



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



The Trinity Centre for Ageing and Intellectual Disability

Annual Report 2023 - 2024



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

**Trinity Centre
for Ageing and
Intellectual Disability**



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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.

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Prof
Mary McCarron,
Director

Message from our Director

In the 2023/24 period, the Trinity Centre for Ageing and Intellectual Disability (TCAID) sustained its profound commitment to generating and translating research to inform policies and services, with our research outputs gaining increasing recognition both nationally and internationally. Public involvement remains a cornerstone of our work. This commitment enables deep collaboration with individuals, families, and community partners, and showcases our expertise in research and knowledge translation.

Through these efforts, TCAID continues to drive positive change in health policy and clinical services for individuals with intellectual disabilities, reinforcing our mission to improve outcomes and quality of life.

Since its inception, the Centre has maintained a focused research direction, contributing to academic discussions and influencing policy and practice over time. The Centre's work has been acknowledged by a diverse range of institutions, demonstrating practical relevance across multiple sectors, continuing to gain recognition within the academic community and informing public understanding of key health and social issues. Overall, these achievements highlight the Centre's ongoing role in advancing evidence-based knowledge and shaping policy under consistent leadership and collaboration.

In 2023, TCAID launched Wave 5 of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) Europe's only study dedicated to ageing in people with intellectual disabilities. Now in its fifteenth year, IDS-TILDA remains the only study of its kind in Europe, dedicated to understanding the ageing experience of people with an intellectual disability. Wave 5 reflects a period of renewal and transformation, capturing the evolving landscape of services, policies, and lived experiences. The wave introduced a refreshed cohort of adults aged 40 and over and saw the return of the Health Fair.

Wave 5 findings show progress in community living, physical activity, and social participation. However, persistent health disparities remain especially among women, individuals with severe disabilities, and those in residential care. These findings have informed and supported a number of events to address key strategic thematic areas throughout the year. A landmark launch event held at Trinity College Dublin brought together stakeholders from across research, policy, advocacy, and lived experience, reinforcing IDS-TILDA's role in shaping inclusive, evidence-based responses to ageing. As IDS-TILDA looks ahead, Wave 5 reaffirms its leadership in advancing person-centred research and driving meaningful change for people ageing with an intellectual disability.

The Centre enhanced its international profile by participating in the 17th IASSIDD World Congress in Chicago, engaging in key discussions on ageing, health, and inclusive research. Dublin was announced as the host city for the next congress in 2027, underscoring TCAID and IDS-TILDA's leadership in the field. Preparations are underway to welcome global researchers, fostering future collaborations and opportunities for researchers at all career stages.

The PPI panel at TCAID remains integral to our research, regularly providing lived experience insights that shape project design, communication, and dissemination. Their involvement has contributed to various outputs, including accessible events, videos, and key publications, ensuring our research is inclusive, impactful, and grounded in the perspectives of people with intellectual disabilities. As our work progresses, the panel will continue to guide our research, reinforcing our commitment to meaningful involvement and fostering a research culture where every voice is 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. 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 2023/24 Annual Report, inviting you to engage with the Centre's accomplishments and join us in building a more inclusive and equitable future for individuals with intellectual disabilities.

Message from Ms Mei Lin Yap

Ambassador Liaison Officer, Trinity Centre for Ageing and Intellectual Disability

As the Ambassador Liaison Officer for the Trinity Centre for Ageing and Intellectual Disability (TCAID), I've had the opportunity to contribute meaningfully in many ways. I helped shape, became a co-author on an article on the impact of PPI in research. I also co-designed and appeared in a video for the EQUIP research project, which help people with intellectual disabilities understand their medication. I've presented at several conferences and events, including one focused on menopause, where I delivered accessible summaries and helped make the event inclusive for everyone. I also spoke alongside Professor Mary McCarron at the 16th International Dementia Conference, where I presented on equity in dementia care for people with intellectual disabilities, and the importance of ageing with pride, and I was proud to meet Minister Mary Butler during the event.

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 well-being, and translating findings to inform models of policy and practice.

STRATEGIC PRIORITIES

THE CENTRE FOCUSES
ON THE FOLLOWING PRIORITIES:





Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Our People

Centre Directors

Prof Mary McCarron, Director
Dr Éilish Burke, Co-Director

Strategic Advisory and Executive Team

Dr Martin McMahon, Associate Director
Dr Eimear McGlinchey, Associate Director
Gavin Dann, Administrative Officer, TCAID
June O'Reilly, Strategic Development Officer, TCAID
Margaret Haigh, Project Manager, IDS-TILDA
Jean Moynihan, Assistant Project Manager, IDS-TILDA
Kieva Leslie, Executive Officer
Dr Caitriona Ryan, Statistician, IDS-TILDA
Pavithra, Data Manager, IDS-TILDA
Aviejay Paul, Data Scientist, IDS-TILDA
Michael Foley, Programme Manager, PPI Office
Dr Pdraig Carroll, Programme Manager, PPI Office
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 Irina Kinchin (Trinity Institute of Neurosciences (TCIN))
Dr Louise Daly (School of Nursing and Midwifery)
Dr Carmel Doyle (School of Nursing and Midwifery)
Dr Eimear McGlinchey (School of Nursing and Midwifery)
Mr Paul Horan (School of Nursing and Midwifery)
Mr Paul Keenan (School of Nursing and Midwifery)
Dr Mary-Ann O'Donovan (University of Sydney)
Dr Dominika Lisiecka (Munster Technological University)
Dr Andrew Wormald (University of Limerick)
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 Academic Advisor

Postdoctoral and Research Fellows

Dr Darren McCausland
Dr Andrew Wormald
Dr Kálya Yasmine Lima

Dr Louise Lynch
Dr Ashleigh Gorman

Research Assistants

Ms Stephanie Corrigan
Ms Iara Faria Synnott
Ms Jean Moynihan

Ms Shauna Walsh
Ms Miriam Fitzpatrick
Mr James Kelly

Meet Our Newest Teammates: 2023 - 2024



Dr Padraig Caroll,
Programme Manager,
PPI Office



Dr Kalya Yasmine Lima,
Research Fellow



Ms Shauna Walsh,
Research Assistant



Ms Miriam Fitzpatrick,
MINDS Project
Administrator



Mr James Kelly,
Research Assistant



Our Impact: 2023 - 2024

Tracking Research Uptake, Policy Influence, and Scholarly Outputs

Since its establishment, the Trinity Centre for Ageing and Intellectual Disability (TCAID) has maintained a strong and strategic research trajectory. The Centre's scholarly contributions are shaping academic discourse and laying the groundwork for long-term societal and policy impact across the lifespan.

While bibliometric indicators alone cannot fully capture the breadth of research impact, they offer valuable insight into the uptake, visibility, and influence of TCAID's outputs within academic, policy, and public domains. The following highlights underscore the Centre's growing reach and significance.

Policy Uptake and Citation by Key Institutions: TCAID's research has been cited by a wide range of national and international government bodies and policy agencies. These include: National Institute for Health and Care Excellence (NICE); Agency for Healthcare Research and Quality (USA); GOV.IE and The Welsh Government; Haute Autorité de Santé (France); European Centre for Disease Prevention and Control; GOV.UK; Publications Office of the European Union; The Commonwealth of Virginia (USA); United Nations Environment Programme; Australian Government Department of Health; New Zealand Ministry of Business, Innovation & Employment; Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (Germany).

This broad spectrum of referencing highlights the real-world relevance and reach of TCAID's research across health, policy, and regulatory environments.

Research Influence and Citations: TCAID's scholarly output continues to gain traction within the academic community. The Centre's Director, **Professor Mary McCarron**, exemplifies this influence. Her body of work (1998–2024) has been cited over **4,219 times** (Scopus), with **18.4%** of her publications ranked in the top 10% most cited globally (Scopus/Scival). This reflects both the academic quality and sustained influence of her contributions over time.

Informing Public Debate and Advancing Understanding: TCAID's research is contributing to greater public understanding of key health and social issues, particularly in relation to ageing and intellectual disability. A notable example is the Centre's research on early-onset dementia in people with Down syndrome. Findings from the *Horizon 21 European Down Syndrome Consortium* (Larsen et al., 2024) were cited by the **Nordic Welfare Centre** in its policy report, *Dementia Prevention in the Nordics*. The citation emphasises the study's identification of sleep disturbances, mental health challenges, and co-occurring conditions as risk factors for early-onset dementia in this population.

Our Impact: 2023 - 2024

Tracking Research Uptake, Policy Influence, and Scholarly Outputs

Altmetric Attention and Public Engagement: An analysis of 106 TCAID publications using **Altmetric** data revealed 151 mentions across platforms. Notably, **47%** of mentions on platforms such as X (formerly Twitter) were positive and **18%** were classified as strongly positive. Finally, **13 mentions** appeared in news articles and blog posts, reflecting the Centre's reach beyond academia into public discourse.

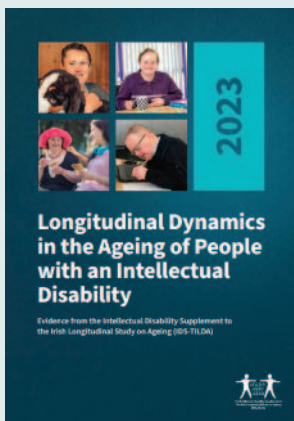
Expanding Digital Presence and Online Engagement: TCAID's online engagement continues to grow steadily, reflecting increasing interest in its research across digital platforms. The Centre's following on X (formerly Twitter) rose by **5.96%** over the past year, reaching **1,991** followers, while its LinkedIn audience expanded significantly—from **153** to **1,079** followers—marking more than a sixfold increase. Engagement metrics further demonstrate the Centre's resonance with online audiences: posts on X achieved an average engagement rate of **6.9%**, while LinkedIn posts averaged **19.3%**, with some posts reaching as high as **57.7%**—well above industry benchmarks. These trends underscore the Centre's growing visibility and influence within broader academic, professional, and public spheres.

These outcomes collectively highlight the Centre's evolving contribution to shaping evidence-based policy, informing public understanding, and enriching the global research landscape. Under the leadership of Professor McCarron, TCAID continues to be a key driver of impactful, interdisciplinary research in the field of ageing and intellectual disability.

*Larsen, F. K., Baksh, R. A., McGlinchey, E., Langballe, E. M., Benejam, B., Beresford-Webb, J., McCarron, M., Coppus, A., Falquero, S., Fortea, J., Levin, J., Loosli, S. V., Mark, R., Rebillat, A.-S., Zaman, S., Strydom, A. (2024). Age of Alzheimer's disease diagnosis in people with Down syndrome and associated factors: Results from the Horizon 21 European Down syndrome consortium. *Alzheimer's & Dementia*, 20(5), 3270–3280. <https://doi.org/10.1002/alz.13779>*



Adding life to years - Celebrating five waves of IDS-TILDA



In 2023, the Trinity Centre for Ageing and Intellectual Disability (TCAID) marked a significant milestone with the completion of Wave 5 of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). Now in its fifteenth year, IDS-TILDA continues to play a central role in building better lives for people ageing with an intellectual disability through evidence-based research, policy monitoring, and partnership.

IDS-TILDA is the only longitudinal study in Europe—and one of very few internationally—dedicated to understanding the ageing experience of people with an intellectual disability. Through its alignment with The Irish Longitudinal Study on Ageing (TILDA), the study offers a rare and invaluable opportunity to compare health, ageing, and quality of life outcomes between those with intellectual disabilities and the general population.

Wave 5 was launched at a time of renewal and transformation. It reflects both the resilience of participants in the aftermath of COVID-19 and the evolution of services, policies, and daily lives over the past decade. This wave included a refreshed cohort, ensuring continued representation of adults aged 40 and over, and the successful return of the Health Fair—a key feature first introduced in Wave 2—expanded to include oral and hearing health assessments.

