

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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