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Daily Life Experiences of Families of People with Disabilities During COVID-19 Pandemic

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Abstract

Background. For people with intellectual and developmental disabilities (IDD) and their families, COVID-19 has introduced additional challenges including significant disruptions to daily life and increased risk in accessing services and supports. Understanding how families are adapting and navigating through the crisis is critical to inform ongoing supports as the pandemic continues and beyond as there will likely be ongoing changes in service and support delivery both directly and indirectly related to COVID-19. The purpose of this study was to survey families in one Midwest state in the U.S. to document experiences during COVID-19 with a focus on understanding how families are navigating current and new support needs related to general health and wellbeing, decision making, support needs, and access to services for their children with IDD.

Method. An online survey was used to study 372 family members or caregivers who supported people with IDD across the life course. Results were analyzed descriptively to capture the experiences of families of children with IDD based on the type of questions for the overall sample as well as for each of the four age groups representing key life course transitions (0-4, 5-17, 18-21, and > 21).

Results. Across the life course, families and caregivers reported challenges from COVID-19 impacting several areas of daily life, including health and wellbeing, decision making, changes in support needs, challenges obtaining supports and services, and managing challenges. Across the ages, almost one third of the sample reported more support needs for behavioral or emotional needs and almost 20% reported having trouble in supporting the increased needs. Further, a majority of family members in this study described fewer opportunities for important daily activities, including decision making and physical activity.

Conclusions. Families of children with disabilities reported increased support need for their child with a disability during the pandemic. Recommendations for planning for supports and services are provided.

Plain Language Summary

This study asked families about their experiences during COVID-19. Families and caregivers described challenges that affected their daily life. Many people said they needed more behavioral or emotional supports. Many people said they had trouble accessing supports they needed. Most family members said there were fewer opportunities for their children to make decisions. This paper includes ideas for how services and supports can be improved.

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Background

The COVID-19 pandemic has introduced significant disruptions throughout the world and necessitated rapid and ongoing changes in the lives of all people, including families and children (Patrick et al., 2020). The long-term impacts across multiple domains of health and functioning are unknown. For people with intellectual and developmental disabilities (IDD) and their families, COVID-19 has introduced additional challenges, including significant disruptions and increased risk in accessing services and supports to meet needs across multiple life domains (e.g., daily living, health, education, social; Eshraghi et al., 2020; Houtrow et al., 2020; Summers et al., 2021). For example, early in the pandemic, Neece et al. (2020) reported that families of young children with IDD experienced decreased access to essential services, struggled to fill the gap, and dealt with significant concerns about the long-term impacts on education and social engagement opportunities. Work is needed to better understand the ongoing impacts of COVID-19 on people with IDD and their families across the life course. Specifically, there is a need to better understand the impact of COVID-19 on the day-to-day experiences of children, youth, and adults with IDD as well as the impacts on support needs and access to supports and services. Understanding how families are adapting and navigating through the crisis is critical to inform ongoing supports as the pandemic continues and to plan for ongoing changes in service and support delivery both directly and indirectly related to COVID-19 (Camden & Silva, 2021). As such, the purpose of this study was to survey families in one Midwest state in the U.S. to document experiences during COVID-19 with a focus on understanding how families are navigating current and new support needs related to general health and well-being, decision making, and access to services for their children with IDD. We specifically targeted developing a better understanding of the day-to-day life and experiences of families with children with IDD across the life course.

