

NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

NEBRASKA PARTNERSHIP

FOR MENTAL HEALTHCARE ACCESS IN PEDIATRICS

A Good State of Mind



www.dhhs.ne.gov/NEPMAP

A Statewide Assessment of Mental Health Needs and Services Among Children in Nebraska: Family Perspectives

Prepared by:

The Center for Reducing Health Disparities
College of Public Health
University of Nebraska Medical Center

November 2021

UNIVERSITY OF
Nebraska
Medical Center



UNMC

COLLEGE
OF PUBLIC HEALTH

Center for Reducing Health Disparities

TABLE OF CONTENTS

Authors/Research Team	2
Executive Summary	3
Acknowledgements	5
Introduction	6
Background	6
Study Objectives	9
Approach and Methods	10
Ethical Considerations	11
Analysis and Results	12
Strengths and Limitations	30
Recommendations	31
Conclusions	32
References	33
Appendix	35

AUTHORS/RESEARCH TEAM

Dejun Su, PhD,
Center for Reducing Health Disparities, UNMC

Jessica Ern, MPH
Center for Reducing Health Disparities, UNMC

Aiden Quinn, MA
Center for Reducing Health Disparities, UNMC

Cady Walker, BS
Center for Reducing Health Disparities, UNMC

Kathy Karsting, RN, MPH
Division of Public Health, Nebraska Department of Health and Human Services

EXECUTIVE SUMMARY

The emergence of COVID-19 required a major shift in how families manage their day-to-day lives, from how their children were educated to how they accessed medical services. Parents and caregivers upended their lives over the course of weeks or months, trying to keep themselves and their children safe and healthy. These unprecedented adaptations to daily life did not come without significant hardships, and families across Nebraska were not immune from these hardships.

This report is based on a primary analysis of a quantitative assessment focusing on the demographics, child health, parent support and needs, adaptation to remote learning, and child access to health services, with oversampling of rural families. A total of 373 parents or caregivers of children in Nebraska responded to an online REDCap survey between June and August 2021.

The following is a summary of the major findings identified in this report:

- Both rural and urban families reported relatively high rates of utilization of telehealth services in the past 12 months.
- About 1 in 4 families reported children with learning disabilities and/or special health needs, whereas the rate of reported support service utilization was almost twice as high, indicating a need among children not previously identified as having special needs.
- The pandemic has caused an obvious decline in children’s emotional wellbeing. Over 50% of children received services related to mental or behavioral health during the pandemic.
- Many immigrant families indicated a strong need for interpretation services in order to access care. A lack of interpreters, distance from provider, and travel were identified by families as barriers to accessing services.
- Nearly 1 in 4 families indicated accessing services was either moderately difficult or impossible to do on their own, and almost 3% of respondents reported they were unable to access needed services during the pandemic.
- About 1 in 3 families pay for accessed support services completely out-of-pocket, and nearly 50% of respondents stated these out-of-pocket expenses cause at least some financial hardship.
- Families experienced upheavals in education delivery. The rate of homeschooling in Nebraska nearly doubled, with almost 5% of families choosing that option, compared to 2.75% of families in 2018-2019 (NE Dept. of Education).

In light of these findings, the following recommendations are offered:

- 1. Continue to grow the use and availability of telehealth as a family-friendly solution to access barriers.** Clearly many families embrace the opportunity to use technology. One of the major barriers to accessing care identified by rural families was the time and distance it took to reach services. Telehealth is an important service that can lessen this barrier and minimize geographic disparities. To expand this potential of telehealth, it becomes necessary for Nebraska to beef up its infrastructure investment in affordable and reliable internet connectivity in all geographic areas, and to continue reimbursement of telehealth services by various insurance providers.
- 2. Recognize that mental and behavioral health issues are not limited to the identified population of children and youth with special health care needs (CYSHCN). Screening, early identification and intervention services, and Family Support Services are universal needs leading to successful access to care.** It is important to continue to educate primary care providers, pediatricians, and community members of mental and behavioral health issues to continue to minimize stigma and increase access to healthcare providers.
- 3. Promote access to qualified and trained health interpreters, to decrease language as a barrier to care.** Language services remain a large barrier for many families to access and retain healthcare services, especially mental and behavioral health services. The provision of in-person or tele-interpreters is crucial to closing disparities; therefore, it is important to explore avenues to make interpretation services available to all providers and patients when needed.
- 4. Continue to actively monitor children and adolescents for developing mental and behavioral health issues as the COVID-19 pandemic continues, and continuously build accessible family supports.** There is a continual need to monitor and screen children for mental and behavioral health issues as pandemic-related stressors continue. This also includes providing resources and financial support to families with parent(s)/caregiver(s) who had to quit their jobs to oversee non-traditional schooling to alleviate impacts on family due to potential loss of income, services, and insurance coverage.

ACKNOWLEDGEMENTS

The purpose of the survey was initially framed by the Nebraska Partnership for Mental Health Care Access in Pediatrics, NEP-MAP, Nebraska's Pediatric Mental Health Care Access Program. This publication/project was made possible by Cooperative Agreement Number U4CMC32322 in the amount of \$445,000 per year from U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA) to the Nebraska Department of Health and Human Services (NE DHHS).

The authors express grateful appreciation to the members of NEP-MAP Technical Workgroup #2 for Culturally- and Linguistically-Appropriate Services and Equity; and NEP-MAP Technical Workgroup #3 for Family-Centered Care, for their dedication and substantial contributions to the development of the survey questions. We would particularly like to thank members Anna Whaley, Candi Koenig, Connie Shockley, Jessie Coffey, Laura Wooters, Mandy Roher, Sarah Swanson, Terri Marti, Tori Sorenson, Tricia Kingsley, and Jennifer Auman. We would also like to show a deep appreciation for Dr. Drissa Toure for his assistance in the planning and development stages of this assessment.

The report contents are solely the responsibility of the authors and do not necessarily represent the official policies or positions of HHS, HRSA, NE DHHS, or the NEP-MAP Technical Workgroups.

The demonstrated commitment of NEP-MAP stakeholders and partners to improving access to care for all children and families, is an inspiration to us all.

INTRODUCTION

The Centers for Disease Control and Prevention (CDC) approximates that 1 in 5 children experience a mental or behavioral health disorder, varying by age group (CDC, 2020). In addition to creating obstacles for children, this widespread prevalence has a deep impact on the lives of parents, caregivers, and families. Parental understanding and awareness of mental health are integral to a children's overall wellness. Parents may use various coping mechanisms and strategies to address these needs, sometimes experiencing hindrances in the process.

The COVID pandemic has been disruptive to the lives of children and youth to the extent of producing adverse experiences and even trauma. The epidemic of childhood mental, emotional, and behavioral health disorders now deserves closer examination and attention. This survey methodology was adopted with the perspective that parents are the experts in their children's well-being, and will provide reliable, insightful information regarding their children's needs, met and unmet.

BACKGROUND

Pediatric Mental Health Disorders

The Mayo Clinic (2020) refers to mental health as the overall wellness of how you think, regulate your feelings and behave. Mental health is significant throughout the lifespan, playing a particularly meaningful role for children. Anxiety and depression disorders are among the most common types of mental health struggles for children and adolescents (CDC, 2021). Children whose parents or caregivers experienced mental health issues reported higher levels of anxiety and depression (Ghandour et al., 2019). Treatment options for anxiety and depression include cognitive-behavioral therapy (CBT), anti-anxiety and anti-depression medication (Bennett et al., 2016; Warwick et al., 2017; CDC, 2021). Furthermore, researchers noted that CBT might be particularly effective and economical for children who experience depression or whose parents experience depression (Ghandour et al., 2019). Acri and Hoagwood (2015) reported on the need for a holistic approach to treating depression in parents and their child, as the family's needs are often intertwined. Since the COVID-19 pandemic began in early 2020, research suggests rates of depression and anxiety in children have surged (Magson et al., 2021; Patrick et al., 2021).

In addition to depression and anxiety, autism spectrum disorder (ASD) is another primary mental and behavioral concern for parents and caregivers. ASD may affect as many as 1 in 68 children in the United States (Da Paz & Wallander, 2017). Parents of children on the autism spectrum are more likely to struggle with their own mental health (Bradshaw et al., 2020), suggesting a need for support services available to parents of children with mental and behavioral health needs (Hoyle, Laditka, J. N., & Laditka, S. B., 2020). Many parents see several providers before finding one that suits their child's needs with ASD, which can be an emotionally and financially taxing process (Myers et al., 2020).

Several barriers have emerged that have affected families ability to seek and maintain treatment for their children with mental and behavioral health disorders. These barriers include financial barriers, racial barriers, and barriers associated with gender and sexual identity.

Low socioeconomic status and poverty are linked with higher rates of mental health disorders, and children from low-income families are at an increased risk. According to the U.S. Census Bureau, children continued to experience poverty rates higher than any other age group at 16.2% in 2018 (Semega, Kollar, Creamer, & Abinash, 2019). Uninsured parents are less likely to seek out mental health services for their children compared to parents with health insurance (Sheryl et al., 2002). Poverty appears to be a strong risk factor for mental health problems in children, and intervention strategies should be employed as early as possible (Dashiff et al., 2009). Receiving housing assistance may help children have better mental and behavioral health outcomes (Fenelon et al., 2018). This provides an opportunity for public assistance programs to have a more robust response in mental health programs for children and families in poverty (Cree et al., 2018). Ameliorating the adverse health effects of poverty should be addressed as early as possible. The longer children lived in poverty, the more likely they were to experience poverty in adulthood (Wagmiller & Adelman, 2009).

The crisis of mental health disparities in children cannot be addressed without the context of race. In 2020, nearly half of all infants born were children of color (Children's Defense Fund, 2020). This highlights the need for more diversity and cultural competency (Betancourt et al., 2003) among mental and behavioral healthcare services for children, as their needs are continually evolving (Gonzalez, 2005). Health disparities contain no age limit; even young children are not immune to racial and ethnic inequalities within the healthcare system. Howell and McFeeters (2008) researched the connection between children's' race and/or ethnicity and their access to mental health services. Black and Hispanic children, in both rural and urban areas, had less access to mental health providers and services (Howell & McFeeters, 2008). Another study, however, cited that white children utilized mental health services with less frequency than all other racial and ethnic groups (Chun-Chung Chow, Jaffee, & Snowden, 2003). This discrepancy may be due to geographical variations among children of different races and the intersectionality of socioeconomic status and other markers and indicates the need for more exploration (Chun-Chung Chow, Jaffee, & Snowden, 2003).

There are various ways parents cope with the challenges of children's' mental and behavioral health needs. Kuhn and Laird found that having multiple levels or systems of support created additional protection layers from poor mental health outcomes in children (Kuhn & Laird, 2013).

Facilitating ways in which healthy mental and behavioral outcomes for children are achieved is critical to ensuring their wellbeing. Exercise is one of the keyways in which mental health can be improved for all ages. Encouraging children to participate in sports or other exercise provided positive effects on mental health (Ekland et al., 2004).

Likewise, Sibold and colleagues (2016) found that children who exercised four or more times per week experienced significantly lower rates of suicidal thoughts and actions. Parental awareness of mental health is a salient component in maintaining healthy children and adolescents, reinforcing positive mental health. Primary care providers may assist children experiencing mental health issues by ensuring a proper transition between pediatric care and their adolescent physician (Leeb et al., 2020). Glascoe (2003) reported that children who had difficulties with social skills or behavioral issues, as documented by parents, were more likely to experience mental health disorders. This research insinuates that parents should continue to report concerns about behavior or social skills to their child's primary care physician (Glascoe, 2003), as this may be a reliable way to identify mental health issues early in childhood.

The role of parents and caregivers in children's mental health cannot be overstated. Unfortunately, many parents perceive children to be worse off today than in prior generations, with Millennials having the most negative beliefs about present childhood health (Freed et al., 2018). Limited research exists regarding how parents and caregivers are affected by their child's mental and behavioral health (Acri & Hoagwood, 2015), calling attention to another important area of needed research. Some parents are more likely to perceive their child's hyperactivity disorder as a problem if it impacts their work (Sayal, Taylor, & Beecham, 2003), which was more likely to occur since more parents are working from home. Furthermore, parents may hesitate to access appropriate mental healthcare services for their children due to fear and stigma associated with asking for help (Gonzalez, 2005). Adolescents, especially young males, echo that stigma is a limitation in their pursuit for better mental health (Chandra & Minkovitz, 2006). Shame, for parents and children alike, is a barrier to equitable health.

Use of Telehealth by Families

The role of telehealth in the medical system is a growing and crucial area of research that needs to be further examined, especially in pediatric populations and during the COVID-19 Pandemic. While telehealth overall has been seen as a way to increase healthcare accessibility and decrease health disparities in certain populations, pediatricians express concern that telehealth will compromise the efficacy of treatment and lack of rigorous research (Olsen et al., 2018). Other major provider concerns are lack of reimbursement, credentialing issues, and liability concerns. Despite these concerns on the provider side, there is an increase of telehealth utilization among pediatric patients. In one assessment, there was 125% growth in telehealth visits and an 88% increase in parents' awareness of telehealth services (HealthLeaders Media, 2017). However, the lack of cohesive use of telehealth services and research in effectiveness has left a large gap in the literature, especially in rural and minority groups.

