



## **Mental Health Among Family Caregivers of Hoosiers With Disabilities During the COVID-19 Pandemic**

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### **INTRODUCTION**

Mental health encompasses emotional, psychological, and social well-being, impacting how we feel, think, and act (Substance Abuse and Mental Health Services Administration, 2023). Mental health also makes it possible for individuals to realize their own abilities, cope with the normal stressors of life, work productively, and make contributions to their community (World Health Organization, 2022). These highlight the fact that mental health is critical to one's quality of life, as well as overall health and well-being.

The COVID-19 pandemic has created great uncertainty and challenges to everyone. It should be noted, however, that the pandemic hit disadvantaged populations harder. The pandemic brought to the forefront disparities faced by people with disabilities (Kalash, 2020; Sabatello et al., 2020). Health care needs for individuals with disabilities have been inadequately recognized during the pandemic (Turk & McDermott, 2020). Furthermore, people with disabilities, except for those with certain high-risk medical conditions, were not included in the initial vaccination efforts (Kaye, 2021; Musumeci & Chidabaram, 2021). It is well documented, however, that people with intellectual and developmental disabilities are at a greater risk for severe COVID-19 outcomes (Boyle et al., 2020; Gleason et al., 2021; Hippisley-Cox et al., 2021; Landes, Turk, & Ervin, 2021; Landes, Turk, & Wong, 2020). Compared to their counterparts without disabilities, individuals with disabilities are more likely to have chronic health conditions, which puts them at an increased risk for COVID-19 infection and worse outcomes (Centers for Disease Control and Prevention, 2023). Vulnerability to COVID-19 infection and severe outcomes among people with disabilities could put pressure on family caregivers of individuals with disabilities to protect the health and well-being of themselves and those with disabilities for whom they care.

Family caregivers of individuals with disabilities play a significant role as they assist their family members with disabilities in many areas such as health care, education, recreation, meals, finances, or home maintenance. The pandemic may have caused undue stressors on the family caregivers. Family caregivers' responsibilities changed significantly during the pandemic to keep

those with disabilities safe (Lightfoot et al., 2021). Family caregivers reported more negative effects of the COVID-19 pandemic compared to non-caregivers across multiple domains such as employment, finances, mental and physical health, food security, and social isolation (University of Pittsburgh, 2020). Given the substantial impact of mental health on overall health and quality of life, and the vital importance of family caregivers for people with disabilities, it is critical to identify mental health experiences and needs among family caregivers of individuals with disabilities in Indiana during the pandemic.

The Center for Health Equity at the Indiana Institute on Disability and Community (IIDC) at Indiana University Bloomington conducted an online survey to have a greater understanding of mental health experiences and needs among family caregivers of Hoosiers with disabilities during the COVID-19 pandemic. To our knowledge, this is the first study on the impact of the COVID-19 pandemic on the mental health of family caregivers of individuals with disabilities in Indiana.

## **METHODS**

The Center for Health Equity conducted an online survey via the Qualtrics survey tool, from February 6 to March 22, 2023. The survey included questions about family caregivers' demographic characteristics, COVID-19 pandemic related experiences, mental health, and characteristics of family members with disabilities (e.g., age, type of disability, type of residential setting, etc.). Any family caregivers of individuals (minor or adult) with disabilities were eligible for the survey, if they met the following criteria: a) they were 18 years old and over, b) they were living in the state of Indiana, and c) the family members with disabilities they cared for were living in Indiana.

Survey participants were recruited through multiple ways, including announcements in organization newsletters, websites, and social media, after obtaining an approval from Indiana University's Institutional Review Board. Indiana disability organizations were asked to assist with the promotion of the survey to the people in their networks. Such organizations included those with a statewide reach such as the Arc of Indiana, Down Syndrome Indiana, Indiana Governor's Council for People with Disabilities, Indiana Family to Family, IN\*SOURCE, Special Olympics Indiana, and United Cerebral Palsy Association of Greater Indiana. Additionally, the project staff promoted the online survey through disability service providers who support people with disabilities and their families in different regions and counties in the state. The survey was also promoted through IIDC's online newsletters and social media.

## **RESULTS**

### ***Survey Participants***

A total of 115 respondents initially participated in the anonymous online survey. After removing 14 ineligible respondents (e.g., 2 respondents who did not meet the inclusion criteria; 3 respondents who accessed the survey but did not provide any responses; and 9 respondents who answered only some of eligibility questions), the final sample size was 101.

