



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



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

Annual Report 2020 - 2021



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

I am delighted to share that in 2020/21, Trinity Centre for Ageing and Intellectual Disability had significant impact. The Centre generated and translated research to inform policies and services. Our publications were used by national and international audiences. We guided talented students across all career stages and positioned colleagues for success, thereby enriching networks here in Ireland and abroad. Through effective in-person and on-line engagement, we grew our community with an emphasis on addressing the challenges we face.

These challenges are not inconsequential. Continuing low levels of awareness exist within health and social care services on the differing needs of people with an intellectual disability and the requirements to reorient services to better suit them. While we see tentative inroads, the technology sector could better serve, inspire and empower this population, as well. We need greater investment by industry and government in innovation pathways, educational opportunities, and skills development, too.

Across society, prevailing low expectations exist and people with an intellectual disability are fielding both disability discrimination and ageism. There is significant scope to engage and encourage this population to better manage their health. At the Centre, we are challenging stereotypes daily through our research, researchers, ambassadors, and liaisons. We seek to further collaborations that grow opportunities for people with an intellectual disability to thrive and live productive, joy-filled lives as valued members of their communities. This includes new and expanded opportunities and roles.

The Centre's flagship research programme, IDS-TILDA, was in the middle of Wave 4 field work when the pandemic emerged, and thanks to the hard work and innovation of the core team and field workers, successfully completed data collection through unprecedented and difficult circumstances. The team had a choice – to pause research or to respond and pursue new and important avenues for research. Choosing to be proactive, IDS-TILDA refined its approaches to safely sustain research while ensuring and prioritising the health of the community. Initially curtailing on-campus activities, virtual data collection strategies were developed and, as the year progressed, the team gradually increased in-person activities when it was safe to do so.



**Prof
Mary McCarron,
Director**

The lessons learned from this period will inform our work into the future, as positive outcomes emerged from both in-person and online engagement. In November 2021, IDS-TILDA was successful in its funding application to the Health Research Board for Wave 5 of the study. During the review process, the International Review Panel noted that IDS-TILDA was “one of the most significant studies on ageing of people with ID in the world.”

Additional funded studies were conducted by the team to better understand the epidemiology and impact of the COVID-19 pandemic on older adults with an intellectual disability, spotlighting the Centre for national and global audiences. I am so proud to share that the strength and stability of the Centre was visible in the compassion and resilience of the team throughout the pandemic. Colleagues rapidly responded to support emergency response efforts to minimize the pandemic’s effect, developing educational offerings for HSE LanD, and a suite of accessible information including weekly master classes to support front line workers. These open access educational opportunities attracted more than 1,000 attendees at each session, along with an additional 10,000 subsequent views.

Our public involvement ethos over many years proved a major strength, also reported on here. The breadth and collaborative nature of our contributions highlight the Centre’s growing influence, shared expertise, and agility in designing and implementing a broad range of research projects and translational activities. Our research is informing and transforming health policy and clinical services for people with an intellectual disability. This report also highlights a major translational innovation – the establishment of Ireland’s National Intellectual Disability Memory Clinic – a major achievement.

I am delighted to present this 2020/21 Annual Report and I hope you will enjoy learning more about the Centre.

The Trinity Centre for Ageing and Intellectual Disability values diversity in the workplace. Work gives individuals a sense of purpose and self-worth. For many, it defines who we are and is a source of justifiable pride. The benefits of being in employment are well documented; however, unemployment is a critical issue for people with intellectual disability. Between 2011 and 2020, IDS-TILDA found that just 6.6% - 8.7% of this population were in paid employment. Aiming to demonstrate what people with intellectual disability can do, Prof McCarron utilised the Health Research Board Inaugural Impact Award to enable meaningful employment opportunities. In 2021, Ms. Christina Corr joined the Centre as a Research Assistant to the Post-Diagnostic Dementia Support Guidelines for People with an Intellectual Disability project. Ms Mei Lin Yap serves as the Centre’s Ambassador Liaison Officer.



Our Impact: 2020 - 2021

Significant achievements are highlighted here:

Generating & Translating Knowledge

- The Centre delivered two reports, three book chapters, 22 journal articles, and 21 oral presentations in 2020/21. The uptake of Centre research is substantial, including utilisation by national, European, and international healthcare organisations, educational institutions, research centres, and governments.
- The Centre's publications have both policy and patent impacts. Twenty-six policy documents from 20 different sources and from nine different countries reference the Centre's research. Of these, 14 are Clinical Guidance documents (Overton) and two publications are cited in two patents (Altmetric).
- The Centre's publications are amongst the most cited and highly visible publications of the scholarly world. For example, 19.3% of Prof Mary McCarron's publications (2011-2020) are in the top 10% of the most cited publications worldwide, with over 1.3k citations accumulated (SciVal).
- 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*, *The Conversation* and other news outlets and blogs (Altmetric).
- In 20/21, the Centre was awarded eight grants, totalling €2,345,292, through the Health Research Board, Irish Research Council, Department of Health, Wellcome Trust, Health Service Executive, and Trinity College Dublin. Eleven active projects also progressed, with a focus on co-creation and advancing meaningful public, patient involvement.