Key findings demonstrate progress in areas such as community living, physical activity, and social participation, alongside persisting health concerns and systemic challenges—particularly for women, those with more severe disabilities, and individuals living in residential care. The study also provides the first data on the early implementation of the Assisted Decision-Making (Capacity) Act, which will continue to be monitored in future waves.

The commitment to interdisciplinary collaboration that underpins IDS-TILDA is reflected in the breadth of its data and its ongoing impact. With contributions from nursing, medicine, dentistry, pharmacy, psychology, social care, and public health, the study is uniquely positioned to inform policy, guide services, and support people with intellectual disabilities as they age.

Wave 5 not only celebrates the achievements of the study to date but reaffirms our ambition to continue leading internationally in the field of ageing and intellectual disability. It stands as a living embodiment of TCAID's mission to add life to years through research that is inclusive, impactful, and person-centred.



Christina (Chrissie)
Patterson, Stewart's Care,
and Prof. Mary McCarron

Marking the Launch of the IDS-TILDA Wave 5 Report

Following the publication of Wave 5, the Trinity Centre for Ageing and Intellectual Disability (TCAID) hosted a landmark event to officially launch the report—Longitudinal Dynamics in the Ageing of People with an Intellectual Disability—on Tuesday, 28th November 2023 at the Trinity Biomedical Sciences Institute, Trinity College Dublin.

This milestone gathering brought together researchers, policymakers, advocates, and individuals with lived experience to reflect on the study's findings and to shape a collective vision for the future of ageing with an intellectual disability in Ireland.

The day began on a high note with a deeply moving musical performance by Emma Kinsella, Eoin Hayden, and Sean Sheekey of the Viewpoint Self Advocacy Group at Sunbeam House. Their performance, supported by Tommy Breen and Rob Quinn, received a well-deserved standing ovation and set a warm, inclusive tone for the proceedings. They were joined by a supportive team including Catherine Craven, Liz Hayden, Steve Browne, Ed Byrne, Ian Harte, and Eileen Kelly, highlighting the vital networks that enable full community participation.

Professor Sinead Ryan, Dean of Research at Trinity College Dublin, opened the event with a powerful address affirming the university's dedication to impactful, inclusive research in the field of intellectual disability.

The formal launch of the IDS-TILDA Wave 5 report was conducted by Minister of State for Disability, Anne Rabbitte, TD, who highlighted the government's recognition of the report's influence on shaping inclusive health and social policy. Her remarks acknowledged the critical importance of the longitudinal research in improving supports for older adults with intellectual disabilities.



Minister
Anne Rabbitte



Prof. Sinead Ryan



Marking the Launch of the IDS-TILDA Wave 5 Report



Prof. Philip McCallion, Dr. Mark Ward, Dr. Rosemary Gowran, Dr. Jean Lane, Ms. Derval McDonagh, Dr. Alison Hartnett, Prof. Mary McCarron, and Ms. Olivia O'Leary



Mei Lin Yap



Prof.
Mary McCarron

Professor Mary McCarron, Principal Investigator of IDS-TILDA at Trinity College Dublin, presented key findings from Wave 5. She reported that people with intellectual disabilities in Ireland are living longer, healthier lives with more autonomy and community inclusion than ever before. However, she cautioned that significant challenges remain, especially regarding women's health, oral health, and dementia. The report's findings provide vital evidence for both the successes of current policies and the areas requiring urgent improvement.

The event also featured a session on the IDS-TILDA Health Fair, led by Dr. Eilish Burke and Ms. Jean Moynihan, who were joined by Mr. Christopher McEvoy, a study participant. Mr. McEvoy spoke candidly about his initial nervousness and eventual enjoyment of the process, offering a compelling testimonial about the power of inclusive research and health engagement.

A highlight of the day was the expert panel discussion moderated by respected broadcaster Olivia O'Leary, which explored the broader implications of the Wave 5 findings. The panel featured a distinguished lineup of leaders in the field: Professor Mary McCarron of IDS-TILDA at Trinity College Dublin; Professor Philip McCallion, Director of the School of Social Work at Temple University, USA; Dr. Rosemary Gowran, Clinical Lead for the National Clinical Programme for People with Disabilities at the Health Service Executive (HSE); Dr. Alison Hartnett, Chief Executive Officer of the National Federation of Voluntary Service Providers; Dr. Jean Lane, Senior Physician at Avista; Ms. Derval McDonagh, Chief Executive Officer of Inclusion Ireland; and Dr. Mark Ward, Senior Research Fellow at TILDA. Their collective insights offered a comprehensive, multidisciplinary view of the progress made—and the work still required—in ensuring that people with intellectual disabilities age with dignity, autonomy, and robust support systems.

The event concluded with closing remarks from Ms. Mei Lin Yap, Ambassador Liaison Officer at TCAID.

“I think this report is so important because it's all about understanding how to improve the lives of people with intellectual disabilities. It's vital that we recognise the different needs, and gaps in health provision, so that we can live longer, healthier, and happier lives. And isn't that what we all want—to create a happy and healthy future together?!”

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Reflections from the Launch

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“The future looks bright for people in our small country for people with an intellectual disability and this is largely thanks to the work you are doing. Very well done”

“The information provided was so informative and I have no doubt will enhance quality of life for all for the future. “

“It was a who’s who of disability in Ireland which was a very unique opportunity in itself. ... There is so much rich data available to shape service and to inform national policy and frameworks!”

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Key Findings from the IDS-TILDA Wave 5 Report

Social Determinants of Health

Wave 5 highlights significant progress in personal choice and decision-making among people with intellectual disabilities, particularly for those under 50 living with family or independently. While more individuals now have formal decision-making agreements in place, many still lack full participation in decisions about their living arrangements. Relationships remained central, with strong family and friendship networks noted—especially for those in group homes and residential care. Community participation saw modest gains, including increased digital engagement and employment for younger adults, although barriers such as staffing shortages and limited transport persist.

Multimorbidity and Physical Health

Physical health improved for those under 50, with fewer reporting chronic conditions. However, health concerns such as osteoporosis, constipation, and gastroesophageal reflux disease (GERD) remain prevalent—particularly among those with severe to profound intellectual disability. Women reported higher levels of pain and arthritis, and fragility fractures were significantly more common in older adults with intellectual disabilities than in the general population. Despite improvements, disparities in bone and foot health were notable, and a significant proportion of participants still experienced hearing issues not captured in self-reports.



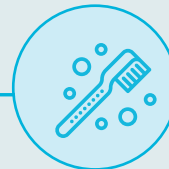
Behavioural Lifestyles

Physical activity levels increased across all age groups since earlier waves, especially among younger participants. Those who engaged in moderate activity reported better mental health and quality of life, while low activity levels were linked to higher rates of depression. Diet quality remained relatively stable, though many reported sedentary behaviours such as watching television daily. Smoking rates declined, particularly among younger participants, reflecting positive lifestyle changes over time. Psychological Well-Being and Cognitive Health

The prevalence of mental health diagnoses declined slightly, though conditions like anxiety and depression remain higher than in the general population. Loneliness also decreased, particularly among younger adults and those in residential settings. While many participants rated their mental health positively, the rate of dementia among people with Down syndrome was markedly high, with earlier onset compared to other groups. Despite increased dementia screening, a substantial proportion of those at risk had never been assessed.

Healthcare Utilisation

Healthcare access and service use improved over time, with increased uptake of vaccinations and bowel screenings exceeding national averages. However, screening rates for cervical cancer were low, with fear cited as a key barrier. Medication use remained high, especially for managing mental health, epilepsy, and constipation. Encouragingly, the use of psycholeptics declined among those aged 40–49, while vitamin D and calcium supplementation increased—showing some alignment with public health recommendations.

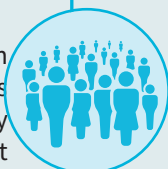


Oral Health

Oral health remains a major concern. One in five participants reported having no teeth, a figure that rises to two in five among those aged 65 and older—far exceeding rates in the general ageing population. This highlights a persistent and urgent need for targeted oral healthcare support for older adults with intellectual disabilities.

Family Carers

Wave 5 also gathered valuable insights from family carers, shedding light on the supports they provide and the challenges they face. Many carers reported positive aspects of their role but also expressed concerns about ageing, future planning, and the adequacy of resources available to help them continue their caring responsibilities over time.



Methodology

Wave 5 of IDS-TILDA retained its strong longitudinal design, tracking changes in the lives of older adults with intellectual disabilities over more than a decade. New elements such as hearing screening and detailed assessments of menopausal health were introduced, enhancing the richness of the data and enabling more comprehensive analysis of health and wellbeing trajectories.



Highlight: Generating and Translating Knowledge



Translating Evidence into Action: IDS-TILDA Conferences Inform Strategic Planning and Service Delivery for Older Adults with Intellectual Disabilities

Throughout 2023 and 2024, TCAID brought the latest IDS-TILDA research to the forefront of national service planning, engaging leaders, clinicians, and frontline staff across Ireland. Beginning with the Brothers of Charity Services Ireland (BOCSI) Health Strategy Scientific Meeting in September 2023, and continuing through a series of regional conferences in 2024, the IDS-TILDA team worked closely with service managers, clinicians, and policymakers to translate longitudinal evidence into meaningful strategic planning.

On Friday, 29th September 2023, Professors Mary McCarron, Eilish Burke, and Dr. Andrew Wormald from TCAID delivered a comprehensive overview of findings from all waves of the IDS-TILDA study at the BOCSI Health Strategy Scientific Meeting in Limerick. The event gathered senior leadership, including the CEO, Directors, and managers from services across Ireland, to collaboratively shape BOCSI's new strategic health plan.

IDS-TILDA's evidence highlighted the complex and evolving health, social, psychological, and mental health needs of individuals with intellectual disability as they age. The presentation was met with strong appreciation, with BOCSI leadership describing it as "inspiring," noting: "It has certainly given a lot of influential people food for thought. This is the start of an exciting journey for the Brothers of Charity Services Ireland in moving forward to change the health outcomes for the people we support." The event was organised by Maria B Murphy, National Lead for Infection Prevention and Control (IPC), and marked a pivotal moment in aligning national service planning with longitudinal research.

Building on this momentum, TCAID partnered with St. Joseph's Foundation, Donegal HSE Disability Services, and the Nursing & Midwifery Planning and Development Unit North West (NMPDU) to host a series of pivotal one-day conferences in 2024 under the theme: Longitudinal Dynamics in the Ageing of People with an Intellectual Disability: How Evidence from IDS-TILDA Can Inform and Support Strategic Planning and Service Delivery. These events brought together over 250 managers, clinicians, and frontline staff from across Ireland's disability services sector. Their shared goal was to explore and apply insights from five waves of IDS-TILDA to improve the quality, responsiveness, and effectiveness of service delivery.



Highlight: Generating and Translating Knowledge

Longitudinal Dynamics in the Ageing of People with an Intellectual Disability: How Evidence from IDS TILDA can inform and support strategic planning and service delivery.



On 30th May 2024, a team from TCAID travelled to Charleville Park Hotel, Cork, to partner with St. Joseph's Foundation in hosting a conference focused on equipping service providers with the latest evidence on ageing with intellectual disabilities. Over 100 participants attended, including senior managers, clinical leaders, and frontline staff, representing services across the South and West of Ireland.

The day featured a compelling programme of presentations delivered by IDS-TILDA experts, including Professor Mary McCarron, Dr Darren McCausland, Professor Eilish Burke, Dr Louise Lynch,

Dr Máire O'Dwyer, Dr Damien Brennan, and others. Topics ranged from dementia care and family caregiving sustainability, to physical health trajectories, social inclusion, and the impact of psychotropic medication use over ten years.

