

Longitudinal report shows challenging reality of ageing with an intellectual disability

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A new report launched today by the Intellectual Disability Supplement to TILDA (The Irish Longitudinal Study on Ageing) conducted by academics from the School of Nursing and Midwifery, Trinity College Dublin, Ireland, has highlighted the serious, complex and unique health and social challenges facing Ireland's intellectual disability population.

The IDS-TILDA study is the first study of its kind in Europe and the only one in the world with the ability to compare the ageing of people with [intellectual disability](#) directly with the general ageing population.

For the first time in history, people in Ireland with an intellectual disability are growing old in considerable numbers. The IDS-TILDA Wave 2 Report, entitled Advancing Years, Different Challenges, looked at how the [ageing process](#) is affecting the physical wellbeing and mental health of the more than 30,000 people in Ireland with an intellectual disability.

Among the key findings from the report which was launched today are a marked increase in the prevalence of dementia for people with Down syndrome, particularly in comparison to the general ageing population; a range of stark findings relating to the levels of genuine connectedness to local communities among even those people with ID who had been moved to more community based residential settings as part of the Irish Government's health policy; and 50% lower rates of hypertension and three times lower rate of heart attack for people with ID compared to the general population despite having a higher risk profile than the general

population.

Dean of the Faculty of Health Sciences in Trinity and Principal Investigator of IDS-TILDA, Professor Mary McCarron said: "This is the first time in history we have ever had a population of people with an intellectual disability who have reached old age and this is something that we should celebrate. However, there are a number of very serious health concerns that we need to better understand in this population. Unless we can address some of these challenges older people with ID are likely to live a poor quality of life as they grow older and ageing in poor health is an empty prize."

Key Findings

Physical Health:

- In the three year period since the first IDS-TILDA study was conducted (in 2010), the prevalence of dementia among people with Down syndrome has almost doubled from 15.8% to 29.9%. These are much higher levels than those seen in the general population. The average age of onset of dementia for people with Down syndrome was 55 years of age with some cases presenting in their early 40's. By comparison the majority of people with dementia in the general population are over 65 years of age.
- Rates of hypertension were more than 50% lower for people with ID (17.5%) than for the general population (37%) while myocardial infarction (heart attack) was almost 3 times higher among the general population (as reported by TILDA) than for people with ID.
- Reported rates of osteoporosis among people with ID had doubled by Wave 2 from 8.1% to 16.4%. However, measurements taken during the study's health assessments found that nearly 70% of people with ID indicated poor bone health

implying a high level of under diagnosis of poor bone health among people ageing with ID.

- Over 70% of participants engaged in only low levels of physical activity, i.e., in levels of activity not likely to result in health benefits.
- Rates of overweight and obesity were 67% however over 60% perceived themselves within a healthy normal weight range.
- There was an almost 50% increase in the prevalence of cataracts since Wave 1 and macular degeneration rates almost doubled. These are higher reported rates compared to the general population.

Social participation and social connectedness:

- Family networks of older people with ID in Ireland looked very different to that of the general population- older people with ID are generally single/unmarried and without any children or grandchildren. They are far more reliant on siblings and extended family to provide family networks, especially as they age and parents pass away. In addition, most family members of older people with ID lived in different neighbourhoods than their relative with ID.
- Two thirds (66.3%) of respondents reported having trouble with reading, writing, numeracy and money management while 62.7% reported they were unable to read their own name. 32% of respondents had no education and the majority (85.7%) of adults with an ID were not currently engaged in further education.
- Regardless of age over 70% of respondents participated in social activities with staff, with those with moderate to severe ID, regardless of whether they lived in the community or an institutional setting being heavily dependent on paid staff. Movement to a community group home did not appear to change the central social role that staff play in the lives of older adults

with ID.

- Internet use grew very slightly from 7.3% to 10.5%, however, this remains far below the usage rates among the [general population](#) of 77% (CSO, 2012). Just 12.6% said that they were able to turn on a computer. Ownership of mobile phones remained essentially the same (23.8%) and continues to compare poorly with mobile phone ownership figures nationally. Less than one in 20 could send a text message.
- A significant proportion of people with ID, almost two-thirds (64.2%) either experience difficulty or else do not travel around their community at all.

Professor McCarron said: "The IDS-TILDA report provides the platform to raise the visibility, needs and experiences of people with ID as they grow older. It ensures there is evidence to underpin policy and evaluate how policy actually affects this population so that not only can we ensure that we have added years to life for people with ID as they grow old but also, and critically, that we have added life to years."

She continued: "In terms of social connectedness, our findings show that movement to the community does not necessarily equate with community integration. A change of geographical location in its own right isn't enough. The report confirms that despite often serving a higher functioning and younger population, community group home experiences in terms of community engagement resemble more traditional settings and a renewed effort is needed to ensure that community group homes are organised to support greater levels of genuine integration."

Professor McCarron concluded: "Our findings raise serious concerns for the planned movement from congregated settings of older adults with more severe and profound levels of ID and higher levels of ill health. We promised that movement to the community would improve the quality of

people's lives. Unless the community is truly organised and resourced to support ageing people with ID when there are complex health issues, their experience may instead be one of social isolation, loneliness and new forms of institutionalisation."

More information: The full report is available here:
[www.dropbox.com/s/y4hkct5m8p85o1b/IDS-TILDA
%20Report%20Wave%202%20September%202014%20-FINAL.pdf?dl
=0](https://www.dropbox.com/s/y4hkct5m8p85o1b/IDS-TILDA%20Report%20Wave%202%20September%202014%20-FINAL.pdf?dl=0)

Provided by Trinity College Dublin

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