National **Dementia** Services





Newsletter

Summer 2024

Welcome

It gives me great pleasure to welcome you to this summer edition of the HSE National Dementia Services (NDS) newsletter 2024. Across the NDS team we are working on a wide range of projects to increase awareness, offer education, and improve access to services.

We are making excellent progress in our Brain Health research study and aim to start collecting data on public attitudes in relation to Brain Health in the coming weeks with results available towards the end of 2024.

In April, the Dementia Services Information and Development Centre (DSiDC) ran a very informative and thought provoking "Wayfinding in Healthcare Settings" seminar. It really highlighted the importance of well-designed facilities and buildings that can support people with dementia to live as independently as possible.

NDS recently sought expressions of Interest to form a number of Special Interest Groups (SIGs) for Post Diagnostic Support, Brain Health and Cognitive Stimulation Therapy. These groups comprise of a wide range of stakeholders including clinical and nonclinical staff across the HSE and voluntary sector. The aim of each group will be to develop exemplar pathways that promote excellence and standardisation of care across the Regional Specialist Memory Clinics and Memory Assessment and Support Services.

I am delighted to say that all six Dementia Quality Improvement, Assistant Director of Nursing posts have been filled by excellent candidates with significant experience in dementia care. These posts were funded through NSP 2022 and were originally aligned with each Hospital Group and more recently with each Regional Health Area. Their roles are critical in leading, supporting, and facilitating dementia inclusive initiatives within the acute setting and NDS look forward to working with this group over the coming years.

In this newsletter we have added a day in the life section entitled "Working Life in the Memory Harbour - a Memory Technology Resource Room" by Senior Occupational Therapist Catherine Daly. I hope you enjoy reading this article as much as I have. It's a fantastic piece highlighting the unique and valuable support that Memory Technology Resource Rooms offer people with memory problems, including people with dementia.

In terms of improving awareness and community inclusion, the Dementia: Understand Together campaign is continuing to develop in terms of engagement with communities and organisations and importantly, building on the 1000 community champions who have signed up. These champions volunteer their time to support people with dementia and their communities and do a huge amount of work in their respective communities for people with dementia. The Dementia: Understand Together Campaign is a national partnership between the HSE, the Alzheimer Society of Ireland, Age Friendly Ireland, Age & Opportunity, Dementia Services Information and Development Centre and Healthy Ireland.

Whilst we have also been steadily progressing the national rollout of the Dementia Care and Support: Homecare Education Programme, I'm delighted to announce that an independent evaluation of the programme has been completed by Dr Maria Pierce. This evaluation is extremely important and highlights the value that this programme offers to Healthcare Assistants who work in people's homes.

Finally, we have added a piece on one of our exemplar services, the National Intellectual Disability Memory Service (NIDMS). The NIDMS offers early detection of dementia in people with an intellectual disability and person centred post diagnostic supports. This really is an incredibly valuable service and huge credit must go to Prof Mary McCarron, Prof Sean Kennelly, the Department of Health, Minister Mary Butler, Tallaght University Hospital and the HSE for designing and operationalising a national service that is so well respected nationally and internationally.

I hope my introduction gives you a flavour of some of the work being undertaken by our team and you enjoy reading about these initiatives in greater detail in this edition of the NDS Newsletter. If you would like further information on any of the topics outlined in the newsletter or indeed would like to know about the on-going work of the office, please feel to contact us at dementia.office@hse.ie

- Paul Maloney Programme Manager, National Dementia Services

QUICK UPDATES

Brain Health

A crucial part of the overall approach to dementia in Ireland is trying to reduce, prevent or delay the onset of dementia in a person, by tackling modifiable risk factors for dementia.

The National Brain Health Expert Working Group is an example of a successful partnership approach between the HSE National Dementia Services (NDS), HSE Health and Wellbeing Services, the Department of Health, healthcare professionals and academia. The focus of the group is to raise awareness of brain health and dementia risk factors and link dementia with other programmes, policies and campaigns on non-communicable disease risk reduction and health promotion.