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: 2020 - 2021

Significant achievements are highlighted here:

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 seven students.
 - The Post Graduate Diploma in Ageing Health and Wellbeing in Intellectual Disability was completed by five students.
 - The MSc in Ageing Health and Wellbeing in Intellectual Disability was completed by two students.
 - Two PhDs were completed and seven were in progress.
 - Improving Health Assessments for People with an Intellectual Disability attracted more than 7,000 learners on the Future Learn platform.
 - A masterclass series, in collaboration with the Health Service Executive, attracted more than 3,750 healthcare professionals.
 - Between 2020 and 2021, the Centre hosted 25 webinars and masterclasses with a wide-range of collaborators, including University of Pennsylvania research interns, COPE Foundation, All Ireland Institute of Hospice & Palliative Care, AVISTA, Brothers of Charity Services Ireland, Department of Health, Age & Opportunity, EIT Health, and Tallaght University Hospital Foundation.
 - A webinar series attracted more than 6,000 attendees and generated 10,000 subsequent views.





Our Impact: 2020 - 2021

Significant achievements are highlighted here:

Contributing to Society

- The Centre 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. Demonstrated impact includes better patient outcomes, better experiences of care, and continued development of staff, substantiated through evaluation data and testimonials. Initially a trial clinic, permanent funding was provided by the Health Service Executive National Dementia Office. This is the only service of its kind in Ireland with only a handful of such clinics available internationally.

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.
- Third year student, Xiaohan Hu, received a summer studentship award from the Health Research Board, working with Assistant Prof. Maire O'Dwyer, looking at changes in prevalence and patterns of antipsychotic prescribing in older adults with intellectual disability.
- Prof Mary McCarron, Director, was inducted as a Fellow into the American Academy of Nursing for her contributions in enhancing the quality of nursing, reducing health disparities and inequalities, and advancing healthy ageing.
- Centre teammates were awarded the Trinity's 2020 Registrar's Engagement Award.

Growing Our Research Community

- Online engagement for the Centre continues to grow, with more than 1,100 social media followers, up 74% on the previous year with content reaching a global audience of 300,000 annually.
- 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, Senior Executive Officer
June O'Reilly, Strategic Development Officer
Margaret Haigh, Project Manager, IDS-TILDA
Fathima Rosmin Bavussantakath, Data Manager
Michael Foley, Programme Manager, PPI Office
Sarah Bowman, Director of Strategic Engagement & Impact Assessment

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 (Waterford Institute of Technology)
Prof Seán Kennelly (Tallaght University Hospital and Medical Gerontology, Trinity College Dublin.)

Academic Advisor

Prof Philip McCallion, Senior Advisor

Postdoctoral and Research Fellows

Dr Darren McCausland
Dr Andrew Allen
Dr Andrew Wormald
Dr Yaohua Chen
Dr Esther Murphy
Dr Amara Naseer
Dr Retha Luus, Statistician

Research Assistants

Ms Áine Ní Ghráda
Ms Holly Dennehy
Ms Louise Lynch
Ms Christina Corr

Meet Our Newest Teammates: 2020 - 2021

Ms Fathima Rosmin Bavussantakath
Data Manager/Assistant Statistician



Dr Retha Luus
Statistician



Ms Áine Ní Ghráda
Research Assistant



Ms Christina Corr
Research Assistant



Ms Mei Lin Yap
Ambassador Liaison Officer





Vision

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

Mission

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

Strategic Priorities

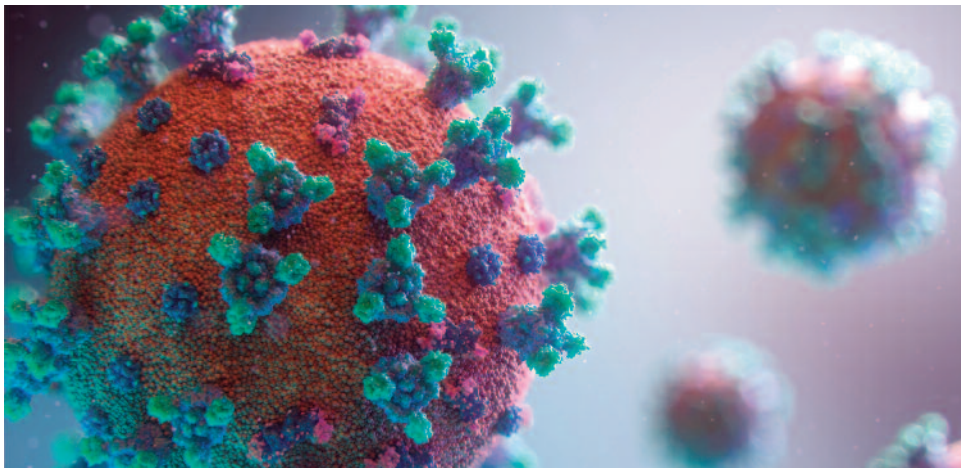
The Centre focuses on the following priorities:

