



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
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The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

THE IMPACT OF COVID-19 on People Ageing with an Intellectual Disability in Ireland



**Evidence from Wave 4 of the Intellectual Disability Supplement
to the Irish Longitudinal Study on Ageing (IDS-TILDA)**

Understanding the impact of COVID-19 on the health and well-being of older adults with an intellectual disability in Ireland

**Findings from Wave 4 of 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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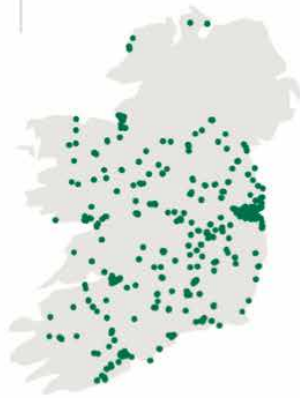
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710



participants completed
the COVID-19 survey
378 female and 332 male

196

mild ID



276

moderate ID

188

severe-profound ID

133

aged 40-49 years

391

aged 50-64 years

186

aged over 65 years



High rate of reported
pre-existing conditions:

- 67% history of
overweight/obesity
- 52% history of
cardiovascular disease

67%



52%



443

participants tested
for COVID-19

11

tested positive



139

participants with
Down Syndrome

69 tested for COVID-19

None tested positive



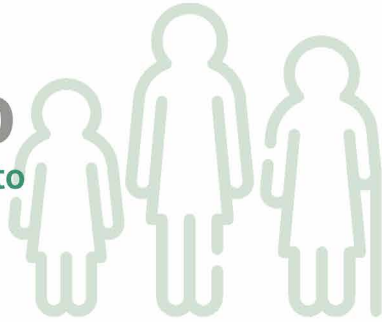
No reports
of COVID-19
mortality



Of those who had symptoms or tested positive



79%
had a plan to
self isolate



61%
were able to
comply with
guidelines

58%



reported some
positive aspects
to the COVID-19 period



Some
positive
aspects to
lockdown:



- Trying new activities (41%)
- Opportunity for more rest (36%)
- Better relations with staff (26%)



55%

reported feeling
stress/anxiety during
the COVID-19 period



Most common
causes of
stress/anxiety

- Not being able to do usual activities (79%)
- Not seeing family (47%)
- Not seeing friends (45%)

Executive Summary

Introduction

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) was established in 2008, with the aim of identifying the principal influences on successful ageing in people with intellectual disability (ID) in Ireland. The study has provided vital longitudinal information about healthy ageing in people with intellectual disability, using a representative sample from across the nation. It also has the advantage of having a comparison sample in the form of the Irish Longitudinal Study on Ageing (TILDA), meaning that the results can be compared to the general older population.

Over the last decade, the rich data collected by IDS-TILDA has helped to inform policy relating to ageing in people with intellectual disability. In this vein, the work of IDS-TILDA allows for longitudinal tracking of progress made in improving the lives of people with intellectual disability, consistent with government policies, such as the *National Disability Inclusion Strategy 2017-2021*, *Healthy Ireland – A Framework for Improved Health and Well-Being 2013-2025*, and *Move from Congregated Settings, 2011*.

Wave 4 of IDS-TILDA began in 2018. Participant retention remained high between Wave 3 and Wave 4, with 31 participants declining to participate and a further 5 unable to be contacted. Sixty-seven participants passed away between Wave 3 and Wave 4. In addition to following up on existing IDS-TILDA participants, for Wave 4, 233 new participants were recruited to refresh the baseline sample. As the COVID-19 pandemic began while data was still being collected for Wave 4, IDS-TILDA adapted for the lockdown. A COVID-19 questionnaire was added to the protocol and administered to 710 IDS-TILDA participants. This report will outline the findings of our investigation into COVID-19 and its impact on older adults with intellectual disability.

COVID-19 survey

The lockdown in Ireland due to the COVID-19 pandemic began on March 13th, 2020, while the data collection for Wave 4 was still in progress. As a result of the restrictions, face-to-face research visits had to be paused and certain aspects of Wave 4 data collection had to be cancelled (e.g. the collection of physiological measures). However, given the commitment of the representative sample participating in IDS-TILDA, we took the opportunity to study how the pandemic was affecting this cohort. We investigated the impact of COVID-19 and the associated lockdown on older adults with intellectual disability via telephone survey.

Key Findings

- A total of 739 participants were enrolled in Wave 4. Of these, 710 completed the COVID-19 survey - a 96% response rate. Of the 710 participants, 378 (53%) were female and 332 (47%) were male. A total of 133 (19%) were aged between 40-50 years, 391 (55%) were aged 50-64 years and 186 (26%) were aged over 65 years. All levels of intellectual disability were represented; 196 (30%) had mild intellectual disability, 276 (42%) had moderate intellectual disability and 188 (28%) had severe-profound intellectual disability.
- There was a high rate of reported pre-existing conditions associated with poorer outcomes for COVID-19, with 365 (66%) participants having a history of overweight/obesity and 371 (52%) participants having a history of cardiovascular disease. There was also a high prevalence of certain psychiatric/neurological conditions: 209 (29.5%) participants had a history of epilepsy, and 29 (4.1%) participants had a history of dementia. A further 61 (8.6%) participants had a history of lung disease/asthma, and 68 (9.6%) had a history of diabetes. Pre-existing mental health problems were high with 380 (53.5%) reporting a history of emotional, nervous or psychiatric disorder.
- A total of 443 (62.4%) participants were tested for COVID-19 with 71 (10%) reporting COVID-19-like symptoms and 11 (2.5%) testing positive.
- For those 11 participants who tested positive, the common symptoms were fatigue (N = 6, 54.5%), fever (N = 5, 45.5%), and cough (N = 3, 27.3%).
- There were no instances of mortality due to COVID-19 in the sample.
- People in residential care had the highest rates of testing (N = 196, 84.8%), positive tests (N = 9, 4.6%) and symptoms (N = 35, 15.2%).

- Fifty-five (7.8%) participants moved from their usual home due to COVID-19, most commonly while waiting for test results (n = 20), relocate to a family home (n = 11), following a period of hospitalization (n=7), or to follow isolation procedures as a precaution (n = 4).
- Of those participants who had symptoms or tested positive, over three-quarters (78.7%) had plans to manage self-isolation according to guidelines. Most were able to comply with guidelines, but one-third were unable to do so.
- More than half of the participants (55%, n = 383) indicated stress or anxiety due to the pandemic. Participants were more likely to indicate stress or anxiety if they were female, aged under 50, having mild to moderate intellectual disability, or living independently, with family or in community group homes.
- The most common cause of stress/anxiety overall was not being able to do usual activities, followed by not seeing friends/family, loneliness/isolation, and fear of getting COVID-19.
- People living independently/with family were more likely to report not being able to do usual activities as a source of stress/anxiety (85%), compared to those living in community group homes (82%) or particularly residential care (69%). Those living independently/with family were less likely to report missing family as a source of stress (28%) compared to those living in residential care (44%) or community group homes (55%). Conversely, those living independently/with family were more likely to report missing friends as a source of stress (61%) than those living in residential care (34%) or community group homes (45%).
- At the same time, 381 (58%) participants also indicated there had been some positive aspects to the lockdown, with the most commonly reported being trying new activities (41%), the opportunity for more rest (36%), better relations with staff (26%) and using technology to communicate (14%).
- There were 139 participants with Down Syndrome. These participants were more likely to have moderate intellectual disability (as opposed to mild/severe-profound), and had lower rates of some high-risk health conditions, including diabetes (3.6% in people with Down Syndrome vs 11.1% in people without Down Syndrome) and cardiovascular diseases (40.3% vs 55.3%), although they also had higher rates of other conditions, such as dementia (12.2% vs 2.1%) and overweight/obesity (68.2% vs 66.2%). A total of 69 participants with Down Syndrome were tested for

COVID-19, 13 participants with Down Syndrome experienced symptoms, and 2 of these participants were hospitalized with COVID-19-like symptoms. However, no one with Down Syndrome received a positive test result for COVID-19.

Summary and Conclusions

The findings reported here represent a moment in time as the first wave of COVID-19 was subsiding but does provide an important picture of the experiences of COVID-19 in people ageing with an intellectual disability. Fortunately, the number who proved symptomatic and positive for COVID-19 was small, there were few hospitalizations and to date no related deaths. In the interviews with people with intellectual disability it was clear that they heard and followed the messages about keeping physical distance, masks, washing hands and monitoring and reporting their symptoms. The responsible acts of people with intellectual disability were matched by the equally responsible acts of their families when living at home and their services providers when they were living in out of home placements. Testing proved feasible for many people with intellectual disability. Some but not most individuals who tested positive were asymptomatic and, similar to the general population, risk rose with age and with the presence of co-morbidities. Despite the small numbers that tested positive our data does support previous concerns reported in other countries that age of risk is younger for people with intellectual disability. Those aged 50-64 were over-represented in those who were positive. Also, greatest attention is needed for those with severe and profound levels of intellectual disability. Others have raised particular concern for people with Down syndrome and while the numbers with Down syndrome who were hospitalized with COVID-19-like symptoms were small in this study (n=2), the need to particularly monitor those with Down syndrome age 40 years and older is supported.

Particularly commendable was that there were active plans and strategies for isolation and quarantining, and most people with intellectual disability were able to comply with these. It was also found that many people with intellectual disability managed well with the community-wide restrictions during the period studied but that others did experience stress and anxiety from not being able to see family and friends or participate in valued activities. For people with intellectual disability the response to any imposed restrictions during the pandemic needs to be as data-driven as it has been for the entire population. IDS TILDA provides useful population data to enable this to happen. The results of this study show that people with intellectual disability who are older and with high levels of comorbidities can be protected from getting COVID-19 by strict adherence to public health guidelines. However, if community transmission is high, extra vigilance is needed. This study did not report any COVID-19 related deaths; however, we know from other published studies that increasing age and other recognized comorbid health conditions result in poorer outcomes

and increased mortality, hence people within this category will benefit from additional vigilance. All others with intellectual disability should be supported and encouraged to follow general public health guidelines including continuation of keeping physical distance, wearing masks, washing hands and monitoring and reporting their symptoms. We need to be cautious not to impose prolonged unwarranted restrictions on the lives of people with an intellectual disability. The results of this study demonstrate that prolonged restrictions had a major impact on the mental health and wellbeing of older adults with an intellectual disability, with increased levels of anxiety and loneliness. Based on this data we would not recommend categorizing people with intellectual disability as extremely vulnerable as the cost of this in terms of poorer mental and indeed physical health outcomes in the long term cannot be underestimated.

As new spikes and waves of COVID-19 occur there is a need to pay further attention to testing. Most participants were tested at least once and subsequent lower numbers of additional tests seemed driven by concerns about potential symptoms and contacts. When people with intellectual disability live in group homes and residential care there is a higher likelihood of multiple people entering and leaving their homes and presenting risk for COVID-19. Consideration going forward should be given to a more frequent testing schedule. Similarly, the relatively good adjustment of many to restrictions may have been influenced by beliefs that those restrictions would be short-term. That short-term has become more long-term. Potential increases in stress and anxiety must be monitored and more generally, this one-time picture of the experiences of people with intellectual disability with COVID-19 must be supplemented with follow-up surveys corresponding to the different spikes and surges to assure that there are no new concerns emerging.

Introduction

The IDS-TILDA study

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) was established in 2008 with the specific aim to identify the principal influences on ageing in people with an intellectual disability aged 40 years and above in Ireland. 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.

IDS-TILDA was the first longitudinal study on ageing amongst the intellectual disability population worldwide to be implemented parallel to a study of ageing amongst the general population. The conceptual framework shown in Figure 1 illustrates the range of data collected by IDS-TILDA. The study is also underpinned by the values of inclusion, empowerment, choice, person centeredness, best practice, promoting people with intellectual disability and contributing to their lives. It was developed in close cooperation with people with an intellectual disability, who have played an integral role throughout the development of the study. Involvement of people with an intellectual disability began with the initial pilot study conducted to develop inclusive Wave 1 protocols and has continued through consultation on changes for each subsequent wave. A 'keeping in touch' strategy – for example using newsletters, cards and art competitions – is also integral to maintaining the voice of people with an intellectual disability as well as engaging people and preserving the study sample through multiple waves of data collection.