The majority of the survey participants were parents (87.4%), followed by sibling (4.6%), spouse or intimate partner (3.4%), and others such as relative or child (5.7%). Most participants were female (95.5%), white (93.1%), married or lived with a partner (83%), received a bachelor's degree or higher (64.8%), and had a household income of \$50,000 or higher (81.4%). They mostly lived in suburban and urban communities (67.0% and 13.6%, respectively). The participants also reported being employed full-time (43.8%) or part-time (20.2%). The average age of the participants was 50.2 years old.

## ***Key Findings***

### Caregiving for the Family Member with a Disability

The pandemic presented unique, unprecedented challenges to many family caregivers of people with disabilities. During the early phase of the COVID-19 pandemic, society shut down in response to COVID-19. Society later eased the restriction, but many schools, social services, and health care and recreational facilities for those with disabilities were not back to full normal operations during the later phase of the pandemic. Such changes must have had an impact on the family caregivers of those with disabilities.

*I already was responsible for everything in a household with a husband and special needs child who are emotionally and physically unsupportive. Then add all of their fears and additional responsibilities (home schooling, home therapy) coupled with my increased risk [due] to immune problems and it has been horrible.*

*Loneliness of lack of socialization. Worked at home stayed home to prevent getting COVID so no personal time for me. Getting back to socializing and maybe being more of a germophobic now.*

The average age of the family member with disabilities caregivers cared for was 23 years old, with the majority aged 15 years or older (69.3%). The family members with disabilities had multiple types of disabilities. Their types of disabilities included vision disability (10.9%), hearing disability (8.9%), cognitive disability (80.9%), mobility disability (29.5%), self-care disability (55.1%), and independent living disability (90.9%). The majority of those with disabilities lived with their family caregiver (78.9%). Some of them lived in their own home (10.5%), and lived in their parents' or relative's home (8.4%). The percentage of those living in community-based group residence and those in long-term care setting, including nursing home, was only 1.1%, respectively.

The average hours that the survey participants spent caring for the family member with a disability in the last 30 days was 454.2 hours. Half of the family caregivers reported that they had provided more than 600 hours of care in the last 30 days, whereas 20 percent of the caregivers spent less than 80 hours on caregiving in the last 30 days. It should be noted that more than four in ten participants (43.6%) reported spending 720 hours attending the family member with a disability in the last 30 days (that is, spending 24 hours a day on the caregiving for those with disabilities).

The following shows that family caregivers assisted persons with disabilities with various tasks:

Type of Care Tasks	Percent
Health care (e.g., making or attending health care appointments, communicating with health care professionals)	9.3%
Meals (e.g., grocery shopping, food preparation, cooking, eating)	8.8%
Arranging and providing transportation	8.4%
Providing companionship and emotional support	8.3%
Health insurance (e.g., selecting coverage, understanding benefits, contacting insurance company including Medicaid)	8.2%
Medical care (e.g., managing medications; helping with injections, blood testing, IVs, wound care, or other medical tasks)	8.1%
Home maintenance or improvement (e.g., cleaning, laundry, dishes, vacuuming, home maintenance)	8.0%
Finances (e.g., paying bills, banking)	8.0%
Community participation (e.g., helping with volunteering, work, recreation/leisure, or religious activities in the community)	7.9%
Personal care (e.g., providing support for activities such as dressing, bathing, or toileting)	7.3%
Coordinating care (e.g., finding or coordinating care at home or outside the home)	6.7%
Assisting with homework	5.2%
Hiring and supervising direct care workers	5.0%
Other	0.9%

Over half of family caregivers (54.3%) reported working from home during the COVID-19 pandemic. Many caregivers (62.0%) acknowledged that working from home affected the care they provided to their family member with a disability during that period. It should be noted that the direction of the impact, that is, whether positive or negative, was not ascertained.

### Mental Health of Family Caregivers

When asked to rate their current mental health status, half of family caregivers reported it as good (49.5%), followed by excellent or very good (32.3%). However, almost one in five family caregivers (18.3%) reported their mental health status as fair or poor. In addition, although more than half of caregivers (52.7%) reported that their current overall mental health was about the same compared to before the COVID-19 pandemic, more than one in four caregivers (28.0%) reported that their overall mental health during the pandemic was worse than before the pandemic.

