

Research Articles and Essays

The Lived Experiences of People with Disabilities During COVID-19

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Societal crises—whether natural disasters, deadly viruses, or mass shootings publicly reveal the deeply embedded attitudinal, interpersonal, and structural forms of oppression that plague our communities living with identities or backgrounds maltreated by society. COVID-19 laid bare the deleterious and dehumanizing effects of ableism on our disabled communities (Pulrang, 2020). While not unexpected by disabled people, the devaluation of our disabled communities during COVID-19 is profoundly disturbing, reflecting persistent and intractable ableist policies, practices, and norms (Andrews et al., 2019; Lund & Ayers, 2020; Lund et al., 2020). To be clear, ableism is the social devaluation of disabled people and its coinciding forms of oppressions (Jampet, 2018). Within the context of COVID-19, ableism spotlighted, most broadly, (a) eugenics—or the more palatable terms, “care rationing” or “ventilator-rationing” (Andrews et al., 2019; Lund & Ayers, 2020), (b) inequitable emergency response policies and practices (International Disability Alliance, 2020), and (c) negative attitudes regarding the overall health status and quality of life of people with disabilities, namely, that disabled people have poor health and low quality of life (Scully, 2020). Moreover, disability often intersects with other oppressed identities and positions with many disabled people experiencing multiple, intersecting forms of oppressions (e.g., ableism, ageism, racism, and classism). Specifically, people with disabilities are more likely to be older adults, African Americans or Native Americans, females, living in poverty, unemployed or underemployed, and less likely to attend or have graduated from college (National Disability Institute, 2019).

While the preponderance of disability and COVID-19-related articles highlight the deleterious impacts of structural ableism and other intersecting forms of oppression on our disabled communities during the pandemic, fewer studies seek to understand the COVID-19 experience through the lens of disabled people. Aligned with the disability justice framework, or the social movement to end ableism in conjunction with ending other systems of oppression (Sins Invalid, 2018), the experiences of disabled communities within any context must be understood through the voices of those most impacted (Sins Invalid, 2018). Moreover, sources of change, access, and collective liberation among our disabled communities is rooted not the provision of care through non-hierarchical and non-capitalistic webs of care and support. According to d-Samarasinha (2018), mutual aid and exchanges of care among precolonial brown, Black, and Indigenous communities occurred long before social work and charity models were in place. Using the disability justice framework as a guide, our study sought to describe the lived experiences of disabled people during the COVID-19 pandemic. Specifically, we asked participants to describe in their own words their experiences with COVID-19. Our study sought to deepen counselor and allied professionals' understanding of the experiences of our disabled communities during the pandemic to learn from their lived experiences and guide present-day preparedness for future crises and disasters.

Method

Participants

Participants had a mean age of 28.7 ($SD = 10.2$). More than half the sample were assigned female sex at birth (68.1%), were cis women (those whose gender identity matches the sex they were assigned at birth) (54%), and identified as heterosexual (54.9%). Regarding race, 71.5% reported one racial background and 16.7% reported two or more racial

backgrounds (12.5% had two racial backgrounds and 4.2% had three or more racial backgrounds). Of the 71.5% with one racial background, 45.1% were White, 13.9% Hispanic or Latinx (7.6% Hispanic, 6.3% Latinx), 9.8% Asian (4.9% East Asian, 2.8% South Asian, 2.1% Southeast Asian), 9% Black or African American (5.5% Black, 3.5% African American), 0.7% Indigenous, 0.7% Middle Eastern, and 0.7% Native Hawaiian or Pacific Islander. Participants had a mean of 16.2 ($SD = 2.3$) years of education and annual income of \$30,770 ($SD = 42,809$). Nearly half of our participants (48.5%) had fixed incomes (i.e., SSI, SSDI, GA, or unemployment), 47.9% received employment income, and 27.9% were supported by family. Most of our participants reside on the West Coast (74.6%) in urban (51.8%) or suburban areas (46.1%). Except for one participant, all participants (94.4%) who responded reported having a disability as defined by the World Health Organization (2023). Most of our participants reported experiencing disability in the social realm (80.6%), workplace (77.6%), school (77.6%), and community participation (55%). On average, participants had 2.1 ($SD = 1.2$) health or mental health conditions and had lived with their condition(s) for an average of 16.2 ($SD = 13.1$) years. Participants reported living with psychiatric conditions (56.5%), physical conditions (39.7%), neurodevelopmental conditions (34.7%), neurological conditions (16.1%), autoimmune conditions (10.5%), and visual or hearing impairments (4%). During COVID-19, 40.7% were employed full-time or part-time and 39.3% were unemployed. Prior to COVID-19, 56.2% were employed full-time or part-time and 25.2% were unemployed. Our sample included 27.3% participants who were essential workers. Almost half of our sample owned a home or an apartment (47.5%) and 29.8% were renting a home or apartment. Most participants lived with family (50.3%), 22.6% lived with a spouse or partner, 15.8% lived with friends or a roommate, and 11.5% lived alone. Participants lived with an average of 3.4 ($SD = 1.7$) people and 28.1% needed in-home

care support. A majority of our sample reported being a member of one or more historically marginalized communities (76.2%).

Table 1

Participant Characteristics (n = 168)

Variable	<i>M</i>	<i>SD</i>	<i>n</i>	<i>%</i>
Age	28.7	10.2		
Sex or Gender*				
Assigned Female at Birth				68.1%
Cis female				54%
Heterosexual				54.9%
Race/Ethnicity				
One Racial Background				71.5%
Black or African American				9%
Asian or Pacific Islander				9.8%
Hispanic or Latino/a				13.9%
Native American				.7%
White				45.1%
Multiracial				16.7%
Two races				12.5%
Three or more races				4.2%
Education	16.2	2.3		
Annual Income	\$30,770	42,809		
Fixed Income				48.5%
Employment Income				47.9%
Supported by family				27.9%
Place of Residence				
West Coast				74.6%
Urban				51.8%
Suburban				46.1%
Disability				94.4%
Social disability				80.6%
Workplace disability				77.6%
School				77.6%
Community Participation				55%
Number of health or mental health conditions	2.1	1.2		
Number of years living with condition(s)	16.	3.1		
	2			
Psychiatric conditions				56.5%
Physical conditions				39.7%
Neurodevelopmental conditions				34.9%
Autoimmune conditions				10.5%
Visual or hearing impairments				4%
Employment Status During Covid				
Full time				40.7%
Part time				39.3%
Employment Status Prior to Covid				56.2%
Full time				56.2%
Part Time				25.1%
Essential workers				27.3%
Living Arrangement				

Owned home or apartment	47.5%
Renting a home or apartment	29.8%
Living with family	50.3%
Living with spouse	22.6%
Living with friend or roommate	15.8%
Living alone	11.5%
Needed in home care support	28.5%

Procedure

The study was approved by the authors' academic institution's Institutional Review Board. The research team consisted of two professors and two graduate students. The professors developed the research survey, recruited study participants, and collected and input data into SPSS and Excel. Participant recruitment and data collection occurred from April 5–May 18, 2021. The survey was closed once the researchers reached their compensation limit of \$4,500. Participants were recruited via email invitation disseminated by Independent Living Centers in California and Disability Programs and Services at California State University settings. The body of the email invitation included: (a) brief description of the study, (b) eligibility criteria, (c) \$25 compensation statement, (d) disability access statement, (e) researchers' names, roles, and emails; and (f) the Institutional Review Board's study protocol and phone number. Eligibility criteria included: (a) being age 18 or older, (b) living with a disabling health or behavioral health condition, and (c) being able to read, understand, and write in English. Persons consenting to participate in the study clicked the option "I consent to participate in this research study." Upon consent, participants were then moved to the survey questions. Captcha questions were sprinkled throughout the survey to ensure human participation. Participants were able to complete the survey at their leisure, stopping and re-starting as needed. The average survey completion time was 42 minutes, with completion times ranging from 20 minutes to four hours.