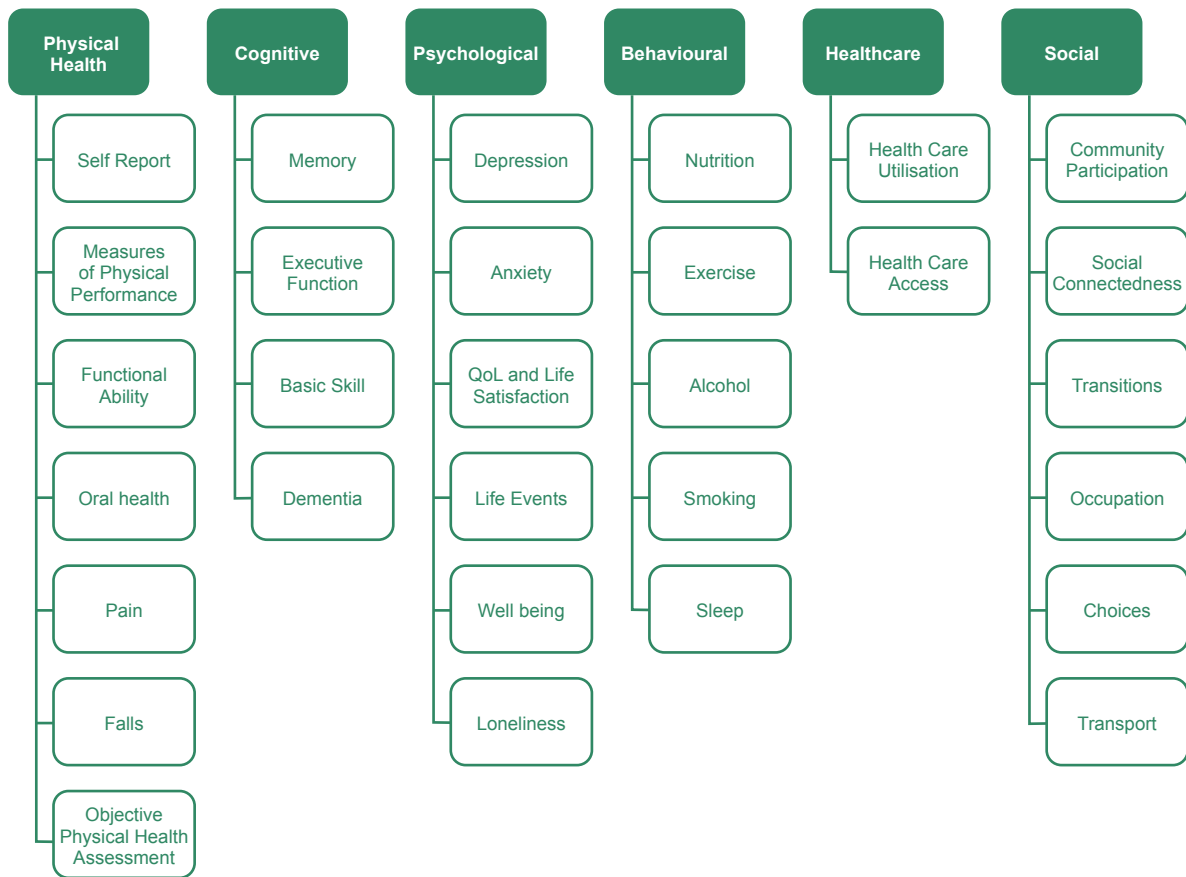


Figure 1. IDS-TILDA conceptual framework

The first three waves of IDS-TILDA data collection were reported in 2011, 2014 and 2017¹, establishing the study as a global leader in research on ageing amongst people with intellectual disability, contributing to policy and service development in Ireland, and supporting the establishment in 2018 of the Trinity Centre for Ageing and Intellectual Disability (TCAID) at Trinity College Dublin (TCD).

COVID-19 prioritisation for IDS-TILDA Wave 4

A unique opportunity emerged during Wave 4 of IDS-TILDA to examine how COVID-19 has affected the lives of people with an intellectual disability who are getting older.

Given that the COVID-19 crisis remains ongoing at the end of 2020, there is an urgency to disseminate knowledge about how the virus and its associated public health measures have impacted people with an intellectual disability in Ireland. The IDS-TILDA COVID-19 survey assessed rates of symptoms and testing, morbidity and treatment, stress and anxiety associated with the pandemic, and any positive outcomes experienced by individuals during the lockdown period. These data were supplemented with main IDS-

1 <https://www.tcd.ie/tcaid/research/publications/reports.php>

TILDA data to explore associations with disease morbidity and other health and well-being outcomes, to consider potential predictors of symptoms and COVID positivity and of differences in people's lives, before and during COVID-19 restrictions.

The findings from this representative sample of older adults with intellectual disability in Ireland presented in this report, will add to our understanding of the impact of COVID-19 on this population, and the impact of public health measures implemented to combat spread of the virus.

Methods

Wave 4 planning & implementation

The purpose of Wave 4 was to continue the steady-state longitudinal data collection of IDS-TILDA – continuing to examine the principal influences on successful ageing in persons with intellectual disability; comparing results with previous waves of IDS-TILDA; determining if they are the same or different from influences on ageing within the general population; and analysing the data to inform and guide the planning, implementation and evaluation of future national policies, programmes and services. To achieve this, the IDS-TILDA study comprised five individual elements:

1. The Pre-interview Questionnaire (PIQ) – a self-completed questionnaire sent out to participants in advance of their main interview, and then collected by fieldworkers when they called to conduct the main interview;
2. A face-to-face interview which used the Main Questionnaire – administered through Computer Assisted Personal Interviewing (CAPI);
3. The IDS-TILDA Carer’s Questionnaire – a self-completed questionnaire normally sent out to family carers in advance of the main interview, and then collected by fieldworkers when they called to conduct the main interview;
4. The IDS-TILDA Health Fair – a programme of objective health measures previously administered in Wave 2, and further developed for Wave 4 with additional assessments and biomarkers; carried out with all consenting participants by a team of research nurses; and
5. The IDS-TILDA End-of-Life Study – a telephone survey administered with the carer or support worker of IDS-TILDA participants who have passed away since the previous wave.

Ethics

As with previous study waves, implementation of IDS-TILDA for Wave 4 was contingent on successfully receiving ethical approval at an organisational level from Trinity College,

as the host institution, and from all participating service providers; as well as obtaining individual consent to participate for all study participants.

The introduction of the General Data Protection Regulation (GDPR) and the Health Research Regulations (HRR) in 2018 added a number of other requirements for Wave 4, including development of a Data Protection Impact Assessment (DPIA) and an application to the Health Research Consent Declaration Committee (HRCDC) for a Consent Declaration, which would provide ethical approval for the inclusion of some participants with ID who lacked the capacity to provide consent directly. At the outset:

- Ethical approval for the study was granted by TCD Faculty of Sciences Research Ethics Committee on 23rd January 2019;
- All participating service providers granted approval to commence data collection within their services and
- The HRCDC granted a full Consent Declaration for the study in December 2019, facilitating the inclusion of proxy-consented participants.

Wave 4 sample

As a longitudinal study targeting an older cohort of people with intellectual disability (aged 40+ years), IDS-TILDA experienced a degree of attrition among participants, which was largely accounted for by participant deaths (105) throughout the first three waves, and a small number who chose to withdraw (39) from the study. This meant that the original Wave 1 sample of 753 had reduced to 609 participants in Wave 3, with further attrition expected prior to the start of Wave 4. To maintain the statistical power required for in-depth analysis, and to address any concerns that might arise for the continued representativeness of the sample, a refreshment of the sample was planned in Wave 4. The refreshment addressed losses likely to impact the representativeness of the sample and to replace the age 40-50 years cohort who by Wave 4 had aged to older than 50 years. As in Wave 1, the Health Research Board (HRB) supported use of the National Intellectual Disability Database (NIDD) to anonymously recruit sufficient numbers of new participants to restore the sample to its Wave 1 size and representativeness.

A targeted recruitment drive successfully addressed underrepresented groupings including in the 40-49-year-old category. A final representative sample of 739 individuals was achieved for Wave 4 with 135 new participants in the new 40-49-year-old cohort.

Fieldworker recruitment and training

In the summer of 2019, a team of 24 field researchers with extensive experience working with people with an intellectual disability was recruited for Wave 4 data collection. A comprehensive 3-day training programme was delivered to field researchers in August 2019. The training programme was delivered by the wider IDS-TILDA team with support from Behaviour and Attitudes (B&A) as the contracted company who provided and managed the CAPI system, and from IDS-TILDA participants who assessed the readiness of field researchers. Topics covered in the training included field researcher roles and responsibilities, ethical research and data protection, and research methods and field techniques, and there were practice sessions addressing use of the CAPI system. A team of five nurse researchers was recruited to implement the Wave 4 Health Fair. This team completed a five-day training programme covering all health assessment and data collection protocols and procedures required for the Health Fair.

Effect of Covid-19 on Wave 4 data collection

Wave 4 data collection commenced in September 2019 and was ongoing until March 2020. By then 559 CAPI interviews had been completed and uploaded to the data system managed by B&A. Health Fair assessments had also been completed for 260 participants.

The Irish Government introduced nationwide restrictions to combat the spread of COVID-19 on Friday 13th March 2020, meaning that all data collection for IDS-TILDA was suspended. There were 180 remaining interviews to be completed including newly recruited and still to be recruited participants.

Measures put in place to address COVID-19

Following the suspension of all data collection in March 2020, the IDS-TILDA team considered and made every effort to adapt to the changed circumstances and to complete as much of the remaining data collection as possible within a reasonable timeframe.

Given the nature of the Health Fair, especially the requirement for close contact with participants, a decision was made in the interests of protecting participants to cease any further Health Fair assessments for Wave 4.

Three adapted/new elements of the study were developed, discussed with the IDS-TILDA Scientific Advisory Committee and Steering Committee, and submitted for additional ethical review:

1. To conduct all remaining CAPI interviews remotely instead of in-person using video conferencing or phone calls, depending on the preference and ability of participants and their supporters;
2. A process to re-affirm consent to participate in the CAPI interview remotely instead of in-person, also using video or phone calls; and
3. The addition of nine new questions for all Wave 4 participants (those who had completed testing by March 2020 and those who had not yet completed testing) focused on symptoms, testing and treatment of COVID-19, and participants' experiences during the crisis.

In May 2020 the team obtained approval to proceed with these changes from TCD Faculty of Health Sciences Research Ethics Committee and the newly established National Research Ethics Committee for COVID-19-related research (NREC). The team also submitted a DPIA amendment to the TCD Data Protection Office, a Consent Declaration Amendment Request to the HRCDC, and wrote to each service provider informing them of changes to the study protocol.

Following additional ethical approval, the IDS-TILDA team developed guidance and delivered training online for a team of nine experienced Wave 4 fieldworkers to now conduct virtual interviews. A successful pilot of the adapted methods and new questions with 40 individuals with an intellectual disability from five service providers highlighted a general preference by participants with intellectual disability for video over phone interviews. There were no issues of concern identified with the new methods and questions.

Wave 4 data collection – completion

A full rollout was undertaken to complete CAPI/PIQ protocols for participants who had not been interviewed prior to the suspension of data collection. In tandem, the 559 participants who had previously completed their CAPI/PIQ were re-contacted and completed the additional COVID-19 questions. By September 2020, the final sample of 739 for Wave 4 included:

- 739 main CAPI interviews:
 - 559 completed in-person prior to the suspension of data collection
 - 180 completed by video/phone following resumption of data collection in May 2020
- 728 Pre-Interview Questionnaires (PIQs)
- 710 COVID-19 surveys
- 74 Carer's Questionnaires
- 260 Health Fair assessments

Reporting of data

Data is presented in this report in some instances by type of residential setting. Residential categories are defined as follows:

- Independent/family residence – grouped category including (1) participants who lived either independently or semi-independently, and (2) participants who lived in their family homes;
- Community Group Homes – are supported service-provided residences based within the general community that house up to six people with an intellectual disability;
- Residential care – includes participants who lived in supported service-provided residences within a segregated service setting rather than a community setting (e.g. in clustered homes or in a larger unit within a campus environment).

Current knowledge of COVID-19

On 30th January 2020, the World Health Organisation (WHO) declared the outbreak of COVID-19 to be a 'public health emergency of international concern' and recognised the outbreak as a pandemic on 11th March 2020. Since first being identified, what is known about COVID-19 has evolved rapidly following an unprecedented focus of scientific research internationally. This chapter aims to summarise the current understanding of COVID-19, including the disease pathogenesis, identified risk factors, rates of morbidity and mortality, and outcomes of the disease and related public health measures. There is also a particular focus on current knowledge about the risk of contraction, infection outcomes and the impact of COVID-19 for people with an intellectual disability. The chapter concludes by identifying lessons that may be learned from the pandemic. The related literature is rapidly evolving, meaning that what is reviewed here is current as of November 2020.

General science of COVID-19

COVID-19 is the name given to the disease associated with a strain of coronavirus not previously identified in humans that was discovered in China in December 2019, called Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2) [1]. Coronaviruses are a family of viruses which may cause illness in animals or humans, some of which are known to cause respiratory infections including the common cold as well as more severe diseases such as Middle East Respiratory Syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS) [2]. COVID-19 spreads primarily from person to person through small droplets expelled through the nose or mouth when a person with the virus coughs, sneezes, or speaks. Other people may catch COVID-19 if they breathe in these droplets from an infected person or if they touch objects or surfaces where droplets have landed and then touch their eyes, nose or mouth [2].

People who become infected with COVID-19 have reported a wide range of symptoms, which usually appear 2-14 days after exposure to the virus and range from mild symptoms to severe illness [3]. Symptoms of COVID-19 are usually mild and begin gradually, the most common being fever, dry cough, and tiredness. Some patients also experience aches and pains, nasal congestion, headache, conjunctivitis, sore throat, diarrhoea, loss of taste or smell, a rash or discoloration of fingers or toes [2]. One systematic review

identified that some patients may be slow to develop symptoms, with most of the 25% who were asymptomatic at time of testing positive going on to develop symptoms, while 8.4% remained asymptomatic [4]. Another review estimated that 16% of those who tested positive for COVID-19 remained symptom free throughout their infection [5].

Morbidity and mortality rates of COVID-19

As of 17th November, 2020, a total of 54.56 million cases of COVID-19 had been reported globally, with 1.32 million confirmed deaths [6]. However, on 5th October, the Executive Director of the WHO's Health Emergencies Programme, Mike Ryan, reported that an estimated 10% of the world's population had contracted the virus, which would put the true number of infections at that time at more than 20 times the known infection rate [7].

Rates of confirmed positive cases and deaths associated with COVID-19 vary significantly between different countries, reflecting variable testing and reporting arrangements in place [8]. Nonetheless, studies have shown globally that the degree of risk regarding infection and adverse outcomes of COVID-19 varies widely within societies, with significant differences in risk evident between different groups based on socio-demographic and health-related factors.

Many countries in Europe experienced a second wave of infection from September 2020. As of November 17th, the 14-day cumulative number of COVID-19 cases per 100,000 population showed that Ireland had the third lowest rate out of 31 countries of the EU/EEA/UK with a rate of 114.3, compared with the highest rates in Luxembourg (1301.7), the Czech Republic (1076.3), and Austria (1055.8), while Finland (54.7) and Iceland (76.8) had the lowest rates [9].

Risk factors of COVID-19

There are two key aspects of risk to consider for COVID-19: (1) increased risk of contracting the disease; and (2) increased risk of adverse infection outcomes.