Facilitated by Dr Barry Coughlan, Principal Clinical Psychologist, and Michael Hegarty, Chief Executive Officer of St. Joseph's Foundation, the conference also provided space for collaborative workshops. These sessions encouraged participants to discuss practical strategies for integrating IDS-TILDA research into daily practice and long-term planning.

Closing remarks by Mr. Hegarty and Deputy Michael Moynihan TD, Chair of the Oireachtas Joint Committee on Disability Matters, emphasised the critical role that research evidence plays in shaping policies and supports for older adults with intellectual disabilities. Deputy Moynihan's presence highlighted the government's commitment to advancing inclusive health and social care through informed decision-making.

“

It is rare that you get such a vast array of expertise on ageing and ID in one room, at a given point in time – St Joseph's Foundation were delighted to collaborate with the IDS-TILDA research team in hosting our conference on Thursday May 30th 2024. The quality and richness of information provided by all speakers was outstanding, and it set the scene for some very informative and thought provoking discussions throughout the day. I believe this collaboration is a very significant step in our journey to provide the best possible care for those within our service who are presenting with age-related health issues. St Joseph's Foundation are looking forward to ongoing collaboration with IDS-TILDA and The Trinity Centre for Ageing and Intellectual Disability. -

Dr Barry Coughlan – Principal Clinical Psychologist and Conference organiser, St. Joseph's Foundation

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Highlight: Generating and Translating Knowledge

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"I would like to extend my heartfelt gratitude to Prof. Mary McCarron and her esteemed colleagues from IDS-TILDA, Trinity College, for their invaluable participation in our recently held conference ...

By sharing their research through personable and engaging presentations, Prof. McCarron and her team enriched our understanding of how we can better support individuals with intellectual disabilities and their families ... Their work underscores the importance of a holistic, person-centered approach, highlighting the diverse needs and aspirations of people with intellectual disabilities as they age.

This evidence-based knowledge empowers providers like St. Joseph's Foundation to develop more effective strategies that promote health, wellbeing, and quality of life. The dedication and expertise of the IDS-TILDA team, combined with their approachable and engaging delivery, made it an learning day for clinicians, healthcare leaders, family care givers and all who attended. Their contributions are invaluable in helping us work towards a more inclusive and supportive future for the individuals we serve."

Michael Hegarty – Chief Executive Officer, St. Joseph's Foundation

”

Building on this momentum, the Trinity Centre for Ageing and Intellectual Disability (TCAID) partnered with Donegal HSE Disability Services and the Nursing and Midwifery Planning and Development Unit North West (NMPDU) to host a further conference focused on the theme "Longitudinal Dynamics in the Ageing of People with an Intellectual Disability: How Evidence from IDS-TILDA Can Inform and Support Strategic Planning and Service Delivery."

Held in Donegal, the conference was attended by over 150 delegates representing a wide range of disability services, including managers, clinical professionals, and frontline staff. The event served as a vital forum for examining how longitudinal data can inform and transform service planning for older adults with intellectual disabilities.

Professor Mary McCarron delivered a powerful keynote address, presenting longitudinal findings that shed light on the intersecting issues of health, brain health, and multimorbidity among people with intellectual disabilities as they age. She was joined by colleagues Professor Eilish Burke, Dr. Martin McMahon, Dr. Ashleigh Gorman, and Dr. Damien Brennan, who presented in-depth findings drawn from Wave 5 of IDS-TILDA.

The conference highlighted the critical need to address persistent disparities that continue to affect this population. Despite improvements in life expectancy, people with intellectual disabilities in Ireland still face significantly poorer health outcomes, living on average 20 years less than the general population and experiencing higher levels of chronic illness, multimorbidity, and social exclusion.

Through a series of data-rich presentations and collaborative discussions, the conference emphasized the value of applying longitudinal evidence to strengthen strategic planning, promote equity in care delivery, and support the design of more inclusive, person-centred services. Key themes included enhancing social inclusion, fostering community participation, and implementing preventative approaches to health and wellbeing in ageing.



Highlight: Generating and Translating Knowledge

This event reinforced the importance of research-driven service reform and marked a significant step in translating IDS-TILDA's extensive findings into actionable change across the disability sector in the North West and beyond.

“Thank you all so sincerely for coming to Donegal and presenting such valuable information. The presentations were so well received and I felt an enthusiasm in the room, that has not been seen for a quite some time in Donegal. I will strive to ensure that we use the information that you shared from your research, to drive service improvement initiatives. Ultimately, we all endeavour to provide evidence based quality person centred care, and we are so fortunate to have Irish longitudinal data from IDS TILDA. Thank you for your commitment to IDS TILDA and research that supports and guides our practice.” –
Carmel Erksine, Candidate Advanced Nurse Practitioner, Donegal Intellectual Disability Services and event organiser

“Disability Services in the area are constantly seeking to be better informed in order to better plan for, represent and respond to the needs of people with intellectual disabilities. The opportunity to have world leaders in this area of research bring their knowledge and expertise to the Community Healthcare area was so very welcome and one which I and the Nursing and Midwifery and Planning Development Unit colleagues were eager to support. We know that the outcomes from the conference will shape and impact services going forward.” –
Ms. Edel Quin, Head of Service for Disability Services in Community Healthcare Cavan, Donegal, Leitrim, Monaghan and Sligo



A Collaborative Vision for the Future

These conferences underscore the vital role that longitudinal research plays in translating evidence into practice. By fostering collaboration among researchers, practitioners, policymakers, and advocates, TCAID and its partners are paving the way for more informed, compassionate, and effective services for older adults with intellectual disabilities.

Together, these gatherings reaffirm a shared commitment to evidence-based strategic planning—ensuring that health, social care, and community supports evolve to meet the complex and changing needs of this growing population.

Highlight: Generating and Translating Knowledge

Sharing the EQUIP Study Findings: From Community Engagement to Policy Impact



In 2023–24, the Trinity Centre for Ageing and Intellectual Disability (TCAID) marked the successful completion of the EQUIP project—*Examining Quality, Use and Impact of Psychotropic (Use) in older adults with intellectual disabilities*. This important research examined the use of psychotropic medicines over a decade, offering critical insights to inform policy and practice around medication use in this population.

Educational events

Let's Chat About Medicines!

As part of its commitment to inclusive, participatory research, EQUIP engaged directly with the projects cohort through the PPI Ignite Festival in October 2023. The event Let's Chat About Medicines! was co-designed by individuals with intellectual disabilities and welcomed people with intellectual disabilities alongside their families and support staff. Attendees learned about psychotropic medicines—their effects, usage trends, and impact—and were encouraged to share their own experiences. Interactive activities, including a paddle board true-or-false game, fostered engagement and made complex information accessible to all participants. This event exemplified EQUIP's mission to empower people with intellectual disabilities to actively participate in conversations about their medicines.

“I really enjoyed learning new facts about medications and there was a lot of good craic and good fun”
Attendee

Saint John of God

Further to TCAID's commitment to engagement and education, Dr Ashleigh Gorman delivered a fun education event to service users and support workers, providing accessible information on the EQUIP study and its findings. To enhance understanding and engagement, we included interactive games, helping to make the session inclusive, informative, and enjoyable for all participants.

“I wanted to thank you for the medication presentation you facilitated in our centre recently. The feedback from everyone was very positive. One of the service users commented that it was fun and the examples and explanations helped him understand what was being said. My supervisor felt that it was a very positive visit. He said that the simple language was perfect for the men and women we support to understand, and that the interactive aspect of the presentation made it more engaging. He said that we need more visits like this. My colleagues also feel that it was a great presentation. It was fun and informative experience for the people we support.

This was the first time we have had a visitor from outside of the service provide a talk like this. It was an important talk because some of the men and women we support take the types of medications that were covered. I feel that with them gaining more information about their medication is empowering and helps them live more independent lives.

We look forward to working with you again in the new year. I hope you have a nice Christmas and enjoy your time off.” **Joe Roshe, Support Worker, St John of God**



Research Findings Launch: Webinar and In-Person Event

In May 2024, the EQUIP findings were formally launched through a two-part event, underscoring the project's translational impact. The in-person launch at Trinity College Dublin featured Dr. Máire O'Dwyer presenting the study's key findings, followed by a dynamic Q&A with experts including Professor Mary McCarron and Dr. Rosemary Gowran. The event also premiered a bespoke dissemination video developed with input from people with intellectual disabilities, presenting the research findings in an accessible and engaging format.

Complementing this, the Psychotropic Use in People with Intellectual Disability webinar brought together over **150 healthcare professionals, researchers, and service providers**. This online session highlighted the decade-long trends and outcomes revealed by the study, including significant reductions in anxiolytic and hypnotic use, a rise in antidepressant prescribing, and important observations on non-pharmacological support access. The webinar remains available on YouTube and has reached a broad audience, reinforcing EQUIP's commitment to making research findings accessible to all stakeholders.

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'This webinar was a great success, and was attended by >150 health care professionals, academics and those who worked in services. There was great engagement and discussion with the panel after the presentation. Future webinars are now in planning for patients, carers, family members and psychiatrists who work with people with intellectual disability. The webinar is now available on youtube, meaning it is available for any health professionals to watch at a time of their choosing, with already >120 people viewing the youtube video. This aligns with our mission in TCAID to make sure our publicly funded research is accessible and equitable for all in order to benefit health of people with intellectual disability' -

Dr Máire O'Dwyer – Principal Investigator, EQUIP

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A Video for Everyone

Central to EQUIP's dissemination was the creation of an informative video featuring members of the EQUIP Steering Group with intellectual disabilities alongside TCAID's PPI panel. This resource explains psychotropic medications and shares key findings in a clear, relatable way, supporting understanding among people with intellectual disabilities, families, and carers.

Together, these initiatives reflect EQUIP's holistic approach to research dissemination—engaging the community, informing professionals, and influencing policy—ensuring that evidence leads to meaningful improvements in the health and wellbeing of adults with intellectual disabilities in Ireland. Watch the video here - <https://youtu.be/zHMSyX3hQ-8>

Highlight: Generating and Translating Knowledge

IDS-TILDA presentation to the Disability Division in the Department of Children, Equality, Disability, Integration and Youth



Mr. Colm O Conaill, Assistant Secretary to the Disability Division of the Department of Children, Equality, Disability, Integration, and Youth (DCEDIY), extended an invitation to Professor Mary McCarron and the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) research team to present their latest findings to the department.

The presentation covered various key areas, including Intergenerational Changes for 40-49 year-olds, Social Determinants of Health such as Interpersonal Relationships, Community Participation and Choice, Loneliness, Multimorbidity and Physical Health Trajectories in People with Intellectual Disability, Outcomes for Older Women with Intellectual Disabilities, Individuals with Severe to Profound Levels of Intellectual Disability, Psychological Well-being and Cognitive Health, Oral Health, and Family Carers.

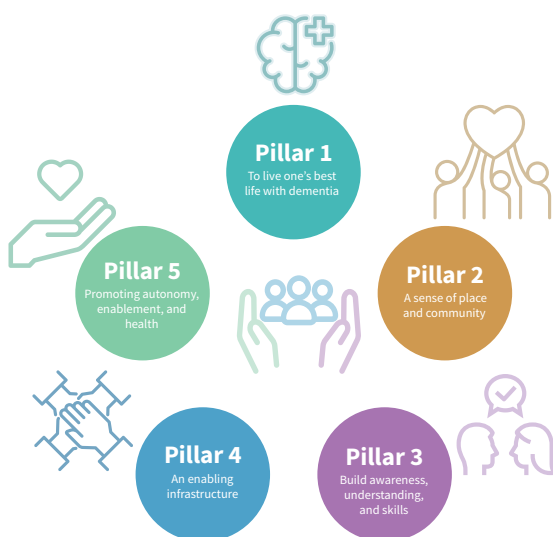
The Department responded positively to the findings and recognised the significant potential for collaboration. This engagement laid the groundwork for deeper partnership opportunities, with contact details exchanged to facilitate future dialogue and alignment with TCAID. The exchange marks an important step toward integrating evidence-based research into policy and practice to improve the lives of people with intellectual disabilities across Ireland.

