



Trinity College Dublin Coláiste na Tríonóide, Baile Átha Cliath The University of Dublin



IDS-TILDA

EASTER NEWSLETTER 2022



GREETINGS FROM PROFESSOR MARY MCCARRON PRINCIPAL INVESTIGATOR

Whilst our suffering and loses during the pandemic will live long in our memories, Easter brings us hope and optimism being mindful that we still have to be cautious and mind ourselves. In our second COVID report, launched in January, we reported that most people had reported positive experiences during the pandemic which included: engaging in new activities, more rest/relaxation, more/better time with staff, and using technology to communicate.

Hopefully as services fully re-open we will see a continued drive to look at deepening and supporting the social connections of their users through supporting direct face to face contacts and technologies such as zoom.

I would like to thank all of you who have engaged with us during COVID-19, including our participants, your family members, support staff and services. As we hopefully move away from COVID-19, I believe that the work IDS-TILDA has done during this time will provide critical data to support the needs of people with intellectual disability.

I hope you all have a lovely Easter time and may Spring and Summer bring light, warmth and joy to all of our lives.

Pest. May M'Gum.

IDS-TILDA WAVE 5

The IDS-TILDA team are now very busy planning for Wave 5 of data collection. We have been running online focus groups to discuss what is important to participants in this and future waves. The outputs from these sessions will be used to enhance our Wave 5 questionnaire. It is important to us that the participant voice continues to be heard in the IDS-TILDA project.

In November we held a planning day and the team gathered in person and via zoom from around the world to discuss improvements to the data collection of the study. One of the major items to come out from this session was the recruitment of more participants into the study. Recruitment procedures will begin soon and we hope to start data collection in September. You will hear from us again soon with further details of our plans for Wave 5 data collection.



The IDS-TILDA Team at the Wave 5 Planning Day





THE CONTINUING IMPACT OF COVID-19 ON PEOPLE AGEING WITH AN INTELLECTUAL DISABILITY IN IRELAND



Minister Anne Rabbitte, TD, Minister of State with responsibility for Disability, formally launched our second COVID report 'Overcoming Adversity: The Continuing Impact of COVID-19 on People Ageing with an Intellectual Disability in Ireland' on Thursday 27th January. Thank you to everyone who answered our questions and made it possible for us to produce this report

KEY FINDINGS

- The rate of positive tests increased from 2.5% in survey 1 to 12.3% in survey 2
- For two-thirds of people who tested positive, COVID-19 symptoms lasted less than two weeks
- Almost all IDS-TILDA participants (99.3%) had received a COVID-19 vaccine
- Nine in 10 participants had less face-to-face contact with family during the Pandemic but an increased use of technology to speak to family
- 69% reported they experienced stress and anxiety during the COVID-19 period
- Almost 90% of participants reported positive experiences during COVID-19

IDS-TILDA REMEMBERS OUR DECEASED PARTICIPANTS

On 3rd December family and friends joined the IDS-TILDA team for a Winter Commemorative ceremony to celebrate the lives of those who so generously participated in the IDS-TILDA study. Over 700 deceased participants were remembered in a moving ceremony which included poetry, readings and music. The event was held in the Trinity College Chapel and was also livestreamed to a wider audience.



Keepsakes sent to families and carers of deceased IDS-TILDA participants.

THE TRINITY HEALTH AND EDUCATION INTERNATIONAL RESEARCH CONFERENCE

The School of Nursing and Midwifery Trinity Health and Education International Research Conference took place on 8th-10th March. The Healthy Ageing and Intellectual Disability stage had 38 presentations across 13 sessions including a presentation given by Ms Christina Corr, TCAID Research Assistant on 'Making an accessible version of the Vitae Researcher Development Framework'.



NEWS AND EVENTS



TCAID SUPPORTS OPERATION TRANSFORMATION LEADER MS UNA COATES

This year we were delighted to hear that Special Olympics athlete Una Coates became the first person with an intellectual disability to take part in RTE's Operation Transformation.

To show support for her journey, and to acknowledge the leadership Una is demonstrating, TCAID held a physical activity class at the Trinity College Dublin Sports Centre on Tuesday 15th February 2022. Una attended with her colleagues and friends from Stewarts Care Ltd. and Special Olympics. She found the event exhilarating and was delighted with the show of support for her inspiring journey.

The class was led by Ms Louise Lynch (PhD student), Ms Mei Lin Yap (Ambassador Liaison Officer) and Una. Great fun was had on the day by all. There was also a serious side to the day, that of encouraging others to get up and move for better health.



Ms Mei Lin Yap, Ambassador Liaison Officer, TCAID and Ms Una Coates, Special Olympics Athlete and Operation Transformation Participant and Online Leader



Special Olympics participants from Stewarts Care LTD with members of the TCAID team.

EASTER CARD COMPETITION

We were delighted to receive so many wonderful pictures for our Easter Card competition. We had more than 700 entries, so it was a difficult job to choose just three artworks from the wonderful pieces received. A big thank you to everyone who entered our competition.



Winning entry in our Easter card competition, by Stephen Mitchell, Mountbellow Hub, Ballinasloe, Co. Galway



Second place winner Anastasiya Solomenenko, Ballyforan, Co. Roscommon



Third place winner Marion Horan, St. Cronans Services, Roscrea, Co. Tipperary



THE IDS-TILDA TEAM

RESEARCH FOCUS

IDS-TILDA was honoured to welcome Ms Laura Garcia Dominguez to Ireland from the University of Salamanca to undertake a research internship under the supervision of Professor Mary McCarron. Laura is in the final year of her PhD in Psychology which examines the area of Disability Research. The main aim of her PhD is to collect and study data on different aspects of the health of people ageing with an intellectual disability in Spain.

Laura spent three months with the IDS-TILDA team. She gave a presentation on her doctoral thesis and was given the opportunity to carry out joint research comparing data from both Spain and Ireland. As well as learning about a longitudinal study like IDS-TILDA, Laura was pleased to have the opportunity to improve her English.

Laura enjoyed her time living in Dublin and did some travelling around Ireland while she was here. However, she would like to travel more and looks forward to returning to Ireland and visiting more places.



KEEP IN TOUCH

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DR EILISH BURKE : WINNER OF THE INTERNATIONAL ASSOCIATION FOR RESEARCH ON SERVICE LEARNING AND COMMUNITY ENGAGEMENT AWARD 2021

IARSLCE recognises researchers who promote and advance the development and dissemination of research on service learning and community engagement. Dr Eilish Burke is the first Irish person to receive this award.

The award was made in recognition of the efforts of Éilish to ensure her research is robust, collaborative and is disseminated meaningfully to the audience it is meant to inform.

Providing people with intellectual disability opportunities to live well underpins the goals of Éilish's research and teaching activities. One of her projects, 'Get Wise about your Health' provides people with the opportunity to engage in an online easy-read accessible health promotion programme. Éilish also leads the second phase of the PPALS programme in collaboration with individuals with intellectual disability. Both these programmes were funded by the EIT Health and were run internationally in Spain, Germany and the Netherlands. Éilish is an advocate for having the end users and key stakeholders involved in all aspects of her research which ensures its relevance and improves the quality.



"I would like to sincerely thank all those who contributed and participated, who were inspiring and brought a different perspective, making the research more focused and inclusive. I am delighted to receive this award in recognition of my research however it would not have been possible without the contribution of those key people".