



Preventing, mitigating, and managing future pandemics for people with an intellectual and developmental disability - learning from COVID-19: A scoping review

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Preventing, mitigating, and managing future pandemics for people with an intellectual and developmental disability - learning from COVID-19:

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ABSTRACT

Background: Many people with an intellectual and developmental disability (IDD) are biologically, socially, and economically/politically vulnerable to developing SARS-COV-2 (COVID-19) compared to the general population. Most governments have developed public-health policies and strategies to address the challenges that COVID-19 has presented. These policies and strategies have been based upon the general population and in fact could be detrimental to the health and well-being of people with IDD.

Aim: This paper provides a review of the key learning points emerging from the COVID-19 literature, together with guidance for the provision of services and government interventions for people with an IDD for future pandemics.

Methods: Using guidance from the Joanna Briggs Institute, a scoping review was used to explore the current literature (scientific and grey) on IDD and COVID-19.

Findings: Three core themes emerged from the review. **Prevention/Protection:** accessible information, handwashing and social distancing, Personal Protective Equipment, shielding, track and trace, testing, vaccine compliance/hesitancy, and training. **Mitigation:** making reasonable adjustments both to where people live, and to community healthcare/clinical practice; and the use of technology as a pandemic-response strategy. **Treatment/Management:** access to acute hospitals and lifesaving equipment, using a suitable Clinical Fatality Assessment instrument, stopping Do Not Resuscitate notices, individualised care plans and hospital passports, family/paid carers to support people in hospitals; and use of telehealth in clinical care.

Conclusion: This is the first international scoping review that provides a narrative synthesis of emerging themes related to the COVID-19 pandemic and people with an IDD. This paper highlights themes related to preventing, mitigating, and treating/managing the care of this population during the COVID-19 pandemic, which can inform future public-health policies. This paper also exposes the negative impacts of public-health interventions in both HIC and LMIC for this population including lapses in upholding human rights. This data provides a basis for learning from the COVID-19 pandemic in planning for future pandemics.

Keywords: intellectual and developmental disability, COVID-19, public-health prevention, mitigation, medical care, pandemic

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INTRODUCTION

Since the start of March 2020, when SARS-COV-2 (COVID-19) was recognised by the WHO, governments have had to make rapid policy and legislative decisions, implement societal and service-based interventions, often based upon limited information in an ever-shifting environment. The scientific community has also moved rapidly to support, inform, and monitor the international effort to deal with the COVID-19 crisis. A significant amount of evidence has been recently published on the current extent of the COVID-19 pandemic (WHO Coronavirus (COVID-19) Dashboard | WHO Coronavirus), country specific (i.e., Australia, China, UK, USA), disease specific (i.e., respiratory conditions, diabetes), and population specific (i.e., BAME community, older people, and those with an IDD) infection and mortality rates.

A continuous process of evaluation and review of this emerging literature is essential, both for the continued response to the current, ongoing pandemic, and for informing policy decisions regarding potential future pandemics. It should not be forgotten however that although COVID-19 is a novel virus, there is a body of literature from previous disasters and pandemics that may still be relevant. For example, Kendall et al. (2020) reported that disasters such as Japan's 2011 earthquake and tsunami, and pandemics such as the COVID-19, disproportionately affect people with disabilities.

Biological, social, and economic/political vulnerability

Biological vulnerability: Empirical research has clearly highlighted that some people with an IDD (such as those with Down syndrome) are biologically vulnerable to developing COVID-19, with many of those with an IDD contracting the virus at a younger age, developing more severe symptoms, at greater risk of hospitalisation, and having a higher mortality rate compared to the general population (Alexander et al., 2020; Clift et al., 2021; Courtney et al., 2021; Gleason et al., 2021; Henderson et al., 2021; Mills et al., 2020; Williamson et al., 2021; Lunksy et al., 2021).

Many people with an IDD have a number of pre-existing health conditions that exposes them to an increased risk of infection from COVID-19 compared with the general population such as respiratory problems, diabetes, high blood pressure, and also obesity (O'Leary et al., 2018). A USA study found that case fatality for adults with an IDD and COVID-19 was 4.5% compared to 2.7% in the general population (Turk et al., 2020). Similarly, with a younger sample in England, case fatality in over 700 adults with an IDD and COVID-19 was higher compared to those without an IDD (NHS England, 2020a; Care Quality Commission, 2020). Adults with Down syndrome were even found to be at a greater risk of developing and dying from COVID-19 compared to other people with an IDD (Clift et al., 2021; Villani et al., 2020). Landes et al. (2020, 2021) in the USA further highlighted that case-fatality rates from COVID-19 were higher for those adults with an IDD living in congregated residential facilities, compared to those adults with an IDD living in their family home, and higher compared to the general population.

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3 **Social and economic/political vulnerability:** It is now started to be argued that many
4 children and adults with an IDD are also socially (due to living conditions) and
5 economically/politically (lack of representation in policy-making) vulnerable to
6 developing COVID-19 (Chakraborty, 2021; Goggin & Ellis, 2020; Hatton, 2021a; Kuper
7 et al., 2020; Mencap Report, 2020). Core strategies in bringing COVID-19 under control
8 include basic public-health and protection measures (i.e., wearing a mask,
9 handwashing, social distancing), however, these may not always be easily accessible to
10 those with an IDD living with their families and living in congregated living settings as
11 they will be at an increased risk due to amplified exposure from these informal and
12 formal care providers (i.e., viral load).
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16 People with IDD are also at greater risk of contracting COVID-19 than the general
17 population as they are more likely to be marginalised within society, more likely to live in
18 poverty, be discriminated against, and have access to sub-standard healthcare leading
19 to poorer health outcomes (Emerson & Hatton, 2014; WHO, 2020). Therefore, when
20 such disasters or pandemics occur, the impact on vulnerable and susceptible
21 populations is significantly greater. In addition, government strategies to overcome the
22 pandemic might, inadvertently, also have a detrimental impact on people with an IDD,
23 leading to further preventable health complications, inadequate care, and premature
24 death.
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27 There is growing research highlighting the additional impact of the lockdown, and the
28 restrictions enforced as a result of COVID-19 on this population regarding poorer
29 physical and mental health, increased behaviours that challenge and overall poorer
30 well-being (Lake et al., 2021; Rosencrans et al., 2021; Totsika et al., 2021).
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33 **Aim and objectives of this scoping review**

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35 Alexander et al. (2020), alongside a team of clinicians and academics in England,
36 reviewed the current evidence and offered guidelines on the *'treatment and*
37 *management of COVID-19 among people with IDD'*. These guidelines were innovative
38 as they offered specific national guidance to care providers which, although UK-specific,
39 could be adapted for use in other countries. These guidelines were designed to inform
40 community health and social care staff about the prevention of infection and how to
41 manage a person with an IDD when diagnosed with COVID-19, as well as the provision
42 of support for their family carers, thereby preventing hospital admissions. In addition,
43 the guidelines provided guidance for acute hospital staff in how to support a person with
44 an IDD when admitted to hospital. Since the publication of this guidance in Sept 2020
45 more has been learnt about those at risk from developing and dying from COVID-19;
46 how to prevent the transmission of infection; the impact that COVID-19 is having on this
47 population, their family/paid carers as well as health and social care organisations; how
48 to treat/manage those infected, and how health services have responded to the
49 pandemic.
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53 The aim of this paper was therefore to provide a narrative synthesis of the emerging
54 themes related to the COVID-19 pandemic for people with an IDD from the literature,
55 18-months after the beginning of lockdown. The purpose of this paper was to focus on
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3 what we can learn from the literature to inform future pandemics and to generate
4 evidence that will answer three objectives:
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6 (1) From a public-health prevention perspective, how can the spread of future
7 pandemics be prevented for people with an intellectual and developmental disability?
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10 (2) From a socio-ecological perspective, how can the impact of future pandemics be
11 mitigated for people with an IDD?
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13 (3) And from a medical perspective, how can medical care and services be provided for
14 people with an IDD during future pandemics?
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METHODS

A scoping review was chosen as the means to explore the wide-ranging current literature on the impact and learnings of COVID-19 on people with an IDD. McKinstry et al. (2014) stated that *'scoping reviews are considered highly useful when an overview of the evidence is needed to determine priorities for future investigations.'*

Identifying the research question

This scoping review was based on the following overarching question: *'What is known from the existing literature about how pandemics can be prevented, mitigated and managed/treated in the future for people with an IDD learnings from COVID-19'*. When taken from a public health, socio-ecological and a medical perspective, the research question evolved into three distinct review questions: (1) From a public health prevention perspective, how can the spread of future pandemics be prevented in people with an IDD? (2) From a socio-ecological perspective, how can the impact of future pandemics be mitigated for people with an IDD? (3) And from a medical perspective, how can medical care and services be provided for people with an IDD during future pandemics? Having developed and refined the research question, several tools were utilised to ensure rigour and transparency (Peters, 2020; Lockwood et al., 2019). Using guidance from the Joanna Briggs Institute, the inclusion criteria were created by defining the participants, concept, and context of the review (see Table 1).

INSERT TABLE 1 HERE

Sources of Evidence

An initial search of online review registers (Joanna Briggs Institute; Figshare and OpenScience) was undertaken to identify any existing scoping reviews using the search terms *learning disability, intellectual and developmental disability, AND COVID-19, AND pandemic*. No scoping reviews using these search terms were found. The current scoping review involved searching several databases (CINAHL, Medline Ovid, Embase, PubMed, PsychInfo, Cochrane Library, Ethos, Proquest and grey literature) using the search terms: learning disability, intellectual and developmental disability, and COVID-19.

Search strategy

P(Populations) E(Exposure) O(Outcomes) (Bettany-Saltikov 2012) was used to develop and refine the search strategy based on the research question: *'What is known from the existing literature about how we prevent, mitigate and treat/manage future pandemics for people with an IDD: learning from COVID-19'*.

