



Overcoming Adversity: The Continuing Impact of COVID-19 on People Ageing with an Intellectual Disability in Ireland

Findings from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) COVID-19 Sub-Study



Trinity College Dublin
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The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

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**The Intellectual Disability Supplement to TILDA
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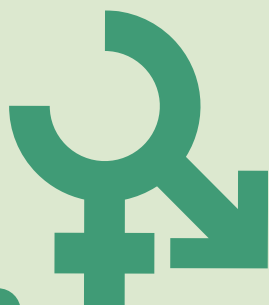
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IDS-TILDA The Impact of COVID-19, Survey II

Participants

682

participants



368 females (54%)
 314 males (46%)

Level of intellectual disability

189

mild intellectual disability (30%)

269

moderate intellectual disability (42%)

177

severe-profound intellectual disability (28%)



Age

129

aged 40-49 years (19%)

380

aged 50-64 years (56%)

173

aged 65+ years (25%)



Residence type

- 119 Independent/family (18%)
- 337 Community group home (50%)
- 219 Residential care (32%)



Cause of intellectual disability

- 125 Down syndrome (21%)
- 557 Other/unknown (79%)

High rate of chronic health conditions

- 67% Overweight/obese
- 51% Cardiovascular disease history





COVID-19 testing, symptoms and outcomes

- 517 participants were tested for COVID-19 (76%)
- 63 tested positive for COVID-19 (12%)
 - Residential care 14.1%
 - Community group homes 12.8%
 - Independent/family 2%
- 124 had COVID-19 like symptoms (18%) – cough and fever were most common
- 13 people were hospitalised
- 3 deaths of IDS-TILDA Wave 4 participants with COVID-19 (COVID-19 not confirmed as cause of death)

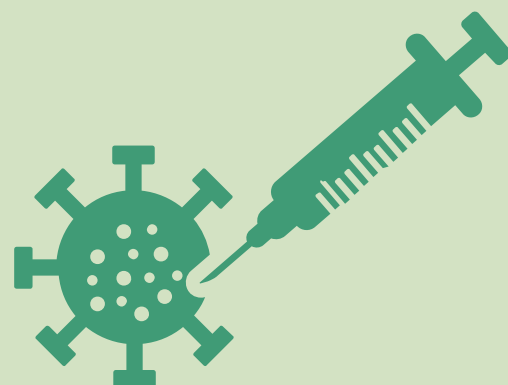
“Really missed going out and about, helping with the shopping and having meals out. It was a difficult time being confined to the house”.



“Before the lockdown, I was planning my new independent life. I proposed to my boyfriend and he said yes. I was going to [name] day services and meeting him there every day. Then lockdown started, I couldn't see my boyfriend in a very long time and I couldn't go to [day service name].”

Vaccines and health behaviours

- 675 participants received a COVID-19 vaccine (99%)
- 202 reported side effects from the vaccine (30%)
- For 9 out of 10 participants, minor side-effects lasted less than 48 hours
- Just over half (56%) found the government vaccine guidelines easy to understand, but 44% found it difficult to understand.
- 73 participants (11%) moved from their home during the pandemic – most often to isolate
- Almost all (99%) who had symptoms or tested positive had a plan to manage self-isolation
- Most participants followed infection control behaviours, like social distancing and wearing a mask, often or always.





Contact with family and friends

- 9 in 10 participants had less face-to-face contact with family
- Over half of participants had increased contact with family using technology
- 8 in 10 participants had less face-to-face contact with friends
- Half of participants had increased contact with friends using technology



“I would ask the government to change the way the vaccine is rolled out so the day services could open. I am away from my family and friends and it drives me mad. I only see them online. I'm really annoyed about not being able to work. I am focusing my new hobbies.”

“It's been alright. I'm very content and we did loads of fun things in the house – I played my accordion a lot, we did the Jerusalem dance challenge, the Easter bunny visited . . . I'm a very positive person.”



Health changes and service utilisation

- Most participants reported changes in their health during the pandemic
- 397 spent more time sitting down or being sedentary (58%)
- 366 did less physical activity or exercise (54%)
- 114 missed their annual health check (19%)
- 130 had a medical test/screening cancelled (20%)



Mental health and well-being

- 473 participants reported some stress or anxiety due to COVID-19 (69%)
- 154 self-reporting participants (56%) said they felt lonely during the pandemic.
- Most participants experienced a significant life event during the pandemic – the most stressful being: a major illness/injury, death of a sibling, and death of a parent
- 142 participants know someone who died during the pandemic (21%)
- Almost 9 in 10 reported positive experiences during the pandemic – most commonly: engaging in new activities, more rest/relaxation, more/better time with staff, and using technology to communicate.



“Have to take it one day at a time. It was very hard but that's life and you just have to get on with.”



“I miss going home at weekends but now I can go home after the virus. I did lots of activities during COVID, writing, colouring, dancing, playing basketball & swing ball. It wasn't a bad time because I had my friends around and I had the support of staff.”



Social and community participation

- 572 were unable to do enjoyable activities or hobbies (84%)
- 474 had reduced work or day service hours (70%)



The Intellectual Disability Supplement to
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Executive Summary

Executive Summary

Introduction

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) was established in 2008, with the aim to identify the principal influences on ageing in people with an intellectual disability aged 40 years and above. The study overall seeks to characterise and understand changes in ageing by examining healthy and successful ageing, determinants of health and longevity, and similarities or differences in ageing for those with and without intellectual disability. It does so with the inclusion of people with intellectual disability in every aspect of the study. The first wave of IDS-TILDA was completed in 2011 and subsequent waves were completed every three years since then, with the fourth wave completed in 2020.

Dissemination and translation of critical data about the health, social inclusion, and the mental health and well-being of this population over the past decade helped to establish IDS-TILDA as a global leader in research on ageing among people with intellectual disability. This also supported the establishment in 2018 of the Trinity Centre for Ageing and Intellectual Disability (TCAID) at Trinity College Dublin (TCD).

The occurrence of COVID-19 has had an immediate effect on people with intellectual disabilities and is likely to be of influence in their ageing going forward; therefore, it has been important that IDS-TILDA collect and present data on the experience of COVID-19 by people with intellectual disabilities. The critical health data collected has informed and will continue to inform decision making and needed public health responses to reduce the risk of poor outcomes and mortality for this at-risk population.

IDS-TILDA COVID-19 survey

In March 2020, data collection for Wave 4 of the IDS-TILDA longitudinal study was interrupted by the outbreak of the COVID-19 pandemic in Ireland, resuming in May 2020 using adapted remote interviewing methods and with a supplementary COVID-19 questionnaire to explore the impact of COVID-19 among Wave 4 participants. Given the urgent need for this data, the IDS-TILDA Wave 4 report in 2020 was dedicated to our first COVID-19 survey reporting then that older adults with intellectual disability managed to avoid the high levels of COVID-19 infections and mortality experienced among the general older population in Ireland. It also found that just over half of participants experienced COVID-19 related stress or anxiety, but a similar proportion also reported positive experiences during this time.

The international literature was already reporting that people with intellectual disability were at far greater risk of hospitalisation and death from COVID-19 infection and were at risk from a younger age. It was confirmed that the health profile of older adults with intellectual disability presented an elevated risk of poor COVID-19 outcomes, while the long-term impacts of prolonged societal restrictions and lockdowns for this population were unknown. The picture in Ireland on these issues was also not yet clear and warranted further research. In 2021 the Department of Health confirmed

additional funding for a second IDS-TILDA COVID-19 survey. This second survey would build on the first and provide longitudinal data about the ongoing and long-term impact of COVID-19 on older adults with an intellectual disability in Ireland. With more time to plan and develop the protocol, the second survey provided an opportunity to assess the impact of the pandemic in greater breadth and depth.

With ethical approval granted in April 2021, data was collected between May 2021 and September 2021 among a final sample of 682 individuals.

Key Findings

The key findings from this second IDS-TILDA COVID-19 survey in the areas of health and service provision, social inclusion, and mental health and well-being, are as follows.

COVID-19 testing, symptoms and outcomes

- Testing for COVID-19 increased from 62.4% of all participants in survey 1 to 75.8% in survey 2. The highest rates of testing was among participants living in residential care (91.8%), which was more than double the rate of participants in independent/family residences (41.2%).
- The rate of positive tests among those who were tested showed a substantial increase from just 2.5% in survey 1 (May 2020) to 12.3% in survey 2; where just 2% (one individual) living in independent/family settings tested positive, compared with 13.9% in residential care and 12.6% in community group homes.
- Participants with moderate intellectual disability were significantly less likely to report testing positive (7.7%) than those with either mild (15.6%) or severe-profound (17%) intellectual disability ($p=0.014$).
- Higher rates of testing positive were reported by residents of grouped accommodation settings (residential care and community group homes) as compared to independent/living with family.
- Rates of testing and positive COVID-19 cases reported for older adults with an intellectual disability are higher than rates for the general population, reported by TILDA in 2021 as 6.2% tested and just 0.2% tested positive, with a further 4% suspected cases.
- Reported COVID-19 like symptoms increased from 10% of participants in survey 1 to 18.2% in survey 2; with cough and fever again the two most common symptoms; compared with 44% reporting symptoms in the general older population in Ireland, where muscle/joint pain and cough were the most common symptoms.

- For two-thirds of the 63 individuals who tested positive, COVID-19 symptoms lasted less than two weeks; eight participants (13.1%) had symptoms for 3-8 weeks; three participants (4.9%) had symptoms for 9-12 weeks; and one individual (1.6%) had yet to recover and had symptoms lasting more than 12 weeks; while 11.5% (7) were asymptomatic.
- Hospitalisations among participants with COVID-19 like symptoms or who tested positive increased slightly from 10.7% in survey 1 to 12% in survey 2.
- Of the 13 participants who were hospitalised, 11 tested positive for COVID-19 including one individual who was admitted to intensive care
- During recruitment, three IDS-TILDA participants were identified as having died and as having COVID-19 – the cause of death has not been confirmed and it is unknown if COVID-19 was a cause.

Vaccines and health behaviours

- Almost all IDS-TILDA participants (99.3%) had received a COVID-19 vaccine, with most receiving the Oxford AstraZeneca vaccine (67.8%) or the Pfizer-BioNTech vaccine (31.9%); with 30.3% experiencing adverse side-effects from receiving the vaccine, most commonly tenderness, swelling or redness of the arm (15.9%) and feeling tired (11.6%).
- Almost eight in ten participants (79.1%) received easy-read accessible information on the government guidelines or the COVID-19 vaccine, while another 18.3% received other information, and just 2.6% received no information. Among those who received the official government information, the majority found it easy to understand (56.2%, 248/441), but 24.5% (108/441) found it 'somewhat difficult' and 19.3% (85/441) found it 'extremely difficult' to understand.
- The number of people who moved from their home during the pandemic increased between survey 1 (7.8%) and survey 2 (10.7%), with isolating remaining the most common reason. Among participants who had symptoms or tested positive, 98.7% had a plan to manage self-isolation, up from 78.7% in survey 1.
- Between 57.3% and 79.2% adhered to recommended infection control behaviours 'often' or 'always', compared with 74% to 98% reported by TILDA for the general older population.
- One in seven participants (14.1%) started taking a new prescribed medication during this pandemic, and 15.4% changed the dose of a prescribed medication; while vitamin D was the prescribed supplement that participants started taking most during the pandemic (12.6%) - where previously 41.5% of IDS-TILDA participants reported taking some Vitamin D supplement.
- People with severe-profound intellectual disability (12.1%) were less than half as likely to eat less healthily during the pandemic compared with people with mild (27.8%) and moderate intellectual disability (25.4%; $p < 0.001$).

- Participants with Down syndrome (66.4%) were the group most likely to spend more time sitting down or being sedentary during the pandemic, and were significantly more likely to do so than participants of other aetiologies (55.3%; $p=0.025$).
- Most participants experienced health related changes since the start of the COVID-19 pandemic, most commonly spending more time sitting/being sedentary (58.2%) and doing less physical activity/exercise (53.7%). Having Down syndrome was associated with being more sedentary, while living in residential care and having severe-profound intellectual disability were associated with doing less physical activity/exercise.
- Around a quarter of participants experienced other health changes – including less medical care than usual, increased health problems not related to COVID-19, and overeating or eating unhealthily.

Health service utilisation

- Most participants (58.2%) had not made any new healthcare appointments since the beginning of the pandemic in March 2020.
- Around a fifth (18.8%) missed their usual health check during the pandemic, with those aged 65+ years (27.2%) most likely to miss their health check compared to participants aged 50-64 (17%) and 40-49 years (13.1%) ($p=0.007$).
- There was a large reduction in face-to-face meetings with health care professionals with 42.5% -70.8% reporting having seen their health care professional ‘not at all’ or ‘not as much’ but 22.2% to 48% had increased phone/online consultations, the highest with psychiatry and clinical psychology.
- Between in-person and phone/online consultations there was an overall net reduction in level of access to healthcare practitioners of 12.5 – 37.6%.

Contact with family and friends

- Nine in 10 participants had less face-to-face contact with non-resident family during the pandemic. People living in residential care and community group homes were more impacted by reduced face-to-face contact with their family, compared with those living independently or with family.
- Reduced face-to-face contact with family may have been alleviated by an increased use of technology to speak to family, experienced by over half (55.9%) of participants. This may explain why independent/family residents were less likely to report contact using technology.

- Eight in 10 participants had less face-to-face contact with non-resident friends; while people with mild (85.6%) and moderate intellectual disability (81.1%), were more impacted than participants with severe-profound intellectual disability (59%), who had higher proportions of co-resident friends.
- Reduced face-to-face contact with friends may also have been alleviated by increased use of technology to speak to friends during the pandemic, reported by half of participants. More people with mild intellectual disability (57.6%) had increased use of technology to speak with friends, compared with less than half with moderate (46.5%), and a third with severe-profound intellectual disability (35%).

Social and community participation

- A majority of participants reported a restricted lifestyle: unable to do enjoyable activities or hobbies (83.9%); separation from family or close friends (79.8%); reduced work hours or hours of day service (69.5%); religious or spiritual activities cancelled or restricted (62.8%); family celebrations cancelled or restricted (62.2%); planned travel or vaccinations cancelled (58.4%); and being unable to participate in social clubs, sports teams, or volunteering (58.2%).
- A number of participants also reported: an increase in verbal arguments or conflict with other adult(s) at home (21.6%); not having the ability or resources to talk to family or friends while separated (18.9%); being unable to attend in-person funeral or religious services for a family member or friend who died (17.6%); unable to visit loved one in a care facility (11.1%); unable to be with a close family member in critical condition (6.9%); and an increase in physical conflict with other adult(s) in home (4.8%).
- More younger participants were affected by reduced work/day services, cancelled/reduced family celebrations, and cancelled travel plans; while more older participants were impacted by cancelled/restricted religious or spiritual activities.
- Participants with a milder level of intellectual disability were more impacted by being unable to do their activities or hobbies; having reduced work or day service hours, participation in social clubs, sports teams and volunteering; and not attending in-person funeral services for family or friends.
- Separation from family or close friends was reported most among residents of community group homes (85.8%), compared with participants living in residential care (75.3%) and independent/family settings (70.6%).
- Participants living independently or with family were impacted most across a number of measures, followed by community group home residents, with those in residential care the least affected – these included measures of reduced work or day service hours; cancellation of planned travel; and reduced participation in social clubs, sports teams and volunteering.

- Participants with Down syndrome were more restricted (67.2%) in participating in their clubs, teams and volunteer activities, compared to 55.1% of participants with intellectual disability of other aetiologies.
- Women were more affected by cancelled or restricted religious or spiritual activities (68.8%), compared to male participants (55.7%).

Mental health and well-being

- Most participants reported that their overall mental health was either excellent, very good, or good. Despite this, 69% reported they experienced stress and anxiety during the COVID-19 period. This had increased from 55% who reported stress and anxiety in the first COVID-19 survey.
- Key sources of stress and anxiety during the lockdown were isolation, not being able to see family or friends and not being able to do usual activities.
- There was little change in depressive symptom scores compared to Wave 3 reports (3 years prior) of IDS-TILDA.
- Just over half (56.4%) of self-reporting participants said they felt lonely during the pandemic.
- For life events, a majority of participants had a change at work/day service, change in frequency of visits from family/friends, and/or a loss of leisure-time activities.
- For a majority of those participants who experienced a major illness or injury, the death of a sibling or the death of a parent, these were associated with a lot of stress.
- Just over 20% of participants knew someone who died during the pandemic.
- Almost 90% of participants reported positive experiences during COVID-19.
- Frequently reported positive experiences included more rest/relaxation (63%), more/better time with staff (60.6%), more free time (50.9%), and using technology to communicate (49.4%).
- Anticipated activities at the end of the pandemic were being able to see family and friends, returning to socialising, eating out and going to the pub, going on a holiday, returning to day service or work, and 'just getting back to normal'.

Summary and Conclusions

Findings reported here from this second IDS-TILDA survey on the impact of COVID-19 among older adults with intellectual disability in Ireland build and expand on our first COVID-19 survey from 2020. Data for this follow-on survey was collected in mid-2021, just after the third wave of COVID-19 in Ireland. Despite the high levels of multimorbidity in older adults with intellectual disability, with greater risk of poorer outcomes reported elsewhere for this population, the addition of risk for COVID 19 does not appear to have increased mortality for older adults with intellectual disability in Ireland. Our findings do indicate that the COVID-19 pandemic had a growing impact on the health, service utilisation, and social inclusion of older adults with intellectual disability. Many participants also experienced pandemic-related stress, anxiety and impactful life events, but a degree of resilience was evident in participants' comments and in the lack of change in self/proxy-rated mental health and in depressive symptoms compared to previous IDS-TILDA reports.

These findings may suggest that, while health, service and social impacts of the pandemic are obvious and immediate, the true impact may only be properly assessed over a more prolonged period. The long-term effects of many of the pandemic impacts reported here, including deeply personal events such as being unable to attend a loved one's funeral or be with them during difficult times, may only become clear in the coming years. Continued monitoring of these impacts is critical to providing required future supports for this population. Wave 5 of the IDS-TILDA longitudinal study, commencing in Autumn 2022, will further assess the social and psychological impact consequential to pandemic experiences, as well as the impact on individuals' health and their access to and use of health services.



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

Introduction

Introduction

The IDS-TILDA study

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) was established in 2008, becoming the first longitudinal study on ageing amongst the intellectual disability population worldwide conducted parallel to a study of ageing amongst the general population. IDS-TILDA aims to identify the principal influences on ageing in people with an intellectual disability aged 40 years and above. The study seeks to characterise and understand changes in ageing by examining healthy and successful ageing, determinants of health and longevity, and similarities or differences in ageing for those with and without intellectual disability using comparative data from the Irish Longitudinal Study on Ageing (TILDA) for the general population.

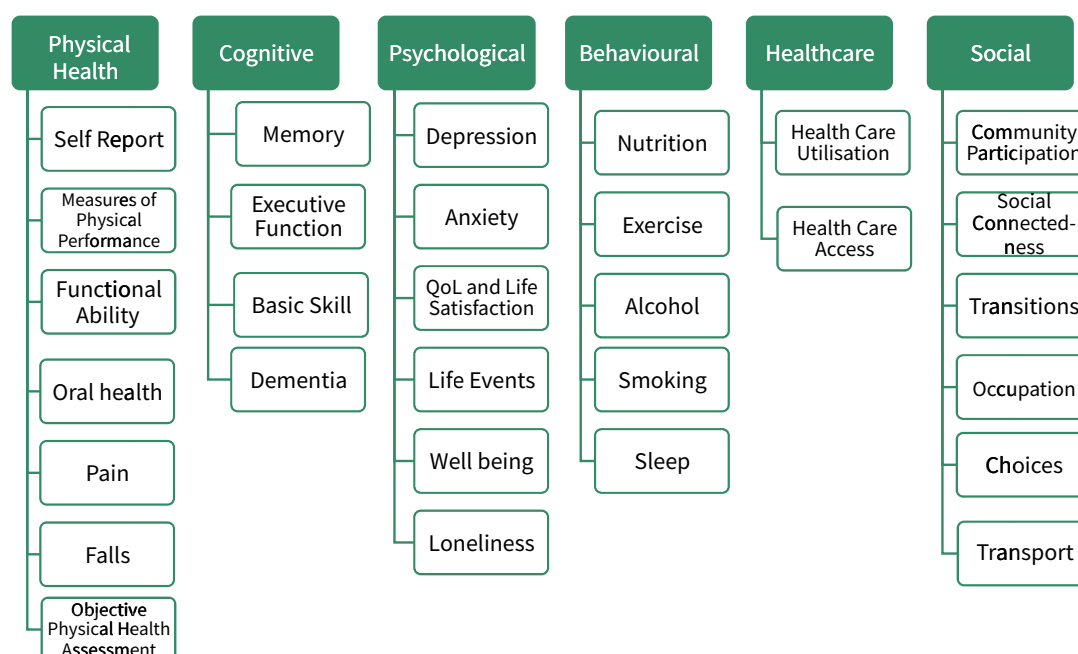


Figure 1. IDS-TILDA conceptual framework

The IDS-TILDA conceptual framework (Figure 1) illustrates the breadth of data collected, from all aspects of ageing and health to social inclusion and community participation. Critically, the study is also guided by the values of inclusion, empowerment, choice, person centeredness, best practice, and promoting and contributing to the lives of people with intellectual disability. In adherence with the best practices in Patient and Public Involvement (PPI), people with an intellectual disability have played an integral role throughout the development of IDS-TILDA, from the initial pilot study conducted to develop inclusive Wave 1 protocols and continuing through consultation on changes for each subsequent wave. Our ‘keeping in touch’ strategy, including newsletters, cards and art competitions, has also been important in engaging people with intellectual disability and preserving the study sample through multiple waves, and particularly throughout the COVID-19 pandemic.

The first three waves of IDS-TILDA data collection were reported in 2011, 2014 and 2017, with additional dissemination of study findings ranging from scientific papers to accessible reports, videos and talks to people with intellectual disability and their families. This helped to establish IDS-TILDA as a global leader in research on ageing amongst people with intellectual disability and supported the establishment in 2018 of the Trinity Centre for Ageing and Intellectual Disability (TCAID) at Trinity College Dublin (TCD).

IDS-TILDA COVID-19 surveys

In March 2020, IDS-TILDA was in the field collecting data for the fourth wave of the longitudinal study when the outbreak of the COVID-19 pandemic in Ireland brought data collection to a halt. When data collection resumed in May 2020, using alternative remote interviewing methods, a supplementary COVID-19 questionnaire was also administered among wave 4 participants. Given the urgent need to disseminate data on the impact of COVID-19 on our population, the IDS-TILDA fourth wave report, launched in December 2020, was dedicated to reporting results from our first COVID-19 survey [1]. Findings from that first IDS-TILDA COVID-19 survey indicated that older adults with intellectual disability managed to avoid the severe impact of the COVID-19 infections and mortality experienced among the general older population, in particular the general nursing home population, despite having a comparable health risk profile. We also found that just over half of participants experienced stress or anxiety related to COVID-19, but that a similar proportion reported some positive aspects from the period [2].

We subsequently continued to explore and disseminate this data in 2021 [2, 3], and were pleased to support representations to Government and the Health Service Executive (HSE) advocating for the prioritisation of people with intellectual disability for vaccinations. In partnership with the National Federation of Voluntary Service Providers, this advocacy resulted in the prioritisation of people with intellectual disabilities for initial vaccines in Spring 2021, and inclusion in the vaccine booster campaign in November 2021.

While findings from the first survey of a less severe impact among older adults with intellectual disability in Ireland were positive, the international literature was showing that people with intellectual disability were at far greater risk of hospitalisation and death from COVID-19 infection and were at risk from a younger age [4-9]. Given that the health profile of older adults with intellectual disability continued to present an elevated risk of poor outcomes from COVID-19 infection, as well as the unknown impacts of 'long Covid' and prolonged societal restrictions and lockdowns for this population, the need for a second IDS-TILDA COVID-19 survey became clear.

Early in 2021, the Department of Health also confirmed additional funding for a second IDS-TILDA survey on the impact of COVID-19 on older adults with an intellectual disability. This second survey would build on the first survey and provide longitudinal data about the ongoing and long-term impact of COVID-19 on older adults with an intellectual disability in Ireland. With more time to plan and develop the protocol compared with the urgency associated with the first survey, this second survey was much expanded and provided an opportunity to assess the impact of the pandemic in greater breadth and depth.



Current knowledge about COVID-19 and the impact on people with an intellectual disability

Current knowledge about COVID-19 and the impact on people with an intellectual disability

Global Impact of COVID-19

COVID-19, a disease associated with a strain of coronavirus (SARS-CoV-2), was declared a ‘public health emergency of international concern’ by the World Health Organisation on 30th January 2020 (WHO) and a pandemic on 11th March 2020 [10].

This section summarises current knowledge about COVID-19 including morbidity, mortality and risk factors; as well as the broader impact the pandemic has had on social inclusion and mental health and well-being. It also considers the specific impact that COVID-19 has had for people with an intellectual disability.

The impact of COVID-19 on health morbidity and mortality

Since the initial outbreak, there have been in excess of 258 million confirmed cases of COVID-19 worldwide, and more than 5.17 million deaths associated with the disease (as of 25 November 2021) [11]. In Ireland there have been 546,909 confirmed cases and 5,652 deaths [12].

Risk factors associated with contracting COVID-19

Factors associated with an increased risk of contracting COVID-19, include living and working in close proximity to other people, meaning living in nursing homes, long-stay settings, and specialist settings raises the risk of contracting COVID-19. Studies have confirmed a high incidence of disease cases and outbreaks among nursing home populations [13, 14], with increased risk associated with asymptomatic infection among residents and symptomatic infection among staff [15], and with a high disease burden in the surrounding community [13, 16].

A US study found that those most at risk through occupational exposure are employed in healthcare sectors, with those working in protective services (e.g., police, firefighters), office and administrative support, education, community and social services, and construction and related occupations also at high risk for exposure [17]. In Ireland, a study found that 4.9% of COVID-19 cases were in healthcare workers, and that females healthcare workers were disproportionately represented among cases, making up 77.7% of cases among healthcare workers, compared with 50% of cases among non-healthcare workers [18]. An Italian study also found those most exposed worked in health, but activities in trade, personal services and leisure sectors were also at risk due to operating in physical proximity to others [19]. Workers in industries with environmental or socio-economic conditions conducive to the spread of COVID-19, as found in meat processing and mining, may also have increased risk [20-22].