The COVID-19 Pandemic and Effects on Mental Health

COVID-19 has affected all families, upending the routine and normalcy of work, school and everyday life. Many, but not all, schools closed in March or April of 2020 and adopted virtual learning. The American Academy of Pediatrics (2020) continues to advocate for children to be physically present in school to meet their educational and health needs, provided the establishment of appropriate safety measures. Although Nebraskan students are now back in school for the 2021-2022 school year, the recent rise in COVID-19 cases has left students in a precarious position. A survey ending in June of 2020 found that 14.3% of parents reported worsened mental health for their children since the start of the pandemic (Patrick et al., 2020). Fortuna and colleagues (2020) cautioned that coronavirus exacerbates health disparities, disproportionately affecting children in poverty. Communication among parents and children can help mitigate the adverse mental health effects of the COVID-19 pandemic (CDC, 2020).

Moreover, understanding the long-term consequences of COVID-19 and pandemic response measures, and impacts on the mental wellbeing of children may not be known for some time since the both pandemic and human development are ~~is~~ ongoing processes. With 1 in 4 COVID-19 cases affecting children in September of 2021 (American Academy of Pediatrics, 2021), and over 700,000 lives lost including many parents and caregivers, it is critical to be vigilant about monitoring and protecting children's wellbeing respecting the impacts of grief and loss.

Children's health is multifaceted, including emotional, mental, and behavioral health. Establishing positive mental health habits and practices are essential to a healthy upbringing for children. Screening, early identification and intervention, and referral, are all aspects of primary care that benefit access to mental and behavioral health care. Alleviating health disparities through early prevention is key to accessing better mental, emotional, and behavioral health outcomes for children. This can only be accomplished through the willingness of parents, providers, and social supports working together to understand children through their vulnerabilities.

STUDY OBJECTIVES

The purposes of our report are to identify and assess:

- 1) Parental satisfaction with their child's mental health screening, care, and/or counseling;
- 2) The extent to which parents feel they are empowered as decision-makers in their child's care;
- 3) The extent to which parents agree they have access to needed family supports,;
- 4) The impact of COVID-19 on the emotional and mental wellbeing of families/children;
- 5) The programs available to assist children and their families to cope with the COVID-19 pandemic.

APPROACH AND METHODS

Study Design

In this study, we adopted a quantitative approach on our data collection by collecting data associated with pediatric mental and behavioral needs through an online survey.

To prepare for this study, the research team collaborated with NEP-MAP partners and stakeholders, in the form of Technical Workgroups #2 (TWG#2) for CLAS and Equity in NEP-MAP priorities and operations; and Technical Workgroup #3 (TWG#3) for Family-centered care. Consistent with NEP-MAP goals, the TWG members were committed to assuring the language of the family survey was plain and respectful to diverse families and reflected recognition of the challenges families face. The members of TWG#2 in particular, family members themselves, had many constructive suggestions for the family survey that were adopted by the research team. The quantitative approach of our data collection on pediatric mental and behavioral needs was executed through an online REDCap survey. The questionnaire was pilot tested before it was finalized and used in the study.

A total of 373 parents or caregivers of children in Nebraska responded with completed surveys between June and August 2021.

NEP-MAP primarily is concerned with improving access to mental and behavioral health services for children and youth in rural and underserved communities of the state. To that end, the survey results were differentiated between “urban” and “rural” family responses. In addition, NEP-MAP leadership specifically requested the evaluation team to assure that responses from rural Nebraska families were obtained from each of Nebraska’s four predominantly rural Behavioral Health regions. As a result, the survey purposefully oversampled rural respondents, compared to the overall Nebraska population.

Data was broken down into urban and rural locations based on US Census designation of ‘counties with a population of 50,000 or more’ (Economic Research Service, n.d.; US Census, 2021). Nebraska counties that fit this definition include Douglas, Hall, Lancaster, and Sarpy. Urban and rural residency was determined by the zip code provided by the respondent. Zip codes located within Douglas, Hall, Lancaster, and Sarpy counties were identified as urban and all others were identified as rural. For this analysis, data are primarily organized into “whole sample” (urban and rural combined) “rural” responses. Results provide new insights into the access needs of Nebraska families statewide, and of rural Nebraska families specifically.

Data Collection

Study data were collected and managed using REDCap (Research Electronic Data Capture) electronic data capture tools hosted at UNMC. REDCap is a secure, web-based application designed to support data capture for research studies. REDCap at UNMC is supported by Research IT Office funded by Vice Chancellor for Research (VCR). This publication’s contents are the sole responsibility of the authors and do not necessarily represent the official views of the VCR and NIH.

The survey started with informed consent and three screening questions to ensure eligibility. Eligibility criteria included at least 19 years of age, currently reside in Nebraska, and currently living with a child or children under the age of 18 years. If the eligibility requirements were met, the participant was then prompted to continue the survey and answer multiple-choice, open-ended, and rated questions regarding their children (Appendix A). Participants were asked to provide an address at the end of the survey in order to receive a \$25 gift card as compensation. This information was not linked to the survey responses.

A recruitment flyer with the eligibility requirements, information on the assessment with a direct link to the survey was emailed to identified organizations throughout Nebraska. Snowball sampling was used to share the survey among families throughout the state. Members of the NEP-MAP Technical Workgroups were particularly helpful in reaching into networks of family service providers including Community Health Workers to promote the survey in rural communities.

ETHICAL CONSIDERATIONS

The Institutional Review Board of the University of Nebraska Medical Center approved this study (IRB # 246-21-EX). Data collection from eligible participants only started after we had obtained informed consent. Participants could choose to withdraw from the study or refuse to answer specific questions based on their judgments at any time during the interview process.

Only de-identified data were used in the final project report and related dissemination of project findings.

ANALYSIS AND RESULTS

Part I. Parent and Child Demographics

Most parent respondents were between the ages of 25 and 44, with most respondents between 35-44 years (45.4%) followed by 25 to 34 years (37.1%). There were more female respondents than male respondents overall (63% vs. 36.5%, respectively). The majority of respondents were non-Hispanic/Latino (72.1%) and Caucasian/White (71.7%). Respondents were more likely to be married (78.5%), with two or more incomes contributing to the household (65.7%), with at least a Bachelor's degree (29.6%). More details of the demographics of the parent or caregiver can be seen in Table 1.

Overall, the majority of respondents reported only one or two children in the household.

Table 1: Household Demographic Breakdown of Sample

Age (n = 372)	n	%
19-24	18	4.8%
25-34	138	37.1%
35-44	169	45.4%
45-54	45	12.1%
55-64	2	0.6%
Gender (n = 373)		
Female	235	63.0%
Male	136	36.5%
Other	2	0.5%
Ethnicity (n = 356)		
Hispanic or Latino/a	87	24.4%
Not Hispanic or Latino/a	269	75.6%
Race (n = 363)		
White	266	73.3%
Black or African American	56	15.4%
American Indian or Alaska Native	23	6.3%
Asian	5	1.4%
Pacific Islander	3	0.8%
Multiracial	7	1.9%
Other	3	0.8%

Table 1: Household Demographic Breakdown of Sample (cont.)

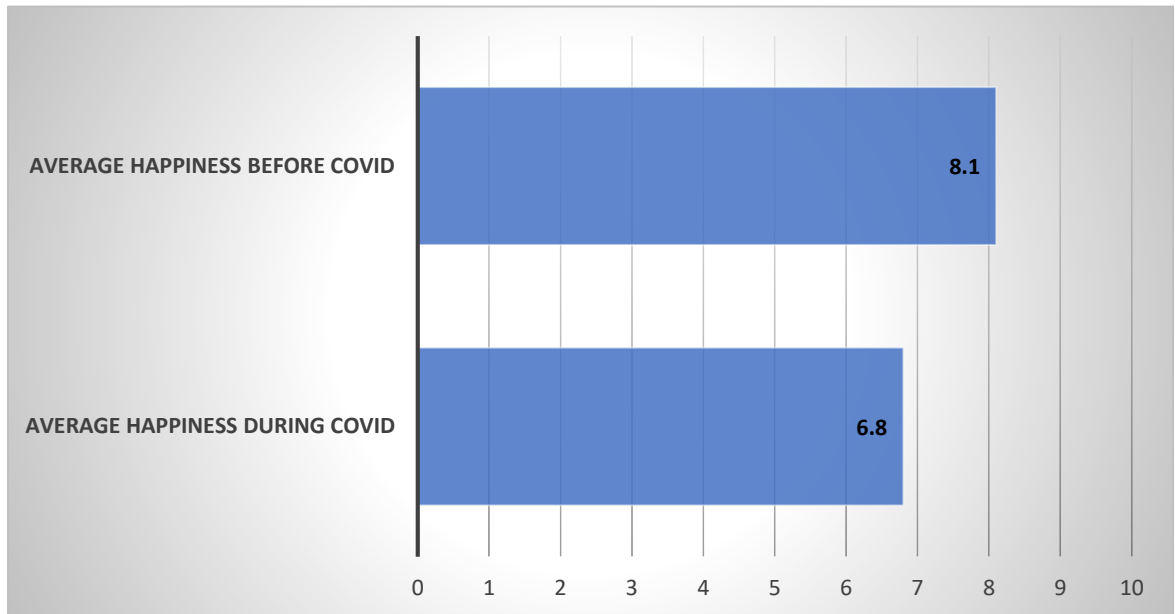
Marital Status (n = 366)	n	%
Married	292	79.3%
Unmarried but Cohabiting	22	6.0%
Widowed	7	1.9%
Divorced	19	5.2%
Separated	6	1.6%
Never Married	20	5.4%
Income* (n = 373)		
Two or more incomes	245	65.7%
1 income	89	23.9%
No Income	7	1.9%
Unemployment benefits	16	4.3%
State Support (e.g., Foster Stipends)	22	5.9%
Child Support	20	5.4%
SSI	6	1.6%
SSA	12	3.2%
Other	1	0.3%
Education (n = 371)		
Less than HS/Ged	20	5.4%
HS Grad/GED	59	15.9%
Some College	76	20.5%
Associates Degree/Trade School	62	16.7%
Bachelor's Degree	110	29.6%
Master's Degree	37	10.0%
Professional Degree (JD, MD, PhD, etc.)	7	1.9%
Number of children in the household (n = 371)		
1	247	66.2%
2	77	20.6%
3	29	7.8%
4	14	3.8%
5 or more children	4	1.2%

*Percentage may total more than 100% due to multiple options available

Part II: Parent-Reported Child Health

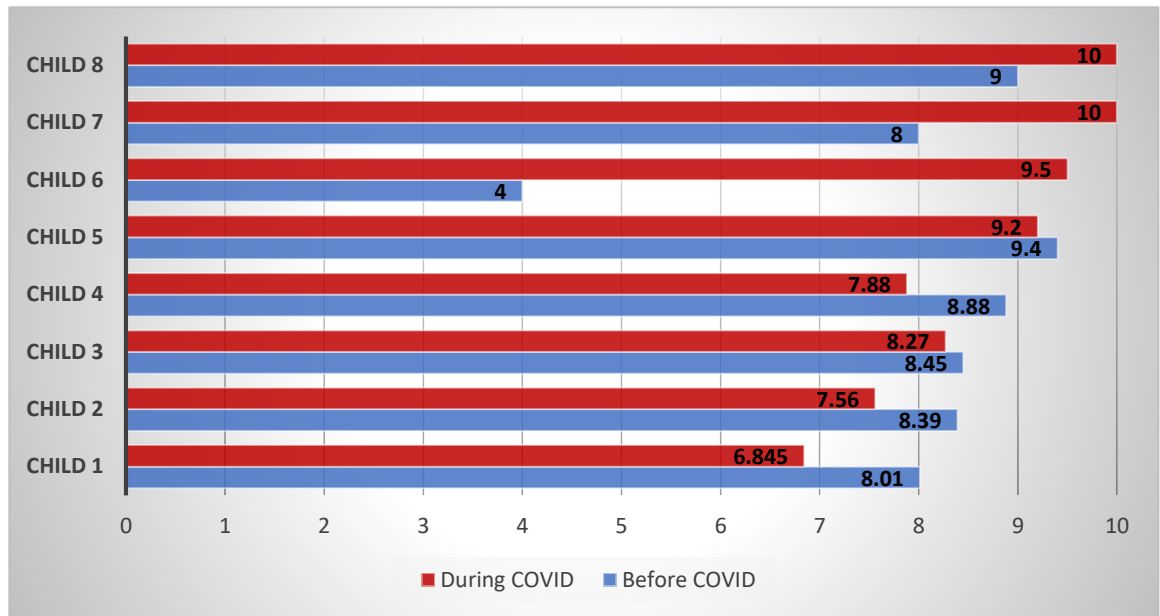
Parents were asked to report their children’s happiness right before the COVID-19 Pandemic (as of Summer 2021) on range of 1 to 10, with 1 being very unhappy and 10 being very happy. Overall, parents reported that children are less happy post-COVID than they reported prior to COVID (Figure 1).

