



IDS-TILDA Newsletter

December 2018



ANNUAL MESSAGE PROFESSOR MARY MCCARRON PRINCIPAL INVESTIGATOR

It is hard to believe it has been 10 years since IDS-TILDA started. We have achieved so much together! This happened because people with an intellectual disability, their families and key workers, along with government and researchers, felt it was important for Ireland to advance policies, services and practices that support happy, healthy ageing for people with an intellectual disability.

Please visit our website at www.idstilda.tcd.ie to watch the videos, view the infographics, read the accessible reports and take a look at the research opportunities. A very interesting picture is emerging on what it means to age with an intellectual disability in Ireland and it's one that people around the world are following.

We are now getting ready for Wave 4. We will also be holding the IDS-TILDA Health Fair in 2019 and we hope this will be, once again, an enjoyable experience. For families and key workers, we will be working with you to arrange appointments.

Lastly, I want to acknowledge the 95.5% response rate from participants in Wave 3 and to close with a word of thanks to each of you and the entire IDS-TILDA team for making 2018 such a success.

I wish you a very Happy Christmas and look forward to the New Year.

LET'S TALK ABOUT IDS-TILDA RESEARCH

The IDS-TILDA team has recently produced a video called *Ageing with PrIDE – 10 Years of IDS-TILDA*. Funded by the Health Research Board, this documentary film follows Mei Lin Yap, a woman with Down syndrome, as she explores what it is like to age in Ireland. The film highlights key findings from three waves of IDS-TILDA.

In the New Year, IDS-TILDA will be organising viewing parties around the country. We want to celebrate the contribution of participants, families and staff to IDS-TILDA and share what we have learned together so far. We also want to speak with you about the exciting developments coming in Wave 4.

If you would like to find out more about having a viewing party, please contact Ms. Margaret Haigh, IDS-TILDA Project Manager, at idstilda@tcd.ie or (01) 896 3187.



Above: Mei Lin Yap takes part in chair yoga at Prosper Fingal during the filming of *Ageing with PrIDE - 10 Years of IDS-TILDA*

News & Events

IDS-TILDA EMPOWERS PEOPLE WITH ID TO BECOME LEADERS IN PHYSICAL ACTIVITY

It is very important to be active. Playing games and sports make a big difference to your health and your mood. To encourage more people to get active, IDS-TILDA was involved in a project this year called PPALS. PPALS gave participants the encouragement they need to lead and run sport and physical activity sessions with groups. We trained 15 people as Physical Activity Leaders (PALs) in Ireland, with more in Spain.

To celebrate the end of the project, we held a PPALS Games morning in Trinity College Dublin Sport Centre on November 30th. The 50 players in the Games came from: Daughters of Charity; KARE; St Michael's House; Stewarts Care; and Sunbeam House Services. Minister Catherine Byrne TD, Minister for Health Promotion, and rugby player Rob Kearney were there to award the certificates to the PPALS and to join in the celebration. The PPALS hope to deliver more fun games and activities back in these services into the future, and we hope that we can roll this programme out to more centres around the country.

The project was run with Trinity College Dublin, Age & Opportunity and the University of Barcelona and was funded by the EIT-Health Campus, a programme of the European Commission.



Above: PPALS trained 15 Physical Activity Leaders to run fun games and sports with their peers through a collaboration between Trinity College Dublin, Age & Opportunity, the University of Barcelona and funded by EIT Health. **Below:** Rugby star Rob Kearney celebrates the year-long physical activity leadership project.



IDS-TILDA WAVE 4 LAUNCHES IN 2019

Wave 4 data collection will begin in September 2019. We will be contacting existing participants in 2019 to schedule your interview and a Health Fair. We look forward to seeing you again. For Wave 4, we will also be recruiting new participants into IDS-TILDA. We will begin our recruitment drive in the Spring of 2019.



WHAT IDS-TILDA PARTICIPANTS CAN EXPECT IN 2019

First, a questionnaire will be sent to you, which you will complete before your face-to-face interview. Then, the IDS-TILDA team will visit you for a face-to-face interview and collect your questionnaire. This will be followed by a Health Fair which includes a health assessment. We're looking forward to seeing you in 2019.

