

## CASE STUDY

# Consolidating the Work of the National Intellectual Disability Memory Service



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## INTRODUCTION

The establishment of Ireland's first **National Intellectual Disability Memory Service (NIDMS)** represents a transformative moment in healthcare, directly stemming from critical research insights gathered through IDS-TILDA (Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing). This research underscored the alarming gap in dementia assessments among individuals with intellectual disabilities, despite their heightened risk of developing the condition—particularly among those with Down syndrome.

### IDS-TILDA's data revealed -



- The risk of people with an intellectual disability developing dementia is **5 times greater** than for those in the general population.



- The risk is even **greater risk** for those with **Down syndrome**.



- The **rate of assessment** for dementia in people with an intellectual disability is **low**, despite the **higher risk**.



- **48%** of people with Down syndrome without a dementia diagnosis found it **difficult to access memory screening or assessment**.

**The findings from IDS-TILDA's data have had a significant impact, leading to the following outcomes:**



- IDS TILDA informed the **Model of Care for Dementia** in Ireland.



- The **National Intellectual Disability Memory Clinic** was established and secured **permanent funding** in the 2022 Budget.



- All people with an Intellectual Disability in Ireland with memory concerns now **have a place to go!**

The risk of people with an intellectual disability developing dementia is

**5 times**

greater than for those in the general population



**48%**

of people with down syndrome found it difficult to access a memory screening or assessment

## UN Sustainable Development Goals



Good Health



Reduced Inequalities

NIDMS delivers a person-centered approach to dementia care, providing timely assessments, diagnoses, treatment options, and support tailored for individuals with intellectual disabilities. NIDMS exemplifies the impact of translational research in improving healthcare outcomes for vulnerable populations.

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## IMPACT AREAS



### Addressing Service Gaps and Promoting Access to Quality Care

Provide equitable access to timely, person-centered dementia assessment, diagnosis, and care.



### Advancing National Dementia Strategies

The NIDMS is aligned with the Irish National Dementia Strategy and Sláintecare, and aligns with the Health Research Board's strategic objectives, enriching Ireland's research ecosystem



### Enhancing Research and Innovation

NIDMS enhances research by integrating intellectual disability studies into brain health research, establishing biobanks, and encouraging participation in research.



### Ensuring Stakeholder Engagement and Capacity Building

Ensuring collaboration with people with intellectual disabilities, their families, and carers, while offering training to enhance involvement.

## IMPACT AT A GLANCE



*"Looking at the Healthy Ireland framework, a very healthy development in the past two years has been the development of the national memory clinic for people with intellectual disabilities. People who have a potential diagnosis of dementia have access to this pathway to have their diagnosis assessed. That had been unavailable in many communities. Some parts of the country had access to memory clinic services and others did not."*

**Alison Hartnett,**  
CEO, National Federation  
of Voluntary Bodies



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### IMPACT AT A GLANCE



*“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.... These few hours are also of huge benefit to letting me have some much-needed time which family carers need.”*

**Family Member**

**338**

NIDMS  
Referrals since  
June 2021



**1774**

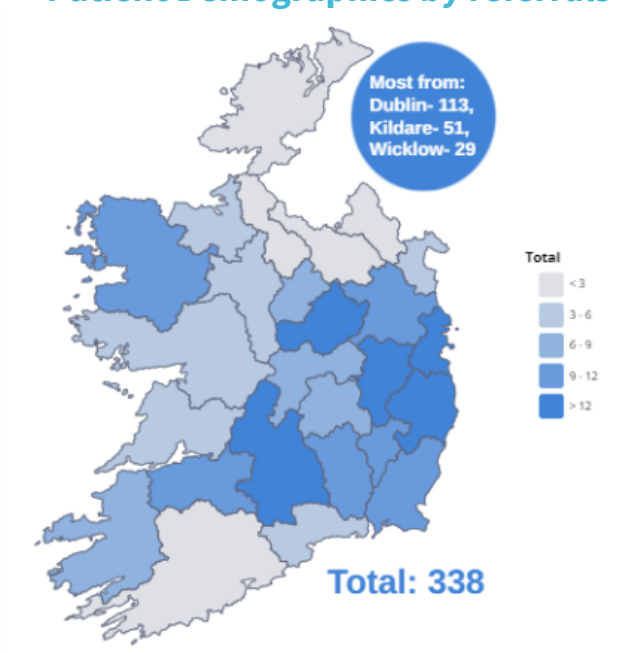
clinical  
assessments have  
now been carried  
out at NIDMS



## ADDRESSING SERVICE GAPS AND PROMOTING ACCESS TO QUALITY CARE

The National Intellectual Disability Memory Service (NIDMS) brings together a multidisciplinary team, including a Consultant Geriatrician, Consultant Psychiatrist in Intellectual Disability, Advanced Nurse Practitioners, Clinical Specialist in Occupational and Speech Therapy, Clinical Neuropsychologist, and Clinic Administrator, to provide specialist health services that result in improved patient outcomes. NIDMS offers clinical assessments to individuals aged 35 and over with an intellectual disability who are experiencing memory concerns. The service provides Brain Health Programme, baseline screening, diagnosis for those assessed, and post-diagnostic support.

### Patient Demographics by referrals



*“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**

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## ADVANCING NATIONAL DEMENTIA STRATEGIES

The NIDMS is making progress against the Health Research Board's Strategic Objectives (2021-2025)

**Delivering high-quality, investigator-led research, to tackle major health challenges in society and impact tomorrow's healthcare. (1.3)**

**Co-designing a new collaborative research initiative with the Department of Health, responding to policy needs. (1.2.2)**

**Involving the public, patients, and carers in HRB-funded research to catalyse cultural change by building capacity and skills for meaningful involvement. (1.4)**

**Supporting applied research that links researchers and knowledge users to optimise knowledge translation into practice. (1.2.3)**

**Collecting, validating and reporting essential data in the area of disability. (3.2)**

**Taking a leadership role in progressing bio-banking infrastructure. (4.3)**

**Investing in clinical trials and intervention studies to drive excellence and innovation, benefiting patients, the health system, and the economy. (1.2.4)**



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### IMPACT AT A GLANCE

1,270



Masterclass series  
attendees from  
over 200  
national service  
providers

Over

970 views

of the masterclass  
on YouTube

“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.”

Masterclass Attendee

### ENSURING STAKEHOLDER ENGAGEMENT AND CAPACITY BUILDING

The NIDMS values the perspectives of individuals aging with an intellectual disability and their supporters, recognising them as key components in shaping service delivery. From November 2020 to April 2021, stakeholder consultations, including focus groups and a survey titled, **"Help us to build a good memory service: Have your say,"** informed strategic planning and the development of key performance indicators. These consultations emphasised the urgent need for effective training and educational supports, leading to the successful NIDMS **four-part masterclass series**. All educational and training opportunities, including masterclasses, are collaboratively developed and delivered by researchers, clinicians, individuals with intellectual disabilities, and carers, providing meaningful opportunities for engagement, involvement, skill development, and the creation of open access, audience-specific resources that acknowledge all contributors.

“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