



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

CHRISTMAS NEWSLETTER 2022



GREETINGS FROM PROFESSOR MARY MCARRON, PRINCIPAL INVESTIGATOR & THE TEAM

I hope this letter finds you happy, healthy and looking forward to Christmas. I am pleased to let you know that 2022 has been another very busy year for the IDS-TILDA team and the Trinity Centre for Ageing and Intellectual Disability. This newsletter includes highlights from a very productive year.

We are now into the fifth wave of IDS-TILDA which includes the IDS-TILDA Health Fair. The IDS-TILDA team may have been in touch with you already to arrange your appointments, while others will meet with the IDS-TILDA team in the New Year. We hope it will be an interesting and enjoyable experience for each of you, and as many of you as possible can take part.

A big thank you to everyone taking part in Wave 5 and also to family members, staff and service providers who give their time to support the study. As always, your involvement is central to the ongoing success of IDS-TILDA.

As we look forward to Christmas, we hope that you are planning to celebrate and that you will enjoy this holiday season. I wish you a Happy Christmas and a wonderful New Year. May 2023 be especially joyful for you, your family and friends. Thank you for your continued support.

IDS-TILDA IS LOOKING FOR NEW PARTICIPANTS - JOIN US!



We have had a terrific response to the Wave 5 IDS-TILDA recruitment drive and now have more than 100 new IDS-TILDA participants on board. We will be continuing recruitment in the New Year, so please encourage your friends to take part. We are looking in particular for people with mild to moderate ID aged 38-50. If you have any questions about joining the IDS-TILDA study, please contact: Ms. Margaret Haigh, Project Manager, at 01 896 3187 or Professor Mary McCarron, Principal Investigator, at 01 896 3186.



IDS-TILDA WAVE 5

IDS-TILDA Wave 5 Field Researcher Training

IDS-TILDA Wave 5 training for 28 field researchers took place in Dublin over three days in August. Training was delivered by the core and wider IDS-TILDA team. People with ID played a key role in assessing the skills of the interviewers as part of this training. A big thank you to our PPI contributors who played a vital role in training our field researchers.



Left: Mr Michael Foley, Programme Manager PPI Ignite and the PPI Panel (Carmel Lynch, Jonathan Roche, Lorraine Keating, and Mei Lin Yap). **Right:** PPI Contributor, Lorraine Keating, assessing the interviewing skills of our field researchers.

IDS-TILDA Wave 5 Health Fair Training

September saw the beginning of Wave 5 of IDS-TILDA and because COVID-19 cut the inclusion of the objective health measures short in Wave 4 the team decided to include the 'Health Fair' in Wave 5. The Health Fair provides the participants with the opportunity of engaging with a comprehensive health assessment from getting your fitness checked, to seeing how strong your bones are to having a comprehensive heart health check. There are over 26 assessments and those taking part can do all or what they feel they are able to do, we would encourage you all to have a look. This year we have secured dedicated space to conduct our Health Fair in Trinity College and are inviting all the participants to come visit us in TCD, enjoy lunch and a visit to the Old Library and have their health assessment complete as part of the study. We know this won't suit everyone, but we are doing our best to ensure everyone is included so we have accessible changing facilities, wheelchair parking and a relaxation space. We have trained four very experienced nurses who are conducting the assessments and with the help of independent advocates who piloted the assessments we are ready to receive all participants. The nurses will be delighted to see you all on your dedicated day, so keep an eye out for your invite the team will be in touch with you all.



Left: Ms Jean Moynihan, Research Nurse Manager and IDS-TILDA Participant **Right:** Ms Jean Moynihan (Research Nurse Manager), Mr Fergal Guihen, Ms Tania Bautista, & Ms Mary Carroll (Research Nurses), Ms Louise Lynch, (Research Assistant) and Dr Eilish Burke (Health Fair Lead)



RESEARCH

INTERNATIONAL COLLABORATION OF TRINITY CENTRE FOR AGEING AND INTELLECTUAL DISABILITY AND ERASMUS MC

In November, TCAID hosted a team from the Healthy Ageing and Intellectual Disability (HA-ID) study at Erasmus MC in the Netherlands. The aim of the visit was to share longitudinal research study findings and identify future opportunities for collaboration. A Memorandum of Understanding was signed with Erasmus MC.



