

Views on the impact of the COVID-19 pandemic on health in people with Down syndrome from diverse backgrounds

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Abstract

Down syndrome (DS) has a unique medical and psychological profile. To date, few studies have asked individuals with DS about their views of health, and fewer have explored the impact of COVID-19 on the health of individuals with DS and their families. We used a mixed methods approach including two studies on the health of individuals with DS and their parents conducted during the COVID-19 pandemic: (1) eight virtual focus groups, comprised of 20 parents and 8 individuals with DS to obtain participants' views of health, and (2) a 20-item questionnaire on health care experience of patients with DS who are African American or come from primarily Spanish-speaking homes. Focus group transcripts were coded using a hybrid inductive/deductive framework and thematically analyzed using the Framework Method. This questionnaire included questions regarding the impact of COVID-19 on caregivers and their loved ones with DS; responses to these questions were summarized using descriptive statistics. Individuals with DS discussed the impact of the COVID-19 pandemic on their physical and social health including masking, online learning, and online communication with friends and family. Parents of individuals with DS discussed how the COVID-19 pandemic negatively impacted their child's physical, social,

and mental health, as a result of virtual schooling and decreased socialization. There were unexpected positives of the pandemic such as improved hygiene and eased scheduling with telehealth visits. Caregivers noted COVID-19 impacted their own anxiety, employment, and other domains that have potential ripple effects on the health of their children. The COVID-19 pandemic had a pervasive impact on the mental health and wellness of caregivers as well as the physical, social, and mental health of individuals with DS.

KEYWORDS

caregiver impact, COVID-19, Down syndrome, quality improvement, Trisomy 21

1 | INTRODUCTION

The COVID-19 pandemic has had broad impacts on children's lives. As of January 2023, more than 15 million total children in the United States have had COVID-19, representing 18.1% of all cases (American Academy of Pediatrics, 2023). In hospitalized children, the risk for severe COVID-19 increases with some co-occurring conditions: chronic lung disease, neurologic disorders, cardiovascular disease, prematurity, and airway abnormalities in children under 2 years old; and feeding tube dependence, diabetes mellitus, and obesity in those 2–17 years (Woodruff et al., 2022).

Down syndrome (DS) is a genetic condition associated with higher prevalence of some of these risk-related conditions (Bull, 2020; Korenberg et al., 1994; Palumbo & McDougle, 2018). Patients with DS, in general, have an increased risk of severe respiratory infections (Santoro, Chicoine, et al., 2021); increased risk for hospitalization, mortality, and need for mechanical ventilator support with respiratory syncytial virus (RSV) infection (Beckhaus & Castro-Rodriguez, 2018); and increased incidence of pneumonia and respiratory failure (Uppal et al., 2015). Although previous research has shown that the physical signs and symptoms of COVID-19 infection in people with DS are similar to that of the general population (COVID-19 and Down Syndrome T21RS survey, 2020; Hüls et al., 2020), the risk for fatal outcomes begins to increase in the 40s for individuals with DS, an earlier age than the general population (COVID-19 and Down Syndrome T21RS survey, 2020; Hüls et al., 2020).

In the general population, the COVID-19 pandemic had an impact on health beyond acute SARS-CoV2 infections. The reported physical health impacts have included an unbalanced diet with an increased risk of weight excess or nutritional deficiencies (Scapatucci et al., 2022), increased binge eating and snacking (Ammar et al., 2020), increased sedentary lifestyle (Scapatucci et al., 2022), and decreased physical activity (Giuntella et al., 2021; McCarthy et al., 2021). Studies have described profound impacts on mental health from the pandemic as well as from isolation and quarantine (Scapatucci et al., 2022), including anxiety, depression, sleep problems, anger, and post-traumatic stress disorder (Imran et al., 2020; Panchal et al., 2021; Panda et al., 2021; Racine et al., 2021; Sprang & Silman, 2013). Social health was affected by the pandemic, due to lack of schooling

(Scapatucci et al., 2022) and social isolation (Scapatucci et al., 2022), and parents observed emotional and behavioral changes in children during isolation (Saladino et al., 2020).

Individuals with intellectual disabilities (Courtenay & Perera, 2020), as well as their caregivers (Doody & Keenan, 2021; Willner et al., 2020), were similarly impacted by the pandemic. For individuals with intellectual disability, the pandemic decreased availability of necessary services and disrupted daily routines, while increasing loneliness, agitation, anxiety, distress, and behavior challenges (Doody & Keenan, 2021). Financial worries were a concern of families of individuals with intellectual disabilities during the pandemic; these families also reported increased depression, anxiety, increased isolation, and decreased coping capacity (Doody & Keenan, 2021; Willner et al., 2020).