Risk factors associated with poor COVID-19 outcomes

Older age, particularly over 70 years, and having specific underlying health conditions are the factors most associated with poor outcomes of COVID-19 infection [23-25]. With age, one study found mortality rates increase exponentially from around 1% under 50 years, up to almost 30% for those

aged 80 years and above, with 60 years a key threshold for increased risk [26]. Levin et al. (2020) confirmed a similar age association, but with fatality rates increasing less sharply from 1.4% at age 55 to 15% at age 85 [27]. Another study estimated mortality rates for COVID-19 patients aged 55-64 was 8.1 times higher than patients under 55 years, while the rate for those aged 65 year or older was 62 times higher than those under 55 [28].

Other studies have looked beyond age to identify other health factors. One Mexican study confirmed increased risk of hospitalisation and mortality with increasing age, but also confirmed an association with co-morbidity of hypertension, obesity, and/or diabetes [29]. A Brazilian study also confirmed age and immunodeficiency, kidney disease, and neurological disease as critical risk factors [30]. Several other studies identified additional increased incidence of hospitalisation, ICU admission and mortality associated with chronic lung diseases, obesity, cardiovascular diseases, hypertension, diabetes, dementia, chronic kidney disease, frailty, and multimorbidity [31-35].

The impact of COVID-19 on social inclusion, mental health and well-being

The impact of COVID-19 has extended to social restrictions, service, business and retail closures and lockdown measures imposed to control the disease, with evident consequences for mental health and well-being becoming a major concern globally. A number of studies confirm such measures have successfully slowed the spread of COVID-19 and reduced the number of adverse outcomes, including saving many lives [36-38]. However, while populations benefitted from reductions in the direct health effects of the disease, these measures also have had indirect negative consequences including on mental health.

Social, economic, and cultural impacts from the pandemic, in addition to fears of contracting the disease, have affected the mental well-being and social connectedness of many people [39-41]. An international survey of adults in the general population reported large decreases in social connection with family and friends/neighbours and in social activities, leading to lower life satisfaction; however, there was an increase in social connection through technology use for some [42]. A study in Ireland by The Irish Longitudinal Study on Ageing (TILDA) on the impact of the pandemic found that almost all community dwelling adults in the general older population visited friends less often (19%) or not at all (80%) during the pandemic; and visited family less often (34%) or not at all (62%). Most TILDA participants also reported an impact on social activities previously engaged in, including leaving the home (69% less often; 14% not at all), attending religious services outside the home (10% less often; 86% not at all), and volunteering (8% less often; 81% not at all), and 37% reported low levels of life satisfaction during the pandemic [43].

In the mental health literature, negative outcomes from COVID-19, such as anxiety, depression, post-traumatic stress disorder, fear and loneliness, have all been reported among the general population [44, 45]. Studies from previous pandemics reported similar short and long-term consequences for mental health following quarantining, restrictions in movement and fears associated with contracting the disease [46]. People with pre-existing mental health conditions have also been reported as at greater risk of experiencing more adverse mental health conditions than those who did not have a mental health illness previously [47]. While an initial decrease in referrals to mental health services in the UK was reported by Tromans, Chester [48], rather than reflecting a decrease in the need for

services, this may have been an attempt by people to adhere to stay-at-home measures, or not recognising changing mental health as medical emergencies. Conversely, Chen, She [49] found accelerated referrals to mental health services in the UK post-lockdown among individuals with pre-existing mental health issues.

The impact of COVID-19 on people with intellectual disability

Over 7,000 people with intellectual disability in Ireland live in grouped residential services, the majority of whom (79%) are aged 40 years or more [50], potentially placing them at increased risk of contracting COVID-19. Health conditions associated with poor COVID-19 outcomes including overweight/obesity, cardiovascular disease, high cholesterol, epilepsy and hypertension are common in this population, while dementia is disproportionately high among adults with Down syndrome [2, 51, 52]. Identified rates of multimorbidity among older adults with intellectual disability of between 53.5% in Australia [53] and 71% in Ireland [54], further raises the potential for adverse COVID-19 outcomes.

Impact of COVID-19 on the health of people with intellectual disability

A previous IDS-TILDA COVID-19 survey in 2020 found that older adults with intellectual disability in Ireland avoided the worst impacts of the early pandemic, especially compared with the general older nursing home population [2]. However, this finding appears something of an anomaly compared to findings internationally, with COVID-19 related mortality rates reported as 3-8 times higher among adults with intellectual disability compared with the general population in one study [5] and 6.3 times higher in another [6]; while a 10-fold increased mortality risk has been reported for people with Down syndrome [7]. A study in the US found that patients with Down syndrome who were hospitalised because of COVID-19 were younger and had more severe disease outcomes [55].

A UK study by Williamson, Walker [56] on behalf of the NHS examined data from 17 million people, finding hazard ratios for adults with intellectual disability (aged 16+) were 5.3 for COVID-19 related hospital admission and 8.2 for COVID-19 related death. A more elevated risk was identified for adults with Down syndrome, with hazard ratios of 10.6 for hospital admission and 36.3 for COVID-19 related death. The consequences of increased incidence were further compounded by apparent differential healthcare responses. Baksh, Pape [57] identified that people with intellectual disability were more likely to require oxygen therapy on admission to hospital, yet were less likely to receive non-invasive respiratory support, intubation, or to be admitted to the ICU. They were found to have had a 56% increased risk of dying from COVID-19 after being hospitalised and were dying 1.44 times faster. Prior to the pandemic, some early deaths of people with intellectual disability were reported as potentially avoidable [58], with avoidable deaths amenable to health care measured as 7.75 times higher than the general population [59], or with potentially in excess of one-third of deaths avoidable [60]; but cause of death is often not investigated [58]. Totsika, Emerson [61] found that older adults with intellectual disability experienced poorer health outcomes during the pandemic compared with those without intellectual disability.

People with intellectual disability also experience the early onset of some age-related health conditions [62]. With COVID-19, this may be an explanation for the significantly lower average age of death found as compared with the general population, reported at 64 years for people with intellectual disability [9] and as low as 51 years for people with Down syndrome [8].

Impact of COVID-19 on the social inclusion, mental health and well-being of people with intellectual disability

Participants in an Irish study reported frustration at the disruption to their daily routine, including the closure of work and day services, and difficulties understanding preventative measures. Participants shared feelings of isolation causing anxiety, fear and panic, missing family and friends, missing sports and holidays, while some reported positive aspects of lockdown such as resilience and increased flexibility in their day [63]. A study of the perceptions of COVID-19 among Spanish people with an intellectual disability found that 91% reported that they had missed either someone or something during that time [64].

A UK study among adults with intellectual disability during the pandemic found that most were able to stay in touch with family and friends as much as they wanted to, but 14% could not; while fewer non self-reporting participants were able to meet family and friends face-to-face, reducing from 32% pre-pandemic to 11% during the pandemic. During the first COVID-19 lockdown, almost all participants (99%) said their community activities had stopped completely or were reduced; day services had stopped completely or were reduced for 89%-98%; and short breaks/respite had reduced or stopped for 92%-95% [65, 66].

Individuals with an intellectual disability experience mental health conditions at a greater prevalence than the general population, with some large-scale studies reporting condition prevalence as high as 50% [67, 68]. Comparison of findings in studies conducted in Ireland on the impact of COVID-19 on the general older population [69] and older adults with an intellectual disability [70] shows that loneliness, stress and anxiety were twice as high in those with an intellectual disability. COVID-19 is therefore both a physical health crisis and a mental health emergency [71]. Gulati, Fistein [72], in highlighting the importance of ensuring that resources remain in place for those with disabilities, raise as a concern staff being redeployed away from mental health and intellectual disability services in response to the pandemic.

Some studies have also identified impacts of the pandemic on the mental health and well-being of support staff. For example, Embregts, Tournier [73] reported staff fears of infection, frustration, and feeling overwhelmed during the pandemic; yet also coping and perseverance by many. McMahon, Hatton [74] found moderate burnout and mild anxiety and depression among staff, but higher levels among staff supporting individuals in independent living settings and individuals with challenging behaviour. A survey by Lunsky, Bobbette [75] found that one in four support workers had moderate to severe emotional distress, but having counselling services available through one's agency, engaging in regular exercise or hobbies outside work, and being older and more experienced were associated with less distress.

Service closures have been a significant cause of anxiety, concern and stress for individuals and their families [76, 77]. For individuals living at home with ageing caregivers, there have been additional negative effects from restrictions such as cocooning, shielding and stay at home directives. While

adhering to these measures, some families provided higher levels of care for their family member with an intellectual disability for fear of the virus being introduced into their family home [78]. For individuals with an intellectual disability who required hospitalisation during the COVID-19 pandemic, the additional negative effects of then being segregated and alone in hospital wards due to visiting restrictions is highlighted by Altshuler and Zeldin [79].

Courtenay, Perera [80] highlight mental health and well-being concerns for individuals with an intellectual disability during lockdown, including obsessional behaviours exacerbated due to increased adherence to hygiene, anxiety and paranoia related to exposure to COVID-19 information leading to behavioural changes, any of which may act as triggers to mental illness. In a study of incident reports conducted in the Netherlands, initial reductions in aggression in participants with intellectual disability were followed by an increase in aggressive incidents following the relaxing of lockdown measures; a worrying trend should this slope continue to increase [81]. Similarly, in an Italian study using the Inter-RAI assessment, aggressive behaviour scores (ABS) did decrease during post-lockdown period but there was also an increased incidence of depressive burden and social isolation measures related to COVID-19 lockdown that had a negative effect on the functional and psychosocial well-being of adults with Down syndrome [82]. Amor, Navas [64] found that 60% of Spanish people with an intellectual disability who participated felt that it had a deleterious effect on their emotional wellbeing, with more women reporting feeling afraid, and those living in disability related services reporting higher levels of anxiety. Although the majority of participants (82.1%) reported that they had received supports during lockdown, 91% reported that they had missed either someone or something during that time.

Lake, Jachyra [83] carried out interviews with individuals with an intellectual disability in Ontario, Canada exploring the impact that COVID-19 and associated restrictions had on their lives. Three major themes emerged following thematic analysis: the impact of the pandemic on daily life and wellbeing, a need for connection and availability, and access to mental health supports.

Participants felt overwhelmed with information (and misinformation), and expressed the need for accessible information on the virus. Participants within this study also expressed resilience and strength and identified ways in which they engaged in mindfulness, journal keeping and attending virtual classes. Participants expressed social and emotional isolation, as well as frustration and exacerbation of pre-existing mental illness. While participants availed of mental health supports virtually, they almost all felt that more supports should be available. Similar themes emerged from a Dutch study by Schuengel, Tummers [81] where participants reported missing social contacts and having people close by, how being housebound had changed daily life and participants also found it hard to understand the preventive measures. Friedman [84] used the POM quality of life tool to compare results between 2019 and 2020 of individuals (N=2284) with an intellectual disability, and each of the following quality of life outcomes were found to be less likely in 2020: participants experiencing continuity and security, interaction with other members of the community, participation in the life of the community, and intimate relationships. Interestingly, choosing personal goals was more likely in 2020, which may suggest that, following day services closures and adaptations in the delivery of services, people may have received more individualised and person-centred supports, however further research is required.

COVID-19 has inevitably had an impact on all areas of life for individuals with an intellectual disability and their families. The research to date is lacking particularly from the perspective of individuals themselves, however feelings of loneliness, isolation, fear and anxiety are reported. People are missing social contacts and the changes to daily life and routines have had an impact. The preventative measures have been largely reported as being difficult to understand and as a source of frustration and anxiety. Some positives have been identified in a number of studies, including increased use of technology to stay in contact and taking up new hobbies, with resilience and resolve among individuals also reported. However, a lack of professional mental health supports has also been reported, with many relying on family and staff for support.



Methods

Methods

Study Aim

The current study aimed to follow and build upon the first IDS-TILDA COVID-19 survey by examining the impact of COVID-19 on older Irish adults with an intellectual disability with regard to: health and COVID-19; responding to COVID-19; infection control behaviours; mental health during COVID-19 pandemic and lockdown; contact with others; life events; positive aspects of the COVID-19 period; frailty; impact of COVID-19 on healthcare utilisation [85]

Background

In January 2021, the Department of Health awarded funding for IDS-TILDA to undertake a second survey of the impact of COVID-19 on older adults with an intellectual disability in Ireland, within the context of the fourth wave of the standing IDS-TILDA longitudinal study. This was to provide longitudinal follow-up on the ongoing impact of COVID-19 on the lives of this population, and to provide a broader and deeper examination of how the pandemic has affected individuals' physical health, mental health and well-being, and their social connection and community participation in the longer term.

Following further review of the international literature, and in consultation with individuals with intellectual disability through the Inclusive Research Network (IRN), as well as the IDS-TILDA Steering Committee and Scientific Advisory Board, the IDS-TILDA team developed a protocol for the second COVID-19 survey [85].

Ethics

Ethical approval for wave 4 of the IDS-TILDA longitudinal study was originally obtained from the Faculty of Health Sciences Research Ethics Committee (REC) at Trinity College, Dublin, in January 2019. The Health Research Consent Declaration Committee (HRCDC) issued a full Consent Declaration for wave 4 of IDS-TILDA in December 2019, facilitating the inclusion of participants with intellectual disability who lacked the capacity to provide informed consent.

An amended wave 4 ethics application to include the first COVID-19 survey was approved by Trinity College REC and by the National Research Ethics Committee (NREC) COVID-19 in May 2020. And an additional amendment request for the second COVID-19 survey was granted by the NREC COVID-19 in April 2021.

Recruitment and sample

The study population is adults with a diagnosed intellectual disability aged 40 years or older living in the Republic of Ireland. The sampling frame for the study included wave 4 participants of the IDS-TILDA longitudinal study (n=739), a representative sample of this cohort in Ireland which was drawn from the National Intellectual Disability Database (NIDD) with support from the Health Research Board (HRB) – see McCarron et al. (2020) for full details [1].

All individuals who took part in wave 4 of the IDS-TILDA longitudinal study were sent accessible study information and invited to participate in the first COVID-19 survey in 2020. Information packs included an accessible easy-to-read study information booklet and consent form. Field researchers then contacted participants by telephone and asked if they wished to participate. For those who said they would like to participate an appointment was made for a time to call back and to conduct the survey interview.

Consent/assent was re-affirmed for the first COVID-19 survey for a total of 710 individuals, a response rate of 96.1% (710/739) among wave 4 participants. For the second COVID-19 survey, consent/assent to participate was achieved in a similar manner, resulting in a final sample of 682 individuals in the current study. With 17 individuals identified as dying between the first and second COVID-19 survey, this gave a response rate of 94.5% (682/722) among surviving wave 4 participants.

Measures

Full details of the specific measures used in the survey may be found in the study protocol, published on HRB Open Research [85]. Many of the measures were drawn from the IDS-TILDA wave 4 protocol, from TILDA protocols, or were drawn from newly emerging international measures used in COVID-19 follow-up studies. The protocol included measures across 11 life areas, as outlined in Table 1a. Survey instruments and scales utilised within the protocol are outlined in Table 1b.

Table 1a. Domains addressed in measures used in the IDS-TILDA COVID-19 Survey II

1. Health and COVID-19
2. Responding to COVID-19
3. Infection control behaviours
4. Mental health during COVID-19 pandemic and lockdown
5. Contact with others
6. Life events
7. Positive aspects of the COVID-19 period
8. Frailty
9. Impact of COVID-19 on healthcare utilisation
10. Vaccinations
11. General impact and most anticipated activity

Table 1b. Survey instruments and scales utilised in the IDS-TILDA COVID-19 Survey II**Survey Instrument / Scale**

- IDS-TILDA COVID-19 survey, McCarron et al., 2021 [2]
- IDS-TILDA Wave 4 protocol
- TILDA COVID-19 survey, Ward et al., 2021 [43]
- Epidemic-Pandemic Impacts Inventory (EPII), Grasso et al., 2020 [86]
- Generalised Anxiety Disorder Assessment (GAD-7), Spitzer et al., 2006 [87]
- Glasgow Anxiety Scale, Mindham & Espie, 2003 [88]
- UCLA loneliness scale, Russell et al., 1980 [89]
- Patient Health Questionnaire (PHQ-9) depression scale, Kroenke et al., 2001 [90]
- Life Events Scale, Hermans & Evenhis, 2012 [91]
- Frailty measures from SARC-F, Woo et al., 2014 [92]; and FRAIL scale items, Morley et al., 2012 [93]

Data collection

The final study protocol was converted to a Computer Assisted Personal Interview (CAPI) for electronic capture of participant data, as used in previous IDS-TILDA data collections. This process was supported by Behaviour and Attitudes, as the contracted company who provided and managed the CAPI system. Existing fieldworkers with extensive previous experience in conducting IDS-TILDA interviews completed additional fieldworker training on conducting remote interviews.

Data collection commenced on 26th May 2021 and was completed at the end of August 2021. As with the first IDS-TILDA COVID-19 survey, participants had the option of doing the interview by telephone or by Zoom video conferencing. Consent/assent was also obtained using this approach, with the fieldworker going through the accessible study information and consent form, before confirming and making a written note of the participant's verbal consent.

As with previous IDS-TILDA waves, individuals could complete their interview in one of three ways – as a self-reported interview without support; as a self-reported interview with support; or with a proxy known well to them responding on their behalf.

In total, 682 participants completed the survey, a response of 94.5% from the 722 surviving IDS-TILDA participants. Table 2 outlines a demographic profile of the current sample.

Table 2. Demographic profile of IDS-TILDA COVID-19 Survey 2 (n=682)

	n	%
Sex (n=682)		
Male	314	46.0
Female	368	54.0
Age (n=682)		
40-49 years	129	18.9
50-64 years	380	55.7
65+ years	173	25.4
Level of Intellectual Disability (n=644)		
Mild	187	29.0
Moderate	283	43.9
Severe-Profound	174	27.0
Aetiology of Intellectual Disability (n=608)		
Down syndrome	125	20.6
Other/unknown aetiology	483	79.4
Residence Type (n=675)		
Residential care	119	17.6
Community group home	337	49.9
Independent/Family	219	32.4

Reporting of results here will be largely descriptive, including both quantitative and qualitative data.



The Impact of Covid-19 on Health & Service Provision

The Impact of Covid-19 on Health & Service Provision

Key Findings

COVID-19 testing, symptoms and outcomes

- Testing for COVID-19 increased from 62.4% of all participants in survey 1 to 75.8% in survey 2. The highest rates of testing was among participants living in residential care (91.8%), which was more than double the rate of participants in independent/family residences (41.2%).
- The rate of positive tests among those who were tested showed a substantial increase from just 2.5% in survey 1 (May 2020) to 12.3% in survey 2; where just 2% (one individual) living in independent/family settings tested positive, compared with 13.9% in residential care and 12.6% in community group homes.
- Participants with moderate intellectual disability were significantly less likely to report testing positive (7.7%) than those with either mild (15.6%) or severe-profound (17%) intellectual disability ($p=0.014$).
- Higher rates of testing positive were reported by residents of grouped accommodation settings (residential care and community group homes) as compared to independent/living with family.
- Rates of testing and positive COVID-19 cases reported for older adults with an intellectual disability are higher than rates for the general population, reported by TILDA in 2021 as 6.2% tested and just 0.2% tested positive, with a further 4% suspected cases.
- Reported COVID-19 like symptoms increased from 10% of participants in survey 1 to 18.2% in survey 2; with cough and fever again the two most common symptoms; compared with 44% reporting symptoms in the general older population in Ireland, where muscle/joint pain and cough were the most common symptoms.
- For two-thirds of the 63 individuals who tested positive, COVID-19 symptoms lasted less than two weeks; eight participants (13.1%) had symptoms for 3-8 weeks; three participants (4.9%) had symptoms for 9-12 weeks; and one individual (1.6%) had yet to recover and had symptoms lasting more than 12 weeks; while 11.5% (7) were asymptomatic.
- Hospitalisations among participants with COVID-19 like symptoms or who tested positive increased slightly from 10.7% in survey 1 to 12% in survey 2.
- Of the 13 participants who were hospitalised, 11 tested positive for COVID-19 including the individual who was admitted to intensive care
- During recruitment, three IDS-TILDA participants were identified as having died and as having COVID-19 – the cause of death has not been confirmed and it is unknown if COVID-19 was a cause.

Vaccines and health behaviours

- Almost all IDS-TILDA participants (99.3%) had received a COVID-19 vaccine, with most receiving the Oxford AstraZeneca vaccine (67.8%) or the Pfizer-BioNTech vaccine (31.9%); with 30.3% experiencing adverse side-effects from receiving the vaccine, most commonly tenderness, swelling or redness of the arm (15.9%) and feeling tired (11.6%).
- Almost eight in ten participants (79.1%) received easy-read accessible information on the government guidelines for the COVID-19 vaccine, while another 18.3% received other information, and just 2.6% received no information. Among those who received the official government information, the majority found it easy to understand (56.2%, 248/441), but 24.5% (108/441) found it 'somewhat difficult' and 19.3% (85/441) found it 'extremely difficult' to understand.
- The number of people who moved from their home during the pandemic increased between survey 1 (7.8%) and survey 2 (10.7%), with isolating remaining the most common reason. Among participants who had symptoms or tested positive, 98.7% had a plan to manage self-isolation, up from 78.7% in survey 1.
- Between 57.3% and 79.2% adhered to recommended infection control behaviours 'often' or 'always', compared with 74% to 98% reported by TILDA for the general older population.
- One in seven participants (14.1%) started taking a new prescribed medication during this pandemic, and 15.4% changed the dose of a prescribed medication; while vitamin D was the prescribed supplement that participants started taking most during the pandemic (12.6%) - where previously 41.5% of IDS-TILDA participants reported taking some Vitamin D supplement.
- People with severe-profound intellectual disability (12.1%) were less than half as likely to eat less healthily during the pandemic compared with people with mild (27.8%) and moderate intellectual disability (25.4%; $p < 0.001$).
- Participants with Down syndrome (66.4%) were the group most likely to spend more time sitting down or being sedentary during the pandemic, and were significantly more likely to do so than participants of other aetiologies (55.3%; $p = 0.025$).

Health service utilisation

- Most participants experienced health related changes since the start of the COVID-19 pandemic, most commonly spending more time sitting/being sedentary (58.2%) and doing less physical activity/exercise (53.7%). Having Down syndrome was associated with being more sedentary, while living in residential care and having severe-profound intellectual disability were associated with doing less physical activity/exercise.
- Around a quarter of participants experienced other health changes – including less medical care than usual, increased health problems not related to COVID-19, and overeating or eating unhealthily.
- Most participants (58.2%) had not made any new healthcare appointments since the beginning of the pandemic in March 2020.
- Around a fifth (18.8%) missed their usual health check during the pandemic, with those aged 65+ years (27.2%) most likely to miss their health check compared to participants aged 50-64 (17%) and 40-49 years (13.1%) ($p=0.007$).
- There was a large reduction in face-to-face meetings with health care professionals with 42.5% -70.8% reporting having seen their health care professional ‘not at all’ or ‘not as much’ but 22.2% to 48% had increased phone/online consultations, the highest with psychiatry and clinical psychology.
- Between in-person and phone/online consultations there was an overall net reduction in level of access to healthcare practitioners of 12.5 – 37.6%.

Impact on physical health

Participants were asked about the impact of the pandemic on their health, including the direct impact of COVID-19 with regard to symptoms, testing and outcomes, as well as health changes not directly related to COVID-19.

COVID-19 like symptoms

A total of 18.2% (124/682) had COVID-19 like symptoms – compared to 10% in the first COVID-19 survey. Figure 2 shows the breakdown of symptoms among demographic groups. People in the younger group, those with Down syndrome, and those living in independent/family residences reported the lowest rates of symptoms, while respondents with mild intellectual disability had the highest, but none of these differences were statistically significant.

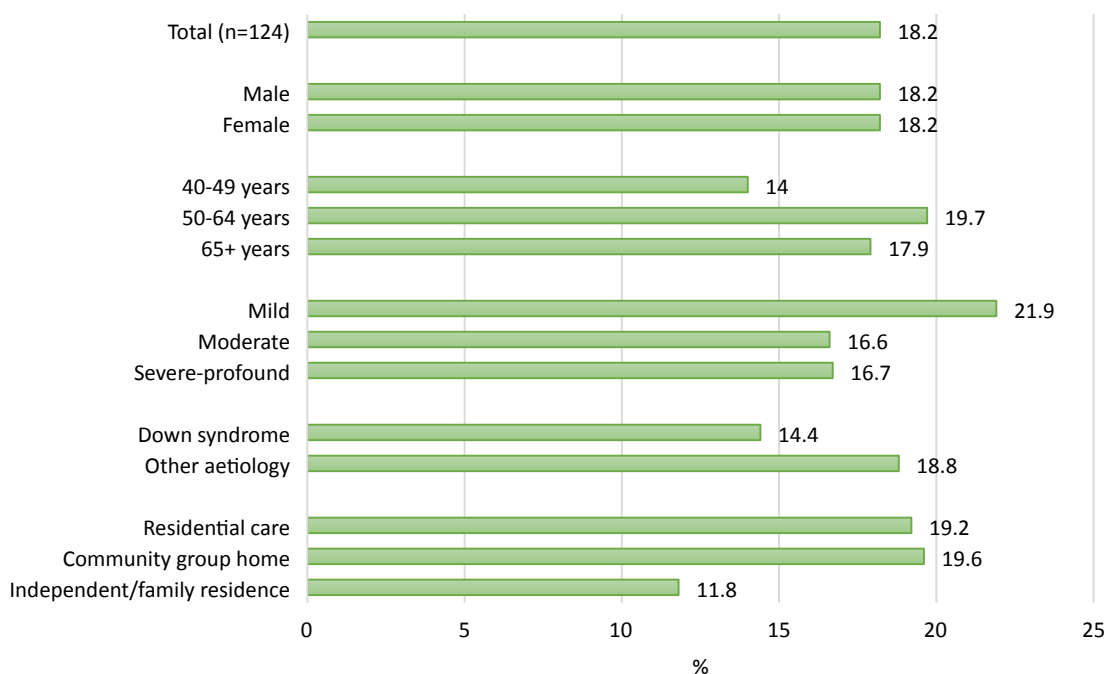


Figure 2. COVID-19 like symptoms by demographic groups

Among the 124 individuals who experienced COVID-19 like symptoms, cough (66.9%) and fever (48.4%) were by far the most common (Figure 3) – similar to the first IDS-TILDA COVID-19 survey but in reverse order, when fever (57.7%) was more commonly reported than cough (43.7%).

