



# Evidence to Action: Mobilising Knowledge for Healthier Ageing

## Developing Positive Ageing Indicators for People with Intellectual Disabilities



### Delivering A More Equitable Health Policy Landscape

Ireland's *National Positive Ageing Strategy* (2013) promotes health, well-being, and quality of life. Its vision balances the many opportunities of ageing alongside the recognition that a greater degree of preparedness is required across sectors. Solidarity between the generations, as well as participation, self-fulfilment, and an ageing experience that upholds dignity are emphasised.

Within the Strategy, Goal 4 calls for the use of research on the experiences of ageing to monitor progress and inform policy responses. Since a similar commitment is included in the *Healthy Ireland Framework* (2013), a set of *Positive Ageing Indicators* was developed through the Healthy and Positive Ageing Initiative (HaPAI), a joint programme led by the Department of Health, The Atlantic Philanthropies, the Health Service Executive, and the Age Friendly Ireland Programme.

The initial *Positive Ageing Indicator Report* (2016) included data on participation, healthy ageing, and security. The authors noted that Irish Travellers and people with an intellectual disability were not adequately reflected in the indicators. The 2018 *Positive Ageing Indicator Report* introduced indicators for both groups.

This was a significant moment in Irish health policy. Supplementing the first set of indicators was aimed at ensuring that those with the poorest health outcomes were central to the national conversation on healthy, positive ageing. Additionally, given the outcomes-focus of the framework, this also demanded accountability for addressing Ireland's greatest health disparities. Minister Jim Daly, Minister for Mental Health and Older People, in the document's Foreword, identified how the knowledge emerging from research could inform future policies and refine services.

IDS-TILDA researchers were approached by the Department of Health to facilitate the development of the Positive Ageing Indicators for People with Intellectual Disabilities. Additionally, data for the baseline report were taken from the IDS-TILDA study (McCarron et al., 2011, 2014, 2017) and the National Intellectual Disability Database (2017). By involving people with an intellectual disability, their carers, and service providers in co-creating solutions, IDS-TILDA is working to improve outcomes. This case study highlights the development of the indicators and efforts to address key issues affecting people ageing with an intellectual disability in Ireland.

#### HEALTH INDICATOR TEAM:

- Prof Mary McCarron, Principal Investigator, Trinity College Dublin
- Dr Eimear McGlinchey
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- Ms Sonia McDermott
- Dr Éilish Burke
- Dr Darren McCausland
- Dr Mary-Ann O'Donovan
- Dr Rachael Carroll
- Ms Margaret Haigh
- Dr Sarah Gibney
- Ms Anne Doyle
- HaPAI Team

#### TRINITY COLLEGE DUBLIN:

- Trinity Centre for Ageing & Intellectual Disability
- Trinity School of Nursing & Midwifery
- School of Education

#### COLLABORATORS:

- Department of Health
- Health Research Board (National Intellectual Disability Database)
- Inclusion Ireland
- Prosper Fingal
- Rehab Group
- WALK

#### PROJECT FUNDERS:

- Department of Health
- Health Research Board
- The Atlantic Philanthropies
- Health Service Executive
- Age Friendly Ireland

#### IMPACT AREAS:

- Enabling the use of data to shape health policy, enhancing delivery and driving improved service provision
- Providing credible evidence to inform decisions of policymakers, practitioners and the public
- Collaborating with national and international partners to address challenges and drive innovation
- Advancing the Health Research Board's Strategic Objectives (2021-2025)

# Evidence to Action

## Enabling the use of data to shape health policy, enhancing delivery and driving improved service provision

IDS-TILDA led the consultation on the development of the *National Positive Ageing Indicators for People with Intellectual Disability*. The indicators recognise the wide range of factors associated with healthy, positive ageing and are monitored biennially, using data from existing research databases, including IDS-TILDA. The goal is to examine changes at a population level and allow Government to monitor the impacts associated with policy initiatives. A systematic approach determined which additional indicators were necessary to capture the unique aspects of ageing for people with an intellectual disability. The Delphi process for developing the indicators closely resembled the process used in the general population, with the addition of easy-read information and consultation groups.

