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Access to Pediatric Mental and Behavioral Health Services in Nebraska: Integrating Perspectives from Educators, Healthcare Providers, and Parents

Prepared by:

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EXECUTIVE SUMMARY

In the U.S., approximately 20% of children will experience some mental or behavioral health problems, which has recently been exacerbated by the COVID-19 pandemic. As part of the Nebraska Partnership for Mental Healthcare Access in Pediatrics (NEP-MAP) project, the present report aims to integrate perspectives from educators, healthcare providers, and parents or caregivers of children based on related data from NEP-MAP to gain an all-encompassing view of the current state of pediatric mental and behavioral health in Nebraska and to identify strategies for improving access to related services in the state. This report has identified several key areas to explore, including the current trends of pediatric mental health in Nebraska, utilization of related health services, screening and referral processes, barriers to care access, the impact of the COVID-19 pandemic on children, and suggestions to improve the pediatric mental and behavioral health system.

This report is based on the qualitative and quantitative data collected between May 2020 and August 2021 that have been used in three previously published reports in NEP-MAP. The data sources included qualitative data from 53 community representatives from the education system (school nurses, school counselors, school social workers, teachers, program managers, or directors at various educational settings), and 17 primary healthcare providers (pediatricians, nurse practitioners, physician assistants, licensed counselors, psychologists, and clinical social workers from various clinical and hospital settings), as well as quantitative survey data from 373 parents or caregivers of children in Nebraska with oversampling of families with children who have special health needs or learning disabilities.

Highlights of Findings

- Key informants from both the educational and healthcare systems identified ADHD, depression, and anxiety as the major mental health issues in pediatric populations. Parent and caregivers reported an increase of mental health issues among children within the last 30 days prior to the survey, with anxiety, depression, and restlessness being the most common issues.
- Approximately 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. This suggests there might be a potential under-diagnosing of pediatric mental and behavioral health disorders in children.
- Parents/caregivers expect pediatric primary care providers and schools to screen, refer, diagnose, and treat their children with mental and behavioral health issues. However, parents learn of available resources predominantly through primary care providers and personal research. While participating educators report providing information and resources for families, parents/caregivers do not reflect this sentiment.
- Children identified with a mental or behavioral health issue are often screened multiple times, with different screening tools, and by professionals in various settings (school, primary care, and specialist). A more streamlined and coordinated approach to the screening is needed to better serve children and their families.
- A major barrier to mental and behavioral health services lies in the inadequacy of health insurance coverage of needed services. The majority of children are covered with health insurance, but one-third of parents/caregivers' report paying out-of-pocket for care.

- There is an urgent need to improve access to pediatric mental and behavioral health services providers in Nebraska, in terms of both quantity and quality. More providers are needed, especially those who are trained to serve diverse pediatric populations in underserved communities across Nebraska.

Recommendations

Based on major findings from this study, the following steps have been recommended to better identify and address the behavioral, mental, and emotional health needs among children and adolescents in Nebraska:

- 1. Develop family-centered care coordination for children with complex mental or behavioral health needs.** Providers in the educational and healthcare settings know that children and families with mental and behavioral health care needs are going to be involved with systems of care for a long time. Primary care providers and education professionals often provide short-term or bridge services until a child can find a long-term, mental health medical home. Families themselves usually cannot sustain the inter-provider communication that needs to occur for adequate planning and a continuum of care. Individual providers may have limited awareness or connection with other providers involved with a family. Children with unmet health needs would be better serviced if there was more coordinated and ongoing, even facilitated, communication amongst primary care providers, schools, therapists, and psychiatrists.
- 2. Improve care providers' knowledge of community resources for family support.** A major area of concern is that pediatric care providers usually lack the time to learn and stay current about local community resources that can be utilized for family support. For some providers, having the capacity to make community referrals is outside of their traditional role and there is evident discomfort. Other providers think that having a Community Health Worker or Parent Resource Coordinator as a member of the clinic team allows them to make a "warm hand-off" to a clinic worker who will spend needed time with a family.
- 3. Strengthen the pediatric mental health system and infrastructure.** This includes decreasing the pediatric mental and behavioral health provider medical deserts, utilizing established or newly developed telehealth services, such as the Tele-Behavioral Health Consultation for Providers implemented at the UMMC Munroe-Meyer Institute (MMI), and implementing evidence-based strategies to improve telehealth access and utilization. For sustainability purpose, it would help to assess the cost and return on investment of established tele-behavioral health programs (See Appendix B).
- 4. Develop a streamlined and efficient referral system to mitigate the burden of families as they navigate a complex healthcare system for access to mental health services.** Children and adolescents with mental health needs are often screened multiple times in the educational and healthcare systems. This can create unnecessary and redundant barriers for parents who are struggling to find proper care. A streamlined system may reduce barriers and enhance the efficiency of referring.

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1. The guidance and direction provided by Kathy Karsting, RN, MPH, from NE DHHS, across the four completed years of this project. And the Nebraska Partnership for Mental Healthcare Access in Pediatrics (NEP-MAP) Advisory Committee for their inputs during the projects' design and development.
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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 NEP-MAP.

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

As part of the program evaluation services provided to the Nebraska Partnership for Mental Health Care Access in Pediatrics (NEP-MAP), the Center for Reducing Health Disparities (CRHD) at the University of Nebraska Medical Center have recently led the efforts in releasing three reports to assess pediatric mental health and access to related health services in Nebraska respectively based on perspectives from educators, health care providers, and parents and caregivers across the state since 2020. These assessments included in-depth interviews with representatives from the educational and healthcare systems (Toure et al., 2020; Su et al., 2021a), and an online survey to collect the perspectives of parents and caregivers in Nebraska (Su et al., 2021b). The rich qualitative and quantitative data from these three assessments allow for a description of: 1) the current state of the mental and behavioral health of children in Nebraska and how it has been impacted by COVID-19; 2) the screening of mental and behavioral health issues and related referral processes; 3) barriers to receiving needed health care; and 4) suggestions for improving access to pediatric mental and behavioral health services in Nebraska.

While each of three previous reports provides unique insights into how educators, parents, and health care providers perceive unmet health needs and barriers in pediatric mental and behavioral health services, so far there has been no efforts in integrating and comparing perspectives across the three groups of stakeholders. This report seeks to provide an agglomeration of data and key findings from previous assessments to identify similarities and differences in the perspectives across educators, parents, and health care providers. The report has identified several key areas to explore, including the current status of pediatric mental health in Nebraska, utilization of related health services, the screening and referral processes, barriers to seeking care, the impact of the COVID-19 Pandemic on children, and suggestions to improve the pediatric mental and behavioral health system. Findings from this report are expected to inform the development of new strategies for improving pediatric mental and behavioral health in Nebraska.

BACKGROUND

Mental health disorders among children, which affect approximately 1 in 5 children in the U.S., are defined as serious changes in the way children typically learn, behave, or handle their emotions (CDC, 2022). These disorders consist of a broad range of conditions, including attention-deficit/hyperactivity disorder (ADHD), depression, anxiety, substance use disorders, and obsessive-compulsive disorder (OCD), all with varying levels of severity across different age groups (CDC, 2022). Between 2016 and 2019, the most commonly diagnosed mental health disorders among children between the ages of 3 and 17 years were ADHD (9.8%), anxiety (9.4%), behavioral problems (8.9%), and depression (4.4%) (Bitsko et al., 2022). One study found that the rates of anxiety in children increased by 29% and depression increased by 27% between 2016 and 2020 (Lebrun-Harris et al., 2022). Comorbidities of mental and health issues are also common. Approximately 75% of children with depression also have anxiety, and 50% of those with depression are also diagnosed with a behavioral problem (Ghandour et al., 2018). Mental, behavioral, and developmental issues are more common with increased age (Cree et al., 2018).

In the U.S., it was estimated that 11% to 20% of children have a behavioral or emotional problem at any given time, and 37% to 39% of children will have behavioral or psychological problems diagnosed by the age of 16 (Data Resource Center for Children's Health [DRCCH], 2016; Whitney & Peterson, 2019); however, of those diagnosed with mental health disorders, only 36% received further treatment through counseling, medication, therapy, or other interventions (Merikangas et al., 2011; US Department of Health and Human Services, 2000; Costello et al., 2003). Even more concerning is that these disorders have not been adequately diagnosed and treated in the current U.S. health care system, leading to countless children and adolescents remaining undiagnosed with major mental and behavioral health issues (Kim-Cohen et al., 2003; Jaffee et al., 2005).

Several barriers have emerged to negatively impact 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 of developing mental and behavioral health issues (CDC, 2022).