Method

Survey Design and Delivery

The survey used in this study was developed through an existing collaboration between a university research center focused on disability, a statewide self-advocacy group, and a statewide parent advocacy group. The project team was working together, prior to COVID-19, on state-wide system change initiatives in education and adult services for children, youth, and adults with IDD, and quickly pivoted to identify and address issues that emerged in March 2020 with the first stay-at-home orders being issued in the state. The project team met using virtual technology to brainstorm and develop the domains and items for the survey. The draft was then refined and shared with other self-advocates and family members from community organizations. These stakeholders reviewed the items and provided feedback on applicability (i.e., does the item apply to the experiences of people with IDD and their families during the pandemic) and accessibility (i.e., is the item easily understood). Items on the survey asked questions about general well-being (e.g., How are you doing during the pandemic? How is your child doing during the pandemic?) and health (e.g., Has your child's physical activity level changed? How are you and your family staying safe?), as well as decision making (e.g., Has COVID-19 changed the opportunities your child has to make decisions?). Families were also asked to rate changes in support needs (e.g., "My child has needed more support for their behavior") and identify areas where there were challenges with accessing supports (e.g., finding enough support workers, getting to doctor's appointments, accessing masks or other personal protective equipment [PPE]). A variety of question formats were used, including yes/no, scaled response, and open-ended questions. For example, questions about family member perceptions of the well-being of their child with a disability were rated on a Likert scale (1 being "Poor" and 5 being "Very good"), while questions regarding challenges with supports and services allowed respondents to select all relevant answers (e.g., "Difficulty with support workers showing up, Difficulty finding enough support works"). General demographic questions were also included. The survey closed with an open-ended question asking families/caregivers about their experiences and the strategies they would share with other families managing COVID-19.

The survey was disseminated to family members by project partners through emails to listservs and via social media platforms maintained by multiple partner organizations, including the state's Family Training and Information Center, University Center on Excellence on Developmental Disabilities, Council on Developmental Disabilities, the statewide self-advocacy group for adults with IDD, and Protection and Advocacy System. The survey was disseminated in May of 2020 and remained open for 1 month. This time period was targeted as this was a time, particularly in the Midwest state where the survey was disseminated, when public health safety measures related to COVID-19 were beginning to be modified and reduced – yet there was great uncertainty about the most effective ways to promote health and safety, particularly in vulnerable populations introducing greater need for individual decision making about health and safety.

Sample

In total, 372 family members or caregivers completed the survey. They supported people with IDD across the life course. We organized the sample into four age groups based on differences in service delivery and supports (i.e., 0-4, 5-17, 18-21, 22 and older). See Table 1 for the breakdown of the sample. The largest age group was the school-aged population (45.4%), and our smallest sample was young children aged 0 to 4 (4.3%). The sample was distributed across urban, suburban, rural, and remote settings, with roughly half of the overall sample living in

Table 1

Children, Youth, and Adults with Disabilities Whose Parents/Caregivers Completed the Survey

Age of child or adult	*n*	%
0-4	16	4.6
5-17	165	47.4
18-21	49	14.1
Over 21	118	33.9
Missing	1	.3

suburban settings. The majority of the family members who completed the survey had children, youth, and adults who had ID or ID and ASD, although a smaller subset had ASD only or other developmental disabilities. The school-aged sample contained the largest proportion of participants who had children with ASD only. Except for the youngest age group, the majority received Medicaid-funded supports and services. The overwhelming majority of the sample was White/European American and non-Hispanic. Overall, the demographics of the sample reflected the relative racial and ethnic composition of the Midwest state where the survey was administered, but Hispanic and African American groups were underrepresented relative to their absolute percentage of the state population. See Table 2 for a breakdown of the survey results by age and other relevant demographics (location, type of disability, race/ethnicity, etc.).

