



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

IDS TILDA drives Evidenced Informed Policy and Service transformation for People Ageing with an Intellectual Disability and Dementia in Ireland

Professor Mary McCarron

Principal Investigator, IDS-TILDA

Director, Trinity Centre for Ageing and Intellectual Disability, Trinity College Dublin

Executive Director, National Intellectual Disability Memory Service

24 June 2021

@ageingwithID

#ageingwithID



Trinity Centre for Ageing and Intellectual Disability

Our Vision and Mission

VISION

Enhanced health, wellbeing and quality of life for people with intellectual disability as they age.

MISSION

Our Centre aims to address the inequalities and health disparities that occur for people with an intellectual disability as they age. We do this by conducting rigorous engaged research on the physical and social determinants of health and well-being, and translating findings to inform models of policy and practice.



Trinity celebrates International Day of Persons with Disabilities, each December 3rd



IDS-TILDA

Joins the Global Family of Longitudinal Studies



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





IDS-TILDA

Objectives



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

- **To understand the health characteristics** of people ageing with an intellectual disability;
- **To examine the service needs and health service utilization** of people ageing with an intellectual disability;
- **To identify disparities in the health status** of adults with an intellectual disability as compared to TILDA findings for the general population; and
- **To support evidence-informed policies, practices and evaluation.**



IDS-TILDA Participant Involvement

“Nothing about us, without us”



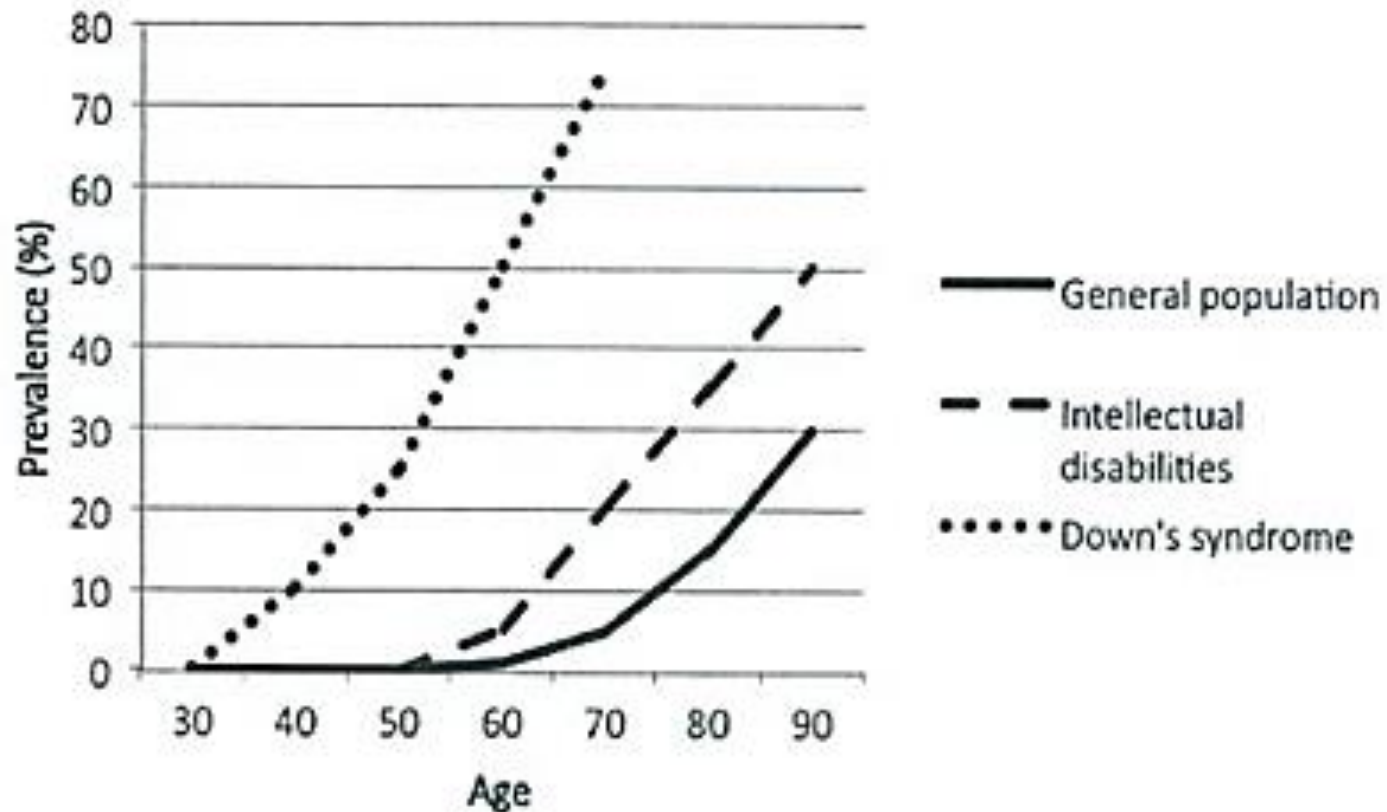
The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)



Prevalence of dementia

The background of the slide is a photograph of Trinity College Dublin, Ireland. The image is heavily filtered with a blue color. In the foreground, a large, spherical sculpture made of many small, dark, rectangular pieces is visible. The building behind it is a multi-story stone structure with many windows. The overall scene is a street view of the college.