One method to screen for, diagnose, and treat pediatric mental health issues is to incorporate mental health services into primary care. Research has shown that an effective approach for identifying and treating pediatric mental health issues is to create a system imbedded within the pediatric primary care realm, that incorporates a proactive, trauma-informed, multidisciplinary care, with integrated mental health and social services support system (Buka et al., 2022). In another recent study of providers in Nebraska, 89.1% of the participating primary care providers and pediatricians stated that screening of pediatric mental and behavioral health issues was 'Very Important', or 'Extremely Important' (Matthews et al., 2022). However, according to the 2020 National Survey of Children's Health, only 46.2% of children in the U.S. and 50.6% of Nebraska children have a medical home (KFF, 2020). Matthews and colleagues (2022) also identified that only 43.6% of primary care providers in Nebraska currently screened pediatric patients, and 8.2% of providers never screen for pediatric mental and behavioral health issues.

Another important platform to conduct screening for pediatric mental health issues is the school system which allows for screening a large number of children and adolescents for mental and behavioral health problems. According to the National Center for Educational Statistics (NCES) in 2021, approximately 54.2 million students were enrolled in the U.S. school system in pre-kindergarten to grade 12 (NCES, 2022). There is evidence that universal screening at the school entry-level could successfully detect children likely to have behavioral problems and provide a means to develop timely targeted interventions (Siceloff, Bradley, and Flory, 2017). Despite the acknowledgment of the need for universal mental health screening among children and youths, less than 15% of schools implement procedures to evaluate students' mental health needs systematically (Burns et al., 2021; Bruhn, Woods-Groves, and Huddle, 2014). One study found that school psychologists felt they could offer successful screening programs if perceived barriers were addressed (Burns et al., 2021).

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 is more likely to occur now as more parents are working from home under COVID-19. Furthermore, parents may hesitate to seek 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 barrier in their pursuit for better mental health (Chandra & Minkovitz, 2006). Shame, for many parents and children alike with unmet mental health needs, is another barrier to equitable health.

The COVID-19 Pandemic and Its Effects on Mental Health

Since the emergence of the COVID-19 pandemic in late 2019, tremendous disruptions to the daily life of children, families, communities, schools, and school mental health workforce have occurred, with rates of depression and anxiety in children surging (Dibner et al., 2020; Magson et al., 2021; Patrick et al., 2021). During the peak of the pandemic, most schools closed and transitioned to the home-based distance-learning models in Spring 2020 (Golberstein et al., 2020). As a result, children were compelled to stay home for prolonged periods due to lockdown and school closure, causing minimal or no communication or interaction with peers and reduced physical activities (Jiao et al., 2020). Although Nebraskan students went back to in-person school for the 2021-2022 school year, the lack of an approved vaccine at the time and increased mental and emotional health issues left students in a precarious position to risk infection or continue in isolation.

During COVID-19, a wide-ranging mental health issues, such as anxiety, stress, depression, and sleeping problems, were reported among pediatric patients (Racine, 2020). Disruptions in day-to-day life of children and adolescents may have included breakdown of routines, family distress, and social disconnectedness (Monroe et al., 2020). 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). Families and adults also have had adverse psychological outcomes due to the prolonged isolation, socioeconomic impacts, frustrations, fear and anxiety over COVID-19 (Loades et al., 2020). These issues point to the pressing need to prevent and treat mental and behavioral problems during and after the pandemic at family and community levels. Moreover, understanding the long-term consequences of COVID-19 and pandemic response measures, and their impacts on the mental wellbeing of children may not be known for some time since the pandemic and response to the pandemic is still ongoing.

Several barriers have emerged since the onset of the COVID-19 pandemic hampering access to mental and behavioral healthcare for children, including financial strain, lack of screening services, and as limited treatment options as healthcare systems are scrambling to cope with the pandemic. Due to the massive loss of employment and insurance coverage throughout the pandemic, many parents and caregivers had to forgo important healthcare

appointments (Mersky et al., 2021). Furthermore, the Centers for Medicare & Medicaid Services (2020) reported that compared to March through May of 2019, there was a dramatic reduction (44%) of childhood screening and outpatient mental health services during March through May of 2020. This may have been due to fear of contracting COVID-19 and lack of timely healthcare options, closure of local health care or reduction in services, and long wait times to receive health care (Bebinger, 2021). This is also exacerbated by the fact that the behavioral health care system has been traditionally isolated from other medical or service centers, such as primary care and care provided within the educational system. Underserved families may lack experience in navigating, much less be equipped to be informed consumers when they are seeking care for their child's mental or behavioral health condition. This creates additional barriers to care for children and families who urgently need mental health services. These additional stressors also emerged when there is a deterioration or short supply of home visiting programs, physical and mental health services, and specialized services (Buka et al., 2020).

Telehealth Services

The benefits of telehealth services become more apparent as COVID-19 and other emerging pandemics continue to affect the delivery of healthcare services. Some of the beneficiaries of telehealth are members of the rural communities in Nebraska who live too far away from major hospitals and who may find telehealth services preferable to commuting miles to visit a provider in person. For many patients, visitations with a care provider via telehealth may also be more affordable than seeing a provider in urgent care or an emergency room.

While telehealth overall has facilitated healthcare accessibility and decreased health disparities in certain populations, some pediatricians are concerned that telehealth might compromise the efficacy of treatment and there is a lack of rigorous research (Olsen et al., 2018). Other major provider concerns are lack of reimbursement, credentialing issues, and liability concerns. Crucial barriers for families and children have also emerged.

Approximately 11 million children in the United States are from homes without a computer or broadband internet access (Smith-East & Stark, 2021), making virtual schoolwork challenging, if not impossible. In Nebraska, some school districts provided notebook computers to students to support remote learning, while other districts made no such provision.

Despite initial hesitations with transitioning to telehealth medicine, many healthcare providers have reported its benefits to the sudden upheaval of traditional, in-person medicine and pediatric patients have reported an increase in the utilization of telehealth services. A mix-methods study found that 82% of childcare providers surveyed felt positive about transitioning to telehealth services for parent-child interaction therapy, noting their mutual willingness to continue telemedicine in the future (Barnett et al., 2021). In another assessment, there was 125% growth in telehealth visits by pediatric patients and an 88% increase in parents' awareness of telehealth services (HealthLeadersMedia, 2017). One study conducted in the first year of the pandemic found that telehealth visits with pediatric subspecialists increased from only 1 per 1000 child enrollees in 2019 to 68 per 1000 child

enrollees in 2020 (Ray et al., 2020). However, the lack of cohesive use of telehealth services and research in its effectiveness has left a large gap in the literature, especially in rural and minority groups.

Role of NEP-MAP

The Nebraska Partnership for Mental Health Care Access in Pediatrics, NEP-MAP, engages stakeholder organizations across the whole state to work together to improve access to mental and behavioral health care for children and families in Nebraska. NEP-MAP, led by a maternal and child health team in the Division of Public Health at the Nebraska Department of Health and Human Services, working closely with partners in the clinical demonstration project at the UNMC Munroe Meyer Institute, and the evaluation team at the Center for Reducing Health Disparities in the College of Public Health at UNMC. The project team also work with an Advisory Committee who actively participate in and guide the work.

Tele-Behavioral Health Consultation for Providers

The primary goal of the Nebraska Partnership for Mental Health Care Access in Pediatrics, NEP-MAP, is to offer provider-to-provider consultation services, with pediatric behavioral health experts offering consultation to primary care providers. As a result, providers are available to offer guidance on diagnosis, medications and psychotherapy interventions to assist primary care providers in better managing patients in their practices. Support is available through phone and synchronous audio/video teleconference consultations to referring primary care providers. Three child and adolescent mental health practitioners were trained and available to provide their consultation services via telehealth and consultation. The service is available to any primary care provider in Nebraska that provides services to pediatric patients. Within the three years of operation, the tele-behavioral consultation program has enrolled 29 primary care providers across the state of Nebraska. In the first year, 10 consultations were provided, followed by 17 consultations in the second year, and nine consultations in the first three quarters of the the third year.

By mutual agreement with NEP-MAP, the current study aims to integrate previously collected data in NEP-MAP to accomplish the following:

- Integrate related data previously collected from educators, health care providers, and parents to comprehensively assess the current state of pediatric mental health in Nebraska.
- Identify similarities and differences across the three groups in their perceptions of unmet needs in the screening, referrals, and treatment associated with mental and behavioral health disorders among children of 18 years or younger.
- Propose recommendations and future steps for improving access to pediatric mental and behavioral health services including expanding and refining tele-consultation programs as exemplified by the NEP-MAP Tele-behavioral Health Consultation Project.

