



Family Voices of Minnesota Family Survey of the Impact of COVID-19

Family Voices of Minnesota conducted an electronic survey of families raising children and youth with special health care needs (CYSHCN). CYSHCN are children who have disabilities, chronic health, mental health conditions or who require other types of extra supports and services. Our goal was to learn directly from families about the experiences and concerns they have had related to the COVID-19 Pandemic.

This survey consists of closed and open-ended questions that ask about demographics, service use prior to COVID-19, how service use has been impacted by COVID-19, and family concerns around how COVID-19 has impacted finances, their child's education, family health, and health insurance. Answers to the open-ended questions were coded and analyzed.

This survey was open from April 15 to May 1, 2020. While the challenges families experience due to COVID-19 are continually changing due to the nature of virus and the changing policies intended to address it, this snapshot from April 2020 provides important information to help families through this difficult time. As of April 30, 2020, there were 8,154 cases of COVID-19 in Minnesota according to the Minnesota Department of Health. Additional data from the Minnesota Department of Health showed an upward trend in the number of test results reported daily, yet officials reported limited testing at the time meant that the actual number of COVID-19 cases was much higher than the numbers confirmed.

All children throughout the state had been receiving education via distance learning, as schools were shut down statewide on March 18th. Governor Tim Walz signed an Executive Order stating that all residents of the state were to shelter in place as of March 27th and non-essential businesses were to remain closed. Many healthcare policies were changing, and telehealth visits were becoming increasingly common.

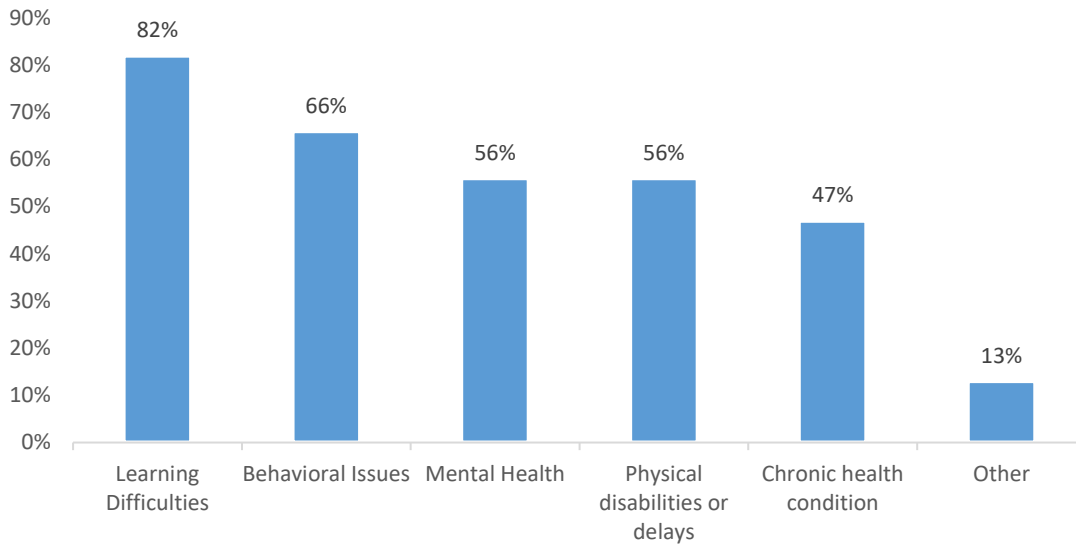
Most families are very worried about their child, themselves or another family member becoming ill or contracting COVID-19, along with the outcome and impact of contracting COVID -19. It is clear that children and their families are being severely impacted by the loss or change of services, including therapies, educational services and the impact of social isolation. Families expressed concerns about the mental health of their children and themselves, along with the lack of access to health care. Families expressed that many of the stressors they regularly face are being exacerbated by COVID-19.

DEMOGRAPHICS

A total of 103 parents or caregivers of CYSHCN (i.e. respondents) completed the survey which reflects their responses regarding a total of 155 children with special healthcare needs (some respondents had more than 1 CYSHCN).

Types of special healthcare needs that impact children

Families were asked to report types of special healthcare needs impacting their children. Learning difficulties and behavioral issues were the needs reported most frequently.

