



## IDS-TILDA Newsletter

December 2019



### ANNUAL MESSAGE PROFESSOR MARY MCCARRON PRINCIPAL INVESTIGATOR

I hope this newsletter finds you happy, healthy and enjoying the holidays. I am so pleased to share with you that 2019 has been a wonderful year for the IDS-TILDA team and the Trinity Centre for Ageing and Intellectual Disability. This newsletter includes highlights from a very productive year.

First, we are now into the fourth wave of IDS-TILDA. Wave 4 includes the IDS-TILDA Health Fair and we hope it will be, once again, an enjoyable experience for each of you. The IDS-TILDA team has been in touch with families and key workers, arranging appointments. Some of you may have already had your health assessment, while others will meet with the IDS-TILDA team in the New Year.

In other exciting news, I am delighted to announce that we are launching the National Intellectual Disability Memory Service. Supported by the Dormant Accounts Fund and the National Dementia Office, this is a two-year project to create the first national memory service for people with an intellectual disability with satellite centres throughout the country, opening in January 2020. A memory clinic will be located at Tallaght University Hospital and developed in partnership with the Daughters of Charity Service and the Trinity Centre for Ageing and Intellectual Disability.

As always, your involvement has been central to these successes. I wish you a Happy Christmas and a wonderful New Year. May 2020 be especially joyful for you, your family and friends. Thank you for your continued support.

### IDS-TILDA WAVE 4 RECRUITMENT HAPPENING NOW - JOIN US!

We have had a terrific response to the Wave 4 IDS-TILDA recruitment drive and now have more than 150 new IDS-TILDA participants on board. We will be continuing recruitment in the New Year, so please encourage your friends to take part if they have received an invitation from IDS-TILDA.

It is important that we have representation from people with all levels of ID - from mild to profound - so that we understand ageing for this diverse population. 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.



**Above:** IDS-TILDA Wave 4 Training for 24 field researchers took part in Dublin over three days. People with ID assessed the skills of interviewers as part of this training.

# News & Events

## LAUNCHING NATIONAL POSITIVE AGEING INDICATORS FOR PEOPLE WITH ID

The IDS-TILDA team collaborated with the Department of Health, through the Healthy and Positive Ageing Initiative, to develop national positive ageing indicators for people with an intellectual disability. IDS-TILDA worked with people with an intellectual disability, family members, academics and researchers, service providers and advocacy services to develop specific positive ageing indicators. The indicators cover a wide range of factors associated with positive ageing, from social, health, security and financial perspectives. These indicators can now be used to measure whether changes in policy are having an impact. Importantly, positive ageing indicators are a useful step in ensuring that people with an intellectual disability are included in the national conversation on ageing.



*Above: The IDS-TILDA Team and representatives from the Department of Health at the launch of the National Positive Ageing Indicators for People with ID.*



*Above: Minister Finian McGrath, Professor Mary McCarron and Mei Lin Yap at the International Symposium on Down syndrome and dementia.*

## IDS-TILDA ATTRACTING INTERNATIONAL RECOGNITION

The IDS-TILDA Team presented numerous research topics during the 16<sup>th</sup> World Congress of the International Association for the Scientific Study of Intellectual and Development Disabilities (IASSIDD) in Glasgow, Scotland, in August 2019. The IASSIDD Congress is the leading international research and practice meeting in the field of intellectual and developmental disabilities. With more than 1,500 participants, the IDS-TILDA team engaged with health and social care workers, educational practitioners, policy makers, family carers, academics, third sector organisations, as well as people with intellectual disability involved in research. The IASSIDD World Conference theme was Future4All and IDS-TILDA research was included throughout, gaining significant international attention.



*Above: The IDS-TILDA Team presents research and translational activities at the 16<sup>th</sup> IASSIDD Congress in Glasgow, Scotland, August 2019.*



# Honours & Awards

## PROFESSOR MARY MCCARRON WINS 2019 HEALTH RESEARCH BOARD IMPACT AWARD

The inaugural Health Research Board Impact Award (2019) was presented to Professor Mary McCarron. The award recognises how her research has transformed the health, care and living environments for people ageing with an intellectual disability.

