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



Trinity Centre for Ageing and the Life Course in Intellectual Disability

Annual Report 2024-2025

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

Trinity Centre for Ageing and the Life Course in Intellectual Disability

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Message from our Director

The 2024/25 period has been one of significant progress for the Trinity Centre for Ageing and Intellectual Disability (TCAID), reflecting our continued commitment to generating research that makes a meaningful difference to the lives of people with intellectual disabilities. Across the year, our work has increasingly connected research evidence with policy, practice and lived experience, strengthening the Centre's contribution nationally and internationally.

A major focus has been preparing for Wave 6 of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). Now entering its next phase, IDS-TILDA continues to provide an unparalleled evidence base on how people with intellectual disabilities are ageing in Ireland. Wave 6 has been developed in consultation with people with intellectual disabilities, researchers, policymakers, healthcare professionals and other stakeholders, ensuring that the study continues to respond to emerging health, social and policy priorities.

This new wave represents an important evolution of the study. Alongside expanded investigation of areas including women's health, employment, relationships, health screening and the implementation of the Assisted Decision-Making (Capacity) Act, new health assessments will deepen our understanding of ageing and intellectual disability. These include gait and mobility assessment, oral and gut microbiome sampling, dried blood spot testing, bone health screening and enhanced cognitive assessment. We have also recruited and trained more than 25 field researchers, with PPI contributors playing an important role in preparing the team for data collection.

Throughout the year, we have continued to ensure that evidence generated through IDS-TILDA reaches those in a position to translate it into change. IDEAS 2024, delivered in partnership with the National Federation of Voluntary Service Providers and the HSE National Clinical Programme for People with Disability, brought researchers, service providers, policymakers and advocates together to consider how evidence can improve supports and services for people with intellectual disabilities as they age.

This commitment to translating evidence into policy was further demonstrated when members of our team presented IDS-TILDA findings directly to the Joint Oireachtas Committee on Disability Matters. The discussion placed longitudinal evidence at the heart of consideration of future health, care and support needs, including preventable and treatable health inequalities, workforce capacity and the contribution of Registered Intellectual Disability Nurses.

Addressing areas of persistent health inequality has remained central to our work. In May, our Breaking Barriers: Enhancing Cancer Care for Individuals with Intellectual Disabilities conference brought together more than 200 people with intellectual disabilities, family members, researchers, healthcare professionals, policymakers, service providers and advocates. The conference provided an important platform to address inequalities across cancer prevention, diagnosis, treatment and care, while demonstrating how lived experience can be meaningfully integrated into research and policy discussion.

We have also seen research translate directly into practice. Work led by Professor Éilish Burke on accessible bone health screening has demonstrated the potential of Echolight technology to overcome barriers experienced by people with intellectual disabilities in accessing traditional osteoporosis screening. Its introduction into clinical practice and integration within IDS-TILDA demonstrate the potential for research to lead to tangible improvements in healthcare access and outcomes.

Meaningful involvement of people with intellectual disabilities remains fundamental to everything we do. Throughout the year, PPI contributors have shaped research, supported researcher training, contributed to conferences and public engagement, and helped make complex research accessible to wider audiences. This commitment extends into education, with new work supporting people with intellectual disabilities to participate as co-educators in the education and assessment of future nurses.

The achievements highlighted throughout this report are made possible through collaboration. They reflect the contribution of our participants and PPI partners, researchers, students, professional and service partners, funders, policymakers and colleagues across Trinity and beyond. I am particularly proud of the recognition received by members of our research community during the year and of the continued growth of the next generation of researchers committed to advancing health and wellbeing for people with intellectual disabilities.

As we move forward, our ambition remains clear: to generate the evidence needed to address health inequalities, to ensure that evidence informs policy and practice, and to work alongside people with intellectual disabilities so that their priorities and experiences remain at the heart of change. The commencement of Wave 6 provides an exciting foundation for this next chapter, while the partnerships and achievements reflected in this report demonstrate what can be accomplished when research, policy, practice and lived experience come together.

It is with great pride that I present the 2024/25 Annual Report and invite you to explore the work, achievements and people that continue to advance our shared ambition of adding life to years for people with intellectual disabilities.



Message from Co-Director, Prof Éilish Burke

'Every finding in this report exists because people with intellectual disabilities trusted us with their time, their stories and their personal and health information. The strength of our evidence depends entirely on the strength of that partnership. TCAID's task is to make sure this trust is repaid because research does not stop at publication but must travel into clinics, services and policy rooms where it can genuinely change lives. This year's work, from Wave 6 preparations to our engagement with the Oireachtas Committee on Disability Matters, shows what is possible when rigorous science and lived experience are treated as equally essential.'



Message from Associate Director, Dr Eimear McGlinchey

'The work of the past year highlights TCAID's strength in ensuring that research translates into policy and practice, while keeping the lived experience of people with intellectual disabilities at its centre. The breadth of work being undertaken by PhD researchers, postdoctoral fellows and early-career researchers also demonstrates the strength of the next generation within TCAID, providing a strong foundation for the Centre's continued growth and for Ireland's leadership in ageing and intellectual disability research.'



Message from Associate Director, Dr Martin McMahon

'This has been another important year for the Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID). Through high-quality research, education, policy engagement and meaningful collaboration, TCAID has continued to advance knowledge and improve the lives of people ageing with intellectual disabilities. Our achievements reflect the commitment of our staff, researchers, students, partners and, most importantly, people with intellectual disabilities and their families. We look forward to building on this work and strengthening its impact on policy, practice and communities into the future.'



Message from Ms Mei Lin Yap

As the Ambassador Liaison Officer for the Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID), I have had another busy and exciting year. An important part of my role is making sure that people with intellectual disabilities have a voice and are included in the work of the Centre.

During the year, I represented TCAID at a number of conferences and events. I spoke on the experiences of women with intellectual disabilities at an event about heart health and menopause. I also spoke alongside Professor Mary McCarron at the Third Annual Conference of the National Chief Academic Officer Group. I enjoyed having the opportunity to talk about my work and why it is important to listen to people with intellectual disabilities.

In September, I attended the launch of the Post-Diagnostic Dementia Support Guidelines for Ageing Adults with Intellectual Disabilities with Professor Mary McCarron. I had been involved in this work as a PPI contributor, so it was very special to see the finished guidelines. The project listened to people with intellectual disabilities, families and carers about the support people need after a dementia diagnosis. I was proud that my experience and views helped with this work.

In October, I took part in IDEAS 2024, which brought people together to talk about how IDS-TILDA research can be used to improve services and supports for older people with intellectual disabilities. I shared my own findings and experiences at the event. I also attended Bridging Gaps, Building Futures, where I was invited to introduce Professor Mary McCarron before her presentation.

One of my highlights of the year was the Breaking Barriers: Enhancing Cancer Care for Individuals with Intellectual Disabilities conference. I helped make the keynote presentations more accessible by explaining the main messages after each presentation. I believe people with intellectual disabilities should be able to understand information about their own health and be part of these important conversations. I was also delighted to meet Minister Hildegarde Naughton and tell her about my role and the work I do at TCAID.

I continue to Chair the TCAID PPI Panel, which has seven self-advocates with intellectual disabilities. We give researchers advice, review Easy Read information and help them make their research more inclusive. This year, we also helped to train the IDS-TILDA Wave 6 field researchers. They practised their interviews with us and we gave them feedback before they started meeting participants.

Working at TCAID gives me the chance to make a difference. I help researchers and students understand how to communicate with people with intellectual disabilities and how to include us properly in their work. It is important that researchers listen to us because we are the experts in our own lives.

I am very proud of my role at TCAID. I feel validated, accepted and included, and I am proud that I can use my experience to help other people. I want people with intellectual disabilities to continue having a strong voice in research – not only taking part, but helping to shape it and lead it too.



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.



STRATEGIC PRIORITIES

THE CENTRE FOCUSES ON THE FOLLOWING PRIORITIES:



Put the voice of people with an intellectual disability at the heart of strategy



End avoidable mortality (treatable and preventable)



Create care pathways for poorly understood diseases such as cancer, dementia, and frailty



Increase quality of life through medicines optimisation and non-pharmacological interventions



Oral Health



Understand and positively influence social determinants of health



Understand and positively influence mental health and wellbeing



Create new service and financing models that support ageing in place and family carers



Death, dying and end-of-life care

Our People

Centre Directors	Prof Mary McCarron, Director Dr Éilish Burke, Co-Director
Strategic Advisory and Executive Team	Dr Martin McMahon, Associate Director Dr Eimear McGlinchey, Associate Director Gavin Dann, Administrative Officer, TCAID June O'Reilly, Strategic Development Officer, TCAID Margaret Haigh, Project Manager, IDS-TILDA Jean Moynihan, Assistant Project Manager, IDS-TILDA Kieva Leslie, Executive Officer Dr Caitriona Ryan, Statistician, IDS-TILDA Pavithra, Data Manager, IDS-TILDA Aviejay Paul, Data Scientist, IDS-TILDA Mei Lin Yap, Ambassador Liaison Officer Dr Padraig Carroll, Programme Manager, PPI Office Dr Liz Farsaci, Programme Manager, PPI Office
Academic Faculty	Prof Martine Smith (Clinical Speech & Language Studies) Dr Caoimhin Mac Giolla Phadraig (School of Dental Science) Dr Peter May (Public Health and Primary Care) Dr Martin Henman (School of Pharmacy) Dr Máire O'Dwyer (School of Pharmacy) Dr Juliette A O'Connell (School of Pharmacy) Dr Damien Brennan (School of Nursing and Midwifery) Dr Frances O'Brien (School of Nursing and Midwifery) Dr Fintan Sheerin (School of Nursing and Midwifery) Dr Irina Kinchin (Trinity Institute of Neurosciences (TCIN)) Dr Louise Daly (School of Nursing and Midwifery) Dr Carmel Doyle (School of Nursing and Midwifery) Dr Eimear McGlinchey (School of Nursing and Midwifery) Mr Paul Horan (School of Nursing and Midwifery) Mr Paul Keenan (School of Nursing and Midwifery) Dr Mary-Ann O'Donovan (University of Sydney) Dr Dominika Lisiecka (Munster Technological University) Dr Andrew Wormald (University of Limerick) Prof Seán Kennelly (Tallaght University Hospital and Medical Gerontology, Trinity College Dublin) Prof Roman Romero-Ortuno (St. James's Hospital and Medical Gerontology, Trinity College Dublin) Prof Blanaid Daly (School of Dental Science) Dr Katie Cremin (Occupational Therapy, School of Medicine) Dr Martin McMahon (School of Nursing and Midwifery)
Academic Advisor	Prof Philip McCallion, Senior Academic Advisor
Postdoctoral and Research Fellows	Dr Darren McCausland Dr Andrew Wormald Dr Kálya Yasmine Lima Dr Louise Lynch Dr Ashleigh Gorman
Research Assistants	Ms Stephanie Corrigan Ms Iara Faria Synnott Ms Jean Moynihan Ms Laura Hunt Ms Shauna Walsh Ms Miriam Fitzpatrick Mr James Kelly Ms Stella Roney

Meet our Newest Teammates



Laura Hunt, Research Nurse

My Role at TCAID
As a Research Nurse with TCAID, I am involved in IDS-TILDA Wave 6, supporting the delivery of comprehensive health assessments with adults with intellectual disabilities. My role involves collecting and ensuring the accuracy of clinical and health data, contributing to the national longitudinal research programme exploring the health and ageing of people with intellectual disabilities.

What I Bring to the Team
I am a dual-qualified Registered Nurse in Intellectual Disability and General Nursing, with 10 years of experience working across intellectual disability services.

I bring a strong person-centred approach to my work, with a particular interest in building positive and trusting relationships with participants. I really value taking the time to get to know each participant, understand their individual needs and help them feel comfortable and supported throughout their involvement in research. I am looking forward to bringing my clinical experience and passion for improving health outcomes for people with intellectual disabilities to the team, while continuing to develop my experience within research.

Getting to Know Me
Outside of work, I love getting out in nature and spending time outdoors. I have an interest in traditional Irish music and I can play both the fiddle and the flute!

Meet our Newest Teammates



Dr Liz Farsaci, PPI Programme Manager

My Role at TCAID
I work as the PPI Ignite Programme Manager for Trinity, which involves supporting and promoting Patient and Public Involvement (PPI) in research throughout the Centre, the Faculty of Health Sciences and beyond. Part of this work also includes engaging with health policy makers and services in order to strengthen the link between lived experience, research, policy and practice.

What I Bring to the Team
I was awarded my PhD from the School of Nursing and Midwifery here at Trinity, where I investigated pregnant people's lived experiences of access to community midwifery care in Ireland. I have also worked as a Research Fellow at the Centre for Health Policy and Management in our School of Medicine, researching health policy, health reform implementation and health financing. Previously, I worked as a journalist, telling people's stories and, during the pandemic, communicating national health guidelines and academic research to members of the public.

Getting to Know Me
I spend most of my spare time on the sidelines of a GAA pitch… but I love to run, swim and dance, and hope to start growing my own vegetables this year.

Meet our Newest Teammates



Stella Roney, Research Assistant

My Role at TCAID
I am a research assistant at TCAID and am primarily involved with the IDS-TILDA study, investigating ageing among adults with intellectual disabilities. I conduct interviews with participants, support our team of 25+ field researchers, and input and process collected data.

What I Bring to the Team
I am a recent graduate from Trinity College Dublin where I studied Psychology and worked as a research assistant in the Trinity Centre for Global Health focused on the experiences of parenting within refugee situations. My undergraduate thesis was on trends in adolescent loneliness, and particularly the protective role of adult support. My background has developed my interest in family processes, well-being and quality of life, and I am excited to use my research skills and enthusiasm to contribute to the TCAID team.

Getting to Know Me
I love being outside and go on loads of long walks and sea swims. I also read a lot, and last year I coached the Trinity ultimate frisbee team!

Tracking Research Uptake, Policy Influence, and Scholarly Outputs

The Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID) continues to build an evidence base with reach beyond academic publication. A review of 2024-25 outputs examined policy citation through Overton and wider scholarly, media and public attention through Altmetric Explorer. Although these indicators do not, by themselves, demonstrate impact, they show that the Centre's research is being found, discussed and used by policy, professional, academic and public audiences.

