



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



The Trinity Centre for Ageing and Intellectual Disability

Annual Report 2021 - 2022



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 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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Message from our Director

In the 2021/22 period, the Trinity Centre for Ageing and Intellectual Disability ('the Centre') made a profound impact on various fronts. The Centre generated and translated research to inform policies and services. Our publications gained significant traction among national and international audiences, effectively influencing the field. We provided guidance to talented students at all stages of their careers fostered success and strengthened networks both locally and internationally. Through diverse engagement methods, including in-person and online platforms, we expanded our community while focusing on addressing the challenges faced by individuals with intellectual disabilities.

However, despite some progress, there is still a pressing need to increase awareness within health and social care services regarding the unique needs of people with intellectual disabilities and the necessary reorientation of services to accommodate them. Additionally, the technology sector has untapped potential to better serve and empower this population. To unlock this potential, greater investment from both industry and government is required to foster innovation, educational opportunities, and skills development. Furthermore, prevailing low expectations and discrimination, based on disability and age, continue to hinder the full integration of individuals with intellectual disabilities. It is crucial to engage and empower them to take charge of their own health and well-being.

At the Centre, we challenge stereotypes daily through our research, researchers, ambassadors, and liaisons. Our aim is to establish collaborations that create more opportunities and roles for people with intellectual disabilities, enabling them to thrive and lead fulfilling lives as valued members of their communities. Our flagship research program, IDS-TILDA, successfully completed data collection for Wave 4 despite the challenges posed by the pandemic. This was achieved through the hard work and innovation of our core team and field workers. Driven by a proactive approach, IDS-TILDA adapted its strategies to ensure the safety of the community while maintaining research activities. Virtual data collection methods were implemented initially, with a gradual return to in-person activities as conditions permitted. The lessons learned from this experience will inform our future work, as we witnessed positive outcomes from both in-person and online engagements.

In November 2021, IDS-TILDA secured funding for Wave 5 of the study, recognized by the International Review Panel as **"one of the most significant studies on ageing of people with ID in the world."** The Centre also conducted additional funded studies to understand the impact of the COVID-19 pandemic on older adults with intellectual disabilities, raising its profile among national and global audiences. The strength and stability of the Centre became evident through the compassion and resilience displayed by our team throughout the pandemic. Colleagues rapidly responded to support emergency response efforts, developing educational offerings, and providing accessible information that reached thousands of attendees and subsequent viewers.

Our longstanding commitment to public involvement has been a major strength, allowing us to collaborate extensively and showcase our expertise in designing and implementing a wide range of research projects and translational activities. As a result, our research is driving positive change in health policy and clinical services for individuals with intellectual disabilities. Notably, the establishment of Ireland's National Intellectual Disability Memory Clinic stands as a significant translational innovation.

With immense pride, we present the 2020/21 Annual Report, inviting you to explore the Centre's accomplishments and ongoing efforts to create a more inclusive and empowering future for individuals with intellectual disabilities.



Prof
Mary McCarron,
Director

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

As the Ambassador for the Trinity Centre for Ageing and Intellectual disability (TCAID) I have had the opportunity to lead the accessible documentary 'Ageing with Pride', disseminating the findings of IDS-TILDA, the impact on health as we age and how we can address issues. This documentary began my journey and determination to promote positive health for all as they age.

I work with TCAID supporting meaningful inclusion of individuals with intellectual disability 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 to learn how to communicate effectively and make accommodations when needed when engaging people with intellectual disability. I also sit on various committees including the steering committees for both IDS-TILDA and The National Intellectual Disability Memory Service. I have also set up a Public and Patient Involvement (PPI) Panel which comprises of seven individuals with life experience of intellectual disability. This panel contributes valuable input to shape the direction and influence the significance of the research being conducted at the Centre.

Working in the Centre with the team provides the opportunity to have real involvement in all aspects of research and places me in the position to represent people with intellectual disabilities as part of the team. I am very passionate about my work here at TCAID. I love my job so much and I am grateful to be part of something so important.



Ms Mei Lin Yap,
Ambassador Liaison
Officer



Our Impact: 2021 - 2022

Significant achievements are highlighted here:

Generating & Translating Knowledge

- The uptake of Centre research is substantial, including utilisation by national, European, and international healthcare organisations, educational institutions, research centres and governments. For example, Prof Mary McCarron's publications (1991-2022) have been cited above the global average for similar publications (**SciVal**), with over **3,000** citations accumulated (**Scopus**).
- The Centre delivered **1** report, **1** book, **12** book chapters, **31** journal articles and **26** oral presentations in 2021/22.
- The Centre's publications for this period have received over **40** citations, performing above the global average for similar publications (Field-Weighted Citation Impact, SciVal). In total, 10 of these publications are the result of international collaborations with countries such as the United States, Australia, and South Africa (**SciVal**).
- The Centre's publications also inform public debate, increasing understanding and awareness of issues addressed in its research. For example, **2** outputs are cited in **2** policy sources from Finland and Australia (**Overton**).
- Publications for this time period have been viewed over **160** times (**SciVal**). This includes abstract views and clicks on the link to view the full text at the publisher's website. They reflect the interests of the whole research community, including undergraduate and graduate students, and researchers operating in the corporate sector, who tend not to publish and cite and who are "hidden" from citation-based metrics.
- The Centre's publications have both policy and patent impacts. **28** policy documents from **21** different sources and from **9** different countries reference the Centre's research. Of these, **14** are Clinical Guidance documents (Overton) and **2** publications are cited in **2** patents (**Altmetric**).



The Centre's publications have been cited by numerous government departments and agencies, including: the National Institute for Health and Care Excellence; the Agency for Healthcare Research and Quality; GOV.IE; Haute Autorité de Santé; Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften; New Zealand Ministry of Business, Innovation & Employment; Australian Government Department of Health; European Centre for Disease Prevention and Control; Publications Office of the European Union; GOV.UK; The Welsh Government; The Commonwealth of Virginia, USA; and the United Nations Environment Programme.

Our Impact: 2021 - 2022

Significant achievements are highlighted here:

- The Centre's publications also inform public debate, increasing understanding and awareness of issues addressed in its research. Scholarly outputs are cited in articles by the Irish Times (*Prevalence, patterns and factors associated with psychotropic use in older adults with intellectual disabilities in Ireland*), The Conversation (*The Role and Timing of Palliative Care in Supporting Persons with Intellectual Disability and Advanced Dementia*) and other news outlets and blogs (**Altmetric**).
- Scholarly outputs are cited in news and blogs, for example The Pharmaceutical Journal (*Optimising medicines in older adults with intellectual disability who have epilepsy: challenges and perspectives*), Information for practice, Learning Disability Practice (*Functional loss in older adults with intellectual disabilities and dementia*) and Wikipedia (*Use of technology by older adults with an intellectual disability in Ireland to support health, well-being and social inclusion during the COVID-19 pandemic*) (**Altmetric Explorer**).
- In 2021/22, the Centre had a total of 11 active grants, totalling **€3,096,616**, through the Health Research Board, Irish Research Council, Department of Health, Wellcome Trust, Health Service Executive, and Trinity College Dublin.
- Scholarly outputs for this same period have received **468** mentions across social media platforms (**Altmetric**).