Figure 1: Child Happiness as Reported by Parent



Overall, younger children were reported happier than their older siblings in both pre- and post-pandemic assessment of child happiness (Figure 2). The greatest change reported was in diminished happiness of the oldest child. Prior to the pandemic, the oldest children reported an average happiness rating of 8.01, while younger children had an average score of 8.39 to 9.4. There was a noticeable lack of pattern in child happiness prior to the pandemic after the fifth child, which may be due to the small sample size. During the pandemic, this trend is also observed, with the first child’s happiness score decreasing to 6.845, with younger children ranging from 7.56 to 10.

Figure 2: Child Happiness as Reported by Parent by Birth Order



Post-COVID happiness levels were reported higher by rural parents compared to the statewide sample, although most happiness ratings dropped overall. One notable difference is that the first child reportedly was happier in the statewide sample than in the rural sample, while rural children tended to be reported as happier overall.

Figure 3: Child Happiness as Reported by Parent Prior to COVID-19 Pandemic

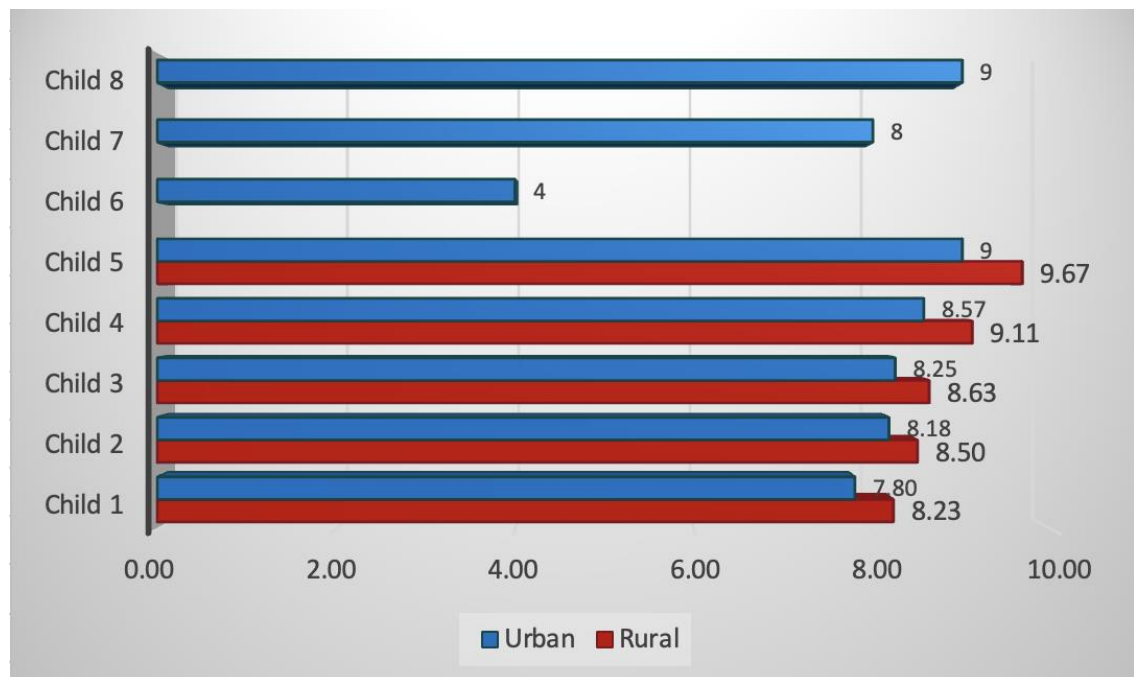
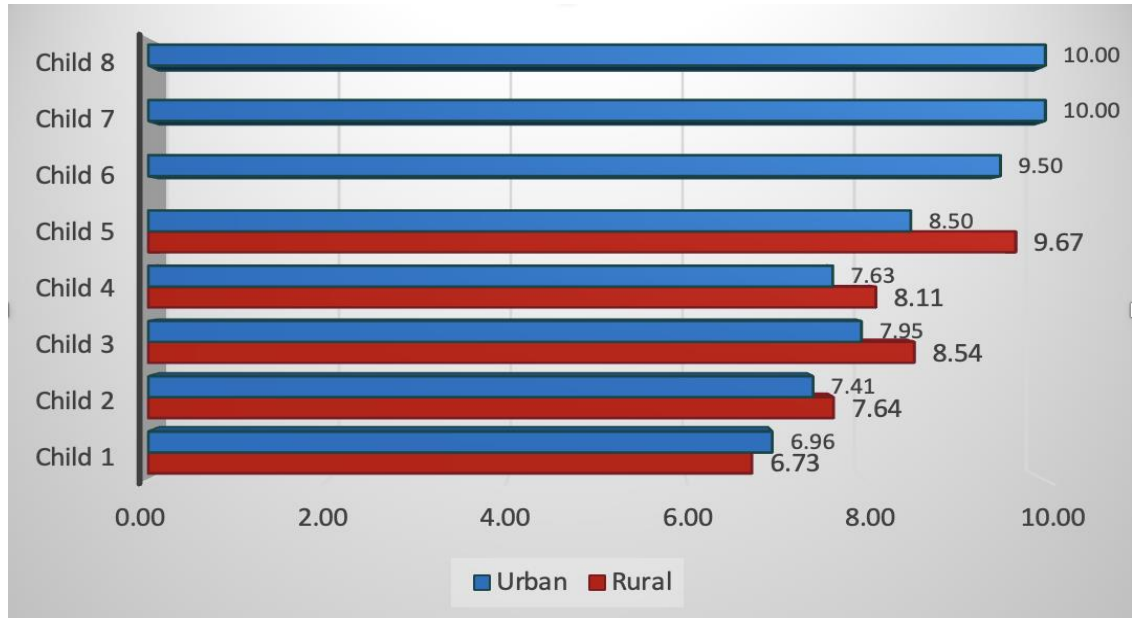
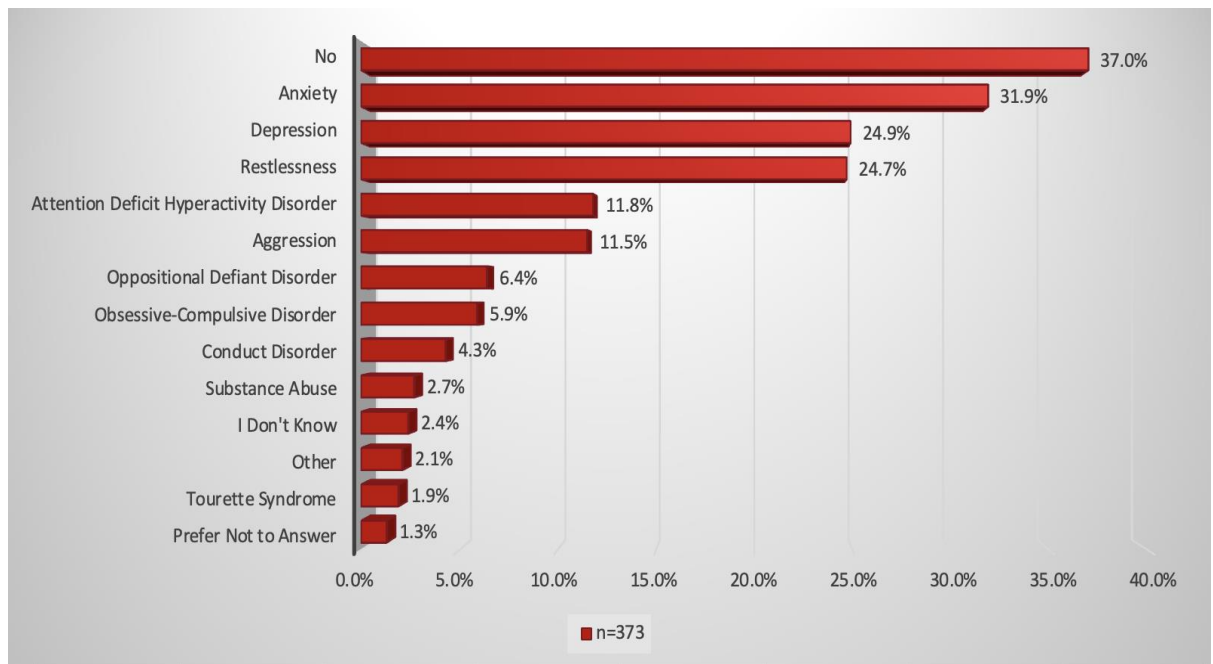


Figure 4: Child Happiness as Reported by Parent Post-COVID-19 Pandemic



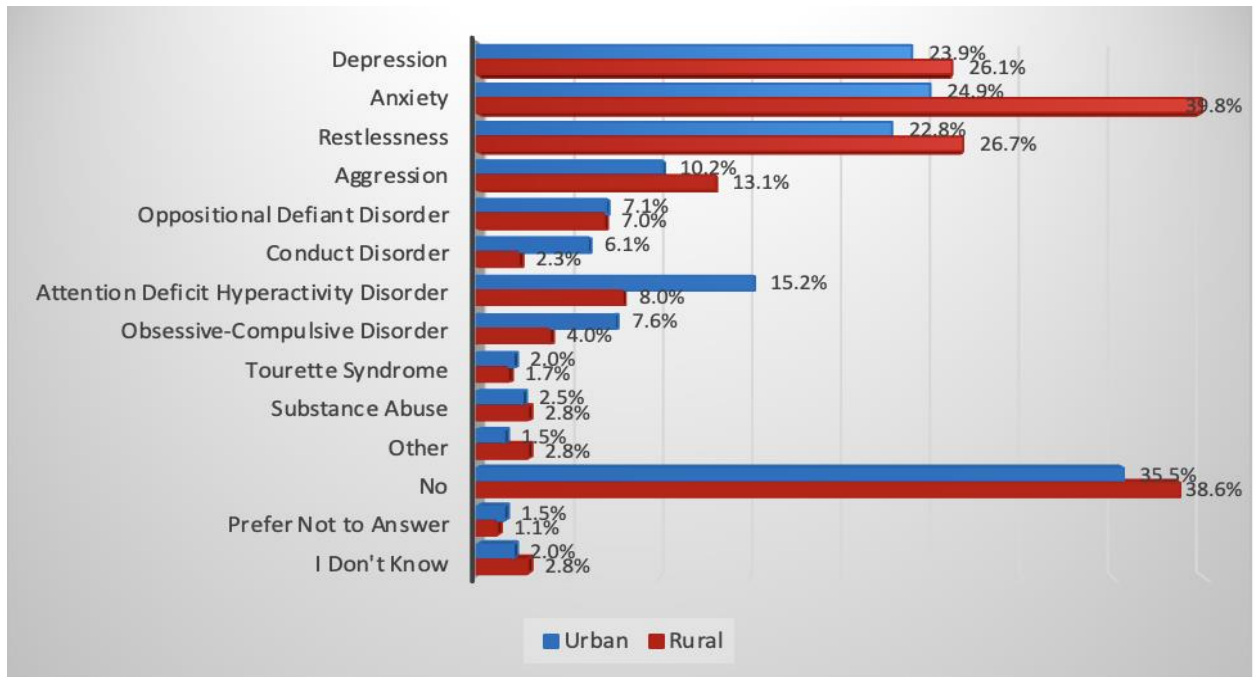
Respondents reported signs of mental and behavioral health issues within the 30 days prior to taking the survey (Figure 5). Over a third of parents indicated their children did not exhibit any signs of mental or behavioral health issues over the last 30 days. Of those parents who replied yes, anxiety was the most reported issue by parents, followed by depression and restlessness.

Figure 5: Parent Reported Signs of Mental or Behavioral Health Issues Within the Last 30 Days



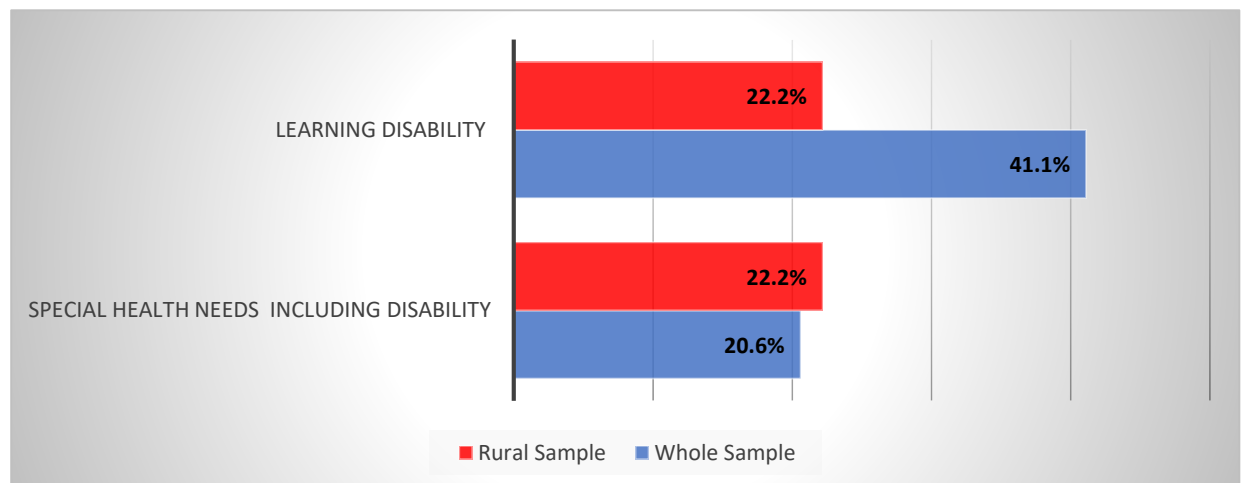
In rural areas, anxiety, depression, and restlessness were reported at higher rates than statewide sample (Figure 6). In urban areas, conduct disorders and ADHD was reported at higher rates than rural areas. Slightly more rural than urban parents reported there were no signs of mental or behavioral issues in their children (38.6% vs. 35.5%).