- 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

IDS-TILDA Data Informed Strategic Responses to COVID-19 by Government, Service Providers and Carers across Ireland



As Ireland joined the world in responding to the first wave of the COVID-19 pandemic, IDS-TILDA researchers adapted rapidly in order to deliver reliable, trust-worthy information to guide policymakers, service providers, and carers, including:

- In collaboration with the Health Service Executive, IDS-TILDA created a module for clinical staff on ‘COVID-19 Assessment and Recognition Among People with Intellectual Disability,’ utilising learnings from the IDS-TILDA Health Fair. Hosted on HSELand, more than 3,750 healthcare professionals in Ireland completed this module.
- In collaboration with the All Ireland Institute of Hospice and Palliative Care, the Daughters of Charity Disability Support Service, St Francis Hospice, and Tallaght University Hospital, TCAID researchers hosted a seven-part masterclass series for carers and service providers, between April and May 2020, to address information gaps, attracting more than 10,000 attendees, and recordings were subsequently viewed more than 10,000 times on the IDS-TILDA website.

“The evidence base provided through the research of the IDS TILDA team has been of enormous importance in grounding the collaborative work undertaken to ensure the health and wellbeing outcomes of people with ID during Covid 19, and of particular importance with regards to the vaccination campaign, a key moment in making real our response to Article 25 of the UNCRPD.”

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



- IDS-TILDA was invited by the Houses of the Oireachtas to prepare a submission to the Special Committee on COVID-19 and this was delivered in June 2020. In February 2021, IDS-TILDA made a submission to Minister Anne Rabbitte, TD, highlighting the case for accelerated COVID-19 vaccination for people with Down syndrome. Also in February 2021, IDS-TILDA provided data to support a submission by the Federation of Voluntary Service Providers to Dr Colm Henry, HSE Chief Clinical Officer, and Dr Tony Holohan, Chief Medical Officer, on the urgent vaccination needs of people with intellectual disabilities. These representations, underpinned by more than 10 years of evidence from IDS-TILDA, helped to inform the decision by Government to classify people with intellectual disability among those at ‘high risk’ of COVID-19, and people with Down syndrome among those at ‘very high risk’ thereby prioritising people with an intellectual disability for vaccination.
- IDS-TILDA was in the process of data collection for Wave 4 of IDS-TILDA when the initial national restrictions were introduced. The IDS-TILDA team formulated an adjustment to data gathering protocol and initially applied for internal ethical approval and review from the Data Protection Office and then applied to the National Research Ethics Committee on COVID-19 and the Health Research Consent Declaration Committee. This process also provided an opportunity to add questions to the protocol about experience of COVID-19. A supplemental COVID-19 survey was developed and administered to 710 IDS-TILDA participants between May and September 2020, in response to the COVID-19 crisis in Ireland. Researchers from Trinity College launched a special report on COVID-19 and older people with an intellectual disability, which has found that COVID-19 was well managed in services and calls for decisions to impose further restrictions during the pandemic were data-driven, as they have been for the non-ID population. The report, *‘The Impact of COVID-19 on People Ageing with an Intellectual Disability in Ireland’* report was formally launched by the Minister of State with responsibility for Disability, Minister Anne Rabbitte TD. Broadcaster Olivia O’Leary led a panel discussion with a variety of stakeholders, exploring different perspectives on the pandemic and lockdown.



Highlight: Contributing to Society

Delivering Ireland's first National Intellectual Disability Memory Service and Advancing the National Dementia Strategy and Sláintecare Strategic Priorities



Initially a trial clinic, permanent funding was provided by the HSE National Dementia Office, in April 2022. This is the only one of its kind in Ireland with only a handful of such clinics available internationally.

- **Better Patient Outcomes:** Includes patient testimonials on positive experiences of assessment, diagnosis, and the delivery of post-diagnostic supports;
- **Better Experiences of Care:** Includes testimonials by patients, carers, and service providers on reductions in feelings of worry and stress, as well as appreciation for timely diagnoses, and the delivery of respite and support services; and
- **Continued Development and Supported Staff:** Includes recognition by staff on process improvements in the delivery of care, as well as greater equity in accessing services, and changes in local practices due to engagement with NIDMS.

“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



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

Ms Mei Lin Yap,
Ambassador Liaison Officer



Highlight: Growing Our Research Community

Enabling Public, Patient Involvement in Health and Social Care Research



In 2021, Trinity joined the national effort to involve public in research processes from the start. The PPI Ignite Network, with a combined €3.3 million funding from the Health Research Board and Irish Research Council, provides a national voice for public and Patient Involvement in health and social care research, and is matched with financial and in-kind supports from the Network partners, totalling a €5 million investment across Ireland.