Prevalence of dementia in people with Down syndrome

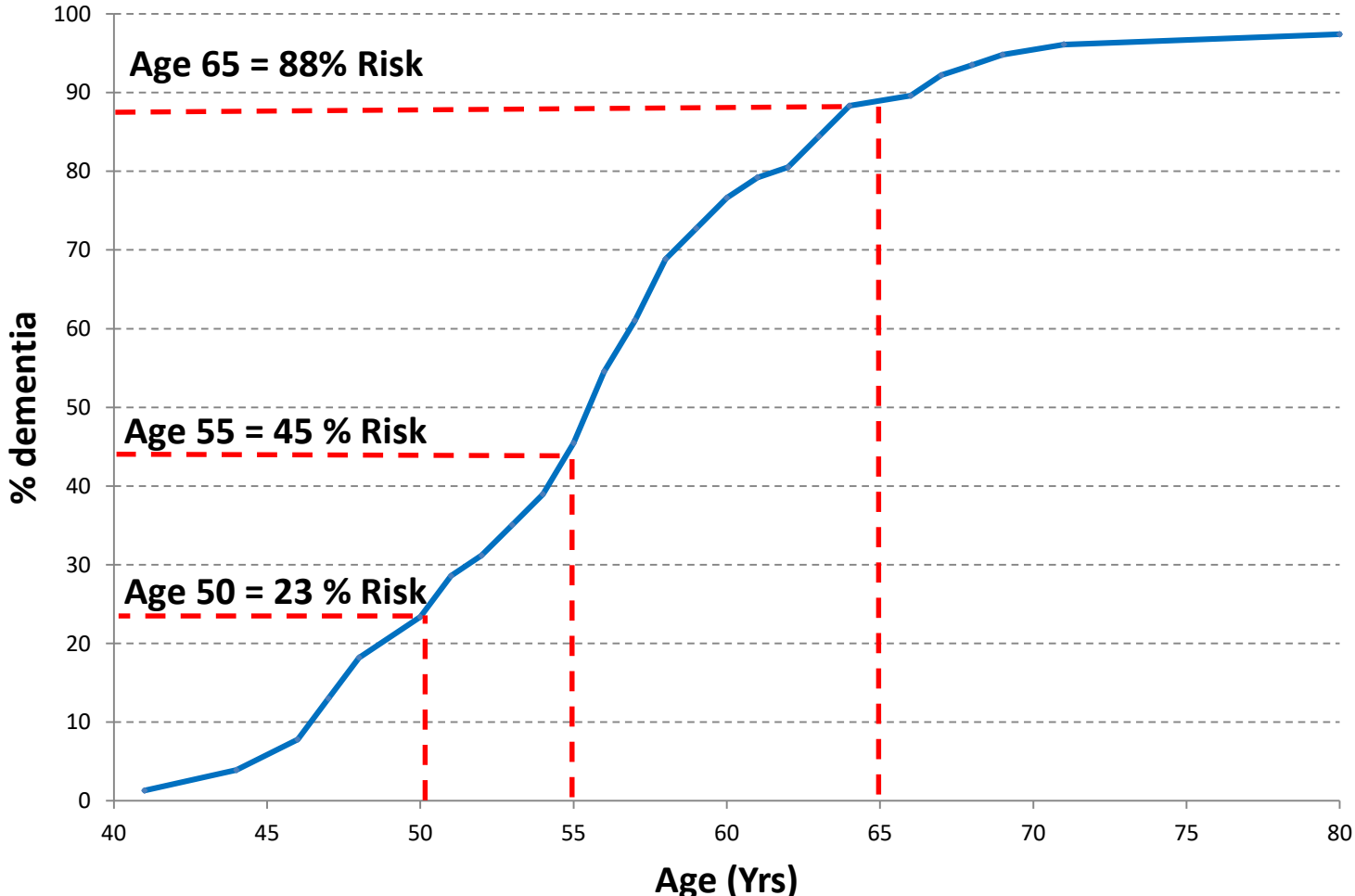


The incidence of dementia could be up to **five times higher** than in people without ID (Strydom *et al*, 2013)

Much higher rates in people with Down syndrome (McCarron *et al*, 2014, 2016; Strydom *et al*, 2010,)

Ageing with Down syndrome

Risk Trajectory by Age



JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

Journal of Intellectual Disability Research doi: 10.1111/jir.12390

843 VOLUME 61 PART 9 pp 843-852 SEPTEMBER 2017

A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome

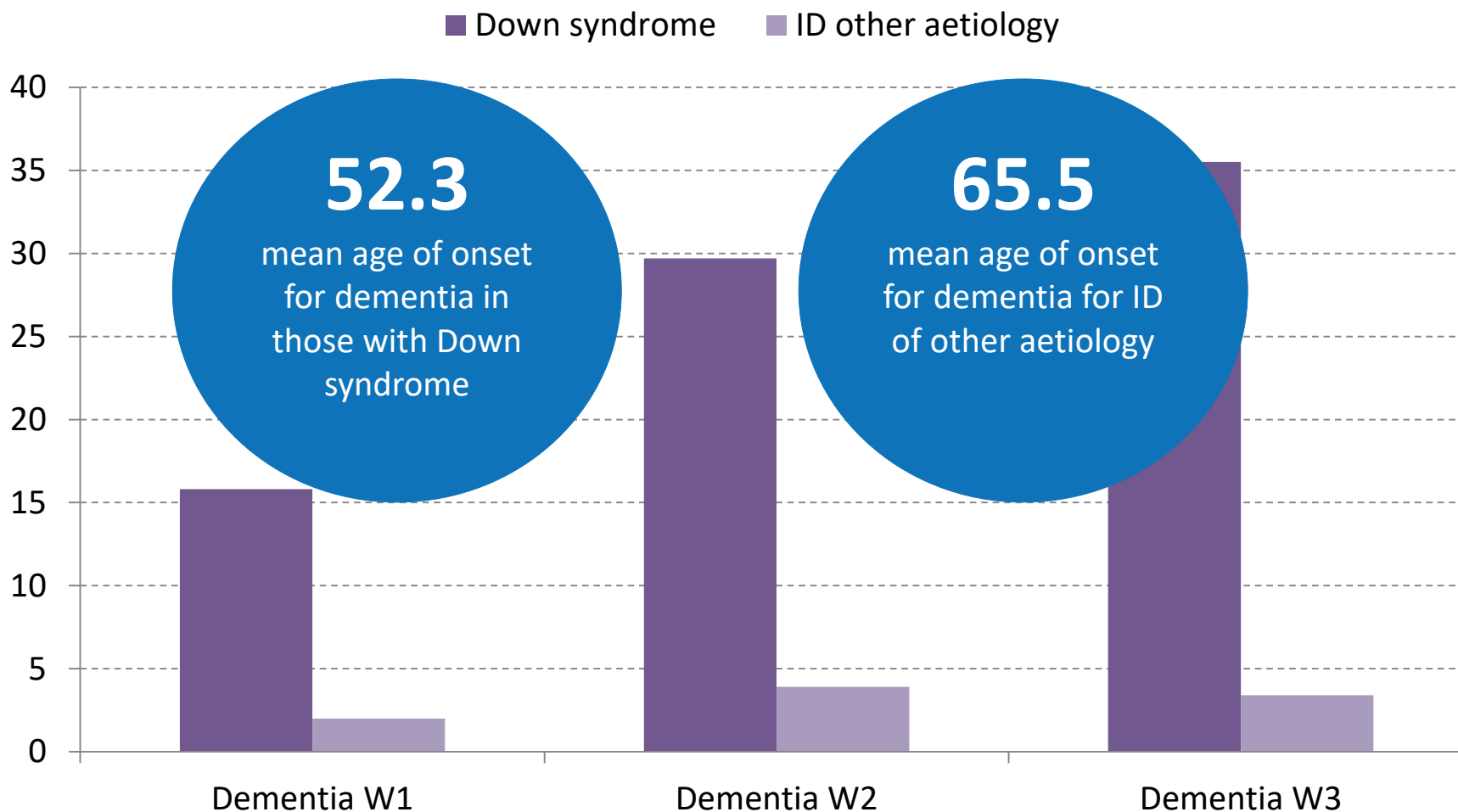
M. McCarron,¹ P. McCallion,² E. Reilly,³ P. Dunne,³ R. Carroll¹ & N. Mulryan³

¹ School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland
² Center for Excellence in Aging & Community Wellness, University at Albany, Albany, NY USA
³ Daughters of Charity Disability Support Service, Dublin, Ireland