Study selection

A priori inclusion and exclusion criteria were established and implemented.

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3 **Inclusion:** Publications included comprised research papers, guidance papers,
4 editorials, commentaries, and letters, published in the English-language, examining the
5 prevention, mitigation and medical care of children and adults with an IDD. For
6 reviewing purpose, publications were limited to articles published between March 2020
7 and Sept 2021 and to those published in English.
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10 **Exclusion:** The following Exclusion Criteria were utilised: (1) studies examining the
11 biological/genetic *risk factors* of COVID-19 on people with an IDD; (2) studies describing
12 the *impact* of COVID-19 on people with an IDD and/or their family and/or carers; and (3)
13 studies describing the *impact* of COVID-19 on professional staff caring for people with
14 an IDD.
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17 The 1st, 2nd and 3rd authors independently screened all available abstracts and titles of
18 the articles and documents found using the search strategy outlined above for the
19 inclusion and exclusion criteria. Discrepancies in selection were discussed and resolved
20 with the 3rd author. The full text of selected articles was further reviewed by the 1st and
21 2nd authors for inclusion, with 100% agreement reached and confirmed by the 3rd
22 author.
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25 **Insert Fig 1 here (PRISMA-ScR Flowchart)**
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27 **Data Extraction**

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29 Data was screened as per the PRISMA-ScR screening guidelines (Page et al., 2020).
30 This tool has been published to support authors in preparing scoping reviews for
31 publication. The flowchart in Figure 1 shows the screening process. An extraction tool
32 was designed to examine the papers identified for inclusion following the screening
33 process. The extract tool focused on citation, country, study population, concept,
34 context, design, and key findings related to the research question. A copy of the
35 extraction tool is available from the first author.
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38 **Analysis and presentation of results**

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40 The authors agreed a final list of articles which were entered into the presentation table.
41 The first author identified themes/categories across the studies which were then verified
42 and developed with the second and third authors. The material was not critically
43 appraised as this is not a requirement of a scoping review (Arksey & O'Malley, 2005).
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FINDINGS

Table 2 identifies the 34 research papers (such as retrospective analysis, surveys, service evaluation, discussion paper,) and grey material (such as commentary, editorial, guidance papers, guideline/protocol development, letters, opinion paper, policy briefing) included within this review.

INSERT TABLE 2 HERE

Theme 1: Preventing the spread of, and managing, future pandemics for people with an IDD?

Sub-Theme 1.1: Accessible information

For many countries, statutory health organisations have been legally required to provide written information on the public-health prevention and protection measures. The importance of having accessible information that clearly explains the respective public-health prevention and protection measures in a format that people with an IDD can understand has been highlighted throughout the literature (Alexander et al., 2021; Hatton et al., 2021a; LeDeR, 2020; Majnemer et al., 2021; Strydom et al., 2021; Tromans et al., 2021; UN, 2020) (see Table 2). The papers reviewed identified important sources of pandemic-related information including leaflets, the television, radio, and social media. For those with an IDD, their family carers and disability organisations *‘living in remote and rural areas without access to technologies [news, social media], they did not have adequate information about the pandemic’* particularly for those from LMIC such as Ethiopia, Malawi, Lesotho, Rwanda, and Zimbabwe (Brennan et al., 2020). Where there was accessible information in HIC:

‘Concerns were also raised about the lack of specific types of information, including preventive measures to prevent infection, where to obtain testing and treatment, the nature of emergency regulations and lockdown rules, and accessing emergency food and social assistance schemes’ (Brennan et al., 2020).

Mulhall et al. (2018) in their systematic review, noted it is vital that a series of information leaflets be available, each matched to different levels of cognitive ability. This is particularly important at times of national crisis where government information (whether media broadcasted or printed) is often not presented in a manner accessible to those at greatest risk. It is likely that those with an IDD rely on care providers to adjust/translate government information into more accessible terms.

Sub-Theme 1.2: Handwashing and social distancing

Handwashing and social distancing have been two global strategies identified for preventing the transmission and reducing the spread of COVID-19 for all. In a large study conducted across the UK, Hatton et al. (2021a) found that the vast majority (85%) of their sample reported that they understood the rules about handwashing and social

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3 distancing. Most of the adults with a mild IDD reported that they received information
4 about the COVID-19 rules/information by watching the television (76%) or by talking to
5 their friends/family (43%) and/or paid carers (35%). Armor et al. (2021) reported that of
6 the 582 adults with an IDD in Spain who participated in a cross-sectional survey, the
7 majority reported that they received transparent information on COVID-19 and could
8 understand the information for the reasons for lockdown, social distancing,
9 handwashing and wearing face masks.
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12 The WHO (2020) stated that people with disabilities may experience greater barriers to
13 basic public-health measures during COVID-19 as a result of: *'lack of accessibility to*
14 *water, sanitation and hygiene wash facilities; a reliance on carers for support;*
15 *inaccessibility of public health information; residing in residential accommodation or an*
16 *institution that can be overcrowded and unsanitary'*.
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19 **Sub-Theme 1.3: Use of Personal Protective Equipment (PPE)**

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21 Guidance regarding the wearing of face masks, aprons, and gloves (PPE) have been
22 issued for all countries, for carers working in a range of community health and social
23 care organisations, and for hospitals/institutions and prisons (Dickson et al., 2020; NHS
24 England, 2020a; b; Strydom et al., 2021; WHO, 2020; UN, 2020). This includes facility
25 sanitisation, social distance measures, frequent handwashing and disposal of tissues
26 when used.
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29 Hatton et al. (2021a) reported that 86% of adults with a mild/moderate IDD and
30 family/paid carers of 56% of adults with multiple and profound IDD across the UK,
31 reported wearing a face mask when out in their local community. Reasons for the lower
32 compliance rate included people were exempt due to difficulty breathing, a risk of
33 seizure and/or skin irritation. Alexander et al. (2020) highlighted further restrictions that
34 family/paid carers encountered when wearing face masks included the person with the
35 disability had difficulty in understanding what was being said, the carer's facial
36 expression was hidden, and provoked anxiety.
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39 Some recent reports highlighted the challenges in obtaining PPE. For example, Hatton
40 et al. (2021b) reported that nine-months after the beginning of the COVID-19 restrictions
41 in March 2020, 51% of family/paid carers still found it difficult to access PPE when
42 caring for adults with multiple and profound IDD across the UK. More so, family carers
43 of people with an IDD were 2.7 times more likely to have difficulties accessing PPE
44 compared to staff working in residential care ($p < .001$).
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46

47 Brennan et al. (2020) in their survey of 134 HIC and LMIC have strongly emphasised
48 that governments worldwide have failed to provide PPE and adequate sanitation for
49 people with disabilities in many community residential facilities and hospitals/institutions.
50 These included accounts from the USA, the UK, Canada, Ireland, and South Africa. For
51 instance, a staff member from a Moldovan institution said that *'they had to buy their own*
52 *PPE, without reimbursement from either the institution or the government'*. Brennan et
53 al. further reported they received *'an overwhelming number of testimonies from around*
54 *the world confirming that governments have not taken sufficient steps to safeguard the*
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3 *right to access food, basic medical supplies, PPE, or measures (such as social*
4 *distancing) to minimise infections and deaths in institutions' for people with disabilities.*
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6 **Sub-Theme 1.4: Shielding**

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8 Government recommendations have emphasized that vulnerable high-risk populations,
9 including people with an IDD, should engage in social distancing measures thereby
10 avoiding public areas, public transport and from those individuals who are displaying
11 symptoms/have a diagnosis of COVID-19 (NHS England, 2020a; b; Strydom et al.,
12 2021; WHO, 2020; UN, 2020). Such recommendations also stated '*shield*' and stay at
13 home. This necessitates avoiding gatherings of people in the local community, in work
14 and social settings. Hatton et al. (2021a) reported that 58% of family/paid carers of
15 those with multiple and profound IDD imposed self-isolation compared to 31% of the
16 adults with a mild/moderate IDD: many of whom were shielding following receiving a
17 letter of instruction from their family physician.
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21 For those adults with an IDD residing in community residential care and
22 hospitals/institutions, this has led again to certain countries providing guidance directing
23 that family and friends should be stopped from visiting the person. McCallion (2020) has
24 argued that many adults with an IDD in residential accommodation will always struggle
25 with adhering to social distancing guidelines given their lack of understanding. Such
26 imposed isolation will be bewildering to those people with multiple and profound IDD
27 and may lead to increases in behaviours that challenge and a deterioration in mental
28 health.
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31 **Sub-Theme 1.5: Track and Trace App**

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33 Governments globally have looked to technologies in the form of a Track & Trace Smart
34 Phone Apps to help them mitigate the risk of COVID-19, identify those diagnosed or in
35 close proximity to someone diagnosed with COVID-19 in order to quarantine such
36 individuals and further diminish the infection rates. Only one study was found in the UK,
37 where adults with an IDD had downloaded a Track & Trace Smart Phone App (for
38 example the NHS COVID-19 app, the Stop COVID Northern Ireland app, or the Protect
39 Scotland app) on their mobile phone. Hatton et al. (2021a) in their UK wide survey of
40 627 adults with a mild/moderate intellectual and developmental disability, reported 25%
41 of the adults reported downloading and using their country specific App onto their phone
42 despite the majority of adults having a mobile phone and internet access.
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46 **Sub-Theme 1.6: Vaccine compliance rates and vaccine hesitancy**

