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# Research in Developmental Disabilities

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## The impact of the COVID-19 pandemic on the health, wellbeing, and access to services of people with intellectual and developmental disabilities

Margaret Rosencrans<sup>a,\*</sup>, Paulina Arango<sup>b,c</sup>, Camila Sabat<sup>b,c</sup>, Andrew Buck<sup>a</sup>,  
Christine Brown<sup>a</sup>, Marcela Tenorio<sup>b,c</sup>, Andrea Witwer<sup>a</sup>

<sup>a</sup> Ohio State University, 1581 Dodd Drive, #357, Nisonger Center, Ohio State University, Columbus, OH 43210, United States

<sup>b</sup> Universidad de los Andes, Monseñor Álvaro del Portillo 12.455, Las Condes, Santiago, Chile

<sup>c</sup> Millenium Institute for Caregiving Research (MICARE), Chile

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### ABSTRACT

**Background:** Individuals with intellectual and developmental disabilities (IDD) may be especially vulnerable to changes associated with the COVID-19 pandemic given an increased likelihood of health concerns, low socioeconomic status, and difficulty accessing services.

**Aims:** The purpose of this study was to explore mental health problems and services in individuals with IDD during the pandemic. We explored whether number of mental health problems differed by disability, age, gender, living situation, physical health, and access to services.

**Methods and procedures:** An online survey about experiences during the pandemic was administered to adults with IDD and their caregivers in the United States and in Chile.

**Outcomes and results:** In both Chile and the United States, few people endorsed increased health problems. Half of the sample in Chile and 41 % of the sample in the United States endorsed increased mental health problems. Approximately 15 % of the sample in the US reported no longer receiving state developmental disability services.

**Conclusions and implications:** Healthcare and disability-specific agencies should consider strategies to tailor supports to improve mental health functioning and access to community.

### What does this paper add?

To date, few researchers have collected data on mental health difficulties of adults with IDD during the pandemic. Our study provided findings related to mental health problems of adults with IDD in two countries: the United States and Chile. In the U.S., a little over 40 % of the sample endorsed increased mental health problems, and in Chile, close to half of the sample endorsed increased mental health problems. We also explored whether there were differences in the number of mental health problems based on disability, age, gender, living situation, physical health, and access to services. We found differences in number of symptoms endorsed based on the individual's living situation, endorsement of physical health problems, and access to services. Our findings highlight some of the contextual variables that may play an important role in one's mental health during the pandemic.

\* Corresponding author.

*E-mail addresses:* [Margaret.Rosencrans@osumc.edu](mailto:Margaret.Rosencrans@osumc.edu) (M. Rosencrans), [parango@uandes.cl](mailto:parango@uandes.cl) (P. Arango), [csabat@miuandes.cl](mailto:csabat@miuandes.cl) (C. Sabat), [Andrew.buck@osumc.edu](mailto:Andrew.buck@osumc.edu) (A. Buck), [Christine.brown@osumc.edu](mailto:Christine.brown@osumc.edu) (C. Brown), [mtenorio@uandes.cl](mailto:mtenorio@uandes.cl) (M. Tenorio), [andrea.witwer@osumc.edu](mailto:andrea.witwer@osumc.edu) (A. Witwer).

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## 1. Introduction

Since its origin in late 2019, the coronavirus disease of 2019 (COVID-19) has spread across the globe, impacting the daily lives, economic functioning, and health outcomes of most countries (Munster, Koopmans, van Doremalen, van Riel, & de Wit, 2020). In January of 2020, the World Health Organization (2020) declared the spread of COVID-19 a public health emergency of international concern, and by March of 2020, the WHO had declared it a pandemic (WHO, 2020). Since this declaration, the landscape of schools, workplaces, and clinical services has changed dramatically, transitioning to remote learning, work, and services (Burbio, 2020; Mehrotra, Chernew, Linetsky, Hatch, & Cutler, 2020; Tanzi, 2020). Beyond shifting how we work, learn, and engage with others in our communities, the COVID-19 pandemic has caused an international health crisis. Recent research has shown that the disease is having a disproportionately negative impact on minority populations (Centers for Disease Control & Prevention (CDC), 2020).

The purpose of this manuscript is to describe COVID-19 outcomes for adults with intellectual and developmental disabilities (IDD) in the U.S. and in Chile. The survey was originally developed to be administered in the U.S. In anticipation of administering this survey to Spanish-speaking populations in the U.S., we reached out to our colleagues in Chile to translate the survey. It was then decided to administer this survey in Chile as well, as it would prove fruitful to understand the experiences of individuals with IDD in a developing Latinx country.

### 1.1. International responses to the COVID-19 pandemic

Countries around the globe have widely differed in their approaches to contain the pandemic. In the United States (U.S.), the government declared COVID-19 a public health emergency in early February 2020 and a national emergency mid-March, following WHO's declaration of COVID-19 as a pandemic days earlier. As a result of this declaration, the government was able to unlock billions of dollars of funding to support Americans (Taylor, 2021). By the end of March 2020, qualifying Americans received direct payments through the Coronavirus Aid, Relief, and Economic Security (CARES) Act. Because the federal government did not instate a national lockdown or related federal mandates, states were required to make decisions about COVID-19 restrictions (e.g., requirements related to masks, quarantining, etc.). The result was immense variability in COVID-19 outcomes and restrictions by state (Taylor, 2021).

