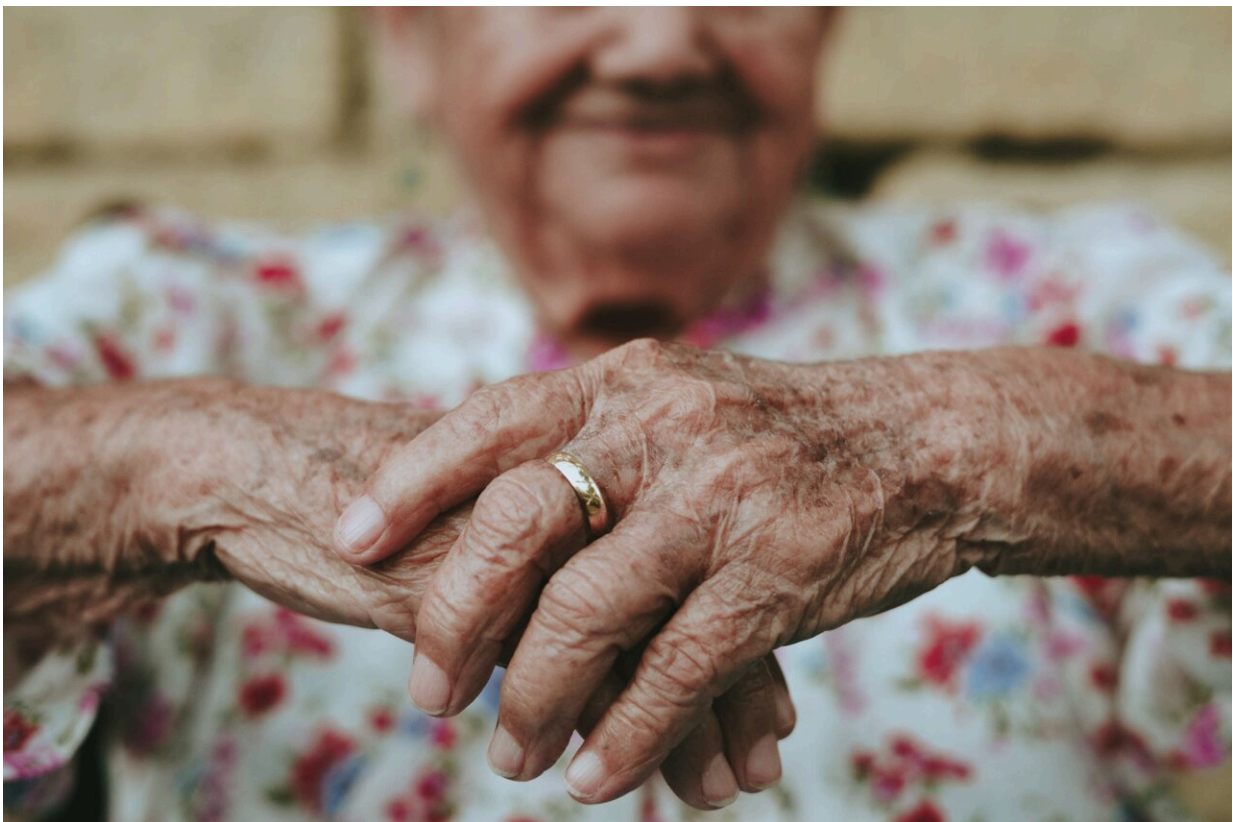


Research on aging with an intellectual disability overwhelmingly positive but concerns also found

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People aging with an intellectual disability are in better health, living in their communities, with more opportunities, and having greater control

in how they live their lives but women's health, oral health and dementia findings concerning

The release of the [Wave 5 report](#) of the Intellectual Disability Supplement to The Irish Longitudinal Study on Aging (IDS-TILDA) shows promising outcomes for persons with [intellectual disabilities](#) in Ireland, but also highlights some particularly worrying findings.

The report was launched by Anne Rabbitte T.D., Minister of State at the Department of Health and at the Department of Children, Equality, Disability, Integration and Youth.

IDS-TILDA has been formally following the lives of older people with intellectual disabilities aged 40 years and over, for the past 15 years. It has provided a wonderful opportunity to track the impact of a range of policies. Researchers led by Professor Mary McCarron, Principal Investigator, IDS-TILDA, Trinity College Dublin, consider it heartening to see people aging with ID in better health, living in their communities, with more opportunities, and having greater control in how they live their lives.

IDS-TILDA provides and will continue to provide essential evidence for the success and challenges in current policy and practice for people aging with an [intellectual disability](#). Where policy and practice need to continue to improve is also highlighted throughout the Wave 5 findings.

