



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



**The Trinity Centre
 for Ageing and Intellectual
 Disability**

Annual Report 2022 - 2023



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

**Trinity Centre
 for Ageing and
 Intellectual Disability**



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



The Trinity Centre for Ageing and Intellectual Disability (TCAID) investigates issues in ageing, intellectual disability and the life course, with the goal of advancing evidence-informed policymaking and service delivery. Underpinned by the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), the Centre aims to address the inequalities and health disparities that occur for people with an intellectual disability as they age.

Table of Contents

Message From Our Director	1
Message from our Ambassador Liaison Officer	2
Vision and Mission	3
Strategic Priorities	4
Our People	5
Impact: 2022 - 2023 Tracking Research Uptake, Policy Influence, and Scholarly Outputs	7
Adding life to years - building better lives for people ageing with an intellectual disability through research and partnership. Trinity Centre for Ageing and Intellectual Disability (TCAID) Launches Five-Year Strategy	9
Highlight: Generating Knowledge and Informing Policy	11
Highlight: Contributing to Society	21
Highlight: Growing Our Research Community	24
Highlight: Achievements and Awards Highlights	29
Highlight: Supporting the Development of Others	32
Active Projects	38
Participant Engagement	43
Research Outputs	44



**Prof
Mary McCarron,
Director**

Message from our Director

In the 2022/23 period, the Trinity Centre for Ageing and Intellectual Disability (TCAID) made a profound impact by generating and translating research to inform policies and services, with our publications gaining significant traction nationally and internationally. Our longstanding commitment to public involvement has been a cornerstone, allowing us to collaborate extensively and demonstrate expertise in diverse research projects and translational activities. Our research drives positive change in health policy and clinical services for individuals with intellectual disabilities. The establishment of Ireland's National Intellectual Disability Memory Clinic stands as a significant translational innovation, reflecting our dedication to improving outcomes and quality of life.

The Trinity Centre for Ageing and Intellectual Disability (TCAID) has translated research into actionable policies and services, with our publications gaining substantial recognition worldwide. Our work has impacted 28 policy documents across 15 countries and influenced 12 patents, with our publications receiving over 3,600 citations and 160,123 views.

Our flagship research program, IDS-TILDA, has advanced into its fifth wave with 762 participants, marking our highest enrolment to date. Field research commenced with the Health Fair, attracting over 500 participants despite the ongoing impact of COVID-19, marking our inaugural use of on-site facilities, ensuring full accessibility. This year marked our inaugural use of on-site facilities, ensuring full accessibility.

In April 2023, we launched our five-year strategy at the Dublin Chamber of Commerce, attended by key stakeholders. This strategy aims to enhance the lives of people ageing with intellectual disabilities and their caregivers, emphasising interdisciplinary collaboration, and addressing health inequalities through innovative research and partnerships, aligning with Trinity College Dublin's mission to improve ageing experiences for all.

The Centre strengthened its international collaboration with researchers from the Healthy Ageing and Intellectual Disability (HA-ID) study in the Netherlands, advancing research on ageing with ID. This partnership, reinforced by a Memorandum of Understanding (MOU) between Trinity College Dublin and Erasmus University Medical Centre, will stimulate future research opportunities, benefiting both early career and experienced researchers.

We have established an advisory panel comprising individuals with intellectual disabilities. Patient and Public Involvement (PPI) is integral to our research ethos, exemplified by our PPI panel chaired by Mei Lin Yap, TCAID's Ambassador Liaison Officer. This panel of eight members meets bi-monthly to offer invaluable insights into our research projects, ensuring our research is inclusive and impactful, fostering a supportive community where every voice is heard and valued.

Despite these achievements, there remains a pressing need to increase awareness within health and social care services regarding the unique needs of people with intellectual disabilities. We must also harness the untapped potential of the technology sector to better serve and empower this population, requiring increased investment and innovation. Addressing prevailing stereotypes and discrimination based on disability and age is essential for the full integration of individuals with intellectual disabilities into society. Through our research, advocacy, and partnerships, we challenge these barriers daily.

With great pride, we present the 2022/23 Annual Report, inviting you to explore the Centre's accomplishments and ongoing efforts to create a more inclusive and empowering future for individuals with intellectual disabilities.

Message from our Ambassador Liaison Officer, Ms. Mei Lin Yap

As the Ambassador for the Trinity Centre for Ageing and Intellectual Disability (TCAID), I have done many important things. I met with the Provost of Trinity College Dublin to talk about jobs for people with disabilities and shared my experience working at Trinity College. I helped make videos called "Building Circles of Support for Adults with Intellectual Disability," which show positive case studies and resources for person-centred planning. I received a Highly Commended Award at the National Diversity and Inclusion Awards. These activities have made me even more determined to help everyone stay healthy as they get older.

I work with TCAID supporting the meaningful inclusion of individuals with intellectual disabilities and ensuring that their voice is central to all activities. Working here has enabled me to make an impact and to change the perspectives of my co-workers, other researchers, and the partners of TCAID. As part of my role, I help people learn how to communicate effectively and make accommodations when needed when engaging with people with intellectual disabilities. I also sit on various committees, including the steering committees for both IDS-TILDA and The National Intellectual Disability Memory Service. I continue to Chair the Public and Patient Involvement (PPI) Panel, which comprises eight individuals with life experience of intellectual disabilities. This panel contributes valuable input to shape the direction and influence the significance of the research being conducted at the Centre.

At this stage, it is hard to put into words how I feel about being in this role. I feel validated, accepted, and included in everything. I feel like I have excelled, and I feel honoured and privileged to be in the position I am in.



Ms Mei Lin Yap,
Ambassador Liaison
Officer



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 wellbeing, 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



Oral Health



Understand and positively influence social determinants of health



End avoidable mortality (treatable and preventable)



Understand and positively influence mental health and well being



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



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



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



Death, dying and end of life care



Our People

Centre Directors

Prof Mary McCarron, Director
Dr Éilish Burke, Associate Director

Strategic Advisory and Executive Team

Gavin Dann, Administrative Officer, TCAID
June O'Reilly, Strategic Development Officer, TCAID
Margaret Haigh, Project Manager, IDS-TILDA
Dr Caitriona Ryan, Statistician, IDS-TILDA
Pavithra, Data Manager, IDS-TILDA
Aviejay Paul, Data Scientist, IDS-TILDA
Michael Foley, Programme Manager, PPI Office
Sarah Bowman, Director of Strategic Engagement & Impact Assessment
Mei Lin Yap, Ambassador Liaison Officer

Academic Faculty

Prof Martine Smith (Clinical Speech & Language Studies)
Dr Duana Quigley (Clinical Speech & Language Studies)
Dr Orla Gilheaney (Clinical Speech & Language Studies)
Dr Yvonne Lynch (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 Annemarie Bennett (Clinical Medicine – Dietetics)
Dr Maria O'Sullivan (Clinical Medicine – Human Nutrition)
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 Sandra Fleming (School of Nursing and Midwifery)
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)
Dr Sinead Foran (Dublin City University)
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 Advisor

Postdoctoral and Research Fellows

Dr Darren McCausland Dr Andrew Wormald
Dr Andrew P. Allen Dr Marina Odalovic

Research Assistants

Ms Louise Lynch Ms Kieva Leslie
Ms Ashleigh Gorman Ms Stephanie Corrigan
Ms Margaret Cleary Ms Lara Faria Synnott
Ms Nadine Buttery

Health Fair Nurses

Ms Jean Moynihan Ms Mary Carroll
Mr Fergal Guihen Ms Tania Chimuris Bautista

Meet Our Newest Teammates: 2022 - 2023

Jean Moynihan
Health Fair Nurse Manager



Fergal Guihen
Health Fair Nurse



Kieva Leslie
Research Assistant



Mary Carroll
Health Fair Nurse



Stephanie Corrigan
Research Assistant



Tania Chimuris Bautista
Health Fair Nurse



Iara Faria Synnott
Research Assistant





Our Impact: 2022 - 2023

Tracking Research Uptake, Policy Influence, and Scholarly Outputs

- The Centre's publications have been cited by numerous government departments and agencies, including: the National Institute for Health and Care Excellence; the Agency for Healthcare Research and Quality; GOV.IE; Haute Autorité de Santé; Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften; New Zealand Ministry of Business, Innovation & Employment; Australian Government Department of Health; European Centre for Disease Prevention and Control; Publications Office of the European Union; GOV.UK; The Welsh Government; The Commonwealth of Virginia, USA; and the United Nations Environment Programme.
- The uptake of Centre research is substantial, including utilisation by national, European, and international healthcare organisations, educational institutions, research centres and governments. For example, Prof Mary McCarron's publications (1991-2022) have been cited above the global average for similar publications (SciVal), with over **3,600** citations accumulated (Scopus).
- The Centre delivered **1** report, **1** book, **12** book chapters, **31** journal articles and **26** oral presentations in 2021/22.
- The Centre's publications for this period have received over **33** citations, performing above the global average for similar publications (Field-Weighted Citation Impact, SciVal). In total, **13** of these publications are the result of international collaborations with countries such as the United States, France, and the United Kingdom (Scopus).
- The Centre's publications also inform public debate, increasing understanding and awareness of issues addressed in its research. For example, **2** outputs are cited in **2** policy sources from Finland and Australia (Overton).
- Publications for this time period have been viewed over **123** times (SciVal). This includes abstract views and clicks on the link to view the full text at the publisher's website. They reflect the interests of the whole research community, including undergraduate and graduate students, and researchers operating in the corporate sector, who tend not to publish and cite and who are "hidden" from citation-based metrics.
- The Centre's publications have both policy and patent impacts. **78** policy documents from **43** different sources and from **15** different countries reference the Centre's research. Of these, **25** are Clinical Guidance documents (Overton) and **1** publication (Health co-morbidities in ageing persons with Down syndrome and Alzheimer's dementia) is cited in **1** patent (Altmetric).

-
- The Centre's publications also inform public debate, increasing understanding and awareness of issues addressed in its research. Scholarly outputs are cited in articles by the Irish Times (Prevalence, patterns and factors associated with psychotropic use in older adults with intellectual disabilities in Ireland), Nursing Standard (Functional loss in older adults with intellectual disabilities and dementia) and other news outlets and blogs (Altmetric).
 - Scholarly outputs are cited in news and blogs, for example information for practice news, new scholarship & more from around the world (Use of technology by older adults with an intellectual disability in Ireland to support health, well-being and social inclusion during the COVID-19 pandemic) Information for practice, Learning Disability Practice (Functional loss in older adults with intellectual disabilities and dementia) and Wikipedia (End of Life and People with Intellectual and Developmental Disability and Suicide and Autism: A Lifespan Perspective) (Altmetric Explorer).
 - Scholarly outputs for this same period have received **182** mentions across social media platforms (Altmetric Explorer).
 - Online engagement for the Centre continues to grow, with an increase of **489** followers to **1,879** Twitter followers, up **35%** on the previous year.



Adding life to years - building better lives for people ageing with an intellectual disability through research and partnership.