Supporting the Development of Others



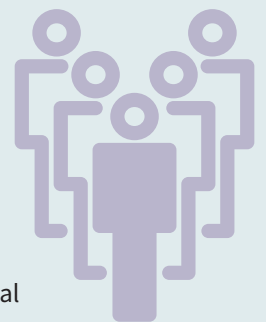
The Centre team provided the following educational opportunities:

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

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

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

Left to right: Dr Eilish Burke and Ms Louise O'Reilly at the MSc in Ageing Health and Wellbeing in Intellectual Disability Graduation.





Our Impact: 2021 - 2022

Significant achievements are highlighted here:

Two PhDs were completed; six PhDs and one MD were in progress.

Left to right: Dr Eilish Burke, Prof. Mary McCarron, Dr Josje Schourfour, Dr Brendan Dee, and Dr. Laurence Tarrant at Dr. Dee's Viva.



Building capacity for the future and addressing gaps in care for people with intellectual disability & dementia with RNIDs completing the Nursing-Advanced Practice (ANP) programme and are now employed as ANP's with Avista and the National Memory Clinic for people with an Intellectual Disability.

Left to right: Ms Pamela Dunne, Prof. Mary McCarron, Ms. Evelyn Reilly, and Ms. Martina Leigh at the Nursing-Advanced Practice (ANP) Programme Graduation.



Improving Health Assessments for People with an Intellectual Disability attracted more than 7,310 learners on the Future Learn platform.



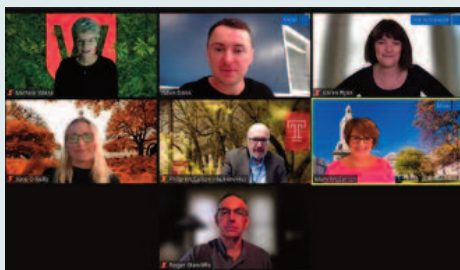
TCAID trained 28 Field Researchers from all across Ireland with expertise and a special interest in Intellectual Disability for Wave 5 of IDS-TILDA on Tuesday, 23rd August 2022 at the Dublin Chamber of Commerce.

Left to right: Prof Mary McCarron, the IDS-TILDA Project Team, and IDS-TILDA Field Researchers



Our Impact: 2021 - 2022

Significant achievements are highlighted here:



TCAID hosted a webinar on End-of-Life Care for People with Intellectual and Developmental Disabilities. Dr Karen Ryan, Consultant in Palliative Medicine, St. Francis Hospice and Mater Misericordiae University Hospital, Dublin provided a keynote on the Process of Dying. There were in excess of 450 attendees.

Left to right: Dr Michele Wiese, Mr Gavin Dann, Prof Karen Ryan, Ms June O'Reilly, Prof Philip McCallion, Prof Mary McCarron and Prof Roger J Stancliffe

A TCAID Data Scientist graduated with a MSc in Computer Science (Data Science) from Trinity College Dublin.

Left to right: Ms Margaret Haigh, Dr Ashleigh Gorman, Mr Aviejay Paul, and Mr Michael Foley



TCAID hosted an Oral Health Programme 'SMILE' at Stewart's Care on 19th – 23rd September 2022. for healthcare workers to improve oral health of people with an Intellectual Disability.

TCAID welcomed a visiting academic from Duke University for a two-week programme 'Learning from IDS-TILDA: Research & Policy'

Left to right: Prof Mary McCarron, Dr Eilish Burke, the IDS-TILDA/TCAID Team and Ms Michelle Franklin





Our Impact: 2021 - 2022

Significant achievements are highlighted here:



'During my time in Dublin and the surrounding areas, I had many opportunities to see the impact of Prof. McCarron and the TCAID team members' efforts. For example, I had one-on-one meetings with TCAID experts learning how they work tirelessly to ensure the IDS-TILDA study is conducted rigorously generates information that will make meaningful difference in the lives of people with intellectual disability. I enjoyed learning more about IDS-TILDA data collection, analysis, and visualization and the strategies they are using to make sure the new knowledge they are generating is accessible to the community and policy makers. I enjoyed traveling by train to community sites and meeting frontline staff, and people with ID. I saw examples of how Prof. McCarron and TCAID's efforts are directly helping people with ID, their families, and their communities. I virtually attended national and international conferences that had invited Prof. McCarron to guest lecturing, and I witnessed first-hand how she translates her research for the national and international audiences. I also appreciated the opportunity to participate in international working groups Prof. McCarron and her team facilitated. These meetings further illuminated their commitment to multidisciplinary engagement and their presence as international thought leaders.' – **Dr Michelle Franklin, Assistant Professor, Duke Department of Psychiatry, Duke-Margolis Center for Health Policy, US**

TCAID partnered with Way2b to create the Digi Academy.

Digi-ID is a pan-European partnership that addresses the challenge of digital inclusion and digital literacy among people with intellectual disabilities. Digi-ID is an EIT Health funded multidisciplinary project involving partners from Ireland, France, Sweden, and The Netherlands who are experts in education, health, and technology. The project is developing an innovative digital skills education programme, delivered via an accessible solution/app, using an inclusive co-creation process with approximately 250 adults with intellectual disability, supporters, professionals, and families/carers.



Dr Esther Murphy, Principal Investigator Digi-ID

Our Impact: 2021 - 2022

Significant achievements are highlighted here:

Contributing to society

- Prof. Mary McCarron, Executive Director, and Prof. Sean Kennelly, Clinical Director of the National Intellectual Disability Memory Service were acknowledged at a Seanad Eireann debate for their significant work they have done around brain health and dementia. The Centre's team led on the delivery of Ireland's National Intellectual Disability Memory Service, in collaboration with Tallaght University Hospital, AVISTA, the Health Service Executive, National Dementia Office, and Department of Health. Initially a trial clinic, Ministers Butler announced that central to the 2022 Budget is the further investment of €7.3 million euro in dementia services in areas such as memory assessment and support services, memory technology resource rooms and the National Intellectual Disability Memory Service. This is the only service of its kind in Ireland with only a handful of such clinics available internationally.
- IDS-TILDA –one of the most significant studies on the ageing of people with ID in the world – hosted a commemorative ceremony from the Trinity Chapel to respectfully remember participants who have given so generously to the study, on the International Day of Persons with Disabilities, Friday, 3rd December 2021. The event allowed an opportune time to reflect and remember the people who shared the details of their lives with IDS-TILDA to benefit others, over the last number of years.
- TCAID ensured the findings of IDS-TILDA continued to be translated into real-world activities. Ms. Una Coates was an online Operation Transformation Leader for 2022 and was invited by Ambassador Liaison Officer, Ms Mei Lin Yap, to run an activity morning in Trinity Sports Centre in February 2022. Una attended with her colleagues and friends from Stewarts Care Ltd. and Special Olympics. The class was led by Ms Louise Lynch (TCAID PhD student), Mei Lin and Una. A Physical Activity Plan was developed jointly by Louise and Mei Lin.