What IDS-TILDA Teaches us about the Prevalence of Dementia



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



What IDS-TILDA teaches us about age and risk of dementia and Down syndrome

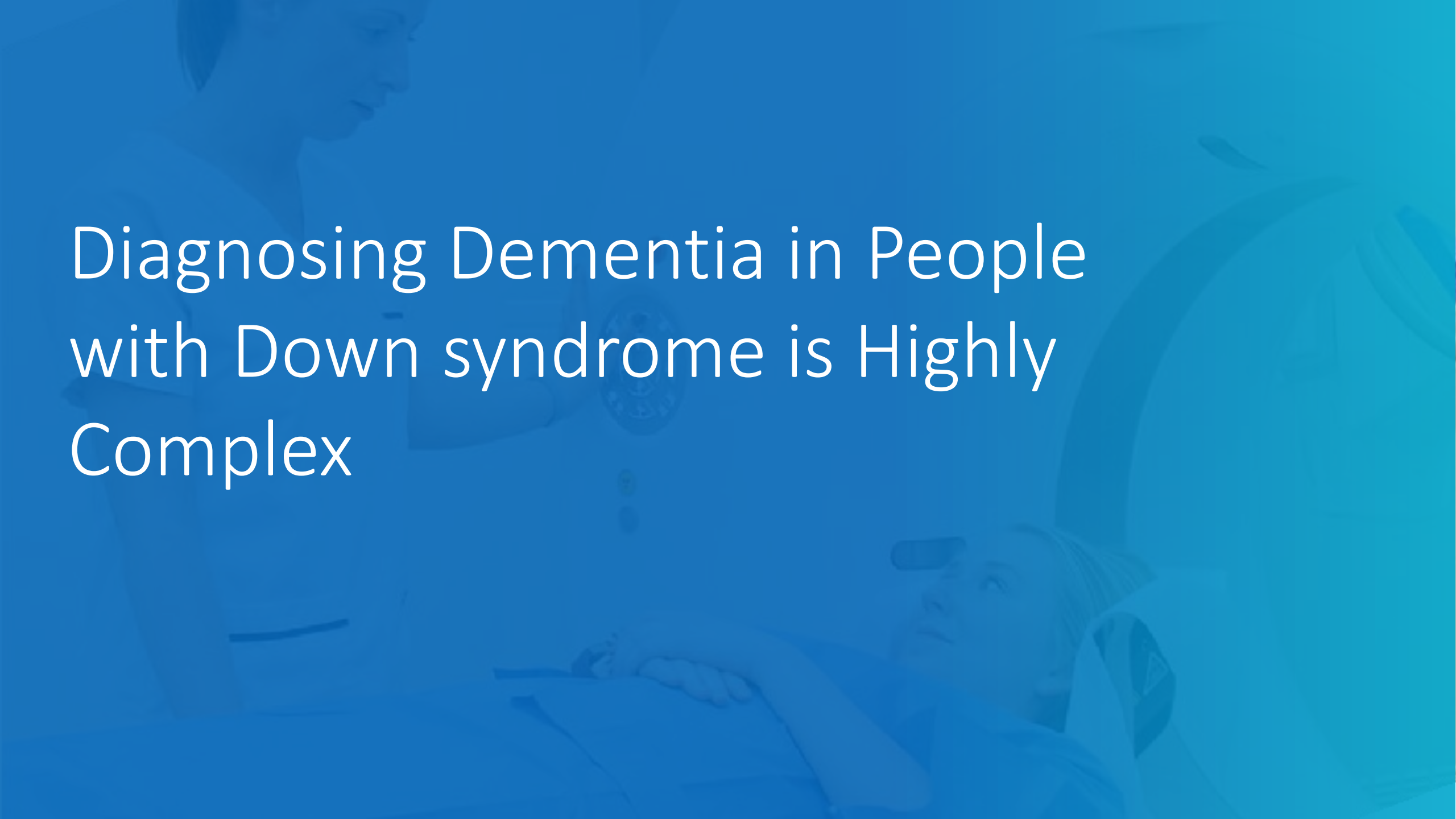


The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

**Opportunity:
National Intellectual
Disability Memory
Service**

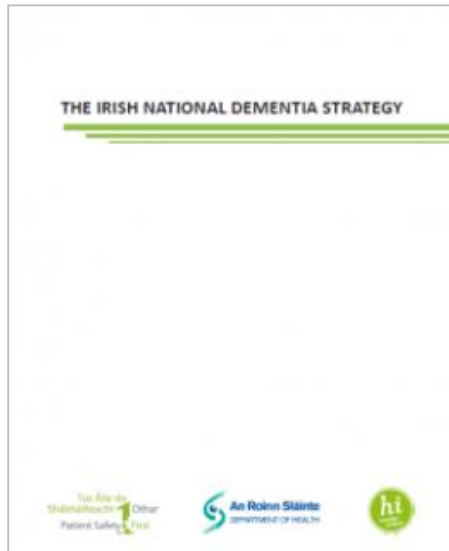
The risk is lower than reported in other research.

Of those with Down syndrome and without a diagnosis of dementia, **47% had never had a dementia assessment.**



Diagnosing Dementia in People with Down syndrome is Highly Complex

Background to the National ID Memory Service



‘stressed the need for systems, structures and age appropriate services specifically **to promote timely diagnosis of people experiencing early onset dementia, including people with Down Syndrome**’

The National Dementia Office (NDO) in accordance with implementing the National Dementia Strategy is working collaboratively with the National ID Memory Service to transform service delivery for persons ageing with intellectual disability.

[Model of Care for People living with Dementia in Ireland (working document 2021)]

National Intellectual Disability Memory Service

The Partnership



TRANSLATION AND POLICTY IMPACT

A Memorandum of Understanding (MoU) was signed in September between Trinity College Dublin, Tallaght University Hospital and the Daughters of Charity Disability Support Services.

The MoU has enabled the development of a new memory service in Ireland specifically for people with an intellectual disability.



Tallaght University Hospital
An Academic Partner of Trinity College Dublin

Ospidéal Ollscoile Thamhlachta



A National Service

The National Intellectual Disability Memory Service aims to provide access for every individual with an intellectual disability in Ireland to a Brain Health Clinic and to specialist assessment and comprehensive diagnostic work-up for memory concerns.