In Chile, the first COVID-19 cases were detected in February of 2020. On March 18th, the Chilean government declared a state of catastrophe (Decreto 104-Marzo 2020), which allowed it to take extraordinary measures to manage the pandemic. Measures included nighttime curfews, mandatory use of masks in public places (e.g., public transportation), limits to maximum capacity in both indoor and outdoor spaces, transition to remote learning and remote working where applicable, and mandated quarantines in regions with the highest number of infections. The declaration also made it possible to allocate funds to support health services and to allocate financial support to low-income families. In many cases, the Chilean government has prioritized work-protection measures and the delivery of food and essential supplies over direct payments in money to individuals and families (Gobierno de Chile, 2020, November 18).

In Chile, individuals with IDD are diagnosed through an early detection system (via school). Individuals with IDD receive government-funded special education and health support services until age 28. In the U.S., individuals with IDD may be administratively diagnosed (i.e., through developmental disability services), and/or receive a medical diagnosis (e.g., via a physician or psychologist). While individuals with IDD may receive government-funded special education services if they are eligible until age 22, it is not guaranteed they will receive services through state-funded developmental disability agencies following high school. The contexts surrounding individuals with IDD differ significantly in Chile versus the U.S., however the conditions of the pandemic (e.g., considerable changes in routines, increased time spent at home) are similar across many countries. In conducting this investigation, we aim to add to the COVID-19 literature by highlighting how individuals with IDD have fared in terms of mental health within context of their countries' sociopolitical environments.

### 1.2. Risks associated with intellectual and developmental disabilities

Individuals with IDD may be especially vulnerable to changes associated with the pandemic. Extensive research has indicated that adults with IDD belong to lower socioeconomic status: people with IDD are more likely to hold lower-paying jobs, experience difficulty seeking employment, or remain unemployed (Emerson, 2011; Pinilla-Roncancio, 2018). One would expect that the pandemic might further complicate socioeconomic difficulties. Individuals with lower-paying jobs may be unable to complete their work remotely. For instance, individuals in the service industry may experience job loss due to businesses closing, or may opt to stay at home due to health concerns, leading to reduced income and social isolation.

Individuals with IDD are also at increased risk for health concerns (Perera, Audi, Solomou, Courtenay, & Ramsay, 2020; Wallén, Ljunggren, Carlsson, Pettersson, & Wändell, 2018; Wilson, Lin, & Villarosa, 2019) and mental health problems (Hughes-McCormack et al., 2017; Perera et al., 2020) relative to the general population. Social isolation and insufficient access to community may contribute to mental health issues in people with IDD (Petroutsou, Hassiotis, & Afia, 2018). The circumstances of the pandemic may increase the risk of social isolation, depending on one's living situation and access to or understanding of technology for communication purposes. Changes in access to services or social supports may decrease one's regular contact with others, which may lead to increased loneliness, depression, or other mental health difficulties.

Despite significantly higher physical health and mental health concerns, access to regular healthcare remains a concern for people with IDD, due to poor integration of healthcare services and insufficient training opportunities in IDD for clinicians (McNally & McMurray, 2015; Summers, Fletcher, & Bradley, 2017). Insufficient access to healthcare may be especially salient during the pandemic, particularly for check-ups that require the individual to be in-person. For instance, individuals with IDD may worry about

exposure to the virus if it is required to attend an appointment in-person.

Individuals with IDD may require more help to access services to support their adaptive functioning, including a need for waivers, planned transportation, inclusion of advocates and/or legally authorized representatives, and help with insurance claims. The amount of support required to gain access to supports increases the likelihood of barriers to services. This may prove problematic during the pandemic as services that have traditionally provided support (e.g., developmental disability services) experience difficulties in access to new supplies (e.g., masks, gloves), experience increased staff turnover, or deal with issues related to funding (The Arc, 2020).

### 1.3. Current state of COVID-19 literature for people with IDD

#### 1.3.1. Mental and physical health

IDD scholars have identified that mental health difficulties would be of concern in this population during the pandemic (Courtenay and Perera, 2020; Tromans et al., 2020) and to date, several studies have provided support for increased mental health problems in the IDD population (Amor, Navas, Verdugo, & Crespo, 2021; Drum, Oberg, Ditsch, Cooper, & Carlin, 2020). Drum et al. (2020) conducted an online survey that included a large sample of individuals with IDD in the U.S. The authors found that, of those experiencing anxiety and depression, 80 % reported they were able to access emotional supports. Of note, they did not report what percentage of participants were experiencing anxiety and/or depression and what constituted an “emotional support.” Amor et al. (2021) found that over 60 % of individuals with IDD in Spain endorsed poorer well-being. Specifically, 60 % of the participants endorsed feeling scared and anxious about the lockdown, and women were more likely to report experiencing anxiety.