Increased risk of contracting COVID-19

In addition to identifying greater risk of adverse outcomes for specific groups, public health guidance internationally has also identified people who may have increased exposure to COVID-19 and thus increased risk of contracting the virus. The European Union (EU) identified people living in long-term care facilities as people at higher risk of infection [10]. In Ireland, high risk groups include residents of nursing homes and other long-stay settings and certain people in specialist disability care [11]. In the US, people who need to take

extra precautions include those with specific individual characteristics (e.g. racial/ethnic minority, disability, developmental and behavioural disorders; drug/substance users), and those in specific residential situations including homelessness, nursing home and longer-term care facilities, and group homes for people with disabilities [12]. Findings in Canada and Australia also found higher risks in ethnic minority groups, people living in aged care facilities and people with disability [13, 14].

In Ireland, as of 27th June 2020, nursing homes accounted for 22% of all cases, 18% of all outbreaks, and 56% of all deaths related to COVID-19 [15]. A study of 13,167 nursing homes in the US found that 71% of facilities had reported a case of COVID-19 amongst residents or staff by June 2020, and 27% of these had reported an outbreak. The strongest predictor of cases and outbreaks in nursing homes was the level of infection within the surrounding community [16]. Another study in Boston, MA, identified sex (male), bowel incontinence and staff residence in a community with a high burden of COVID-19 as factors in increased infection risk for COVID-19 [17]. A study in Ireland identified an increased risk of transmission associated with asymptomatic infection amongst nursing home residents, and found a significant correlation between staff with symptomatic COVID-19 and resident numbers with confirmed/suspected COVID-19 [18].

Increased risk of adverse COVID-19 outcomes

Older age and specific underlying health conditions are frequently identified as the factors which place individuals at the highest risk of adverse outcomes from COVID-19 infection. This is reflected in public health guidance internationally, where being over the age of 70 years or having specific pre-existing medical conditions (including organ replacement, receiving cancer treatment, severe cystic fibrosis or severe respiratory conditions) places individuals in the highest risk categories – as seen for example in Ireland [11], the United Kingdom (UK) [19], United States (US) [12], Canada [13] and Australia [14]. These countries also identify increasing age generally and the presence of less severe health conditions (for example less severe asthma, chronic obstructive pulmonary disease (COPD), heart disease, diabetes or obesity) as also increasing the risk of adverse outcomes of COVID-19.

In the scientific literature, an analysis of data for 611,583 patients from China, Italy, Spain, United Kingdom, and New York State found the mortality rate was <1.1% in patients aged under 50 years and increased exponentially above 50 years in all five regions, up to 29.6% in patients aged ≥80 years. The study confirmed the determinantal effect of age on mortality due to COVID-19, with age >60 years identified as a key threshold, and concluded that preventive measures should be prioritised for older adults [20].

A study among 10,544 patients in Mexico examined risk factors of hospitalisation and mortality associated with COVID-19. The study found that the risks of hospitalisation and mortality increased with age; and increased in patients with comorbidities of hypertension, obesity, and diabetes. It also found that men were more likely than women to be hospitalised and to die from COVID-19 [21]. A study of case mortality rates (CMR) in 93 countries found that Alzheimer's Disease, COPD, depression and higher Gross Domestic Product (GDP) predicted increased death rates; concluding that comorbid illnesses such as Alzheimer's and lung diseases may be more influential in COVID-19 mortality than aging alone [22]. A retrospective, dual-centre study in the United States, involving 7,246 patients hospitalised with COVID-19, identified 12 patients with Down Syndrome. These patients were ten years younger than patients without Down Syndrome, and had an increased incidence of mechanical ventilation as well as sepsis; three of these twelve participants (25%) were deceased at study end, compared to four out of sixty in the comparison group (6.7%) [23]. The authors concluded that the patients with Down Syndrome had a more severe presentation of the disease.

A systematic review and meta-analysis of 16 studies examined the impact of a range of comorbidities on serious events in COVID-19 patients, including ICU admission, Acute Respiratory Distress Syndrome (ARDS), mechanical ventilation, pneumonia, and death. Serious events were seen in approximately 13% of patients, and increased risk of a serious event were identified for patients with COPD, chronic kidney disease (CKD), cardiovascular diseases (CVD), hypertension and diabetes [24]. A meta-analysis of 18 studies examined associations between underlying CVD and worse prognosis in COVID-19 patients. It found that pre-existing CVD was associated with worse outcomes among patients with COVID-19, with increased risks of a severe form of COVID-19 and of related mortality when controlling for age and sex [25].

Studies continue to explore other risk factors as the pandemic develops, highlighting the emerging complexity of the disease.

Combined, these findings highlight increased risks of severe COVID-19 infection for older people on the basis of increasing age, particularly for those aged 70 and above, as well as increased risks of exposure to and contraction of the virus for people living in congregated care settings such as nursing homes. This has been compounded by the effect of increasing morbidities generally as people age. For older people living in congregated care settings there exists a multiplier effect whereby they are (1) more exposed to contracting the virus due to their environment and (2) more vulnerable to worse outcomes due to age and increased comorbidities [18].

Public health measures to reduce spread of COVID-19

In response to the progress and widespread nature of the pandemic since first being identified, a range of public health measures have been implemented globally, aimed at suppressing and reducing the spread of the disease. Measures ranged from social distancing and minor restrictions to full 'lockdown' of countries. Given that age emerged early in the pandemic as a key risk factor for COVID-19, specific measures to curb transmission of the virus focused on older populations and others deemed 'high-risk' or 'vulnerable'. For example, in Ireland, in addition to general public health measures, people aged 70 or above and other extremely vulnerable individuals were advised to 'cocoon' within their homes during stages of the pandemic [26]. In the UK, high risk groups were advised to take extra precautions for a period of time, a measure called 'shielding' [19].

A US study examined the effects of state-wide 'shelter-in-place' orders issued in 42 states and Washington, D.C. It found that shelter-in-place orders reduced the daily growth rates of COVID-19 deaths after three weeks and hospitalisations after two weeks; with the daily mortality growth rate reduced by 6.1% and the daily hospitalisation growth rate reduced by 8.4% after 42 days. The study estimated that these shelter-in-place orders averted the loss of 250,000-370,000 lives between March and May 2020 [27].

A review of 29 studies to assess the effects of quarantine measures on the spread of disease found that quarantine was important in reducing incidence and mortality of COVID-19, and that early implementation of quarantine and combining quarantine with other public health measures (including school closures, travel restrictions and social distancing) was important [28]. Generally, it was felt that public health measures and social restrictions introduced globally were successful in bringing the first wave of the virus back under control by summer 2020 [29].

Impact of the pandemic and public health measures on mental health and well-being

The potential for secondary impacts of the pandemic and associated restrictions on mental health and well-being have also emerged as important.

For the general population who have not been infected, the true impact of the pandemic on mental health may only become clear in the long-term; however, the psychological impacts may be profound and there is a critical need for research to understand the scale and nature of any such impact [30].

One review of literature published early in the COVID-19 pandemic found that symptoms of anxiety and depression (16–28%) and self-reported stress (8%) were common psychological reactions and may be associated with disturbed sleep [31]. A study in March 2020 to assess anxiety levels in Iran during the initial outbreak found that approximately one-fifth of the general population had experienced severe/very severe anxiety [32].

A global survey examined the psychological impact of COVID-19, resultant restrictions, impact on behaviours and mental wellbeing, with half of almost 8,000 participants being healthcare professionals. It found that 32% of participants had suicidal thoughts, healthcare professionals reported more mild depression and anxiety, and participants who reported suicidal thoughts pre-COVID were less likely to communicate with friends and family, or engage in coping strategies [33].

A panel study following the behaviour of over 55,000 adults in the UK between March and May found that changes in activities were associated with changes in mental health and wellbeing. Outdoor activities including gardening and exercising predicted subsequent improvements in mental health and wellbeing, while increased time following news about COVID-19 predicted declines in mental health and wellbeing [34]. A review of the impact of quarantine on the mental health of children and adolescents found increases in restlessness, irritability, anxiety, clinginess and inattention with increased screen time in children during COVID-19 quarantine [35].

Considering the impact of the pandemic for the over-70s in Ireland, TILDA warned that lockdown measures may especially affect people who previously relied on social engagement outside their immediate family, including the widowed and those without children or close relatives, and those who rely on community or church-based social participation and engagement [36].

Within nursing homes, in addition to a sense of fear of themselves or family members contracting the virus, Irish nursing home residents reported a deep sense of isolation and loneliness due to restrictions placed on visiting. While many used phones and computers to keep in touch, the absence of human contact was keenly felt [37].

Overall, some beneficial aspects of the pandemic have been identified, for example the vast majority of workers were positive about home-working and wished to retain choice and flexibility in working from home post-pandemic [38]. However, in addition to the immediate health impact of COVID-19, studies cited here demonstrate the emerging risks to mental health and well-being due to the pandemic and associated public health restrictions, both for the general population and within certain cohorts.

COVID-19 and intellectual disability

This section now examines the COVID-19 pandemic from the perspective of people with intellectual disability, including knowledge to date about health risk factors for the disease as well as secondary outcomes of the pandemic for people with intellectual disability such as mental health and well-being. Relevant literature and data published up to mid-November 2020 was included in the review.

Risk factors of COVID-19 for people with intellectual disability

Reports of higher mortality rates for people with Down Syndrome during the 2009 H1N1 flu pandemic [39] have been cited as setting a worrying precedent for the risk to people with intellectual disability during the COVID-19 pandemic [40]. In Ireland, people with an intellectual disability have been identified as a high-risk group for more severe outcomes of COVID-19 (but not considered 'extremely vulnerable' or very high-risk) [11]. Other countries have varying positions. For example, while the United Kingdom (UK) initially did not classify any people with intellectual disability within higher risk groups, they later in November 2020 added all adults with Down syndrome (aged 18+ years) to the list of "clinically extremely vulnerable groups" [41]. The United States (US) does not classify people with intellectual disability as high-risk but classifies intellectual disability as a factor which may require extra precautions for preventing COVID-19 [12]. Canada identifies people living in group settings and those with reduced capacity (for example, to understand information or engage in preventative measures) as being more exposed to COVID-19, while not specifying people with intellectual disability as 'vulnerable' [13]. Australia issued additional advice for some groups including people with disabilities, while not including them among high-risk groups [14].

The section on increased risk of adverse COVID-19 outcomes above identified the heightened risk of outcomes that have been associated with a range of chronic health conditions. There is evidence in the literature that some health conditions associated with poorer outcomes for COVID-19 are more prevalent in the intellectual disability population, for example diabetes and obesity [42, 43]. Data from Wave 3 IDS-TILDA identified that diabetes prevalence was just over 9% and was higher in women (11%) compared to men (7%); diabetes increased with age to 12% for those aged 65 or more, and was higher among people with mild intellectual disability (13%) compared with moderate (11%) and severe-profound intellectual disability (5%). IDS-TILDA previously found that 80% of older adults with intellectual disability (aged 40+) were overweight or obese, similar to the general older population (aged 50+), but with higher rates among people with mild intellectual disability (88%) and women (83%). Reported rates of hypertension (19%) were

half of those objectively measured among the general population (40%), but over the age of 65 hypertension increased more in women (35%) compared to men (23%).

Evidence from the UK prior to the pandemic suggested that people with intellectual disability were more than twice as likely to die from avoidable causes that would be amenable to change by good quality healthcare [44]. A recent US study found that, like people without intellectual disability, the leading cause of death for adults with intellectual disability was heart disease. Adults with intellectual disability had a substantially higher risk of death from pneumonitis and influenza/pneumonia; and adults with mild/moderate intellectual disability also had higher risk of death from diabetes mellitus. Women with intellectual disability had a higher risk of death from dementia/Alzheimer's and diabetes mellitus; and men with intellectual disability had higher risk of death from pneumonitis and influenza/pneumonia. There was also a race/ethnicity factor, where Non-Hispanic Whites with intellectual disability had increased risk of death from pneumonitis, Non-Hispanic Blacks from heart disease and diabetes mellitus, and Hispanics from diabetes mellitus [45].

People with intellectual disability experience the early onset of some age-related health conditions [46], some of which are associated with increased risk for COVID-19. As such, this population may benefit from the suggestion that, rather than simply relying on chronological age, screening for underlying comorbid health conditions may be clinically more informative in assessing COVID-19 risk [47], with more targeted screening for COVID-19 in these specific high risk groups.

People with Down Syndrome also show signs of long-term dysregulation of the immune system, suggesting another potential source of added risk for this population [48].

Prevalence of dementia among the IDS-TILDA sample at Wave 3 was 9% but was much higher among participants with Down Syndrome (36%). Over half of the sample at Wave 3 (52%) reported a diagnosis of a mental health disorder, with anxiety most prevalent (32%), followed by depression (16%) and mood swings (15%). A sub-sample of participants completed the Glasgow Anxiety Scale for People with a Learning Disability (GAS-LD) [49] and the Glasgow Depression Scale for People with a Learning Disability (GDS-LD) [50], identifying 15% with anxiety and 10% with depression [51]. This compares with findings that 13% of the general older population experienced 'case-level' symptoms for anxiety, and 2% with manic depression [52].

Outcomes of COVID-19 for people with intellectual disability

A small number of studies have identified outcomes for people with intellectual disability from the COVID-19 pandemic – in terms of both the immediate health outcomes and secondary outcomes including mental health and well-being.

Health outcomes for people with intellectual disability

A US study using data of COVID-19 related deaths up to 14th May 2020 reported similar overall case-fatality rates for people with intellectual and developmental disability (COVID-19) (5.1%) and those without COVID-19 (5.4%). However, higher mortality rates were found in adults aged 18-75 years with COVID-19 (4.5%) compared to those without COVID-19 (2.7%) [53], indicating greater risk at a younger age for people with COVID-19. Data from Wales indicated that at least 31 people with intellectual disability had died from COVID-19 between March and May 2020. While the proportion of deaths involving COVID-19 for people with intellectual disability was comparable to the general population, the age-standardised rate of deaths involving COVID-19 was three to eight times higher for people with intellectual disability compared to the general population [54]. Data from the Netherlands found that, by end-October 2020, 67 people with intellectual disability diagnosed with COVID-19 had died, with a mortality rate of 11% among those with a confirmed infection [55]. Most confirmed COVID-19 infections among people with intellectual disability lived in a group home (83%), with 17% living in their own apartment.