Villani et al. (2020) used a standardized assessment tool for 46 adults with DS in Italy and found that after the COVID-19 lockdown, there was increased depression, worsened social withdrawal, and worsened ability to complete activities of daily living, but a decrease in aggressive behavior. A separate survey of 115 caregivers in the United Kingdom found lower anxiety levels for individuals with DS, more worry about friendships, and less worry about family-related aspects compared to the other groups with other disabilities (autism spectrum disorder, unspecified intellectual disability, Williams syndrome, attention-deficit hyperactivity disorder, and other unspecified syndromes or diagnoses) and their typically developing siblings (Sideropoulos et al., 2023). Given the potentially unique positive and negative impacts of the pandemic on individuals with DS, compared to individuals with other intellectual or physical disabilities, additional research is needed to evaluate the experience of COVID-19 for these individuals and their families, especially within the United States as there is a relative paucity of such data.

In this mixed-methods study, we analyzed the views from people with DS and their parents, all primary caregivers, through focus groups (FGs) and a survey. Capturing these lived experiences helped identify unique aspects by which the COVID-19 pandemic impacted individuals with DS and their parents. We aimed to describe the impact of COVID-19 on the health and wellness of individuals with DS and their parents from diverse backgrounds. This data can highlight continuing health needs of individuals with DS and their parents

as the COVID-19 pandemic persists and guide allocation of resources to address these needs.

2 | MATERIALS AND METHODS

This study on the impact of COVID-19 pandemic was part of two larger studies (Krell et al., 2023; Santoro, Cabrera, Haugen, et al., 2023). We used a mixed-methods convergent design where qualitative data from FGs and quantitative data from a survey were collected in parallel and analyzed separately, but then merged together for comparison and integration through narrative (Fetters et al., 2013). The complementarity between our qualitative and quantitative data sources allowed us to gain an in-depth understanding of the impact of the pandemic on individuals with DS and their parents within the United States, while also highlighting the ways the pandemic affected two groups known to experience health disparities in the United States (individuals who identify as Black, African American, of African descent, or mixed race, and individuals who speak primarily Spanish) (Palinkas et al., 2011).

2.1 | Data sources

2.1.1 | Focus groups

We conducted four virtual FGs of teens and young adults with DS, and four virtual FGs of parents of individuals with DS using Zoom videoconferencing technology between November 2020 and March 2021. Individuals included in the FGs were English speaking, had access to Zoom, and were either (1) an individual with DS aged 13–21 or (2) a parent of an individual with DS aged 0–21 (Santoro, Cabrera, Haugen, et al., 2023). Each parent included was the primary caregiver of their child with DS, and the individuals with DS were children of the parents that participated in the study (Santoro, Cabrera, Haugen, et al., 2023).

FG recruitment: Participants were recruited through the Massachusetts General Hospital Down Syndrome Program, the Massachusetts Down Syndrome Congress (MDSC), the LuMind IDSC Down Syndrome Foundation, and the NIH's DS-Connect[®] patient registry. Potential participants were sent information describing the study as well as a link to an electronic screening form on REDCap, which collected demographic information (Harris et al., 2019; Harris et al., 2009; Santoro, Cabrera, Haugen, et al., 2023). Eligible parents were then contacted by the research team to further discuss the study and schedule FGs for them and their child with DS, as applicable. The research assistant spoke with the parents to discern if participants with DS had sufficient expressive language to participate in a Zoom conversation.

FG procedures: Participants with DS and parents had separate FGs, organized to group individuals with DS of similar age (13–17; 18–21) and parents of similarly aged children. Consent information was shared prior to FGs via e-mail. At the start of the FGs, consent information was reviewed, and verbal consent was obtained. Parent

FGs were held first, and parents consented for both themselves and for their child with DS to participate in the FGs. At the start of the FGs for individuals with DS, consent information was reviewed, and consent/assent was provided. During the FGs, two researchers facilitated a “semi-structured discussion” (Santoro, Cabrera, et al., 2023); individuals with DS and parents were asked to discuss health conceptually and the specific social, emotional, and physical factors that contribute to their health or the health of their child as it pertains to DS (Santoro, Cabrera, Co, et al., 2023; Santoro, Cabrera, Haugen et al., 2023). In all FGs, the topic of the COVID-19 pandemic arose spontaneously.

FG analysis: Audio recordings of the FGs were transcribed, coded, and analyzed for themes. After transcription, audio recordings were coded to a 40-item codebook using an inductive/deductive coding approach focused on building consensus across team members (Hemmler et al., 2022; Hsieh & Shannon, 2005). After coding, we then used conventional content analysis to summarize all material coded as relating to the COVID pandemic, and categorized these findings by domains of health: physical, mental, and social. The source of quotes is defined as “D,” representing an individual with DS, or “P,” for a parent of an individual with DS.

