intake of sweets and snacks from 52% to 45.5%.

Level of fast food consumption has been associated with overweight and obesity (Bowman, 2004). In Wave 2 of IDS-TILDA, a question was added in relation to frequency of fast food consumption. Overall, 28.8% (*n*=197) reported eating fast food once a week or more, 25.8% (*n*=177) reported 1-3 times a month and 45.4% (*n*=311) reported rarely or never eating fast food. Of those who reported eating fast food once a week or more, 20.5% (*n*=23) were living independently, 35.1% (*n*=104) were living in the community and 25.3% (*n*=70) were living in a residential setting. More men than women reported eating fast food once a week or more at 34.7% (*n*=104), compared to 24.2% (*n*=93) of women (see table 3.A.11).

Figure 3.16: Dietary consumption changes from Wave 1 to Wave 2.

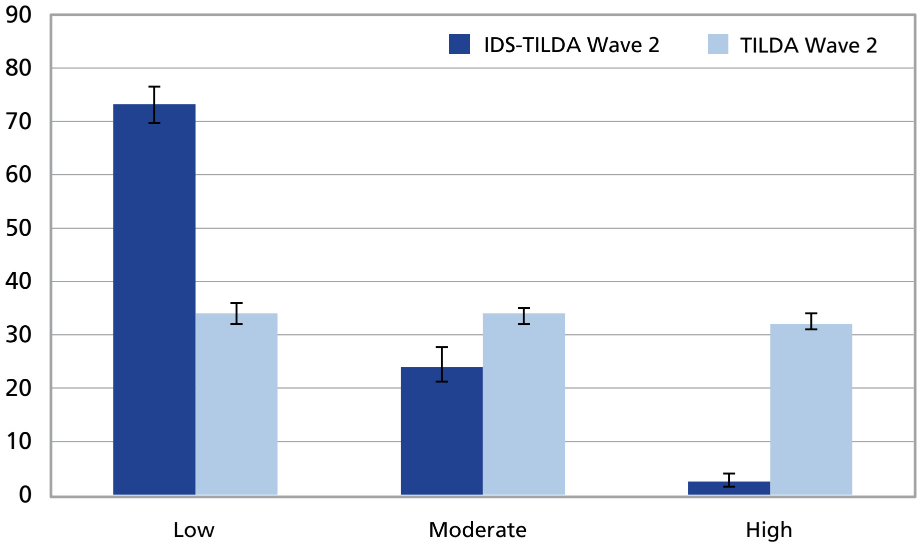


3.12 Physical Activity

Physical activity is essential in maintaining lifelong health, reducing the risk of chronic disease and promoting benefits in psychological and mental health (National Physical Activity Guidelines Steering Group, 2014). In Ireland, reported levels of inactivity have been associated with those who are more likely to present with physical, psychological or mental health disorders (Harrington *et al.,* 2008).

In Wave 2 of IDS-TILDA, participants were specifically asked how many days they had engaged in physical activity in the 7 days prior to their interview. Activity level was categorised into low, moderate or high based on The International Physical Activity Questionnaire (IPAQ) (Craig *et al.,* 2003). This permitted at Wave 2 comparison between IDS-TILDA and TILDA findings.

Figure 3.17: Comparing levels of physical activity between Wave 2 IDS-TILDA and Wave 2 TILDA.



The majority of IDS-TILDA Wave 2 participants engaged in low levels of physical activity (73.2%, *n*=506), with 24.3% (*n*=168) engaging in moderate activity and just 2.5% (*n*=17) reporting engagement in high levels of physical activity. These findings contrast with TILDA findings of 34% of people engaging in low levels of physical activity, 34% in moderate physical activity and 33% in high levels of physical activity (see *figure 3.17*). Levels of activity for IDS-TILDA participants at Wave 2 were similar to findings at Wave 1 and it is concerning that low levels of reported activity continue among people with ID. Levels of moderate and vigorous activity among people with ID remain too low to accrue health benefits.

3.13 Obesity

Obesity is a major concern for the Irish population and is both classified as an epidemic and is associated with chronic conditions such as cardiovascular disease and diabetes (WHO, 2000). For the purposes of this report the obesity figures are based on Body Mass Index (BMI) calculations as an indicator of overall body adipose. BMI is calculated as weight in kilograms divided by height in meters squared (kg/m2) and the WHO cut-offs are used to define if the person is underweight, normal, overweight or obese (table 3.4).

Table 3.4: World Health Organisation body mass index classifications.

Classification	BMI (kg/m2)
Underweight	<18.50
Normal	18.50 - 24.99
Overweight	25.00 - 29.99
Obese	≥30.00

In Wave 2, height, weight and waist circumference were objectively measured. The feasibility of these measures with people with ID has been previously been established by Swinburne (2014). In Wave 2, 55.4% (*n*=417) of people were able to have their height measured and 65.5% (*n*=493) were able to engage in weight measurement. Surrogate measurements in the form of the Mid Upper Arm Circumference (MUAC) or Ulna length to measure height were used to estimate BMI (BAPEN, 2012; Weekes, Marinos, & Emery, 2004). This resulted in three categories of objectively measured BMI:

A. Those who engaged in height and weight measurement

B. Those who could engage in neither height or weight

C. Those who were unable to engage in height whereby ulna length was used

3.13.1 Prevalence of obesity

Overall levels of overweight and obesity were significant for IDS-TILDA participants. However, when compared with BMI reported for the general population, the overweight/obese prevalence is somewhat lower at 66.7% versus 79% respectively (table 3.5).

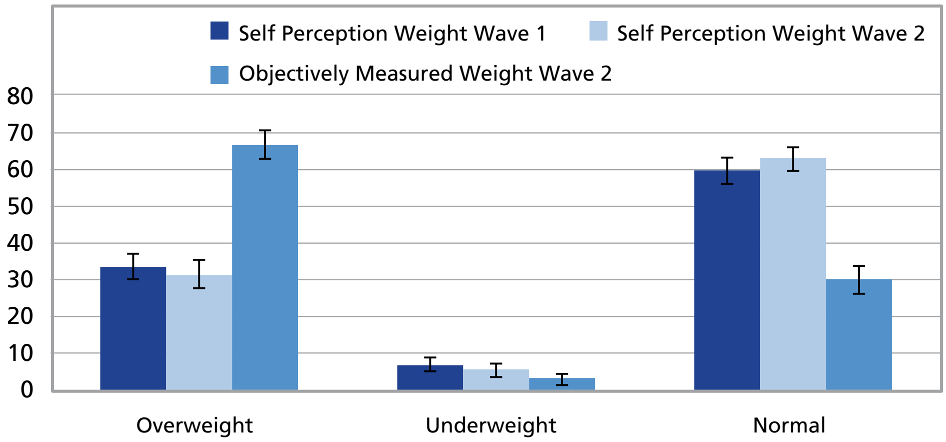
Table 3.5: BMI Findings

Category		Underweight	Normal	Overweight	Obese
		% *f*	% *f*	% *f*	% *f*
A	*n*=405	0.7 (*n*=3)	22 (*n*=89)	34.8 (*n*=141)	42.5 (*n*=172)
B	*n*=104	11.5 (*n*=12)	52.9 (*n*=55)	35.6 (*n*=37)	
C	*n*=80	5.0 (*n*=4)	42.5 (*n*=34)	31.3 (*n*=25)	21.3 (*n*=17)
IDS-TILDA Combined categories		3.2 (*n*=19)	30.1 (*n*=178)	66.7 (*n*=392)	
TILDA (Leahy *et al.*, 2014)		–	21%	79%	

3.13.2 Self-perception of weight verses objectively measured

Although these IDS-TILDA figures were lower than general population BMI findings, they are still unacceptably high. People were also asked if they perceived themselves as being overweight/obese, underweight or of normal weight in both Waves 1 and 2. Just over 30% in both Waves perceived themselves as overweight/obese and over 60% perceived themselves as being just right. However, the opposite was found in the objective measurement of weight, with 66.7% measured as being overweight or obese and 30% measured within the normal range (see *figure 3.18*). Considering people with ID may be less conscious of the health effects of excess weight, such perceptions do not encourage actions to avoid poor health outcomes as a consequence of increased weight.

Figure 3.18: Comparison of self-perception of weight status and actual measured weight.



The majority of those within the younger age category (40 – 49 years) were overweight or obese (69.5%, *n*=167), followed closely by the middle age category (50 – 64 years) at 68.1% and 59.0% of those in the older age category. Higher levels of overweight and obesity were identified among women at 69.9%; however the levels among men were also high at 62.3%. TILDA found the reverse with overweight/obesity in men at 85% compared to women at 79% (Leahy *et al.,* 2014).

People with mild or moderate levels of ID were found to have the highest levels of overweight and obesity at 84.9% and 71.6% respectively. Less than half of those with severe/profound ID (46.9%) fell within this category; for comparisons see tables 3.A.12a, 3.A.12b, and 3.A.12c. Levels of those who perceived themselves as underweight were similar between Wave 1 (6.7%) and Wave 2 (5.6%); however on objective measurement levels were somewhat lower at 3.2%.

3.13.3 Waist circumference

Increased waist circumference is associated with increased risk of diabetes and cardiovascular disease such as high cholesterol and hypertension. Using WHO cut-offs (see table 3.6), those having central obesity and are at higher risk of developing cardio metabolic complications may be identified (WHO, 2008).

Table 3.6: WHO cut-off categories for waist circumference.

Risk Classification	Waist circumference (cm)	
	Males	Females
Normal	<94	<80
Increased risk of metabolic complications	94-101	80-87
Substantially increased risk of metabolic complication	≥102	≥88

In IDS-TILDA, 64.6% of the population were at substantially increased risk of cardio metabolic disease based on objective measures of waist circumference. By comparison, TILDA reported risk rates of 53% among Irish adults over the age of 50 years (Leahy *et al.,* 2014). WHO risk classification for cardio metabolic disease for females in TILDA was 56% compared to 78.4% for females in IDS-TILDA. There was very little difference in risk rates in the younger or middle age categories at 61.2% versus 63.1% respectively but, similar to the TILDA findings, the older age category were more likely to have larger waist circumferences at 74.5%. It was also notable that those with a mild level of ID were more likely to present with substantially increased waist circumference (76.9%), compared to 68.9% for people with a moderate level of ID and 47.1% for those with more severe/profound ID (Appendix table 3.A.13).

3.14 Conclusion

This chapter has provided an overview of the physical and behavioral health of adults with ID aged 40 years and older in Ireland, and has tracked changes in prevalence and plotted incidence in an effort to understand how health and health behaviours have changed over the three-year period between Wave 1 and Wave 2 of the IDS-TILDA study. Comparisons with related TILDA findings have also helped to provide a context in which to understand where and how the ageing of people with ID is the same or different from the general population. As policy responses to population ageing in Ireland emerge, as in recent health policy documents such as Healthy Ireland – A Framework for Improved Health and Well-Being 2013-2025(DoH, 2013a), it is important that there is data on people with ID influencing such policy formation as there are important differences in their ageing particularly in the areas of physical and behavioral health.

For the general population there is considerable interest in cardiovascular disease as people age and in the management of risk factors. The data here points out that there are very high levels of risk factors to be managed for people with ID, but also highlight that the cardiovascular picture is much different; less hypertension angina and myocardial infarction for people with ID and more concerns with diabetes, stroke and TIA. More striking is the concern about osteoporosis and osteopenia, with almost seven out of ten people with ID being measured as having such concerns, particularly when levels of reported diagnosis of osteoporosis were so much lower (16.4%). This is a health crisis for people with ID as they age and will require more systematic and concerted efforts throughout health care and health promotion if it is to be addressed. Rising figures for hip fracture help highlight the seriousness of the concern.

Eye diseases are another major story of the Wave 2 data collection. The doubling from Wave 1 of rates of cataracts and of macular degeneration and their higher incidence in people with ID compared to the general population also demands that planning for health and well-being target these issues for people with ID.

Epilepsy continues to be higher in people with ID and its point prevalence increased from 30.5% in Wave 1 to 35.9% in Wave 2 and from 19.2% to 27.9% for those with Down syndrome. The finding for Down syndrome highlights the linkage found between late onset epilepsy and onset of dementia.

Constipation was further highlighted as a major health concern for people with ID. Point prevalence of chronic constipation more than doubled from 17.3% at Wave 1 to 38% at Wave 2. Although rates were highest in the oldest cohort (50%), it was also a complaint for 38.1% of those aged 40-49 years. Untreated or poorly treated chronic constipation is a major barrier to experiencing quality of life and its high levels among people with ID requires greater attention.

It is encouraging that most people with ID continue to view their health as good but of concern that they see their weight and their nutritional health as good and normal when more objective evidence suggests that there are serious concerns. Positive findings are the relatively low levels of fast food consumption, smoking and alcohol abuse. However the picture that emerges is of a clear need for more health education, health promotion and health management specifically targeted at people with ID and their more unique health concerns.

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Appendix 3A: Tables on Changes in Physical and Behavioural health in Older Adults with an Intellectual Disability in Ireland

Appendix Table 3.A.1: Prevalence and incidence of self-rated health at Wave 2

Prevalence Wave 2	Excellent/V. Good		Good		Fair/Poor	
	%	(95% CI)	%	(95% CI)	%	(95% CI)
Gender:						
Male	46.7	(41.0 – 52.5)	37.8	(32.4 – 43.6)	15.5	(11.7 – 20.1)
Female	46.4	(41.3 – 51.5)	37.8	(32.9 – 42.8)	15.9	(12.5 – 20.0)
Age:						
43-49	48.2	(41.0 – 55.4)	41.0	(34.1 – 48.3)	10.8	(6.9 – 16.2)
50-64	48.7	(43.4 – 54.1)	37.2	(32.2 – 42.6)	14.0	(10.7 – 18.2)
≥65	38.9	(31.0 – 47.4)	34.7	(27.1 – 43.2)	26.4	(19.6 – 34.5)
Level of ID:						
Mild	51.3	(43.1 – 59.5)	37.3	(29.7 – 45.6)	11.3	(6.9 – 17.8)
Moderate	48.6	(42.8 – 54.5)	36.1	(30.7 – 41.9)	15.2	(11.4 – 19.9)
Severe/Profound	37.0	(30.2 – 44.4)	41.8	(34.7 – 49.2)	21.2	(15.7 – 27.8)
Total	46.5	(42.7 – 50.3)	37.8	(34.2 – 41.5)	15.7	(13.1 – 18.7)

Table 3.A.2: Hypertension prevalence: Comparison between doctor's diagnosis Wave 1, Wave 2 and objectively measure blood pressure

	Wave 1 doctor's diagnosis hypertension			Wave 2 Doctor's diagnosis hypertension			Objectively measured Hypertension		
	%	95% CI	Number in sample	%	95% CI	Number in sample	%	95% CI	Number in sample
Gender:									
Male	14.3	10.82-18.70	328	18.5	14.3-23.53	292	22.7	17.48-28.81	225
Female	17.2	13.72-21.35	401	17.8	14.12-22.09	377	15.8	11.87-20.56	292
Age:									
43-49	7.6	4.87-11.52	277	5.5	2.8-10.1	183	12.3	7.55-19.26	138
50-64	18.2	14.26-22.86	330	19.5	15.55-24.21	343	20.2	15.71-25.59	272
65+	28.7	21.05-37.7	122	30.8	23.47-39.12	143	23.4	15.95-32.72	107
Level of ID:									
Mild	23.4	17.22-30.94	158	25.2	18.55-33.12	147	19.7	13.25-28.05	122
Moderate	17.7	13.7-22.48	311	18.5	14.25-23.55	287	18.3	13.71-23.85	241
Severe/Profound	6.4	3.58-10.89	204	11.8	7.72-17.57	186	17.5	11.29-26.03	114
Total	15.9	13.37-18.82	729	18.1	15.16-21.37	699	18.8	15.54-22.45	517

Table 3.A.3: Incidence of cardiovascular conditions by gender, age and level of ID.

	Hypertension	Diabetes	Heart Attack	Angina	TIA	Stroke	Heart Failure
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:							
Male	6.8 (4.3 – 10.5)	0.7 (0.1 – 2.6)	1.0 (0.2 – 3.1)	0.0	1.7 (0.6 – 4.2)	1.3 (0.4 – 3.6)	1.0 (2.6 – 3.1)
Female	6.9 (4.6 – 10.0)	1.8 (0.1 – 3.9)	0.3 (0.0 – 1.7)	0.5 (0.1 – 2.1)	2.1 (1.0 – 4.3)	2.1 (1.0 – 4.3)	1.0 (0.3 – 2.8)
Age:							
43-49	2.7 (1.0 – 6.6)	0.5 (0.0 – 3.3)	0.0	0.0	0.5 (0.0 – 3.4)	0.5 (0.0 – 3.3)	0.0
50-64	7.0 (4.7 – 10.4)	1.7 (0.1 – 3.9)	0.9 (0.2 – 2.7)	0.3 (0.0 – 1.8)	1.8 (0.7 – 4.0)	1.7 (0.7 – 3.9)	0.6 (0.1 – 2.3)
≥65	11.8 (7.2 – 18.5)	1.4 (0.2 – 5.4)	0.7 (0.0 – 4.4)	0.7 (0.0 – 4.4)	4.3 (1.8 – 9.5)	3.4 (1.3 – 8.3)	3.4 (1.3 – 8.2)
Level of ID:							
Mild	6.1 (3.0 – 11.6)	0.7 (0.0 – 4.2)	0.0	0.0	2.7 (0.9 – 7.2)	1.3 (0.2 – 5.2)	0.0
Moderate	7.6 (5.0 – 11.5)	1.7 (0.6 – 4.1)	0.7 (0.1 – 2.7)	0.3 (0.0 – 2.2)	1.8 (0.6 – 4.3)	2.4 (1.0 – 5.1)	1.4 (0.4 – 3.7)
Severe/Profound	6.4 (3.5 – 11.3)	1.6 (0.4 – 4.9)	0.5 (0.0 – 3.4)	0.5 (0.0 – 3.4)	1.6 (0.4 – 5.1)	1.1 (0.2 – 4.2)	1.1 (0.2 – 4.2)
Total	6.9 (5.1 – 9.1)	1.3 (0.6 – 2.6)	0.6 (0.2 – 1.6)	0.3 (0.0 – 1.2)	1.9 (1.1 – 3.4)	1.8 (1.0 – 3.1)	1.0 (0.4 – 2.2)

Table 3.A.4: Prevalence of cardiovascular conditions by gender, age and level of ID.