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48 Vaccination is a major component of the international community's attempt to flatten the
49 infection curve, however vaccine hesitancy and vaccine compliance rates vary in the
50 general population and even within the medical professions. Dror et al. (2020) reported
51 that a contributing factor in vaccine willingness relies upon a '*personal risk-benefit*
52 *perception*' that may be influenced by prevailing available information. Ladarola et al.
53 (2021) in a study of 91 adults with an IDD in New York, reported high vaccine intent
54 (81%). Hatton et al. (2021b) in their study indicated that the majority of this population
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3 would be willing to receive the COVID-19 vaccination. Predictors included having an
4 existing health condition that placed a person in the high-risk category, already
5 receiving the flu vaccination, gaining appropriate accessible information, and having
6 already shielded.
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8 9 **Sub-Theme 1.7: Testing for COVID-19**

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11 Although internationally a policy of *'test, track and trace'* is central to the response to the
12 COVID-19 pandemic, in the first 12-14 months, many countries only encouraged
13 citizens to present for a COVID-19 test if displaying symptoms. However, testing
14 (whether PCR Tests for those displaying symptoms or Lateral Flow Test for those
15 without symptoms) for COVID-19 can pose challenges for many people IDD given their
16 cognitive impairment, communication difficulties and other presenting behavioural
17 issues. Some individuals may also be resistant to the nasal and throat swabbing that is
18 required for both a PCR Test and a Lateral Flow Test, thereby diminishing the accuracy
19 of the testing thus further impeding diagnosis and early intervention: key components to
20 improved outcomes following infection.
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24 People with an IDD might have difficulty in communicating and expressing medical
25 symptoms to their family/paid carers and general physician (such as feeling unwell,
26 headaches, loss of smell and taste, etc) of COVID-19. Likewise, family/paid carers
27 might also lack the knowledge in recognising the signs/symptoms in people with more
28 profound needs. According to Sulks (2020) *'such limitations have resulted in*
29 *longstanding difficulties with access to healthcare for people with an IDD* and access to
30 COVID-19 test centres.
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32
33 Brennan et al. (2020) in their international survey of 134 countries of over 1,100 people
34 with an IDD found reports that staff were inadequately trained in the prevention,
35 protection, and management of COVID-19 in both community residential
36 accommodation and hospitals/institutions across both HIC and LMIC, thereby allowing
37 for the further and unnecessary spread of infection. McCallion (2020) and others
38 (Dickson et al., 2020; LeDeR, 2020; WHO, 2020; UN, 2020), highlighted that training
39 was needed for front-line paid staff and family carers regarding all aspects of public-
40 health prevention including identifying the risk factors of infection, the signs/symptoms
41 of COVID-19, wearing of PPE, handwashing, and facility sanitation, shielding and social
42 distancing, using appropriate accessible literature and in a language in each country's
43 own language.
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46 **Theme 2: How do we mitigate the impact of future pandemics for people with an** 47 **IDD**

48 49 **Sub-Theme 2.1: Adjustments to living conditions and community supports**

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51 In many countries, core components in the fight against infection of COVID-19 are
52 public-health prevention and protection measures (i.e., reduced social contact, social
53 distancing and shielding). Such measures can be challenging for those with an IDD
54 living with families and in residential settings as they are forced to be alone and isolated
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3 from their supports (such as family and friends, school, education, structured day-care,
4 respite, employment, community activities, etc), and health and social care. This may in
5 part explain the increased risk rates for this population (Solis et al., 2020; CDC, 2020).
6

7 Reports from around the globe highlight higher infection rates of COVID-19 and greater
8 mortalities in community residential accommodation and institutions/hospitals for adults
9 with an IDD (Brennan et al., 2020; Hakim, 2020; Landes et al., 2021). Several sources
10 have reported how COVID-19 and the subsequent lockdowns have negatively impacted
11 upon the lives of people with an IDD whether living at home with their family, in a
12 community residential facility or in an inpatient setting (Alexander et al., 2020; Brennan
13 et al., 2020; McCallion, 2020, Lake et al., 2021; Rosencrans et al., 2021; Totsika et al.,
14 2021; Williamson et al., 2021).
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18 In Spain, Armor et al. (2021) reported living in a community residential facility was
19 associated with being more anxious during the COVID-19 pandemic, *'with these*
20 *services reporting to have been overwhelmed because of the lack of resources to*
21 *prevent contagion between carers and people with IDD and the lack of time to prepare*
22 *and explain the measures taken'*. In addition, many people with an IDD have
23 encountered unexpected changes in their living environments such as: changes in
24 routine and staff, loss of contact and isolation from their families/friends, reduction in
25 access to day activities (education, day-care, respite, employment), and reduced
26 engagement in their local community, and access to health and social care (Hatton et
27 al., 2021a, b). Armor and colleagues stated that almost 10% of adults with an IDD living
28 in a residential facility returned to live with their families.
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31 Brennan et al. (2020) found that people with an IDD living in community residential
32 facilities, and hospitals/institutions, in over these 134 HIC and LMIC reported:
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36 *'That the emergency measures that were taken by governments to control the*
37 *spread of COVID-19, have exacerbated existing human rights abuses and failed*
38 *to prevent further human rights abuses in this population. These measures*
39 *included the denial of access to healthcare, bans on visitors [family, friends or*
40 *others], bans on residents leaving the institutions and isolating residents when*
41 *there was an outbreak of COVID-19'*
42
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44 Brennan and colleagues (2020) further noted that staff working within these disability
45 organisations highlighted *'additional human rights abuses would occur behind closed*
46 *doors, in the absence of monitoring mechanisms [independent human rights authorities]*
47 *or family visits to institutions ... leading to a lack of care, lack of transparency and*
48 *concealment of dangerous abuses'*.
49

50 Hatton et al.'s (2021a; b) large UK study reported that the majority of adults with an IDD
51 had not attended a day service since the start of lockdown (figures varied across the
52 four countries from 69.8% to 83.3% respectively). Likewise, for those adults with an IDD
53 who were engaged in employment, education, and used respite/short break services,
54 access to these activities was reduced drastically across the four UK countries.
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4 Jeste et al.'s (2020) international survey (mainly USA) of 818 family carers exploring
5 access to education and healthcare for children and young people with an IDD reported
6 that they lost the majority of these services. The parents also reported barriers to
7 obtaining medical supplies, medications, and respite care. Telehealth (both
8 tele-education and telemedicine) was reported to be helpful when available but parents
9 needed to supplement these remote delivery services.
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12 **Sub-Theme 2.2: Making reasonable adjustments to community healthcare and** 13 **clinical practice** 14

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16 When COVID-19 started, many community healthcare systems such as family
17 physicians, community/district nurses, and the UK's '*community learning disability*
18 *teams*', drastically reduced contact with those with an IDD (Alexander et al., 2020;
19 Tromans et al., 2020). Hatton et al. (2021a) found that access to family physicians,
20 community learning disability nurses and other health professionals reduced by over
21 50%-90% across the four UK countries between Dec 2020 and Feb 2021. Hatton and
22 colleagues also reported that the provision of annual health checks was also severely
23 reduced.
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25
26 Alexander et al. (2020) have argued that community teams should be contacting people
27 with an IDD and family/paid carers more so via the use of telephones and
28 videoconferencing at this time. Evidence concerning the occurrence, and effectiveness,
29 of the levels of support provided this way so far during the pandemic is inconsistent.
30 Amor et al. (2021) in Spain described that the adults with IDD reported being positively
31 supported by staff face-to-face and via online media to help alleviate these fears and
32 anxieties early during the COVID-19 pandemic and lockdown. However, Brennan et al.
33 (2020) found that 45% of the participants in their large study over 134 HIC and LIMC
34 reported that '*their government took no measures to protect the life, health, and safety*
35 *of persons with disabilities living in the community... they were trapped at home...*
36 *essential services were not available during the pandemic... abandoned by the*
37 *government*'.
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40 **Sub-Theme 2.3: Use of technology as a pandemic-response strategy** 41

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43 As COVID-19 hit and lockdown began in early 2020 schools, education, day-care,
44 respite, employment, and community activities stopped immediately, families went into
45 '*self-forced isolation*' and residential homes went into '*quarantine overnight*'. All the
46 government's advice was, where possible, people should work from home. Many people
47 with an IDD, and their family/paid carers, were further isolated from their families and
48 friends, as well as health professionals and social supports. For those to whom it was
49 available technology in the form of computers, smart phones, iPads, Skype, and Zoom
50 became a lifeline for many adults with an IDD and family carers. For some, it was their
51 main way to stay in contact with family and friends, and also with health and social care
52 professionals. Innovative ways to engage people with an IDD online such as interactive
53 games, quizzes, cookery classes and physical activity classes developed quickly
54 (Bradley, 2020).
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3 Hatton et al. (2021a; b) found that many adults with an IDD and family/paid carers did
4 have access to the internet and embraced the move to more frequent online
5 communication. Common online activities included: being with friends and family (e.g.,
6 video calls), going on social media, participating in online activities with other people,
7 and streaming television and films. Zaagsma et al. (2020) in a retrospective descriptive
8 research study in the Netherlands of adults with an IDD living independently in the
9 community during the COVID-19 lockdown found that *'online support enabled service
10 providers to be flexible and responsive towards fluctuations in both support needs and
11 onsite support availability during a social crisis'*. However, Brennan et al. (2020) found
12 that many children and adults with an IDD in LMIC did not have access to online
13 activities with advocacy organisations, and engagement with family/friends and health
14 professionals because they did not have access to the technology required and internet,
15 particularly in LMIC.
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19 **Theme 3: How do we provide medical care and services for people with an IDD** 20 **during future pandemics?** 21