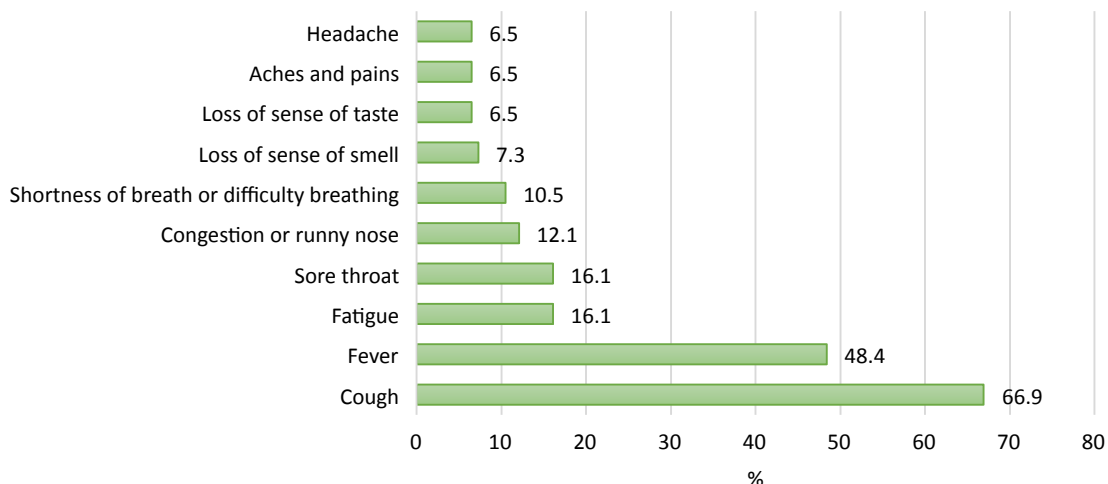


Figure 3. COVID-19 like symptoms reported among those with symptoms (n=124)

COVID-19 testing

In total, 75.8% (517/682) of all participants were tested for COVID-19, compared with 62.4% in the first IDS-TILDA COVID-19 survey. Among those tested in wave 2, 45.1% (231/512) were tested once and 54.9% (281/512) were tested more often. Figure 4 shows that respondents with mild intellectual disability ($p=0.003$) and those living in independent/family residences ($p<0.001$) were significantly less likely to be tested for COVID-19 than others, and there was an increase in rates of testing as age increased, though not statistically significant. These findings are similar to wave 1, when participants living in residential care had the highest rates of testing, and those with severe-profound intellectual disability and those in the oldest age group were also more likely to get tested.

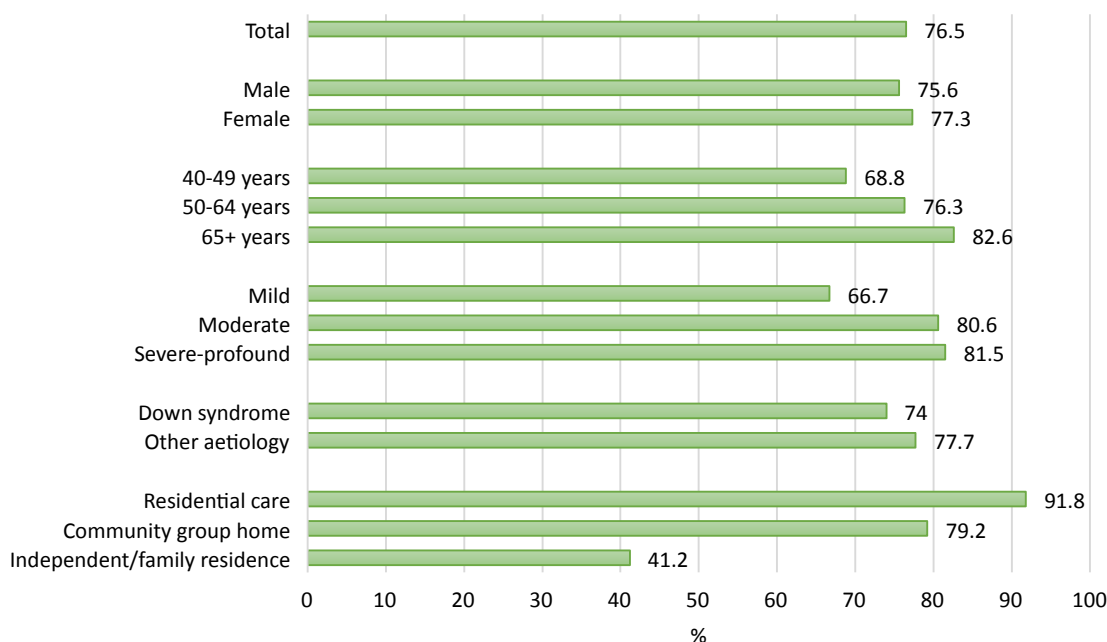


Figure 4. Tested for COVID-19 by demographic groups (n=682)

Among participants who were tested for COVID-19, a total of 12.3% (63/511) tested positive, compared with just 2.5% (11/443) at wave 1. Figure 5 shows that participants with moderate intellectual disability were significantly less likely to test positive (7.7%) than those with either mild (15.6%) or severe-profound (17%) intellectual disability ($p=0.014$). Participants from independent/family residences were far less likely to test positive (2%) than participants living in residential care (14.1%) or community group homes (12.8%), with the difference just outside of statistical significance ($p=0.066$); and participants aged under 65 years were more likely to test positive (11.5-14.3%) than those aged 65 years or older (8.7%), but the difference was not significant ($p=0.246$).

The international literature has identified a number of factors associated with contracting COVID-19, including grouped/congregated residences, mental health diagnosis, and mobility impairment. As shown in Figure 4, the current study identified substantially higher rates of testing positive among residents of grouped accommodation settings (residential care and community group homes).

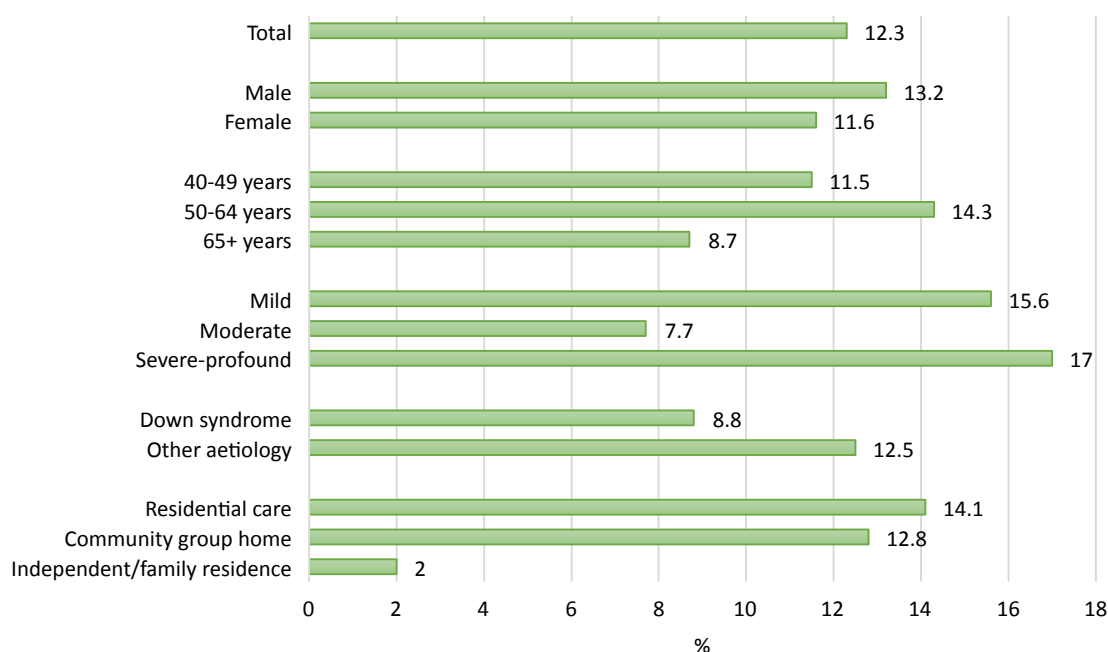


Figure 5. Tested positive for COVID-19 (of those tested) by demographic groups (n=511)

We found no association between mobility impairment (measured as difficulty walking across a room) and testing positive for COVID-19, with almost two-thirds (64.4%) of those who tested positive reporting no mobility impairment ($p=0.611$). Regarding mental health, we found only a marginal difference in rates of positive COVID-19 tests between those with anxiety (13%) and those without anxiety (11.8%, $p=0.824$) (measured with the Glasgow Anxiety Scale). We identified a bigger difference in testing positive for COVID-19 between those with good-excellent self/proxy-rated mental health (11.3%) and those with fair-poor mental health (16.5%), but the difference was not statistically significant ($p=0.162$).

Outcomes for those who tested positive for COVID-19

Participants who tested positive for COVID-19 ($n=63$) were asked about outcomes including duration of symptoms and hospitalisation.

Symptomatic COVID-19

Participants who tested positive for COVID-19 were asked how long their symptoms lasted. For two-thirds, symptoms lasted less than a week (27.9%, 17/61) or 1-2 weeks (41.0%, 25/61). Eight participants (13.1%) had symptoms for 3-8 weeks; three participants (4.9%) had symptoms for 9-12 weeks; and one individual (1.6%) had yet to recover and had symptoms lasting more than 12 weeks. Among those who tested positive, 11.5% (7/61) had no symptoms, compared with four of the 11 individuals (36.4%) who tested positive in wave 1.

Hospitalisation

Among participants who had symptoms and/or tested positive for COVID-19, 12% (13/108) were hospitalised, with one individual admitted to intensive care; compared with 10.7% (8/75) hospitalisations in wave 1. The median length of hospital stay was 3 days, with a range of 0-180 days. Of the 13 participants who were hospitalised, 11 tested positive for COVID-19 including the individual who was admitted to intensive care.

Mortality

While not included in our wave 2 survey sample, three participants of the IDS-TILDA longitudinal study were identified during recruitment as having died and who had COVID-19. Cause of death has not yet been confirmed and it is unknown at this stage if COVID-19 was a factor in these instances.

Health changes since start of the pandemic

Participants were asked about changes in their physical and behavioural health since the beginning of the pandemic which were not related to COVID-19. Figure 6 shows that a majority reported spending more time sitting down/being sedentary, and getting less physical activity or exercise during this period. Around a quarter reported increases in health problems, getting less medical care, and eating unhealthily.

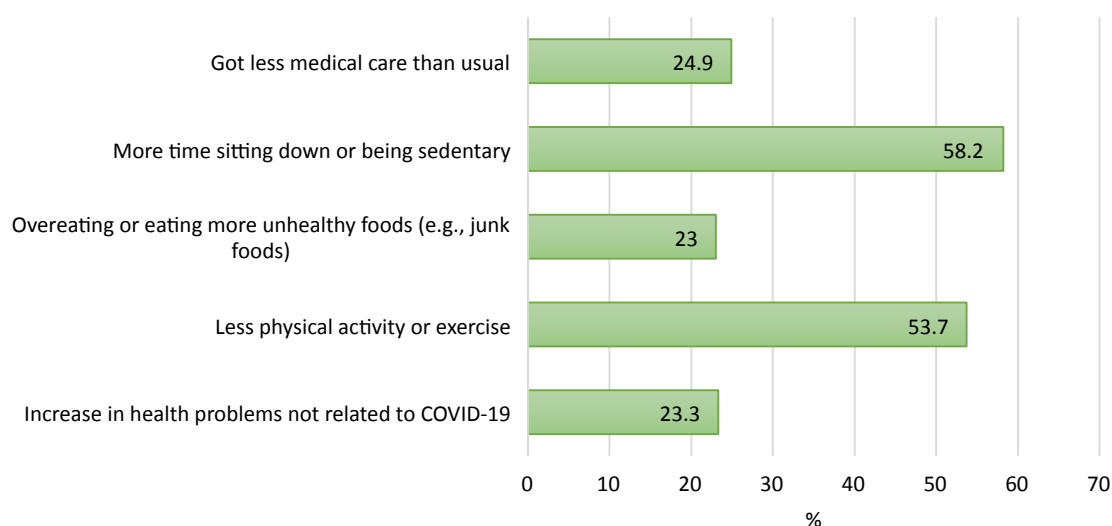


Figure 6. Changes in health since the start of the pandemic (n=682)

Figures 7-11 outline differences between demographic groups within the sample who reported changes in health during the pandemic.

Increase in health problems

There were significant differences in increased health problems during the pandemic based on level of intellectual disability. People with a moderate (26.1%) and severe-profound level (27%) were more likely to report an increase in health problems compared with people with mild intellectual disability (17.1%; $p=0.039$) (Figure 7). There was a notable increase in health problems as age increased; and participants residing in residential care and community group homes reported a greater increase in health problems compared with those in independent and family settings; but these differences were not statistically significant.

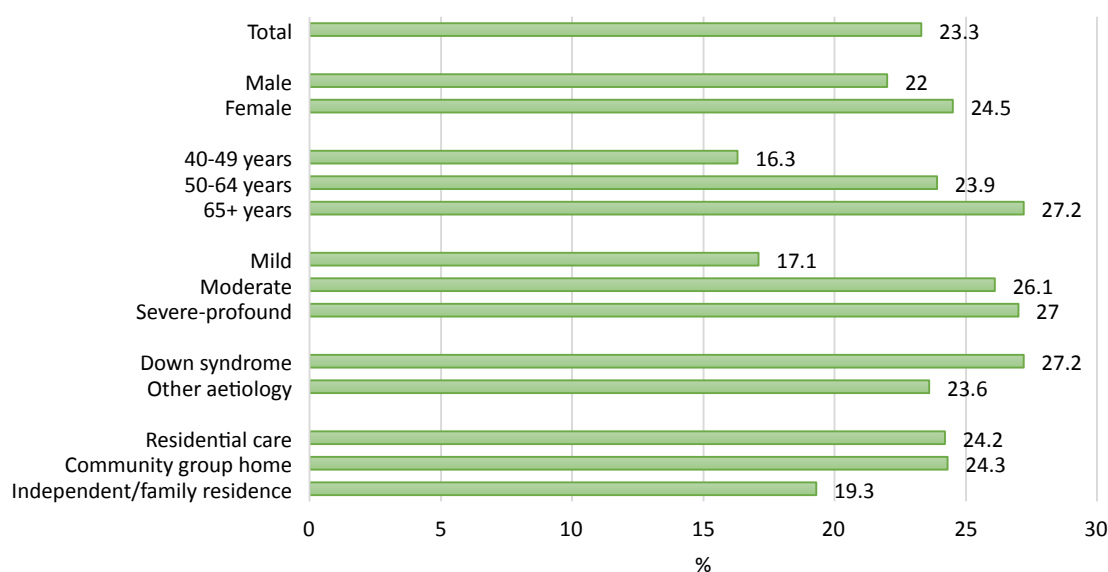


Figure 7. Increase in health problems during the COVID-19 period by demographic groups (n=682)

Physical activity and exercise since the COVID-19 period began

There was a significant reduction in physical activity/ exercise, which was related to both level of intellectual disability and living circumstances (Figure 8). Lower levels of physical activity were reported across all groups, but fewer people with mild intellectual disability (42.2%) were impacted compared with those with a moderate (55.8%) and severe-profound level (60.9%) ($p=0.001$); and people living in independent/family settings were the least impacted (47.1%), even though almost half reported reduced activity, compared with people living in community group homes (51.3%) and those living in residential care (61.2%). More participants were affected among the older age groups, but differences due to age were not significant.

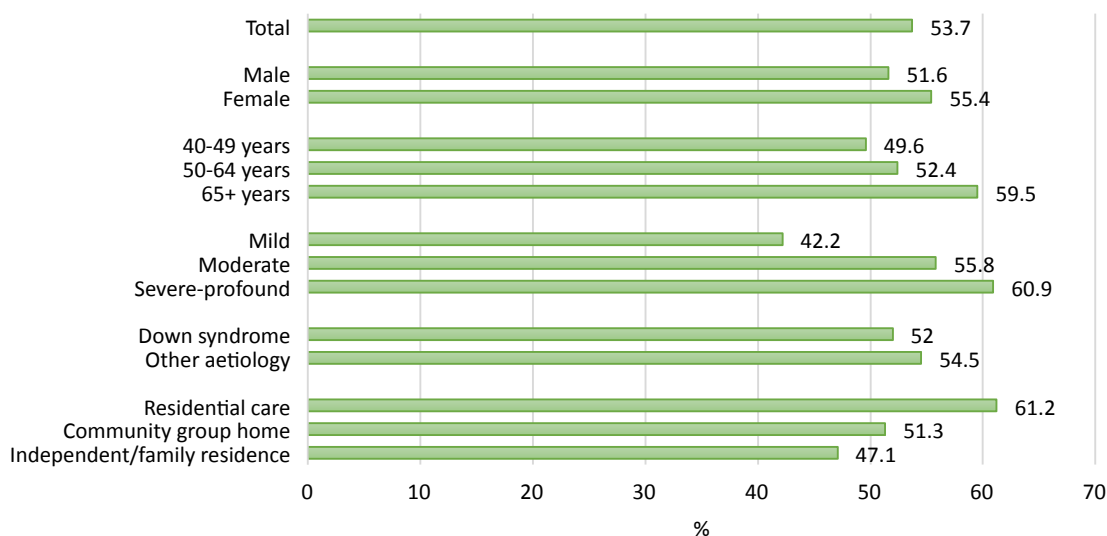


Figure 8. Less physical activity or exercise during the COVID-19 period by demographic groups (n=682)

Overeating or eating more unhealthy foods

There were also significant differences by level of intellectual disability and residence type for overeating or eating more unhealthy foods (Figure 9). People with severe-profound intellectual disability (12.1%) were less than half as likely to eat less healthily during the pandemic compared with people with mild (27.8%) and moderate intellectual disability (25.4%; $p < 0.001$); and a similar pattern was observed regarding residence type, where people living in residential care (16.9%) were half as likely to eat unhealthily compared with those living in independent/family settings (32.8%), with residents of community group homes between these two groups (23.7%; $p = 0.004$). Notably, comparatively fewer participants among the older groups reported increased unhealthy eating, but differences between age groups were just outside of statistical significance.

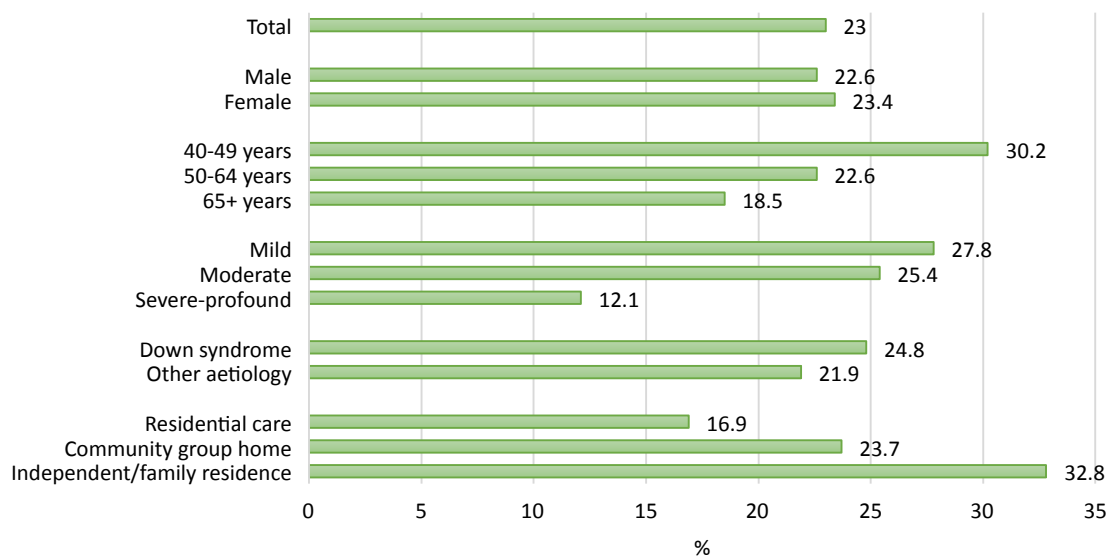


Figure 9. Overeating or eating more unhealthy foods (e.g., junk foods) since the COVID-19 period began by demographic groups (n=682)

More time sitting or being sedentary

Participants with Down syndrome (66.4%) were the group most likely to spend more time sitting down or being sedentary during the pandemic, and were significantly more likely to do so than participants of other aetiologies (55.3%; $p=0.025$) (Figure 10). Participants in the younger age groups were more likely to spend more time sitting or being sedentary than older participants, but these differences were not significant.

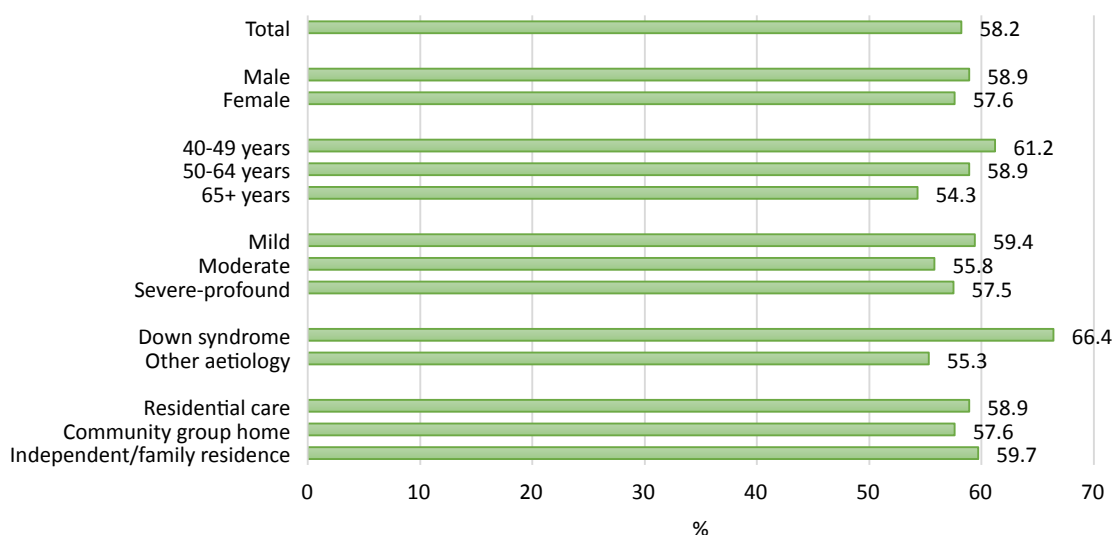


Figure 10. More time sitting down or being sedentary during COVID-19 by demographic groups (n=682)

Got less medical care than usual

There were no significant differences among demographic groups for receiving less medical attention than usual during the pandemic (Figure 11). The highest rates of receiving less medical attention were reported among the oldest participants, participants with Down syndrome, and participants living in community group homes; while the lowest rate was among people living in residential care.

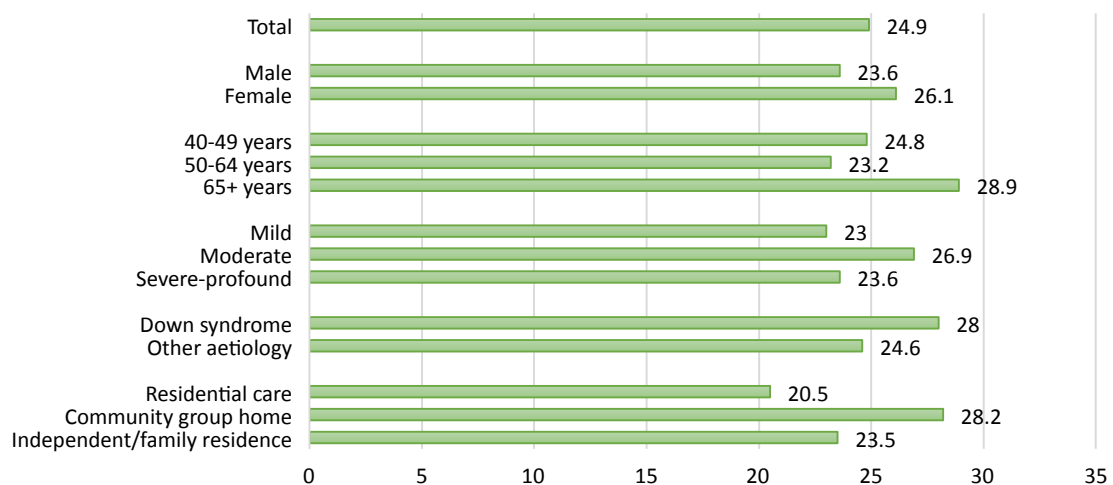


Figure 11. Got less medical care than usual during COVID-19 by demographic groups (n=682)

Responses to the pandemic

Moving from home and isolation measures

One in ten participants (10.7%, 73/681) moved from their usual home during the pandemic, compared with 7.8% (55/705) in wave 1. As in wave 1, the most common reason for moving from home during wave 2 was to isolate as a precaution or while awaiting test results (30.6%, 22/72), followed by relocating to a family residence and isolating after discharge from hospital (Figure 11).

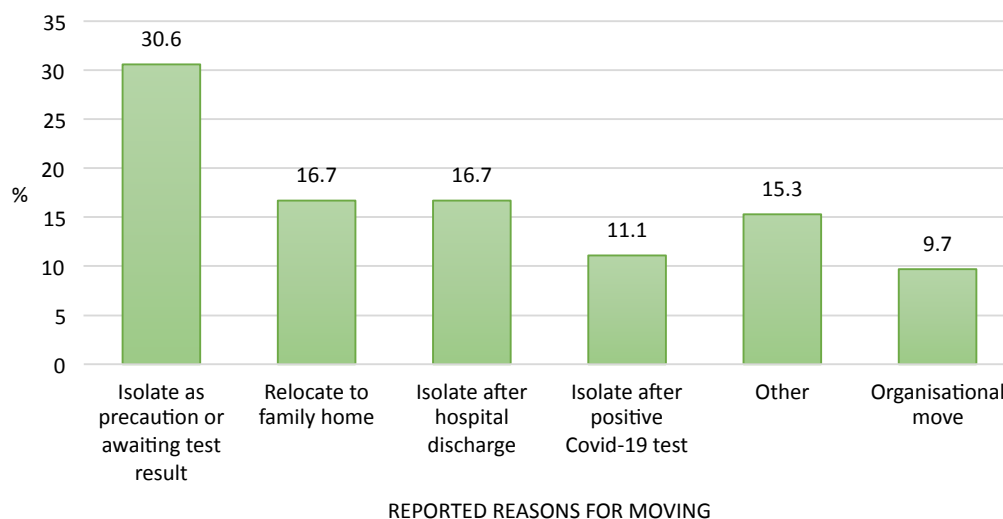


Figure 12. Reasons for moving from your home during the pandemic (n=72)

Among participants who had symptoms and/or tested positive for COVID-19, almost all (98.7%, 116/118) had a plan in place to manage self-isolation in line with COVID-19 guidelines – an increase from the 78.7% reported among this cohort in wave 1.

