

**INVITED ARTICLE**

# The mental health and well-being of adults with intellectual disability during the COVID-19 pandemic: A narrative review

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**Abstract**

Prior to the start of the pandemic, adults with intellectual disability (ID) were more likely to experience mental health difficulties and face barriers obtaining mental health care. COVID-related public health restrictions, combined with heightened challenges to obtain timely mental health care, have served to worsen this situation internationally, with a combination of new onset conditions and worsening mental health for those already struggling. In this narrative review, we summarize literature on the mental health of adults with ID during the COVID-19 pandemic to describe what is known based on clinician perceptions, existing administrative health data, family and staff perceptions, and self-report. In addition to noting similarities and differences in findings based on the source of information, we also explored how experiences differed depending on where and when the research was conducted. Based primarily on research conducted during the first six months of the pandemic, there is a consistent finding across sources of increased anxiety, stress, and isolation. This review also explored the delivery of virtual mental health care and the impact of pandemic-based mental health interventions. There have been very few research studies evaluating clinical care during this time but clinicians have managed to provide supports virtually, which has been evaluated positively by some individuals. This narrative review concludes by identifying gaps in the literature and suggests key directions for future mental health research, policy, and practice efforts. Any mental health efforts now and during pandemic recovery need to have an understanding of how the mental health needs and services for adults with ID have evolved over the course of the pandemic. Further research is needed on the impact of both clinical interventions and other nonclinical efforts on the mental health of people with ID.

**KEYWORDS**

COVID-19, intellectual disability, mental health, practice, well-being



## INTRODUCTION

The COVID-19 pandemic has had a significant impact on the lives of people with intellectual disability (ID). Research from different parts of the world has shown that adults with ID are more likely to be infected with COVID-19 and, once infected, suffer higher rates of hospitalization and mortality (Gleason et al., 2021; Lunsky et al., 2022; Williamson et al., 2021). Due to higher rates of infection, mortality, and pre-existing medical risks, much of the research and policy attention has focused on promoting safety and preventing contagion (see also Taggart et al., 2022 in this issue). Rapid changes in healthcare delivery combined with pandemic related restrictions have had a disproportionate impact on the mental health and well-being of adults with ID, leading to an even greater number of disruptions and restrictions in their lives. Relatively few research studies have considered these impacts, and fewer still have identified strategies to treat mental health or improve quality of life at this time.

The purpose of this paper is to provide a broad overview of the impact the pandemic has had on the mental health of adults with ID internationally. While it is not an exhaustive review, this narrative review attempted to address two key issues. First, we considered what is known about the impact of pandemic restrictions on the mental health and well-being of adults with ID, taking into account how the data were collected, where the study was conducted, and the point in the pandemic when the research was carried out. Second, we explored how various supports and intervention efforts (both in person and virtual) have benefited the mental health of adults with ID throughout the pandemic. Our review concludes with a synthesis of gaps and topics we believe should be prioritized in the next phase of the pandemic and during the pandemic recovery to improve the mental health of adults with ID.

## METHODS

To carry out this narrative review, we executed an electronic search across four databases, including EBSCO, PubMed, Google Scholar, and OVID, where we applied relevant Boolean operators and a series of search terms. Our search strategy included terms such as ID, mental health, well-being, COVID-19, and coronavirus. In addition to searching through databases, we manually selected additional publications from the reference lists of the initially retrieved articles. This iterative process continued until no new studies emerged.

To refine the scope of our narrative review, we established a set of inclusion criteria: articles published

between March 2020 and September 2021; opinion pieces and all types of research studies (e.g., intervention studies and observational studies); articles focused on adults, 18 years of age or older, with ID. Although some studies in this review included a broader sample of participants with disabilities, all included studies comment specifically on individuals with ID. Our review included papers focusing on youth and adults. We excluded articles that focused broadly on disabilities, articles that were not available in English, and articles that strictly focused on children.

Importantly, we focused on the impacts of the COVID-19 pandemic on the mental health and well-being of individuals with ID, not their families or paid staff who support them. This aforementioned focus on family caregivers and workers is covered in other review papers in the *Journal of Policy and Practice in Intellectual Disabilities* (for example, Wanjagua et al., 2022, this issue). That said, although our focus was not on caregiver mental health, it is important to recognize that the mental health of caregivers and mental health of the people they support are interrelated. This overlap is discussed in the section on mental health interventions.