22 **Sub-Theme 3.1: Access to acute hospitals and lifesaving equipment** 23

24 There is a growing body of evidence suggesting that access to acute hospitals and
25 lifesaving equipment (such as triage services, medications, intensive care beds,
26 ventilators) are being withheld from some people with an IDD. McKinney et al. (2020)
27 found that triage policies and practices in South Africa often excluded people with an
28 IDD from gaining intensive care unit (ICU) access and receiving ventilators if they
29 became ill. Brennan et al. (2020) also reported that in a number of both HIC and LMIC,
30 adults with an IDD have not been able to access acute care hospitals and lifesaving
31 equipment. It has been reported that people with an IDD have not been a prioritised
32 population for emergency medical intervention due to being perceived as lower priority
33 than non-disabled individuals leading to *'medical rationing'* (Andrews et al., 2020).
34 Furthermore, it has also been argued that medical and health professionals are making
35 value judgements about the quality of life of persons with an IDD (Baart & Taaka, 2017;
36 Bagenstos, 2020). It is not clear whether this is a historical overlay, or as a direct
37 response to the pressures of dealing with COVID-19.
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41 It has been argued that the same clinical management guidelines for people without
42 disabilities who have been diagnosed with COVID-19 be applied for this IDD population:
43 although reasonable adjustments will be needed for this population (Alexander et al.,
44 2020; LeDeR, 2020; NHS England, 2020a; b; 2021a, b, c; UN, 2020). Callea et al.
45 (2020) and Buono et al. (2021) in Italy have developed a protocol that *'contains
46 instructions related to the importance for children with Down syndrome of having earlier
47 access to diagnostic tests and antiviral management, especially in states of immune
48 dysfunction, recurrent pulmonary infections, congenital heart disease and obesity'*.
49 Buono et al. (2021) again in Italy developed remote and in person psychological support
50 for people with IDD and their family carers.
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Sub-Theme 3.2: Clinical Fatality Assessment

In the early stages of the COVID pandemic there was widespread concern in many countries about availability of ventilators. This led to the possibility of clinicians having to decide upon who could receive critical care. In many countries, clinical weakness or frailty is assessed by medical staff triaging older individuals. It is vital that this process is monitored in crisis response, or pandemic situations, such as COVID-19, when there is a lack of access to intensive care and lifesaving equipment to support everybody. The clinical fatality assessment involves using a standardised assessment tool such as the Clinical Fatality Scale (CFS: Rockwood et al., 2005), and involves some form of estimating the benefits of treatment to the person's survival, life expectancy and quality of life. People with an IDD are already at a higher risk of developing co-morbidities, and for a number of reasons, including inequalities of health care access, are at risk of premature death (Heslop et al., 2014; O'Leary et al., 2018). It is understandable therefore that concerns have been raised about the use of the CFS for adults with an IDD, and the very real potential for the exclusion of this population from intensive care and lifesaving equipment. Alexander et al. (2020) in their COVID-19 guidelines and Festen et al. (2021) in their retrospective analysis 982 individuals with an IDD of ≥ 50 years, both argued that:

'The CFS is not suitable to evaluate frailty in individuals with IDD with potential dramatic consequences for triage and decision-making during the COVID-19 pandemic. We strongly recommend using the IDD-frailty index when assessing probability of survival for individuals with IDD'.

Sub-Theme 3.3: Do Not Resuscitate Orders (DNR)

DNR orders are instructions which direct that a medical practitioner should not do cardiopulmonary resuscitation (CPR) if a person's breathing stops or if the person's heart stops. There is evidence of increased rates of DNR orders being placed on people with IDD during the COVID pandemic (Alexander et al., 2020; Gulati et al., 2020; LeDeR, 2020; Kavanagh et al., 2021; NHS England 2020a; Thomas, 2020; Tromans et al., 2020). This raises considerable concerns about the protection of human rights for those with an IDD and is of particular importance given the UN Convention on the Rights of Persons with Disabilities (2006). Brennan and colleagues purported that such DNR orders have been used in HIC including Austria, Canada, France, Luxembourg, the Netherlands, South Africa, UK, and the USA:

'Governments have indicated that hospital triage should discriminate against COVID-19 patients with disabilities in the event of a shortage of hospital places. Triage guidelines explicitly or implicitly instructed health workers to decide on a person's right to life based on their disability'.

It is essential that when DNRs are being considered, that they are done in full compliance with existing legal frameworks.

Sub-Theme 3.4: COVID-19 individualised care plan and hospital passports

In their earlier guidance document, Alexander et al. (2020) emphasised that when a person with an IDD has been diagnosed with COVID-19, an advance care plan should be developed collaboratively with the person, carers, and care team. The person's risk factors, their needs, their treatment and management plan, the reasonable adjustments needed for example, should all be clearly identified within this care plan. Family carers and paid staff within residential facilities, and hospital staff, need to be fully involved in these decisions. In addition, any end-of-life or DNR should also be discussed and recorded within the care plan.

Alexander et al. (2020) highlighted that all people with an IDD should have an updated hospital or health passport which provides a succinct summary of the person's medical information and their potential risk factors for developing COVID-19 (i.e., BMI, respiratory problems, dysphagia, diabetes, sensory problems, mental health problems, smoker, etc.), how they communicate and their preferences. NHS England (2021c) developed a guide designed in partnership with people with an IDD, families and nurses that will support hospital staff to include information on: ability to communicate, medical history, medication, and administration, indicating pain/worry/upset, hearing and eyesight.

Sub-Theme 3.5: Role of families in hospital

Many countries enacted a series of measures in hospitals which reduced or stopped visitors from attending. This policy, whilst aimed at reducing the spread of the virus, had unintended negative consequences for people with IDD who rely heavily upon family/paid carers for supporting them regarding communication, personal care and general support. The experience of people with an IDD who had to be hospitalised during the COVID-19 pandemic emphasised the adverse effects of no visitor rules. Without support from family and/or paid staff, people with an IDD were left to sort through the complex consequences of treatment decisions (Alexander et al., 2020; Dickson et al., 2020; Strydom et al., 2021). As yet, it is not known whether this policy has had a long-term detrimental impact on this population.

Sub-Theme 3.6: Telehealth in Clinical Care

Telehealth has been shown to have many advantages and has been a necessary means of providing healthcare for many professionals during the COVID-19 pandemic. Despite the many advantages, Constantino et al. (2021) have argued that telehealth for people with an IDD can be challenging, especially in verbalizing symptomology and pain. Likewise, untrained family/paid carers may not have the appropriate knowledge or experience to accurately assess symptomatology or pain levels. During the first few months of COVID-19 many healthcare appointments for people with an IDD were cancelled or postponed (Loman et al., 2020; Hatton et al., 2021a). Taddei & Bulgheroni (2020) conducted a study testing the feasibility of switching from a hospital face-to-face appointment approach with family carers and children with an IDD in Italy, to a

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3 telehealth clinic. The authors found that this model was very successful and was highly
4 rated by the family carers and staff.
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7 Telehealth/telecare/telemedicine has potential advantages for people with an IDD with
8 access to such services improving healthcare. Barriers to transportation, having
9 support, physical access to primary healthcare centres and hospitals are immediately
10 removed with telehealth/telecare/telemedicine. However, technology is not without its
11 barriers as the availability of a computer/Ipad/phone, broadband, Wi-Fi, user
12 accessibility interface for example affects populations affected by the digital divide.
13 Valdez et al. (2021) has claimed that the extensive use of telehealth resulting from the
14 COVID-19 has *'the potential to further exacerbate health inequities faced by people with*
15 *disabilities.'* Constantino et al. (2020) have stated that technology is an *'inadequate*
16 *substitute'* for a population already isolated from their communities.
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Discussion

The aim of this scoping review was to provide a narrative synthesis of the emerging themes related to the COVID-19 pandemic for people with an IDD, 18-months after the beginning of lockdown. The purpose of this paper was to focus on what we can learn and to generate evidence that can prevent the spread, limit the impact, and provide appropriate medical care for this population in future pandemics. In this review we describe a range of reported experiences related to this population during COVID-19 and claims advanced in relation to these experiences. The review process highlights common themes that emerged most frequently in this literature. But what kind of evidence are these experiences, claims, and themes? And how might this evidence provide a basis for key learnings? For example, some claims are empirical (e.g., outcomes of COVID-19 infection among a case-series of people with Down syndrome). These can, in principle, be generalized to all people with Down syndrome regardless of the jurisdiction in which they live. Other claims are epidemiological (e.g., surveys of people with an IDD or proxies of health and other outcomes during COVID-19 of people in different jurisdictions). Such claims cannot be readily generalized to other jurisdictions unless healthcare systems are similar (unlikely between HIC and LMIC). Still other claims, by advocacy groups, propose policy changes they purport are practical and would better address inequities experienced by people with an IDD during the COVID-19 pandemic. Given such a mixed bag of evidence, the best such a review can do is attempt to describe this range of evidence, the range of positions on common issues, the gaps in the literature, and future research questions.

The lessons learnt from this scoping review mainly pertain to the social and economic/political vulnerabilities of this population (Chakraborty, 2021; Goggin & Ellis, 2020; Hatton, 2021a; Kuper et al., 2020; Mencap Report, 2020). This has been shown to manifest in public-health policies and strategies that have been made without an awareness and involvement of the specific needs or of the negative impacts of such policies on many people with an IDD, their family and paid carers.

Access to public health prevention and protection measures

This paper has clearly identified the global disparity in the availability and accessibility of a range of public-health prevention and protection measures which could prevent the spread of future viruses and prevent future global pandemics. Several studies have shown the importance of having accessible information, in all languages and regularly updated given the changing nature of viruses, that explains these public health prevention and protection measures (Alexander et al., 2021; Hatton et al., 2021a; LeDeR, 2020; Majnemer et al., 2021; Tromans et al., 2021; UN Policy Brief, 2020). Although some studies in HIC reported people with an IDD understood the rules about COVID-19, social distancing, shielding, wearing face masks and handwashing (Armor et al., 2021; Hatton et al., 2021a; b), a note of caution is warranted here as this was the persons' perceptions of the literature, however both studies did not examine the accessibility and effectiveness of this information. In addition, those with an IDD in both studies also had a number of supports to further help explain the restrictions caused by COVID-19.