TCAID welcomed Stewarts Care AND Special Olympics Ireland to Trinity College Dublin on Tuesday, 15th February 2022 to support Una Coates on her Operation Transformation journey.



Our Impact: 2021 - 2022

Significant achievements are highlighted here:



Recognised for Excellence

Dr. Éilish Burke, Ussher Assistant Professor in Ageing and Intellectual Disability, was honoured with the 2021 International Association for Research on Service-Learning and Community Engagement (IARSLCE) award for Diversity, Equity, and Inclusion in acknowledgment of her research work.

https://www.tcd.ie/news_events/articles/dr-eilish-burke-wins-international-award-for-engaged-research-with-people-with-intellectual-disabilities/

'I would like to sincerely thank all those who contributed and participated, who were inspiring and brought a different perspective, making the research more focused and inclusive. I am delighted to receive this award in recognition of my research however it would not have been possible without the contribution of those key people' –
Dr Eilish Burke, Associate Director



Prof. Mary McCarron was selected to the honour of Fellow of IASSIDD by the Council and Awards Committee in 2022. Fellowship in IASSIDD is recognition by peers of outstanding contributions in the field of intellectual disabilities.

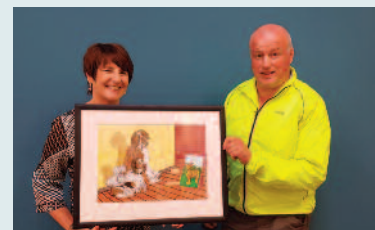
<https://iassidd.org/about/iassidd-fellows/>

Left to right: Associate Director of TCAID, Dr Eilish Burke presented Director of TCAID, Prof. Mary McCarron with a bouquet of flowers on behalf of TCAID as a recognition of her honour of Fellow of IASSIDD by the Council and Awards Committee in 2022

Prof. Mary McCarron, Professor of Ageing and Intellectual Disability, was recognised as an Expertscape World Expert in Intellectual Disability.

<https://expertscape.com/ex/intellectual+disability>

Left to right: Prof Mary McCarron and Alan Tarpey, Service User



Digi-ID was nominated and shortlisted in the Learner Voice Category at the Aontas STAR Awards 2022.

<https://www.aontas.com/knowledge/news/aontas-star-awards-2022-shortlist-announcement>

Growing our Research Community

- Online engagement for the Centre continues to grow, with an increase of 386 followers to 1,390 Twitter followers, up 28% on the previous year.
- The Centre has active collaborations with 10 national partners and 25 international partners.

Growing Our Research Community

Advancing National and International Collaborations

National Collaborations

Ireland

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

International Collaborations

Europe

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

Australia

- Centre for Disability Studies, University of Sydney

Canada

- Reena, Toronto, Canada

United States

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

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

Support Staff



Our People

Centre Directors

Prof Mary McCarron, Director
Dr Éilish Burke, Associate Director

Strategic Advisory and Executive Team

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

Academic Faculty

Prof Martine Smith (Clinical Speech & Language Studies)
Dr Duana Quigley (Clinical Speech & Language Studies)
Dr Orla Gilheaney (Clinical Speech & Language Studies)
Dr Yvonne Lynch (Clinical Speech & Language Studies)
Dr Caoimhin Mac Giolla Phadraig (School of Dental Science)
Dr Peter May (Public Health and Primary Care)
Dr Martin Henman (School of Pharmacy)
Dr Máire O'Dwyer (School of Pharmacy)
Dr Juliette A O'Connell (School of Pharmacy)
Dr Annemarie Bennett (Clinical Medicine – Dietetics)
Dr Maria O'Sullivan (Clinical Medicine – Human Nutrition)
Dr Damien Brennan (School of Nursing and Midwifery)
Dr Frances O'Brien (School of Nursing and Midwifery)
Dr Fintan Sheerin (School of Nursing and Midwifery)
Dr Sandra Fleming (School of Nursing and Midwifery)
Dr Louise Daly (School of Nursing and Midwifery)
Dr Carmel Doyle (School of Nursing and Midwifery)
Dr Eimear McGlinchey (School of Nursing and Midwifery)
Mr Paul Horan (School of Nursing and Midwifery)
Mr Paul Keenan (School of Nursing and Midwifery)
Dr Mary-Ann O'Donovan (University of Sydney)
Dr Dominika Lisiecka (Munster Technological University)
Dr Andrew Wormald (University of Limerick)
Dr Sinead Foran (Dublin City University)
Prof Seán Kennelly (Tallaght University Hospital and Medical Gerontology, Trinity College Dublin)
Prof Roman Romero-Ortuno (St. James's Hospital and Medical Gerontology, Trinity College Dublin)

Academic Advisor

Prof Philip McCallion, Senior Advisor

Postdoctoral and Research Fellows

Dr Darren McCausland
Dr Andrew P. Allen
Dr Andrew Wormald
Dr Esther Murphy
Dr Amara Naseer
Dr Marina Odalovic

Research Assistants

Ms Áine Ní Ghráda
Ms Holly Dennehy
Ms Louise Lynch
Ms Christina Corr
Ms Ashleigh Gorman
Ms Margaret Cleary
Ms Nadine Buttery

Meet Our Newest Teammates: 2021 - 2022

Ms Pavithra
Data Manager



Mr Aviejay Paul
Data Scientist



Dr Caitriona Ryan
Statistician



Ms Margaret Cleary
Research Assistant



Dr Marina Odalovic
Research Fellow



Ms Nadine Buttery
Research Assistant



Ms Ashleigh Gorman
Research Assistant





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:

- Conduct high-quality, partnership-driven research and advance knowledge mobilisation through ongoing cross-sectoral engagement.
- Develop and strengthen national and international collaborations, focused on increasing capacity in ageing and intellectual disability-related research.
- Serve as policy advisors to local, national, and international governments as they address system inequalities and obstacles to healthy, happy ageing for people with intellectual disabilities.
- Advance policy briefs, strategies, and interventions to address society-wide concerns, particularly regarding determinants of health, quality of life and social supports for an ageing population.
- Offer evidence-based teaching and learning opportunities to develop practice leaders who are ready to improve service delivery across sectors, through a wide-range of educational opportunities.
- Engage industry to advance technologies which improve economic, social and health indicators for older adults with intellectual disability and serve as a hub for development efforts.
- As a national exemplar in public and patient involvement in health research, promote the inclusion of people with intellectual disability in all aspects of research and to become a thought leader in tackling exclusion in this field.
- Translate co-created knowledge in creative, engaging ways to further advance research, practice, education, and advocacy.