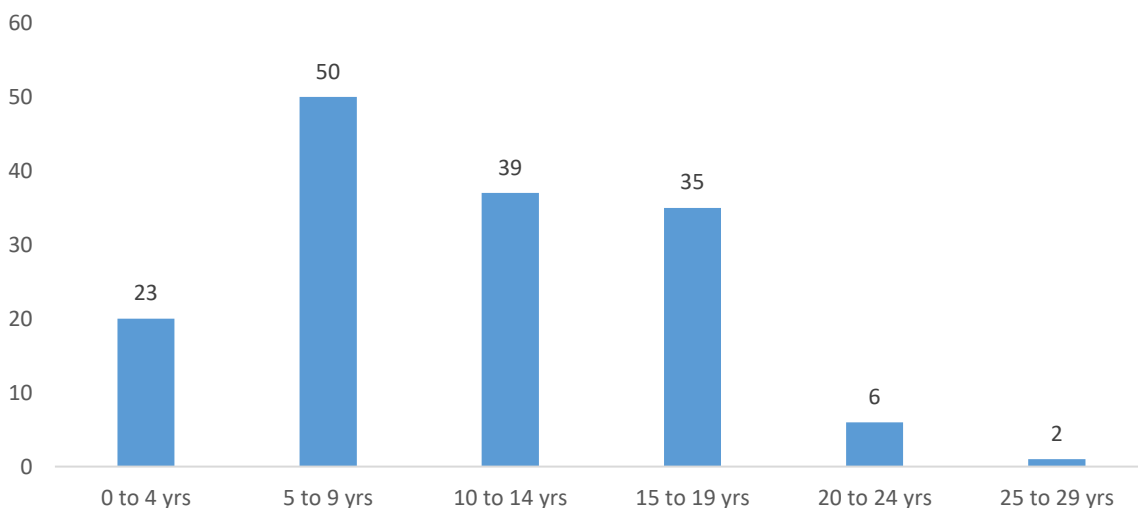


n = 103; Respondents were able to select a response in more than 1 category when applicable.

The 'other' needs reported include Autism (6), Seizure disorder (2), hearing loss (2), autonomic dysfunction (1), rare disorder (1), ADHD (1), PTSD (1), and terminal condition (1).

Age of CYSHCN

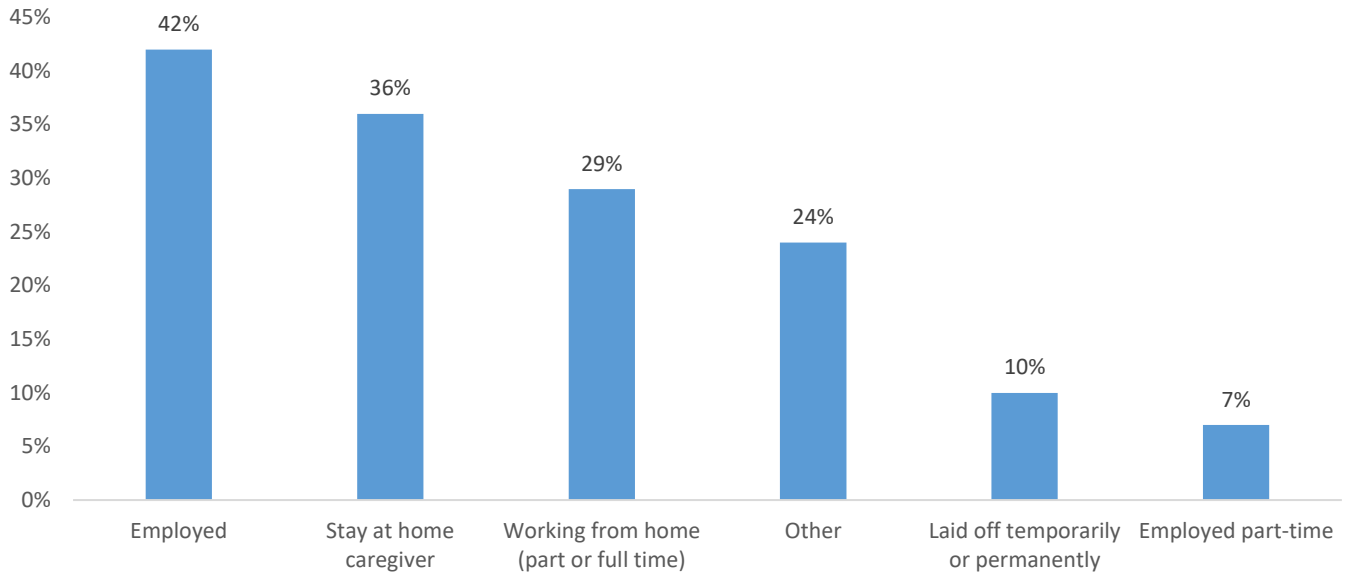
Families reported their children's ages from between 8 months to 27 years old. 80% of the CYSHCN were between the ages of 5 and 19, which indicates they are mostly of school age.



n = 155

Respondent employment status

When this survey was completed in April 2020, 78% of families indicated they were still employed either part or full time. 10% reported being either permanently or temporarily laid off. 29% of families indicated they were employed but working from home either full time or part time. Other responses included individuals who were retired, a student or self-employed.



n = 102; Respondents were able to select a response in more than 1 category when applicable.

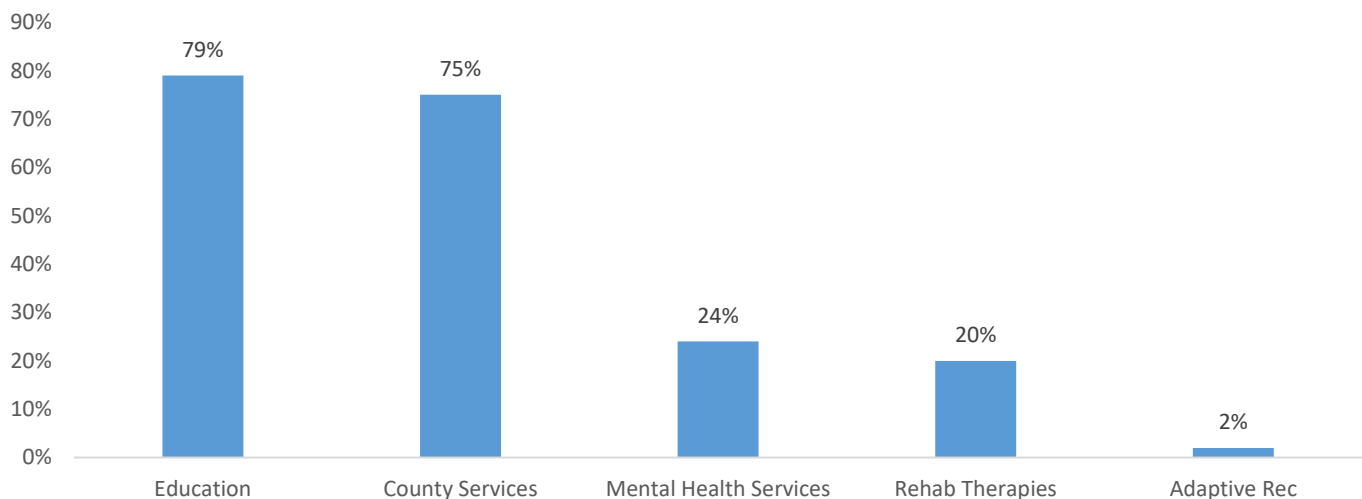
- Responses for “Other” include disabled, retired, student, self-employed, and details about spouse employment.

