



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.

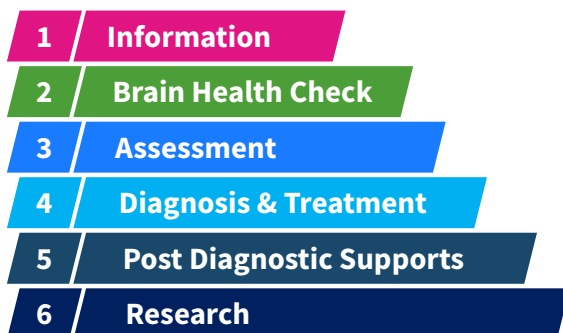


Image: The activities coordinated by the National Intellectual Disability Memory Service (NIDMS), a collaboration between Trinity College Dublin, Tallaght University Hospital, and the Daughters of Charity Disability Support Services.



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



“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 | BRAIN HEALTH PROMOTION | ASSESSMENT & DIAGNOSIS | POST-DIAGNOSTIC SUPPORT |
|---|---|--|--|
| <p>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.</p> | <p>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.</p> | <p>NIDMS CLINICAL RESEARCH Aimed at characterising the physical and cognitive trajectories of brain health in people with an intellectual disability.</p> | <p>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.</p> |
| | <p>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.</p> | <p>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.</p> | |
| | | <p>CAMCOG-DS2 & CAMDEX-DS 2 VALIDATION FUNDED 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 Foundation.</p> | <p><i>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</i></p> |

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

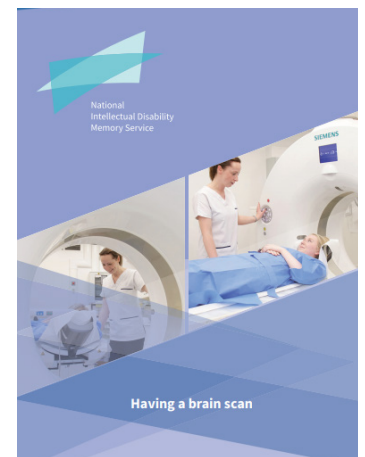
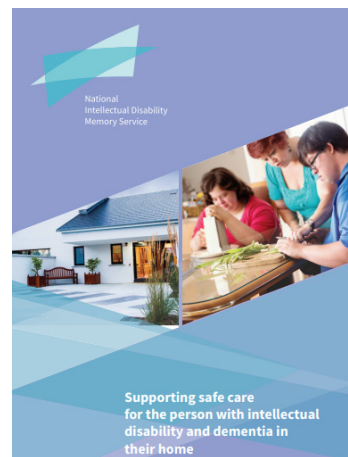


Image: Easy-read, open access publications co-created by researchers, service providers, and people with intellectual disability, are available on the NIDMS website, reaching a global audience monthly