Upon survey completion, participants clicked “submit,” allowing the survey data to record into the first author’s Qualtrics XM software folder. All data was transferred from Qualtrics into an Excel file. The quantitative data was then input into SPSS and the qualitative data was input into a separate Excel file for coding. The Qualtrics, SPSS, and Excel files are secured by a two-factor authentication password process managed by the authors’ university. In addition, the Qualtrics survey was further secured by allowing access to only those receiving the invitation, providing an anonymous survey link, anonymizing responses (e.g., no record of IP address, location data, and contact information), and disabling the multiple submission and indexing features. Once the survey was submitted by a participant, a post-survey message occurred thanking the individual for their participation and providing specific directions for requesting the \$25 compensation. To receive compensation and ensure participant responses were decoupled from the compensation request, participants were asked to send an email to the first author with “SURVCOM21” in the subject line. Upon receipt of the email, a \$25 Amazon gift card was sent electronically to the participant within 24 hours of receipt of compensation request email. All emails received from participants were stored in a two-factor authenticated password protected email file in Outlook until an email from Amazon was received by the first author noting the gift card was delivered and received. Once received, the email was deleted from the researcher’s computer.

Measures

Our primary measure used to investigate the lived experiences of participants during COVID-19 was a qualitative inquiry that asked participants to respond to the following question: “Please describe in your own words your experience with COVID-19.” Participants typed their responses directly into the survey. In addition, participants were asked to respond to 25 demographic, disability-related, and healthcare access/quality questions. Participants

were also asked to rate their level of daily stress in general, level of stress as it relates to COVID-19, and level of stress as it relates to specific areas including: (a) basic living stress (e.g., food, shelter, clothing), (b) health/symptom management stress, (c) financial stress, (d) transportation stress, (e) isolation stress, (f) healthcare stress, and (g) parenting and relationship stress. Participants were also asked to rate the impact of COVID-19 on their life and their level of preparedness. Participants rated these areas on a 10-point ratio scale with possible scores ranging from 0 (not stressed at all) to 10 (extremely stressed).

Data Analysis

Quantitative data was analyzed using descriptive statistics to analyze our sample and to describe the level of stress and preparedness. Qualitative data was analyzed using the content analysis method of Krippendorff (2004). Content analysis is systematic and replicable, and distills written, verbal, or visual communication into content categories with explicit procedures for coding raw data (Stemler, 2001). Researchers can derive captured meanings, intentions, consequences, and contexts of communications (i.e., images, videotapes, and text) using an inductive or deductive content analysis, depending on the purpose of the study (Elo & Kyngas, 2008). For this study, we employed an inductive content analysis (i.e., emergent coding) due to the lack of previous information on the topic of interest. An inductive content analysis moves from a specific to a general analysis, and individual responses are coded and then combined into a larger statement (Chinn & Kramer, 2014). The inductive content analysis involves five steps to organize and code the data, including (a) open coding, (b) the development of coding sheets (i.e., coding protocol), (c) grouping, (d) categorization, and (e) abstraction (Elo & Kyngas, 2008). In this study, we developed our coding sheets or coding protocol after initial groupings and categorization had occurred. We approached our study in the following order: (a) open coding, (b) grouping, (c)

categorization, (d) coding sheets/protocol, and (e) abstraction. Microsoft Excel was used to organize and code the participant responses to the open-ended question using the five-step process for content analysis.

In the first step, the open coding process allowed the researchers to freely explore meanings and actions found in the text by coding each word, sentence, or segment of the data (Charmaz, 2006). Two coauthors, who are well trained in qualitative research, and two graduate students individually analyzed the text responses by coding the text line by line, and categories were freely generated at this stage. Second, the researchers met multiple times to discuss meanings and patterns in the text and group the data. Third, similar categories were collapsed into higher-order categories to eliminate any outliers or irrelevant categories. The researchers continued to meet to discuss interpretations of the data and compared relationships between categories until consensus was reached. The grouping and categorization process occurred over several meetings and included consultation with an external auditor to reconcile any overlap or differences in the categories coded. Fourth, the researchers developed a coding protocol and used this protocol (i.e., consolidated coding checklist) to independently apply the coding to the text responses. The researchers checked the reliability of the coding and repeated the previous steps until reliability was reached and then applied the coding protocol to the entire data set. Fifth, during the abstraction process, several broad themes and mutually exclusive subcategories were generated from the coding protocol. The researchers continued to follow an exhaustive process of meeting regularly to compare categories and relationship between categories and themes.

Credibility

Credibility establishes that the interpretation of the meaning of the data is accurate and believable (Creswell & Creswell, 2017). To confirm credibility, data collection, analysis

and findings are systematically described in the research process (Creswell & Creswell, 2017). In this study, peer debriefings and an external audit, which are commonly used by qualitative researchers, were conducted. A question-and-answer process between the external auditor and researchers was used to evaluate the research process and findings. For peer debriefing, a qualitative researcher was invited to review and provide critical feedback on data collection and analysis, findings, and interpretations. While reviewing the methodology of the study, our peer asked several questions about coding procedures (e.g., What is your coding protocol?) and findings (e.g., How can you identify patterns and relationships among your findings?). The peer confirmed that coding procedures and findings were systematically grounded in this study. The external auditor, a professor with no connection to the study, was invited to examine whether findings and interpretations are supported by the data. The external auditor requested to observe the coding process. While reviewing the coding process, the auditor had several questions about data analysis (e.g., What do the data say to you?) and interpretation (e.g., What does it mean to you?). Our auditor confirmed that findings and interpretations were believable in this study.

Results

Findings revealed the following nine themes: a) social isolation, b) social responsibility, c) returning home, d) barriers to resources, e) job loss, f) positive impacts, g) academic impacts, h) emotional and physical impacts, and i) adjustment and coping.

Social Isolation

Social isolation was described as losing contact, feeling alienated and being disconnected from people, places and support networks, and was accompanied by negative emotions. For example, one participant noted, “the isolation from friends and family is my worst part. Second-worst is the amount of alienation I feel at school (I’m a teacher) and

disconnect from my students.” Another participant stated, “I did not have any real time contact with friends or family as most of them drifted away and lost contact with me and my family.” A participant also described the negative emotions, or subjective experience of social isolation, stating:

“Because of the lack of socializing, I have become very depressed not being able to even sit at a coffee shop and do homework has been really hard...as humans we crave human interaction and without it, life doesn't feel as meaningful.”

Similarly, a participant described the negative impact of social isolation on their sense of being cared for, their ability to trust others, and becoming less comfortable opening up to others, stating:

“It has been really difficult to not have more of an external support system. None of my friends checked in on me Covid has made me a bit more introverted than I used to be because it's hard to talk about my health and trust people.”

Isolation was also described to include periods of sensory deprivation whereby participants described the loss of sensorial connection to others—through sight, hearing, smell or touch—reduced the scope of information taken in to make sense of oneself and the world. For example, one participant stated, “being isolated has led me to being in my head even more than before,” and another noted how “the mask can keep you from life interaction.” Finally, isolation was also described to include physical confinement or being restricted to a physical space or specific people, that contributes to emotional and physical discomfort. For example, several participants described being confined to small spaces, stating “because of Covid-19, I am stuck in

my small room” and “I never leave my room since our house is small and is basically an office.” Others described being trapped or stuck in their homes, with specific family members, in traumatic spaces, or restricted to a particular geographical area. For example, several participants described being confined to specific family members, stating “it is very isolating being here with family, not being able to go anywhere much,” and “I am an in-home care provider for my 83-year-old mother-in-law who lives with me and my spouse. I have income but I feel trapped here and can’t get a break.” Participants described being trapped in their home and in traumatic spaces. For example, one participant stated, “I stayed home for most of 2020 without really going out,” and another noted “now I have no separation...it feels like I'm stuck in a physically negative space (literally sleeping in the room my childhood traumas took place in).” Finally, a participant described “being confined to my urban neighborhood and not being able to be in nature was hard on both my body and mental state.”