## General findings: Impact of pandemic on the mental health and well-being of people with ID

In the first four months of the pandemic, numerous opinion pieces were published, highlighting clinicians' concerns about the disproportionate impact of COVID-19 restrictions on the mental health and well-being of people with ID and other neurodevelopmental disorders (Ameis et al., 2020; Constantino et al., 2020; Courtenay, 2020; Courtenay & Perera, 2020; Hughes & Anderson, 2020; Matuska & Gallagher, 2020; Rose et al., 2020). Some reports noted lower levels of distress in certain individuals presumably related to having fewer activities and fewer demands compared to prepandemic times (Ameis et al., 2020; Cassidy et al., 2020; den Houting, 2020). However, the negative impact of the loss of services and supports on mental health has been widely recognized. Common concerns included difficulties understanding public health restrictions, impacts of loss of routine on mental health, and the consequences of losing both informal and paid supports. The closures of in-person clinical supports and, relatedly, the increased demands on family caregivers were also considered to harm the mental health of those with ID. Independent of the pandemic, social isolation experienced by adults with ID is a major risk factor for negative mental health outcomes (Forrester-Jones et al., 2006; Giesbers et al., 2019; Scott & Haverkamp, 2014). With quarantine-imposed social isolation, many people, including adults with ID,

have turned to the internet. Unfortunately, they have also faced many barriers (“digital poverty”) in doing so related to limited skills, inadequate technology, and limited support of people to help them (Chadwick et al., 2022). For those individuals with ID using social media and the internet as a means to broaden their network of friends, receive support, and participate more fully in real and virtual communities (Sallafranque-St-Louis & Normand, 2017), increased use of digital technologies also carries risks. For example, people with ID may be especially vulnerable to online disinformation, victimization, and cyberbullying related to difficulties interpreting social communication and understanding social nuances, elevated levels of trust, and feelings of social isolation and loneliness (Krysta et al., 2021).

Data from research studies reflect concerns similar to those expressed in clinician opinion pieces. Over a 15-month period, several studies explored the impacts of pandemic-related closures and restrictions on the mental health and well-being of people with ID from numerous countries, including Chile (Rosencrans et al., 2021), Italy (Zingale et al., 2020), South Korea (Kim et al., 2021), United Kingdom (Courtenay, 2020; Courtenay & Perera, 2020; McKenzie et al., 2021; Murray et al., 2021; Rawlings et al., 2021; Willner et al., 2020), United States (Jeste et al., 2020), Canada (Lake et al., 2021), Ireland (McCarron et al., 2020; McCausland et al., 2021), France (Nollace et al., 2020), Spain (Amor et al., 2021; Navas, Amor, et al., 2021), Netherlands (Embregts et al., 2020; Scheffers et al., 2021; Schuengel et al., 2020; Zaagsma et al., 2020), and Israel (Araten-Bergman & Shpigelman, 2021). To date, there has been a prominent focus on the challenges experienced by children and youth with ID and their families as a result of pandemic response plans, such as the transition of in-person learning to virtual education. However, the realities of the pandemic have also negatively impacted the mental health of adults with ID. The next section reviews findings on the influence of the COVID-19 pandemic on the mental health of adults with ID in greater detail. Our findings are organized by the source of data reporting, specifically whether the data is sourced from clinician perspectives, health systems research, caregiver perspectives, or first-hand accounts from people with ID.

## Approaches to measuring the impact of COVID-19 on ID communities

Pandemic-related research studies have utilized a variety of approaches to explore the impact of COVID-19 on ID communities, such as reviewing administrative health data and clinical documentation, along with gathering the perspectives of family caregivers, paid workers, and direct accounts from people with ID. To develop a more

comprehensive understanding of the effects on mental health, it is important to consider specific elements of research methodologies, including participant demographics, data collection strategies, and when data collection occurred (namely, the multiple waves of the pandemic) recognizing that responses in each country and even within one country can differ. For example, in the United States, each of the 50 states have varied with regard to pandemic responses.