Infection control responses

Participants were questioned about their response to public health guidance for infection control. Figure 13 shows that between 57.3% and 79.2% of respondents adhered to the recommended behaviours either 'often' or 'always'. The behaviour least adhered to was paying special attention to covering coughs and sneezes, but this was still followed 'often' (13.6%) or 'always' (43.7%) by a majority of participants.

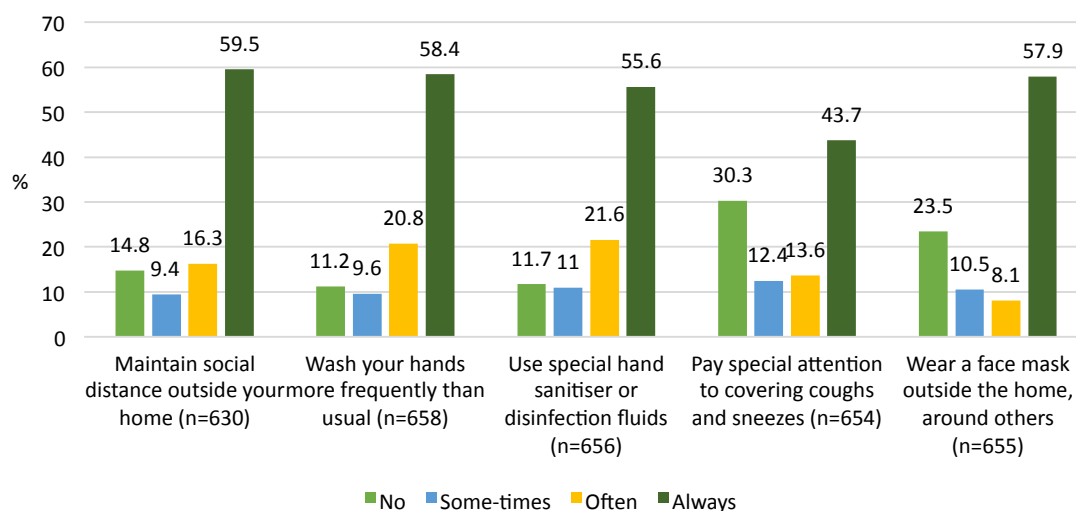


Figure 13. Adherence to public health guidelines for infection control during the pandemic

Healthcare utilisation during the pandemic

Some participants reported that they had planned healthcare appointments cancelled during the pandemic (Figure 13). The most commonly reported cancellation was a medical test/screening, reported by around one in five (19.6%); while 12.6% had a day hospital appointment cancelled, and 15.2% had another type of appointment cancelled.

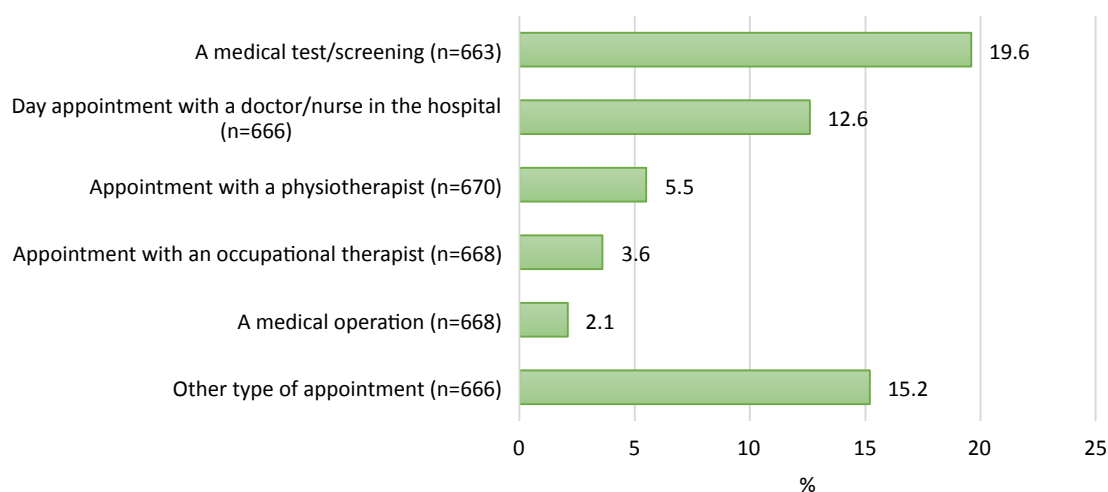


Figure 14. Planned appointments cancelled since the start of the pandemic

The vast majority of participants (94.3%, 630/668) reported that they normally had an annual health check. Among these participants, a large majority reported having their annual health check since the start of the pandemic in March 2020. Most of these checks were in person (73.7%, 446/605) but also a small amount by video/phone call 4.8% (29/605), while a further 2.6% (16/605) had an appointment booked. Almost one in five participants (18.8%, 114/605) who normally had an annual health check had not had their check since the start of the pandemic.

Figure 15 shows that participants aged 65+ years (27.2%) were significantly more likely not to have had their regular health check since the start of the pandemic compared with those aged 50–64 (17%) and 40–49 years (13.1%) ($p=0.007$). Participants from other aetiologies (20%) were more likely not to have had their health check compared with participants with Down syndrome (14.8%), and those living in independent/family settings (21.3%) and community group homes (20.9%) were more likely than those in residential care (15.5%) not to have had their health check, but these differences were not statistically significant.

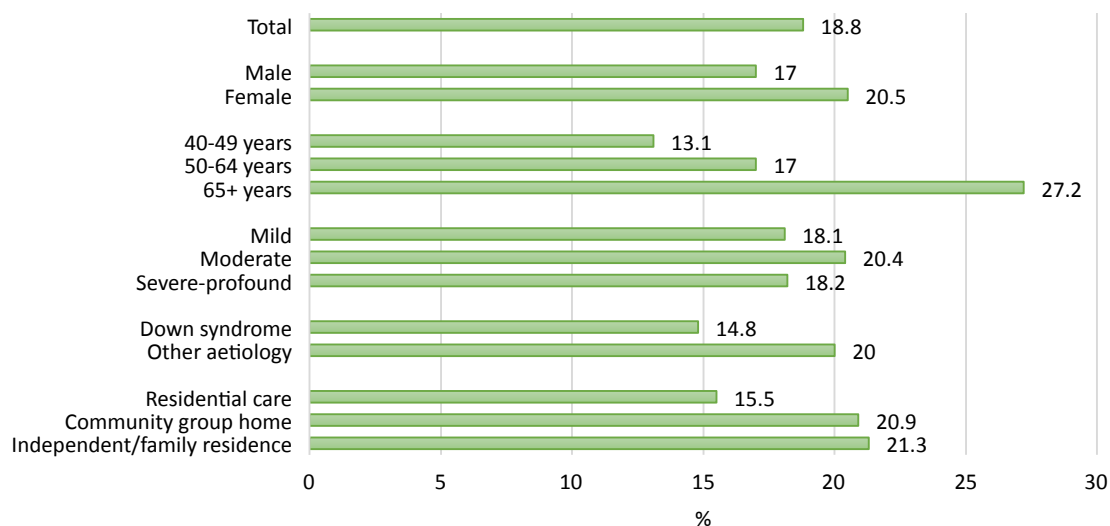


Figure 15. Did not have annual health check since start of the pandemic by demographic groups (n=605)

Participants were asked if they normally saw a range of healthcare professionals at least once a year prior to the start of the pandemic in March 2020, and if they did whether they had seen those professionals since the start of the pandemic (Table 3). The vast majority saw their GP at least annually pre-pandemic (96.9%), but many also saw other healthcare professionals, including 44.3% had a consultation with a psychiatrist, 35% with a speech and language therapist, and 29.8% with a physiotherapist.

Those who saw healthcare professionals at least annually pre-pandemic were asked how often they had seen them since the pandemic started in March 2020, either in person or by phone/online. As may be seen in Table 3, between 42.5% and 70.8% reported seeing their health professionals in person either ‘not at all’ or ‘not as much’ during the pandemic. Of these, psychiatry (70.8%) and clinical psychology (61.2%) were the most impacted. On the other hand, all health professionals were seen by phone/online either ‘the same’ or ‘more’ by a majority of participants who previously saw them regularly pre-pandemic. Between 22.2% and 48.0% saw health professionals by phone/online more during the pandemic, with psychiatry (48.0%) and clinical psychology (42.6%) the professions to show the greatest increase in phone/online consultations with participants. Between 14% and 30% of participants consulted the named health professionals not at all or less by phone/online during the pandemic; the highest named being counsellor (30%), social worker (28.2%) and physiotherapist (25.5%). However, 45.3% also noted consulting ‘other’ unnamed healthcare professionals, who they normally consulted pre-pandemic, not at all or less during this period.

Table 3. Frequency of seeing healthcare professionals since the start of the pandemic

Healthcare professional	Saw annually pre-pandemic n (%)	Saw in person during pandemic n (%)				Saw online/phone during pandemic n (%)			
		Not at all	Not as much	The same	More	Not at all	Not as much	The same	More
General Practitioner	653 (96.9)	95 (14.7)	204 (31.5)	333 (51.5)	15 (2.3)	47 (9.0)	42 (8.0)	246 (47.0)	188 (35.9)
Psychiatrist	295 (44.3)	126 (44.4)	75 (26.4)	74 (26.1)	9 (3.2)	25 (10.0)	10 (4.0)	95 (38.0)	120 (48.0)
Clinical psychologist	169 (25.5)	64 (38.8)	37 (22.4)	60 (36.4)	4 (2.4)	17 (11.5)	9 (6.1)	59 (39.9)	148 (42.6)
Counsellor	25 (3.8)	6 (24.0)	8 (32.0)	11 (44.0)	0	6 (25.0)	1 (5.0)	7 (35.0)	7 (35.0)
Social worker	112 (16.8)	39 (35.1)	20 (18.0)	43 (38.7)	9 (8.1)	14 (15.2)	12 (13.0)	38 (41.3)	28 (30.4)
Nurse specialist	185 (27.9)	36 (19.9)	47 (26.0)	93 (51.4)	5 (2.8)	15 (10.4)	10 (6.9)	78 (54.4)	41 (28.5)
Speech & language therapist	234 (35.0)	68 (30.1)	52 (23.0)	97 (42.9)	9 (4.0)	26 (13.8)	18 (9.5)	95 (50.3)	50 (26.5)
Occupational therapist	189 (28.4)	31 (16.7)	48 (25.8)	100 (53.8)	7 (3.8)	22 (13.9)	12 (7.6)	89 (56.3)	35 (22.2)
Physiotherapist	199 (29.8)	35 (18.2)	56 (29.2)	96 (50.0)	5 (2.6)	25 (15.9)	15 (9.6)	80 (51.0)	37 (23.6)
Other	187 (28.0)	58 (32.0)	43 (23.8)	76 (42.0)	4 (2.2)	48 (34.5)	15 (10.8)	43 (30.9)	33 (23.7)

When in-person and remote methods of consultation used during the pandemic are combined, we may observe the net effect of utilisation of these healthcare professionals during this period (Table 4). Here we can see an overall net reduction in combined consultations of between 12.5% and 37.6% across the range of healthcare professionals.

Table 4. Frequency of seeing healthcare professionals since the start of the pandemic – combined in-person and online/phone consultations

	Combined Consultations % (In Person & Remote)					
	Not at all	Not as much	The same	More	Total	Net Service Use
General Practitioner	11.9	19.8	49.3	19.1	100	-12.5%
Psychiatrist	27.2	15.2	32.1	25.6	100	-16.8%
Clinical psychologist	25.2	14.3	38.2	22.5	100	-16.9%
Counsellor	24.5	18.5	39.5	17.5	100	-25.5%
Social worker	25.2	15.5	40.0	19.3	100	-21.4%
Nurse specialist	15.2	16.5	52.9	15.7	100	-16.0%
Speech & language therapist	22.0	16.3	46.6	15.3	100	-23.0%
Occupational therapist	15.3	16.7	55.1	13.0	100	-19.0%
Physiotherapist	17.1	19.4	50.5	13.1	100	-23.4%
Other	33.3	17.3	36.5	13.0	100	-37.6%

Participants were asked if they had made any new healthcare appointments since the beginning of the pandemic in March 2020. Just over a third of respondents (36.5%, 242/663) said they had made a new appointment during that period. Over half said they had not made any new appointments (58.2%, 386/663), and perhaps did not have a need for such appointments. A small number of participants said they had tried but were unable to make a new appointment (5.3%, 35/663).

Changes in medication

Participants were asked about changes in medications during the pandemic. Just 3.7% (25/682) had stopped taking a prescribed medication, but 14.1% (96/682) had started taking a new prescribed medication during this period, while 15.4% (105/682) had changed the dose of a prescribed medication.

Participants were also asked if they had started taking any health supplements during the pandemic. Table 5 shows that vitamin D was the supplement that participants started taking most during the pandemic (12.6%) - where previously 41.5% of IDS-TILDA participants reported taking some Vitamin D supplement.

Table 5. Started taking health supplement during the pandemic (n=682)

Supplement	Yes (n)	Yes (%)
Vitamin D	86	12.6
Other	55	8.1
Multivitamin	25	3.7
Vitamin C	22	3.2
Iron	8	1.2
Fish oil/omega	5	0.7
Any B supplements	5	0.7
Folic acid	3	0.4
Zinc	2	0.3

COVID-19 vaccines

Almost eight in ten participants (79.1%, 522/660) received easy-read accessible information on the government guidelines for the COVID-19 vaccine, while another 18.3% (121/660) received other information, and just 2.6% (17/660) received no information. Among those who received the official government information, the majority found it easy to understand (56.2%, 248/441), but 24.5% (108/441) found it 'somewhat difficult' and 19.3% (85/441) found it 'extremely difficult' to understand.

Almost all participants (99.3%, 675/680) had been given a COVID-19 vaccine, including those fully vaccinated with two doses (84.4%, 574/680) or one dose (3.5%, 24/680), and those who received a first dose and were waiting for their second (11.3%, 77/680). Just 0.7% (5/680) had not been vaccinated.

Two-thirds of participants who had been vaccinated received the Oxford AstraZeneca vaccine (67.8%, 444/655), 31.9% (209/655) received the Pfizer-BioNTech, while just one individual was given the Janssen vaccine, and one was given the Moderna vaccine.

Participants were asked if they experienced any side effects from receiving the COVID-19 vaccine. Overall, 30.3% (202/666) of participants experienced side effects from the vaccine with the most common side effect reported being tenderness, swelling or redness of the arm where the vaccine was received, followed by feeling tired (Table 6).

Among those who experienced side effects, two-thirds (65.2%, 163/250) reported that the side effect(s) lasted for less than 24 hours, a further 24.8% (62/250) said the effects lasted for 24-48 hours, and 10% (25/250) said they lasted for more than 48 hours.

Table 6. Side effects experienced from the COVID-19 vaccine (n=675)

Side effect	Yes (n)	Yes (%)
Tenderness, swelling or redness of the arm	107	15.9
Feeling tired	78	11.6
Fever	32	4.7
Headache	28	4.1
Nausea	17	2.5
Muscle pain	11	1.6
Other	7	1
Sleeplessness	5	0.7
Joint pain	4	0.6
Itchiness where you had the vaccine	1	0.1

Finally, participants were asked what it meant to them to have been given the vaccine. Table 7 provides a small selection of participant responses. Many participants spoke about their relief and excitement of receiving the vaccine, and how it meant being able to see loved ones again and a return to their valued activities.

Table 7. What does it mean for you to have had the vaccine?

“Delighted and happy, can’t wait for the other one so I can start travelling again next year”.

“I was delighted. Anything to get rid of this beast of a virus and be free of it”.

“I was thrilled to get it. I didn't want to get the virus and I want to be healthy and I'm glad I got it”.

“I'm happy. I was very excited. I could go back to work”.

“Nervous. I got it over it pretty quickly, but it was a shock to the system at first”.

“Best thing is that I can go out and about, can come into centre, can go to parents for the day”.

“I am brave. It will keep me safe. I anxious and nervous”.

“I am excited to get back out to meet my friends and go for coffee”.

“I am happy to get it. I don't know why”.

“I can be an independent lady. I can go and see my boyfriend and my dad. I'm going to the pub for a pint of Smithwicks”.

“I can get back to work and see my girlfriend. I can meet my cousins and go to the pub. I am a DJ and would do some gigs in the local pubs”.

Summary: Impact on Health and Service Provision

Findings presented in this chapter illustrated how the COVID-19 pandemic had a significant impact on the health and service utilisation of many older adults with intellectual disability in Ireland. A more extensive survey of experiences for this second wave has built upon the first wave and demonstrated the impact of the pandemic on this population over a longer period.

Testing for COVID-19 increased from 62.4% of all participants in wave 1 to 75.8% in wave 2. The highest rate of testing was among participants living in residential care (91.8%), which was more than double the rate of participants in independent/family residences (41.2%). People with mild intellectual disability were also significantly less likely to have been tested compared with those with moderate-profound intellectual disability. The rate of positive tests among those who were tested showed a substantial increase from just 2.5% in wave 1 to 12.3% in wave 2. The most notable difference among participants related to residence type, where just 2% (one individual) living in independent/family settings tested positive, compared with 13.9% in residential care and 12.6% in community group homes.

Comparative rates of testing and positive tests for COVID-19 among the general older population in Ireland were far lower than those reported here. TILDA reported, notably at an earlier stage of the pandemic and among community dwelling persons, that just 6% reported a negative test and 0.2% reported a positive test for COVID-19. Even accounting for an additional 4% with self-suspected cases (3.5%) or doctor-suspected cases (0.5%), rates of testing and of cases of COVID-19 remain lower than reported here [43]. In the UK, a longitudinal study of people with intellectual disability by Flynn et al. (2021) surveyed participants about testing for COVID-19, including a first self-reporting cohort of people with intellectual disabilities and a second cohort of proxy respondents for individuals with intellectual disability who were unable to self-report, primarily those with severe-profound intellectual disability. They found at wave 1 in March 2021 that 31-37% of participants had been tested for COVID-19. Individuals with intellectual disability living with their family were between 1.8 times (cohort 1) and 2.8 times (cohort 2) less likely to have been tested for COVID-19 [66]. At wave 2 in July 2021, 10% of cohort 1 and 13% of cohort 2 were confirmed or suspected as having COVID-19, including 5% and 9% confirmed by diagnosis or test respectively [94]. At wave 3 in September 2021, 38% and 37% reported being tested in the preceding four weeks [65].

Our data showed an increase in COVID-19 like symptoms reported, from 10% in wave 1 to 18.2% in wave 2; with cough and fever the two most common symptoms, as in wave 1. This compares with 44% among the general older population (60+ years) in Ireland, where muscle and joint pain (17%) and cough (9%) were the most common symptoms. For two-thirds of our 63 participants who tested positive, symptoms lasted for less than two weeks; while 11.5% were asymptomatic – compared to 36.4% in wave 1, although numbers who tested positive were much smaller (11 individuals). In the UK study, 10% in cohort 1 and 6% in cohort 2 had not fully recovered more than a month after contracting COVID-19 [94].

Hospitalisations among our participants who had symptoms or tested positive increased slightly from 10.7% in wave 1 to 12% in wave 2. While not included in our wave 2 study sample, during recruitment we identified three participants of the IDS-TILDA longitudinal study who had died and who had COVID-19 – though the cause of death has not been confirmed and it is unknown if COVID-19 was a factor. Our data compares with a hospitalisation rate of 4.2% and death rate of 1.2% among confirmed cases of COVID-19 in the general Irish population [95]. In the UK study, between 20% (n=4) and 31% (n=5) of people with intellectual disability with a confirmed or suspected case of COVID-19 were hospitalised, though numbers reported are small [65].

There was a small increase in the number of people who moved from their home during the pandemic between wave 1 (7.8%) and wave 2 (10.7%), while the most common reason remained to isolate as a precaution or while awaiting test results. Among participants who had symptoms or tested positive, 98.7% had a plan to manage self-isolation, up from 78.7% in wave 1. A majority of participants (between 57.3% and 79.2%) reported adherence to recommended infection control behaviours, such as social distancing and wearing a mask, either ‘often’ or ‘always’. TILDA reported higher adherence among the general older population in Ireland, with 97% adhering to social distancing ‘often’ or ‘always’, 98% washing their hands more often, 92% using hand sanitiser, 98% paying close attention to coughs and sneezes, and 74% wearing a mask when around other people outside the home [43].

A majority of participants experienced changes in their health since the start of the COVID-19 pandemic. The most commonly reported health changes were spending more time sitting/being sedentary and doing less physical activity/exercise, both of which were reported by more than half of respondents. Having Down syndrome was associated with being more sedentary during the pandemic; while living in residential care and having severe-profound intellectual disability were associated with doing less physical activity/exercise. TILDA found that, while 69% of the general older population in Ireland reported leaving their home less often during the pandemic, a majority did some physical activities either 'about the same' or 'more often', including exercise at home (48% about the same; 16% more often); walk outside your home for more than 20 minutes (37% about the same; 26% more often); and doing garden work or home repair (35% about the same; 44% more often) [43]. In the UK survey, prior to lockdown (December 2020), 78% of cohort 1 reported leaving the house for outdoor exercise, but this was just 21% for cohort 2; however, during lockdown in early 2021, these figures fell to around 63% and 10% respectively [66].

Around a quarter of IDS-TILDA respondents also reported other health changes – including less medical care than usual, increased health problems not related to COVID-19, and overeating or eating more unhealthy foods. People with mild intellectual disability were less likely to report increased health problems not related to COVID-19, but people with severe-profound intellectual disability were far less likely than others to overeat or eat unhealthily. People in residential care were also less likely to overeat or eat unhealthily compared with residents of community group homes, while those living independently or with family were the most likely to do so.

The vast majority of participants said they usually had an annual health check prior to the pandemic, and most of these had completed (or booked) their regular check during the pandemic. However, 18.8% did not have their regular health check, and those aged 65+ years were significantly more likely not to have had their health check. Between 42.5% and 70.8% of participants had seen previously seen health professionals in person 'not at all' or 'not as much' during the pandemic, with the highest impact in psychiatry and clinical psychology. This may have been alleviated to some degree by between 22.2% and 48% reporting an increase in phone/online consultations, with the highest rates for psychiatry and clinical psychology. When the methods of consultation (in-person and online/phone) were combined, a net reduction in utilisation of healthcare professionals of 12.5-37.6% was observed. A small number of participants (5.3%) said they had tried but were unable to make a new appointment.

TILDA reported that 30% of the general population aged 60+ years either delayed or did not receive medical care that they needed during the pandemic. Most commonly, the reason was that the care could wait (39%), but 25% said the appointment was cancelled, 21% said they were unable to get an appointment when needed, while 18% reported being afraid to attend an appointment. Services most commonly delayed or not received when needed included dental care (43%), GP (31%), optician (19%), other services (12%) and delays in minor surgery (10%). TILDA also found that 46% of participants had telephone or online appointments with a GP during the pandemic, 39% with a pharmacist, 21% with a hospital doctor, and 10% with another health professional [43]. In the UK study, over 60% of people with intellectual disabilities who had routinely seen a healthcare practitioner prior to the pandemic (including GP; community nurse; psychiatrist, clinical psychologist, or counsellor; and speech and language, occupational therapist, or physiotherapist) had seen these practitioners less or not at all since the first lockdown in March 2020. Additionally, 22-28% had a planned medical test cancelled, 4-5% had

a planned operation cancelled, and 23-41% had a planned hospital appointment cancelled; while 46% of participants who usually had an annual health check prior to the pandemic had not had their health check since the first lockdown [66].

Finally, almost all IDS-TILDA participants (99.3%) had received a COVID-19 vaccine, with most receiving the Oxford AstraZeneca vaccine (67.8%) or the Pfizer-BioNTech vaccine (31.9%). This compares with around 90% of the general population aged 12+ years who have received a COVID-19 vaccination, most of which (72.8%) were Pfizer-BioNTech, 16.2% Oxford AstraZeneca, 7.8% Moderna, and 3.2% Janssen [96]. High vaccination rates reported here are similar to those reported in the UK, where 92% of people with intellectual disabilities had received both doses of their COVID-19 vaccine; while the vast majority (87%) also indicated a willingness to take a booster shot of the COVID-19 vaccine during the autumn/winter 2021 should it be required [65]. While IDS-TILDA participants were not questioned about a booster vaccination dose, the huge level of uptake of the vaccine when originally offered would suggest a willingness at least on a par with that expressed by people with intellectual disability in the UK. Overall rates of experiencing adverse side-effects from receiving a COVID-19 vaccine reported here (30.3%) compare to rates of systemic (whole body) side-effects of 13.5-22% and local side effects of 58.7-71.9% reported in one general population study [97].



The Impact of COVID-19 on Social Inclusion

The Impact of COVID-19 on Social Inclusion

Key Findings

Contact with family and friends

- Nine in 10 participants had less face-to-face contact with non-resident family during the pandemic. People living in residential care and community group homes were more impacted by reduced face-to-face contact with their family, compared with those living independently or with family.
- Reduced face-to-face contact with family may have been alleviated by an increased use of technology to speak to family, experienced by over half (55.9%) of participants. This may explain why independent/family residents were less likely to report contact using technology.
- Eight in 10 participants had less face-to-face contact with non-resident friends; while people with mild (85.6%) and moderate intellectual disability (81.1%), were more impacted than participants with severe-profound intellectual disability (59%), who had higher proportions of co-resident friends.
- Reduced face-to-face contact with friends may also have been alleviated by increased use of technology to speak to friends during the pandemic, reported by half of participants. More people with mild intellectual disability (57.6%) had increased use of technology to speak with friends, compared with less than half with moderate (46.5%), and a third with severe-profound intellectual disability (35%).