In December the group commissioned a Brain Health research study focused on women aged 18+ to

- Understand public awareness and knowledge of dementia risk factors and the importance of maintaining a healthy brain in order to reduce the risk
- Explore health behaviours in relation to brain health and dementia risk reduction, openness to them, as well as barriers and enablers
- Provide insights that help the HSE make decisions on how best to support and communicate to the public to help them reduce their risk of dementia.

The research includes expert interviews, an online survey and focus groups and findings will be available in Q3 2024.

Conferences & Presentations

- Paul Maloney (Programme manager) presented at the Engaging Dementia conference "The Model of Care for Dementia in Ireland and its implementation". This presentation outlined what the Model aims to deliver for the people of Ireland and how we aim to implement it, including recent updates.
- Together with Community Champions Emer Finn, HSE's Memory Technology and Resource Room Occupational Therapist and Fiona Crotty, Tipperary Age Friendly Programme Manager, Fiona Foley presented on the Dementia: Understand Together campaign at the Engaging Dementia International Dementia Conference. She also spoke about the campaign and social movement framework to fellows of the Global Brain Health Institute in Trinity College Dublin and to students of UCCs Msc in dementia. Members of the Irish Dementia Working Group Marguerite Keating and Kathleen Farrell spoke about the importance of inclusive communities at Boots Ireland's ESG Champion conference.
- Fiona Foley held talks on dementia inclusive communities at the Dun Laoghaire Rathdown Age Friendly Alliance, the Soroptomist Society celebration of International Women's Day in Mullingar, and in Clontarf as part of a dementia inclusive community evening.
- Mairéad Bracken-Scally presented at the Engaging
 Dementia International Dementia Conference "Support
 pathways for people with non-cognitive symptoms of
 dementia", providing information on the resources and
 education materials developed through the Implementation
 Programme for National Clinical Guideline no. 21. Rachel
 Ward delivered a poster presentation on behalf of the
 Implementation Programme team on the use of facilitator
 education in implementing National Clinical Guideline no.
 21.

Wayfinding in Healthcare Settings Seminar

This event took place in Trinity Business School on the 19th April 2024. This was a collaboration between the Dementia Services Information and Development Centre (DSiDC) and the Understand Together campaign. It is recognised that hospitals, health centres and long term care settings pose very particular wayfinding problems for the patients, public and staff who use them. A knowledgeable and engaging panel of experts from both home and abroad were invited to present. This included Professor Gesine Marquardt (Technical University of Dresden) and Lucy Richards (Studio LR and Better Company) who covered both the academic and aesthetic elements of wayfinding. The new Wayfinding Centre in Dublin was represented by Jody Morris who gave a virtual tour of this innovative space. The complexities of implementing wayfinding solutions into healthcare settings were explained to the audience by Derek Dockrell (HSE Estates), Aiden Turley (SJH) and Noel Greene (evolve). The line-up was completed by the Alzheimer Society's Saoirse Kelly interviewing Catherine Murphy Irish Dementia Working Group who gave the audience a valuable insight into the experience of wayfinding from the perspective of a person living with dementia.



Special Interest Groups

The National Dementia Workstream recently developed a high level clinical pathway for the Regional Specialist Memory Clinics (RSMC) and Memory Assessment and Support Services (MASS). The pathway is divided into three segments:

- Phase 1 Identification of Symptoms and Initial Assessment
- Phase 2 Diagnosis & Management
- Phase 3 Post Diagnostic Support

As an expansion of Phase 3, NDS sought expressions of Interest for the below Special Interest Groups (SIGs).

- Post Diagnostic Support
- Brain Health
- Cognitive Stimulation Therapy

All three SIGs have held an initial meeting with great enthusiasm shown by all. The SIGs are made up of numerous stakeholders who are currently working in RSMCs, MASS, NDS, wider HSE and voluntary services.