Policy Uptake Across Countries and Sectors:

The Overton review identified **seven** TCAID-linked outputs cited in policy. **Eight** citations were recorded from seven organisations across six countries and one intergovernmental source. These included NIJZ (Slovenia), the Australian Government Department of Health, NHS Trusts, the Nordic Council, PublicPolicy.ie, SINTEF and the Commonwealth of Virginia. Sources spanned government, think-tank and intergovernmental bodies; leading topics included health, intellectual disability, disability, health care, ageing and cardiovascular disease.

From Evidence to Guidance and Practice:

Two recent examples demonstrate the practical relevance of this uptake. Slovenian guidance on physical activity, ageing and health cited McDermott et al.'s (2023) study on enabling older adults with intellectual disability to become physical activity leaders in their communities. A Commonwealth of Virginia Health Safety Alert on heart disease in people with intellectual and developmental disabilities cited Lynch et al.'s (2022) review of the physical health effects of sedentary behaviour. These citations connect TCAID evidence with practical guidance on participation, prevention and cardiovascular health.

Scholarly, Media and Public Reach:

The Altmetric export returned **49** outputs with recorded attention. Together they attracted **392** mentions: **313** on social media; **74** in news, blogs and podcasts; four peer-review mentions; and one video mention. The news dataset captured **60** stories from **43** outlets across **13** countries. The top-performing output, Next generation brain health: transforming global research and public health to promote prevention of dementia and reduce its risk in young adult populations, generated **52** news stories and **140** combined mentions on X and Bluesky, placing TCAID research in international discussion of dementia prevention and brain health. The same **49** outputs had **944** Mendeley readers and **390** Dimensions citations in August 2026.

Expanding Digital Presence and Online Engagement

Digital Reach at a Glance

156,413
Impressions

25,845
Engagements

19,950
Post clicks

1,264
Organic followers gained



Expanding Digital Presence and Online Engagement: TCAID continued to expand its digital reach during the reporting period, using LinkedIn to communicate research findings, celebrate researcher achievements and connect the Centre's work with policy, practice and public engagement. Across the four available reporting periods from September 2024 to September 2025, TCAID content generated **156,413** impressions, **25,845** engagements and **19,950** post clicks. The Centre also recorded **1,264** organic followers gained across these periods, demonstrating sustained growth in the audience engaging with its work.

The strongest period was September-December 2024, when the Centre achieved **44,819** impressions, **10,049** engagements and **8,160** post clicks. Engagement performance during this period ranked in the **94th percentile** with an engagement rate of **22.42%** **compared with a 50th-percentile network benchmark of 8.99%.**

What Is Resonating With Our Audience?

People and achievement	Researcher recognition and achievement repeatedly feature among high-performing posts, indicating that audiences connect strongly with the people behind TCAID's research.
Policy and real-world engagement	Posts showing TCAID researchers and PPI contributors participating in policy, human-rights and public-engagement activity generated strong interaction, helping make the pathway from research to impact visible.
Inclusion and lived experience	Content linked to disability inclusion and participation performed strongly, reinforcing the value of accessible stories that foreground lived experience alongside research expertise.
Visual, accessible storytelling	Photo-led and event-based content forms an important part of TCAID's publishing approach, helping communicate research activity in an immediate and accessible way.

" I was introduced to new, innovative ways of communicating myself, and I couldn't have done it without the incredible guidance I received through TCAID. A colleague in the tax industry was advised to enhance their LinkedIn visibility and increase posts for work opportunities. After showing them the TCAID examples, they were thoroughly impressed with the quality. It would be fantastic to present these insights in the Faculty someday, as no one is doing anything close to this standard" – **Faculty of Health Sciences Associate Professor**

Performance by Reporting Period

Period	Impressions	Engagements	Post clicks	Organic followers gained	Engagement Rate
Sep-Dec 2024	44,819	10,049	8,160	371	22.42%
Jan-Mar 2025	32,709	5,930	4,727	323	18.13%
Apr-Jun 2025	40,005	4,954	3,573	345	12.38%
Jul-Sep 2025	38,880	4,912	3,490	225	12.63%
TOTAL	**156,413**	**25,845**	**19,950**	**1,264**	**-**

The Next Chapter: Launching IDS-TILDA Wave 6



Following the hugely successful launch of the Wave 5 Report *'Longitudinal Dynamics in the Ageing of People with an Intellectual Disability',* IDS-TILDA began planning for Wave 6. This wave began in January 2025 and will continue for three years.

The first key task early in 2025 was to review the Wave 6 protocols to ensure recent policy changes that may impact people with intellectual disabilities, are included. Protocols were also amended to reflect the changing landscape in terms of health, well-being and social inclusion for people with intellectual disabilities. Protocol amendments were discussed in consultation with key stakeholders such as PPI contributors, governing committee members, representatives from government, funding bodies and non-government organisations, researchers and healthcare professionals, to understand their requirements. As a result, the Wave 6 protocols included new questions on autism, relationships and quality of life for people with intellectual disabilities. Existing questions on employment, women's health, health screening and the impact of the Assisted Decision-Making (Capacity) Act 2015 were extended to reflect the increased focus on these topics.

As well as new questions, important new objective measures will be introduced in Wave 6 as part of the Health Fair. A gait assessment will be conducted using innovative technology – the Gaitkeeper App. This will measure participants' gait speed, steps, stride length, flexion and step dynamics. Gait is effective in identifying frailty, falls risk, functional status and mobility and is an important indicator of the person's overall well-being.

Other exciting new health measures to be introduced as part of Wave 6 include checks on the mouth and gut health of our participants as these can tell a lot about overall wellbeing. This will involve collecting oral and gut microbiome samples from participants. These samples will then be used to investigate the relationships between the microbiomes and important health outcomes. The aim is to establish change with age and identify what contributes to specific morbidity prevalence and patterns.

Participants will also be invited to take part in dried blood spot testing. These tests can be used to measure a key biomarker for Alzheimer's disease. This testing will be done using a finger prick, which is a simple, non-invasive way to monitor the disease.



The Health Fair will also include bone screening which will be done using the Echolight device. Echolight has concordance rates of up to **98%** with the gold standard DXA. Importantly, it has the potential to alleviate the major challenges encountered with access to bone health screening for people with intellectual disabilities.

The Cambridge Cognition (CAMCOG) examination will be introduced to measure the extent of dementia and to assess the level of cognitive impairment. This is a standardised instrument and will assess the participant's orientation, language, memory, praxis, attention, abstract thinking, perception and calculations.

In addition to preparing for the above new measures, another key activity was the recruitment and training of 25 field researchers for data collection. All field researchers completed a comprehensive and immersive 2-day training programme which was complemented by an initial online training programme. Training was delivered by core and wider IDS-TILDA team members. There was a focus on hands-on training and PPI contributors played a key role in training. The training was very informative and enjoyable, as the comments from our field researchers show.

Data collection for Wave 6 of IDS-TILDA is scheduled to start in September 2025. Looking ahead, the data collected will provide new opportunities to understand the health, well-being and social inclusion of people with intellectual disabilities in Ireland and how their lives are changing. In particular, the new measures being introduced will provide unique insights into how IDS-TILDA participants are ageing.



'Wave 6 introduced new measures to explore the oral and gut microbiomes and their relationship with health and ageing in people with intellectual disability (ID). The microbiome contains microorganisms or 'germs' that support digestion, medication processing and overall health. The types and proportions of these germs changes with age and may be linked to oral health problems, infections, digestive difficulties, constipation, obesity, diabetes and mental wellbeing. Oral microbiome samples were collected using swabs of the tongue and teeth, while participants collected a small stool sample at home for gut microbiome analysis. These samples were successfully collected from consenting subsets of IDS-TILDA participants and will help address important gaps in understanding healthy ageing in people with ID.'

Dr Aisling O'Halloran, Assistant Professor in Health Research

'Mei Lin's talk was inspirational'

'Having the practice interviews with members of the PPI was absolutely invaluable'

'I think the training ran very well and was very well organised. I feel ready to go out and complete good field research'

'The PPI ladies and gents really enhanced the training'

'I felt that the training was exceptionally informative and extremely well organised. Thank you for the great experience'

'Excellent two days. Most enjoyable experience'

'This helped me to feel supported and reassured – help is at hand!'





Highlights: Generating and Translating Knowledge

Integrating Disability Evidence into Action for Supports and Services for Older People with an Intellectual Disability

In October, TCAID hosted *Integrating Disability Evidence into Action for Supports and Services (IDEAS) for Older People with an Intellectual Disability* in collaboration with the National Federation of Voluntary Service Providers and the HSE National Clinical Programme for People with Disability.

IDEAS 2024 brought together researchers, service providers, policymakers and advocates to consider how research evidence can be translated into meaningful improvements in policy, practice and service provision for older people with intellectual disabilities. Drawing on evidence from IDS-TILDA and wider expertise, the event provided an important forum for connecting research with the experiences and priorities of those working within and using disability services.

Through shared learning and discussion, IDEAS 2024 supported the translation of evidence into practice and strengthened collaboration across the research, health and disability sectors. The event reinforced TCAID's commitment to ensuring that research extends beyond academic outputs to inform decision-making, strengthen services and contribute to improved health, wellbeing and quality of life for people with intellectual disabilities as they age.

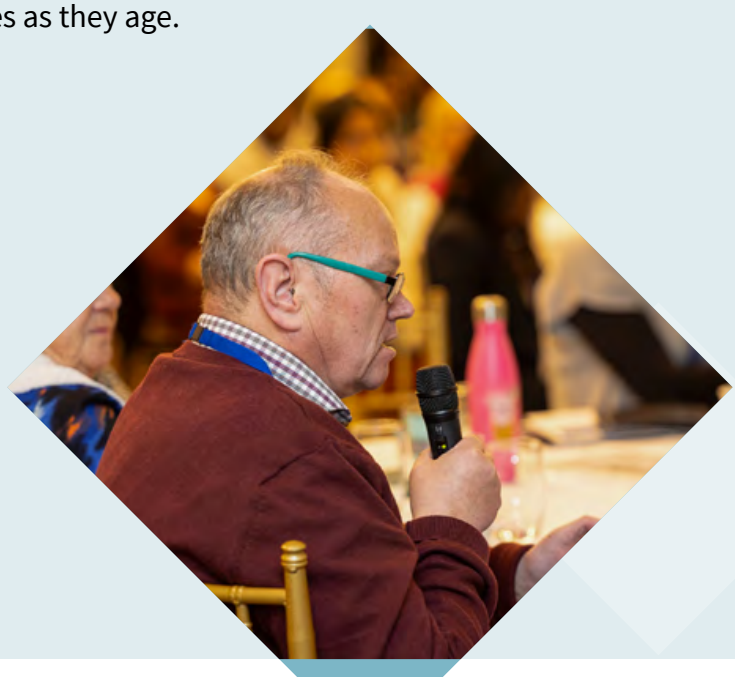




Day One: Moving Research to Practice

Day One focused on translating findings from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) into practice. Researchers, service providers, healthcare professionals and advocates shared examples of how evidence is being used to respond to the changing needs of older adults with intellectual disabilities.

Discussions reflected the breadth of evidence generated through IDS-TILDA, spanning social inclusion and participation, mental health and loneliness, dementia and cancer, oral and bone health, medicines optimisation, gastrointestinal health, women's health and end-of-life care. Importantly, the programme brought research evidence together with examples from practice, highlighting opportunities to improve services and address health inequalities experienced by people with intellectual disabilities as they age.





Service professionals working in collaboration with TCAID shared examples of how research findings are informing developments within their services. Lived experience was also central to the programme. Shannon O'Farrell-Molloy contributed her experience of managing medication to discussions on medicines optimisation, demonstrating the importance of including the perspectives of people with intellectual disabilities when considering improvements to healthcare.

IDS-TILDA participant Philip O'Donnell reflected on his 15-year involvement in the study and the positive impact that research participation has had on his life and health. Philip's contribution to IDS-TILDA has since developed further through his appointment to the IDS-TILDA Steering Committee as an advocate, strengthening the role of lived experience in the ongoing direction of the study.

"We stand at a pivotal moment in our field, where the intersection of ageing and intellectual disabilities presents both challenges and opportunities. Over the past 15 years, Ireland has led the way in understanding the ageing of people with intellectual disabilities. The findings from IDS-TILDA have directly influenced policy and services across sectors, but our real challenge is ensuring this research drives evidence-informed policy that transforms lives. Our commitment, alongside key partners like the HSE and the National Federation of Voluntary Service Providers, remains strong, and today's discussions will be a crucial step in moving from evidence to action."

Prof Mary McCarron, Director of TCAID, PI of IDS-TILDA and Professor of Ageing and Intellectual Disability







Day Two: Family Caregiving and Informing Future Policy

Day Two placed a particular focus on family caregiving, drawing on research led by Dr Damien Brennan and providing an opportunity to consider the experiences, contributions and changing needs of families supporting older adults with intellectual disabilities.

The programme also created an important link between research and national policy development. Members of the Commission on Care for Older People joined the event as part of its consultation process, providing attendees with an opportunity to contribute their perspectives and experiences directly to the Commission's work.

In alignment with the UN Decade on Healthy Ageing, IDEAS 2024 underscored its commitment to shaping future care models that not only prolong life but also add quality and dignity to the lives of people with intellectual disabilities. The discussions and insights generated over the two days will have a lasting impact on how care is provided, ensuring that older adults with intellectual disabilities are supported to live healthier, more fulfilling lives as they age.

"The hugely valuable research from IDS-TILDA has demonstrated that people with intellectual disability experience the effects of ageing at an earlier age than the general population and have many associated health and social support needs. It is essential that service providers who support people with intellectual disability, are empowered with evidence to support people to have the best possible outcomes and quality of life as they age, and to develop sustainable models of practice that acknowledge the challenges of the changing needs of older adults with intellectual disabilities. We are delighted to be partnering with Trinity Centre for Ageing and the Life Course in Intellectual Disability, and the HSE to create this important space to share and reflect on research findings and how these can influence and support practice now and into the future."

Dr Alison Harnett, Chief Executive Officer, National Federation of Voluntary Service Providers



Translating IDS-TILDA Evidence into National Policy

In November, Professor Mary McCarron, Professor Éilish Burke, Dr Martin McMahon and Dr Eimear McGlinchey presented evidence from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) to the Joint Oireachtas Committee on Disability Matters, as part of its consideration of future-proofing supports to improve the life and longevity of people with disabilities.