Trinity Centre for Ageing and Intellectual Disability (TCAID) Launches Five-Year Strategy

The Trinity Centre for Ageing and Intellectual Disability (TCAID) officially launched its five-year strategy on Thursday, 6th April 2023 at the Dublin Chamber of Commerce. The strategy serves as a roadmap that aligns our objectives with broader scientific and societal goals, benefiting people who are ageing with an intellectual disability, their caregivers, Irish Society, and the wider world. It provides clear direction, ensuring efficient allocation of resources and fostering innovation by prioritising key areas of research. Our strategic approach enhances collaboration, attracts funding, and elevates the centre's reputation of demonstrating a commitment to impactful, forward-thinking, and high-quality research. This is demonstrated by the inter-disciplinary nature of the Centre, with thematic leads from the School of Nursing and Midwifery, Pharmacy and Pharmaceutical Science and Dental Science, with Speech and Language, Dietetics now collaborating and positioned to lead specific subthemes. This is evidenced by the interdisciplinary nature of the Centre, featuring thematic leads from the Schools of Nursing and Midwifery, Pharmacy and Pharmaceutical Science, and Dental Science. Additionally, collaborations with Speech and Language, and Dietetics are now in place, positioning these fields to lead specific subthemes.

The launch was attended by Professor Brian O'Connell, Dean of the Faculty of Health Sciences, Dr. Fintan Sheerin, Head of the School of Nursing and Midwifery, Dr. Sharon O'Donnell, Director of Research at the School of Nursing and Midwifery, along with representatives from Avista, the Alzheimer's Society of Ireland, Brothers of Charity, Stewart's Care, and St. John of God Liffey Services. The presence of these key stakeholders underscores the importance of collaborative engagement and shared commitment to the Centre's strategic vision.

Adding Life to Years: Building better lives for people ageing with an intellectual disability through research and partnership contributes to Trinity College Dublin's mission to respond with creativity and imagination to the formidable challenges faced by people with an intellectual disability in leading longer, healthier lives. This strategy addresses health inequalities faced by this population as they age, highlighting critical health and well-being issues. It stands as a testament to the Centre's past achievements and future ambitions.



“I am delighted to launch the Strategic Plan 'Adding Life to Years: Building better lives for people ageing with an intellectual disability through research and partnership.' This plan will shape the future of the Trinity Centre for Ageing and Intellectual Disability (TCAID), benefiting individuals ageing with an intellectual disability, their caregivers, Irish society, and the global community. By addressing health inequities and fostering research, mentorship, and international collaboration, we aim to enhance lives and reshape care for this vulnerable population.” - Prof. Mary McCarron, Director of the Trinity Centre for Ageing and Intellectual Disability ”

Trinity Centre for Ageing and Intellectual Disability (TCAID) Launches Five-Year Strategy

“TCAID has laid solid foundations in human, physical, research, and clinical infrastructure, ensuring lasting impact in an ever-changing landscape. This plan will guide us in advancing our strategic priorities, fostering equitable policies, and enhancing lives through strong national and global networks.”
– Dr Elisha Burke, Associate Director of the Trinity Centre for Ageing and Intellectual Disability

This infographic outlines the core areas that guide our strategy, ensuring a comprehensive and cohesive effort toward achieving our goals and advancing the well-being of our community.

Strategic Priorities





Highlight: Generating and Translating Knowledge

IDS-TILDA Health Fair: A Comprehensive Overview and Nurse Manager's Perspective

The Health Fair: Objective health measures in the IDS-TILDA study

Driven by the results of the IDS-TILDA study, which pointed to higher levels of inactivity and sedentary behaviours, high rates of health risk factors such as obesity, and high levels of mental health conditions, physical assessments were introduced in Wave 2 of the study, known as ‘the Health Fair, and again in Wave 4 and 5. In Wave 2 the Health Fair proved extremely successful with over 85% of participants involved in the overall study engaging in at least one objective measure. The suite of objective measures was all non-invasive and were complete in 30 minutes. The health assessment took place in the person’s home/day service or service provider site at a time and date convenient to the participant. The onset of COVID19 interrupted Wave 4 data collection and the Health Fair was suspended. However, the Health Fair was reinstated in Wave 5. It consisted of a more comprehensive suite of measures encompassing familiar and new measures driven by the results emanating from the IDS-TILDA previous waves. This was to keep the study in line with the TILDA study and other large-scale longitudinal studies that collect such measures. Overall, there were 27 individual assessments [see figure 1 below] encompassing physical fitness, oral health, cardiovascular health, musculoskeletal health, psychological and sensory health. People were invited to come to the Trinity Centre for Ageing and Intellectual Disability in TCD to undertake the assessments. The team also travelled to service sites to reach additional participants who were unable to travel to TCD. A total of 506 participants took part in the Health Fair which was 70% of the total IDS-TILDA participation.

There is a dearth of systematically gathered data on older adults with intellectual disability. As IDS-TILDA continues to collect objectively measured health data it is contributing to providing a comprehensive and accurate picture of the characteristics, needs and contributions of older people with intellectual disability in Ireland which is proving to be invaluable to policy makers and public sector service planners and to services engaged in activities seeking to enhance the social and community integration of people with intellectual Disability.

Domain	Measurement	
Neuro-psychological	Test for severe impairment [TSI] Brief Praxis DSQIID	
Cardiovascular	Mobilograph - Pulse Wave Velocity - Central Blood Pressure	
Mobility and muscular skeletal	Sitting and standing blood pressure Kardia ECG Pulse Oximeter ActivPal	Sit to stand test 2-minute step test Timed up and go test Balance assessment
Anthropometric	Height Weight Ulna length Mid Upper Arm Circumference (MUAC) Waist & hip circumference	Foot assessment – Brunswick Quantitative heel ultrasound Calf measurement Grip strength
Oral health	Modified Oral Status Survey Modified Dental Anxiety Scale	
Other	Adult eating behaviour scale Computer proficiency assessment	Audiology Adult/Adolescent Sensory Profile

Figure 1: Suite of objective health measures included in the IDS-TILDA Health Fair

Testimonial from Research Nurse Manager, Jean Moynihan



I had the privilege of being appointed the Research Nurse Manager for Wave 5 of the health fair from October 2022 – June 2023 with the IDS-TILDA study in TCAID. One of the primary aims of our health fair was to engage in both quantitative and qualitative data collections across over 26 objective health assessments for individuals with an intellectual disability aged over 40 years across Ireland. Prior to the commencement of the health fair, the team received a comprehensive training programme of masterclasses from trained health care professionals who were experts in their field, thus ensuring that the research nursing team were confident, competent, and efficient in the administration of all the health assessments to be conducted.

The establishment of a new dedicated health assessment facility within TCAID offered an accessible and person-centred space for all our participants engaging in health measures, whilst also providing accommodation for reasonable adjustments if required, to promote optimum inclusivity and meaningful engagement with assessments.

Not all our assessments took place in Trinity college, and we engaged in outreach starting in March 2023 to facilitate those participants, who for various reasons were unable to travel to us. We were totally bowled over by the enthusiasm and warm welcome we received from each participant and the service providers who hosted us throughout Ireland. Not only did we conduct thorough health assessments and collect valuable data, but many conversations were initiated by participants and their families or support staff, often which highlighted the challenges faced by people with an intellectual disability in closing the gap to accessing appropriate services which supports them to lead longer healthier lives.

The health fair experience gave them a sense of empowerment, ownership, inclusivity and choice and it was truly wonderful to receive such positive feedback from participants, their families, and support staff.

An important element of the success of the Health Fair was the invaluable contribution received from support staff and family members who accompanied many of the participants along to their appointments. Their presence, support and encouragement ensured that participants felt confident and understood, particularly for those participants who experience communication challenges or anxiety.

The high compliancy rates of attendance with over 500 participants visiting the health fair both in Trinity college and through our outreaches across the country, reflected the success and importance of recognising the valuable contribution of people with an intellectual disability in shaping the future of their own health care landscape and health care needs through rigorous engagement with health research.

“ I would like to take this opportunity to give special thanks to all the participants who were so generous with their time and demonstrated enormous willingness to engage with the objective health measures and to all the family members, support staff and service providers who assisted the participants and the health fair team in facilitating the collection of such rich and valuable data. Developing a body of knowledge on the physical determinants of successful, healthy ageing for people with an intellectual disability in Ireland is imperative in order to influence and make impactful changes for an improved quality of life for everyone. ”

- Ms Jean Moynihan, Research Nurse Manager



503
Participants attended the Health Fair

70%
Attendance

“ I was nervous coming along today but you made me feel relaxed. ”

Incorporating Oral Health into Our Health Fair: Utilising the MOSST



Objectively measured oral health data was collected in the health fair in Wave 5, which used the Modified Oral Status survey Tool (MOSST). The MOSST is a data collection tool that collects important data regarding oral health with concepts relating to oral function and oral disease indicators. The MOSST was devised to be used by well-trained non dental health professionals. An intensive training programme involving theory and practical sessions was delivered to research nurses by Dr Caoimhin Mac Giolla Padraig and PhD researcher Katrina Byrne. People with Intellectual disabilities came to one of the training days to assist with the training of the research nurses. Thank you to Joan Maguire, Sean Monks, Gerry Cornally and James Rynne from Stewarts Care who all came to TCAID in Trinity College Dublin to help with the training and enable the research nurses develop their skills.

This group also gave feedback and guidance on the being asked questions on dental anxiety and the easy read support we had developed. We key feedback helped us shape how collect this data in the health fair.

During the training on the MDAS, Gerry remarked that he “*didn’t know what Anxiety was and we needed to explain this better*”. This led to the development of a new easy read support document explaining what anxiety may feel and look like in addition to easy read guidance on the survey questions. Sean said he “*really enjoyed visiting and didn’t mind the nurses looking in his mouth and counting his teeth*”. Joan thoroughly enjoyed the day and said “*I enjoyed visiting Trinity College and being a part of teaching the nurses*”. James spoke at the training of his enjoyment of the day and meeting everyone involved. During the Wave 5 health the MOSST under-went psychometric measures data collection to ensure its reliability and feasibility. Feedback from both research nurses and participants showed the MOSST was acceptable, pain free and quick.

“The use of the MOSST in the IDS TILDA wave 5 health showed that RNID research nurses who have experience supporting people with intellectual disability have the ability once trained to carry out a simple oral assessment with their skillset to implement reasonable adjustments and person centred communication”
Ms. Katrina Byrne, PhD Student

Within the oral health component of the health fair a dental anxiety survey is used called the Modified Dental Anxiety Survey (MDAS). Dental anxiety is reported to affect 30% of the general population but is unknown in people with intellectual disabilities. The data gathered with this survey will give a great opportunity to explore dental anxiety experienced by people with intellectual disabilities and how in some instances how it affects their oral health.

Highlight: Generating and Translating Knowledge

The Care of Older Adults with Intellectual Disabilities and Complex Age-Related Conditions

Project Team: Dr Fintan Sheerin, Dr Sandra Fleming, Dr Peter May, Prof Mary McCarron, Prof Philip McCallion, Dr Amara Naseer, Dr Maureen D'eath, Ms Georgia Lalor

The Trinity Centre for Ageing and Intellectual Disability (TCAID) and the National Disability Authority (NDA) formally launched the report titled "**The Care of Older Adults with Intellectual Disabilities and Complex Age-Related Conditions**" on Thursday, 19th of January 2023.

This comprehensive report sheds light on significant shortcomings in current policy frameworks, funding mechanisms, and the glaring absence of a cohesive national policy to guide the delivery of services for individuals with intellectual disabilities (ID). As advancements in healthcare and supportive services have enabled people with intellectual disabilities to live longer, there is a growing population of individuals advancing into older age. While this longevity is a testament to improved health care, it also presents unique challenges in providing suitable care and services for older adults with intellectual disabilities who develop complex, age-related conditions.