Mary McCarron
Executive
Director



Seán Kennelly
Clinical Director



Janette Tyrrell
ID Psychiatrist



Evelyn Reilly
Advanced Nurse
Practitioner



Pamela Dunne
Clinical Nurse
Specialist



Cathy McCarthy
Clinical Nurse
Specialist



Marianne Fallon
Education and
Training Officer



Eimear McGlinchey
Psychologist
Research Lead



June O'Reilly
Strategic Support
Officer



Overarching Principles of NIDMS



Equitable access to safe, timely, person-centred dementia assessment



Person ageing with ID valued as key components in shaping service delivery



Effective training and educational supports



Actively partner with researchers to facilitate research

@NidmsIrl

What the service offers

Russell Centre
Iodac Ruiséil

RUSSELL CENTRE

Beauty

Gifts

Russell Centre

Beauty Centre

Health & Beauty

What's New

Services and Supports offered at NIDMS

1 Information

2 Brain Health Check

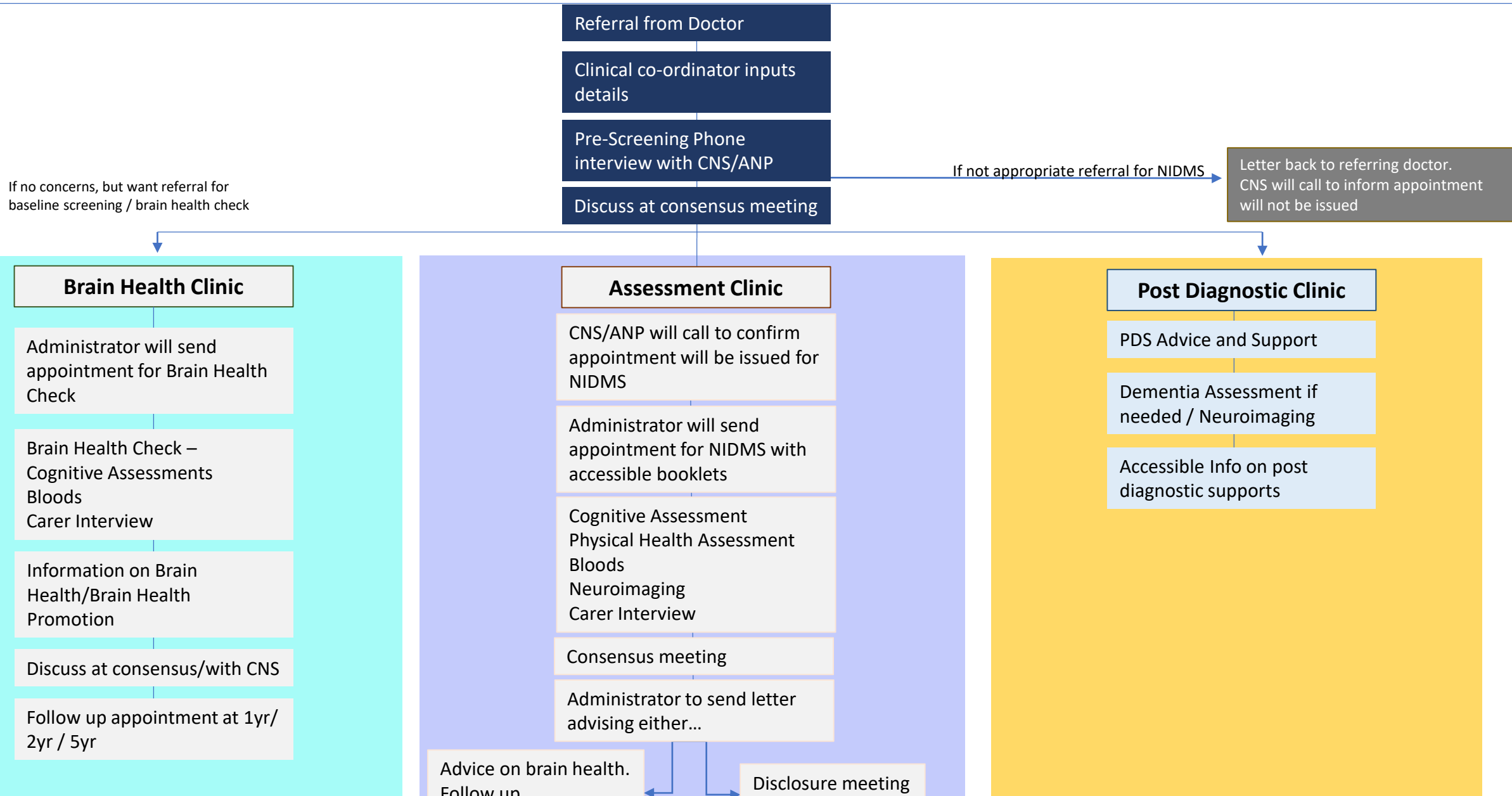
3 Assessment

4 Diagnosis and Treatment

5 Post Diagnostic Support

6 Research

REFERRAL PATHWAY





Brain Health Promotion at NIDMS



Brain Health Check

Recommended from age 30-35

Personal Prevention Plan

Opportunity for early intervention

It is never too early, never too late

Keeping your
brain healthy

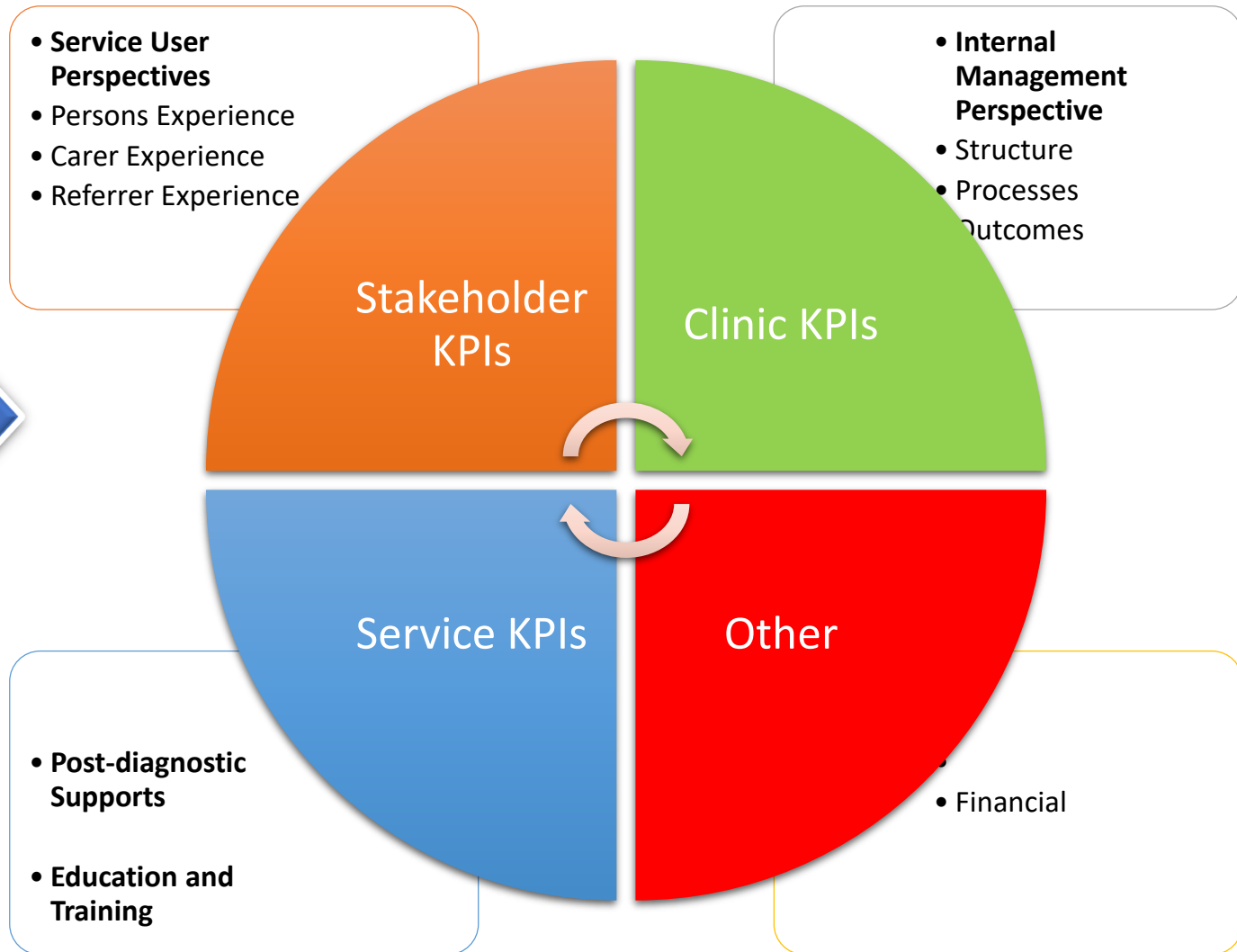
National Intellectual
Disability Memory Service

Stakeholder consultation as part of KPI development



KEY PERFORMANCE INDICATORS - OVERVIEW

Snapshot overview of a balanced suite of measures of strategic importance to short and long-term activities



KPI DEVELOPMENT

People Ageing
with ID Survey

Carer Focus Group

Staff Focus Group

Agency Meetings

Stakeholder Consultation

- Consultation with stakeholders to develop NIDMS KPIs took place in December to build the service performance indicators on the needs voiced by our service users. This was piloted in November with a small group and is ongoing.
- There is ongoing engagement with service providers as part of the stakeholder consultation
- A focus group for consultation with service providers took place in February 2021. Consultation with a carer focus group is scheduled to take place in March.

