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HEALTHY HAPPY AGEING
The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

Evidence to Action: Responding to COVID-19

Activating Research Infrastructure to Safeguard a Vulnerable Population

Encouraging Evidence-Informed Decision-Making By Carers, Service Providers and Policymakers

When the World Health Organisation declared COVID-19 a global pandemic, in March 2020, IDS-TILDA researchers were in the field collecting data, as planned, for Wave 4 of the longitudinal study. Ireland entered its first restrictions on March 13th and all IDS-TILDA data collection was suspended in adherence with public health guidelines.

The IDS-TILDA team assessed the situation and the health threat of COVID-19 for people with intellectual disability. Given the emerging risks associated with ageing, alongside the prevalence of chronic conditions in this population, the research team felt an urgent response was required to:

- Engage with carers, service providers, and policymakers to disseminate IDS-TILDA data, providing evidence on the risk to older adults with intellectual disability;
- Elevate the voices of people with an intellectual disability in national conversations on COVID-19 responses;
- Advocate for the prioritisation of people with intellectual disability in vaccination roll-out, given health and demographic profiles; and
- Develop and implement a supplementary COVID-19 survey to monitor the impact of the virus and public health restrictions on IDS-TILDA participants.

This case study highlights outcomes from IDS-TILDA's response to COVID-19 and the team's efforts to advocate for the health and well-being of people ageing with intellectual disability in Ireland.

Image: IDS-TILDA received 300+ creative contributions from people with intellectual disability in response to the campaign to better understand COVID-19

RESEARCH TEAM:

- Prof Mary McCarron, Applicant & Principal Investigator, Trinity College Dublin
- Prof Philip McCallion, Co-Applicant & Principal Investigator, Temple University
- Dr Éilish Burke
- Dr Eimear McGlinchey
- Dr Darren McCausland
- Dr Andrew Allen
- Dr Retha Luus
- Ms Margaret Haigh
- Ms Mei Lin Yap
- Mr Gavin Dann
- Ms June O'Reilly
- Mr Michael Foley
- Ms Sarah Bowman
- Ms Holly Dennehy

TRINITY COLLEGE DUBLIN:

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

COLLABORATORS:

- All Ireland Institute of Hospice and Palliative Care
- Brothers of Charity Services
- Cope Foundation
- Daughters of Charity Disability Support Service
- Global Brain Health Institute
- Health Information and Quality Authority
- MuireÍosa Foundation
- National Federation of Voluntary Service Providers
- Saint John of God Community Services
- St Francis Hospice Raheny
- StewartsCare Service
- Tallaght University Hospital

CORE FUNDERS:

- Department of Health
- Health Research Board

IMPACT AREAS:

- Ensuring IDS-TILDA data informed strategic responses to COVID-19 by carers and service providers
- Utilising IDS-TILDA data to successfully advocate for the increased risk status and vaccination prioritisation of people with intellectual disability in Ireland
- Mobilising existing research infrastructure to provide a rapid response to COVID-19 and enabling research in Ireland and abroad
- Advancing the Health Research Board's Strategic Objectives (2021-2025)

Evidence to Action

Ensuring IDS-TILDA data informed strategic responses to COVID-19 by carers and service providers

As Ireland joined the world in responding to the first wave of the COVID-19 pandemic, the IDS-TILDA research team recognised that people with intellectual disability were particularly vulnerable to the adverse outcomes associated with this virus. IDS-TILDA data showed that they had extremely high prevalence of co-occurring diseases across the entirety of adulthood. Older people with Down syndrome were particularly at risk, as many also had preexisting cardiovascular and respiratory problems, compounded by higher rates of dementia at much younger ages. Given their smaller social networks and fewer social supports, people with an intellectual disability were particularly at risk to disruptions to their routines, placing them at greater risk for social isolation and loneliness, and poorer mental health outcomes. Many who lived at home with family co-resided with ageing parent carers, who themselves were among the higher risk groups for COVID-19. There was significant worry about how to communicate about COVID-19, advance health promotion materials, and prepare for the best health outcomes.