	High BP	Diabetes	Heart Attack	Angina	TIA	Stroke	Heart Failure
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:							
Male	18.5 (14.3 – 23.5)	7.1 (4.6 – 10.7)	1.6 (0.6 – 3.9)	1.0 (0.2 – 3.0)	3.6 (1.9 – 6.5)	2.6 (1.2 – 5.2)	2.3 (1.0 – 4.8)
Female	17.8 (14.1 – 22.1)	11.1 (8.1 – 14.6)	0.5 (0.0 – 3.2)	1.3 (0.5 – 3.1)	4.6 (2.8 – 7.3)	3.1 (1.7 – 5.4)	2.0 (0.9 – 4.1)
Age:							
43-49	5.5 (2.8 – 10.1)	2.0 (0.7 – 5.5)	0.5 (0.0 – 3.2)	0	1.5 (0.4 – 4.8)	1.5 (0.4 – 4.8)	0
50-64	19.6 (15.4 – 24.0)	11.5 (8.5 – 15.4)	2.0 (0.9 – 4.0)	1.4 (0.5 – 3.4)	2.8 (1.4 – 5.3)	2.5 (1.2 – 4.9)	1.4 (0.5 – 3.4)
≥65	30.8 (23.5 – 39.1)	13.5 (8.6 – 20.3)	2.0 (0.5 – 6.3)	2.0 (0.5 – 6.3)	10.8 (6.5 – 17.2)	5.4 (2.5 – 10.7)	6.8 (3.5 – 12.4)
Level of ID:							
Mild	25.2 (18.5 – 33.1)	12.3 (7.8 – 18.8)	0.6 (0.0 – 4.1)	1.3 (0.2 – 5.1)	3.9 (1.6 – 8.7)	1.9 (0.5 – 6.0)	1.3 (0.2 – 0.5)
Moderate	18.5 (14.2 – 23.5)	9.0 (6.1 – 12.9)	2.0 (0.8 – 4.5)	1.3 (0.4 – 3.6)	3.3 (1.7 – 6.2)	2.7 (1.2 – 5.4)	2.3 (1.0 – 4.9)
Severe/Profound	11.8 (7.7 – 17.6)	8.3 (5.0 – 13.4)	1.6 (0.4 – 4.9)	1.0 (0.2 – 4.1)	4.7 (2.3 – 9.0)	3.1 (1.3 – 7.0)	1.6 (0.4 – 4.9)
Total	18.1 (15.3 – 21.3)	9.3 (7.3 – 11.7)	1.6 (0.8 – 2.9)	11.4 (0.5 – 2.3)	4.1 (2.8 – 6.0)	2.8 (1.8 – 4.4)	2.1 (1.2 – 3.6)

Table 3.A.5: Comparison of prevalence of doctor's diagnosis of osteoporosis Wave 1, Wave 2 & objectively measured W2 by gender, age and level of ID

	Wave 1 Osteoporosis			Wave 2 Osteoporosis			OM Osteoporosis left			OM Osteoporosis right			OM Osteopenia left			OM Osteopenia right		
	%	95% CI	Number in sample	%	95% CI	Number in sample	%	95% CI	Number in sample	%	95% CI	Number in sample	%	95% CI	Number in sample	%	95% CI	Number in sample
Gender:																		
Male	3.0	1.52-5.57	337	5.6	3.37-8.92	306	32.4	26.53-38.75	238	26.3	20.9-32.38	240	32.8	26.92-39.18	238	37.1	31.02-43.56	240
Female	12.3	9.37-15.93	415	19.6	15.87-24.03	387	37.0	31.72-42.51	322	38.7	33.36-44.38	315	33.9	28.75-39.34	322	30.8	25.8-36.26	315
Age:																		
43-49	3.1	1.54-6.08	287	5.2	2.64-9.54	194	27.5	20.89-35.21	160	23.9	17.66-31.43	159	33.1	26.02-41.07	160	31.4	24.45-39.36	159
50-64	9.3	6.56-13.04	343	13.3	10.03-17.41	353	33.8	28.36-39.71	281	33.2	27.78-39.1	280	34.5	29.03-40.44	281	35.7	30.16-41.66	280
65+	16.4	10.53-24.42	122	24.7	18.08-32.61	146	47.9	38.73-57.21	119	46.6	37.32-56.01	116	31.1	23.1-40.31	119	31.0	22.95-40.39	116
Level of ID:																		
Mild	6.6	3.52-11.85	166	9.9	5.85-16.13	151	23.2	16.32-31.76	125	17.9	11.79-26.05	123	35.2	27.02-44.31	125	35	26.73-44.14	123
Moderate	7.1	4.67-10.64	323	14.7	10.97-19.3	300	27.1	21.78-33.21	247	27	21.69-33.08	248	36.0	30.11-42.4	247	38.3	32.29-44.70	248
Severe/ Profound	9.7	6.18-14.80	206	14.8	10.23-20.87	189	59.7	51.37-67.58	149	58.0	49.5-66.15	143	25.5	18.88-33.41	149	23.1	16.63-31.01	143
Total	8.1	6.31-10.35	752	13.4	11.02-16.24	693	35	31.08-39.13	560	33.3	29.45-37.45	555	33.4	29.52-37.49	560	33.5	29.62-37.63	555

Table 3.A.6: Prevalence chronic conditions (non-cardiovascular) at Wave 2 by gender, age and level of ID.

	Arthritis	Osteoporosis	Wrist Fracture	Lung disease	Hip Fracture	Cancer	Age related macular degeneration	Glaucoma	Cataracts
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:									
Male	11.6 (8.4 – 15.9)	7.4 (4.9 – 11.1)	4.5 (2.6 – 7.7)	5.2 (3.1 – 8.4)	3.9 (2.1 – 6.9)	6.1 (3.8 –9.6)	3.9 (2.1 – 6.9)	2.9 (1.4 – 5.6)	14.2 (10.6 – 18.7)
Female	20.9 (17.1 – 25.3)	23.5 (19.4 – 28.0)	5.1 (3.2 – 7.9)	4.3 (2.6 – 7.0)	3.1 (1.7 – 5.4)	5.1 (3.2 –7.9)	5.9 (3.8 – 8.8)	2.5 (1.3 – 4.8)	23.0 (18.9 – 27.5)
Age:									
43-49	9.2 (5.7 – 14.3)	5.6 (3.0 – 10.1)	3.6 (1.6 – 7.5)	3.6 (1.6 – 7.5)	1.2 (1.2 – 6.8)	2.5 (0.9 6.2)	4.1 (1.9 – 8.2)	0.5 (0.0 – 3.2)	18.9 (13.8 – 25.2)
50-64	16.6 (13.0 – 21.0)	16.6 (13.0 – 21.0)	5.3 (3.3 – 8.4)	3.4 (1.8 – 6.0)	3.1 (1.6 – 5.6)	4.5 (2.7 – 7.4)	5.6 (3.6 – 8.7)	3.4 (1.8 – 6.0)	17.7 (14.0 –22.2)
≥65	27.0 (20.2 – 35.0)	29.7 (22.6 – 37.9)	5.4 (2.5 –10.7)	9.5 (5.5 – 15.6)	4.7 (2.1 – 9.9)	12.2 (7.6–18.8)	4.7 (2.1 – 9.9)	4.0 (1.7 – 9.0)	23.0 (16.6 – 30.7)
Level of ID:									
Mild	21.4 (15.4 – 28.9)	13.0 (8.3 – 19.6)	5.8 (2.9 – 11.1)	5.8 (2.9 – 11.1)	1.3 (0.2 – 5.1)	7.8 (4.3 –13.5)	3.9 (1.6 – 8.7)	1.3 (0.2 – 5.1)	14.9 (9.9 – 21.8)
Moderate	16.9 (13.0 – 21.8)	17.3 (13.3 – 22.1)	6.0 (3.7 – 9.4)	5.3 (3.2 – 8.7)	4.0 (2.2 – 7.0)	5.6 (3.4 – 9.1)	6.3 (3.9 – 9.8)	2.3 (1.0 – 4.9)	21.3 (16.9 –26.4)
Severe/ Profound	14.1 (9.6 – 20.0)	17.2 (12.3 – 23.4)	1.6 (0.4 – 4.9)	2.6 (1.0 – 6.3)	4.7 (2.3 – 9.0)	4.7 (2.3 – 9.0)	4.2 (1.9 – 8.3)	3.1 (1.3 – 7.0)	19.8 (14.5 –26.3)
Total	16.8 (14.2 – 19.8)	16.4 (13.8 – 19.4)	4.8 (3.4 – 6.8)	4.7 (3.3 – 6.6)	3.4 (2.2 – 5.1)	5.6 (4.0 – 7.6)	5.0 (3.5 – 6.9)	2.7 (1.7 – 4.3)	19.1 (16.3 – 22.3)

Table 3.A.7: Incidence of chronic conditions non-cardiovascular by gender, age and level of ID.

	Arthritis	Osteoporosis	Wrist Fracture	Lung disease	Hip Fracture	Cancer	Age related macular degeneration	Glaucoma	Cataracts
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:									
Male	3.6 (1.9 – 6.6)	4.2 (2.4 – 7.3)	1.0 (0.2 – 3.0)	2.0 (0.8 – 4.5)	1.9 (0.8 – 4.4)	2.6 (1.2 - 5.3)	1.7 (0.6 – 4.2)	1.0 (0.3 – 3.2)	3.0 (1.5 – 5.8)
Female	8.2 (5.7 – 11.5)	11.9 (8.9 – 15.6)	1.8 (0.8 – 3.8)	1.0 (0.3 – 2.8)	1.0 (0.3 – 2.8)	0.8 (0.2 – 2.4)	2.5 (1.2 – 4.8)	0.8 (0.2 – 2.5)	8.1 (5.7 - 11.5)
Age:									
43-49	2.6 (0.9 – 6.2)	3.6 (1.7 – 7.5)	1.0 (0.2 – 4.0)	0.5 (0.0 – 3.3)	1.5 (0.4 – 4.7)	0.5 (0.0 – 3.2)	3.3 (1.3 – 7.3)	0.5 (0.0 – 3.4)	5.2 (2.7 – 9.6)
50-64	6.4 (4.1- 9.6)	8.5 (5.9 – 12.1)	1.7 (0.7 – 3.8)	1.1 (0.4 – 3.1)	1.1 (0.4 – 3.1)	1.7 (0.7 – 3.8)	1.8 (0.7 – 4.1)	1.2 (0.4 – 3.2)	6.1 (3.9 – 9.3)
≥65	10.6 (6.3 – 17.2)	15.1 (9.9 – 22.1)	1.3 (0.2 – 5.3)	3.4 (1.3 – 8.2)	2.0 (0.5 – 6.3)	2.7 (0.9 – 7.3)	1.4 (0.2 – 5.6)	0.7 (0.0 – 4.4)	6.2 (3.1 – 11.8)
Level of ID:									
Mild	9.3 (5.3 – 15.3)	6.0 (2.9 – 11.3)	1.9 (0.5 – 6.0)	2.0 (0.5 – 6.2)	0.6 (0.0 - 4.1)	0.6 (0.0 – 4.1)	1.4 (0.2 – 5.3)	0.0	3.9 (1.6 – 8.8)
Moderate	6.2 (3.8 – 9.8)	10.7 (7.5 – 14.9)	2.3 (1.0 – 4.9)	1.4 (0.4 – 3.7)	1.7 (0.6 – 4.0)	2.0 (0.8 – 4.5)	3.2 (1.5 – 6.1)	1.4 (0.4 – 3.7)	7.8 (5.1 – 11.7)
Severe/ Profound	3.8 (1.7 – 7.9)	7.9 (4.7 – 13.0)	0.0	1.6 (0.4 – 4.9)	1.6 (0.4 – 4.9)	2.1 (0.7 – 5.6)	1.7 (0.4 – 5.2)	1.1 (0.2 – 4.3)	4.8 (2.3 – 9.1)
Total	6.0 (4.4 – 8.1)	8.4 (6.5 – 10.8)	1.4 (0.7 – 2.7)	1.4 (0.7 – 2.7)	1.4 (0.7 – 2.7)	1.6 (0.8 – 2.9)	2.0 (1.1 – 3.4)	0.9 (0.3 – 2.0)	5.7 (4.2 – 7.8)

Table 3.A.8: Prevalence of falls Wave 2 by gender, age and level of ID by gender, age and level of ID.

	Total Falls	One Fall	Recurrent Falls	Injurious Falls
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:				
Male	24.0 (19.4 – 29.3)	9.1 (6.2 – 13.0)	14.3 (10.7 – 18.8)	11.0 (7.8 – 15.2)
Female	31.6 (27.0 – 36.5)	13.7 (10.5 – 17.7)	16.3 (12.8 – 20.5)	15.8 (12.4 – 19.9)
Age:				
43-49	22.4 (16.9 – 29.1)	10.6 (6.8 – 16.0)	11.6 (7.7 – 17.1)	11.1 (7.2 – 16.5)
50-64	33.1 (28.3 – 38.4)	12.6 (9.4 – 16.6)	18.9 (15.0 – 23.4)	15.5 (12.0 – 19.8)
≥65	24.5 (17.9 – 32.4)	11.0 (6.6 – 17.5)	12.3 (7.7 – 19.0)	12.8 (8.1 – 19.6)
Level of ID:				
Mild	29.8 (22.8 – 37.9)	15.8 (10.6 – 22.8)	12.5 (7.9 – 19.1)	16.9 (11.5 – 23.9)
Moderate	31.1 (25.9 – 36.7)	12.1 (8.7 – 16.5)	17.5 (13.5 – 22.4)	14.3 (10.6 – 18.9)
Severe/Profound	21.6 (16.1 – 28.2)	7.8 (4.6 – 12.8)	13.5 (9.2 – 19.4)	7.8 (4.6 – 12.8)
Total	28.3 (25.0 – 31.8)	11.5 (9.3 – 14.2)	15.3 (12.7 – 18.2)	13.7 (11.3 – 16.5)

Table 3.A.9: Prevalence of other chronic conditions (non-cardiovascular) in Wave 2 by gender, age, level of ID.

	Epilepsy	Thyroid disease	Chronic constipation	Gastroesophageal reflux disease	Stomach ulcers
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:					
Male	32.9 (27.7 – 38.5)	15.0 (11.3 – 19.6)	36.3 (30.9 – 42.0)	15.4 (11.6 – 20.0)	7.5 (4.9 – 11.2)
Female	38.2 (33.4 – 43.3)	25.6 (21.4 – 30.3)	39.1 (34.3 – 44.2)	13.7 (10.5 – 17.6)	3.9 (2.3 – 6.5)
Age:					
43-49	34.8 (28.3 – 42.0)	19.4 (14.2 – 25.8)	38.3 (31.5 – 45.5)	8.7 (5.3 – 13.7)	3.1 (1.2 – 6.8)
50-64	36.6 (31.6 – 41.9)	21.1 (17.0 – 25.8)	33.4 (28.6 – 38.7)	15.1 (11.6 – 19.4)	4.8 (2.9 – 7.8)
≥65	35.4 (27.8 – 43.7)	22.6 (16.3 – 30.4)	47.9 (39.7 – 56.3)	20.5 (14.5 – 28.2)	10.3 (6.1 – 16.7)
Level of ID:					
Mild	26.0 (19.4 – 33.8)	13.2 (8.5 – 20.0)	21.2 (15.1 – 28.7)	10.6 (6.4 – 16.9)	5.3 (2.5 – 10.5)
Moderate	33.8 (28.5 – 39.5)	23.7 (19.1 – 29.0)	34.8 (29.4 – 40.5)	13.0 (9.5 – 17.5)	5.0 (2.9 – 8.3)
Severe/Profound	51.6 (44.3 – 58.8)	22.7 (17.1 – 29.5)	58.2 (50.8 – 65.2)	21.2 (15.7 – 27.8)	6.3 (3.5 – 11.1)
Total	20.9 (18.0 – 24.2)	20.9 (18.0 – 24.2)	37.9 (34.2 – 41.6)	14.4 (11.9 – 17.3)	5.5 (4.0 – 7.5)

Table 3.A.10: Incidence of other chronic conditions (non-cardiovascular) Wave 2 by gender, age and level of ID.