Launch of Post-Diagnostic Support Guidelines for People Aging with an Intellectual Disability



As part of our commitment to generating evidence-based knowledge and informing inclusive policy, the Trinity Centre for Ageing and Intellectual Disability (TCAID) launched the *Post-Diagnostic Support Guidelines for People Aging with an Intellectual Disability* in September 2024. This milestone event, delivered through a national webinar, marked the culmination of a multi-year research initiative focused on addressing the complex needs of adults with intellectual disability following a dementia diagnosis.

The guidelines were developed in response to a critical gap in care identified during the COVID-19 pandemic: the lack of structured, person-centred supports for individuals with intellectual disabilities at the point of dementia diagnosis. People with intellectual disability—especially those with Down syndrome—are at increased risk of developing dementia, and often experience abrupt and distressing changes in their living situations. These new guidelines seek to address that risk by outlining a framework that prioritises continuity, dignity, and the right to age in place.



Co-produced with individuals with lived experience, family carers, clinicians, and service providers, the guidelines are built on a foundation of collaboration and inclusion. They are accompanied by a suite of practical tools, including an accessible information leaflet and a “Voices of Experience” resource, to support wide implementation across services.

The launch event, attended by professionals from health, disability, and social care sectors, featured a comprehensive presentation of the guidelines followed by a panel discussion on implementation strategies. Awarded one CPD hour by the Nursing and Midwifery Board of Ireland (NMBI), the event reinforced the clinical and practical relevance of the guidelines and highlighted the urgent need for their adoption across policy and practice.

This work exemplifies how TCAID continues to generate impactful knowledge that informs national policy, shapes service delivery, and advocates for the rights of people with intellectual disabilities to age with autonomy and support. The Post-Diagnostic Support Guidelines represent a major step toward ensuring that ageing and dementia care is equitable, person-centred, and informed by those it seeks to serve.

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Quote from Paul Maloney, Programme Manager, National Dementia Services, Enhanced Community Care Programme & Primary Care Contracts, HSE

National Dementia Services are extremely proud to have supported the development and long-term stability of the National Intellectual Disability Memory Service (NIDMS) through recurring funding via NSP22. The NIDMS provides such a vital service that is both nationally and internationally respected. The development of these guidelines are another key milestone in its development. These guidelines are critical to ensuring that people with an intellectual disability and a diagnosis of dementia receive an exemplar and standardised service no matter where they live in Ireland. These guidelines will inform the healthcare system and indeed all key stakeholders as to what is needed by a person with intellectual disability after they receive a diagnosis of dementia, this may include practical supports and education and/or information that will support them along the post diagnostic pathway. I'm certainly looking forward to seeing these guidelines being implemented, resulting in positive outcomes for people who require this critical service.

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Rita Walsh

Parent of an adult daughter, Helena, with Down syndrome aged 35yrs

“We are parents who have had to advocate, challenge and fight for all the services our daughter needed for the last 35yrs – services including medical card, speech therapy, medical procedures ie; cardiac surgery. We have had to advocate for her inclusion in mainstream education and all the supports that she needed in that. We have had to challenge the system with regard to support for her when she left formal education to give her a quality of life that she deserves. All of this has come at a cost of huge reserves of time and energy on our behalf. Yet we find as we ourselves age and tire we possibly face the greatest challenge of all with the very real threat to our daughter of early onset dementia/alzheimers. Therefore, it is with great appreciation that we welcome the launch of these guidelines which will be of great assistance to us should we need them in the future. Because they are based on scientific evidence and professional best practice, we and her extended family or her support circle will be able to use these to advocate on her behalf for her care needs as she ages. These guidelines will not just be our wishes or our thoughts but are the results of much scientific and medical research and therefore they will carry great value in professional circles.”

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Highlight: Generating and Translating Knowledge



PhD Student Profile: Stephanie Corrigan



Stephanie's PhD project is titled **"Menopause and mental health in women with intellectual disabilities: a mixed methods study"**. Women with intellectual disabilities have historically been omitted from research on sexual and reproductive health – including menopause research. To date, there has been no research carried out on the mental health implications of menopause in women with an intellectual disability despite higher rates of mental health challenges, communication difficulties and psychotropic medication use faced by this group. Therefore, the aim of the study is to investigate any potential effects of menopause on the mental health of women with an intellectual disability. This study will follow an explanatory sequential mixed methods design; comprising an initial quantitative component using IDS-TILDA data to examine any associations between menopause and mental health in this population which will inform a subsequent qualitative exploration of the perceptions and experiences of menopause in this population. The mixed methods approach informed by a transformative worldview, and developed in tandem with expert PPI contributors, will ensure the voice of the woman with an intellectual disability is at the heart of the research to ensure the research is applicable and relevant to the target population.

Stephanie has been very fortunate to secure PhD funding from Stewarts Care Service Provider to carry out her study in partnership with the organisation. The findings from her PhD will inform a health education intervention on menopause for women with intellectual disabilities that will be developed in collaboration with members of the organisation. This will take the form of a multi-modal intervention involving the use of easy-to-read materials and videos that will be accessible for women with an intellectual disability to improve knowledge and education on menopause in this population.

Throughout her PhD Stephanie has carried out a wide range of dissemination activities, including workshops on women's health. An example of this was an event held in the Dublin Chamber in September 2024 entitled: "Sexual and Reproductive Health in Women with Intellectual Disability: Time to End the Taboo!" These events are such an important step in including women with an intellectual disability in mainstream conversations around their own health – particularly around topics such as menopause.



Dissemination

Corrigan, S., McCarron, M., McCallion, P., & Burke, É. (2024). The impact of menopause on the mental health of women with an intellectual disability. *Journal of Intellectual Disability Research, IASSIDD 17th World Congress 2024, Chicago, 5 - 8 August, 2024*

Corrigan, S., McCarron, M., McCallion, P., & Burke, É. (2024). The impact of menopause on the mental health of women with an intellectual disability: a scoping review. *Trinity Health & Education International Research Conference (THEconf2024), Trinity College Dublin.*



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

World Osteoporosis Day 2023: Promoting Bone Health and Preventing Frailty in People with Intellectual Disability

On World Osteoporosis Day 2023, we focused on bone health and frailty, a significant health issue impacting many with intellectual disability as they age. Research consistently shows that this population faces significantly increased rates of poor bone health, a challenge compounded by factors such as polypharmacy, sedentary lifestyles, and imbalanced diets. Importantly, these are modifiable risk factors, making awareness and early intervention key to improving health outcomes.

Findings from IDS-TILDA reveal that 54.5% of men in the middle age group presented with a prevalence of osteoporosis vs 48% for women in the same age group. What was concerning was that just 38% of the overall sample had attended for diagnostic DXA screening. When considering Vitamin D supplementation, only 27% of individuals within the osteoporotic range, and 28% within the osteopenic range were taking vitamin D supplementation, increasing the risk of fragility fractures for this cohort. These statistics underscore the urgent need for targeted screening, preventative care, and tailored interventions across the lifespan.


To mark this important awareness day, Stewarts Care hosted an insightful and timely event focused on bone health, falls prevention, and frailty in individuals with intellectual disability. The event welcomed expert speakers who brought clinical and research perspectives to the forefront, including: Prof. Eilish Burke, Professor in Intellectual Disability Nursing, Trinity College Dublin; Dr. Aoife McFeely, Specialist Registrar in Geriatric Medicine, Tallaght University Hospital and MD student with IDS-TILDA and Ms. Anne Power, Advanced Nurse Practitioner in Chronic Health Conditions in Intellectual Disability (Adult), Wexford Residential Intellectual Disability Service.

Together, the speakers shared the latest evidence on osteoporosis screening and management in intellectual disability services, highlighting the need for improved access to diagnostics and preventative strategies. The conversation also explored how bone health intersects with broader issues of frailty and falls prevention, reinforcing the importance of multidisciplinary, lifespan-informed care.


This event brought together clinicians, researchers, and health promotion professionals to examine what bone health means in the context of intellectual disability, and how services can better respond to this growing area of need. Most importantly, it reinforced a message central to all of our work: people with intellectual disability deserve equitable access to preventative health care and should be supported to live strong, healthy lives as they age.

Osteoporosis presents itself in

54.5% of middle aged men and **48%** and in middle aged women



Only **38%** attended diagnostic DXA screening



Only **27%** use vitamin D supplements





Highlight: Contributing to Society

World Down Syndrome Day 2024: Ending the Stereotypes, Championing Women's Health

On March 21st, we joined the global celebration of World Down Syndrome Day 2024, to raise awareness, promote inclusion, and champion the rights of people with Down syndrome. This year's theme, "End the Stereotypes", invited us to confront outdated narratives, and we chose to place a spotlight on women with Down syndrome, a group whose unique health experiences are too often overlooked. With a focus on women's health, our video aimed to amplify the voices of women with Down syndrome from around the world, asking them directly: *What does health mean to you?*

Through a powerful video, women with Down syndrome shared their personal reflections on health: how they care for themselves, what supports their well-being, and how they defy stereotypes every day. Their stories were honest, inspiring, and diverse, a clear reminder that women with Down syndrome are the experts in their own lives and deserve to be heard, respected, and supported.

This initiative not only highlighted their strength and agency, but also challenged assumptions about their ability to understand and advocate for their own health. Across countries and cultures, a common message emerged: a desire to be seen, to be heard, and to be supported as active participants in their health journeys.

To celebrate their voices, we hosted a special event at our centre, where the women featured in the video were invited to view the final piece together. It was a joyful and moving gathering that reinforced the importance of connection, representation, and visibility. We were proud to mark this important day alongside such a powerful group of women who continue to inspire and shape the work of TCAID. By giving centre stage to women with Down syndrome, we aimed to challenge outdated narratives and promote a more accurate, empowering understanding of what it means to live a healthy life with Down syndrome. As we continue this work, we remain committed to ensuring that the voices and experiences of women with Down syndrome are heard, valued, and central to conversations on health and inclusion.

You can watch the full video here: <https://youtu.be/FGnsaDAGpKQ>

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“Another fantastic example of the work of TCAID to empower women with Down syndrome to improve their health and well-being, break down stigma and raise awareness on what we all can do to promote inclusion and equity in healthcare. Well done”

**Maria Kavanagh, Director of Nursing,
Stewarts Care**



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Highlight: Contributing to Society

Sexual and Reproductive Health in Women with an Intellectual Disability



Often times women with an intellectual disability are excluded from conversations surrounding their sexual and reproductive health. In efforts to address this disparity an exciting event was held in September, led by Stephanie Corrigan, PhD student at TCAID and Prof Éilish Burke. In attendance were women with lived experience of intellectual disability, along with nurses, doctors, psychologists, and representatives from the HSE, the Women's Health Taskforce, and various services nationwide. It represented the first of many conversations to be held amongst women with an intellectual disability on this important topic.

The theme of the event was to end the taboo around sexual and reproductive health in women with an intellectual disability, with the main aim of encouraging women with an intellectual disability to open up the conversation around their sexual and reproductive health to ensure they get the services they require. The event comprised of talks from experts in the field of Women's Health including invited professors Dr. Rachael Eastham from Lancaster University, UK, and Dr. Alex Kaley from Essex University, UK, alongside Prof. Mary McCarron, Prof. Éilish Burke, Stephanie Corrigan, and Patricia Blee. Each academic presentation was accompanied by an accessible interpretation by Ms Mei Lin Yap, Ambassador Liaison Officer for TCAID, to ensure that all attendees could understand the important messages from the day.