The PPI Ignite Office at Trinity includes members of the public and patients on decision-making committees, executive committees, and governance boards. A growing number of strategic plans at institutional, college, and school level include, acknowledge and reward PPI activities. Supports are being embedded across the University to facilitate clinics, workshops, train-the-trainer activities, research teaming, brokerage events and other opportunities to scale efforts. A strong culture for training exists, with emphasis on accessibility, inclusion, and mutually-beneficial experiences for partners. As Trinity's efforts mature, our focus is placed on engaging with human resources, financial services, and research ethics to investigate process improvement opportunities to fully develop and embed PPI across the institution to exemplary standards, alongside assessment of outcomes and impact.

In 2020, the PPI Ignite Office celebrated Phase 1 accomplishments, which included:

- 22 training workshops and more than 100 clinics, reaching 783 researchers and support staff.
- 37 networking events which engaged more than 3,400 PPI contributors, researchers, support staff and members of the public.
- Proposal development assistance which resulted in €7.5 million for research activities.
- 12 co-authored publications, including a toolkit for research charities to begin a PPI relationship, with Health Research Charities Ireland.
- Successful applications for the 2020 Registrar's Engagement Award; the 2020 Irish Cancer Society Cancer Research Engagement Award; and the 2020 shortlist for Health Service Executive (HSE) Excellence Awards.



Highlight: Growing Our Research Community

2020/21 Active Research Projects

Prevent Dementia DS and Building Bridges

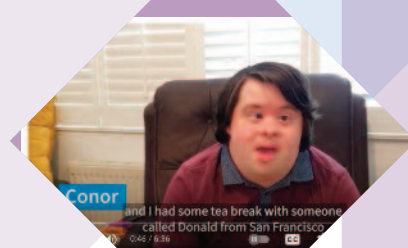
A project examining early biomarkers of Alzheimer's disease in people with Down syndrome, and to develop best practice guidelines for Post Diagnostic Dementia Support for people with an Intellectual Disability, in collaboration with the Centre and the Global Brain Health Institute. This project team is Dr Eimear McGlinchey, and Dr Andrew P. Allen.

Digi-ID: Digital skills education to support health and social inclusion for adults with intellectual disabilities

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 adults with intellectual disability, supporters, professionals, and families/carers. This project team is Dr Esther Murphy, Dr Darren McCausland, Citizen Advisory Panellists, and Áine Ní Ghráda.

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

This project is exploring the current models of care available for adults with intellectual disabilities as they age. People ageing with intellectual disability are more likely to have complex health issues. Given that complexity, this study seeks to examine the care of older adults with intellectual disability and complex age-related conditions, with a focus on the effectiveness of different care models in relation to outcomes and quality of life, and with consideration to their respective cost implications. This project team is Dr Fintan Sheerin, Dr Sandra Fleming, Prof Mary McCarron, Prof Philip McCallion, Dr Peter May, Dr Amara Naseer, and Dr Amara.



Building Bridges for Better Brain Health is a fantastic project organized by the Atlantic Fellows and Trinity Centre for Ageing and Intellectual Disability that is connecting people living with Down syndrome from Ireland and San Francisco to talk about and promote good brain health.



IDS-TILDA: Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing, Wave IV

IDS-TILDA is a large scale nationally representative study of people with an intellectual disability aged 40 years and over. The longitudinal design entails interviewing participants at incremental time periods over a number of waves. The project team is Prof Mary McCarron, Margaret Haigh, Gavin Dann, Dr Darren McCausland, Dr Andrew P. Allen, Dr Rachael Carroll, Dr Retha Luus, Fathima Rosmin Bavussantakath, Michael Foley, Catherine Nealon, Louise Lynch, Sonia McDermott, Kathyan Kelly, Cathy McCarthy, Mary Carroll, Fidelma Flannery, Dr Andrew Wormald, and Dr Catriona Ryan.

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

The aim of the study is to develop accessible best practice guidelines for post-diagnostic dementia supports for people with an intellectual disability in Ireland. The project team is Prof Seán Kennelly, Prof Mary McCarron, Prof Philip McCallion, Holly Dennehy, Christina Corr, Pamela Dunne, Dr Eimear McGlinchey, Dr Louise Daly, and Dr Andrew P. Allen.

Questions of Inclusion: What inclusion means for adults with an intellectual disability, and the role of technology (INCLU-ID)

INCLU-ID is a collaborative study involving the National Federation of Voluntary Service Providers, and the Trinity Centre of Ageing with an Intellectual Disability to engage with people with intellectual disabilities to find out what inclusion means for them, and also hear from their support services. The project team is Dr Esther Murphy, Dr Darren McCausland and Mei Lin Yap.



"It's a great time to be someone living with a learning disability, and I am fortunate to have such a rich digital life. I like to help others use technology to reach their goals."

Fionn Crombie Angus, Citizen Advisory Council, Digi-ID

EIT SOOTHE: First Response to Mental Health Concerns in Mid and Older Aged People with Intellectual Disability

Older people with ID experience poorer mental health than those in the mainstream population, the typical manifestations of such mental health concerns have historically led to difficulties in achieving accurate diagnoses. Therefore, mental health needs are often unmet, resulting in significant health decline. SOOTHE assists in re-establishing a locus of control for the person and thus supporting empowerment, in a connected context. This project supports older people with ID to take on ownership and control for their own mental health and wellness. The project team is Dr Fintan Sheerin, Dr Sandra Fleming, and Dr Niamh Mulryan.