Figure 6: Parent Reported Signs of Mental or Behavioral Health Issues Rural vs Statewide



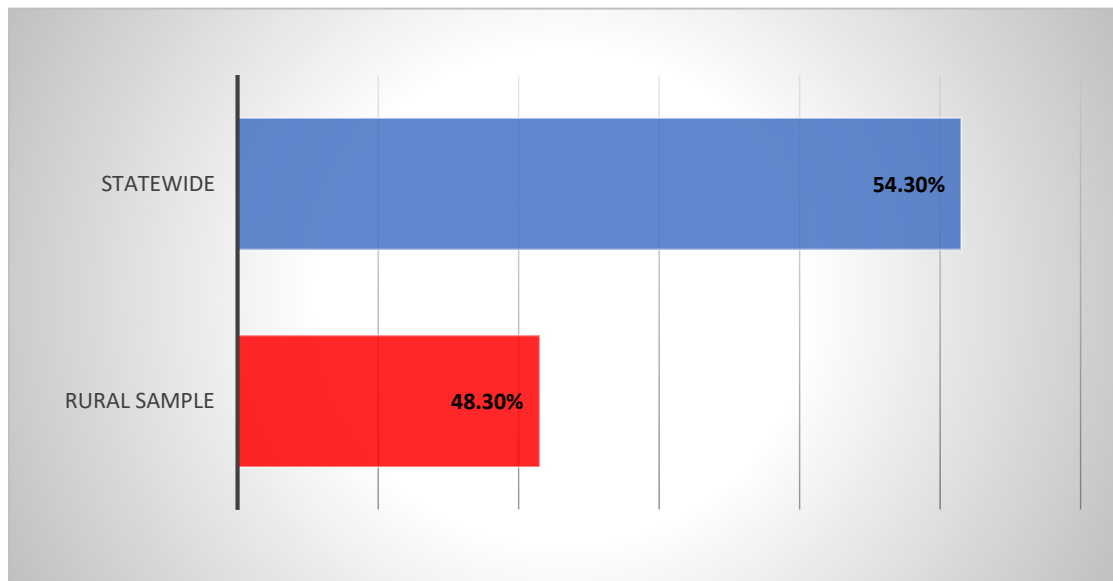
Over 1 in 5 parents reported at least one of their children had either a learning disability or had special needs, including disability. Figure 7 shows the percentage of parents reporting one or more children with learning disabilities; and with special needs including a disability, among respondents in the whole sample, and for the rural subgroup. Rural parents reported a slightly higher proportion of children with special health needs including disability than the overall statewide sample; however, the proportion of children with learning disability was much lower in rural families than in the whole sample.

Figure 7: Parent Reported Health Needs and Disability



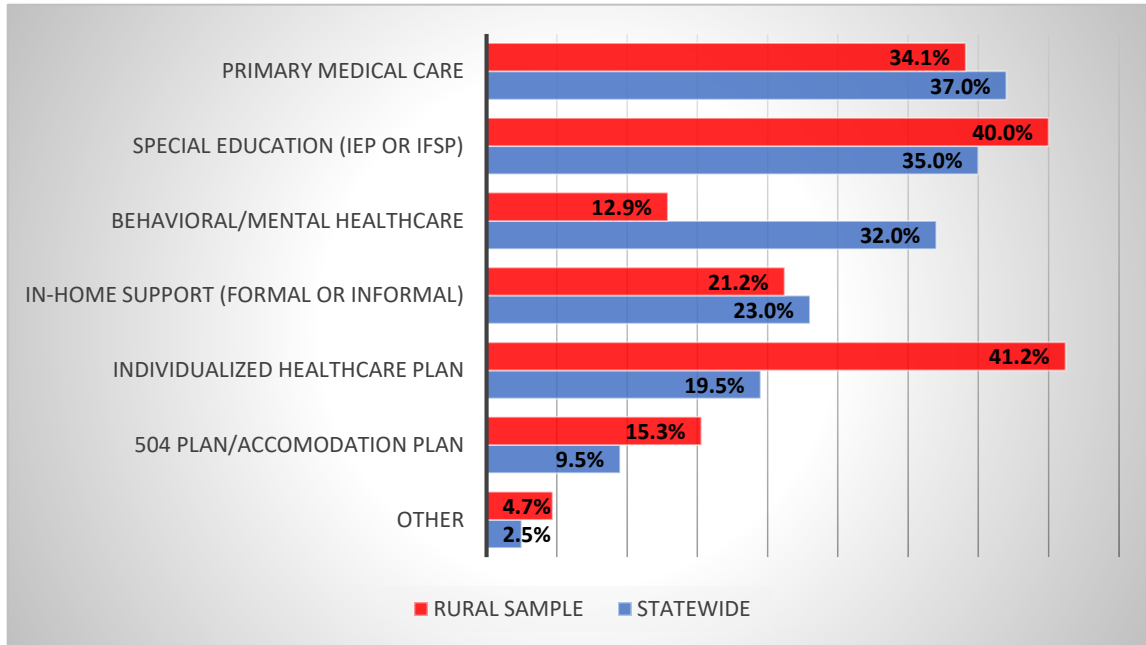
While less than 30% of all parents reported children with special health needs or learning disabilities, parents reporting use of various support services were higher, with 48.3% of rural parents and 54.3% of all parents reporting use of services. This measure suggests that a significantly larger population of children and youth than previously identified are in need of support services. (Figure 8).

Figure 8: Parent Utilization of Support Services



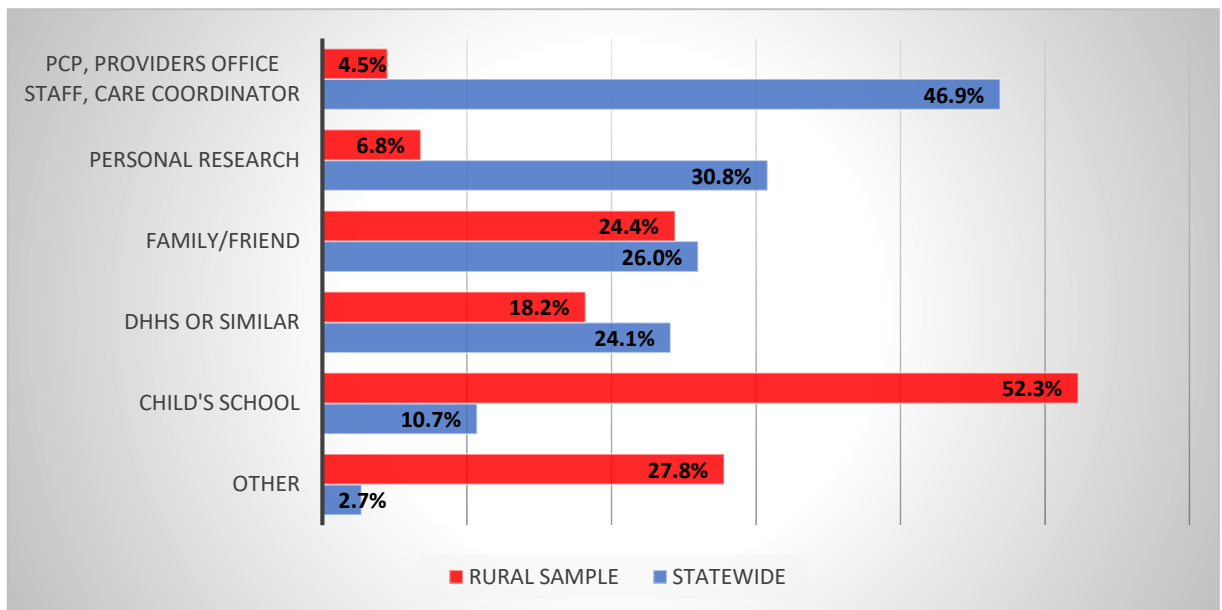
Among those families utilizing support services, the most common utilized is primary medical care, followed by special education and behavioral/mental healthcare (Figure 9). Rural parents specifically reported using the following services most: individualized healthcare plans (41.2%), special education (40%), and primary medical care (34.1%). This may be due to the accessibility of school resources in rural areas and resilience of parents to develop and sustain healthcare plans that are specific to their children. Comparatively, rural residents used special education and individualized healthcare plans at a higher rate than the statewide sample (35% and 19.5%, respectively).

Figure 9: Services Utilized by Parents



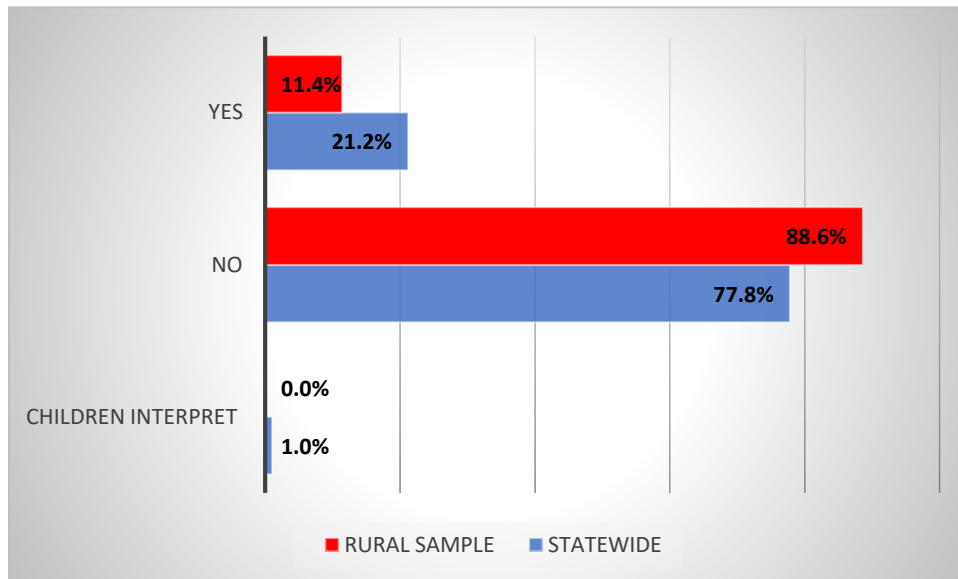
Overall, parents indicated that they learned about these services from their primary care providers (46.9%) or through personal research (30.8%) (Figure 10). Rural respondents were more likely to learn about services from the child’s school (52.3%) and family or friends (24.4%). Significantly, rural respondents were less likely to rely on providers or personal research to learn about services, which may speak to a lack of medical resources in the community or inability to confidently identify reliable sources on the personal level. It is important to further examine the significant reasons behind this disparity.

Figure 10: Education of Parents of Services Available



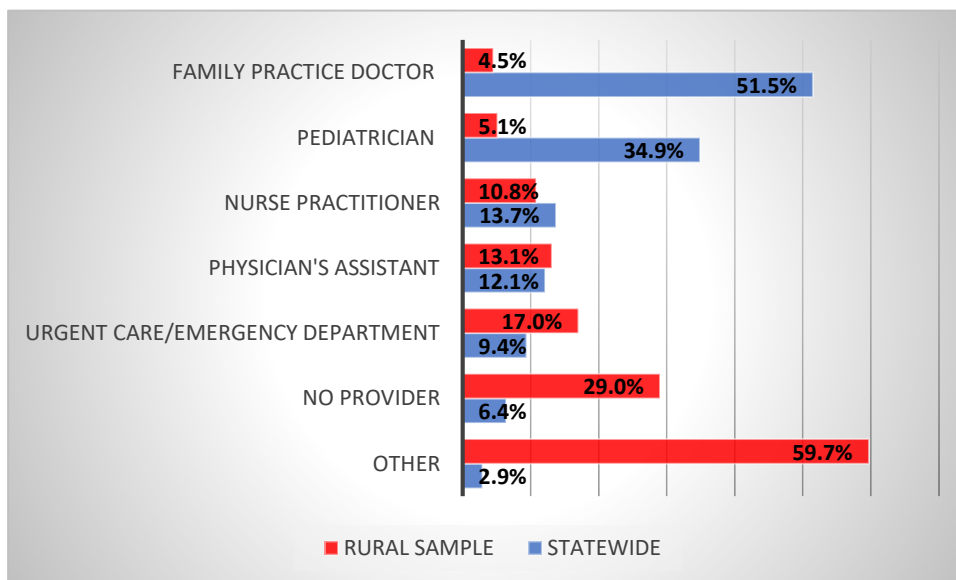
NEP-MAP asked the study team to explore with families their use of linguistic interpreters, in order to access services (Figure 11). Overall, 21.2% of families reported using interpreters outside of their homes. The percentage of rural families utilizing interpreters was less than the sample overall, 11.4%. It is not clear from the survey whether this is the result of lesser demand or lesser availability. While there was some reports of children being used as interpreters, this was not reported in the rural sample.