The total number of study participants for Wave 5 was 762. Out of those, 408 took part in all 5 Waves. For Wave 4, 214 were newly recruited, and 140 were recruited for Wave 5.

On the report, Mei Lin Yap, Ambassador Liaison Officer for Trinity Center for Aging and Intellectual Disability (TCAID), said,

"I think this report is so important because it's all about understanding how to improve the lives of people with intellectual disabilities. It's vital that we recognize the different needs, and gaps in health provision, so that we can live longer, healthier, and happier lives. And isn't that what we all want—to create a happy and healthy future together?!"

Findings to celebrate

- In 2007, 44.8% of participants aged 40–49 years were living in residential and campus-based care. In 2023, for a similar group of 40- to 49-year-olds, that figure has reduced to 7.7%.
- Many [older adults](#) with intellectual disabilities in Ireland live full social lives, with rich interpersonal relationships, and they are engaged in their communities. For example, 93.8% had friends and 76.6% had weekly contact with non-resident friends, and on average participants did over five different activities in the community each month.

There has also been a reduction in medication use, for example the use of psycholeptics (including antipsychotics, anxiolytics, hypnotics and sedatives) reduced from 56.3% to 33.9% from Wave 1 (data collected from Feb 2010 to July 2011) to Wave 5 (data collection from Sept 2022 to the end of June 2023).

- There were impressive increases in use of calcium and Vitamin D supplements in the overall population.
- We have seen a positive improvement in family contact and friendships for most participants and physical activity levels have improved, with those with moderate intensity activity reporting the best quality of life scores and being least likely to experience loneliness. Those least likely to experience feelings of loneliness were those doing moderate activity levels (34.1%), based on IPAQ (International Physical Activity Questionnaire) scores.

- The positive upsurge in the use of technology among older adults with ID during the COVID 19 pandemic has continued with 89.6% reporting access to the internet in Wave 5.

Findings of concern

- The overall physical and mental health of women is much poorer than men with an intellectual disability, with concerning increases in musculoskeletal (9.7%), endocrine (5.7%), gastrointestinal (5.1%) conditions since Wave 2.
- Women reported higher levels of loneliness than men, with 45.2% of women reporting loneliness compared with 33.7% of men. Similarly, 10.6% of women reported depressive symptoms compared with 4.3% of men.
- 6% of women had gone through the menopause, with very little support or discussion with trusted others, or a health professional. Only 37.9% reported that they had discussed the menopause with someone else.
- Dementia remained a significant concern, particularly for people with Down syndrome with 22.7% reporting the condition and an average age of onset of 53 years.

The Wave 5 study broke new ground in screening for oral health concerns and a worrying picture emerged. One in every 5 participants had no teeth at all, and this increased to 2 in 5 for those aged 65 and over. Seven out of 10 who had lost their teeth reported that they did not have dentures or other restorative options meaning increased nutrition and health concerns.

With regard to this finding, Professor McCarron said, "Some improvements, but we have a very long way to go; poor oral health impacts every aspect of our lives, physically and mentally; as one family member said 'since she lost her front teeth, people no longer stop to say

hello, and more often look at her with disgust.' This is a real tragedy. It is very concerning that so many women with ID were not able to report or even recognize symptoms of menopause, with 8 out of 10 not having received any easy read materials on what to expect or how to manage symptoms."

There are unique issues for women aging with an ID. Policy must address the 20-year longevity gap between women with an ID and women in the general population. We need a much greater focus on reducing risk with targeted brain health programs for this increasingly at risk population, and greater access to new disease modifying agents being developed for the general population."

Findings on family care-givers

The study found that most caregivers were committed and energized each day by the desire to care for their loved one; but they found care difficult, many were completely overwhelmed yet expected to be still providing at least the same level of care to their family member in five years' time.

Professor McCarron, summed up the findings: "We have been tracking the changes that de-congregation, SlainteCare, person-centered planning, changes in employment and day programming and implementation of the UN Charter on Disability promised. It is great to see progress across a number of areas with many older adults with intellectual disabilities in Ireland living full social lives, actively engaged and embedded in their communities; but health, particularly [health](#) of women with intellectual disabilities, [oral health](#), dementia, and support of caregivers must continue to be monitored."

More information: Longitudinal Dynamics in the Ageing of People With an Intellectual Disability: [www.tcd.ie/tcaid/assets/pdf/id ...](http://www.tcd.ie/tcaid/assets/pdf/id...)

[tildawave5report.pdf](#)

Provided by Trinity College Dublin

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