Staff Mental Health while Providing Care to People with Intellectual Disability during the Covid-19 Pandemic

COVID-19 placed 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 people with intellectual disabilities have increased vulnerability to more negative effects of COVID-19, with significantly higher mortality rates, caused considerable concern. It is against this backdrop and a dearth of research on the mental health of staff working with people with an intellectual disability that this study is undertaken. The project team is Dr Fintan Sheerin and Dr Yaohua Chen.

Get Wise about your Health, supporting people with intellectual disability to become health savvy

The 'Get Wise' project is a European project funded by EIT Health. The project partners include Erasmus MC from the Netherlands. Guided by the mission of the project to promote empowerment through knowledge, the programme targets specific health disparities identified among individuals with intellectual disabilities to deliver health education on an innovative online platform in an accessible easy-read manner for people with ID. The project team is Dr Eilish Burke, Holly Dennehy, Áine Ni Ghráda, Sarah Bowman, Gavin Dann, Alex Verbinschi, Dr Esther Murphy, Dr Alyt Oppewal, Dr Anna Bakker, Dr Dederieke Maes-Festen, Anne Cosgrove, Darren Heduan and Catherine O'Connor.

PPALS trains people with intellectual disability to be physical activity leaders among peers. Despite COVID-19 they moved online to great effect and were congratulated for their outstanding efforts by Minister Jack Chambers TD, entertainer Daniel O'Donnell, and the Irish Women's Rugby Team!





PPALS2 People with intellectual disability as Physical Activity Leaders

PPALS2 is a leadership programme designed to engage and promote individuals with intellectual disability as physical activity leaders. It follows the successful role out of the programme in 2018 at which time 15 individuals in Ireland and 20 individuals in Spain were trained to be PPALS leaders, leading games, and physical activity among their peers. In PPALS2 an additional element called 'Ageing with Confidence' was included in Ireland. Led by Age & Opportunity this programme supports individuals explore and grow their confidence. The project team is Dr Eilish Burke, Sonia McDermott, Sue Guildea, Paul Gallier, Ciaran McKinney, Brian Dooney, Dr Maria Carbó Carreté, Joan Guardia Olmos, Guillermo Ruben Oviedo, Daniela Schwarz, Elke Langbein, and the Brothers of Charity Roscommon.

The experience and risk of homelessness for people with intellectual disabilities and/or autism and their families in Dublin

This is a small mixed-methods research study looking at the experiences of people, or families of people, with an intellectual disability (ID) and/or autism spectrum disorder, around housing and homelessness. The study was funded by the National Disability Authority and facilitated by the daughters of Charity Disability Support Services at their Dublin base. The project team is Dr Mary-Ann O'Donovan, Emer Lynch, Linda O'Donnell, Kathyan Kelly and Michael Foley.



Get Wise Rainbow

We asked people with an intellectual disability to share their tips for keeping healthy and staying well. Elizabeth Callaghan created a rainbow collage of all her favourite healthy fruit and vegetables.

Highlight: Supporting the Development of Others

Education and Training Opportunities Delivered

The Centre provided the following educational opportunities in 2020/21:

- Post Graduate Certificate in Ageing Health and Wellbeing in Intellectual Disability, completed by seven students
 - Post Graduate Diploma in Ageing Health and Wellbeing in Intellectual Disability, completed by five students
 - MSc in Ageing Health and Wellbeing in Intellectual Disability, completed by two students
 - Two PhDs completed and seven in progress
 - A Massive Open Online Course: Improving Health Assessments for People with an Intellectual Disability which has attracted more than 7,000 learners on the Future Learn Platform
 - A Masterclass Series which attracted more than 3,750 healthcare professionals
 - A Webinar Series which attracted more than 6,000 attendees and 10,000 subsequent views
-

Completed Masters in Ageing Health and Wellbeing in Intellectual Disability



Dr Shiling Chen:

An exploration of the factors associated with mobility limitations in adults with intellectual disability in Ireland.



Ms Bronagh Ganley:

A Descriptive Quantitative Exploration of Choice in the Lives of Older Adults with Intellectual Disabilities in Ireland



Highlight: Supporting the Development of Others

Education and Training Opportunities Delivered

MSc/PhD Students



Ms Hadiah Khalaf Almutairi

Completed 2020. The prevalence, effectiveness, and side effects of gastro-intestinal medications among adults with an Intellectual disability.



Ms Maureen D'eath

Completed 2021. A Study of Family Carers of Older People with Intellectual Disability in Ireland and the Social Policy Context of their Caregiving.



Ms Rosemary Monaghan

In progress. Patterns of medication use associated with epilepsy and comorbid behavioural and mental disorders in older people with 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 behavior 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.



Mr Brendan Dee

In progress. Determinants of frailty among older adults with an intellectual disability.