To address these challenges, the NDA commissioned TCAID to conduct an in-depth examination of the care and service options available to older adults with intellectual disabilities and complex age-related conditions across various service settings. This research aims to inform future policy and improve service delivery, ensuring that the needs of this vulnerable population are met with the appropriate support and resources.

The report recommends four key strategies to improve outcomes for older people with intellectual disabilities, aligned with UNCRPD principles:

National Model for Healthy Ageing:

Develop a consistent, quality service model across Ireland with dedicated funding and integration with mainstream services.



1

Reconfigure Services:

Implement evidence-based ageing service pathways, invest in retirement and health needs, and enhance collaboration between care providers.



2

Responsive Resource Models:

Create new funding models for personalised support and ensure housing follows universal design principles.



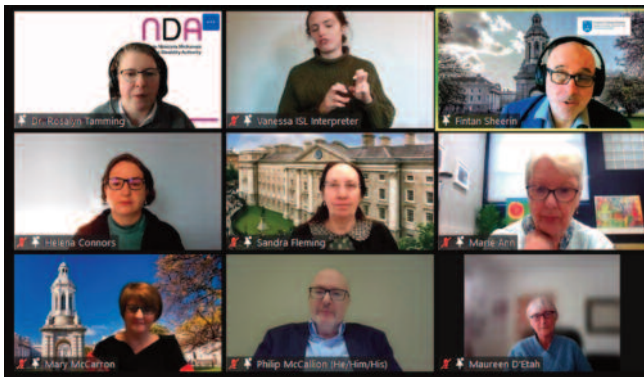
3

Build Caregiver Knowledge and Skills:

Implement dynamic staff rostering, provide targeted education and training, and improve recruitment of specialised nurses.



4



The study highlights the disjointed development of service systems, workforce capabilities, and funding mechanisms for ageing individuals with intellectual disabilities. While community-based initiatives originally aimed to integrate young adults into society, they did not foresee the specific needs of ageing individuals, such as retirement planning and increased healthcare requirements. The findings underscore the urgent need for dedicated resources and preparedness in healthcare and intellectual disability services.

Exemplar models, like the HSE's initiatives, offer potential solutions but require wider adoption and adequate funding. The study emphasizes the necessity of comprehensive planning and support to sustainably meet the evolving needs of older individuals with intellectual disabilities in Ireland.

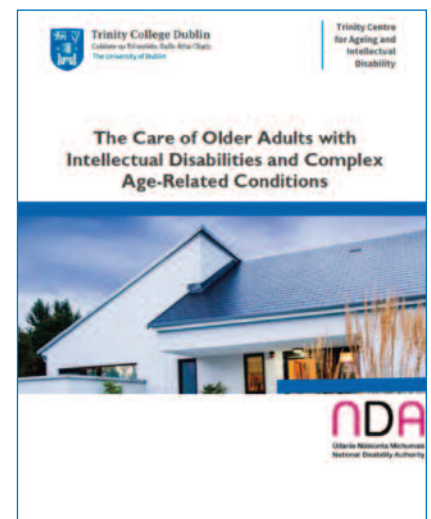
The launch included a presentation of the findings and recommendations, followed by an engaging panel discussion and a question and answer session. Pictured here are the Panel Members.

Dr. Fintan Sheerin	Associate Professor in Intellectual Disability Nursing, TCD School of Nursing & Midwifery
Dr. Rosalyn Tamming	Head of Policy, Research & Public Affairs, NDA
Helena Connors	Policy & Research Officer, National Federation of Voluntary Bodies
Dr. Sandra Fleming	Assistant Professor, TCD School of Nursing & Midwifery
Marie Ann Byrne	Family Member
Prof. Mary McCarron	Professor of Ageing and Intellectual Disability, TCD School of Nursing & Midwifery
Prof. Philip McCallion	Professor/Director at the School of Social Welfare, Temple School of Social Work, Temple University, Philadelphia
Dr. Maureen D'Eath	Research Fellow, TCD School of Nursing & Midwifery



“As principal investigator of the 'Care of Older Adults with Intellectual Disabilities and Complex Age-Related Conditions' project, I am proud to highlight the transformative findings unveiled through our collaboration with the Trinity Centre for Ageing and Intellectual Disability and the National Disability Authority. Our report identifies critical gaps in current policies and funding mechanisms, emphasizing the urgent need for a national model of healthy ageing, enhanced service reconfiguration, responsive resource allocation, and targeted caregiver training. These recommendations, aligned with UNCRPD principles, aim to ensure dignified and effective support for ageing individuals with intellectual disabilities across Ireland.”

Dr Fintan Sheerin, Associate Professor and Principal Investigator



Highlight: Generating and Translating Knowledge

PhD Student Profile: Louise Lynch



The title of Louise's PhD project is '**Uncovering sedentary behaviour: a comprehensive exploration of patterns and health effects among older adults with an intellectual disability**'. The primary aim of this study is to investigate the effects of sedentary behaviour (SB) on the physical health of older adults with an intellectual disability. This will be achieved through four objectives: 1. Determine the state of the science in the literature, 2. Examine the self-reported SB longitudinally, 3. Compare the Wave 4 objectively measured and self-reported measures, 4. Measure the relationship between measured SB & age, sex, level of intellectual disability, living circumstances, comorbidities and functional capabilities. Multiple self-report measures including time watching TV and activity questionnaires, as well as objective measures using a miniature accelerometer called an activPAL, were used to determine the sedentary level of participants.

Research around Sedentary Behaviour has shown that it is detrimental to health, but the specific harmful quantities are yet to be determined. Furthermore, there is very limited research around SB for people with an intellectual disability. The evidence in this study showed that SB has unfavourable health effects, however replacing it with activity of any type or intensity could have health benefits. Simple changes like standing up more frequently would be an easy, cost-effective way to be less sedentary and consequently healthier.

Louise's research has the following publications:

Lynch, L., McCarron, M., McCallion, P. and Burke, E., 2020. Sedentary behaviour levels in adults with an intellectual disability: a systematic review protocol. *HRB Open Research*, 3.

Lynch, L., McCarron, M., McCallion, P. and Burke, E., 2021. Sedentary behaviour levels in adults with an intellectual disability: a systematic review and meta-analysis. *HRB Open Research*, 4.

Lynch, L., McCarron, M., Eustace-Cook, J., Burke, É. and McCallion, P., 2022. Physical health effects of sedentary behaviour on adults with an intellectual disability: a scoping review. *Journal of Intellectual Disabilities*, p.17446295221107281.





Highlight: Generating and Translating Knowledge

PhD Student Profile: Katrina Byrne



Katrina's PhD project is titled **'The oral health status of older adults with intellectual disabilities in Ireland & its bidirectional relationship with pneumonia.'** The primary aim of this study is to investigate the oral health status of older adults with an intellectual disability in Ireland. To achieve this, an oral health assessment tool, the Modified Oral Status Survey Tool (MOSST), was developed as part of Katrina's PhD. The MOSST records a range of oral features critical for creating a national representative database of the oral health of older adults with an intellectual disability in Ireland. These features include Functional Tooth Units, Aesthetics, presence of the Front Twelve Teeth, Denture Wear, Tooth Count, Cavitated Teeth, Gum Condition, and Oral Cleanliness.

Katrina is a Registered Intellectual Disability Nurse, having completed her undergraduate degree in the School of Nursing at Trinity College in 2013 and a MSc in nursing research at the Royal College of Surgeons (RCSI) School of Nursing in 2019. Her career supporting people with intellectual disabilities has spanned over 20 years in various roles. Katrina commenced her PhD in the School of Dental Science, Trinity College Dublin, in March 2022.

The secondary aims of Katrina's research are twofold: to determine the dental anxiety experienced by older adults with an intellectual disability in Ireland and its association with their oral health status, and to explore the relationship between oral health status and pneumonia among this population. This will be achieved through quantitative research using data from Wave 5 of the IDS-TILDA study and a scoping review of the literature on the relationship between oral health, pneumonia, and intellectual disability.

Katrina's Research has the following dissemination:

Byrne, K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The Oral Health Status of Older People with Intellectual Disabilities in Ireland. Initial Findings., Irish Society of disability and oral health (ISDH), Kilkenny, Ireland, 23rd of June 2022, oral presentation.

Byrne, K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The Oral Health Status of Older People with Intellectual Disabilities in Ireland. Initial Findings., International association of disability and oral health (IADH), Paris, France, 24th-26th August, 2022, poster presentation

Highlight: Generating and Translating Knowledge

PhD Student Profile: Katrina Byrne

“ This research as part of my PhD is bridging the gap on oral health and intellectual disability and the lack clinical data on the oral health of people with ID in Ireland which contributes to health disparities, disease burden and oral disability. This often stems from exclusion from oral health research, due to issues around training, cost, consent, data collection and a lack of appropriate data collection tools. This has led to a blind spot with a failure to understand the causes and implications of oral disease among this population and an inability to improve oral health and healthcare through evidence-based policy. The MOSST is an inclusive research tool designed specifically to include people with intellectual disability that can shine a light on the oral health of this population and many more. The MOSST was also designed to be used by non-dentist. The unique skill set of the RNID make them key in collect data with people with intellectual disabilities with this tool, as the reasonable adjustments implemented and communications skill unutilized enabled oral data collection with is shown with the 92% of wave 5 participants taking part in a MOSST assessment.

The implications of poor oral health are substantial, with emerging research highlighting the impact poor oral health can have on general health, including significant associations with aspiration pneumonia and other major chronic disease. Research is increasingly highlighting the links between oral health and pneumonia. A relationship between oral hygiene in particular and bacterial pneumonia in the ageing general population is vast. With a growing amount of evidence indicating the involvement of dental plaque as a reservoir for pathogenic organisms associated with pneumonia. Building a body of research in the area of intellectual disabilities , oral health and pneumonia with substantiate the need for oral health interventions to improve oral health outcomes and quality of life for people with ID. ”

Ms Katrina Byrne, PhD Student





Highlight: Generating and Translating Knowledge

PhD Student Profile: Eilish King



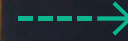
The title of Eilish's PhD project is **'An exploration of sensory processing of adults ageing with intellectual disabilities in Ireland.'** The primary aim of this study is to investigate patterns of sensory processing in adults ageing with intellectual disabilities using data from Wave 5 of IDS-TILDA. This research aims to inform recommendations and strategies to support the creation of inclusive environments that enable participation in daily life for adults ageing with intellectual disabilities in Ireland.

In order to achieve this aim, the following study objectives were identified: (i.) To explore the current evidence base with regards to sensory processing and adults with intellectual disabilities, (ii.) To examine the usefulness of a measure of sensory processing with a population of adults ageing with intellectual disabilities, (iii.) To

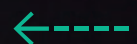
explore sensory processing patterns and their associations with participation in daily life activities for adults ageing with intellectual disabilities through use of descriptive and inferential statistical analysis. Eilish began her PhD research with IDS-TILDA/TCAID in September 2022. During the 2022/2023 period, the Adult/Adolescent Sensory Profile was included for the first time in the IDS-TILDA Wave 5 Health Fair. This marks the first inclusion of a sensory processing measure in a longitudinal study with adults ageing with intellectual disabilities.