Social and community participation

- A majority of participants reported a restricted lifestyle: unable to do enjoyable activities or hobbies (83.9%); separation from family or close friends (79.8%); reduced work hours or hours of day service (69.5%); religious or spiritual activities cancelled or restricted (62.8%); family celebrations cancelled or restricted (62.2%); planned travel or vaccinations cancelled (58.4%); and being unable to participate in social clubs, sports teams, or volunteering (58.2%).
- A number of participants also reported: an increase in verbal arguments or conflict with other adult(s) at home (21.6%); not having the ability or resources to talk to family or friends while separated (18.9%); being unable to attend in-person funeral or religious services for a family member or friend who died (17.6%); unable to visit loved one in a care facility (11.1%); unable to be with a close family member in critical condition (6.9%); and an increase in physical conflict with other adult(s) in home (4.8%).
- More younger participants were affected by reduced work/day services, cancelled/reduced family celebrations, and cancelled travel plans; while more older participants were impacted by cancelled/restricted religious or spiritual activities.

- Participants with a milder level of intellectual disability were more impacted by being unable to do their activities or hobbies; having reduced work or day service hours, participation in social clubs, sports teams and volunteering; and not attending in-person funeral services for family or friends.
- Separation from family or close friends was reported most among residents of community group homes (85.8%), compared with participants living in residential care (75.3%) and independent/family settings (70.6%).
- Participants living independently or with family were impacted most across a number of measures, followed by community group home residents, with those in residential care the least affected – these included measures of reduced work or day service hours; cancellation of planned travel; and reduced participation in social clubs, sports teams and volunteering.
- Participants with Down syndrome were more restricted (67.2%) in participating in their clubs, teams and volunteer activities, compared to 55.1% of participants with intellectual disability of other aetiologies.
- Women were more affected by cancelled or restricted religious or spiritual activities (68.8%), compared to male participants (55.7%).

Impact on contact with family

Participants were asked about how the pandemic had impacted different forms of communication and connection with their families, including meeting face-to-face, written communication and using technology to speak.

Impact on face-to-face contact with family

The vast majority of participants (87.8%, 553/630) reported less face-to-face contact with family members during the pandemic. Just 7.5% (47/630) had no change in family contact, while 4.8% (30/630) reported more contact with family during this period.

Figure 16 shows changes in face-to-face contact with family by demographic groups. There was little variation across gender and different levels and aetiologies of intellectual disability. However, there was a significant difference between residence types, with participants living in independent/family settings (78.2%) less impacted by reduced contact than those in community group homes (91.7%) and residential care (87.1%) ($p=0.001$). Participants in the 40-49 years age group (81.8%) were also less impacted than older participants (87.7-89.9%), but these differences were not statistically significant.

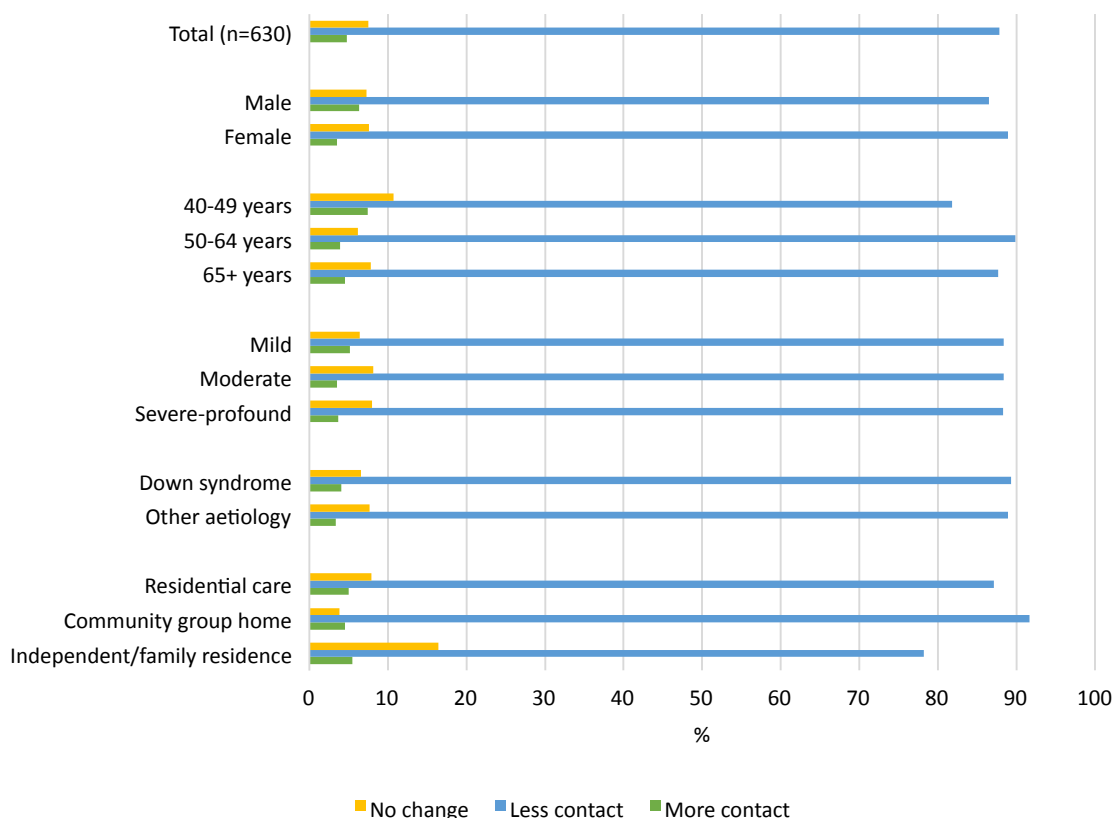


Figure 16. Changes in face-to-face contact with family during the pandemic by demographic groups

Impact on written communication with family

Overall, there was no clear trend in frequency of written communication with family during the pandemic, with 42.1% (136/323) indicating no change, just over a third (36.8%, 119/323) reporting more written contact, and 21.1% (68/323) reporting less written contact during this period.

Figure 17 shows differences between demographic groups. While none of the differences were statistically significant, there were some notable differences within the sample. Respondents in the 50-64 age group were more likely to have reduced written contact with family than other age groups; respondents with mild intellectual disability were also more likely to have reduced written contact than others; individuals of other intellectual disability aetiology were more likely to have increased written contact than those with Down syndrome; and respondents living in community group homes also showed a greater increase in written contact with family during this period.

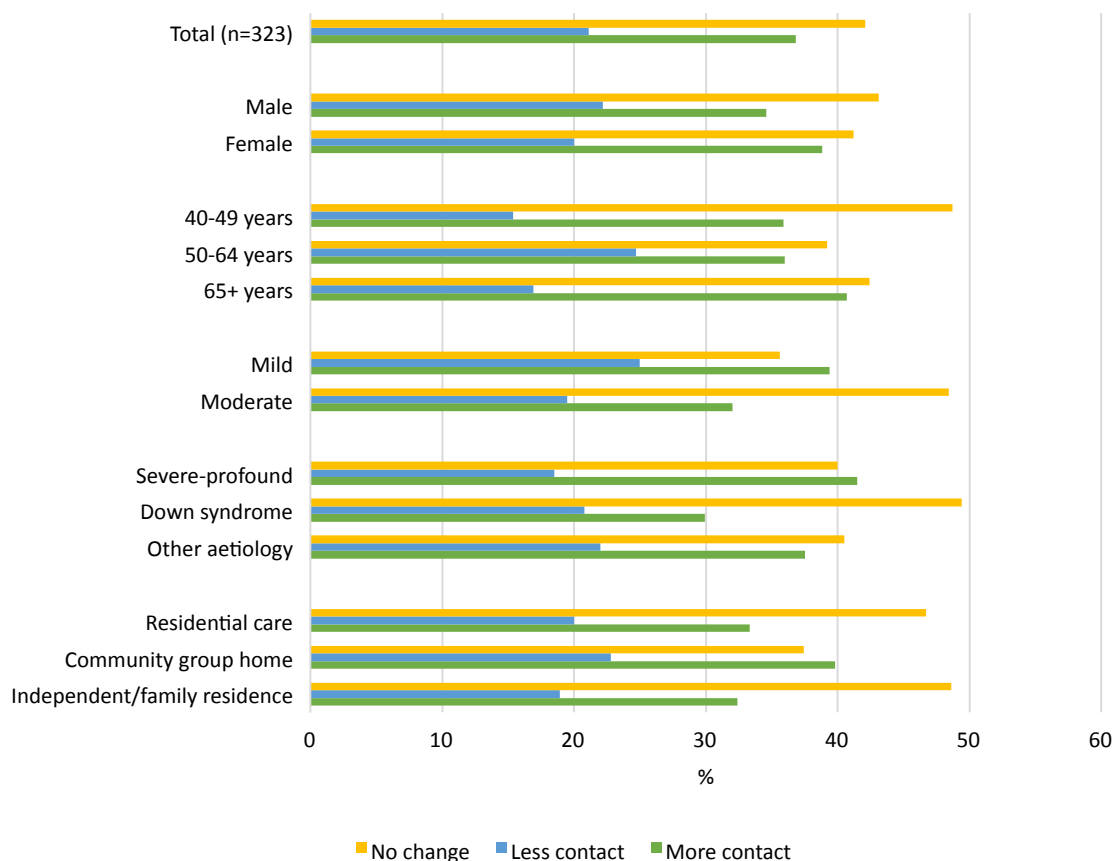


Figure 17. Changes in written contact with family during the pandemic by demographic groups

Impact on use of technology to speak with family

With regard to the amount of time spent speaking with family members using technology, over half of respondents (55.9%, 321/574) reported an increase during the pandemic, a further 19.0% (109/574) reported no change, with 25.1% indicating a reduction in this type of contact with family. Figure 18 shows differences between the demographic groupings. While none of the differences were statistically significant, there were some notable differences. Participants in the over-65 age group (61%) were more likely than younger participants (54.3%) to report an increase in speaking to family using technology, as were participants with mild intellectual disability (61.2%) compared with those with moderate (52.5%) and severe-profound intellectual disability (55.6%), and participants without Down syndrome (57%) compared with those with Down syndrome (48.6%). Participants living in independent/family settings reported the lowest increase in using technology to speak with family (46.7%) as well as the highest reported decrease in this form of communication (29.9%) in comparison with participants living in residential care (25.1%) and community group homes (23.7%).

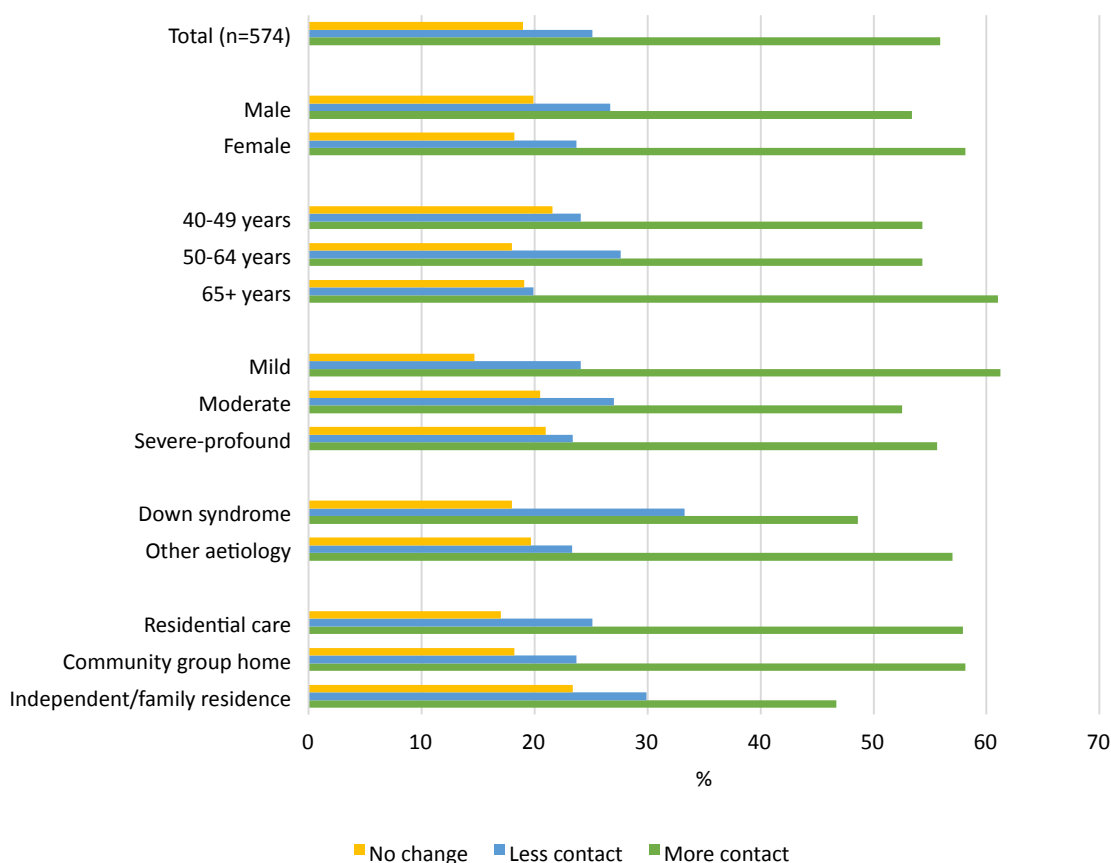


Figure 18. Changes in time spent speaking with family using technology during the pandemic by demographic groups

Impact on contact with friends

Participants were also asked about how the pandemic had impacted different forms of communication and connection with friends who they do not live with, including meeting face-to-face, written communication (e.g., letters, texts, email or social media), and using technology to speak (e.g., telephone or online).

Impact on face-to-face contact with friends

Around four in five participants (79.1%, 387/489) reported less face-to-face contact with non-resident friends during the pandemic, with 17.8% (87/489) reporting no change, and just 3.1% (15/489) reporting an increase during this time.

Figure 19 outlines differences between demographic groupings. The most significant difference related to level of intellectual disability, where participants with mild (85.6%) and moderate intellectual disability (81.1%) were far more likely to have reduced face-to-face contact with their friends, compared with participants with severe-profound intellectual disability (59%) ($p < 0.001$). Other differences between groups were more marginal; for example, face-to-face contact with friends was more likely impacted for people living independently or with family (82.7%) compared with other residence types (75.5-78.8%), as was contact for participants in the youngest age group (40-49 years) (83.3%) compared with older participants (77.1-80%); but these differences were not statistically significant.

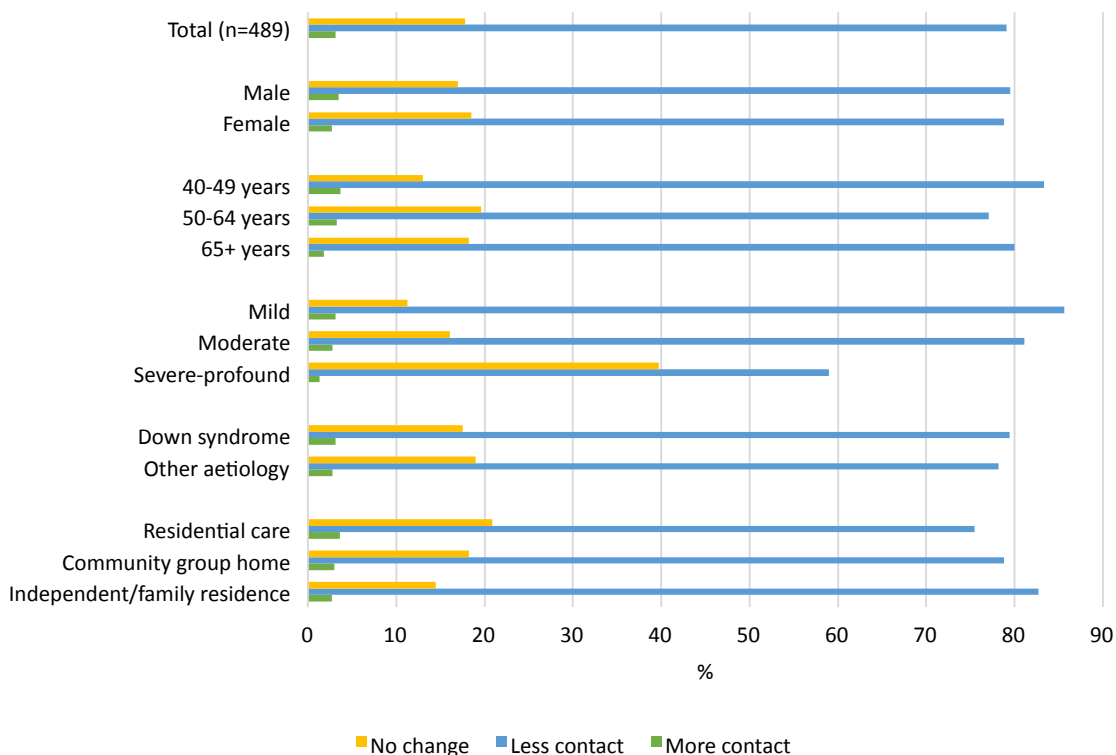


Figure 19. Changes in face-to-face contact with friends during the pandemic by demographic groups

Impact on written communication with friends

Around two-thirds of respondents (64.1% (177/276) indicated no change in written communication (e.g., letters, texts, email or social media) during the pandemic. Just under a quarter (22.1%, 61/276) reported an increase in writing to friends, while 13.8% (38/276) reported a decrease.

Figure 20 shows differences between groups for written communication with friends during the pandemic. While not statistically significant, there were notable differences between some groups in the sample. Increases in written communication during this period were more likely for younger participants (31%), for those with mild intellectual disability (23.7%), for community-based and especially independent/family residents (26.1%), and for respondents with Down syndrome (23.1%).

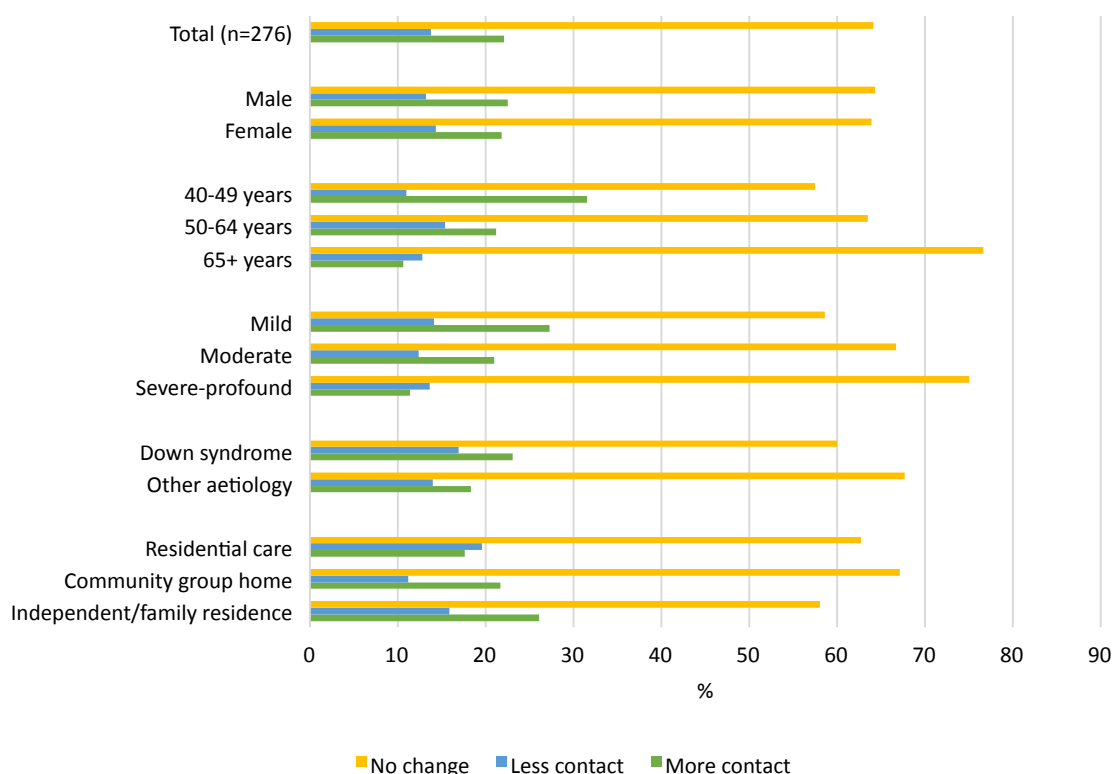


Figure 20. Changes in written communication with friends during the pandemic by demographic groups

Impact on use of technology to speak with friends

Almost half of respondents (49.3%, 218/442) reported increased use of technology to speak with friends during the pandemic. For 14.7% (65/442) there was less of this type of contact with friends during the pandemic, while just over a third (36.0%, 159/442) reported no change.

Figure 21 shows variation between the different demographic groups. The most significant difference related to level of intellectual disability ($p=0.027$), with increased communication of this type more likely for participants with mild (57.6%) and moderate (46.5%) compared with those with severe-profound intellectual disability (35%). Community-based residents, in particular those living in independent/family settings (54.9%), were more likely to speak more with friends using technology, but this difference was not statistically significant; and female participants (52.1%), younger participants (53.4%), and those with Down syndrome (53.6%) were marginally more likely to speak with their friends more using technology during the pandemic.

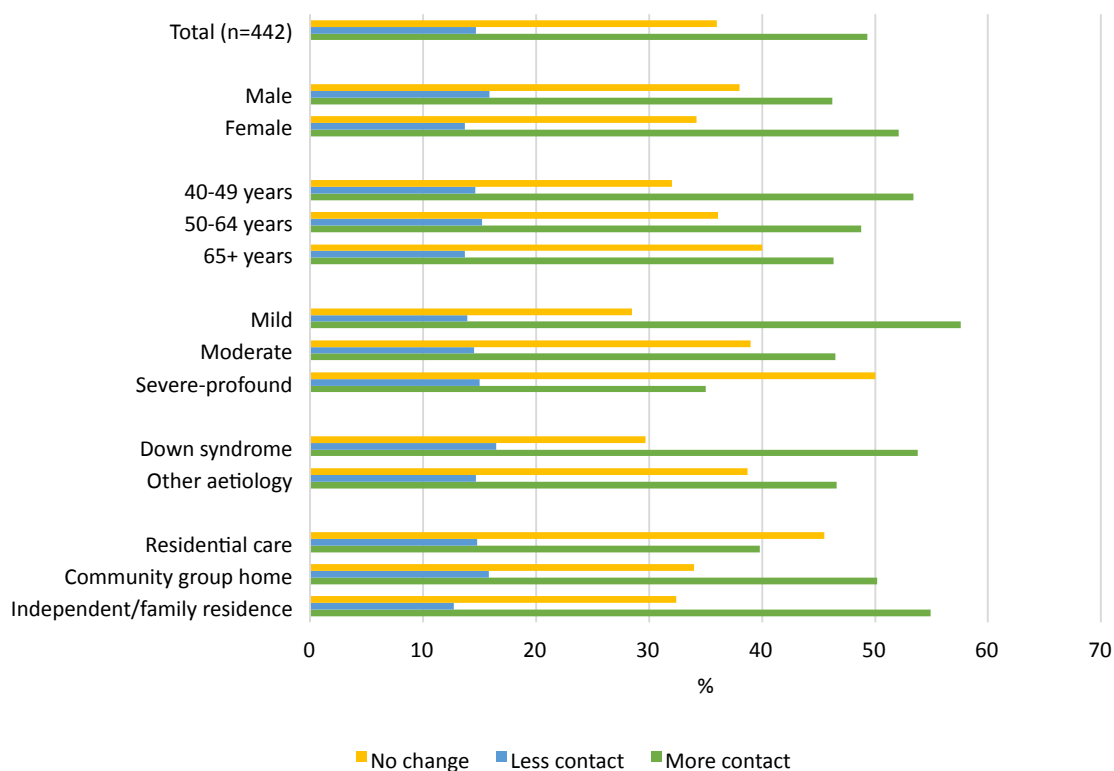


Figure 21. Changes in time spent speaking with friends using technology during the pandemic by demographic groups

Impact on social inclusion and community participation

Participants were asked about how the pandemic had impacted them across a range of social inclusion measures, including impact on their occupation, domestic life, connections with family and friends, and participation in social and community activities.

Figure 22 outlines the overall impact among participants across each of these measures, in order of the magnitude of impact within the sample. The large majority of participants felt the impact in terms of the regular activities that add value and meaning to their lives – for example, most were unable to engage in their usual activities and hobbies (83.9%), unable to engage in their regular work or day service (69.5%), unable to participate in religious and spiritual activities (62.8%), and unable to engage with their clubs, teams and voluntary activities (58.2%).

The impact was also felt in disruption of social circles and supports – with most separated from family or close friends (79.8%), and having celebrations cancelled or restricted (62.2%). The separation from family and friends was exacerbated for many, almost one in five participants (18.9%), who reported that they did not have the ability or resources to talk to family or friends while separated. In addition, some participants also reported how the pandemic had affected other activities of a more occasional or one-off, yet deeply personal, nature – for example, being unable to attend the funeral of a family member or friend (17.6%), to visit loved ones in care facilities (11.1%), or to be close to family members in a critical condition (6.9%).

And for some, the pandemic saw an increase in conflict where they lived – with nearly a quarter of participants reporting an increase in verbal conflict with other adults in their home (21.6%), while a smaller proportion worryingly reported an increase in physical conflict (4.8%).