Participant Engagement

The 2020/21 IDS-TILDA Christmas Card and Easter Card competitions received more than 600 entries from people with an intellectual disability from across Ireland. The 2020/21 newsletters reached a national audience of more than 2,000 individuals and service providers.





Appendix

Research Outputs 2020/2021

Reports

Between 2017 and 2021, TCAID issued **12 reports**. The 2020/2021 reports were:

1. McCarron, M., McCausland, D., Allen, A.P., Luus, R., Sheerin, F., Burke, E., McGlinchey, E., Flannery, F., & McCallion, P., The Impact of COVID-19 on *People Ageing with an Intellectual Disability in Ireland. Evidence from Wave 4 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)*. Trinity College Dublin, December 2020. Available at: <https://idstilda.tcd.ie/assets/docs/wave4idstildareport.pdf>
2. O'Donovan, M.A., Lynch, E., O'Donnell, L. & Kelly, K. *The experience and risk of homelessness for people with intellectual disabilities and/or autism and their families in Dublin. A mixed methods study*. The National Disability Authority, November 2020. Available at: <https://nda.ie/publications/disability-supports/autism/the-experience-and-risk-of-homelessness-for-people-with-intellectual-disabilities-and-or-autism-and-their-families-in-dublin-a-mixed-methods-study-.pdf>

Book Chapters

Between 2017 and 2021, TCAID has issued **14 book chapters**. The 2020/2021 book chapters were:

1. Exploring the intellectual disability data landscape for policy and service directions: An Irish perspective in, editor(s) Šiška, J. & Beadle-Brown, J., *The Development, Conceptualisation and Implementation of Quality in Disability Support Services*, Prague, Karolinum Press, 2021, [O'Donovan, M-A., Craig, S., McCallion, P., McCarron, M. & Byrne, E.]
2. Sheerin, F., McCallion, P., McGlinchey, E., O'Dwyer, M., Reilly, E., & McCarron, M. (2020). Aging with Intellectual Disability: Dementia and Cognitive Decline. In Matson, E., *Handbook of Dual Diagnosis*. (pp 311-330). Switzerland: Springer Nature.
3. Choice as people age with intellectual disability – an Irish perspective in, editor(s) Roger J. Stancliffe, Michael L. Wehmeyer, Karrie A. Shogren, Brian H. Abery, Choice, preference, and disability: *Promoting self-determination across the lifespan*, Springer Books, 2020, [O'Donovan, M-A., McCausland, D., McCallion, P. & McCarron, M.]

Journal Articles

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

1. 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 DOI:10.12688/hrbopenres.13238.2
2. 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 DOI:10.12688/hrbopenres.13340.2.
3. McCausland, D., Luus, R., McCallion, P., Murphy, E., & McCarron, M., The impact of COVID-19 on the social inclusion of older adults with an intellectual disability during the first wave of the pandemic in Ireland, *Journal of Intellectual Disability Research*, 65, (10), 2021, p879 - 889 DOI: 10.1111/jir.12862
4. Dee, B., Burke, E., Romero-Ortuno, R., McCallion, P., & McCarron M., Factors associated with the progression of deficit accumulation frailty among adults with an intellectual disability: a systematic review revealing research gaps, *HRB Open Research*, 4, (58), 2021 DOI:10.12688/hrbopenres.13257.1
5. 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*, 34, 2021, p1 – 10 DOI: 10.1111/jar.12891
6. Burke, E., Dennehy, H., Bakker, A., Bowman, S., Murphy, E., Maes-Festen, D., McCallion, P., McCarron, M., & Oppewal A., The Methodological Approach to the Co-Creation of Online Health Education with and for Individuals with Intellectual Disability, *Global Journal of Intellectual & Developmental Disabilities*, 7, (5), 2021 DOI: 10.19080/GJIDD.2021.07.555725

