



Evidence to Action: Responding to COVID-19

Activating Research Infrastructure to Safeguard a Vulnerable Population



Encouraging Evidence-Informed Decision-Making By Carers, Service Providers and Policymakers

When the World Health Organisation declared COVID-19 a global pandemic, in March 2020, IDS-TILDA researchers were in the field collecting data, as planned, for Wave 4 of the longitudinal study. Ireland entered its first restrictions on March 13th and all IDS-TILDA data collection was suspended in adherence with public health guidelines.

The IDS-TILDA team assessed the situation and the health threat of COVID-19 for people with intellectual disability. Given the emerging risks associated with ageing, alongside the prevalence of chronic conditions in this population, the research team felt an urgent response was required to:

- Engage with carers, service providers, and policymakers to disseminate IDS-TILDA data, providing evidence on the risk to older adults with intellectual disability;
- Elevate the voices of people with an intellectual disability in national conversations on COVID-19 responses;
- Advocate for the prioritisation of people with intellectual disability in vaccination roll-out, given health and demographic profiles; and

- Develop and implement a supplementary COVID-19 survey to monitor the impact of the virus and public health restrictions on IDS-TILDA participants.

This case study highlights outcomes from IDS-TILDA's response to COVID-19 and the team's efforts to advocate for the health and well-being of people ageing with intellectual disability in Ireland.



Image: IDS-TILDA received 300+ creative contributions from people with intellectual disability in response to the campaign to better understand COVID-19

RESEARCH TEAM:

- Prof Mary McCarron, Applicant & Principal Investigator, Trinity College Dublin
- Prof Philip McCallion, Co-Applicant & Principal Investigator, Temple University
- Dr Éilish Burke
- Dr Eimear McGlinchey
- Dr Darren McCausland
- Dr Andrew Allen
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- Ms Margaret Haigh
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- Mr Gavin Dann
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- Mr Michael Foley
- Ms Sarah Bowman
- Ms Holly Dennehy

TRINITY COLLEGE DUBLIN:

- Trinity Centre for Ageing & Intellectual Disability
- School of Nursing & Midwifery

COLLABORATORS:

- All Ireland Institute of Hospice and Palliative Care
- Brothers of Charity Services
- Cope Foundation
- Daughters of Charity Disability Support Service
- Global Brain Health Institute
- Health Information and Quality Authority
- Muireíosa Foundation
- National Federation of Voluntary Service Providers
- Saint John of God Community Services
- St Francis Hospice Raheny
- StewartsCare Service
- Tallaght University Hospital

CORE FUNDERS:

- Department of Health
- Health Research Board

IMPACT AREAS:

- Ensuring IDS-TILDA data informed strategic responses to COVID-19 by carers and service providers
- Utilising IDS-TILDA data to successfully advocate for the increased risk status and vaccination prioritisation of people with intellectual disability in Ireland
- Mobilising existing research infrastructure to provide a rapid response to COVID-19 and enabling research in Ireland and abroad
- Advancing the Health Research Board's Strategic Objectives (2021-2025)

Evidence to Action

Ensuring IDS-TILDA data informed strategic responses to COVID-19 by carers and service providers

As Ireland joined the world in responding to the first wave of the COVID-19 pandemic, the IDS-TILDA research team recognised that people with intellectual disability were particularly vulnerable to the adverse outcomes associated with this virus. IDS-TILDA data showed that they had extremely high prevalence of co-occurring diseases across the entirety of adulthood. Older people with Down syndrome were particularly at risk, as many also had preexisting cardiovascular and respiratory problems, compounded by higher rates of dementia at much younger ages. Given their smaller social networks and fewer social supports, people with an intellectual disability were particularly at risk to disruptions to their routines, placing them at greater risk for social isolation and loneliness, and poorer mental health outcomes. Many who lived at home with family co-resided with ageing parent carers, who themselves were among the higher risk groups for COVID-19. There was significant worry about how to communicate about COVID-19, advance health promotion materials, and prepare for the best health outcomes.

In the midst of a crisis which was also affecting them, IDS-TILDA researchers adapted rapidly in order to deliver reliable, trust-worthy information to guide carers and service providers, including:

- In collaboration with the Health Service Executive, IDS-TILDA created a module for clinical staff on ‘*COVID-19 Assessment and Recognition Among People with Intellectual Disability*’, utilising learnings from the IDS-TILDA Health Fair. Hosted on HSElanD, more than 3,750 healthcare professionals completed this module.
- In collaboration with the All Ireland Institute of Hospice and Palliative Care, the Daughters of Charity Disability Support Service, St Francis Hospice, and Tallaght University Hospital, and other organisations and services, IDS-TILDA researchers hosted a seven-part webinar series for carers and service providers, between April and May 2020, to address information gaps, attracting more than 10,000 attendees, and recordings were subsequently viewed more than 5,700 times on the IDS-TILDA website.