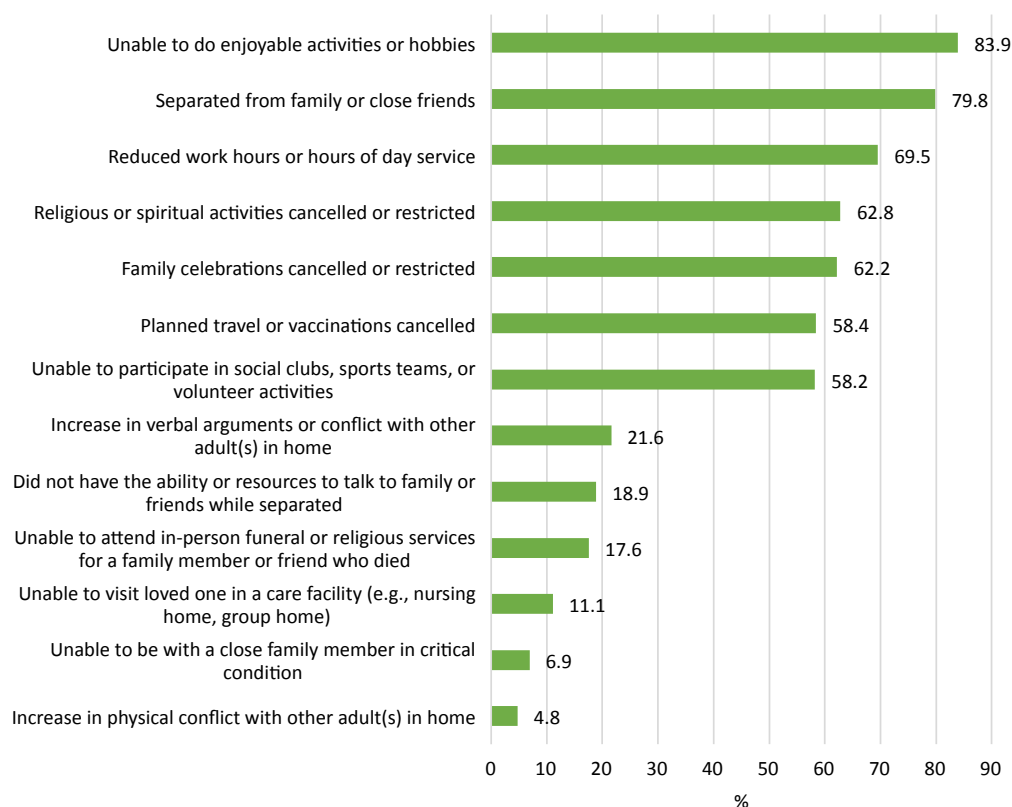


Figure 22. How has the pandemic affected you? (n=682)

Differences among demographic groups within the sample are outlined in Table 8. With regard to gender differences, female participants were significantly more likely to experience an impact on their religious or spiritual activities compared with men. Other gender differences included a marginally greater impact among female participants regarding separation from family or close friends, reduced work/day service hours, and clubs, teams and voluntary activities; and a marginally greater impact among male participants regarding family celebrations, and the ability or resources to talk to family or friends while separated.

In relation to age, the impact of reduced work/day service hours and cancelled/restricted family celebrations increased significantly with younger age. Impact on religious or spiritual activities increased significantly with older age; while significantly fewer in the oldest group had planned travel or vaccinations cancelled. Respondents in the 50-64 age group experienced a significantly higher increase in verbal arguments or conflict, while the oldest group had the lowest rates. Other non-statistically significant differences included lower rates of separation from family or close friends among the 65+ age group; also, less impact among this older group regarding ability or resources to talk to separated family or friends; and higher impact on participation with clubs, teams and voluntary activities among the 40-49 age group.

With respect to level of intellectual disability, there was a significantly increased impact for those with a milder/less severe level of intellectual disability for a number of items, including: inability to do enjoyable activities or hobbies; reduced work/day service hours; participation in clubs, teams and voluntary activities; and attendance of in-person funeral or religious services for family or friends. Similar trends were observed for cancelled/restricted family celebrations, and for inability to be with a close family member in a critical condition; however, these differences were not significant. Participants with moderate intellectual disability were significantly more likely to experience an increase in verbal arguments or conflict with other adults in their home.

Regarding aetiology of intellectual disability, participants with Down syndrome were significantly more likely to experience an impact to participation in clubs, teams and voluntary activities compared with other participants. More participants with Down syndrome also reported the cancellation or restriction of family celebrations, and cancellation of planned travel or vaccinations; but these differences were non-significant. Participants of other aetiology were more likely to be unable to do enjoyable activities or hobbies, but this was not a significant difference.

Finally, in relation to type of residence, there was a trend of significantly increasing impact when moving from residential care (lowest) to community group homes and independent/family residences (highest), for a number of measures, including: reduced work/day service hours; cancelled travel plans or vaccinations; and participation in clubs, teams and voluntary activities. Residents in community group homes were significantly more likely than other participants to experience separation from family or close friends. Participants in residential care were more likely to have religious or spiritual activities cancelled; and participants in independent/family residences were more likely to have family celebrations impacted compared with others; but these differences were not statistically significant.

Table 8. Effects of the pandemic by demographic groups (%)

Pandemic Effect	Gender		Age			Level of ID			ID Aetiology		Residence Type			TOTAL (n=682)
	Male (n=314)	Female (n=368)	40-49 (n=129)	50-64 (n=380)	65+ (n=173)	Mild (n=187)	Mod. (n=283)	Sev- Prof. (n=174)	Down synd. (n=125)	Other (n=483)	Ind/ family (n=119)	CGH (n=337)	Res. Care (n=219)	
Unable to do enjoyable activities or hobbies	83.1	84.5	84.5	83.4	84.4	88.8	84.1	77.6	78.4	84.5	84.9	85.8	80.8	83.9
Separated from family or close friends	77.7	81.5	82.2	81.8	73.4	79.7	79.9	78.2	82.4	78.5	70.6	85.8	75.3	79.8
Reduced work hours or hours of day service	66.2	72.3	79.1	70.3	60.7	78.6	71.4	55.2	72.0	67.1	88.2	70.0	59.4	69.5
Religious or spiritual activities cancelled or restricted	55.7	68.8	50.4	62.1	73.4	63.6	64.3	60.3	60.0	64.0	63.9	59.3	68.5	62.8
Family celebrations cancelled or restricted	64.0	60.6	69.0	64.5	52.0	66.8	60.4	56.9	68.0	59.8	71.4	60.8	59.4	62.2
Planned travel or vaccinations cancelled	58.3	58.4	61.2	61.3	49.7	63.1	55.8	55.7	65.6	56.9	67.2	61.1	48.9	58.4
Unable to participate in social clubs, sports teams, or volunteer activities	56.4	59.8	67.4	56.6	54.9	70.1	63.6	36.8	67.2	55.1	67.2	60.5	49.3	58.2
Increase in verbal arguments or conflict with other adult(s) in home	21.0	22.0	19.4	25.5	14.5	18.2	28.3	15.5	24.8	20.1	16.8	24.6	19.6	21.6
Did not have the ability or resources to talk to family or friends while separated	22.0	16.3	22.5	20.5	13.9	19.8	17.7	19.5	20.8	18.8	24.4	19.3	15.1	18.9
Unable to attend in-person funeral or religious services for a family member or friend who died	16.9	18.2	17.1	17.1	19.1	23.5	16.6	13.2	16.8	17.8	19.3	18.1	15.5	17.6
Unable to visit loved one in a care facility (e.g., nursing home, group home)	10.8	11.4	12.4	10.8	11.0	10.2	12.4	9.2	8.8	11.2	12.6	12.2	9.1	11.1
Unable to be with a close family member in critical condition	6.4	7.3	5.4	7.6	6.4	10.2	5.7	4.6	3.2	7.5	10.9	6.5	5.0	6.9
Increase in physical conflict with other adult(s) in home	4.8	4.9	3.9	5.8	3.5	4.8	4.6	5.7	1.6	5.4	3.4	5.9	4.1	4.8

Figures in bold are statistically significant ($p < 0.05$)

Summary: Impact on Social Inclusion

This chapter has illustrated how the COVID-19 pandemic impacted the social inclusion of older adults with intellectual disability since first emerging in Ireland in March 2020. The most obvious and immediate impact was in relation to social contacts that participants had with family and friends outside their own residence. Around nine in 10 participants had less face-to-face contact with family during the pandemic, while eight in 10 had less face-to-face contact with friends. Significantly more people living in residential care and community group homes had reduced face-to-face contact with their family, compared with those living in independent/family settings. Previous studies demonstrated that individuals living in independent/family residences had better contact with non-resident family than those in residential care or community group homes [3, 98]. So, while a large majority of all participants had less contact with family, those who were already at a disadvantage may have felt the impact more. Reduced face-to-face contact with family may have been alleviated to some degree by an increase in use of technology to speak to family, experienced by over half (55.9%) of participants. That residents of independent/family settings had the smallest increase in this type of contact during the pandemic confirms previous findings that they benefitted least from using technology during the pandemic, highlighting deficits in skills and/or support [3] – however, they may also have had less need for technology given that they better maintained their already higher level of in-person family contact during the pandemic.

There were significant differences in the impact the pandemic had on face-to-face contact with friends with regard to level of intellectual disability; with the biggest impact among people with mild (85.6%) and moderate intellectual disability (81.1%), compared with 59% of participants with severe-profound intellectual disability. A previous study showed that individuals with severe-profound intellectual disability were less likely to have non-resident friends (as assessed here) and more likely to have co-resident friends [99] – therefore, social restrictions imposed during the pandemic may have impacted friendship contacts less given the makeup of their social network. Reduced face-to-face contact with friends may also have been alleviated to some degree by increased use of technology to speak to friends, reported by half of participants. And again, there were significant differences in this increased use of technology in relation to level of intellectual disability. More people with mild intellectual disability (57.6%) had increased use of technology to speak with friends during the pandemic, compared with less than half of those with moderate intellectual disability (46.5%), and a third of those with severe-profound intellectual disability (35%). This confirms previous findings that individuals with mild intellectual disability were more likely to have better access to and use of technology, which increased during the pandemic [3].

TILDA's study of the community dwelling general population aged 60+ years in Ireland, carried out between July and November 2020, identified that almost all participants visited friends less often (19%) or not at all (80%) during the pandemic; while almost as many visited family less often (34%) or not at all (62%) at this time. For some in this population, reduced face-to-face contact may also have been alleviated to some degree by contact through technology, with 28% reporting more frequent social meetings online using Zoom and other video conferencing tools [43]. A UK survey of people with intellectual disability during the pandemic found that 72% of self-reporting participants (cohort 1) were staying in touch with family and friends as much as they wanted to, with 14% not

doing so. Participants unable to self-report (cohort 2) saw a reduction in the number who were able to meet family and friends face-to-face, from 32% pre-pandemic to 11% during the pandemic. However, this group also recorded an increase in staying in touch with family and friends by telephone (from 11% to 21%), and by video calls (from 7% to 28%) [66].

Findings here also highlight how the pandemic has had a deep and wide-ranging impact on the lives of most older adults with an intellectual disability. Many reported how it affected their usual social, cultural and leisure activities; their work and day service; connections, celebrations and occasions with family and friends; planned travel; and relationships within their home.

Significant differences emerged among participants in different age groups – where more younger participants were affected by reduced work/day services, cancelled/reduced family celebrations, and cancelled travel plans; while more older participants were impacted by cancelled/restricted religious or spiritual activities. Significantly more participants with milder levels of intellectual disability were affected in terms of being unable to do their activities or hobbies; having reduced work or day service hours; participation in social clubs, sports teams and volunteering; and being unable to attend in-person funeral services for family or friends.

The impact across some measures was also significantly different depending on residence type. Separation from family or close friends was felt most among residents of community group homes, followed by those in residential care and independent/family settings. Participants living independently or with family were impacted most across a number of measures, followed by group home residents, with those in residential care the least affected – including, reduced work or day service hours; cancellation of planned travel; and participation in social clubs, sports teams and volunteering. More participants with Down syndrome were also unable to participate in their clubs, teams and volunteer activities, compared with participants of other aetiologies. The only significant difference between male and female participants saw more women affected by cancelled/restricted religious or spiritual activities.

Some findings here compared with those reported by TILDA for the general older population in Ireland aged 60+ years, many of whom also felt the effect of the pandemic on their social, cultural and leisure activities. However, the pandemic also appeared to offer an opportunity for alternative activities for some in the general older population. Since the start of the pandemic, a majority of TILDA participants did some activities either ‘less often’ or ‘not at all’, including leaving your home (69% less often; 14% not at all); attending religious services outside the home (10% less often; 86% not at all); and volunteer (8% less often; 81% not at all). Conversely, a majority of older adults did some activities either ‘about the same’ or ‘more often’, including exercise at home (48% about the same; 16% more often); walk outside your home for more than 20 minutes home (37% about the same; 26% more often); do hobbies, crafts, or puzzles (40% about the same; 23% more often); do garden work or home repair (35% about the same; 44% more often); watch TV, Netflix, stream movies, or shows (55% about the same; 35% more often); read (52% about the same; 35% more often); and meet social groups using online video conference (27% about the same; 28% more often 43%)[43].

For people with intellectual disabilities in the UK, the pandemic also had a major impact on their social inclusion and regular activities. For example, 99% of participants said their community activities had stopped completely or reduced; day services had stopped completely or reduced for 89% of self-reporting participants, increasing to 98% of cohort 2 participants; and short breaks/respite had reduced or stopped for 92% and 95% respectively since the start of lockdown in March 2020. Of those in cohort 1 (n=198) and cohort 2 (n=15) who were in paid employment prior to the pandemic, just 53% and 29% were still working in the job; and of those in cohort 1 (n=307) and cohort 2 (n=56) who were doing voluntary work prior to the pandemic, just 35% and 17% were still actively volunteering [66].

Clearly, the pandemic has had a major impact on the lives of people ageing with an intellectual disability in Ireland, and this is an experience shared with the general older population in Ireland and by other adults with intellectual disabilities in other jurisdictions.



Mental Health, Life Events and Experiences during COVID-19

Mental Health, Life Events and Experiences during COVID-19

Key Findings

- Most participants reported that their overall mental health was either excellent, very good, or good. Despite this, 69% reported they experienced stress and anxiety during the COVID-19 period. This had increased from 55% who reported stress and anxiety in the first COVID-19 survey.
- Key sources of stress and anxiety during the lockdown were isolation, not being able to see family or friends and not being able to do usual activities.
- There was little change in depressive symptom scores compared to Wave 3 reports (3 years prior) of IDS-TILDA.
- Just over half (56.4%) of self-reporting participants said they felt lonely during the pandemic.
- For life events, a majority of participants had a change at work/day service, change in frequency of visits from family/friends, and/or a loss of leisure-time activities.
- For a majority of those participants who experienced a major illness or injury, the death of a sibling or the death of a parent, these were associated with a lot of stress.
- Just over 20% of participants knew someone who died during the pandemic.
- Almost 90% of participants reported positive experiences during COVID-19.
- Frequently reported positive experiences included more rest/relaxation (63%), more/better time with staff (60.6%), more free time (50.9%), and using technology to communicate (49.4%).
- Anticipated activities at the end of the pandemic were being able to see family and friends, returning to socialising, eating out and going to the pub, going on a holiday, returning to day service or work, and 'just getting back to normal'.

Mental health

Participants were asked about their general mental health, depression, anxiety, stress and loneliness. These were assessed using a single item measure of general mental health (asked in common with the TILDA COVID-19 survey [43]); a single item measure on reasons for feeling anxious/stressed during the COVID-19 pandemic (developed for first IDS-TILDA COVID-19 survey [2]); the Patient Health Questionnaire (PHQ-9) for depression [90]; the GAD-7 Anxiety Scale [87]; additional items from the Glasgow anxiety scale [88]; and the three-item loneliness scale [100] with a self-labelling loneliness item. Life events were assessed using the life events scale from Hermans and Evenhuis (2012) [91]. Positive experiences were assessed using a checklist of items taken from the Epidemic-Pandemic Impacts Inventory (EPII) [86] and from analysis of responses to an open-ended item on positive experiences in the first IDS-TILDA COVID-19 survey [2]. Finally, two additional items asked participants to describe in their own words: (a) the general impact that the COVID-19 pandemic had on their life, and (b) what they were most looking forward to once the COVID-19 pandemic ends.

General mental health

In response to the question “How has your mood/emotional health been?”, mental health was reported as excellent by 11.3% (76), very good, 21.1% (142), good, 40.7% (274) fair, 19.6% (132) and poor, 7.4% (50). Those responding by proxy only were more likely to report fair or poor mental health compared to self-report with support or self-report only, who were more likely to report excellent or very good mental health.

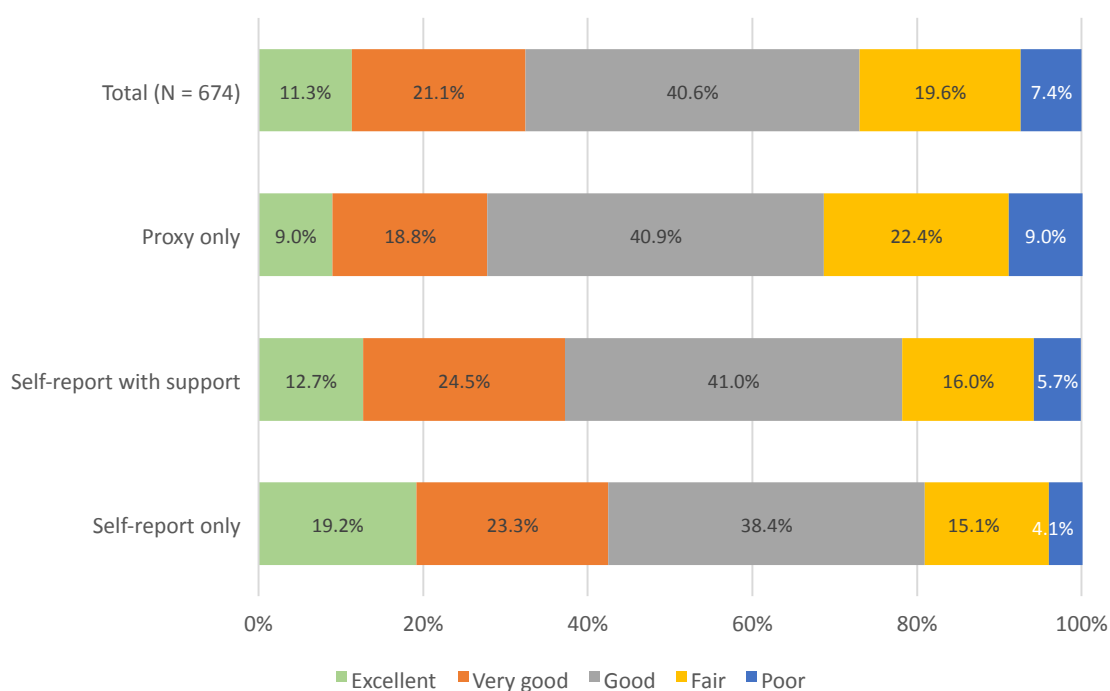


Figure 23. Reported general mental health by method of reporting

For general mental health, there was no significant differences across gender, age categories, level of intellectual disability, aetiology of intellectual disability or residence type (Figure 24).

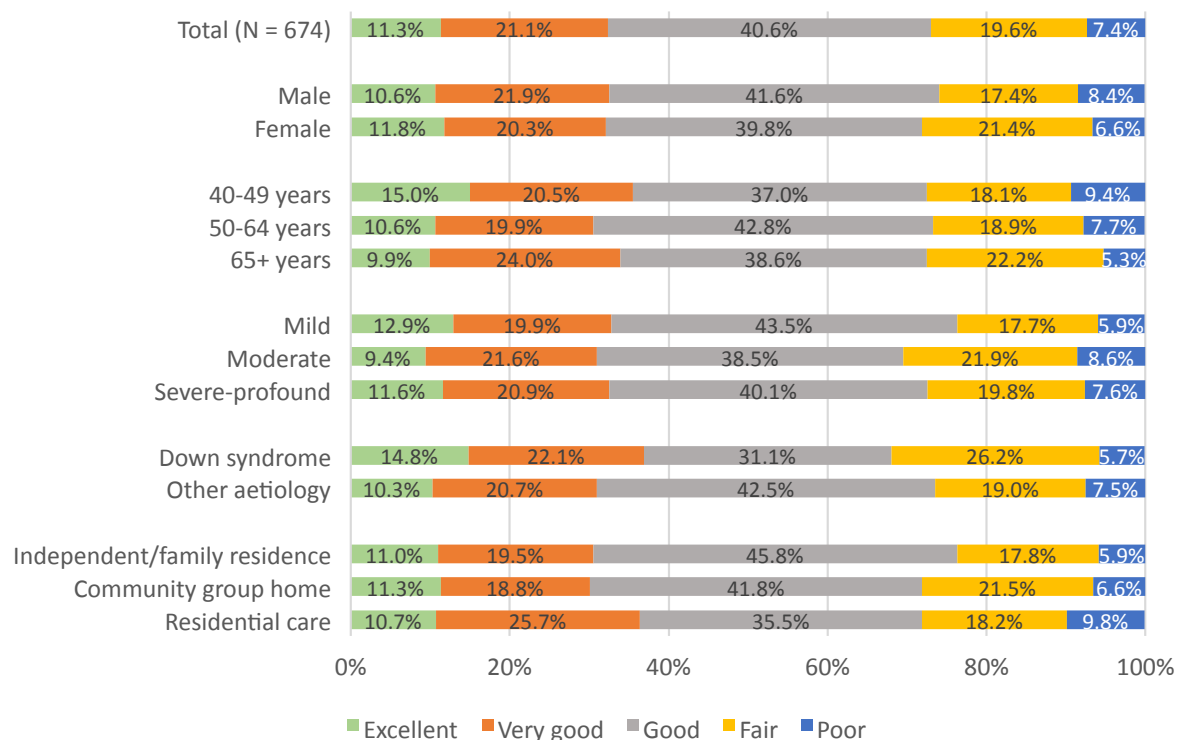


Figure 24. Reported general mental health by demographics

Anxiety and stress

Reasons for stress/anxiety during the pandemic

Overall, 473 participants (69%) reported feeling stressed/anxious during the COVID-19 pandemic. The most commonly reported reasons were not being able to do usual activities, not seeing family, not seeing friends, and isolation. Fear of getting COVID-19 oneself, or fear of friends/family getting COVID-19, were less frequently cited as a source of stress or anxiety.

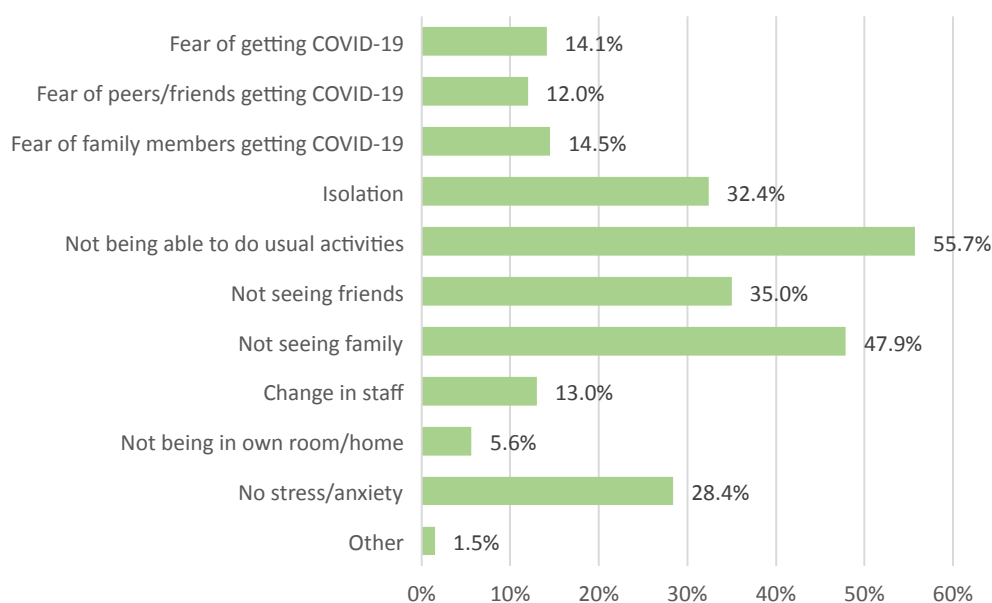


Figure 25. Reported reasons for stress/ anxiety during COVID-19 period

Other reported reasons for stress or anxiety were:

Changes within house to make sure everyone had individual spaces within the house - not allowed to be in the same room as another resident at any time.

Didn't like staff wearing facemasks/wearing them herself.

Participant loves her drinks and had fluids restricted for medical purposes.

Overall anxiety levels

In terms of overall anxiety levels, there was a mean GAD-7 score of 2.61 (SD = 3.8); this is below the cut-off for mild anxiety. Reported anxiety was slightly higher for those who self-reported only (M = 2.8, SD = 4.4) compared to those who self-reported with support (M = 2.5, SD = 3.6), but this was not statistically significant ($p = 0.6$) (this assessment was not completed in the case of proxy report only). Reported anxiety was quite similar for women (N = 161, M = 2.6, SD = 3.7) and men (N = 120, M = 2.7, SD = 4) ($p = .87$), and was slightly higher for those aged < 50 (N = 74, M = 3, SD = 4.9) compared to those aged 50-64 (N = 136, M = 2.7, SD = 3.6) and those aged 65+ (N = 71, M = 2.1, SD = 3) ($p = .31$), although these age and gender differences were not statistically different.

For the question “Do you worry a lot?”, 72/279 (25.8%) of participants responded “yes”, while 207/279 (74.2%) responded “no”. As may be seen in Figure 26, participants were more likely to report worrying about family and friends and the future.

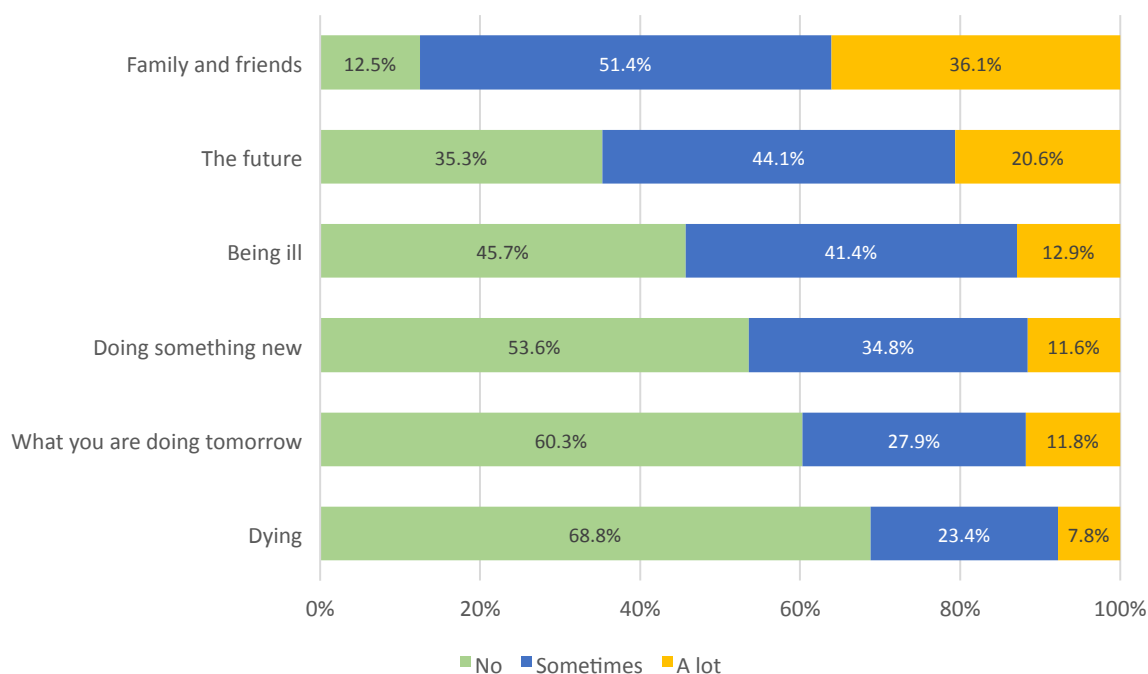


Figure 26. Sources of worry for participants

Depression

For the sample overall, there was a mean PHQ-9 value of 2.35 (SD = 3.8), which is suggestive of minimal depression, with 51/682 or 7.5% scoring above the cut-off of 8 for depressive symptoms [102]. PHQ-9 scores were similar for those who self-reported independently (N = 73, M = 2.5, SD = 4), and for those who had proxy report only (N = 395, M = 2.5, SD = 4.1), with slightly lower scores for those who self-reported with support (N = 214, M = 1.9, SD = 3). Women had slightly higher scores (N = 368, M = 2.5, SD = 3.9) than men (N = 314, M = 2.2, SD = 3.7). Scores were slightly lower for younger age groups, with those aged <50 (N = 129, M = 2.2, SD = 3.5) having lower scores than those aged 50-64 (N = 380, M = 2.3, SD = 3.8), who in turn had lower scores than those aged 65+ (N = 173, M = 2.4, SD = 3.9). However, a difference of less than one point is of limited clinical significance.