SURVEY QUESTIONS

Families were asked ten open-ended questions about services, supports, and impacts related to the COVID-19 pandemic and their child/children with special healthcare needs. These open-ended questions allowed respondents to share the issues that they were experiencing or were of most concern in their own words.

Question 1: Families were asked which formal services and supports they received for their CYSHCN prior to the COVID-19 pandemic.

101 families indicated that their child did receive formal services prior to COVID-19. Of those parents receiving formal services and supports before COVID-19 76% reported using at least one education service, and 32% reported using some form of waiver (i.e. CAC, CADI, DD, CDCS). Most parents indicated educational and county supports/services were in place for their child prior to the pandemic.

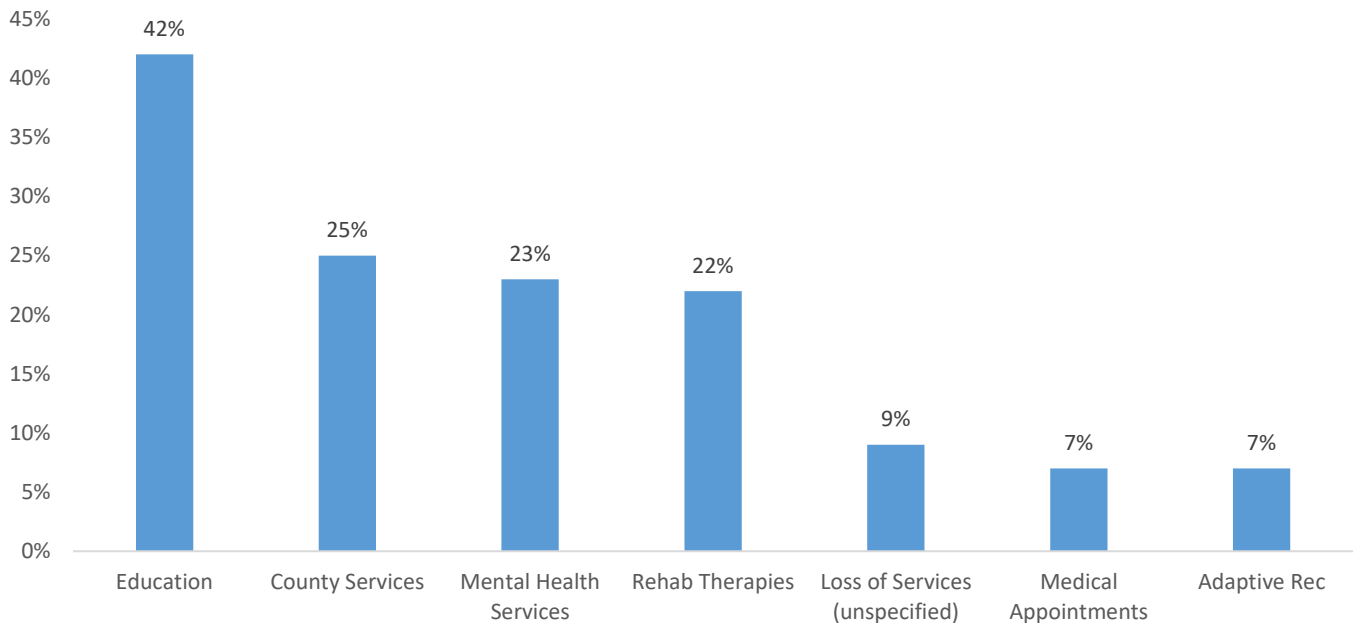


n = 97; Respondents were able to have more than one response.

- **Education Services** include Individualized Education Plan (IEP), 504 Plan, Special Education Services, Paraprofessional, Early Intervention, Educational Case Management
- **County Services** include Case Management/Social Worker, Personal Care Attendant, Respite Care, Medical Assistance (MA), Waivers, Consumer Support Grant
- **Mental Health Services** include Counseling/Therapies, County Mental Health Services, Autism/Developmental Delay Services such as Applied Behavioral Analysis therapy (ABA) and Early Intensive Developmental and Behavioral Intervention services (EIDBI).
- **Rehab Therapies** include Physical Therapy, Occupational Therapy, Speech Therapy and Feeding Therapy

Question 2: Families were asked which formal services and supports they have no longer been able to use or have lost altogether since the COVID-19 pandemic.