#### 1.3.2. Social difficulties

Thus far, research on the impacts of COVID-19 on individuals with IDD has found numerous barriers to quality of life during the pandemic. In a qualitative study for adults with mild ID, Embregts et al. (2020) identified that adults with IDD were missing social contact with others and felt that quarantining had changed their lives. In a large-scale online survey for adults with IDD in Spain, researchers found that adults with IDD most missed social relationships (Navas, Amor, Crespo, Wolowiec, & Verdugo, 2020). Their findings also revealed that participants missed recreational and leisure activities that had been restricted. These findings are consistent with Tromans et al. (2020)'s priority concerns related to social circumstances, which included social isolation and change in access to social support services, among others. While these researchers did not directly measure mental health variables, they highlighted difficulties that may serve as antecedents to mental health problems in a vulnerable population.

#### 1.3.3. Access to services

Several studies have explored sources of social support and regular healthcare services during this time period. Drum et al. (2020) found that a little over half of the sample (56 %) of individuals with IDD reported that their regular healthcare had been disrupted, but the majority of the sample reported no problems with getting their prescriptions. Thirty-eight percent of the sample reported experiencing difficulties accessing new healthcare services. Similarly, Amor et al. (2021) found that 21 % of individuals with IDD reported not receiving adequate social support for their mental health concerns since the start of the pandemic.

Zaagsma, Volkers, Swart, Schippers, and Van Hove (2020) explored whether individuals with IDD in the Netherlands increased their use of “Digisupport” during the pandemic. “Digisupport” is a remote technology service for adults with IDD who live independently. Individuals can schedule appointments with service providers or seek help immediately through this technology. The authors found that both scheduled and unscheduled online supports increased during the first few months of the COVID-19 lockdown. The authors hypothesized that the increase was likely due to increased stress, worry, and uncertainty during the first few weeks.

Jeste et al. (2020) conducted an online study on COVID-19 impacts for caregivers of children and adults with IDD in the U.S. and several other countries. The authors illuminated important issues in access to education and care, such as loss of one or more therapies for the majority of the sample and loss of all therapies for 30 % of people within the US and 50 % of people outside the US. The authors also found that approximately half of the sample was unable to see a healthcare provider when needed.

Taken together, it is clear from the literature that the lives of individuals with IDD have changed in a way that may negatively impact their mental and physical health. To date, the literature has provided limited data on well-being, changes in social support, changes in daily activities (e.g., recreation or leisure activities), and changes in access to services in adults with IDD. Scholars have anticipated difficulties related to services and social support, as well as difficulties related to health and well-being (Tromans et al., 2020).

### 1.4. Purpose of the current study

The purpose of this study is to explore patterns of mental health problems and service access in individuals with IDD during the pandemic. This is an exploratory study with a focus on three areas of importance: (1) mental and physical health, (2) access to healthcare (including mental health services), and (3) access to DD services. We explored whether number of mental health problems differed by daily difficulties due to disability, age, gender, living situation, physical health, and access to services.

Our study is unique in that it involved data collection from both the U.S. and Chile. Having utilized methodologies with several notable differences, we were unable to compare results; however, we provide descriptions of outcomes in each country to highlight how the IDD population has fared in countries with different legal systems and social norms.

## 2. Methods

Results for this study are drawn from an ongoing longitudinal investigation on the impacts of COVID-19 on the health, well-being, employment, and access to services for adults (i.e., ages 18+) with IDD. The study involved completion of a 20-minute online survey at two time points, separated by four months, across two countries. In the U.S., the survey was administered to adults with IDD and their caregivers, if applicable. In Chile, the survey was administered to caregivers of adults with IDD, and they had the option to answer online or by phone.

Differences in methodology by country (i.e., inclusion of caregivers and use of phone as an option to complete surveys in Chile) can be accounted for by legal and socioeconomic differences. It was decided that participants could have the option to complete the survey via phone or via internet in Chile because it is considered a developing country with less access to the internet relative to the U.S. In Chile, many legal barriers exist that significantly slow the progress of a research study when researchers plan to involve adults with IDD as participants. Consequently, it was decided to include caregivers only during the first wave of data collection while awaiting state approval. We made this decision in an attempt to minimize the amount of time that had passed between the first wave of data collection in the US and the first wave of data collection in Chile and to capture impressions of the impact of COVID-19 closer to the start of the pandemic. This study was approved by the Institutional Review Boards of both hosting universities.

## 3. Participants

### 3.1. United States

To be eligible for the study, participants in the U.S. had to be at least 18 years of age with an intellectual and/or developmental disability. In the screening questionnaire, participants reported if they had an intellectual disability and/or a developmental disability. IDD status was not verified in any other way. We did include the six questions about functional limitations that are commonly used as proxies for disability status in U.S. federal health surveillance surveys (Havercamp et al., 2019). For the purposes of this study, these questions served as a proxy for experience of daily difficulties. Sixty-two percent endorsed 0–2 difficulties, while 38 % endorsed 3 or more difficulties. See Table 1 for more detail on percentages of daily difficulties endorsed by the sample.