Drawing on findings from IDS-TILDA, the TCAID team highlighted progress in the inclusion and participation of people with intellectual disabilities in their communities, while also identifying areas requiring continued attention. These included preventable and treatable health inequalities, the contribution of Registered Intellectual Disability Nurses (RNIDs), workforce and resource pressures, and the need for continued research into poorly understood health issues affecting people with intellectual disabilities.

The engagement provided an important opportunity to bring longitudinal research evidence directly into national policy discussion and to demonstrate how IDS-TILDA data can support longer-term planning for the health, care and support needs of people with intellectual disabilities.



"IDS-TILDA data demonstrates that the lives of people with intellectual disabilities have improved—sometimes dramatically—in many areas over time... We have the strongest data in the world on the physical and social determinants of health and wellbeing for people with intellectual disabilities as they age. Let's use it wisely to inform policy and the necessary support to ensure that people with intellectual disabilities can age with dignity—age with pride."

Professor Mary McCarron, Professor of Ageing and Intellectual Disability

The evidence presented by TCAID generated discussion among Committee members on the importance of data for planning, access to healthcare, workforce capacity, community living, health inequalities and supports across the life course.

Deputy Pauline Tully specifically highlighted the value of IDS-TILDA, describing the work as "fantastic" and emphasising the importance of using the evidence for forward planning:

"We need to use it to plan for our citizens and ensure we have inclusive communities where everybody is equal, catered for and valued." **- Deputy Pauline Tully**

Senator Fiona O'Loughlin similarly emphasised the importance of having robust evidence available to policymakers, noting the wider lack of disability data before stating:

"One of the big issues that we have come up against in all the different groups that we meet is the lack of data. It is difficult to measure and to put programmes in place, but Professor McCarron has the data." **- Senator Fiona O'Loughlin**

The discussion also demonstrated how the evidence prompted consideration of specific policy and service challenges. Deputy Dessie Ellis highlighted the significance of Ireland having what Professor McCarron described as the strongest data of its kind internationally and questioned how this evidence could be used to future-proof supports and improve longevity. Deputy Frankie Feighan focused particularly on the stark oral-health inequalities identified by the research and the need for improved access to appropriate services.

The meeting was attended by Deputies Michael Moynihan (Chair), Dessie Ellis, Frankie Feighan, Jennifer Murnane O'Connor and Pauline Tully, with Senator Fiona O'Loughlin present and Senator Victor Boyhan in attendance.



Breaking Barriers: Enhancing Cancer Care for Individuals with Intellectual Disabilities

In May, TCAID hosted *Breaking Barriers: Enhancing Cancer Care for Individuals with Intellectual Disabilities*, a landmark conference addressing the under-researched intersection of cancer and intellectual disability. The event created a forum for sharing emerging evidence, lived experience and practice-based knowledge, with a focus on addressing inequalities across cancer prevention, diagnosis, treatment and care.

People with intellectual disabilities experience significant inequalities in cancer care, including barriers to screening and early detection, challenges in accessing appropriate services, and poorer outcomes. Breaking Barriers responded to the need for greater research, awareness and coordinated action by bringing together more than 200 participants, including people with intellectual disabilities, family members, healthcare professionals, researchers, policymakers, service providers and advocacy organisations.



Art competition winners - Anastasiya Solomonenko, and Carlos Zurbito with Stephanie Corrigan

Caroline Ryan and Lisa McGuinness

The programme brought national and international expertise together to examine cancer epidemiology, screening and early detection, treatment, ethics and advocacy, health surveillance, and inclusive policy and practice. Contributors included researchers and representatives from Radboud University Medical Centre, Queen's University, Canada, Trinity St James's Cancer Institute, the HSE National Cancer Control Programme, the Irish Cancer Society, the National Screening Service, the Decision Support Service, CUPID COST Action and Stewarts Care.

The conference was opened by Minister Hildegarde Naughton, Minister of State with responsibility for disability, and Professor Brian O'Connell, Dean of Trinity's Faculty of Health Sciences. Their contributions reinforced the importance of research-informed policy and coordinated action to address inequalities in cancer care for people with intellectual disabilities.

Accessibility and meaningful participation were embedded throughout the conference. Following each expert presentation, PPI advocates Mei Lin Yap and Shannon O'Farrell Molloy provided accessible summaries of the research and key messages, enabling participants with different communication and information needs to engage with the evidence and subsequent discussions.

This approach provided a practical model for inclusive knowledge translation, demonstrating how accessibility can be incorporated into the design of research and policy events rather than treated as an addition. The model developed through Breaking Barriers also provides an approach that can be shared with others seeking to make research dissemination and engagement more accessible.

The conference also created opportunities for people with intellectual disabilities to shape the conversation beyond traditional presentations. A national art competition invited participants to express their perspectives on cancer and inclusion, receiving more than 70 entries. Selected artwork was showcased alongside *Through Our Eyes: Art as a Voice of Participation*, providing another medium through which lived experience could inform discussion and understanding.

Concurrent sessions further enabled participants to explore practical and research-informed responses across ethics and advocacy, early detection and health surveillance, and inclusive policy and practice, connecting evidence with challenges and opportunities across healthcare and disability services.

Breaking Barriers marked an important step in developing a stronger research, policy and practice agenda around cancer and intellectual disability. By bringing together research evidence, clinical expertise, policy perspectives and lived experience, the conference identified areas for future collaboration and highlighted practical approaches to improving inclusion and accessibility within cancer services.

The knowledge and relationships developed through the conference will inform TCAID's continued work in this emerging area, supporting further research and cross-sector collaboration aimed at improving cancer prevention, diagnosis, treatment and care for people with intellectual disabilities.

"Breaking Barriers marked a milestone in recognising and responding to the long-overlooked intersection of cancer and intellectual disability. This was the first event of its kind to bring together such a diverse and committed group of voices — from lived experience to clinical and policy expertise — all focused on a shared goal: to improve cancer care for individuals with intellectual disabilities. We are deeply grateful to everyone who contributed to the day and look forward to building on this momentum in collaboration with partners across healthcare, research, and advocacy." - **Dr Martin McMahon**

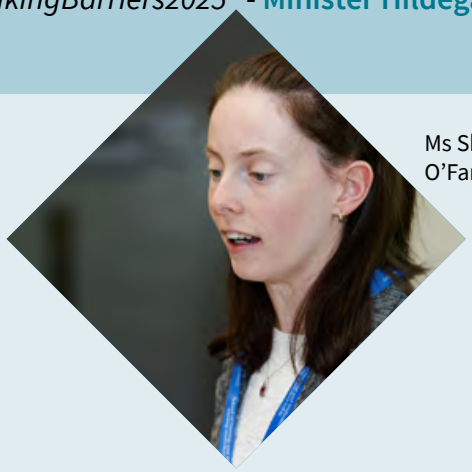


Dr Martin McMahon

"Wonderful to open Breaking Barriers Enhancing Cancer Care for Individuals with Intellectual Disabilities. A real highlight was meeting Shannon & Mei Lin-their lived experience & passion are powerful reminders that the best solutions come from listening first #BreakingBarriers2025" - **Minister Hildegarde Naughton @1Hildegarde**



Minister
Hildegarde Naughton



Ms Shannon
O'Farrell Molloy



Broken Systems and Too Little Money: Informing the Future of Disability and Ageing Policy

The Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID) convened a high-level policy roundtable, Broken Systems and Too Little Money: How Will We Meet the Needs of Ageing People with an Intellectual Disability?

The discussion brought together senior policymakers, regulators, service leaders, researchers, clinicians, and advocates from Ireland and internationally. Attendees included representatives from government departments, the Health Service Executive, regulatory bodies, national advocacy organisations, and universities, alongside people with lived experience and family members. This breadth of perspectives enabled discussion across policy design, service delivery, regulation, and rights-based practice.

A central focus of the roundtable was the question of what constitutes a fair, sustainable, and rights-based model of care for ageing populations with intellectual disabilities—particularly for those who wish to age in place within their communities. The absence of simple solutions underscored the need for coordinated policy action across health, housing, social care, and disability services.

By creating a space for open dialogue between evidence, lived experience, and policy leadership, the roundtable contributed directly to ongoing national conversations on disability reform, ageing policy, and service sustainability. Insights from the event will inform future policy engagement, research priorities, and cross-sector collaboration aimed at supporting long-term, person-centred solutions.

PhD Student Profile



Stephanie Corrigan

My Research

My research examines menopause in women with intellectual disabilities. Research on menopause in this population is scarce, particularly surrounding the effect of menopause on the mental health, despite extensive research on this topic in the general population. Given the significant mental health difficulties, behaviours that challenge and communication difficulties typically faced by this group, I thought it pertinent to examine menopause and its related effect on mental health in women with intellectual disabilities.

Why It Matters

This research is critical to provide the first empirical evidence examining menopause and mental health in this population. Raising awareness around the potential effects of menopause on mental health such as increased anxiety, mood changes and behaviours that challenge could help to improve knowledge on menopause among women, their carers and healthcare providers. Increased awareness of menopause and related effects on mental health could help to reduce the possibility of diagnostic overshadowing, whereby mental health symptoms are incorrectly attributed to the wrong causes.

From Research to Impact

The findings from my PhD journey could be used to inform Women's Health policy in Ireland, which currently lacks tailored guidance and action points to improve menopause care and treatment for women with intellectual disabilities. Furthermore, the findings could be used to inform guidelines to improve clinical practice and menopause care for this population. Finally, the educational materials I plan to develop as the primary output from my PhD can be used to empower women to improve their education on menopause and seek help for menopause to ultimately improve health outcomes

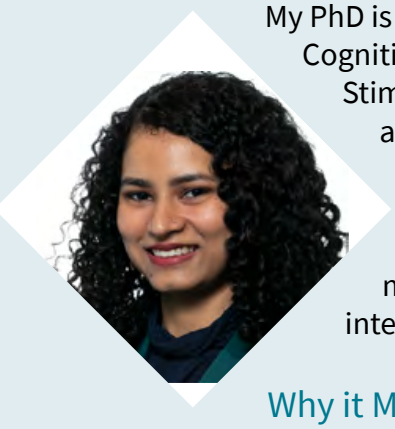
Highlights from My PhD Journey

Key highlights have been:

- Presenting my preliminary PhD findings at the IASSIDD World Congress in Chicago in 2024.
- Collaborating with women with intellectual disabilities to run dissemination events on menopause. Read more here: https://www.tcd.ie/tcaid/research/tcaid-in-focus/september-2024/september-tcaid-in-focus-sexual--reproductive-health-in-women-with-an-intellectual-disability/
- Publishing my scoping review The Impact of Menopause on the Mental Health of Women with an Intellectual Disability. Available here: https://doi.org/10.1111/jar.70017
- Working with PPI contributors to inform and guide qualitative data collection on menopause.
- The privilege of learning about women's experiences of menopause through their lived experience perspective.

Pavithra

My Research



My PhD is titled the CASTLE Study: Cognitive Stimulation Therapy for Quality of Life and Cognitive Engagement in Intellectual Disability. It examines whether group Cognitive Stimulation Therapy (CST) can support adults with intellectual disabilities who are ageing and at risk of dementia, including people with Down syndrome. The key gap is that CST is well established for dementia in the general population, but evidence for people with intellectual disabilities remains limited and mostly feasibility focused. My study also explores how CST impacts cognition, mood, quality of life and it also studies brain activity and engagement with the intervention and with the group using EEG.

Why it Matters

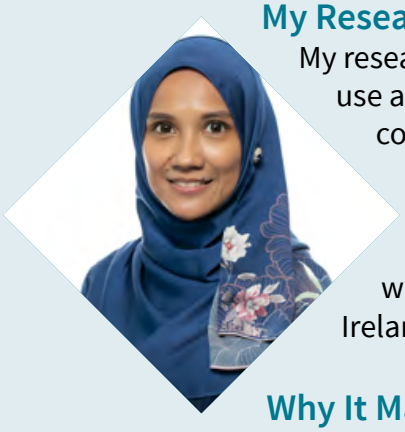
It matters because there is very little evidence regarding how CST may work for this population. I am collecting qualitative experiential data, quantitative outcome data, as well as neurophysiological EEG data which show how, why and if CST could be a valuable intervention to be added in the routine of a day-service.

From Research to Impact

The results of the study will provide more evidence for this understudied area and potentially help in promoting an intervention scalable at a national level.
Highlights from my PhD Journey

I got my scoping review paper published in Frontiers for Neuroergonomics and presented at the SNM conference at THEConf 2026.

Dr Noor Syahidah Binti Husamuddin



My Research

My research utilises valuable data from IDS-TILDA to examine oral health service use among older adults with intellectual disabilities in Ireland. Through three complementary studies, I investigated current patterns and determinants of dental attendance, continuity of service use across five waves spanning 13 years, and intergenerational changes between comparable age cohorts. I also compared the experiences and oral health outcomes of older adults with intellectual disabilities with those of the general older population in Ireland.

Why It Matters

People with intellectual disabilities experience substantial oral health inequalities, yet their use of dental services across the life course remains under-researched. My findings revealed an important gap between attending dental services and achieving good oral health. Although older adults with intellectual disabilities reported higher levels of regular dental attendance than the general older population, they experienced poorer oral health outcomes. Only just over half of the participants maintained regular attendance across all five IDS-TILDA waves. Living arrangements, structured support, dental provider and dentition status also influenced access to and continuity of care. These findings demonstrate that regular attendance alone does not necessarily ensure appropriate, preventive and person-centred oral healthcare.

From Research to Impact

My research provides evidence to support the development of more equitable and preventive oral healthcare for people with intellectual disabilities as they age. The findings can inform Irish oral health policy, disability service planning and the implementation of Smile agus Sláinte, particularly by highlighting the need to address the gap between service attendance and oral health outcomes. Recommendations include strengthening preventive care, expanding access to Special Care Dentistry, providing mobile and outreach services, and ensuring that people without natural teeth continue to receive regular oral health assessments. Ultimately, the research advocates for oral healthcare that responds to changing needs across ageing, living environments and levels of support.