Figure 11: Reported Utilization of Interpreter Services



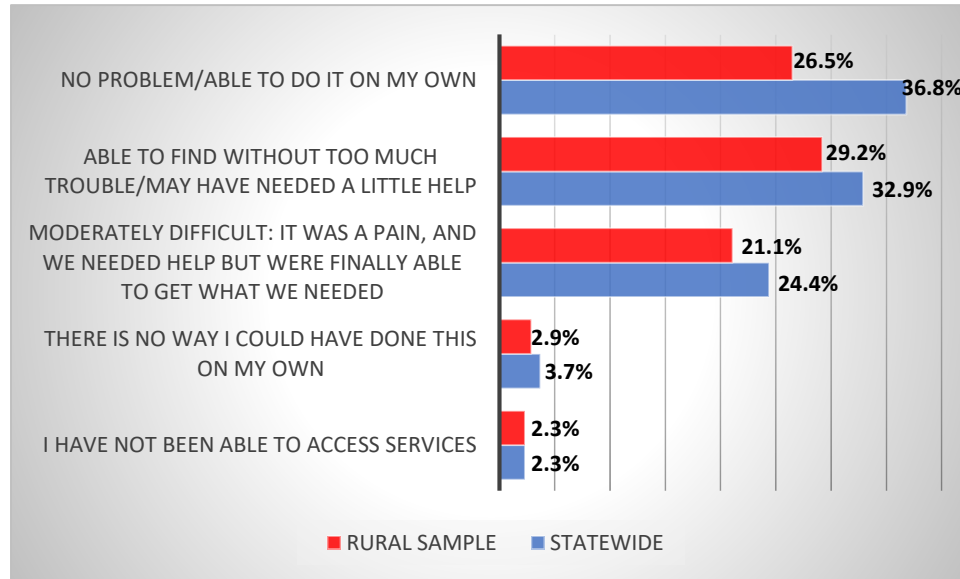
Specific to medical services, all families most often reported utilizing family practice doctors and pediatricians. Rural respondents utilized family practice physicians more than pediatricians, likely due to relatively fewer pediatricians in rural areas. Utilization of mid-level providers, Nurse Practitioners and Physician Assistants, was higher for rural respondents than the sample overall, as was urgent care and emergency department use. Notably, 6.4% of all respondents reported no provider type that they utilize for services (Figure 12).

Figure 12: Medical Services Utilized by Families



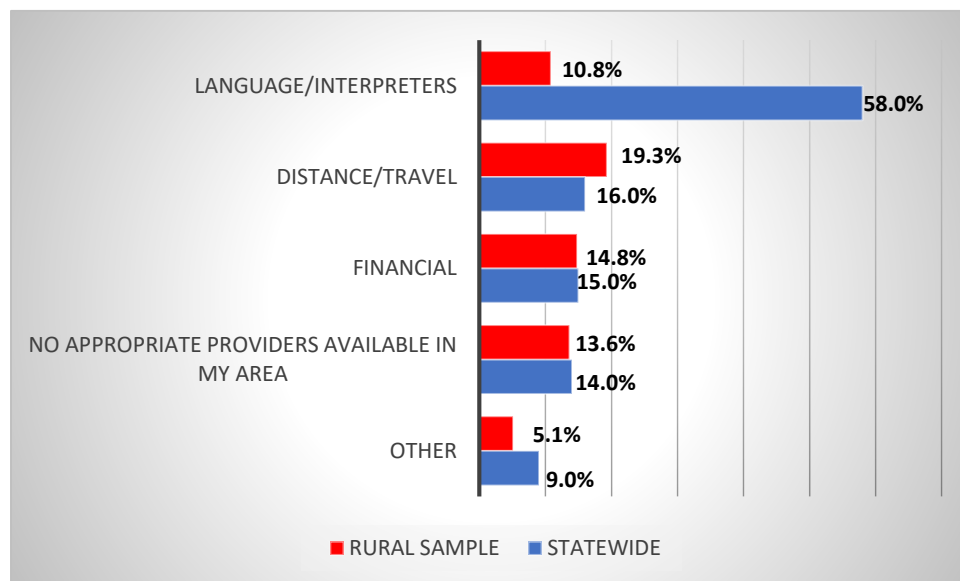
Forty-percent (40%) of all respondents indicated that they had no issue accessing services on their own. Approximately 60% of respondents required at least a little help, and nearly 3% were completely unable to access needed services (Figure 13).

Figure 13: Reported Ease of Accessibility to Services



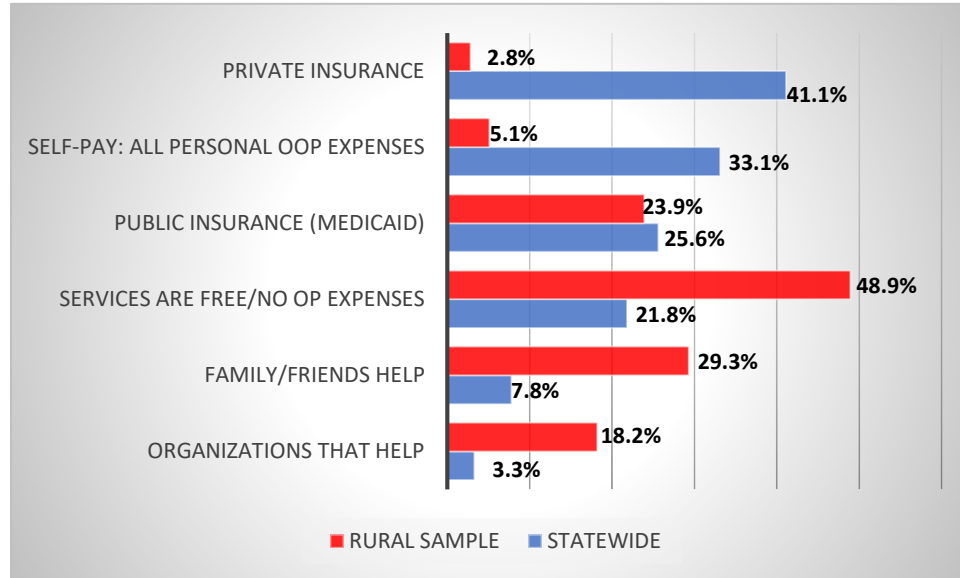
When asked about barriers faced in accessing health care services, by far, the greatest issue to accessing healthcare services for all respondents was language or interpretation services (58%) (Figure 14). Rural respondents reported distance and travel, financial burdens, and lack of appropriate providers as the greatest barriers to accessing services. As expected, rural respondents reported distance and travel as a greater burden than the overall sample.

Figure 14: Reported Barriers to Accessing Services



Further, a full third of respondents pay for their accessed services completely out-of-pocket (Figure 14). Over half of respondents indicated that these out-of-pocket expenses cause financial hardship or strain at least some of the time.

Figure 15: Reported Payment Method of Services

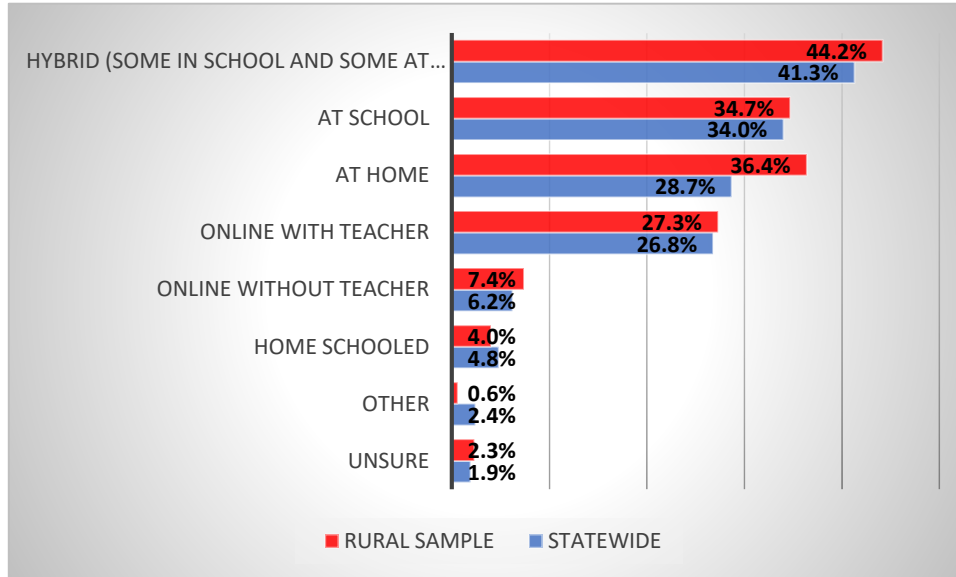


Nearly 35% of respondents reported out-of-pocket financial expenses as a financial hardship in comparison to only 40% of rural respondents. However, both rural respondents and the statewide sample stated that out-of-pocket expenses are similarly sometimes a burden (30%). This shows that out-of-pocket expenses are financially draining on the majority of families.

Part III: Adaptation to Remote Learning

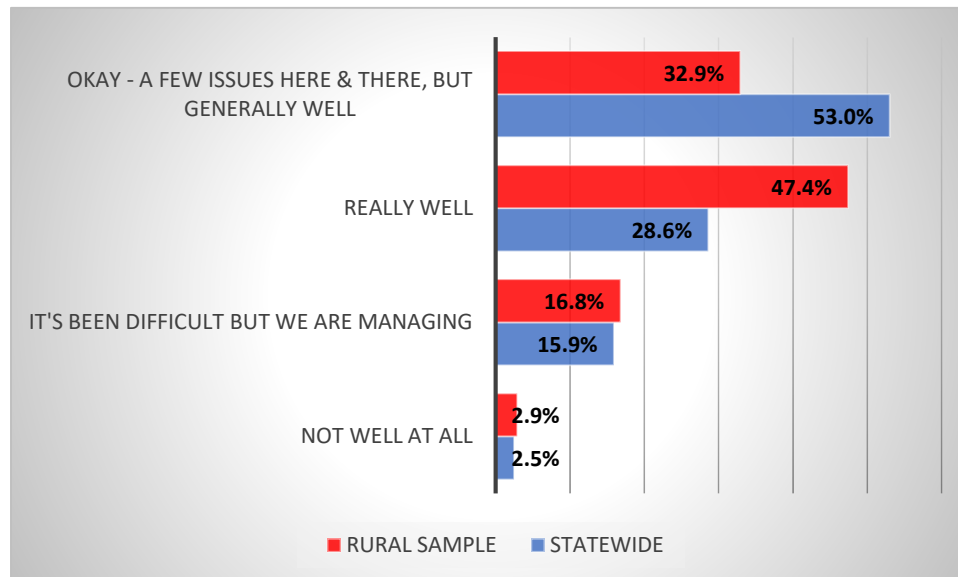
The 2020/2021 school year was an unprecedented experiment in multi-modal education delivery, and implications for families have been uneven and at times severe. Rural children tended to attend in-person more (either through strictly in-person or some sort of hybrid method) than the statewide sample overall (Figure 16), which was related to some rural schools remaining open throughout the first phases of the pandemic.

Figure 16: Education Method in 2020/2021 School Year



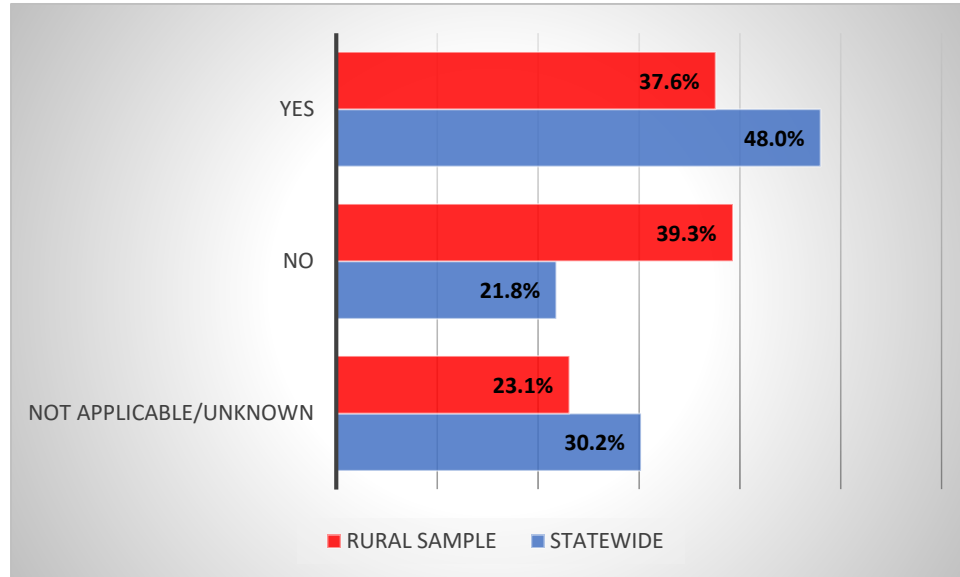
Nebraska experienced considerable variation between rural and urban school districts, with each district able to set their own policies. Considerable variation also exists in quality and affordability of internet connections across the state. Overall, parents reported their children experienced some struggles with changes in schedules, masking requirements, and social distancing (Figure 17). The majority expressed adapting generally or really well to these changes.