In the U.S., 404 adults with IDD participated. Six hundred and fourteen individuals initially clicked on the link to the survey. Two hundred and seventy-two people did not complete the survey (i.e., 44 % of the individuals who originally clicked on the link). Of the 272 individuals who did not complete the survey, 78 % did not go beyond the consent form, and 22 % completed at least some of the survey. Approximately 75 % of the sample completed the survey with the help of a family member, friend, or healthcare provider. Help from others meant the “helper” (e.g., family member, friend) was filling it out with the participant or filling it out for the participant (e.g., reading questions and answer options out loud). Most of the participants reported their race as White (79 %), while 12 % reported their race as Black or African American, 3.5 % as Latinx, 2.5 % as Asian American, 2% as American Indian or Alaskan Native, and 0.2 % as Native Hawaiian or other Pacific Islander.

**Table 1**  
Sociodemographic information of the participants.

	United States (%) (n = 404)	Chile (%) (n = 64)
Age		
18 to 30 years of age	51.7	76.6
31 to 45 years of age	30.9	15.6
46 to 60 years of age	11.6	6.3
More than 60 years of age	5.4	1.6
Gender		
Male	51.2	62.5
Female	47.3	37.5
Transgender	0.2	0
Nonbinary	0.2	0
Prefer not to answer	0.7	0
Home setting		
On their own	17.3	3.1
With other people (not family members)	12.4	0
In a group home	3.7	0
At a family member's house	59.2	96.9
Prefer not to answer	7.4	0
Daily difficulties due to disability		
Deafness	6.2	3.1
Blindness	10.1	9.4
Difficulty concentrating, remembering, or making decisions	67.1	60.9
Difficulty walking or climbing stairs	25.2	14.1
Difficulty dressing or bathing	33.9	10.9
Difficulty doing errands alone	79.0	67.2

### 3.2. Chile

Participants in Chile were 64 caregivers of adults with an intellectual and/or developmental disability (18+). They answered questions regarding the experiences of the adults with IDD. Three participants participated via phone. The remainder of the sample completed the survey online. Five participants (7.8 %) identified as Indigenous American. Sixty-four percent of participants reported living in Región Metropolitana (the central region of Chile), while the remaining 36 % live in nine out of the 15 surrounding regions of Chile. Seventy-five percent of the Chilean sample endorsed 0–2 daily difficulties due to their disability. See [Table 1](#) for more demographic characteristics. Data is not available regarding percentage of people who clicked on the survey or who did not complete the survey in Chile.

## 4. Procedures

This manuscript provides data from the first wave of data collection from an ongoing longitudinal study of COVID-19 outcomes for adults with IDD. The study includes two waves of data collection separated by four months. Participants in the U.S. completed the first wave of data collection in July of 2020, and participants in Chile completed it in October of 2020. Data collection occurred after a long period of lockdowns in both the United States and Chile (i.e., public policy measures implemented to limit the spread of the disease, including temporary shutdowns of business and curfews). We did not provide compensation for the first wave of data collection.

### 4.1. Recruitment

In the U.S., we recruited participants by sending an online flyer to be distributed via state DD agencies in all 50 states. State DD agencies were contacted via email with reminders about the study four times (approximately once every four or five days). The survey remained open for participants to complete for three weeks.

In Chile, we recruited the majority of participants through organizations that provide services to adults with IDD and their families across the country. We sent one email to these organizations. We directly contacted caregivers of individuals with IDD via email one time who had participated in previous studies. Lastly, we posted the flyer and link to the survey via social media. As stated previously, in Chile, participants were given the option to answer the survey by phone. The survey remained open for three weeks.

### 4.2. Survey

Originally, we planned to use the Epidemic-Pandemic Impacts Inventory (EPII; [Grasso, Briggs-Gowan, Ford, & Carter, 2020](#)) and adapt it for the IDD population. However, we ultimately modified it to the extent that it could no longer be considered an adapted version of the EPII. We collected survey input from the Department of Developmental Disabilities, the Developmental Disabilities Council and Self-Determination Association (i.e., DD professionals and self-advocates), researchers from a national mental health collaborative in the U.S., and researchers and self-advocates from the university [state information omitted for peer review]. Survey design entailed making initial adaptations to the EPII (e.g., changing questions to be DD-specific and translating questions to plain language) and sharing the modified version with the above groups, who made suggestions regarding a) questions to add or remove, b) language modifications, and c) general content areas to consider. The authors made adjustments per their suggestions and shared the updated version with them for additional feedback. Following this last round of feedback, the authors submitted the survey along with other study materials for institutional approval. The survey was originally edited in a Microsoft Word document. We ran readability statistics to confirm that the survey was below a 6th grade reading level.

The survey was translated to Spanish and adapted to accommodate social, cultural and legal differences for individuals with IDD in Chile. The main adjustments included modifications to questions about state-funded DD services and other supports offered by the government. Other modifications included adjustments to region names and income ranges. The question regarding race was changed to identification with indigenous groups. This adapted version was then back translated to English, to ensure that the questions were equivalent in both versions.

In addition to input from disability professionals and self-advocates, we used prior research to guide survey development. Most notably, past research has indicated increased mental and physical health problems ([Perera et al., 2020](#); [Wallén et al., 2018](#); [Wilson et al., 2019](#)), as well as difficulties with access to services ([Havercamp & Scott, 2015](#)) and employment opportunities ([Ellenkamp et al., 2016](#); [Siperstein, Parker, & Drascher, 2013](#)). Consequently, we wanted to understand if the pandemic had further complicated these areas of life. Areas of focus included: (a) demographics, (b) healthcare and disability-related services, (c) employment, (d) mental and physical health, and (e) COVID-19 related issues.