Currently, little is known about sensory processing in adults ageing with intellectual disabilities. Responses to sensory stimuli can vary greatly amongst individuals and populations. When a mismatch exists between an individual's internal processes of registering and interpreting sensory information and factors in their surrounding environment, barriers to participation in daily life can arise. Many existing sensory processing measures are not specifically designed for adults with intellectual disabilities. To enhance opportunities for self-reporting sensory preferences among this population, researchers developed visual supports and provided training in sensory processing and administration procedures. Over 95% of IDS-TILDA Health Fair participants completed the Adult/Adolescent Sensory Profile during Wave 5.





Ms. Mei Lin Yap has shown everyone that she is a skilled maven and communicator, showing people with an intellectual disability that there is a space for them at the research table and, with the right supports, that the voices of people with intellectual disability can shape and drive research which leads to real change.



“At this stage, it is hard to put into words how I feel about being in this role, I feel validated, accepted and included in everything. I feel like I have excelled and I feel honoured and privileged to be in this position I am in.”

Ms Mei Lin Yap,
Ambassador Liaison Officer



Highlight: Contributing to Society

In Conversation with the Provost- International Day of Persons with Disabilities 2022

The Trinity Centre for Ageing and Intellectual Disability (TCAID) was delighted to welcome our Provost to have coffee and conversation on International Day of Persons with Disabilities 2022. In alignment with the overarching theme for the day, this event showed how innovative solutions for employment can create meaningful opportunities for individuals with far reaching impact. TCAID has proactively driven innovation and transformative solutions for inclusive development of individuals with an intellectual disability. To talk about the impact of this, Ms Mei Lin Yap and Ms Christina Corr, were delighted to voice their experience about what it is like to work in Trinity College Dublin and their career development. Ms Mei Lin Yap is the acting the Ambassador Liaison Officer for TCAID, advising researchers, representing TCAID at events related to the centre or PPI activity and managing PPI Panel meetings. Ms Christina Corr joined the Team in 2021 as a Research Assistant to the Post-Diagnostic Dementia Support Guidelines for People with an Intellectual Disability project, working to develop easy read materials and designing an accessible version of a researcher career development framework. Mei Lin and Christina's stories are exemplar of how innovative solutions for employment can create meaningful opportunities for individuals with far reaching impact not only on their roles in the workplace but also build their social network and independence. Inclusive employment in TCAID is about focusing on the abilities, empowering colleagues with ID to take advantage of opportunities, become their own agents of change and embrace their immense strengths and contribution they bring to Trinity College Dublin and broader society as a whole.

"The Trinity Centre for Ageing and Intellectual Disability plays a significant role in the life of our university, reminding us of the huge value of inclusion and leading the way in creating real opportunities for people with disabilities."

**Prof. Linda Doyle, Provost,
Trinity College Dublin**



Highlight: Contributing to Society

Empowering Connections: Enhancing Circles of Support for Adults with Intellectual Disabilities Showcasing Positive Case Studies and Resources for Person-Centred Planning

Building Circles of Support for People with Intellectual Disabilities, a Health Research Board (HRB) funded knowledge translation project, aims to showcase exemplary Circles of Support through positive case studies of participants' lived experiences. The project's primary goal is to develop resources that enhance Circles of Support for adults with intellectual disabilities, facilitating their involvement in person-centred planning processes. Over 15 years, IDS-TILDA research has underscored the pivotal role of individualised Circles of Support in fostering social inclusion and community participation for older adults with intellectual disabilities. The model encompasses Circles of Intimacy, Friendship, Participation, and Exchange, illustrating diverse support networks. Accessible resources, including downloadable booklets and videos featuring firsthand experiences, were created in collaboration with Stewarts Care in Dublin and supported by partners such as the HSE, National Federation of Voluntary Service Providers, and Temple University in the United States. These resources aim to inspire others with the impactful relationships highlighted by our participants.



“This grant will help to translate what we have learned about social networks through IDS-TILDA into practical resources to improve Circles of Support for people with an intellectual disability. By partnering with Stewarts Care, we can also ensure that these resources have an immediate impact for the individuals they support and their families. Additional partnership with the National Federation and Temple University will also help to increase the reach of the project both nationally and internationally.” –

Dr. Darren McCausland, Senior Research Fellow



Highlight: Contributing to Society

Menopause Café; increasing awareness, a conversation about women's health at menopause.



IDS-TILDA was delighted to be invited to partake as key speakers in a mainstream symposium 'A conversation about women's health at menopause'. Our knowledge and understanding of the menopause among women with intellectual disability is limited. This event aims to highlight that the menopause is a unique experience that's part of every woman's life, and encouraged conversation and education on the menopause. The event was organised by Dr. Katie O'Connor and Fiona Brown of the Faculty of Health Sciences and chaired by Dr. Eilish Burke, Associate Director of TCAID. The event included champions of women's health including our TCAID colleague Stephanie Corrigan who is currently undertaking a Masters by Research on Menopause, Mental Health and Women with

Intellectual Disability. Stephanie highlighted recent research indicates that the knowledge of women with an intellectual disability surrounding their sexual and reproductive health is very poor noting that experiencing the menopause as a woman from the general population is extremely stressful and confusing however having an intellectual disability adds another layer of complexity. Each of the champions involved in the event embraced and emphasised the aims of changing the approach to menopause care, aspiring to increase public awareness and support, and examining creatively a way to make access better to information on women's health at different stages of life. Most importantly each of these champions were true advocates who wanted to lift the voices of women so that they are active participants in their own health decisions, acting as a start point for conversation around menopause in women with intellectual disabilities.

Speakers:

Dr Mary Ryan, Physician, Endocrinologist Lecturer and Author, Eimear Galvin, Strategic Director and Manager of the Health Innovation Hub Ireland (HIHI), Prof. Fiona Wilson in School of Physiotherapy, Oonagh O'Hagan, Pharmacist, Owner and Managing Director of Meagher's Pharmacy Group



"I felt very fortunate to be a part of a panel of powerful, inspirational women working to advance the field women's health research. Women with an intellectual disability are so often left out of mainstream conversations about sexual and reproductive health, and having the opportunity to speak on behalf of these women to ensure their representation at this event was a privilege. Fellow panel and audience members were shocked when they discovered the difficulties faced by women with an intellectual disability when experiencing the menopause. Researchers at IDS-TILDA are working tirelessly to ensure that women with an intellectual disability are included in women's health research and policy initiatives going forward to ensure that they are no longer left behind and marginalised when it comes to their reproductive health." - Ms Stephanie Corrigan, PhD Student

"What you all have done is amazing. It's great to have the international support system for people with ID."

Support Staff

Growing Our Research Community

Advancing National and International Collaborations

25 The Centre has active collaborations with **10** national partners and international partners.

National Collaborations

Ireland

- The National Federation of Voluntary Bodies
- Health Service Executive
- Tallaght University Hospital
- Down Syndrome Ireland
- Global Brain Health Institute
- Daughters of Charity Disability Support Services (AVISTA)
- Stewarts Care Services
- Peamount Health Care
- All Ireland Institute of Hospice and Palliative Care
- University of Limerick

International Collaborations

Europe

- Jerome Lejeune Institute Paris
- University of Caen, Normandy
- Parc Sanitari, Sant Joan de Déu, Barcelona
- Fundacio Catalana Sindrome de Downs, Barcelona
- University of Cambridge
- Kings College London
- Cardiff University
- Royal College of Psychiatrists
- Bournemouth University
- University of Southampton
- University of Bath
- Faculty of Health Sciences and Sport, Stirling
- Erasmus MC Rotterdam
- University Medical Centre, Radboud University
- Academisch Ziekenhuis Groningen
- Technical University of Munich
- LMU Munich
- Ageing & Health NAU, Oslo
- University of Gothenburg
- Karolinska University

Australia

- Centre for Disability Studies, University of Sydney

Canada

- Reena, Toronto, Canada

United States

- Temple University
- Duke University
- University of Illinois at Chicago



Highlight: Growing Our Research Community

International collaboration with researchers from the Healthy Ageing and Intellectual Disability (HA-ID) study in the Netherlands

The Trinity Centre for Ageing and Intellectual Disability (TCAID) was delighted to host a two-day international collaborative event with researchers from the Healthy Ageing and Intellectual Disability (HA-ID) study, a prospective multicentre cohort study from the Netherlands, in Trinity College Dublin on 17th and 18th November 2022. To consolidate the collaboration, a Memorandum of Understanding was signed between Trinity College Dublin and Erasmus University Medical Centre on 18th November and this collaboration will stimulate international research progress in understanding ageing with ID.

The collaborative event was an exciting conduit for discourse and dialogue among ID researchers across disciplines to drive interdisciplinary research collaboration. It was an opportunity to promote the exchange and dissemination for the latest research findings, with the sharing of longitudinal research study findings in Ireland and the Netherlands which will stimulate interesting future opportunities for collaboration. The collaboration provided an opportunity for early career researchers to interact with experts from the Netherlands and Ireland, advancing their knowledge and career development.

The Healthy Ageing and Intellectual Disability (HA-ID) study started in 2008 and includes 1050 older adults (aged ≥ 50) with intellectual disabilities (ID). The study is designed to learn more about the health and health risks of this group as they age. Compared with the amount of research in the general population, epidemiological research into the health of older adults with ID is still in its infancy. Longitudinal data about the health of this vulnerable and relatively unhealthy group are needed so that policy and care can be prioritised and for guiding clinical decision making about screening, prevention and treatment to improve healthy ageing.

To consolidate the collaboration, a Memorandum of Understanding was signed between Trinity College Dublin and Erasmus University Medical Centre on 18th November and this collaboration will stimulate international research progress in understanding ageing with ID.



The international collaborative event was a wonderful opportunity for colleagues to meet in person and have in depth discussions leading to action and impact for people with intellectual disability.

Pictured here at the signing from left to right, Dr. Alyt Oppewal (Erasmus MC), Dr. Dederieke Festen (Erasmus MC), Dr. Eilish Burke (Trinity College Dublin) and Professor. Mary McCarron (Trinity College Dublin)

Highlight: Growing Our Research Community

Advancing Global Health: Collaborative Efforts to Develop a Combined Frailty Index for Intellectual Disability Communities

As part of an ongoing international collaboration between the Trinity Centre for Ageing and Intellectual Disability (TCAID) and researchers from the Healthy Ageing and Intellectual Disability (HA-ID) study at Erasmus MC, Netherlands, TCAID was privileged to be the host of a Frailty Roundtable on the 2nd and 3rd August, to discuss and move forward in the development of a combined frailty index. This collaboration builds on the work of PHD student Marco van Maurik at Erasmus University Medical Centre Rotterdam who has developed a frailty index from the HA-ID study, and MD Student Dr. Aoife Mcfeely who is in the process of developing a frailty index using data from IDS-TILDA. The aim of this collaboration is to compare, validate, and in turn eventually adapt each index into one standardised, combined frailty index specific to ID communities.

This roundtable presented the opportunity for discussion on the area of frailty and its application to better health provision for intellectual disability (ID) communities, and the steps moving forward of how a combined frailty index can benefit this. The discussion centred on topics including how frailty is defined in the context of developing a frailty index and its value as a measure of health, public and individual perceptions of frailty and its relationship to ageism, the benefit and utilization of specialised frailty index for ID communities, and how to better advocate and provide equitable healthcare through the study of frailty.