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3 Other studies have highlighted the difficulties family and paid carers had in obtaining
4 PPE across both HIC and LMIC (Alexander et al., 2020; Brennan et al., 2020; Hatton et
5 al., 2021a; b). Hakim (2020) has argued that community residential accommodation and
6 hospitals/institutions for people with IDD were not prioritized for PPE distribution at the
7 start of the COVID-19 pandemic: our findings also highlight this for family carers too.
8 Bradley (2020) further stated disability organisations:
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12 *‘Will need to stockpile PPE for use in the event of a second wave and/or a viral*
13 *outbreak in the future. It took too long for people with disabilities, family*
14 *members, and direct support professionals to have access to PPE. The*
15 *availability of protective gear should be part of provider, individual, and family*
16 *disaster plans.’*
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19 Only one study was found in the UK where some adults with a mild/moderate IDD had
20 downloaded the Track and Trace App onto their mobile phone (Hatton et al., 2021a),
21 although how successful this is still needing to be examined. Despite the controversy
22 that surrounds the Track and Trace App for COVID-19, it has been argued that this is
23 one of a number of significant core steps for countries effectively exiting lockdown.
24 Numerous benefits have been cited for such Track and Trace Apps in order to reduce
25 the spread of transmission and infection. However, there are also a number of
26 limitations with regard to the availability of such apps in all HIC and LMIC in terms of
27 accessibility to phones, having access to the internet, the app user interface for people
28 with disability, and human rights and data protection laws.
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31 This study only found a few HIC where people with an IDD are now being offered
32 COVID-19 vaccinations. Access to vaccinations is a public health concern for each
33 country however where vaccinations are available, those with an IDD should be
34 identified as a priority group (Hotez et al., 2021) as seen within the UK when
35 vaccinations became available early in 2021. However, government policy to plan,
36 identify, encourage, and vaccinate those in specific high-risk categories is reliant upon
37 accurate figures regarding population size and need. In the UK, most of this strategy
38 relied upon General Practitioner databases to identify, contact, and administer the
39 vaccines. Unfortunately, the UK, like many countries, does not have a unified register of
40 people with an IDD.
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44 **Mitigating the impact of future virus-related pandemics for people with IDD**

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46 This review has clearly shown that people with an IDD have shielded, avoided public
47 areas, public transport, and stayed at home. This has led to many people with an IDD
48 and their family carers across the world no choice but to *‘enforce self-isolation’* from
49 family members and friends, and from the persons’ main structures during the day.
50 Likewise, disability care organisations also went into *‘forced isolation’* overnight (Tanzi,
51 2020). Family units and care organisations were neither prepared, resourced, financed,
52 nor organized for such extensive and extended isolation, to protect a population who
53 are at high-risk from developing COVID-19 and more susceptible to dying from this
54 virus. Family units and care organisations were also not able to implement public-health
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3 prevention and protection measures and manage or treat those who were diagnosed
4 with COVID-19 across many HIC and LMIC again because they were not prepared,
5 resourced, financed, and organized (Hakim, 2020). McCallion (2020) argued that
6 residential service providers although in 'lockdown' have had minimal, if any testing of
7 staff, PPE for staff and had few alternative choices but to allow staff to continue working
8 even if unwell: *'service systems are unprepared for COVID-19 at multiple levels'*.
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11 A number of studies have indicated that primary healthcare organisations withdrew
12 family physicians and community/district nurses, as well as *'learning disability*
13 *community teams'* drastically reducing contact with people with an IDD and their
14 family/paid carers (Alexander et al., 2020; Hatton et al., 2021a). For those countries that
15 provided health checks, these too were also drastically diminished: concerns have been
16 raised regarding not detecting potential preventable illnesses within this population over
17 the course of the COVID-19 restrictions (Tromans et al., 2020). For many face-to-face
18 contact was suddenly replaced with virtual contact (i.e., phone, videoconferencing,
19 social media) (Tanzi, 2020). Future studies need to explore the benefits and enablers,
20 and also the challenges and barriers, of such technology in the midst of a pandemic
21 crisis and thereby better prepare organisations for such prompt changes in delivery of
22 services.
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26 In fact, it has been strongly suggested that the need for health and social care services
27 for children and adults with an IDD as well as education, structured daytime activities,
28 employment, and community engagement should not stop during a pandemic. The UN
29 Policy Brief (2020), the WHO Policy Brief (2020a) and a number of NHS England
30 Reports (NHS England, 2020a, b; 2021a, b, c) on people with an IDD during COVID-19
31 reported that *'additional support, including good practice in engagement and*
32 *communication, making reasonable adjustments to healthcare systems and clinical*
33 *practice will be needed at times of crisis'*. Where possible, community and district
34 nursing teams should provide advice, guidance, and support virtually and avoid overly
35 restrictive practice.
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38 Several studies found that when statutory and voluntary services stopped overnight
39 such as schools, day-care, respite, employment, and community activities,
40 voluntary/charitable organisations quickly adapted and responded with online virtual
41 engagement using computers, smart phones, iPads, Skype, and Zoom. Those studies
42 that examined the use of technology and people with IDD highlighted positive
43 experiences (Hatton et al., 2021a; b; Zaagsma et al., 2020). Others, Brennan et al.
44 (2020), reported many children and adults with an IDD across numerous LMIC had not
45 access to the technology and internet needed, thereby further isolating them from family
46 and friends, and their local communities.
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49 In HIC where there are statutory IDD services, these services stopped overnight with
50 many non-government organisations (NGOs) and self-advocacy organisations having to
51 step in and support people with an IDD and their family carers immediately (Kavanagh
52 et al., 2021). There is a significant challenge here for those mandated to plan,
53 administer, and manage international pandemic responses. There is clear evidence of
54 the utility, and acceptance, of online care provision in a pandemic-response situation,
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3 but there also appears to be significant pockets of populations that do not yet have the
4 required levels of availability and infrastructure to utilise this response strategy which
5 may pre-exist the need for a pandemic response.
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7 **Access to mainstream services and use of reasonable adjustments**

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10 Many HIC and LMIC experienced periods when their healthcare systems, particularly
11 acute hospital settings, were stretched to capacity, with shortages of ICU beds and
12 breathing apparatus, and personnel. Thus, medical personnel were routinely triaging
13 clinically vulnerable and ill people and having to make clinical-decisions about which
14 patients accessed which interventions, or not, as the case may be. This has the
15 potential to inadvertently discriminate against people with an IDD.
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18 This scoping review paper has shown that the IDD population has been excluded
19 across many HIC and LMIC in regard to; triage services, receiving medications,
20 accessing acute hospitals, intensive care beds and lifesaving equipment (such as
21 mechanical ventilators) (Brennan et al., 2020; McKinney et al., 2020). There is potential
22 that if generic frailty assessment tools (i.e., Clinical Fatality Scale [CFS]) are used to
23 assess the need for persons' with IDD to be admitted to hospital and lifesaving
24 equipment, such instruments could exclude and discriminate against individuals with an
25 IDD from medications, hospital admissions, intensive care beds, and life safe saving
26 equipment. A number of studies have strongly argued that the IDD-frailty index should
27 be used instead of the CFS (Alexander et al., 2020; Festen et al., 2021).
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31 When the person with an IDD is diagnosed with COVID-19, or another virus-related
32 infection, and needs treatment and management, it is important that a range of
33 reasonable adjustments are put in place to support the person, and their carers, to
34 successfully obtain the appropriate hospital care and lifesaving equipment (Alexander et
35 al., 2020; LeDeR, 2020; NHS England, 2020a; b; 2021a, b; UN Policy Brief, 2020).
36 Such reasonable adjustments include listening to the individual, developing an
37 advanced care plan and health passport (Alexander et al., 2020; NHS England; 2021c),
38 involving families when the person with an IDD is admitted into hospitals, and the use
39 and adaptation of telehealth in clinical care (Taddei & Bulgheroni, 2020; Constantino et
40 al., 2021).
41

42
43 One of the most disturbing findings of this review paper has been the growing rates of
44 '*Do Not Resuscitate Notices (DNRs)*' on people with an IDD across both HIC and LMIC
45 (Alexander et al., 2020; Brennan et al., 2020; Gulati et al., 2020; LeDeR, 2020;
46 Kavanagh et al., 2021; NHS England 2020b; Thomas, 2020; Tromans et al., 2020): and
47 also, on people with other cognitive disabilities such as the elderly and those with
48 dementia. It has been reported by many that governments and health professionals
49 across the globe are making clinical-decisions decisions and judgements based upon
50 perceptions of a person's quality of life. This is ethically, morally, and legally
51 inappropriate and always needs to be challenged. Brennan et al.'s (2020) survey
52 reported that one member of staff from a UK disability organisation stated:
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3 *'A eugenics programme has been undertaken covertly... Do Not Resuscitate*
4 *Notices (DNRs) were placed on people with no consultation, especially older*
5 *persons and persons with learning disabilities.'*
6