Highlight: Generating & Translating Knowledge

Longitudinal IDS-TILDA data tracked the long-term impact of COVID-19 and provided the basis for re-building through informed policy and practice.



The COVID-19 pandemic profoundly influenced the world and had a dramatic impact on the lives of people with intellectual disability. Congregated living and high levels of co-morbid conditions left people with an intellectual disability more vulnerable to COVID-19 infection and at an increased risk of severe effects including hospitalisation and mortality. The COVID-19 lockdowns had an immediate and life-altering effect on people living with an intellectual disability and those caring for them.

Minister Anne Rabbitte, TD, Minister of State with responsibility for Disability, formally launched '*Overcoming Adversity: The Continuing Impact of COVID-19 on People Ageing with an Intellectual Disability in Ireland - Findings from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) COVID-19 Sub-Study*' Report on Thursday 27th January 2022.

Following on from the first COVID-19 survey in 2020 this report explored the experiences of older people with an intellectual disability during the second year of the pandemic in 2021. The findings offer a unique insight to the longer-term effects of COVID-19, highlighting the impact on physical health, service utilisation, social connection, participation, mental health, and well-being. This provided a vital resource for policymakers, service providers, carers, people with an intellectual disability and their families.

The report finds that COVID 19 did not appear to increase mortality for older adults with intellectual disability in Ireland despite the increased risks and the poorer outcomes reported elsewhere. Our findings indicated that the COVID-19 pandemic had an impact on health, service utilisation, and social inclusion, with many participants experiencing pandemic-related stress, anxiety, and impactful life events. However, a degree of resilience was evident in participants' comments and in the lack of change in reported mental health and in depressive symptoms compared to previous IDS-TILDA reports.



Through the richness of the data provided in the IDS-TILDA STUDY, Ireland is now recognised as a global leader in the field of ageing and intellectual disability. Each wave of this study deepens our knowledge and how people with an intellectual disability may be supported to age successfully. The insights are so important for policy. The Department of Health has been pleased to sponsor this programme of pathway breaking research funded via the Health Research Board.'

Minister Anne Rabbitte, Minister of State at the Department of Health with responsibility as Minister of State for Disability

COVID-19 placed an enormous strain on health systems around the world, undermining the mental health and wellbeing of healthcare workers. Anecdotal accounts from intellectual disability services suggested that there were significant pressures on staff, as the public health restrictions imposed on ‘vulnerable’ people resulted in changes to routines, staffing and work patterns. Furthermore, the fact that many people with intellectual disabilities have increased vulnerability to the more negative effects of COVID-19 caused considerable concern. It was against this backdrop and a dearth of research on the mental health of staff working with people with an intellectual disability that a study looking at staff mental health during the COVID-19 pandemic was undertaken;

‘Staff mental health while providing care to people with intellectual disability during the COVID-19 pandemic’

Findings

Thirteen staff who provided healthcare to people with intellectual disabilities during the pandemic were interviewed. A number of themes were generated during analysis of the interview transcripts. The participants spoke in depth about 1) challenges of the work environment; 2) the impact of providing care during the pandemic on mental health; 3) supporting their mental health; and 4) lessons learnt.

The pandemic has had a wide range of psychological, social, and economic consequences, and the relative impact and contribution these have had on population-level mental health remain to be clarified. However, researchers from around the world have been contributing to the study of mental health issues during the COVID-19 pandemic. IDS-TILDA PhD Student, Ms Fidelma Flannery, is investigating the ***‘Impacts on the mental health and wellbeing of older adults with an intellectual disability during the COVID-19 pandemic in Ireland’***.





Highlight: Generating & Translating Knowledge

PhD Student Profile: Fidelma Flannery



Fidelma's research is investigating the impact of COVID-19 on the mental health and wellbeing of older adults with an intellectual disability in Ireland. The primary aim of this study is to understand the personal and social resources associated with mental health outcomes for older adults with an intellectual disability in the context of the COVID-19 pandemic. The secondary aim is to provide evidence to inform those planning services and policy makers on the promotion of mental health and wellbeing in the aftermath of COVID-19, and in the event of further pandemics or public health emergencies.

Within this, there are three research objectives, and they are (i) To measure how life events (losses) experienced during the pandemic impacted on mental health and wellbeing; (ii) To measure how events perceived as positive during the pandemic impacted on mental health and wellbeing; (iii) To identify factors associated with mental health outcomes for this population during the COVID-19 associated restrictions.


'There is little disagreement within the literature that individuals with an intellectual disability experience mental health illness at a greater prevalence than the general population. It has been widely established both from previous pandemics such as SARS and MERS, and from the COVID-19 pandemic that associated lockdowns have impacted on the mental health and wellbeing of the general population. There is limited evidence to understand how these lockdowns have impacted on individuals with an intellectual disability, however, there exists well founded concerns that as a population that already have greater needs in this area and research to suggest that people with pre-existing mental health conditions are at greater risk from the effects of lockdown such as fear, isolation, loneliness, and PTSD. Conversely, there is also evidence emerging of people experiencing positive aspects of the pandemic and these are experiences which must also be explored and understood. The research being carried out in the mental health strand of the IDS TILDA study exploring the impact of COVID-19 on the mental health and wellbeing of older adults with an intellectual disability in Ireland will provide critical evidence to guide policy planners and service providers in the aftermath of the COVID-19 pandemic and in the event of further similar public health emergencies' - Fidelma Flannery, PhD Student

Fidelma's research has produced several conference papers and journal publications.

McCarron, M., McCausland, D., Luus, R., Allen, A., Sheerin, F., Burke, E., McGlinchey, E., Flannery, F. & McCallion, P., The impact of coronavirus disease 2019 (COVID-19) on older adults with an intellectual disability during the first wave of the pandemic in Ireland, *HRB Open Research*, 4, 93, 2021 <https://doi.org/10.12688/hrbopenres.13238.1>

McCarron, M., Allen, A., McCausland, D., Haigh, M., Luus, R., Bavussantakath, F.R., Sheerin, F., Mulryan, N., Burke, E., McGlinchey, E., Flannery, F. & McCallion, P., The impact of COVID-19 on people ageing with an intellectual disability in Ireland: Protocol for a follow-up survey., *HRB Open Research*, 4, 95, 2021 <https://doi.org/10.12688/hrbopenres.13340.1>





“You have given me a platform and a voice to advocate for people like me.”