Social Responsibility

Social responsibility was defined by participants as being accountable for taking COVID-19 safety precautions for the welfare of themselves and others. Specifically, participants described social responsibility to include practicing social distancing, masking, and accepting—versus denying—the seriousness of COVID-19. For example, one participant stated, “it's the burden involving what is essential, how to get groceries, what is safe for myself, what can I do to increase safety for others.” Participants also shared that social responsibility was particularly critical to themselves and/or their families because of pre-existing health conditions. For example, one participant noted “because of my and my family's health issues, we have

been extremely cautious to only leave the house for necessary food and groceries, to always send the healthiest person, and to double-mask.” Another participant stated, “I have a family of five, three of which are immunocompromised. Like almost everyone, extended family is practicing social distancing.” Participants described experiencing worry, frustration, discomfort, and a sense of aloneness in response to the lack of social responsibility by others who denied the existence or trivialized the severity of COVID-19, resisted public health orders, and/or may have scapegoated Asian American and Pacific Islander communities for COVID-19. For example, participants shared feelings of “discomfort and frustration aboard public transit due to forgetful and resistant passengers who board without mask,” being “worried caregivers are not taking illness seriously,” and “it has been terrifying to see people deny Covid, not take precautions, blame AAPI people etc.” Participants also described how others did not take COVID-19 seriously, and/or did not follow public health orders. For example, one participant noted “no one enforces the rules, so we're pretty much on our own to keep ourselves safe,” and another participant shared “before, when people wore their masks without complaint, I could at least continue at work. But then that change[d], people stopped taking things as seriously, putting me at risk, so I had to stop working because it wasn't safe anymore.” Finally, a participant described how the impact of COVID-19 was easier on those with resources, reducing its seriousness:

“She’s [roommate] now home all the time. She has access to resources I don't that have made her experience of the pandemic easier and more comfortable. This has given her the impression that it isn't as serious as it is—which has meant problems with encountering her and workers she's hired unmasked & not distancing.”

Returning Home

Returning home during the pandemic was a common theme for many participants. Specifically, participants described returning home as a sudden, psychologically impactful transition. For example, many participants described the unexpected, negative experience of moving home, including such statements as: “When the pandemic first hit, I moved back in with my family, which was/is not good because they are toxic”; “With the shelter in place, it affected my mental health a lot with me having to move home so suddenly”; “The stress of living with my immediate family has made it increasingly hard to manage my depression and anxiety and hence, productive in my daily life”; “Then I moved back home with my family. However, it was a small apartment, and my family was overly critical of me which really hurt my mental health”; “It has been awful. I had to move back in with my parents, and they both work from home. I never leave my room . . .”; and “Now I have no separation it feels like I'm stuck in a physically negative space (literally sleeping in the room my childhood traumas took place in).” Notably, most participants described returning home as an abrupt, negative experience.

Barriers to Resources

Barriers to resources was another theme described by study participants. Specifically, participants described the significant impact of COVID-19 on accessing essential services including in-home care, medical care not related COVID-19, mental healthcare, dental care, prescriptions, transportation, and health insurance. Several participants described how the dire nature of COVID-19 impacted their health and functioning. For example, one participant described the potentially life-threatening impact of COVID-19 on their in-home care:

“I rely on eight caregivers seven days a week, 24 hours a day. I use a ventilator 24 hours a day. Covid created barriers on my access to my

health care workers. Many were exposed to covid. I had to juggle all my workers constantly.”

Another participant described the significant impact of COVID-19 on timely access to essential vision care stating,

“Instead of being able to see a doctor in a week, or two I have had to wait up to three months. In those three months, I almost went blind and had to have emergency surgery to be able to keep my sight.”

Similarly, a participant described the impact of COVID-19 on timely access to healthcare for epilepsy, stating “it’s difficult to get access to my healthcare workers that deal with my Epilepsy Seizures. It takes more time to actually get an appointment, because COVID has become the main focus that my doctors are treating.” Other participants described difficulties accessing quality, in-person health and dental care. For example, one participant stated “it’s been difficult for me to receive full and accessible health and dental care, which has had me going through many trials and tribulations to find what works best for me.” Another participant noted “my quality of healthcare has decreased due to the limited access to in-person health services.” Yet another shared “it was really difficult to make in person appointment with my healthcare provider as offices were closed in the beginning.” Finally, participants described difficulty accessing mental health care with one participant stating, “I have not been able to get a therapy session since all the therapists in my county are not accepting new clients.” Another shared:

“My mental health took a drastic toll on me. It’s been 2 years now since I’ve had a therapist because I rely on Medi-Cal as my insurance and COVID-19 has made it difficult to get a hold of government offices.”

Job Loss

Job loss and income instability was another common theme among study participants. Participants described unexpected job loss and its negative impacts on paying bills, housing stability, mental health, and healthcare access. For example, one participant noted:

“It has been hard being able to take care of myself. I’ve lost my job, which gave me the access to healthcare, and I couldn’t seek the help I need since health insurance takes a while to kick in. Paying for bills also took a toll on me. I had to miss multiple payments because of not having enough funds to pay for it.”

Other participants described the negative impacts of job loss, for example, participants stated, “It’s terrible, I lost most of my job, and I almost lost my place.” Another said, “I am barely making ends meet.” A third said “with unemployment, I couldn’t really afford these services anymore.” Finally, one participant noted the impact of job loss on finances and mental health stating, “when I lost my teaching job finances became very tight. Not working for months took a large toll on my mental health.” Participants also described job loss as a primary consequence of COVID-19 stating, “the main effect COVID-19 has had on me is my loss of a job in theatre,” and “work life is very affected.” Another participant described the depth to which COVID-19 had on their career, stating, “I lost a lot from Covid. I lost my fashion brand. I lost my job.” Most participants described job loss because of layoffs from their place of employment. For example, one participant noted, “I planned to teach, and teachers are being laid off in droves.” Another stated “because I have intermittent mental illness, under the influence of covid, the company had to lay me off to reduce the pressure of the company.” Still another reported, “I was doing pet care to supplement my social security and that work evaporated.”

Positive Impacts

Participants defined the positive impacts of the pandemic as salutogenic (staying well during periods of stress) or described resources and benefits that occurred in the face of the pandemic. Participants described pandemic-related resources to include occupational, financial, personal, psychological and disability-related assets, and strengths and motivations. For example, several participants described the occupational benefits that emerged during the pandemic. One participant stated, "I quit that job ASAP and started my own company." One participant described an opportunity: "I was furloughed due to the COVID-19 pandemic but took the opportunity to attend grad school."

Others described a healthier work experience. For example, participants stated: "Covid-19 has helped my work life balance" and "I also work alone more often these days which I sometimes get bored of, but it is also a lot less stressful than when I worked with my bosses nearby. And I feel just as productive." Financial resources were also noted, with participants sharing "the stimulus was used for investments have given me a high return. Working from home had saved me a lot of money." Another shared: "When I gained unemployment benefits, I was making a lot more than I did before." Participants also described the personal and psychological benefits that emerged during the pandemic, including establishing boundaries, self-awareness, self-care, asking for help, and increased self-efficacy. One participant shared, "I love that I have learned to take care of myself and learn to say no to people," and another participant noted, "It helped me reconnect with myself and learn how to better take care of myself." One participant poignantly described the personal and psychological salutogenic effects of the pandemic stating:

"I've grown and at times thrived. but it's also taught me how precious life is, and how being alone in life doesn't mean that there isn't value

and light to be found. I've started to learn how to live for myself and why that's important, and I've also learned that asking for and needing support isn't something to be ashamed of. All in all, this has been one of the hardest years of my life, but I have found the light in the darkness, and I've found confidence in my ability to get through things that seem impossible.”