Almost two-thirds of infections (62%) occurred in the 40-69 age group, with a further 15% in the 70+ age group [56].

For people with Down syndrome, a UK study estimated a four-fold increased risk of hospitalisation and a 10-fold increased risk of death related to COVID-19 for people with Down syndrome. This was after adjustment for cardiovascular and pulmonary diseases and care home residence, which explained some but not all of the increased risk [57]. Another UK study found that, for people with Down syndrome, the leading signs or symptoms of COVID-19 (fever, cough and shortness of breath) and risk factors for severe disease course (age, male gender, diabetes, obesity, dementia) were similar to the general population. However, individuals with Down syndrome presented significantly higher rates of mortality, especially from age of 40, and average age of death from COVID-19 was 51 years [58].

A review of 50 deaths of people with intellectual disability related to COVID-19 in the UK identified increased infection risk with mobility impairments and/or mental health needs; increased mortality risk with epilepsy; and one in five cases reviewed were discharged from hospital but readmitted soon afterwards [59]. An updated review of 163 COVID-19-

related deaths of people with intellectual disability that occurred up to June was published in November 2020. This identified a striking difference in age of death for people with intellectual disability compared with the general population. Among the general population, almost half (47%) of COVID-19 deaths were among people aged 85 years or more, compared with just 4% of COVID-19 deaths among people with intellectual disability being in the 85+ years category [60]. Another review of 66 deaths related to COVID-19 in the UK and Ireland found a younger mean age of death (64 years) than the general population, and observed high rates of moderate-to-profound intellectual disability (n=43), epilepsy (n=29), mental illness (n=29), dysphagia (n=23), Down syndrome (n=20) and dementia (n=15) [61].

A review by Public Health England estimated that 956 people with intellectual disability died from COVID-19 in England between February and June 5th, 2020. The mortality rate per 100,000 was estimated as 6.3 times the rate of the general population when adjusted for age and sex. Disparities were much higher among younger age cohorts given that the highest proportion of deaths among people with intellectual disability took place in the 55-64 years group, compared with over 75 years for the general population [62].

The growing evidence regarding infection and mortality rates of COVID-19 among people with intellectual disability suggests there are differences in the infection and mortality risk profiles between the intellectual disability population compared with the general population. There appears to be increased risk of infection and death for people with intellectual disability under the age of 70 years compared with the general population, where poorer outcomes are mostly reported over 80 years. Reported mortality rates for people with intellectual disability are multiples of those reported for the general population.

Mental health and well-being outcomes for people with intellectual disability and carers

Mental health and behavioural difficulties in people with intellectual disability may become more severe during the COVID-19 restrictions when daily routines are heavily disrupted; research from the Netherlands found that although incident reports of challenging behaviour initially fell during lockdown, there was also an unexpected fall in medication error reports, suggesting a fall in reporting of actual incidents, and while medication error reports remained stable, reports of other incidents (particularly those involving aggression) increased [63]. Furthermore, people with intellectual disability may also be more vulnerable to exploitation or abuse where broader networks of social support are no longer available [64]. The pandemic may also represent a particular challenge for caregivers, who are at increased risk of social isolation when services close, and where their usual social support network is less available [65].

A small number of studies have documented the impact of the pandemic and associated service closures and social restrictions for people with intellectual disability and carers. An Inclusion Ireland survey of 346 individuals with intellectual disability and family members found some evidence of positive experiences from the lockdown period, with 30% of respondents with intellectual disability reporting they were happier at home. However, 38% of all respondents reported increased behaviours of concern, 36% indicated increased loneliness, and 33% increased anxiety. Amongst respondents with intellectual disability, 56% reported significant loneliness [66].

A small study conducted by people with intellectual disability examined the experiences of adults with intellectual disability in Ireland during the COVID-19 crisis. All participants found the lockdown period very disruptive to their normal work/day service and social activities. For example, one participant commented: *“My job came to an end... my Special Olympics. My brother couldn't come for my birthday. Couldn't go out for dinner, or go for hot chocolates.”* (p.7). Participants also expressed the frustration and emotional impact of lockdown: *“I was very panicky... annoyed, upset, anxious – can't see staff, can't see friends.... It's lonely, and scary, and worried. I miss my friends, I miss my family, I miss my loved-ones. [When hearing the news about the crisis] I go mad, and pull out my hair.”* (p.9). And while expressing their sadness with the situation, participants also spoke of resilience and coping mechanisms: *“I am having a very tough life because of lockdown. I'm feeling like pissed off and everything but thing is I've been doing meditation to help me feel better. I've also been going out for walks—I haven't been out for walks for couple weeks but did go out with my granny yesterday and did have a little walk around.”* (p.16) [67]. These findings echo similar results from a US study, where lockdown measures were found to greatly affect access to health and educational services for people with COVID-19 [68].

A UK study compared effects of the pandemic on informal carers of children and adults with intellectual disability and carers of children without intellectual disability. It found that carers of children and adults with intellectual disability had significantly greater levels of a wish fulfilment (maladaptive) coping style, defeat/entrapment, anxiety, and depression; and differences had increased compared with earlier pre-pandemic data. Despite their greater mental health needs, carers of people with intellectual disability had fewer sources of social support [69]. In a survey by Family Carers Ireland, a majority of carers expressed concern about declining health and well-being of the person they cared for (63%), about their own mental health and well-being (60%), and about their loved one displaying increased challenging behaviours (56%) [70].

An Indian study found the mental health status of carers of children with intellectual disability was negatively impacted by the COVID-19 pandemic. High prevalence of

depression (62.5%), anxiety (20.5%) and stress symptoms (36.4%) were reported, with significant increases in caregiver strain compared to pre-pandemic levels [71].

While a huge research effort has seen a substantial amount of data published about COVID-19 and its impact on the general population, to date there has been a relative lack of comparable data regarding its impact on people with intellectual disability. However, from what data has been published to date, and from previous knowledge of the health status for this population, there are indications that older people with intellectual disability are exposed to similar and sometimes greater risk given comorbidities associated with worse outcomes for COVID-19. Critically, however, preliminary data suggests this appears to manifest at an earlier age, consistent with evidence of the early onset of certain health conditions and lower life expectancy, and is now further evidenced by higher mortality rates among middle-aged and older adults with intellectual disabilities but not the very old. Further research is needed but what is emerging from the few published studies to date is the worrying impact that the pandemic and its associated public health restrictions is having on the mental health and well-being of people with intellectual disability and carers.

Lessons learned from the pandemic

Some lessons may be drawn from knowledge gained during the COVID-19 pandemic to date. We hope that new data presented in this report will add to existing knowledge of the impact of the pandemic on people with intellectual disability.

Differences between the general and intellectual disability populations

This review has highlighted that people ageing with specific high-risk comorbidities are at the greatest risk of negative outcomes of COVID-19, and that those in congregated care settings experience a multiplier effect of high risk of exposure and high risk of poor outcomes. Older people with intellectual disability appear to face at least the same risk of adverse outcomes of COVID-19, and long-term care and residential facilities including specialist disability care have been identified as having potentially increased risk of infection. Yet, while there is evidence of increased mortality rates among people with intellectual disability who were COVID-19 positive, there is no evidence or reports to date of outbreaks among this population comparable to the general nursing home population. Data from the Netherlands suggests greater risk of infection in group homes compared with independent living, but no other evidence has yet confirmed this in other jurisdictions.

With no evidence to date of widespread outbreaks in residential care settings for people with intellectual disability in Ireland or elsewhere, exploring the underlying reasons for this may be instructive for their future care and for care of the general older population.

Asymptomatic infection was a key factor in increased risk of transmission in nursing homes [18]. However, there is no apparent reason why this would not also be the case (at least to date) in intellectual disability residential care.

Models of care and other factors

The Health Information and Quality Authority (HIQA) examined the impact of COVID-19 on nursing homes in Ireland. Among other findings, the report examined preparedness and contingency planning in nursing homes that remained free of COVID-19. It found that the vast majority were compliant with the regulations assessed, had comprehensive contingency plans, were proactive and resourceful regarding resident safety, quickly implemented infection prevention and control measures, were vigilant in monitoring residents for symptoms and adhered to the public health guidance in order to minimise the risk of introducing or spreading COVID-19 [37]. It is possible that some element of luck also played a part in keeping these nursing homes COVID-19 free, but this is impossible to assess.

HIQA also highlighted its previous identification of gaps in clinical governance arrangements for private and statutory nursing homes and lack of integration with community health programmes. It cited the need for a review of staff skills and skills-mix to ensure access to enhanced nursing staff and advanced nurse practitioners, including those skilled in infection prevention and control or care of older people. In light of the COVID-19 outbreak, HIQA also questioned existing models of residential care in Ireland for older people and others. It stated that multi-occupancy rooms and the outmoded premises of some nursing homes “*undoubtedly created a situation where the spread of infection was difficult to contain*” (p.42). HIQA recommended review of nursing home occupancy levels in the short-medium term to enable them to respond to any future disease outbreaks. It said that wider reform of the current system, which predominately directs people towards a single model of residential care when other options such as assisted living or homecare may be more suitable, is now necessary [37].

The infrastructure of residential care, governed by current policy, may be one area underlying the differences to date in outbreaks of COVID-19 between the general older and intellectual disability populations. While the large nursing home model predominates in Ireland, policy governing residential care for people with intellectual disability in Ireland has followed international best practice for people with disabilities [72] in undertaking a programme of deinstitutionalisation [73], with closures of large institutions for people with disability across the country. The current profile of residential care for people with intellectual disability shows that, among people with an intellectual disability aged 55 years or above, less than a quarter (23%, 965/4246) live in ‘residential centres’. The largest

group within this age cohort (38%, 1607/4246) live in group homes in the community, which typically house fewer than 6 residents [74]. Whether or not these policy and infrastructural differences are related to differences in COVID-19 outbreaks requires further research. Only one UK study was found in this review that associated size of nursing home with rates of outbreak once other factors were controlled for [75]. Another analysis found substantial disagreement between the crude number of deaths reported in nursing homes and mortality rate per 100 beds [76].

Like the HIQA review, the report of the Nursing Homes Expert Panel appointed by the Minister for Health also highlighted the need to address aspects of nursing home procedures, staffing levels and skills-mix, oversight and guidance, and preparedness for future disease outbreaks. The Expert Panel also questioned the need for a revised model of care for nursing homes, highlighting alternatives such as homecare to allow dependent older people to continue living safely and happily in their own homes, and seeing nursing homes as part of a continuum of long-term care choices for older people with support needs rather than the default option [15].

Other factors highlighted in the literature may provide additional insight for learning. In addition to assessed quality, noted above, studies have identified increased risk of disease outbreaks in nursing homes where the corresponding infection rate of the surrounding community was high [16, 17], and correlated infection in residents with symptomatic COVID-19 in staff [18]. These findings reinforce the need for effective public health measures to keep infections out of residential centres, especially given the high incidences of asymptomatic infection.

Mitigating the impact on mental health and well-being

Studies have also identified areas of potential learning for secondary effects of the pandemic and public health restrictions introduced, in particular for mitigating effects on mental health and well-being. A number of studies highlighted the potential for online approaches to address increased needs for psychological supports emanating from the pandemic, providing for example online training modules for mental health facilitators [77], or providing online options for consultation, telehealth and other services [31, 68, 71].

IDS-TILDA has previously highlighted a deficit in access and skills for using technology among people with intellectual disability [78] that needs to be bridged if this population is to benefit from online support services in the future. The potential for online supports was highlighted by a Dutch study which found that disability service providers were better able to respond to support demands by service users living independently and to compensate for restrictions to in-person supports during a crisis like COVID-19 [79]. On the other

hand, over half of people with intellectual disability and families surveyed in Ireland reported having little or no contact from support services during the lockdown period [66], highlighting a need for services to adjust to newer models of provision in such times. The deep personal impact of closed services for individuals with intellectual disability has also been highlighted [67].

In May 2020, the HSE issued a 'Framework for the Resumption of Adult Disability Day Services', outlining guidance for day service provision post COVID-19, when there is likely to be reduced service provision capacity and a reduced quantum of day services available. This emphasised provision based on the personal plans of individuals with intellectual disability, and recognition that COVID-19 may have had negative consequences for some service users and positive impacts for others; and highlighted the opportunity the current situation presents to progress the person-centred New Directions policy governing provision of day services [80].

The UN Secretary-General, Antonio Guterres, stated on 6th May that the COVID-19 crisis provides *“a unique opportunity to design and implement more inclusive and accessible societies”*, urging Governments to consult people with disabilities in achieving this. The inclusion of the experiences and views of older people with an intellectual disability expressed in this report is an important addition to our understanding of how the COVID-19 crisis has impacted this population in Ireland.

Results

Profile of the sample

A total of 739 participants were enrolled in Wave 4 of IDS-TILDA. Of these, 710 completed the COVID-19 survey. Table 1 below provides an overview of the demographic profile of the total sample for Wave 4 and for the sample that completed the COVID-19 survey. As outlined in Table 1, the COVID-19 survey sample is representative of the full IDS-TILDA sample at Wave 4 across gender, age, aetiology and level of intellectual disability and type of residence.