In the midst of a crisis which was also affecting them, IDS-TILDA researchers adapted rapidly in order to deliver reliable, trust-worthy information to guide carers and service providers, including:

- In collaboration with the Health Service Executive, IDS-TILDA created a module for clinical staff on '*COVID-19 Assessment and Recognition Among People with Intellectual Disability*,' utilising learnings from the IDS-TILDA Health Fair. Hosted on HSELanD, more than 3,750 healthcare professionals completed this module.
- In collaboration with the All Ireland Institute of Hospice and Palliative Care, the Daughters of Charity Disability Support Service, St Francis Hospice, and Tallaght University Hospital, and other organisations and services, IDS-TILDA researchers hosted a seven-part webinar series for carers and service providers, between April and May 2020, to address information gaps, attracting more than 10,000 attendees, and recordings were subsequently viewed more than 5,700 times on the IDS-TILDA website.

Utilising IDS-TILDA data to successfully advocate for the increased risk status and vaccination prioritisation of people with intellectual disability in Ireland

Engagement with policymakers occurred immediately and included the following highlights:

- IDS-TILDA was invited by the Houses of the Oireachtas to prepare a submission to the *Special Committee on COVID-19* and this was delivered in June 2020.
- In November 2020, IDS-TILDA presented to the Health Service Executive National Clinical Lead for Disability Services and other staff regarding the risks of COVID-19 to people with an intellectual disability.
- In February 2021, IDS-TILDA made a submission to Minister Anne Rabbitte TD, highlighting the case for accelerated COVID-19 vaccination for people with Down syndrome.
- Also in February 2021, IDS-TILDA provided data to support a submission by the Federation of Voluntary Service Providers to Dr Colm Henry, HSE Chief Clinical Officer, and Dr Tony Holohan, Chief Medical Officer, on the urgent vaccination needs of people with intellectual disabilities.

These representations, underpinned by more than 10 years of evidence from IDS-TILDA, helped to inform the decision by Government to classify people with intellectual disability among those at 'high risk' of COVID-19, and people with Down syndrome among those at 'very high risk'. This classification prioritised people with an intellectual disability for vaccination.

> "Just a huge word of thanks for this morning. it was so powerful to have the data to bring to our members – not only does it ground our submission for the Article 25 response to the Government Report, but I think it was also a wonderful opportunity to bring the findings of IDS-TILDA to an important audience of organisations who have direct influence in how services and supports are provided. We had very positive feedback following your presentation, so thanks again. - Dr Alison Harnett, Acting Chief Executive Officer, National Federation of Voluntary Service Providers

Evidence to Action

Mobilising existing research infrastructure to provide a rapid response to COVID-19 and enabling research in Ireland and abroad

In addition to informing the national debate on COVID-19 using IDS-TILDA longitudinal data, there was also an urgent need to provide new data on how the emerging crisis was impacting people with intellectual disability. Along with a proposal to resume Wave 4 interviews remotely using video and phone, IDS-TILDA researchers applied for ethical approval for a supplementary COVID-19 survey among Wave 4 participants. Ethical approval was granted by the Trinity College Dublin Research Ethics Committee and the newly established COVID-19 National Research Ethics Committee. Data collection resumed between May and September 2020, and included the COVID-19 questionnaire. 710 Wave 4 participants completed this questionnaire, delivering a 96% response rate, despite the pandemic.

Given the urgency for data on how COVID-19 and associated public health measures were impacting people with intellectual disability, cleaning and analysis of the COVID-19 data were prioritised and the IDS-TILDA Wave 4 report, *The Impact of COVID-19 on People Ageing with An Intellectual Disability in Ireland,* was launched in December 2020. The online event attracted more than 600 attendees and was moderated by broadcaster Olivia O'Leary. The report examined rates of symptoms and testing, morbidity and treatment, stress and anxiety associated with the pandemic, and experiences of the lock-down period. These data were supplemented with main IDS-TILDA data to explore associations with disease morbidity and other health and well-being outcomes, to consider potential predictors of symptoms and infection, and to identify differences in people's lives before and during COVID-19 restrictions (McCarron et al., 2020). Since the report launch, IDS-TILDA has continued to disseminate data on the impact of COVID-19, with two open access journal articles (HRB Open; *JIDR Open Access*) and numerous conference presentations.

> "A thousand times thank you and please keep up the good work. So important."
> - Family member of IDS-TILDA participant, COVID-19 Report Launch

THE IMPACT OF COVID-19
on People Ageing with an
Intellectual Disability in Ireland

2020

The rapid response by IDS-TILDA to adapt methods, including remote interviewing, also singled out the study as a pioneer in the field, generating interest from researchers in Ireland, the United Kingdom, Australia, and the United States. IDS-TILDA researchers met with TILDA researchers, for example, prior to their decision to implement remote interviewing for Wave 6 of the national longitudinal study on ageing among the general population. Following the first COVID-19 survey, funding was obtained by IDS-TILDA for an expanded COVID-19 survey among participants, to track the long-term impact of the virus and associated public health measures. These data and subsequent data from Wave 5 will be critical to informing the re-opening and re-building of services post-pandemic.