	Epilepsy	Thyroid disease	Chronic constipation	Gastroesophageal reflux disease	Stomach ulcers
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:					
Male	4.0 (2.2 – 7.0)	5.9 (3.6 – 9.3)	22.5 (18.1 – 27.7)	7.5 (4.9 – 11.2)	4.9 (2.9 – 8.1)
Female	5.6 (3.6 – 8.5)	6.2 (4.1 – 9.2)	24.9 (20.7 – 29.5)	6.5 (4.3 – 9.5)	2.8 (1.5 – 5.2)
Age:					
43-49	3.6 (1.6 – 7.5)	5.1 (2.6 – 9.4)	24.0 (18.3 – 30.7)	2.0 (0.7 – 5.5)	2.0 (0.7 – 5.5)
50-64	5.4 (3.4 – 8.5)	5.1 (3.2 – 8.1)	22.3 (18.1 – 27.1)	8.5 (5.9 – 12.1)	3.7 (2.1 – 6.4)
≥65	5.5 (2.6 – 10.9)	9.6 (5.5 – 15.9)	27.4 (20.5 – 35.5)	9.6 (5.5 – 15.9)	6.2 (3.0 – 11.7)
Level of ID:					
Mild	2.6 (0.8 – 7.0)	3.3 (1.2 – 8.0)	15.2 (10.1 – 22.2)	7.9 (4.4 – 13.8)	4.0 (1.6 – 8.8)
Moderate	4.0 (2.2 – 7.1)	7.7 (5.0 – 11.4)	24.4 (19.7 – 29.8)	7.3 (4.8 – 11.0)	3.7 (1.9 – 6.7)
Severe/Profound	8.6 (5.1 – 13.8)	5.3 (2.7 – 9.8)	30.7 (24.3 – 37.9)	6.9 (3.9 – 11.7)	4.2 (2.0 – 8.5)
Total	4.8 (3.4 – 6.8)	6.0 (4.4 – 8.1)	23.5 (20.5 – 26.9)	6.8 (5.1 – 9.0)	3.7 (2.5 – 5.5)

Table 3.A.11: Prevalence of fast food consumption Wave 2 by gender, age and level of ID

	Once a week or more		1 – 3 times a month		Less than once a month or never		
	%	95% CI	%	95% CI	%	95% CI	Number in sample
Gender:							
Male	34.7	29.35-40.39	22.3	17.83-27.55	43.0	37.36-48.82	300
Female	24.2	20.03-28.81	28.6	24.16-33.41	47.3	42.21-52.39	385
Age:							
43-49	32.5	26.04-39.61	24.2	18.51-31	43.3	36.28-50.59	194
50-64	28.2	23.63-33.34	27.7	23.09-32.75	44.1	38.82-49.49	347
65+	25.0	18.33-33.03	23.6	17.11-31.55	51.4	42.96-59.75	144
Level of ID:							
Mild	27.5	20.68-35.54	26.8	20.08-34.84	45.6	37.53-53.98	149
Moderate	30.3	25.14-35.92	26.2	21.34-31.68	43.5	37.83-49.43	294
Severe/Profound	28.6	22.36-35.66	22.2	16.65-28.95	49.2	41.91-56.54	189
Type of Residence:							
Independent/Family	20.5	13.72-29.43	21.4	14.47-30.39	58.0	48.34-67.18	112
Community Group Home	35.1	29.76-40.91	25.3	20.57-30.77	39.5	33.97-45.37	296
Residential	25.3	20.35-30.89	28.2	23.02-33.92	46.6	40.61-52.63	277
Total	28.8	25.43-32.34	25.8	22.63-29.32	45.4	41.64-49.22	685

Table 3.A.12a: Prevalence of perceived weight Wave 1: IDS-TILDA by gender, age and level of ID.

	Overweight/Obese		Underweight		About right		
	%	95% CI	%	95% CI	%	95% CI	Number in sample
Gender:							
Male	26.4	21.84-31.57	7.8	5.26-11.37	65.8	60.37-70.80	333
Female	39.9	34.55-44.2	5.9	3.86-8.70	54.9	49.92-59.75	410
Age:							
43-49	33.7	28.26-39.57	6.7	4.22-10.49	59.6	53.57-65.30	282
50-64	34.8	29.79-40.18	5.0	3.04-8.05	60.2	54.73-65.39	339
65+	29.5	21.78-38.56	11.5	6.65-18.83	59.0	49.74-67.73	122
Level of ID:							
Mild	37.2	29.89-45.12	4.3	1.88-8.94	58.5	50.58-66.09	164
Moderate	35.3	30.13-40.85	5.0	2.98-8.15	59.7	54.07-65.07	320
Severe/Profound	32.0	25.76-38.98	10.3	6.66-15.57	57.6	50.52-64.47	203
Total	33.5	30.14-37.05	6.7	5.08-8.84	59.8	56.12-63.29	743

Table 3.A.12b: Prevalence of perceived weight Wave 2: IDS-TILDA by gender, age and level of ID.

	Overweight/Obese		Underweight		About right		
	%	95% CI	%	95% CI	%	95% CI	Number in sample
Gender:							
Male	22.8	18.21-28.1	5.8	3.51-9.26	71.4	65.84-76.45	294
Female	36.3	31.52-41.45	5.6	3.57-8.52	58.1	52.92-63.09	377
Age:							
43-49	32.4	25.92-39.71	3.7	1.64-7.82	63.8	56.48-70.61	188
50-64	31.2	26.35-36.44	6.5	4.19-9.77	62.4	56.94-67.48	340
65+	25.9	19.08-33.98	6.3	3.1-11.96	67.8	59.43-75.25	143
Level of ID:							
Mild	29.5	22.49-37.64	4.0	1.65-8.95	66.4	58.18-73.83	149
Moderate	35.8	30.28-41.69	4.2	2.3-7.43	60.0	54.04-65.69	285
Severe/Profound	25.7	19.7-32.66	9.1	5.54-14.39	65.2	57.9-71.95	187
Total	31.2	26.97-34.06	5.6	4.09-7.76	63.1	60.15-67.55	671

Table 3.A.12c: Prevalence of objectively measured weight Wave 2: IDS-TILDA by gender, age and level of ID.

	Overweight/Obese		Underweight		Normal		
	%	95% CI	%	95% CI	%	95% CI	Number in sample
Gender:							
Male	62.3	55.97-68.25	4.0	2.03-7.40	33.7	55.97-68.25	252
Female	69.9	64.68-74.74	2.7	1.31-5.20	27.4	22.75-32.54	336
Age:							
43-49	69.5	61.79-76.22	3.0	1.11	27.5	21.06-35.08	167
50-64	68.1	62.48-73.23	3.0	1.45-5.74	28.9	23.99-34.46	304
65+	59.0	49.48-67.86	4.3	1.58-10.18	36.8	28.17-46.21	117
Level of ID:							
Mild	84.9	77.2-90.45	1.6	0.28-6.2	13.5	8.28-21.0	126
Moderate	71.6	65.7-76.95	1.1	0.3-3.6	27.2	21.98-33.10	261
Severe/Profound	46.9	39.01-54.9	8.1	4.58-13.78	45.0	37.2-53.05	160
Total	66.7	62.68-70.44	3.2	2.01-5.09	30.1	26.45-34.01	588

Table 3.A.13: Prevalence of increased risk of cardio metabolic disease according to WHO waist circumference (WC) reference, by gender, age and level of ID

	Substantially increased risk		Increased risk		Normal WC		
	%	95% CI	%	95% CI	%	95% CI	Number in sample
Gender:							
Male	48.3	41.76-54.88	22.6	17.56-28.66	29.1	23.42-35.4	234
Female	78.4	73.02-83.01	13.3	9.66-18.01	8.3	5.43-13.31	278
Age:							
43-49	61.2	52.81-69.03	16.3	10.94-23.53	22.4	16.16-30.21	147
50-64	63.1	57.02-68.8	19.9	15.44-25.29	17	12.81-22.09	271
65+	74.5	64.25-82.66	12.8	7.06-21.62	12.8	7.06-21.62	94
Level of ID:							
Mild	76.9	68.15-83.83	12.4	7.34-19.93	10.7	6.07-18.0	121
Moderate	68.9	62.54-74.71	17.4	12.95-23.05	13.6	9.63-18.83	235
Severe/Profound	47.1	37.92-56.39	23.5	16.45-32.36	29.4	21.6-38.58	119
Total	64.6	60.31-68.76	17.6	14.44-21.22	17.8	14.61-21.42	512

4

Mental Health, Well-being and Cognitive Function in Older Adults with an Intellectual Disability

Niamh Mulryan, Eimear Cleary, Mary McCarron and Philip McCallion

Contents

4

Mental Health, Well-being and Cognitive Function in Older Adults with an Intellectual Disability

Key Findings

- Emotional, nervous or psychiatric disorders continued to be prevalent, nearly 60% of respondents reported receiving such a diagnosis from their doctor.
- The prevalence of reported mental health problems was higher in females and increased with age and level of disability.
- The mean annual incidence of receiving a diagnosis of mental ill health between Wave 1 and Wave 2 was 3.1% overall, 4.2% for anxiety and 2.8% for depressive disorder.
- The prevalence of mental health disorder reported by those with Down syndrome was 33.6% which is nearly half that for those without Down syndrome (DS) at 65.8%. The 3 year mental ill-health incidence for the Down syndrome cohort is 11.5% which is higher than the 9.6 % reported for the non-DS group.
- 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 84.1% and 67.8% respectively.
- The mean annual depreciation in the perception of positive mental health is 5.1% in the group as a whole.
- 14.6% of those completing the CES-D reported case level depressive symptomatology with a further 30.5% reporting sub-threshold symptom burden.
- The point prevalence of case level depressive symptomatology increased by 3% since Wave 1.
- The mean score on the Energy and Vitality Index (EVI) was 67.2. This compares favourably with the reported national average of 68 for individuals without an intellectual disability.
- Males, those in the youngest age cohort and those living independently reported the highest EVI scores.
- Two-thirds of respondents had experienced at least one significant life event in

the previous year. Nearly one third experienced a change of staff and one in five had a change of key-worker in the previous year.

- At Wave 1, 15.8% of participants with Down syndrome reported a diagnosis of dementia which increased to 29.9% by the Wave 2. This group that are at most risk from dementia had a mean incidence of 4.7% per annum.
- Dementia screening for those with Down syndrome improved between Wave 1 and Wave 2. Over half (51.2%) of this cohort had memory screening in the previous 2 years, a considerable improvement from the 32.9% noted in Wave 1.

4.1 Introduction

This chapter reports the findings regarding mental health, well-being and cognitive function from Wave 2. In addition to revisiting the measures used in Wave 1 to assess levels of mental ill-health, in Wave 2 additional items enquiring into vitality and life events were added. Preliminary findings on the incidence of some disorders are also presented in the context of other similar studies in those with and without an intellectual disability.

4.2 Mental Health

Prevalence and incidence rates of mental health disorders may vary due to different populations, survey methods and diagnostic criteria. Similar methodological issues apply to studies in populations with ID, with the added complexity of aetiology and phenotype differences. Smiley *et al.,* (2007), reported a 2 year mental ill-health incidence rate of 12.6% when problem behaviours were excluded from the analysis. The 2 year incidence rate in those with Down syndrome is reported to be between 3.7% and 14.9% depending on the criteria used (Mantry *et al.,* 2008). Point prevalence rates of major depression (7.6%) and anxiety disorder (4.4%) have been reported from an older ID population, with the noted symptom prevalences of 16.8% and 16.3% respectively (Hermans et al., 2013).

4.2.1 Reported diagnosis

Respondents were asked if they had received a diagnosis from their doctor of an emotional, nervous or psychiatric condition. If so, a number of possible diagnoses were offered and the respondent was asked to indicate any or all that applied. See Appendix table 4.A.1 for overall mental health prevalence for Wave 2 for gender, age and level of ID.

The overall prevalence of diagnosed mental health disorders in IDS-TILDA Wave 2 was nearly 60% (Wave 1=49%), (see *figure 4.1*). Anxiety was the most prevalent (39.2%) followed by depression (26.7%) and manic depression (4.7%). All diagnoses tended to be more prevalent in women or with increasing age (see *figure 4.2*) and the overall prevalence was highest in those with severe or profound intellectual disability.

The 3 year incidence, from Wave 1 to Wave 2, of psychiatric conditions was 9.6%. The mean annual incidence of anxiety was the highest (4.2%), followed by depression (2.8%). The incidence tended to be lowest in males, younger age cohorts or those with a mild ID (see Appendix table 4.A.2).

Figure 4.1: Prevalence of doctor's diagnosis of emotional and psychiatric conditions Wave 1 & Wave 2.

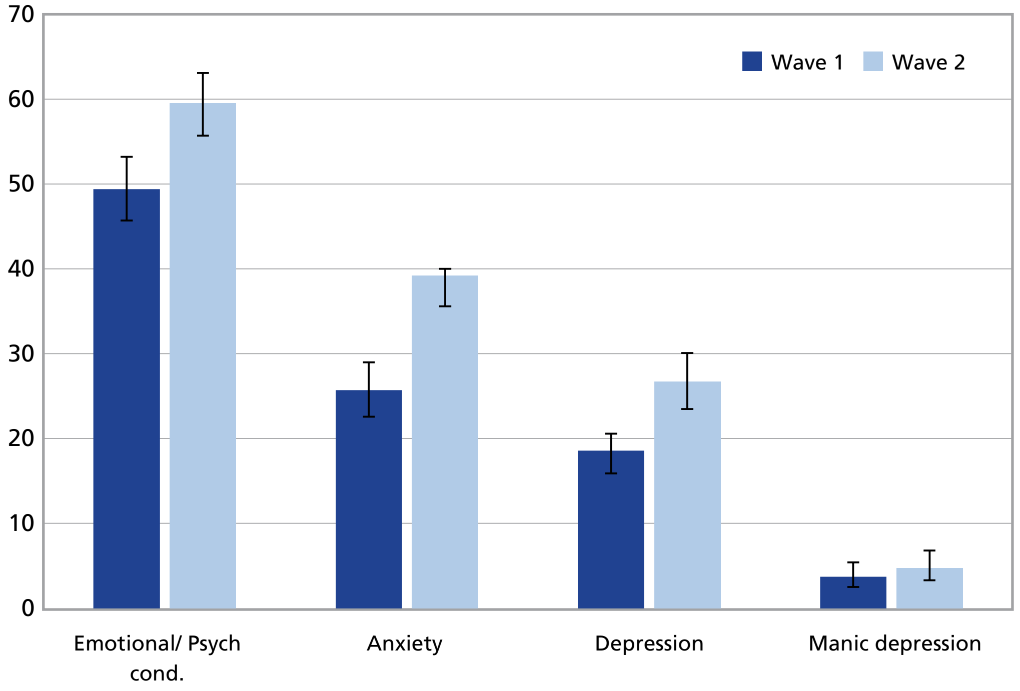
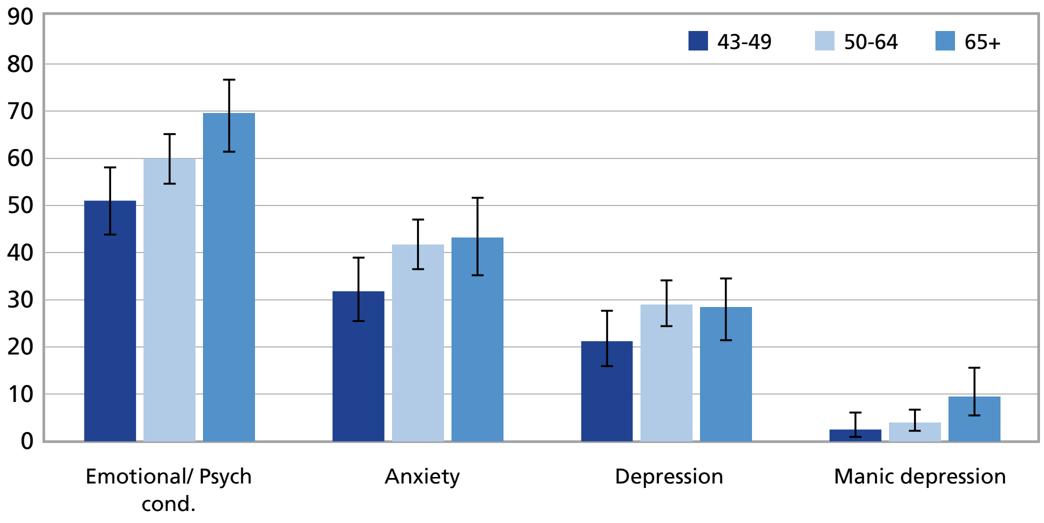


Figure 4.2: Mental health conditions by age.