Table 1. Demographic profiles of IDS-TILDA Wave 4 sample and COVID-19 survey sample

	Wave 4 Participants % (n)	COVID-19 Participants % (n)
Gender		
Male	46.5 (344)	46.8 (332)
Female	53.5 (395)	53.2 (378)
Age		
40-49 years	18.3 (135)	18.7 (133)
50-64 years	55.1 (407)	55.1 (391)
65+ years	26.7 (197)	26.2 (186)
Level of Intellectual Disability¹		
Mild	29.6 (204)	29.7 (196)
Moderate	42.5 (293)	41.8 (276)
Severe-Profound	27.9 (192)	28.5 (188)
Aetiology of Intellectual Disability		
Down syndrome	19.6 (145)	19.6 (139)
Other aetiology/Unknown	80.4 (594)	80.4 (571)
Residence Type		
Independent/Family	17.3 (126)	17.4 (122)
Community Group Home	49.0 (358)	49.6 (348)
Residential Care	33.8 (246)	33.0 (231)
Total	100.0 (739)	100.0 (710)

1 50 participants had an unverified level of intellectual disability

Health profile for high-risk COVID-19 comorbidities

The literature review earlier identified a range of comorbid health conditions that were associated with an increased risk of adverse outcomes from COVID-19 infection. This section provides a profile of the participants (n=710) that completed the COVID-19 survey. All results discussed here are based on participants having a history of the disease and not just incidence in Wave 4, i.e. a disease was counted as present if the participant reported ever having it in any of the four waves of IDS-TILDA.

Figure 2 below shows the prevalence of chronic conditions among this group. From this we can see that BMI overweight/obesity (66.6%, 365/548) and cardiovascular disease (52.3%, 371/709) were the most common high-risk comorbidities, reported by two-thirds and just over half of the sample respectively. Following these, substantial proportions have a history of high cholesterol (38.6%, 274/709), epilepsy (29.5%, 209/708) and hypertension (21.6%, 153/709), and around one in ten participants also have a history of arthritis (15.0%, 106/708), smoking (10.5%, 74/704), and diabetes (9.6%, 68/709). Lower rates were also reported for other high-risk chronic conditions including lung disease/asthma (8.6%, 61/710), stroke/TIA (4.8%, 34/709) and dementia (4.1%, 29/708).

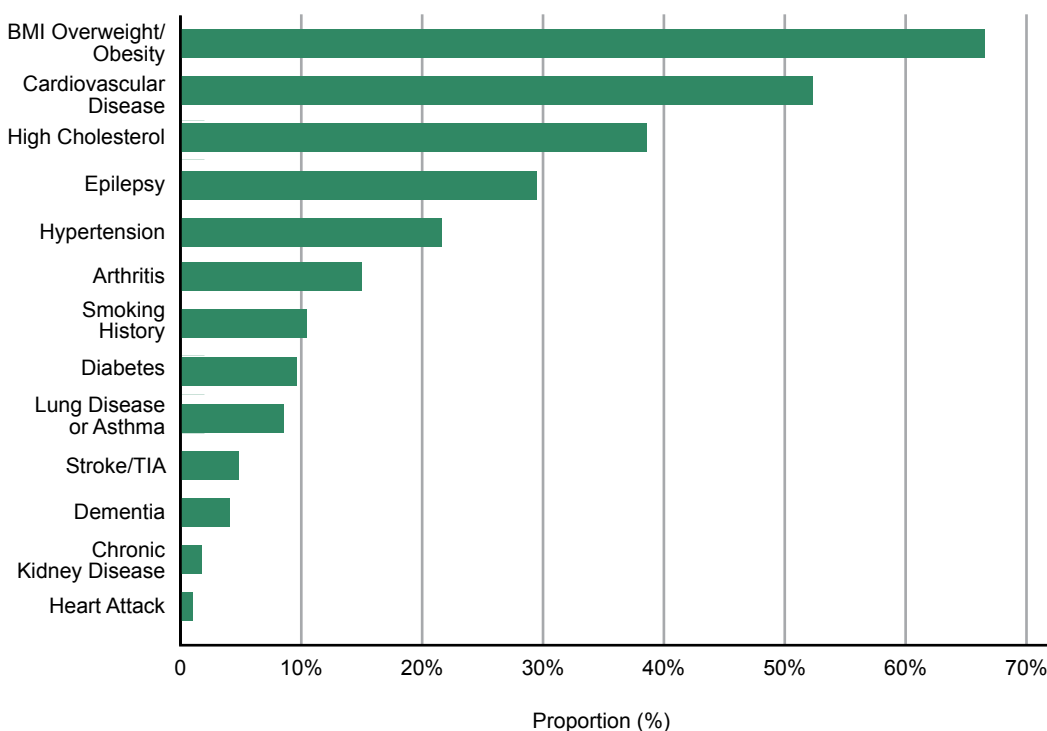


Figure 2. Prevalence of health conditions with high risk of adverse COVID-19 outcomes

Mobility was identified in the literature as a possible risk factor for contracting COVID-19. Almost half of participants (45.2%, 295/652) reported difficulty walking 100 yards, while almost a third (31.5%, 209/664) had difficulty walking across a room.

Table 2 below shows the prevalence based on a history of high-risk chronic conditions reported by age group of participants. From this, a pattern of increased prevalence with older age, and therefore increased risk of adverse outcomes of a COVID-19 infection, is observed in most conditions. This includes increased rates/risk in older participants for cardiovascular disease, high cholesterol, hypertension, arthritis, smoking history, diabetes, lung disease or asthma, stroke/TIA, dementia and heart attack. Comparing the current results to results on the general population from TILDA (where data available) [81], prevalence rates were higher in people with ID for cardiovascular disease (in TILDA, prevalence was 44.7% at 50-69 years of age and 66.6% at 70+ years of age), but lower for hypertension (TILDA prevalence: 42.9% at 50-69 years of age and 61.1% at 70+ years of age) and chronic kidney disease (TILDA prevalence: 5.7% at 50-69 years of age and 28% at 70+ years of age). (Participants in TILDA were aged 50+, so no comparison is possible for those aged under 50 years). Diabetes was more prevalent in TILDA than in IDS-TILDA for people aged 50-69 (10.5%) but less prevalent for people aged 70+ (14.9%). There was a higher overall prevalence in TILDA than in IDS-TILDA for high cholesterol (TILDA prevalence: 58.5%), arthritis (TILDA prevalence: 45.6%), lung disease/asthma (TILDA prevalence: 18.3%), and heart attack (TILDA prevalence: 6.2%), although rates of stroke/TIA were slightly lower in TILDA than in IDS-TILDA (TILDA prevalence: 4.7%). However, it should be noted that propensity matching has not been performed for these comparisons.

Table 2. Prevalence of high-risk chronic conditions by age in older adults with ID

Chronic Condition	40-49 years prevalence %	50-69 years prevalence %	70+ years prevalence %	Total prevalence %
BMI Overweight/Obesity (n=548)	65.7	67.4	64.4	66.6
Cardiovascular Disease (n=709)	21.8	56.1	73.4	52.3
High Cholesterol (n=709)	10.5	42.8	55	38.6
Epilepsy (n=708)	22.7	31.3	30.3	29.5
Hypertension (n=709)	6.8	20.8	43.1	21.6
Arthritis (n=708)	4.5	15.2	26.6	15
Smoking (n=704)	5.3	10.6	16.7	10.5
Diabetes (n=709)	6	8.8	17.4	9.6
Lung Disease or Asthma (n=710)	5.3	8.5	12.8	8.6
Stroke or TIA (n=709)	0.8	3.2	16.5	4.8
Dementia (n=708)	0.8	4.5	6.4	4.1
Chronic Kidney Disease (n=708)	2.3	1.9	0.9	1.8
Heart Attack (n=709)	0.8	0.6	2.8	1

COVID-19 symptoms, testing and outcomes

Almost two-thirds of participants were tested for COVID-19 (62.4%, 443/710). Just 14 individuals were invited for a test but did not consent, and two others commenced but did not complete a test. Of those who were tested, the large majority (80.6%, 357/443) were tested once and around one in five tested multiple times. Table 3 shows that participants aged 65 years and above (74.2%, 138/186) and those with severe-profound intellectual disability (76.6%, 144/188) were more likely to be tested. However, the biggest differentials were between types of residence, where 84.8% (196/231) of people living in residential settings and 63.8% (222/348) in community group homes were tested, compared with just 17.2% (21/122) of those living in independent/family settings. If we combine respondents from community group homes and residential care settings, we can see that almost three-quarters (72.2%, 418/579) of respondents living in these service-provided facilities for

multiple residents were tested for COVID-19. Participants with Down syndrome were less likely to be tested (49.6%, 69/139) than other participants (65.5%, 374/571).

Overall, just 2.5% (11/443) of those who were tested were positive for COVID-19. While the numbers were small, higher rates were found in male respondents (3.8%, 8/211), respondents with severe-profound intellectual disability (4.2%, 6/144) and people living in residential care (4.6%, 9/196). No participants with Down syndrome tested positive for COVID-19.

Table 3. COVID-19 tested, positive tests and symptomatic participants

	Tested for COVID-19 % (n)	Tested Positive % (n) of those tested	Symptomatic % (n) of Cohort in COVID-19 sample
Gender			
Male	63.6 (211)	3.8 (8)	8.4 (28)
Female	61.4 (232)	1.3 (3)	11.4 (43)
Age			
40-49 years	53.4 (71)	2.8 (2)	9.0 (12)
50-64 years	59.8 (234)	3.0 (7)	9.0 (35)
65+ years	74.2 (138)	1.4 (2)	12.9 (24)
Level of Intellectual Disability			
Mild	55.6 (109)	0.9 (1)	10.2 (20)
Moderate	60.5 (167)	1.8 (3)	8.7 (24)
Severe-Profound	76.6 (144)	4.2 (6)	12.2 (23)
Aetiology of Intellectual Disability			
Down syndrome	49.6 (69)	0.0 (0)	9.4 (13)
Other aetiology/Unknown	65.5 (374)	3.0 (11)	10.2 (58)
Residence Type			
Independent/Family	17.2 (21)	0 (0)	4.9 (6)
Community Group Home	63.8 (222)	0.9 (2)	8.6 (30)
Residential Care	84.8 (196)	4.6 (9)	15.2 (35)
Total	62.4 (443)	2.5 (11)	10.0 (71)

One in ten survey respondents (10%, 71/710) experienced COVID-19-like symptoms. The highest rates were reported among participants living in residential care settings (15.2%, 35/231), with higher rates also among respondents aged 65 years and above (12.9%, 24/186), those with severe-profound intellectual disability (12.2%, 23/188) and female respondents (11.4%, 43/378). Figure 3 below shows that the most common COVID-19-like symptoms reported by participants were fever (57.7%, 41/71), cough (43.7%, 31/71), fatigue (12.7%, 9/71) and shortness of breath (9.9%, 7/71).

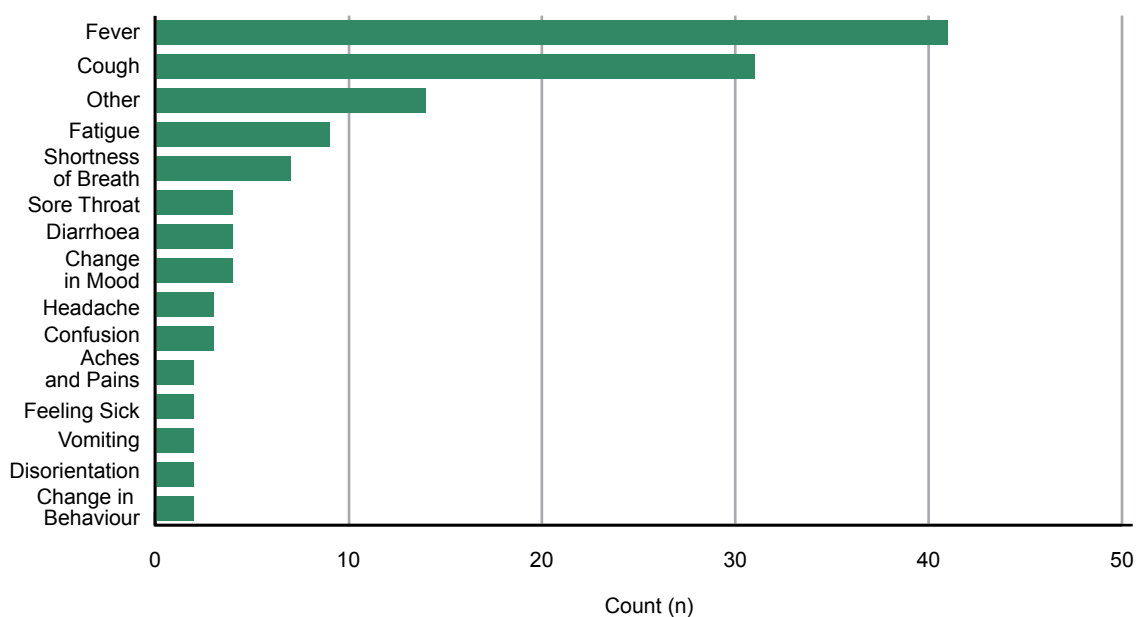


Figure 3. COVID-19-like symptoms reported

Of the 11 individuals who tested positive for COVID-19, seven (63.6%) experienced symptoms of COVID-19 and four (36.4%) were asymptomatic. The profile of respondents who tested positive is outlined in Table 4, showing that a majority were male (72.7%, 8/11), aged 50-64 years (63.6%, 7/11), had severe-profound intellectual disability (54.5%, 6/11), and lived in residential care (81.8%, 9/11). Nine of the 11 participants who tested positive had a history of conditions with a high risk of adverse COVID-19 outcomes. Three individuals who tested positive for COVID-19, all of whom reported symptoms and had high-risk comorbidities, were hospitalised.