The primary aim of the groups will be to design nationally agreed, exemplar pathways across all RSMC and MASS in relation to Post Diagnostic Support, Brain Health and Cognitive Stimulation Therapy. The SIG will offer frontline staff the opportunity to share their expertise and influence the design of these pathways based on existing research and clinical experience. The SIGs will also work in partnership with any national committees/groups on subject matter of commonality. The pathways developed by these SIGs will be implemented by existing and future RSMC and MASS to share locally developed programmes that could be utilised and scaled nationally across RSMC and MASS sites.

Dementia Quality Improvement Assistant Directors of Nursing

An Assistant Director of Nursing, Dementia Quality Improvement has been appointed to each Hospital Group to lead, support, and facilitate dementia inclusive initiatives within the acute setting in collaboration with our community partners, and aligning with the National Dementia Services' initiatives.



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WORKING LIFE IN THE MEMORY HARBOUR

A Memory Technology Resource Room by Senior Occupational Therapist Catherine Daly

Senior Occupational Therapist Catherine Daly brings us through a typical day for her in the Memory Harbour based in Clonskeagh.

No two days are ever the same at the Memory Harbour in Clonskeagh because no two people are the same, and everyone affected by memory problems or dementia have their own unique lived experience of the condition. The Memory Harbour is one of 26 Memory Technology Resource Rooms nationwide, where Occupational Therapists provide post-diagnostic support to people affected by memory problems and dementia.

Over the course of a typical week, I will provide individual consultations, deliver group work, manage my administration and waiting list, respond to telephone and email queries, support carers through the organisation of carers' talks, support colleagues and facilitate visits to the Memory Harbour and network with interested organisations around brain health and living well with memory issues.

At an individual consultation, as an Occupational Therapist I am most interested in how the person is functioning and where their memory concerns may be causing them issues. Together, with the person and their family member, we will problem solve so that the person can continue to live their life in the way that they wish. Three key things are important for me in helping someone to live with memory issues - "I am still me", "I can understand", "I can manage". In every interaction I have, I am aiming to ensure the person continues to feel like themselves by doing things that bring them meaning; that they understand that memory is a process, where their strengths are and what their diagnosis means, and that they have a roadmap for managing their memory issues. Some of this work involves the introduction of technology where it's appropriate, but mostly, it is our Occupational Therapy therapeutic skills that are used. My aim is that they leave with a plan about what they can do to maintain their brain health and the hope that they can live their life well.

Group work involves delivering cognitive rehabilitation techniques over a number of weeks and meeting other people who are experiencing similar issues with their memory. In essence, the aim here is to rehabilitate people's spirit, not just their cognition, and help them feel better about their memory as well as providing practical information on how they can support their memory. Feeling better about your memory and finding the right activities or community supports, is crucial in reducing the inclination to isolate oneself when experiencing memory difficulties. We know from a brain health perspective, that social connection is one of the most important powerful actions you can do to maintain your brain health.

Here at the Memory Harbour, with my colleague Gillian Dullea, we've prioritised our Harbour Friends programme which is a therapeutic group programme, co-created with clients affected by Younger Onset Dementia. Through collaboration and partnerships, we are delivering a bespoke programme and respecting the HSE values of right care, in the right place and at the right time.

So, one day is never the same as another and that's what makes this job challenging and rewarding. We may have technology in our title, and we do facilitate that, but overall, we aim to provide a direction and a sense of hope that life continues, and can be lived well, when memory concerns or dementia become part of it.

EDUCATION & TRAINING

Utilising a co-production approach to strategically plan dementia education for diverse populations in Ireland

The Assistant Directors of Nursing Dementia Quality Improvement and Deirdre Lang, Director of Nursing/National Lead Older Persons Services, supported by the National Dementia Services are currently reviewing national dementia education programmes in Ireland.