APPROACH AND METHODS

Detailed descriptions of the data used in this report can be found in the prior three published NEP-MAP reports, *Community Screening of Pediatric Behavioral and Emotional Disorders in Nebraska* (Toure et al., 2020), *Provider Perspectives of Mental Health Needs and Services Among Children in Nebraska* (Su et al., 2021a), and *A Statewide Assessment of Mental Health Needs and Services Among Children in Nebraska: Family Perspectives* (Su et al., 2021b), which can be found at the Nebraska Partnership for Mental Healthcare Access in Pediatrics (NEP-MAP) website (www.dhhs.ne.gov/NEPMAP). The previous projects consisted of an initial phase of qualitative data collection of semi-structured interviews of key informants associated with educational organizations in 2020, followed by concurrent qualitative data collection based on semi-structured interviews with key informants from primary care settings and quantitative data collection from online surveys of parents and caregivers regarding family perspectives on pediatric mental and behavioral health in Nebraska in 2021.

Community Screening of Pediatric Mental and Behavioral Health Needs and Services

Fifty-three key informant semi-structured interviews were performed with community organizations representatives, including school nurses, teachers, program managers, or directors at various educational settings, including early childhood education centers, schools, foster care organizations, Head Start programs, and evidence-based home visiting programs in different regions across Nebraska between May and August 2020. The goal of this assessment was to gather a multi-perspective view of the similarities and differences in the perceptions and experiences of participants and to integrate suggestions from different organizations for improving screening and early identification of emotional or behavioral problems among children and youth.

Participants were identified initially through purposive sampling, followed by snowball sampling to recruit diverse participants involved in the delivery, management, and coordination of services for children and youths in Nebraska in various community settings. We conducted purposeful participant recruitment to represent various educational agencies across geographic regions in Nebraska and reflect experiences with children and youth at different ages. To be eligible, the participants needed to be 19 years of age or older and effectively communicate in English.

Potential participants were provided the informed consent and sent the interview questions prior to the interview. The semi-structured interviews were conducted and recorded through Zoom and lasted approximately 45 minutes. Key informants were compensated with a gift card for participation.

A more detailed explanation of methods and list of interview questions can be found in the report, *Community Screening of Pediatric Behavioral and Emotional Disorders in Nebraska* (Toure et al., 2020).

Provider Perspective of Pediatric Mental and Behavioral Health Needs and Services

Eighteen interviews with primary care providers were conducted to gain the perceptions and experiences of different providers regarding the unmet needs in the screening, treatment, and referral associated with mental and behavioral health disorders among children, as well as COVID related changes, working adjustment, use of telemedicine and its integration into current pediatric primary care. To be eligible, participants needed to be 19 years of age or older and able to effectively communicate in English. Participants included representatives that provided pediatric health care services, such as pediatricians, nurse practitioners, physician assistants, clinical social workers, psychologists, and licensed professional counselors.

Development of questions for the semi-structured interviews with primary care providers was enhanced by collecting feedback from NEP-MAP Technical Workgroup members, including providers, systems professionals, community providers, and family representatives. In commissioning the study, NEP-MAP intended to assure that results would be actionable and relevant to the overarching purpose of improving access to mental health care for all children.

Potential participants were provided the informed consent and sent the interview questions prior to the interview. The semi-structured interviews were conducted and recorded through Zoom and lasted approximately 45 minutes. Key informants were compensated with a gift card for participation. A more detailed explanation of methods and list of interview questions can be found in the report, *Provider Perspectives of Mental Health Needs and Services Among Children in Nebraska* (Su et al., 2021a).

Family Perspectives of Pediatric Mental and Behavioral Health Needs and Services

Between June and August 2020, altogether 373 parents and caregivers of children in Nebraska participated in the online REDCap survey regarding family perspectives of their child/ren health, parent support and needs, adaptation to remote learning, and child access to health services, with an intentional oversampling of rural parents or caregivers.

The research team drafted a survey questionnaire and updated the questionnaire with input from NEP-MAP partners and stakeholders, including the Technical Workgroup #2 (TWG#2) for CLAS and Equity in NEP-MAP priorities and operations, and Technical Workgroup #3 (TWG#3) for Family-centered care. The Technical Workgroup (TWG) members verified that the survey was accessible and appropriate for diverse families and reflected recognition of the challenges families face. The members of TWG#2, family members themselves, pilot tested the questionnaire before it was finalized.

Data collection in the survey was primarily managed using REDCap (Research Electronic Data Capture) hosted at UNMC. REDCap is a secure, web-based application designed to support data capture for research studies. REDCap at UNMC is supported by the Research IT Office funded by Vice Chancellor for Research (VCR). The published contents in this report are the

sole responsibility of the authors and do not necessarily represent the official views of the VCR and NIH.

The survey started with an informed consent letter, a brief introduction to the goals of the NEP-MAP Family Perspective Survey, and 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. Participants were asked to provide an address at the end of the survey to receive a 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 and individuals throughout Nebraska.

ETHICAL CONSIDERATIONS

Full ethical considerations can be found in the three prior published reports, *Community Screening of Pediatric Behavioral and Emotional Disorders in Nebraska* (Toure et al., 2020), *Provider Perspectives of Mental Health Needs and Services Among Children in Nebraska* (Su et al., 2021a), and *A Statewide Assessment of Mental Health Needs and Services Among Children in Nebraska: Family Perspectives* (Su et al., 2021b). The studies were approved by the Institutional Review Board of the University of Nebraska Medical Center (IRB # 235-20-EX and IRB # 246-21-EX).

Data collection from eligible participants only started after we had provided and 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 survey or interview process. Confidentiality has been maintained by using numbers instead of names (e.g., key informant 1 or survey respondent 1) and removing identifying information before data analysis. All audio recordings and transcripts were saved on a password-protected computer.

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

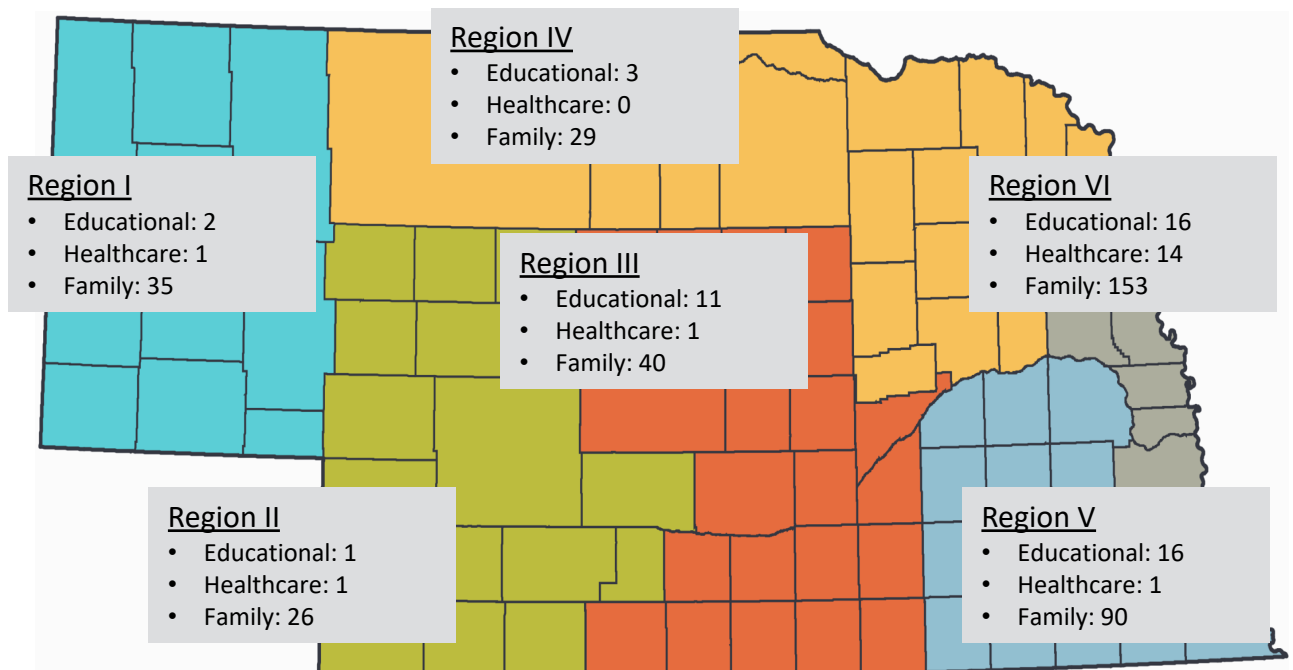
ANALYSIS AND RESULTS

Between Spring 2020 and Fall 2021, individuals employed within the educational and healthcare systems across Nebraska, as well as parents or caregivers were assessed to identify unmet mental and behavioral health needs of children in Nebraska. The following results are based on secondary analysis of the survey data collected from the 373 parent or caregiver respondents and the 71 key informants from the educational and healthcare setting (53 from the educational system and 18 from the healthcare setting), in order to provide a comprehensive assessment of the current state of the mental and behavioral health of children in Nebraska, including current trends, utilization of current services, status of screening and referral processes, barriers to seeking care, the impact of the COVID-19 Pandemic on children, and suggestions to improve the pediatric mental and behavioral health system.