Table 4. Profile of respondents who tested positive for COVID-19

Gender	Age	Level of Intellectual Disability	Type of Residence	Symptoms	Chronic Condition(s)	Hospitalised
Male	40-49	Severe/ Profound	Residential Care	Fever, Cough, Fatigue, Change in mood, Other	No chronic conditions, No BMI, Immobility	No
Male	50-64	Mild	Residential Care	Fever, Aches and pains, Fatigue, Sore throat, Other	High cholesterol, Hypertension, Arthritis, Diabetes, Epilepsy, No BMI, Immobility	Yes
Male	50-64	Moderate	Community group home	None	High cholesterol, Overweight	No
Male	50-64	Moderate	Residential Care	Fever, Cough, Shortness of breath, Fatigue, Confusion, Disorientation, Other	High cholesterol, TIA, Stroke, Epilepsy, Overweight, Some immobility	Yes
Male	50-64	Severe/ Profound	Residential Care	None	No chronic conditions, Moderate immobility	No
Male	50-64	Severe/ Profound	Residential Care	None	Epilepsy, Overweight, Some immobility	No
Male	50-64		Residential Care	Fatigue, Feeling sick	High cholesterol, Hypertension, Arthritis, Heart murmur, Obese, Some immobility	No
Male	65+	Severe/ Profound	Residential Care	Fever, Cough, Shortness of breath, Aches and pains, Fatigue, Change in mood	TIA, Stroke, CHF, Epilepsy, Overweight, Moderate immobility	No
Female	40-49	Severe/ Profound	Community group home	Other	Epilepsy, No BMI, Some immobility	Yes
Female	50-64	Severe/ Profound	Residential Care	None	High cholesterol, Epilepsy, No BMI, No mobility	No
Female	65+	Moderate	Residential Care	Fever, Fatigue, Confusion	Arthritis, Stroke, Obese, Immobility	No

Management of COVID-19 within services and other settings

A number of respondents (7.8%, 55/705) moved from their usual home due to the COVID-19 crisis. The most common reasons for moving was to isolate as a precaution or while waiting for test results (n=24), to relocate to a family home (n=11), and for isolation after discharge from hospital (n=7). A higher proportion of the 71 respondents who had COVID-19-like symptoms moved during the crisis, with just over one-third reporting they relocated (36.6%, 26/71).

Of those who had COVID-19-like symptoms or tested positive, over three-quarters (78.7%, 59/75) reported having a plan to manage self-isolation according to the COVID-19 public health guidelines; and a majority (61.3%, 46/75) were able to comply with prevention guidelines, but one-third were unable to comply (33.3%, 25/75). Also, among those who had COVID-19-like symptoms or tested positive, one in ten individuals were hospitalised (10.7%, 8/75) during this period.

Stress and Anxiety due to COVID-19

Participants were asked if they felt any stress or anxiety due to COVID-19. Just over half of the respondents (55.3%, 383/692) reported feeling stress/anxiety during the crisis. Differences in rates of stress/anxiety experienced between different groups are outlined in Table 5 below. This shows that female respondents (57.8%, 214/370), those aged under 50 years (59.5%, 78/131), those with mild intellectual disability (63.9%, 122/191), and those living in independent or family residences were the most likely to report stress/anxiety due to COVID-19.

Table 5. Rates of stress/anxiety reported by gender, age, intellectual disability and residence

	Felt Stress/Anxiety %	n
Gender		
Male	52.5	169
Female	57.8	214
Age		
40-49 years	59.5	78
50-64 years	54.2	206
65+ years	54.7	99
Level of Intellectual Disability		
Mild	63.9	122
Moderate	59.8	159
Severe-Profound	36.8	68
Aetiology of Intellectual Disability		
Down syndrome	53.3	72
Other aetiology/Unknown	55.8	311
Residence Type		
Independent/Family	59.5	72
Community Group Home	58.1	197
Residential Care	49.8	111
Total	55.3	383

With regard to residence, rates of stress/anxiety for respondents living in community group homes were almost as high as people living in independent/family settings, and both were substantially higher than rates reported for people in residential settings. An even bigger differential was identified with regard to level of intellectual disability, where a majority of people with mild and moderate intellectual disability reported stress/anxiety, compared to just over one-third of people with severe-profound intellectual disability.

Pre-existing mental health conditions may be important factors in coping with COVID-19 related stress/anxiety. Using the Glasgow Depression Scale, the rate of depression reported by self-reporting participants was 7.2% (23/321); and 7.7% (30/388) reported by the Carer Supplement. The rate of anxiety among participants, measured by the Glasgow Anxiety Scale, was reported as 21.6% (69/319). The relationship between pre-existing anxiety and reported COVID-19 related stress/anxiety was explored. Figure 4 below shows that participants who reported COVID-19 related stress/anxiety had higher rates of pre-existing anxiety (26.7%, 54/202) than those who did not report COVID-19 stress/anxiety (12.6%, 14/111).

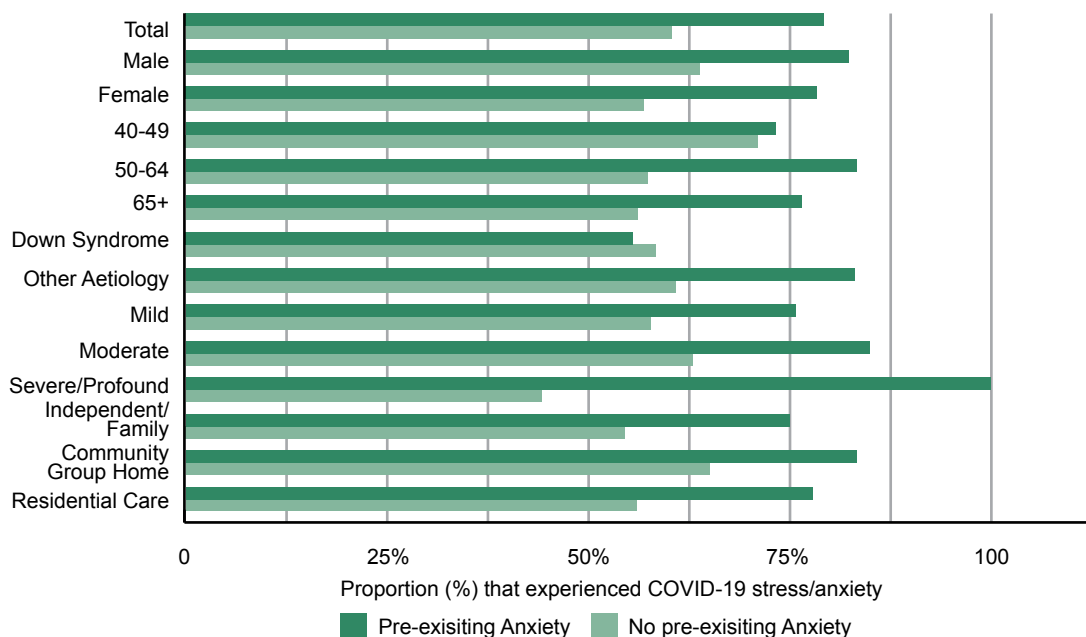


Figure 4. Pre-existing anxiety and COVID-19 related stress/anxiety

Causes of COVID-19 related Stress and Anxiety

Figure 5 illustrates the causes of feeling stress/anxiety related to COVID-19. By far, the most common cause of stress/anxiety was not being able to do one’s usual activities, cited by four in every five participants who felt stress/anxiety (79.1%, 303/383). The next most common causes of stress/anxiety were not seeing family (47.0%, 180/383), not seeing friends (45.4%, 174/383), loneliness (26.9%, 103/383), isolation (15.9%, 61/383), and fear of getting COVID-19 (15.7%, 60/383).

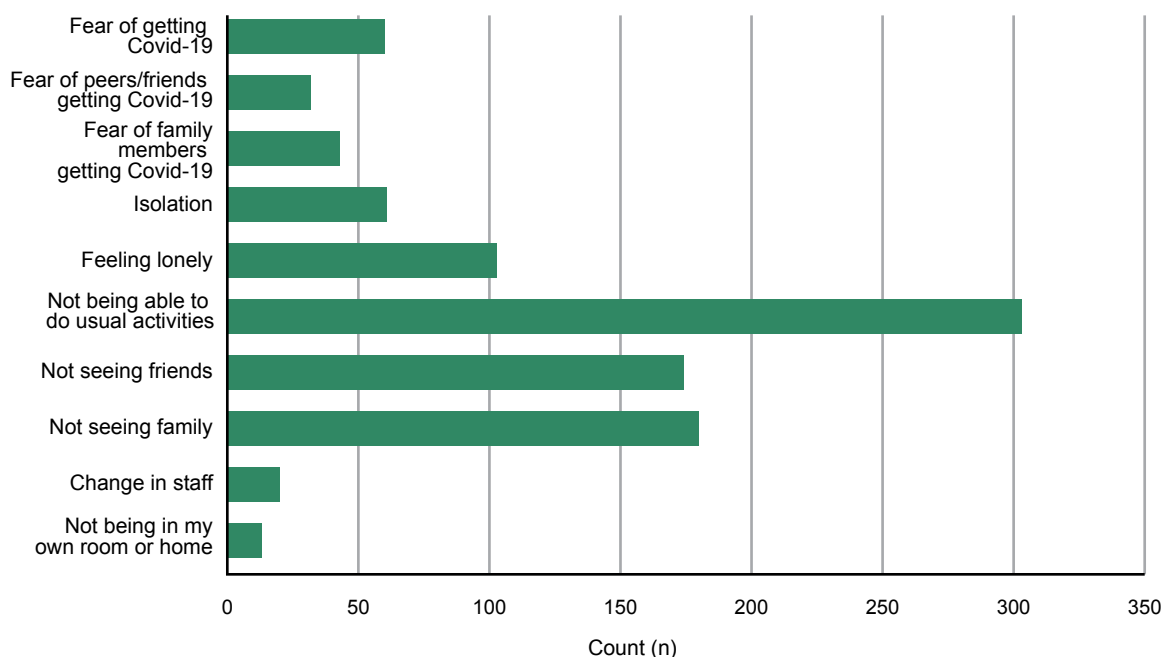


Figure 5. Causes of COVID-19 stress/anxiety

The most commonly reported causes of stress/anxiety related to COVID-19 were further analysed by residential setting. Figure 6 below shows that similar proportions of people living in independent/family settings (84.7%, 61/72) and community group homes (82.2%, 162/197) reported stress/anxiety due to being unable to do their usual activities, while a smaller majority of people in residential care reported this cause of stress/anxiety (69.4%, 77/111). As may be expected, fewer people living in independent/family settings (27.8%, 20/72) reported stress/anxiety caused by not seeing family, compared with those living in community group homes (55.3%, 109/197) and residential settings (44.1%, 49/111). Conversely, substantially more respondents living in independent/family settings (61.1%, 44/72) felt stress/anxiety due to not seeing their friends, compared to respondents living in community group homes (45.2%, 89/197) and residential settings (34.2%, 38/111). Finally, loneliness as a cause of stress/anxiety during the COVID-19 crisis was also substantially higher among those residing in independent/family homes (38.9%, 28/72), compared with residents of community group homes (25.9%, 51/197) and residential settings (20.7%, 23/111).

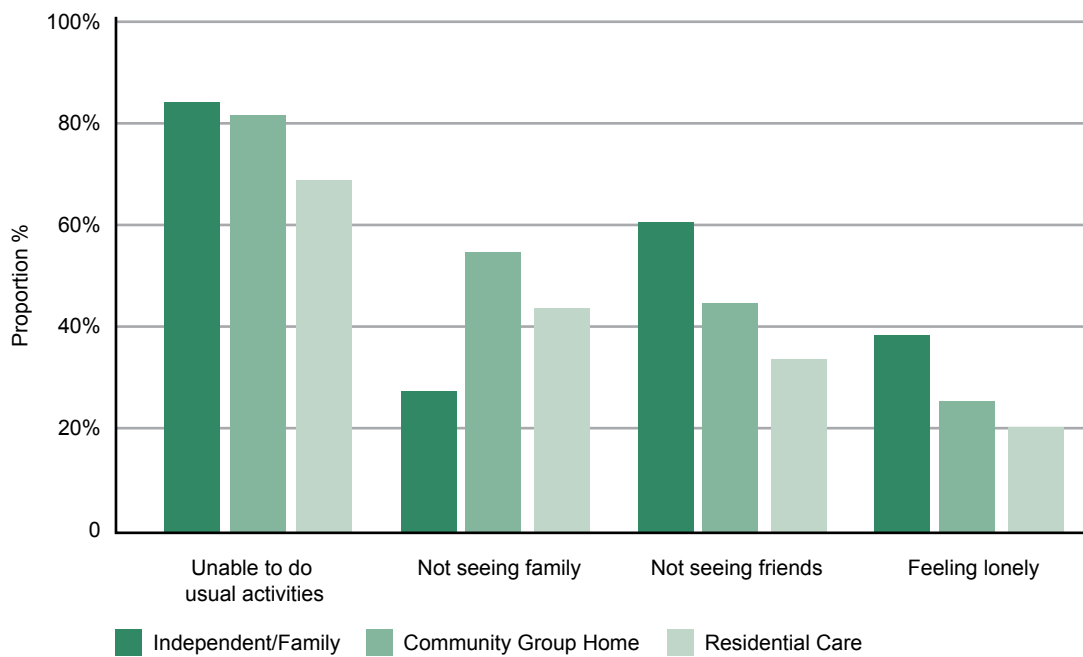


Figure 6. Causes of stress/anxiety by residential setting

Comparing self-reported and proxy reported rates of stress and anxiety

The biggest differences in rates of stress/anxiety reported in Table 5 above related to level of intellectual disability and residence type. Respondents with severe-profound intellectual disability and those living in residential settings had substantially lower rates of stress/anxiety reported. One possible reason underlying these differences is whether the response to the question was self-reported or reported by a proxy on behalf of the participant who was unable to self-report. Figure 7 shows that participants who self-reported on their own had the highest rates of stress/anxiety, with almost seven out of ten of these respondents feeling stress/anxiety due to COVID-19 (69.4%, 68/98), compared with half of proxy respondents (49.7%, 227/457). A third group who self-reported with some support were between these other groups but closer to the self-reporters, with almost two-thirds feeling stress/anxiety (64.2%, 88/137).