Ms Mei Lin Yap,
Ambassador Liaison Officer

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.



Highlight: Contributing to Society

TCAID activities continue to advance the National Dementia Strategy and Sláintecare Strategic Priorities by Advocating for national recognition of dementia while supporting individual needs.

On Wednesday, 9th March 2022, Prof. Mary McCarron, Executive Director, and Prof. Sean Kennelly, Clinical Director of the National Intellectual Disability Memory Service, were acknowledged at a Seanad Éireann debate for the significant work they have done around brain health and dementia. This essential work continues to advocate for national recognition of dementia among those with intellectual disability while promoting and supporting individual needs.



"Professor Mary McCarron is just the most amazing advocate in this area. There are about 700 people with Downs syndrome and dementia in Ireland who are living at home with ageing parents"

Mary Butler,
Minister of State at the
Department of Health.

The Seanad debate on Group Brain Health and Dementia in Leinster House



The Seanad debate was preceded by the All Party Oireachtas Group Brain Health and Dementia Briefing in Leinster House on 8th March 2022 where political representatives heard from speakers Professor Mary McCarron, Professor Sean Kennelly, Professor Iracema Leroi, Mr. Kevin Quaid, and Ms Samantha Taylor about the importance of Brain Health. Professor McCarron highlighted the need to focus on the criticalness of brain health in terms of dementia prevention and said how the National Intellectual Disability Memory Service aims to provide access for every individual with an intellectual disability in Ireland to a Brain Health Clinic and to specialist assessment and comprehensive diagnostic work-up for memory concerns.

Minister Butler announced that central to the 2022 Budget is the further investment of €7.3 million in dementia services in areas such as memory assessment and support services, memory technology resource rooms and the National Intellectual Disability Memory Service. This is the only service of its kind in Ireland with only a handful of such clinics available internationally.

Highlight: Contributing to Society

"My brother received a diagnosis of dementia. I found the whole process from assessment to post-diagnostic support so positive. I was listened to by the staff in NIDMS. My brother is benefitting from having the diagnosis as he now gets home care support hours. He enjoys the one-to-one time, walks and coffee with the paid carer, opening up a new social dimension he has not had previously. These few hours are also of huge benefit in allowing me to have some (rest) time."
Family Carer



"This new Memory Clinic is a National Centre of Excellence and is rapidly improving the timely detection of dementia in people with an intellectual disability. I would like to pay tribute to the multidisciplinary team including specialist clinicians, nurses, psychologists, and health and social care practitioners. Their work in research and developing our dementia services over the past number of years has laid the groundwork for this important new service," **Prof Seán Kennelly, NIDMS Clinical Director and Director of the TUH Institute for Memory & Cognition**



"The Trinity Centre for Ageing and Intellectual Disability really understand the commitment required to grow a diverse and inclusive research community. Honoring #IDPW2021 by recognising IDS-TILDA participants who have died and thanking them for their generous contribution and devotion to a better tomorrow"

**Ms Sarah Bowman, Director of Strategic Engagement & Impact Assessment,
Office of the Dean of Research, Trinity College Dublin**



'It is very befitting on this International Day of Persons with Disabilities to remember and say thank to the 200+ participants who have passed away. Unfortunately, the longevity dividends witnessed for the general population have not occurred for people with Intellectual disability who die on average 20 years earlier than the general or non-disabled population.

We need to do much more to create a fairer and more equitable society and IDS TILDA are endeavoring to understand determinants of health and being and what are the issues that contribute to earlier and higher mortality. We remember people with an ID who have passed away and given so generously of their time to improve the lives of future generations.'

Prof Mary McCarron, Principal Investigator IDS-TILDA

People shared the details of their lives with IDS-TILDA so that we could improve the lives of future generations. We remember them and we thank them.



IDS-TILDA hosted a commemorative ceremony from Trinity Chapel to respectfully remember participants who have given so generously to the study, on the International Day of Persons with Disabilities on Friday, 3rd December 2021.

IDS-TILDA is the first nationally representative longitudinal study on ageing with an intellectual disability (over 40 years of age) comparable to the general population. For more than 10 years, IDS-TILDA has been a leader in meaningfully involving patients, carers, policymakers, and service providers in the development of co-created research and healthcare delivery systems. The event allowed an opportune time to reflect and remember the people who shared the details of their lives with IDS-TILDA to benefit others, over the last number of years.

"The learning and the love will not pass away"

Reverend Dr Julian Hamilton



Family members and staff were presented with keepsakes on behalf of their loved ones who have given so generously to IDS-TILDA

Highlight: Growing Our Research Community

Promoting the voice of lived experience through Public and Patient Involvement (PPI)

The involvement of people with a 'lived experience' of a disability, long-term condition, illness or different identity has come more to the fore in how Irish health and social care research is carried out. Through the national PPI Ignite Network, officially launched in November 2021, greater numbers of people are encouraged and supported to play an active part in the development, delivery, and dissemination of research. As a founding member of the Network, Trinity promotes, encourages, and celebrates the involvement of those with lived experience across the research cycle, building relationships and partnerships that refine and research what research is done, how it is done and the potential impact that it can achieve.



Left to right: Ms Mei Lin Yap and Prof. Mary McCarron



Left to right: Prof. Mary McCarron, Ms Mei Lin Yap and Mr. Michael Foley

The Trinity PPI Ignite Office has a national remit to improve the quality of Irish PPI. During the year, it delivered a number of Collective Intelligence Workshops to reach a consensus among PPI contributors and PPI-experienced researchers from across the country on what constitute the fundamental values and principles that drive excellent PPI. This Framework of Values and Principles, launched in October 2022, will now form the basis of Quality Improvement activities for the PPI Ignite Network.

During this year, the Trinity PPI Ignite Office ran 130 clinics, supporting research teams with their PPI activities, and 42 training events or education offerings. Overall, it has reached over 1,000 researchers, support staff, PPI contributors and partner agencies. It has also co-developed 'Engaged Research and Innovation for Societal Impact', a train-the-trainer course for Campus Engage in the Irish Universities Association. The course, open to universities across Ireland, gives learners the knowledge and skills they need to deliver workshops in their own institutions on engaged research. This work was presented by the PPI Ignite Office to the 9th Living Knowledge Conference, Groningen in June 2022.