2.1.2 | Survey

As previously reported (Krell et al., 2023), we administered a novel questionnaire on health care experiences to caregivers of individuals with DS who are Black, African American, of African descent, of mixed race, or come from primarily Spanish-speaking homes from August to October 2021. The survey was available in either English or Spanish. Among the questions included in a larger study, we asked caregivers how serious of an impact the COVID-19 pandemic was having on various aspects of their families' lives including caregiver employment and anxiety, access to health services, and the health of individuals with DS. Answer response options to these questions were “Very serious,” “Somewhat serious,” “Not serious,” and blank.

Survey recruitment: Caregivers were recruited through social media platforms, personal networks, the NIH's DS-Connect, and an e-mail to 321 DS nonprofit organizations, asking them to share the survey link with their members and giving them the opportunity to request hard-paper copies of the survey either in English or Spanish for local distribution. Paper copies, in English and Spanish, accompanied with a self-addressed stamped envelope, were also offered to 321 nonprofit groups for DS, 65 of whom requested paper copies although none were completed and received before analysis (Krell et al., 2023).

Survey procedures and analysis: Written informed consent was waived and participants provided informed verbal consent prior to participation. Survey data was collected and managed using REDCap electronic data capture tools hosted at Massachusetts General Hospital (Giuntella et al., 2021; McCarthy et al., 2021). Eligible caregivers were asked to fill out the survey although they were not required to answer every question. Response options to all questions on impacts of the COVID pandemic were “Very Serious,” “Somewhat Serious,”

and “Not Serious.” Quantitative responses were analyzed using standard summary statistics.

De-identified data are available from author by request. Both studies were approved by Massachusetts General Brigham Institutional Review Board (MGB IRB).

3 | RESULTS

3.1 | Participants

Across eight FGs, eight adolescents (ages 13–21 years old) with DS and 20 parents of individuals with DS (ages 0–21 years old) participated (Table 1) (Santoro, Cabrera, Haugen, et al., 2023). Our online survey was completed by 109 parents, of whom 68 were English-speaking parents who had children with DS who were Black, African American, of African descent, or of mixed race and 41 were primarily Spanish-speaking parents of individuals with DS (Table 1) (Krell et al., 2023)

3.1.1 | Impacts of COVID-19 on the physical health of individuals with DS

Of surveyed parents, 49% who had Black children with DS (Figure 1) and 34% of parents who were primarily Spanish-speaking (Figure 2) felt that the pandemic had at least a somewhat serious impact on the overall health of the person with DS (Krell et al., 2023). Parents of Black children with DS (26%) and primarily Spanish-speaking parents (44%) often felt that this was due, in part, to changes in access to healthcare services for the person with DS. Discussions with FG participants illuminated that reduced access to in-person services could have both positive and negative impacts.

As therapies, activities, and school transitioned to virtual experiences or were altogether canceled, many participants with DS described an increased use of electronics and decreased daily exercise. Parents in FGs largely noted the negative effect this had on their children's physical health, and one parent stated that their child has a healthy day when “he eats healthy, gets a little exercise, and if I can get him off the iPad ... that's my biggest concern is the iPad. But we're all on electronics too much, especially nowadays.” (P6, FG6, February 2021). However, one parent noted how their child's physical health had actually improved since the beginning of quarantine and virtual schooling as a result of decreased exposure to people who were potentially infectious with a variety of illnesses:

“[He] wasn't going to school. He wasn't going to therapy. So he wasn't getting sick at all. I mean, COVID was like a beautiful, healthy [laughter] time.”—P2, FG1, November 2020

FG participants discussed the positive and negative impacts of the increased emphasis on preventative health behaviors like masking and washing hands during the pandemic. Most individuals with DS in FGs confirmed that they were masking and discussed the value of washing

hands to avoid getting sick, and parents identified the increased emphasis on hygiene as an unexpected positive result of the COVID-19 pandemic. One parent noted that their child's hygiene was improved:

“She's washing her hands. She's never loved sanitizer, but she's not so adverse to it any more ... So we've kind of been able to actually get some better hygiene practices just ingrained in her because everyone else is doing it”—P7, FG8, December 2020

However, some parents noted unique difficulties in masking and hygiene for their child with DS. Due to sensory issues, masking was not always possible for some children. This inability to wear a mask limited the in-person activities available to them and resulted in social stigma, driving the need for modifications to masks or alternatives such as a facial shield.