The presentations covered topics such as Ireland's history of sexual and reproductive health for women with intellectual disabilities, long-acting contraception, menstruation, sex, pregnancy, menopause, and health disparities in women over 40. The day sparked vital conversations around consent, abortion, and inclusive care.

Feedback showed that women with intellectual disabilities value consistent, accessible information and prefer female health professionals who understand their experiences. They emphasized the need for adequate time and support to make informed decisions, as well as tailored communication and resources for those with higher support needs or communication difficulties. It is vital to include women with an intellectual disability in the conversation around sexual and reproductive health, and this event was the first of many conversations on this topic with a powerful group of self-advocates in attendance.

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'I am honoured to have had the opportunity to host such an inspiring event which highlighted the under researched topic of sexual and reproductive health in women with an intellectual disability. ... It is my hope that this event will be the first of many conversations held amongst women with an intellectual disability, their carers, staff, and healthcare providers on this critical topic to ensure this topic is no longer swept under the carpet. Thank you to all of the wonderful speakers and attendees who made the day so special. What a wonderful, powerful, inspiring group of women. ... Lets keep the conversation going about all things sexual and reproductive health!'

Stephanie Corrigan, Event Organiser and PhD Student TCAID

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*"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, University of New England

Canada

- Reena, Toronto, Canada

United States

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

Singapore

- Happee Hearts Movement, IDHealth

Highlight: Growing Our Research Community

TCAID at IASSIDD 2024: Showcasing Research and Looking Ahead to Dublin 2027



In August, members of the Trinity Centre for Ageing and Intellectual Disability (TCAID) and the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) attended the 17th International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) World Congress in Chicago. The team delivered an impressive 34 presentations and actively participated in symposiums and roundtable discussions focused on key thematic areas such as ageing, Down syndrome, health issues, and inclusive research. The congress provided a valuable opportunity to share cutting-edge work, engage with international colleagues, and strengthen global research networks.

A highlight of the event was the announcement by Professor Mary McCarron that Dublin has been selected to host the next IASSIDD World Congress in 2027. Scheduled to take place from 17–20 August at the Convention Centre Dublin, the congress will bring together over 1,200 international delegates for four days of collaboration, innovation, and knowledge exchange. The successful bid for Dublin reflects the international recognition of TCAID and the IDS-TILDA study as leaders in the field of ageing and intellectual disability. The announcement was followed by the first official meeting of the Local Management Committee with IASSIDD President Professor Angus Buchanan, Treasurer Professor Colleen Adnams, and PCO Director Ms. Margaret Sherry, marking the beginning of preparations for what promises to be a landmark event.

We look forward to welcoming colleagues from around the globe to Ireland to experience our innovative research culture and warm hospitality.

IASSIDD 2027 promises to be a defining moment for advancing research, strengthening global partnerships, and shaping the future of support and inclusion for people with intellectual and developmental disabilities.



Highlight: Growing Our Research Community

Advancing Alzheimer's Research for Individuals with Down Syndrome: Insights from the Horizon 21 Consortium Meeting in Dublin

In April 2024, Prof. Mary McCarron, Professor of Ageing and Intellectual Disability, Dr. Eimear McGlinchey, Assistant Professor in Intellectual Disability, and Miriam Fitzpatrick, Research Administrator to the MINDS project of TCAID, were delighted to host the Horizon 21 consortium, a research group that aims to identify and prevent the factors influencing the development of Alzheimer's Disease in people with Down Syndrome. The group meets regularly online and in person throughout the year and on this occasion was attended by Prof. Andre Strydom (UK), Prof. Shahid Zaman (UK), Phoebe Ivain (UK), Sarah Khoo (UK), Dr. Anne-Sophie Rebillat (France), Diane Martet (France), Dr. Bessy Benejam (Spain), Dr. Eleni Baldimtsi (Greece), Lisa Engberg (Sweden), and Katja Sandkühler (Germany). The group was also joined by Prof. Mark Mapstone (University of California, Irvine) who gave an overview of his project Alzheimer Biomarker Consortium: Down Syndrome (ABC-DS), a study of adults with Down syndrome to detect early biomarkers of Alzheimer's Disease.

Due to enormous improvements in healthcare and medicine over the past decades, people with an intellectual disability can now enjoy longer lives, with the average life expectancy currently at 60 years of age in developed countries. Such remarkable progress means greater opportunities for research into healthy ageing, which benefits people with intellectual disabilities themselves, their families and caregivers.

One of the research findings that has emerged is a higher prevalence of dementia among people with an intellectual disability and an earlier age of onset compared to the general population. In particular, Alzheimer's Disease – a form of dementia – is related to Trisomy 21 in Down syndrome. This is because chromosome 21 involves an increased accumulation of the amyloid beta (A β) peptide in the brain. However, it is important to note that not everyone with Down syndrome will progress to develop dementia, which is why it is critical to detect preventative factors.

Until recently, dementia research focused mainly on the general population, as diagnosing dementia for someone with Down syndrome requires appropriate evaluation tools and a specialised team. Along with identifying and preventing factors contributing to the onset of Alzheimer's in people with Down Syndrome, Horizon 21 also aims to develop cognitive assessment tools and biomarkers.

During the two-day meeting, the group provided updates on current trials, and also discussed how non-pharmacological interventions to prevent dementia in people with Down syndrome could be carried out. These would include modifications to exercise, diet, sleep, social connectedness and management of cardiovascular issues. Careful consideration was also given to factors that might impede participation, such as: time, transport, support from caregivers or family members, participating alone or in a group, using computerised platforms and using apps or online sessions. People with Down syndrome may also have a different cardiovascular risk profile, diabetes or thyroid disease, a higher BMI at a younger age, differences in lipids processing pathways and hypertension – which would mean adapting previous studies on the general population for people with Down syndrome.

After many thought-provoking exchanges, and a chance for some Horizon 21 members to enjoy a quick glimpse of Dublin, the meeting concluded with an agreement to reconvene in October 2024.

This event was funded by Forte (Research council and government agency under the Swedish Ministry of Health and Social Affairs).

Highlight: Growing Our Research Community

Forging Bonds: Singaporean Delegation Visits Trinity College Dublin

As part of our commitment to growing our research community and fostering international collaboration, the Trinity Centre for Ageing and Intellectual Disability (TCAID) welcomed a distinguished delegation from IDHealth, Singapore, during the week of April 22nd. The visit was organised by Professor Eilish Burke, with the goal of exploring global best practices in healthcare for people with intellectual disabilities and establishing long-term partnerships in research, education, training, and service development.

IDHealth is a community-based, integrated health team dedicated to serving adults with intellectual disability and their caregivers. The delegation included Dr Shiling Chen (Founder & Executive Director), Joy Teo (Head, Community Building and Enablement), Low Soo Wen (Senior Medical Social Worker), and Nadzira (Senior Staff Nurse).

The week commenced with an in-depth overview of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), followed by thematic sessions that explored key areas such as dementia, oral health, sedentary behaviour, bone health, medication use, and the social determinants of health. These sessions were delivered by experts Dr Eimear McGlinchey, Katrina Byrne, Dr Louise Lynch, Anne Power, Dr Lamya Al Shuhaimi, and Lara Faria Synnott, offering valuable insights into current research and practice.

Over the following days, the delegation engaged with a number of leading service providers. At Stewarts Care, they met with Programme Manager Donal Moynihan and Director of Care – Residential Services, Aidan Farrell. Their visit continued with Avista, where they were hosted by Advanced Nurse Practitioner Pamela Dunne, followed by a trip to Galway to discover the work of the Brothers of Charity with Sector Manager for West Galway Adult Services, Marina Moore, and National Lead for Infection Prevention and Control, Maria Murphy.

The visit concluded at Trinity with a roundtable discussion hosted by TCAID, providing an opportunity for shared learning and reflection, followed by a cultural experience at the Book of Kells exhibition.

This visit marked an important step in strengthening international ties and promoting mutual learning in the field of intellectual disability care and research.





Highlight: Growing Our Research Community

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

PPI Panel Sept 2023 – Aug 2024

September 2023

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, we had two researchers present to the panel. In preparation for her event for the PPI Ignite Festival on the 3rd October "Let's chat about medicines", Dr Ashleigh Gorman presented her ideas to the panel to ask for their advice on accessibility when discussing information about medications to people with an intellectual disability. The panel helped her to choose the correct wording for easy comprehension, and even made suggestions about the design of her props for the event to ensure they were visually appealing and easy to use. Next, 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). The panel shared their own experiences with both types of language and other more hurtful, discriminatory language and concluded that they preferred the use of person-first language in research concerning people with intellectual disabilities.

October 2023

On October 3rd the panel attended Ashleigh's PPI event "Let's chat about medicines" as part of the National PPI Festival. Ashleigh secured funding from PPI Ignite to host this event in conjunction with the PPI panel to provide people with intellectual disability with accessible information on psychotropic medications. In preparation for the event, the panel were involved in securing funding, planning, and co-designing the event. The panel advised on accessibility measures for the event, including the design of colourful paddleboards to indicate whether audience members understood the content of the presentation. The panel were also involved in facilitating the smooth running of the event on the day; one panel member welcomed attendees as they entered the event space and another helped with registration at the event, ticking off attendees as they arrived. The panel actively participated in the event and encouraged others to participate too.

Highlight: Growing Our Research Community

November 2023

On the 21st of November, panel members attended their regular bimonthly meeting. On this day, panel members were invited to Popcorn day: a screening of the videos they advised on for Lara's Circles of Support project. Panel members had previously participated in a workshop providing invaluable advice on the accessible creation of videos illustrating circles of support. Lara provided popcorn and sweets and showed panel members the videos that were created in line with their guidance – the fruits of their labour. Following this, panel members were faced with the difficult task of selecting the top 3 Christmas card entries for the 2023 Christmas card competition. After much deliberation, the panel members selected three finalists from a shortlist of very talented artists.

On 28th November, members of the PPI panel attended the IDS-TILDA Wave 5 Report Launch. The PPI panel were integral to the 5th iteration of IDS-TILDA as they were involved at each stage of the research cycle, from training field researchers to conduct interviews with IDS-TILDA participants, to their active involvement in the dissemination of findings. The panel were heavily involved on the day; with one panel member helping with the registration desk and another panel member providing the closing speech for the launch.

January 2024

The panel met for their bimonthly meeting on 23rd January 2024 and advised on two ongoing projects. They provided their perspective on the content validity of the Modified Oral Status Survey Tool (MOSST) - a dental assessment tool developed for people with intellectual disabilities by a researcher in TCAID. They also advised on the video dissemination of the EQUIP study. They will be participating in the filming of the video for the EQUIP project in March.

March 2024

In early March, the PPI panel participated in the filming for the EQUIP project. The researchers on the EQUIP project met with PPI panel members in advance of the filming day to rehearse their lines to ensure panel members were prepared and comfortable. Options were provided to panel members to participate in the video recording or to provide a voiceover if they were not comfortable appearing on screen. This ensured full enjoyment by all. Please see the EQUIP website for more information

The PPI panel met on the 26th March 2024 for their bimonthly meeting. The women of the PPI panel were invited to advise on a PhD study concerning menopause that is currently being conducted by one of the researchers in the centre. They advised on the overall project direction and determined the project's relevance to their lived experience. They also gave invaluable advice concerning recruitment and provided strategies for discussing sensitive topics with women with an intellectual disability. Following this, the panel were *consulted regarding an article being written on PPI entitled: "The impact of PPI engagement in research - a case study of a panel of individuals with intellectual disabilities"*. The panel are co-authors on the paper. One of the researchers who is also a co-author on the paper presented initial findings to the panel in an accessible manner to validate and verify the progress that had been made on the article. This was to ensure that the panel agreed with any decisions that had been made so far. The panel were happy with the progress made so far and felt that it aligned with their understanding of the purpose of the article, which is to provide guidance to other researchers on how to conduct good PPI in other research centres.