An invitation to participate was sent to family members, carers, researchers, and academics working in the field of intellectual disability, as well as intellectual disability service providers, advocacy services, and Government departments. In Round One, 109 participants completed the online Delphi process, with 92 completing Round Two, and 79 people completing Round Three activities. In addition to the online Delphi survey, 49 individuals with intellectual disability took part in the consultations hosted in Dublin, Kerry, Tipperary, Mayo and Louth. In total, 336 individuals informed the development of the indicators. The table below captures the full set of indicators and asterisks denote additional indicators for people with an intellectual disability. The resulting framework monitors progress, supports planning, and advocates for evidence-informed policy development.

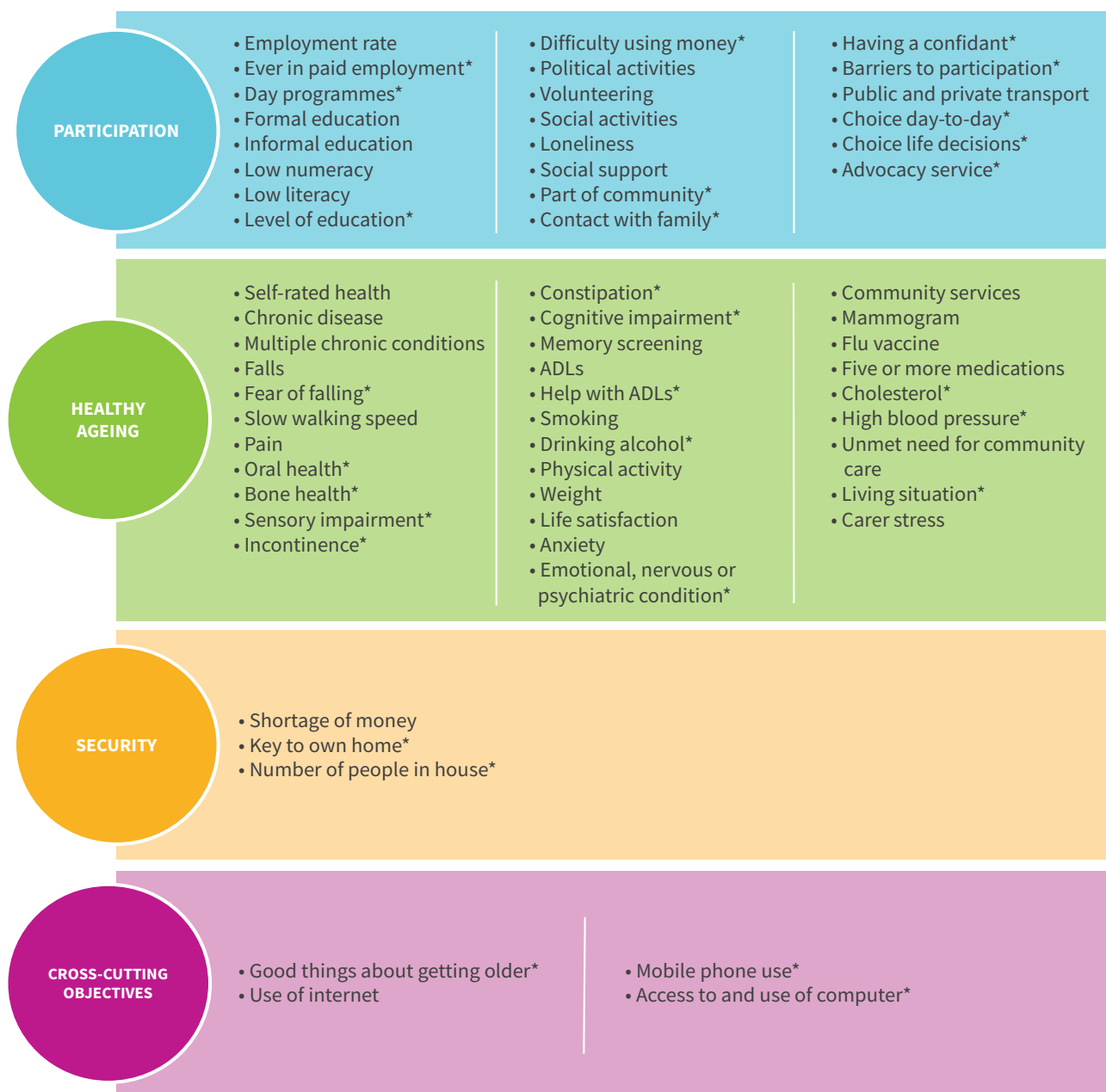


Image: IDS-TILDA led the consultation for the development of the *National Positive Ageing Indicators for People with Intellectual Disability*, 2018. The \* denotes additional indicators for people with an intellectual disability, to monitor policy impacts and progress towards goals.