### *Clinician perspectives*

In addition to several clinical opinion papers, more systematic approaches have been used to investigate clinicians' perspectives about the mental health of people with ID. For instance, one UK-based study examined clinicians' and advocacy organizations' priorities regarding the mental health and physical health of people with ID, their social circumstances and the support they received (Tromans, Kinney, et al., 2020). Access to mental health care was identified as the top priority, followed by the need to prevent both relapse and further deterioration in the mental health of people with ID. Experts also prioritized the risks of prolonged disruptions to routines, carer strain and concerns about psychotropic medications. A second UK-based study (Sheehan et al., 2021), summarized the experiences of 648 mental health professionals who supported people with ID during the mid-stage phase of the UK's first national lockdown between April and May 2020. This study documented the early challenges (infection control procedures, challenges engaging with outpatients remotely and work-life balance) and opportunities (benefits of remote operations and the flexibility it allowed for patients, as well as organizational improvements that allowed for speedier and more efficient processes) related to mental healthcare delivery to adults with ID. A more recent qualitative study of psychologists supporting people with ID in the United Kingdom highlighted similar challenges. In this study, psychologists argued that virtual mental health interventions were less successful than when provided in person, and that there was a much greater need for services than prior to the pandemic, with people in very serious situations (Chemerynska et al., 2021).

### *Health utilization data*

Administrative health data have also been utilized to explore healthcare utilization patterns during the pandemic. For instance, studies have reviewed the type, frequency, and reason for healthcare use. Using metadata from over 14 000 adults with ID in the Netherlands from 2016 to 2020, Schuengel et al. (2020) reviewed changes in incident reports specific to aggression and medication errors. Although they observed an increase in aggression



incident reports over time, they described an initial decrease in incident reports immediately after the first lockdown in 2020 followed by a slow increase shortly thereafter. A UK-based study looked at psychiatric referrals for adults with ID from January 2020 until May 2020 (Tromans, Chester, et al., 2020) and reported that the number of referrals were reduced at the start of the pandemic. This may reflect fewer people experiencing poor mental health, although, this could also suggest more restrictive criteria for psychiatric services, or more people avoiding care due to fear of contracting COVID-19. Another interpretation could be that there was a lower turnover of support workers during the initial phase of the pandemic, with reduced levels of absence and sickness, leading to more consistent support for people.

A Canadian study (Durbin et al., n.d.) explored all-cause healthcare patterns prior to and during the first year of the COVID-19 pandemic for the adult population of Ontarians with and without ID. Similar to the Tromans, Chester, et al. (2020) study, reductions in hospitalizations and emergency visits during the pandemic were noted in both those with and without ID. However, in contrast to adults without ID, the proportion of mental health-based emergency visits and hospitalizations remained especially high in the ID group. The proportion of people who received at least some of their medical care virtually increased from 3% to 43% in adults with ID. Unfortunately, the rate of virtual mental health visits was not reported separately from virtual care visits for physical health concerns.

Rauf et al. (2021) also led a UK-based study comparing psychotropic medication prescribing patterns in the 12 weeks before the pandemic (January 1 to March 22, 2020) with the first 14 weeks of the pandemic (March 23 to June 30, 2020), within a specialized ID community-based mental health team. They reported that the most common prescriptions in the early part of the pandemic were hypnotics and benzodiazepines and that there was an overall increase in specialized psychiatric consultations for adults, consistent with the concerns flagged by providers in the Tromans, Kinney, et al. (2020) study.

Further research is needed that utilizes health services data from different jurisdictions over time during the pandemic, particularly beyond the first wave. This would provide a better understanding of the factors that contribute to changes in mental health service needs and use, and to identify who among those with ID has needed these services the most.

#### *Caregiver perspectives on the mental health of adults with ID*

Reports from caregivers, such as parents, siblings, and staff, have contributed to research findings concerning

the mental health of adults with ID. Studies focusing on caregiver perspectives are primarily based on online surveys, which may be biased toward those comfortable with technology. These studies have examined the impact of the pandemic on the mental health of both caregivers and individuals with ID, and the reciprocal nature of their mental well-being. One international study (Linehan et al., 2020) has been focused on pandemic impacts on people with ID according to family and paid caregivers from 18 countries with findings available in 2022.

