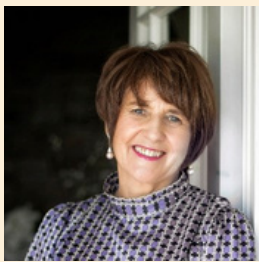


# IDS-TILDA SUMMER NEWSLETTER 2024



## GREETINGS FROM PROF. MARY MC CARRON, PRINCIPAL INVESTIGATOR & THE IDS-TILDA TEAM

We are delighted to send you our IDS-TILDA summer newsletter which we hope you enjoy reading. As you will see, the IDS-TILDA team here at the Trinity Centre for Ageing and Intellectual Disability has been as busy as ever. Following the hugely successful launch of our Wave 5 report, we continue to share our findings based on the valuable information that you gave us in Wave 5.

As always, your involvement has been central to the ongoing success of IDS-TILDA. A big thank you to all our participants and to family members and support staff who give their time so generously. Your support has been so important to the success of IDS-TILDA and we thank you for your ongoing commitment to our study.

We hope you enjoy the rest of the Summer and we look forward to seeing you again soon.

*Prof. Mary McCarron*

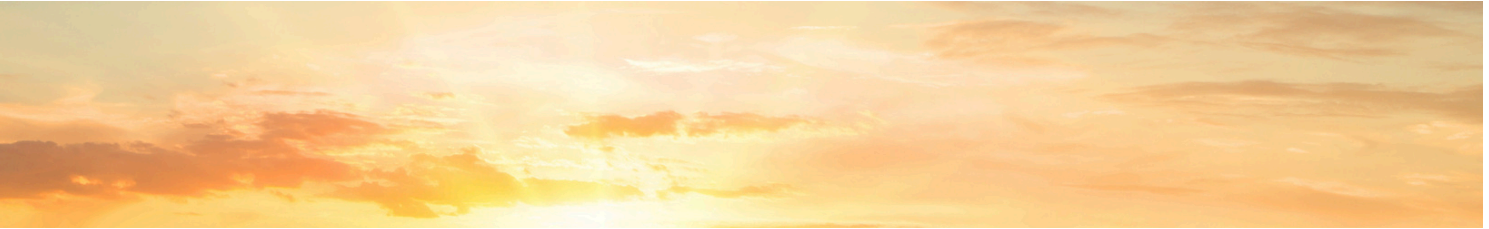
## TCAID AT 16TH INTERNATIONAL DEMENTIA CONFERENCE, MULLINGAR

BY MS MEI LIN YAP  
AMBASSADOR LIAISON OFFICER

I got the wonderful opportunity to speak at the Engaging Dementia Conference in Mullingar on 8th May alongside Professor Mary McCarron. On the day, myself and Prof McCarron got down to Mullingar in time for tea and coffee. It was a nice experience mixing with the other delegates. I got to meet Minister Mary Butler, it was great to be in her presence! After that the presentations started. My presentation was after Prof McCarron's and she is a tough act to follow! She was presenting on the Post-Diagnostic Supports for Dementia. After that I got up to speak. It was an honour to follow on from Prof McCarron who is such an expert in her field. I may not be an expert in research but I am an expert in my own disability and I love speaking from my perspective. I love what I do and I put my heart and soul into what I speak. I summarised the post-diagnostic supports from my own point of view and spoke about what I do to keep my brain healthy. It was an amazing experience.



*Left to right: Prof Mary McCarron, Ms Mei Lin Yap, Minister Mary Butler TD*



## Empowering voices: women with Down syndrome speak on Health

To mark World Down Syndrome Day 2024, at the Trinity Centre for Ageing and Intellectual Disability we decided to focus on women with Down syndrome to raise awareness of the poor health outcomes often faced by these women.

We asked women with Down syndrome from all over the world to tell us what health means to them. We wanted to hear from the women themselves how they take care of their own health and what is important to them and how they choose to end the stereotypes each day. Based on what they told us, we put together a video which we hope you enjoy watching.