Creative Brain Week Living Library (photo above)



Highlight: Growing Our Research Community

The PPI Ignite Office also supported a number of events and activities over the year such as: the launch of the Network, with a speech from the TCAID Ambassador Liaison, Mei Lin Yap; the 2021 START European Research Night exploring the IPPOSI Citizen Jury on Access to Health Information; the inaugural Trinity Creative Brain Week by creating a 'Living Library' of people with dementia who were open to conversations about living with dementia or supporting someone who has dementia; a Trinity Faculty of Health Sciences Faculty Forum on PPI; the 2022 Trinity Civic Engagement Awards; the 2022 FibroForum for people living with fibromyalgia; a number of Trinity St James Cancer Institute events and clinics on PPI in cancer research; a SPHeRE learning event on PPI within PhD research; a Pride in Research event on the inclusion of LGBTQI+ PPI contributors; the National Doctors Training and Planning (NDTP) Academic Intern Track on research impact and PPI; and a workshop on PPI in the establishment of Dementia Trials Ireland.

Active Projects 2021/22:



Project title: IDS-TILDA Wave 5

PI: Prof Mary McCarron

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) research ageing among people with an intellectual disability (ID) 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 ID 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 ID and the general population. The design and planning for Wave 5 of data collection are underway. Recruitment of new participants is also underway, focussing on the recruitment of participants in the 40-49 age group to ensure the IDS-TILDA sample is representative of the overall ID population.

The purpose of Wave 5 data collection is to continue the steady-state longitudinal data collection carried out in previous waves of IDS-TILDA. Wave 5 of IDS-TILDA will continue 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.

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 the study will balance longitudinal continuity and will introduce 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 ID as they transition between residential settings.

Highlight: Growing Our Research Community



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

Aim: 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 greater risk of developing dementia than the general population. In particular, those with Down syndrome (DS) are the world's largest group with a genetic risk for Alzheimer's disease (AD), given overexpression of the amyloid precursor protein (APP) gene located on chromosome 21. Despite this high risk, services, both in the general population and ID specific services, are ill prepared to provide post-diagnostic support to people with an ID and dementia and their carers, meaning unequal and inadequate access to supports for many across the country. The aim of the study, therefore, is to develop accessible best practice guidelines for post diagnostic dementia supports for people with an intellectual disability in Ireland. The resulting guidelines will identify needed adjustments and make recommendations for all services on how best to provide post-diagnostic dementia supports to people with ID and their families/carers.



Project title: Prevent Dementia DS
PI: Dr. Eimear McGlinchey

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 DS represent the world's largest population with a genetic predisposition to AD. Everyone with DS has the neuropathological hallmarks of AD by age 40 and a cumulative dementia risk of 88% by age 65.4. The most common cause of DS is an extra copy of chromosome 21 – trisomy 21. This is a cross sectional study that will establish an adapted PREVENT protocol for people with DS and, using the data from this process, will analyse the neuroimaging (diffusion and functional MRI), plasma (NfL) data and neuropsychological performance data.



Highlight: Growing Our Research Community



Project Title: EQUIP

PI: Dr. Maire O'Dwyer

Aim: The aim of this study is to examine the quality and trends of psychotropic use of older adults with intellectual disability over a ten-year period in Ireland to inform practice and policy and optimise medicines use and health outcomes.

Project overview: Widespread, and sometimes inappropriate, use of psychotropics in adults with intellectual disability has been an international concern. These medicines have been used to treat mental health conditions, but also controversially behaviours 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. In the past ten years changes in regulation, policy and decongregation for people with intellectual disability has taken place. The HSE National Clinical Programme for People with Disability (NCPDD) was established in 2020 and has medicines optimisation as a key priority. Existing multi-wave data from the IDS-TILDA study and the HSE national prescribing database offers an opportunity for the Medicines Optimisation Group in IDS-TILDA, the Faculty of Learning Disability in the College of Psychiatrists of Ireland, the HSE NCPDD, and patient stakeholders to better understand psychotropic medicine use. The study uses health and medication data from ten years (four waves) of the IDS-TILDA study, a nationally representative longitudinal study of adults with intellectual disability over 40 years of age, and medicines data from the HSE-PSCR prescribing database. Descriptive and longitudinal analysis will examine the impact of long-term psychotropic use, changes in trends of use, and the impact of decongregation on medicines use.

'I'm an EQUIP Steering Committee Member and independent advocate. I have the chance to make sure the study knows what it is like to take a lot of tablets and it's important for people to know side effects, to know the correct dosage and have accessible support to know what medications to take.' –
Ms Lorraine Keating, PPI Advocate and Steering Committee Member.





Highlight: Growing Our Research Community



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

PI: Dr. Juliette O'Connell

Aim: To develop an evidence-based tool: OPTIMA-ID (Optimising Pharmaco-Therapy and Improving Medication for Ageing with Intellectual Disability) to guide medicines optimisation.

Project Overview: Medicine optimisation in older adults improves medication appropriateness and reduces adverse effects and harm. Despite availability of tools to optimise older people's prescriptions, there is no comprehensive tool specific for use in older adults (i.e., ≥40 years) with intellectual disabilities. This research aims to develop a pharmacotherapy optimisation tool, OPTIMA-ID.



"As an ID-physician, I was very pleased to participate in a focus group meeting concerning the OPTIMA-ID. Polypharmacy is common in people with intellectual disabilities (ID), but available tools for systematic medication reviews in polypharmacy are not specifically developed for people with ID. They often have different multimorbidity patterns, and they also often use other medications. The OPTIMA-ID will therefore be an important tool and make an enormous contribution to optimizing medication use, and thus to the health of people with an intellectual disability." **Dr. Dederieke Festen, Assistant professor, Erasmus MC, General Practice**



Project Title: HEA COVID 19 costed extension to Get Wise about your health, supporting individuals with intellectual disability to become health savvy.

PI: Dr Eilish Burke

Project Overview: The COVID 19 pandemic severely impacted the application and implementation of the Get Wise project. The team feared a negative impact on the roll out of the programme and the dissemination activities planned. Along with this, there were concerns that the final product would not be what was intended. However, further funding was secured from the HEA following the onset of COVID 19 which directly enabled operationalising the intended plans. The research team was able to subsequently change their methods of engagement with participants, change the interview process, move online, and remodel the way the teams engaged their participants online. The funding also enabled the team to work on the accessibility of the website and make the content more audio visual friendly. You can access the final programme [here](#).