67% of families stated they had experienced loss of access to services. 42% reporting loss of access to education services, with 25% of families reported losing access to County services, 23% reported losing access to mental health services, and 22% losing access to rehab therapies.



n=69; Respondents were able to have more than one response.

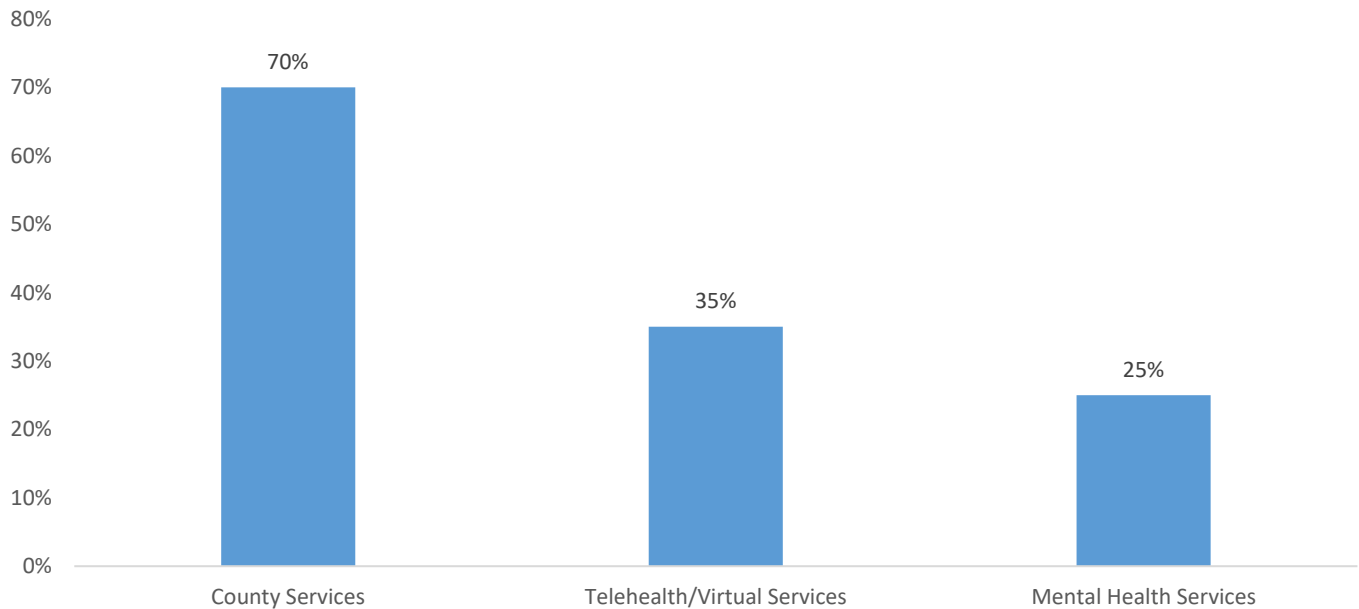
- **Education Services** include IEP, 504 Plan, Special Ed Services, Paraprofessional, Early Intervention, Educational Case Management
- **County Services** include Case Management/Social Worker, PCA, Respite Care, MA, Waivers, Consumer Support Grant
- **Mental Health Services** include Counseling/Therapies, County Mental Health Services, Autism/Developmental Delay Services such as Applied Behavioral Analysis therapy (ABA) and Early Intensive Developmental and Behavioral Intervention services (EIDBI)
- **Rehab Therapies** include PT, OT, Speech and Feeding therapy

Parent Comments:

- *All of the special ed services my child normally receives at school have now fallen upon me, a single parent who's also disabled. It's horrible.*
- *Not safe to have the PCA come into our home.*
- *[Child] is not able to use behavioral support in the same manner anymore...video is not helpful.*

Question 3: Families were asked which formal services and supports have increased since the COVID-19 pandemic.

Out of 102 families responding, 23% reported that some formal services and supports for their CYSHCN have increased. Parents reported that the increase in county services were most commonly the result of a shift from using outside staff as a PCA to the parent and/or other family member now taking on the PCA duties to support the CYSHCN in the home.