KPI DEVELOPMENT – STAKEHOLDER CONSULTATION

People Ageing with ID Survey

Easy-read service user consultation survey



National Intellectual Disability Memory Service

**Help us to Build a Good Memory Service:
Have Your Say!**



It is important to me that the Clinic is easy to get to.

It is important to me that the Clinic is easy to move around in.



It is important that I can say if my visit to the Clinic was good or bad

It is important that my carers and doctor get a report about my health so they can support me



KPI DEVELOPMENT – STAKEHOLDER CONSULTATION

Agency Meetings

Support needed from NIDMS

A standardised approach to dementia assessment, screening and care

To work as a regional satellite team for the National Memory Clinic – to further streamline services for people with ID and dementia across the country

Access to up to date research and best practice in the area

To consult with the National Memory Clinic in relation to individual cases or complex management

To drive initiatives that improve quality of life and service delivery in the area of ID and dementia

Education, Training and Upskilling of frontline staff and carers

Access to information on brain health and how best to maintain it to enhance the supports provided in services

Helpline for queries from healthcare professionals

A resource to send people to with issues ranging from concerns about memory to complex cases

KPI DEVELOPMENT – STAKEHOLDER CONSULTATION

Staff Focus Group

Equity of access for people living in every area of Ireland was a strong theme raised by focus group participants

Themes arising from KPI Structure, Process and Outcomes Prompts

- Ease of Access to NIDMS
- Easy read supports
- Brain health promotion
- Clear simple referral process
- Need for holistic geriatric assessments
- Need for 'train the trainer' training
- Comprehensive post-diagnostic supports and follow up with person's doctor


CLINIC KPI DEVELOPMENT AND OPERATIONALISATION

Service user satisfaction surveys as part of KPI development.


The surveys will enable us to collect both quantitative and qualitative data.






National Intellectual Disability Memory Service



My Visit to the National Intellectual Disability Memory Service








The Clinic was easy to travel to

  
 Yes Not Sure No





The Clinic was easy to get around in

  
 Yes Not Sure No






I felt safe from Covid-19 during my visit

  
 Yes Not Sure No



People were nice to me during my visit

  
 Yes Not Sure No



People in the Clinic listened to what I had to say

  
 Yes Not Sure No

CLINIC KPI DEVELOPMENT AND OPERATIONALISATION

Service user satisfaction surveys for Carers/Supporters following their visit to the NIDMS



National Intellectual Disability Memory Service



Satisfaction Survey for Carers/Supporters following their Visit to the National Intellectual Disability Memory Service



Staff were pleasant to us on our arrival to the Clinic

Yes
 Not Sure
 No



The Nurses explained about the Clinic and what was going to happen during memory testing

Yes
 Not Sure
 No



We did not feel rushed during the meeting

Yes
 Not Sure
 No



We were able to talk about our concerns during the meeting

Yes
 Not Sure
 No

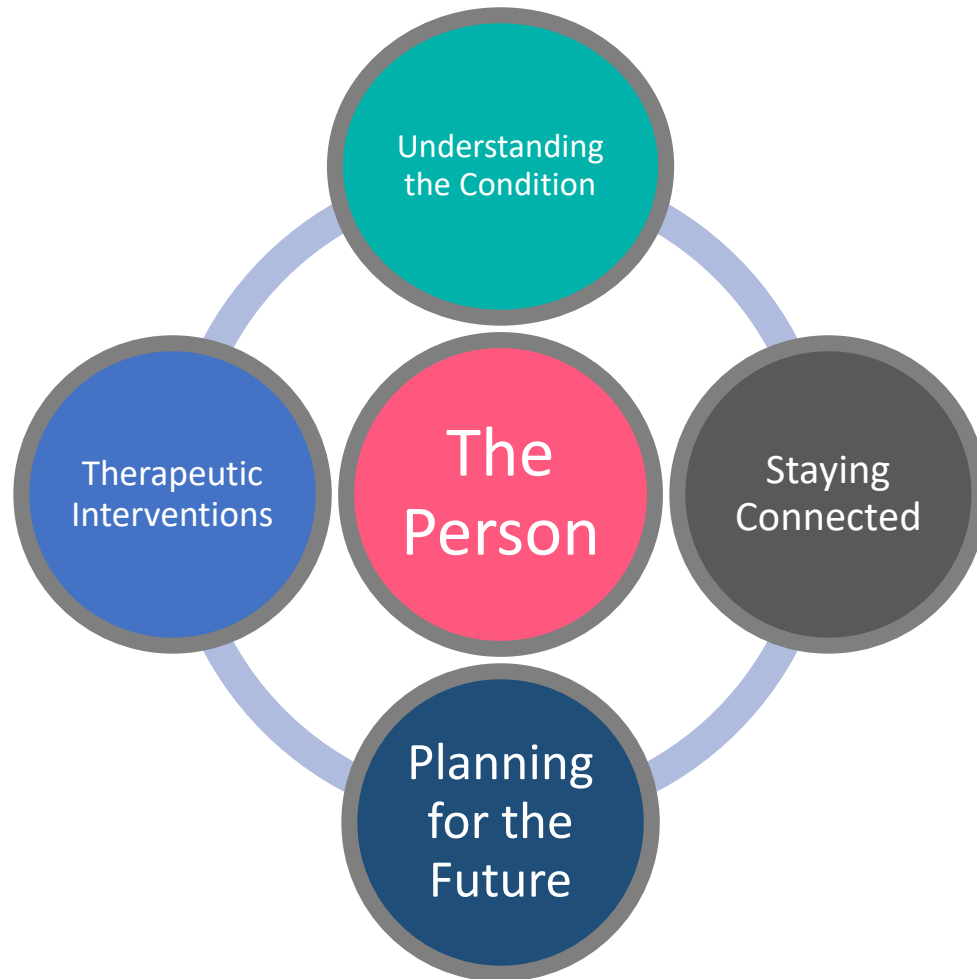


The person I support received information about brain health during the appointment

Yes
 Not Sure
 No



Four Foundations of Post-Diagnostic Support



National Intellectual Disability Memory Service

Education and Training

Education and Training – Masterclass Series

Masterclass Series 2021

National
Intellectual Disability
Memory Service



@Nidmsrl @ageingwithid
#dementia
#intellectualdisability

1270+
registrations
for
masterclass
series 2021

Attendees
from over
200 National
Services

Promoting Brain Health across the Lifespan

Tuesday, 13th April 11.00am – 12.00pm

Chair: Professor Mary McCarron, Executive Director,
National Intellectual Disability Memory Service

Speakers: Prof. Sean Kennelly, Clinical Director, National
Intellectual Disability Memory Service; Dr. Eimear
McGlinchey, Associate Professor, Trinity Centre for
Ageing and ID; Marianne Fallon, Chartered Health
Psychologist, Brothers of Charity Services, Ireland