Table 2

Demographic Data Broken Down by Age Ranges

	Overall		0-4		5-17		18-21		> 21	
Demographic	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
Place										
Urban	54	15.5	2	12.5	20	12.1	8	16.3	24	20.3
Suburban	195	55.9	7	43.8	100	60.6	29	59.2	58	49.2
Rural	89	25.5	7	43.8	38	23.0	10	20.4	34	28.8
Remote	9	2.6	0	0	6	3.6	2	4.1	1	.8
Missing	2	.6	0	0	1	.6			1	.8
Parent or caregiver										
Parent	321	92.0	16	100	152	92.1	48	98.0	105	89.0
Caregiver	26	7.4	0	0	12	7.3	1	2.0	13	11.0
Missing	2	.6			1	.6	0	0	0	0
Disability										
ID	102	29.2	4	25.0	25	15.1	17	34.7	56	47.5
ASD	92	26.4	4	25.0	60	36.4	11	22.4	16	13.6
ID_ASD	97	27.8	0	0	44	26.7	15	30.6	38	32.8
Other[a]	58	16.6	8	50.0	36	21.8	6	12.2	8	6.8
Receives Medicaid-funded supports										
No	104	29.8	8	50.0	72	43.6	16	32.7	8	6.8
Yes	242	69.3	8	50.0	93	56.4	33	67.3	108	91.5
Missing	3	.9	0	0	0	0	0	0	2	1.7
Race										
African American	8	2.3	1	6.3	6	3.6	1	2.0	0	0
White	315	90.3	10	62.5	145	87.9	45	91.8	114	96.6
Asian	5	1.4	0	0	3	1.8	0	0	2	1.7
≥ 2 races	12	3.4	3	18.8	7	4.2	0	0	2	1.7
Other	3	.9	0	0	2	1.2	1	2.0	0	0
Missing	6	1.7	2	12.5	2	1.2	2	4.1	0	0
Hispanic										
No	321	92.0	10	62.5	150	90.9	45	91.8	115	97.5
Yes	20	5.7	5	31.3	12	7.3	1	2.0	2	1.7
Missing	11	3	1	6.3	3	1.8	3	6.1	1	.8

[a] "Other" includes mental health disability, learning disability, visual impairment or blindness, hearing loss, physical disability, speech language disability, and/or traumatic brain injury.

Analysis

To descriptively explore the experiences of families of children with IDD, we calculated descriptive statistics (e.g., frequencies, means, standard deviations) based on type of questions for the overall sample as well as for each of the four age groups. Open-ended questions were reviewed for key themes; exemplars of family experiences are shared to contextualize findings.

Results

Health and Well-Being During COVID-19

Table 3 presents the descriptive findings for items asked of families/caregivers for overall health and well-being during COVID. Eighty-four percent of families and caregivers in this study reported that they were doing average or better during the pandemic, although more families and caregivers reported below average well-being in the school-age (5-17) age group. Interestingly, parents/caregivers tended to report that their child with a disability was not doing as well (74% reported their child was doing average or below) during the pandemic, perhaps reflecting differences in child and parent experiences.

A large majority of families reported less physical activity for their children during the pandemic and slightly less than half reported diet changes. A large minority of families (40.7%) also reported their children did not have enough to do, particularly for the 18-21 sample (49%). While a quarter to one third of family members and caregivers reported worrying about getting sick themselves, much higher numbers reported worrying about this for this child, ranging from 60% to 69% of the sample.

Decision Making During COVID-19

Table 4 provides information on how families/caregivers have supported their child to engage in decision making about what to do during the day during the pandemic and if there have been changes. A large majority of families (72.5%), but particularly families with school-age and adult children (65-77%), felt opportunities to make decisions had been restricted because there were fewer opportunities to go places, although a small minority (slightly less than 10%) felt their children were making more decisions.

Changes in Support Needs During COVID

Table 5 provides an overview of changes in support needs reported by parents/caregivers. Across the ages, more than one third of the sample reported more support needs for behavioral (35%) or emotional (32%) health and one fourth reported concerns with changes in social skills. Over 20% reported having trouble supporting their child because of increased needs. This was particularly pronounced for young children (44% reported increased behavioral support need and 19% reported increased emotional support need) and school-aged children (43% reported increased behavioral support need and 37% reported increased emotional support need).