Figure 17: Reported Adaptations to COVID-19 Safety Protocols



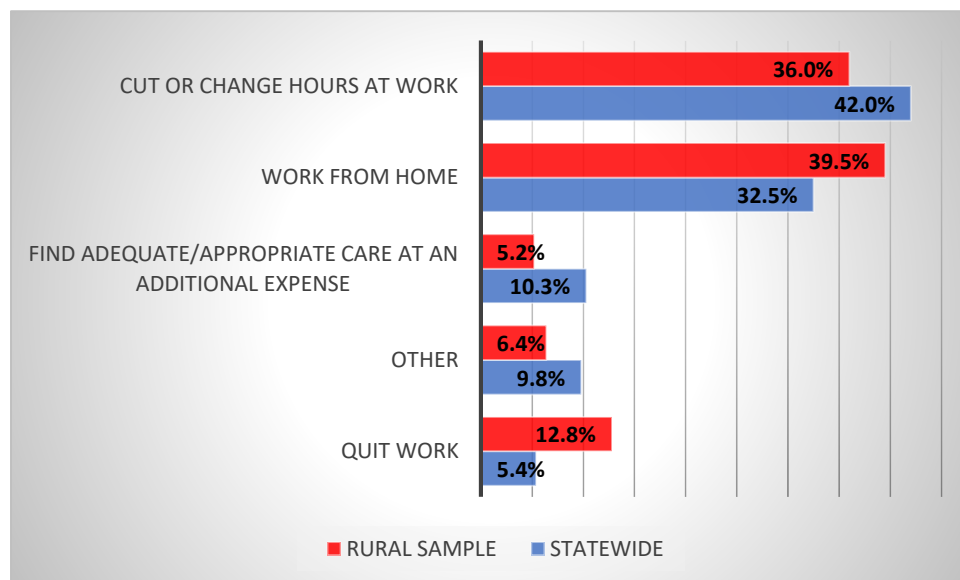
Families with children identified by their schools as having special needs impacting learning that were receiving an IEP/IFSP were asked if their schools were providing the services and/or supports identified in the plan during the time spent in virtual or at home learning scenarios. Forty-eight percent stated they were provided with specified accommodations overall; however, significantly more rural respondents stated they were not provided with these supports or services (Figure 18), a significant difference deserving of further investigation and consideration of factors involved.

Figure 18: Reported School Support for IEP/IFSP during Home/Virtual Learning



A large percentage of parents adjusted their lives to better accommodate online/remote/hybrid learning. In our sample, more rural parents than the overall average worked from home. Fewer rural parents than the overall sample reported cutting or changing hours at work. Compared to the statewide average, fewer rural parents reported additional expenses related to finding adequate and appropriate childcare during disruptions of the pandemic. A significantly larger share of rural parents (12.8%) compared to the statewide average (5.4%) reporting quitting work in order to better accommodate children’s learning needs. This is noteworthy not only as part of a national trend, particularly where childcare is unavailable, unaffordable, or undesirable, particularly with women leaving (or not re-entering) the workforce. Job loss by any means may have far-reaching consequences for family security, and economic viability of small rural communities.

Figure 19: Life Changes to Support Children at Home/Virtual Schooling

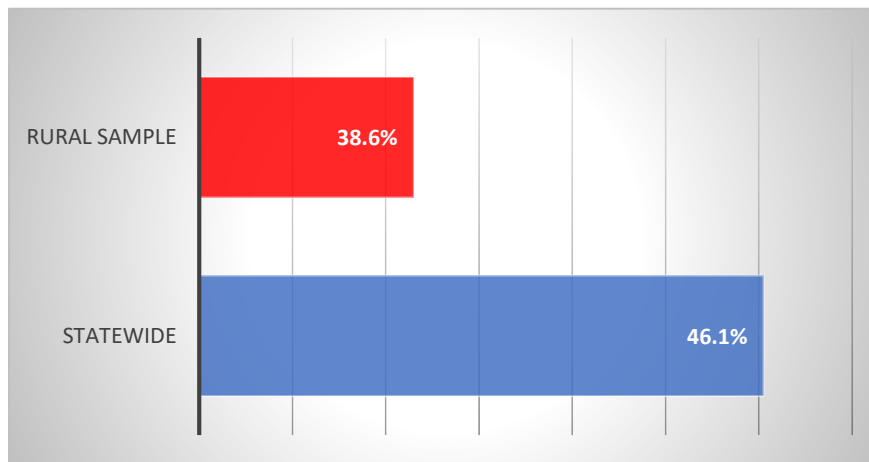


Part V. Child Access to Health Services

Overall parents reported high rates of insurance coverage, both for themselves and their children. Rural children are insured at a slightly higher percentage than the overall sample, 91% compared to 89.7%. Recent Medicaid Expansion in Nebraska since October of 2020 means that over 55,000 new adult enrollees have health insurance, many of them parents and caregivers.

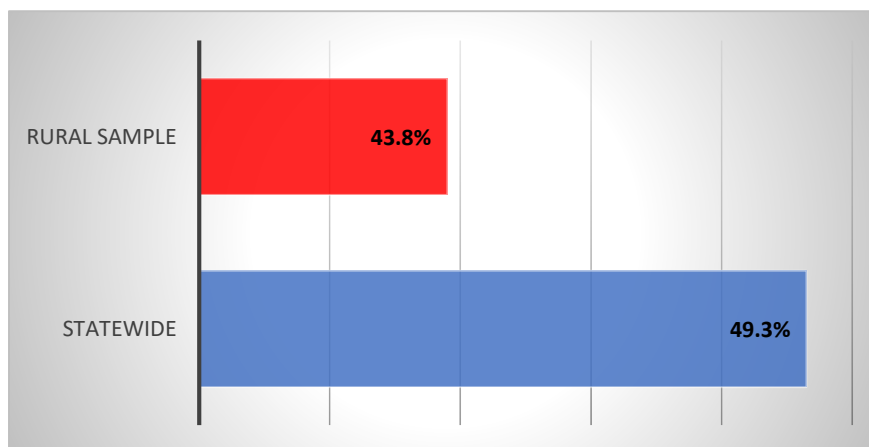
Families in all locations reported delaying their children’s medical care due to concerns surrounding COVID. Rural parents reported less delayed care than the sample average (Figure 20).

Figure 20: Delay in Care due to COVID-19



The survey also inquired about utilization of telehealth during the COVID-19 Pandemic. We found a significant proportion of parents incorporated telehealth in their Covid-19 health arsenal (Figure 21), to an extent higher than reported in studies prior to the pandemic (Williams et al., 2021). Such strong utilization of telehealth by families suggests telehealth is a satisfactory option for families, technology developments are supporting the adoption of telehealth, and providers are also using technology to reach their patients.

Figure 21: Reported Utilization of Telehealth Services

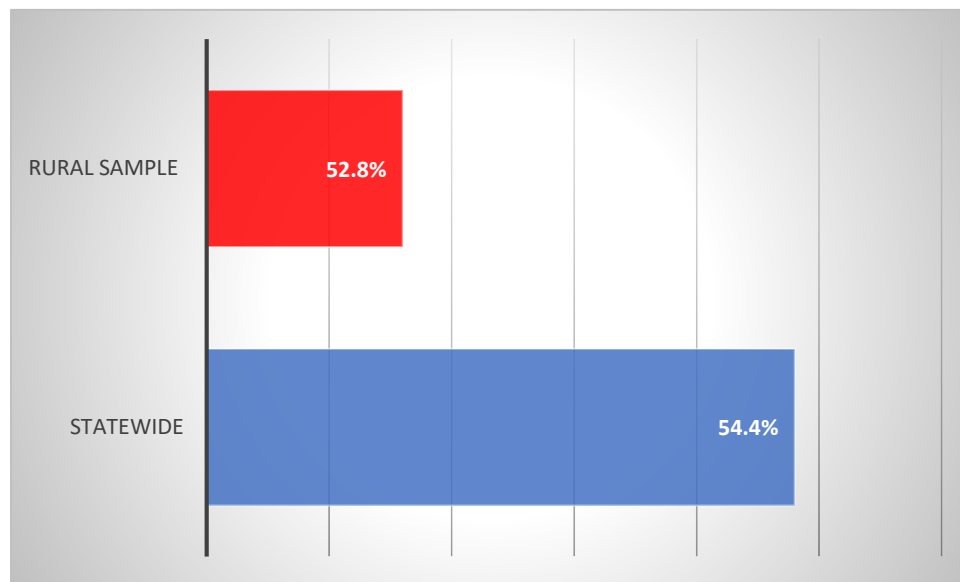


A primary concern of NEP-MAP is improving access to mental and behavioral health care services for children in youth in rural and underserved communities. In particular, NEP-MAP seeks to grow the capacity of primary care providers to screen, refer, and treat mild-to-moderate mental health conditions.

Much of rural Nebraska is classified as Health Professions Shortage Areas for many provider roles, including pediatric mental and behavioral health care providers. Over half of parent respondents in the survey reported their child(ren) received health services for mental and behavioral health during the pandemic (Figure 22), with relatively little difference between rural and statewide reported rates (rural = 52.8% received mental health services; overall sample = 54.4%).

This high level of utilization suggests both need and available providers, statewide and in rural areas in particular. Combined with findings on high utilization of telehealth, more research is needed to determine the extent to which, family uptake of telehealth helps meet children’s mental health needs.

Figure 22: Reported Utilization of Mental and Behavioral Health Services



A major goal of the survey was to assess dimensions of trust in a provider-patient relationship. A series of statements was offered with a standard five-point scale to designate level of agreement. Table 2 summarizes responses by combining “Strongly Agree” and “Agree” into a single column; “Disagree” and “Strongly Disagree” into a single column, and “Neutral” in middle column. For the purpose of this assessment, “Neutral” is identified as a state of neither agreement nor disagreement, and therefore will be analyzed as its own category. For interpretation, the study team proposes stakeholders focus on “Disagree” findings for the overall and rural samples, in order to identify quality improvement opportunities.

In assessing the findings of this portion of the survey, the research team looked at the Statewide and Rural “Disagree” columns for the highest percentages indicating dissatisfaction. In the Statewide and Rural column, these were:

- *My provider helps me to identify areas where I may need additional support (14.9% vs 18% disagreement);*
- *The provider helps me with information and educational materials that I can easily read or that don't need reading, like videos I can watch (13.9% vs 14.9% disagreement);*
- *Written materials were provided in a literacy level that is plain, clear, concise, and not technical (13.5% vs 12.9% disagreement).*

Upon further examination, the Rural “Disagree” columns purported a higher percentage than Statewide counterparts:

- *The provider employs staff that reflect who lives in my community (12.3% disagreement);*
- *I feel comfortable letting my provider know if/when I disagree with medical advice due to my cultural beliefs (12.2% disagreement); and*
- *If an interpreter is used during my visit, the provider invites my feedback regarding my satisfaction with the interpreter (12.1% disagreement).*

Table 2: Parent Reported Satisfaction Rating for Feelings around Provider

Feelings Around Provider	Agree		Neutral		Disagree	
	Statewide	Rural	Statewide	Rural	Statewide	Rural
I feel comfortable with my provider	69.0%	70.7%	24.1%	20.7%	6.9%	8.6%
I feel I can share my needs, issues, and barriers with my provider	68.4%	72.4%	21.8%	16.7%	9.8%	10.9%
I feel comfortable letting my provider know if/when I disagree with medical advice due to my cultural beliefs	63.4%	67.7%	25.4%	20.1%	11.1%	12.2%
Written materials were provided in a literacy level that is plain, clear, concise, and not technical	64.2%	69.4%	22.3%	17.6%	13.5%	12.9%
If an interpreter is used during my visit, the provider invites my feedback regarding my satisfaction with the interpreter.	53.9%	57.6%	34.3%	30.3%	11.8%	12.1%
The provider helps me with information and educational materials that I can easily read or that don't need reading, like videos I can watch	61.5%	59.7%	24.5%	25.3%	13.9%	14.9%
The provider employs staff that reflect who lives in my community	64.0%	66.1%	25.2%	21.6%	10.8%	12.3%
My provider helps me to identify areas where I may need additional support	62.4%	60.5%	22.7%	21.6%	14.9%	18.0%
My provider lets other providers know about my need for interpretation services when making a referral	43.3%	47.2%	43.3%	41.7%	13.3%	11.1%

Similar results were found when parents were questioned about their satisfaction with services provided (Table 3). Both urban and rural respondents ‘Agreed’ with most statements provided regarding satisfaction. While responses were largely in agreement, the most highly reported disagreement by parents in the statewide sample and the rural sample was in the area, “I feel listened and respected to.”