Participants also described how pandemic-related stressors had positive impacts on living with a disability. For example, one participant noted: “In some ways it made it better for some of us with disabilities because everything moved to Zoom, I didn’t need to deal with events where people use fragrance and was spending less time getting to events.” Similarly, another participant shared:

“In some ways, it has been a lot easier to manage my sensory processing issues during the pandemic. I can be home a lot more where I can better control the environment to my needs (temperature control, being able to change my clothes easily when needed, ability to snack throughout the day).”

Other participants described how the easing of pandemic-related stressors allowed for a healthier pace and energy conservation, stating “mostly, it has decreased stress around having enough energy to go places and get things done” and “COVID-19 aided me in better understanding my conditions and how I need slower paced learning.” Finally, participants described how the pandemic fostered participants’ ability to pursue interests and goals and gain self-efficacy. For example, several participants described pursuing personal goals/interests: “On the brighter side, I learned how to drive and got my driver's license and a car.” Another noted, “I'm exercising way more and getting out in nature more.” Other

participants described a sense of self-efficacy and pride in pursuing personally meaningful goals/activities. For example, one participant shared, “I’ve done well in school due to online classes,” and another noted, “it has been both a great opportunity to refocus my energy on my academics and improving my marketability for internships and the future labor force by taking on more leadership positions/projects as well.”

Academic Impacts

Participants described academic impacts as physical, psychological, and cognitive difficulties occurred during the pandemic as well as environmental and disability-related academic stressors. Specifically, participants described a loss of motivation towards school, a sense of isolation related to remote learning, anger and sadness linked to the loss of the expected college experience, feeling misunderstood by faculty, and having reduced attention, concentration and task completion. For example, participants described difficulty with focus and motivation stating, “in terms of school, my ability to focus was negligible and my motivation was nonexistent,” “learning online has been a struggle to stay focused, and “. . . I have had to delay my master's program a little, it is really hard to concentrate.” One participant described how difficult it was to complete homework tasks stating, “It has been brutally difficult to write or finish homework.” Participants also described negative feelings related to remote learning and the loss of the college experience. For example, one participant described feeling isolated, stating “the isolating factor took some getting used to and it showed itself most with the inability to adapt well to online schooling.” Another participant described sadness and anger towards the loss of their college experience, sharing “my last year of undergrad were stolen away from me. When I heard we would not be having an in-person graduation, I was so sad. I also felt robbed of my experiences during my last year.” Participants also described how academic impacts intersected with disability. For example,

one participant shared that “being forced to take classes online was stressful. I'm dyslexic, so in-person instruction is important, I tried waiting this out, but unfortunately, it went on too long and I'm just struggling now to keep my head above water.” Similarly, participants shared “because of my learning disability, I normally ask a lot of questions to my professors to understand a new material. But because of Covid-19, it has been very challenging to do so” and “my ADHD did not mesh well here.” One participant described the physical consequences of online learning stating: “It was stressful because school was online making it difficult for me to learn as it caused more migraines.” Participants also described academic impacts linked to such environmental factors as online learning and physical space. Participants also described feeling both misunderstood and a lack of support from their course instructors. For example, one participant noted, “The workload has been insane, and sometimes I wonder if some of my professors do not understand what we as students are going through.” Another participant shared, “It’s very hard to be able to be in contact with professors as some do not reply at all.” A third participant shared:

“School, though, was the worst. Many faculty said they were understanding but heavily penalized me for late work even when flexible due dates was part of my accommodation. Between the illness and lack of understanding & compassion from a faculty member, I felt stressed and wondered why I was even in school.”

Finally, participants described the academic impacts of loss of space and being in community. For example, one participant noted, “COVID-19 has been challenging for some students who don't have extra space and quiet places to do work and due to the Pandemic.” Another shared “not being able to even sit at a coffee shop and do homework has been really hard.”

Health and Mental Health Impacts

Participants described health and mental health impacts as part of another theme.

Mental health impacts were described as negative thoughts, feelings, and behaviors that occurred or worsened because of pandemic-related phenomena. For example, one participant described how COVID-19 contributed to behavior changes, worsening of mood, and having an overall deleterious impact on their life.

“I reverted back to more dependent behavior, and I experienced an increase in depression because I no longer had to keep myself active; overall COVID has caused significant environmental trauma for me that heavily affected my mental health and irrevocably changed my life.”¹

Other participants described a similar experience of declining mental health. For example, participants shared “it has really taken a toll on my mental health. It increased my anxiety which in turn made my depression worse. It made me overthink everything”; “my mental health has been on a steady decline”; and “the experience has made my quality of life worse than it was already.” Participants also described a sense of hopelessness and loss of energy, noting “there is no future anymore”; “I am losing my will to keep going”; and “I struggle to find focus and vigor to complete important tasks.” Mental health impacts also included feelings of frustration and regret. One participant shared, “It has been awful, I am frustrated on a daily basis, I also feel a lot of feelings of regret.” Others described trauma-related responses including fear, nightmares, avoidance, and negative thoughts and imagery. For example, one stated: “It’s a very high level of stress and scared of dying if I contracted COVID-19.” Another participant described avoidance and nightmares:

“I try to avoid social media and news programs as I often feel triggered and experience grief for the suffering and life lost. I have nightmares

of forgetting to wear a mask in public. I often avoid going to bed probably because when I try to sleep that's when my mind becomes overactive with worry.”

Other participants described fears associated with leaving the house and negative imagery. For example, one participant shared:

“I struggle with leaving the house. My anxiety hits me harder than ever to even run to the grocery store. I never leave, only for walks to get my son out of the house. I have bad thoughts any time I leave the house because I fear something bad will happen.”

Similarly, another participant noted:

“It has just been a disaster. Every time I left the house to ride the bus to buy groceries, I felt I was taking my life in my hands. I kept seeing images of people on ventilators dying alone in hospital. People were and are dropping like flies.”

Participants also described how the pandemic negatively impacted their body image, eating patterns, weight, and sleep. For example, one participant shared, “It has also taken a toll on my body image as now I'm inside and like most people have gained weight, and being on social media more I compare myself more and more to people.” Other participants shared, “I either didn't eat or overate depending on the day” and “I gained a lot of weight that worsened my other health problems.” Participants described the impact on their sleeping patterns as well stating, “I lost a family member before lock-down, this affected my sleeping habits, my eating patterns.” Another stated, “My insomnia and sleep apnea had gotten really bad during the pandemic, I am also always exhausted as a result.”

Participants described the physical or health impacts of the pandemic. For example, one participant shared, “I have asthma and have had a lot of fear and anxiety about the possibility of getting Covid, my health fell apart.” Other participants stated, “I went from getting sick two days a month to more than every two weeks,” and the “stress I am under has triggered more symptoms with my mental health and has begun to take a toll on my physical health.” One participant described pandemic-related fatigue and its impact on their mental and physical health stating:

“Mentally I am exhausted. Everything has to be meticulously planned...I get anxious. When I get stressed, I usually fall into a depression, and I have a fibromyalgia flare up. That leads to not being able to take care of things.”

Finally, participants described the impact of pandemic-related isolation and loneliness in their social functioning. For example, one participant stated, “My interactions with others became awkward.” Another participant shared:

“I am scared to go back to normal now because I don't know how I'm going to be interacting with friends. I feel very lonely but am struggling with talking with friends as I only now know how to be around my family.”