Highlights from My PhD Journey

- Completing the first comprehensive mapping of oral health items across all five waves of IDS-TILDA, establishing a structured foundation for the analysis and improvement of oral health data of IDS-TILDA.
- Working closely with the statistician and data team to develop meaningful derived variables that enhanced the IDS-TILDA data dictionary and strengthened its value for future research.
- Presenting the preliminary findings from my PhD research at the MADPHS 2024 Conference in Malaysia and engaging with the wider dental public health research community.
- Developing expertise in harmonising complex multi-wave data and undertaking complementary cross-sectional, longitudinal and intergenerational analyses.
- Collaborating with researchers across the fields of intellectual disability, ageing, oral health and health services research, which strengthened the interdisciplinary interpretation and relevance of the findings.
- Preparing a programme of peer-reviewed publications arising from the three PhD studies, with the aim of completing their publication by 2027.
- Bringing together oral health, ageing and intellectual disability perspectives to support the translation of research evidence into recommendations for policy, service planning and clinical practice.



Eilish King



My Research

My research focuses on sensory processing patterns of adults ageing with intellectual disabilities in Ireland. How we register and respond to sensory information from the world around us can change how we participate in daily life. To date, most of the research in this area has focused on children and neurodivergent young people. My research explores sensory processing patterns amongst adults with intellectual disabilities, and the associations between patterns of sensory processing, and participation in daily life.

Why It Matters

Some adults with intellectual disabilities may present with patterns of sensory processing that differ from the neurotypical general population. However, the associations between sensory processing patterns and participation in daily life activities for adults with intellectual disabilities are not well understood. Developing a greater understanding of sensory processing patterns is important to inform supports to enable adults with intellectual disabilities to participate in daily life.

From Research to Impact

Through developing greater understanding of the impact of sensory processing patterns on participation in daily life activities, my research aims to inform occupational therapy practice and ultimately promote greater understanding of the sensory preferences of adults with intellectual disabilities.

Highlights from My PhD Journey

I have had many wonderful opportunities to learn from adults with intellectual disabilities, my colleagues in TCAID, academic experts and fellow occupational therapists during my PhD journey. A particular highlight of this year was the opportunity to attend and present my research at the International Association for the Scientific Study of Adults with Intellectual and Developmental Disabilities (IASSIDD) World Congress.



Katrina Byrne

My Research

My PhD examines the oral health of older adults with intellectual disabilities in Ireland and its relationship with wider health, including pneumonia, functional decline and mortality. People with intellectual disabilities have traditionally been excluded from national oral health surveys, leaving significant inequalities hidden from services and policymakers.

To address this gap, I developed and validated the Modified Oral Status Survey Tool (MOSST) and embedded it within IDS-TILDA. This created the first nationally representative, clinically assessed oral health dataset for older adults with intellectual disabilities in Ireland. My findings demonstrate substantial levels of tooth loss, untreated oral disease and reduced oral function. They also show associations between oral health, wider health vulnerability and mortality.

Why It Matters

Oral health affects comfort, dignity, nutrition, communication, social participation and overall health. Oral pain and deterioration may not always be easily recognised or communicated, particularly when a person depends on others for daily care.

My research challenges the assumption that poor oral health and tooth loss are inevitable consequences of intellectual disability or ageing. Instead, these outcomes reflect lifelong barriers to preventive, restorative and rehabilitative care. Making these inequalities visible provides people with intellectual disabilities, families, services and policymakers with evidence to advocate for earlier intervention and more equitable care.

From Research to Impact

My ambition is to ensure that people across all levels of intellectual disability are included in oral health research. This includes people with severe or profound intellectual disabilities, those who communicate in different ways and people with complex support needs. No voice, experience or health outcome should be left out because traditional research methods are not sufficiently accessible or flexible.

MOSST demonstrates that inclusive oral health research is both possible and scientifically robust when reasonable adjustments and person-centred approaches are provided. It has the potential to inform national surveillance, professional education, supported mouth care, earlier recognition of deterioration and timely referral to dental services.

The research also provides evidence to support the oral health commitments within Ireland's National Human Rights Strategy for Disabled People 2025–2030. Inclusive data can help translate these commitments into meaningful action by identifying inequalities, informing services and measuring progress towards oral health equity.

Highlights from My PhD Journey

Key highlights have included:

- Successfully including 469 people in the IDS-TILDA oral health assessment, demonstrating that people across all levels of intellectual disability can participate meaningfully in clinical research.
- Working with a PPI panel of adults with intellectual disabilities to ensure MOSST was accessible, relevant and respectful.
- Raising awareness that poor oral health is not a minor or isolated issue, but can affect eating, communication, dignity, wider health and mortality.
- Publishing two peer-reviewed papers and presenting my research at national and international conferences.
- Receiving an RCSI Clinical Bursary and awards from the Dental Health Foundation and IADR DASCR.
- Contributing to and reviewing the WHO policy brief, Oral Health Equity for Persons with Disabilities.

The most rewarding part of my PhD has been working alongside people with intellectual disabilities, families, nurses, dental professionals, advocates and passionate researchers who are eager to create change. Seeing the research contribute to greater awareness and begin to influence education, policy and practice has been one of the proudest aspects of my PhD journey.



Dr Shiling Chen

My Research

My research examines sarcopenia in older persons with intellectual disabilities. Research on sarcopenia in this population is scarce, despite the vast amounts of research in the general ageing population demonstrating that the condition can potentially be prevented and even reversed. Given the likely complex negative consequences of developing sarcopenia in this group, I thought it pertinent to examine the prevalence of sarcopenia and its related determinants and health outcomes in persons with intellectual disabilities.

Why It Matters

This research is critical in being the first to use established criteria from the general population to assess risk of sarcopenia in this population. Understanding the prevalence of sarcopenia and its associations such as age, level of intellectual disability and health outcomes such as falls and mortality will improve knowledge on sarcopenia amongst clinicians and researchers. This can lead to improved diagnosis and interventions in this group, potentially reducing the negative consequences of secondary disability on people with intellectual disabilities and their carers.

From Research to Impact

The findings from my PhD journey will add knowledge to this field, but more importantly, can promote early screening and diagnosis, resulting in timely interventions to improve quality of life. Furthermore, using criteria and tools from the general population may allow greater uptake and ease of assessment in mainstream health services to promote inclusion and reduce diagnostic overshadowing.

Highlights from My PhD Journey

- Published my scoping review protocol ‘’Sarcopenia in Adults with Intellectual Disability: A Scoping Review Protocol to map and describe the existing research’’ in HRB Open Research in May 2025
- Presented the findings of my scoping review on sarcopenia at the 5th IASSIDD Asia Pacific Congress in Singapore in October 2025
- Submitting my scoping review ‘’Sarcopenia in Adults with Intellectual Disability: A Scoping Review’’ for publication in 2026
- The privilege of working closely with the IDS-TILDA team particularly the invaluable experience of meeting some of the participants of the longitudinal study firsthand

Margaret Haigh



My Research

My research explores good quality end-of-life care for people with intellectual disabilities. This includes establishing what factors comprise this care and who are the people in need of it. My research particularly focusses on developing a means of identifying in advance those people with intellectual disabilities who may be in need of end-of-life care. This will allow appropriate care measures to be put in place early.

Why It Matters

This research is important because the challenges that people with intellectual disabilities face throughout their lives extend to end-of-life care. Not only do people with intellectual disabilities experience barriers accessing end-of-life care, but their need for end-of-life care is often not recognised until a late stage. Identifying a person's end-of-life care needs early, ensures that the person is provided with the best possible symptom management and can maximise opportunities to plan for their remaining time.

From Research to Impact

By identifying what good quality end-of-life care looks like, my research will set a benchmark against which everyday end-of-life care can be measured. This will highlight where gaps in current practice may occur and improvements are required.

By developing a tool to identify those potentially in need of end-of-life care, my research will support readiness on the part of organisations and caregivers to deliver good quality end-of-life care, ensuring that the needs of the person are met.

Highlights from My PhD Journey

Key highlights from my PhD journey to date focus on the presentations I have made and articles published in relation to my research. These include presenting my preliminary findings at the Trinity Health and Education International Research Conference (THEconf2025) and at the IASSIDD 5th Asia-Pacific Congress in Singapore. Both of these conferences were held in 2025.

The protocol for my literature review was published in 2024.



Isabel Ryan

My Research

My research centres around the feasibility and impact of the new Optimising Pharmaco-Therapy and Improving Medication for Ageing with Intellectual Disability (OPTIMA-ID) screening tool, which has been specially-designed for medicines optimisation in older adults with intellectual disability to ensure they are prescribed the most appropriate and effective medicines for their medical conditions as they age.

Why It Matters

People with intellectual disabilities often experience a high burden of medicines use including greater rates of psychotropic, anticholinergic, and sedative medications. They also have unique healthcare needs and frequently experience health disparity. Medicines optimisation is an important aspect of care that aims to ensure safe and effective use of medicines, preventing unnecessary medication, adverse drug events, falls, and hospitalisation.

From Research to Impact

My work is providing new insight into the prevalence of potentially inappropriate prescribing (PIP) and other healthcare management issues and their association with health outcomes. Research findings are relayed to the individuals who will benefit from use of this tool in practice through the TCAID PPI panel. The goal is to further contribute to evidence-based practice and improve health status and quality of life for older adults with intellectual disability in the l ong-term.

Highlights from My PhD Journey

- Presenting my PhD findings at the Trinity Health and Education International Research Conference and the Health Services Research & Pharmacy Practice Conference at Queen's University Belfast this year.
- Performing data collection for the sixth Wave of IDS-TILDA and learning more about the experience of medicine and healthcare directly from the people who will benefit from my research.
- Undertaking postgraduate certificates in healthcare innovation and statistics and data science to develop new skills to support my PhD work.
- Publishing my study protocol on the computational application of OPTIMA-ID to Wave 5 of IDS-TILDA

Marianne Fallon



My Research

There remains a gap in the conceptualisation of dementia risk and subsequent modelling of dementia risk factors for those ageing with Down syndrome. This is particularly pertinent given the significant likelihood of Down syndrome related Alzheimer's Disease (DSAD) developing in this population with age. The aim of my research is to explore the influence of various biopsychosocial factors on the risk of developing dementia in a sample of people ageing with Down syndrome. The research objectives include exploring if people ageing with Down syndrome have a different biopsychosocial risk factor profile for dementia, examining if generic dementia risk factors emerge as statistically significant for this population and if there is a cumulative effect of these risk factors on age of dementia diagnosis in the sample.

Why It Matters

This research addresses under-explored questions in the literature, researching the biopsychosocial experience of those ageing with Down syndrome and particularly how these biopsychosocial factors influence dementia risk. Given the differing life experiences of those ageing with a pre-existing disability, a varying dementia risk profile may pertain to those ageing with Down syndrome. Attention has been paid in the literature on reviewing some potential risk and resilience factors for this population in recent times. However, there remains a need for a dementia risk model to be developed and tested for this population. This requires an exploration of how risk profile may differ from the general population, including consideration of risk factors that may be more specific to this population. This information needs to be drawn from the biopsychosocial life experience of those ageing with Down syndrome.

From Research to Impact

Whilst the genetic risk for DSAD is almost universal for people ageing with Down syndrome, this research is exploring the biopsychosocial dementia risk factors that may be important to target for intervention as people with Down syndrome age.

Although such biopsychosocial targeted risk interventions may not reduce the risk of developing dementia, it may delay the onset of dementia and / or support more positive ageing overall for this cohort. This is a population deserving careful consideration of their ageing experiences and how these may diverge from the experience of the general population, leaving them at risk of adverse ageing circumstances, as well as their increased dementia risk. A focus on increased health span promotion and compression of morbidity, even with the acknowledged ceiling on lifespan due to higher dementia risk, is crucial for people ageing with Down syndrome in Ireland.

Highlights from My PhD Journey

Particular highlights for me in recent years have been travelling with Professor Mary McCarron to the Horizon 21 Consortium gathering in Munich 2023 and participating in the international Expert group revising the CAMCOG-DS-1 into a second edition. These opportunities enabled me to listen to and learn from eminent researchers, scientists and clinicians in the field of intellectual disability and dementia.

I have greatly enjoyed the opportunities gained during my PhD journey to improve the clarity, precision and depth of my thinking and writing, to grow my confidence in presenting my ideas and to be able to respond to challenging questions in an open and considered way. A particular thanks to my supervisors Dr. Eimear McGlinchey, Professor Mary McCarron, Professor Philip McCallion and Dr. Jan de Vries, for their support and mentorship, enabling me to grow and develop as a researcher.

Highlights: Contributing to Society

Civic Engagement Through Inclusive Teaching and Learning

The Trinity Centre for Ageing and the Life Course in Intellectual Disability is thrilled to share that Dr Eimear McGlinchey, Assistant Professor in Intellectual Disability, has been awarded the Civic Engagement Award for Teaching and Learning for her work in supporting the inclusion of people with intellectual disabilities within the School of Nursing and Midwifery nursing programme. Provost Linda Doyle presented four Civic Engagement Awards to staff at a ceremony on Friday, 6 December 2024. The Awards, sponsored by the Civic Engagement for Societal Impact unit, are for proposed civic engagement projects to take place in 2025.

Dr McGlinchey's project is focused on creating resources to support the inclusion of people with intellectual disabilities as co-educators and participants in assessments within the intellectual disability nursing programme. The project aims to keep people with intellectual disabilities involved in teaching and assessment structures to ensure that the lived experience of people with intellectual disability shapes how future nurses learn, enabling empathy, critical thinking and person-centred care skills.

Traditional nursing education has often excluded the direct voices of people with intellectual disabilities, instead presenting their experiences through the interpretative lens of non-disabled educators. This exclusion perpetuates hierarchical structures that marginalise people with an intellectual disability and limits opportunities for students to engage authentically with the lived experiences of the population they are training to support.

Through the award, the team, led by Dr McGlinchey, will co-develop practical resources, such as classroom guides, training materials, and an assessment framework for Objective Structured Clinical Examinations (OSCEs). These resources will ensure that inclusion is both effective and meaningful, equipping everyone involved with tools to collaborate confidently. Over the course of the project, the team will work closely with people with intellectual disabilities to ensure their expertise shapes every stage. They will also focus on making all materials clear, accessible, and practical for educators, participants, and students.

This will build on the leadership Dr McGlinchey has shown as the lead of her current models through the engagement of two people with an intellectual disability as paid guest lecturers. However, while this has promoted the voice of lived experience, it remains largely restricted to this one module and participation in OSCEs remains underexplored for this population. Through this award, this work can be expanded for increased inclusion of people with intellectual disabilities within the Nursing and Midwifery Programme, targeting these underexplored areas.