Table 3: Parent Reported Satisfaction Rating for Services Provided

Services	Agree		Neutral		Disagree	
	Statewide	Rural	Statewide	Rural	Statewide	Rural
I am treated as an expert in my child(ren)s needs	71.3%	69.4%	22.5%	21.5%	6.2%	9.2%
I am empowered to access, take charge, or change the supports, resources, and/or services my child receives	67.8%	69.6%	25.1%	21.6%	7.1%	8.8%
If I have questions or concerns about the services your child need or receives, I feel like I am listened to and respected.	70.2%	71.3%	20.2%	17.0%	9.7%	11.7%

STRENGTHS AND LIMITATIONS

This study has several strengths and limitations that are noteworthy. To our knowledge, this study represents the first statewide assessment to identify parental satisfaction with their children's mental health screening, care, and/or counseling, the extent to which parents feel they are empowered as decision-makers in their children's care, the extent to which parents agree they have access to needed family supports, the impact of COVID-19 on the emotional and mental wellbeing of families/children, the programs available to assist children and their families to cope with the COVID-19 pandemic.

This assessment documented the opinions of families of diverse ethnic and racial backgrounds from a variety of geographic locations across the state of Nebraska. Through purposeful sampling, the study team was able to gather robust family input from every behavioral health region of the state, and in doing so over-sampled rural and diverse families.

The information provided by the survey respondents only represents their perspectives and may not entirely reflect or provide a complete picture of the needs and issues of families with children and adolescents during the COVID-19 Pandemic. The information gathered relied on self-reports from respondents, which may be subject to recall biases, a limitation very common in cross-sectional surveys collecting self-report data. Additionally, the survey was only offered in English and may not include individuals who do not speak or read English proficiently.

RECOMMENDATIONS

In light of the main findings from this study, the following recommendations are offered:

- 1. Continue to grow the use and availability of telehealth as a family-friendly solution to access barriers.** Clearly many families embrace the opportunity to use technology. One of the major barriers to accessing care identified by rural families was the time and distance it took to reach services. Telehealth is an important service that can lessen this barrier and minimize geographic disparities. To expand this potential of telehealth, it becomes necessary for Nebraska to beef up its infrastructure investment in affordable and reliable internet connectivity in all geographic areas, and to continue reimbursement of telehealth services by various insurance providers.
- 2. Recognize that mental and behavioral health issues are not limited to the identified population of children and youth with special health care needs (CYSHCN). Screening, Early identification and intervention services, and Family Support Services are universal needs leading to successful access to care.** It is important to continue to educate primary care providers, pediatricians, and community members of mental and behavioral health issues to continue to minimize stigma and increase access to healthcare providers.
- 3. Promote access to qualified and trained health interpreters, to decrease language as a barrier to care.** Language services remain a large barrier for many families to access and retain healthcare services, especially mental and behavioral health services. The provision of in-person or tele-interpreters is crucial to closing disparities; therefore, it is important to explore avenues to make interpretation services available to all providers and patients when needed.
- 4. Continue to actively monitor children and adolescents for developing mental and behavioral health issues as the COVID-19 Pandemic continues, and continuously build accessible family supports.** There is a continual need to monitor and screen children for mental and behavioral health issues as pandemic-related stressors continue. This also includes providing resources and financial support to families with parent(s)/caregiver(s) who had to quit their jobs to oversee non-traditional schooling to alleviate impacts on family due to potential loss of income, services, and insurance coverage.

CONCLUSIONS

This report identified many ways in which the COVID-19 pandemic has impacted families and children in Nebraska and in particular explored the ways in which rural and underserved communities have been uniquely affected compared to our understanding of “statewide” impacts. Results from this report can easily be used to instigate many other research avenues into the long-term impacts of the pandemic on children, families, and providers.

Participating families reported ways in which their children’s mental health has been affected, by reporting happiness as well as service utilization and the consequences of disrupted school schedules. Parents reported resourcefulness and resilience as well, from self-reported ability to seek out services for their children, use telehealth to obtain care, alter work schedules, and seek out information for themselves. The pandemic completely rewrote the ways in which education is delivered – the true effects of which may not be known for years. A record 5% of families homeschooled their children, and more than half of students experienced some sort of interruption to in-person learning.

The survey results begin to reveal at least a few areas of family experience and adaptation during the COVID pandemic that are deserving of more attention and greater understanding, from family uptake of telehealth technology to disruptions in economic security. And, through an equity lens, an understanding of the real distribution of benefits and disadvantage as a result.

For providers, our survey shows families are impacted by COVID, adopting telehealth, suffer financial hardship, have children with behavioral and mental health needs at greater levels than previously assumed in the general population, successfully obtain services for their children, and are generally satisfied with their trust relationships with, and level of care from, their providers.

For NEP-MAP stakeholders and partners, the survey results point to several possible action steps including promoting and facilitating best practices by providers in the use of medical interpretation, provider education on identifying community partnerships and resources for addressing patients’ unmet social needs to improve patient outcomes, reduce costs, and increase satisfaction, and promoting health literacy practices among providers in order to better meet families’ communication needs. The common use of telehealth by Nebraskan families during the current pandemic reinforces the need and promise of NEP-MAP’s emphasis on integrating into pediatric primary care tele-behavioral health consultations and referrals to enhance access to mental and behavioral health services for children and youths in the state.

REFERENCES

- Acri, M. C., & Hoagwood, K. E. (2015). Addressing Parental Mental Health Within Interventions for Children: A Review. *Research on Social Work Practice, 25*(5), 578-586. <https://doi.org/10.1177/1049731514546027>
- American Academy of Pediatrics. (2020). COVID-19 Planning Considerations: Guidance for School Re-entry. *American Academy of Pediatrics*. Retrieved from: <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/covid-19-planning-considerations-return-to-in-person-education-in-schools>
- American Academy of Pediatrics. (2021). Children and COVID-19: State-Level Data Report. *American Academy of Pediatrics*. Retrieved from: <https://www.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/children-and-covid-19-state-level-data-report/>
- Bennett, K., Manassis, K., Duda, S., Bagnell, A., Bernstein, G.A., Garland, E.J., Miller, L.D., Newton, A., Thabane, L., & Wilansky, P. (2016). Treating child and adolescent anxiety effectively: Overview of systematic reviews. *Clinical Psychology Review, 50*, 80-94. doi: 10.1016/j.cpr.2016.09.006
- Betancourt, J. R., Green, A. R., Carrillo, J. E., & Ananeh-Firempong, O. (2003). Defining Cultural Competence: A Practical Framework for Addressing Racial/Ethnic Disparities in Health and Health Care. *Public Health Reports, 118*, 293-302.
- Bradshaw, J., Gillespie, S., McCracken, C., King, B. H., McCracken, J. T., Johnson, C. R., Lecavalier, L., Smith, T., Swiezy, N., Bearss, K., Sikich, L., Donnelly, C., Hollander, E., McDougle, C. J., & Scahill, L. (2020). Predictors of caregiver strain for parents of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-020-04625-x>
- Centers for Disease Control and Prevention. (2020). COVID-19 Parental Resources Kit: Ensuring Children and Young People's Social, Emotional, and Mental Well-being. *Centers for Disease Control and Prevention*. Retrieved from: <https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/parental-resource-kit/index.html>
- Centers for Disease Control and Prevention. (2021). What Are Childhood Mental Disorders? *Centers for Disease Control and Prevention*. Retrieved from: <https://www.cdc.gov/childrensmentalhealth/features/child-mental-health.html>
- Chandra, A., & Minkovitz, C. S. (2006). Stigma starts early: Gender differences in teen willingness to use mental health services. *Journal of Adolescent Health, 38*(6), 754.e1-754.e8. <https://doi.org/10.1016/j.jadohealth.2005.08.011>
- Children's Defense Fund. (2020). The State of America's Children. *The Children's Defense Fund*. Retrieved from: <https://www.childrensdefense.org/the-state-of-americas-children-2020/>
- Chun-Chung Chow, J., Jaffee, K., & Snowden, L. (2003). Racial/Ethnic Disparities in the Use of Mental Health Services in Poverty Areas. *American Journal of Public Health, 93*(5), 792-797. <https://doi.org/10.2105/AJPH.93.5.792>
- Christina A. Olson, S. David McSwain, Alison L. Curfman, John Chuo
Pediatrics Mar 2018, 141 (3) e20172334; DOI: 10.1542/peds.2017-2334
- Cree, R. A., Bitsko, R. H., Robinson, L. R., Holbrook, J. R., Danielson, M. L., Smith, C., Kaminski, J. W., Kenney, M. K., & Peacock, G. (2018). Health Care, Family, and Community Factors Associated with Mental, Behavioral, and Developmental Disorders and Poverty Among Children Aged 2-8 Years - United States, 2016. *MMWR. Morbidity and Mortality Weekly Report, 67*(50), 1377-1383. <https://doi.org/10.15585/mmwr.mm6750a1>
- Da Paz, N. S., & Wallander, J. L. (2017). Interventions that target improvements in mental health for parents of children with autism spectrum disorders: A narrative review. *Clinical Psychology Review, 51*, 1-14. <https://doi.org/10.1016/j.cpr.2016.10.006>
- Dashiff, C., DiMicco, W., Myers, B., & Sheppard, K. (2009). Poverty and adolescent mental health. *Journal of Child and Adolescent Psychiatric Nursing, 22*(1), 23-32. <https://doi.org/10.1111/j.1744-6171.2008.00166>
- Ekeland, E., Heian, F., Hagen, K.B., Abbott, J. M., & Nordheim, L. (2004). Exercise to improve self-esteem in children and young people. *Cochrane Database of Systematic Reviews, 1*. DOI: 10.1002/14651858.CD003683.pub2
- Fenelon, A., Slopen, N., Boudreaux, M., & Newman, S. J. (2018). The Impact of Housing Assistance on the Mental Health of Children in the United States. *Journal of Health and Social Behavior, 59*(3), 447-463. <https://doi.org/10.1177/0022146518792286>
- Fortuna, L. R., Tolou-Shams, M., Porche, M. V., & Robles-Ramamurthy, B. (2020). Inequity and the Disproportionate Impact of COVID-19 on Communities of Color in the United States: The Need for a Trauma-Informed Social Justice Response. *Trauma Psychology, 12*(50), 443-445. Retrieved from: <https://psycnet.apa.org/fulltext/2020-37320-001.pdf>
- Freed, G. L., Davis, M. M., Singer, D. C., Gebremariam, A., Schultz, S. L., Matos-Moreno, A., & Wietecha, M. (2018). Variation in Generational Perceptions of Child Health and Well-being. *Academic Pediatrics, 18*(4), 384-389. <https://doi.org/10.1016/j.acap.2017.09.004>

Ghandour, R. M., Sherman, L. J., Vladutiu, C. J., Ali, M. M., Lynch, S. E., Bitsko, R. H., & Blumberg, S. J. (2019). Prevalence and Treatment of Depression, Anxiety, and Conduct Problems in US Children. *The Journal of Pediatrics*, 206, 256. <https://doi.org/10.1016/j.jpeds.2018.09.021>

Glascoe, F. P. (2003). Parents' Evaluation of Developmental Status: How Well Do Parents' Concerns Identify Children With Behavioral and Emotional Problems? *Clinical Pediatrics*, 42(2), 133. <https://doi.org/10.1177/000992280304200206>

Gonzalez, M. J. (2005). Access to Mental Health Services: The Struggle of Poverty Affected Urban Children of Color. *Child and Adolescent Social Work Journal*, 22(3-4), 245-256. DOI: 10.1007/s10560-005-0036-3

HealthLeaders Media. Pediatric telemedicine poised for growth spurt. Available at: www.healthleadersmedia.com/technology/pediatric-telemedicine-poised-growth-spurt#. Accessed November 2021.