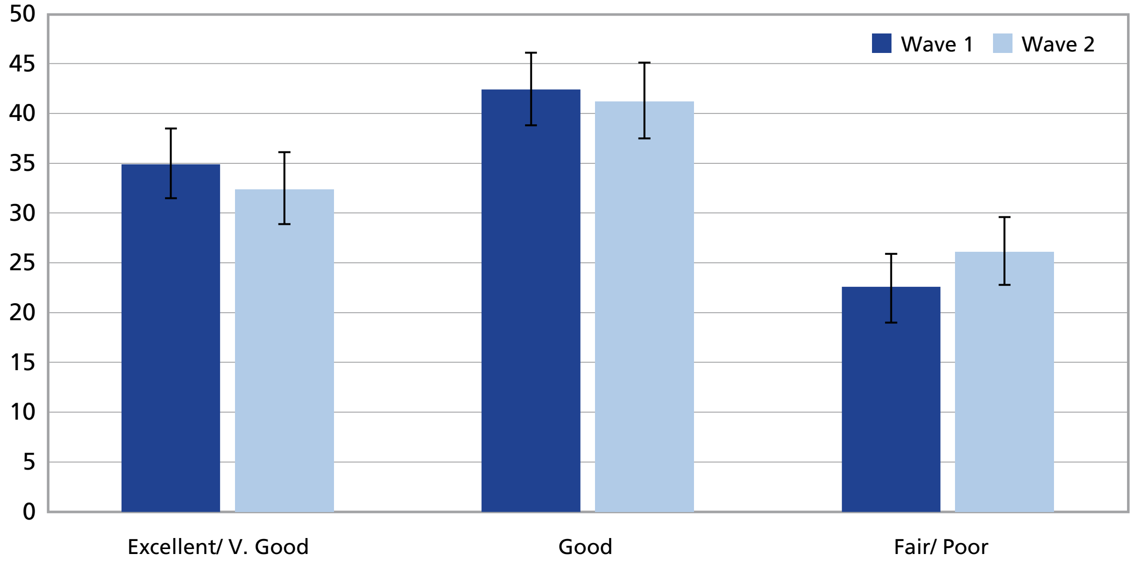


The prevalence of mental health disorder reported by those with Down syndrome was 33.6% which was nearly half that for those without Down syndrome (DS) at 65.8%. The 3 year mental ill-health incidence for the Down syndrome cohort is 11.5% which is higher than the 9.6 % reported for the non- DS group (see Appendix table 4.A.3).

4.2.2 Self/proxy rated emotional and mental health

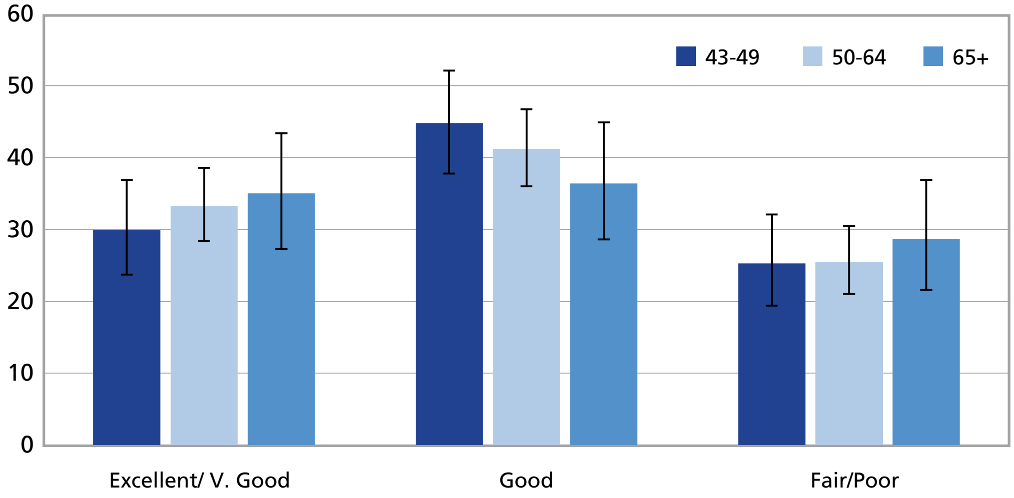
Respondents and/or their proxies were asked to rate their perception of the participant's mental and emotional health on a five point likert scale, with options ranging from excellent to poor. A total of 679 valid responses were collated of which 138 were entirely self-report. Despite the relatively high levels of reported mental health problems, almost three quarters (73.9%) rated their overall mental health favourably in Wave 2. Rating of overall positive emotional and mental health in people with intellectual disability was less than that reported for the general population at 73.9% versus 90% respectively.

Figure 4.3: Self-rated mental health Wave 1 & Wave 2.



Gender appeared to have little influence on the perception of mental health in Wave 2. Those with a mild ID reported a more positive appreciation of their mental health status as opposed to those with moderate or severe/ profound ID. Also the rates of those that regarded their mental health favourably (excellent, v. good or good), changed little across age groups. Rates of highly rated mental health are marginally lower in those aged 65 + years, at 74.7%, 74.5% and 70.7% respectively, see *figure 4.4*.

Figure 4.4: Self-rated mental health by age.



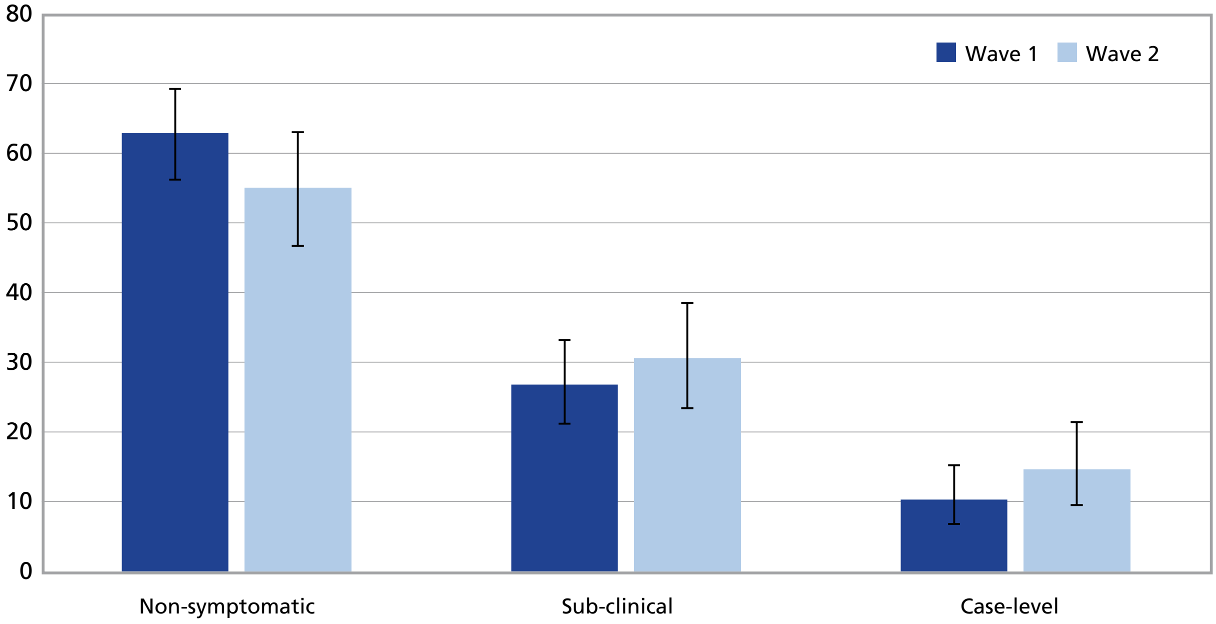
Those participants who self-reported were more likely to rate their emotional or mental health as excellent, very good or good than those who had proxy only replies, at 84.1% and 67.8% respectively. In addition, there has been attrition in perceived mental health wellbeing in the IDS-TILDA study population since Wave 1 in which 89.2% self-reported self-rated positive mental health (see Appendix table 4.A.5).

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

The CES-D is a self-report scale devised by Radloff, (1977) to assess depressive symptomatology in epidemiological studies. The scale consists of 20 items with four answer options; scored from zero to three. Four of the statements are positively framed, in which case the scoring schema 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. The cut off score of >16 was applied to indicate case level depressive symptomatology. Sub-threshold scores of 8-15 were also collated representing those who may have functional impairment due to their depressive symptom burden. Given the potential comprehension difficulties in this population, a score was considered valid if the scale was completed in its entirety or if one or two responses were absent. If data for individual items were missing, personal mean scores were imputed (Bono *et al.*, 2007) for those items. The CES-D instrument was completed as a self-report scale only (*n*=151).

The results from Wave 2 indicate a high level of depressive symptomatology, almost one third (30.5%) of the study population reported a significant sub-threshold depressive symptom burden. A further 14.6% had symptom levels above the cut off for a depressive disorder. In comparison to IDS-TILDA Wave 1 there was an increase in both sub-threshold (27.1%) and case level (11.6%) scores (see *figure 4.5*), representing a 3 year incidence rate of 3% for case level depression and 3.1% for sub-threshold symptomatology. Both waves of IDS-TILDA reported higher CES-D symptom scores than Wave 1 TILDA (Barrett *et al.,* 2011) where 10% of study participants had depression case scores and a further 18% reported sub-threshold symptomatology. For overall prevalence of depressive symptoms in Wave 2 measured by the CES-D see Appendix table 4.A.6

Figure 4.5: CESD – Wave 1 and Wave 2 Results



4.3 Energy and Vitality Index

Initially devised to support the Medical Outcomes Study (Wells *et al.,* 1989), the 36 item Short Form Health Survey (SF-36) has been widely utilised in monitoring outcomes in adult patients (Ware & Sherbourne, 1992). A subset of these items, the Energy and Vitality Index (EVI), assesses psychological wellbeing. It comprises 4 questions which enquire into aspects of psychological status over the previous 4 weeks. The response options are recorded on a 6 point likert scale from 'None of the time' to 'All of the time'.

Offered for the first time in Wave 2, six hundred and eighty one individuals completed the EVI. The mean score for all participants was 67.2. The score was higher in males

(67.9) than females (66.6), in younger participants (43-49yrs=68.7, 50-64yrs=68.2, 65+yrs=62.3), those with milder levels of disability (mild=71.3, moderate=67.7, severe/profound=62.9) or those living independently (independent=73.5, community house=67.7, residential=64.2). However few of these differences were significant (see Appendix table 4.A.7).

The 2007 Survey of Lifestyle, Attitudes and Nutrition (SLAN) interviewed over 10,000 Irish adults and reported an overall mean EVI score of 68 (Morgan *et al.,* 2008). The score tended to be higher in males, younger individuals or those in higher social classes. These findings echoed an earlier Europe-wide study reporting comparative data from 11 EU countries (EORG 2003). This Eurobarometer 2002 study while noting similar gender and age trends additionally reported associations with social support, marital status and between country differences in EVI score (Lehtinen *et al.,* 2005). The study of positive mental wellbeing in those with an intellectual disability has received little attention to date. The EVI data reported by IDS-TILDA suggest that participants in this study experience energy and vitality levels favourably comparable with those in the general population. These findings are all the more interesting because 57.7% of the respondents to the vitality index items were completed by proxy. As reported by Ball *et al.,* (2001) proxies tend to under rather than over report vitality. Further work will be under taken to examine difference in vitality reports among self-report participants as compared to those for whom a proxy was used.

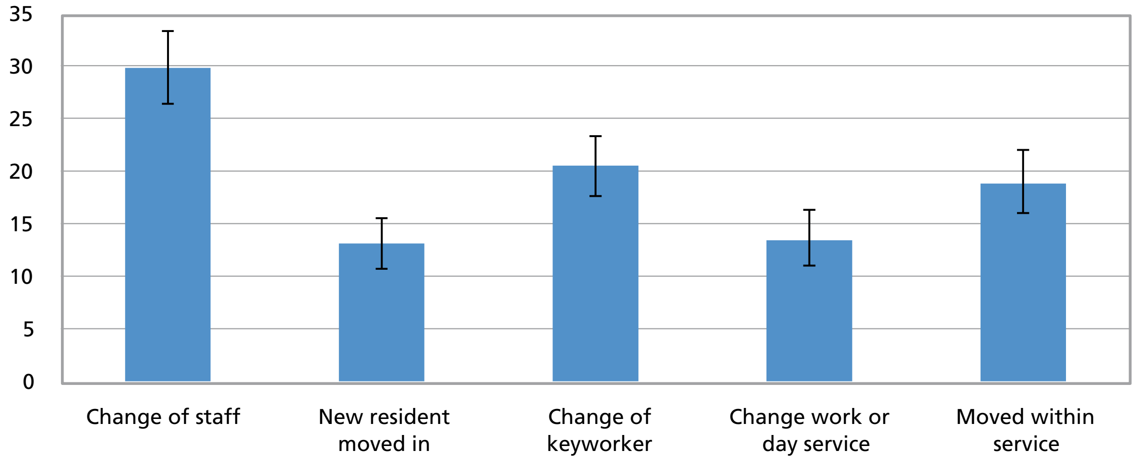
4.4 Life events

Life events are part of the human experience, for both individuals with and without an intellectual disability. There is evidence to support the viewpoint that persons with an intellectual disability have more frequent and negatively perceived life events (Tsakanikos *et al.,* 2007).

A 20 item checklist was devised to capture information regarding life events of participants over the previous year. The checklist included items on relationships, living arrangements and bereavements. The respondent was asked to attribute a positive, negative or neutral perception to each event.

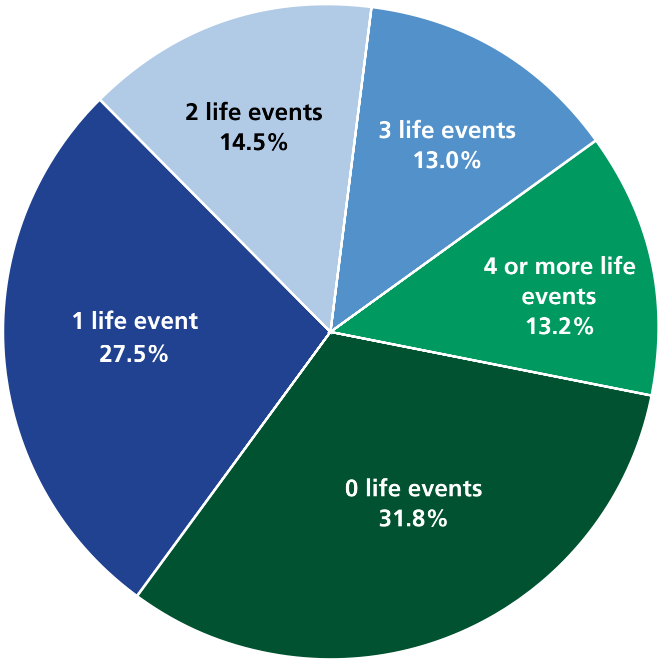
Two thirds of respondents reported multiple life events in the preceding 12 month period with over 13% experiencing 4 or more such events. The most frequently recorded changes related to a change of key-worker (20.5%) or other staff (29.8%) (See *figure 4.6* and *figure 4.7*)

Figure 4.6: Most prevalent life events



The occurrence of multiple life events in those with an intellectual disability may differ from the rest of the population due in part to the level of support needed, multiple carers and living arrangements which supports the findings from Tsakanikos *et al.,* 2007. The accumulation of these events has been associated with an increase in prevalence of depression and anxiety symptoms (Hermans & Evenhuis, 2012) and as a predictive risk factor for later psychological dysfunction (Hulbert-Williams *et al.,* 2014).

Figure 4.7: Number of life events



4.5 Cognitive findings

The increasing life expectancy of those with an ID is to be welcomed. Improved living circumstances, medical intervention and a better understanding of the pathological processes have allowed for more effective support of this vulnerable group. Unfortunately, ageing may introduce other challenges such as age related chronic diseases most notably dementia. The risk of developing dementia appears higher in those with an ID possibly due to decreased cognitive reserve or underlying genetic predisposition (Stern, 2012, Strydom *et al.,* 2010). The reported incidence is up to five times greater than the non-ID population (Strydom *et al.,* 2013).

A noted increase in life expectancy (Bittles & Glasson, 2004), in particular in those with Down syndrome, has unmasked a link with dementia (Oliver & Holland, 1986). Estimated prevalences vary but the risk of developing dementia is up to 80% at age 65 (McCarron *et al.,* 2014).

Assessment of cognitive function is a priority given the risk of illness and the potential to support the individual from an early stage of the disease. The advent of disease modifying medicines further increases the impetus to ensure adequate screening. International consensus recommends annual screening of individuals with DS from the age of 35 years and for others with ID from the age of 50 years (Aylward *et al.,* 1997). Screening tests for the non-ID population such as the Folstein Mini-Mental State Examination (Folstein *et al.,* 1975) are of not sensitive enough to indicate change in those with already compromised intellectual function (Deb & Braganza, 1999). Ideally, a screening battery should include instruments which can identify changes in memory, functional skills and cognition (Burt *et al.,* 2000).

4.5.1 Reported memory impairment

Respondents were asked if they had received a diagnosis of dementia or Alzheimer's dementia. The overall prevalence had increased from 5.8% in Wave 1 to 9% in Wave 2 representing a 3 year incidence of 3.2%. There had been a notable increase in the Down syndrome (DS) sub-group in particular; at Wave 1, 15.8% reported a diagnosis which increased to 29.9% by the Wave 2 assessment. This group that are at most risk from dementia had a mean incidence of 4.7% per annum. Those participants without DS experienced a more modest increase in prevalence from 3.6% to 4%.

4.5.2 Dementia Screening

Dementia screening availability for those with DS improved between Wave 1 and Wave 2. Over half (51.2%) of the Wave 2 cohort had memory screening in the previous 2 years, a considerable improvement from the 32.9% noted in Wave 1.

The screening of those with an ID of other aetiology increased from 9.9% in Wave 1 to 16.5% in Wave 2. It is acknowledged that some proportion of those screened may have become eligible for local memory screening due to advancing age which they would not have been eligible for at Wave 1. However, the numbers involved are not sufficient to fully explain the increase in screening. It is likely that screening opportunities have improved across the country over the past 3 years as a result of local demand and increased awareness (see Appendix table 4.A.8).

4.6 Conclusion

This chapter reported on the mental health, wellbeing and cognitive function of the participants. As the second wave of a longitudinal study it is possible to make initial comments on incidence rates and also to compare the findings to those in the general population.