“Because of his sensory problems with the [co-occurring diagnosis of] autism, he refuses to wear a mask. Scared to death of it and scared when we have them on. So that has been a huge problem. You can't go anywhere. You can't do anything because people stare at you, say things. And so that has been extremely hard. I did find a shield finally that attaches to his glasses because he's already used to those”—P6, FG8, December 2020

3.1.2 | Impacts of COVID-19 on the emotional health of individuals with DS

In the parent questionnaire, 26% parents who had Black children with DS and 34% of parents who are primarily Spanish speaking felt that the pandemic had at least a somewhat serious impact on the access to mental health services for their loved one with DS (Figures 1 and 2) (Krell et al., 2023). In addition, parents in FGs discussed observing changes in their child's moods throughout the COVID-19 pandemic. One parent noted that their child was no longer “always happy” stating that their child has:

“used a lot of different emotional words, like, I'm sad or I'm worried or I don't like that. And it's all COVID related or lack of social interaction related, or got left out of a social outing and has been able to verbalize that, or concerned about her grandparents who are aging.”—P4, FG6, February 2021

While this child's use of expressive words indicated the negative impact of COVID-19 on their emotional health, it also led to a benefit in their ability to communicate with their family about their emotions:

“We've been able to discuss it a lot more and she's starting to learn her own coping mechanisms. Where

TABLE 1 Demographics.

Response	N (%)
Focus group participants: individuals with DS (N = 8)	
Age	
13–17	4 (50)
18–21	4 (50)
Gender	
Female	4 (50)
Male	4 (50)
Race	
White	8 (100)
Black or African American	0 (0)
Asian	0 (0)
Indian	0 (0)
Focus group participants: parent (N = 20)	
Gender	
Female	19 (95)
Male	1 (5)
Race	
White	17 (85)
Black or African American	1 (5)
Asian	1 (5)
Indian	1 (5)
Age of son or daughter with Down syndrome	
0–5	5 (25)
6–12	4 (20)
13–17	5 (25)
18–21	6 (30)
Biological sex of son or daughter with Down syndrome	
Female	10 (50)
Male	10 (50)
To what extent does your son or daughter with Down syndrome, in your opinion, have significant health problems? (1 = “not a problem”; 7 = “very much a problem”)	
1	2 (10)
2	7 (35)
3	4 (20)
4	3 (15)
5	0 (0)
6	1 (5)
7	0 (0)
To what extent does your son or daughter with Down syndrome, in your opinion, have significant educational/learning difficulties? (1 = “not a problem”; 7 = “very much a problem”)	
1	0 (0)
2	1 (5)
3	1 (5)
4	4 (20)

(Continues)

TABLE 1 (Continued)

Response	N (%)
5	5 (25)
6	4 (20)
7	2 (10)
Caregiver survey participants (N = 109)	
Primary language/race	
English speaking caregivers who had children with DS who were Black, African American, of African descent, or of mixed race	68 (62)
Spanish-speaking caregivers	41 (38)
Survey: English speaking caregivers who had children with DS who were Black, African American, of African descent, or of mixed race (N = 68)	
Relation to person with DS	
Mother or step-mother	50 (74)
Father or step-father	6 (9)
Sibling, half-sibling, or stepsibling	1 (2)
Blank	11 (16)
Race of caregiver	
Black/African American	44 (65)
White	8 (12)
More than one race	5 (7)
Other	2 (3)
Blank	9 (13)
Hispanic, Latino/a, or Spanish origin	
No	52 (77)
Yes	6 (15)
Blank	10 (9)
Survey: Primarily Spanish-speaking caregivers (N = 41)	
Relation to person with DS	
Mother or step-mother	28 (68)
Father or step-father	3 (7)
Sibling, half-sibling or step-sibling	2 (5)
Blank	
Race of caregiver	
Black/African American	0 (0)
White	13 (32)
More than one race	5 (12)
Other	15 (37)
Blank	8 (20)
Hispanic, Latino/a, or Spanish origin	
No	0 (0)
Yes	34 (83)
Blank	7 (17)

maybe in the past, if she was sad or lonely, maybe she would kind of sit in the corner of the couch and get quiet. So if she's quiet, we know something's not right,