Going forward, the aim of this study is to improve the lives of people with ID internationally, for whom the process of aging has an added degree of complexity due to not only biological factors but also external, lifestyle factors, each of which are determinants of healthy aging and frailty level. In doing this, the study aims to improve perceptions of frailty, highlighting its dynamic and reversible nature as well as its ability, as a measure, to provide a nuanced and multidisciplinary view of health, and progress the prevention of avoidable mortality.



Attendees: Prof. Mary McCarron, Director of the Trinity Centre for Ageing and Intellectual Disability; Prof. Philip McCallion, Senior Advisor, Temple University; Prof. Sean Kennelly, Consultant Physician in Geriatric and Stroke Medicine in Tallaght University Hospital; Prof. Roman Romero-Ortuno, Professor in Medical Gerontology, School of Medicine and Consultant Physician in St. James's Hospital, Dublin; Dr. Aoife McFeely, MD Student & Specialist Registrar in Geriatric Medicine, Tallaght University Hospital; Marco van Maurik, PhD Student, Department of General Practice, Intellectual Disability Medicine, Erasmus MC, University Medical Center Rotterdam; Dr. Eilish Burke, Associate Director of the Trinity Centre for Ageing and Intellectual Disability; Dr. Alyt Oppewal, Assistant Professor, Department of General Practice, Intellectual

Disability Medicine, Erasmus MC, University Medical Center Rotterdam; Dr. Mylene Bohmer, PhD and Postdoctoral Researcher, Department of General Practice, Intellectual Disability Medicine, Erasmus MC, University Medical Center Rotterdam; and Dr. Eimear Connelly, Specialist Registrar in Geriatric Medicine, Tallaght University Hospital; Dr. Darren Fitzpatrick, ID Nursing Student and Kieva Leslie, Research Assistant.



Highlight: Growing Our Research Community

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

PPI Panel Sept 2022 to Sept 2023

The Trinity Centre for Ageing and Intellectual Disability (TCAID) are very fortunate to have established an advisory panel of people with an intellectual disability. Patient and Public Involvement (PPI) is a key tenet of research carried out in TCAID and is exhibited through the formation of the PPI panel who provide their lived experience to shape research carried out in the centre. The panel is chaired by Mei Lin Yap - the Ambassador Liaison Officer of TCAID - and consists of eight people with an intellectual disability who meet bimonthly to advise on various research projects carried out in the centre. Below is a summary of their activities from **September 2022- September 2023**.

The panel had their inaugural meeting on the **24th of August 2022** where they met to help to train field researchers who were preparing to interview people with an intellectual disability. The panel observed the field researchers practicing their interview technique and provided feedback to ensure that field researchers were equipped with the necessary skills to carry out interviews with people with an intellectual disability.

The next meeting took place on the **25th October**. This was the first meeting to take place in TCAID and the panel met to be formally welcomed to the centre by the Director of the centre Prof. Mary McCarron.

On the **22nd November 2022**, the PPI panel met to judge the IDS-TILDA Christmas card competition. Fun was had by all as the panellists had the difficult task of narrowing down 15 shortlisted entries to just 3 winners who would appear on the 2022 Christmas card!



In the next PPI Panel meeting on **31st Jan 2023** the PPI Panel launched “Mei Lin’s Change Maker’s Collage” at a celebration with other researchers from TCAID. Mei Lin asked researchers from TCAID as part of a Connection Initiative in TCD to send in photos representing gratitude for the past and aspirations for the future, which were combined into a beautiful collage as a symbol of hope for the new year.

The panel were busy in **March 2023**. On the **14th March 2023**, the Panel judged the Easter card entries, once again having to whittle down a shortlist of talented entries to find three winners to appear on the card.

“Getting to know people in the community and interacting with people in the community built my confidence as I didn’t interact with people beforehand. It gives me something to work on. To get out of the house for a few hours. I never had confidence. Since I came to the panel the confidence I get, the bunch of staff I meet are such a great bunch. [...] I’ve built up a lot of confidence.” **PPI Panel Member**

Highlight: Growing Our Research Community

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



On the **21st March**, the panel had their busiest meeting yet with presentations from three different researchers. The panel were consulted for advice on a range of projects involving topics such as the over-prescription of psychotropic medication among people with intellectual disabilities, costings for intellectual disability services and circles of support. In addition, cake was provided to celebrate World Down Syndrome Day 2023.

On the **12th April 2023**, the panel were invited to take part in their first workshop. The panel were consulted on how to disseminate findings from a project concerning "Circles of Support". The panel concluded that a video would be the most accessible means of dissemination for this topic for people with an intellectual disability.

On the **30th May 2023**, the panel were consulted on data visualisations that were developed by the data team for IDS-TILDA for a target audience of people with intellectual disabilities. The panel were able to determine that the data visualisations were not suited to such an audience and they provided valuable feedback for how the visualisations could be adapted to ensure accessibility.

On the **25th July**, the panel met and were consulted to see if they would like to participate in an article being developed on PPI conducted in the centre. This article could be used to show other researchers how to run PPI panels in other research centres around the country. Panel members agreed to take part and to be recognised as co-authors on the article. They also provided their initial insights into important aspects of the PPI for inclusion in the article.

On the **12th September**, the panel were called to participate in an impact workshop. The purpose of this workshop was to inform the panel of the impact of their contributions so far. Researchers were invited to provide feedback to the panel on projects they had advised on. This workshop was also aimed at reminding the panel of the work they had carried out to promote further discussion for the article being developed on the model of PPI.

On the **26th September 2023**, the panel consulted with a PhD researcher from the centre who wanted to discuss her use of language in her PhD thesis. The panel engaged in a meaningful discussion on the use of person-first language (i.e., person with an intellectual disability) compared to identity-first language (i.e., intellectually disabled people) and concluded that they preferred the use of person-first language in research concerning people with intellectual disabilities.

"I think I wanted to help people in the core of the study [the participants] as we are at the heart of the research. I think it's about sharing our opinions and our lived experiences in the shaping of the research".

Ms. Mei Lin Yap - Ambassador Liaison Officer



Highlight: Achievements and Awards Highlights

Recognised for Excellence

Recognising excellence among staff is a pivotal driver of organisational success. By celebrating achievements and honoring outstanding contributions, we not only acknowledge individual dedication and talent but also inspire a culture of continuous improvement and innovation. Awards and accolades serve as milestones that reinforce our commitment to excellence, fostering a motivated and engaged workforce. This recognition not only boosts morale but also cultivates a supportive environment where every member feels valued, ultimately contributing to the collective achievement of our research goals and enhancing our impact in the community.



Trinity Innovation Awards

Trinity's leading researchers and inventors have been recognised for their innovative research and entrepreneurship at the **2022 Trinity Innovation Awards**. Professor. Mary McCarron won an award in the Societal Impact category.

"Innovation can happen anywhere - we research so that we can know better; when we know better, we must do better."

Prof. Mary McCarron

The National Diversity and Inclusion Awards

The **National Diversity & Inclusion Awards** has announced its inaugural winners, celebrating outstanding achievements in Diversity & Inclusion across Ireland. After reviewing over 150 submissions, the judging panel selected five finalists per category, recognizing their exceptional contributions to D&I initiatives. Ms. Mei Lin Yap, Ambassador Liaison Officer, received the Highly Commended Award in the Employee of the Year category, reflecting her significant impact and commitment to advancing diversity and inclusion efforts.

"I am thrilled and deeply honoured to have received the Highly Commended Award at the National Diversity & Inclusion Awards. This prestigious recognition celebrates my dedication to championing disability inclusion in the workplace and serving as an inspiration for individuals with intellectual disabilities to aspire towards their dreams. As the Ambassador Liaison Officer, I am committed to continuing this important work and fostering a more inclusive and diverse environment for all."

Ms. Mei Lin Yap, Ambassador Liaison Officer



Highlight: Achievements and Awards Highlights

Recognised for Excellence

HRB Knowledge Transfer awards

Professor. Mary McCarron and **Dr. Darren McCausland** were honored with one of the prestigious HRB Knowledge Transfer awards for their proposal, '**Building Circles of Support for people with intellectual disabilities**'. Person-centred planning, which prioritises individual needs, strengths, and goals, is at the heart of their initiative. The HSE's National Framework for Person-Centred Planning emphasises the importance of creating Circles of Support (COS) around individuals to facilitate goal achievement. These circles typically include family, friends, neighbors, advocates, and community members chosen by the individual. Despite its recognised benefits, research shows that comprehensive COS are often lacking in planning for people with intellectual disabilities. IDS-TILDA aims to leverage its research to develop multimedia resources that enhance COS, thereby promoting more effective person-centred planning and goal attainment for adults with intellectual disabilities.

The proposed project will translate IDS-TILDA's findings into practical and scalable resources to support COS-based person-centred planning. These resources will improve planning, support, and resource allocation for individuals with intellectual disabilities, their families, and service providers. By enhancing personal goal achievement and quality of life outcomes, this initiative seeks to foster more targeted and impactful support systems for the intellectual disability community.

"This award presents an opportunity to make a huge difference to how people with intellectual disabilities are supported to shape their own future and pursue their life's ambitions." - Prof. Mary McCarron , Director of the Trinity Centre for Ageing and Intellectual Disability

"This grant will help to translate what we have learned about social networks through IDS-TILDA into practical resources to improve Circles of Support for people with an intellectual disability. By partnering with Stewarts Care, we can also ensure that these resources have an immediate impact for the individuals they support and their families. Additional partnership with the National Federation and Temple University will also help increase the project's reach nationally and internationally."

- Dr. Darren Mc Causland, Senior Research Fellow





Highlight: Achievements and Awards Highlights

Recognised for Excellence



Honorary Professorial Appointment- Queen's University

Professor. Mary McCarron has been appointed as Honorary Professor at the Faculty of Medicine, Health and Life Sciences at Queen's University Belfast, marking a significant milestone in her distinguished career. This appointment highlights Professor. McCarron's esteemed reputation and expertise in healthcare and academia, particularly in the field of ageing with intellectual disability. Her contributions are poised to enhance research and educational initiatives at both Trinity College Dublin and Queen's University Belfast. This appointment underscores mutual recognition of Professor. McCarron's exceptional achievements and the prestigious academic environment at Queen's University Belfast's Faculty of Medicine, Health and Life Sciences.

Relevance for Patient Care Award – PGR Day Tallaght University Hospital

Dr. Aoife Mcfeely's MD thesis delves into Frailty Identification and Transitions in an Aging Population with Intellectual Disability. Her groundbreaking research has garnered recognition, with Dr. McFeely receiving the **"Relevance for Patient Care" Award** at our recent PGR day at Tallaght University Hospital. This accolade underscores the significant impact of her work in advancing our understanding of frailty in ageing individuals with intellectual disability and its implications for patient care. Dr. Mcfeely's dedication to this vital area of study is commendable and highlights her commitment to improving healthcare outcomes for vulnerable populations.



Dean of the Faculty of Health Sciences Professional and Support Awards

Mr. Gavin Dann, TCAID's Administrative Officer, received the **'Leading by Example' Award** at the **Dean of Health Sciences Awards for Professional & Support Staff**. Among over 50 nominations, Gavin stood out for his inclusive leadership and dedication to fostering a supportive work environment. His empathy, kindness, and advocacy for diversity and inclusion have been instrumental in creating a positive workplace culture within TCAID.