Cognitive Stimulation Therapy for Dementia

Tuesday, 27th April 11.00am – 12.00pm

Chair: Professor Mary McCarron, Executive Director,
National Intellectual Disability Memory Service

Speakers: Dr. Gunnar Scheibner, Clinical Psychologist,
St. Michael's House; Pauline Smyth, Psychology
Support Worker, Brothers of Charity Services, Ireland-
Western Region (Roscommon)

Supporting People with Dementia to Age in Place

Tuesday, 11th May 11.00am – 12.00pm

Chair: Professor Mary McCarron, Executive Director,
National Intellectual Disability Memory Service

Speakers: Evelyn Reilly, Candidate Advanced Nurse
Practitioner; Pamela Dunne, Clinical Nurse Specialist,
National Intellectual Disability Memory Service &
Daughters of Charity Services

Supporting Nutrition in the Later Stages of Dementia

Tuesday, 18th May 11.00am – 12.00pm

Chair: Professor Mary McCarron, Executive Director,
National Intellectual Disability Memory Service

Speakers: Michelle Hurley, Senior Dietitian, Cope
Foundation, Cork; Jenna Pyne, Senior Speech and
Language Therapist, Cope Foundation, Cork

EDUCATION AND TRAINING

“Thank you very much ladies, very informative, relaxed and highly professional presentations. The commitment to progressive research and the establishment of the Memory Centre is impressive”

“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”

“It was very much formulated with the staff/ family/ caregivers in mind and there were lots of tips and ideas for navigating through each day and making life more meaningful and enjoyable for persons with dementia”.

NIDMS MATERIALS AND RESOURCES – CLINIC VISIT


A suite of resources is available in both digital and print form for **'Your Visit'** to the clinic



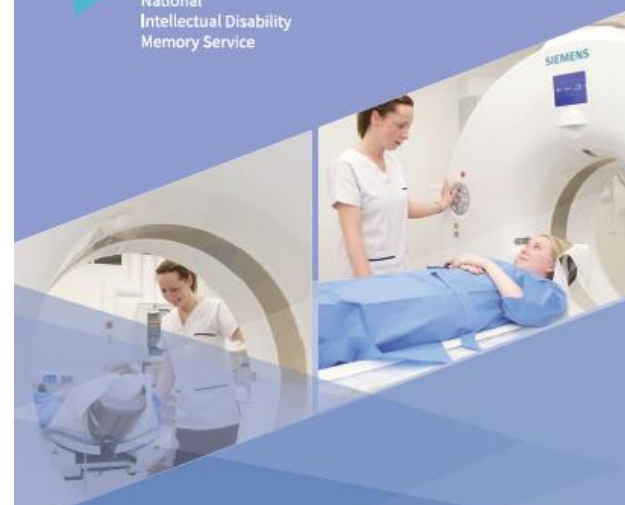
National Intellectual Disability Memory Service



Answers to your questions about intellectual disability and dementia



National Intellectual Disability Memory Service




Having a brain scan



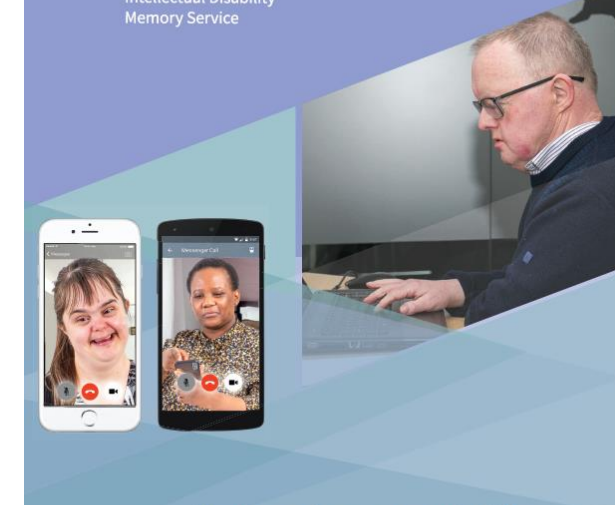
National Intellectual Disability Memory Service



Your visit to the National Intellectual Disability Memory Service



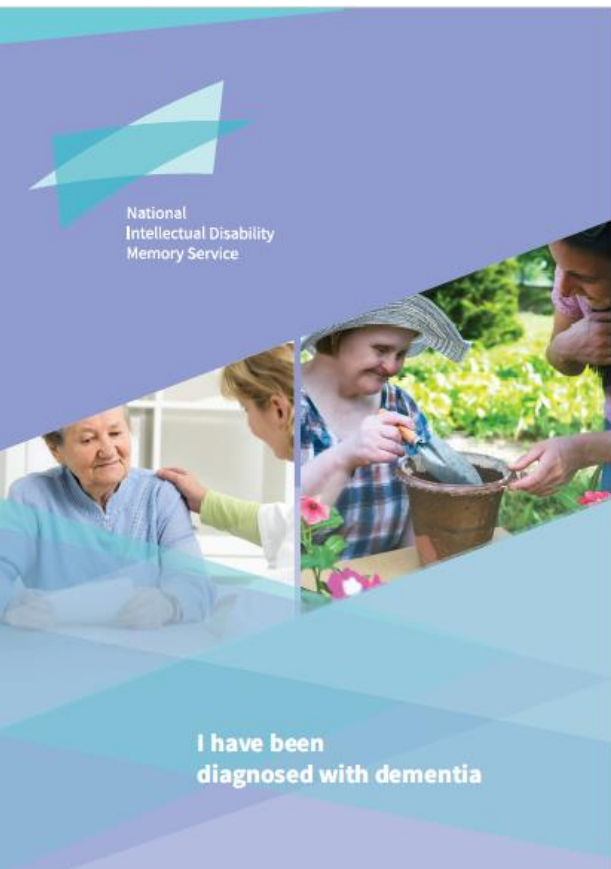
National Intellectual Disability Memory Service



Your remote assesment at the National Intellectual Disability Memory Service

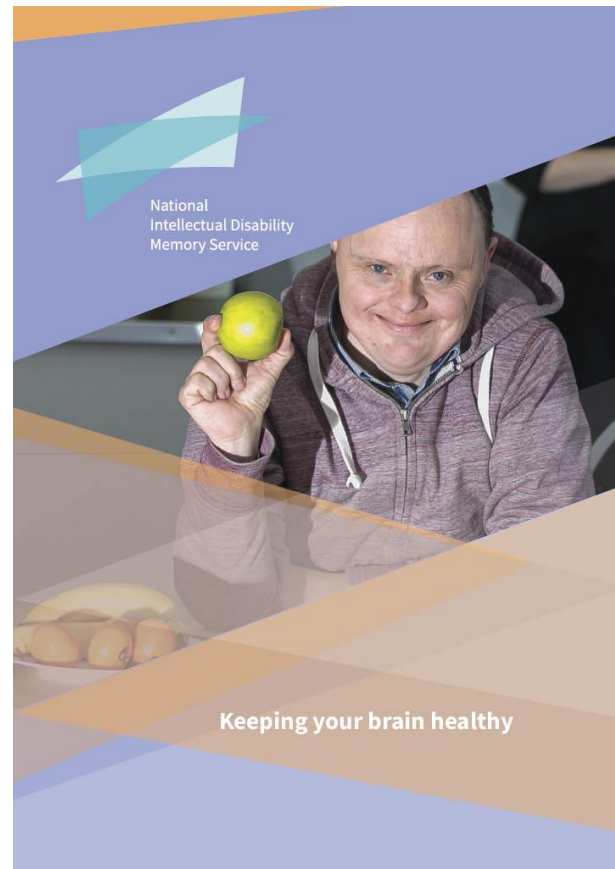
NIDMS MATERIALS - POST-DIAGNOSTIC SUPPORT