These programmes span all care groups and areas of work, including a 4-hour programme, a 2-day programme and HSeLanD modules. However, there is concern that these programmes may not meet the needs of modern learners or be impactful for care delivery. Adopting a co-production approach in designing dementia education initiatives is essential to ensuring that these programmes effectively inform healthcare professionals' attitudes, beliefs and care practices, meeting the needs of people from diverse populations and cultural backgrounds.

This initiative consisted of two key components. Firstly, a dementia education online survey for facilitators of national programmes to ascertain the benefits, challenges and impact on care practices. Secondly, a national event using World Café methodology to share insights and ideas, and co-produce a vision for advancing dementia education in Ireland. Primary stakeholders included individuals living with dementia, their advocates, and delegates from various demographics and cultural backgrounds.

Key themes that emerged include the significance of understanding the lived experience and recognising diversity and cultural differences. Additionally, there is a need to explore various teaching and delivery methods, such as incorporating technology, simulation, and a tiered approach. Challenges identified include staff turnover, difficulties releasing staff from clinical areas and organisational culture.

Next steps involve developing a preliminary report from the World Café event and facilitator survey. This will be forwarded to interested parties for further review and feedback. A working group will be established to design the future direction and content of national dementia education programmes. Crucially, people living with dementia and their supporters are at the heart of planning and decision-making processes in designing dementia education initiatives.



The six Dementia Quality Improvement ADONs at the World Café event with Deirdre Lang, Seán O'Dowd and Paul Maloney

THE DEMENTIA CARE AND SUPPORT HOME CARE WORKER PROGRAMME

Training and Education is a priority action area in The National Dementia Strategy 2014. It highlights the need to develop and facilitate education and training for health care staff, for families, for carers and for the general public (DoH,2014). This is to ensure that those who provide care or who interact with people with dementia have the skills, competency and confidence to preserve personhood and provide appropriate care and support. The Dementia Care and Support Home Care worker programme was designed to address this need.

The programme has been designed by National Dementia Services and DCU in consultation with people living with dementia, family carers and experienced healthcare staff from all levels of community care. The team then worked in partnership with Irish Times Training to accredit the programme as a QQI level 5 award.

The target learners for the programme are Health Care Support Assistants working with people living with Dementia. The overall approach is that the learner is not only learning about the illness but also about themselves, their ability to recognise stress, practice self-care, establish and maintain boundaries, to build relationships of trust, develop ethical approaches and fundamentally take a strength-based, rather than loss-based approach to Dementia care. The new programme aims to develop skilled, reflective and self-aware Health Care Support Assistants who are equipped to care for people with dementia with humanity, empathy, and dignity, so that they may live well for longer in their own homes and communities.

Three pilot areas were chosen for the initial delivery of the programme, CHO One, Four and Five. 149 participants completed the initial pilot phase and secured their QQI award. Upon completion of the pilot phase it was felt that some changes needed to be made to the programme prior to further roll out of the training. Dr Maria Pierce, University College Dublin carried out a Process evaluation of the programme. The final report outlined a number of recommendations regarding the future rollout of the Dementia Care and Support Programme, some of which are outlined below:

- 1. Address challenges associated with the supervisory element of the programme
- State and clearly define the roles and responsibilities of all organisation's and stakeholders involved in the implementation of the programme
- The NDS should not have any responsibility for the day-to-day operations of implementing the programme and its role restricted to strategic planning, oversight, monitoring, review and evaluation.
- 4. Encourage and support the development of a strong organisational ethos supporting continued training and education, included dementia-specific education, for HCSA's within the HSE and among approved home support providers.

Participants and Local Managers reported that the programme was very positive and supportive. "So there is an absolute need that we continue this programme," "100 percent. I would welcome it again in the area"

The National Dementia Service was also successful in securing funding for the national rollout of the programme. This rollout has already commenced with several areas currently undertaking the training and expressing an interest in delivering the programme. National Dementia Services would like thank all those who participated in the pilot phase of the programme, those who participated in the evaluation and in particular Dr Maria Pierce for all her work and commitment to this evaluation.