Highlight: Growing Our Research Community



April 2024

Members of the PPI panel attended the EQUIP dissemination event on the 2nd April. The dissemination video that panel members participated in was played and panel members were presented with certificates and vouchers to thank them for their continued contribution throughout the project duration.

May 2024

The next bimonthly meeting took place on 28th of May and two researchers from the centre, Pavithra and Iara, presented on their upcoming project in collaboration with Avista Services. The project entitled: "Engaging the brain through Cognitive Stimulation Therapy" is due to start in the coming months and the PPI panel's contribution was critical at this foundational stage of the project. The panel advised on the feedback form that would be provided to participants after the intervention. The feedback form is essential to the intervention study as it determines if the intervention was useful, if participants found it enjoyable and enables participants to provide recommendations for any future iterations of the intervention. Panel members reviewed the form to ensure that it was accessible for potential participants of the CST study.

July 2024

The most recent bimonthly meeting took place on 30th July. Two researchers from the centre presented to the panel. Dr Andrew Wormald presented on his project on loneliness. The panel advised Andrew on his Easy-to-Read report detailing findings from the study. They provided invaluable guidance around the accessibility of the document from advice on sentence structure, to enlarging fonts and photo symbols for clearer visibility. Next, Dr Ashleigh Gorman consulted with the panel to attain their feedback on their participation in the EQUIP project. Any knowledge garnered from this meeting will be utilised for a paper to be written by Ashleigh in partnership with the PPI panel. The panel provided insights into their experience participating in the EQUIP project with particular emphasis on their enjoyment participating in the dissemination video.

Highlight: Achievements and Awards Highlights

Recognised for Excellence



Professor Mary McCarron appointed to the Commission on Care for Older People

Professor Mary McCarron was appointed to the Commission on Care for Older People by Minister for Health, Stephen Donnelly and Minister of State for Mental Health and Older People, Mary Butler. The Commission on Care for Older People examines the health and social care services and supports for older people across the continuum of care and make recommendations for their strategic developments.

Professor McCarron was announced as one of 12 members of the new commission, which will provide expert recommendations to help Ireland prepare for the care of an ageing population, which will include a growing number of older adults with an intellectual disability.

“*“Being appointed to the Commission on Care for Older People is an honour, as it represents a crucial opportunity to ensure that as we address the pressing needs of our ageing population, we include those ageing with intellectual disabilities. A richer society is one where everyone, regardless of ability, is supported. I firmly believe that adults with intellectual disabilities should have the opportunity to live in homes of their choice, within their communities, surrounded by family and friends. I am a strong advocate that together, we can effect real change and build a society that values and supports every individual enjoying meaningful engagement, lifelong learning, and dignity as they age.”* – **Prof. Mary McCarron**

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Inaugural Lecture at Queens University Belfast by Prof. Mary McCarron

Prof. Mary McCarron hosted her Inaugural Professorial Lecture at Queen's University Belfast, entitled “Leadership in Academia, Health Research and Health Care: Charting a Personal Journey.” This lecture followed her appointment as an honorary professor at Queen's School of Nursing and Midwifery the previous year.

To celebrate the occasion, Queen's University hosted distinguished guests from the Department of Health, the Health and Social Care Trusts, as well as colleagues and students from the University. The lecture was opened by Professor Ian Bruce, Pro-Vice-Chancellor for the Faculty of Medicine, Health and Life Sciences.

The event marked a significant milestone in Prof. McCarron's career, recognising her contributions to academia, health research, and healthcare. It was an opportunity to reflect on her journey thus far and to acknowledge the continued partnership between Queen's and her professional work. The event also underscored her ongoing commitment to advancing knowledge and discovery in these fields.



Highlight: Achievements and Awards Highlights

Recognised for Excellence

Professor Éilish Burke Appointed as Professor in Intellectual Disability Nursing



Warmest congratulations to Professor Éilish Burke on her appointment as Professor in Intellectual Disability Nursing at the School of Nursing and Midwifery, Trinity College Dublin. This well-deserved appointment followed a highly competitive interview process and marked a significant milestone in a career dedicated to excellence in research, education, and practice.

Professor Burke is internationally recognised for her work in ageing and intellectual disability. As Co-Director of the Trinity Centre for Ageing and Intellectual Disability and a long-standing contributor to IDS-TILDA, her research has had a profound impact on inclusive healthcare, particularly in areas such as osteoporosis screening and empowering people with intellectual disabilities to actively participate in research.

We look forward to her continued leadership in shaping the future of Intellectual Disability Nursing. Her vision and dedication will undoubtedly guide the ongoing development and growth of this vital field, both in Ireland and globally.

Dr. Juliette O'Connell Was Awarded Prestigious Fulbright Fellowship



We are delighted to celebrate the achievement of Dr. Juliette O'Connell, who was awarded a highly prestigious Fulbright Award for 2023/24. As a Fulbright-HRB Health Impact Scholar, Juliette was hosted by the College of Pharmacy at the University of Kentucky, where she collaborated with leading experts to explore opioid prescribing practices and stewardship strategies.

Juliette, an Assistant Professor in Therapeutics and Pharmacy Practice at Trinity's School of Pharmacy and Pharmaceutical Sciences, was also a valued member of the Medicines Optimization group within IDS-TILDA. This international recognition was a testament to the significance of her work and her ongoing contribution to advancing healthcare practice and policy. We warmly congratulate Juliette on this outstanding accomplishment and look forward to the impact of her research during and beyond her Fulbright experience.

Highlight: Achievements and Awards Highlights

Recognised for Excellence

School of Nursing and Midwifery Research Impact Case Study Competition



The School of Nursing & Midwifery held the inaugural TCD School of Nursing and Midwifery Research Impact Case Study Competition which encouraged researchers to enter a case study demonstrating the impact of their research. Research Impact Case Studies provide the opportunity to communicate how research is making a positive impact on healthcare and people's lives.

Prof. Eilish Burke won the Individual Entry Category for her case study, *"Empowering Healthcare: From Research to Practice in Intellectual Disability Health Assessment."* This case study addressed health disparities faced by individuals with intellectual disabilities. As community-based care grows, many practitioners lack the training to meet their unique needs. Prof. Burke's work aims to bridge this gap, improving care and outcomes for this vulnerable group.

The IDS-TILDA team won the Group Entry Category for their case study, "Transforming Health Care Delivery: Launching the National Intellectual Disability Memory Service," highlighting the creation of the National Intellectual Disability Memory Service (NIDMS). This centre of excellence focuses on proactive dementia assessment and diagnosis for individuals with intellectual disabilities. The case study included insights from both the NIDMS team and a family carer.

MOSST recognised at the 77th World Health Assembly



At the 77th World Health Assembly, Ireland hosted a side event on the WHO Global Oral Health Action Plan: Time for Commitment and Action: Defining and Measuring Success of the WHO Global Oral Health Action Plan. The event focused on addressing oral health inequalities in vulnerable groups, with Dr. Dymphna Kavanagh, Chief Dental Officer, presenting the Modified Oral Status Survey Tool (MOSST). The MOSST is a data collection tool that collects important data regarding oral health and was developed through collaborative efforts between TCAID and the School of Dental Science at Trinity College Dublin. The tool's success in Ireland, particularly within the IDS-TILDA health fair, was showcased as an example of inclusive oral health research aimed at improving care for people with intellectual disabilities.


The continued global recognition of the MOSST highlights its potential to shape future oral health policies, offering a scalable model for inclusive research and practice in oral healthcare for vulnerable groups worldwide. Its widespread adoption could play a key role in reducing health disparities and ensuring that people with intellectual disabilities receive the care they need.



Highlight: Achievements and Awards Highlights

Recognised for Excellence


The Improved Supports for Underserved Communities Award 2023 - Timely access to Early Diagnosis Award



Dr. Martin McMahon was awarded The Improved Supports for Underserved Communities Award 2023 - Timely Access to Early Diagnoses Award, a €100,000 grant from the Irish Cancer Society. The main goal of this study was to investigate the factors affecting timely access to cancer diagnostics for individuals with intellectual and physical disabilities, as well as those over 65 years. Using longitudinal data from IDS-TILDA and TILDA, Dr. McMahon and the research team undertook interviews with regional cancer organisations and engaged with these underserved groups to uncover barriers and facilitators to prompt cancer detection.

These are very competitive grants and huge congratulations to Dr. McMahon for his leadership in moving forward one of the major priorities outlined in TCAID's Research Strategy 2023 – 2028. This was to create care pathways for poorly understood diseases where we specifically committed to developing new understandings of the epidemiology of cancer including what is different for people with an intellectual disability as compared to the general population.

Congratulations to other members of the project team – Dr. Louise Lynch, Ms. Shauna Walsh, Professor Philip McCallion, Dr. Mark Ward, Dr. Eilish Burke, Professor Maeve Lowery, Dr. Alyson Mahar, Dr. Andrew Wormald, Ms. Audrey O Halloran, Professor Roman Romero-Ortuno and Dr. Caitriona Ryan.



Project Launch: Echolight Screening Device – A Feasibility Assessment for Individuals with an Intellectual Disability

In 2024, we launched a new research project: *“Echolight Screening Device – A Feasibility Assessment for Individuals with an Intellectual Disability.”* Funded by the Nursing and Midwifery Planning and Development Unit, Health Service Executive South-East, this project explored the potential of the Echolight bone screening device as a more accessible alternative to traditional bone health diagnostics for individuals with all levels of intellectual disabilities.

Unlike the standard DXA scan—which can be challenging for individuals with intellectual disabilities due to physical and environmental demands—the Echolight device offers a non-invasive, quick and user-friendly method for measuring bone mineral density and diagnosing osteoporosis.

This collaborative effort between the Trinity Centre for Ageing and Intellectual Disability (TCAID) and Wexford Residential Intellectual Disability Service assessed the feasibility and practicality of the device in everyday care settings. The goal was to improve access to vital bone health assessments for a population often overlooked by conventional methods.

Highlight: Achievements and Awards Highlights

Recognised for Excellence



SNM Seed Funding Awardee: Exploring Sedentary Behaviour, Obesity, and Cancer in Adults with Intellectual Disabilities

Dr. Louise Lynch was awarded the SNM Seed Funding to conduct a scoping review on the “Effects of Sedentary Behaviour and Overweight/Obesity on Cancer Outcomes in Adults with Intellectual Disability.” To support this important project, Dr. Kálya Yasmine Lima was recruited to assist with the review process.

The review revealed a significant lack of research in this area. Only two studies investigating the impact of overweight/obesity on cancer outcomes met the criteria for inclusion, and no studies were found on the effects of sedentary behaviour.

These results highlighted a notable gap in the research on sedentary behaviour, overweight/obesity, and cancer among individuals with intellectual disabilities. This critically needs to be addressed as a priority, in order to ensure equitable care and prevention strategies can be developed and tailored to the specific needs of this population.

Dr Martin McMahon Recognised for Teaching Excellence



Dr. Martin McMahon was recently presented with the 2024 School Award for Teaching Excellence by the Provost, Dr. Linda Doyle. This prestigious award recognized Dr. McMahon’s exceptional contribution to education, particularly his ability to create an engaging and impactful learning experience for his students.

The Trinity Excellence in Teaching Awards & School Awards were established to honour those who have made significant contributions to teaching excellence, with nominations open to all academic staff and academic-related professionals who support teaching and learning. Congratulations to Dr. McMahon.



Katrina Byrne awarded RCSI Faculty of Nursing & Midwifery Clinical Bursary Award 2023-2024

Congratulations to PhD student, Katrina Byrne who was awarded the RCSI Faculty of Nursing & Midwifery Clinical Bursary Award 2023-2024 for her exceptional work on the Modified Oral Status Survey Tool (MOSST). Her contributions are a testament to the impact of well-designed tools and training programs in enhancing oral health research and practice.