Mental health problems remained prevalent with nearly 60% of participants receiving a diagnosis of an emotional or psychiatric disorder at some point to date. On a positive note psychological wellbeing was assessed for the first time in this study using the EVI. Levels of vitality compare favourably with the general Irish population and Europe as a whole.

Mental and cognitive wellbeing are crucial to ensuring a good quality of life. The longitudinal study of ageing in individuals with an intellectual disability will enhance our evidence base to optimise support and care. By investigating mental and cognitive function and its associated factors and in particular mental wellbeing in an ageing population it will be possible to increase our knowledge-base. Derived from this it will be possible to optimise interventions and supports to enhance a positive life experience adding quality to the years gained by individuals with an intellectual disability.

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Appendix 4.A Tables from Mental Health, Well-being and Cognitive Function in Older Adults with an Intellectual Disability

Appendix 4.A.1: Doctor's diagnosis of mental health conditions prevalence Wave 2

	Emotional psychiatric condition	Anxiety	Depression	Manic Depression
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:				
Male	58.1 (52.3 - 63.6)	20.7 (16.4 – 25.7)	20.7 (16.4 – 25.7)	4.5 (2.6 – 7.7)
Female	60.6 (55.5 - 65.4)	31.4 (26.9 – 36.3)	31.4 (26.9 – 36.3)	4.8 (3.0 – 7.6)
Age:				
43-49	51.0 (43.8 - 58.1)	31.8 (25.5 – 38.9)	21.2 (15.9 – 27.7)	2.5 (0.9 – 6.1)
50-64	60.0 (54.6 - 65.1)	41.7 (36.5 – 47.0)	29.0 (24.4 – 34.1)	3.9 (2.2 – 6.7)
≥65	69.6 (61.4 - 76.7)	43.2 (35.2 - 51.6)	28.4 (21.4 – 36.5)	9.5 (5.5 – 15.6)
Level of ID:				
Mild	55.6 (47.3 - 63.5)	29.9 (22.9 – 37.9)	29.9 (22.9 – 37.9)	3.9 (1.6 – 8.7)
Moderate	57.0 (51.1 - 62.6)	24.9 (20.2 – 30.3)	24.9 (20.2 – 30.3)	5.6 (3.4 – 9.1)
Severe/Profound	67.7 (60.5 - 74.1)	27.6 (21.5 – 34.6)	27.6 (21.5 – 34.6)	4.2 (1.9 – 8.3)
Total	59.5 (55.7 – 63.1)	39.2 (35.6 – 43.0)	26.7 (23.5 – 30.1)	4.7 (3.3 – 6.6)

Appendix 4.A.2: Doctor's diagnosis of mental health conditions incidence Wave 2

	Emotional psychiatric condition	Anxiety	Depression	Manic Depression
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:				
Male	9.2 (6.3 – 13.3)	12.3 (8.9 – 16.6)	8.4 (5.7 – 12.3)	0.6 (0.1 – 2.6)
Female	10.6 (7.8 – 14.3)	13.0 (9.9 – 16.9)	8.2 (5.7 – 11.5)	1.3 (0.5 – 3.2)
Age:				
43-49	9.5 (5.9 – 14.8)	9.1 (5.7 – 14.3)	6.1 (3.3 – 10.6)	0.0
50-64	10.2 (7.2 – 14.1)	15.5 (12.0 – 19.8)	9.0 (6.4 – 12.6)	0.8 (0.2 – 2.7)
≥65	10.3 (6.1 – 16.7)	10.8 (6.5 – 17.2)	9.5 (5.5 – 15.6)	2.7 (0.9 – 7.2)
Level of ID:				
Mild	9.7 (5.6 – 16.0)	13.0 (8.3 – 19.6)	8.4 (4.7 – 14.3)	0.6 (0.0 – 4.1)
Moderate	9.0 (6.0 – 13.0)	11.3 (8.1 – 15.6)	7.7 (5.0 – 11.5)	1.0 (0.3 – 3.2)
Severe/Profound	12.9 (8.6 – 18.8)	14.6 (10.1 – 20.6)	7.8 (4.6 – 12.8)	1.6 (0.4 – 4.9)
Total	9.6 (7.5 – 12.0)	12.7 (10.4 – 15.4)	8.3 (6.4 – 10.6)	1.0 (0.4 – 2.1)

Appendix Table 4.A.3: Mental Health Conditions Prevalence and Incidence Wave 2 Down Syndrome

	%	(95% CI)	Number in sample
Prevalence			
Down Syndrome	33.6	25.88-42.22	137
Not Down Syndrome	65.8	61.6-69.7	549
Total	59.3	55.54-63.02	686
Incidence			
Down Syndrome	11.5	6.77-18.48	131
Not Down Syndrome	9.6	7.24-12.49	523
Total	9.9	7.81-12.56	654

Appendix Table 4.A.4: Self-rated mental health Wave 2

	Excellent/ V. Good	Good	Fair/Poor
	% (95% CI)	% (95% CI)	% (95% CI)
Gender:			
Male	32.9 (27.7 – 38.5)	41.2 (35.6 – 47.0)	25.9 (21.1 – 31.3)
Female	32.5 (27.9 – 37.5)	41.3 (36.3 – 46.4)	26.2 (21.9 – 31.0)
Age:			
43-49	29.9 (23.7 – 36.9)	44.8 (37.8 – 52.1)	25.3 (19.4 – 32.1)
50-64	33.3 (28.4 – 38.6)	41.2 (36.0 – 46.7)	25.4 (21.0 – 30.5)
≥65	34.3 (26.7-42.7	36.4 (28.6 – 44.9)	28.7 (21.6 – 36.9)
Level of ID:			
Mild	38.4 (30.7 – 46.7)	40.4 (32.6 – 48.7)	21.2 (15.1 – 28.7)
Moderate	34.1 (28.8 – 39.9)	38.9 (33.3 – 44.8)	27.0 (22.0 – 32.5)
Severe/Profound	25.0 (19.0 – 32.0)	43.5 (36.3 – 51.0)	31.5 (25.0 – 38.8)
Total	32.7 (29.2 – 36.4)	41.2 (37.5 – 45.1)	26.1 (22.8 – 29.6)

Appendix Table 4.A.5: Self-reported favourable self-rated mental health, Comparison Wave 1 and Wave 2

	Wave 1			Wave 2		
	%	95% CI	Number in sample	%	95% CI	Number in sample
Self-report	89.2	82.54-93.63	139	85.6	78.27-90.71	138
Assisted interview	79.5	75.34-83.18	430	79.4	73.37-84.47	289
Proxy only	62.3	53.64-70.31	138	65.2	59.71-70.36	322
Total	77.4	74.11-80.3	733	73.9	70.42-77.16	679

Appendix Table 4.A.6: Prevalence of depressive symptoms at Wave 2 measured by the CES-D

	Non-symptomatic	Sub-clinical symptoms	Case level symptoms
	% (95% CI)	% (95% CI)	% (95% CI)
Gender:			
Male	54.0 (39.4 – 67.9)	24.0 (13.5 – 38.5)	22.0 (12.0 – 36.3)
Female	55.4 (45.2 – 65.2)	33.7 (24.7 – 43.8)	10.9 (5.8 – 19.0)
Age:			
43-49	56.2 (41.3 – 70.2)	31.2 (19.1 – 46.4)	12.5 (5.2 – 25.9)
50-64	51.8 (40.7 – 62.6)	32.9 (23.4 – 44.1)	15.3 (8.7 – 25.1)
≥65	66.7 (41.2 – 85.6)	16.7 (4.4 – 42.3)	16.7 (4.4 – 42.3)
Level of ID:			
Mild	57.4 (44.1 – 69.7)	21.3 (12.3 – 34.0)	21.3 (12.3 – 34.0)
Moderate	51.4 (39.3 – 63.4)	40.0 (28.7 – 52.4)	8.6 (3.5 – 18.3)
Severe/Profound	100 (0)	0	0
Total	55.0 (46.7 – 63.0)	30.5 (23.4 – 38.5)	14.6 (9.5 – 21.4)

Appendix Table 4.A.7: Vitality Score Index

	Mean Score	(95% CI)
Gender:		
Male	67.9	(65.3 – 70.5)
Female	66.6	(64.3 – 68.8)
Age:		
43-49	68.7	(65.6 – 71.9)
50-64	68.2	(65.9 – 70.6)
≥65	62.3	(58.2 – 66.3)
Level of ID:		
Mild	71.3	(68.1 – 74.5)
Moderate	67.7	(65.2 – 70.2)
Severe/Profound	62.9	(59.6 – 66.1)
Type of Residence:		
Indep/Family	73.5	(69.7-77.4)
Community group home	67.7	(65.1-70.0)
Residential Care	64.2	(61.7-66.9)
Total	67.2	(65.6 – 68.8)

Appendix Table 4.A.8: Dementia screening by ID aetiology Wave 1 & Wave 2

	Dementia Screening	
	Wave 1	**Wave 2**
	% (95% CI)	**% (95% CI)**
Within last two years		
Down Syndrome	32.9 (23.4 – 44.1)	51.2 (42.2 – 60.0)
Not Down Syndrome	9.9 (6.9 – 13.9)	16.5 (13.4 – 20.1)
Total	14.5 (11.3 – 18.5)	23.2 (20.5 – 26.7)
Before last two years		
Down Syndrome	8.2 (3.7 – 16.8)	8.5 (4.5 – 15.1)
Not Down Syndrome	2.6 (1.2 – 5.3)	3.8 (2.4 – 5.9)
Total	4.0 (2.4 – 6.6)	4.6 (3.2 – 6.6)

5

Health Care Utilisation among Older Adults with an Intellectual Disability

Philip McCallion, Rachael Carroll, Mary Ann O'Donovan
and Mary McCarron

Contents

An Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing

5

Health Care Utilisation among Older Adults with an Intellectual Disability

Key Findings

- There was little change between Wave 1 and Wave 2 in the use of health, specialist health and social care services and medications for people with ID as they age. Those rates of usage remained higher than what is being reported for the general ageing population
- Between Wave 1 and Wave 2, 120 participants changed where they lived and those changes were lateral (61) to more restrictive settings (15) and to less restrictive settings (31) with the remainder (13) in more temporary settings.
- Most individuals with ID reported not participating in choosing the new location to live and that they were not part of the decision to move.
- Participants who moved to more restrictive settings were more likely to use occupational therapy and physiotherapy, and access social, psychological/counselling, dental, neurological, geriatrician and palliative services. It will require further investigation to understand if the need for such services necessitated the move to more restrictive settings.
- On a positive note there is clearly a greater effort for people with ID to prevent influenza with vaccination levels at over 90% compared to 57% found for TILDA participants.

5.1 Introduction

Independent, successful ageing and retirement for the general population is usually supported by pensions, other financial resources, social networks and family supports and by good health and health care (McCallion, *et al.,* 2013). Van Schrojenstein Lantaman-De Valk et al. (2000) previously compared 318 people with ID 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. Also, Bhaumik *et al.,* (2008) have highlighted higher psychiatric morbidity among elderly (compared with younger) adults with ID. These same researchers and others (for a review, see Haveman, *et al.,* 2009) also found that such physical and mental health conditions and good health in general are highly influenced by the level of and appropriateness of health care access.

Findings in Wave 1 were of a group of people with ID who were satisfied with the healthcare they received and who accessed healthcare services on a regular basis with levels of health care and utilisation similar to general population reports except for higher rates of hospitalisation. There were also high levels of utilisation of social care services (McCarron *et al.,* 2011). Given austerity issues, during the last few years, there was interest in Wave 2 in exploring the extent to which levels of utilisation may have changed. Also, with increased interest in moving persons with ID out of congregated settings, Wave 2 offers an opportunity to take a first look at how movement to different settings influences utilisation of health and social care services.

5.2 Key methodological considerations

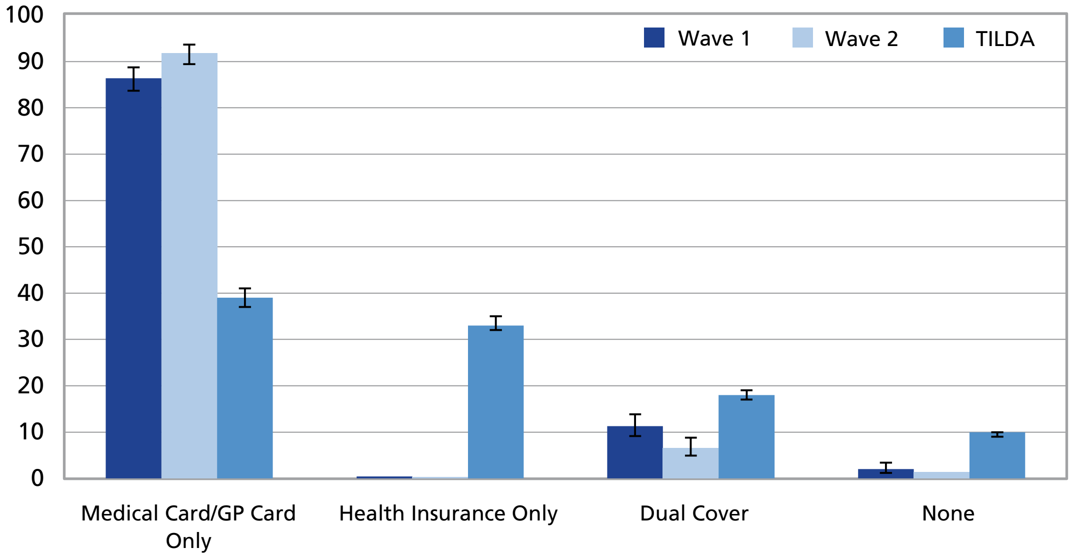
In this chapter data will be initially reported for all persons who completed questions on their use of both health and social care services including availability of medical cards and medical insurance, access to health services such as GP, outpatient, emergency department and hospitalisation services, utilisation of health screening and access to a range of health-related and other professionals and to a range of social care services. In addition, those individuals who moved living situation will be described in terms of those who made a less restrictive, lateral and or more restrictive move and the impact of these moves will be considered in terms of the resulting utilisation differences across settings in terms of health-related and other professionals and social care services.

5.3 Changes in Service Use

5.3.1 Medical Cover

As may be seen in *figure 5.*1 there were few changes in medical cover from Wave 1 to Wave 2 for IDS-TILDA respondents although there was a small increase in medical card/GP card coverage (almost everyone held both) and a reduction in the numbers with dual (medical card and insurance) coverage. The only difference of note was that there was a small increase (from 4.3% to 5.9%) in the numbers of individuals aged 50-64 with private health insurance. Rates of availability of medical cards/GP cards by respondents remained higher and health insurance availability was lower for IDS-TILDA respondents as compared to TILDA reports.

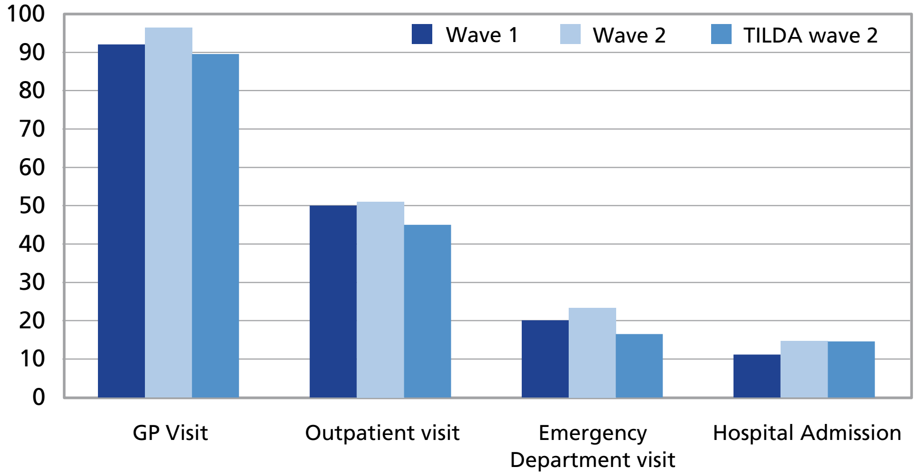
Figure 5.1: Comparison of prevalence of medical cover between IDS-TILDA Wave 1, Wave 2 and TILDA Wave 2.



5.3.2 Use of health services

Use of GP, outpatient, emergency department, and hospital services remained similar across Waves; utilisation rates were a little higher than for the general population as reported by TILDA, but not markedly so (see *figure 5.2* below).

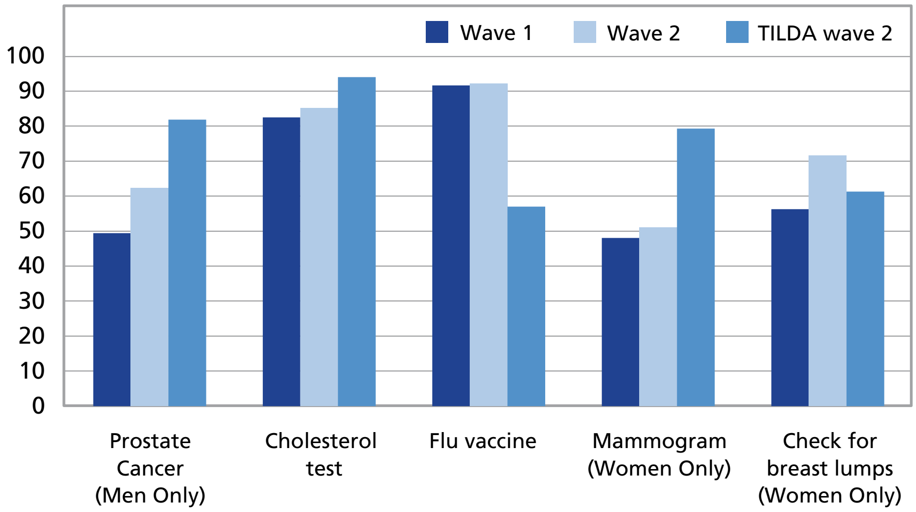
Figure 5.2: Comparison of the use of health services between IDS-TILDA Wave 1, Wave 2 and TILDA Wave 2.