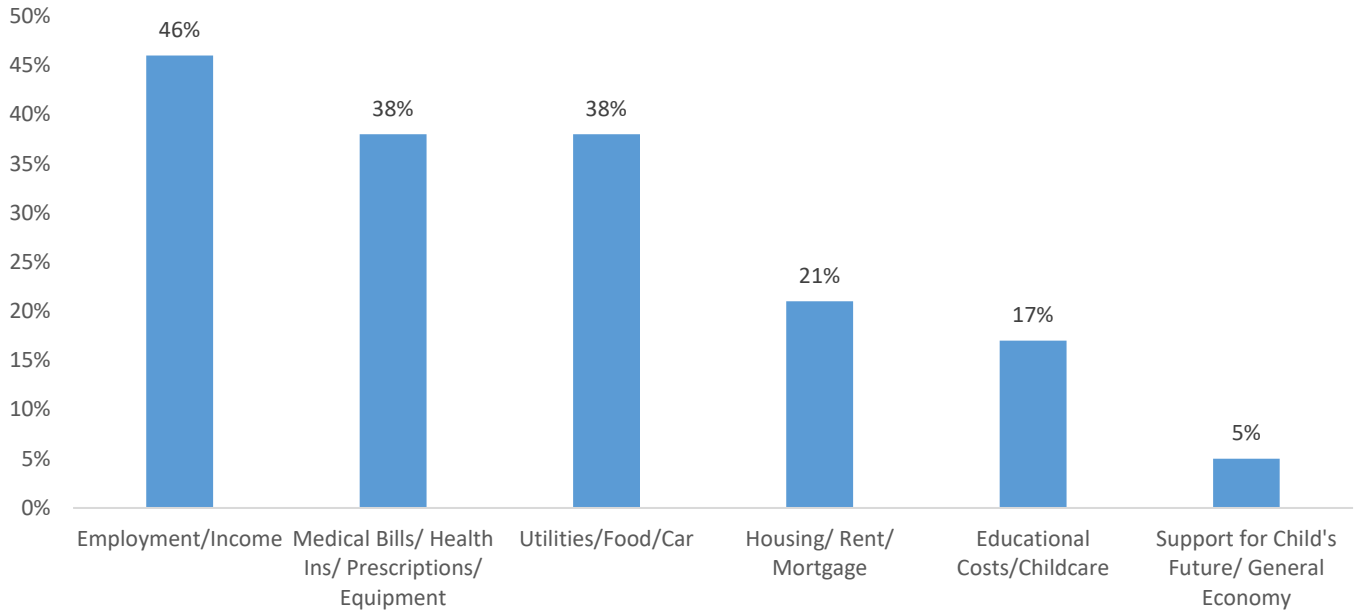


n = 24; Respondents were able to have more than one response.

- **County Services** included PCA services, respite care, parent paid as PCA, case management, and grant funds.
- **Telehealth/Virtual Services** included medical appointments, rehab therapies such as PT, OT, Speech, and distance learning/education
- **Mental Health Services** included Autism services, therapy, and inpatient services

Question 4: Families were asked to share their financial concerns related to the COVID-19 pandemic.

Families expressed several financial concerns. Nearly half were concerned about their employment and income. Most concerning were the shared fears of homelessness, not being able to feed their children, and not being able to afford necessary medications for their CYSHCN.



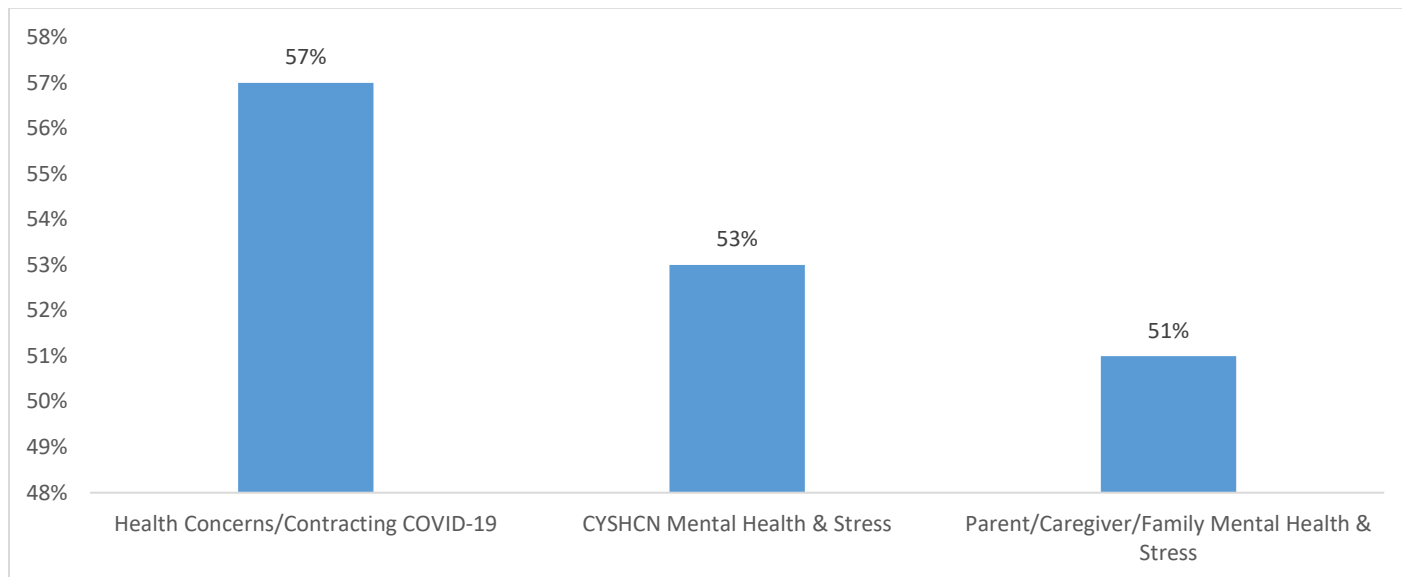
n = 77; Respondents were able to have more than one response.

Parent Comments:

- *The cost of groceries has gone up significantly.*
- *Paying the high cost of medical insurance premiums but not able to use it to access services/providers because they are not available.*

Question 5: Families were asked to share their concerns regarding their family's health, mental health, and wellness related to the COVID-19 pandemic.

The concerns families expressed were evenly divided between health/concerns of contracting COVID-19, their children's mental health and the parent's mental health.