Ambassador Liaison Officer **Ms. Mei Lin Yap** was nominated earlier this year for a **Dean of Research award** in the category of 'Engaging profoundly with our publics'. She recently obtained her nomination certificate, recognizing her significant contributions in this domain. This acknowledgment underscores her dedication to fostering meaningful engagement with various stakeholders.



Highlight: Supporting the Development of Others

Darren Fitzpatrick: Bridging Genetics and Nursing to Address Health Inequalities in Intellectual Disability

Dr. Darren Fitzpatrick
Intellectual Disability Nursing Student
BA (Mod.), M.Res, PhD, CertHE, Sch.



Dr. Darren Fitzpatrick is currently a student of Intellectual Disability Nursing at Trinity where he was elected a scholar in 2023. Dr. Fitzpatrick originally worked as a research geneticist having completed his initial studies at Trinity followed by postgraduate study at York and UCD. In 2021, after some reflection during the Covid-19 lockdown, Dr. Fitzpatrick returned to Trinity to study nursing. His interests in this area include physical health, health inequalities, marginalisation and social inclusion, and statistical methods.

Supported by his supervisor, Dr. Eilish Burke, Dr. Fitzpatrick began a research placement with IDS-TILDA in the Summer of 2021 where he researched the epidemiology of constipation in older people with intellectual disability in Ireland. Here Dr. Fitzpatrick employed a cross-sectional approach to examine the influence that factors such as demographics, morbidity, physical activity, diet and hydration have on a person's constipation status. The research, recently published in the Journal of Intellectual and Developmental Disability indicates that constipation is highly prevalent, affecting 43.5% of participants. Factors that influence constipation status are being female, living in a residential setting, having a severe/profound level of intellectual disability, a low-fat diet, high cholesterol, the number of medical conditions a person has and physical activity where even minimal activity has a positive effect.

Dr. Fitzpatrick continues to disseminate his work at conferences and is currently finalising a follow-up study that examined factors that influence the severity of constipation in older people over time. Of his experience of intellectual disability nursing and research at IDS-TILDA, Dr. Fitzpatrick says,

“Returning to university to study intellectual disability nursing has opened a whole new world to me. Like all nursing disciplines, intellectual disability nursing is concerned with health but is so in the context of serving a population which is often marginalised and forgotten. As well as becoming a nurse, I am learning to communicate with, empower and give voice to a hidden population. Also, I get to spend my placements in the company of sincere, non-judgemental, joyful people – I wish everyone could see what I get to see. My research placement in IDS-TILDA has given me the chance to meet people dedicated to affecting positive change. The research here is truly values driven, where participation from everyone, student, service user and academic is encouraged and facilitated. It’s a very positive environment in which to work.”

– **Dr. Darren Fitzpatrick, Intellectual Disability Nursing Student**



Highlight: Supporting the Development of Others

Ms. Anne Power is a Registered Nurse Intellectual Disability and is currently employed as an “Advanced Nurse Practitioner in Chronic Health Conditions in Adults with Intellectual Disabilities” in Wexford Residential Intellectual Disability Service.

In 2019 Anne completed a postgraduate diploma in “Ageing, Health & Wellbeing in Intellectual Disability” in Trinity College Dublin. This course strengthened, developed and increased Anne’s knowledge on the physical and social determinants of health in people with intellectual disabilities and equipped Anne with the knowledge, skillset and competencies to successfully transition to the role of a “Candidate Advanced Nurse Practitioner in Chronic Health Conditions in Adults with an Intellectual Disability” in 2020. The theoretical knowledge acquired from this course has been invaluable in directing the core elements and structure of Anne’s advanced practice service.

As part fulfilment of Anne’s masters in advanced nursing practice she completed her dissertation titled “To longitudinally examine the bone health status, the bone health screening patterns and factors that negate screening in adults with an intellectual disability over the age of forty in Ireland and identify changes over time”. The data for this study was generated from the first four waves of “The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)”.

The findings of the study identified that the prevalence of doctor-diagnosed osteoporosis increased considerably over the four waves of the study. In wave 1, only 8.1% had a doctor’s diagnosis of osteoporosis, which increased significantly to 21% in Waves 3 and 4. There was almost a threefold improvement observed in DXA attendance between Wave 1 and Wave 4, with results identifying that 16.8% and 44.8% had attended respectively. Among the strongest predictors for attending were residing in supported accommodation and aged >65 and older. Factors that negate DXA attendance were analysed and the strongest predictors for attending DXA was having difficulty walking and not troubled with pain.

Although access to DXA attendance has improved for people with intellectual disabilities, it still remains suboptimal and it is likely that the prevalence rate of osteoporosis in this population is largely underestimated. This suboptimal access to bone health screening is likely to be attributed to the challenges with the gold standard DXA, as it is often not feasible for people with intellectual disabilities due to physical abnormalities or behavioural and communication issues. Recommendations from this research calls for education and policy development to guide bone health promotion, associated risk factor identification and screening protocols. Furthermore recognition of alternative screening devices for those who can’t access DXA is urgently required to ensure appropriate diagnosis and timely management of osteoporosis in this high risk cohort.

Post completing this research, Anne has sourced an Echolight machine which is an alternative bone screening device. In collaboration with Professor Eilish Burke and the Trinity Centre for Ageing and Intellectual Disability, Anne plans to engage in research to assess the feasibility of Echolight in people with intellectual disabilities.



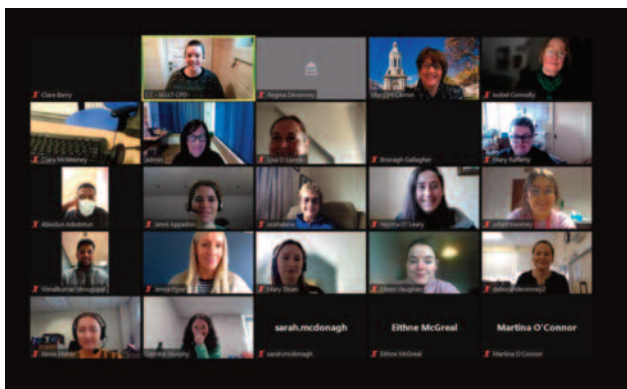
“Through the implementation of Shaping the Future of the RNID (McCarron et al. 2018) and Slaintecare (HSE 2019) the expansion of practice of nurses will maximise high quality care and transform the future of healthcare”

- Ms. Anne Power - Advanced Nurse Practitioner

Ms. Anne Power is a Registered Nurse Intellectual Disability and is currently employed as an “Advanced Nurse Practitioner in Chronic Health Conditions in Adults with Intellectual Disabilities” in Wexford Residential Intellectual Disability Service.”

Highlight: Supporting the Development of Others

Enhancing Professional Excellence: CPD Training Sessions on Ageing and Dementia for IASLT Members



The Trinity Centre for Ageing and Intellectual Disability (TCAID), in collaboration with the National Memory Clinic for People with Intellectual Disability (NIDMS), recently provided six CPD Training Sessions to the Irish Association of Speech & Language Therapists (IASLT). IASLT, the professional body representing Speech & Language Therapists in Ireland, is dedicated to supporting and empowering SLTs through setting standards, informing policy and service delivery, fostering professional excellence, advancing scientific understanding, and advocating for its members and those they serve. The training sessions addressed critical topics such as the determinants of health and

wellbeing for older adults with intellectual disabilities, cognitive changes and dementia, types and symptoms of dementia, stages of dementia and common care challenges, assessment and interventions, creating dementia-friendly environments, end-of-life care, and strategies for alleviating distress in individuals with dementia and intellectual disabilities. This initiative aligns with the HSE's Integrated Care Programme for Older Persons, the national HSCP office's objectives, and the CPD needs of IASLT members.

Course presenters:

Prof. Mary McCarron, Dr. Eimear McGlinchey, Ms. Evelyn Reilly and Ms. Pamela Dunne

Following the training sessions, a group of Speech and Language Therapists collaborated with IDS-TILDA, contributing to the protocol and reviewing pertinent interview questions posed by our Field Researchers.

"Thank you so much for today's presentation. Incredibly interesting for those of us who are working with adults with Intellectual Disability. And for those of us who have family members with a disability!" - Speech and Language Therapist, Saint John of God Liffey Services

"I have just this month taken up a new post as a Senior SLT in Donegal Adult ID services. My remit will be residential services for Adults with ID in two Networks in Donegal. This is the first ever Adult ID SLT service in this area. I am just starting now to build the service and am delighted that I have had to opportunity to take part in the current training programme. It was mentioned that there may be an opportunity to become involved with the Speech and Language Team in IDS TILDA. I would be very interested in doing this, both to gain information that may support me in setting up a new service but also to support any work you are doing in any way that I can." - Speech and Language Therapist, Adult Intellectual Disability Service Donegal (Southwest and East Networks)



Highlight: Supporting the Development of Others

Internship Testimonials: Pharmacy Students' Experience with Medication Data Input at IDS-TILDA



As a Pharmacy student with a keen interest in research, the opportunity to contribute to the IDS-TILDA study was a fantastic experience for myself to develop my learning and to be involved in a multidisciplinary study. During my 6-week placement, Angela and I helped the data management team with the input and cleaning of the medication data from Wave 5. It was such an enjoyable experience to meet and work with so many people from different professional backgrounds who are so passionate about the work they do at IDS-TILDA.

Although my time at IDS-TILDA was relatively short, it was an eye-opening experience for me. During my studies in college and my part-time work in the community pharmacy, intellectual disability is something that I have not encountered too often. But I have come to realise and appreciate through this placement the multi-faceted issues surrounding the topic and the additional care required for patients with intellectual disability. The term 'patient-centred care' has been repeatedly emphasised during my studies and following my time at IDS-TILDA, I can't think of another patient cohort to which this term applies more to. I will certainly carry with me into my future practice a greater appreciation for the issues surrounding intellectual disability and the need to promote best practice and make a positive contribution to the lives of patients with intellectual disability that I encounter.'

Mr. Jack Reed, Student Research Assistant IDS-TILDA



"Myself and another pharmacy student worked in the IDS-TILDA office for 6 weeks during summer 2023. We input and coded data collected about the medications participants used in Wave 5 of the study. I really enjoyed my time there, the whole team was very welcoming and included us in occasions like lunches, coffee mornings etc. The office is a very friendly environment and it seems like everybody involved in IDS-TILDA really loves their job and is passionate about the project. It was rewarding to play even a small part in such an important research project, and it felt like our work was really appreciated by the team. I learned a lot about the number and types of medicines older people with intellectual disabilities use and was struck by the potential for pharmacist intervention in this area. I feel I understand this group of people much more after doing this work and will be more aware and considerate of their care needs in my future practice. It was great to meet people from different backgrounds like nursing, dentistry and occupational therapy who were all working on different research topics or projects. It was also lovely to see many participants attending the IDS-TILDA Health Fair and how supportive and caring all the staff were when working with them. I am very grateful to have had this opportunity and would recommend any healthcare student to take a work experience or placement with IDS-TILDA if they get the chance!"

Ms. Angela Sheehy, Student Research Assistant IDS-TILDA

Highlight: Supporting the Development of Others

Education and Training Opportunities Delivered

The Centre provided the following educational opportunities in 2022/23:

The Post Graduate Certificate in Ageing Health and Wellbeing in Intellectual Disability was completed by five students.