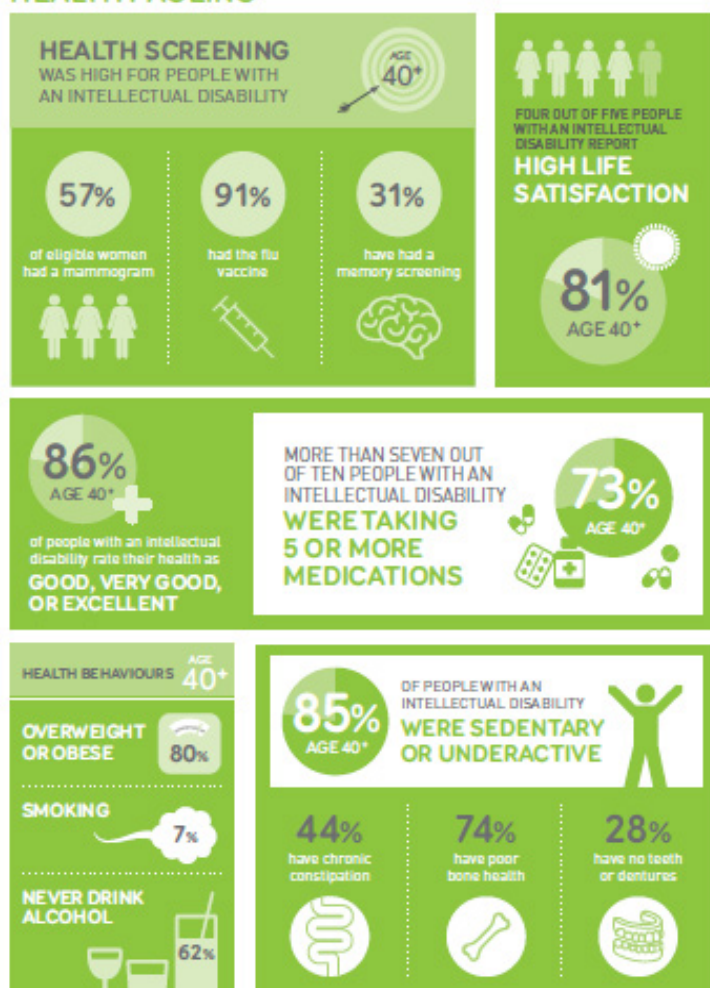


## Providing credible evidence to inform decisions of policymakers, practitioners and the public

In addition to delivering the updated indicators, the IDS-TILDA team provided the baseline data for the 2018 report, utilising data from IDS-TILDA (McCarron et al., 2011, 2014, 2017) and the National Intellectual Disability Database (2017). The data demonstrates that the ageing experience for people with an intellectual disability differs markedly from the general population. Not only is prevalence of certain conditions higher among a younger age group, different patterns of disease are also present. There are significant differences in the structure of social participation and family networks. Employment opportunities, the use of technology, and attitudes associated with ageing are troubling when compared to the general population. While some of the poor health choices that plague the general population are largely absent, such as smoking and alcohol use, high rates of overweight and obesity, alongside sedentary lifestyles, are a major cause of concern. Key opportunities were identified by the IDS-TILDA team to drive responses based on the baseline data and aligned with the *National Positive Ageing Strategy Goals*:

- To support people as they age to maintain, improve, and manage their physical and mental health, programming is required to address excessive rates of under-activity (85%) and high rates of overweight and obesity (80%). Additionally, excessive prescribing (73% of individuals are taking five or more medications daily) alongside significant levels of moderate or severe pain (42%) require better medication management.
- To enable people to age with confidence and remain in their own homes and communities for as long as possible, reasons for the very low levels of internet use (12%) and device ownership (18% tablet/computer; 22% phone) require further investigation and intervention.
- To encourage social participation and employment, skills development must address literacy problems (87%), numeracy problems (81%), and money handling challenges (79%).
- To truly advance an ageing experience that upholds the person's dignity, we must address the preventable suffering associated with poor bone health (74%) and poor oral health. For example, 28% have no teeth; of those with no teeth, 68% had never received a prosthetic device, denture, or implant.