*I think my mental health is worse after Covid. I'm pretty sure my spouse has long haul Covid symptoms. Health issues have added additional stress to my life and I can tell my mental health isn't as strong as it used to be.*

*My daughter's mental health declined significantly during the pandemic and the stress of dealing with that had a significant impact on me and my husband. I developed symptoms of PTSD because she became very violent towards me.*

Family caregivers were asked to complete a validated screen for symptoms of depression, the Patient Health Questionnaire-9 (PHQ-9). This self-administered instrument is used to detect the presence and severity of depression, more specifically symptoms of depression in the last 2 weeks (Kroenke & Spitzer, 2002; Perlis et al., 2021). A score of 10 or more is considered moderate to severe depression. About one-fourth of the family caregivers (23.6%) reported scores of 10 or higher on the PHQ-9, indicating moderate or greater depression. These findings may indicate that family caregivers were exposed to negative experiences and challenges during the pandemic.

Family caregivers reported that the COVID-19 pandemic had impacted their day-to-day life: extremely (19.4%), very (22.6%), moderately (36.6%), and a little (15.1%). They reported they had had the following various experiences during the pandemic, many of which could have adversely affected their mental wellness:

<b>Family Caregivers' Experience During the Pandemic</b>	<b>Percent</b>
Worrying about friends, family, partners, etc.	10.9%
Fear of getting COVID-19	10.4%
Fear of giving COVID-19 to someone else	10.1%
Frustration or boredom	9.0%
Feeling that I was contributing to the greater good by preventing myself or others from getting COVID-19	8.5%
Feeling loss due to changes to daily routines and ways of life	8.3%
Loneliness	7.6%
Getting emotional or social support from family, friends, partners, a counselor, or someone else	5.5%
Personal financial loss (e.g., lost wages, job loss, investment/retirement loss)	5.3%
More sleep, less sleep, or other changes to your normal sleep pattern	5.3%
Other difficulties or challenges	3.6%
Stigma or discrimination from other people (e.g., people treating you differently because of your identity, having symptoms, or other factors related to COVID-19)	3.2%
Loss of a loved one	3.0%
Confusion about what COVID-19 is, how to prevent it, or why social distancing/isolation/quarantines are needed	2.7%
Not having enough basic supplies (e.g., food, water, medications, a place to stay)	2.2%
Increased alcohol or other substance use	1.8%
A change in sexual activity	1.3%
Getting financial support from family, friends, partners, an organization, or someone else	1.3%

As shown above, family caregivers most often reported worrying about significant others such as friends, family, or partners. They were concerned about getting COVID-19 or about spreading the virus to someone else. The caregivers experienced a sense of loss and loneliness, as well as a financial loss and loss of a loved one. The following comments made by family caregivers capture the impact of their experiences during the pandemic on their mental health:

*I am sad and feel isolated and like the people at work and my family do not understand how difficult it has been to juggle everything. My son with Down syndrome had three surgeries during the pandemic. My long-term partner had a mental health crisis and withdrew from the family. I changed jobs and moved to a new city in July of 2020. I just need a break to catch up, but I can't get one. I am on the brink of collapse.*

*The first year of the pandemic I was exhausted from being so frightened. The next two years were very confusing and emotionally draining, especially coupled with the political situation which further confused progress during the pandemic.*

*We are struggling and cannot afford \$80-100 per person for therapy. We are struggling.*

Family caregivers reported the following various challenges encountered while assisting their family member with a disability during the pandemic:

<b>Challenges Encountered While Providing Care to Persons with Disabilities</b>	<b>Percent</b>
Emotional fatigue	13.3%
Lack of time for my own self-care	11.9%
Physical fatigue	10.1%
Balancing my work or other responsibilities	9.8%
Balancing time with my family/friends	8.7%
Lack of help/support from other family/friends	8.5%
Difficulty coordinating help/support with other family/friends/disability service providers	7.1%
Difficulty hiring and supervising direct care workers	6.4%
Navigating care options and/or decisions	5.5%
Lack of appreciation from the person I help	4.4%
Difficulty getting needed medical care for the person I help	3.7%
My own financial problems	3.0%
Confusion on recommended public health guidance	2.8%
Lack of knowledge or training in how to provide help	2.3%
Other	2.0%
None	0.2%

The top five challenges experienced by the caregivers include emotional and physical fatigue, lack of time for self-care, balancing work and other responsibilities, and balancing time with family/friends. Such challenges were also followed by hardships related to providing care to those with disabilities: lack of help/support from other family or friends; difficulty coordinating help/support with other family, friends, or disability service providers; and difficulty hiring and supervising direct support professionals.