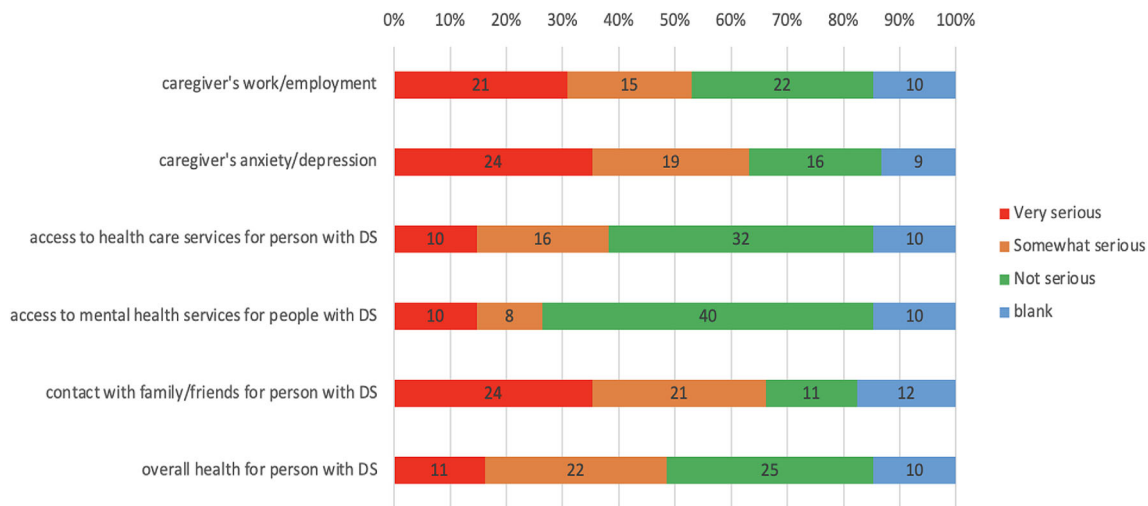


FIGURE 1 “In the past year, has the COVID pandemic had a *very serious*, *somewhat serious*, or *not serious* impact on...” $N = 68$ people with Down syndrome who are Black, African American, of African descent, or of mixed race, as reported by their caregivers (counts per response choice listed in bars).



FIGURE 2 “In the past year, has the COVID pandemic had a *very serious*, *somewhat serious*, or *not serious* impact on...” $N = 41$ people with Down syndrome where Spanish is the primary spoken language at home, as reported by their caregivers (counts per response choice listed in bars).

where now she's been able to verbalize the feelings and learn what to do when you have those feelings.”—
P4, FG6, February 2021

3.1.3 | Impacts of COVID-19 on the social health of individuals with DS

Surveyed parents affirmed that COVID-19 negatively impacted socialization; 66% of parents of Black children with DS and 54% of parents who are primarily Spanish speaking felt the pandemic had at least a somewhat serious impact on the ability of their loved one with DS to connect with family and friends (Krell et al., 2023). Individuals with DS in FGs confirmed that COVID-19-related activity restrictions limited

their opportunities to socialize, especially with their friends. One individual mentioned that she had been spending time only with her family because of COVID-19; another individual discussed how COVID-19 restricted their indoor activities with peers: “For swimming, I can't do that simply because of COVID” (D4, FG4, March 2021). However, individuals with DS demonstrated resilience and described attempts to mitigate these negative social effects of the pandemic by engaging in different activities (such as switching from swimming to dance) and by changing how they spent time with friends (such as meeting friends outside, using FaceTime to communicate, and using social media more).

Parents in FGs discussed how COVID-19 impacted their child's schooling, socialization, and therapy. School was often modified or transitioned to virtual learning; multiple parents discussed the negative effects of this on their child's socialization.

“My son is still a senior in high school. It's COVID so he's not going ... I would have concerns ... because he will not have a normal school social network”—P3, FG7, February 2021

Parents noted that they were able to see the consequences of social isolation including increased behavior issues and defiance as well as speech regression. One parent stated that their child “thrives in the social aspect more so COVID about crushed her” (P6, FG6, February 2021). Parents wondered how reduced social interaction through canceled activities and the shift to online learning would impact their child's emotional health and long-term development.

“The kids aren't really socializing because they're not used to it. They're kindergartners. [I'm] worrying about how that will impact her long term. And she's such a social kid that I worry about how that affects her emotionally.”—P4, FG8, December 2020

Multiple parents reported that the negative impact of the pandemic on socialization was less pronounced for individuals with DS who had a sibling with whom they could interact, stating that having a sister or brother was “super helpful, especially since he's not going to daycare right now and [is] pretty isolated with friends” (P4, FG1, November 2020). For parents of children with DS who do not have siblings, their isolation was more salient, and parents had to weigh the benefits of increased socialization against the risk of COVID-19 infection:

“I could tell that she was... not doing as great mentally without having that social interaction ... there's the risk of physical- like COVID risk as well, but we just felt like that social interaction was really important for her and her development”—P7, FG1, November 2020

3.1.4 | Impacts of COVID-19 on parents of individuals with DS

Among surveyed parents, 53% of parents of Black children with DS and 51% of parents who are primarily Spanish speaking confirmed that the pandemic was having at least a somewhat serious impact on their own work/employment (Krell et al., 2023). This was expanded on in the FGs, where parents discussed the financial stressors of COVID-19 and “concerns around losing their jobs” (P2, FG1, November 2020). One parent noted housing instability:

“My landlord just recently gave me a letter saying that they were not going to renew my lease ... Now, I'm at a standstill. Where am I going to go with my son and me?... on top of not only my son's medical issues ... I got housing issues”—P5, FG1, November 2020

While these stressors were discussed in FGs as impacting the parent themselves, the ripple effect of insecure housing or decreases to

income impacted the whole family unit, including their children with DS.