7 **A Human Rights Failure**

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10 Kavanagh et al. (2021) highlighted that governments around the world have been slow
11 to *'recognise, and respond to, the unique and diverse healthcare needs of people with*
12 *IDD during COVID-19 pandemic'*. Kavanagh and colleagues compared and contrasted
13 how two HIC such as Australia and England have responded differently to the
14 healthcare crisis of the COVID-19 pandemic for people with an IDD. England recorded
15 one of the highest death rates for people with an IDD as a result of not supporting this
16 disability population, whereas Australia recorded one of the lowest death rates for this
17 population as a result of improving access to high quality healthcare. Brennan et al.
18 (2020) stresses similar disparities in healthcare provision across other HIC and also in
19 LMIC.
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22 More troubling is that this scoping review paper has emphasised the global failure
23 across many HIC and LMIC countries in protecting the human rights of people with an
24 IDD during the COVID-19 pandemic. To summarize there have been:
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- 27 ● Limited availability and access to basic public-health prevention and protection
- 28 measures
- 29 ● A lack of information and digital information in a format that this population can
- 30 understand
- 31 ● Imposing lockdowns on people with an IDD and their carers, has significantly
- 32 impacted upon the persons' behavioural presentation and/or mental health as
- 33 well as the well-being of family carers
- 34 ● Closures of schools, education, day-care, respite, community activities and
- 35 employment.
- 36 ● Compulsory covert DNR orders placed upon this population
- 37 ● Restrictions of access to acute hospitals and lifesaving equipment; and
- 38 ● Violations of the rights of life to people with an IDD.
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42 Consequently, many countries have clearly breached the UN Convention on the Rights
43 of Persons with Disabilities (2006), the UN Sustainable Development Goals (UN, 2015)
44 and the WHO (2020a) Policy Brief on *'A Disability-Inclusive Response to COVID-19'*.
45 These striking findings presented in this paper strongly highlight that those with an IDD
46 have been *'left behind'* in both HIC as well as LMIC in responding to the COVID-19
47 pandemic. We cannot let this happen again in planning for future pandemics. Brennan
48 and colleagues concluded *'one of the most common faults has been the failure to*
49 *genuinely include persons with disabilities in the collective response – both at national*
50 *and global levels'*.
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Learning from the responses of COVID-19: preparing for future pandemics

So, what has been learned from COVID-19 in preparing and planning for future pandemics? There have been a number of research articles and government documents that have explored country specific approaches to managing the current COVID-19 pandemic but also exploring what country infrastructures would be needed in preventing, mitigating, and managing/treating future pandemics for this and people with other cognitive disability populations (Kavanagh et al., 2021; Kuper et al., 2020; Majnemer et al., 2021; Strydom et al., 2021; Tromans et al., 2021; UN Policy Brief, 2020; WHO, 2020a; b;).

Inclusion International (2021) in their report *'A Global Agenda for Inclusive Recovery: Ensuring People with IDD and Families are Included in a Post-COVID World'*, involved over 115 countries based upon Brennan et al.'s (2020) survey. They argued that as governments worldwide need to make plans to recover from COVID-19 and come out of lockdown, they will need to *'build back better...to ensure no one is left behind'*.

'Building back better' will require recognition of the barriers in place prior to the pandemic, as well as the exclusion that was amplified due to the global crisis. 'Building back better' does not only mean restoring the pre-pandemic status quo, but aims to create a recovery that addresses the systemic issues which predated and were amplified by COVID-19, to ensure that our 'new normal' is inclusive.'
(Inclusion International, 2021)

Likewise, Baumbusch et al. (2021) in their Canadian report *'Time to be Counted: COVID-19 and IDD'*, further highlighted that this population need to be *'recognised and valued through a disability-inclusive approach to Canada's pandemic policy response planning...this requires mainstreaming of disability inclusion into all COVID-19 response and recovery policies as well as disability specific-policies'*.

The WHO (2020b) in their planning guidelines to support country preparedness and response to COVID-19, identifies a number of pillars including: country-level preparedness, planning, and monitoring; risk communication and community engagement; surveillance, rapid response teams and case investigation; points of entry (i.e., borders, travelers); laboratories; infection prevention and control; case management; and operational support and logistics. Of particular note for people with an IDD is the importance on *'multi-sectoral, multi-partnership collaborations such as between health and disability services; tailored messaging with 'at risk' groups through engagement with trusted community groups; surveillance systems particularly for 'at risk' groups; establishment of rapid response teams to investigate outbreaks and contact trace within 24 hours; prioritised training of healthcare workers in infection control and ongoing monitoring; and development of workforce surge capacity'*.

The WHO (2020a) in their Policy Brief (*'A Disability-Inclusive Response to COVID-19'*) highlighted four key actions and recommendations to make the COVID-19 response and recovery inclusive for persons with disabilities:

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- 4 1. *'Ensure mainstreaming of disability in all COVID-19 response and recovery*
- 5 *together with targeted actions*
- 6 2. *Ensure accessibility of information, facilities, services and programmes in the*
- 7 *COVID-19 response and recovery*
- 8 3. *Ensure meaningful consultation with and active participation of persons with*
- 9 *disabilities and their representative organisations in all stages of the COVID-19*
- 10 *response and recovery*
- 11 4. *Establish accountability mechanisms to ensure disability inclusion in the COVID-*
- 12 *19 response'.*
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14 **Limitations and shortcomings**

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17 This scoping review has some limitations. The review is only based upon the 18-months
18 after COVID-19 as of 30th September 2021 and only those papers found written in
19 English. We acknowledge there will be unpublished reports from other countries that
20 have not been reviewed. Many of the research papers cited within this review have
21 reported upon adults with a mild/moderate IDD and may not be representative of the
22 wider IDD population and sub-populations. Nevertheless, Hatton et al. (2021a, b)
23 provided reports from family/paid carers regarding adults with multiple and profound
24 IDD and their experience of COVID-19 and lockdown. Another limitation of this study is
25 that most if not all of the papers reviewed undertook data collection digitally in the form
26 of online questionnaires and/or telephone/zoom interviews because of the restrictions
27 imposed by COVID-19. We have reported on over 30 papers and grey literature but
28 many of these papers are from HIC (Canada, Italy, Netherlands, Spain, USA, UK)
29 where responses to the COVID-19 pandemic and recovery models have been further
30 advanced given their developed economies. Although the Brennan et al. (2020) study
31 did explore over 1100 adults with an IDD across 134 HIC and LMIC.
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35 **Policy and Practice recommendations**

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37 The scoping review paper provides some answers on how countries have responded, or
38 not, to the COVID-19 pandemic. We can use this surveillance data to learn from and
39 prepare for future pandemics regarding public-health prevention measures, mitigate the
40 impact of future pandemics, and provide medical care and services for this population.
41 The review also poses a number of questions needing further exploration. Despite mass
42 vaccination of people with an IDD in some HIC focusing on adults, *'has this programme*
43 *disrupted the link between peaks of COVID-19 cases and subsequent hospitalisations*
44 *and death'* (Hatton, 2021b). More research is required on: whether children are going to
45 be targeted for vaccinations; should mandatory vaccinations for paid staff be prescribed;
46 recognising the risk factors for people from ethnic minorities; are residential homes
47 providing PPE and the mandatory use of PPE by paid staff; whether family and friends
48 are allowed to visit their relatives in their family homes and residential facilities; impact
49 on the person who has to continue to shield as a result of enduring health problems;
50 impact on family/paid carers for those shielding long-term; how family carers are being
51 supported long-term; continued access to acute hospital care and lifesaving equipment;
52 impact of being admitted into hospital from COVID-19, their medical care and
53 experiences; the impact of social distancing regulations on the return of statutory
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3 services; and reporting on the continuing long-term human rights abuses of this IDD.
4 Despite some countries developing government guidance in how to prevent and protect,
5 mitigate, and treat/manage whole populations and have some documents aimed at this
6 population, we need to develop pandemic guidelines targeted for people with an IDD to
7 prevent and protect, avoid unnecessary deaths and future human rights abuses.
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10 **Conclusion**

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12 This is the first international scoping review that provides a narrative synthesis of
13 emerging themes related to people with an IDD and the COVID-19 pandemic. This
14 paper highlights themes related to preventing, mitigating, and managing the care of this
15 population during the COVID-19 pandemic and provides guidance for informing future
16 public-health policies, the provision of services and government interventions for this
17 population for future pandemics. However, this paper also exposes the negative
18 impacts of public-health interventions in both HIC and LMIC for people with an IDD and
19 their family/paid carers, during the pandemic: including lapses in upholding human
20 rights. This data provides a basis for learning from the COVID-19 pandemic in planning
21 for future pandemics.
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32 population based cohort study using the OpenSAFELY
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39 756. <https://doi.org/10.1111/jir.12770>.
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Table 1: Defining the participants, concept, and context of the review