Appendix

Research Outputs 2020/2021

7. McCallion, P., Shi, J., Ferretti, L., & McCarron, M., Utilizing the China Health and Retirement Longitudinal Study (CHARLS) to Understand the Aging of People Living in the Community with Intellectual and Developmental Disabilities, *Health*, 13, (1), 2021, p47 – 59 DOI: 10.4236/health.2021.131005
8. Bracken-Scally, M., Keogh, B., Daly, I., Pittalis, C., Kennelly, B., Hynes, G., Gibb, M., Cole, N., McMahon, G., Lawlor, B., McCarron, M., & Brady AM., Assessing the Impact of Dementia Inclusive Environmental Adjustment in the Emergency Department, *Dementia*, 20, (1), 2021, p28 – 46 DOI:10.1177/1471301219862942
9. O'Brien, F., McCallion, P., Carroll, R., O'Dwyer, M., Burke, E., & McCarron M., The prevalence, awareness, treatment, and control of hypertension in older adults with an intellectual disability in Ireland: a cross sectional study, *European Journal of Cardiovascular Nursing*, 20, (4), 2021, p315 – 323 DOI:10.1093/eurjcn/zvaa019
10. Monaghan, R., O'Dwyer, M., Luus, R., Mulryan, N., McCarron, M., McCallion, P., & Henman, M., Antiepileptic drugs, occurrence of seizures and effect of co-administration of potential seizure threshold lowering psychotropic drugs in adults with intellectual disability who have epilepsy, *Journal of Applied Research in Intellectual Disabilities*, 34, (3), 2021, p816 – 829 DOI: 10.1111/jar.12857
11. 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, p1 – 5 DOI: 10.1177/20420986211025157
12. Al Shuhaimi, L., Henman, M., McCallion, P., McCarron, M., & O'Dwyer M., The impact of long-term exposure to anticholinergics among people with intellectual disabilities: a scoping review protocol, *HRB Open Research*, 4, (62), 2021 DOI: 10.12688/hrbopenres.13266.1
13. Lynch, L., McCarron, M., McCallion, P., & Burke, E., Sedentary behaviour levels in adults with an intellectual disability: a systematic review and meta-analysis, *HRB Open Research*, 4, (69), 2021 DOI: 10.12688/hrbopenres.13123.2
14. Monaghan, R., O'Dwyer, M., Luus, R., Mulryan, N., McCallion, P., McCarron, M., & Henman, MC., The relationship between antiepileptic drug load and challenging behaviors in older adults with intellectual disability and epilepsy, *Epilepsy & Behaviour*, 122, 2021 DOI: 10.1016/j.yebeh.2021.108191
15. O'Brien, F., McCallion, P., Carroll, R., O'Dwyer, M., Burke, E., & McCarron, M., Reflections about hypertension in older adults with an intellectual disability: the importance of Home Blood Pressure Monitoring (HBPM)—Authors' reply, *European Journal of Cardiovascular Nursing*, 20, (4), 2021, p391 DOI: 10.1093/eurjcn/zvab024
16. Burke, E., Carroll, R., Ding, AW., Yaman, M., Walsh, JB., McCallion P., & 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 DOI: 10.21926/obm.geriater.2104182
17. 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*, 89, (2), 2021, p135-146 DOI:10.1177/00084174211073257
18. McCausland, D., McCallion, P., Carroll, R., & McCarron, M., The nature and quality of friendship for older adults with an intellectual disability in Ireland, *Journal of Applied Research in Intellectual Disabilities*, 34, 2021, p763 - 776 DOI: 10.1111/jat.12851
19. Keogh, B., Ting To, W., Daly, L., Hynes, G., Kennelly, S., Lawlor, B., Timmons, S., O'Reilly, S., Bracken-Scally, M., Ciblis, A., Cole, N., Drury, A., Pitalis, C., Kennelly, B., McCarron, M., & Brady A.M., Acute hospital staff's attitudes towards dementia and perceived dementia knowledge: a cross-sectional survey in Ireland, *BMC Geriatrics*, 20, (376), 2020 DOI: 10.1186/s12877-020-01783-6
20. McGlinchey, E., McCallion, P., & McCarron, M., Down syndrome, and Dementia: Advances in the field, *Current Opinion in Psychiatry*, 33, (3), 2020, p278 – 283 DOI: 10.1097/YCO.0000000000000589
21. O'Dwyer, M., McCallion, P., McCarron, M., O'Connell, J., & Henman, M., Measuring drug burden in older adults with intellectual disabilities: Critical issues for consideration in finding the optimal measure to improve safety of medicines use., *Expert opinion on drug safety*, 19, (6), 2020, p649 – 652 DOI: 10.1080/14740338.2020.1751119
22. Bond, L., Carroll, R., Mulryan, N., O'Dwyer, M., O'Connell, J., Monaghan, R., Sheerin, F., McCallion, P., & McCarron, M., Biopsychosocial factors associated with depression and anxiety in older adults with intellectual disability: results of the wave 3 Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing., *Journal of intellectual disability research: JIDR*, 64, (5), 2020, p368-380 DOI: 10.1111/jir.12724



Appendix

Oral Presentations

Between 2017 and 2021, TCAID has issued **63 oral presentations**. 2020/2021 oral presentations were:

