

Aging with an intellectual disability—new longitudinal report

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Increased rates of important health screenings and access to GPs amongst people with an intellectual disability have been highlighted in a new report launched this week. These health gains, however, are potentially being offset by poorly managed chronic health problems and emerging social isolation issues amongst the same population. The report was conducted by The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) by academics from Trinity College Dublin.

The IDS-TILDA Wave 3 Report, entitled Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland, looked at how the ageing process is affecting the physical and mental [health](#) of those aged 40 years and over with an [intellectual disability](#) in Ireland.

The report marks 10 years since the inception of IDS-TILDA, which 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. The launch of the report marked the United Nations' International Day of Disabled Persons (December 3rd).

Physical and mental health:

The report found that almost half of participants rated their health as excellent/very good and over three-quarters of participants were either

satisfied or extremely satisfied with life. As well as continued high levels of access to GPs and other health care professionals, uptake of screenings for dementia, prostate cancer, cholesterol, and breast cancer now match or, in some cases, exceed that of the general population.

However, significant challenges highlighted in this report include increased levels of chronic conditions that are not always being well managed. Overall, 28.3% of participants reported that they had no teeth at all, and 67.8% of participants with total tooth loss did not receive prosthetic dentures. This compares to only 5.3% of the general population who did not receive dentures. Chronic constipation rose from 17% in Wave 1 to 43% in Wave 3, placing people with an intellectual disability at increasing risk for pain, delirium, high levels of laxative use, and even death. Dementia continues to be very high for people with Down syndrome. Despite this, 47% of those with Down syndrome and without a diagnosis of dementia had never had any dementia assessment. This is of significant concern as the mean age of onset of dementia for people with Down syndrome within IDS-TILDA is 52 years of age.

Lead author and principal investigator for the Irish Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), Professor Mary McCarron said: "People with an intellectual disability deserve the same attention as the rest of the population when it comes to how we plan, deliver and evaluate services. It's heartening to see the increased uptake of some screenings. However, significant differences in the prevalence of such chronic health conditions between the general population and people with an intellectual disability highlights the need for targeted health intervention programmes for oral health, bowel health, brain health, medication management and preventative care."

Social connectedness:

The report also highlighted serious social isolation issues faced by people

with an intellectual disability that run contrary to the ideas underpinning the decongregation policy introduced by Government six years ago. Key issues included a decrease in the rate of individuals moving to community-based settings (11.4 % in Wave 3 compared to 26.7% at Wave 2) and increased numbers of [older people](#) with an intellectual disability living further away from family compared to Wave 2.

The report also highlighted a continued reliance of older people with an intellectual disability on siblings and their families. Respondents continued to have the highest rates of frequent contacts with their mothers and fathers, but fewer still had living parents and this trend will inevitably continue as they age. A concern, according to the report authors, is that many older people with an intellectual disability lose the people with whom they have their most frequent social contacts, and this may have knock-on effects on their social participation more broadly and overall quality of life, while also raising questions about long-term living arrangements.

The report also found that a large majority of those living in institutional settings reported co-resident friends but fewer than half had any non-resident friends. This compares to a large majority of respondents living independently or with family who reported friendships outside their home. In addition, while the rate of participating in social and leisure activities had increased from Wave 1, the proportion of respondents who did these activities in their local community actually decreased. The report found little change in the use of technology and social media to enhance the social and community participation of older people with intellectual disability.

Professor McCarron continued: "We are all working hard to increase community-based moves and to improve [social connectedness](#), but the Wave 3 report has highlighted that movement over time is more likely to be about movement to settings with more supports, largely due to

changing health needs. This raises two questions: what additional community supports are needed so that people with an intellectual disability may age in place and how can we better manage chronic conditions, especially in community settings?"

"Our findings are critical for the proper planning of services as we seek to realise the fullest lives possible for people with an intellectual disability and to support people living within their communities for longer. Unless we address some of the challenges outlined in this [report](#), people living with an intellectual disability will continue to age in poor health."