In the survey, 63% of parents of Black children with DS and 56% of parents who are primarily Spanish speaking reported at least a somewhat serious increase in their own anxiety or depression (Figures 1 and 2) (Krell et al., 2023). Parents in FGs noted added anxiety from fear of their child contracting COVID-19, as well as financial and housing considerations noted above. Parents discussed having heightened anxiety that their child's DS-related comorbidities could increase their risk of complications should they acquire a respiratory virus like COVID-19. For example, one parent said “prior to COVID [I] wouldn't maybe have been as stressed out about a runny nose or anything that seemed just to be like a mild cold symptom but now it just seems like everything is cause for alarm” (P7, FG1, November 2020). Anxieties were mitigated by having a plan to treat their child should they become infected and having a strong relationship with their pediatrician.

“We have had severe airway inflammation issues that have hospitalized her ... so my anxiety comes in not just with the current coronavirus, but in the past ... any upper respiratory ... okay, I've got the breathing treatment. I've got this, I've got that ... by doing that planning and having a good relationship with my pediatrician, I'm able to find confidence and comfort in being prepared”—P2, FG8, December 2020

Only parents in FGs brought up the impact of decreased access to in-person medical services and schooling during the pandemic. Some parents found the transition to virtual appointments was beneficial because it reduced driving time and eased scheduling. However, other parents described online therapies (such as physical therapy, occupational therapy, and speech language therapy) as less effective when delivered online. To facilitate online instruction or replace services that were canceled altogether, some parents had to assume the role of an untrained therapist to maintain their child's development. As one parent stated, they “have to be a therapist ... I know prompting. I know sign language. I know PT” (P2, FG1, November 2020). Similarly, parents were expected to take larger roles in their child's schooling. For some, the transition to online learning and ability to be present during class allowed them to be more active in advocating for their child's learning. For other parents, especially with less flexible work schedules, the increased responsibilities were more difficult to manage. One parent noted, “I'm still working full time, I couldn't keep her engaged, doing things. So, like I said, it ended up being a lot of screen time” (P7, FG8, December 2020).

4 | DISCUSSION

During the COVID-19 pandemic, from November of 2020 to October of 2021, eight FGs were conducted with parents and individuals with DS, and a survey containing COVID-specific questions was administered to parents who had children with DS who were Black, African

American, of African descent, of mixed race, or were from primarily Spanish-speaking households. FG participants repeatedly and spontaneously discussed the social, emotional, and physical health impact that COVID-19 had on individuals with DS and their families, while survey participants endorsed the salient impact of the pandemic on parents.

The impacts of the COVID-19 pandemic on health were particularly evident, and concordant with our previous findings that some aspects of health maintenance worsened during the pandemic (Santoro, Howe, et al., 2023). In this study, individuals with DS in FGs mentioned that they had been masking and washing/sanitizing hands, which parents endorsed and largely considered a positive outcome of the pandemic. Conversely, difficulties in masking due to sensory issues and social stigma from not masking resulted in the expressed need for alternatives such as a face shield. Indeed, other reports show that individuals with DS may struggle with masking due to sensory issues or communication barriers (Hartley et al., 2022). Increased accessibility to mask alternatives, such as shields, and a more robust conversation around inclusive infection prevention could benefit individuals with DS and their families to mitigate COVID-19 risk while decreasing the stigma surrounding mask alternatives.

Individuals with DS were impacted by virtual schooling, limited activities, and decreased socialization throughout the pandemic. While there is a lack of previous self-report studies of individuals with DS (Santoro et al., 2022), we report views that are similar to Villani et al. (2020) regarding the impact on education and social skills with worsened social withdrawal in adults with DS during the pandemic. Socialization is particularly relevant for individuals with DS given the increased risk of dementia (Lott & Head, 2019) which can, in part, be mitigated by socialization (Agaronnik et al., 2019; Livingston et al., 2020). Decreased socialization was endorsed by all groups including individuals with DS, FG parents of individuals with DS, and surveyed parents of individuals with DS. A majority of parents who had Black children with DS or were primarily Spanish-speaking felt that the COVID-19 pandemic had somewhat seriously impacted their loved one's with DS' ability to connect with family and friends. Parents discussed weighing the risk of acquiring COVID-19 with the benefit of socialization as parents highlighted the importance of social interaction for their child's health and development. Indeed, positive social contact has been reported as a necessity for psychological and physical health (Baumeister & Leary, 1995). Further, researchers in Italy found that the COVID-19 pandemic induced lockdown resulted in increased social withdrawal and increased depression burden for individuals with DS, which might be attributed to social isolation (Villani et al., 2020). Participants with DS discussed modifications they made to maintain a social life such as shifting from in-person communication to phone-based communication including texting, FaceTime, and social media. As the COVID-19 pandemic wanes and resources begin to return, providing educational and social supports will be important to prioritize to address some of these concerns felt by individuals with DS.