Nicola McCabe
 Carolina Nogeuras
 Claire Coffey
 Jun Leong Loke
 Linda Martin Craig

The Post Graduate Diploma in Ageing Health and Wellbeing in Intellectual Disability was completed by seven students.

Claire Henderson	Sarah Jane Boyle
Slaney Bonnaville Cox	Niamh Downey
Suzanne Kennedy	Rita Walsh
Samira Bouktib Gogarty	

The MSc in Ageing Health and Wellbeing in Intellectual Disability was completed by two students.

Meadhbh Catherine O'Donnell - 'A quantitative exploration of pain in older adults with intellectual disability in Ireland.'

Mfoneno Uwemedimo - 'An exploration of the experience and treatment of pain in older people with intellectual disability living in residential settings: descriptive quantitative study.'



“ This course strengthened, developed and increased my knowledge enabling me to promote person centred and holistic care and healthy ageing. Completion of this course equipped me with the knowledge, skillset and competencies to successfully transition to the role of a “Candidate Advanced Nurse Practitioner in Chronic Health Conditions in Adults with an Intellectual Disability” in 2020. The theoretical knowledge acquired from this course has been invaluable in directing the core elements and structure of my advanced practice service. ”

Ms. Anne Power, ANP: Chronic Health Conditions in Intellectual Disability (Adult)



Highlight: Supporting the Development of Others

Education and Training Opportunities Delivered

MSc/PhD/MD Students



Dr. Aoife McFeely,
Frailty Identification and Transitions in an Ageing Population with Intellectual Disability



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



Ms Judy Ryan
An Exploratory Study of Overweight and Obesity in People with an Intellectual Disability in Ireland.



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



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



Ms Fidelma Flannery
The impact of COVID-19 on the mental health and wellbeing of older adults with an intellectual disability in Ireland.



Ms Louise Lynch
What are the sedentary behaviour and physical activity levels of Adults with Intellectual Disability and how does this affect their health and wellbeing?



Ms Lamya Al Shuhaimi
Enhancing medicine use in older adults with intellectual disabilities.



Ms Katrina Byrne
The oral health status of older adults with intellectual disabilities in Ireland & its bidirectional relationship with pneumonia.



Dr Karen Ryan
A repeated cross-sectional, mixed methods study of the palliative care needs of people with intellectual disability in Ireland and of staff responses to those needs.

Active Projects

Project title: IDS-TILDA Wave 5

PI: Prof. Mary McCarron

Funder: Health Research Board (HRB)

Aim: To identify the principal influences on ageing in persons with ID by examining healthy/successful ageing, determinants of health and longevity, and similarities/differences in ageing among people with ID and the general population.

Project Overview: The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) study examines ageing among people with an intellectual disability aged 40+ years in the Republic of Ireland. The first of its kind in Europe, IDS-TILDA, through alignment with The Irish Longitudinal Study on Ageing (TILDA), remains the only study able to directly compare ageing among people with an intellectual disability with ageing among the general population. IDS-TILDA identifies the principal influences on ageing in persons with ID by examining healthy/successful ageing, determinants of health and longevity, and similarities/differences in ageing among people with an intellectual disability and the general population. IDS-TILDA is a dynamic research process, in which participants' perspectives and responses are used to continually refine the research process and survey instrument. Wave 5 of IDS-TILDA continues to examine the principal influences on successful ageing in persons with ID - comparing results with previous waves of IDS-TILDA - to determine if they are the same or different from the influences on the ageing lives of the general population. Analysed data from Wave 5 will be used to inform and guide the planning, implementation and evaluation of future national policies, programmes, and services. Wave 5 of the study aims to balance longitudinal continuity and has introduced only a small number of new questions to examine the impact of the COVID pandemic on participants. Wave 5 continues to explore the implications for people with an intellectual disability as they transition between residential settings. Wave 5 data collection set out to continue the steady-state longitudinal data collection carried out in previous waves of IDS-TILDA. A total of 762 participants took part in Wave 5 interviews. This was the highest number of participants ever with a retention rate among surviving Wave 4 participants of more than 94%. Over 500 participants also took part in the Health Fair which for the first time was held at the fully accessible assessment centre at TCAID. Following analysis of the data collected the Wave 5 report will be produced. A total of 141 new IDS-TILDA participants were recruited in Wave 5. Recruitment of new participants focussed on those in the 40-49 age group to ensure the IDS-TILDA sample is representative of the overall intellectual disability population.



Project title: Prevent Dementia DS

PI: Dr. Eimear McGlinchey

Funder: The Alzheimer's Society of Ireland, and Wellcome Trust

Aim: To establish an adapted PREVENT protocol that is suitable for a population with Down syndrome (DS); to compare the organization of structural and functional brain networks in people with Down syndrome at the asymptomatic stage of Alzheimer's disease (AD) to people in the general population at 1) high risk for AD and at 2) low risk for AD; and to examine the association between neurofilament light protein (NfL) and connectomics in people with DS and its effect on cognitive processes.

Project Overview: People with Down syndrome (DS) have the highest genetic predisposition to Alzheimer's disease (AD). By age 40, nearly all individuals with DS exhibit the neuropathological hallmarks of AD, with an 88% cumulative risk of dementia by age 65. The most common cause of DS is trisomy 21, an extra copy of chromosome 21. This cross-sectional study aims to establish an adapted PREVENT protocol for individuals with DS and will analyze neuroimaging data (diffusion and functional MRI), plasma neurofilament light protein (NfL) levels, and neuropsychological performance data.





Active Projects

Project Title: EQUIP PI: Dr. Maire O'Dwyer

Funder: Health Research Board (HRB)



Aim: The aim of this study is to examine the quality and trends of psychotropic use among older adults with intellectual disabilities in Ireland over a ten-year period. The findings will inform practice and policy to optimize medication use and improve health outcomes.

Project overview: The widespread and sometimes inappropriate use of psychotropics in adults with intellectual disabilities has raised international concern. These medications are often prescribed for mental health conditions but are also controversially used to address behaviors in the absence of a diagnosis. Results from the IDS-TILDA study of older adults with intellectual disability in Ireland revealed that 60% were taking psychotropics in 2010. Over the past decade, changes in regulations, policies, and decongregation for this population have occurred. The establishment of the HSE National Clinical Programme for People with Disability (NCPDD) in 2020 has made medicines optimization a key priority. Leveraging existing multi-wave data from the IDS-TILDA study and the HSE national prescribing database, the Medicines Optimization Group in IDS-TILDA, the Faculty of Learning Disability in the College of Psychiatrists of Ireland, the HSE NCPDD, and patient stakeholders aim to better understand psychotropic medication use. The study utilizes health and medication data spanning ten years (four waves) from the IDS-TILDA study, a nationally representative longitudinal study of adults with intellectual disabilities over 40 years of age, in conjunction with medicines data from the HSE-PSCR prescribing database. Descriptive and longitudinal analyses will explore the impact of long-term psychotropic use, changes in usage trends, and the influence of decongregation on medication utilization.



Quote from Member of Steering Committee:

My name is Shannon O'Farrell-Molloy I am 26 years old. I have Cerebral palsy, Epilepsy, and a mild learning disability. I live in the Sunny South-East. I attend Cumas, New Ross which is a day service and I also work in a leisure centre in New Ross known as the Apex. Being disabled is like being on a remarkable journey you meet so many incredible people on the way. I have loved working on the EQUIP Project. I strongly encourage people with disabilities, brain injury, strokes, etc to take control of their health. If your condition requires Medication do your research or speak with your doctor. Every medication has massive benefits but it also has side effects. I once had a bad experience with medication and its side-effect so now I do my research before starting any new Medications. I look at the side effects and how they might affect my body or how they may impact the way I may feel so when I start a medication, I am aware of these possible side effects. Everyone's body responds differently to Medications. At age 25 Trinity College showed me and my mum this cool Machine to test your bones they then explained the importance of bone health. I went home and booked a DEXA scan. In my 20s never thought of worrying about bone health but with my disabilities, I know now it's something I need to keep an eye on. Be proactive with your health. I really enjoyed the project, meetings, chats, tea, laughter, and friendships.

Active Projects

Project Title: Development of OPTIMA-ID: Optimising Pharmaco-Therapy and Improving Medication for Ageing with Intellectual Disability

PI: Dr. Juliette O'Connell



Funder: Faculty of Health Sciences, Trinity College Dublin

Aims: To develop OPTIMA-ID (Optimising Pharmaco-Therapy and Improving Medication for Ageing with Intellectual Disability), an evidence-based tool for guiding medication optimisation.

Project Overview: Medicine optimisation in older adults improves medication appropriateness and reduces adverse effects and harm. Although tools exist for optimising prescriptions in older populations, there has been an oversight in providing a comprehensive tool specifically for older adults (≥ 40 years) with intellectual disabilities. With the development of OPTIMA-ID, we aim to combat this oversight through the development of a pharmacotherapy optimisation tool for this population.

Project title: Including best practices and the voices of experience in developing post-diagnostic dementia support guidelines for people with an intellectual disability

PI: Prof. Mary McCarron



Funder: Health Research Board (HRB)

Aims: To develop accessible best practice guidelines for post-diagnostic dementia supports for people with an intellectual disability in Ireland.

Project overview: People with an intellectual disability (ID) are at a higher risk of developing dementia than the general population. Those with Down syndrome (DS) are especially vulnerable due to a genetic predisposition to Alzheimer's disease (AD) from the overexpression of the amyloid precursor protein (APP) gene on chromosome 21. Despite this high risk, current services, both general and ID-specific, are poorly equipped to provide post-diagnostic support for people with ID and dementia and their carers. This results in unequal and inadequate access to necessary supports across the country. Therefore, the aim of this study is to develop accessible best practice guidelines for post-diagnostic dementia support for people with intellectual disabilities in Ireland. These guidelines will outline necessary adjustments and provide recommendations for all services on how to best support people with ID and their families/carers after a dementia diagnosis.



Active Projects

Project title: Building Circles of Support for People with Intellectual Disabilities

PI: Prof. Mary McCarron

Funder: Health Research Board (HRB)



Aims: The aims of the "Building Circles of Support for People with Intellectual Disabilities" project are to demonstrate good practices in Circles of Support through case studies of positive lived experiences, develop accessible resources based on research and lived experiences to aid in person-centred planning processes, and enhance social inclusion and community participation for adults with intellectual disabilities by advocating for individualized support networks. Additionally, the project seeks to work closely with its collaborators to develop and disseminate these resources, and to share the learnings from these positive examples to promote broader adoption of effective support practices.

Project Overview: This project, funded by the Health Research Board (HRB), aims to showcase best practices in Circles of Support through case studies highlighting positive experiences of participants with intellectual disabilities and their support networks. Drawing on 15 years of IDS-TILDA research, which underscores the importance of individualized Circles of Support for enhancing social inclusion and community participation, the project seeks to develop accessible resources. These resources, including a downloadable booklet and videos, are based on the lived experiences of individuals with intellectual disabilities, their families, and their wider support networks.

Project title: The Care of Older Adults with Intellectual Disability and Complex Age-Related Conditions

PI: Dr. Fintan Sheerin

Funder: National Disability Authority (NDA)



Aims: This research aims to examine the care and service options for older adults with intellectual disabilities and complex age-related conditions.