> "The IDS-TILDA COVID-19 survey was a real inspiration to us in the UK for the project we're doing at the moment interviewing adults with intellectual disabilities and surveying mainly family carers. We've published data from two waves of the project and we start Wave 3 in a couple of weeks. The IDS-TILDA COVID-19 study inspired me to believe what we were doing in the UK was possible!"
>
> - Professor Chris Hatton
> Department of Social Care and Social Work
> Manchester Metropolitan University
> IDS-TILDA International Scientific Advisory Board

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

IDS-TILDA's response to COVID-19 has been both swift and sustained, advancing the following strategic objectives:

- Supporting the Department of Health in advancing research actions in the *Resilience and Recovery 2020-2021 Plan for Living with Covid-19* (1.2.1);
- 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);
- Playing a leading role in stimulating dialogue with stakeholders, including the public, to respond to emerging developments in research, health and society (2.3);
- Facilitating open dialogue and debate to enable the exchange of different ideas, opinions and perspectives on emerging and important health research issues (2.3.2);
- 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); and
- Collecting, validating and reporting essential data in the area of disability (3.2).

Learn more about the IDS-TILDA response to COVID-19 at: https://www.tcd.ie/tcaid/about/covid19.php

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Evidence to Action: Transforming Health Care Delivery

Launching the National Intellectual Disability Memory Service

Addressing Service Gaps, Promoting Access to Quality Care & Delivering Better Health Outcomes through Collaboration

For people with an intellectual disability, the risk of developing dementia is five times greater than for their peers in the general population (Strydom et al., 2009). For those with Down syndrome, the risk is even greater due to genetic factors. This means that virtually everyone with Down syndrome has the hallmarks of Alzheimer's disease by age 40. In fact, research has shown an 88% risk of developing the clinical symptoms of dementia for people with Down syndrome by age 65 (McCarron, 2017).

Symptoms associated with dementia begin at earlier ages for people with an intellectual disability, therefore, efforts to promote brain health and diagnose disease also need to begin at earlier ages. Yet, data from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) shows that the rate of assessment for dementia in people with an intellectual disability is low, despite the higher risk. Of those with Down syndrome and without a diagnosis of dementia, for example, almost half had never had a dementia assessment (McCarron et al., 2017).

IDS-TILDA had informed the development of the *Irish National Dementia Strategy* (2014), and that document stressed the need for systems, structures, and age-appropriate services to promote timely diagnosis for those experiencing early onset dementia, including people with Down syndrome. IDS-TILDA hosted a working group with the National Federation of Voluntary Service Providers to identify a coordinated approach for delivering routine screening by identifying where the opportunities for intervention were. A dedicated facility, along with training and tools, were required to ensure reliable assessment, timely diagnosis, and appropriate care pathways.

In response, Trinity College Dublin, Tallaght University Hospital, and the Daughters of Charity Disability Support Services signed a memorandum of understanding, in 2020, to develop Ireland's first National Intellectual Disability Memory Service (NIDMS). Supported by the Health Service Executive, National Dementia Office, and Department of Health, NIDMS was funded through the Dormant Accounts Disbursement Fund. This case study highlights outcomes, to date, and progress aligned with national and international research and development priorities.

CLINICAL / RESEARCH TEAM:

- Professor Mary McCarron, Executive Director & Principal Investigator
- Professor Sean Kennelly, Clinical Director
- Dr Janette Tyrrell, Consultant Psychiatrist
- Dr Eimear McGlinchey, Research Lead
- Evelyn Reilly, Clinical Advanced Nurse Practitioner
- Pamela Dunne, Clinical Nurse Specialist
- Marianne Fallon, Education & Training Officer
- June O'Reilly, Strategic Support Officer
- Mei Lin Yap, Ambassador Liaison Officer

TRINITY COLLEGE DUBLIN:

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

COLLABORATORS:

- Tallaght University Hospital
- Daughters of Charity Disability Support Services

FUNDERS:

- Health Service Executive
- National Dementia Office
- Department of Health
- Dormant Accounts Disbursement Fund