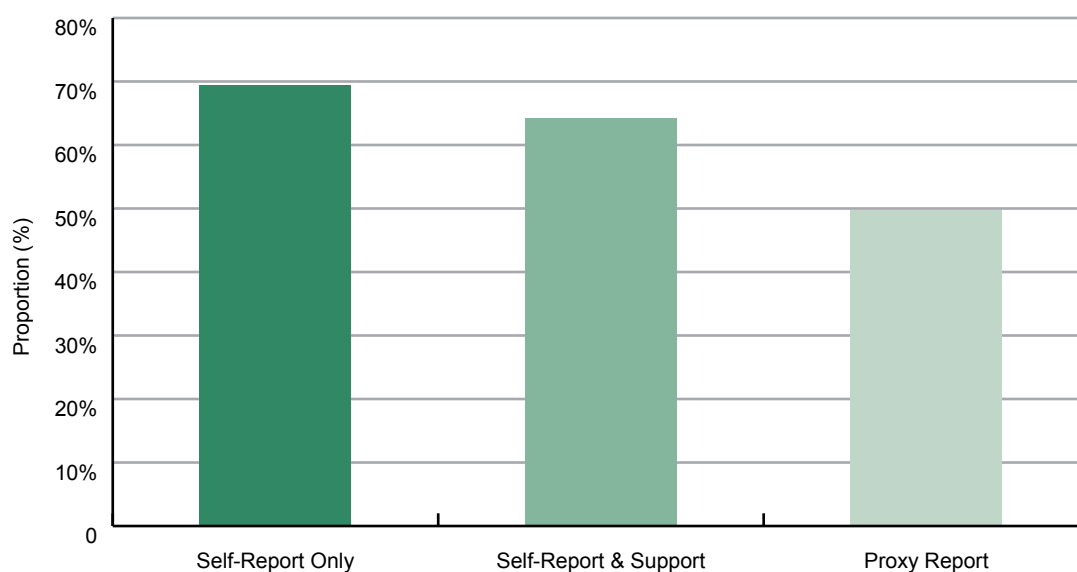


Figure 7. Rates of stress and anxiety reported by respondent type

Given the fact that higher proportions of participants with severe-profound intellectual disability and living in residential services are unable to self-report, lower rates of stress/anxiety among these groups may be related to under-reporting of these affects by proxy respondents. Additional multivariate analysis in later reports will explore the significance of this association.

Positive aspects of the COVID-19 period

When asked if there were any good things about the COVID-19 period, almost 60% of participants (58.3%, 381/654) said that there were some good aspects. Female respondents (60.3%, 207/343) were more likely to identify positive aspects of this period than male respondents (55.9%, 174/311). Rates of positivity increased slightly with increasing age, from 55.5% (61/110) for respondents aged under 50 years, to 58.0% (210/362) for those aged 50-64 years, and 60.4% (110/182) for the group aged 65 years and above. Respondents with mild (61.1%, 110/180) and severe-profound intellectual disability (60.8%, 107/176) had marginally higher rates of positivity than the group with moderate intellectual disability (55.8%, 140/251). The largest differences related to residential setting, where respondents living in community group homes (61.3%, 198/323) had substantially higher positivity rates than those living in independent/family settings (50.9%, 55/108), with those in residential care settings between these groups (57.5%, 123/214).

Respondents who said there were good things about the COVID-19 period were asked to identify what those things were. Figure 8 below illustrates the positive aspects of the COVID-19 period identified by respondents. The most common positive aspects of the COVID-19 were the opportunity to engage in new/more activities (41.2%, 157/381), the opportunity for more rest and relaxation at home (36.0%, 137/381), more time and/or better relations with staff (26.0%, 99/381), and using technology to communicate (13.6%, 52/381).

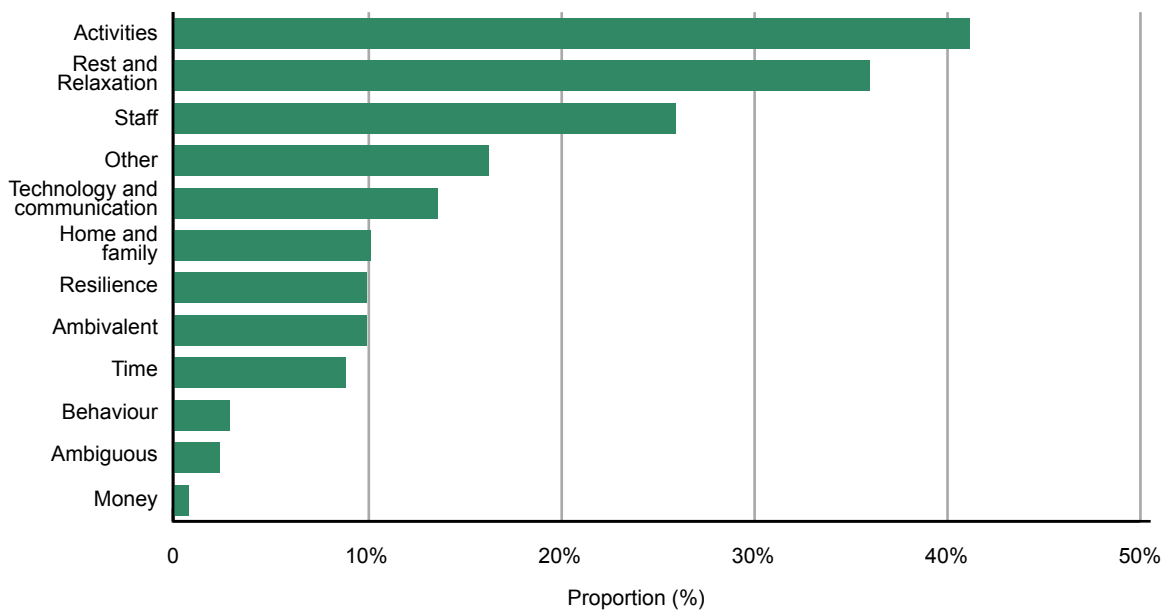


Figure 8. Good things about the COVID-19 period

Participants were asked to express in their own words what the positive aspects of the COVID-19 period were for them. Some examples from participants and proxy respondents are illustrated below (quotes are from different respondents; the first two are self-report, while the remainder are from proxy respondents):

“Keeping people locked down is keeping people safe”

“I learned a lot”

“Physical health has been very good during lockdown”

“Lost some weight”

“The lockdown gave him more time to settle into new house and surroundings”

“Move in house expedited by COVID-19 crisis.”

“Enjoyed the move to the apartment and having his own space”

“He appears to enjoy time alone and therefore appeared to benefit from extra time self-isolating in his room”

“Has more privacy in her own space”

“When she came back from hospital, environment was quieter for recuperation”

“Residents got on very well and were supportive of each other”

“One day care staff had been a hairdresser previously, so everyone got their hair done”

“...likes the fact the government are doing a good job keeping everyone safe”

Experiencing both positive & negative effects during COVID-19

Almost a third who responded to the questions about stress/anxiety and good things about the COVID-19 period (31.4%, 203/646) reported experiences of both stress/anxiety and positive aspects. It was reported in the previous sections that the most common cause of stress/anxiety and most commonly-cited positive aspect of COVID-19 both related to activities – respondents not being able to do their usual activities but also enjoying opportunities to engage in new activities. There was overlap for 84 individuals

who reported experiencing both the positive and negative aspects of activities during the COVID-19 period. Consistent with this observation, some responses to the question on positive aspects of the lockdown were ambivalent, often highlighting both positive and negative aspects. Such ambivalent responses tended to come from proxy respondents rather than self-report. Some examples of ambivalent responses are illustrated below (the first is self-report with proxy, the remainder are from proxy respondents):

“Initially liked change, not so much now.”

“...increasing activities such as arts and crafts, colouring. This was not done in the house before COVID and he has enjoyed this activity, although missing work”

“...he was happy enough, quite contented. Recently he started looking forward to returning to his job in a hotel and his day services which are starting up again soon.”

“More equipment such as sports equipment and gardening items were made available, but he did not engage with these.”

“...would have liked the lie ins but misses his day service.”

“...gets more rest not having to be up early to get transport to day services, albeit lack of structure/routine did affect her mental health”

“...the residents doing better than the staff.”

“Generally they went from doing loads to doing nothing and this suited for a short time but staff would have concerns about the mental health and communication skill regression with some of the more sociable residents.”

Impact of COVID-19 on respondents with Down Syndrome

The review of the literature identified that a particular risk for adverse outcomes of COVID-19 infection may be associated with Down syndrome. This section will examine the data with regard to participants with Down syndrome. Within the overall COVID-19 survey sample of 710 individuals with intellectual disability, 139 people had Down syndrome.

Table 6 identifies a number of potentially important differences in participants with and without Down syndrome. A slight majority of participants with Down syndrome were male,

whereas a slight majority of participants without Down syndrome were female. Differences in the age profile of the two groups sees few participants with Down syndrome aged 65 years and above and more than double the proportion of participants aged under 50 years. The Down syndrome group includes fewer participants with both mild and severe-profound intellectual disability than the non-Down syndrome sample, with over half of the Down syndrome sample comprised of people with moderate intellectual disability. Perhaps also significant in respect to the risk of contracting COVID-19, as highlighted in the literature review, the Down syndrome sample had a higher proportion of participants living in independent/family homes and a smaller proportion in residential care settings.

Table 6. Demographic profiles of participants with and without Down syndrome

	Participants without Down syndrome % (n)	Participants with Down syndrome % (n)
Gender		
Male	45.2 (258)	53.2 (74)
Female	54.8 (313)	46.8 (65)
Age		
40-49 years	14.9 (85)	34.5 (48)
50-64 years	53.6 (306)	61.2 (85)
65+ years	31.5 (180)	4.3 (6)
Level of Intellectual Disability		
Mild	30.5 (161)	26.5 (35)
Moderate	39.2 (207)	52.3 (69)
Severe-Profound	30.3 (160)	21.2 (28)
Residence Type		
Independent/Family	15.8 (89)	24.3 (33)
Community Group Home	48.8 (276)	52.9 (72)
Residential Care	35.4 (200)	22.8 (31)
Total	100.0 (571)	100.0 (139)

A comparison of the chronic condition history of participants with and without Down syndrome is shown in Figure 9. A similar proportion of participants with Down syndrome vs those with intellectual disability from other aetiologies were overweight or obese at 68.2% vs 66.2% respectively. Participants with Down syndrome had substantially lower rates of many other high-risk conditions associated with COVID-19. This includes lower rates for cardiovascular disease (40.3% compared with 55.3%), high cholesterol (24.5% compared with 42.1%), epilepsy (13.7% compared with 33.4%), hypertension (5.0% compared with 25.6%), diabetes (3.6% compared with 11.1%) and a history of smoking (2.2% compared with 12.4%). These differences should, in theory, better predispose participants with Down

syndrome against more severe outcomes of COVID-19 infections. However, participants with Down syndrome had much higher rates of dementia at 12.2% vs 2.1% in participants with ID from other aetiologies.

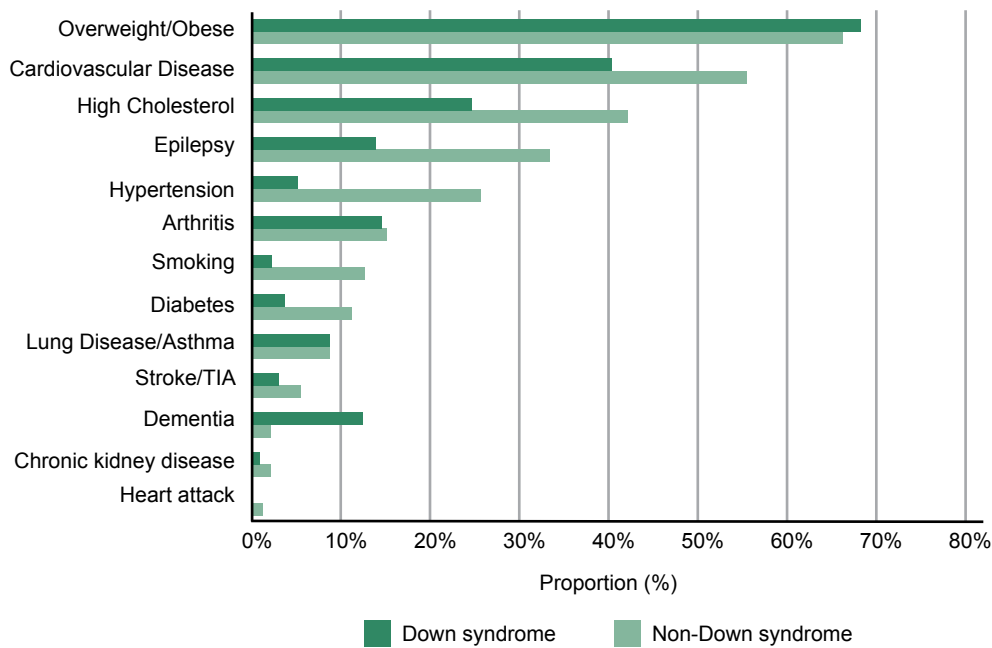


Figure 9. Prevalence of high-risk health conditions for participants with/without Down syndrome

With regard to pre-existing mental health conditions, participants with Down syndrome (6.9%, 4/58) had a similar rate of depression as other participants (7.2%, 19/263) in the self-reported Glasgow Depression Scale. Participants with Down syndrome (9.9%, 8/81) had marginally higher rates of depression on the Carer Supplement to the Glasgow Depression scale than other participants (7.2%, 22/307). However, participants with Down syndrome also reported lower rates of anxiety on the Glasgow Anxiety Scale (15.8%, 9/57) compared with other participants (22.9%, 60/262).

Comparing symptoms, testing and outcomes of COVID-19

Half of the participants with Down syndrome (50.0%, 69/138) were tested for COVID-19, which was lower than the participants without Down syndrome (69.6%, 339/487). Figure 10 below shows differences between participants with and without Down syndrome for presenting with COVID-19-like symptoms, for hospitalisation with symptoms or a positive test, and for positive COVID-19 tests. Participants with Down syndrome had slightly lower rates of COVID-19-like symptoms (9.4%, 13/139) compared with those without Down syndrome (11.6%, 57/493). Just two participants with Down syndrome with symptoms

or who tested positive were hospitalised (15.4%), compared with six (9.8%) participants without Down syndrome. No participants with Down syndrome tested positive for COVID-19.