Adjustment and Coping

Participants described coping with and adjusting to the pandemic. Specifically, participants described employing behaviors and emotions to minimize or buffer the negative impact of pandemic-related stressors. For example, participants described behavioral coping stating, “I found ways to sort of relieve myself of the stress by walking with my dog,” “to combat this, I go for long walks to give my legs some sensory input and to let my mind

wander,” and “I got a job, transportation, continued therapy.” In addition, participants described coping through positive emotions. For example, participants described coping by having faith and hope, stating, “I had faith everything would be okay,” and “somedays I had to rely purely on the slight hope that it might get better.” Participants also described relying on persistence or grit; for example, participants shared, “. . . just push through with any energy I could find left in my system,” “just kept going, even when it felt like there was no reason to go on,” and “I have to force myself to adjust everything around me.” In addition, participants described coping with pandemic-related stress by allaying their fears and those around them. For example, a participant stated, “I have to ease my fears and the fears of others around me in order to function.” Participants also described a pandemic adjustment process characterized by an initial phase of abrupt adversity that over time shifted to adaptive, resilient responses. For example, “Covid-19 was very scary in the first few months of 2020 but then I did my best to adapt and live a quality life in accordance with the guidelines”; “my experience with covid was rough at first and now I'm flourishing, at first it was an adjustment but now I'm doing well”; “it was extremely hard getting used to staying inside all day, in the summer, it was routine”; and “it completely changed the way and where I had to live, work and go to school. My world slammed to a halt and changed direction.” One participant described a slow, arduous adjustment process and the benefits of seeking help, stating:

“When COVID first began I was uprooted from my life. The first 4 months I just got worse and worse until I reached out for help. Getting healthy again was hard and slow and over the next few months I went from low functioning to functioning but still less capable than before COVID.”

Discussion

Our findings revealed nine themes: a) social isolation, b) social responsibility, c) returning home, d) barriers to resources, e) job loss, f) positive impacts, g) academic impacts, h) emotional and physical impacts, and i) adjustment and coping.

Social Isolation

Participants described social isolation as physical confinement, sensory loss, and losing contact with and connection to people, places, and support networks. Participants also described the affective experience of social isolation, namely, loneliness, sense of alienation, and emotional abandonment (i.e., not being cared about). Our findings are aligned with existing models of social isolation that include both an objective dimension, or the amount or degree of social contact, and the subjective or affective dimension (Findlay & Cartwright 2002; Fine & Spencer, 2009). While forced isolation impacted society-at-large during COVID-19 and the negative impacts were pervasive, the impact of mandatory isolation on those affected by pre-existing social isolation and other intersecting social harms (e.g., ableism, racism, and poverty) is particularly deleterious (Cornwell & Waite, 2009). The pandemic response highlighted, and likely exacerbated, the pre-existing social isolation experienced by our disability communities (Macdonald et al., 2018). Indeed, it is well documented that people with disabilities are more socially isolated, have fewer friends, experience higher levels of loneliness, and have less social support than the general population (Gilmore & Cuskelly, 2014; Krahn et al., 2015; Mithen et al., 2015). The protective factors associated with social integration and its allied constructs (e.g., social support) have long been empirically documented (Lakey & Cohen, 2000), and include such outcomes as longevity, lower rates of mortality, and other positive outcomes (Cohen, 2017). For people with disabilities, social contact and integration may also be vital to daily living

and tangible benefits. In addition, casual and regular encounters with neighbors and other community members may serve to protect against the harmful impacts of isolation and ableism. In fact, studies show that secondary sources of support (e.g., neighbor, coffee shop barista, grocery clerk, and UPS delivery person) may provide those who are most at risk for isolation with sources of positive social exchange (Thoits, 1985, 2021). While the academic scholarship suggests that disabled communities have smaller social networks and are more isolated than their nondisabled peers, what is not captured by the academy is that many disabled people maybe isolated because of lack of access and resources. Moreover, the breaking of relationships and isolation experienced by disabled people is also shaped by capitalism, oppression, fear, criminalization, and violence (Mingus, 2016). According to Goulden and colleagues, disabled people have relied on each other “through non-hierarchical and non-capitalistic webs of care and support for centuries” (Goulden et al., 2023, p. 3). Mutual aid and interdependency amongst the disability community are bedrocks of survival for many disabled people. Mingus (2016) proposed reconceptualizing communities of support through a transformative justice lens whereby “pods” are specifically built to include people who can turn to each other for on-going safety, accountability, and support directly related to harm and violence. Simply put, pods are focused on individual and collective healing and resiliency (Mingus, 2016) and have the potential to counteract the isolation inherent within, and a consequence of, the capitalist and oppressive structures that keep people isolated (Mingus, 2016).

Social Responsibility

Participants identified social responsibility as a collective practice of social distancing, masking, and accepting—versus denying—the seriousness of COVID-19 to mitigate the risk of contracting COVID. Broadly speaking, social responsibility is about cooperating

with others for the benefit of the community, or a commitment to civic responsibilities that may benefit both the individual and their community (Alliance, 2021). In the context of COVID-19, social responsibility is most aligned with adherence to public health policies and practices, such as social distancing, masking, and sheltering-in-place (Lim et al., 2021). Our participants described being vigilant agents of social responsibility during COVID-19, adhering to public health policies for their own protection and for the protection of others. These findings are well aligned with prior studies showing that social responsibility was one of the most frequently described motivations for social distancing, greater disinfecting, and fewer hoarding behaviors during COVID-19 (Oosterhoff & Palmer, 2020; Oosterhoff et al., 2020). At the same time, participants perceived others as not being socially responsible during COVID-19. For example, participants experienced a lack of COVID-19-related social responsibility by others on public transportation, with in-home care providers, and among co-workers, which in turn, contributed to anxiety, discomfort, and a sense of being alone. Thus, while participants were not burdened by abiding by COVID-19 policies, they did experience negative emotions associated with relying on these policies (and others to uphold these policies) to protect against sickness and death. This experience is aligned with prior studies showing that while those who practiced social distancing to prevent getting sick were less burdened by upholding COVID-19 protections (as compared to those not motivated by the fear of getting sick), they were more likely to experience greater anxiety (Oosterhoff et al., 2020).

The factors underlying why a person engages in socially responsible behavior, particularly during a global pandemic, are related to multiple personal and environmental factors (Oosterhoff & Palmer, 2020; Harper et al., 2020). For example, several studies noted factors that likely influence adhering to public health policies such as political orientation

(Harper et al., 2020; Kushner et al., 2020), social responsibility, social trust, self-interest (Oosterhoff & Palmer, 2020), and attitudes about COVID-19 severity or fear of the virus (Oosterhoff & Palmer, 2020; Harper et al., 2020). While all people faced some degree of COVID-19-related external “rules” or norms, it may be that for many, particularly nondisabled people, the externally imposed policies and practices held less personal meaning and impact than for disabled people. For our participants, having a disabling health condition(s) coupled with an already unreliable, and for some, harmful healthcare context that was becoming even less accessible, being socially responsible was perhaps not a choice, but a way of survival. As such, it is not surprising that while social responsibility is generally a prosocial act, for our participants, being socially responsible was not only a prosocial act, but an act fueled by the anxiety, discomfort, and a sense of loneliness associated with not feeling protected by society from COVID-19. Moreover, our participants described COVID-19-related social responsibility to worsen overtime. The latter made sense; as COVID-19 progressed, the public health messages became more politicized and were often mixed with false information and mistrust of our public health system. In addition, some of the COVID-19-related safety precautions such as masking may not have been physically possible for some disabled people due to respiratory or other physiological impairments. These likely also contributed to additional worries about not being protected from the virus and being judged by others as not taking appropriate precautions. Disabled people were also receiving harmful ableist messages (i.e., threats of care rationing) and actions (i.e., not prioritizing early vaccines for disabled people) from our healthcare system, which likely further exacerbated their worries, discomfort, and sense of loneliness in protecting themselves and their communities. Indeed, the perceived lack of COVID-19-related social responsibility by others

was likely a painful reminder of the pervasive and longstanding devaluing, ableist attitudes that plague society and our disability communities.