### HEALTHY AGEING



### HOUSING



### TECHNOLOGY



### PARTICIPATION

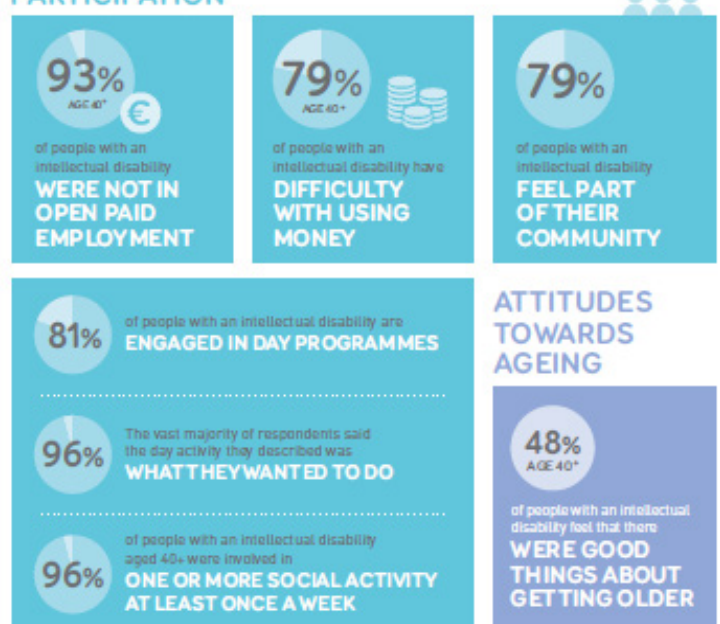


Image: The 2018 National Positive Ageing Indicators for People with Intellectual Disability included baseline data, utilising the IDS-TILDA dataset (McCarron et al., 2011, 2014, 2017) and data from the National Intellectual Disability Database (2017).

# Evidence to Action

## Collaborating with national & international partners to address challenges and drive innovation

Seeking to deliver co-created solutions that address disparities in health promotion and participation, the IDS-TILDA team secured funding and coordinated both national and international partners to deliver the following programmes, aimed at progressing the *National Positive Ageing Strategy* Goals:

### • P-PALS: Empowering People with Intellectual Disabilities as Physical Activity Leaders

In collaboration with Age & Opportunity, the University of Barcelona, and the Technische Universität München, IDS-TILDA developed the P-PALS program, which is designed to promote individuals with intellectual disability as physical activity leaders. Funded by the European Institute of Technology, the Phase 1 programme trained 15 individuals in Ireland and 20 individuals in Spain. In total, 56 P-PALS were trained, in 2020, through Phase 2 activities – 13 in Ireland, 25 in Germany, and 20 in Barcelona. More than 200 individuals attended the P-PALS Virtual Sports and Awards Ceremony, with Minister Jack Chambers TD, actor Daniel O'Donnell, and the Ladies Irish Rugby Team, who congratulated the P-PALS on their achievements.

“The P-PALS leadership course has had such a positive impact on the leaders themselves, to their peers and to the wider community. One of the leaders from the original pilot has continued to teach weekly classes to her peers and has gone on to become a national tutor to deliver a physical activity education programme using her skills to teach others in her community. Huge improvements witnessed in confidence, autonomy and overall health & wellbeing.”  
- Support Worker



Image: P-PALS are trained in games and exercises, then serve as ambassadors to encourage greater physical activity amongst peers

### • Get Wise About Your Health: Delivering Accessible Health Promotion

Aligned with the 2030 Agenda for Sustainable Development Goals 4, 8, 10 and 17, and United Nations Educational, Scientific and Cultural Organization Goals (UNESCO, 2005), which advocate for education for all citizens, the ‘Get Wise About Your Health’ project has been co-created and co-developed with people with an intellectual disability and their carers. Led by Dr Éilish Burke and funded by the European Institute of Technology, partners included Erasmus MC, Access Earth, and service providers in Ireland and the Netherlands. The aim of the project was to provide accessible health education for people with intellectual disability. The initial module, “*Get wise about going to the doctor*”, offers a key lesson, given that one in three people with intellectual disability report challenges in talking to healthcare professionals. The module prepares the individual for what to expect and how to get the most out of the experience. The second module, ‘*Get wise about your bone health*,’ provides learners with practical information about their bone health and how to improve it. Available in both English and Dutch, the resources have been accessed 400+ times, with 114 people, in Ireland, completing both modules.