Howell, E., & McFeeters, J. (2008). Children's Mental Health Care: Differences by Race/Ethnicity in Urban/Rural Areas. *Journal of Health Care for the Poor and Underserved*, 19(1), 237-247. doi:10.1353/hpu.2008.0008

Hoyle, J. N., Laditka, J. N., & Laditka, S. B. (2020). Mental health risks of parents of children with developmental disabilities: A nationally representative study in the united states. *Disability and Health Journal*. <https://doi.org/10.1016/j.dhjo.2020.101020>

Kuhn, E. S., & Laird, R. D. (2014). Family support programs and adolescent mental health: review of evidence. *Adolescent health, medicine and therapeutics*, 5, 127-142. <https://doi.org/10.2147/AHMT.S48057>

Leeb, R. T., Danielson, M. L., Bitsko, R. H., Cree, R. A., Godfred-Cato, S., Hughes, M. M., Powell, P., Firchow, B., Hart, L. C., & Lebrun-Harris, L. A. (2020). Support for Transition from Adolescent to Adult Health Care Among Adolescents With and Without Mental, Behavioral, and Developmental Disorders - United States, 2016-2017. *MMWR. Morbidity and Mortality Weekly Report*, 69(34): 1156-1160. <https://doi.org/10.15585/mmwr.mm6934a2>

Magson, N. R., Freeman, J. Y. A., Rapee, R. M., Richardson, C. E., Oar, E. L., & Fardouly, J. (2021). Risk and Protective Factors for Prospective Changes in Adolescent Mental Health during the COVID-19 Pandemic. *Journal of Youth and Adolescence*, 50(1):44-57. doi: 10.1007/s10964-020-01332-9

Mayo Clinic Staff. (2020). Mental illness in children: Know the signs. Mayo Clinic. Retrieved from: <https://www.mayoclinic.org/healthy-lifestyle/childrens-health/in-depth/mental-illness-in-children/art-20046577>

Myers, L., Karp, S.M., Dietrich, M.S. et al. (2020). Family-Centered Care: How Close Do We Get When Talking to Parents of Children Undergoing Diagnosis for Autism Spectrum Disorders? *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-020-04765-0>

Olson, K. R., Durwood, L., DeMeules, M., & McLaughlin, K. A. (2016). Mental Health of Transgender Children Who Are Supported in Their Identities. *Pediatrics*, 137(3), e20153223. <https://doi.org/10.1542/peds.2015-3223>

Patrick, S. W., Henkhaus, L. E., Zickafoose, J. S., Lovell, K., Halvorson, A., Loch, S., Letterie, M., & Davis, M. M. (2020). Well-being of Parents and Children During the COVID-19 Pandemic: A National Survey. *Pediatrics*, 146(4). DOI: 10.1542/peds.2020-016824

Ryan, C., Russell, S. T., Huebner, D., Diaz, R., & Sanchez, J. (2010). Family Acceptance in Adolescence and the Health of LGBT Young Adults. *Journal of Child Adolescent and Psychiatric Nursing*, 23(4), 205-213. <https://doi.org/10.1111/j.1744-6171.2010.00246.x>

Sayal, K., Taylor, E., & Beecham, J. (2003). Parental perception of problems and mental health service use for hyperactivity. *Journal of the American Academy of Children and Adolescent Psychiatry*, 42(12), 1410-1414. doi: 10.1097/00004583-200312000-00007.

Semega, J., Kollar, M., Creamer, J., & Mohanty, A. (2019). Income and Poverty in the United States: 2018 Current Population Reports. United States Census Bureau.

Sheryl, H., Kataoka, S.H, Zhang, L., & Wells. (2002). Unmet Need for Mental Health Care Among U.S. Children: Variation by Ethnicity and Insurance Status. *American Journal of Psychiatry*, 159(9), 1548-1555. <https://ajp.psychiatryonline.org/doi/full/10.1176/appi.ajp.159.9.1548>

Sibold, J., Edwards, E., Murray-Close, D., & Hudziak, J. J. (2015). Physical activity, sadness, and suicidality in bullied US adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(10), 808-815. <https://doi.org/10.1016/j.jaac.2015.06.019>

Wagmiller, R. L., & Adelman, R. M. (2009). Childhood and Intergenerational Poverty: The Long-Term Consequences of Growing Up Poor. National Center for Children in Poverty.

Warwick, H., Reardon, T., Cooper, P., Murayama, K., Reynolds, S., Wilson, C., & Creswell, C. (2017). Complete recovery from anxiety disorders following Cognitive Behavior Therapy in children and adolescents: A meta-analysis. *Clinical Psychology Review*, 52, 77-91. doi: 10.1016/j.cpr.2016.12.002

Williams, S., Hill, K., Xie, L., Mathew, M. S., Ofori, A., Perry, T., ... & Messiah, S. E. (2021). Pediatric Telehealth Expansion in Response to COVID-19. *Frontiers in Pediatrics*, 9.

APPENDIX**Questionnaire for Family Survey**

Eligibility criteria:

1. Living with a child or children under the age of 18 years
2. Being 19 years or older;
3. Living in Nebraska

Survey date: _____

Part 1: Questions about you as the parent

1. What is your age?
 - 1) 19 to 24 years
 - 2) 25 to 34 years
 - 3) 35 to 44 years
 - 4) 45 to 54 years
 - 5) 55 to 64 years
 - 6) 65+ years
 - 7) Prefer not to answer

2. Your gender is:
 - 1) Male
 - 2) Female
 - 3) Other
 - 97) Prefer not to answer

3. What is your home zip code? _____
 - 97) Prefer not to answer
 - 98) Don't know

4. In which country were you born? _____
 - 97) Prefer not to answer

4a. If you were born in a foreign country, in which year did you first come to the U.S.? _____

5. What is your current marital status?
 - 1) Married
 - 2) Unmarried but living together
 - 3) Widowed
 - 4) Divorced
 - 5) Separated
 - 6) Never Married
 - 7) Other
 - 97) Prefer not to answer
 - 98) Don't know

6. How many parents or adult caregivers are in the home?
 - a. Single caregiver/parent household
 - b. Two-caregiver/parent household
 - c. Two single-caregiver/parent households
 - d. Child resides in multiple homes
 - i. How many homes?
 - ii. How many caregivers/parents in each home?
 - e. Foster/ Temporary care
 - f. Other: _____

7. What is your household income source. (Please select all that apply.)
 - 1) 2 or more incomes
 - 2) 1 income
 - 3) No income
 - 4) Unemployment benefits
 - 5) State support including foster stipends
 - 6) Child support
 - 7) Other (please specify _____)

8. Do you use language interpretation services outside the home?
 - 1) Yes
 - 2) No
 - 3) The children usually interpret for us

9. What is the highest grade or year of school you have completed?
 - 1) Less than a high school diploma/GED
 - 2) High School Graduate/Earned GED
 - 3) Some college
 - 4) Associates Degree/Trade School
 - 5) Bachelor's degree
 - 6) Master's degree
 - 7) Professional degree (MD, JD, PhD, etc.)
 - 97) Prefer not answer

10. Overall, how would you rate your current health?
 - 1) Excellent
 - 2) Very good
 - 3) Good
 - 4) Fair
 - 5) Poor
 - 97) Prefer not answer
 - 98) Don't know

11. Are you Hispanic or Latino/a?
 - 1) Yes
 - 2) No
 - 97) Prefer not answer
 - 98) Don't know

12. Which one the following group would you primarily identify with?
 - 1) White
 - 2) Black or African American
 - 3) American Indian or Alaska Native
 - 4) Asian
 - 5) Pacific Islander
 - 6) Multiracial
 - 7) Other
 - 97) Prefer not answer
 - 98) Don't know

13. Do you have health insurance coverage?
 - 1) Yes
 - 2) No

14. Do all your children have health insurance coverage?
 - 1) Yes
 - 2) No

Part 2. Now we would like to know about your child (children).

1. How many children do you have now?_____

2. For each of your children, please provide his/her demographic information, starting from the oldest.

List of Children	Age	Gender	Grade	Does your child have any special health needs including disabilities? (Yes or No)	Does your child have any learning disabilities? (Yes or No)
Child #1					
Child #2					
Child #3					
Child #4					
Child #5					
Child #6					
Child #7					
Child #8					
Child #9					
Child #10					

3. Using the following image, on a scale of 1 to 10 with a score of 1 indicating that your child is “very unhappy” and a score of 10 indicating that the child is “very happy”, please indicate in the following table how happy your child was right before the pandemic and how happy he/she is right now.



List of Children	How happy was your child right before the pandemic (prior to March 2020)?	How happy is your child now (in 2021)?	Any comment on why you gave the score and its potential changes before and during the COVID-19 pandemic?
Child #1			
Child #2			
Child #3			
Child #4			
Child #5			
Child #6			
Child #7			
Child #8			
Child #9			
Child #10			

4. Based on your observation, during the past 30 days, did any of your children show symptoms or signs of mental or behavioral health issues such as depression, anxiety, restlessness, aggression, oppositional defiant disorder (ODD), conduct disorder, attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), Tourette Syndrome, or substance abuse?

1. Yes
2. No
97. Prefer not to answer
98. Do not know

4a. If yes, what was the issue? _____

4b. If yes, did you do anything to cope with the issue?

- 1) Yes (Please briefly describe what you did _____)
- 2) No (Please explain why you decided not to address the issue. _____)

Part 3. Now we would like to ask about your children's access to health services.

1. Are you currently utilizing any supports or services for your child?
 - Yes **(move to question 2)**
 - No **(move to question 4)**

2. What services are you utilizing? *(Check all that apply)*
 - Primary medical care
 - Special Education (IEP: Individual Education Plan or IFSP: Individual Family Service Plan)
 - 504 Plan/ Accommodation Plan
 - Individualized Healthcare Plan (medical needs)
 - Behavioral/Mental healthcare
 - In-home support (formal- agency or informal- relative/friend)
 - Other: _____

2a. What type of provider does your family use?

- Family Practice Doctor
- Pediatrician
- Nurse Practitioner
- Physician's Assistant
- No Provider
- Other: _____

3. If your family is receiving services, where did you learn about them? *(Check all that apply)*

- Personal Research: internet, pamphlets, support group
- Primary medical care provider, doctor's office staff, or care coordinator
- Dept. of Health & Human Services or other similar organizations
- Family/friend
- Child's school
- Other (Please specify) _____

4. Are there barriers to your accessing services/supports for your child(ren)?

- No
- Language/ use of interpreters/ lack of qualified healthcare interpreters
- Distance/travel
- Financial
- No appropriate providers available in your area
- Other: _____

5. If you do receive services, how easy was it to access needed services?
 - No problem; I was able to do it on my own.
 - Okay, was able to find without too much trouble/ may have needed a little help
 - Moderately difficult; it was a pain, and we needed help but finally was able to get what we needed.
 - There is no way I could have done this on my own.
 - I have not been able to access services

6. Do you utilize any of the following financial means in order to access needed services?
 - Services we use are free/ no personal out-of-pocket expense
 - Self-pay – all personal out-of-pocket expense
 - Private Insurance
 - Public Insurance (Medicaid)
 - Family/friends help
 - Organizations that help

7. If you have personal out-of-pocket expense in order to help support your child(ren)'s learning, does it cause significant financial hardship or burden?
 - Yes
 - No
 - Sometimes

8. Now we want to ask you about your experience with the care provider of you and your children.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Not Applicable
I feel comfortable with my provider.						
I feel I can share my needs, issues, and barriers with the provider.						
I feel comfortable letting my provider know if/when I disagree with medical advice due to my cultural beliefs.						
Written materials were provided in a literacy level that is plain, clear, concise, and not technical.						
If an interpreter is used during my visit, the provider invites my feedback regarding my satisfaction with the interpreter.						
The provider helps me with information and educational materials that I can easily read or that don't need reading, like videos I can watch.						
The provider employs staff that reflect who lives in my community						
My provider helps me to identify areas where I may need additional support.						
The provider let other providers know about my need for						

interpretation services when making a referral.						
---	--	--	--	--	--	--

9. Based on your experiences with accessing services for your child(ren):

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I am treated as the expert in my child(ren)'s needs.					
I am empowered to access, take charge, or change the supports, resources and/or services my child receives.					
If I have questions or concerns about the services your child needs or receives, I feel like I am listened to and respected.					

10. Is there anything else you would like us to know about barriers you have encountered in receiving appropriate/adequate supports and/or services?

Part 4. Impact of the COVID-19 pandemic on you and your family

- How well has your child(ren) adapted to changes in school schedules (virtual learning/home school) and/or requirements to wear masks/social distance due to COVID?
 - Really well
 - Okay- a few issues here & there, but generally well
 - It's been difficult but we're managing
 - Not well at all

- If your child has an IEP (Individual Education Plan) or IFSP (Individual Family Service Plan), is the school providing you with the services and/or supports identified in your child's plan during the time spent at home/virtual learning?
 - Yes
 - No
 - Not applicable or Unknown

- Did your child's school (any representative) offer other support or resources during the time spent at home/virtual learning?
 - Yes
 - They contacted me
 - I had to ask/advocate for it
 - No

4. Did you have to make significant life changes in order for your child(ren) to stay home/ do virtual school?
- Work from home
 - Cut or change hours at work
 - Quit work
 - Find adequate/appropriate care at an additional expense
 - Other: _____
5. For each of your children who are currently living with you, please describe their health care utilization during the pandemic based on your best knowledge.

List of Children	Did the child delay his/her care due to the pandemic? (Yes or No)	Did you or your child use telehealth to communicate with the child's care providers during the pandemic? (Yes or No)	Did your child receive any health services related to mental or behavioral health issues during the pandemic? (Yes or No)	If you child received health services related to mental or behavioral health, how satisfied are you with the services? Why?
Child #1				
Child #2				
Child #3				
Child #4				
Child #5				
Child #6				
Child #7				
Child #8				
Child #9				
Child #10				

6. In consideration of the health needs of your child(ren), do you have any suggested changes to our health care system that you think would help improve access to, as well as the quality of health care for your child(ren)?
- 1) Yes (Please explain _____)
 - 2) No