Happy, Healthy Ageing: What You Can Do Today

As 2018 comes to a close and 2019 begins, let's make health and happiness a priority. We each have the opportunity to make healthier choices every day. Take a look at the ideas below and see if you can choose at least one recommendation for better health and well-being in 2019. Remember to check with your doctor before beginning a new exercise routine.

Take Care of Your Teeth & Gums

- Cut down on sugary foods and drinks.
- Brush your teeth twice per day.
- If you find brushing or flossing difficult, ask for help.
- Visit your dentist at least once per year.

Try Something New

- Gardening reduces stress and allows you to learn new skills.
- Yoga and chair yoga can reduce stress and improve strength and balance.
- New learning is good for your brain, so learn more about something that interests you.
- Ask your key worker about having new activities included in your daily routine.

Eat Well & Get Active

- Eat when you are hungry and watch your portion sizes.
- Aim for 30 minutes of physical activity every day, if possible.
- Dancing can be great fun with friends, so why not give it a try?
- Remember to have fun, as you are more likely to continue to exercise if you enjoy it.



Right: Mei Lin Yap learns strategies for oral health, brain health and physical health during the filming of the documentary, *Ageing with PRiDe - 10 Years of IDS-TILDA*. Athletes take part in the Physical Activity Leaders Program (PPALs) Games Day at Trinity College in November.

IDS-TILDA SPOTLIGHT: DR EILISH BURKE USSHER ASSISTANT PROFESSOR AGEING & INTELLECTUAL DISABILITY



Detecting poor health and supporting people with an intellectual disability in managing their health can be challenging for healthcare professionals. In 2018, I developed an online course, *Improving Health Assessments for People with an Intellectual Disability*, which has reached more than 3,000 healthcare professionals in 100+ countries through the FutureLearn platform.

Over three weeks, learners explored the inequalities that individuals with an intellectual disability experience that often obstruct their engagement in health assessment. They identified the changing landscape of healthcare for older people with an intellectual disability and learned how to communicate better. They shared best practices in developing accessible materials for health assessments. Underpinned by the IDS-TILDA study, this course is improving health assessments and has resulted in accessible materials in doctor's offices around the world.

IDS-TILDA SPOTLIGHT: DR EIMEAR MCGLINCHEY ATLANTIC FELLOW



In order to reduce the scale and impact of dementia, there is a need for collaboration across disciplines, sectors and countries. We also need to focus on prevention across the lifespan, rather than focusing on dementia solely as a disease of old age. My work, to date, has focused on delaying the early symptoms of dementia in people with Down syndrome through computerized cognitive training, focusing on executive functions. I want to further explore the area of prevention, particularly relating to early biomarkers of dementia.

During my fellowship at the Global Brain Health Institute, I have the opportunity to be part of a global discussion on brain health. I want to ensure that people with an intellectual disability are included in the agenda of positive ageing and are given the same opportunities as the general population to be included in research. If you would like to find out more about becoming involved in dementia research, please contact Eimear at mcgline@tcd.ie.

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

IDS-TILDA IS ADVANCING AGEING AND INTELLECTUAL DISABILITY RESEARCH

The IDS-TILDA team is pleased to acknowledge the following researchers who were awarded degrees in 2018. They have advanced our understanding of ageing with an intellectual disability and have contributed significantly to the IDS-TILDA study. Congratulations to:

- Andrew Wormald, PhD
- Eilish King, MSc
- Michael Foley, MSc
- Sharon Ellis, MSc
- Mary Cuneen, MSc

IDS-TILDA supports career development for researchers at all stages. To learn more about research opportunities, please contact Ms. Margaret Haigh, Project Manager, at idstilda@tcd.ie.

AWARDS

Congratulations to Hadiyah Almutairi, who won the prize for Best Poster in Medicines and Health at the FIP 2018 World Congress of Pharmacy and Pharmaceutical Sciences in Glasgow in September.

Congratulations, also, to Sharon Ellis who was awarded Distinction and first place in Masters in Dementia at the End of Year School of Nursing and Midwifery Awards.

2018 IDS-TILDA CHRISTMAS CARD DESIGN

The 2018 IDS-TILDA Christmas Card cover was designed by Jason Carroll and the inside image was designed by Stephen Lawton. On behalf of the IDS-TILDA Team, thank you for the lovely artwork which has been shared widely. More than 70 entries were received this year. Thank you to all who participated.

KEEP IN TOUCH

You can reach the IDS-TILDA Team at:

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