Moreover, these resources will be designed for sharing with others beyond Trinity College Dublin who wish to adopt similar practices. By encouraging wider uptake, the project can contribute to fostering a more inclusive approach to healthcare education across institutions. The project is supported by members of the intellectual disability nursing team in the School of Nursing and Midwifery, Ms. Mei Lin Yap, individuals with intellectual disability, and also includes the expertise of AVISTA CLG.

"I have been co-lecturing with Eimear in Trinity for the last few years and I feel like I've made a difference. Inclusion gives me a voice in training the next generation and this project will help many more people with intellectual disability to be included."
Ms. Mei Lin Yap, Ambassador Liaison Officer, TCAID

"I'm delighted to collaborate with people with intellectual disability, as their inclusion helps to shape how future nurses learn. Their lived experience is at the heart of empathy and person-centred care." **Dr Eimear McGlinchey, Assistant Professor in Intellectual Disability**





Promoting the Health and Wellbeing of Women with Intellectual Disabilities

To mark the International Day of Action for Women's Health 2025, the Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID), led by Gavin Dann, Louise Lynch, and Kieva Leslie, hosted a meaningful and inclusive day of activities focused on supporting the health and wellbeing of women with intellectual disabilities.

On 28 May 2025, TCAID hosted a specially designed Women's Health and Wellbeing Exercise Class at the Trinity College Sports Centre. Thirty women from Stewarts Care, Avista, and St. Michael's House participated in the hour-long session, which was tailored to suit a range of physical abilities and needs.

Led by the engaging and supportive instructors Caitríona and Belinda from Trinity Sport Centre, and assisted by TCAID staff, the class provided an enjoyable and energising experience for all involved. Their positive energy and encouragement created an inclusive atmosphere where everyone felt welcomed and motivated to participate. We also received excellent support from Naz Velic, Participation & Engagement Officer, whose assistance contributed greatly to the success of the session.



At the end of the session, each woman received a certificate of participation, a goodie bag, and a home exercise booklet to continue promoting physical activity beyond the day itself. A well-earned lunch followed the class, offering time to relax and celebrate the achievements of the morning together.

The celebration continued the following day, 29 May 2025, with a dedicated webinar exploring the unique health and wellbeing challenges faced by women with intellectual disabilities. This session brought together researchers, practitioners, and advocates to share current research, frontline experience, and practical strategies for improving care and support. Topics discussed included bone health, menopause, obesity, social determinants of health, loneliness, and mental health. Speakers included: Prof Éilish Burke, Dr Judy Ryan, Dr Fidelma Flannery, Dr Kálya Lima, Anne Power, Carmel Erksine, Stephanie Corrigan, Niamh Carberry, Angela Colgan, Monika Carter, Lisa McGuiness, and Kelly Fitzgerald.

The webinar highlighted the importance of inclusive healthcare, accessible services, and the value of lived experience in shaping better outcomes. It was a rich exchange of ideas that underlined the need to bridge the gap between research and practice in women's health. Together, the exercise class and webinar showcased the importance of recognising and responding to the specific health needs of women with intellectual disabilities.

We are incredibly proud of the women who took part with such enthusiasm, commitment, and positivity, and we extend our thanks to the instructors, staff, and speakers who helped bring this celebration to life.

Events like this serve as a powerful reminder that health and wellbeing must be inclusive, empowering, and accessible to all. When we come together in partnership, we move closer to a future where every woman is supported to thrive.



In Gratitude, In Memory, In Celebration: Honouring the Lives and Legacy of IDS-TILDA Participants

The Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID) hosted a special commemorative ceremony in Trinity Chapel to mark the International Day of Persons with Disabilities and honour the lives and contributions of people who participated in the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA).

The ceremony, themed “In Gratitude, In Memory, In Celebration,” provided an opportunity to remember the more than 270 IDS-TILDA participants who have passed away, while celebrating the lasting contribution of all participants to research on ageing and intellectual disability in Ireland.

The programme included opening remarks from Professor Mary McCarron and Provost Linda Doyle, alongside readings from Trinity College Dublin, Stewarts Care, Avista, and family members. Music and readings by people with intellectual disabilities brought a strong sense of participation and celebration to the occasion. Musical contributions included the Sunbeam Music Programme and Viewpoint Advocacy Group, accompanied and supported by members of the Sunbeam and wider community, as well as David Banfield and Deirdre Banfield.

A candle procession provided a particularly poignant moment of remembrance, with candles carried by representatives from Trinity College Dublin, St Hilda’s Services, and other disability services. The ceremony also featured commemorative keepsakes created by the St Raphael’s CETB Art Group in collaboration with St Raphael’s Therapy Garden and Youghal Community Garden, and a personal reflection by Teresa Healy.



The ceremony recognised the generosity of participants who shared their lives and experiences with IDS-TILDA, helping to build knowledge that can improve the lives of future generations of people with intellectual disabilities. TCAID extends its sincere thanks to the participants, families, staff, contributors and supporters whose continued commitment makes this work possible.

The commemoration was a meaningful opportunity to remember those who are no longer with us, to celebrate their lives and contributions, and to acknowledge the enduring legacy of everyone who has participated in IDS-TILDA.

"I do want to say most sincerely that being a small part of such a special event is something that will stay with me forever. The occasion from start to finish was a credit to you at the helm, and all involved. Remembering loved ones, who no longer sit at our tables, is very important to me- and you are keeping these memories alive while giving acknowledgement and importance for the role they played in our lives." – **Commemorative Committee Service Representative**

"I will wear the token of appreciation with pride, this special Irish emblem, so apt in representing IDS-TILDA as I reflect on all who have been involved in IDS-TILDA." – **Family Member**

"Everybody was so delighted to be part of this very special and moving occasion. It was so respectful, calm, meaningful and inclusive. In keeping with your theme of memory and gratitude this will be cherished as a beautiful memory." – **Independent Advocacy Facilitator**

"It is a privilege to be involved in such a unique project watching everyone excel, having fun and accomplishing an enormous sense of pride." – **Independent Advocacy Facilitator**



Bone Health Screening: A Game Changer for People with Intellectual Disability

European Researchers' Night at Trinity College Dublin provided an opportunity to share the impact of IDS-TILDA research into improving bone health screening for people with intellectual disability. The event included the launch of a new video about the research, followed by a panel discussion bringing together researchers, healthcare professionals and PPI contributors.

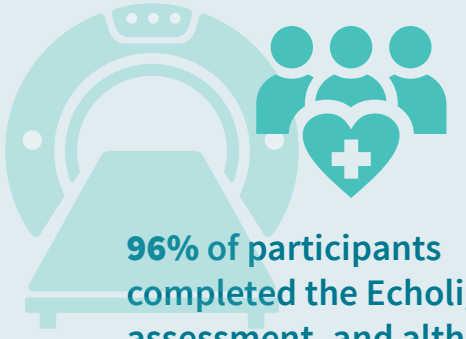
Research led by Professor Éilish Burke has highlighted the significant gap in osteoporosis screening among people with intellectual disability. Osteoporosis can develop at a younger age in this population due to a range of risk factors, yet traditional DXA scanning can be difficult or impossible for some people with intellectual disability due to a range of challenges.

Professor Burke and Anne Power, Advanced Nurse Practitioner at Wexford Residential Intellectual Disability Services, introduced Echolight, a portable Radiofrequency Echographic Multi-Spectrometry (REMS) device that offers a flexible alternative for assessing bone health. Unlike conventional DXA scanning, Echolight can be used in clinics, residential settings and, where appropriate, in people's own homes.

Importantly, people with intellectual disability were involved throughout the project. Lisa McGuinness, Shannon O'Farrell Molloy and Kelly Fitzgerald contributed their perspectives and lived experience to the research and were involved in the development of the video and the European Researchers' Night panel discussion. Their involvement helped ensure that the research and its impact were communicated in a meaningful and accessible way, while bringing the voices and experiences of people with intellectual disability to the centre of the conversation.

A feasibility study funded by the Nursing and Midwifery Planning and Development Unit (NMPDU) Southeast demonstrated the potential of this approach. **96%** of participants completed the Echolight assessment, and although **20%** of participants were anxious before the assessment, **100%** reported feeling more relaxed and informed after meeting the nursing team. **96%** also reported that the scan was easy to do.

The research has already translated into practice. Echolight has been endorsed by the Irish Osteoporosis Society for the diagnosis of osteoporosis in people with intellectual disability, and in 2023 the Health Service Executive funded the purchase of the first Echolight device in Ireland. The device is now being used by Anne Power to provide bone health screening within Wexford Residential Intellectual Disability Services.



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The event provided an opportunity to highlight this important journey from research to real-world impact and demonstrate the value of collaboration between researchers, healthcare professionals and people with intellectual disability. The integration of Echolight into the IDS-TILDA longitudinal study at Trinity College Dublin will enable further research into bone health across a larger population of people with intellectual disability in Ireland, with the potential to improve early detection, reduce fractures and enhance quality of life.

"The ladies directly involved still speak so highly of all they achieved via the short film and wonderful event, and they want to push themselves and achieve more… a key goal for so many of them is promoting their health, advocating for themselves and bringing what they learn to help others upskill." - **Lynda Smyth, Social Care Leader, Liffey Hub, Stewarts Care**





Growing Our Research Community

Person-centricity as an Approach to Well-being of People with Intellectual and Developmental Disabilities

In October, members of the Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID) and the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) attended the 5th International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Asian-Pacific Congress in Singapore. The theme for the congress was *'Person-centricity as an approach to well-being of People with Intellectual and Developmental Disabilities'.*

The congress provided an important opportunity for the TCAID and IDS-TILDA teams to share their research with an international audience and to explore how person-centred approaches can be applied across policies, services, programmes, practice and research for people with intellectual and developmental disabilities.

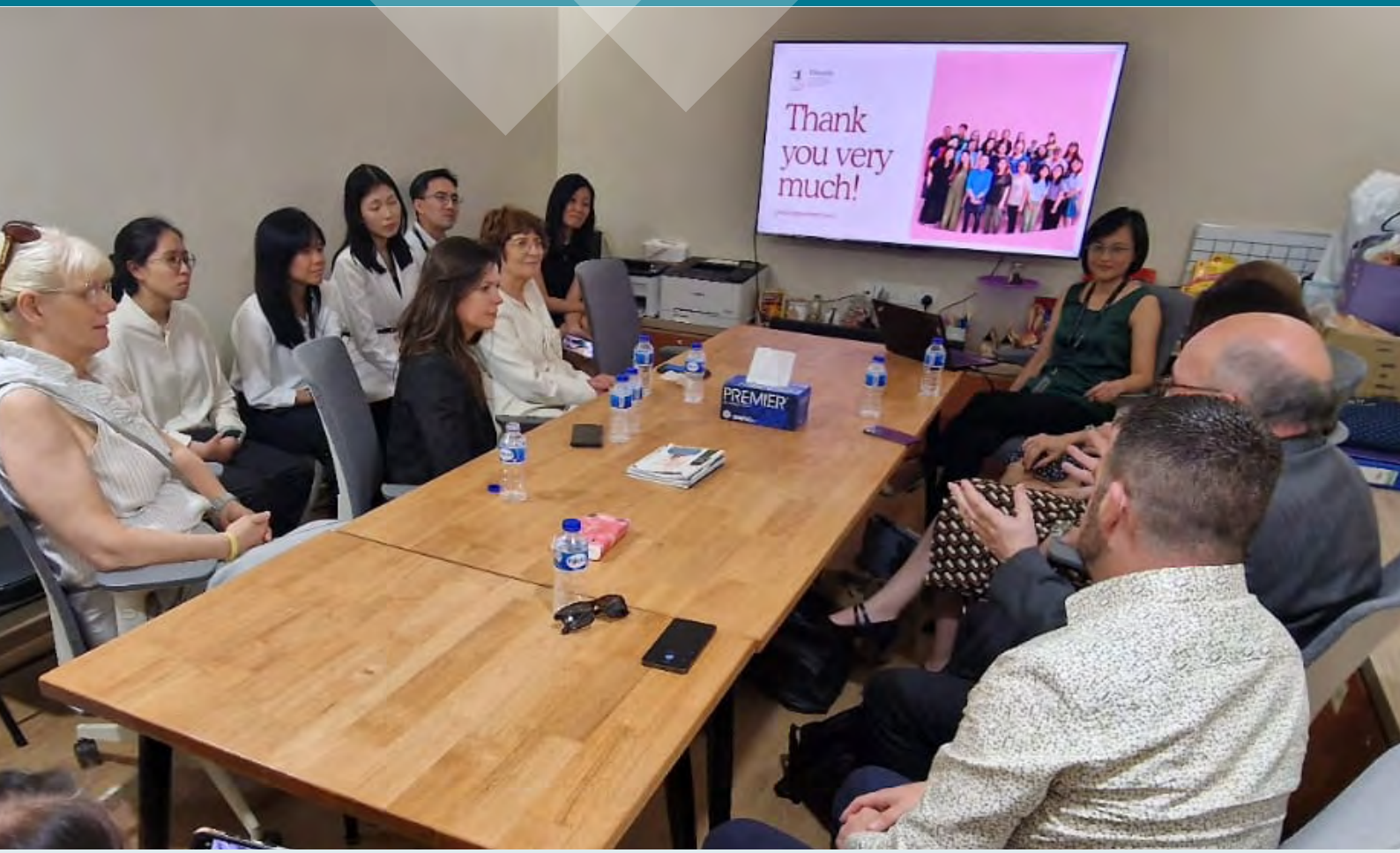
As part of the pre-congress programme, Prof Mary McCarron and Prof Philip McCallion delivered a workshop on supporting people with intellectual disabilities as they age and experience symptoms of dementia. Drawing on examples from Ireland and the United States, the workshop explored policies, innovative programmes, training, guides and guidelines that can be adapted and implemented in other settings. It highlighted the need for approaches to dementia assessment and care that are specifically tailored to people with intellectual disabilities, while emphasising that a return to institutional models of care is neither necessary nor acceptable. The workshop also demonstrated that effective, tailored and community-based approaches to dementia assessment, care planning, caregiver support and later-stage care are feasible and can be incorporated into broader dementia strategies and services.