Several studies explored family caregiver views about their loved ones from the first lockdown or shortly thereafter. The majority of these studies focused on parents of children, but some have included or focused exclusively on family caregivers of adults. For example, in a study of 323 family caregivers in Spain, 80% were family members of adults with ID (Navas, Verdugo, et al., 2021). Among those who stopped receiving or experienced significant changes in social service provision (74.3%), almost half experienced a decline in previously acquired skills and problem behaviors during the first lockdown, while 6 in 10 showed heightened anxiety and nervousness. According to 64 family caregivers in Chile who completed an online survey in the Autumn of 2020 (Rosencrans et al., 2021), 52% of adults with ID experienced an increase in mental health symptoms and only 25% of them had accessed mental health therapy during the pandemic. Among Chilean adults with ID, the most commonly reported symptom was sadness (31%), along with more than 25% reporting feeling stressed, impatient, and having trouble sleeping (Rosencrans et al., 2021). A qualitative study from South Korea based on interviews with parents of adults in July 2020 (Kim et al., 2021) reported deteriorations in physical health due to inactivity, increased and prolonged isolation, regression in skills, and an increase in challenging behaviors. That said, some parents also reported that, with effort over time, their loved ones learned to make certain adjustments and developed new skills such as wearing a mask or spending time alone. Few studies have focused specifically on the mental health of adults with ID living in congregate care settings from the family perspective. An Israeli study of parents of adults with ID reported however, on how effective they found virtual technology to maintain connections with their loved ones during the first wave. While most families found virtual technology to be helpful, the authors recognized that virtual technologies were insufficient for some families, on the basis that reduced face-to-face contact and relying on digital modalities of communication jeopardized their ability to provide meaningful social support (Araten-Bergman & Shpigelman, 2021).

The Coronavirus LD study (Flynn et al., 2021) included the perspective of families and paid staff supporting adults with more extensive support needs who were unable to provide their own accounts. Carer perspectives were captured via online surveys over three time points, starting in December 2020. Over 60% of caregivers reported between December 2020 and February 2021 worse mental well-being for the people they cared for compared to prior to the pandemic. Between July and August 2021, caregivers reported that the majority (70%–80%) of adults with ID had experienced anger, sadness, or anxiety some or most of the time in the previous four weeks, with most mental health support coming from the caregivers. Indeed very few of these individuals had accessed more formal mental health supports in that time period (Flynn et al., 2021). A smaller Canadian study explored the experience of adult siblings over time. After the first lockdown, over half of the 91 siblings reported a decline in the mental health of their siblings with ID (Redquest et al., 2021a) and this was observed both in siblings living with family and living apart. Six months later, almost all siblings expressed concerns about the mental health of their siblings with ID and described the impact of this on their own mental health (Redquest et al., 2021b).

A handful of studies focused on the health of staff supporting people with ID and, within those studies, have also explored the mental health and well-being of the people they supported (Hewitt et al., 2020; Kavanagh et al., 2020; Lunsy, Bobbette, Chacra, et al., 2021; McMahan et al., 2020; Navas et al., 2020). These studies have consistently indicated an increase in aggression, challenges with behavior, an increase in mental health issues, and heightened social isolation and loneliness among the people they were supporting. The majority of these reports were limited to the initial impact of the pandemic in the first 3–6 months.

A national study of workers in the US-surveyed ID sector staff at multiple time points (Hewitt et al., 2021, 2020). Staff reported slight decreases over time in terms of boredom (from 80% to 71% to 68%), mood swings and depression (from 57% to 51% and 49%), and behavior issues (from 52% to 48%). Authors of the 12-month follow-up report (Hewitt et al., 2021) hypothesized that the reduced rates of difficulties may have been due to more people being allowed to see friends and families in person as restrictions eased.

In a Canadian survey, administered to 861 workers, 75% reported worsening mental health and 62% reported increased aggression in the adults with ID that they supported between April and June 2020 (Bobbette et al., 2020). Notably, this rise in mental health concerns and aggressive behavior occurred when all community

services were closed and no visits with family or friends were permitted. Data from July 2021 based on 462 workers suggested continuing struggles, with 83% of workers reporting worsening mental health and 68% reporting increased aggression in the people they supported (Bobbette et al., 2021). When the survey was completed (July 2021), individuals were just being allowed to spend unsupervised time with their families again. Longitudinal data about the same individuals with ID over time is required to understand these impacts fully.