Loneliness

Many participants reported that they felt lonely, with 154/273 (56.4%) of participants answering “yes” to the question “do you ever feel lonely?”. Among those reporting feeling lonely, 30 (19.5%) reported feeling lonely most of the time, 115 (74.7%), some of the time, and 9 (5.8%), hardly ever/never. Women were more likely than men to report feeling lonely, but there were no significant differences relating to age group, level of intellectual disability aetiology of intellectual disability, or residence type (see Figures 27a and 27b).

Further findings were that 78/267 (29.2%) participants reported that they had ever felt left out with 15/78 (19.2%) reporting feeling left out most of the time, 60/78 (76.9%), some of the time, and 3/78 (3.8%), hardly ever/never. In terms of friendships, 108/266 (40.6%) participants reported that they found it difficult to make friends; 29/108 (26.9%) lacked friendship/friends most of the time, 66/108 (61.1%) some of the time, 13/108 (12%) hardly ever/never. Finally, 126/273 (46.2%) reported that they felt isolated, with 29/126 (23%) feeling isolated most of the time, 86/126 (68.3%) some of the time, 11/126 (8.7%) hardly ever/never.

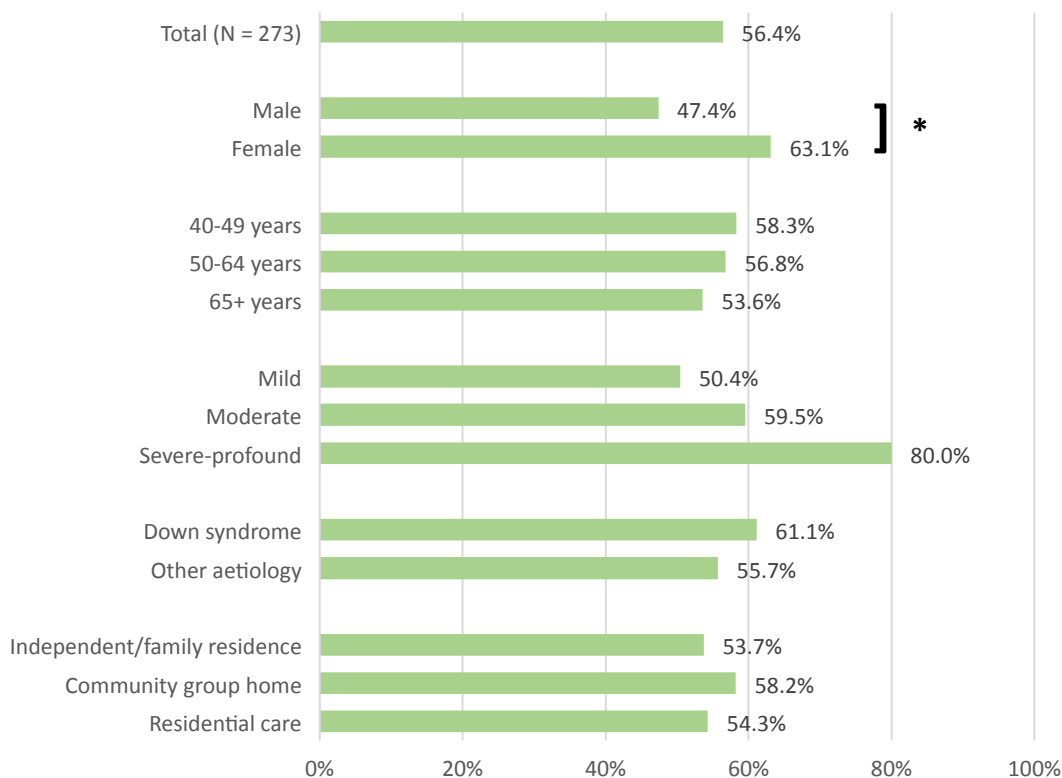


Figure 27a. Frequency of Loneliness (* indicates $p < 0.05$)

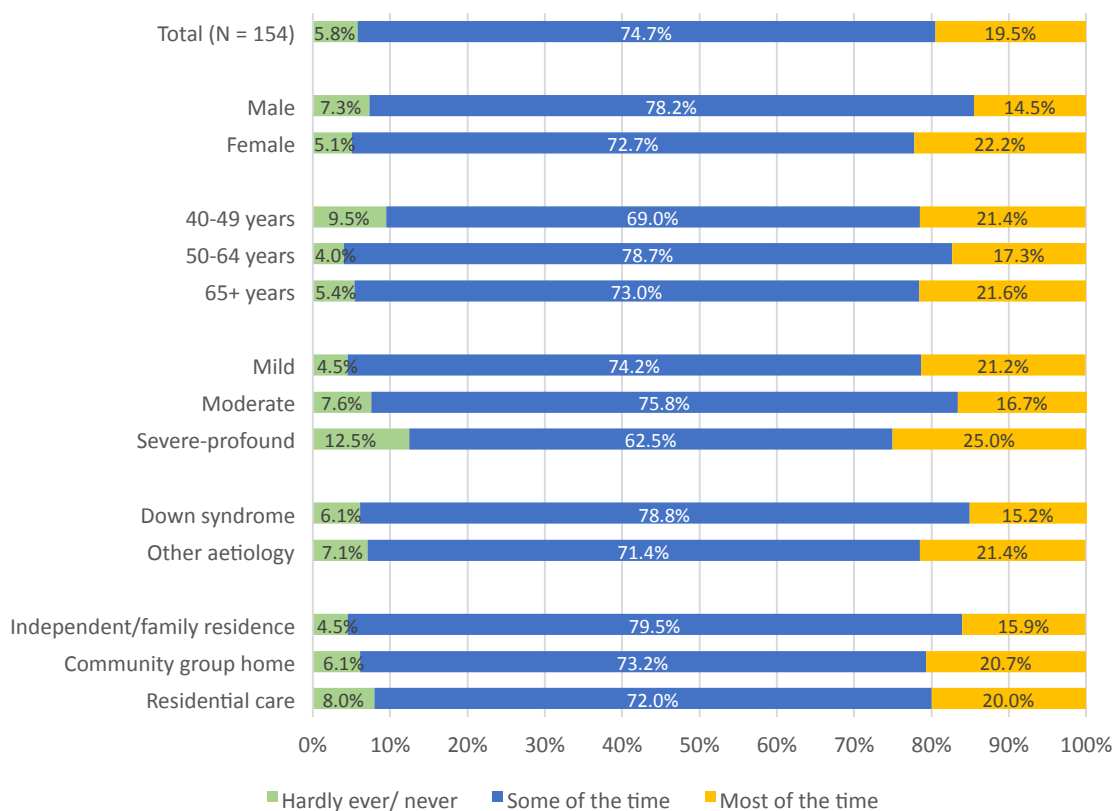


Figure 27b. Extent of loneliness in those reporting loneliness

Life events

As may be seen in Figure 28a, a majority of participants had a change at or from work/day service, changes in frequency of visits to family/friends, or loss of leisure-time activities, and for most of those participants experiencing these life events, it was perceived as causing them either a little or a lot of stress. For those participants experiencing the following life events, they were most likely to cause a lot of stress: a major illness/injury (78.3%), death of a sibling (65%) and death of a parent (61.5%); other (75%) was also likely to be reported as causing a lot of stress (Figure 28b). It may be the case that life events causing lower levels of stress were harder to remember while completing the interview.

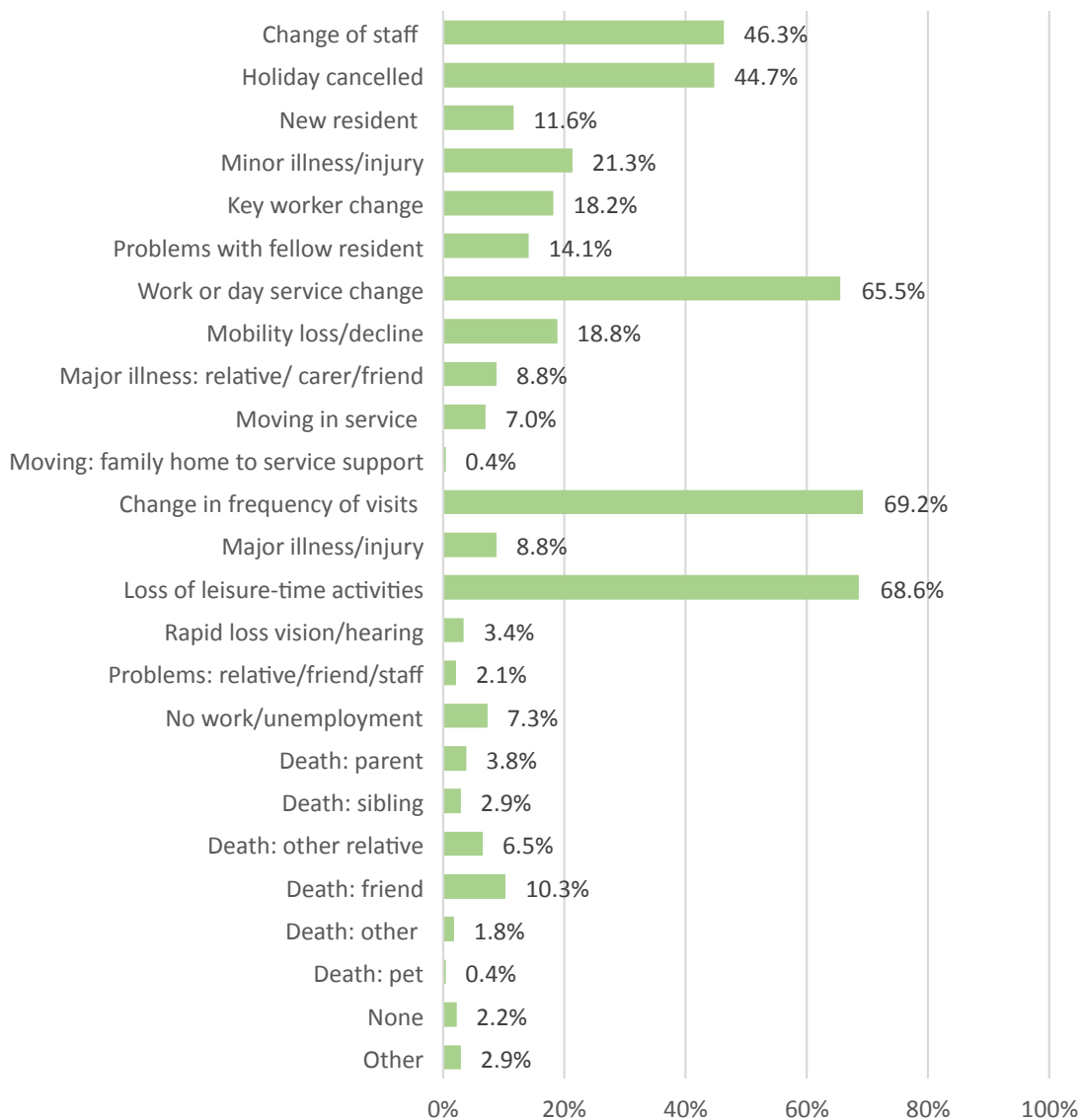


Figure 28a. Frequency of Life events during the pandemic

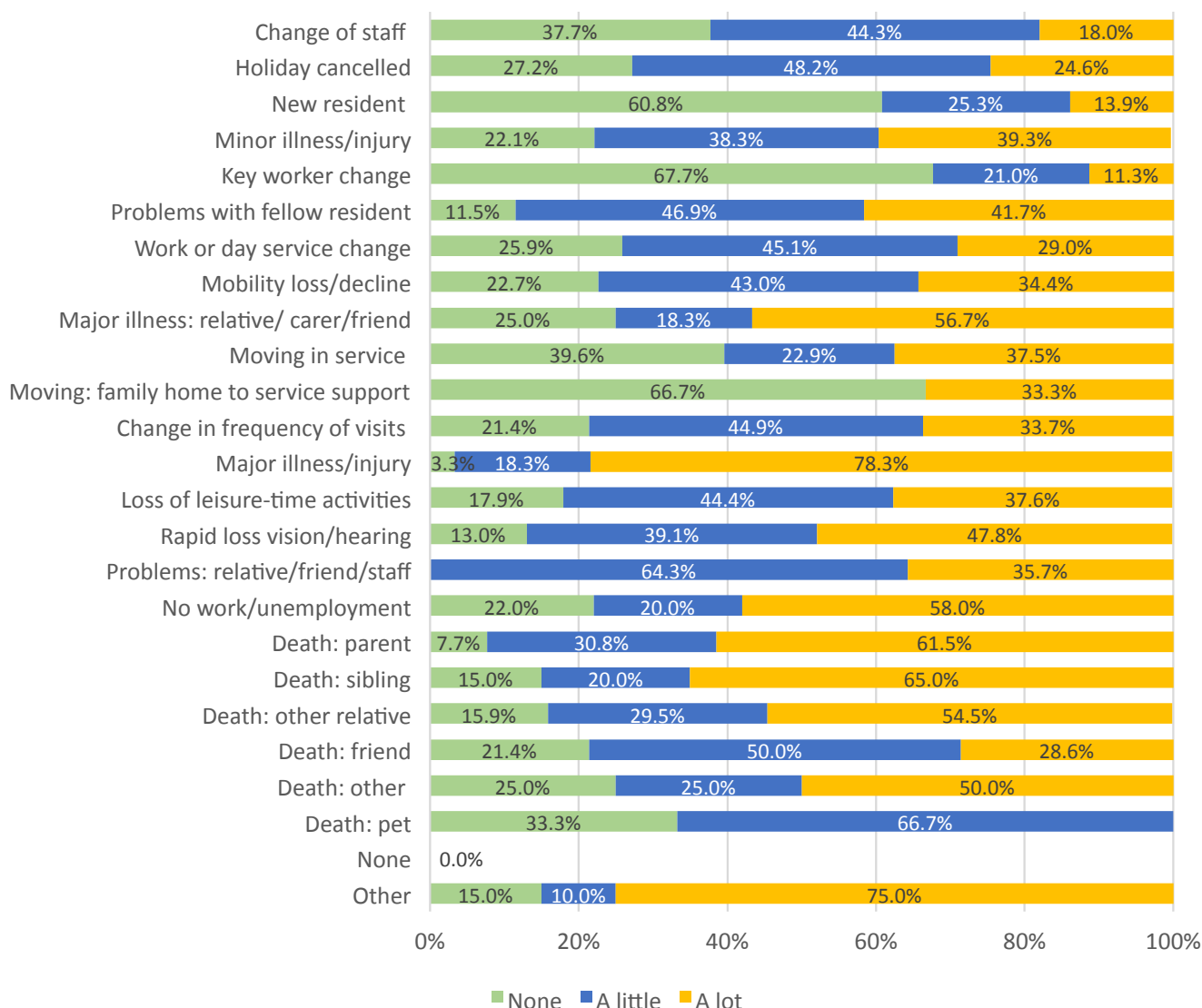


Figure 28b. Level of stress caused by life events

Other significant life events included:

Another resident moved out of the house, they had been in the same house for 30 years.

Couldn't go home for his mum's month's mind mass or to see his family after her funeral.

Day programme ceased from March to June 2020. This caused her significant stress.

Deaths as a life event due to COVID-19

A total of 142 participants (20.8% of the full cohort) knew someone who died during the pandemic; for 28, death was a result of COVID-19, with six reporting friends had died, 15 peers in a residential setting, two parents, five other relatives, one sibling, and one “my friend’s mother and father”.

Positive experiences

Almost 90% of participants reported positive experiences during COVID-19. More rest and relaxation, more/better time with staff and more free time were all endorsed by a majority of participants (Figure 29). The least frequently reported positive experiences were donating time or goods to a cause related to this disease, and either finding greater meaning or being more efficient/productive in work, employment, or school.

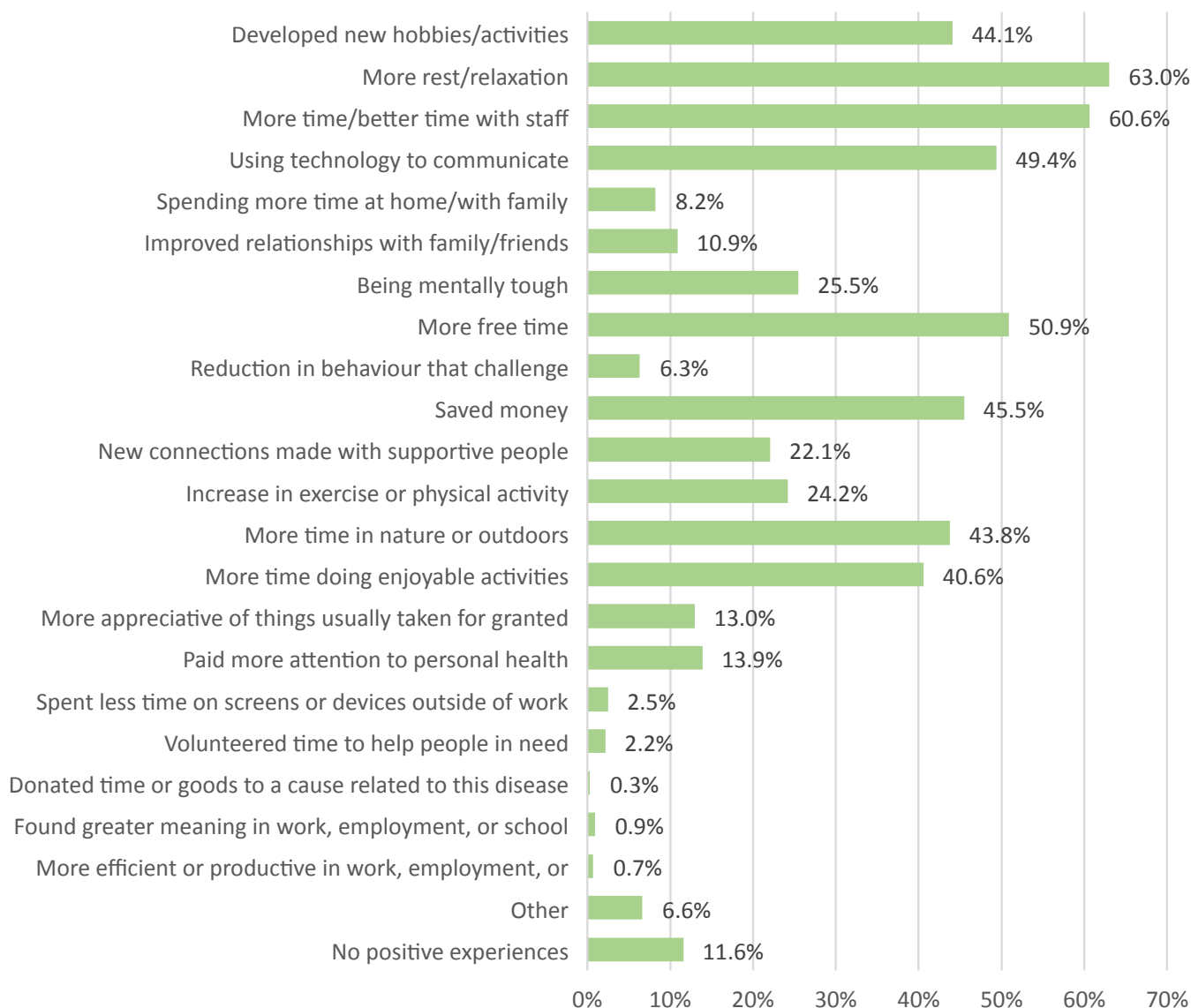


Figure 29. Reported positive experiences of life during COVID-19 pandemic

Other positive experiences reported during the lockdown included:

More individualised day service:

“Activities more suited to her needs.” Support Worker #208

“Decided to retire from day service as this pace of life suits much better, episodes of elation have reduced, falls have reduced.” Support Worker #209

“Can do activities more meaningfully when not racing around.” Support Worker #210

Moving to a new home:

“Participant moved house during Covid so was busy choosing colours furniture etc., and it kept her going.” Support Worker #211

“Participant moved to her new home in Feb 2021 and is very happy there.” Support Worker #212

Getting the vaccine:

“Getting the injection.” Participant #501

“I'm proud of myself that I went in by myself for my vaccine.” Participant #502

Improvements in communication and day to day participation:

“Communication was better.” Support Worker #513

“Encouraged to make more choices for herself.” Support Worker #514

“More active with PECS.” Support Worker #515

Other positives:

“No one hassling me. Met girlfriend during lockdown.” Participant #502

“Participant is really thoughtful and cares about people and friendships. She writes poetry. She wrote a poem advising on how to make friends.” Support Worker # 207

“Got new pet (tortoise).” Participant #503

General impact of pandemic on life

There was a total of 268 narrative responses from participants who self-reported, or reported with support, and these were organized under several emerging themes: missing family, missing friends, missing going out socialising, services closures, negative feelings and impacts on mental health, positive experiences, resilience, and acceptance of the public health measures. Opinions on the government's response to the pandemic are also shared. Smaller numbers of responses were provided relating to difficulties with PPE and social distancing, bereavements and missed healthcare appointments. A sample of responses from participants are provided below under each of the major themes.

Missing family

For some participants (64/268), missing their family was the most difficult aspect of the restrictions related to the pandemic, and some expressed that it had impacted on their mental health. For people living in residential care facilities, there were additional restrictions on visitors for prolonged periods of time since March 2020.

*"The biggest thing for [Participant] was missing family members as this was the highlight of his life"
Support Worker #201*

"I used to visit my brother once a month and stay for the weekend or longer. I couldn't do that. My brother lives alone and he misses it too" Participant #101

"Will be great when all over, it caused me a lot of anxiety missing family" Participant #102

"There were lots of changes in my life and it made me feel lonely when I couldn't see my family. The past few months have become harder and I'm very tired". Participant #103

For participants that included missing family in their responses, some identified alternative ways used to stay in contact;

"I missed my family but my sister had family photos made into jigsaws and sent them to me from England. My family kept in touch a lot" Participant #104

*"It was a nuisance not seeing my family, was very hard, they had to talk in the window to me"
Participant #105*

"I am away from my family and friends and it drives me mad. I only see them online" Participant #106

*"My family sent me a video message from everyone for my birthday and they sent goodies for me"
Participant #107*

Missing friends

For many participants (52/268), missing friends was linked to not being able to attend day services or their work.