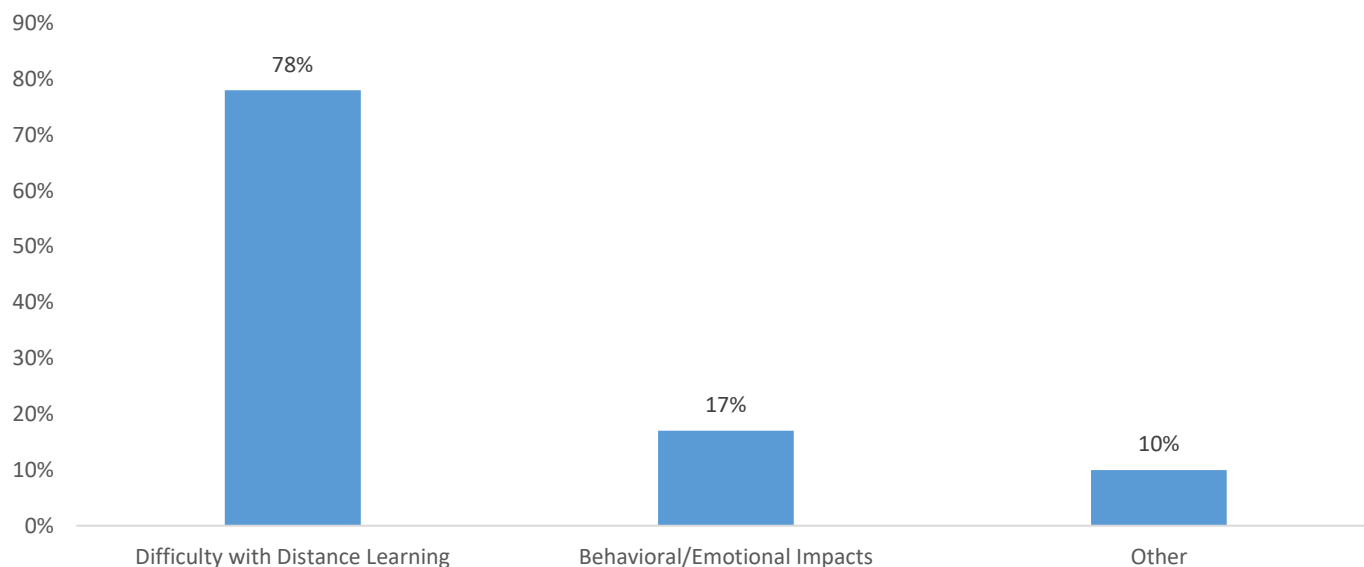
n=99; Respondents were able to have more than one response.

Parent Comments:

- *I feel like I'm going to explode most of the time - it's incredibly overwhelming and anxiety-inducing.*
- *Total care-giver burnout.*
- *We are struggling. We need the outside people to come back again to give us a break.*
- *I am concerned about shortages of medical supplies to keep our son alive.*
- *My son lives for social interaction. This is his living hell.*

Question 6: Families were asked to share their concerns regarding their child's education related to the COVID-19 pandemic.

78% of families had trouble with distance learning, including lack of support for the child and parent from school staff, along with concerns about their child losing skills and/or regressing. Families also expressed concerns that their child was not receiving needed IEP services.



n = 91; Respondents were able to have more than one response.

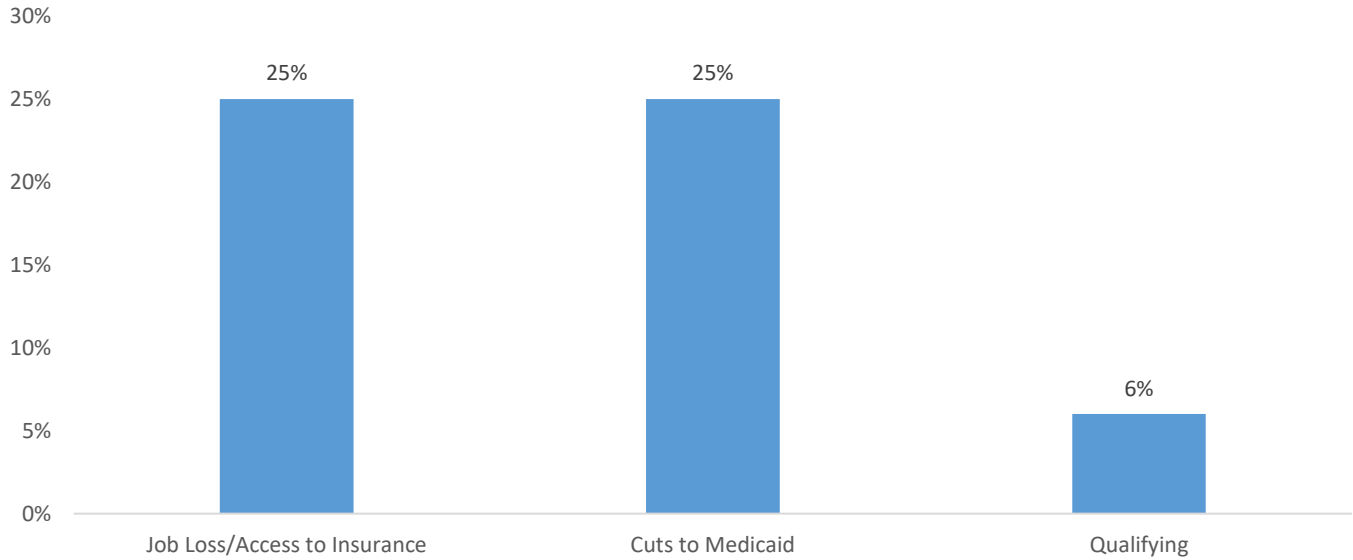
- **Other** included safety, future uncertainty, missing milestones.