*Increased stressors and worry about keeping my family safe emotionally, physically, socially, etc. Difficulty getting the supports with my child's educational needs. Advocating prior to the pandemic was already difficult, and*

*the pandemic magnified systemic issues within the school system which made these barriers even more of a hurdle. Balancing work and family is tricky already, and the pandemic made it near impossible.*

*The access to services for my 2 autistic children have been delayed. We have been approved for Waiver services and we have spent 8 months waiting for any company to call us off the waitlist (respite, music, rec, and behavior).*

Family caregivers were notably concerned about the impact of potential COVID-19 infection and related severe outcomes on their family.

*I worry about my child dying if they get sick and the general lack of concern so many people have.*

*My fear was that if I were to become infected, I would not be able to help my disabled family member as well as the other responsibilities I have.*

To address their mental health needs, many family caregivers reported that they turned to various strategies. Some made lifestyle changes, such as exercise, meditation and diet (59.8%), some used app or web-based programs (24.2%), and some started or adjusted their mental health medication (23.3%).

### Mental Health Services During the COVID-19 Pandemic

Family caregivers reported that they were very comfortable (42.4%) or somewhat comfortable (44.6%) talking about their mental health. Caregivers also reported that they had talked about their mental health with the following people in the last two years: other family/friends (26.8%), spouse/partner (26.3%), primary care provider (23.5%), mental health professional such as counselor, therapist, and psychiatrist (14.6%), and religious clergy (5.2%).

When asked about whether they had been referred to a mental health professional (e.g., counselor, therapist, psychiatrist) in the past two years, the majority of the caregivers (54.8%) reported that they had not been referred to the mental health professional. More than one-fifth of caregivers (22.6%) reported that they had been referred to services in the past two years, and another one-fifth (22.6%) were considering seeking services.

When asked about whether they had ever seen a mental health professional, more than one-fifth of family caregivers (22.6%) had seen the professional within the past year. Around 11 percent also reported that they had seen the professional more than two years ago, but after the COVID-19 pandemic began. About 31 percent had already received professional services before the COVID-19 pandemic. One-third of the caregivers (33.3%) said they had never seen the mental health professional.

Regarding challenge with access to mental health service, approximately half of family caregivers (48.4%) did not get or delayed counseling or treatment when they felt they needed the professional service in the past 12 months. The following are various reasons caregivers

reported:

<b>Reasons for Delayed or Forgone Mental Health Service</b>	<b>Percent</b>
I did not have respite for the family member with a disability	15.3%
No appointments available	13.3%
I could not find a mental health professional who accepts insurance plan	12.2%
I could not afford it	11.2%
I didn't think it would help	6.1%
I did not know where to go to get care	6.1%
I could not get time off work	5.1%
Coronavirus pandemic (COVID-19)	5.1%
Mental health professional too far away from where I live	4.1%
I didn't think I would need it	3.1%
No transportation	2.0%
Other	16.3%

Some of the “other” reasons reveal that the idea of mental health treatment may be overwhelming to family caregivers, and that they were struggling to find time for mental health services:

*Seemed too overwhelming.*

*Overwhelmed with everything else that needs to get done.*

*I just didn't have time for me.*

*I am a single mom with three kids. I don't have time.*

The top five reasons indicate that family caregivers delayed or did not receive needed mental health services due to a lack of respite services for the person with a disability; limited mental health system capacity; and caregivers' perceptions of professional mental health service.

*My mental health provider changed to virtual visits, but my insurance wouldn't cover virtual visits. Eventually, insurance started covering virtual visits, but by that point, the counseling center had a long wait list, so it took a long time to get an appointment.*

### Limitations

This brief provides important information about the mental health experiences and needs of the family caregivers of individuals with disabilities in Indiana during the COVID-19 pandemic. However, the findings need to be considered in the context of several limitations. First, participation was limited to caregivers who had internet access. Some caregivers, such as those who live in rural areas, may not have been aware of the survey or did not have stable access to do the survey. Second, the majority of caregivers in the survey were white, well-educated, married, lived in urban or suburban communities, and had an annual family income of \$50,000 or more. Their survey responses may not represent the mental health experiences of all family



caregivers of Hoosiers with disabilities. Disadvantaged groups, such as rural residents and racial/ethnic minorities were not adequately represented in the survey. Third, this survey does not provide a comprehensive picture of the mental health experiences that the family caregivers had during the COVID-19 pandemic. We did not ask questions about smoking, alcohol consumption, or substance use. These factors may reflect caregivers' stress and anxiety, and they can contribute to their ability to care for their family. Additionally, our survey did not have extensive questions about family caregivers' mental health history before the COVID-19 pandemic.