You can scan here to watch the video on Youtube.



## Inaugural lecture at Queen's University Belfast by Professor Mary McCarron

Professor Mary Mc Carron was delighted to host her Inaugural Professorial Lecture at Queen's University Belfast on Tuesday 21st May 2024, entitled 'Leadership in Academia, Health Research and Health Care: Charting a Personal Journey'.

This lecture followed Professor McCarron's appointment as an honorary professor at Queen's School of Nursing and Midwifery last year. To celebrate the occasion and mark this major achievement, the University hosted distinguished guests from the Department of Health, the Health and Social Care Trusts as well as colleagues and students from the University.



Prof Mary McCarron with academics from Queen's University Belfast

*'It's a privilege to contribute to the academic community in this capacity and to be recognised as an honorary professor at Queen's School of Nursing and Midwifery. I look forward to continuing this journey of knowledge and discovery together.'*

## Research Participants Wanted



In March the Trinity Centre for Ageing and Intellectual Disability launched a new project called 'EuCan'. This project is funded by the Irish Cancer Society and aims to explore the barriers that people who are members of marginalised groups can face when getting a cancer diagnosis. The project will investigate any problems that exist for people when accessing cancer care, so others may learn from them. Recruitment of individuals with an intellectual disability will begin in the coming weeks. If you currently have cancer, or ever had cancer, we would love to hear from you! Please contact Shauna at [WALSHS89@TCD.IE](mailto:WALSHS89@TCD.IE) or [086 196 6824](tel:0861966824), to talk about taking part in the EuCan study.



## Optimizing oral health: Training and calibration of the Modified Oral Status Survey Tool

The Trinity Centre for Ageing and Intellectual Disability, in collaboration with the School of Dental Science at Trinity College Dublin, developed a data collection tool to collect important data regarding the oral health of people with intellectual disabilities. The Modified Oral Status Survey (MOSST) was used last year in the IDS-TILDA Wave 5 Health Fair. This showed that nurses and other non-dental professionals have the ability, once trained, to carry out a simple oral assessment.

In March, Katrina Byrne (RNID and IDS-TILDA PhD student) and Dr Caoimhin Mac Giolla Phadraig, (Assistant Professor in the School of Dental Science) led a training initiative on the MOSST for a group of nurses working in Intellectual disability services throughout Ireland.

This training is key to empower nurses and other frontline clinical professionals to collect valid and reliable data on oral health needs within their services.



Participants and attendees at the MOSST training day



## Building Circles of Support for People with Intellectual Disabilities

Our project called 'Building Circles of Support for People with Intellectual Disabilities' set out to showcase positive examples of support for individuals from their Circles of Support. It also aimed to highlight the strategies used to build and maintain those relationships. The project used research information to develop resources that can be used in person-centred planning processes. These resources include a downloadable booklet and videos featuring the lived experiences of six individuals with intellectual disabilities. The aim is for others to learn from the wonderful examples of supportive relationships demonstrated by the participants in these videos. All the resources and further information on this project can be found on our website if you scan here.



The project was led by a team from the Trinity Centre for Ageing and Intellectual Disability, which included Dr. Darren McCausland, Senior Research Fellow, and Ms. Iara Faria Synnott, Research Assistant. The team collaborated closely with Stewarts Care and received support from partners, including the HSE, the Federation of Voluntary Service Providers, and Temple University in the United States.



Participants in the Building Circles of Support video



## IDS-TILDA Easter card competition

We were delighted to receive so many wonderful pictures for our Easter Card competition. A big thank you to everyone who entered. Our panel of judges had a difficult job choosing just three winners but you can see the winning entries below.

*Congratulations!*



1st place

Donna Fusco, Sunbeam House Services, Wicklow



2nd place

Maureen Cullen, Sunbeam House Services, Wicklow



3rd place

Karen Vaughan, CoAction, Cork

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