A suite of resources is available in both digital and print form for 'Post Diagnostic Support'



National Intellectual Disability Memory Service

I have been diagnosed with dementia



National Intellectual Disability Memory Service

Keeping your brain healthy



National Intellectual Disability Memory Service

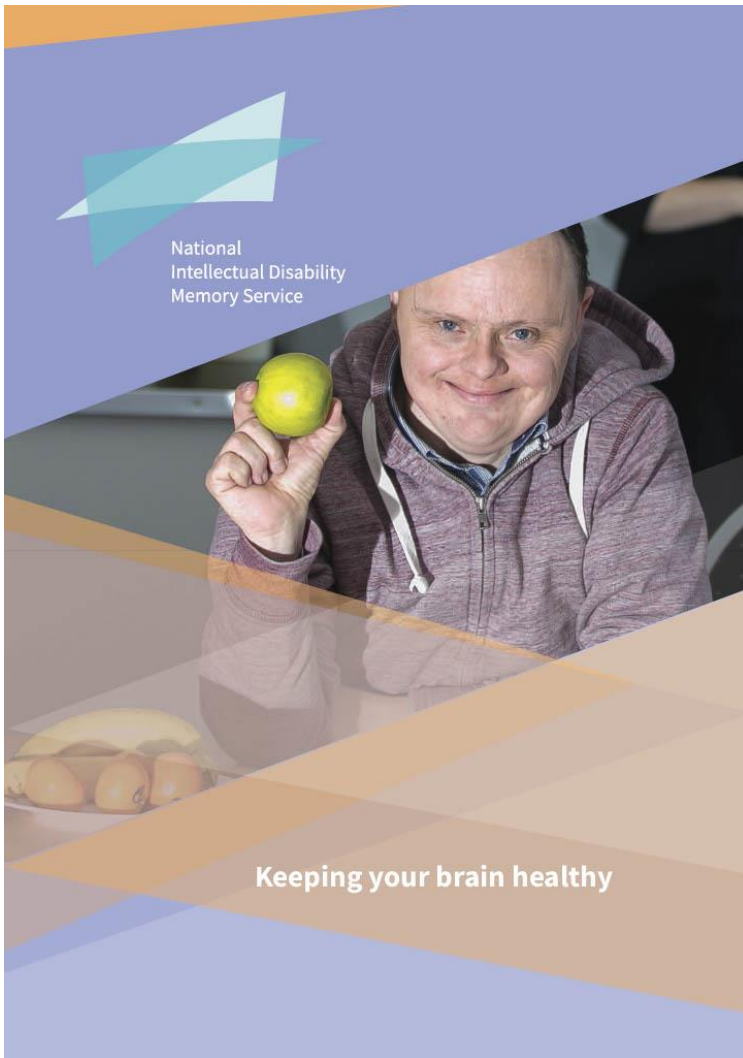
Supporting someone with intellectual disability and dementia




National Intellectual Disability Memory Service


Supporting safe care for the person with intellectual disability and dementia in their home


NIDMS MATERIALS AND RESOURCES – EASY READ MATERIAL





Tips for Keeping your Brain Healthy!

- 

Keep moving!
- 





Keep your heart healthy
- 

Spend time with family and friends
- 

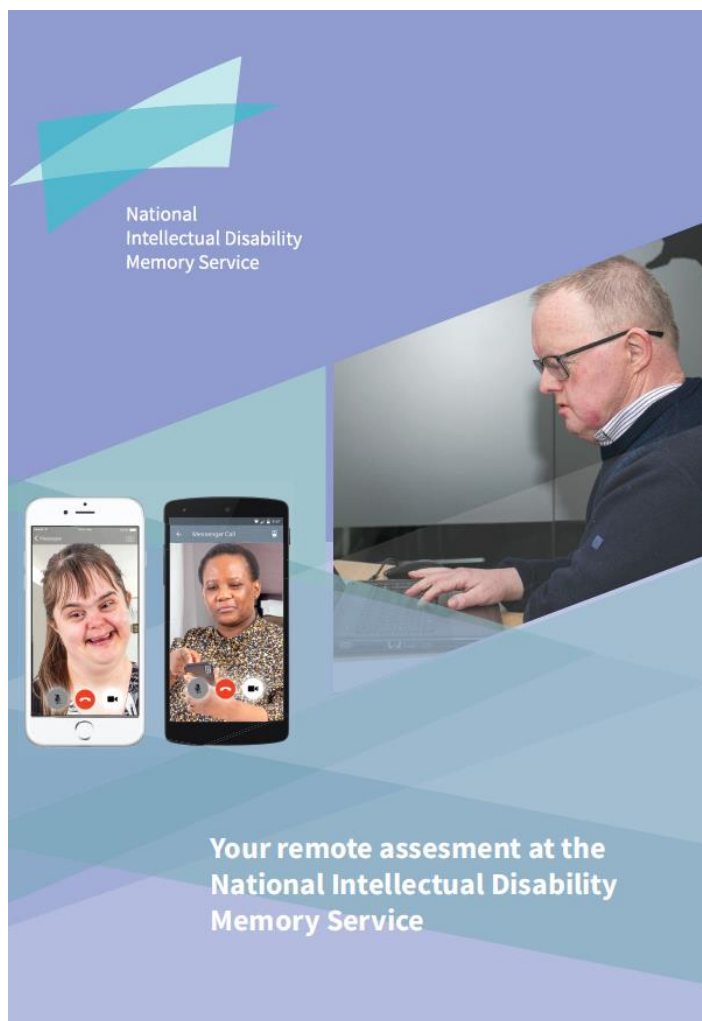
Try something new
- 

Get enough sleep

Tip 2: Keep Your heart healthy

	<p>Stay active to keep your heart healthy.</p>
	<p>Get your blood pressure checked to see how well your heart is pumping blood around your body.</p>
	<p>Eat healthy foods to feed your heart and brain.</p>
	<p>Check your weight and get help to lose weight if you need to.</p>




NIDMS MATERIALS AND RESOURCES – RESPONDING TO COVID 19







National Intellectual Disability Memory Service

Your remote assesment at the National Intellectual Disability Memory Service

What will happen at my remote visit?

	<p>As people get older, their brains may start to change.</p> <p>It is important to know if there are any changes happening. If you have concerns about your memory you can get help.</p>
	<p>Find a quiet room so you have privacy and a quiet space to talk.</p> <p>Your support person will set up the laptop for the appointment to begin.</p>
	<p>You will see the nurse specialist on a laptop screen at your appointment.</p> <p>She will explain what will happen.</p>

	<p>The nurse will ask you some questions about your memory.</p> <p>You can ask any questions you want.</p>
	<p>They will do some puzzles with you to check your memory.</p> <p>The support person will help you with the puzzles.</p>
	<p>The nurse will talk to your family or keyworker too.</p>
	<p>We may make an appointment to do some blood tests with you.</p>

NIDMS MATERIALS AND RESOURCES – FOR THE CARER



Daily Life

Support the person to continue to have daily chores and areas of responsibility in their day.