Project Overview: The project, funded by the National Disability Authority, will review the existing evidence base regarding the care of older adults with complex age-related conditions, generate additional evidence regarding current models of care, generate additional evidence regarding expected future needs and compare outcomes and quality of life in different care settings. The findings will guide policymakers and service providers in relation to various models of service and support, including the HSE, the Department of Health and the Department of Public Expenditure and Reform (DPER).

Active Projects

Project title: Loneliness as experienced by people with an intellectual disability (LEID); Theory development.

PI: Dr. Andrew Wormald



Funder: Faculty of Health Sciences, Trinity College Dublin

Aims: The project aims to create a theoretical understanding of the causes and temporal nature of loneliness in older people with intellectual disabilities. By recruiting up to 15 participants from the IDS-TILDA study who reported chronic loneliness, conducting semi-structured interviews, and analyzing the data using grounded theory, the research seeks to uncover the unique aspects of loneliness in this population. The ultimate goal is to inform a larger grant application to develop effective loneliness prevention and intervention strategies tailored to older adults with intellectual disabilities.

Project Overview: Loneliness, described as a modern social pandemic, affects nearly two-thirds of the population, but little is known about its impact on people with intellectual disabilities. Existing research relies on models derived from the general population, which poorly understand loneliness in this specific group. This project aims to develop a theoretical understanding of the causes and temporal nature of loneliness in older people with intellectual disabilities. By recruiting up to 15 participants from those who reported chronic loneliness in the IDS-TILDA study and conducting semi-structured interviews, the research will use grounded theory to analyze the data. Building on previous research by the team, the findings will inform a larger grant application aimed at developing loneliness prevention and intervention strategies for this population.



Participant Engagement

The 2022/23 IDS-TILDA Christmas Card and Easter Card competitions received more than 700 entries from people with an intellectual disability from across Ireland.

*Front artwork cover:
Michael Campbell,
Eve Estuary Centre, Swords.*

*Runner Up: Michael Tighe,
Carlanstown, Kells*

*Runner Up: Rachel Coen,
Stewarts Care, Dublin*



Easter Card 2023

*Front artwork cover:
Maria Quigley, Mountbellew
Hub, Galway.*

*Runner Up: Edward Hosty,
Ability West, Galway.*

*Runner Up: Mathew Colgon,
Eve Estuary, Dublin.*



*Runner up
Rachel Coen with her
winning entry.*

Appendix

Research Outputs 2022/2023

Book

Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., End of Life and People with Intellectual and Developmental Disability. Contemporary Issues, Challenges, Experiences and Practice., 1, Switzerland, Palgrave Macmillan Cham, 2022, XXXIV - 519

<https://doi.org/10.1007/978-3-030-98697-1>

Book Chapters

From Adulthood to Older Age - Ageing and Intellectual Disability., Sheerin, F. & Doyle, C., Intellectual Disabilities: Health and Social Care Across the Lifespan., Switzerland., Springer Cham., 2023, 147 - 158, McCallion, P. & McCarron, M.

<https://doi.org/10.1007/978-3-031-27496-1>

Accessible Funerals and People with Intellectual Disability, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., End of Life and People with Intellectual and Developmental Disability - Contemporary Issues, Challenges, Experiences and Practice, Switzerland, Palgrave Macmillan Cham, 2022, 265 - 296, Forrester-Jones, R., McCallion, P., McCarron, M., Stancliffe, R.J. & Wiese, M.Y.

<https://doi.org/10.1007/978-3-031-27496-1>

Building Shared End-of-Life Supports and Cross-Training for Hospice/Palliative and Intellectual Disability Services Providers, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., End of Life and People with Intellectual and Developmental Disability - Contemporary Issues, Challenges, Experiences and Practice, Switzerland, Palgrave Macmillan Cham, 2022, 211 - 233, Ferretti, L.A., McCarron, M. & McCallion, P.

<https://doi.org/10.1007/978-3-031-27496-1>

Experience of End-of-Life Issues by People with Intellectual Disability, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., End of Life and People with Intellectual and Developmental Disability - Contemporary Issues, Challenges, Experiences and Practice, Switzerland, Palgrave Macmillan Cham, 2022, 29 - 57, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M.

<https://doi.org/10.1007/978-3-031-27496-1>

Living and Dying Well with Dementia, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., End of Life and People with Intellectual and Developmental Disability - Contemporary Issues, Challenges, Experiences and Practice, Switzerland, Palgrave Macmillan Cham, 2022, 179 - 209, McCarron, M., Allen, A.P., Mulryan, N., Leigh, M., O'Reilly, L., McCarthy, C., Dunne, P., Reilly, E. & McCallion, P.

<https://doi.org/10.1007/978-3-031-27496-1>

Positioning the Issues: An Agenda for Future End-of-Life Research, Policy and Practice, End of Life and People with Intellectual and Developmental Disability - Contemporary Issues, Challenges, Experiences and Practice, Switzerland, Palgrave Macmillan Cham, 2022, 435 - 463, Wiese, M.Y., Stancliffe, R., McCallion, P. & McCarron M.

<https://doi.org/10.1007/978-3-031-27496-1>

Supporting People with Intellectual Disability at End of Life: Moral Distress among Staff Caregivers During COVID-19, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., End of life and people with intellectual and developmental disability: Contemporary issues, challenges, experiences and practice, Switzerland, Palgrave Macmillan Cham, 2022, 235 - 264, McCarron, M., Kelly, K., McCallion, P., Burke, E., Haigh, M. and Wormald A.

<https://doi.org/10.1007/978-3-031-27496-1>



Appendix

Research Outputs 2022/2023

Use of Do-Not-Resuscitate Orders, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., End of Life and People with Intellectual and Developmental Disability - Contemporary Issues, Challenges, Experiences and Practice, Switzerland, Palgrave Macmillan Cham, 2022, 407 - 434, McCallion, P., Ferretti, L.A. & McCarron, M.

<https://doi.org/10.1007/978-3-031-27496-1>

Journal Articles

Kelly, K., Haigh, M., McCarron, M., McCallion, P., Burke, E-A. & Wormald, A-D., Moral distress in carers for people with an intellectual disability who died during the COVID-19 pandemic, a template analysis extending the Barlem and Ramos model of moral distress., Journal of Applied Research in Intellectual Disabilities, 2023, 1 - 9

<https://doi.org/10.1111/jar.13073>

Wormald A, McGlinchey E, D'Eath M, Leroi I, Lawlor B, McCallion P, McCarron M, O'Sullivan R. & Chen Y., Impact of COVID-19 Pandemic on Caregivers of People with an Intellectual Disability, in Comparison to Carers of Those with Other Disabilities and with Mental Health Issues: A Multicountry Study., International Journal of Environmental Research and Public Health., 20, 4, 2023

<https://doi.org/10.3390/ijerph20043256>

Brennan, D., D'eath, M., McCallion, P. & McCarron, M., Health and well-being of sibling carers of adults with an intellectual disability in Ireland: Four waves of data., British Journal of Learning Disabilities., 2023

<https://doi.org/10.1111/bld.12532>

Fitzpatrick, D., McCallion, P., McCarron, M., and Burke, EA., Epidemiology of constipation and its associated factors in an ageing population of people with an intellectual disability in Ireland: A cross-sectional study., Journal of Intellectual & Developmental Disability, 2023

<https://doi.org/10.3109/13668250.2023.2271759>

McDermott, S., McCarron, M., Burke, EA., McCallion, P. and O'Donovan, MA., Enabling older adults with intellectual disability to become physical activity leaders in their community: Pilot study, Journal of Intellectual Disability Research, 2023

<https://doi.org/10.1177/17446295231177190>

O'Brien, F., McCallion, P., Ryan, C., Paul, A., Burke, É., Echiverri, S., & McCarron, M., Does Arterial Stiffness Predict Cardiovascular Disease in Older Adults With an Intellectual Disability?., Journal of Cardiovascular Nursing, 2023

<http://dx.doi.org/10.1097/JCN.0000000000001013>

Allen, A-P, McGlinchey, E., Fallon, M., McCallion, P. & McCarron, M., Cognitive reserve and dementia risk management in people with an intellectual disability., International Journal of Geriatric Psychiatry, 2023

<https://doi.org/10.1002/gps.5906>

McCausland, D., McCallion, P., Carroll, R. & McCarron, M., Barriers to Community Participation for Adults Aging With an Intellectual Disability in Ireland: A Longitudinal Study, Inclusion, 11, 3, 2023, 204, 217

<http://dx.doi.org/10.1352/2326-6988-11.3.204>

Brennan, D., D'eath, M., Dunne, N., O'Donovan, M-A., McCallion, P., & McCarron, M.,). Irish Social Policy to Family Carers of Adults with an Intellectual Disability: A critical analysis, Journal of Intellectual Disability, 2022

<https://doi.org/10.1177/17446295221115296>

Gorman, A., Odalovic, M., McCallion, P., Burke, EA., MacLachlan, M., McCarron, M., Henman, M., Moran, M., O'Connell, J., Walsh, M., Shankar, R. & O'Dwyer, M, Examining Quality, Use and Impact of Psychotropic (Use) in older adults with intellectual disabilities: study protocol, HRB Open Research, 5, 71, 2022

<https://doi.org/10.12688/hrbopenres.13645.1>

Appendix

Research Outputs 2022/2023

Kirwan, R., Sheerin, F., McGlinchey, E., McCallion, P. & McCarron, M., Functional loss in older adults with intellectual disabilities and dementia, Learning Disability Practice, 2022

<http://dx.doi.org/10.7748/ldp.2022.e2184>

O'Brien, F., McCallion, P., Carroll, R., O'Dwyer, M., Burke, E-A. & McCarron, M., Hypertension in Older Adults. The prevalence, awareness, treatment and control of hypertension in older adults with an Intellectual Disability: a cross sectional study., JBI Evidence Synthesis, 20, 7, 2022

<https://doi.org/10.1093/eurjcn/zvaa019>

Lynch, L., McCarron, M., Eustace-Cook, J., McCallion, P. & Burke, E., Physical health effects of sedentary behaviour on adults with an intellectual disability: A scoping review, Journal of Intellectual Disabilities, 2022, 1 - 27

<http://dx.doi.org/10.1177/17446295221107281>

McCarron, M., McCausland, D., McGlinchey, E., Bowman, S., Foley, M., Haigh, M., Burke, E. & McCallion, P., Recruitment and retention in longitudinal studies of people with intellectual disability: A case study of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), Research in Developmental Disabilities, 124, 2022

<https://doi.org/10.1016/j.ridd.2022.104197>

McCausland, D., McCarron, M. & McCallion, P., Use of technology by older adults with an intellectual disability in Ireland to support health, well-being and social inclusion during the COVID-19 pandemic, British Journal of Learning Disabilities., 2022, 1 - 16

<https://doi.org/10.1111/bld.12514>

Report

McCarron, M., Haigh, M., Dann, G., & McCallion, P. (Eds.), Longitudinal Dynamics in the Ageing of People with an Intellectual Disability: Evidence from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) Wave 5, 2023

<https://doi.org/10.25546/104365>







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



For more information

Phone: 01 896 3183/3187

Address: Trinity Centre for Ageing
and Intellectual Disability
Trinity College Dublin
Lincoln Place, Dublin 2

Email: dannng@tcd.ie

Website: <https://www.tcd.ie/tcaid/>



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

**Trinity Centre
for Ageing and
Intellectual Disability**