IMPACT AREAS:

- Advancing the Actions of the National Dementia Strategy and Sláintecare
- Delivering a thriving research ecosystem by linking research to health service development
- Ensuring meaningful opportunities for engagement and involvement, leading to new knowledge and skills, for people with an intellectual disability, their families, carers, and the wider research community
- Advancing the Health Research Board's Strategic Objectives (2021-2025)

Evidence to Action

Advancing the Actions of the National Dementia Strategy and Sláintecare

The *UN Convention of Rights of People with Disabilities* (2006) highlighted the right of all people with disabilities to freely access the same standard of health services available to their peers *and* to access specialist health services as required because of their disabilities. Analysis of the *World Health Survey Data* by the World Health Organisation, however, noted that it was significantly less easy for people with disabilities to access health care worldwide than for their peers (Krahn, 2011). Both the *National Dementia Strategy* and *Sláintecare* promote timely diagnosis and person-centred care.

In response to the recognised service gap in the Irish context identified by the IDS-TILDA study, Prof Mary McCarron, Executive Director, and Prof Sean Kennelly, Clinical Director, brought together a multidisciplinary team which includes a Consultant Geriatrician, Consultant Psychiatrist, Advanced Nurse Practitioner, and Clinical Nurse Specialist to form Ireland's first national memory service for people with an intellectual disability. A referral from a doctor is required to access NIDMS and services include:

- Assessment of people with an intellectual disability, age 35 and up, who are worried about memory loss;
- Baseline screening and diagnosis, including differential diagnosis, for those assessed;
- An individualized Brain Health Plan targeting modifiable dementia risk factors;
- Post diagnostic supports, including educational programming on living well with dementia;
- Delivery of accessible, easy-read information and programming on how to maintain and improve brain health;
- Educational and training opportunities for people with an intellectual disability, staff and family carers; and
- Access to and enrolment in research studies.

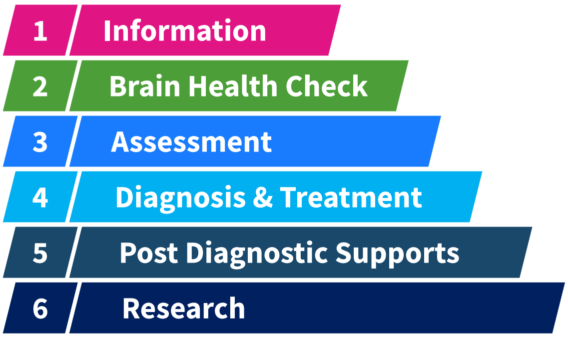

Image: The activities coordinated by the National Intellectual Disability Memory Service (NIDMS), a collaboration between Trinity College Dublin, Tallaght University Hospital, and the Daughters of Charity Disability Support Services.

Image: The Framework for Improving Quality in our Health Service, 2016, identifies the 'combined and unceasing efforts' that define Quality Improvement

The *Framework for Improving Quality in our Health Service* (2016) notes that everyone - healthcare professionals, patients and their families, researchers, commissioners, providers and educators - must each make the changes that will lead to better patient outcomes and better experiences of care, while ensuring the continued development and supports for staff to deliver quality care.

NIDMS is ensuring that people with an intellectual disability have equitable access to safe, timely, person-centred dementia assessment, diagnosis, treatment options and post-diagnostic supports. Between August 2020 and February 2021, NIDMS delivered 79 clinics, 40 consensus meetings, and 32 consultations. Based on these activities, NIDMS has collected data which supports:

- **Better Patient Outcomes:** Includes patient testimonials on positive experiences of assessment, diagnosis, and the delivery of post-diagnostic supports;
- **Better Experiences of Care:** Includes testimonials by patients, carers, and service providers on reductions in feelings of worry and stress, as well as appreciation for timely diagnoses, and the delivery of respite and support services;
- **Continued Development and Supported Staff:** Includes recognition by staff on process improvements in the delivery of care, as well as greater equity in accessing services, and changes in local practice due to engagement with NIDMS.