Both the consent form and the survey were written in plain or clear language and included the option to be read aloud. A glossary was included of relevant terms. Responses to survey items often included simple yes, no, or N/A options, and occasionally included frequency options. The survey was designed to take between 15–30 min. We anticipated that participants may need breaks. As such, participants were allowed to stop and return the survey at any time.

Upon clicking on the link to access the survey, participants were directed to the screening questions. If they were deemed eligible, they were able to proceed to the consent form. Participants were required to answer several comprehension questions after reading the consent form and prior to providing consent to participate. If participants selected an incorrect answer, the survey automatically displayed the correct answer (e.g., if a participant selected “No” in response to the question, “Can you leave this study at any time?” the survey automatically routed to the correct answer: “Yes, you can leave this study at any time and no harm will come to you.”). The

comprehension questions did not prevent participants from completing the survey if they did not answer the questions correctly. Instead, they served as an accommodation to ensure participants sufficiently understood the consent form and what to expect from the study.

#### 4.3. Variables of interest

For the current manuscript, we explore the presence of mental health and physical problems, access to mental and physical health care, and demographic variables. We measured mental health by asking participants if they were experiencing increased mental health problems since the pandemic. Participants who endorsed this question were then shown a list of common mental health symptoms and indicated whether or not they were experiencing them (i.e., yes or no). Regarding physical health and access to healthcare, participants indicated whether or not they were experiencing problems or difficulty with access, respectively (i.e., yes or no). Readers can access the full survey at the following link if they are interested: [insert link].

### 5. Data analysis plan

We conducted descriptive statistics for all variables of interest (i.e., mental health problems, physical health problems, access to services, and demographic variables). We conducted chi square analyses (or a Fisher's Exact *t*-test where needed) to compare mental health outcomes by daily difficulties due to disability, gender, age, living arrangement, service access, and presence of health problems.

### 6. Results

For clarity, we have presented our results separately for each country. Under each country, we present our findings related to disability-specific services, healthcare, physical health, and mental health.

#### 6.1. United States

Eighty-one percent of participants reported that they received state or county DD services prior to COVID-19. Of that group, seventy-one percent reported they were still receiving services, while 19 % indicated they were not receiving services at the time. Ten percent selected "N/A" in response to this question. Thirty percent reported difficulty in accessing DD services since COVID-19, and 44 % reported that their DD services had changed since COVID-19.

Regarding healthcare and physical health, 9% of the sample reported increased health issues since the start of the pandemic. Fifteen percent indicated difficulties in accessing medical treatment since COVID-19 while only 3% of the sample reported difficulty in accessing medicine (i.e., prescriptions). Relatedly, 29 % of the sample reported feeling scared to go to the hospital or doctor if they were sick. Only 1% of the sample reported using more alcohol, cigarettes, or drugs; however, 71 % of the sample reported spending more time on screens and devices.

In regards to mental health, 42 % of the sample reported accessing mental health therapy since the pandemic began. Of that group,

**Table 2**  
Types of mental health symptoms experienced during the COVID-19 pandemic.

Question	United States (%) (n = 404)	Chile (%) (n = 64)
Are you having more mental health problems or symptoms?	41.3	51.6
Number of mental health symptoms		
None (0)	59.4	48.4
Some (1–2)	5.9	7.8
Significant (3–4)	11.9	18.8
Very significant (5+)	22.8	25.0
Mental health symptoms		
Worried	28.0	23.4
Stressed	27.2	28.1
Scared	16.6	14.1
Nervous	22.5	18.8
Sad	23.8	31.3
Angry	13.9	20.3
Annoyed easily	19.3	23.4
Impatient	17.8	26.6
Tired	17.8	6.3
Over-excited	3.7	7.8
Jumpy	6.9	9.4
Problems sleeping	18.8	26.6
Other	4.5	3.1
Prefer not to answer	0.7	0

10 % reported that therapy was great, 61 % reported it was good, 23 % reported it was fair, and 6% reported it was poor. Out of the whole sample, 41 % reported experiencing more mental health problems since the pandemic began. Six percent of the sample reported 1–2 mental health symptoms, 12 % reported 3–4 symptoms, and 23 % endorsed five or more symptoms. The most endorsed symptoms in the United States included worry and stress, with over 27 % of the sample reporting these symptoms. See Table 2 for details on types of mental health symptoms experienced.

6.2. Comparisons

Results from a chi square analysis ( $X^2(3, N = 289) = 11.62, p = .009$ ) indicated that participants no longer receiving DD services were more likely to report increased mental health symptoms. Participants who endorsed more physical health problems were significantly more likely to report a significant number (5+) of mental health symptoms ( $X^2(3, N = 357) = 39.56, p < .001$ ). Participants who endorsed more daily difficulties due to disability status were significantly more likely to report more mental health symptoms ( $X^2(12, N = 369) = 25.71, p < .012$ ). A Fisher’s exact test showed significant differences in mental health symptoms by housing arrangement (i.e., living alone, living with non-family members, living in a group home, or living with family),  $p = .039$ . We found that 31.4 % of people living with family endorsed three or more symptoms, compared to 38.6 % of people living alone, 40 % of people living in group homes, and 46 % of people living with non-family members. See Table 3 for more details on mental health symptoms by living situation. There were no significant differences in mental health symptoms by age or gender.