The TCAID and IDS-TILDA team presented research across a number of areas. Under Exemplary Policies and Support, presentations focused on quality end-of-life care for people with intellectual disabilities, including *Key Factors for Quality End-of-Life Care for People with Intellectual Disabilities: A Critical Interpretive Synthesis Review Using a "Best-Fit" Framework Approach and An Exploration of End-of-Life Care for People with Intellectual Disabilities Using Framework Analysis.*

Under Physical and Mental Health, the team presented *Inclusive Bone Health Screening Using Echolight REMS Technology, Bridging the Gap Beyond DXA.* Two posters also focused on cancer and intellectual disability: *Cancer and Intellectual Disability: Lived Experiences and Healthcare Professionals' Perspectives (The EuCan Study)* and *A Longitudinal Exploration of Cancer and Associated Mortality in Older Adults with Intellectual Disability: Findings from IDS-TILDA.*

The latter poster, presented by Dr Martin McMahon and co-authored by Dr Louise Lynch, Ms. Shauna Walsh, Dr Andrew Wormald, Prof Mary McCarron, Prof Philip McCallion, Prof Éilish Burke, Prof Maeve Lowery, Dr Alyson Mahar, Ms Audrey O'Halloran, Dr Mark Ward, Prof Roman Romero-Ortuno, Dr Caitriona Ryan and Dr Martin McMahon, received an award for high-impact poster presentation. The research sheds important light on cancer risk, mortality and health inequities among older adults with intellectual disabilities, drawing on longitudinal data from IDS-TILDA. The award recognised Dr McMahon's contribution to advancing knowledge in this important area of health research.

TCAID also contributed to a roundtable with colleagues from the University of Southern Denmark, presenting *Addressing Inequities in Cancer Prevention and Diagnostics for Adults with Intellectual Disabilities: Insights from the CUPID COST Action*. This provided an opportunity to discuss international approaches to addressing inequalities in cancer prevention and diagnosis for adults with intellectual disabilities and to strengthen connections with colleagues working in this area internationally.



Participation in IASSIDD 2025 highlighted the breadth of research being undertaken by TCAID and IDS-TILDA, while providing valuable opportunities to share learning, develop international collaborations and grow our research community. The congress also provided an opportunity to look ahead to IASSIDD 2027 in Dublin, where TCAID will have the opportunity to welcome the international intellectual disability research community and build on these growing partnerships.

"I was delighted to attend the IASSIDD Asia-Pacific Congress in Singapore and to present our research alongside colleagues from TCAID and IDS-TILDA. The congress provided a wonderful opportunity to reconnect with longstanding friends and collaborators, share our collective work on ageing and intellectual disability, and strengthen international connections across research, practice and policy.

On a personal note, I was honoured to receive an Award for my High Impact Poster, recognising the contribution and impact of our ongoing research in this important area. I am already looking forward to welcoming colleagues and collaborators to Dublin for the IASSIDD 2027 World Congress." **Dr Martin McMahon, Associate Professor in Intellectual Disability Nursing**

IDS-TILDA Contributes to IDHealth Forum on Integrated Intellectual Disability Care

The IDS-TILDA team participated in the IDHealth Forum on Intellectual Disability Health in Singapore, engaging with Ministry representatives and health system leaders on building integrated, person-centred care. Trinity researchers shared Irish policy and practice experience informed by IDS-TILDA, contributing to cross-country dialogue with Singapore and Australia on health equity, dementia, and service integration for people with intellectual disabilities.



TCAID Leads European Collaboration on Equitable Cancer Prevention for People with Intellectual Disabilities

Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID) at Trinity College Dublin is a member of the COST Action CUPID (Cancer-Understanding Prevention in Intellectual Disabilities), a European network working to address inequalities in cancer prevention and screening for people with intellectual disabilities. TCAID's involvement in CUPID is led by Dr Martin McMahon, who leads Working Group 2 (WG2) on Cancer Prevention Policies: Audit and Evaluation.

CUPID brings together researchers, practitioners and stakeholders from across Europe and beyond to develop the evidence and knowledge needed to improve cancer prevention for people with intellectual disabilities. This is an important area of work, given the significant inequalities experienced by people with intellectual disabilities in cancer prevention, diagnosis and outcomes. WG2 is examining how different health systems deliver cancer prevention initiatives and screening programmes, with a particular focus on whether people with intellectual disabilities have equitable access to these services.

A major milestone for CUPID during 2024–2025 was the WG2/WG3 Joint Training School, *"Equitable Cancer Prevention and Screening: Advancing Inclusion for People with Intellectual Disabilities,"* held at Trinity College Dublin in May 2025. Organised by Working Groups 2 and 3 of the COST Action, the two-day training school brought together colleagues from across Europe and beyond to share knowledge, develop practical skills and explore approaches to improving equity in cancer prevention and screening.



The training school included expert presentations, interactive workshops and collaborative discussions examining health systems, policy, implementation and access to cancer screening. Forty-eight participants attended in person, with a further 20 joining selected sessions online. The programme generated valuable learning and recommendations for policy, practice and research, which will contribute to the ongoing work of the CUPID Action.

The training school was followed by the "Breaking Barriers: Enhancing Cancer Care for People with Intellectual Disabilities" conference at Trinity College Dublin on 14 May 2025, providing a further opportunity to bring the international community together and highlight the importance of addressing inequalities in cancer care.

CUPID has also supported international knowledge exchange through Short-Term Scientific Missions (STSMs). During 2025, Dr Bahar Aksoy from Akdeniz University, Türkiye, undertook an STSM at Trinity College Dublin under the guidance of Dr Martin McMahon. Her visit provided an opportunity to learn about intellectual disability nursing education in Ireland, cancer prevention and screening, and research undertaken through TCAID. As part of the visit, she also visited Stewarts Care to gain insight into the delivery of health and social care services for people with intellectual disabilities.

Reflecting on her experience, Bahar highlighted the distinctive role of intellectual disability nursing in Ireland and the importance of education in cancer prevention, early identification of cancer and promotion of healthy lifestyles. She also identified opportunities for learning from the Irish approach to inform the development of cancer prevention and screening strategies for people with intellectual disabilities in Türkiye.

Through CUPID, TCAID is helping to build a growing international research community focused on reducing cancer inequalities and improving access to prevention and screening for people with intellectual disabilities. The Action provides an important platform for researchers and practitioners to share expertise, develop new collaborations and translate evidence into policy and practice across Europe and beyond.

"My Short-Term Scientific Mission at Trinity College Dublin provided a valuable opportunity to learn about intellectual disability nursing education, cancer prevention and screening, and the research being undertaken to address health inequalities for people with intellectual disabilities. I particularly valued learning about the role of intellectual disability nurses in cancer prevention and early diagnosis in Ireland, as well as visiting Stewarts Care and seeing how multidisciplinary services support people with intellectual disabilities. I will take this knowledge back to Türkiye and use it to inform my work in developing more equitable cancer prevention and screening approaches for people with intellectual disabilities."
Dr Bahar Aksoy, Akdeniz University, Türkiye

Growing International Research Connections: An Erasmus+ Placement at TCAID - Aleksandra Obradović

TCAID was delighted to welcome two international students from the University of Belgrade, Aleksandra Obradović and Ana Momčilović. The eight-week Erasmus+ internship provided an opportunity for them to contribute to the analysis of the study's medication data. Reflecting on their experience, Aleksandra shared:

"I am grateful for the opportunity to be part of the Trinity Centre for Ageing and the Life Course in Intellectual Disability during 2 months Erasmus+ internship at Trinity College Dublin.
Thanks a million to my host and home university mentors Juliette O'Connell and Marina Odalovic for sharing their knowledge and expertise!

My research focused on identifying and quantifying longitudinal patterns of co-prescribing antipsychotics with anticholinergic medications for managing extrapyramidal symptoms in older adults with intellectual disabilities.

This experience strengthened my practical skills in clinical data analysis, statistical modelling, and enhanced my understanding of ensuring full compliance with GDPR and Health Research Regulations while working collaboratively with my amazing colleagues Ana Momčilović and Isabel Ryan.

I look forward to applying the skills and knowledge I have gained to future clinical research opportunities!"





Empowering Voices: The Impact of TCAID's Advisory Panel of People with Intellectual Disabilities











Empowering Voices: The Impact of TCAID's Advisory Panel of People with Intellectual Disabilities

September 2024

On 10 September, the PPI Panel met to advise researchers on the EuCan project, which investigates access to cancer care for people with physical and intellectual disabilities. Panel members shared ideas with the researchers about the types of interventions and information that could help people with intellectual disabilities notice cancer in time. Panel members also provided advice on participant recruitment materials and the Participant Information Leaflet.

November 2024

On 26 November, the PPI Panel met to judge the annual and highly anticipated Christmas card competition. They discussed co-designing an academic article with one of TCAID's researchers.

January 2025

The PPI Panel met on 22 January to co-write an accessible abstract for a journal article co-written with one of TCAID's postgraduate researchers. PPI Panel members helped the research team by validating the abstract and ensuring it was accessible.

March 2025

The PPI Panel met on 25 March to provide their feedback on the use of EEG for one of TCAID's PhD students. The Panel discussed EEGs, what they are and how they work, with the researcher demonstrating with one. PPI Panel members then each tried on the EEG cap and shared their thoughts and experiences about it.

June 2025

On 3 June, the PPI Panel gave advice on the development of the gut and oral microbiome collection that researchers at the Centre and School of Nursing and Midwifery were developing for Wave 6 of IDS-TILDA. Specifically, Panel members spoke about their understanding of gut health and gut microbiome and their attitudes around the idea of collecting a gut microbiome (poo) sample at home as part of the research. Panel members also advised researchers on adjustments to the sample collection protocol and on the Easy Read Patient Information Leaflet, instructions and questionnaire.

July 2025

The PPI Panel met to discuss the upcoming Field Researcher Training Day for IDS-TILDA Wave 6 and develop Easy Read instructions.

August 2025

The PPI Panel members led participation in the Field Researcher Training Day for IDS-TILDA Wave 6 on 20 August. During mock interviews, the Panel members advised new researchers on the best ways to conduct interviews with people with Intellectual Disabilities, as the researchers prepared to go out to the field to conduct interviews.

Highlights:
Achievements and Awards Highlights

Recognised for Excellence



Advancing Inclusive Dementia Research: Dr Eimear McGlinchey Secures Alzheimer's Association Award

Dr Eimear McGlinchey, Assistant Professor and researcher at the Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID), was successful in securing funding from the Alzheimer's Association through its Health Disparities, Policy and Ethics in Alzheimer's Disease and Dementia Research (HPE-ADRD) programme.

The $240,000 award will support FUNDISA – Framework for Understanding Neurocognitive Disorders and Down syndrome in Indigenous/Biomedical Systems in South Africa, an international research project led by Dr McGlinchey.

Fundisa, meaning *"to teach"* or *"to educate"* in Zulu and Xhosa, reflects the collaborative ethos at the heart of the project.

FUNDISA will explore how Alzheimer's disease and related dementias, Down syndrome and intellectual disability are understood across Indigenous and biomedical knowledge systems in South Africa. Working collaboratively with traditional healing practitioners, medical practitioners, researchers and community partners, the project will develop a culturally appropriate framework and language to strengthen understanding, communication and collaboration between these knowledge systems.

The project has a strong focus on equity and representation, addressing the underrepresentation of South Africa, people with Down syndrome, and Indigenous knowledge systems within dementia research. By bringing these perspectives together, FUNDISA aims to strengthen understanding and communication between traditional healing practitioners, medical practitioners, researchers and communities, and contribute to more culturally appropriate approaches to dementia research and care.

A key output of the project will be the development of a shared lexicon and conceptual framework for understanding Alzheimer's disease and related dementias, Down syndrome and intellectual disability across Indigenous and biomedical knowledge systems. The lexicon will be translated into isiZulu, isiXhosa and Afrikaans and disseminated to participating communities and medical organisations in South Africa.

The award further strengthens TCAID's international research collaborations and expertise in dementia and intellectual disability, while supporting the development of research approaches that recognise cultural context, different knowledge systems and the importance of meaningful community engagement.

Dr Aoife McFeely recognised during the 25th Anniversary celebration of the Discipline of Medical Gerontology



Congratulations to Dr Aoife McFeely, Specialist Registrar in Geriatric Medicine at Tallaght University Hospital and Medical Doctorate student, on being awarded a medal for her outstanding presentation!

Dr McFeely's research, conducted alongside Prof Mary McCarron and Prof Sean Kennelly, leveraged data from the Intellectual Disability Supplement to the Irish Longitudinal Study of Aging (IDS-TILDA). Her presentation, titled *Frailty identification and trajectory in an ageing population with intellectual disability*, was recognised during the 25th Anniversary celebration of the Discipline of Medical Gerontology. This well-deserved accolade highlights important advancements in understanding ageing within the intellectual disability community.



Professor Mary McCarron Honoured by the Faculty of Health Sciences

Professor Mary McCarron was honoured by the Faculty of Health Sciences with the unveiling of a new portrait and the inaugural Dean's Award for Distinguished Service to Health Sciences. The recognition reflects her exceptional and sustained contributions to health sciences, research, teaching, and innovation.

Professor McCarron served two terms as Dean of the Faculty of Health Sciences, becoming the first woman and first nurse to hold the role at Trinity College Dublin. She is Professor of Ageing and Intellectual Disability, Director of the Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID), and Executive Director of the National Intellectual Disability Memory Service. As founder and Principal Investigator of IDS-TILDA, the world's first longitudinal study on ageing in people with intellectual disabilities, her work has significantly advanced clinical knowledge and influenced policy and practice in Ireland and internationally. She has published over 200 peer-reviewed papers, secured more than €20 million in research funding, and supervised numerous doctoral and clinical researchers. McCarron's research has shaped major strategies, including Ireland's National Dementia Strategy and the report Shaping the Future of Intellectual Disability Nursing, and she was appointed to the Commission on Care for Older People in 2022. Her contributions to public and patient involvement in research, through initiatives such as the PPI Ignite Programme, and her leadership across health sciences continue to have lasting impact.



Excellence in Professional Practice Education

Eilish King was awarded the Faculty of Health Sciences Dean's Award for Outstanding Contribution to Teaching in Professional Practice. The award recognises her commitment to teaching and learning and her contribution to supporting high-quality professional practice education within the School of Nursing and Midwifery.



Post-Diagnostic Dementia Support Guidelines recognised with HCRI's 2024 Research Impact Award

Trinity Centre for Ageing and the Life Course in Intellectual Disability (TCAID) launched the Post-Diagnostic Dementia Support Guidelines. Co-funded by the Alzheimer Society of Ireland, the guidelines explore existing post-diagnostic dementia supports for people with intellectual disabilities and identify ways to improve them.