1. Fallon, M., McGlinchey, E., McCallion, P. & McCarron, M., Developing A Biopsychosocial Model of Cognitive Decline in People Ageing with Intellectual Disability, IASSIDD Virtual 2021, Amsterdam, the Netherlands, 6-8th July 2021, 2021
2. Lynch, L., McCallion, P., McCarron, M. and Burke, E., Examining the sedentary behaviour levels among older adults with intellectual disability, Journal of Applied Research in Intellectual Disabilities, 6th IASSIDD Europe Congress: Value Diversity, Amsterdam, The Netherlands, 5th – 8th July 2021, 34, (5), Blackwell Publishing LTD, 2021, pp1181 – 1371
3. Chen, S., McCarron, M., McCallion, P. and Burke, E., The use of Timed up and Go: Identifying mobility issues among adults with intellectual disability, Journal of Applied Research in Intellectual Disabilities, 6th IASSIDD Europe Congress: Value Diversity, Amsterdam, The Netherlands, 5th – 8th July 2021, 34, (5), Blackwell Publishing LTD, 2021, pp1181 – 1371
4. Molloy, R., McCarron, M., McCallion, P. and Burke, E., A longitudinal exploration of the foot health status of older adults with intellectual disability, Journal of Applied Research in Intellectual Disabilities, 6th IASSIDD Europe Congress: Value Diversity, Amsterdam, The Netherlands, 5th – 8th July 2021, 34, (5), Blackwell Publishing LTD, 2021, pp1181 – 1371
5. Donohoe, N., McCarron, M., McCallion, P. and Burke, E., A novel approach to engaging people with intellectual disability as contributors in research, IASSIDD 6th European Congress, Value Diversity, Amsterdam, The Netherlands, 5th – 8th July 2021, 2021, IASSIDD
6. Flannery, F., Sheerin, F., McCallion, P., Eustace-Cook, J., The impact of COVID-19 on the mental health and well-being of adults with an intellectual disability, THEconf2021: Transforming healthcare in a changing world: new ways of thinking and working, Trinity College Dublin, 10th and 11th March, 2021.
7. Fallon, M., McGlinchey, E., McCallion, P., & McCarron, M., Developing a biopsychosocial model of cognitive decline in people ageing with intellectual disability, Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
8. Wormald, A., McCallion, P., & McCarron, M., A life without loneliness: What results from the IDS-TILDA tell us is the best way to avoid loneliness in the lives of older people with an intellectual disability, Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
9. McCarron, M., McCausland, D., Allen, A., Luus, R., & McCallion, P., The impact of the COVID-19 crisis for older people with an intellectual disability in Ireland, Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
10. McCausland, D., McCallion, P., Murphy, E., Luus, R., & McCarron, M., The impact of the COVID-19 crisis on the social inclusion and well-being of older people with an intellectual disability in Ireland, Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
11. Molloy, R., Burke, E., McCallion, P., & McCarron, M., A descriptive quantitative exploration of the foot health status of older adults with intellectual disability in Ireland over 10 years., Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
12. Lynch, L., McCarron, M., McCallion, P. & Burke, E., Sedentary behaviour levels in adults with an intellectual disability: a systematic review, Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', 9th - 11th March, 2021
13. McGlinchey, E., McCallion, P., & McCarron, M., Patterns of onset of dementia and epilepsy in adults with Down syndrome: Findings from IDS-TILDA., Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021

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Oral Presentations

14. Monaghan, R., O'Dwyer, M., McCallion, P., McCarron, M., & Henman, M., The relationship between anti-epileptic drug load and behaviours that challenge in older adults with intellectual disability and epilepsy., Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
15. Monaghan, R., O'Dwyer, M., Luus, R., Mulryan, N., McCallion, P., McCarron, M., & Henman, M., Anti-epileptic drugs, seizures, and effect of co-administration of potential seizure threshold lowering psychotropic drugs in adults with epilepsy & intellectual disability., Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 2021
16. McDermott, S., O'Donovan, M-A., McCarron, M., McCallion, P., Lynch, L., & Burke, E., Training Older Adults with intellectual disabilities (ID) as Physical Activity leaders 2020 (PPALS2), Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
17. Murphy, E., McCausland, D., Korfage, I., Flygare Wallen, E., Koster, R., McCallion, P., & McCarron, M., Digi-ID: Digital Skills education to support better health and well being and social inclusion outcomes for adults with intellectual disabilities (ID), Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
18. Dee, B., Burke, E., Romero-Ortuno, R., McCallion, P., & McCarron, M., Exploring a Social Conceptualisation of Frailty among Older Adults with an Intellectual Disability, Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
19. Burke, E., Carroll, R., Walsh, J., McCallion, P., & McCarron, M., An exploration of the association between bone health and hand grip strength among older men with intellectual disability, Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
20. Reilly, E., Carroll, R., McCallion, P., McCarron, M., & Burke, E., The impact of ageing for people with down syndrome over the age of 40-years living in Ireland. A 10-year longitudinal follow-up, Trinity Health and Education International Research Conference 2021 (THEconf2021): 'Transforming healthcare in a changing world: new ways of thinking and working', Dublin, 9th - 11th March, 2021
21. Tuffrey-Wijne, I., Dholander, N., Forrester-Jones, R., Westergård, B-E., Karbasi, C., Oliver, D., Abu-Saad Huijjer, H., Uitdehaag, M., Echteld, M., Groot, M., McCarron, M., McCallion, P., Schäper, S., Todd, S., Wark, S., Roemer, A. & Previous, K., Palliative and End-of-life Care, People with IDD & Covid-19 (PEPIC-19): an international survey, Journal of Applied Research in Intellectual Disabilities, 6th IASSIDD Europe Congress Value Diversity, Virtual, 6th July - 8th July, 34, (5), Blackwell Publishing LTD, 2021, pp1468 – 1371



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The Intellectual Disability Supplement to
Irish Longitudinal Study on Ageing
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