Highlight: Achievements and Awards Highlights

Recognised for Excellence



TCAID Member, Pavithra, Awarded Trinity Research Doctorate Award

Ms Pavithra was awarded the Trinity Research Doctorate Award (TRDA) Studentship to undertake her PhD project titled: *“Cognitive stimulation therapy for quality of life and cognitive engagement in intellectual disability”* with support from her supervisor Dr. Eimear McGlinchey.

“I am feeling honoured to be awarded with this scholarship. It has always been my passion to engage in brain health research especially for the underserved population. I am truly overwhelmed and falling short of words. I would like to thank Prof. Mary McCarron who has supported me throughout my career and Dr Eimear McGlinchey who spent hours and hours in guiding me. This is really the first step in my journey and I am thrilled for the future.” – **Pavithra**

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Lamya Al Shuhaimi Recognised at Trinity’s Three-Minute Thesis Final

Lamya Al Shuhaimi, TCAID PhD Researcher, was one of eight finalists to compete in the 2024 Trinity College Dublin Three-Minute Thesis (3MT) competition. The event brought together graduate students from across all faculties and challenges them to present their research clearly and engagingly to a non-specialist audience, using just one slide and within three minutes.

Lamya’s presentation, titled *“Enhancing Prescribing in Older Adults with Intellectual Disabilities,”* earned her the Runner-Up position in the university-wide competition. In addition to impressing the judging panel, her talk also resonated strongly with the audience, earning her the People’s Choice award.

Her research addresses an important and often overlooked issue in healthcare, aiming to improve prescribing practices for older adults with intellectual disabilities. Her recognition at the event reflects both the significance of her research and her skill in making it accessible and impactful to a broad audience.



Tallaght University Hospital’s ‘Let’s Talk About Down Syndrome’ podcast series shortlisted for the Irish Healthcare Awards 2024

Tallaght University Hospital’s “Let’s Talk About Down Syndrome” podcast series was shortlisted in the Patient Education Project of the Year - Non-Pharmaceutical category of the Irish Healthcare Awards 2024. Prof. Mary McCarron contributed to episode 4 and 5 of the podcast, discussing the risks associated with dementia in those with Down syndrome while providing practical advice on ageing with Down syndrome. She also discussed the ongoing work of IDS-TILDA, and the establishment of the National Intellectual Disability Memory Service, showcasing the improvements that have been made in the health of people with Down syndrome and the ongoing need to ensure health screening takes place regularly.

Highlight: Supporting the Development of Others

Louise O'Reilly: Healthcare Staff Experience of Supporting Older Adults with Intellectual Disability who are in pain: A systematic review.



Louise O'Reilly

**Clinical Nurse Specialist - Health Promotion
RNID, BSc Nursing, MSc AHWID, PgCert.**

At the Trinity Centre for Ageing and Intellectual Disability (TCAID), supporting the development of emerging researchers remains a core priority. One such example is Louise O'Reilly, Clinical Nurse Specialist in Health Promotion at Stewarts Care, who completed her MSc in Ageing Health & Wellbeing in Intellectual Disability at Trinity College Dublin in 2022 under the supervision of Dr Eilish Burke.

Louise brought to her studies nearly three decades of frontline experience as a Registered Nurse in Intellectual Disabilities. Her dissertation, *Healthcare Staff Experience of Supporting Older Adults with Intellectual Disability who are in Pain: A Systematic Review*, examined how healthcare professionals recognise and manage pain in older adults with intellectual disabilities. The findings highlighted persistent challenges, including diagnostic overshadowing, misconceptions about pain thresholds, and a lack of consistent use of pain assessment tools.

With mentorship and academic guidance from TCAID, Louise has continued to disseminate her research through conferences and professional forums. She presented her findings at the Trinity Health & Education International Research Conference 2023 and was awarded second prize for her poster at the Nurse Midwifery Practice Development – Dublin South, Kildare and Wicklow Annual Conference.

Louise's ongoing contributions are a strong example of how TCAID nurtures and supports the development of clinician-researchers, enabling them to translate their expertise into evidence-informed practice that drives meaningful change.





Highlight: Supporting the Development of Others

Meaningful Employment at TCAID



In April, we were delighted to welcome James Kelly to the Trinity Centre for Ageing and Intellectual Disabilities (TCAID) as a Research Assistant on a one-year internship. James joined the team through our commitment to meaningful employment and inclusion, bringing with him a range of valuable skills and a fantastic attitude.

Since joining TCAID, James has provided key administrative support - setting up meetings, scanning and managing our PIQs, and helping to organise the office. James's strong interpersonal skills, and warm presence have helped him quickly become a valued and well-liked member of the team. His reliability and diligence have had a positive impact on our day-to-day work.

One of the most important aspects of James's role is his contribution to PPI. Drawing on his lived experience, James often meets with researchers to offer thoughtful feedback on how to make our research more inclusive and accessible for people with intellectual disabilities. His insights help shape how we design and deliver our projects in a way that truly reflects the voices of those with intellectual disabilities.

James is also an active member of our PPI Panel, which meets bimonthly to engage directly with researchers. The panel plays a crucial role in helping us make key decisions about our research, including how we share findings and which messages are most meaningful and important. James's contributions through this panel have been invaluable in ensuring our work remains relevant and impactful.

In addition, James sits on the committee for our upcoming Commemorative Ceremony, which will honour the participants of IDS-TILDA who have sadly passed away. This meaningful event will take place in December, and James will play an important role in the ceremony itself, helping to ensure it is respectful, thoughtful, and guided by the voices of those with lived experience.

James continues to grow into an excellent member of the TCAID team, and we are proud to support his journey through this meaningful and important role.

“Working here is a great experience for me. I work with lots of people and I'm happy to see my workmates and colleagues. Everyone at IDS-TILDA is very friendly. They taught me a lot and I could always ask questions. The PPI panel is my favourite and I love going. I've learned a lot from research. I feel proud to be part of the commemorative ceremony.” – James Kelly

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Highlight: Supporting the Development of Others

Optimising Oral Health: Training and Calibration of the Modified Oral Status Survey Tool

A lack of data on the oral health of people with intellectual disabilities contributes to health disparities, disease burden, and oral disability. This stems from systemic exclusion from research due to challenges around training, cost, consent, and a lack of suitable data collection tools. As a result, there's a major blind spot in understanding and addressing oral disease in this population.

In collaboration with TCAID and the School of Dental Science, Trinity College Dublin, we developed the Modified Oral Status Survey (MOSST) and tailored training programs for assessing oral health in people with intellectual disabilities. The MOSST is a data collection tool that collects important data regarding oral health. Content covers concepts relating to oral status and function. The MOSST consists of two elements: Modified Oral Status Survey Tool (MOSST) Health Evaluation Survey and Self Report Supplement (MOSST-SRS). The MOSST can record a range of clinical oral features that are important for policy makers and service providers.

Recently we received funding via the clinical bursary awards for from the RCSI faculty of nursing and midwifery for and an initiative titled: "The implementation of the Modified Oral Status Survey Tool into intellectual disability services to identify the oral health status of people with intellectual disabilities in Ireland". This initiative will empower trained nurses to collect valid and reliable data on oral health and oral health needs within their services using the MOSST. This data will inform local needs assessments for oral health preventive and therapeutic services for people with disabilities.



Empowering Nurses Through MOSST Training

In March, Katrina Byrne and Dr Caoimhin Mac Giolla Phadraig, led this training initiative with a group of nurses working in Intellectual disability services in Ireland and dental professional on the MOSST. All trainees undertook an element of virtual training by completing the MOSST course on EdApp, gaining an understanding of the concepts in the MOSST: functional tooth units, aesthetics, denture wear, tooth count, cavitated teeth, oral cleanliness, gum condition. Aswell as an understanding on the MOSST SRS which explores oral healthcare utilization, oral health behaviours, homecare and oral health related quality of life.

The training day in TCAID involved a review of the concepts of the MOSST and reviewing questions, practice sessions using the MOSST and calibration of trainees knowledge of the MOSST. We had support and input on the day of teaching assistants who acted as volunteer participants who gave feedback on the trainee's approach on using the MOSST in practice.

Training on the MOSST empowers nurses and other non-dental professionals to perform basic oral health assessments and make appropriate adjustments for individuals with intellectual disabilities. This approach supports inclusive research and promotes oral health equity by equipping frontline professionals with the skills to contribute meaningfully to data collection and policy advocacy. Together, we can advocate for policies and practices that prioritize oral health equity for individuals with intellectual disabilities.





Highlight: Supporting the Development of Others

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



TCAID were delighted to host a number of students from the University of Pennsylvania, who interned as Research Assistants with our Principal Investigators as part of the PENN Global Research & Internship Program (GRIP), an 8-week internship programme during the summer of 2024.

Mikayla Danon, PENN Student

“My time at Trinity College was a valuable experience enhanced by our amazing research team. Initially we worked on a potential research idea regarding social determinants of health which did not end up being used. While at first this was a bit disappointing, it ultimately was beneficial for us in the long run to switch gears to a project that was more fitting for Kennedy and I. For the remainder of our time at TCD we focused on cancer treatment and diagnostic options in patients with intellectual disabilities. The researchers we worked with were extremely helpful and I appreciated how they took us step by step through writing the narrative review. Instead of telling us everything that needed to be done at once we were given each part of the project in small doses and this kept the project from becoming overwhelming. I also feel as though we were given an appropriate amount of work which filled our time in the office, however it did not cause stress outside the office hours and allowed for us to enjoy our time in Ireland. At least one of the members of our research team would always be available to answer questions so I never felt as though we were in the dark with our project. ... The experience taught me so much about the research process specifically that I did not know before, and throughout our time there I felt extremely supported by Shauna, Martin and Louise.

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Highlight: Supporting the Development of Others

Kennedy Smihula, PENN Student

This internship exceeded my expectations and taught me more than I could have ever imagined. The team at Trinity College, including Martin, Shauna, Louise, and Grainne, ensured our entire group felt welcomed, comfortable, and safe in a new country, making us feel at home right away. Once we were settled, we were able to hit the ground running with our research project.

Our project focused on completing a narrative review of current literature on people with intellectual disabilities who have cancer. My partner and I started with database searches and developed an exclusion and inclusion criteria to conduct a title and abstract review. We narrowed the original 8,000 articles down to a few hundred for full-text review, which further reduced our articles to about 37. Then we extracted the articles we decided to use and began a thematic analysis to determine similarities and commonalities within the literature. We grouped our articles and were able to identify the strongest four themes. With this information, we were set up for success in the writing portion. We worked on the paper consisting of an abstract, introduction, methodology, discussion, and conclusion. We also developed various diagrams and figures to add depth to our research. Throughout this process, our team provided valuable support by making comments, answering questions, and guiding us in the right direction.

Reflecting on the project I have learned how to analyse and synthesize data, adapt my writing to different forms of English (in this case UK grammar and spelling), and prepare a paper for publication with conciseness and adherence to submission guidelines. Additionally, this internship provided significant behind-the-scenes learning since it took place in a new country. I learned about new cultures, history, independence, adaptability, and incredible food.

I initially thought we were assisting with a project, but I never imagined we would conduct our own research. Yet, with the incredible guidance of the team, we were able to start and complete our research. Now, I am beyond proud to say that I will be a first-name published author in an academic journal. I am confident that this accomplishment will open many new doors in the research world, which I did not consider much before, but am now eager to explore.

Amanda He, PENN Student

I really enjoyed my time at the TCAID for the past two months! Everyone in the office was truly so lovely and kind and made us feel welcome in a space that we didn't know. I really appreciated how helpful everyone was willing to be throughout the past 8 weeks, whether that was through navigating the different aspects of research or navigating Dublin. I learned a lot about research that I'll be able to take away with me throughout my time in university, and I'm so thankful that I got the opportunity to be in the TCAID for my research internship in Dublin!