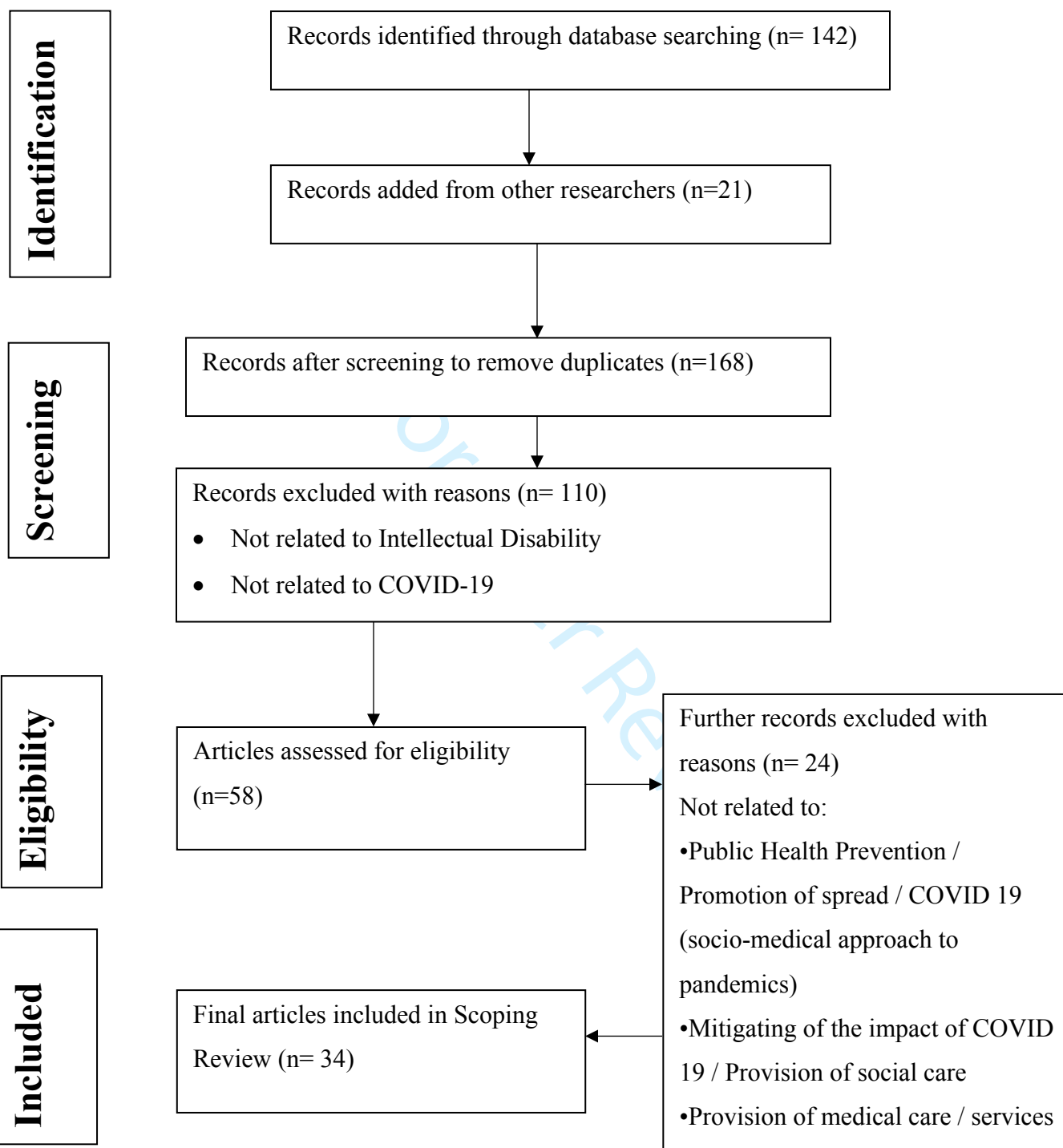
Title	Objectives	Review question	Population / Participants	Concept	Context
Preventing, mitigating, and managing future pandemics for people with an IDD- learning from COVID-19	To compile a comprehensive review of written material relating to how we prevent, mitigate, and manage future pandemics for people	What is known from the existing literature about how we prevent, mitigate, and manage future pandemics for people with an	Children/adults with a learning disability, IDD.	(1) How do we prevent the spread of COVID 19 and future pandemics for people with an IDD? (2) How do we mitigate the impact of COVID 19 and future pandemics for people with IDD? (3) How	Research papers, guidance papers, editorials, commentaries , and letters, in any type of English-language peer reviewed journals. The searches were limited to articles

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	with an IDD	IDD– a scoping review		do we provide medical care and services for people with an IDD?	published between February 2020 and Sept 2021.

For Peer Review

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2 **Figure 1 PRISMA Screening tool**
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Table 2: Papers and Documents included in Review

Citation	Country of origin	Study population	Concept	Context	Design	Key findings related to research question
Alexander et al. (2020)	UK	People with IDD during Covid-19 pandemic	Guidelines for the care and treatment of people with IDD.	Community teams and inpatient settings	Guideline development	COVID-19 care plans, creating or updating hospital passports, improving psychological support and communication, the creation of a ceiling of care/treatment escalation plan.
Amor et al. (2021)	Spain	People with IDD during Covid-19 pandemic	Exploring the perceptions of individuals with IDD	Access to information, emotional experience, effects on living conditions and access to support	Online survey	Spaniards with IDD perceived that their access to information and support was good overall. Participants reported difficulties with their emotional experiences and maintaining their work or study.
Andrews et al. (2020)	USA	People with IDD during Covid-19 pandemic	The psychology of ableism, perceptions about QoL, social determinants of health, how attitudes towards disability can affect rationing decisions and access to care	Vulnerability of people with disabilities to exposure and complications	Discussion paper	Underrepresentation of people with disabilities in all levels of health care systems. Decisions about rationing of supplies or care should be made by committees composed of interdisciplinary perspectives, which include representation from the disability advocacy community.

Bradley (2020)	USA	People with IDD during Covid-19 pandemic	Use of technology to maintain family contact	Weaknesses of the service systems for people with LD	Discussion paper	The importance of technology to keep people connected. The creation of more inclusive residential and community activities. Self-directed services.
Brennan et al. (2020)	134 HIC and LMIC	People with - disabilities from around the world, including 1100 people with IDD, during Covid-19 pandemic	To raise the alarm globally as to the catastrophic impact of the COVID-19 pandemic on persons with disabilities worldwide and to catalyse urgent action in the weeks and months to come.	The report sets out the outcomes of a rapid human rights-based global monitoring initiative – the COVID-19 Disability Rights Monitor.	International survey and testimonies of persons with disabilities, their carers, and organisations from 134 HIC and LMIC	Lack of specific information for people in LMIC. Where there is information in HIC information not detailed. Many people with IDD and their carers lacked PPE, access to vaccinations, etc. Families forced into self-isolation, and residential homes guaranteed overnight. A series of human rights abuses occurred as result of the absence of appropriate planning, resources, prioritisation and actions of many governments.
Buono et al. (2021)	Italy	People with IDD during Covid-19 pandemic	Clinical management of patients with ID admitted to hospital	Clinical procedures and remote/in person psychological support services provided to people with IDD and their families	Multi-phase implementation of a clinical intervention model	Immediate, modular, and flexible multidisciplinary approaches are required. Timely and appropriate health interventions. Remote/in person psychological support for patients, their families/carers

1 2 3 4 5 6 7 8 9 10 11 12 13	Callea et al. (2020)	Italy	People with IDD during Covid-19 pandemic	The importance for children with Down Syndrome having earlier access to diagnostic tests and antiviral management	Children in states of immune dysfunction, re-current pulmonary infections, congenital heart disease and obesity	Ad hoc protocol development	Modified testing, communication about suspicious symptoms, remote consultation for parents
14 15 16 17 18 19 20 21 22 23 24 25	Constantino et al. (2020)	USA	People with IDD during Covid-19 pandemic	Necessary measures for prevention and disease mitigation adversely and disproportionately affect individuals with IDD	Strategy for supporting people with IDD through COVID-19	Letter	Staff measures to protect clients, impact of social distancing, inequity in education, telehealth can be positive and negative, access to testing for and appropriate medical care.
26 27 28 29 30	Dickinson et al. (2020)	Australia	People with IDD during Covid-19 pandemic	Personalisation schemes during the pandemic.	Exacerbation of risks during a pandemic	Discussion paper	Issues of: accessibility, de-prioritisation, options for control, professional carer input & PPE provision
31 32 33 34 35 36 37 38 39 40	Festen et al. (2021)	Netherlands/USA	People with IDD during Covid-19 pandemic	The classification of individuals with ID into different frailty categories	To determine suitability of Clinical Frailty Scale	Retrospective analysis	The scale is not suitable to evaluate frailty in individuals with ID. The ID-frailty index is more suitable for assessing probability of survival for individuals with ID.

Gulati et al. (2020)	Ireland	People with IDD during Covid-19 pandemic	Health service delivery	Equitable access to life-saving treatments and ensuring that healthcare resources are not diverted inappropriately at a time of enhanced need.	Letter	People in care homes and other residential facilities are particularly vulnerable to outbreaks of COVID-19.
Hatton et al. (2021a)	UK	People with IDD during Covid-19 pandemic. Wave 1 data were collected between Dec 20 and Feb 2021.	This study was designed to track the experiences of adults systematically and responsively with learning disabilities through the COVID-19 pandemic over time across the four UK nations.	Adults with IDD living on their own, with their families and in community supported living / residential facilities across the UK	Online survey with 621 adults with mild IDD were interviewed by a researcher (Cohort 1). And 378 family carers or paid support staff took part in an online survey about the experiences of the adult with profound/multiple IDD who they	The vast majority of participants in both cohorts (>80%) indicated that they, or the person they supported/cared for, would take the COVID-19 vaccine if it were offered to them. Of those who regularly used day services before the first lockdown, 99% of participants in Cohort 1 reported community activities had stopped completely or reduced by the time of the interviews, and 89% reported their day service had stopped completely or reduced.

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					supported/cared for (Cohort 2).	
Hatton et al. (2021b)	UK	People with IDD during Covid-19 pandemic. Wave 2 data were collected between April and May 2021.	This study was designed to track the experiences of adults systematically and responsibly with learning disabilities through the COVID-19 pandemic over time across the four UK nations.	Adults with IDD living on their own, with their families and in community supported living / residential facilities across the UK	In Cohort 1, 598 adults with mild IDD were interviewed by a researcher using an online survey tool. In Cohort 2, family carers or paid support staff took part in an online survey about the experiences of 273 adults with profound / multiple IDD who they supported/cared for.	92% of people with mild IDD in Cohort 1 and 91% of people with profound/multiple IDD in Cohort 2 had received at least one dose of the COVID19 vaccine. 34% of people with IDD in Cohort 1 and 48% of people with IDD in Cohort 2 had received both doses of the COVID-19 vaccine. For 66% of people in Cohort 1 and 45% of people in Cohort 2, family members or support workers wear PPE (like masks, gloves or aprons) when they are with them. <15% of adults with IDD in Cohort 1 and < 20% of adults with IDD in Cohort 2 attended their day service in person. < third of the adults with IDD in both Cohorts had an annual in the last five months (either by phone/zoom).
Jeste et al. (2020)	USA	Caregivers of people with IDD during Covid-19 pandemic	Capturing changes in access to healthcare and educational services for individuals	Resources that could improve services for individuals with IDD	Online survey	Most families reported a loss of at least some educational or healthcare services. Those that needed to access healthcare providers did so primarily through telemedicine.

			with IDD that occurred shortly after restrictions were initiated			
Kavanagh et al. (2020)	Australia/ UK	People with IDD during Covid-19 pandemic	Health care recommenda tions for rapidly improving health care for people with disability in the pandemic and beyond.	England and Australia response	Description	People with disability should be listened to about their health and involved in planning healthcare reform. Regular provision of a range of health care modalities including telehealth and outreach into homes. Social care workforce recognised as an essential workforce.
Ladarola et al. (2021)	New Yok, USA	People with IDD during Covid-19 pandemic	To explore COVID-19 vaccine perceptions in individuals with IDD, their family members, and paid staff, to inform a state-wide vaccine information and messaging project	Understandin g community perceptions of the COVID-19 vaccine is critical to providing equitable vaccine education	Survey	Majority of adults with IDD had received the vaccine. Greater vaccine hesitancy was reported in younger individuals with IDD. Concerns included side-effects and the swiftness of vaccine development. Black and Hispanic participants had heightened concerns about being an “experiment” for the vaccine.