Returning Home

Participants described returning home as an abrupt, negative transition from not living with family to living with family. Returning home not only involved isolation from society but isolation within the family home, with many participants describing being confined to a childhood bedroom or small space. Participants also described the negative impact of returning home on their mental health, describing their environments as toxic and contributing to increased depression and anxiety. For some, returning home was re-traumatizing. Our findings are aligned with prior research indicating increased mental health difficulties within families who have a member with a disability (Bougéard et al., 2021; Rydzewska et al., 2021) and poorer family functioning (Desquenne Godfrey et al. 2024). In addition, our findings are aligned with contemporary COVID-19 research that reveals an increase in abuse, neglect, domestic violence, and aggression in the home during the pandemic (Jesus et al., 2021; Khan et al., 2021).

For people with disabilities, returning home during the pandemic may have been particularly upending and tenuous given the historical and present-day harms experienced by many disabled people in spaces they consider their “home.” While most adults have some control over decisions regarding their living situation (Murray, 2018), life decisions for people with disabilities, including those related to housing, have historically been partially, if not entirely, made by others (Murray, 2018). Moreover, “home” for disabled communities has been corrupted by historical and present-day sociopolitical harms and injustices. The abrupt, forced return home for disabled people may have reignited the pains of existing in a space where choice, personal decision-making, dignity, and identity are lost or compromised

and a stark reminder of the contextual nature of self-determination. For some people with disabilities—particularly those from western cultures—moving out of the home into the community may have offered a space where autonomy and self-determination could develop and power and control by others lessened. According to Blunt (2005), “intimate and personal spaces of home are inextricably linked to wider power relations” (p. 4). Research also confirms this hypothesis; for example, one study found that persons with intellectual disabilities who moved into their own place of residence reported greater control and choice in their lives, more community engagement, and increased personal relationships (McConkey et al., 2016).

Barriers to Resources

Participants experienced difficulties accessing in-home care, health, mental health and dental care, medications, and transportation. Accessing resources was an abrupt barrier for many people, however, our disabled communities that already experience significant access barriers rooted in ableism, were particularly harmed. During COVID-19, public transportation, paratransit, accessible taxi, and rideshare services were disrupted and not reliable. Public transportation is typically the most frequent form of transportation for disabled people (, & Chowdhury, 2018) and is a particularly salient requirement for community participation, social connectedness, employment, and access to a wide range of basic needs (Jansuwan et al., 2013; Park & Chowdhury, 2018). However, public transportation has been, and continues to be, a significant barrier to community participation, social connectedness and accessing basic needs for disabled people (Bezyak et al., 2020; Sabella & Beyzak, 2019). Our findings are well aligned with prior studies revealing public transportation barriers experienced by disabled people (e.g., Taylor et al., 2010; Bezyak et al., 2020; Sabella & Beyzak, 2019). For example, one study found that 34% of disabled

people (as compared to 16% nondisabled people) have problems with inadequate transportation (Taylor et al., 2010); more recent studies have found that two-thirds of a community sample of people with disabilities reported experiencing problems with public transportation (Bezyak et al., 2020), and nearly 90% reported at least one barrier to using public transportation, and on average, experienced at least three barriers to transportation (Sabella & Bezyak, 2019). Notably, disabled people with other intersecting positions, including being Hispanic/Latino/a/x, low income, and/or female increased transportation barriers (Sabella & Bezyak, 2019).

Access to healthcare including mental and dental health care was also impeded. Ableism in our health and mental healthcare systems is the norm, not the exception, and, like other societal injustices experienced by people with disabilities daily, were highlighted during the pandemic. The attitudinal barriers were rampant, with disabled people experiencing medical rationing (Goggin & Ellis, 2020), or the fear of medical rationing. While considered most "at risk," disabled people were often the last to get access to vaccinations and quality care. At the same time, many disabled people live with multiple or co-occurring health conditions that require ongoing healthcare and medication access. Our findings are well aligned with prior studies showing that disabled communities experienced significant barriers to healthcare during COVID-19, including insufficient ambulance and transportation resources to go to the hospital, difficulty finding medications, abrupt changes to usual care, and lack of available outpatient appointments (Lebrasseur et al., 2021; Jumreornvong et al., 2020). Importantly, in some ways, disabled people may have been more psychologically prepared than nondisabled people, given environmental barriers rooted in ableism (Mingus, 2016). Indeed, access barriers to healthcare, transportation, and other resources existed long before the pandemic, and disabled people have relied on their disabled communities and

those from other historically marginalized groups to break through ableist and other oppressive resource barriers. Nonetheless, barriers to resources significantly intensified during COVID, while at the same time support amongst disability communities was compromised due to quarantine policies and reduced transportation options (Jumreornvong et al., 2020).

Job Loss

Participants described job loss as an unexpected and destabilizing disappearance of paid employment. Job loss was described as having destabilizing impacts on personal and familial finances, housing, mental health, and healthcare access. Participants shared that job loss was linked to business closures, suspension of operations, furloughs, and forced self-termination due to lack of enforced safety protocols at the workplace. Others pivoted to opportunities to return to school or make a career change. Our findings are not surprising given the historically high rates of unemployment and underemployment among people with disabilities. Specifically, prior to the pandemic, less than one in three (30.9%) working-aged people with disabilities were employed, as compared to three-fourths (74.6%) of their nondisabled peers (Bureau of Labor Statistics [BLS], 2020). People with disabilities are also historically underrepresented in white-collar jobs and overrepresented in service and blue-collar jobs (BLS, 2020; Schur et al., 2023) and, compared to nondisabled people, exit the workforce during economically challenging times at higher rates (Livermore & Honeycutt, 2015). Regarding job loss among people with disabilities during COVID-19, the research is more complicated and fluid. For example, some research indicates that a significant percentage of people with disabilities lost their job during the pandemic (Bishop & Rumrill, 2021) and employment dropped more among workers with disabilities as compared to those without disabilities (Schur, Van der Meulen & Rogers, 2021). Other studies, however,

suggest that early in the pandemic, there was an equal number of disabled and nondisabled workers who lost employment or exited the workforce and later in the pandemic, the employment rate grew quicker for people with disabilities than for people without disabilities (Ne'eman & Maestras, 2023).

The complexities associated with understanding job loss for people with disabilities during COVID-19 is likely linked to other factors such as living with multiple intersecting positions/identities and the type of occupation and industry to which the disabled person was employed. For example, studies suggest that employment loss during COVID-19 was more severe for Hispanic, Latinx, Black, African Americans, and females (Bishop & Rumrill 2021; Schur et al., 2023). Studies also showed that workers with disabilities were more likely to be employed in occupations and industries that had larger employment declines during COVID-19 (e.g., building and grounds cleaning, food preparation and serving, and transportation and material moving) whereas disabled workers using telework who were essential, and were non-frontline workers, made gains in employment (Ne'eman & Maestras, 2023). For disabled workers, the ability to pivot to telework or having the support of employers to work from home experienced much less economic uncertainty and destabilization. Part-time workers, non-union disabled, and public-facing disabled workers faced the greatest economic uncertainty (Maroto et al., 2021).