DEMENTIA: UNDERSTAND TOGETHER

Inclusive community awareness thriving across the country

HSE staff and partners are continuing their support for the Dementia: Understand Together campaign by connecting with local Dementia Alliances, and supporting actions such as dementia and brain health awareness events across the country.

In Mullingar, an event was organised to celebrate International Women's Day in partnership with the Soroptomist Society. Over 100 people attended to find out about the impact of brain health on our health and wellbeing and how staying socially connected and engaged in community life can make all the difference.

The event was hosted by Sarah McCormack, National Healthy Ireland lead. Guests including many health care professionals from the Midlands region, heard from Cathy McHale, Registered Advanced Nurse Practitioner in the Institute of Memory & Cognition of Tallaght University Hospital, Kim Tully, Chief Executive of Engaging Dementia, and Fiona Foley, senior project manager with the National Dementia Services.

In Cork, Sheena Cadoo, Occupational Therapist at HSE Cork Kerry Community Healthcare's Memory Technology Resource Room in Mallow, colleagues Margaret McEntee and Marguerite Doran, and Ber O'Leary from Kanturk Community Hospital helped to run an event aimed at raising awareness for dementia and giving some practical advice to individuals, groups and local businesses about how they can build a Dementia Inclusive Kanturk. The evening was introduced by Michael Moynihan TD, speakers also included Dr Siobhán Fox, Lecturer at the Centre for Gerontology and Rehabilitation at University College Cork along with local resident Kevin Quaid, Chair of the Irish Dementia Working Group and Amy Murphy, Dementia Advisor from The Alzheimer Society of Ireland.

In Bantry businesses, services and residents came together as part of the Bantry Dementia Alliance to make Bantry dementia inclusive. A memory café has been established, dementia awareness trainings and information campaigns have taken place. Over the past few months, consultation with the wider Bantry community has begun to broaden the focus of their work. Following on from the very practical actions the wider community is exploring further ideas about how they can continue to include people living with dementia and their families. You can follow the Bantry Alliance on Facebook here.

Dementia Inclusive Listowel held a Memory Wellness evening with a focus on dementia. The audience listened to expert speakers on ways to look after your brain health and on dementia. They received practical advice from local services about supporting yourself and loved ones.



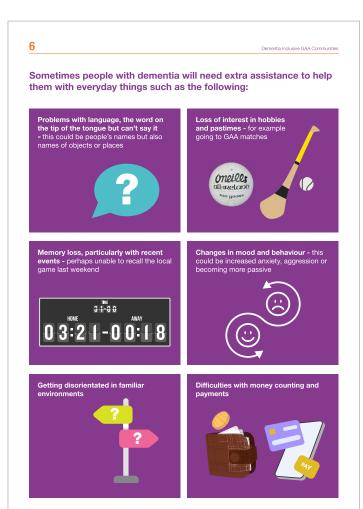
Members of the Dementia Inclusive Listowel Inter-agency group at the Memory Wellness & Dementia Awareness evening.

DEMENTIA INCLUSIVE COMMUNITY SUPPORTS AND RESOURCES

Dementia Inclusive GAA Communities booklet

The Dementia Friendly Tralee Interagency Group was established in May 2019 with the aim of raising awareness of dementia in the community and to encourage everyone to share responsibility for ensuring that people with dementia felt understood, valued and able to continue to contribute to their community. Kerry GAA are one of the very active participants on this group and want to encourage people with dementia to continue to be part of this community. One of the first initiatives undertaken by Kerry GAA in support of this was the delivery of dementia awareness training to both the Health and Wellbeing committees in 2020, and to club stewards from Austin Stack Park and Fitzgerald Stadium in 2022. Following on from the positive feedback of the training, and in response to a request for a user-friendly guide for clubs, Dementia Friendly Tralee in consultation with the HSE and Kerry GAA produced the Dementia Inclusive GAA Communities booklet.