### *Experiences from people with ID*

Several studies have measured the consequences of the pandemic through interviews and online surveys with adults with ID, sometimes completed with the support of carers. A large study from Spain, completed in June 2020, found that almost 60% of 582 adults with ID reported feeling afraid or anxious because of the pandemic and resulting lockdown in the first wave, with greater anxiety reported by those in residential care settings than those living alone or with families (Amor et al., 2021). Authors highlighted that people with ID were not only supported by other people, but they also played a role in supporting others. In an online survey of 404 adults with ID in the United States conducted in July 2020, Rosencrans et al. (2021) found that 41% of adults reported worsening mental health during the pandemic and 42% of participants had accessed mental health therapy. The most common mental health symptoms reported by adults with ID were worry (28%) and stress (27%), with 29% feeling scared to go to the hospital or doctor if sick. A secondary analysis of personal outcome measures from 2248 interviews with people with ID in the United States found that reported quality of life in the first year of the pandemic had deteriorated from the year prior (Friedman, 2021). Another longitudinal study of adults with ID age 40 and older in Ireland (IDS-TILDA) found that 60% of people self-reported (independently or with support) stress and anxiety following the first lockdown with the pandemic being worse for people with pre-existing anxiety. Self-reported anxiety was higher than ratings given by caregivers about people with more severe disabilities. How much of this difference is attributable to different experiences, or different ways of measuring the experience is not known. The most common stressors reported varied based on who a person lived with, with people living independently reporting the most loneliness. Over half of study participants identified positive aspects of the first lockdown, including new skills they developed with technology (McCarron et al., 2020). Adults living in staffed settings used technology more frequently than adults living with family (McCausland et al., 2021).



Smaller studies from different countries revealed similar themes to the larger interview or survey studies. A study of 15 adults with mild to severe ID from South Korea conducted in July 2020 (Kim et al., 2021) reported that, during lockdown, those individuals struggled to connect virtually with peers from day program activities and that spending time with family also led to conflicts; they felt lonely and spent a fair bit of time by themselves. At the same time, these adults found ways to adapt to their situation. In a qualitative study of six adults from the Netherlands (Embregts et al., 2020) that occurred during the first lockdown period (March 15–May 11, 2020), participants reported loneliness, challenges understanding restrictions and rules, and difficulties with the loss of routine. A study of nine Canadian adults with ID interviewed between June and August 2020 who had participated in some form of virtual group-based mental health support during lockdown, reported similar negative impacts on their well-being as well as a sense of isolation and need for social contact, and barriers to obtaining mental health care. Despite the fact that each of the study participants had developed the skills to use virtual meeting software, there was variation in the degree to which they struggled and adapted to the new technology and the willingness of mental healthcare providers to connect with them in this way (Lake et al., 2021).

In the United Kingdom, the Coronavirus LD study interviewed 621 adults with ID from December 2020 to February 2021 and again at two subsequent time points, including April and May 2021 and July and August 2021 (Flynn et al., 2021). In terms of their mental health at end of 2020 and the beginning of 2021, as the United Kingdom entered its second lockdown, over half of the people reported being worried about leaving their house and most were worried about people they knew getting COVID. This worry was greater for older than younger individuals. Two thirds of individuals reported that they felt angry or frustrated, sad or down, and worried or anxious at least some of the time. In summer of 2021 when communities had fully reopened, closer to 60% of respondents reported these symptoms, suggesting slight improvements. Almost 90% of respondents had not seen a psychiatrist, psychologist, or counselor in the summer of 2021 despite activity restrictions being lifted. Only 8% of people said they were able to get support from a mental health professional with most of them relying on paid staff (35%), family (44%), or friends (24%).

The Coronavirus LD study is one of the few studies to explore the impact of the pandemic longitudinally. It is important to understand how people have managed over time. Comparisons across jurisdictions is challenging in this regard because each country has had different responses and different changes to guidance with each

wave of the pandemic. Even within one country, responses can be very different. For example, in Canada, different provinces have had different COVID rates, and therefore different rules. For the most part, people living in Atlantic Canada experienced fewer service closures, compared to those in parts of the country where COVID rates were higher, for example.

## Accessible mental health treatments/ services during the pandemic

### Virtual care

Globally, mental health supports and services quickly transitioned to a virtual mode of delivery, which posed both advantages and disadvantages. There was a rapid expansion of asynchronous mental health care and online supports, allowing people to get help in their own time, at their own pace (Datlen & Pandolfi, 2020; Lunsky, 2021; Thakur, Pereira, et al., 2021; Thakur, Volpe, et al., 2021; Zaagsma et al., 2020). However, such an approach creates challenges, as it requires good digital literacy skills which is a gap for many people with disabilities (Sachdeva et al., 2015), and can be quite text heavy, which may be inaccessible and challenging to decipher for some people with ID. Synchronous virtual mental health supports (individual appointments and group treatment) have also become more widely available. Although less text heavy, some digital literacy or support from someone with good digital literacy is still a requirement to participate. Challenge and barriers related to digital participation during the pandemic were identified in 14 of 16 articles in a scoping review, further exacerbated by dependence and reliance on others (Chadwick et al., 2022).