Distribution of the Respondents

NEP-MAP primarily is concerned with improving access to mental and behavioral health services for children and youths in rural and underserved communities of the state. In addition, NEP-MAP leadership specifically requested the evaluation team to assure that responses from rural Nebraska respondents were obtained from each of Nebraska's predominantly rural Behavioral Health regions. As a result, the survey purposefully oversampled rural respondents, compared to the overall Nebraska population. While the evaluation team was successful in oversampling in the educational system and family perspective assessments, there were some limitations in identifying healthcare providers in the rural setting (Figure 1).

Figure 1: Study Participants By Behavioral Health Regions in Nebraska



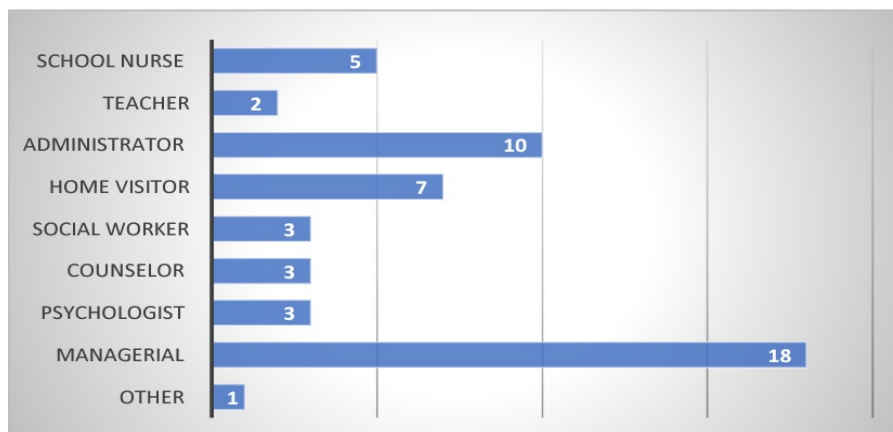
Among the representatives of the educational system, approximately 52% were employed in educational settings in rural areas in comparison to 46% that worked in urban settings, and 2% that were employed in statewide organizations. Similarly, rural respondents to the family perspective assessment were oversampled, with 47.5% of the sample residing in rural settings and 52.8% in urban settings (in comparison to statewide data with 33.6% of the population living in rural areas in 2021) (RHHHub, 2022). In comparison, 83% of healthcare representatives respondents were from urban areas (Behavioral Health Regions V and VI). This may be due to the concentration of healthcare providers in this area, difficulty identifying rural healthcare respondents, or sampling difficulties.

Demographics and Description of the Sample

There were 71 key informant participants that participated from the educational and healthcare settings across Nebraska, with 53 interviewees coming from the educational system and 18 identifying as primary healthcare workers.

Among the participants from the educational setting, the majority were employed by the public school system (39.6%), early education programs (16.7%), home visiting programs (16.7%), non-profit organizations (11.3%), foster care programs (3.8%), governmental agencies (3.8%), tribal organizations (3.8%), a federally qualified health center (1.9%), and an independent living center (1.9%)(Figure 2). Job descriptions included school nurses, teachers, administrators, home visitors, social workers, counselors, school psychologists, and program managers (Figure 2). On average, educational workers were employed at their current organization between 6 and 10 years.

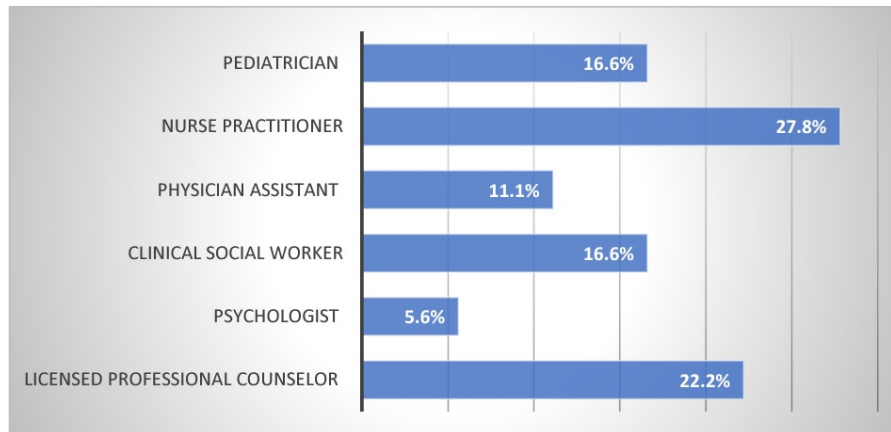
Figure 2: Educational Setting Key Informant Job Titles



Most respondents from the healthcare setting worked at primary care clinics (33.3%), followed by a hospital setting (either academic or non-VA associated) (28%), federally qualified health center (16.6%), or independent care clinic (5.8%). Almost all of the providers were associated with a healthcare organization (83.3%) and worked in a clinic or other ambulatory care setting within the last 30 days (94.4%). Professional titles of the respondents included pediatricians, nurse practitioners, physician assistants, clinical social

workers, psychologists, and licensed professional counselors (LIMHP OR LMHP) (Figure 3).

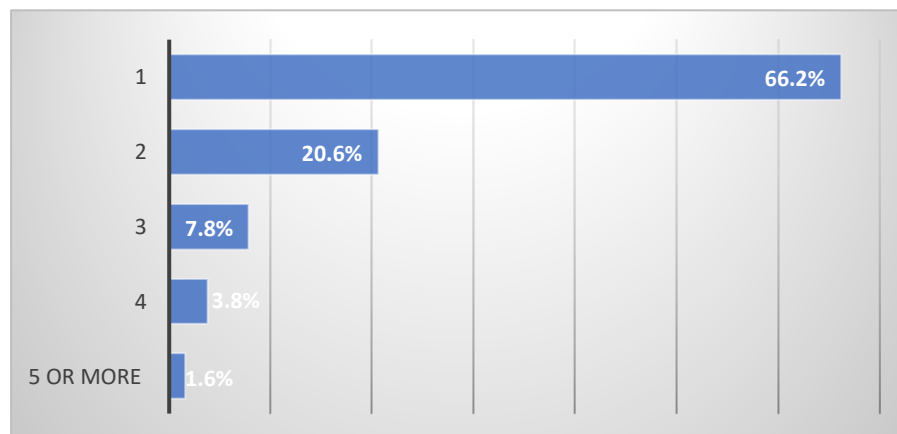
Figure 3: Healthcare Setting Key Informant Job Titles



Demographic information was collected from the parent or caregiver respondents as well as basic information regarding the child/ren in their care. Parent/caregiver respondents were between the ages of 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). Approximately 25% of the sample identified as Hispanic/Latino and 26.7% identified as some other race than white/Caucasian. Respondents were more likely to be married (78.5%), with two or more incomes contributing to the household (65.7%). The majority of respondents stated they had obtained at a minimum an Associate’s Degree or trade school certificate (58.2%). More details of the demographics of the parent or caregiver can be seen in Appendix A.

Overall, the majority of respondents reported only one or two children in the household (Figure 4), with rural households reporting a higher prevalence multi-child households than their urban counterparts. This is congruent with the U.S. average of 1.93 children under the age of 18 in the home and the Nebraska average of less than 2 children in the home.

Figure 4: Number of Children per Household Reported by Parents/Caregivers



Characteristics of Children Served

Parents/caregivers reported a total of 581 children within 373 households. The average age of the child/ren living in their homes was 9.86 years, with a range of 0 to 27 years old. The majority of children identified as school-aged children (6 to 12 years of age), followed by adolescent (13-19 years of age), early childhood (0 to 5 years of age), and adult (19 years or older). This sample included predominantly male children, and those in elementary school (grades 1 through 5). More details regarding child/ren characteristics can be found in Table 1.