Highlight: Supporting the Development of Others

Education and Training Opportunities Delivered

The Centre provided the following educational opportunities in 2021/22:

Post Graduate Certificate in Ageing Health and Wellbeing in Intellectual Disability, completed by six students

Caroline Buckley
Elizabeth Burke
Pamela Calma
Claire Coffey
Jun Leong Loke
Patrick Murray

Post Graduate Diploma in Ageing Health and Wellbeing in Intellectual Disability, completed by one student

Slaney Cox (PT)

MSc in Ageing Health and Wellbeing in Intellectual Disability, completed by four students



Meadhbh O'Donnell (PT):
Completed and graduated

Thesis title: *A quantitative exploration of pain in older adults with intellectual disability in Ireland.*



Louise O'Reilly (PT):
Completed and graduated

Thesis title: *Healthcare Staffs Experiences of Supporting Older Adults with an Intellectual Disability who are in Pain: a Systematic Review*



Halley Stapleton (FT):
Completed and graduated

Thesis title: *A quantitative exploration of the impact of one's perception of ageing in association with longevity, quality of life and satisfaction*



Ulrike Gnann (FT)*:
Completed and graduated

Thesis title: *A cross sectional exploration of the prevalence and impact of urinary incontinence among ageing adults with intellectual disability in Ireland*

**Awarded school prize*



Highlight: Supporting the Development of Others

Education and Training Opportunities Delivered

MSc/PhD/MD Students



Dr Rosemary Monaghan

Completed 2021
Patterns of medication use associated with epilepsy and comorbid behavioural and mental disorders in older people with intellectual disability.



Dr Brendan Dee

Completed 2022
Determinants of frailty among older adults with an intellectual disability.



Ms Judy Ryan

In Progress
An Exploratory Study of Overweight and Obesity in People with an Intellectual Disability 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 Fidelma Flannery

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



Ms Louise Lynch

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



Ms Lamya Al Shuhaimi

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.



Dr Karen Ryan

In Progress
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.

Participant Engagement

The 2021/22 IDS-TILDA Christmas Card and Easter Card competitions received more than 700 entries from people with an intellectual disability from across Ireland.

Front artwork cover:
Caroline Glynn, Mountbellow Hub,
Ability West, Co. Galway

Runner up: Alicia Power, Daughters
of Charity Disability Support Services

Runner up: Michelle Scanlon,
Mountbellow Day Service, Ability
West, Co. Galway



Front artwork cover:
Stephen Mitchell, Mountbellow Hub,
Ballinasloe, Co. Galway

Runner up:
Anastasiya Solomonenko,
Ballyforan,
Co. Roscommon

Runner up:
Marion Horan,
St Cronans Services, Roscrea,
Co. Tipperary



Left to right: Mr Aviejay Paul, Ms Lucy
Benndorf, Ms Margaret Cleary, Ms
Pavithra, Ms Ashleigh Gorman, Ms
Margaret Haigh and Dr Andrew Allen

*The 2021/22 newsletters reached a
national audience of more than 2,000
individuals and service providers.*



Appendix

Research Outputs 2021/2022

Reports

McCausland, D., Allen, A.-P., Haigh, M., Sheerin, F., Burke, E., McGlinchey, E., Flannery, F., Mulryan, N., McCallion, P., & McCarron, M. *Overcoming Adversity: The Continuing Impact of COVID-19 on People Ageing with an Intellectual Disability in Ireland. Findings from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) COVID-19 Sub-Study*, Trinity College Dublin, December 2021 (<https://doi.org/10.25546/98103>)

Book

Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., *End of Life and People with Intellectual and Developmental Disability. Contemporary Issues, Challenges, Experiences and Practice.*, 1, Switzerland, Palgrave Macmillan Cham, 2022, XXXIV – 519 (<https://doi.org/10.1007/978-3-030-98697-1>)

Book Chapters

Building Shared End-of-Life Supports and Cross-Training for Hospice/Palliative and Intellectual Disability Services Providers, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., *End of Life and People with Intellectual and Developmental Disability – Contemporary Issues, Challenges, Experiences and Practice*, Switzerland, Palgrave Macmillan Cham, 2022, 211 – 233, Ferretti, L.A., McCarron, M. & McCallion, P. (<https://doi.org/10.1007/978-3-030-98697-1>)

Experience of End-of-Life Issues by People with Intellectual Disability, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., *End of Life and People with Intellectual and Developmental Disability - Contemporary Issues, Challenges, Experiences and Practice*, Switzerland, Palgrave Macmillan Cham, 2022, 29 - 57, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M. (<https://doi.org/10.1007/978-3-030-98697-1>)

Living and Dying Well with Dementia, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., *End of Life and People with Intellectual and Developmental Disability – Contemporary Issues, Challenges, Experiences and Practice*, Switzerland, Palgrave Macmillan Cham, 2022, 179 – 209, McCarron, M., Allen, A.P., Mulryan, N., Leigh, M., O'Reilly, L., McCarthy, C., Dunne, P., Reilly, E. & McCallion, P. (<https://doi.org/10.1007/978-3-030-98697-1>)

Positioning the Issues: An Agenda for Future End-of-Life Research, Policy and Practice, *End of Life and People with Intellectual and Developmental Disability – Contemporary Issues, Challenges, Experiences and Practice*, Switzerland, Palgrave Macmillan Cham, 2022, 435 – 463, Wiese, M.Y., Stancliffe, R., McCallion, P. & McCarron M. (<https://doi.org/10.1007/978-3-030-98697-1>)

Supporting People with Intellectual Disability at End of Life: Moral Distress among Staff Caregivers During COVID-19, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., *End of life and people with intellectual and developmental disability: Contemporary issues, challenges, experiences and practice*, Switzerland, Palgrave Macmillan Cham, 2022, 235 – 264, McCarron, M., Kelly, K., McCallion, P., Burke, E., Haigh, M. and Wormald A. (<https://doi.org/10.1007/978-3-030-98697-1>)

Use of Do-Not-Resuscitate Orders, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., *End of Life and People with Intellectual and Developmental Disability – Contemporary Issues, Challenges, Experiences and Practice*, Switzerland, Palgrave Macmillan Cham, 2022, 407 – 434, McCallion, P., Ferretti, L.A. & McCarron, M. (<https://doi.org/10.1007/978-3-030-98697-1>)

Accessible Funerals and People with Intellectual Disability, Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., *End of Life and People with Intellectual and Developmental Disability – Contemporary Issues, Challenges, Experiences and Practice*, Switzerland, Palgrave Macmillan Cham, 2022, 265 – 296, Forrester-Jones, R., McCallion, P., McCarron, M., Stancliffe, R.J. & Wiese, M.Y. (<https://doi.org/10.1007/978-3-030-98697-1>)

Health and wellness among persons ageing with intellectual disability, M. Putnam, & C. Bigby (Eds.), *Handbook on Ageing with Disability*, London, Taylor & Francis, 2021, 229 – 239, McCausland, D., McCallion, P., & McCarron, M. (<https://doi-org.elib.tcd.ie/10.4324/9780429465352>)