Table 3

Overall Health and Well-Being During COVID

	Overall		0-4		5-17		18-21		> 21	
Question	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
How are you doing during the COVID19 pandemic?										
Very good	27	7.7	2	12.5	8	4.8	2	4.1	15	12.7
Above average	100	28.7	4	25.0	36	21.8	15	30.6	45	38.1
Average	165	47.3	6	37.5	81	49.1	30	61.2	48	40.7
Below average	42	12.0	2	12.5	29	17.6	2	4.1	9	7.6
Poor	14	4.0	2	12.5	11	6.7	0	0.0	1	.8
Missing	1	.3	0	0.0	0	0.0	0	0.0	0	0.0
How is your child with a disability doing during the COVID19 pandemic?										
Very good	25	7.2	2	12.5	10	6.1	6	12.2	7	5.9
Above average	64	18.3	4	25.0	27	16.4	6	12.2	27	22.9
Average	153	43.8	4	25.0	71	43.0	25	51.0	53	44.9
Below average	80	22.9	5	31.3	40	24.2	10	20.4	25	21.2
Poor	26	7.4	1	6.3	17	10.3	2	4.1	6	5.1
Missing	1	.3	0	0.0	0	0.0	0	0.0	0	0.0
How have your child's physical activity levels changed during COVID19?										
More activity	48	13.8	0	0	34	20.6	8	16.3	6	5.1
less activity	240	68.8	11	68.8	110	66.7	32	65.3	87	73.7
No changes	60	17.2	5	31.3	21	12.7	9	18.4	25	21.2
Missing	1	.3	0	0.0	0	0.0	0	0.0	0	0.0
How has your child's diet changed during COVID-19? My child easts…										
More than usual	99	28.4	2	12.5	55	33.3	12	24.5	30	25.4
Less than usual	40	11.5	2	12.5	20	12.1	5	10.2	13	11.0
About the same	209	59.9	12	75.0	90	54.5	32	65.3	75	63.6
Missing	1	.3								
My child doesn’t have enough to do.										
Yes	142	40.7	4	25.0	64	38.8	24	49.0	49	41.5
I am worried about me getting sick										
Yes	96	27.5	4	25.0	49	29.7	13	26.5	30	25.4
I am worried about my family members or child getting sick										
Yes	216	61.9	11	68.8	95	57.6	29	59.2	80	67.8

Table 4

Decision Making During COVID

	Overall		0-4		5-17		18-21		> 21	
Question	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
How do you support your child with a disability to decide what to do during the day?										
Child decides on their own	67	19.2	2	12.5	32	19.4	17	34.7	16	13.6
I give my child choices on what to do and they decide	123	35.2	4	25.0	65	39.4	15	30.6	39	33.1
My child has developed a routine, and that works well for them	117	33.5	5	31.3	48	29.1	16	32.7	48	40.7
I decide what my child will do	35	10.0	5	31.3	20	12.1	1	2.0	9	7.6
Missing	7	2.0	0	0.0	1	.6	0	0.0	6	5.1
Has COVID-19 changed the opportunity your child has to make decisions? Choose one.										
I make more decisions for my child now	28	8.0	2	12.5	16	9.7	6	12.2	4	3.4
My child makes the same amount of decisions as before	66	18.9	7	43.8	26	15.8	10	20.4	23	19.5
Because we can't go to as many places, there are fewer opportunities to make decisions	253	72.5	7	43.8	123	74.5	32	65.3	91	77.1
Missing	2	.6	0	0.0	0	0.0	1	2.0	0	0.0

Table 5

Mean Changes in Support Needs During COVID

	Overall		0-4		5-17		18-21		> 21	
Statement	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
My child has needed more support for their behavior	123	35.2	7	43.8	71	43.0	12	24.5	32	27.1
My child has needed more support for their emotional needs	113	32.4	3	18.8	61	37.0	15	30.6	34	28.8
I am having trouble supporting my child because of increased support needs.	71	20.3	6	37.5	44	26.7	7	14.0	14	11.9
I am concerned with the changes in my child’s social skills	93	26.6	5	31.3	53	32.1	11	22.4	24	20.3

Challenges in Supports and Services

Table 6 reports on challenges families and caregivers identified with supports and services during COVID-19. Twenty percent of the sample reported challenges with finding support providers, with a higher percentage of families of school-aged children having difficulty (27%). Fifteen percent of the sample also reported having trouble getting a mask or other PPE. A minority of participants reported difficulty with support workers showing up (8.3%) and difficulty getting to doctor appointments (9.2%). We attempted post-hoc comparisons to investigate differences in challenges accessing supports and services between participants receiving versus not receiving Medicaid-funded services; however, the sample size and number of people reporting challenges in supports and services were too small to be analyzed.