Despite these limitations, the findings from the survey can help us better understand the mental health experiences and needs among family caregivers of people with disabilities in Indiana during the COVID-19 pandemic. Family caregivers are integral in family units, especially for family members with disabilities. The survey participants provided insight about how family caregivers' mental health might have been affected by their experiences during the pandemic, and what challenges they had encountered regarding their mental health. Such findings can offer important guidance to policymakers and public health professionals about what to further examine in relation to family caregivers' mental health challenges and how to address them.

## IMPLICATIONS

The findings of the survey indicate that the COVID-19 pandemic had a great impact on the mental health of family caregivers of people with disabilities in Indiana. More than one-fourth of the survey participants reported that their overall mental status was worse than before the pandemic. The pandemic highlighted the unique challenges faced by family caregivers of Hoosiers with disabilities. The pandemic upended many of their daily routines and services, and increased their anxiety about COVID-19 infection and severe outcomes. The COVID-19 pandemic placed additional stressors and responsibilities of safely attending a family member with a disability among family caregivers. Some people with disabilities required additional care that was interrupted during the pandemic. Caregivers had to contend with additional responsibilities that they were not well prepared for, such as additional responsibilities with their children's schooling because of the pandemic lockdown. Some caregivers could not receive emotional or physical support from family and friends. The challenges of caring for a family member with a disability during the pandemic created constant pressure and stressors that were not always easy to address. This could have increased the likelihood of negative mental health among family caregivers. It is paramount that mental health be addressed for family caregivers of individuals with disabilities because they have the important responsibility of ensuring stability in their family unit, especially for persons with disabilities.

Given the stressful and burdensome caregiving role, it is well documented that caregiving affects physical and mental health of informal caregivers who provide care to family members, relatives, or friends, usually without payment (Adelman et al., 2014; Leggett et al., 2021; Park, 2020; Schulz & Sherwood, 2008). It must be noted that about one-fourth of family caregivers reported symptoms of moderate or greater depression in the survey, but that almost half of the caregivers reported they had delayed or had not received needed mental health services during the pandemic. They struggled with the cost and availability of services and juggling their responsibilities with their family member with a disability. Also, some caregivers did not see the

benefits of mental health services or found the idea of treatment overwhelming.

It is imperative to recognize the mental health experiences and needs of family caregivers of those with disabilities during the pandemic and address their related issues and challenges. Even as the COVID-19 Public Health Emergency has ended and cases of COVID-19 have decreased, many of the mental health consequences from the pandemic will linger unless they are appropriately addressed. For example, some caregivers experienced the loss of significant others and financial hardships. Some caregivers could not afford or utilize mental health services during the pandemic. The findings of the survey indicate that there should be programs and resources available that caregivers can easily access to help them to identify their concerns and to find sustainable solutions to alleviate their concerns (e.g., telehealth services and support groups). In addition, awareness of mental health services should be promoted among family caregivers of individuals with disabilities. Respite services for people with disabilities should be expanded statewide as well. Also, mental health programs should collaborate with programs addressing social determinants of health to reach more disadvantaged groups.

Mental health services are especially important for events like public health emergencies when people need mental health strategies to cope with and manage unforeseen stressors. Improving mental health systems and services is especially critical in Indiana. The 2023 “State of Mental Health in America” report ranked Indiana 39<sup>th</sup> in the United States in overall prevalence of mental disorders and access to care (Mental Health America, 2023). More specifically, Indiana ranked 43<sup>rd</sup> in access to care and 21<sup>st</sup> in prevalence of any mental illness issues. When it came to mental health workforce availability (e.g., therapists, nurses with mental healthcare specialty, counselors, etc.), Indiana ranked 44<sup>th</sup> with one mental health provider for every 560 individuals. Establishing accessible, affordable, and culturally appropriate mental health resources can help family caregivers and their families achieve mental wellness and better health outcomes, which will improve their quality of life.

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### **Acknowledgment**

The survey was conducted as part of the “Expanding the Public Health Workforce Within the Disability Networks” project funded by the Administration for the Community Living (ACL), U.S. Department of Health and Human Services. The content of this brief does not necessarily represent the views of ACL.