Image: More than 400 learners have been encouraged to use the Get Wise About Your Health tools to prepare for visiting the doctor and to improve bone health

“Thank you for all the hard work and commitment put into this. Annmarie had a great time participating and she still speaks about it to this day. You and your team made a great impression on Annmarie, she still passes on the knowledge she gained throughout the programme.”  
- Support Worker

“Having an intellectual disability does not mean you don’t want to know anything about health or in this case about your body. I think projects like Get Wise are very suited for people to get ahead. You can also see where your interest lie. What interests me and what can I pick up from that?”  
- Get Wise Learner



## • Brush My Teeth: Preventing Poor Oral Health

People with intellectual disability develop unnecessary oral disability due to preventable diseases like gum disease, tooth decay, and tooth loss. Led by Dr Caoimhin MacGiolla Phdraig, Brush My Teeth provides accessible videos and checklists for toothbrushing without help, with a little bit of help, and with a lot of help. Resources have been accessed more than 4,200 times and guide individuals and carers on proper techniques and how to develop an Oral Healthcare Plan for better outcomes.

“Hello, I am a Speech and Language Therapist working with adults with learning disabilities in Cheshire, England. This website is my new favourite tool to help service users engage with teeth brushing! The videos are fantastic! Thank you very much.” - Service Provider



## • Accessible End of Life Planning: Dying Well

The focus of end-of-life care is to ensure comfort and support for the person who is dying to have a good death. End-of-life care planning and openness around death are essential elements, ensuring people have a sense of control and autonomy in their final days. IDS-TILDA researchers have developed an accessible planning tool to support ongoing conversations and build knowledge and confidence in managing death, so that personal choices are respected. These resources have been used widely.

“Sadly, a person we had supported for the last number of years living with dementia recently died peacefully in her community home supported by staff and community palliative care team. This person had recorded her end of life wishes using the Trinity planning document a few years ago following dementia diagnosis (with staff support). The team mentioned that the local funeral home staff were very high in their praise of the completed document as it helped them to plan the funeral in accordance with the person’s wishes. This person had no remaining family in Ireland so it was doubly helpful for the undertakers to be able to be guided by her own wishes as recorded. I just wanted to pass on the very positive feedback given for this support document to you, it is a great resource. - Service Provider

## • Massive Open Online Course: Improving health assessment for people with intellectual disability

Detecting poor health and supporting people with an intellectual disability in managing their health can be challenging for healthcare professionals. This open access course delivers valuable knowledge that learners can transfer into their daily practice on how to include people with an intellectual disability in health assessments. Structured over three weeks, the course presents practical advice and demonstrations on how to perform health assessment with reasonable adjustment. This course has been accredited by the CPD Certification Service of the Nursing and Midwifery Board of Ireland, the independent, statutory organisation which regulates the nursing and midwifery professions in Ireland. More than 6,500 learners from 76 countries have engaged with the programme.

“The course was very informative and practical. The resources and links were very beneficial. I have made some adjustments to clinics I work in and the impact has been very satisfactory from the service user’s perspective.” - Service Provider

## Advancing the Health Research Board’s Strategic Objectives (2021-2025)

Involving the intellectual disability community in the development of the indicators, delivering baseline data, and advancing accessible health promotion to address major challenges advances the following *Strategic Objectives*:

- Co-designing collaborative research with the Department of Health that is responsive to the Department’s policy needs (1.2.2);
- Building capacity and skills for the meaningful involvement of the public, patients and carers in health research (1.4.2);
- Employing innovative knowledge translation activities to provide key information in accessible formats and to optimise uptake and impact on policy and practice (2.1.5);
- Actively engaging researchers, practitioners, the public and policy-makers to build consensus and to drive change in areas of importance in health research, data and evidence (2.3.3);
- Collecting, validating and reporting essential data in the area of disability (3.2); and
- Forging strategic alliances with European and international partners to tackle global health challenges and complex societal issues and strengthen Ireland’s profile as a knowledge economy (5.1).