5.3.3 Health screenings

Rates of health screening remained largely the same although there were some increase in prostate checks and check for breast lump screening for respondents with ID and receipt of flu vaccine remained higher for respondents with ID than what TILDA reported for the general population. As may be seen in *figure 5.3*, the most notable deficit is the level of mammography completed for people with ID which remained below rates for general population.

Figure 5.3: Prevalence of health screening: Comparison between IDS-TILDA Wave 1, Wave 2 and TILDA Wave 2.

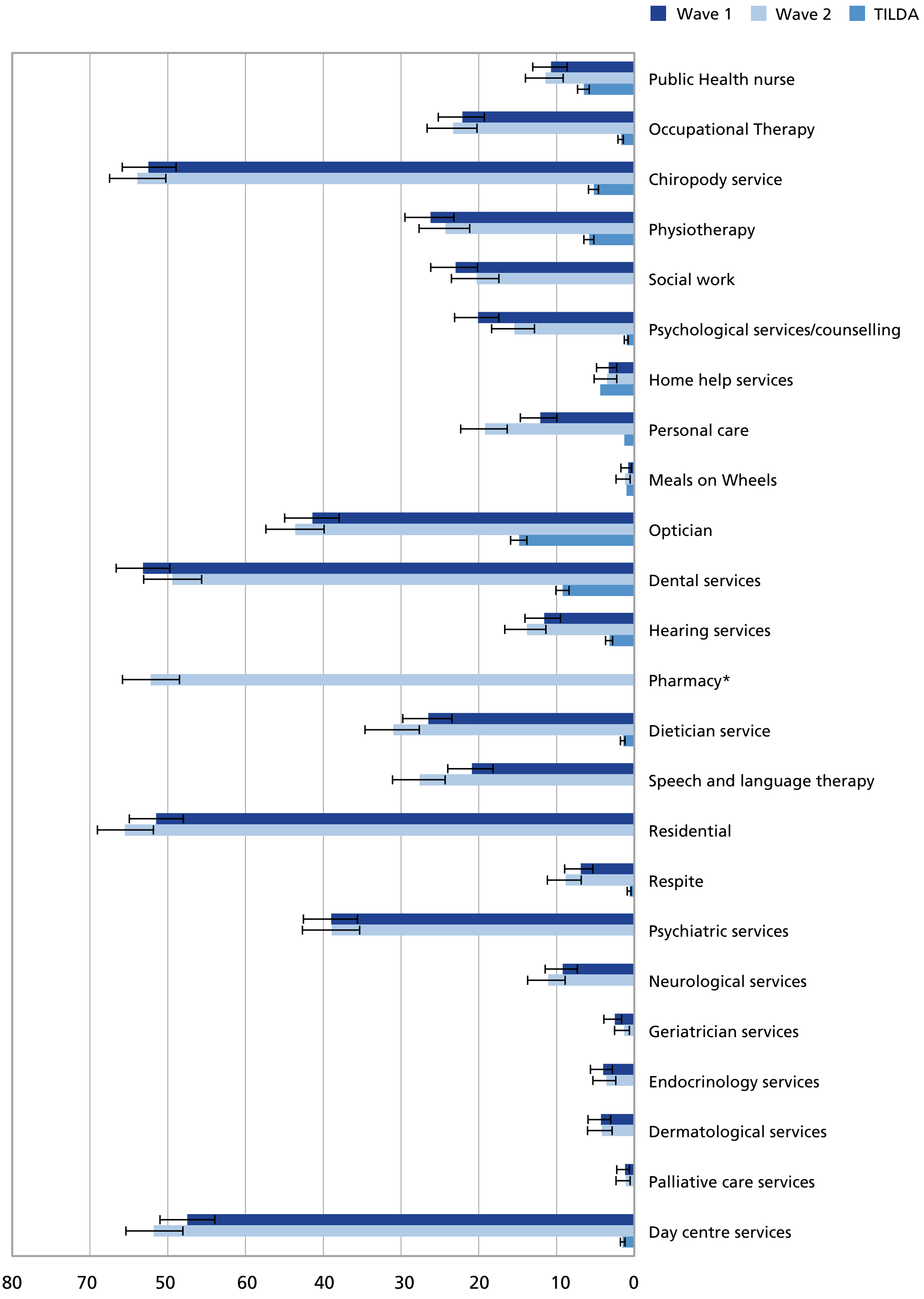


On a positive note there is clearly a greater effort for people with ID to prevent influenza with vaccination levels at over 90% compared to 57% found for TILDA participants.

5.3.4 Use of specialist health and social care services

Across the Waves as may be seen in *figure 5.4,* there was little change in percentages of persons with ID using a range of specialist health and social care services. One area noted of significant increase was in personal care which increased from 12.1% in Wave 1 to 19.2% in Wave 2. This compares with personal care support in the general population of 1.3%. When compared to TILDA responses, use of services by persons with ID was high in all areas but was dramatically higher for psychiatry, chiropody, dental, optician, residential and day centre services.

Figure 5.4: Specialist health and social care services.



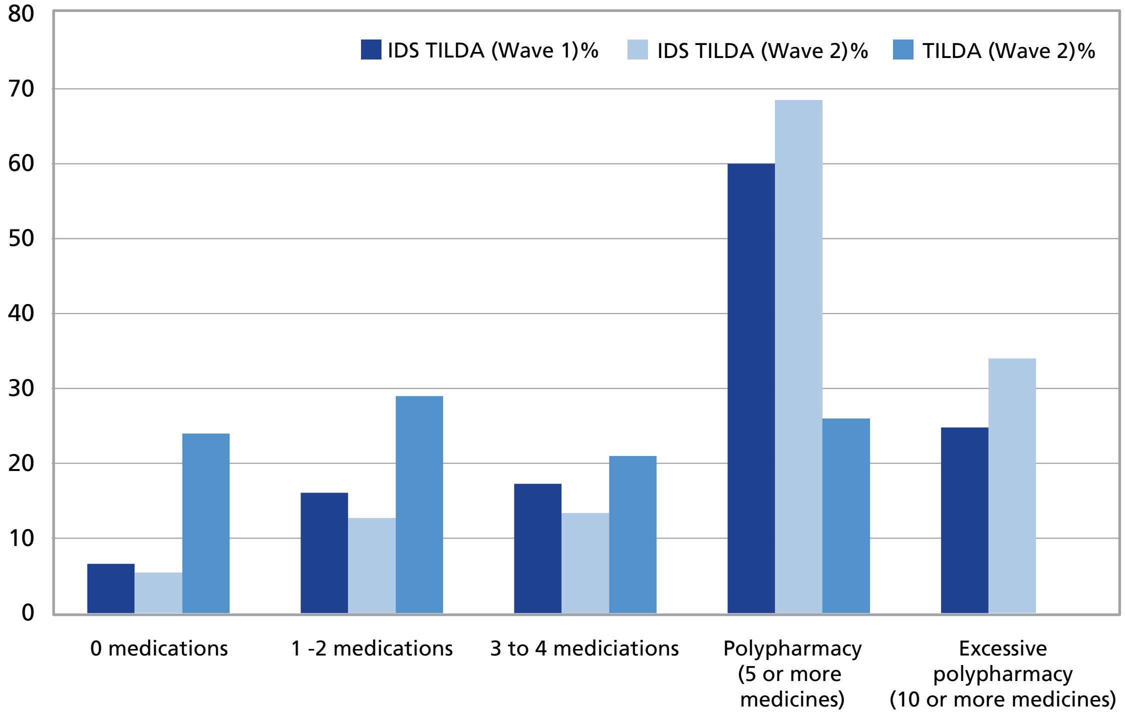
Note: Where there are no TILDA comparison this implies this question was not available from the TILDA report.

*The Pharmacy question was only asked in Wave 2 IDS-TILDA

5.3.5 Use of medications

As may be seen in figure 5.5, at Wave 2 not only do levels of medication use remain much higher overall than for TILDA participants but the percentage of IDS-TILDA participants on five or more medicines and supplements rose from 59% in Wave 1 to almost 69% by Wave 2 and for excessive polypharmacy (10 or more medicines and supplements) from 24.8% at Wave 1 to 34% at Wave 2. This compares to 26% for polypharmacy (5 or more medicines) in the TILDA population.

Figure 5.5: Prevalence of the use of medications: Wave 1, Wave 2 and TILDA Wave 2.



5.4 Movement within and between settings and its relationship to service use

5.4.1 Understanding movement between Wave 1 and Wave 2

A total of 120 people (17.1% of the Wave 2 sample) moved their living situation during the period between Wave 1 and Wave 2 data collection. As may be seen in Table 5.1, there were more women than men who moved (66 females versus 54 males), the largest (54) were in the 50=64 years age range and most (64) had a moderate ID. However, all genders, all ages and all levels of ID were represented.

Table 5.1: Profile of confirmed movers.

	n	%
Gender:		
Male	54	45.0
Female	66	55.0
Age:		
43-49	30	25.0
50-64	54	45.0
65+	36	30.0
Level of ID:		
Mild	17	14.8
Moderate	64	55.7
Severe	28	24.3
Profound	6	5.2
Marital status:		
Single	119	99.2
Has a partner but not living with him/her	1	0.8

As may be seen in table 5.2 movement was from the full range of settings and into an equally full range of settings with three persons in the residential grouping moving to nursing homes but none moving out of such a setting.

Table 5.2: Living arrangements.

Wave 1 Residence	Moved to Residence at Wave 2							
	Family/ Independent		Community Group Home		Residential		Other	
	n	%	n	%	n	%	n	%
Family/ independent	6	66.7	4	6.5	0	0.0	0	0.0
Community group home	2	22.2	28	45.2	11	23.9	2	66.7
Residential	0	0.0	29	46.8	33	71.7	0	0.0
Other	1	11.1	1	1.6	2	4.3	1	33.3
Total	9	100.0	62	100.0	46	100.0	3	100.0

Each move was then examined and categorized into:

- lateral moves (movement to another living unit within a campus setting or institution, movement to another community group home or movement to a different family or independent home).

- More restrictive setting (movement from a community group home or from family/ independent to a campus setting or institution or to a nursing home or a closed mental health unit; or movement from family/independent to a community group home).
- Less restrictive setting (movement from a campus setting or institution to a group home or to family/independent; movement from a community group home to family or independent home).

As may be seen in table 5.3, there were 66 lateral moves, 15 moves to more restrictive settings and 31 moves to less restrictive settings. Again, moves in all three groupings included both males and females, all ages and all levels of ID but men were a little more likely to be involved in moves to less restrictive settings, and women in lateral moves; most movers were aged 50-64 but there were a high number of movers (42) over 65; and those with moderate ID featured most in all types of moves.

Table 5.3: Mover demographics by type of move

Demographic and health profile	Lateral *n*=66	%	More Restrictive *n*=15	%	More Community Based *n*=31	%
Gender:						
Male	24	36.4	7	46.7	19	61.3
Female	42	63.6	8	53.3	12	38.7
Age:						
43-49	16	24.2	3	20.0	9	29.0
50-64	30	45.5	9	60.0	13	41.9
65+	20	30.3	3	20.0	9	29.0
Level of ID:						
Mild	10	16.1	3	20.0	3	10.0
Moderate	36	58.1	10	66.7	14	46.7
Severe/ Profound	16	25.8	2	13.3	13	43.3

5.4.2 Understanding how decisions were made about moving

As may be seen in table 5.4, there were a variety of reasons offered for the move, regardless of type of move. Lateral moves were most often reported to be about accommodations to the service (45.5%), movement to more restrictive setting were usually (60%) in response to changes in health and mental health status and movement to less restrictive settings appeared driven by policy and transitioning planning considerations (61.3% and 41.9% respectively).

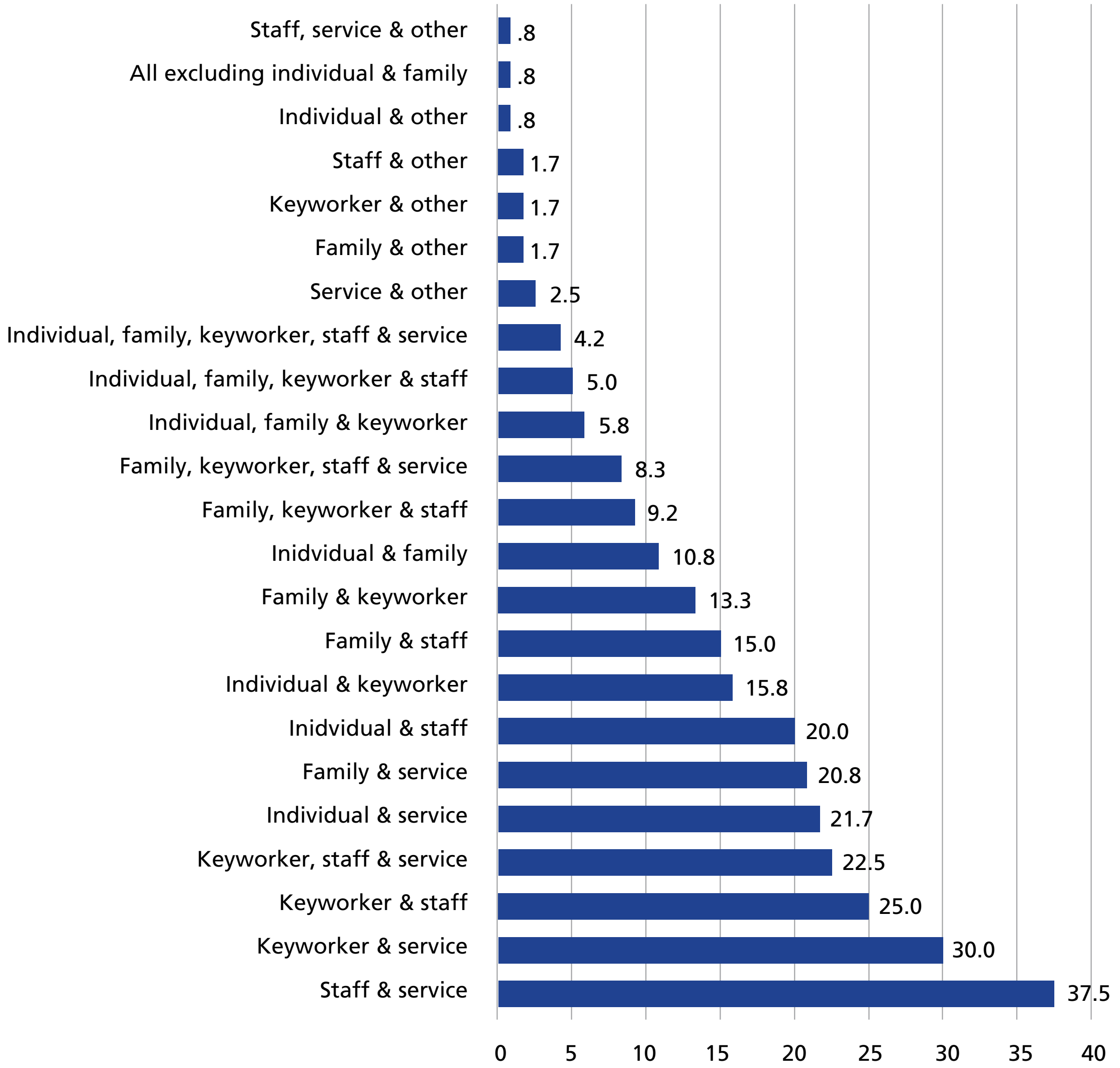
Table 5.4: Reasons for Moves*

Reason for move	Lateral *n*=66	%	More Restrictive *n*=15	%	Less Restrictive *n*=31	%
Change in health or mental health status	13	19.7	9	60.0	2	6.5
Loss or infirmity of primary carer	1	1.5	3	20.0	0	0.0
Service policy	3	4.5	1	6.7	19	61.3
Accommodate service	30	45.5	1	6.7	7	22.6
Not happy in previous residence	6	9.1	2	13.3	2	6.5
Funding/staff shortages	3	4.5	0	0	0	0.0
Lack of accessibility or other suitability of previous residence	7	10.6	2	13.3	1	3.2
Lack of nursing support	5	7.6	2	13.3	1	3.2
Lack of 24 hour care	5	7.6	2	13.3	1	3.2
Part of transition process	9	13.6	2	13.3	13	41.9
Personal Choice	8	12.1	2	13.3	3	9.7
Don't know reason	3	4.5	1	6.7	0	0.0
Other	3	4.5	0	0.0	1	3.2

*Note: Because there could be more than one reason, total "n's" and "%" may add up to more than the total number.

A review of the reasons for moving does raise a question about who was involved in the related decision-making. In *figure 5.6* it is clearly illustrated that there were a variety of decision-makers. It was equally clear that almost all decisions involved staff, and many only involved staff and the services administration. This means that in a large number of cases the individual with ID did not feel that they were involved in the decisions around their move.

