

# Research details impact of COVID-19 on persons ageing with an intellectual disability

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Professor Mary McCarron, Trinity College (L) and Ms Mei Lin Yap, member of the IDS-TILDA Steering Committee, Trinity College. Credit: Trinity College Dublin

Researchers from Trinity College have launched a special report on COVID-19 and older people with an intellectual disability (ID) which has found that COVID-19 was well managed in ID services but calls for decisions to impose further restrictions during the pandemic to be as data-driven, as they have been for the non-ID population. The report has recorded a small number of COVID-19 infections amongst their respondents and no deaths during the initial lockdown of 2021.

"The Impact of COVID-19 on People Aging with an Intellectual Disability in Ireland' report was formally launched by the Minister of State with responsibility for Disability, Minister Anne Rabbitte TD. It is part of the Intellectual Disability Supplement to the Irish Longitudinal Study on Aging (IDS-TILDA) study for Trinity and marks the United Nations International Day of People with Disabilities.

## **Key research findings**

- Two-thirds (62.4%) of the older adults with ID surveyed were tested for COVID-19, with only 11 people testing positive, and no reported deaths. This gives an overall infection rate of 2.5%.
- There was a high rate of reported pre-existing conditions which are associated with poorer outcomes for COVID-19. 371 (52%) participants having a history of cardiovascular disease and 365 (66%) participants having a history of overweight/obesity. There was also a high prevalence of certain psychiatric/neurological conditions: 209 (29.5%) participants had a history of epilepsy, and 29 (4.1%) participants had a history of dementia. A further 61 (8.6%) participants had a history of lung disease/asthma, 68 (9.6%) had a history of diabetes, and 380 (53.5%) had a history of emotional, nervous or psychiatric disorder.
- More than half of the participants indicated stress or anxiety due to the pandemic.
- The most common cause of stress/anxiety overall was not being

able to do usual activities, followed by not seeing friends/family, loneliness/isolation, and fear of getting COVID-19.

- Of those participants who had symptoms or tested positive, over three-quarters (78.7%) had plans to manage self-isolation according to guidelines. Most were able to comply with guidelines, but one-third were unable to do so.
- 710 people over 40 years of age with intellectual disabilities completed the COVID-19 survey.

The research found that almost two-thirds (62.4%) of the 710 older adults with ID surveyed were tested for COVID-19, with only 11 people testing positive, and no reported deaths. This gives an overall infection rate of 2.5%, lower than the national positivity of 3.4% in the same period. Infection rates of 4.6% among participants in residential care were much lower than incidences of infection reported internationally for general nursing home populations. For example, by June 2020, over 70% of facilities in the US reported cases of COVID-19 and Irish nursing homes accounted for 22% of all cases in the country and over half of all deaths.

Overall, 10% of IDS-TILDA participants reported COVID-19-like symptoms. Of those participants who had symptoms or tested positive, over three-quarters (78.7%) had plans to manage self-isolation according to guidelines. Most were able to comply with the guidelines. There were 139 older adults with Down syndrome included in this study and none tested positive for COVID 19. This is a welcome finding given the high-risk of adverse infection outcomes among this population. A recently reported UK study which estimated a four-fold increased risk of hospitalization and a ten-fold increased risk of death related to COVID-19 for people with Down syndrome.

More than half of respondents said they felt stress or anxiety due to the pandemic. The study found respondents were more likely to indicate

stress or anxiety if they were female, aged under 50, had mild to moderate ID, or lived independently, lived with family or lived in community group homes. The most common causes of stress or anxiety were not being able to do usual activities, not being able to see friends or family, feelings of loneliness and isolation, and a fear of getting COVID-19.

Respondents also indicated positive aspects to the lockdown included being able to try new activities, opportunities for more rest, more time with staff and using technology to communicate.

Principal Investigator Professor Mary McCarron said: "It is particularly commendable that there were active plans and strategies for isolation and quarantining, with which most people with ID complied." She also acknowledged concerns arising from how people have been living with the social restrictions due to the pandemic: "While we are very thankful that the numbers who tested positive for COVID-19 have been so small, with no reported deaths in this study, we must consider the effect that restrictions have had on people aging with an [intellectual disability](#). It is undoubtedly a good news story that many services and families reacted so rapidly to keep people safe. It is also very positive that over half did state that they found positive aspects to the change in circumstances. It is worrying, however, to hear of the stress and burden experienced by people aging with an intellectual disability."

## **Risks to People with Intellectual Disability**

Professor McCarron went further and stressed that decisions to impose restrictions during the pandemic need to be as data-driven as they have been for the non-ID population:

"The results of this study show that people with ID who are older and with high levels of co-morbidities can be protected from getting

COVID-19 by strict adherence to public health guidelines. However, if community transmission is high, extra vigilance is needed. This study did not report any COVID-19 related deaths; we know, however, from other published studies that increasing age and other recognized co-morbid health conditions result in poorer outcomes and increased mortality, hence people within this category will benefit from additional vigilance. All others with ID should be supported and encouraged to follow general [public health guidelines](#) including continuing to keep physical distance, to wear masks, to wash hands and to monitor and report their symptoms."

## **Imposing further restrictions**

Professor McCarron emphasized the need to be cautious about prolonged unwarranted restrictions on the lives of people with an ID: "The results of this study demonstrate that prolonged restrictions had a major impact on the mental health and wellbeing of [older adults](#) with an ID, with increased levels of anxiety and loneliness. This is particularly concerning for people with ID previously diagnosed with mental health concerns. The data here does not support categorizing people with ID as extremely vulnerable as the cost of this, in terms of poorer mental and physical health outcomes in the long term, cannot be underestimated."

Professor McCarron raised the issue that these figures do not take the second wave of infections into account: "In order for us to really understand the effects of the virus among this population, there is a need to repeat these COVID-19 questions in the spring and, again, in the summer of 2021. That will allow us to better grasp how the pandemic has affected this population and what characteristics put this population at greater risk."

Minister Rabbitte said, "It's positive news that to date so few people were infected with COVID-19 in this population. For this, we can be

very grateful to intellectual disability services for their efforts to control the spread of the virus and for families and staff following public health advice. I'm acutely aware of how much of a strain the pandemic has had on people with a disability across the country. Although very tough at times, the strength and determination shown is admirable. These results highlight that the public health advice, while hard going at times, has meant the virus can be controlled and people protected. Needless to say, COVID-19 has not gone away and still poses a threat to the health of people with intellectual disability. We must all continue to follow public health advice."

Ms Mei Lin Yap, PPI contributor, IDS Steering Committee member and person with Down syndrome, said, "Because many people with ID are isolated due to this pandemic, it's so important to keep engaged and to stay fully connected with other people. This has benefits for your brain health. It lifts your spirits and your soul. Even just seeing people on my computer screen means a lot, even if we can't get together. People with ID should try to stay positive until we can all meet again."

Provided by Trinity College Dublin

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