While a certain level of skill is still required, international researchers agree that many adults with ID can navigate virtual platforms with support (Krysta et al., 2021). Mastery of telehealth skills among adults with ID and family members can be hindered by variable strength of internet connections depending on where someone lives, available software, type of computer or tablet, and inconsistent rules across and within countries regarding the privacy standards required for providing mental health care virtually. This inconsistency has led to the use of different telehealth platforms by different health systems, and even by different providers in the same system. For example, without additional support, someone who became familiar with Zoom, utilized for social encounters or a recreational program, might still struggle to access mental health care using a different online platform required for clinical purposes. To

overcome barriers hindering the use of modern technologies among people with ID (as well as among older adults), it would be helpful to design telemedicine applications and electronic devices using universal design principles so that they are accessible to every user (Krysta et al., 2021). Jeste et al. (2020) found that, among parents/caregivers of people with ID in the United States, 65% had lost access to counseling services in the first wave of the pandemic (April 2020), while 22% had continued access to counseling via video. Similarly, 53% of caregivers reported that their child had lost access to psychiatry, while 39% reported accessing psychiatry via video. Parents/caregivers reported that telehealth was helpful when available, although augmentation of remote delivery services was needed.

In one of the few studies on virtual mental health care and adults with ID (Rawlings et al., 2021), several individuals opted not to have virtual therapy when it was offered to them toward the start of the pandemic, saying that they preferred to wait for in-person services. The authors suggested that it may be simpler to adapt mental health care from in-person to virtual delivery when a therapeutic relationship has already been established, rather than trying to build a therapeutic relationship online. Of the seven people in that study who opted to receive therapy virtually, all but one requested telephone over video-based care. Adults in the Netherlands who received video conferencing training prepandemic reported that remote online support was useful during the pandemic (Zaagsma et al., 2020). Similarly, a qualitative study of providers trying to deliver positive behavior supports during the first wave noted that online supports seemed helpful to individuals when home-based care was not permitted (McKenzie et al., 2021).

Group-based therapy can also be offered virtually, but there are challenges for people with ID in a group environment. For example, turn taking is harder virtually than in person, and technical difficulties can be quite frustrating and impact the entire group. A small qualitative study described the impact of art therapy with a small group of adults. Participants were accustomed to meeting together in person prior to the pandemic and adjusted to meeting virtually (Datlen & Pandolfi, 2020). The paper documents the adaptations to their approach and successes in reducing social isolation. In addition to studies on therapy, several studies from around the world have demonstrated that many of the key skills required for virtual group therapy can be learned. These skills have been developed outside of the therapy environment over the course of the pandemic, and could likely be applied to group-based mental health care. More formal evaluation is needed (see also Chadwick et al., 2022).

When studying virtual mental healthcare use, it is important to recognize how the capacity of paid and informal caregivers to provide support during virtual health care has evolved over the pandemic. While on the one hand, technology has become easier and more familiar to people with ID, clinicians, and caregivers, there have been anecdotal reports of fatigue with virtual interactions. How this has impacted the quality of virtual mental health care for this group over time has not been evaluated.

## Evaluation of pandemic-related mental health treatments

Although there have been some discussions about how mental healthcare services have been delivered virtually, there is surprisingly little research on the efficacy of mental health supports for this group during the pandemic. This may be, in part, because of the time lag in studying and evaluating interventions as opposed to simply describing issues. Here, we briefly review a few examples of current efforts targeting adult mental health during the pandemic with some early evidence of their benefits and important lessons learned, from different parts of the world.

Anticipating the need for online mental health support, Special Olympics hosted 10 weeks of free mindfulness sessions for people with ID and their families during the first wave (April–June 2020). Weekly one-hour sessions focused on teaching and practicing mindfulness skills, including deep breathing techniques, progressive muscle relaxation, mindful movements, and guided meditation (Dease, 2021). In addition to these hour-long sessions, all participants received a Strong Minds Activity Guide, which was designed to support the development of mindfulness coping skills (Special Olympics, 2020). Of over 300 people who registered for these webinars, between 50 and 80 people attended each week. A small subgroup of individuals completed a feedback evaluation following the program. Ratings of the group were quite positive but the rapid launch of the program did not allow for a more extensive evaluation. A follow-up project evaluating a 6-week virtual mindfulness course for Special Olympic athletes is underway (Howe et al., 2020).