6.3. Chile

In Chile, 19 % of the sample reported that they received government or municipal DD services prior to COVID-19. Of that group, 92 % reported they were still receiving services since the pandemic began. Eighty-three percent of participants receiving state services reported difficulty accessing services since the pandemic started, and 75 % of this group reported that their services had changed.

Nine percent of the sample reported increased health issues since the start of the pandemic. Seventeen percent reported difficulty in accessing necessary medical treatment and 16 % reported difficulty in obtaining medicine. Twenty-five percent of the sample reported feeling scared to go to the hospital or doctor if they were sick. Eighty-three percent of the sample reported spending more time on screens and devices. No one in the sample reported increased use of drugs, cigarettes, or alcohol.

Regarding mental health, 51.6 % of the sample reported increased mental health problems. Eight percent of the sample endorsed one to two mental health symptoms, 19 % three to four mental health symptoms, and 25 % endorsed five or more symptoms. The most endorsed symptom was sadness (31.3 %). Over 25 % of the sample reported feeling stressed, impatient, and having trouble sleeping. See Table 2 for details on types of mental health symptoms experienced. Twenty-five percent of the sample was accessing mental health therapy at the time: 12.5 % reported it was great, 68.8 % reported it was good, and 18.8 % reported it was fair. There were no significant differences in mental health symptoms by age, gender, daily difficulty due to disability, access to services, health problems, or housing situation.

7. Discussion

The COVID-19 pandemic has posed challenges for individuals and families across the globe. However, the IDD population is especially vulnerable due to their dependence on formal support systems, increased susceptibility to mental and physical health difficulties, and inequitable access to services. Consistent with past research on difficulties individuals with IDD are facing during the pandemic, we found that a significant percentage of both samples endorsed changes in access to services, as well as increased mental health problems. Below, we provide interpretation of and context for our findings, in addition to suggestions for practice and future research directions.

7.1. Health

Unsurprisingly, given the circumstances of lockdown and quarantining, the majority of respondents were spending more time on

**Table 3**  
Number of mental health symptoms by home setting<sup>a</sup>.

			Home setting				Total
			Alone	Non-family	Group home	Family	
Number of mental health symptoms	None (0)	Count	41	25	7	150	223
		Percentage of home setting	58.6	50.0	46.7	62.8	59.6
	Some (1–2)	Count	2	2	2	14	20
		Percentage of home setting	2.9	4.0	13.3	5.9	5.3
	Significant (3–4)	Count	4	12	3	27	46
		Percentage of home setting	5.7	24.0	20.0	11.3	12.3
	Very significant (5+)	Count	23	11	3	48	85
		Percentage of home setting	32.9	22.0	20.0	20.1	22.7

Notes: <sup>a</sup>United States’ sample ( $n = 374$ ).



screens and devices. This finding was consistent with Tromans et al. (2020)'s priority concerns related to physical health in the IDD population. While the majority of our sample did not endorse increased physical health difficulties, participants in the U.S. who did endorse an increase were significantly more likely to report mental health problems. Physical health problems might become more apparent as individuals continue to spend the majority of their time at home. Clinicians may benefit from considering interventions that target physical health problems due to inactivity.

Results in both countries were very similar in answers related to health and the access to health services. In both Chile and the U.S., only 9% of the participants reported more health problems since the beginning of the COVID-19 pandemic. A quarter of the sample in Chile and 29% of the sample in the US reported feeling scared to see a doctor or go to a hospital if sick. Lastly, 16% of respondents in Chile and 17% of respondents in the U.S. reported difficulty in accessing medical treatment. We could attribute these results to recommendations at the beginning of the pandemic to avoid hospitals or health centers unless it was necessary, as the priority were patients with COVID-19. These measures decreased preventive and chronic disease check-ups and emergency room visits (Chudasama et al., 2020; Lange et al., 2020), prompting the use of telehealth (Mirsky & Horn, 2020), which could have been a barrier for some people with IDD. There is some evidence that points to sustained disparities in accessing health care, particularly affecting individuals with lower incomes and disabilities (Nash, Angelo, Nash, Gleason, & Meyer, 2020).

As measures have relaxed, hospitals and clinics are re-opening their doors and encouraging people to attend necessary check-ups using COVID-safe strategies (e.g., wearing masks) in-person and/or through hybrid set-ups (Mirsky & Horn, 2020). Future researchers may benefit from exploring whether increases in healthcare access match pre-pandemic numbers as healthcare facilities and individuals adapt to new structures and strategies to reduce transmission and enable access to care.