Responding to Changing Workforce Realities: One Professions Experience, Putnam, & C. Bigby (Eds.), *Handbook on Ageing with Disability*, London, Taylor & Francis, 2021, 323 – 336, Sheerin, F., McCallion, P. & McCarron, M. (<https://doi-org.elib.tcd.ie/10.4324/9780429465352>)

Appendix

Research Outputs 2021/2022

The emergence of aging with long-term disability populations, M. Putnam, & C. Bigby (Eds.), Handbook on Ageing with Disability, London, Taylor & Francis, 2021, 219 - 228, McCallion, P., Ferretti, L.A., & McCarron, M. (<https://doi-org.elib.tcd.ie/10.4324/9780429465352>)

Exploring the intellectual disability data landscape for policy and service directions: An Irish perspective, ġġka, J. & Beadle-Brown, J., The Development, Conceptualisation and Implementation of Quality in Disability Support Services, Prague, Karolinum Press, 2021, O'Donnovan, M-A., Craig, S., McCallion, P., McCarron, M. & Byrne, E.

Health and wellness among persons ageing with intellectual disability, M. Putnam, C. Bigby, Handbook on Aging with Disability, Routledge, 2021, McCausland, D.; McCallion, P.; McCarron, M.

Lynch, L., McCarron, M., Eustace-Cook, J., McCallion, P. & Burke, E., *Physical health effects of sedentary behaviour on adults with an intellectual disability: A scoping review*, Journal of Intellectual Disabilities, 2022, 1 - 27 (<http://dx.doi.org/10.1177/17446295221107281>)

McCarron, M., McCausland, D., McGlinchey, E., Bowman, S., Foley, M., Haigh, M., Burke, E. & McCallion, P., *Recruitment, and retention in longitudinal studies of people with intellectual disability: A case study of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)*, Research in Developmental Disabilities, 124, 2022 (<https://doi.org/10.1016/j.ridd.2022.104197>)

Sheerin, F., Allen, A.P., Fallon, M., McCallion, P., McCarron, M., Mulryan, N., Chen, Y., *Staff Mental Health while Providing Care to People with Intellectual Disability during the Covid-19 Pandemic*, British Journal of Learning Disabilities, 2022 (<https://doi-org.elib.tcd.ie/10.1111/bld.12458>)

Journal Articles

Between 2017 and 2021, TCAID has issued **58 journal articles**. 2020/2021 journal articles were:

Brennan, D., D'eath, M., Dunne, N., O'Donovan, M-A., McCallion, P., & McCarron, M. *Irish Social Policy to Family Carers of Adults with an Intellectual Disability: A critical analysis*, Journal of Intellectual Disability, 2022 (<https://doi.org/10.1177/17446295221115296>)

Gorman, A., Odalovic, M., McCallion, P., Burke, EA., MacLachlan, M., McCarron, M., Henman, M., Moran, M., O'Connell, J., Walsh, M., Shankar, R. & O'Dwyer, M, *Examining Quality, Use and Impact of Psychotropic (Use) in older adults with intellectual disabilities: study protocol*, HRB Open Research, 5, 71, 2022 (<https://doi.org/10.12688/hrbopenres.13645.1>)

Kirwan, R., Sheerin, F., McGlinchey, E., McCallion, P. & McCarron, M. *Functional loss in older adults with intellectual disabilities and dementia*, Learning Disability Practice, 2022 <a (<http://dx.doi.org/10.7748/ldp.2022.e2184>)

O'Brien, F., McCallion, P., Carroll, R., O'Dwyer, M., Burke, E-A. & McCarron, M., *Hypertension in Older Adults. The prevalence, awareness, treatment, and control of hypertension in older adults with an Intellectual Disability: a cross sectional study.*, JBI Evidence Synthesis, 20, 7, 2022 (<https://doi.org/10.1093/eurjcn/zvaa019>)

Chen Y, Allen A P, Fallon M, Mulryan N, McCallion P, McCarron M and Sheerin F, *the challenges of mental health of staff working with people with intellectual disabilities during COVID-19 - A systematic review*, Journal of Intellectual Disabilities, 2022 (<https://doi.org/10.1177/17446295221136231>)

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Dennehy H., Allen A.P., McGlinchey E., Buttery N., Garcia-Dominguez L., Chansler R., Corr C., Dunne P., Kennelly S., Daly L. McCallion P. and McCarron M., *A scoping review of post-diagnostic dementia supports for people with intellectual disability, Aging and Mental Health*, 2022 (<https://doi.org/10.1080/13607863.2022.2130171>)

Todd, S., Bernal, J., Worth, R., Shearn, J., Brearley, S., McCarron, M., & Hunt, K., *Hidden lives and deaths: the last months of life of people with intellectual disabilities living in long-term, generic care settings in the UK*, Journal of Applied Research in Intellectual Disabilities, 2021, 1 - 10 (<http://doi.org/10.1111/jar.12891>)



Appendix

Research Outputs 2021/2022

Burke, E., Carroll, R., Ding, AW., Yaman, M., Walsh, JB., McCallion P and McCarron M., *Men's Bones Matter Too, a Cross Sectional Study Examining Bone Health among Men with Intellectual Disability in Ireland.*, OBM Geriatrics, 5, 4, 2021 (<http://dx.doi.org/10.21926/obm.geriatri.2104182>)

O'Dwyer M, Watkins L, Henman M, McCallion P, McCarron M, Shankar R., *Optimising Medicines Use in Older Adults with Intellectual Disability who have epilepsy: Challenges and Perspectives*, Therapeutic Advances in Drug Safety, 12, 2021, 1 - 5 (<https://doi.org/10.1177/20420986211025157>)

Ryan, J., McCallion, P., McCarron, M., Luus, R., Burke, E.A., *Overweight/obesity and chronic health conditions in older people with intellectual disability in Ireland*, Journal of Intellectual Disability Research, 2021 (<https://doi.org/10.1111/jir.12900>)

King, E., Brangan, J., McCarron, M., McCallion, P., O'Donovan, MA., Bavussantakath, F.R., *Predictors of Productivity and Leisure for People aging with Intellectual Disability.*, Canadian Journal of Occupational Therapy, 2021 (<https://doi.org/10.1177/00084174211073257>)

O'Brien, F., McCallion, P., Carroll, R., O'Dwyer, M., Burke, E., and McCarron, M., *Reflections about hypertension in older adults with an intellectual disability: the importance of Home Blood Pressure Monitoring (HBPM)*, European Journal of Cardiovascular Nursing, 20, 4, 2021, 391 (<https://doi.org/10.1093/eurjcn/zvab024>)

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The Intellectual Disability Supplement to
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