Support the person to continue to engage in normal household activities, even if they need extra support to undertake these.

Support the person to remain as independent as possible with their self-care skills, only increasing support to the level it is required.

Encourage the person to spend time in the garden, perhaps feeding the birds, watering plants or sowing seeds.

Support the person to continue to engage regularly with members of their local community and to visit their favourite community locations.

Use photos and pictures to help the person to remember their daily schedule.



Self-Care for the Carer

Every carer needs to invest in self-care. Here are some ideas for keeping yourself healthy and motivated to support someone with dementia.

Maintain a healthy diet.

Get adequate sleep and rest.

Ask for help when you need a break.

Request professional support where you need it.

Try to stay active as a way to reduce stress.

Keep in touch with family and friends.

Join a local carer network to get support from and to provide support to others.

Find out what community supports are available to you in your area, e.g. Dementia Cafés, Carers' Groups, Respite Breaks.

Talk to your doctor if you are feeling very stressed or tired.

Plan ahead for the supports the person living with dementia might need into the future.

And above all else, please be kind to yourself. You're doing the best that you can.



National Intellectual Disability Memory Service

Research Activities

AGEING WITH DOWN SYNDROME

Include the voices of people with Down syndrome in the conversation on dementia

“Like everybody here, I have dreams for the future. There are things that I want to do and I know dementia might play a part of my life too.

So, when you start talking about dementia, I want to be included in that conversation. I want to be included in the conversation about my future.

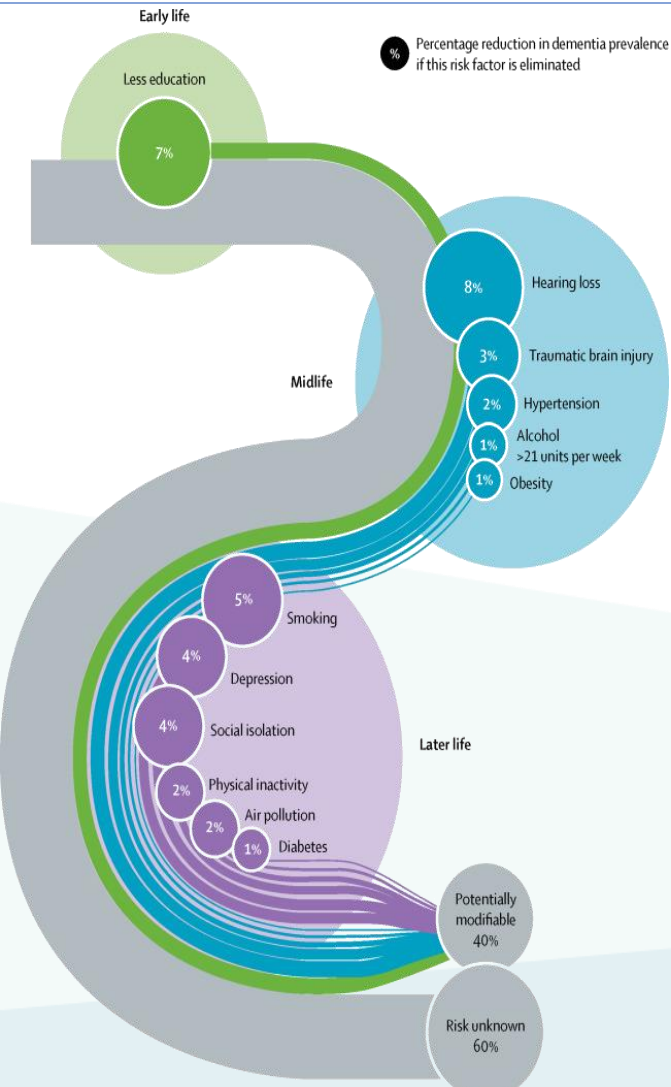
I want to be empowered so that I can choose how to reduce the risk of dementia”

- Mei Lin Yap



Risk for Dementia: What does data from IDS-TILDA tell us?

<https://assets.gov.ie/9674/abcdfeef1474423b983e531d2bde645d.pdf>



	Intellectual Disability	General Population
Education	32% none, 51% some primary	43% Secondary, 34% HE
Hearing Loss	10% (22% for people with DS)	
Hypertension	18.7%	40%
Alcohol	62% never drink alcohol	12% problem alcohol use
Obesity	36% (overweight) 43% (obese)	33% obese
Smoking	7%	14%
Depression	10-16%	11%
Social Inclusion	7% employment, 56% difficulty	
Physical Inactivity	85% underactive	39% low PA
Diabetes	9.3%	11%

McGlinchey et al, 2019



Research at NIDMS

Projects

Prevention

Brain Prom

tinuum



Post-Diagnostic Support

PREVENT dementia – DS

Examining early biomarkers of AD in people with DS

Brain Buzzers Club

HORIZON 21 RESEARCH CENTRES ALL OVER EUROPE
The Horizon 21 consortium gathers 10 European centers.

- Antonia COPPUS**
Dichterbij Center for Intellectual Disabilities, Gennep
- Henrik ZETTERBERG**
Institute of Neuroscience and Physiology, Göteborg
- Ellen MELBYE LANGBALLE**
Ageing and Health Norwegian National Advisory Unit, Oslo
- Agneta NORDBERG**
Klinisk geriatrik, Karolinska Institute, Stockholm
- Shahid ZAMAN**
Disabilities Research Group, Department of Psychiatry, University of Cambridge
- Mary MC CARRON**
Trinity Centre for Ageing and Intellectual Disability, Trinity College Dublin
- Andre STRYDOM**
Institute of Psychiatry, Psychology & Neuroscience, Kings College London
- Anne-Sophie REBILLAT**
Jérôme Lejeune Institute, Outpatient geriatric clinic for people with Down syndrome, Paris
- Juan FORTEA**
Hospital de la Santa Creu i Sant Pau, Fundació Catalana Síndrome de Down, Barcelona
- Johannes LEVIN**
Department of Neurology, University Hospital, LMU Munich

Including the Voices of Experience in Developing **Best Practice Guidelines of Post-Diagnostic Dementia Support**

Validation of MCOG-DS2 and CAMDEX-DS 2





Trinity Centre for Ageing and Intellectual Disability



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



Faculties and Schools Courses Research A-Z

Search Trinity Centre for Ageing and Intel



Trinity Centre for Ageing and Intellectual Disability

Menu Home About Education & Knowledge Transfer People Research Themes Contact Gaelige



The Trinity Centre for Ageing and Intellectual Disability is an international and multi-disciplinary research centre examining key issues in ageing and the life course, informing policy and debate at the national and local level.

ABOUT

IDS-TILDA



Participant Involvement



Research Themes



Education and Knowledge Transfer



PPI Ignite@TCD



www.tcd.ie/tcaid



IDS-TILDA

Acknowledgements



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

- The IDS-TILDA Team extends grateful appreciation to:
 - Participants, Families and Carers
 - The IDS-TILDA Steering Committee and International Scientific Advisory Board
 - Advisors and Advisory Groups
 - Our Funders



National Intellectual Disability Memory Service

Dementia Specific Homes



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Thank You

Professor Mary McCarron

Principal Investigator, IDS-TILDA

Director, Trinity Centre for Ageing and Intellectual Disability, Trinity
College Dublin

Executive Director, National Intellectual Disability Memory Service