



## IDS-TILDA Newsletter

December 2020



### ANNUAL MESSAGE PROFESSOR MARY MCCARRON PRINCIPAL INVESTIGATOR



This has been a year like no other year. When we started 2020, the IDS-TILDA team were interviewing people and inviting others to take part in our Health Fair for Wave 4. Then, in March, face-to-face meetings had to stop. Instead, we started calling people on the telephone or over Zoom. By the autumn, we had finished all of our data collection for Wave 4. We have now produced our first Wave 4 report, which looks at COVID-19.

Across the Intellectual Disability sector, everyone adapted to keep infections down and showed great strength and creativity in the face of the pandemic. For our part, we prepared easy-read information about COVID-19, created a training course for healthcare staff, ran webinars to support services, and advised Government where we could.

In other positive news, we were able to launch the National Intellectual Disability Memory Service in Tallaght University Hospital which is now seeing people, so we have clearly been busy!

As we head towards Christmas, we hope that you are planning to celebrate and that you will enjoy this holiday season. We also wish you happiness for 2021.

*Prof. Mary McCarron*

### IDS-TILDA WAVE 4

We are delighted to have now completed the IDS-TILDA Wave 4 interviews. In all, 739 participants were interviewed, many of whom also took part in the IDS-TILDA Health Fair.

Some of our participants are new to IDS-TILDA. A total of 233 participants joined the study as part of our Wave 4 recruitment drive. We hope that you enjoyed taking part in Wave 4 of IDS-TILDA and we were delighted to meet so many of you. A big thank you to everyone who took part and also to family members, staff and service providers who gave their time to support the study.

We are now examining the information we collected and are excited to start sharing our findings with you. Our first report looks at the experiences of people with an intellectual disability during COVID-19 and is based on responses to the questions we asked our participants over the summer. We are supplying an easy-read report of the findings with this newsletter.

In the New Year, we plan to produce further Wave 4 reports which we will let you know about soon.

# News & Events



From left: Lucy Nugent, CEO, Tallaght University Hospital; Prof Mary McCarron, Executive Director, NIDMS; Prof Orla Sheils, Dean of Faculty of Health Sciences, Trinity College Dublin; Prof Sean Kennelly, Clinical Director, NIDMS; Natalya Jackson, CEO, Daughters of Charity Disability Support Service.

We have signed a Memorandum of Understanding for the National Intellectual Disability Memory Service (NIDMS) with our partners. NIDMS provides access to specialist assessment and comprehensive diagnostic workups for people with intellectual disability worried about memory loss. NIDMS operates through a central coordinating Memory Clinic in Tallaght University Hospital, with satellite services. While the service is free, a referral from your GP or a doctor is required to access the service. To contact NIDMS, call Sharon Mulligan on (01) 414 2577 or email Sharon.Mulligan@tuh.ie.

Alan Tarpey, an artist from Roscommon, presents Prof Mary McCarron and TCAID with his commissioned painting.



Get Wise is co-creating online health education materials with people with intellectual disabilities, funded by EIT Health with partners in the Netherlands.

PPALs 2, funded by EIT Health, has provided people with intellectual disabilities with the skills they need to lead physical activities within their groups in Ireland, Spain and Germany. It will now be sustained in the longer term through Age & Opportunity.



An eQuilt of images created by people in Ireland, Spain and the Netherlands was part of the EIT Health SOOTHE project, exploring responses to mental health and well-being in people with an intellectual disability.

## IDS-TILDA IS ADVANCING AGEING AND INTELLECTUAL DISABILITY RESEARCH

The IDS-TILDA team is advancing our understanding of ageing with an intellectual disability. Our PhD and MD candidates are currently investigating the following topics:

- **Maureen D'Eath:** A longitudinal study of the health and wellbeing of carers of older people with intellectual disability.
- **Brendan Dee:** Determinants of frailty among older adults with an intellectual disability.
- **Marianne Fallon:** Exploring a biopsychosocial model of risk and protective factors for dementia in an Irish population with intellectual disability.
- **Fidelma Flannery:** The impact of COVID-19 on the mental health and wellbeing of older adults with an intellectual disability.
- **Dorothy Hanly:** Prevalence of hypertension and risk factors for hypertension in people ageing with an intellectual disability in Ireland.
- **Louise Lynch:** Sedentary behaviour and physical activity levels in people with an intellectual disability and how this affects their health and wellbeing.
- **Rosemary Monaghan:** Patterns of medication use associated with mental health, behavioural and neurological problems in older people with intellectual disability.
- **Judy Ryan:** An exploratory study of obesity and people with an intellectual disability on the island of Ireland.
- **Dr Karen Ryan:** A repeated cross-sectional, mixed methods study of the palliative care needs of people with intellectual disability in Ireland and of staff responses to those needs.

IDS-TILDA supports career development for researchers at all stages. To learn more about research opportunities, please contact Ms. Margaret Haigh, Project Manager, at [haighm@tcd.ie](mailto:haighm@tcd.ie).

# What IDS-TILDA Found Out

**IDS-TILDA WAVE 4 REPORT SHOWS SMALL NUMBER OF COVID-19 INFECTIONS AND NO DEATHS. COVID-19 WELL MANAGED IN INTELLECTUAL DISABILITY SERVICES.**

Thank you to everyone who answered our questions during Wave 4 of IDS-TILDA.

We have now produced our first report from this wave: 'The Impact of COVID-19 on People Ageing with an Intellectual Disability in Ireland'.





# Christmas Celebrations

## CHRISTMAS CARD COMPETITION

Once again, we were delighted to receive so many wonderful pictures for our Christmas Card competition. We had entries from 776 individuals, so it was a difficult job to choose just three artworks from the wonderful pieces received. Our judging panel loved John Lyons' painting of Santa caught on a railing. We really liked that Santa was wearing his face mask, too, and staying safe, even if he was in a spot of bother.

## SAVING CHRISTMAS

We know that Christmas will be a little bit different but we hope that everybody will have a chance to celebrate the end of 2020 and to look forward to the New Year. In November, we hosted a discussion with services called 'Saving Christmas' where ideas were shared. We have also set up our own online Advent Calendar full of songs, jokes, activities and ideas for getting into a Christmas mood. Take a look here: [www.tcd.ie/tcaid/xmas/](http://www.tcd.ie/tcaid/xmas/)

## THIS YEAR'S WINNERS



Left: Winning Entry in our Christmas Card Competition, by Artist John Lyons, Galway; Top Right: Second Place Winner, by Artist Kevin Malone, Dublin; and Bottom Right: Third Place Winner, by Artist Tony McWalter, Galway



## KEEP IN TOUCH

You can reach the IDS-TILDA Team at:

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