Some therapies and means for socialization that were cited by FG parents as beneficial, like Gigi's Playhouse, an organization aimed at

providing free educational support, therapies, and career development for people with DS and their family (About Gigi's Playhouse. Inc, n.d.), adapted to the pandemic by creating a virtual platform. Gigi's Playhouse, which serves over 25,000 people with DS across the United States, created a virtual programming option in April of 2020 with Live and OnDemand programs as well as resources and information (GiGi's Playhouse Down Syndrome Achievement Centers, 2020). Transitioning educational and social resources to an online platform or hybrid would benefit individuals with DS and their families during the next possible pandemic or when returning to normal through the increased accessibility. As seen by Gigi's Playhouse, over 300 new families joined the community after the virtual option became available (GiGi's Playhouse Down Syndrome Achievement Centers, 2020).

Parents mentioned how the transition to online schooling was particularly impactful as it decreased socialization, decreased exercise, and increased time using electronics, which was perceived negatively by FG parents. This concern is reinforced by findings that state 43% of adults with DS either did not exercise or exercised 1–2 days per week during the pandemic (Hartley et al., 2022), and individuals with DS had a significant increase in sedentary behavior and screen time during the pandemic (Amatori et al., 2022) despite the benefits of exercise being well documented (Li et al., 2013; Rimmer et al., 2004).

For some, online schooling was beneficial as parents noted that they were able to better advocate for their child when direct observation of their learning was on view at home. Some parents saw the pandemic as an opportunity for their child to develop coping skills as they explored feelings like loneliness and communicated those emotions. Parents cited increased ease of scheduling virtual appointments as a benefit which aligns with our findings of positive views of telemedicine during the COVID-19 pandemic (Santoro, Donelan, et al., 2021). The shift online led to decreased adherence to preventative care measures, specifically audiograms, among patients with DS though rates later returned to baseline (Santoro, Howe, et al., 2023); this could be attributed to wariness in attending in-person visits at the start of the pandemic or testing site closure. Steps could be taken in the future to carry-over some of these benefits after the COVID-19 pandemic, such as continuing to offer telemedicine visits when appropriate, considering ways to virtually “visit” a child's classroom to bridge the gap between home and school, and continuing to explore and communicate a full range of emotions.

Parent participants in the FG and through the surveys discussed the negative impact of the pandemic on their own anxiety, employment, and housing. While these experiences are not specific to parents of individuals with DS, families of children with special health care needs have significantly heightened risk of housing insecurity (Ghosh & Parish, 2015; Rose-Jacobs et al., 2019) which can decrease mental and physical health of the parent (Guerrero et al., 2020; Suglia et al., 2011) and decrease the overall health (Ghosh & Parish, 2015; Rose-Jacobs et al., 2019) and academic performance (Barling et al., 1999) of the child. Caregivers of individuals with DS report higher anxiety compared to caregivers of individuals with different disabilities and caregivers of typically-developing individuals (Sideropoulos et al., 2023). Increased parental stress and anxiety has

been shown to negatively affect parent/child relationships and child well-being (Rose-Jacobs et al., 2019). Awareness of caregivers' mental health is important to consider in moving forward from the COVID-19 pandemic, and in preparation for future pandemic-like states. This may be especially important for parents of children with DS given the feeling of "having heightened anxiety" described by FG parents due to co-occurring conditions and perceived "increased risk of complications should they acquire a respiratory virus like COVID". While we now know that the mortality rate from COVID-19 is lower for children with DS compared to adults with DS (Hüls et al., 2021), the higher frequency of medical conditions that increase the risk for severe COVID-19 disease in individuals with DS (Bull, 2020; Korenberg et al., 1994; Palumbo & McDougle, 2018) likely fomented parental anxiety.

Importantly, families completing the survey were intentionally from diverse backgrounds, and the COVID-19 pandemic has disproportionately impacted individuals with disabilities (Jesus et al., 2021; Turk & Mitra, 2021) and racial and ethnic minority groups in the United States (Tai et al., 2021). When comparing the findings from the FGs, composed predominantly of white participants, to survey responses of parents who had children with DS who were Black or from primarily Spanish speaking households, the findings were largely similar. While the COVID-19 pandemic was repeatedly and spontaneously discussed among FGs indicating its salience to participants, it may not be as important as other concerns; less than half of the surveyed parents felt that the pandemic had at least a "somewhat serious" impact. Similarly, in a review of the top concerns caregivers of individuals with DS reported on pre-visit intake forms, COVID-19 constituted 1% of concerns (Cabrera et al., 2022), indicating a low level of concern surrounding COVID-19 compared to other health topics. Both groups reported COVID-19 as impacting parents anxiety and depression, caregiver work and employment, as well as the socialization of their loved one with DS. Of note, survey participants were asked about access to mental health services with 26% of parents who had Black children with DS and 34% of primarily Spanish-speaking parents reporting that the pandemic had at least a somewhat serious impact on access. This relatively low percentage may reflect access disparities that are independent of COVID-19 as racial and ethnic minorities have been reported to have less access to mental health services compared to white individuals regardless of a pandemic state (McGuire & Miranda, 2008). FG participants, who were predominantly white, were not specifically asked about access to mental health services as they relate to COVID-19 and did not discuss the topic spontaneously.