Irrespective of the nuances during the pandemic, for our participants, job loss was harmful and abrupt, and impacted their ability to support themselves and their families. These findings are well-aligned with studies indicating that people with disabilities experienced more financial difficulties than nondisabled people during COVID-19. Specifically, people with disabilities were nearly three times more likely to experience financial hardship during the pandemic than nondisabled people, and 52% of people with disabilities had difficulty

paying usual household expenses (Friedman, 2022). Financial hardship can have long lasting impacts on people with disabilities, including on their physical and mental health, well-being, and overall quality of life (Friedman, 2022). The global pandemic changed the way people work for both disabled and nondisabled workers, with working from home or using technology to engage in virtual work commonplace. This sudden shift to virtual and work from home had both advantages and disadvantages for all people, including disabled workers. For disabled people, the flexibility that comes with remote work coupled with less reliance on unpredictable transportation and coping with ableist work environments may at times outweigh the potential costs of being isolated in one's home and less connected with people. At the same time, remote connection may increase opportunities for social connection for those who are physically isolated.

Positive Impacts

Positive impacts included occupational, financial, personal, psychological and disability-related assets, strengths and motivations. For example, participants shared being able to leave unhealthy work environments, gain financial stability due to unemployment benefits and stimulus funds, and leverage technology and outdoor spaces (i.e., nature) to improve access, reduce stress, and address health-related issues in creative ways. Participants also described that, during COVID-19, they were able to conserve energy and better control their daily environment (i.e., temperature, access to food, and clothes). Participants reported taking risks they would not have taken prior to COVID-19, establishing and achieving personally meaningful goals, developing a better work-life balance, and gaining confidence and self-efficacy in such spaces as school and work. In addition, participants reported that classes, events, and many other forms of social participation were immediately accessible through Zoom and other forms of live, online platforms. While our findings suggest that

remote platforms increased access for our participants, it is important to note the digital divide between people with disabilities and those without disabilities during the pandemic (Cho & Kim, 2022). Specifically, internet use during the pandemic increased among those without disabilities yet remained the same for those with disabilities, with the most significant discrepancy seen in social network use. Further, people without disabilities were more likely to be aware of, utilize, and perceive the usefulness of digital services during COVID-19, including application, information, delivery, and subscription services (Cho & Kim, 2022). While online platforms may have increased access for some people with disabilities, it is likely that many of the available digital services that emerged during COVID-19 were not fully accessible for marginalized groups, including people with disabilities (Cho & Kim, 2022). According to Cabero-Almenada et al. (2022), digital competency among people with disabilities must also be met with digital services that are designed to meet the needs of people with all types of disabilities.

Participants also described improved boundary setting, increased self-awareness regarding their values, interests, and life goals, better self-care, and being more comfortable asking for help. These findings stand in stark contrast to the overarching body of COVID-19 and disability research, which has predominantly revealed the COVID-19-related harms inflicted on people with disabilities (Negrini et al., 2020). At the same time, our findings are aligned with the literature that suggests trauma is also grounds for personal growth, deeper connections, appreciation of life, and spiritual change (Sidener, 2019; Splevins et al., 2010; Calhoun & Tedschi, 2008). While there are numerous studies investigating post-traumatic growth related to disability onset, few studies have investigated it within the context of a universal or societal-wide trauma such as COVID-19 experienced by cultural groups. According to Jayawickreme et al. (2021), post-traumatic growth research is not generalizable

to people from marginalized groups, particularly those who have been systematically excluded from mainstream, social, economic, cultural, or political life because of power inequalities. Jayawickreme et al. (2021) posit that post-traumatic growth and response to adversity should be defined within a given “bounded group-community” (Fuller & Garcia Coll, 2010), or defined within the social context, time, and space (Jayawickreme et al., 2021). Many social contexts, including the United States, rely upon social position variables—like race, ethnicity, gender, sexuality, ability, citizenship, and social class—to stratify individuals into existing social hierarchies. Thus, these social positions both help to define bounded group-communities, to influence the types of exposures those communities have (e.g., to adversity and different traumas), and to shape their desired competencies (e.g., character strengths). Members of any given bounded group-community are constantly adapting to the opportunities and challenges they encounter across contexts and settings (White et al., 2018). In this way, the types of adversities encountered, the notions of competence, and the mechanisms of growth—all key features of post-traumatic growth—may depend on the specific bounded group-community under investigation, and extending post-traumatic growth research to more diverse populations and settings will depend upon definitions of adversity, trauma, character, and growth in those bounded group-communities. Our findings address this gap in the research by shedding light on how people with disabilities both respond to adversity and experience post-traumatic growth.

Academic Impacts

Participants described difficulties abruptly transitioning to the online learning environment. Access to learning and to the college experience was impacted in several ways. While some of the impacts were likely common to any college student (e.g., being isolated and disconnected from peers, mourning the loss of the college experience, and losing

motivation to engage in learning), other impacts were specific to being disabled. Aligned with prior studies showing that the transition to online learning was more difficult for disabled college students than nondisabled students (Scott & Aquino, 2020), our participants described COVID-19 as having mostly negative academic impacts. Indeed, like the pre-existing inequities and access barriers in healthcare, employment and other societal structures that worsened during COVID-19, the education realm was no different. Participants described isolation, disconnection, low mood, lack of support from instructors and overall difficulty accessing the online learning environment. Particularly, engaging in discussions, asking questions for clarity and understanding, and completing homework were academic consequences that were likely linked to the interaction between reduced attention, concentration, physical symptoms (e.g., migraines) and the online learning context. It may be that disabled college students' pre-existing accommodations were less effective in an online context or new accommodations needed to be instituted, a hypothesis aligned with prior studies finding that transition to online education created barriers to accessing and receiving appropriate accommodations (Scott & Aquino, 2020). For example, students with learning or attention-related disabilities—which comprised a large proportion of our sample—may have benefited from access to recorded and/or pre-recorded classes, extended time to complete assignments, frequent in-class breaks, a structured plan for turning on/off their video, and learning options that include both asynchronous and synchronous platforms. While the chat function is now a standard option for participating in an online environment, using chat was novel at the time, and may have worsened classroom engagement and increased isolation for those with attentional or learning impairments. These findings are aligned with prior research finding that college students with disabilities experienced difficulties accessing equipment,

Wi-Fi, technological support, examinations and libraries, using online platforms, and communicating with instructors and peers (Scott & Aquino, 2020).

Participants also described difficulty communicating with, and getting support from, course instructors. These findings likely reflect the chaotic structural response to the impact of quarantine orders on educational institutions generally and instructors more specifically. Guidance on how higher education institutions responded to COVID-19 was limited to recommendations that these institutions consult with public health officials and comply with federal nondiscrimination laws (U.S. Department of Education, Office for Civil Rights, 2020). Simply put, limited concrete guidance on protecting the rights of college students with disabilities was available, reflecting the lack of consensus on how to adhere to public health recommendations and nondiscrimination laws (Chugani & Houtrow, 2020). Moreover, for most traditional 2- and 4- year educational institutions, remote/online learning options prior to COVID-19 were, by far, the exception not the norm. As such, institutions and instructors were ill-prepared to transition to online learning in general and, more particularly, to ensure disability access and accommodations occurred within these contexts. Indeed, educators learned that providing instruction in a classroom setting and providing instruction in an online setting is not only different but challenging (Young & Donovan, 2020), and those who lacked technology training and resources faced many barriers when teaching students with disabilities in an online environment. According to Hamilton et al. (2022), 42% of teachers reported difficulty in receiving adequate support and guidance for working with students with disabilities. In addition, campus ADA coordinators reported encountering difficulties more frequently than other professionals. At the same time, the transition to online platforms forced instructors and institutions to teach creatively and adopt practices that are fundamentally more accessible to our disabled students. The academic impacts of COVID-

19, while reported as mostly negative by our participants, may eventually improve educational access through institutional acceptance and de-stigmatization of accessible online teaching platforms, disability services that utilize more accessible and justice-oriented registration, better documentation and accommodation protocols, and establishing an educational structure that is accessible and sustainable irrespective of abrupt environmental changes.