Prior to the pandemic, Jahoda et al. (2017) conducted a large-scale randomized controlled trial evaluating the effectiveness of guided-self-help booklets for adults with ID. In response to COVID-19, the team adapted these booklets as part of a major mental health initiative to mitigate depression and anxiety during the pandemic (Maguire et al., 2022). The six book COVID-19 specific series included an introductory guide, information on



coping when feeling down or feeling anxious, a guide to problem-solving, getting a good night's sleep and "You can do it," promoting participation in active, meaningful activities. A relaxation video was also included along with tip sheets for carers on how to use the booklets. In line with the original format of the booklets, there were stories about different characters' experiences, checklists to complete relating to the user's own experiences, views and thoughts about the best ways of coping and sections to write or draw planned changes.

Although the booklets were written and professionally illustrated in an accessible style, it is important to recognize that very few people with ID have the skills to be able to use the booklets without any support. Prior to the pandemic, these booklets were completed in person with a therapist alongside a supporter who was a significant other in the individual's life. However, during the pandemic, the supporter facilitated the person's use of the booklet alone, either in person or virtually. The booklets are meant to promote a dialogue and provide the opportunity for individuals with ID to talk about their feelings and concerns. In addition to providing online access to the resources, funding was obtained to produce printed copies of the booklets in Scotland, and more than 12 500 copies of the booklets were requested. The books were also translated into French and Dutch, and adapted for use in other countries including Canada and the Netherlands. In a subsequent impact evaluation (Maguire et al., 2022), individuals with ID, family members and social care organizations all emphasized the value of having a physical object that the person could take possession of and keep for future reference. One of the challenges of producing resources of this nature was that the evolving pandemic situation meant that the booklets have required revisions to ensure they remained relevant. For example, it was necessary to take account of the changing practices, such as mask wearing, and different levels of restrictions within the text and illustrations. This illustrates the importance of being able to rapidly respond to jurisdictional needs, while also being flexible as situations evolve.

Prior to the pandemic, a mental health telehealth capacity building intervention (Project ECHO) was launched focused on adults with ID in Ontario, Canada. This quickly pivoted to focus on pandemic-related mental health concerns (Thakur, Pereira, et al., 2021) and has since expanded to reach people from across the country. Mental health and disability service providers who participated in the program reported greater knowledge and self-efficacy in supporting the mental health of adults with ID and reported making specific changes to their practice after completing the course. However, the subsequent impacts on the adults with ID supported were not measured. A similar course was developed for self-advocates and for families, teaching some of the same mental health principles and sharing similar

resources as the COVID Project ECHO program (Lunsky, 2021). Several lessons were learned from this combined effort. First, diverse audiences can benefit from learning similar content, such as how to assess and understand mental health concerns or strategies to address pandemic anxiety or depression. This suggests that opportunities to codesign programs with stakeholder groups, including adults with ID, families, and service providers are needed to create a suite of tools, tailored to each audience. A second lesson was that it can be very effective to deliver interventions jointly with clinicians and with people who use services. Engaging service users in the program can make the content more relevant, engaging, and easier to understand. Service providers, family caregivers, and people with ID all noted the benefits of shared instruction in their evaluations. The third lesson was that there are ways to foster a sense of community virtually even with groups of over 100 people at a time. Families, staff, and people with ID can learn to use new virtual platforms and engage in this interactive manner when appropriate supports are provided (Thakur, Volpe, et al., 2021).

Caregivers play an important role in facilitating and supporting mental health interventions for people with ID. In fact, some mental health interventions were designed for people with ID to participate in together with their caregivers. While there are examples of successful virtual mental health care supports targeted toward family caregivers (e.g., Flynn et al., 2020; Lunsky, Albaum, et al., 2021), it is important to consider the incredible demands on—and exhaustion of—caregivers during the pandemic. While caregivers are needed to support the mental health of people with ID, paid and unpaid caregivers themselves need mental health care. Improving caregiver mental health directly impacts the mental health of the person they support (Singh et al., 2016). One barrier to meeting the mental health needs of caregivers is the fact that caregivers prioritize the needs of those they support, often neglecting their own self-care. They may be unable or unwilling to set aside time to participate in mental health treatments that are designed for them. To best address the mental health of adults with ID, an understanding of both caregiver distress and capacity is crucial. Research is needed to better understand how the role of caregivers, both paid and family, has evolved over the course of the pandemic, and to learn more about what facilitators help caregivers to cope and to support the mental health of the people they are caring for.