## 7.2. Mental health

Forty-two percent of the sample experienced increased mental health problems in the U.S.; a little over half of the sample experienced increased mental health problems in Chile. Prevalence of mental health symptoms was higher in Chile, with more than a quarter of the sample reporting sadness, stress, impatience and problems sleeping. We could attribute this difference to reporters in the U.S. versus Chile. It is possible that caregivers were able to notice symptoms that individuals with IDD may not have noted in themselves (e.g., increased impatience or irritability). Further, the Chilean sample completed the questionnaire several months later than the U.S. sample. It is possible they were experiencing more emotional exhaustion given the timing (i.e., more than six months into the pandemic). The most endorsed symptoms in the U.S. were stress and worry. Increased symptoms in both countries could be due to social isolation, rapid changes in COVID-19 measures and difficulties accessing services. High levels of confusion, uncertainty, and loss of control could play a role in their symptoms.

In the U.S., loss of services, health problems, and daily difficulties due to disability were associated with an increase in report of mental health problems. Loss of routine, regular contact with peers, and general support services could explain how loss of DD services was associated with an increase in mental health problems. Regarding physical health, evidence points to a transactional relation between physical and mental health, in which both influence each other (Ohrnberger, Fichera, & Sutton, 2017).

Finally, we found that participants with more endorsed daily difficulties were more likely to experience mental health problems. Many explanations could account for this link. It is possible that individuals with more difficulties require more help in their daily activities; a dramatic change in availability of and access to supports could explain why individuals with more difficulties (and thus, more needs) reported more mental health problems. The link between daily difficulties and mental health problems was not significant in the Chilean sample. This may be in part explained by differences in frequencies. Only a quarter of the Chilean sample endorsed three or more difficulties, compared to nearly 40% of the U.S. sample.

Another factor that may lead to increased prevalence of mental health symptoms is social isolation (Hawkey & Capitanio, 2015; Kinne, Patrick, & Doyle, 2004). Accordingly, we identified that only 31% of people living with families endorsed three or more symptoms, compared to 38.6% of people living alone, 40% of people living in group homes, and 46% of people living with non-family members. Individuals living with housemates (i.e., non-family members) may not have relationships with them that can serve as a source of comfort during times of stress. Family may serve as a buffer for mental health difficulties, particularly during a stressful time. However, it is worth noting that one third of people living with family members endorsed three or more mental health symptoms. Further, it is possible that people living with family members previously lived elsewhere before the pandemic. Major disruptions to regular routines—such as housing—could have contributed to symptom endorsement. We did not collect data on living situations prior to the pandemic, and plan to address this limitation in the next wave of data collection.

## 7.3. Disability-specific services

Only about 20% of people with IDD were receiving state services in Chile prior to the start of the pandemic compared to 80% of the U.S. sample. Recruitment strategies might account for this. In the U.S., we mainly recruited participants through state DD agencies, while in Chile, recruitment included state agencies, advocacy organizations, and other community agencies serving individuals with IDD. Further, in Chile, services provided by governmental agencies for people with IDD are mostly provided to children and adults up to age 28 through the school system. In addition, both children and adults with IDD often receive support private organizations, and for adults, most of these services involve vocational rehabilitation. This could explain the low percentage of participants receiving government-funded services prior to the start of the pandemic. Because disability supports typically focus on workplace training and placement (rather than mental health) in Chile, this population may be more likely to experience untreated mental health symptoms.

While the majority of people receiving services reported changes in services since the pandemic in both countries, a small but

noteworthy percentage of the U.S. sample reported they were no longer receiving services. Several possibilities may account for this. First, it is possible that respondents considered not having seen their service coordinator in-person as meaning they were no longer receiving services. Similarly, participants may have endorsed this question if they experienced a break in services while their agency mobilized and attempted to redesign pandemic-appropriate DD services following a lockdown. Lastly, it is possible that participants endorsed “no longer receiving services,” because they had opted not to receive them due to fear of exposure or other health concerns. We plan to address some of these unknowns in our next wave of data collection.

Regardless of the reason, a loss of DD services in nearly 15 % of the U.S. sample brings to light issues that have existed prior to the pandemic. First, DD agencies experience staff turnover regularly (Ryan, Bergin, & Wells, 2021), and the pandemic has been no exception to staffing issues (The Arc, 2020). Initial research on government-mandated closures of IDD organizations in the U.S. has shown that increased staff turnover during the pandemic has influenced funding issues, due to increased overtime of current staff and onboarding and training of new staff (The American Network of Community Options and Resources, 2020). Second, funding for DD services has historically been significantly limited in the U.S. The cost of new equipment to accommodate CDC guidelines (e.g., face masks, face shields, plexiglass dividers, gloves, etc.), in addition to changes in service-delivery (virtual or socially distanced), has likely exacerbated funding issues and possibly led to an inability to provide certain services. Indeed, Navas et al. (2020) found that 20 % of their sample of Spanish individuals with IDD reported no longer receiving the formal supports they needed. Further, Jeste et al. (2020) reported that 30 % of caregivers of children and adults with IDD lost access to DD-specific services (e.g., speech therapy, occupational therapy, recreational activities, etc.)

## 8. Implications

Results from this study highlight several noteworthy implications regarding support for the IDD population during the pandemic. First, regarding disability-specific services in the U.S., regular updates in accessible language about what ways services are (and are not) changing may help to reduce confusion and worry around access to services. Second, while this is beyond the scope of this study, it is clear from the literature that staff turnover may significantly contribute to funding issues and to changes at the individual level in terms of services. Implementation of organization-wide strategies to retain staff, particularly during a time where service-users are especially vulnerable, may be a worthwhile investment.