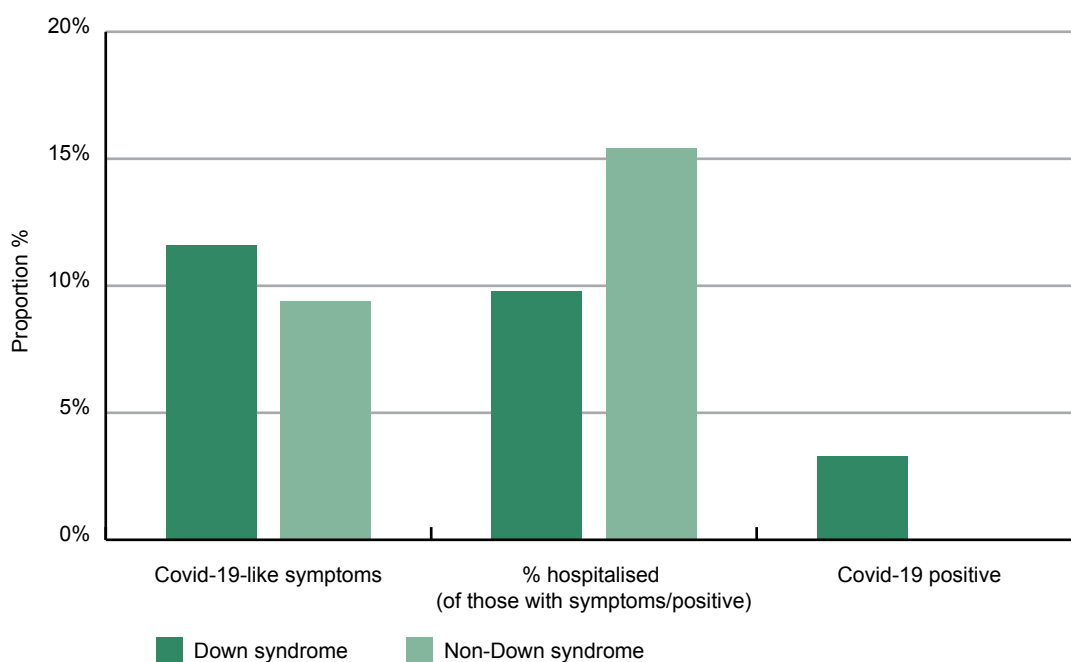


Figure 10. Symptoms, hospitalisation and positive COVID-19 test results for participants with/without Down syndrome

Of the eight individuals who were hospitalised with COVID-19-like symptoms, two were persons with Down syndrome. Neither of these individuals tested positive for COVID-19.

One participant stayed in hospital for 3 days:

- Female, age 57 years, severe intellectual disability, living in residential care;
- Multimorbidity – cirrhosis or serious liver damage, stroke;
- Symptoms – fever, diarrhoea.

The other participant stayed in hospital for 10 days:

- Male, age 55 years, mild intellectual disability, living in residential care;
- Multimorbidity – osteoporosis, severe anaemia, diabetes;
- Symptoms – fever, cough, shortness of breath, fatigue.

Discussion & Conclusions

This report provides some insights on the impact of the COVID-19 crisis on an older cohort of adults with intellectual disability in Ireland in the first six months of the pandemic in Ireland. Despite presenting many similar risk factors, compared to the reports for the vulnerable general older population, particularly in nursing homes, the data here suggests that there have been minimal effects from COVID-19 in terms of infection and hospitalisation, and no deaths. Our data also paints a picture of a population who responded to the crisis with adaptability, creativity and resilience, while at the same time enduring challenges from the huge disruption to their normal routines and social connections. That said, data reported here must also be viewed in the context in which it was collected – namely, during and immediately after the first wave of COVID-19 in Ireland. The pandemic continues and the disease remains a present threat at the end of 2020, meaning vigilance of the disease remains essential. Alongside continuing concerns for social inclusion and mental well-being caused by public health restrictions and service closures, both risks highlight the critical need for continued support for this population at this time.

Exposure and risk of infection for older adults with intellectual disability

Our findings reveal that almost two-thirds of IDS-TILDA participants had been tested at the time of data collection, and this increased to six out of seven of those individuals in residential care; with an overall infection rate of 2.5%. This compares to an overall national positivity rate of 3.4% at the end of September when IDS-TILDA data collection was completed. Rates of testing were higher than for the general population as with 1.2 million tests completed nationally, testing coverage overall was less than a quarter of the total population considering that people were often tested multiple times. Comparative testing rates for older people in nursing homes were not available to be part of this report, but it has been noted that widespread testing in nursing homes was not in place when recommended by the Nursing Homes Expert Group in July. A 4.6% positivity among IDS-TILDA respondents in residential care settings is lower than the high rates of contagion reported within many nursing homes. Reports in Ireland, for example, are of 22% of all cases and 56% of all deaths occurring in nursing homes. It remains to be established

what contributed to such low infection and mortality rates to date among people with intellectual disability despite what are considered high risk living situations adding to high risk characteristics for COVID-19 infection. At the time of publication, there continues to be no evidence of widespread outbreaks for IDS-TILDA participants and in reports nationally in residential care for people with intellectual disability of a scale comparable to rates reported in general population nursing homes.

COVID-19 Infection and outcomes among IDS-TILDA participants

Having no COVID-19 related fatalities among 11 individuals who tested positive is to be celebrated, and the mortality rate is currently lower than rates for intellectual disability highlighted internationally and for the general older population, with rates of less than 1.1% under 50 years but rising to almost 30% over the age of 80 years. Those with intellectual disability in Ireland must, however, continue to be followed. After initial reports of lower mortality rates in other countries, several more recent international reports have identified mortality between 3-8 times higher for people with intellectual disability [54, 62], and 10 times higher for people with Down syndrome [57]; and often at younger age for these populations, compared with the general population. Average age of deaths is now reported as 64 years for people with intellectual disability [61] and 51 years for people with Down syndrome [58].

In IDS-TILDA, no infections or deaths were recorded among participants with Down syndrome, but longitudinal health data has highlighted the heightened rates of known risk factors such as obesity, epilepsy and dementia. The small number of infections found for participants with intellectual disability do highlight that age 50-64 may be of most concern and this is not what was at least initially reported for the general population. Also, severe and profound intellectual disability, again based on small numbers, appears associated with infection, a group who is the least likely and often ill-equipped to self-report symptoms. Rates were somewhat higher in residential settings, but those participants were also likely to be older, with severe to profound levels of ID and to have multiple chronic conditions and to be non-ambulatory. Numbers were too small to statistically establish what were the primary risk factors for infection, but descriptive statistics suggest we should be paying greatest attention to age, health characteristics and level of intellectual disability.

Impact on social inclusion, mental health and well-being

The primary health effects of COVID-19 are reported to be compounded by the secondary effects of public health restrictions, social distancing, service closures and general worry and stress about the virus. Findings presented here confirm that, during the first wave of

the pandemic in Ireland, over half of the IDS-TILDA sample reported feeling some stress or anxiety about COVID-19. Among those who reported stress and anxiety were a number with pre-existing mental health diagnoses. Pre-existing anxiety was reported by 22% of participants here and was associated with higher rates of COVID-19 related stress/anxiety. Nevertheless, it does appear that for people with intellectual disability, COVID-19 presented additional stress. Over half of all participants reported stress/anxiety related to COVID-19, which is higher than rates of between 16-28% reported in the general literature [31, 32]. It is also important to note that a similar proportion of participants reported good things about their COVID-19 restriction experience and a number had both positive and negative experiences. The balance of experiences may also change as restrictions are extended and/or renewed and the consequences of additional stress for those with pre-existing mental health diagnoses must also be monitored.

There were differences in the rates and types of stress/anxiety reported between sub-groups of IDS-TILDA participants. Notably, self-reporting participants had higher rates of stress/anxiety in comparison to proxy survey respondents. This raises several possibilities: perhaps those who are most independent and able to speak for themselves have experienced the greatest sense of restriction from COVID-19. Alternately, the extent of COVID-19 related stress/anxiety for participants who relied on proxy respondents may be underreported. Restrictions on social connections vary among individuals, as does how they feel about the connections now lost, and increased contact with staff when there are restrictions may be more valued by others. Also, increases found in family contact particularly through the use of technology is noteworthy. IDS-TILDA reports in the past have drawn attention to the persistent digital divide experienced by people with intellectual disability. In Wave 4 the data supports that there has been a noticeable increase in access as well as in use of technology. Perhaps digital connectedness has been positive for people with intellectual disability. If so, post COVID-19 it is important that levels of access and use not return to previous low levels.

With all of that said, it is concerning that more participants living in independent/family residences reported that they missed friends and felt lonely compared with other residential settings. Previous IDS-TILDA findings were that people living in community group homes and residential care were more likely to identify co-resident peers and support staff as their friends – meaning perhaps they would continue to see these friends even during full COVID-19 lockdown. Here too access to technology and lack of personal transportation may mean that the most independent, during COVID-19, became the most isolated. That said, fewer participants in independent/family residences missed family compared with residents of community group homes and residential care facilities. This finding confirms that those most at risk for isolation and related concerns are those living

independently without links to family. That comparatively fewer participants in residential care settings missed their usual activities may be explained by under-reporting by proxy respondents, this group being less active than other persons with intellectual disability and/or the benefit they accrued from more consistent access to the same staff.

It was heartening to find overall that people with intellectual disability had responded to the COVID-19 crisis with resilience and adaptability, despite the challenges of the period. However, as noted above, these data were collected during the first wave of COVID-19 in Ireland, and with the second 'lockdown' experience underway at least through November 2020 there are reports and anecdotal evidence emerging of 'lockdown fatigue'. A repeat of the IDS-TILDA COVID-19 measures after a second lockdown experience and if there are continued restrictions into 2021, would provide further insight into infection rates, and positive and negative experiences after a year or more of living with the virus.

The UK Government placed all individuals with Down syndrome over the age of 18 on the 'extremely vulnerable list' for COVID-19, which required their 'shielding'. Based on their COVID-19 study findings, the Trisomy 21 Research Society (T21RS) has stated that it could not recommend shielding for people with Down syndrome under the age of 40 years, except for those with high-risk comorbidities. They did not believe that "the generalized confinement of the entire population of adults with Down syndrome to be sufficiently justified. The risk needs to be balanced against the potential negative consequences of confinement or shielding on the mental and physical health" [82]. The IDS-TILDA participants were aged 40 years and older, and many reported high levels of multimorbidity. The low infection and mortality rates reported here suggests that the safeguarding and other public measures that were taken in Ireland were justified. Additional data collection and time series analysis will give a clearer understanding of COVID-19-related physical and mental health consequences.

Comparing models of care with the general older population

Findings here of lower transmission of COVID-19 among older adults with intellectual disability compared with the general older population, especially in residential care, raise questions about why such differences exist. The reviews of nursing homes in Ireland during the COVID-19 crisis by HIQA and the Nursing Home Expert Group offered potential reasons for how some nursing homes may have failed or succeeded in preventing COVID-19 outbreaks. Questions were raised regarding clinical oversight and governance and reviews of staff skills and skills-mix recommended to ensure access to enhanced nursing staff and advanced nurse practitioners. They also highlighted characteristics of the facilities that succeeded up to that point including high rates of testing, good planning

and procedures and adherence to public health guidelines. There was evidence of similar strategies by those caring for the IDS-TILDA participants as well as a high level of planning for isolation as needed and successful implementation of those plans. One of the more structural or systemic factors raised in the reviews questioned the existing model of care for older people in Ireland, which predominantly places older people who need additional supports towards large nursing homes, rather than options to enable them to remain in their homes and communities.

Since 2011 in Ireland, there has been a policy focus on de-congregation of people with intellectual disability living in large segregated institutions with movement to smaller community-based residences, and the closure of larger residential units. Numbers are too small in IDS-TILDA to be able to draw conclusions. The suggestion of an association between transmission of COVID-19 and size of care facility remains tentative. Internationally, most studies found that size of nursing home facility was not a significant factor once other variables, for example extent of the outbreak within the surrounding community or assessed quality rating of facilities, were controlled for. As such, additional research is required to explore this in an Irish context.

Conclusions

Findings from this IDS-TILDA COVID-19 survey suggest that the people with intellectual disability, their families and service providers who support them are to be commended for their efforts to avert the worst impacts of COVID-19 during the initial outbreak and lockdown in Ireland. A high rate of testing and evidence of good planning and adherence to public health guidelines within services and by people with intellectual disability are indicative of the type of good practice for all highlighted by HIQA and the Nursing Home Expert Group. The adaptability also evident among participants, even in the face of stresses and anxieties reported, again highlights the resilience of people with intellectual disability who are often under-estimated. However, data presented, combined with international evidence, emphasises the difficulties that will arise in a prolonged fight against COVID-19, especially for those with pre-existing mental health and behavioural difficulties. For as long as COVID-19 remains a threat within society, this vulnerable older population with histories of high-risk comorbidities requires continued safeguarding efforts against the disease. Based on the literature and findings here, assessing for COVID-19 risk in people with intellectual disability should be based primarily on screening for high-risk comorbidities or frailty while also considering chronological age. The secondary threat to mental health and well-being presented by the ongoing curtailment of normal routines, social and community participation and service closures equally requires a continued effort by services to provide flexible and responsive support to people with intellectual

disability and their families during this time. Given the occurrence of the second COVID-19 wave and subsequent lockdown in Ireland through the autumn 2020, a repeat of the measures reported here is recommended to monitor the ongoing effects of the pandemic on this population.

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THE IMPACT OF COVID-19 on People Ageing with an Intellectual Disability in Ireland

2020