> "My brother received a diagnosis of dementia. I found the whole process from assessment to post diagnostic support so positive. I was listened to by the staff in NIDMS. My brother is benefitting from having the diagnosis as he now gets home care support hours. He enjoys the one-to-one time, walks and coffee with the paid carer, opening up a new social dimension he has not had previously. These few hours are also of huge benefit to letting me have some much needed time also which family carers need to keep energised to care for their loved ones 24/7 but we do not often get." - Family Carer

Evidence to Action

> “We would like to express our gratitude at having advice and support available at the end of the phone. It is so important that we can seek expert advice for people with ID and at risk of or with dementia.” - Service Provider

> “My brother-in-law attended the NIDMS for a neurocognitive assessment. We were so happy and surprised at how well he performed during the neurocognitive assessment. I felt the interaction during the assessment process was very positive. His day service said he was in the best form they have seen in a long time after his visit to the memory clinic and they phoned NIDMS to relay this. He recounted elements of the assessment to his staff and was very proud of himself.” - Family Carer

Delivering a thriving research ecosystem by linking research to health service development

Fundamentally, intellectual disability research is at the frontier of brain health research. Since the population has been largely excluded from clinical trials and other research opportunities, it requires the development of novel research techniques, alongside validation of emerging findings. Already this inclusion has yielded significant understanding, including the implication of Trisomy 21 in the production of amyloid plaques associated with Alzheimer’s disease (de França Bram et al, 2019).

NIDMS is enriching Ireland’s research ecosystem and making progress against the Health Research Board’s strategic priorities through the following actions:

- Co-creating easy-read, accessible clinical research materials *with* people with an intellectual *for* people with an intellectual disability, to encourage participation in research;
- Establishing protocols and refining work plans to assure ethics are safeguarded when working with vulnerable populations;
- Collecting baseline data on the incidence and prevalence of dementia in people with an intellectual disability, which is currently unknown in Ireland;
- Bio-banking blood samples from people with an intellectual disability, a first in Ireland;
- Developing and delivering brain health promotional campaigns *with* people with an intellectual *for* people with an intellectual disability, leveraging international funding;
- Integrating intellectual disability research into mainstream brain health research, such as Dementia Trials Ireland, to ensure access to opportunity and comparative analyses;
- Growing the research network across and beyond Ireland, including current research through the Clinical Trials Network and the Horizon 21 European Down syndrome Consortium, as examples;
- Delivering an enabling environment for researchers, including access to infrastructure, as well as datasets for use in further research; and
- Promoting and enabling the use of data to shape health policy, enhance healthcare delivery, and drive innovation.

PREVENTION

PREVENT DEMENTIA - DS
This project examines early biomarkers of Alzheimer's disease in people with Down syndrome, including cognitive, neuroimaging and blood based markers. Collaborating with the Horizon 21 European Down syndrome Consortium. Funded by the Global Brain Health Institute, Alzheimer's Society (UK), Alzheimer's Association, Wellcome Trust ISSF and Dean’s Research Initiative, Trinity College Dublin.

BRAIN HEALTH PROMOTION

BRAIN BUZZERS CLUB
In association with Down syndrome Ireland, this club creates a space to learn about and talk about brain health. Club members will also advise and input on research in brain health.

BUILDING BRIDGES
This initiative, funded by the Equality Office in Trinity College Dublin, connected people with Down syndrome in Ireland and San Francisco through a series of tea breaks focused on raising awareness of brain health and providing a platform to share tips.

ASSESSMENT & DIAGNOSIS

NIDMS CLINICAL RESEARCH
Aimed at characterising the physical and cognitive trajectories of brain health in people with an intellectual disability.

DEMENTIA TRIALS IRELAND
Integration of intellectual disability research into world-class clinical trials infrastructure to support and grow dementia intervention studies for the >150,000 people with or at risk of developing dementia in Ireland.

CAMCOG-DS2 & CAMDEX-DS 2 VALIDATIONFUNDED
In collaboration with the Horizon 21 European Down syndrome Consortium, this project is aimed at validating the use of the Cambridge Cognitive Examination and Assessment Tools for Older Adults with Down syndrome. Funded by Jerome LeJeune Foundaton.

POST-DIAGNOSTIC SUPPORT

PUBLIC, PATIENT INVOLVEMENT
Utilising ‘Voices of Experience’ in developing best practice guidelines for post-diagnostic dementia support. Funded by the Health Research Board, Health Research Charities Ireland, and Alzheimer's Society Ireland.