## CONCLUSION: TRANSITION INTO PANDEMIC RECOVERY

This review sought to address two questions: How has the pandemic impacted the mental health and well-being



of adults with ID over time around the world? And what has been helpful in terms of mental health interventions at this time? Across data sources, negative impacts were reported on the mental health of adults with ID, likely due to pandemic restrictions, reduced mental health care, and reduced supports more generally. Some individuals have had more difficulties than others and this can be related to the intensity of the supports they need and their living situation. Some individuals with ID reported positive aspects of the pandemic and mental health seemed to improve with reopening of services and supports in some jurisdictions (e.g., Hewitt et al., 2021). However, it also appears that negative impacts may be long-lasting. More longitudinal research is needed, and it is important to recognize the unique contexts in each country based on how the pandemic has evolved over time. There have been very few intervention-based studies published with regard to adults with ID. While some people with ID were able to connect with one another virtually, and to access virtual mental health care, many people with ID continue to rely on in-person supports in addition to needing print-based copies of mental health resources.

As vaccination rates continue to increase, many countries are slowly easing public health restrictions. At the same time, new waves of the virus (e.g., Omicron) lead to repeated waves of lockdowns. Even when some people can continue with their daily lives, adults with ID are considered to be more vulnerable and may experience additional restrictions at these times. The variation across and within countries in vaccination rates and reopening plans also produces varying effects on the different subgroups of people with ID. This is relevant to the mental health of adults with ID with regard to what restrictions continue to remain in place, the impact of further lockdowns and the challenge of coping with uncertainty. There are also concerns associated with the lifting of public health measures. Some adults with ID and caregivers express concerns and anxiety about the safety of returning to in-person activities as many services and supports transition back from virtual modalities (Ameis et al., 2020; den Houting, 2020). Even seemingly positive changes, such as the return of face-to-face activities, may be a challenge for people who struggle with changing demands and routines. More research is needed to understand the impact of the pandemic on individuals with ID and on those providing care and support.

Studies on virtual care in the general population as well as on people with ID and other disabilities have argued for the continued use of virtual technology when it improves the mental health of the individual (Ameis et al., 2020; den Houting, 2020; Lunskey, Bobbette, Selick, et al., 2021; Selick et al., 2021). The pandemic should not be used to justify a radical shift to online approaches or a

general reduction in activity or services for people with ID, although it may provide an opportunity to adapt programming for people who find too many activities or specific types of activities to be quite stressful.

There are many valuable lessons to be learned from the pandemic, which can inform how mental health supports should be provided to adults with ID moving forward. Prolonged social isolation has major harmful impacts, but can be reduced through a combination of supportive in-person, virtual, or safe, socially distanced activities. Importantly, people living in staffed residential settings should not be prevented from seeing their families (Hewitt et al., 2021). Mental health care can and should be provided to people when needed, and some of this care can be provided virtually. To be effective, we must better understand the role that caregivers can play in facilitating mental health supports. To support adults with ID, it is also important to support family and paid caregivers. Although the focus of this review has been on mental health, there are clearly important overlaps between mental health and physical health for people with ID, and this intersection is important to consider. In particular, there is a need to study the mental health impacts of long COVID in people with ID, and the effects of COVID-related and other illnesses on mental health.

People with ID can struggle with managing their mental health because of social determinants of health including income, social status, employment and working conditions, gender, culture, and racism. Additional efforts are needed to support the people who are most marginalized due to a complex interplay of risk factors. Given the obvious need for mental health supports for people with ID, there is an urgent need to evaluate the outcomes of interventions for this group, and to ensure that mental health intervention research and policy are inclusive of people with ID and other disabilities moving forward. Unfortunately, general mental health investments tend to be inaccessible to adults with ID. Hence, given the increased mental health difficulties seen in adults with ID and the cumulative loss and grief experienced during the pandemic, there will need to be investments in the mental health of the ID population for years to come. Without targeted attention toward this group, general mental health investments will remain inaccessible.

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