Utilising IDS-TILDA data to successfully advocate for the increased risk status and vaccination prioritisation of people with intellectual disability in Ireland

Engagement with policymakers occurred immediately and included the following highlights:

- IDS-TILDA was invited by the Houses of the Oireachtas to prepare a submission to the *Special Committee on COVID-19* and this was delivered in June 2020.
- In November 2020, IDS-TILDA presented to the Health Service Executive National Clinical Lead for Disability Services and other staff regarding the risks of COVID-19 to people with an intellectual disability.
- In February 2021, IDS-TILDA made a submission to Minister Anne Rabbitte TD, highlighting the case for accelerated COVID-19 vaccination for people with Down syndrome.
- Also in February 2021, IDS-TILDA provided data to support a submission by the Federation of Voluntary Service Providers to Dr Colm Henry, HSE Chief Clinical Officer, and Dr Tony Holohan, Chief Medical Officer, on the urgent vaccination needs of people with intellectual disabilities.

These representations, underpinned by more than 10 years of evidence from IDS-TILDA, helped to inform the decision by Government to classify people with intellectual disability among those at ‘high risk’ of COVID-19, and people with Down syndrome among those at ‘very high risk’. This classification prioritised people with an intellectual disability for vaccination.

“Just a huge word of thanks for this morning. it was so powerful to have the data to bring to our members – not only does it ground our submission for the Article 25 response to the Government Report, but I think it was also a wonderful opportunity to bring the findings of IDS-TILDA to an important audience of organisations who have direct influence in how services and supports are provided. We had very positive feedback following your presentation, so thanks again. - Dr Alison Harnett, Acting Chief Executive Officer, National Federation of Voluntary Service Providers



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Mobilising existing research infrastructure to provide a rapid response to COVID-19 and enabling research in Ireland and abroad

In addition to informing the national debate on COVID-19 using IDS-TILDA longitudinal data, there was also an urgent need to provide new data on how the emerging crisis was impacting people with intellectual disability. Along with a proposal to resume Wave 4 interviews remotely using video and phone, IDS-TILDA researchers applied for ethical approval for a supplementary COVID-19 survey among Wave 4 participants. Ethical approval was granted by the Trinity College Dublin Research Ethics Committee and the newly established COVID-19 National Research Ethics Committee. Data collection resumed between May and September 2020, and included the COVID-19 questionnaire. 710 Wave 4 participants completed this questionnaire, delivering a 96% response rate, despite the pandemic.

Given the urgency for data on how COVID-19 and associated public health measures were impacting people with intellectual disability, cleaning and analysis of the COVID-19 data were prioritised and the IDS-TILDA Wave 4 report, *The Impact of COVID-19 on People Ageing with An Intellectual Disability in Ireland*, was launched in December 2020. The online event attracted more than 600 attendees and was moderated by broadcaster Olivia O’Leary. The report examined rates of symptoms and testing, morbidity and treatment, stress and anxiety associated with the pandemic, and experiences of the lock-down period. These data were supplemented with main IDS-TILDA data to explore associations with disease morbidity and other health and well-being outcomes, to consider potential predictors of symptoms and infection, and to identify differences in people’s lives before and during COVID-19 restrictions (McCarron et al., 2020). Since the report launch, IDS-TILDA has continued to disseminate data on the impact of COVID-19, with two open access journal articles (HRB Open; [JIDR Open Access](#)) and numerous conference presentations.

“A thousand times thank you and please keep up the good work. So important.”

- Family member of IDS-TILDA participant, COVID-19 Report Launch



The rapid response by IDS-TILDA to adapt methods, including remote interviewing, also singled out the study as a pioneer in the field, generating interest from researchers in Ireland, the United Kingdom, Australia, and the United States. IDS-TILDA researchers met with TILDA researchers, for example, prior to their decision to implement remote interviewing for Wave 6 of the national longitudinal study on ageing among the general population. Following the first COVID-19 survey, funding was obtained by IDS-TILDA for an expanded COVID-19 survey among participants, to track the long-term impact of the virus and associated public health measures. These data and subsequent data from Wave 5 will be critical to informing the re-opening and re-building of services post-pandemic.

“The IDS-TILDA COVID-19 survey was a real inspiration to us in the UK for the project we’re doing at the moment interviewing adults with intellectual disabilities and surveying mainly family carers. We’ve published data from two waves of the project and we start Wave 3 in a couple of weeks. The IDS-TILDA COVID-19 study inspired me to believe what we were doing in the UK was possible!”

- Professor Chris Hatton
Department of Social Care and Social Work
Manchester Metropolitan University
IDS-TILDA International Scientific Advisory Board

Advancing the Health Research Board’s Strategic Objectives (2021-2025)

IDS-TILDA’s response to COVID-19 has been both swift and sustained, advancing the following strategic objectives:

- Supporting the Department of Health in advancing research actions in the *Resilience and Recovery 2020-2021 Plan for Living with Covid-19* (1.2.1);
- Employing innovative knowledge translation activities to provide key information in accessible formats and to optimise uptake and impact on policy and practice (2.1.5);
- Playing a leading role in stimulating dialogue with stakeholders, including the public, to respond to emerging developments in research, health and society (2.3);
- Facilitating open dialogue and debate to enable the exchange of different ideas, opinions and perspectives on emerging and important health research issues (2.3.2);
- Actively engaging researchers, practitioners, the public and policy-makers to build consensus and to drive change in areas of importance in health research, data and evidence (2.3.3); and
- Collecting, validating and reporting essential data in the area of disability (3.2).