Table 6

Mean Challenges with Supports and Services

	Overall		0-4		5-17		18-21		> 21	
Statement	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
Difficulty with support workers showing up	31	8.3	1	6.3	18	10.9	2	4.1	10	8.5
Difficulty finding enough support workers	76	0.4	3	18.8	44	26.7	9	18.4	20	16.9
Having trouble getting to doctor appointments	32	9.2	0	0.0	15	9.1	7	14.3	10	8.5
Having trouble getting a mask or other equipment to protect me or family members	55	15.8	1	6.3	26	15.8	9	18.4	19	16.1

Managing Challenges

Responses to the open-ended question about strategies families/caregivers would share with other families to navigate COVID-19 highlighted several key issues. While we did not ask specifically about supports received from schools, many participants with school-aged children described experiences (both positive and negative) related to supports received from schools during remote education. Multiple family members described struggling with getting supports from their schools. One family member stated “*People who have immunocompromised children need more support through their school district. The schools are not wanting to help as much and just brush us off*." Another family member noted a need for more support as “*Being [my child's] special education teacher/PT/OT/Adaptive PE & Speech Teacher while working & caring for other siblings has been incredibly challenging.*” Another family highlighted the importance of a team approach to education during remote learning: “*I insisted the school support with teachers and paras working with my child to accomplish her work using Zoom. This has been THE reason she has been able to complete schoolwork.*”

Family members of adults with IDD focused on the significant difficulties in accessing paid, well-trained supporters who could assist with activities and maintain health and functioning during the pandemic. For example, one parent wrote "*I only survived once I got some good personal care attendants. It was hard to train them quick.... But now I can rest. It takes a village*." Another parent noted the significant difficulties associated with organizing supports remotely when their child lived outside the home and worries about what would occur beyond the pandemic.

> *My son lives in an apartment and receives residential supports through a provider organization. We are doing his grocery shopping, buying in bulk, and coaching by phone on meal preparation as he has been in lock-down for the past 10 weeks. He is in the HCBS wait list and pays [out of pocket] for his supports, including job coaching. We have reduced his level of services, so he does not run out of money in his trust. He has been on the wait list for 5 years and there's little hope that relief will come anytime soon. My greatest concern right now is that Congress has not appropriated any relief for direct support staff who are underpaid and underappreciated already. Then what will happen to support services my son and others rely on?*

Another family who received paid supports noted the changes in their roles and the emotional toll.

> *Our adult son lives in a group home, but we talk with him multiple times daily, visit outside his house and wave and talk briefly through his house window. Even though he doesn't live with us, we still bear much of the responsibility for his care and well-being, and in Covid-19, of course, we worry about him lots! Because of his quarantine, we are unable to be with him, or to bring him to our home overnight weekly as we have done as a routine before. Covid 19 has been very hard on our son emotionally.*

Across the life course, families emphasized the role of routines and creating meaningful opportunities to focus on choice and decision making, including embedding these opportunities within activities in the home—like cooking and eating. One family highlighted their focus on keeping "*a routine around simple things. Give [the child] as many small choices as possible embedded in their routines. Eat healthy*." Another noted,

> *I focus on things she likes. For example, she likes cooking. I let her choose a recipe and we talk through what is needed and I give her the time she needs to make something. I am nearby if she has questions or needs assistance. I put together her own recipe book and I will give it to her on her birthday.*

Another central area that families emphasized was the importance of technology. For those who had access, using technology to maintain communication and support was critical: "*If you have access to internet, suggest your child use FaceTime or Zoom to have instant face-to-face communication with friends and family.*" For some parents of adults in residential settings, such technology provided the only means of interaction available. One family member noted, "*My daughter is living in an apartment with residential support, so my direct input is limited to phone calls, emails, and video chat*." One family whose child received day services emphasized the critical role of a virtual program offered by their adult child's day service,

> *My child's day service has developed an online virtual program, he Zooms with them Mon-Fri from 10:00 a.m.-3:00 p.m. His behavior has improved as a result of them implementing this, he loves the interaction with day service staff and with his friends.*