Continued access to community remains a significant issue to consider for the IDD population. For recreational services, providers have had to consider how to re-format community gatherings to be virtual, or to be in-person in compliance with Centers for Disease Control (CDC) guidelines for social distancing. Some private organizations that foster opportunities for socialization for people with IDD have transitioned to being exclusively virtual (e.g., Best Buddies International). Organizations that have transitioned to virtual services or gatherings should consider training staff in best practice strategies to teach people with IDD how to use virtual platforms (Courtenay & Perera, 2020).

Lastly, given that over 40 % of the sample in the U.S. and over half the sample in Chile endorsed increased mental health symptoms, access to virtual mental health treatment is warranted. Particularly in Chile, only half the individuals who endorsed mental health symptoms were accessing therapy. Mental health providers and disability services may consider producing plain-language resources that include psychoeducation around common mental health symptoms (e.g., depression, anxiety) and evidence-based strategies to treat them. Virtual group therapy may be an especially helpful modality as it could provide both alleviation of symptoms and access to a community with shared experiences. Relatedly, as the majority of respondents in both countries reported increased access to their devices, providers may consider encouraging individuals with IDD to engage in safe, socially distanced exercise (e.g., YouTube exercise videos, or going on walks outside with masks). Increase in exercise may help to alleviate mental health symptoms, in addition to physical health issues (Tremblay, Colley, Saunders, Healy, & Owen, 2010).

## 9. Limitations and future directions

This study has a number of limitations. First, the methodologies are different for the U.S. and Chilean studies, which did not allow for comparisons to be made. In the U.S., respondents included adults with IDD and their caregivers if they needed support. In Chile, only caregivers completed the survey, which could have influenced our results. Notably, this may have accounted for differences in reporting of mental health problems (i.e., self-report versus caregiver report). We will address this limitation in the next wave of data collection, where we will include Chilean participants with IDD. In Chile, participants had the option to complete the survey by phone so people with difficulties using technology or without internet access could participate. In the U.S., the survey was exclusively online. This could have limited the participation in the U.S. to people with internet access. Regarding sample sizes, we could attribute differences in sample size to the population size of each country: the U.S. population is around 330 million people (United States Census Bureau, 2021, February 28), while the Chilean population is around 19 million (Instituto Nacional de Estadística, 2018). Lastly, in Chile, only people who reported the presence of mental health symptoms answered the questions regarding specific symptoms, while in the U.S., all participants were able to answer mental health questions. We will address this discrepancy in the next wave of data collection.

Regarding data collection, we did inquire about the severity of mental health symptoms or whether the services were received in-person, virtual, or hybrid. We did not ask follow-up questions to verify disability status (e.g., where the individual had been diagnosed), nor did we ask questions about socioeconomic status. We have included these questions for our next wave of data collection.

The representativeness of the sample is worth noting. In the U.S., we recruited from DD agencies, which limits our participants to those who receive services or are in some kind of contact with DD agencies. Similarly, in Chile, recruitment was limited to DD-specific

organizations, again limiting the sample to individuals who receive support at least communications (e.g., email updates) from these organizations. Finally, we did not include a control sample of adults without IDD, which limits the scope of our conclusions about the impact of the COVID-19 pandemic in comparison to the general population.

Future researchers may consider conducting qualitative analyses to provide more context for findings in this study and other studies examining outcomes associated with the pandemic in the IDD population. For instance, understanding why some individuals are not accessing DD services can drive policy recommendations. Future research should include a more detailed examination of mental health problems in adults with IDD (e.g., a more comprehensive list of symptoms, in addition to the severity and frequency of individuals' symptom presentations). Lastly, a study investigating both the mental health of caregivers and adults with IDD may be beneficial in understanding clinical recommendations (e.g., individual vs. the family system). Because of limitations to in-person interactions, online or remote studies may persist until the pandemic has been appropriately controlled. Our study highlights that individuals with IDD were able to complete an online survey, with supports as needed. Future research projects should consider incorporation of technology with modifications to improve access.

## 10. Conclusions

Limitations notwithstanding, our study filled a gap in the COVID-19 literature for individuals with IDD. Our study underscores concerns that are specific to the IDD population and that require special accommodations and supports. To best support this population, service providers must consider a range of proactive strategies and practices to provide continuity of care and to prevent mental and physical health difficulties. Future research can help to further document barriers this population faces and as well as to provide insights into novel practices to remedy pandemic-specific concerns.

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## CRedit authorship contribution statement

**Margaret Rosencrans:** Conceptualization, Methodology, Software, Investigation, Writing - original draft, Writing - review & editing. **Paulina Arango:** Methodology, Software, Investigation, Formal analysis, Data curation, Writing - original draft, Writing - review & editing. **Camila Sabat:** Methodology, Software, Investigation, Formal analysis, Data curation, Writing - original draft, Writing - review & editing. **Andrew Buck:** Conceptualization, Methodology, Writing - review & editing. **Christine Brown:** Conceptualization, Methodology. **Marcela Tenorio:** Writing - review & editing. **Andrea Witwer:** Conceptualization, Writing - review & editing, Supervision.

## Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.ridd.2021.103985>.

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