Emotional and Physical Impacts

Participants described substantial emotional health and physical health impacts during the pandemic. Many described worsening of existing mental health symptoms, declining emotional health, and increased depressive and anxiety symptoms. Anxiety was attributed to worries about leaving the home, as a response to the news, and of catching COVID-19 and of dying. Changes to sleeping and eating patterns were reported, such as disturbed sleep, oversleeping, lack of quality sleep, and lack of appetite or overeating as a response to the pandemic. Others reported decreased quality of life, difficulty concentrating, and trauma responses such as persistent fear and recurrent nightmares. Increased daily stressors triggered mental health and physical health issues, such as those that exacerbate with stress, autoimmune conditions, and other health problems. For participants who experienced weight gain, the physical changes contributed to negative body image and increased health issues. Participants with asthma, preexisting respiratory conditions, or other health conditions feared catching COVID and experienced pandemic fatigue. The fatigue was attributed to the need to meticulously plan to get groceries and leave the house for work or errands. Lastly, participants reported that long periods of social isolation created barriers to reconnecting with friends and the larger community, increased social awkwardness, and other difficulties with social functioning.

Among people with chronic health conditions and disability, unique traumas and stressors were experienced during the pandemic, leading to worsening of mental health and physical health conditions. Stressors and worries about access to medical treatment, supplies, or medications as well as risk for severe illness from COVID-19, led to worsening mental health and health outcomes for disabled communities (Okoro et al., 2022). Many experienced health care rationing, ableism in health care, social isolation, and were grieving significant losses in their community due to COVID-related deaths (Lund et al., 2020). Sleep quality was worse for people with disabilities, including people with blindness and visual impairments, compared to those without disabilities. However, over the span of the pandemic, nondisabled communities experienced worsening of their sleep quality compared to disabled individuals (Heinze et al., 2021). Adults living with disabilities reported significantly more depressive symptoms, mental distress, suicidal ideations, and substance use as during the pandemic compared to adults without disabilities (Okoro et al., 2021). The health conditions and disability were compounded by the impact of stress and worry about being infected with COVID-19. Along with social isolation, this led to increased vulnerability to negative health and mental health impacts for the disabled community. A literature review on the effects of lockdown measures on disabled communities during the early phase of the pandemic (up to September 2020) found that disabled communities experienced many mental health and physical impacts, including disrupted access to essential healthcare, reduced physical activity leading to health decline, social isolation, and loneliness due to physical distancing. Further, negative effects included psychological impacts from the loss of routine and support, disruptions in personal assistance and support networks, experienced increased risk for maltreatment, vulnerability to violence, and self-harm (Jesus et al., 2021).

Calls for a more responsive policy at the state, federal, and local levels related to inclusive emergency preparedness and response plans are warranted to reduce negative impacts to the overall health of disabled communities during a pandemic and other emergencies. Aligned with disability justice principles, the establishment of mutual aid pods among disabled and nondisabled communities with pre-arranged response plans during emergencies that identify needed resources, caregivers, and support by the pod community members is a viable solution. Pod-mapping is a concept developed by disability activist, Mia Mingus (2016), which offers a tool to map out the mutual aid sources of support, resources, and access for disabled communities developed in response to community violence and harm. These tools can be used to help mitigate the impact of any future disaster, health, and climate response which may not be reliable and can reduce overreliance on response by public health officials to mitigate the negative impacts unique to disabled communities and aligns with the disability justice principle of mutual aid provided by disabled communities and their allies.

Adjustment and Coping

Participants employed coping strategies to minimize the emotional and negative pandemic-related stressors on their overall well-being. Participants found going for walks outside to be helpful in releasing physical and mental stress. Others held on to hope and faith that things were going to get better with time, pushed through difficult times, and found the grit within themselves to persevere through the challenges. Some worked through fears and found ways to function despite starting off not functioning well and discovered ways to respond with more resilient and adaptive responses. Many described debilitating responses initially to the pandemic and then adjusting to the protocols, staying inside for long periods of time and adhering to the social requirements to isolate. Others reported that through adjustments, they continued to find a way to live their lives, go to work, and continue with

therapy and other treatments. Some participants reached out for help when they exhausted their personal coping resources.

Our findings align with some of the coping strategies deployed by people with disabilities. A study found a correlation between perceived stress and active coping mechanisms, such as distractions, venting to others, use of emotional support, religion (faith), and humor for people living with disabilities and chronic health during the pandemic (Umucu & Lee, 2020). A study of Canadian college students found that students with mental health disabilities experienced more difficulties adjusting and coping with the pandemic compared to nondisabled students; females living in urban areas with a disability were particularly vulnerable to increased stressors from the pandemic (Larose et al., 2024). In a study of youth and young adults with disabilities, helpful coping strategies during the pandemic included social support, financial support, keeping busy (establishing routines), and work-life balance. Particularly helpful for young adults and the youth were assistance with creating routines that helped them to get outdoors and exercise and allowed their minds to wander as a distraction from the pandemic and to reflect on life's purpose (Lindsay et al., 2021). As our study included many young adults with disabilities, these recommendations are particularly pertinent; those who adjusted well may have received some help or found ways to create healthy routines to better cope with the pandemic restrictions. Younger age, chronic pain, higher disability-related stigma, and more worries about contracting the COVID-19 were among the predictors of a lack of adjustment and coping strategies and higher prevalence of anxiety and depression among the disabled during the pandemic (Wang et al., 2022). These predictors are important in identifying elevated risk for mental health concerns and needed coping strategies for people with disabilities during a pandemic or other crisis.

Limitations

First, our research is a qualitative study; therefore, the findings cannot be generalized to a larger representative population. Second, most of our participants were White, heterosexual, educated cis women from urban or suburban areas residing on the West Coast who lived with their disability for an average of 16 years. In addition, most of our participants lived with psychiatric, neurodevelopmental, or physical disabilities. These lived experiences likely influenced our findings and should be considered within that context. Third, while our study focused on the lived experiences of disabled people during COVID-19, none of the research team members were disabled at the time that the study idea was conceived or executed. As such, our study was constrained by not having input by disabled people—an important disability justice principle. Our study is also limited by data collection methods. Specifically, our data was textual and collected via online survey. Consequently, we did not capture the voices of those without online access nor those who experience barriers related to typing out responses. In addition, we could not control for other factors that may have influenced participant response. Finally, we were unable to conduct member checks—a method for increase credibility—given the anonymized data gathered through our online survey.

Conclusions

Our findings highlight the multiple ways in which disabled people's lives were impacted by COVID-19, including social isolation, experiencing barriers to resources, job loss, academic difficulties, and mental health impacts. At the same time, our participants experienced positive impacts and effectively coped with the crisis. While these impacts likely affected society at large, our disabled communities were placed at higher risk given the significant changes in access to transportation, healthcare, and vital support services—

services that are vital for those with disabilities. At the same time, it may be that many people with disabilities were more prepared than nondisabled people for the pandemic given the creative and ingenious ways that disabled people have managed ableism long before COVID-19. Specifically, lack of access to reliable transportation, services, and resources are a common daily experience for disabled people. The drastic change that nondisabled people felt at the onset of the pandemic may have been incremental or even slight for disabled people. Unfortunately, the voices of disabled people in disaster preparedness continue to be omitted, which is a particular flaw given their lifelong experiences of coping with access issues and managing limited supports and resources.

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