Left: Visitors from Erasmus MC, Netherlands with the TCAID team.



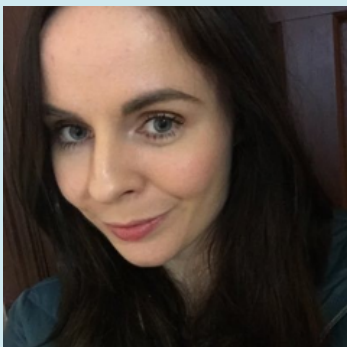
Right: Dr Dederieke Maes-Festen, Chair of Intellectual Disability Medicine at Erasmus MC and Prof Mary McCarron, Director, Trinity Centre for Ageing and Intellectual Disability sign a Memorandum of Understanding.

CONGRATULATIONS TO OUR IDS-TILDA RESEARCHERS WHO WERE RECENTLY AWARDED THEIR PHDS



Dr Brendan Dee

'Characteristics of Social Frailty among Adults with an Intellectual Disability'



Dr Rosemary Monaghan

'Patterns of medication use associated with mental health, behavioural and neurological problems in older people with Intellectual Disability.'

JUDGING THE ENTRIES

We were delighted to receive so many wonderful pictures for our Christmas Card competition. We had more than 700 entries! A big thank you to everyone who entered our competition.

Our panel of PPI contributors had a difficult job choosing just three artworks from the wonderful pieces received.



Our PPI panel judging the Christmas card entries.

Our winners!



Left: The winning entry in our Christmas card competition came from Michael Campbell, Eve Estuary Centre, Swords.

Centre: Second place went to Rachel Coen, Stewarts Care, Dublin.

Right: Our third place winner was Michael Tighe, Carlanstown, Kells.

IASSIDD FELLOWSHIP

Prof Mary McCarron was awarded the honour of Fellow of The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) by the Council and Awards Committee.

This is a clear testament to Prof. McCarron's exemplary research accomplishments and outstanding scientific reputation within the international research community in the field of Intellectual Disability.



Prof. Mary McCarron

SOCIETAL IMPACT

Prof Mary McCarron was selected as the winner of the Societal Impact Award at The Trinity Innovation Awards. The Societal Impact Award recognises academics "whose research has had a significant impact for Trinity, society and industry".

Prof. McCarron is recognised for leadership and commitment to driving change in healthcare practice and national policy for persons with an Intellectual Disability.



Prof. Mary McCarron and Prof. Linda Doyle, Provost, Trinity College Dublin

DEAN'S RESEARCH INITIATIVES

Dr Andrew Wormald was selected as one of the seven winners of the Dean's Research Initiatives Fund 22-23 for his proposal on 'Loneliness as experienced by people with an intellectual disability (LEID); Theoretical framework development to support future intervention studies.'



Dr. Andrew Wormald and Prof. Brian O'Connell, Dean of the Faculty of Health Sciences

THE MISSING BILLION INITIATIVE

Dr Eilish Burke's MOOC on 'Improving Health Assessments for People with an Intellectual Disability' has been included as an example of inclusive good practice on health workers training in the "Reimagining Health Systems that Expect, Accept, and Connect 1 Billion People with Disabilities" report.



Dr. Eilish Burke

RESEARCH OUTPUTS

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>

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>

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

Lynch, L., McCarron, M., Eustace-Cook, J., Burke, E. & McCallion, P., 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>

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>

Dennehy H., Allen A.P., McGlinchey E., BATTERY 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>

You can reach the IDS-TILDA Team at:

Phone: (01) 896 3186 or (01) 896 3187

Email: haighm@tcd.ie

Website: <http://www.idstilda.tcd.ie/>

Twitter: [@idstilda](https://twitter.com/idstilda)/@ageingwithID

Address: IDS-TILDA, Trinity College Dublin, Chemistry Extension, Lincoln Gate, Dublin 2