Figure 5.6: Who was involved in making decisions about Moves*



*Note: Other here tended to be individuals external to the service not known to the individual with ID, e.g., the administration of a receiving service.

As may also be seen in table 5.5, people with ID reported they were only involved in 25-33% of decisions, with surprisingly, the lowest percentage (25.8%) involved in decisions about movement to less restrictive settings

Table 5.5: Decision-makers by type of setting

Who was involved in decision to move?	Lateral *n*=66	%	More restrictive *n*=15	%	Less Restrictive *n*=31	%
Myself	22	33.3	5	33.3	8	25.8
Family	14	21.2	6	40	10	32.3
Keyworker	20	30.3	6	40	12	38.7
Staff	30	45.5	7	46.7	17	54.8
Service	54	81.8	11	73.3	29	93.5
Other	1	1.5	2	13.3	2	6.5

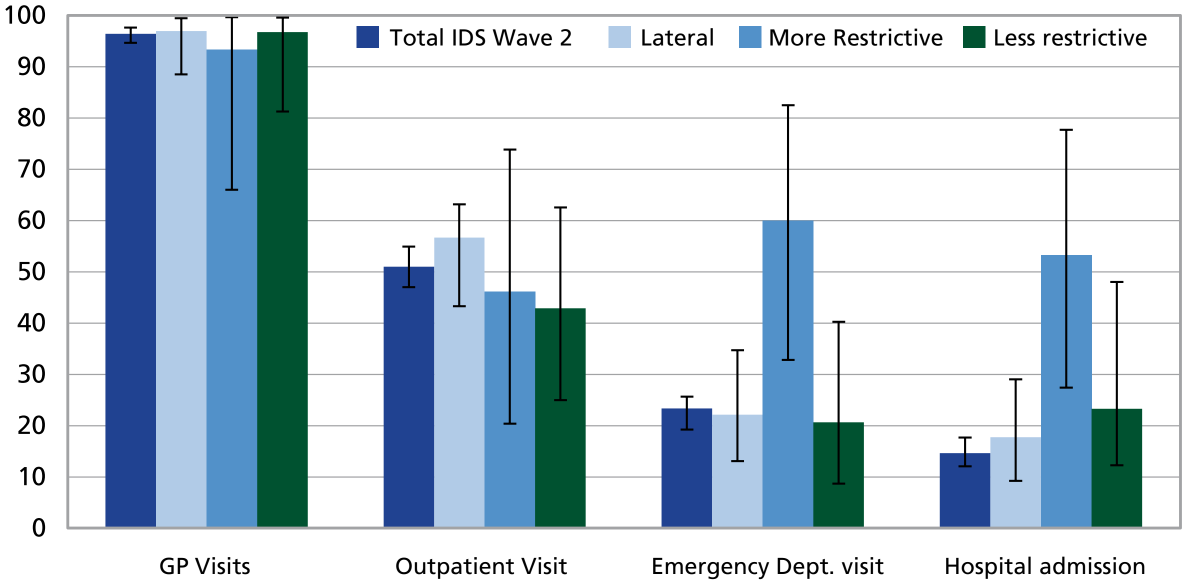
A particular concern was that only 20% of those who moved indicated that they that they had the opportunity to view the proposed alternative accommodation prior to their move and no more than 60% said that they had wanted to move. However it should be noted that post-movement, 82.4% of the 120 movers indicated that they were happy with their move to another living situation.

5.5 Services utilisation after a change in living situation

5.5.1 Health service utilisation

There were little changes for all movers in GP and outpatient visits. However, as illustrated in figure 5.7, for those who moved to more restrictive settings there was an increase in their rate of use of emergency departments (60% as compared to 22% and 20.7%) and hospitalisations (53.3% as compared to 17.8% and 23.4%). The extended CIs argue for some caution in the interpretation of these findings; however they do seem consistent with the prior findings that changes in physical and mental health status were a primary reason for movement to more restrictive settings.

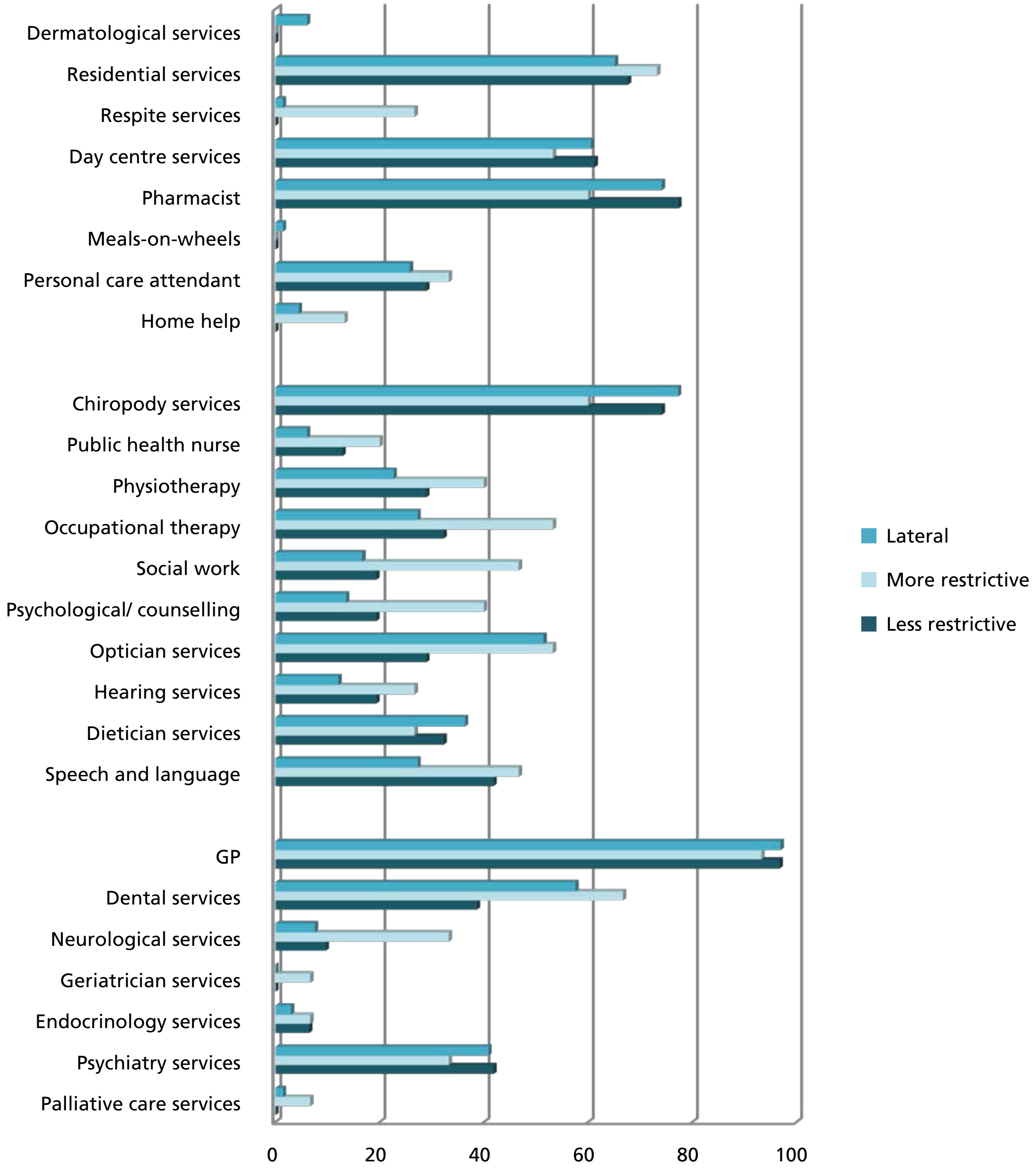
Figure 5.7: Health service utilisation by people who moved between Wave 1 and Wave 2.



5.5.2 Specialist health and social care services

A more complex picture emerges in terms of use of specialist health and social care services as is illustrated in *figure 5.8*. The most striking differences are for people who moved to more restrictive settings. For this group there are higher levels of use of occupational and physiotherapy, and of social work, psychological/counselling, dental, neurological and respite services with rates ranging from 26.7% to 53.3%. Geriatrician and palliative care service utilisation has increased substantially for people in more restrictive type settings reflecting the more complex health needs of this population. What is unclear is whether movement to more restrictive settings was influenced by the need for such services or that placement in more restrictive settings means that such services will be offered and availed of.

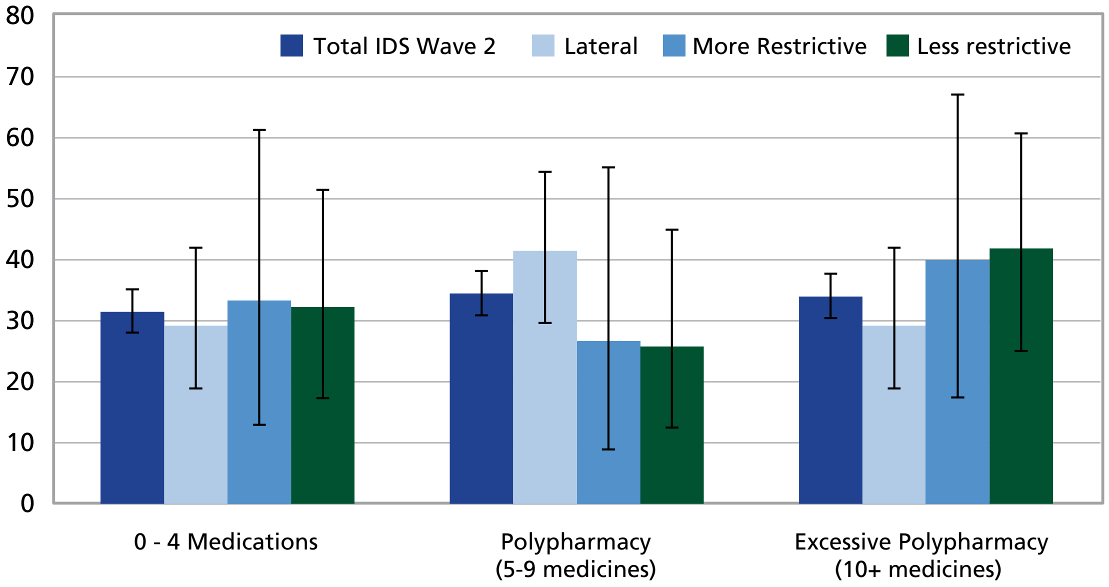
Figure 5.8: Specialist health and social care service utilisation by people who moved between Wave 1 and Wave 2.



5.5.3 Medication use

Figure 5.9 suggests that levels of polypharmacy (5-9 medicines) are somewhat higher for those who were involved in lateral moves (41.5% as compared to 26.7% and 25.8%) and that excessive polypharmacy was higher for those moving to more and to less restrictive setting but again the size of confidence intervals and opposite findings for polypharmacy versus excessive polypharmacy would suggest that there is no effect on medication use. However the relatively high levels of polypharmacy and excessive polypharmacy overall are still of concern.

Figure 5.9: Use of medications by people who moved between Wave 1 and Wave 2.



5.6 Conclusion

In the midst of general population austerity-related concerns about loss of Medical and GP visit cards and reported difficulties in accessing health services and specialist health and social care services, level of access and usage of all such services appear similar from Wave 1 to Wave 2 for people with ID.

The most interesting changes in service utilisation occurred for people (*n*=120; 17.1%) who moved living situation between Wave 1 and Wave 2. The influence of the HSE report (2011), Time to move on from congregated settings: a strategy for community inclusion would have suggested that most moves would be to less restrictive settings; the finding in IDS-TILDA that there were more lateral moves and moves to more restrictive settings helps illustrate the complexity in people's lives influencing moves including the impact of health and mental health concerns. Of greatest concern in this data are the relatively low levels of personal involvement in such moves reported by people with ID and the additional finding that most decisions around moves were reflecting services needs and concerns and discussions and decisions among services administration and staff. If there is actually more opportunity for people with ID to be part of these decisions than the data suggests, at the least this means that the need for moves and transfers is not being well discussed with people with ID so that they fully understand the role they do and may play in those decisions. This needs to be better addressed.

The apparent differences in service use experience for those who move, with for example persons moving to more restrictive settings reporting having higher levels of use of occupational and physiotherapy, and of social work, psychological/counselling, dental, neurological, geriatrician and palliative services deserves further investigation. If movement to more restrictive settings was to facilitate access to such services because they were not available in less restrictive settings, then it will be more difficult to realize public policy intent around the reduction of congregate settings if such health and social care services, when needed, are not easily accessed in the community.

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6

Methodology

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Contents

6

Methodology

6.1 Key Findings

- At Wave 1, the National Intellectual Disability Database (NIDD) provided the sampling frame for the study and a nationally representative group of 753 respondents with an ID over the age of 40 years were successfully enrolled in the study.
- At Wave 2, all living Wave 1 respondents were invited to complete a pre-interview questionnaire (PIQ) and also undertake an extensive face-to-face computer assisted personal interview (CAPI).
- The overall response rate to Wave 2 of the study was 94%. Of those not participating 34 had died.
- Two new data collection elements were added to Wave 2 consisting of a health assessment and an end of life (EoL) interview conducted with carers of Wave 1 participants who had died.
- Strategic harmonisation of questions with The Irish Longitudinal Study on Ageing (TILDA) have ensured that there are opportunities to compare the experiences of people with ID with experiences of the general population.
- Attention to key policy documents in Ireland have ensured that there are questions and data available to assess how the implementation of key policies is influencing over time the ageing experience of people with ID.

6.2 Target population at Wave 2

The IDS-TILDA sample was originally drawn from The National Intellectual Disability Database (NIDD) which collates information on all people with an ID in the Republic of Ireland eligible for or receiving services (Kelly & Kelly, 2007). The population included persons with all levels of ID, and the full range of residential circumstances age 40 years and over were selected, as opposed to TILDA who selected those age 50 and over. This reflects the fact that people with ID present with older age conditions at a much younger age, accounts for the lower longevity of people with ID, and ensures that there would be sufficient subjects for future waves of data collection, thus providing opportunities for insights into ageing for those who may age prematurely. The completed Wave 1 sample was 753 persons with an ID, aged 40 and older; which represented 46% from the drawn sample, comprising 8.9% of the total population of persons aged 40 and over registered on the 2008 NIDD database. Comparison with the published demographics of the 2008 NIDD cohort confirmed that the IDS-TILDA sample was also representative of the larger sample. In Wave 2, considering the impact of deaths and those lost to follow-up, the continued representativeness of the sample was also assessed (see section 6.2 for greater detail) and it was determined that the sample continued to be representative.

6.2.1 Recruitment

In 2013, IDS-TILDA interviewers contacted each of the living original 753 first wave participants, 719 individuals in all, and invited them to take part in the next Wave of the study. No active recruitment of new respondents was carried out at Wave 2.

6.3 Refinement of Protocol

Before completing the CAPI, each respondent received and completed a pre-interview questionnaire (PIQ). This questionnaire repeated a range of questions covering demographics, health status, healthcare utilisation and medicine usage with some additional detail such as gathering more complete data on dosage and frequency of medications.

Each respondent or a proxy then completed a computer-assisted personal interview (CAPI) in their own residence which included detailed questions regarding socio-demographic characteristics, physical health, behavioural health, mental and cognitive health, social participation and social connectedness, health care utilisation, employment, income and life-long learning.

The CAPI questions in Wave 2 were largely a repeat of the questions asked in Wave 1. However, reflecting input from the scientific advisory committee, Wave 1 questions unlikely to change were not repeated. Such questions included aetiology of ID, and date of birth. A number of other questions were amended to obtain further detail. A number of new questions were added to obtain greater insight into issues which emerged from Wave 1 findings, and to better ensure an ability to consider over time the impact of the implementation of strategies related to new policy directions emerging from congregated settings report, the disability strategy, and changes contemplated in the changing structure of health care delivery. In particular there has been an interest to align IDS-TILDA in ways to measure how well the lives of people with ID are reflecting the priorities of *Healthy Ireland; A framework for Improved Health and Wellbeing 2013-2025* (DoH, 2013). Some examples of new questions were supplemental questions on emerging health concerns such as constipation, dental concerns and obesity; a life events questionnaire and questions on numeracy and literacy competence, as well as questions designed to track transitions in living situations.

Throughout this process the research team also worked to ensure that opportunities for comparisons with TILDA data were not lost but rather enhanced. A total of 77 new questions were added, 16 questions were modified and a further 98 were removed (see table 6.1 for details on rationale of amendments). Prior to conducting Wave 2 interviews, all new and amended questions were then examined by focus groups of people with ID who assessed and offered insights on the most effective wording. The research team then finalized the protocol and arranged for its development as a CAPI.

Table 6.1: Amendments to Wave 2 protocol, items removed or modified and rationale.

Instrument: Pre-Interview Questionnaire		
New Questions	15	• To improve comparability with TILDA. • To extend and build on data gathered in Wave 1. • To reflect policy changes.
Modified Questions	9	• To improve flow of questions & understanding • To reduce participant burden • To clarify for analysis purposes • Some questions have been amalgamated as an extra option in other questions
Removed Questions	12	• Data already collected and will not change for Wave 2. • To reduce participant burden
Instrument: Main Questionnaire		
New Questions	62	• To improve comparability with TILDA. • To extend and build on data gathered in Wave 1. • To reflect policy changes. • To replicate government recommendations and health promotion.
	7 Objective measures	• To support the accuracy of self-report data ensure comparable analysis • To improve comparability with TILDA. • To pioneer instrument development to improve health markers for people with intellectual disability and so assist with confirming levels of both frailty and of independence. • To develop objective baseline health markers for PWID therefore enabling the identification of critical concerns in the advance of ageing.
Modified Questions	7	• To improve flow & understanding of questions • To clarify for analysis purposes
Removed Questions	86 (Which includes 2 instruments IDS-TILDA did not administer in Wave 2)	• To reduce the participant burden • Not necessary to gather a second time e.g. DOB. • Too soon to identify any significant change -may be reintroduced in subsequent waves.