Advancing authentic public engagement and involvement, Professor McCarron was recognised for her dedication to ageing and ID research. The data gathered over the first ten years of IDS-TILDA shows that ageing is so similar and yet so different in many ways for people with ID. The data also provides a true understanding of how lives and chronic conditions change over time. In addition to excellent and rigorous research, Professor McCarron's numerous impacts were shared including:

- Working with people with ID, their families, carers and service providers to advance co-created research;
- Improving health outcomes for people with ID;
- Improving health and social care services for people with ID;
- Informing policies at local, national and international levels; and
- Building a research workforce with national and global significance across disciplines and sectors.



**Above:** Professor Mary McCarron accepts the inaugural Health Research Board Impact Award (2019). **Below Left:** Dr Eilish Burke accepts the Dean's Award for Teaching Innovation. **Below:** The IDS-TILDA Team received the Registrar's Civic Engagement Award (2019).



## PROFESSOR EILISH BURKE HONOURED WITH DEAN'S INNOVATION IN TEACHING AWARD

This award went to Dr Éilish Burke for incorporating the 'Health Assessment for People with Intellectual Disability' Massive Open Online Course into the on-campus learning experience for Junior Fresh students from the School of Nursing and Midwifery intellectual disability nursing programme. This included access to the Simulation Suite at St James's Hospital as well as online and in-person learning.

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

## IDS-TILDA RECOGNISED WITH REGISTRAR'S 2019 CIVIC ENGAGEMENT AWARD

The Registrar's Civic Engagement Award aims to recognise exceptional contributions made by staff to civic engagement, advancing Trinity College's goal of benefiting the public good. The award acts as an inspiration to the College community and highlights valuable activities. The 2019 Registrar's Civic Engagement award recognised the IDS-TILDA Team for building an inclusive research environment.



# Research Spotlight

# IDS-TILDA

## IDS-TILDA SPOTLIGHT: DR DARREN MCCAUSLAND



As the Theme Lead for Social and Community Research, Darren looks at social inclusion and community participation for older adults with intellectual disabilities. His work in 2019 included analysis of IDS-TILDA data on a range of topics including:

- Use of public transport and other travel options by older people with intellectual disabilities.
- Employment and other types of occupational activity including day services.
- The nature and quality of friendship for this population.
- The impact that technology use may have on social inclusion.

Other projects include:

- The impact of person-centred planning on community integration for adults with intellectual disabilities.
- An action research study to enhance future care planning for adults with intellectual disabilities and family carers.

In 2020, Darren will lead a HSE study of the lived experience of de-congregation for adults with an intellectual disability. You can reach Darren at 01 896 2485 and [dmccaus@tcd.ie](mailto:dmccaus@tcd.ie).

## 2019 IDS-TILDA CHRISTMAS CARD DESIGN

The 2019 IDS-TILDA Christmas Card cover was designed by Aidan Forrister, Mill Lane Training Centre, Stewarts Care, Palmerstown; the inside image was designed by Theresa McGuigan, St John of God, Kenmare; and the back cover was designed by Susan Dale, Coach House, Stewarts Care, Palmerstown. On behalf of the IDS-TILDA Team, thank you for the lovely artwork which has been shared widely. More than 150 entries were received this year. Thank you to all who participated.



## KEEP IN TOUCH

You can reach the IDS-TILDA Team at:

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

**Email:** [haighm@tcd.ie](mailto:haighm@tcd.ie)

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

**Twitter:** @idstilda

**Address:** IDS-TILDA, Trinity College Dublin, Office 1.25  
1st Floor, Chemistry Extension, Lincoln Gate, Dublin 2

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

## 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 candidates are currently investigating the following topics:

- **Hadiah Almutairi:** The prevalence, effectiveness and side effects of gastro-intestinal medications among adults with an intellectual disability.
- **Maureen D'Eathe:** A longitudinal study of the health and wellbeing of carers of older people with intellectual disability.
- **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.
- **Brendan Dee:** Understanding frailty in older adults with an intellectual disability.
- **Louise Lynch:** Sedentary behaviour and physical activity levels in people with an intellectual disability and how this affects their health and wellbeing.
- **Fidelma Flannery:** The role of subjective vitality in the relationship between depression and physical activity in older adults with intellectual disability.
- **Dorothy Hanly:** Prevalence of hypertension and risk factors for hypertension in people ageing with an intellectual disability in Ireland.
- **Marianne Fallon:** Exploring a biopsychosocial model of risk and protective factors for dementia in an Irish population with intellectual disability.

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).