Image: With the goal of delivering an enabling environment to better understand brain health, NIDMS is involved in research and translational activities, aligned with four priority areas

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Evidence to Action

Ensuring meaningful opportunities for engagement and involvement, leading to new knowledge and skills, for people with an intellectual disability, their families, carers, and the wider research community

The perspectives of the person ageing with an intellectual disability and those who support them have been valued as key components in shaping service delivery. Stakeholder consultation took place between November 2020 and April 2021 and included focus groups, along with a survey entitled, *'Help us to build a good memory service: Have your say,'* to inform strategic planning and the development of key performance indicators for NIDMS.

Effective training and educational supports were flagged as urgently required during consultation. In 2021, more than 1,270 individuals registered for the four-part NIDMS masterclass series, with attendees from more than 200 service providers. Building on the success of the series, a *Training Needs Analysis* survey was distributed to attendees, which collected information on topics and preferred methods of delivery for 2021-2022. All masterclasses are developed and delivered by researchers, clinicians, people with an intellectual disability, and carers working collaboratively. This focus on co-creation assures meaningful opportunities for those involved, builds researcher and contributor's skills, and results in open access, audience-specific resources which acknowledge all authors.

> "Huge thank you to the team for the presentation recording and notes. The quality is fantastic and so valuable for my work place. These lectures are such a massive bonus to staff efforts to improve the quality of life for our residents and we are so grateful that the masterclass is accessible to us. Keep up the wonderful standards."
> - Masterclass Attendee, 2021

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

NIDMS is making progress against National and European research targets, including the following strategic objectives:

- Co-designing a new collaborative research initiative with the Department of Health that is responsive to the Department's policy needs (1.2.2);
- Supporting applied research projects, in which researchers and knowledge users come together to optimise knowledge translation into practice (1.2.3);
- Investing in clinical trials and intervention studies to drive excellence and innovation and to deliver benefits for patients, the health system, and the economy (1.2.4);
- Delivering high-quality, investigator-led research to create new knowledge that, over time, will help to address major health challenges in society and have an impact on tomorrow's healthcare (1.3);
- Involving the public, patients, and carers in HRB-funded research to catalyse cultural change by building capacity and skills for meaningful involvement (1.4);
- Collecting, validating and reporting essential data in the area of disability (3.2); and
- Taking a leadership role in progressing bio-banking infrastructure (4.3).

> "They have been so informative and have alerted me to areas I may need to be aware of in the future for my son. I was also so appreciative of the concentration and emphasis placed continually on the importance of Person Centredness in all approaches to an individual. It is absolutely essential toward respecting the dignity of the person." - Masterclass Attendee, 2021

Image: Easy-read, open access publications co-created by researchers, service providers, and people with intellectual disability, are available on the NIDMS website, reaching a global audience monthly

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Learn more about the National Intellectual Disability Memory Service at: https://www.tcd.ie/tcaid/research/NIDMS

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
- Prof Philip McCallion
- Mr Michael Foley
- 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.

PARTICIPATION

- Employment rate
- Ever in paid employment*
- Day programmes*
- Formal education
- Informal education
- Low numeracy
- Low literacy
- Level of education*

- Difficulty using money*
- Political activities
- Volunteering
- Social activities
- Loneliness
- Social support
- Part of community*
- Contact with family*

- Having a confidant*
- Barriers to participation*
- Public and private transport
- Choice day-to-day*
- Choice life decisions*
- Advocacy service*

HEALTHY AGEING

- Self-rated health
- Chronic disease
- Multiple chronic conditions
- Falls
- Fear of falling*
- Slow walking speed
- Pain
- Oral health*
- Bone health*
- Sensory impairment*
- Incontinence*

- Constipation*
- Cognitive impairment*
- Memory screening
- ADLs
- Help with ADLs*
- Smoking
- Drinking alcohol*
- Physical activity
- Weight
- Life satisfaction
- Anxiety
- Emotional, nervous or psychiatric condition*

- Community services
- Mammogram
- Flu vaccine
- Five or more medications
- Cholesterol*
- High blood pressure*
- Unmet need for community care
- Living situation*
- Carer stress

SECURITY

- Shortage of money
- Key to own home*
- Number of people in house*

CROSS-CUTTING OBJECTIVES

- Good things about getting older*
- Use of internet

- Mobile phone use*
- Access to and use of computer*

*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.*

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Evidence to Action

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.

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 Phadraig, 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

Welcome to Brushmyteeth.ie

This web site shows you how to brush your own teeth and help others brush theirs

- **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 follow*ing 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).

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Find other examples of knowledge mobilisation by IDS-TILDA at: https://www.tcd.ie/tcaid/research/dissemination.php