“I was stuck inside and still am and I am bored. I miss seeing my friends in day services and that is hard” Participant #108

“It was awful [COVID-19]. I hope it will never come back again I missed my job; I missed my friends in day service”. Participant #109

“[Participant] couldn’t see her friends especially her friend, [friend’s name], who she used to stay with on overnights and is happy to be able to get back to that again now”. Participant #110

“I was bored because I had to sit at home all day. I missed my friends, discos, cinema, dinners out, and club”. Participant #111

Missing social activities

For some participants (60/268) not being able to go out socially and attend recreational activities caused annoyance and upset;

“I want to go the pictures again, love the cinema.” Participant #112

“Really missed going out and about, helping with the shopping and having meals out. It was a difficult time being confined to the house”. Support Worker #202

“I hated being inside, I just can’t do that, I need to get out ‘n clear my head. If I stay inside, it drives me mad. At the first lockdown sometimes, I just didn’t listen to the advice and went off out into town”. Participant #113

“Couldn’t go shopping. It was done online which isn’t the same. This made [Participant] sad.” Support Worker #203

Service closures

Day services and respite services were closed in response to the pandemic on 13th March 2020 with full resumption of services in October 2021. For a number of participants (47/268) the closures were cited as a negative;

“Before the lockdown, I was planning my new independent life. I proposed to my boyfriend and he said yes. I was going to [name] day services and meeting him there every day. Then lockdown started, I couldn’t see my boyfriend in a very long time and I couldn’t go to [day service name].” Participant #114

*“It was a bad time for me because I felt uncomfortable and I missed meeting friends in day service”
Participant #115*

*“In the early part of the pandemic, it was very very difficult to manage, day services closed, we could only have telephone support from the service and it was about a year before I saw staff in person.”
Support Worker #204*

“I didn't get my wages from work. I had a cleaning job and they stopped paying me. This was in the service. This could and should have been paid. It wasn't my fault that I couldn't work”. Participant #116

“I was stuck inside and still am and I am bored. I miss seeing my friends in day services and that is hard. I don't know when I am going back to day services and that causes me anxiety. I wish they would tell me.” Participant #108

There were also some positives to the closures identified by those self-reporting with support:

“[Participant] has now changed to a community-based day service supported by residential staff. There has been a decrease in arguments and in behaviours of concern since service changes and he appears to be in better humour now.” Support Worker #205

“[Participant] so loves his own company. Loves home and is a home bird and would stay at home all day if he could so he actually needs a little encouragement to go out and do things. He was involved in the day service but it was actually too stimulating for him and he would come back in bad form and so I think he might start doing that a bit less.” Support Worker # 206

Negative feelings and mental health outcomes

For 45/268 participants, the pandemic and related restrictions impacted on independence and on their mental health:

“I got COVID-19. I stayed in bed for 2 weeks. The pandemic has made me more confused. I miss my family.” Participant #117

“The pandemic has been annoying, and I wish the whole thing was over.” Participant #118

“The pandemic made me sad. I couldn't go out for spins and see my friends from work. I missed everything.” Participant #119

“It was a pain. I'm fed up of it. I'd love it to be over. I was going cracked with it.” Participant #120

“Get everything up and running again, so I can be more independent. I used to collect my own medication, now my sister has to get it.” Participant #120

“It impacted on my social interaction and I went back 'into myself' quite a bit. I lost interest in the things I used to love, like weekly outings. Because I knew they weren't happening, I stopped asking about them and gradually lost interest.” Participant #122

“The last year and a half have been very difficult lost her mother, her sister and brother since the pandemic started. Could not attend any funerals. [Participant] said that she has been bored and browned off. Feeling very down and upset I will never forget this last year, never. I hope we never have to go through it again.” Support Worker #123

Positive impacts

There were also positive impacts reported from the pandemic and the associated restrictions (for 22/268 participants);

“The virus did not really impact on (my) life and (I) was grateful that life has slowed down. It is nice and relaxed.” Participant #124

“It's been alright. I'm very content and we did loads of fun things in the house – I played my accordion a lot, we did the Jerusalem dance challenge, the Easter bunny visited . . . I'm a very positive person.” Participant #125

“I miss going home at weekends but now I can go home after the virus. I did lots of activities during COVID, writing, colouring, dancing, playing basketball & swing ball. It wasn't a bad time because I had my friends around and I had the support of staff.” Participant #126

There were also responses (39/268) which highlighted the resilience and acceptance by participants of the new measures that were put in place;

“Helping me to become more sociable, calmer. Staff are good to me.” Participant #127

“Have to take it one day at a time. It was very hard but that's life and you just have to get on with.” Participant #128

“I didn't mind it all so I didn't, I wasn't worried or anxious or nothing I go walking on the greenway, it's very close to my house and at the weekends, I get an ice cream and a coke and sit outside.” Participant #129

“I was grand. Getting out walking can make things better.” Participant #130

“My life is good. I had to stay home to stay safe. I didn't mind. I kept myself busy.” Participant #131

Views on government's response to COVID-19

Participants (20/268) shared their views on the government's response to the pandemic:

"The government didn't talk about people with disabilities. They spoke about children but not adults. I couldn't kiss my girlfriend and these things are not spoken about. We have been left out." Participant #132

"I know they are doing their best. But if they could get the second vaccine on quicker it would be good. I think it got people to wash and take more care of germs, so we could have less sickness." Participant #133

"I like Leo Varadkar. The Late Late show about COVID was helpful for me too. I cocooned with my parents and it worked very well - respite 3 nights a month stopped and my share a break 2 nights a week all stopped." Participant #134

"I would ask the government to change the way the vaccine is rolled out so the day services could open. I am away from my family and friends and it drives me mad. I only see them online. I'm really annoyed about not being able to work. I am focusing my new hobbies." Participant #106

"No social benefit yet because I'm considered under residential centre guidelines yet, still can't see family except for restricted visits, no day services or social clubs back. Seems overly restrictive when I'm fully vaccinated." Participant #135

Anticipated activities post-pandemic

Participants also identified what they were most looking forward to when the pandemics ended: Being able to see family (N=87) and see friends (N=54); returning to socialising, such as shopping, cinema, sports events, live music and mass (N=69); eating out in café's, restaurants and going to the pub (N=56); going on a holiday (N=55); returning to day service or work (N=35); and 'just getting back to normal' (N=28).

A sample of direct quotations from participants under each of the above themes include:

Being able to see family

"Seeing family and friends whenever I want and have visitors." Participant #401

"I'm looking forward to visiting family and having my independence back." Participant #402

"To go to see my family. It's going on too long." Participant #403

"I am looking forward to seeing my family. I missed them so much." Participant #404

Being able to see friends

“Seeing my friends - but is it ever going to be gone!” Participant #405

“To get together with my loved ones, my family, my girlfriend and her family and my colleagues. When I went to see my girlfriend for Valentine's Day, I had almost forgotten where her house was.” Participant

“Getting back to a few pints and friends.” Participant #406

“To sit in the company of my friends and be close to them.” Participant #407

Returning to social events and recreational activities

“Going into Marks & Spencer to look around and shop properly and have food, to go to a concert.” Participant #407

“Going into town shopping and listening to live music.” Participant #408

“Going out to see places and mixing with society. Going to the church to say a prayer, lit candles and put money in the box. Go on the bus and show the driver my new bus pass.” Participant #409

“Going to get my hair coloured and cut. Going to the salon for beauty treatments. Going to get new sandals for the summer.” Participant #410

Eating out in cafés, restaurants and going to the pub

“Going out and going for dinner and sitting in restaurants.” Participant #411

“I am looking forward to going out for coffee and something to eat with my boyfriend.” Participant #412

“I am looking forward to be going out to the pub and enjoy life. I will have a hot whiskey.” Participant #413

“I'm looking forward to having a proper party with the rest of my family when it's safe - I like to bring them out for a meal when it's my birthday.” Participant #414

Going on a holiday

“Going on holiday - I missed my planned trip to America last year.” Participant #415

“A holiday in Killarney.” Participant #416

“Getting back to the shops, more holidays, more freedom.” Participant #417

“I am mostly looking forward to going on a holiday. Getting away from the house.” Participant #418

Returning to day service or work

"I am looking forward to getting back to day services and see all my friends in [service name]. We like to listen to music together." Participant #419

"The thing I am looking forward to most is going back to day services and going out for coffee and meeting friends." Participant #420

"Getting my freedom and independence back, getting back to day services especially drama, I love that." Participant #421

"Getting back to the office and seeing my colleagues at work." Participant #422

Getting back to normal

"Everything getting back to normal!" Participant #423

"Getting back to normal - it's all been ridiculous!" Participant #424

"Just being able to go out normally again." Participant #425

"To be out and go on drives, for things to be back to normal." Participant #426

Summary: Impact on Mental Health

This chapter illustrates that overall mental health was reported as excellent, very good, or good by over 73% of participants. These are rates very similar to those reported in IDS-TILDA Wave 3 and are similar to rates reported for the general population in the TILDA COVID-19 survey.

Nevertheless, this survey highlighted that the pandemic and associated lockdown were sources of stress and anxiety to many older people with intellectual disabilities, reported by 69% of participants. Primary causes of stress and anxiety included not being able to do usual activities, not seeing family, not seeing friends, and feelings of isolation; stresses very similar to what was reported in the first IDS-TILDA COVID-19 survey. Fear of getting COVID-19 oneself, or fear of friends/family getting COVID-19, was less frequently cited as a source of stress or anxiety. This contrasts somewhat with results from the United Kingdom, where over 50% of participants worried about getting COVID-19, and just over 70% of participants worried about friends or family getting COVID-19 [65]. Consistent with those findings however, those participants in the current survey who reported worrying a lot, also worried about friends/family but not necessarily that they would get COVID-19. The findings here on feelings of isolation are also consistent with a study on students in the general population in the Republic of Ireland and Northern Ireland, where increased social isolation was reported as a source of moderate to very severe stress for just under 64% of participants [101].

There was also little change in rates of depressive symptoms. Although not formally matched, whereas in Wave 3 of IDS-TILDA, 10% of participants scored above the depressive cut-off of 13 on the Glasgow

Depression Scale, 36/545 or 7% of participants in the COVID-19 survey scored above the similar cut-off of 8 for depressive symptoms for the PHQ-9 [102]. This contrasts with the TILDA COVID-19 survey of general population older adults, where 21% scored above the cut-off score for clinically significant depressive symptoms (using the CES-D [103]). Here, 56.4% of participants in the current survey answered “yes” to the question “do you ever feel lonely?” whereas only 43.3% answered “yes” in Wave 3 of IDS-TILDA. That said, on the GAD-7, the mean reported anxiety level was below cut-off points for concerning anxiety symptoms.

The pandemic also appears to have been a time of pervasive life events for the participants, with only 2.2% reporting no significant life events, compared to 12.7% in Wave 3 of IDS-TILDA. A significant event for many (142/20.8%) was the death of a family/friend. In a recent survey from the United Kingdom, a higher proportion of participants (26% of self-reporting and 30% of proxy reports) had known someone who died during the pandemic. For IDS-TILDA participants there were also commonly reported life events that were likely a direct result of the pandemic (e.g., changes to work or day service, changes in frequency of visits to family or friends), as well as some that may have other causes e.g., 18.8% reported a decline or loss of mobility.

The findings on positive experiences were quite similar to those of the first IDS-TILDA COVID-19 survey, including the opportunity to engage in new activities, more rest and relaxation, more/better time with staff and using technology to communicate.

When asked to describe the general impact of COVID-19 on their lives, participants talked about missing family, friends and enjoyable activities, negative mental health effects, service closures, and concerns with the government’s response to the pandemic. Previously stated positive effects of the pandemic were also referred to. Anticipated activities after the pandemic ends echoed TILDA responses for the general population [104]: hopes for returning to normality with family and friends, reengaging with activities and broader hopes for a better society.

COVID-19 and the associated restrictions have been shown in this repeat of the survey to continue to have effects on the mental health and wellbeing of participants both in terms of fears and life experiences. Nonetheless, despite many difficult experiences for IDS-TILDA participants, the COVID-19 period brought with it signs of resilience, innovation and change, with many participants reporting positive changes in their lives and expressing hope for the future.

Discussion

Discussion

This report presented findings from the second IDS-TILDA survey on the impact of COVID-19 among older adults with intellectual disability in Ireland, building and expanding upon our first COVID-19 survey from 2020. Data for this follow-on survey was collected in mid-2021, just after the third wave of COVID-19 in Ireland. We found that the COVID-19 pandemic has had a growing impact on the health and health behaviours, service access and utilisation, and social connections and community participation of older adults with intellectual disability. Effects on mental health and well-being were also evident in the experience by many participants of pandemic-related stress and anxiety, and of adverse life events during this period. However, the high rates of vaccination and continued adherence to guidelines are very positive findings. A degree of resilience was also evident in many participants' comments and in the lack of change in self/proxy-rated mental health and depressive symptoms between surveys and as compared to IDS-TILDA measurement prior to the pandemic.

COVID-19 infection, outcomes and health impact

An increase in the proportion of participants tested (75.8%) since the first survey (62.4%) was expected, and these rates remained much higher than the 31-37% reported for people with intellectual disability in the UK [66]. Increased rates of positive tests, from 2.5% to 12.3%, indicate that rates of infection reported here have overtaken those reported earlier by TILDA for the general population of older adults (around 4.2% including confirmed and suspected cases), and are similar to rates of 10-13% reported for people with intellectual disability in the UK [94]. A total of 63 individuals reported a positive COVID-19 test in this second survey, compared with just 11 individuals in the previous survey. Among this group, 11.5% were asymptomatic and symptoms lasted for less than two weeks for two-thirds, while eight participants (13.1%) had symptoms for 3-8 weeks, three participants (4.9%) had symptoms for 9-12 weeks, and one individual (1.6%) had yet to recover and had symptoms lasting more than 12 weeks; which compares with 6-10% of people with intellectual disability in the UK who had not fully recovered more than a month after contracting COVID-19 [94]. Hospitalisations among those with COVID-19 like symptoms or a positive test increased slightly to 12%, almost three times the rate reported in the general Irish population (4.2%) [95]. During study recruitment we identified three participants from wave 4 of the IDS-TILDA longitudinal study who had died and who had COVID-19 – though the cause of death has not been confirmed and it is unknown if COVID-19 was a factor. Even if confirmed as related to COVID-19, the mortality rate (three individuals from a sample of 739 in wave 4) would remain lower than the 1.2% of confirmed cases in the general Irish population [95], whereas mortality rates internationally are reported as higher among people with intellectual disability [5-7, 56]. This may be influenced by the exceptionally high rate of vaccination among participants, which has been shown to reduce the worst effects of COVID-19 infection including mortality [105, 106], and perhaps also reflects the good service planning and procedures reported by services around isolation for those with symptoms or a positive test.

A majority of participants reported health related changes since the start of the COVID-19 pandemic, most commonly spending more time sitting/being sedentary (58.2%) and doing less physical activity/exercise (53.7%). Having Down syndrome was associated with being more sedentary, while living in residential care and having severe-profound intellectual disability were associated with doing

less physical activity/exercise. Around a quarter of participants also experienced other health changes – including receiving less medical care than usual, increased health problems not related to COVID-19, and overeating or eating unhealthily.

People with mild intellectual disability were less likely to report increased health problems not related to COVID-19, but people with severe-profound intellectual disability were far less likely than others to overeat or eat unhealthily. People in residential care were also less likely to overeat or eat unhealthily compared with residents of community group homes, while those living independently or with family were the most likely to do so. TILDA found that, while 69% of the general older population in Ireland reported leaving their home less often during the pandemic, a majority did some physical activities either ‘about the same’ or ‘more often’, including exercise at home (48% about the same; 16% more often); walk outside your home for more than 20 minutes home (37% about the same; 26% more often); and doing garden work or home repair (35% about the same; 44% more often) [43]. Among people with intellectual disability in the UK, the number of people who left the house for outdoor exercise fell (pre- to post-lockdown) from 78% to 63% among self-reporters and from 21% to 10% for participants unable to self-report [66].

The long-term implications of health changes among older adults with intellectual disability during the pandemic is something which needs to be monitored as the pandemic continues and also post-pandemic. This population already were at risk of poor health outcomes pre-pandemic, including high levels of overweight and obesity [51], sedentary behaviour and poor bone health [107, 108], and multimorbidity [54]. Policy makers and service providers must be cognisant of these risks and put in place the supports needed to avoid the long-term exacerbating of health problems among this population.

Responses during the pandemic

There was a small increase in the number of people who moved from their home during the pandemic between wave 1 (7.8%) and wave 2 (10.7%), with isolating as a precaution or while awaiting test results remaining the most common reason for a move. Among participants with symptoms or who tested positive, almost all (98.7%) had a plan to manage self-isolation, an increase from 78.7% in wave 1, reflecting an even greater awareness and preparedness amongst individuals, families and services since the early stages of the pandemic. Most participants (between 57.3% and 79.2%) adhered ‘often’ or ‘always’ to infection control behaviours recommended by public health guidance, including social distancing and wearing a mask. TILDA reported higher adherence among the general older population in Ireland, with 97% adhering to social distancing ‘often’ or ‘always’, 98% washing their hands more often, 92% using hand sanitiser, 98% paying close attention to coughs and sneezes, and 74% wearing a mask when around other people outside the home [43]. Findings from people with intellectual disability in the UK show that 86% of self-reporting persons had worn a face mask/covering in the preceding 4 weeks, with just 10% stating they had not and 3% stating they had not been out. However, much fewer UK participants who were unable to self-report (56%) had worn a face mask/covering in that period, while 27% had not and 14% had not been out. The UK study also found that one in five self-reporters (20%) and more than half of those unable to self-report (52%) were exempt from wearing face masks/coverings [66]. These findings may partly help to explain the lower rates of

compliance in Ireland among older adults with intellectual disability compared to the general older population. There are lessons here for all research on the experience of COVID-19 among people with intellectual disabilities, to pay close attention to both the rules that were applied and to differences based upon levels of intellectual disability when making judgements about compliance as compared to the general population.

Healthcare utilisation

Regarding healthcare, most IDS-TILDA participants (58.2%) had not made any new appointments since the beginning of the pandemic in March 2020. Almost a fifth (18.8%) missed their annual health check during the pandemic, with those aged 65+ years most likely to miss their health check. By comparison, TILDA found that 30% of the general population aged 60+ years either delayed or did not receive medical care that they needed during the pandemic, with 25% reporting the appointment was cancelled, 21% unable to get an appointment when needed, and 18% were afraid to attend an appointment. Services most commonly delayed or not received when needed included dental care (43%), GP (31%), optician (19%), other services (12%) and delays in minor surgery (10%). The long term consequences of missed appointments and delayed treatment will need to be followed for everyone.

Between 42.5% and 70.8% of participants with intellectual disabilities saw health professionals in person 'not at all' or 'not as much', with the highest impact in psychiatry and clinical psychology; but 22.2% to 48% had increased phone/online consultations, the highest with psychiatry and clinical psychology. TILDA also found that 46% of participants had telephone or online appointments with a GP during the pandemic, 39% with a pharmacist, 21% with a hospital doctor, and 10% with another health professional [43]. Over 60% of people with intellectual disabilities in the UK who had routinely seen a healthcare practitioner prior to the pandemic saw them less or not at all since during the pandemic; 22-28% had a planned medical test cancelled, 4-5% had a planned operation cancelled, and 23-41% had a planned hospital appointment cancelled; while 46% of participants who usually had an annual health check prior to the pandemic had not had their health check since the first lockdown [66]. It will be interesting to follow whether the movement from in-person to phone/online consultations will continue in the future and to examine the impact of such changes, if any, on the quality and appropriateness of care given.

COVID-19 vaccines

Almost all IDS-TILDA participants (99.3%) received a COVID-19 vaccine, with most receiving the Oxford AstraZeneca vaccine (67.8%) or the Pfizer-BioNTech vaccine (31.9%). This compared with around 90% of the general population aged 12+ years who received a COVID-19 vaccination, most of which (72.8%) were Pfizer-BioNTech, with 16.2% receiving Oxford AstraZeneca, 7.8% Moderna, and 3.2% Janssen [96]. High vaccination rates reported here are similar to those reported in the UK, where 92% of people with intellectual disabilities had received both doses of their COVID-19 vaccine. The vast majority of people with intellectual disability in the UK (87%) also indicated a willingness to take a booster shot of the COVID-19 vaccine [65]. While IDS-TILDA participants were not questioned about a booster vaccination dose, the huge level of uptake of the vaccine when originally offered may suggest a

willingness at least on a par with that expressed in the UK. Adverse side-effects from receiving a COVID-19 vaccine were reported by 30.3% of IDS-TILDA participants, compared to rates of systemic (whole body) side-effects of 13.5-22% and local side effects of 58.7-71.9% reported in one general population study [97]. If there were concerns about the uptake of vaccines in people with intellectual disabilities, they were not established in the studies to date. Instead, the value of offering vaccination to people with intellectual disabilities on the same basis as the general population was confirmed.

Connections with family and friends

The impact of the pandemic on social connections was evident in the findings that nine in 10 participants had less face-to-face contact with family and eight in 10 had less face-to-face contact with friends. More people living in residential care and community group homes had reduced face-to-face contact with their family, compared with those living in independently or with family. Previous studies demonstrated that individuals living in independent/family residences had better contact with non-resident family than those in residential care or community group homes [3, 98], meaning that those who were already at a disadvantage may have felt the impact more. Reduced face-to-face contact with family may have been alleviated to some degree by an increase in use of technology to speak to family, experienced by over half (55.9%) of participants. That residents of independent/family settings had the smallest increase in this type of contact during the pandemic confirms previous findings that they benefitted least from using technology during the pandemic, perhaps highlighting deficits in skills and/or support [3]; but they may also have had less need for technology given they better maintained their already higher level of in-person family contact during the pandemic. This is an area for further research. People with mild (85.6%) and moderate intellectual disability (81.1%), were more impacted regarding face-to-face contact with friends than those with severe-profound intellectual disability (59%) – who, previous data shows, have higher proportions of co-resident friends [99]. Reduced face-to-face contact with friends may also have been mitigated by increased use of technology to speak to friends during the pandemic, reported by half of participants. More people with mild intellectual disability (57.6%) had increased use of technology to speak with friends, compared with less than half with moderate (46.5%), and a third with severe-profound intellectual disability (35%). Such findings do suggest that more attention is needed in boosting access and use of communication technologies for persons with moderate and severe-profound intellectual disability.

By comparison, TILDA found that almost all of the community dwelling general population aged 60+ years in Ireland visited friends less often (19%) or not at all (80%) during the pandemic, and visited family less often (34%) or not at all (62%). For some, the effects of reduced contact may also have been alleviated by contact using technology, with 28% reporting more frequent social meetings online using video conferencing tools [43]. In the UK, 72% of self-reporting participants stayed in touch with family and friends as much as they wanted, with 14% unable to do so. The number of individuals unable to self-report who were able to meet family and friends face-to-face fell from 32% to 11% during the pandemic; however, this group also recorded an increase in staying in touch with family and friends by telephone (from 11% to 21%), and by video calls (from 7% to 28%) [66].

Social and community participation

IDS-TILDA participants reported a major impact on their social and community participation. A majority of participants reported they were unable to do enjoyable activities or hobbies (83.9%); were separated from family or close friends (79.8%); had reduced work or day service hours (69.5%); had religious or spiritual activities cancelled or restricted (62.8%); had family celebrations cancelled or restricted (62.2%); had planned travel or vaccinations cancelled (58.4%); and were unable to participate in social clubs, sports teams, or volunteering (58.2%). Additionally, a significant minority of participants also reported an increase in verbal arguments or conflict with other adult(s) at home (21.6%); not having the ability or resources to talk to family or friends while separated (18.9%); being unable to attend in-person funeral or religious services for a family member or friend who died (17.6%); unable to visit loved one in a care facility (11.1%); unable to be with a close family member in critical condition (6.9%); and an increase in physical conflict with other adult(s) in home (4.8%).

Our findings are comparable with findings in other studies, with TILDA reporting that most participants felt the pandemic impact on their social and community activities, including leaving their home (69% less often; 14% not at all); attending religious services outside the home (10% less often; 86% not at all); and volunteering (8% less often; 81% not at all). Among people with intellectual disabilities in the UK, almost all (99%) saw community activities stopped completely or reduced; day services stopped completely or reduced for 89-98%; and short breaks/respite reduced or stopped for 92-95% since the start of the pandemic. Just 29-53% of those who were in paid employment prior to the pandemic were still working; and just 17-35% of those who did voluntary work prior to the pandemic were still actively volunteering [66]. The UK findings suggest further areas for research on the impact of COVID-19 and all findings point to significant and sustained disruption to participation in valued and desired activities. The consequences of these disruptions to physical and mental health needs additional investigation and the longer term effects will be a focus in Wave 5 data collection by IDS-TILDA.

Mental health impact

For now, our study found that, at the time of data collection in mid-2021, the COVID-19 pandemic had yet to have a major impact on the overall mental health of participants. Rated mental health was similar to previous levels found in Wave 3 of the IDS-TILDA longitudinal study, with 73% rating mental health as good-excellent, which is also similar to ratings among the general population in the TILDA COVID-19 survey. There was also little change in rates of depressive symptoms. The study identified 7% of participants as having depressive symptoms on the PHQ-9 [102] compared with 10% in Wave 3 IDS-TILDA assessed by the Glasgow Depression Scale. This contrasts with the TILDA findings among the general older population, where 21% had clinically significant depressive symptoms (using the CES-D [103]). Our findings also differ from findings of a study of students in Ireland, where depression (assessed using the PHQ-9 [90]) increased following the onset of the COVID-19 pandemic [101]. The current survey also found that anxiety levels were below cut-off points for anxiety symptoms.

However, 56.4% of participants in the current survey reported being lonely, compared with 43.3% in Wave 3 of IDS-TILDA. The pandemic and associated lockdown was also identified as a source of stress and anxiety to many participants, because they were unable to do their usual activities, could not see family and friends, and felt isolated. These causes of stress and anxiety are very similar to those reported in the first IDS-TILDA COVID-19 survey. Fear of participants getting COVID-19, or fear of their friends/family getting COVID-19, were less frequently cited sources of stress or anxiety. This contrasts with findings from the UK, where over 50% of people with intellectual disability were worried about getting COVID-19, and just over 70% of participants worried about their friends or family getting COVID-19 [65]. The findings here on feelings of isolation are also consistent with a study on students in the general population in the Republic of Ireland and Northern Ireland, where increased social isolation was reported as a source of moderate to very severe stress for just under 64% of participants [101]. In future data collection the continuation of feelings of loneliness and stress will be addressed.

Lived events and impact during the pandemic

Our study found that the pandemic was a time of pervasive and often adverse life events for participants, with only 2.2% reporting no significant life events, compared to 12.7% in Wave 3 of IDS-TILDA. One in five participants (20.8%) knew someone who died during the pandemic. In the UK, a higher proportion of participants with intellectual disability (26-30%) had known someone who died during the pandemic [65]. For IDS-TILDA participants, there were also commonly reported life events that were likely a direct result of the pandemic, including changes to work or day service, changes in frequency of visits to family or friends, as well as some that may have other causes – for example, 18.8% reported a decline or loss of mobility. Many of these life events are permanent (losses) or have the potential not to be reversed (e.g., employment changes). Future work needs to build understanding of how the lives of people with intellectual disabilities change as a result.

General impact and positive experiences

Findings on positive experiences during the pandemic were quite similar to the first IDS-TILDA COVID-19 survey, including the opportunity to engage in new activities, more rest and relaxation, more/better time with staff, and using technology to communicate. When participants were asked to describe the general impact of COVID-19 on their lives, many talked about missing family, friends and enjoyable activities, negative mental health effects, service closures, and concerns with the Government's response to the pandemic. The activities which participants most anticipated after the pandemic ends echoed responses from the general population [104] – hopes for returning to normality with family and friends, reengaging with activities, and broader hopes for a better society.

COVID-19 and the associated restrictions have been shown in this second survey to continue to have effects on the mental health and wellbeing of participants both in terms of fears and life experiences. Nonetheless, despite many difficult experiences for IDS-TILDA participants, the COVID-19 period brought with it signs of resilience, innovation and change, with many participants reporting positive changes in their lives and expressing hope for the future. This is somewhat contrary to findings by, Flynn et al. [66] in the UK, who reported that many participants said nothing good had happened

because of COVID-19; however, positives cited among those who reported something good included, as in Ireland, being able to spend more time with their family or people they lived with, making lifestyle changes (e.g., losing weight, exercising more), and some had improved their technology/digital skills to help them to stay in touch with other people and/or do their jobs from home. It will be interesting to see in the future what reported gains made are sustained.

Conclusions

Our findings suggest that, while the health, service and social impacts of the pandemic are relatively obvious and immediate, the true psychological impact may only be properly assessed over a more prolonged period. The long-term effects of many of the pandemic impacts reported here, including deeply personal events such as being unable to attend a loved one's funeral or be with them during difficult times, may only become clear in the coming years. Continued monitoring of these impacts is critical to providing required future supports for this population. Wave 5 of the IDS-TILDA longitudinal study, commencing in Autumn 2022, will further assess the social and psychological impact that such events had, both during the pandemic period and in the future, as well as health and health services utilisation by people with intellectual disabilities.



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