Table 1: Demographics of Children in the Sample based on Parental Report

Age Group (n = 525)	n	%
Early childhood	95	18.1%
School age	297	56.6%
Adolescent	115	21.9%
Adult	18	3.4%
Gender (n = 530)		
Female	222	41.9%
Male	308	58.1%
Academic Level (n = 455)		
Early Education	50	11.0%
Elementary school	225	49.5%
Middle school	76	16.7%
Highschool	77	16.9%
Highschool graduate	11	2.4%
College	16	3.5%

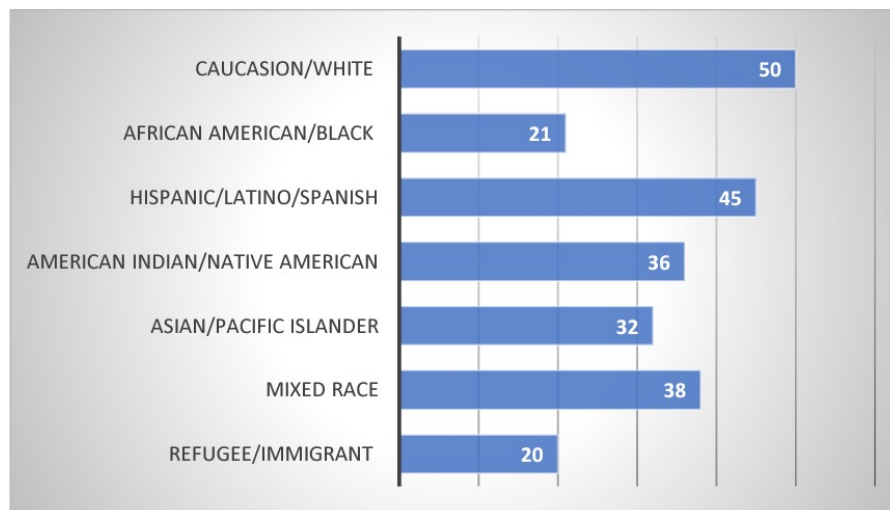
Within the educational setting, key informants stated they worked predominantly with early childhood age children, followed by school-aged, adolescent, adult, prenatal, and across the lifespan. Healthcare setting key informants reported serving patients from birth to 19 years, with some pediatric providers keeping some patients older than 19 years if a developmental disability is present. Licensed counselors were more specific in the age groups they served, with some only treating patients in the preschool-aged, school-aged, or adolescents. All of the key informants see children in the school-aged and adolescent group for mental and behavioral health issues.

Key informants from both the educational system and the healthcare system were asked to identify racial and ethnic groups that were represented within their organization. In both situations, the proportion of children from non-white racial and ethnic minority groups was dependent on the key informant and their respective location, ranging from 5% of the total pediatric population to 100% of the pediatric population served.

Figure 5 depicts the number of educational organizations that work with children and families of each specific race and ethnicity. The predominant racial background of children

served was Caucasian/White (94.3%), followed by mixed-race (71.7%) (Figure 5). Approximately 85% of the participants reported that their organizations serve Hispanic or Latino children and youths. All racial and ethnic backgrounds were represented in the key informant organizations.

Figure 5: Racial and Ethnic Make-up of Children and Adolescents Served in Educational Settings



About 37% of informants from the educational setting and 72% from the healthcare setting also stated they worked with refugees or immigrant families currently or within the organizational history. The majority of refugees identified in the healthcare setting stated the predominant countries of origin were Somalia, Burma, and Afghanistan.

Identified Mental and Behavioral Health Issues among Children in Nebraska

Key informants were asked to identify how common behavioral or emotional issues were among children and adolescents in their organization or clinical setting. All of the clinical providers and 74% of the educational respondents identified some concern with the state of the mental, emotional, and behavioral health issues of children in Nebraska. In combination, 63% of parent/caregiver respondents also reported signs of mental or behavioral health issues in their child/children within the last 30 days. The range and severity of issues expressed by the key informants varied by organization type, age range served, and key informant designation (educational or healthcare).

Within the educational setting, key informant respondents identified on average 20% of children or adolescents showed some mental or behavioral health concern while at school. Similarly, 1 in 5 parents/caregivers reported at least one of their children had a learning disability (41.1%) or special needs issue (20.6%).

Select quotes from key informants from the educational setting regarding the proportion of mental or behavioral health issues among their pediatric populations served are as follows:

“Our preschool we typically average about a third of the kids... so like 30 children that have come into the program with some kind of delay due to their development.” [EKI]

“At the school I’m at right now, I would say probably 25% of the students fall into that category. But they don’t have like an official diagnosis.” [EKI]

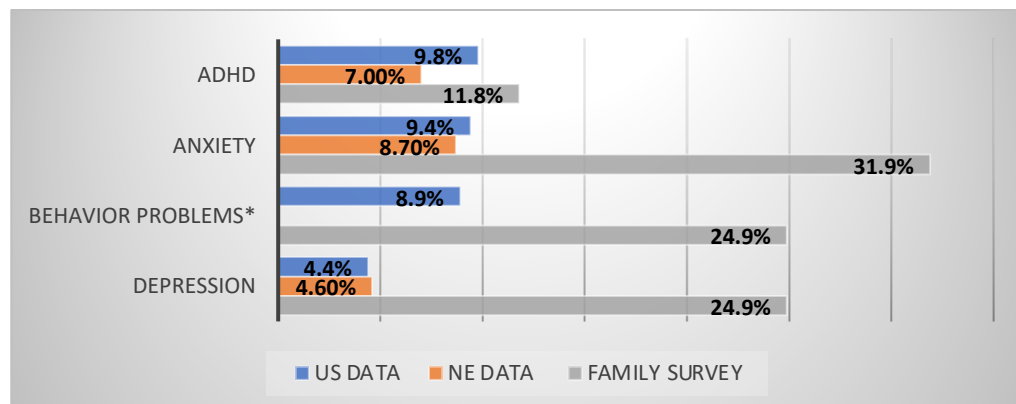
There does appear to be a difference between responses regarding emotional and behavioral concerns due to differences in age ranges served by the organization. For example, most of the respondents who expressed concerns regarding emotional and behavioral problems worked with older children (school-aged children and older). Those who stated no concerns were more likely to work with children between the ages of birth and five years. This is similar to national trends, in which more mental and behavioral health issues emerge as the age of the child increase. For example, those that work in the early childhood group stated:

“I would say we're not seeing that, especially with the age of children we're working with right now.” [EKI]

“I will say not very often, since we work with kids from zero to three, I feel that there's not a lot. It's hard to identify somebody that is having any kind of problem at that age.” [EKI]

Parents/caregivers, educational representatives, and clinicians were all asked to identify the predominant issues that are present in the pediatric populations they serve. Similar to nationwide and statewide trends, participants identified Attention-Deficit/Hyperactivity Disorder (ADHD), anxiety, depression, and behavioral problems were identified as the major issues present in this sample (Figure 6)(US DHHS, 2021; United Health Foundation, 2022). Our sample percentages of ADHD, anxiety, behavioral health issues, and depression are represented at a higher proportion than the statewide sample due to sampling techniques; our partners were associated with family groups of known pediatric neurodivergent issues and therefore oversampled this population.

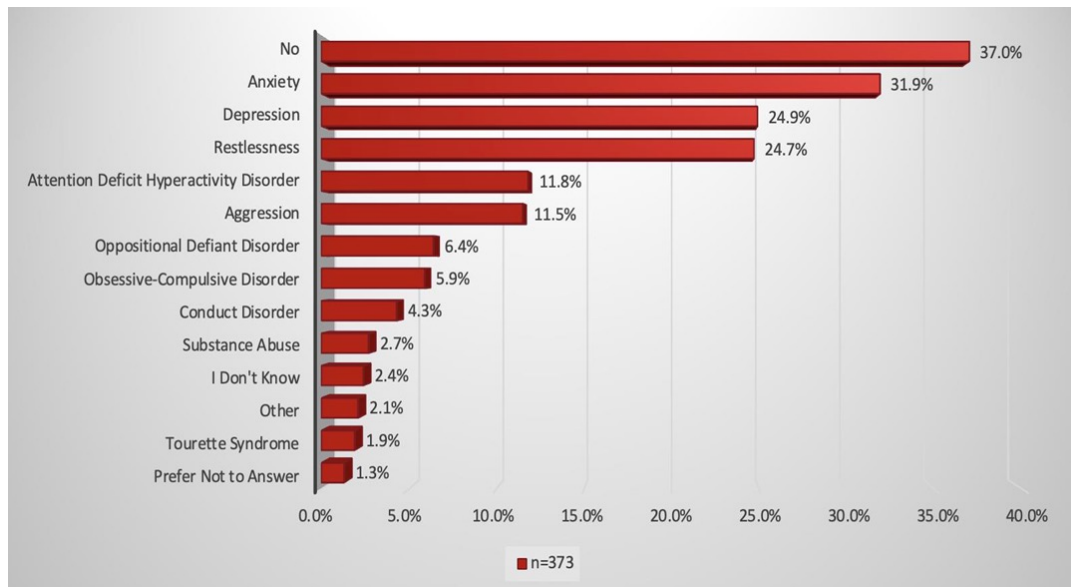
Figure 6: Comparison of Reported Mental and Behavioral Health Issues among Nationwide, Statewide, and Family Survey Data



* Statewide behavioral problems not reported

Healthcare and educational representatives both identified the top three issues present in the pediatric populations they served as ADHD, anxiety, and depression. Parents/caregivers identified 'Restlessness' as the third most common issue, followed by ADHD. Figure 7 identifies the predominant issues as reported by parents/caregivers.