However, some families expressed concern about the limitations of technology. For example, one family member noted, "*Now we literally are home all day every day and he is not getting any stimulation other than computer/iPad*," while another said that therapy via video chat was "*not ideal.*"

Discussion

This article reports the results of a survey of family members in one Midwest state in the U.S. designed to understand how families are navigating current and new support needs during the COVID-19 pandemic. The survey sought to understand the day-to-day experiences of families during COVID-19 related to general health and well-being, decision making, support needs, and access to services for their children with IDD. Below we highlight implications of this research to inform planning as the pandemic continues and in the future.

Overall, family members reported being concerned about the health and well-being of their child with a disability. Over 30% of family members and caregivers reported an increase in behavioral and emotional support needs and noted difficulty obtaining needed supports and services during the pandemic. These numbers were highest for school-aged children, perhaps suggesting the significant and negative impacts of the rapid pivot to remote learning. A national survey found that 14% of families with children with and without disabilities reported an increase in behavioral support needs for their children (Patrick et al., 2020); therefore, our finding suggests that the impacts on children with disabilities may be even more pronounced. It is possible that youth with disabilities may be even more vulnerable to the social isolation and decreased supports that resulted from the pandemic. Ongoing planning to provide supports for families during the pandemic and beyond must more systematically consider how to build meaningful, individualized approaches for people with disabilities. It must also consider access and comfort with technology and student support needs. For example, schools and community organizations must build and test protocols that anticipate increased behavioral and emotional support needs when in-person supports are not an option.

Further, a majority of family members in this study described fewer opportunities for important daily activities, including decision making and physical activity, which has been reported in other studies (Neece et al., 2020). These findings tended to be more pronounced for families of school-aged children with disabilities. Related to decision making, the pandemic has increased the complexity of every-day decisions for all people. For example, a trip to the grocery store during the pandemic requires considerably more planning (e.g., planning for the time of day with the fewest number of people, using PPE, ensuring safe social distancing in the store). This increased complexity may be why family members report making more decisions for their child or adult with a disability during the pandemic, which could reflect that many people with disabilities did not have the experience and supports needed to navigate the complex decision-making context necessary to promote their health and safety during the pandemic. This finding highlights the importance of supporting people with disabilities to make decisions early in life, so they have the experience and supports needed for more complex decision making related to health and safety during a pandemic, and other times, such as during transition from high school to adult life (Shogren et al., in press). Further, this finding emphasizes the need for plain language supports needed for people with IDD to fully participate in decision making regarding safety, such as explanations of the precautions (masks, social distancing).

Regarding technology-based supports and comments made by families and caregivers, it is important to first note that a limitation of this survey was that it was only distributed online; therefore, we only reached families who had access to technology. As such, their comments may not generalize to other families and their children with disabilities who have limited access to technology or the internet. Of the respondents, however, open-ended comments did suggest that technology played a key role for some families, although it clearly did not fully address the range of support needs. This suggests that while technology can be a valuable form of support for some and for some situations, it cannot fully address all of the support needs of people with disabilities. Further, when considering technological solutions, consideration should be given for the support the person with IDD may require from family members to take advantage of social or daily supports being offered virtually. Individualized planning is needed to determine effective methods of support provision when face-to-face interaction is not possible as well as the role of technological supports as opportunities for face-to-face interaction reemerge. If remote delivery of supports is needed, remote supports should be practiced on a regular basis during “normal” times to support people with disabilities and their families to learn the technology and prepare for virtual supports.

In summary, this article highlights experiences of families of children with disabilities during a critical period during the COVID-19 pandemic and provides insight into how families navigated existing and new support needs for their children with IDD in daily life. While this study adds to the literature on the experiences of families of children with disabilities during the pandemic, we should note that it represents one time point early in the pandemic. Ongoing and longitudinal work is needed to better understand short- and long-term impacts on support needs. Further, more work needs to be done to compare and contrast experiences accessing supports and services for those receiving Medicaid-funded services versus those who do not.

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