Parent Comments:

- *What is [my child] really learning?*
- *Not having the bandwidth and expertise to work with my son.*

Question 7: Families were asked to share concerns they had regarding health insurance for their family or child with disabilities.

Out of 102 families, 16% responded that they had concerns about health insurance for their child or family.



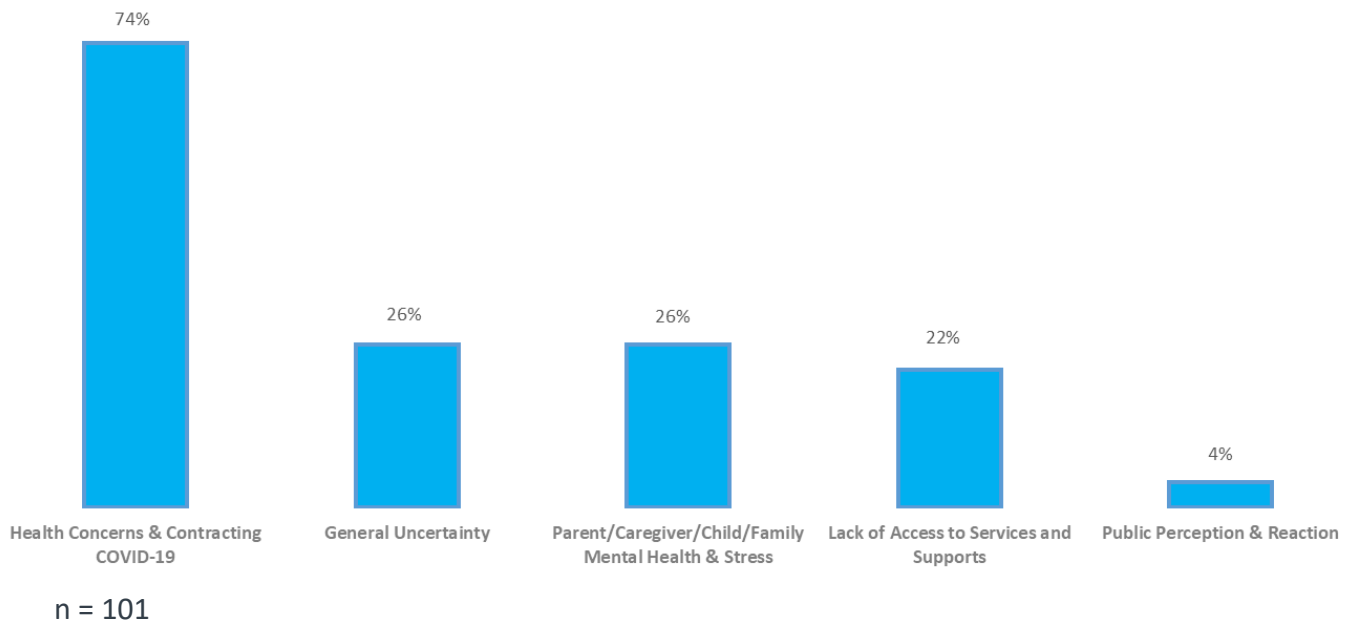
n=16

Parent Comments:

- *Mainly just the cost of it. We have to use TEFRA for my son and MNSURE private health insurance for the rest of the family – very expensive.*
- *If I lose my job, I lose health insurance.*

Questions 8: Families were asked to list their main/top concerns related to the COVID-19 pandemic.

74% of families expressed concerns that a member of their family would become sick and/or contract COVID-19, including their child, the parent, or other family members. Families expressed concerns almost equally between general uncertainty, mental health, and lack of access to services.



Respondents were able to have more than one response.