An additional interview on end of life issues to be completed by carers on those who had died since Wave 1 and a health assessment were introduced at Wave 2. The carer end of life interviews are carried out for deceased participants within 6 – 12 months of death. Services notified IDS-TILDA of a death and the end of life interview was completed with a primary care giver/key worker who cared for the participant in the final stages of life.

6.4 Response rates

Of the original 753 Wave 1 respondents, 708 completed at least one element of Wave 2. As may be seen in Table 6.1, 595 participants completed all elements of PIQ, CAPI and health assessment, 104 completed the PIQ and CAPI only, 7 completed the health assessment only and 2 completed the PIQ only.

Table 6.2: Wave 2 participation.

		Frequency	Wave 1 Percent	Wave 2 Percent
Wave 2	PIQ, CAPI and Health Assessment	595	79.02	84.04
	PIQ and CAPI only	104	13.81	14.69
	Health assessment only	7	0.93	0.99
	PIQ only	2	0.27	0.28
	Total	708	94.02	100
Missing	No element of Wave 2	45	6.0	
Total		753	100	

The Wave 2 response rate is calculated as the number who completed at least one element of the Wave 2 data collection as a percentage of the original Wave 1 respondents. This yielded an overall response rate of 94.02%. The number of respondents (*N* = 708) by age, gender and level of ID is provided in Table 6.2 (a) as are the corresponding number of registrations on the NIDD in 2008 (*N* = 7381) from which the sample was originally selected. The corresponding proportions are then given in Table 6.2 (b). Although there are some differences in individual proportions the sample remains largely representative of overall NIDD figures.

Table 6.2 (a): Wave 2 response rates by age, gender and level of ID and corresponding NIDD registrations.

		Level of Intellectual Disability									
		Unknown/Missing		Not Verified		Mild		Moderate		Severe/Profound	
Age		Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
43-49	**IDS-TILDA**	6	3	2	3	17	19	45	47	29	30
43 -49	**NIDD**	37	33	26	22	373	384	592	527	451	329
50-64	**IDS-TILDA**	10	10	2	4	38	56	55	86	44	54
50-64	**NIDD**	54	24	44	25	481	483	742	822	463	422
65+	**IDS-TILDA**	2	6	5	1	14	13	28	43	16	20
65+	**NIDD**	16	13	15	10	116	148	226	280	110	113
Total	**IDS-TILDA**	18	19	9	8	69	88	128	176	89	104
	NIDD	107	70	85	57	970	1015	1560	1629	1024	864

Table 6.2 (b): Wave 2 response rates by age, gender and level of ID and corresponding NIDD registrations proportions.

		Level of Intellectual Disability									
		Unknown/Missing		Not Verified		Mild		Moderate		Severe/Profound	
Age		Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
43-49	**IDS-TILDA**	0.85	0.42	0.28	0.42	2.4	2.68	6.36	6.64	4.1	4.24
43 -49	**NIDD**	0.5	0.45	0.35	0.3	5.05	5.2	8.02	7.14	6.11	4.46
50-64	**IDS-TILDA**	1.41	1.41	0.28	0.56	5.37	7.91	7.77	12.15	6.21	7.63
50-64	**NIDD**	0.73	0.33	0.6	0.34	6.52	6.54	10.05	11.14	6.27	5.72
65+	**IDS-TILDA**	0.28	0.85	0.71	0.14	1.98	1.84	3.95	6.07	2.26	2.82
65+	**NIDD**	0.22	0.18	0.2	0.14	1.57	2.01	3.06	3.79	1.49	1.53
Total	**IDS-TILDA**	2.54	2.68	1.27	1.13	9.75	12.43	18.08	24.86	12.57	14.69
	NIDD	1.45	0.95	1.15	0.77	13.14	13.75	21.14	22.07	13.87	11.71

Table 6.2 (c) does show that there was a decrease in Wave 2 in the percentage of respondents in the youngest age group. This decrease was not unexpected as the sample was not replenished at Wave 2. A corresponding increase was also observed in the older age groups in line with the aging of the sample. Gender and levels of ID were largely unchanged.

Table 6.2 (c): Wave 1 and Wave 2 response rates by age, gender and level of ID.

	Wave 1 %	Wave 2 %
Age at Wave 1:		
40-49	38.2	28.1
50-64	45.6	51.0
65+	16.2	20.9
Gender:		
Male	44.9	44.5
Female	55.1	55.5
Level of ID:		
Mild	23.9	24.0
Moderate	46.5	46.5
Severe/Profound	29.6	29.5

6.4.1 Reasons for non-response and attrition at Wave 2

A total of 45 Wave 1 respondents did not participate in Wave 2. See tables 6.3 (a) and 6.3(b). Of these 76% (*n*= 34) had died and 24% (*n*= 11) refused to take part in at least one element of Wave 2.

Table 6.3 (a): Reasons for non-response.

Reasons for Attrition	Number	Percent
Deceased	34	76
Refusal	11	24
Total	45	100

Table 6.3 (b) examines Wave 2 attrition by age, gender and level of ID. The highest proportion (61%) of those who refused had a mild ID.

Table 6.3 (b): Attrition at Wave 2 by age, gender and level of ID.

		Level of Intellectual Disability								
		Not Verified		Mild		Moderate		Severe/Profound		
Age at Wave 1		Male	Female	Male	Female	Male	Female	Male	Female	Total
40-49	**Refusal**	0	0	1	2	0	0	0	0	3
	Deaths	0	0	0	0	2	1	3	0	6
50-64	**Refusal**	0	0	1	3	0	0	0	0	4
	Deaths	1	0	0	0	2	4	4	3	14
65+	**Refusal**	0	2	0	1	0	0	0	0	3
	Deaths	0	0	1	0	7	3	0	3	14
Total	**Refusal**	1	2	4	7	2	1	0	1	11
	Deaths	1	0	1	0	11	8	7	6	34

Note: For one participant who refused their age and level of ID were unknown

The strong retention rate achieved by IDS-TILDA may be at least partially attributed to a comprehensive post-Wave 1"keeping in touch" strategy used by IDS-TILDA which included sending greeting cards to mark all holiday occasions, organizing occasional competitions, mailing regular newsletters and providing regular updates on the IDS-TILDA website.

6.5 Field researcher training

Consistent with the approach in Wave 1, all field researchers recruited for this Wave (*n*=22) were required to have experience with people with ID and field researchers were selected from across the country to ease the process of completing interviews in a timely manner.

Attendance at three days of a standardized training was required for all field researchers and the topics covered included: 1) effective scheduling and interviewing, 2) confirming assent, 3) administering the CAPI protocol, the Test for Severe Impairment, and the mental health tools, 4) maintenance of quality and 5) confidentiality in all protocol administrations. Researchers were also trained to upload all CAPI materials to a secure share drive to be completed immediately after interviews.

6.6 Dataset

The results provided in this report are based on the IDS-TILDA dataset version 2.0.0 which comprises PIQ, CAPI and Health Assessment data from all 708 Wave 2 respondents. Various subsamples reported throughout this report are defined in the relevant sections. End of life and health assessment data will be reported separately.

6.7 Objective physical health measures

The physical health measures were comparable to those used in TILDA and included grip strength, waist to hip measurement, height, weight, Ulna length and Mid upper arm circumference, blood pressure, timed up and go, and Quantitative Ultrasound (QUS). The assessments, measures used, related equipment and rationale for their use are summarized in Table 6.4.

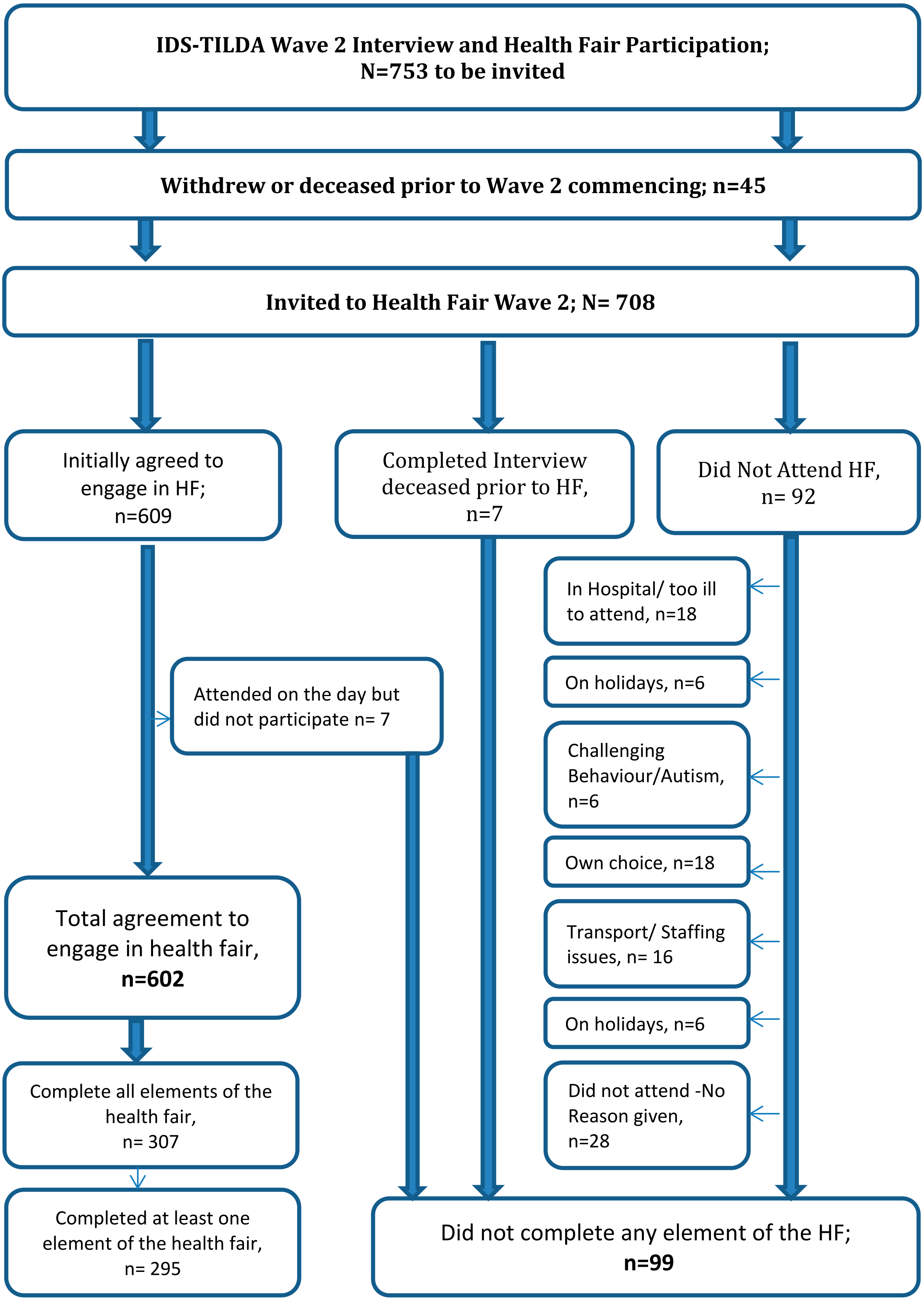
Table 6.4: Summary of assessments included in the Health Fair.

Assessment	Measurement	Equipment used	Rationale
Grip Strength	2 (alternately on each hand)	Hydraulic hand dynamometer	Diminished handgrip is associated with premature mortality, disability and other health risks of older adults.
Blood Pressure	4 (Two sitting & two standing)	Digital automated oscillometric blood pressure monitor (Omron M10-IT)	Hypertension is an important risk factor for cardiovascular disorders such as stroke, angina or myocardial infarction. Orthostatic hypotension can be indicative of unexplained falls in the elderly.
Waist size	2	SECCA tape measure	Central obesity is an indicator of the risk of diabetes and heart disease. Waist to hip ratio provides vital information on body fat distribution
Hip size	2	SECCA tape measure	Waist to hip ratio provides vital information on body fat distribution
Timed up and go (TUG test)	1	Standardised chair, tape, measuring tape and stopwatch	Assess proximal muscle strength, balance and gait speed which reflects general health and functional status.
Height	1	SECCA wall mounted standiometer	Used to calculate Body Mass Index (BMI)
Weight	1	SECCA digital floor scales	Used to calculate BMI
Bone Mineral Density	2 (right heel and left heel)	GE Achilles Quantitative Ultrasound (QUS)	Osteoporosis increases with age QUS method of assessing bone strength and osteoporotic fracture risk

Note: Not all of these measures are reported on in this report as analyses are continuing.

The scientific advisory committee, field experts and self-advocacy groups advised on effective completion of each specific measure and reviewed the accessible materials intended to promote engagement and participation. Similar to the main questionnaire focus groups of people with ID reviewed the materials and administration also.

Figure 6.1: Health Fair Attendance Flow Chart (Burke *et al.*, 2014).



All participants in IDS-TILDA Wave 2 (*N*=708) were invited to participate in the objective health assessments. In total, 609 participants agreed to take part with 7 participants changing their minds on the day (*n*=602). Of those who took part, 51% (*n*=307) completed the objective measures in their entirety and 49% (*n*=295) completed at least one measure (see *figure 6.2*).

The difficulties encountered by the participants who were unable to complete the health assessments included immobility, challenging behaviour and poor comprehension of the assessment or technique needed to complete the assessment, for example understanding the concept of the grip strength posed some of the greatest challenges for a number of participants.

Quality of assessments was influenced by location, experience of the assessor and the supportiveness of the assessment environment. Again, informed by the Scientific Advisory Committee and focus groups conducted with people with ID:

- Assessments were conducted in familiar service provider environments
- A Health Fair format was developed designed to be non-threatening and encouraging of participation
- All assessments were supported with easy read pictorial description which the health assessor used to explain and demonstrate the procedure
- Augmented and alternate communication was utilised such as ‘hand over hand’ modelling or Lamh to ensure clear understanding and promote participation
- All assessments were performed by the same assessor, someone with considerable experience in working with people with ID, using practiced standardized assessment approaches
- A preliminary feasibility study established the value of procedures and any adaptations to support participant engagement.

6.8 Analytical methods employed in this report

6.8.1 Confidence intervals and statistical significance

The majority of the estimates in this report are the percentage (or proportions) of older people with ID who fall into various groups and/or averages (mean or median) of the responses. The IDS-TILDA sample is a representative sample of the population of interest, but there is uncertainty in these estimates due to the sampling process. To reflect this uncertainty 95% confidence intervals including continuity correction are provided where appropriate. The confidence interval can be interpreted to mean in 95% of the confidence intervals in repeated sampling the true population mean will be included. Smaller confidence intervals indicate more precise estimates.

6.8.2 Weighting

Weighting was not applied in Wave 1 or Wave 2 of IDS-TILDA analyses. Table 6.5 includes the p-values for the results of a z test for significant difference between proportions of the various levels of ID in IDS-TILDA as compared to NIDD. The majority of sub categories by age, gender and level of ID did not differ significantly from the population (NIDD) from which the IDS-TILDA sample was drawn. There were, therefore, no systematic differences to be accounted for in Wave 2 estimates.

Table 6.5: P-values for test for significant difference in proportions between Wave 2 participants and corresponding NIDD proportions in 2008.

	Level of Intellectual Disability									
	Unknown/ Missing		Not Verified		Mild		Moderate		Severe/Profound	
Age	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
43-49	0.23	0.93	0.76	0.56	<0.001	<0.001	0.12	0.62	0.03	0.79
50-64	0.05	<0.001	0.29	0.34	0.23	0.16	0.05	0.42	0.95	0.04
65+	0.73	<0.001	0.01	0.97	0.41	0.76	0.19	<0.001	0.11	0.01
Total	0.02	<0.001	0.78	0.31	0.01	0.33	0.06	0.09	0.34	0.02

6.8.3 Software

All analysis presented in this report was conducted using SPSS 21.0.

6.9 Limitations of this report and future analysis

Although the IDS-TILDA sample is representative of the NIDD, it may not be fully representative of all those with an intellectual disability in Ireland as some may be unknown to NIDD data collection mechanisms which rely heavily on provider services.

The report has described the health and well-being of persons with ID as they age in Ireland. These analyses are preliminary and of a descriptive nature. Future analysis using the dataset will include more complex statistical modelling to provide in depth explorations that are outside the scope of this report.

This is the first report to document changes over time in the IDS-TILDA population. However, changes presented in this report are over a relatively short period of three years and for many measures and questions this has not been a long enough period to observe substantive change. Additional objective measures of health were introduced in Wave 2 to enhance the opportunities to better understand health status and opportunities for change consistent with the Healthy Ireland policy document desire for everyone including health disparity populations such as people with ID to enjoy the fullest physical and mental health and wellbeing. As the study matures and the numbers of waves increases, the opportunities to compare with TILDA are sustained and key policy concerns continue to be tracked, change will be measured more precisely, enabling a greater understanding of the key determinants of health and well-being of older adults with an intellectual disability in Ireland.

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