The guide contains tips on communication that will enhance interaction with those with memory difficulties, and practical advice on making the physical environment dementia inclusive. It provides solutions on how GAA clubs can support those with memory difficulties to continue to contribute to their local GAA communities—whether that is through attending matches or volunteering if they choose to. Kerry GAA want to encourage people with dementia to continue to be an active apart of the GAA. The HSE's Dementia: Understand Together campaign team contributed to the production of the booklet and are looking forward to helping to promote the resource to partners and champions nationwide as an example of best practice.



YOUNG ONSET DEMENTIA PILOT PROGRAMME

The Wexford Dementia Alliance was convened in 2019. Presently. this group consists of over 30 members of statuary and nonstatuary bodies. In line with the national dementia strategy, one of the alliance's objectives was to create Dementia Friendly Communities. The purpose of this alliance was to encourage more collaboration between non-governmental organisations (NGOs) and local services, and ensure that there is a better awareness, understanding, and sensitivity throughout the local community about the needs of people with dementia. Through collaboration of alliance members a pilot project was rolled out for people diagnosed with Young Onset Dementia. This initiative used already existing services where facilitators had previously undertaken dementia awareness training. The programmes were adapted to meet the needs of this group. Focus groups with people living with dementia were established during which they outlined the activities they wished to include as part of this project. In total there were 6 people living with Young Onset Dementia in the group. The first activity was meeting up for walks by the beach/forest walks and this was supported by the Health Promotion team. This continued over a period of 3 months, with the local Garda supporting this initiative by providing transport on one of the day trips to Avondale. It was great for the community to get behind this initiative. The feedback from the group was fantastic, they felt included in their community and had a voice as they were part of the co-design of what this pilot should look like. Group members met with their peers who were non-judgmental and understood each other's experience on their journey with dementia. One group member commented 'I'm now not afraid to speak'. Family feedback was very positive. They could see their loved one's confidence growing as they had their specific group and activity belonging only to them. Going forward the goal is to provide a supportive therapeutic space where clients can meet their peers. The primary aim is sustainability. As a community where everyone collaborates with existing services supported by dementia awareness training, creating inclusive services will be the norm instead of the exception.

We all know the importance of engaging with people in communities to talk about dementia, the risk factors associated with developing dementia and to inspire people across the country to come together to create inclusive communities. If you'd like to share your local dementia initiatives, please email the campaign team at understandtogether@hse.ie or to find out more about the campaign visit www.understandtogether.ie

INFOGRAPHICS ON PSYCHOTROPIC MEDICATIONS AND NON-COGNITIVE SYMPTOMS OF DEMENTIA

As part of the Implementation Programme for National Clinical Guideline No. 21 (Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia), an information guide was developed for people living with dementia and their family carers and supporters. This is available in both Plain English and Easy Read format. The Implementation Programme team have recently launched three infographics to accompany the information guide. Each infographic aims to convey a key message from the guide and signposts to additional information within the guide. These will serve as important resources for people living with dementia and their family carers and supporters, as well as staff providing care to people with dementia.



What are psychotropic medications and what are the benefits and risks of these in people with dementia?

These are drugs that act on your brain and can influence your emotions, your mood, or your behaviour. Some psychotropic medications may help cognitive or non-cognitive symptoms of dementia. All medications can cause side effects. These vary between the different types of psychotropic medications, and also vary from person to person. Side effects might include: drowsiness and confusion, poor balance and falls, weight gain and diabetes.



Scan the code for more information in Plain English



Scan the code for more information in Easy Read





Why might I be prescribed a psychotropic medication for my non-cognitive symptoms of dementia?