Developed during the COVID-19 pandemic, these guidelines provide a tailored, person-centred framework to support individuals in ageing comfortably in the setting of their choice. The guidelines aim to equip caregivers and practitioners with tools to deliver compassionate and effective support throughout the dementia diagnosis and treatment process. By fostering informed care, they seek to empower practitioners to make a meaningful difference in the lives of those they serve.

We are proud to share that this project was recently recognised with HCRI's 2024 Research Impact Award for its far-reaching and wide-ranging contributions to the field.



Recognising Excellence in Care and Advocacy

Dr Darren Fitzpatrick, an Intellectual Disability Nursing student at Trinity College Dublin, was among the recipients of the 2025 Davis Coakley Undergraduate Award for Outstanding Professionalism in the Care of Older Patients. He was nominated in recognition of his commitment to inclusion, collaborative interdisciplinary practice, and leadership and advocacy in the care of older adults with intellectual disabilities.

Exploring Social Prescribing to Address Loneliness



Dr Ashleigh Gorman was awarded funding through the School of Nursing & Midwifery Seed Funding Initiative to explore the potential of social prescribing as an approach to addressing loneliness among people with intellectual disabilities. Based within TCAID, the project brings together a multidisciplinary team including Dr Martin McMahon, Andrew Wormald, Professor Mary McCarron and Professor Philip McCallion.



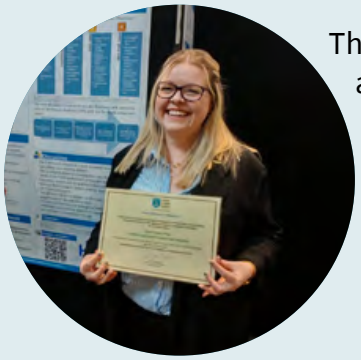
Advancing Earlier Detection of Alzheimer's Disease in Down Syndrome

Dr Antoinette O'Connor was awarded a prestigious HRB Emerging Clinician Scientist Award – Clinical Research for her project, Biomarkers in the Identification of Alzheimer's Disease in People with Down Syndrome (Bio MinDS). The highly competitive award provides €1.34 million to advance research addressing an important clinical need.

Bio MinDS will investigate blood-based biomarkers for the detection and monitoring of Alzheimer's disease in people with Down syndrome, a population at significantly increased risk of developing the disease but historically underrepresented in clinical trials. The research will examine the role of inflammation in disease onset, identify blood-based measures with the greatest diagnostic potential, and investigate how biomarker profiles change over time. The project will also generate evidence to support the inclusion of people with Down syndrome in future clinical trials, helping to ensure that advances in Alzheimer's disease diagnosis and treatment are accessible to this population.

Advancing Evidence for Future Support Needs

Dr Ashleigh Gorman was awarded the Poster Prize in the Healthy Ageing and Intellectual Disability strand at the Health and Education International Research Conference (THEconf2025), hosted by the School of Nursing & Midwifery, Trinity College Dublin. Her winning poster, Designing and Assigning Level of Support Needs to Older Adults with Intellectual Disability Aged 40 Years and Older, forms part of the HRB-funded AARC-ID study.



The research aims to strengthen understanding of the support needs and living arrangements of older adults with intellectual disabilities in Ireland, generating evidence to inform future service planning, resource allocation and investment as the population ages.

Highlights: Supporting the Development of Others



Internship Testimonials: University of Pennsylvania Students Reflect on their experiences at TCAID

TCAID was delighted to host two students from the University of Pennsylvania, who interned as Research Assistants with our Principal Investigators as part of the PENN Global Research & Internship Program (GRIP), an eight-week internship programme during the summer of 2025. During their time at TCAID, Claire Zhou and Megan Graves undertook a research project with Dr Martin McMahon, exploring inclusive approaches to cancer research for people with intellectual disabilities through the analysis of artwork. Their work resulted in the publication of *Visual Voices, an Interpretive Methodology: Advocating for Inclusion in Cancer Research for People With Intellectual Disabilities Through Artwork Analysis in the British Journal of Learning Disabilities.* We are delighted to share their experiences of their time at TCAID below.

"My experience at Trinity helped me grow as a person, researcher, and collaborator. My PI Dr McMahon was incredibly generous and organized. He thoughtfully provided a unique and engaging project [...] and every single member of the team did their best to make us feel comfortable and provide guidance anytime we needed it. Occasionally, we had tea and scones or Irish soda bread in the break room. Those were great opportunities to get to know everyone and feel welcomed in the office".

Through our research project, I polished my skills in scanning journal articles and synthesizing a background and methods section. I also got to execute a thematic analysis of visual artwork, a methodology I have never even read about before. I was able to think critically and expand my way of thinking for each art piece I examined. Working through the findings with my research partner was very enriching and helped develop my communication skills. Together, we discussed different approaches and smoothly wrote the rest of the paper as a unit. By the closing ceremony, I presented our research project and felt nothing but pride and gratitude." - **Claire Zhou**

"During my internship, I was given a lot of freedom to work independently. I had the overarching responsibility of completing the study, and I am very proud to say we led and completed an entire research paper from start to finish over the 8 week period we have been here. […] Having never been involved on a paper before, I learned very practical tools. Being very independent during this process, I learned soft skills such as time management and self-sufficiency, but I also relied on collaboration and communication within the team. I have learned so much about the disparities that exist for people with intellectual disabilities and the internship has unlocked a new area of interest for me moving forward with a career in medicine.

I was welcomed so warmly by amazing staff who was there for anything I needed. I am so thankful that the team trusted me with such a large project and was willing to give me and Claire the chance to develop into our own researchers. […] Leading a research project helped me grow in so many ways and I have become so much more confident in my abilities as an academic. […] I was always treated with such warmth by my co-workers, and I could tell they were rooting for my success. […] It's hard to express how grateful I am for the opportunities Martin and the team gave me. This will help me build a trajectory towards medical school and the future I have always wanted." - **Megan Graves**

Zhou, C., M. Graves, S. Walsh, et al. 2026. " Visual Voices, an Interpretive Methodology: Advocating for Inclusion in Cancer Research for People With Intellectual Disabilities Through Artwork Analysis." *British Journal of Learning Disabilities* 54: 362–372. https://doi.org/10.1111/bld.70043.





Education and Training Opportunities Delivered

Cert, Diploma, MSc

PG. Cert - Avril Hearne
PG. Diploma - Sharon Kehoe

MSc Students

Katarzyna Michalik - A systematic review of nurses' views towards pain in experienced by people with an intellectual disability -

Sarah O'Shea - The identification of primary healthcare providers and caregivers experiences when supporting the person with intellectual disability access cervical screening services: A systematic review.

Temitope Rowaiye - Exploring caregivers' recognition, assesment and perception of pain in adults with ID. Systematic Review.

Sarah-Jane Kennedy - Nurse's Experience in the Identification and Management of pain among Adults with Intellectual Disabilities: A Systematic review.

Claire Henderson - A Descriptive Quantitative Study on the Impact of Gait Speed on the Risk of Falls in Older Adults with Intellectual Disabilities and Dementia.

PhD/MD Students



Dr Aoife McFeely
Completed - Frailty Identification and Transitions in an Ageing Population with Intellectual Disability



Dr Lamya Al Shuhaimi
Completed - Enhancing medicine use in older adults with intellectual disabilities



Noor Syahidah Hisamuddin
In Progress - Inequality of oral health service use amongst older people with an intellectual disability in Ireland



Eilish King
In Progress - An exploration of sensory processing of adults ageing with intellectual disabilities in Ireland



Marianne Fallon
In Progress - Risk and Protective Factors in the Development of Dementia in an Irish Population Ageing with Down Syndrome: A Biopsychosocial Approach



Katrina Byrne
In Progress - The oral health status of older adults with intellectual disabilities in Ireland & its bidirectional relationship with pneumonia



Stephanie Corrigan
In Progress - Menopause and mental health in women with intellectual disabilities



Margaret Haigh
In Progress - End of life care for individuals with intellectual disabilities



Isabel Ryan
In Progress - Optimising Medicines for Older Adults with Intellectual Disability using the OPTIMA-ID Tool



Dr Shiling Chen
In Progress - Sarcopenia in older adults with intellectual disability in Ireland: prevalence, determinants and associations with adverse health outcomes



Pavithra
In Progress - Cognitive stimulation therapy for quality of life and cognitive engagement in intellectual disability

Active Projects

Project title: IDS-TILDA Wave 6

PI: Prof. Mary McCarron

Funder: Health Research Board (HRB)

Aim:

To continue examining the health, wellbeing and experiences of ageing among adults with an intellectual disability in Ireland, building on the longitudinal evidence generated across previous waves of IDS-TILDA.

Project Overview:

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) is a nationally representative longitudinal study of ageing among people with an intellectual disability aged 40 years and over in Ireland. Through its alignment with The Irish Longitudinal Study on Ageing (TILDA), IDS-TILDA provides a unique opportunity to examine and compare ageing among people with an intellectual disability and the general population.

Wave 6 continues to follow IDS-TILDA participants over time, examining changes in health, wellbeing, living circumstances and experiences of ageing. Alongside the longitudinal interview, Wave 6 expands the study's health assessment programme, including new measures of gait and mobility and the collection of gut and oral microbiome samples.

A key focus of Wave 6 is strengthening the translation of IDS-TILDA evidence into policy and practice. This includes closer engagement with policymakers, the development of a Research-to-Policy Steering Group, and increased access to and use of IDS-TILDA data by the wider research community. Findings will continue to provide an important evidence base to inform policy, services and supports for people with intellectual disabilities as they age.

Project title: Translating the HSE National Health Promotion Strategic Framework for People with Intellectual Disabilities

PI: Prof. Mary McCarron

Funder: HSE Nursing and Midwifery Planning and Development Unit (NMPDU), through Avista

Aim:

To translate the HSE National Health Promotion Strategic Framework into an accessible format that supports people with intellectual disabilities and communication challenges to understand, manage and improve their health and wellbeing.

Project Overview:

This project focused on making the National Health Promotion Strategic Framework relevant, accessible and usable for people with intellectual disabilities. Working with Avista, the project sought to ensure that the framework reflected the needs and experiences of people with communication challenges and supported a person-centred approach to health promotion. The work involved stakeholder engagement and the analysis of quantitative and qualitative data to inform the development of an accessible, user-friendly resource. The intended outcome was a resource that could empower people with intellectual disabilities to take a more active role in their own health and support improved health promotion in everyday life.

Project title: Engaging the Brain through Cognitive Stimulation Therapy
PI: Prof. Mary McCarron

Funder: HSE Nursing and Midwifery Planning and Development Unit (NMPDU), through Avista

Aim:

To evaluate the implementation and impact of Cognitive Stimulation Therapy as an initiative to support people with intellectual disabilities, drawing on the research expertise of IDS-TILDA and the National Intellectual Disability Memory Service (NIDMS).

Project Overview:

"Engaging the Brain through Cognitive Stimulation Therapy" is an Avista-led initiative supported through the HSE Nursing and Midwifery Service Improvement Initiatives programme. The research component is led by Prof. Mary McCarron, Principal Investigator of IDS-TILDA and Director of the National Intellectual Disability Memory Service (NIDMS).

The project provides research expertise to evaluate the initiative, including the collection, management and analysis of quantitative and qualitative data and the production of a final research report. The findings will contribute to understanding the implementation and outcomes of Cognitive Stimulation Therapy for people with intellectual disabilities.

Project title: Pilot Feasibility Study on the Use of Echolight Bone Screening in People with Intellectual Disabilities

PI: Dr Éilish Burke

Funder: HSE Nursing and Midwifery Planning and Development (NMPDU), South East

Aim:

To evaluate the feasibility of using Echolight as an accessible, non-invasive bone health screening method for people with intellectual disabilities, particularly for individuals who may experience barriers to conventional DXA scanning.

Project Overview:

People with intellectual disabilities experience a high prevalence of osteoporosis and related bone health problems yet can face significant barriers in accessing conventional DXA screening. This pilot study evaluates the feasibility of Echolight, a portable, non-ionising bone health assessment technology, as an alternative approach for this population.

The study examines the accessibility, ease of use and effectiveness of Echolight across different levels of intellectual disability. It also explores participants' experiences of the screening process and the potential for Echolight to support earlier identification of poor bone health and more accessible, person-centred assessment. The findings will help determine the potential for wider use of Echolight within intellectual disability services.

Project title: Exploring the Unmet Needs of Irish Cancer Patients from Underserved Communities

PI: Dr Martin McMahon

Funder: Irish Cancer Society

Aim:
To explore the barriers to and enablers of timely access to cancer diagnostics for underserved communities, with a particular focus on people with intellectual and physical disabilities and adults aged 65 and over.

Project Overview:
This mixed-methods project examines inequalities in access to timely cancer diagnosis among underserved communities in Ireland, focusing on people with intellectual disabilities, people with physical disabilities and adults aged 65 and over. It investigates cancer diagnosis and mortality, the influence of social and demographic factors on diagnosis, barriers and enablers within cancer services, and the experiences of people from underserved communities living with or beyond cancer.

The project combines analysis of nationally representative IDS-TILDA and TILDA data with qualitative research involving healthcare professionals and people from underserved communities. Findings will be used to identify disparities in cancer diagnosis and inform recommendations to improve equitable and timely access to cancer diagnostic services.

Project title: Addressing Age-Related Complexity in Intellectual Disability (AARC-ID): an economic analysis of different support models

PI: Dr Martin McMahon

Funder: Health Research Board (HRB)

Aim:
To provide economic evidence on the needs, resources and outcomes associated with supporting people aged 40+ with intellectual disability to age in place as the population grows older and experiences increasingly complex age-related needs.

Project Overview:

AARC-ID examines how Ireland can sustainably support people with intellectual disability to age in place rather than having to move to inappropriate settings as their needs become more complex. The project estimates current and future support needs, compares the costs and quality-of-life outcomes associated with different models of support, and projects population-level costs and outcomes under different policy and funding scenarios to 2034. It also incorporates the perspectives of people with intellectual disability, families, carers and service providers.

The project brings together TCAID, the Trinity Centre for Health Policy and Management and the National Federation of Voluntary Service Providers, combining health economics, intellectual disability research, service-provider expertise and PPI. IDS-TILDA is a key data source, with longitudinal data used to estimate age-related complexity and levels of support need and, alongside national NASS data, to project how these needs may change as the population ages.