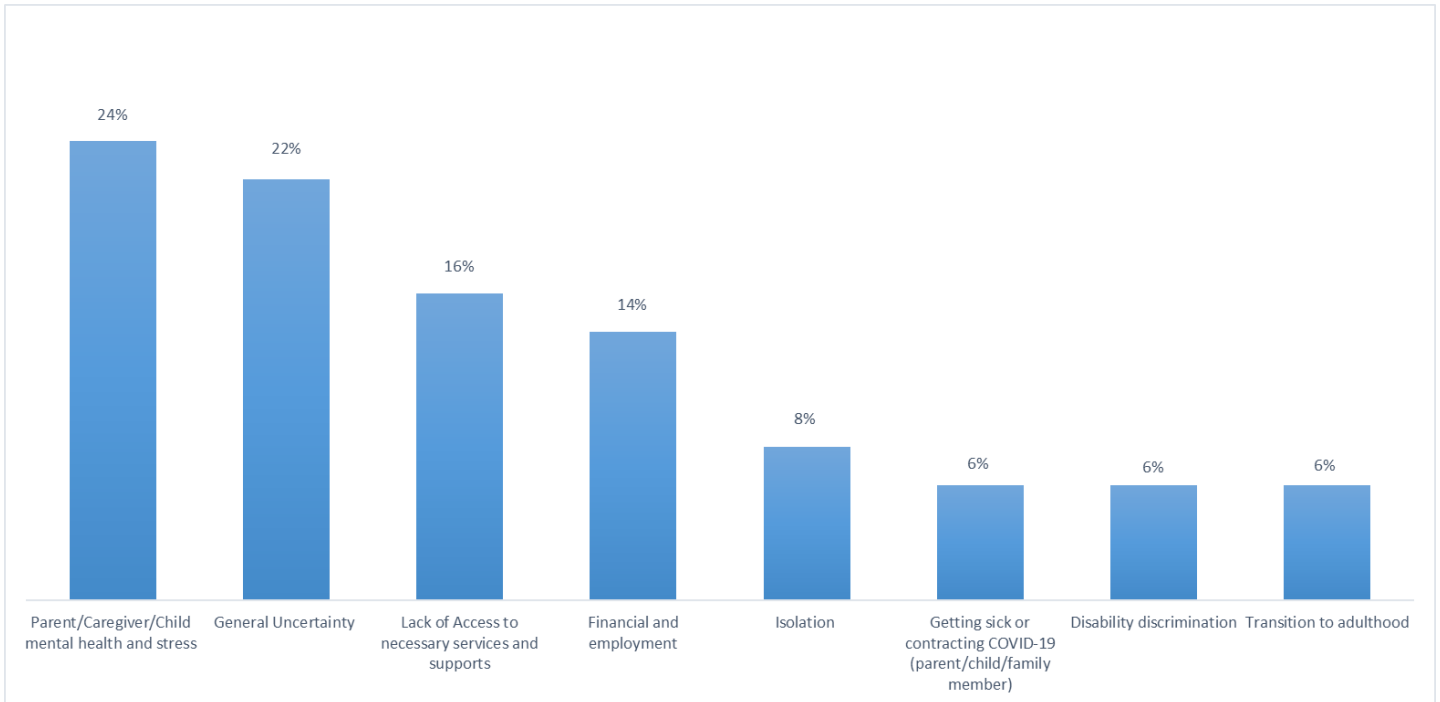
- **Health Concerns** includes survival if COVID-19 is contracted, who will care for the child if the parent becomes ill, vulnerability/high-risk, and underlying conditions, and finding effective treatments and vaccine.
- **General Uncertainty** includes comments from respondents regarding how long the situation will last/when it will end, and long-term shutdowns of schools and clinics.
- **Mental Health and Stress** includes isolation, worry, anxiety, caregiver burnout, and stress of financial strain.
- **Lack of Access to Necessary Services and Supports** includes childcare, medications, medical services, respite, and shutdown
- **Public Reaction** includes concern for how the media/news reports information related to COVID-19.

Parent Comments:

- *If I get sick, who will take care of my son?*
- *That my child won't survive.*
- *I worry that loosening restrictions will lead to further spread of [COVID-19].*

Question 9: Families were asked if there were other things they were concerned about.

This question was asked to try to capture additional issues that may not have been expressed in responses to previous questions. Of the fifty responses 24% expressed concerns related to mental health and stress among all family members, however 22% expressed general uncertainty about the future, such as when will the pandemic end, and concerns about the long-term impact on the child and family.



n=50; Respondents were able to have more than one response.

Parent Comments:

- *I feel alone and isolated. My family and friends do not seem to understand the added stress I am experiencing.*
- *We are more isolated than ever.*
- *How am I going to get groceries and supplies that I need when I'm not supposed to be shopping for myself? how do I explain to my family that every time I do go shopping I'm playing Russian roulette with my life.*
- *Long term effects on our day to day life.*

Parents were asked if there was anything else, they would like to tell us that we may not have asked or things that have been helpful for their family.

All parent responses are listed below as quotes but may have been edited for clarity.

- *Kids like my son are suffering tremendously & I'm angry because I can't change it. We've lost all services & have been put on hold indefinitely for services we'd already been waiting months for. The only thing that's been helpful is the school having realistic expectations & working with us.*
- *Talking with other parents is helpful.*
- *We need N95 masks, goggle, and disposable gowns too in-home care, not just hospitals.*
- *Family Voices support group has been awesome for my family. I wish I would have found it sooner.*
- *We are fortunate because we have a yard and last year, we had a temporary waiver that allowed us to put up a fence due to elopement issues. Without those resources we would be in so much trouble. We can't go for walks because it's dangerous without one on one coverage for the boys.*
- *There needs to be more help for essential workers and care for older disabled children.*
- *Now that getting Medical assistance but cannot get into providers due to COVID 19.*
- *Need more support and resources for young adults. Need respite care and actual PCA support.*
- *Single mom taking on all the kids because I'm working from home.*
- *Help thru support and encouragement... Someone, something uplifting would be helpful. Also, there is a fear of repercussions due to my son's inability to do ANY school work.*
- *The support of other families. Sharing ideas of things that are helping their families.*

Survey Limitations:

- While 103 parents responded to the survey overall, not all respondents answered each question.
- This survey is not intended to be a validated or published survey.
- Families were asked to share their concerns about COVID-19 in their own words.
- Limited demographic questions were asked as a method of keeping the survey short and less intrusive to families.

Family Voices of Minnesota is a nonprofit, parent run organization with services throughout the state to support parents raising children with special needs or a disability. Family Voices of Minnesota is the Minnesota State Affiliate Organization of Family Voices National and the Minnesota State Alliance Member of Parent to Parent USA (P2PUSA).

Our vision is that strong connected families who are empowered advocates ensure the best health care for children and youth with special healthcare needs and disabilities. Our mission is to cultivate strong families across Minnesota by connecting them with one another for support, resources, and information.