Your healthcare provider should explore your non-cognitive symptoms to see if they are due to dementia or another reason. For example, you may be in pain, be constipated, or have an infection or vision or hearing problems or find it hard to sleep.



Scan the code for more information in Plain English



Scan the code for more information in Easy Read format Healthcare professionals should only consider psychotropic medication when:

- · other approaches have not worked
- · you are in severe distress
- · you are likely to hurt yourself or others
- where possible, its use aligns with your previously expressed wishes and preferences

It is very important for your healthcare provider to support you to try other approaches before using medication.



Have you asked for a review of your psychotropic medications prescribed for dementia?

When psychotropic medications are started, it is likely that your healthcare provider will arrange a review after a short interval to check your response. They should reassess your condition regularly to see if you still need the medication and if there are any side effects. Some patients need to use psychotropic medications long term and some do not. At a review, your healthcare provider should let you know if you need to continue the medications and why. Contact your healthcare provider immediately if you think a medication is making you unwell.



Scan the code for more information in Plain English



Scan the code for more information in Easy Read format



THE NATIONAL INTELLECTUAL DISABILITY MEMORY SERVICE (NIDMS)

The National Intellectual Disability Memory Service (NIDMS) is committed to improving the early detection of dementia in people with an intellectual disability and offering post diagnostic supports. People with an intellectual disability, particularly people with Down syndrome, are at increased risk of developing dementia as they age.

The NIDMS provides access to a Brain Health Clinic and to specialist assessment and comprehensive diagnostic work-up for memory concerns.

Based at the Centre for Memory and Cognition at Tallaght University Hospital, NIDMS was established as a collaboration between Trinity College Dublin, Tallaght University Hospital and Avista. In 2023, there were 497 appointments attended from 25 counties throughout Ireland.

The interdisciplinary team at the NIDMS consists of a clinical director, an executive director, a consultant psychiatrist, Advanced Nurse Practitioners, a clinical specialist occupational therapist, a principle neuropsychologist, a clinical specialist speech and language therapist, and a clinic administrator who provide:

- Support to people who are worried about memory loss problems
- Baseline screening for people with Down syndrome and other intellectual disabilities
- · Diagnosis, including differential diagnosis
- Information on improving and maintaining good brain health
- Dementia treatment information including the preventative use of anti-dementia drugs
- Sensitive and honest discussion of diagnoses with the person/carer in accordance with their wishes
- Formal feedback and follow-up reports to the person's GP or doctor
- Post diagnostic support including easy access information and training/education on living well with dementia
- Access to and enrolment in research studies and clinical trials.

"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" - Family member.

"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

The NIDMS further advances the National Dementia Strategy priorities by offering webinars and other trainings for staff and family carers, developing easy read materials in collaboration with people with an intellectual disability, piloting and delivery of evidence-based supportive brain health and post diagnostic interventions, and exploring biomarker and other innovative additions to available assessments targeting persons with an intellectual disability.

NIDMS is further enriching Ireland's dementia care ecosystem by supporting memory clinics and dementia supportive services being offered by intellectual disability providers throughout Ireland and by encouraging participation in research through:

- Co-creating easy-read, accessible clinical research materials with people with an intellectual for people with an intellectual disability,
- Establishing protocols 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,
- Bio-banking blood samples from people with an intellectual disability, a first in Ireland,
- Leveraging international funding for brain health promotional campaigns with people with an intellectual disability for people with an intellectual disability,
- Integrating intellectual disability research into mainstream Dementia Trials Ireland brain health research to ensure access and comparative analyses,
- Growing the research network collaborating with the Clinical Trials Network and the Horizon 21 European Down syndrome Consortium,
- Ensuring data collected shapes health policy, enhances healthcare delivery, and drives innovation.

Prof Sean Kennelly Clinical Director

Prof. Mary McCarron Executive Director



Pictured are Prof. Mary McCarron (Executive Director) and Prof Sean Kennelly (Clinical Director) of the NIDMS

National **Dementia** Services





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