Loman et al. (2020)	USA	Paediatric neuropsychologists	Health service delivery during the COVID-19 global pandemic	Suggested processes and procedures to continue to provide neuropsychology services	Discussion paper	Video telehealth visits will continue indefinitely. Challenges faced during the pandemic have highlighted ways in which services can effectively adapt to changing demands, altered practices and areas for additional research.
Majnemer et al. (2021)	Canada	People with IDD during Covid-19 pandemic	Focuses on the impacts of COVID-19 across the lifespan for individuals with IDD	Provides specific policy recommendations to mitigate further negative impacts and optimize outcomes for this population	Policy Briefing	A series of 19 recommendations are provided, which can be divided into two types, both of which are essential components of a disability-inclusive approach: those that mainstream inclusion of persons with IDD in COVID-19 policy responses and those that address disability-specific considerations.
McCallion (2020)	USA	People with IDD during Covid-19 pandemic	A radical response by service providers to protective strategies for the home	Those with I/DD and the individuals they live with	Letter	Research needs include documenting among people with I/DD the incidence and experience of COVID-19, successes, and failures in offering support, and development and testing of interventions. The inclusion of people with I/DD and family members as co-researchers should be supported.
McKinney et al. (2020)	South Africa	People with IDD during Covid-19 pandemic	Access to intensive care units (ICU) and receiving ventilation for	Current triage policies and practices in South Africa	Opinion paper	Some current South African triage policies appear to completely exclude many disabled people.

			people with IDD			
NHS England (2020a)	UK	People with IDD and/or mental health issues during Covid-19 pandemic	Supporting patients of all ages who are unwell	The impact of the COVID- 19 pandemic on people with mental health problems or a learning disability and/or autism.	Guidance	These individuals may need additional support, including making reasonable adjustments to care systems and clinical practice. Where possible, community and district nursing teams should provide advice, guidance, and support virtually. Continue to guard against overly restrictive practice. Individuals and their families/carers as should be involved in key decisions about the patient's care and should be provided with all relevant information in an accessible format. Refresher physical health training to all relevant clinical staff.
NHS England (2020b)	UK	People with IDD and/or mental health issues during Covid-19 pandemic	Actions resulting from the University of Bristol report (See No. 34 below)	Deaths of people with a learning disability from COVID- 19	Response paper	Identifying deterioration in health, DNR, diagnostic overshadowing: reasonable adjustments
NHS England (2021a)	UK	People with IDD and/or mental health issues during Covid-19 pandemic	The impact of COVID-19 on the use of the Mental Health Act	Supporting systems to safeguard the legal rights of people receiving mental health, learning disabilities and specialised commissione	Guidance	There are no changes to the Mental Health Act 1983 (MHA) legislation. d advice on using the MHA Code of Practice during the COVID-19 pandemic period. Services should continue to operate in the least restrictive way possible and in accordance with the MHA and MCA codes of practice. Swab testing or other invasive testing procedures should be avoided in absence of consent from the individual.

				d mental health services.		
NHS England (2021b)	UK	People with IDD and/or mental health issues during Covid-19 pandemic	Patient, carer and family engagement and communication during the pandemic	Advice for commissioners, healthcare providers, family members/carers	Guidance	Good practice in engagement and communication. Accessing support from services. Engaging with services. Advice for carers of children/young people.
NHS England (2021c)	UK	People with IDD during Covid-19 pandemic	Information that doctors and nurses will need if people with an ID have to go to hospital because of COVID-19.	A guide designed in partnership with people with learning disabilities, families and nurses.	Grab & Go Guidance	The form should be completed to include info on: ability to communicate, medical history, medication and administration, indicating pain/worry/ upset, hearing & eyesight.
Strydom et al (2021)	UK / France	People with IDD during Covid-19 pandemic	Setting out the issues that need to be considered in response to future health crises and pandemics	Needs of individuals with neurodevelopmental disorders during the COVID-19 pandemic	Editorial	An urgent focus is needed on improving and coordinating efforts to prevent, detect, contain and treat infections involving people with NDD during the current and future pandemics, while addressing mental health and quality of life concerns.
Sulkes (2020)	USA	People with IDD during Covid-19 pandemic	Treat all patients using the same set of rules	Strategies for care homes	Discussion paper	Specific health risks, testing challenges, behavioural risks and staying safe, the residential challenge; ethical challenges, how to help.

Taddei & Bulgheroni (2020)	Italy	People with IDD during Covid-19 pandemic	Adapting the Child Neurology and Developmental Neuropsychology Service	Cognitive and behavioural assessment of children with neurodevelopmental disorders and neurological diseases	Service evaluation	Preliminary data about the users' satisfaction regarding the introduction of telemedicine showed that the telemedicine experience has been accepted by caregivers. There was also evidence of some limitations in the use of telemedicine such as the perceived lack of empathy in comparison with the in-person visits and internet connectivity issues.
Thomas (2020)	UK	People with IDD during Covid-19 pandemic	Legality of 'do not resuscitate' forms	A learning disability care provider receives an "unprecedented" number of do not resuscitate forms from doctors	Commentary	Challenging the lawfulness of orders received in one month, which appear to have been carried out without consultation with patients or their families.
Tromans et al. (2020)	UK	UK-based professional and service user representative organisations with a stake in the care of people with IDD and/or autism	Priority concerns for people with IDD and/or autism regarding the COVID-19 pandemic.	Three domains: mental health and challenging behaviour, physical health and epilepsy, and social circumstances and support'.	Systemised evidence-based information	Individuals with IDD may be at greater risk of mental health deterioration during COVID-19. The risks are likely elevated for a section of the IDD population based on the spectrum of comorbid medical conditions. The impact of reduced day centre care and professional carer support during the pandemic presents a substantial challenge to the IDD community.

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<p>United Nations Policy Brief (2020)</p>	<p>International collaboration</p>	<p>People with IDD during Covid-19 pandemic</p>	<p>The global crisis of COVID-19 is deepening pre-existing inequalities, exposing the extent of exclusion and highlighting that work on disability inclusion is imperative.</p>	<p>People with disabilities are one of the most excluded groups in society and are among the hardest hit in the pandemic in terms of fatalities</p>	<p>Policy brief</p>	<p>Identifies four overarching areas of action: (1) ensure mainstreaming of disability in all COVID-19 response and recovery together with targeted actions (2) ensure accessibility of information, facilities, services and programmes in the pandemic response and recovery (3) ensure meaningful consultation with and active participation of persons with disabilities and their representative organisations in all stages of the pandemic response and recovery (4) establish accountability mechanisms to ensure disability inclusion in the pandemic response.</p>
<p>University of Bristol: The Learning Disabilities Mortality Review (LeDeR) Programme (2020)</p>	<p>UK</p>	<p>People with IDD during Covid-19 pandemic</p>	<p>Deaths of people with learning disabilities from COVID-19</p>	<p>The circumstances leading to death of a representative sample</p>	<p>A comparator analysis of 206 deaths</p>	<p>Striking difference in age at death between COVID-19 deaths in the general population compared with people with learning disabilities. 35% who died lived in residential care homes, rising to almost half of those with Down's syndrome. A need to improve preventative measures in care homes. A loss of sense of smell or taste is more difficult to identify in people with learning disabilities. Access to healthcare that was problematic for some people. Where the need for reasonable adjustments was indicated no such adjustments had been made. Concerns were raised about the absence of equipment to detect acute clinical deterioration, particularly in primary care and community settings. Further reminders that 'learning disabilities' or a clinical frailty score are not appropriate reasons for a DNACPR decision in people with learning disabilities may be required. Broader impact of restrictions on people with LD.</p>

1 2 3 4 5 6 7 8 9	Valdez et al (2021)	USA	People with IDD during Covid-19 pandemic	The potential to further exacerbate inequities faced by people with disabilities.	The widespread use of telehealth resulting from the COVID-19 pandemic	Discussion paper	Failure to explicitly account for people with disabilities in the design, implementation, and policy dimensions of telehealth will lead to further marginalization and poor health outcomes for this population.
10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46	Zaagsma et al (2020)	Netherlands	People with IDD during Covid-19 pandemic	Use of online support for people with IDD	Individuals living independently during the pandemic	A retrospective, descriptive research design	Increased use of an online support service by independently living people with ID during the first weeks of the pandemic. An increase in unplanned online support use is likely due to people feeling considerably worried and experiencing a high level of anxiety especially during the first weeks of the pandemic. Concept of homeostatic effects on subjective well-being. The unplanned use of online support may have decreased because service users experienced that unplanned contacts were not (sufficiently) effective in helping them and stopped initiating these contacts. This study focused on the first weeks of the pandemic only.