Minister of State for Disability Issues, Finian McGrath, added: "The work being carried out by IDS-TILDA is providing evidence to inform education, practice and policy, to address challenges, and to enhance the lived experiences of people with an intellectual disability as they age. Ultimately, this research is changing the delivery of care for people with an intellectual disability and building a dynamic new generation of researchers and practitioners who are investigating the complex nature of ageing for people with an intellectual disability. Importantly, people with an intellectual disability are involved in informing research questions and delivering training. I am a strong advocate of people with intellectual [disabilities](#) being afforded the opportunity to manage their own lives where possible and I witness this happening on a daily basis with great pleasure. This is something that I want us to celebrate proudly as we recognise the International Day of Disabled Persons."

Among surviving participants, the Wave 3 response rate was 95.5%, a rate rarely reported in longitudinal studies, and is indicative of the level of sustained engagement between re-searchers, participants, family members, carers and the entire intellectual disability community.

Key findings:

Physical and [mental health](#):

- 28.3% of participants reported that they had no teeth at all, with 50% of those aged 65+ reporting no teeth at all. When total tooth loss occurred, 67.8% did not receive prosthetic dentures to restore function. This compares to only 5.3% of the general population without teeth who did not receive dentures (as measured by TILDA wave 3).
- Reported diagnosis of constipation increased from 17.3% in Wave 1 to 43.5% in Wave 3.
- 35.5% of people with Down syndrome had a doctor's diagnosis of dementia, which rose from 15.6% in Wave 1. However, dementia screening within the last two years rose from 14.5% in Wave 1 to 30.5% in Wave 3 for all and for people with Down syndrome from 13.9% in Wave 1 to 61.4% in Wave 3.
- Dementia screening within the last two years rose from 14.5% in Wave 1 to 30.5% in Wave 3 overall and from 13.9% in Wave 1 to 61.4% in people with Down syndrome.
- Doctor's diagnosis of osteoporosis at 21%, had increased almost three-fold since Wave 1; but remained lower than objectively measured osteoporosis at 42% reported in Wave 2.
- Objectively measured overweight and obesity increased from 66% in Wave 2 to 79.7% in Wave 3 meaning it was now similar to rates reported by TILDA for the general older population.
- Polypharmacy remained high in Wave 3 at 39.5% and excessive polypharmacy (5-9 medications) at 32.7%.
- Prevalence of depression, as measured using the GDS-LD, was significantly higher than that in the general population with 10% of participants reporting symptoms. There was no significant difference in prevalence of depression between those in institutions (11.1%) and community group homes (11.3%).

Social connectedness:

- Older people with an intellectual disability continued to be more socially excluded than their counterparts in the [general population](#); while those with severe-profound levels of ID and those living in institutional settings remain the most excluded across practically all measures.
- Overall there has been a decrease in the number of older people with an intellectual disability who live in close proximity to their family members.
- The vast majority of respondents had friends (92.4%), the most common type being a co-resident friend (71.8%); however, a majority also reported they had friends outside their home (62.0%), and a similar number reported their keyworker/support staff were their friend (62.5%).
- Just over half (56.6%) reported that they had a best friend and almost two-thirds (63.2%) said that their best friend was someone with an intellectual disability.
- The vast majority of older people with an intellectual disability continued to engage in a broad range of social activities and most do these activities within their local communities; while the most popular organisations were 'Sports, Social or Leisure Club', 'Arts or Music' and 'Advocacy Group'. 'Special Olympics' fell from the first to fourth most popular between Waves 1 and 3.
- Older people with ID continue to be dependent on others for their transport, in contrast to the general older population. Overall, 92.7% were driven as a passenger (just one person reported driving themselves), while just 29.7% used bus transport. Just over a quarter of respondents felt that a lack of transport facilities in their area affected their lifestyle (25.2%), and that they would like to use more public transport (26.7%).

More information: For the full report, please visit:

www.tcd.ie/tcaid/research/publications/reports.php

Provided by Trinity College Dublin

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