Our study is based on data collected from two larger studies with inherent differences in methodology. In the survey, the role of COVID-19 was asked about specifically in the context of a broader survey on the experience of underserved minorities in navigating the health care system; in the FGs, this was discussed spontaneously. Without consistently and directly asking all FGs preestablished questions regarding the COVID-19 pandemic, it is possible that we have not fully captured views from all participants on how the COVID-19 pandemic impacted health. Similarly, if survey respondents had been asked open-ended questions or participated in FGs, we would be able to compare findings to a larger extent. However, we feel that clear

themes have emerged which, although captured in two ways, provide important information on the impacts of the COVID-19 pandemic. Our sampling plan has possible limitations; while we recruited through all of the available resources in the DS community, the findings may not generalize to the greater population of caregivers of people with DS who are Black, African American, or primarily Spanish-speaking given the small sample size. It is possible that the same participant completed the survey and participated in a FG, as we did not collect the names of survey participants to cross reference with FG participants. Although DS-Connect is a large national database, our recruitment methods may not have captured all families types resulting in associated selection bias. Our two studies may not generalize to all people with DS and their families, but we feel that our research survey of diverse families is especially important to share despite this limitation.

Further exploration of the impact of COVID-19 and pandemic-like states, including quarantine and isolation, on caregivers of individuals with DS would be beneficial in finding ways to mitigate stress and improve well-being of both caregivers and individuals with DS. Future study may further expand upon our results by evaluating how white caregivers of individuals with DS perceived fluctuating access to mental health care during the pandemic compared to African American and primarily Spanish-speaking caregivers. Future study could also investigate the extent to which a strong relationship with a pediatrician mitigated concerns during COVID. Further analysis of the impact of race on access to health care services for individuals with DS and their families would allow for increased awareness of the implicit or explicit barriers to health.

In summary, we found the COVID-19 pandemic had impacts on broad aspects of health of individuals with DS. We aimed to identify the aspects of health which would benefit from additional resources, support, and prioritization as the COVID-19 pandemic wanes. Our results demonstrate the educational and social impact of COVID-19 felt by individuals with DS, the mental health impact on caregivers, and the caregiver-perceived impact on the mental, physical, and social health of their loved ones with DS. These are important considerations in preparation for future pandemics and as families and communities recover from COVID-19. The transition to online schooling was a concern for parents of individuals with DS largely due to their child's decreased socialization, confirming parental and caregiver awareness of the value of socialization especially for individuals with DS. The added anxiety of a pandemic for caregivers of individuals with DS, a cohort who at baseline have increased stress burden compared to the general population (Barros et al., 2017; Hart & Neil, 2021), highlights the necessity of additional support. Caregivers of individuals with disabilities have found that they have inadequate support (Hart & Neil, 2021) with parent caregivers of children with disabilities citing a lack of access to information and services, financial barriers, school and community, and family support as barriers to parent well-being (Resch et al., 2010). Lack of access and support for caregivers has been compounded by the pandemic. Knowledge of requisite support systems and barriers to caregiver well-being is crucial in addressing pandemic heightened anxiety of caregivers both for caregivers and their loved ones.

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CONFLICT OF INTEREST STATEMENT

SLS has received research funding from LuMind IDSC Down Syndrome Foundation to conduct clinical trials for people with DS within the past two years. She serves in a non-paid capacity on the Medical and Scientific Advisory Council of the Massachusetts Down Syndrome Congress, the Board of Directors of the Down Syndrome Medical Interest Group (DSMIG-USA), and the Executive Committee of the American Academy of Pediatrics Council on Genetics.

BGS occasionally consults on the topic of DS through Gerson Lehrman Group. He receives remuneration from DS non-profit organizations for speaking engagements and associated travel expenses. This past year, Dr. Skotko received annual royalties from Woodbine House, Inc., for the publication of his book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*. Within the past two years, he has received research funding from F. Hoffmann-La Roche, Inc., AC Immune, and LuMind IDSC Down Syndrome Foundation to conduct clinical trials for people with DS. Dr. Skotko is occasionally asked to serve as an expert witness for legal cases where DS is discussed. Dr. Skotko serves in a non-paid capacity on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress and the Professional Advisory Committee for the National Center for Prenatal and Postnatal Down Syndrome Resources. Dr. Skotko has a sister with DS.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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