Figure 7: Child Mental or Behavioral Health Issues Within the Last 30 Days



Key informants described in detail the types of mental and behavioral issues that have been seen in their pediatric populations. Samples of these descriptions are as follows:

“We see a lot of ADHD, autism, learning disorder, reactive attachment disorder. I would say we even start to see some beginnings of bipolar; these tend to be our main diagnoses.” [HKI]

“Everything from anxiety, to depression, to PTSD to even getting into more long-term mental health stuff like developing with schizophrenic tendencies. Even like getting into substance abuse.” [HKI]

Other identified issues that were identified by respondents are identified in Table 2. Differences in identified issues may be due to age group specified or organizational setting.

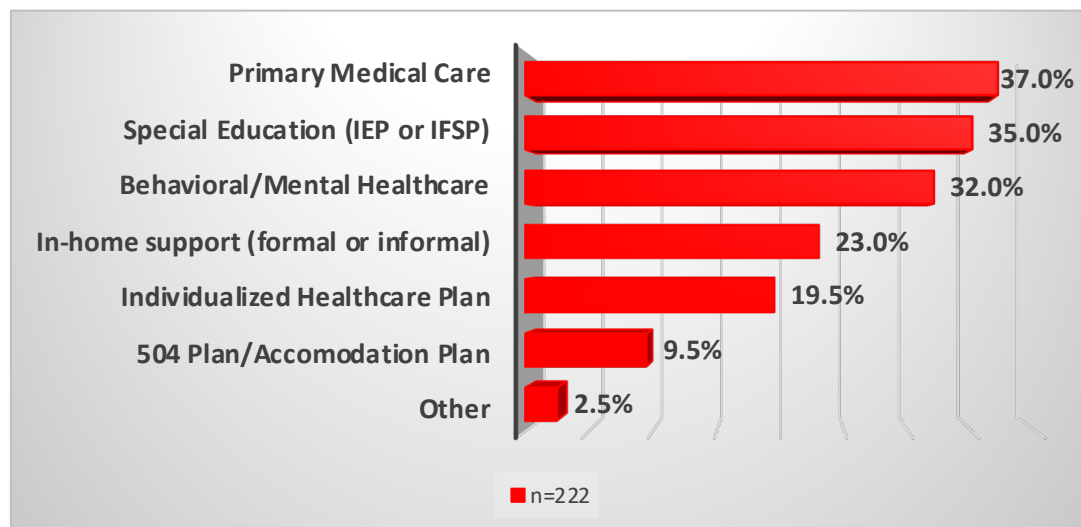
Table 2: Commonly Identified Mental and Behavioral Health Concerns across Data Sources

	Educational Setting	Healthcare Setting	Home Setting
Aggression			X
Oppositional Defiant Disorder		X	X
Obsessive-Compulsive Disorder			X
Substance Use	X	X	
Tourette’s Syndrome			X
Post-Traumatic Stress Disorder	X	X	
Autism	X	X	
Developmental Disabilities	X		
Behavioral Disruptions		X	
Learning Disorders	X	X	X
Eating Disorders		X	
Suicidal ideation/self-harm	X	X	

Utilization of Pediatric Mental and Behavioral Health Services

According to parents/caregivers, approximately 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 (54.3%), indicating a need among children not previously identified as having special needs. Among those families utilizing support services, the most common utilized is primary medical care, followed by special education and behavioral/mental healthcare (Figure 8). Rural residents used special education and individualized healthcare plans at a higher rate than the statewide sample (35% and 19.5%, respectively), which 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.

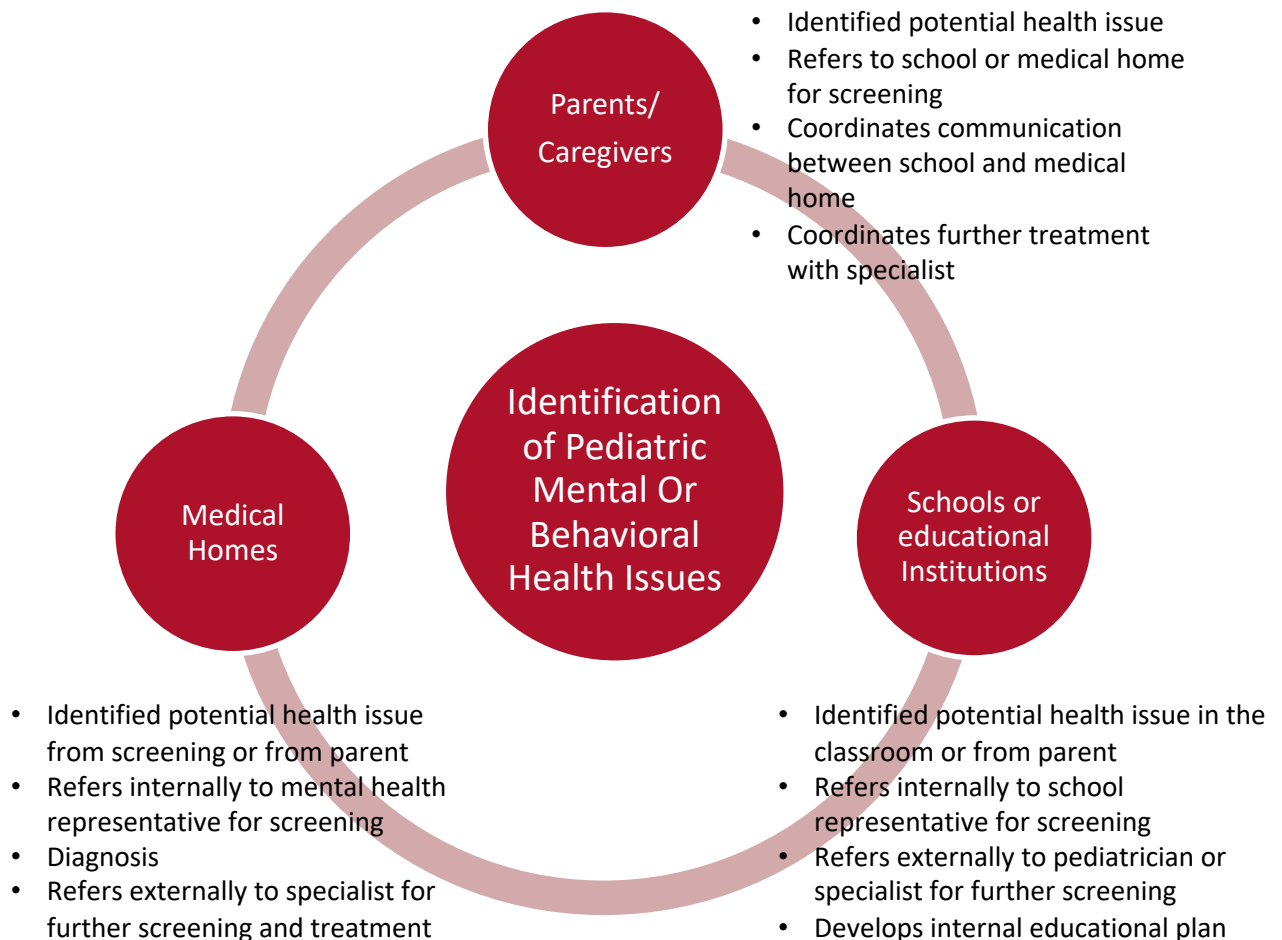
Figure 8: Reported Services Utilized by Parents



Overall, parents indicated that they learned about these services from their primary care providers (46.9%) or through personal research (30.8%). Only 10.7% of respondents stated they learned of resources from their child/ren’s school. However, 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.