Project title: FUNDISA: Framework for Understanding Neurocognitive Disorders via Indigenous Systems in South Africa

PI: Dr Eimear McGlinchey

Funder: Alzheimer's Association – Health Disparities, Policy and Ethics in Alzheimer's Disease and Dementia Research (HPE-ADRD)

Aim:

To develop a culturally appropriate framework and language for understanding Alzheimer's disease and related dementias (ADRD) and Down syndrome in South Africa, bridging Indigenous and biomedical knowledge systems and improving communication and collaboration between traditional healing practitioners, medical practitioners, researchers and communities.

Project Overview:

FUNDISA addresses an important gap in understanding how Alzheimer's disease and related dementias and Down syndrome are conceptualised within South Africa's traditional healing and biomedical systems. Working collaboratively with traditional healing practitioners and medical doctors, the project is developing a culturally appropriate lexicon and framework, examining knowledge and attitudes across both groups, and refining the framework through mixed-methods research involving interviews, surveys and focus groups.

The resulting framework is intended to support better communication across Indigenous and biomedical health systems and inform future research and health interventions. It will be translated into isiZulu, isiXhosa and Afrikaans to support its relevance and accessibility within the South African communities involved in the research.

Project title: MINDS Working Group – Development of a Multimodal Intervention Framework for Alzheimer's Disease in People with Down Syndrome

Lead: Dr Eimear McGlinchey

Funder: EU Joint Programme – Neurodegenerative Disease Research (JPND)

Aim:

To develop an agreed, evidence-informed multimodal lifestyle intervention framework for Alzheimer's disease in people with Down syndrome, adapted to the specific needs, support structures and lived experiences of this population.

Project Overview:

The MINDS Working Group brings together an international and interdisciplinary network of researchers, clinicians and allied health professionals to adapt the principles of the FINGER multimodal lifestyle intervention for people with Down syndrome. The work responds to the high genetic risk of Alzheimer's disease in this population and the limited evidence on non-pharmacological approaches specifically designed for people with intellectual disabilities. The group will review evidence on modifiable lifestyle factors and relevant interventions, then use two consensus-building workshops to agree suitable intervention targets, delivery approaches and reasonable adjustments. People with Down syndrome and family carers are involved throughout the process, including through a Europe-wide PPI group, to ensure the resulting framework is feasible, accessible and meaningful.

The principal output will be an adapted FINGER-DS framework that can support future research and larger European grant applications for a multimodal intervention study in people with Down syndrome.

Participant Engagement

Christmas Card competition



Front Artwork:
Isabella Gielarowska,
Abbeyview Residences



Runner-up:
Lee Shannon,
Stewarts Care



Runner-up:
Miriam Roche,
Peamount Healthcare

Easter Card competition



Front Artwork:
Carl Farrelly,
Stewarts Care,
Palmerstown, Dublin



Runner-up:
Florin Nolan, Cope
Foundation, Cobh,
Cork



Runner-up:
Mark Conway,
Brothers of Charity,
Castletroy, Limerick

Research Outputs 2024/2025

Research Making an Impact: Our Most-Cited Publications

McGlinchey, E., Duran-Aniotz, C., Akinyemi, R., Arshad, F., Zimmer, E.R., Cho, H., Adewale, B.A., & Ibanez, A. (2024). Biomarkers of neurodegeneration across the Global South. *The Lancet Healthy Longevity,* 5(10)

37 Scopus-indexed citations since publication

Published in *The Lancet Healthy Longevity* in 2024, this international collaborative review examines the significant geographical inequalities that exist in neurodegeneration research, particularly in the development, validation and availability of biomarkers across the Global South.

With 37 Scopus-indexed citations, the paper has seen strong uptake since publication. Analysis of the citing literature demonstrates its relevance across a broad range of research concerned with neurodegenerative disease, dementia, biomarkers, neuroimaging, genetics, brain health and health equity.

The citation profile also reflects the paper's central focus on global representation and research equity. Subsequent publications have drawn on the work in examining neurodegeneration and brain health among populations historically underrepresented in research, as well as the need to strengthen research infrastructure, increase population diversity and ensure that advances in biomarkers and precision medicine are applicable across different geographical and socioeconomic contexts.

The breadth of this uptake demonstrates the relevance of the work beyond a single disease or discipline, contributing to a growing international conversation about how advances in the understanding, detection and treatment of neurodegenerative disease can be made more globally representative and equitable.

Global South • Neurodegeneration • Biomarkers • Brain Health • Health Equity

Larsen, F.K., Baksh, R.A., McGlinchey, E., Langballe, E.M., Benejam, B., Beresford-Webb, J., McCarron, M., Coppus, A., Falquero, S., Fortea, J., Levin, J., Loosli, S.V., Mark, R., Rebillat, A.-S., Zaman, S., & Strydom, A. (2024). Age of Alzheimer's disease diagnosis in people with Down syndrome and associated factors: Results from the Horizon 21 European Down syndrome consortium. *Alzheimer's & Dementia*, 20(5), 3270–3280.

29 Scopus-indexed citations since publication

Published in *Alzheimer's & Dementia* in 2024, this international collaborative study included data from 1,335 people with Down syndrome across five European countries. The research provided important evidence on the age at which Alzheimer's disease is diagnosed in people with Down

syndrome and identified factors associated with earlier diagnosis, including sleep-related problems, mental-health conditions and a greater number of co-occurring health conditions.

With 29 citations recorded in Scopus, it is currently TCAID's most-cited publication within this reporting dataset. Its uptake reflects the relevance of the findings across an interdisciplinary field spanning Down syndrome and intellectual disability research, Alzheimer's disease and dementia, ageing, neurology, psychiatry and clinical care.

The paper is also a good example of the value of international research collaboration. The Horizon 21 consortium brought together expertise and data across multiple European research centres, enabling questions around Alzheimer's disease and Down syndrome to be examined at a scale that would be difficult to achieve within any individual country. The subsequent citation of the work demonstrates how TCAID researchers are contributing to a wider international evidence base aimed at improving understanding, diagnosis and ultimately care for people with Down syndrome as they age.

Diagnosis • Genetics • Biomarkers • Neuroimaging • Gait • Sleep • Behaviour • Clinical Care

Lynch, L., McCarron, M., Eustace-Cook, J., Burke, É., & McCallion, P. (2025). Physical health effects of sedentary behaviour on adults with an intellectual disability: A scoping review. *Journal of Intellectual Disabilities,* 29(1), 167–193.

16 Scopus-indexed citations since publication

Published in the *Journal of Intellectual Disabilities,* this scoping review examined the physical health effects of sedentary behaviour among adults with intellectual disabilities. Since publication, it has received 16 Scopus-indexed citations, demonstrating growing uptake of the research within the physical activity, health and intellectual disability literature.

The citing research shows that the review is contributing to a broader evidence base concerned with sedentary behaviour, physical activity, physical fitness, health promotion and quality of life among people with intellectual and developmental disabilities. Its influence extends beyond research describing health risks, with subsequent studies examining practical approaches to increasing physical activity and reducing sedentary behaviour.

The paper has been referenced in research exploring barriers to physical activity participation, functional fitness and quality of life, adapted fitness programmes, inclusive sport, mobile-health interventions and physical activity programmes for people with intellectual disabilities. It has also informed work examining nutrition and wider healthy behaviours, demonstrating the relevance of sedentary behaviour within a broader approach to improving health and wellbeing.

Notably, the citing literature includes both reviews and intervention-based research, indicating that the findings are being used not only to understand the existing evidence base but also to inform the development and evaluation of approaches designed to support healthier and more active lives for people with intellectual disabilities.

Sedentary Behaviour • Physical Activity • Physical Health • Intellectual Disability • Health Promotion

Beyond the featured publications, citation activity across TCAID's wider research portfolio demonstrates the breadth of scholarly engagement across areas including social inclusion, workforce wellbeing, health promotion, mortality, medicines, cancer, caregiving and healthy ageing.

Research Focus	Publication	Scopus Citations
Dementia Prevention & Brain Health	Farina, F.R., Bridgeman, K., Gregory, S., Crivelli, L., Foote, I.F., Jutila, O.-E.I., Kucikova, L., Mariano, L.I., Nguyen, K.-H., Thayanandan, T., Akindejoye, F., Butler, J., Calandri, I.L., Čepukaitytė, G., Chiesa, S.T., Dawson, W.D., Deckers, K., Cruz-Góngora, V.D.L., Dounavi, M.-E., Govia, I., Guzmán-Vélez, E., Heikal, S.A., Hill-Jarrett, T.G., Ibáñez, A., James, B.D., McGlinchey, E., Mullin, D.S., Muniz-Terrera, G., Pintado Caipa, M., Qansuwa, E.M., Robinson, L., Santuccione Chadha, A., Shannon, O.M., Su, L., Weidner, W., & Booi, L. (2024). Next generation brain health: transforming global research and public health to promote prevention of dementia and reduce its risk in young adult populations. *The Lancet Healthy Longevity,* 5(12)	34
Alzheimer's Treatment & Down Syndrome	Hillerstrom, H., Fisher, R., Janicki, M.P., Chicoine, B., Christian, B.T., Esbensen, A., Esralew, L., Fortea, J., Hartley, S., Hassenstab, J., Keller, S.M., Krinsky-McHale, S., Lai, F., Levin, J., McCarron, M., McDade, E., Rebillat, A.S., Rosas, H.D., Silverman, W., Strydom, A., Zaman, S.H., & Zetterberg, H. (2024). Adapting prescribing criteria for amyloid-targeted antibodies for adults with Down syndrome. *Alzheimer's and Dementia*, 20(5), 3649–3656.	16

Research Focus	Publication	Scopus Citations
Alzheimer's Disease Resilience	Boyle, R., Koops, E.A., Ances, B., Andrews, E.J., Arenaza-Urquijo, E.M., Benjanin, A., Brickman, A.M., Buckley, R.F., Clas, G.S., Costello, E., Coughlan, G.T., Conley, A.C., Deng, F., de Paula Faria, D., Edwards, N., Flores-Aguilar, L., Fortea, J., Ghazi Saidi, L., Head, E., Hom, C.L., Koenig, K., Lao, P., Lengyel, I., Li, Y.-J., Loi, S., Loughrey, D., McGlinchey, E., Newhouse, P., Pertierra, L., Prokopiou, P.C., Qi, Q., de Paula França Resende, E., Russell, J., Scanlon, C.E., Schneider, C., Schultz, S.A., Seto, M., Shaka, S., Soldan, A., Vaqué Alcázar, L., Weng, Y., Wilson, J.E., Zaman, S.H., Zsadányi, S.E., & Hartley, S. (2025). Resistance and resilience to Alzheimer's disease in Down syndrome. *Alzheimer's and Dementia*, 21(4)	13
Down Syndrome Health & Research	Fortea, J., McGlinchey, E., Espinosa, J.M., & Rafii, M.S. (2024). Addressing challenges in health care and research for people with Down syndrome. *The Lancet*, 403(10439), 1830–1833	13
Oral Health & Behaviour Support	Mac Giolla Phadraig, C., Ahmad Fisal, A.B., Bird, J., Kammer, P.V., Fleischmann, I., & Geddis-Regan, A. (2024). A scoping review of interventions and outcome measures in trials of dental behavior support. *Special Care in Dentistry*, 44(3), 676–685.	12

Research Focus	Publication	Scopus Citations
Dementia Assessment & Diagnosis	Ivain, P., Baksh, A., Saini, F., Idris, M., Tamayo-Elizalde, M., Wells, J., Benejam, B., Loosli, S.V., Sandkühler, K., Wlasich, E., Wagemann, O., Levin, J., Martet, D., Sacco, S., Falquero, S., Clert, M., Rebillat, A.-S., Khoo, W.M., Smith, M.A., Beresford-Webb, J., Zaman, S., Carmona-Iragui, M., Videla, L., Fortea, J., Langballe, E.M., Medbøen, I.T., Larsen, F.K., Baldimtsi, E., Paradisi, R., Ntailakis, P., Tsolaki, M., Papantoniou, G., McGlinchey, E., McCarron, M., Kennelly, S., & Strydom, A. (2025). Validation of the CAMCOG-DS-II, a neuropsychological test battery for Alzheimer's disease in people with Down syndrome: A Horizon 21 European Down syndrome Consortium study. *Alzheimer's and Dementia,* 21(3)	10
Medicines & Healthy Ageing	Odalović, M., Gorman, A., Paul, A., McCallion, P., Burke, É., Maclachlan, M., McCarron, M., Henman, M.C., Moran, M., O'Connell, J., Walsh, M., Shankar, R., Ryan, C., & O'Dwyer, M. (2024). Psychotropic medicines' prevalence, patterns and effects on cognitive and physical function in older adults with intellectual disability in Ireland: Longitudinal cohort study, 2009–2020. *BJPsych Open,* 10(2)	10
Cancer & Health Inequalities	McMahon, M., McCallion, P., & McCarron, M. (2024). An invisible population: Late-stage cancer diagnosis for people with intellectual or developmental disability. *Cancer,* 130(5), 668–670	10
Care & Service Provision	Sheerin, F., Fleming, S., May, P., McCallion, P., McCarron, M., Naseer, A., Lalor, G., & D'Eath, M. (2024). Challenges in care and service provision for older adults with intellectual disabilities and complex age-related conditions in Ireland. *British Journal of Learning Disabilities*, 52(2), 248–259.	10

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Byrne, K., Lisiecka, D., Moran, G., Daly, B., Fleischmann, I., McCallion, P., McCarron, M., & Phadraig, C. (2025). Oral health and pneumonia in adults with intellectual and developmental disabilities: A scoping review. *Journal of Intellectual Disability Research*. Advance online publication.

Chen, S., McMahon, M., Eustace-Cook, J., & Burke, E. (2025). Sarcopenia in adults with intellectual disability: A scoping review protocol to map and describe the existing research. *HRB Open Research*, 8, 61. F1000 Research Limited.

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Fitzpatrick, D. J., Burke, E., Hussain, R., Wark, S., & McMahon, M. (2025). Ageing across continents: Insights into the physical health of older adults with intellectual disability from Ireland and Australia. *Journal of Policy and Practice in Intellectual Disabilities*, *22*(4), e70028.

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Book Chapter

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