Highlight: Supporting the Development of Others

Education and Training Opportunities Delivered

The Centre provided the following educational opportunities in 2023/24:

The Post Graduate Certificate in Ageing Health and Wellbeing in Intellectual Disability was completed by one student.

Sharon Kehoe



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

Elaine Moloney
Katarzyna Michalik
Sarah O'Shea

Temitope Rowaiye
Sarah-Jane Kennedy
Claire Henderson

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

Samira Bouktib Gogarty

Rachel Coyne

Sarah-Jane Boyle

Suzanne Kennedy

Slaney Cox

The Use of Antiepileptic Drugs Among Adults with Intellectual Disability and Epilepsy

A Longitudinal Examination of Quality of Life among Adults with an Intellectual Disability over the Age of 40 years in Ireland.

A Descriptive Quantitative Study Exploring the Associated Risk Factors for Falls Among Older Adults with Intellectual Disability

An Exploration of General Nurse's Experiences in Caring for Acutely Ill Patients with an Intellectual Disability in the Acute Hospital Setting; A Qualitative Approach

The Predictive Factors Associated with the Prescription of Psychotropic Polypharmacy in Adults with Intellectual Disability; A systematic Review and narrative Synthesis.

Highlight: Supporting the Development of Others

Education and Training Opportunities Delivered

MSc/PhD/MD Students



Dr Judy Ryan
Completed

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



Dr Fidelma Flannery
Completed

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



Dr Louise Lynch
Completed

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



Dr Karen Ryan
Completed

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.



Dr. Aoife McFeely
In progress

Frailty Identification and Transitions in an Ageing Population with Intellectual Disability



Noor Syahidah Hisamuddin
In Progress

Inequality of oral health service use amongst older people with an intellectual disability in Ireland



Eilish King
In Progress

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



Ms Marianne Fallon
In progress

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



Ms Lamya Al Shuhaimi
In progress

Enhancing medicine use in older adults with intellectual disabilities.



Ms Katrina Byrne
In progress

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



Ms Stephanie Corrigan
In progress

Menopause and mental health in women with intellectual disabilities



Ms Pavithra
In Progress

Cognitive stimulation therapy for quality of life and cognitive engagement in intellectual disability



Ms Margaret Haigh
In Progress

End of life care for individuals with intellectual disabilities



Ms Isabel Ryan
In Progress

Optimising Medicines for Older Adults with Intellectual Disability using the OPTIMA-ID Tool



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: EuCan- Exploring the Unmet Needs of Irish Cancer Patients from Underserved Communities

PI: Martin McMahon

Funder: Irish Cancer Society



Aims: To identify barriers to and enablers of timely cancer diagnosis for underserved communities, with a focus on people over the age of 65 and individuals with physical and intellectual disabilities.

Project Overview: Cancer is the leading cause of death in Ireland, and global projections indicate that annual cancer cases will rise from 18 million in 2020 to 28 million by 2040. Timely access to cancer diagnosis and treatment is essential to improve outcomes, yet underserved populations—particularly older adults and people with disabilities—face significant challenges in accessing care. These challenges lead to later-stage diagnoses and poorer prognoses, contributing to widening health inequities.

This study, a collaboration between the School of Medicine at Trinity College Dublin, the Trinity St James's Cancer Institute, The Irish Longitudinal Study on Ageing (TILDA), and Queen's University in Canada, aims to address this gap in evidence. Using a mixed methods approach, the research will combine analysis of nationally representative longitudinal data with qualitative engagement involving healthcare professionals and members of underserved communities. The study will explore associations between social vulnerability and late-stage cancer diagnoses, investigate current cancer service provision, and capture the lived experiences and concerns of individuals from underserved groups.

By placing the voices of these communities at the forefront, this project will identify actionable measures to improve timely access to cancer diagnosis. Findings will inform future service delivery and policy development aimed at reducing inequities in cancer care.



Active Projects

Project Title: Echolight Screening Device – A Feasibility Assessment for Individuals with an Intellectual Disability

PI: Prof. Eilish Burke and Ms Anne Power

Funder: Nursing and Midwifery Planning and Development Unit, HSE South East



Aims: This study aims to evaluate the viability of using an alternative bone health assessment system, namely the Echolight and to comprehensively evaluate the applicability and feasibility of the Echolight device across diverse demographics and intellectual disability levels, encompassing mild, moderate, severe, and profound. The Echolight stands as an innovative technology utilising REMS (Radiofrequency Echographic Multi-Spectrometry) to measure bone mineral density. It serves as a diagnostic and monitoring device, devoid of ionizing radiation, portable, and less demanding in terms of patient positioning compared to the conventional DXA scan.



Project Overview: This project will assess the suitability of the Echolight Bone Screening system for individuals with intellectual disabilities as an alternative to DXA scanning. Osteoporosis has emerged as a significant health concern among individuals with intellectual disabilities. The prevalence of this condition is higher and manifests at an earlier age in this demographic due to multifaceted reasons such as comorbid health complications, extensive medication usage, and inadequate emphasis on bone health promotion throughout their lifespan. Previous research has identified prevalence rates of osteoporosis at around 40% with both sexes equally at risk, a different picture than the general population.

The Echolight study will involve 80 participants with varying levels of intellectual disabilities inclusive of mild, moderate, severe and profound. Inclusion of all levels of ability is critical in seeing how well this new method worked for all individuals within the intellectual disability population and to achieve a comprehensive demographic analysis which aims to understand the correlation between intellectual disability levels and bone health issues, providing nuanced insights into the specific needs of various subgroups within the intellectual disability population. By exploring the feasibility of this technology, we aim to improve access to early bone health assessments and promote inclusivity in healthcare.

Active Projects

Project title: Engaging the Brain through Cognitive Stimulation Therapy

PI: Prof. Mary McCarron, Ms. Pamela Dunne

Funder: Nursing and Midwifery Planning and Development Unit



Aims: To investigate the feasibility of implementing group Cognitive Stimulation Therapy (CST) with adults with an intellectual disability (ID) at Avista Disability Services.

Project Overview: Cognitive Stimulation Therapy (CST) is a structured, evidence-based psychological intervention shown to support cognitive function and enhance quality of life in individuals with cognitive impairment, including dementia. While widely used in older adult populations, there is limited research on its application for adults with intellectual disabilities (ID)—who are at higher risk of cognitive decline and often lack access to tailored interventions.

This feasibility study, in collaboration with Avista Disability Services explores (change here from ‘will explore’) whether CST can be effectively adapted and implemented in group settings for adults with ID. Participants are individuals supported by Avista, ensuring relevance to real-world care contexts. The study assesses (change from will assess) the feasibility of recruitment, programme acceptability, and the practicality of using standardised assessment tools with this population. It explores (change from will explore) the potential impact of group CST on cognitive functioning, quality of life, and global functioning.

“At Avista, we are committed to inclusive, person-centred care. This collaboration with TCAID presents an exciting opportunity to explore how Cognitive Stimulation Therapy (CST) can be meaningfully adapted for adults with intellectual disabilities. Our goal is to make CST more accessible and responsive to the unique needs of this population, ultimately enhancing their cognitive, emotional, and social wellbeing.”

Project Title: The Maltings - Avista

PI: Prof. Mary McCarron



Funder: Avista CLG

Aims: The aim of this project is to determine the current needs and wishes of individuals supported by The Maltings Avista in relation to their health, accommodation, and social inclusion. It will explore the existing support and service arrangements in place to meet these needs and assess their adequacy. Furthermore, the project seeks to identify what additional supports and services are required to enable individuals to age well and maintain a good quality of life into the future.

Project Overview: Avista provides community-based living for 104 individuals with an intellectual disability throughout North Tipperary and Offaly, aged in their 30s to late-70s, with moderate to profound diagnoses of intellectual disability. In 2021, Avista initiated a study to assess the current wishes and support needs of this group with a view to identifying future support needs as it ages and strategically planning for these supports. Avista obtained ethical approval for the study and gathered data from representative samples of supported individuals – including a quantitative survey (n=72) and semi-structured qualitative interviews (n=29). Subsequently, Avista engaged the Trinity Centre for Ageing and Intellectual Disability (TCAID) at Trinity College Dublin (TCD) to undertake data analysis and reporting.

It was clear from the qualitative data in particular that residents receive a high level of person-centred care and support, which is the basis for a high-quality, individualised service. Residents clearly feel supported, respected, and seen by staff. The theme of home, belonging, and security emerged very strongly throughout the interviews, reflecting positive relationships between residents and with staff. Having this culture in place positions Avista well in building a strategy to support its residents as their needs evolve with age.



Active Projects

Project Title: MINDS

PI: Dr Eimear McGlinchey

Funder: Forte - JPND - Concepts for health and social care research for neurodegenerative disease



Project Overview: People with Down syndrome (DS) represent the largest population globally with a known genetic predisposition to Alzheimer's disease (AD). By the age of 40, nearly all individuals with DS exhibit the neuropathology associated with AD. Despite this, they have been significantly underrepresented in both pharmacological and non-pharmacological AD research. The MINDS Working Group at TCAID seeks to address this gap by developing a multimodal intervention framework tailored specifically for individuals with DS.

This international and interdisciplinary initiative focuses on social and lifestyle factors that may delay cognitive decline and improve quality of life. The project involves a coordinated programme of research, knowledge exchange, and public and patient involvement (PPI) activities. It includes the organisation of virtual and in-person workshops, cross-country team coordination, and the standardisation of engagement strategies with people with lived experience. Dissemination efforts, including video production, are integral to ensuring the project's outcomes reach a wide and inclusive audience.

Cancer Outcomes, Sedentary Behaviour and Overweight/Obesity in Adults with Intellectual Disability: A Scoping Review

PI: Dr Louise Lynch

Funder: School of Nursing and Midwifery Seed Funding



Aims: To explore the effects of sedentary behaviour and overweight/obesity on cancer outcomes in adults with an intellectual disability (ID), and to identify key data gaps to inform future research, policy, and practice.

Project Overview: There is a well-established relationship between overweight/obesity and cancer outcomes in the general population, as well as emerging evidence linking sedentary behaviour to increased cancer risk. However, research examining these factors among adults with intellectual disabilities is extremely limited. This scoping review seeks to address this gap by systematically examining the existing literature on the impact of sedentary behaviour and overweight/obesity on cancer outcomes in this population.

Using Arksey and O'Malley's scoping review framework, a comprehensive search strategy was developed and implemented. Out of 10,241 studies initially identified, only two met inclusion criteria—both focused on obesity, with one study highlighting a significant association between obesity and breast cancer in women with intellectual disability. No studies were found that examined the role of sedentary behaviour.

In addition to synthesising existing evidence, the project aimed to identify relevant data sources and variables that could enhance understanding of cancer risks in this population. The project also established an interdisciplinary team to guide future research and support the development of a grant proposal aimed at improving data collection, service provision, and policy development.

Participant Engagement

The 2023/24 IDS-TILDA Christmas Card and Easter Card competitions received more than 700 entries from people with an intellectual disability from across Ireland.

Christmas Card

*Front artwork: Billy Toomey,
Saint John of God, Louth*

*Runner Up: James McKenna,
Saint John of God, Louth*

*Runner Up: Emma Coonan,
St Cronan's Association,
Tipperary*



Easter Card

*Front artwork: Donna Fusco,
Sunbeam House Services,
Wicklow*

*Runner Up: Maureen Cullen,
Sunbeam House Services,
Wicklow*

*Runner Up: Kaven Vaughan,
CoAction, Cork*





Appendix

Research Outputs 2023/2024

Book Chapter

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Appendix

Research Outputs 2023/2024

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