Further examination of the services utilized by families revealed that families and caregivers are often in contact with both the educational and healthcare setting prior to referral to a mental or behavioral health specialist. The successful identification of pediatric and mental health issues in children relies on the interplay of screening and referrals between the school system and the medical home, with the parent/caregiver acting as the predominant communication method between the system. Figure 9 depicts the relationship between the major areas of screening and treatment.

Figure 9: The Identification of pediatric mental and behavioral health issues



Both the educational and healthcare setting have developed specific referral processes once a child or adolescent has been identified with a potential behavioral or emotional concern. Both settings offer two referral methods, one internally within the organization and one outside of the organization. While specialized services were established, internal providers act as bridge providers, until long-term care is established. Most educational professionals will refer children to their primary care providers, unless a relationship with a specialist is already established, such as the Nebraska Early Development Network (EDN).

Descriptions of the referral process are as follows:

“They might be looking at referring to our school-based licensed mental health practitioners or school social workers that are in the district, if there's something that they can do. And then from there, we'd probably go on the advice of the doctors or what the next level professional, a school psychologist or whoever they were referred to.” [EKI]

“Let's say someone is struggling in the classroom or has some behavior early, or I feel like there's something going on at home. A lot of times we refer to community counseling. We have a Connections program. I will make a referral to the parent and contact the parent and ask them if they would like to sign up for Connections counseling, which oftentimes happens at school where the therapist comes to the school and works with their child or if they would rather, they can set it up during non-school times if the parent is willing to take them.” [EKI]

“Parents ARE ALWAYS the ones making the decisions and IF they want more evaluations done it is then that we make the call together and sign releases to start the referral process. We all work together as a team and as resources for the families.” [EKI]

All interviewees within the school system acknowledged they are not medical professionals, and therefore do not provide a diagnoses. Students are referred to outside resources for evaluation and diagnosis if a school provider is not available. If the school is included in the care plan for the child (i.e. informed of the diagnosis and treatment plan, including medications), the school providers will incorporate this into the care management plan. However, some key informants stated that children do not receive a formal diagnosis or information from care providers is not shared with the school.

There are some common barriers that prevent referrals to specialists immediately . These include:

- Financial responsibility
- Lack of consistent screening tools
- Forced transition plans
- Lack of knowledge of community resources
- Lack of communication between organizations
- Waitlists
- Age limits for services
- Insurance limitations
- Lack of provider training

Key informant descriptions of these barriers are as follows:

“We have this intake process, so we usually make a lot of calls together and then when they feel comfortable, sometimes they’ll sign a release of information to get direct information for medical providers.” [EKI]

“If you’re seeking outside help besides what the special education program can provide...it’s very difficult to recommend because any recommendation of the district would wind up paying for it, so you have to be careful.” [EKI]

“Especially working with kiddos, especially working with families who again, don’t know the resources. (They) are very hesitant to even utilize what is out there. Then I think with the resources that are out there, I don’t think they’re (the resources) necessarily openly available or communicated about frequently.” [HKI]

“They are only taking their own patients. So, they only take people who are seeing those pediatricians. We can’t refer to them as my understanding. That is the main resource in town and is unavailable....it’s very territorial, it’s weird. I think it’s a disservice to our community.” [HKI]

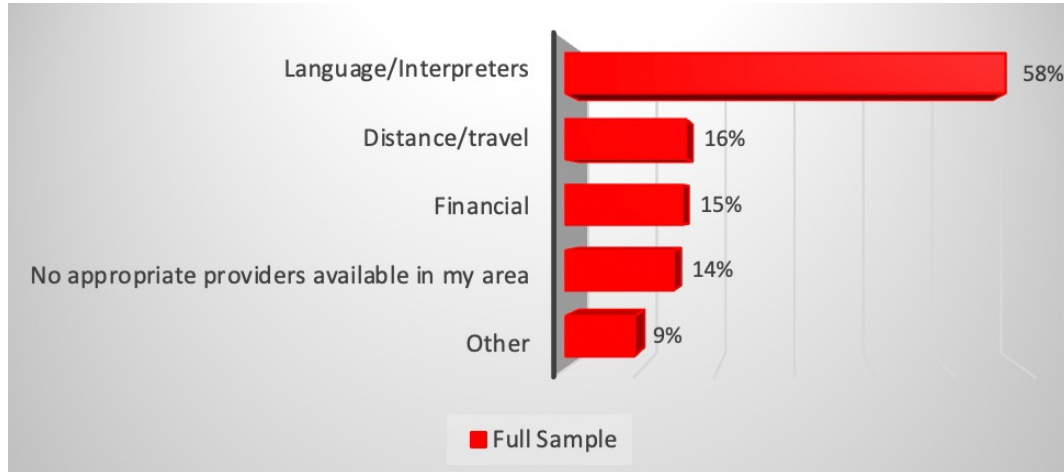
Barriers to Seeking Care

All of the key informants and parent/caregiver respondents identified barriers to preventing children from receiving mental health services in Nebraska in three different categories: barriers external to the professional setting, barriers within the professional setting, and individual barriers. While barriers are specific to the individual situation, the most common barriers are identified below.

A. Barriers External to the Professional Setting

Barriers external to the professional setting are barriers that are presented to parents and caregivers prior to accessing professional help, either through the school system or medical home. Approximately 58% of parents and caregivers identified some barrier to receiving care, with travel and distance the greatest external barrier parents/caregivers face in obtaining care for their children, followed by financial issues, and available providers (Figure 10). Rural respondents tended to experience less reported barriers than their urban counterparts (41.5% vs. 43.1%, respectively); however, rural respondents reported more issues with distance and travel (19.3% vs. 16%, respectively), financial burden (14.8% vs. 13.7%, respectively), and a greater lack of access to appropriate providers than their urban counterparts (13.6% vs. 5.1%) than their urban counterparts (19.3% vs. 16%, respectively). Those in urban areas identified financial barriers (13.7%) as the greatest barrier experienced.

Figure 10: Parent/Caregiver Reported Barriers to Accessing Services



Examples of these barriers provided by parents and caregivers are as follows:

“There are not enough mental health providers in the Panhandle for our children.” [P/C]

“The state of Nebraska has a limited number of child psychologists in rural areas. In the area between North Platte to Lincoln, there is one provider with a full medical degree.” [P/C]

“Since there is one provider there is no other options and therefore you are stuck with the one provider who does not have enough time to actually see patients, so it feels like a drive through.” [P/C]

“Mental health services such as basic counseling and evaluation are very hard to access in my community. Most do not have appointments available for 3 months or more and many providers are 50-150 miles away.” [P/C]

Key informant professionals within the educational and healthcare system identified similar barriers to each other and parents/caregivers: transportation, lack of qualified mental health providers, and financial costs as major barriers (Table 3). Educational professionals identified a lack of age-appropriate providers available and healthcare professionals identified mental health stigma as unique barriers to each other.

Educational and healthcare professionals identified insurance coverage as the major barrier most families face. Educational providers have identified that there are few mental health providers that accept Medicaid or have a sliding scale. Healthcare professionals identified the lack of in-network providers for mental healthcare. For example, one provider stated:

“The biggest issue that I see with families is that (a provider) used to accept my insurance, and now they don't, and then they're (the family is) scrambling to find another service (provider).” [HK1]

Table 3: Key Informants Identified Barriers External to Professional Settings

	Educational Setting	Healthcare Setting
Age-appropriate treatment	X	
Financial/cost	X	X
Transportation	X	X
Availability of qualified providers	X	X
Stigma towards mental health		X

The cost or financial barrier that families experience while trying to seek mental and behavioral healthcare does not seem to be tied to insurance rates, but lack of available services or overall insurance coverage of mental health services. Nearly all of the parent and caregiver respondents identified that their child/ren was insured (89.3%) at the time of the survey assessment, which is less than the Nebraska rate of 94.3% (U.S. Census Bureau, 2022). However, only 41.1% report that their private insurance and 25.6% of public insurance covers all of their mental health needs. Over 33% of parents/caregivers reported paying out-of-pocket for all mental healthcare needs.

For example, one caregiver stated:

“I have paid for help privately and am willing to travel for what we need. My ability to do that is extremely rare.”

B. Barrier Internal to the Professional Setting: Communication

Once a child/ren has been seen within the professional setting, barriers also emerge that make seeking further care difficult or inefficient. The primary barrier within the professional setting that was identified by the parent/caregiver respondents and professional key informants is communication, including both linguistically- and culturally-appropriate communication and communication between service providers.

Nearly 60% of parent and caregiver respondents identified language and interpretation as a major barrier preventing effective care (Figure 10). Urban parent/caregiver respondents identified language and interpretation barriers as a significantly greater carrier than their rural counterparts (20.3% vs. 10.8%). Both education professionals and healthcare professions also identified language and interpretation as major barriers within their respective settings. The issue named by all key informants in serving minority families was language barriers with families, and having insufficient resources, time, or knowledge to address this need satisfactorily on families’ behalf. While there are interpretation services

available, these may be limited to more common languages (Spanish or French) for in-person services or incorrect dialects for video or phone interpretation services. Examples of interpretation issues include:

“I wish we were more mindful within our health system about people who speak different languages.” [HKI]

“We’ll use, you know, Google Translate and try to have some of those. But the dialectic is a pain. So, I feel like there’s pieces missing.” [HKI]

“There is a lack of availability of interpreters to private providers. Not only in Spanish but other services.” [HKI]

Even if interpretation was available, key informants discussed major issues that emerged in the use of interpretation services. These included:

- In-person vs. phone interpretation
- Video vs. audio-only interpretation
- Use of community member vs. professional interpreter
- Trust in interpreter by patient and provider
- Interpreter training and knowledge in medical terminology
- Ability to incorporate body language and cultural nuances

Most key informants stated there was a lack of qualified in-person or distant interpreters to assist with any language presented in professional settings, and the tools provided to help bridge this gap were insufficient in certain instances. This was more predominant in locations that served a more diverse population, such as urban settings, but was an issue in every location. On top of these identified issues, 12.1% of parents or caregivers stated they were not asked by their provider any feedback regarding their satisfaction with their interpreter during their visit. This shows there is a lack of concern of the opinion of the family in consideration of the interpretation service as well.

While interpretation and language services were identified as a major barrier many families face, over 97% of the sample reported speaking English in the home as the primary language, and only 16.9% of the parent/caregiver respondents used language interpretation services outside of the home. The incongruence between the reported use of language interpretation and the number of parents and caregivers that reported language as barrier needs to be further investigated. This finding can be explained by the lack of knowledge that interpretation services can be utilized within care settings, the underreporting of the utilization of children as interpreters, or communication outside of language issues.

The concern with treating children from diverse racial and ethnic backgrounds extends past

the ability to communicate in an appropriate language, but also to provide culturally appropriate healthcare services, especially in the mental health care arena. This also includes the inclusion of racially and ethnically congruent healthcare providers to overcome this barrier. For example, some professionals stated:

“We struggle to get staff of ethnic and diverse backgrounds, which then I think kind of hinders on implementation of some of those strategies (that might help families).” [HKI]

“I think one of the things that is helpful for families and minority families that (I’ve) come across is that I also have a different background. Even though we may not speak the same language, I feel what they told (tell) me through an interpreter in general is that they feel like they can talk to me.” [HKI]

Equally, parents/caregivers expressed concern that the provider did not employ staff that lives in their community (12.3%) or felt comfortable letting the provider know if/when the disagreed due to cultural beliefs (12.2%).

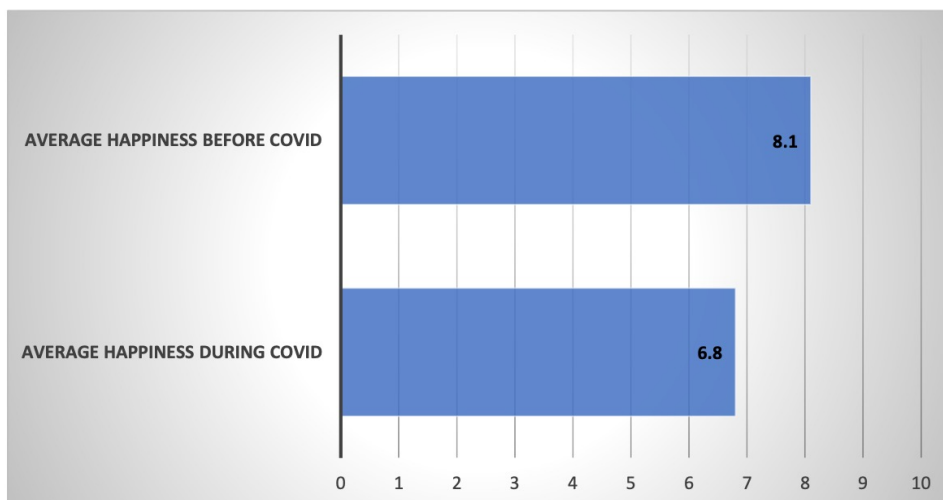
Impact of the COVID-19 Pandemic of Pediatric Mental and Behavioral Health

The current COVID-19 Pandemic has posed unprecedented risks for both short- and long-term emotional and behavioral outcomes of many children and adolescents in Nebraska. Three key areas have been identified as primary concerns: developing mental and behavioral health issues, issues within the education setting, and concerns developing within the home or with the family.

A. Developing Mental and Behavioral Health Concerns

As seen across the nation during the COVID-19 Pandemic, the number of children with new mental and behavioral health issues, as well as the severity of those previously diagnosed, has increased. The overall happiness of children has been noted to decrease over the pandemic, from a reported average happiness rating of 8.3 prior to the pandemic to 6.8 during the pandemic (Figure 11).

Figure 11: Reported Child Happiness Prior to and During the COVID-19 Pandemic



There were several predominant reasons provided by parents and providers describing the reasons for this reported rating during the pandemic. Common reasons included:

- Isolation at home
- Increased anxiety in social groups
- Racial tension in community
- Lack of social interaction
- Family stress
- Lack of routine
- Issues with distance schooling
- Negativity on media

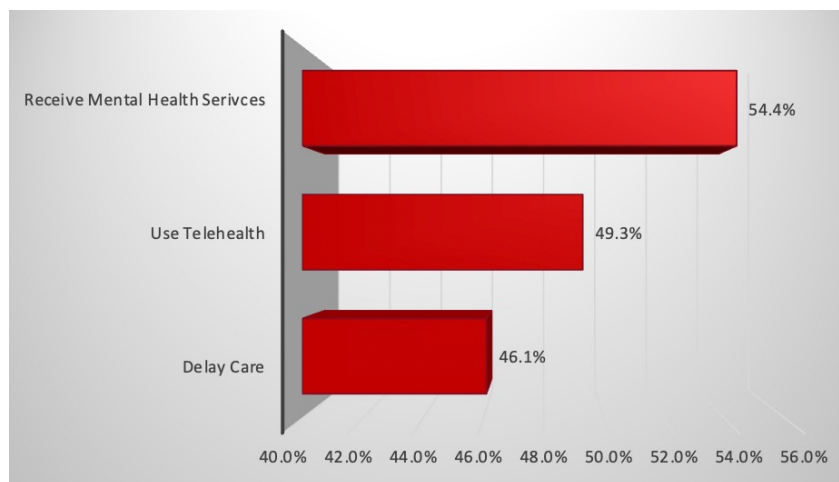
Nearly all Key Informants described seeing an increase in anxiety, depression, and family stress during the pandemic. Key Informants described experiences both of seeing pediatric patients with new symptoms, and of seeing more severe symptoms in previously diagnosed patients. Some providers identified self-harm tendencies, suicidal ideation, and familial stress as major concerns in their populations. The following quotes illustrate these perspectives:

“Many people who were having underlying problems with depression or anxiety before the pandemic; it (the pandemic) just tended to exacerbate it. But I don’t think my partners and I saw more people coming in with depression.” [HKI]

“We’ve seen an increase in mental health symptoms with COVID. When they weren’t coming (to school) in person, things (mental and behavioral health issues) tended to increase. Because they weren’t having that connection. We were seeing more significant behavioral concerns. We are seeing more significant depression, anxiety. All of those are rising considerably.” [EKI]

Parents and caregivers responded with an increase in the use of mental health services, telehealth utilization, or a delay in care due to the COVID-19 Pandemic (Figure 12).

Figure 12: Family Utilization of Health Services during the Pandemic



Key informants identified a large portion of their professional services were provided through telehealth during the height of the pandemic. Healthcare providers expressed a

view of the utilization of telehealth services, especially among pediatric populations.

Some key informants supported the transition to telehealth services, especially in communities in which mental health stigma is high and/or areas in which availability of mental health services is low. Telehealth contributes to increased accessibility, decreased stigma, and provided families the flexibility to schedule appointments at their convenience. Several parents and caregivers agreed with the healthcare professionals:

“Due to COVID-19, I think telemedicine is very good, and I hope to develop better telemedicine technology.” [P/C]

On the other hand, some providers felt that telehealth services were creating or exacerbating existing gaps in mental health access or creating challenges for effective engagement. For example, providers and parents stated:

“I think the biggest thing that I saw in our clinic and our patient population is most of the mental health care visits went virtual. And a lot of our families didn't have great internet or an ability to access that. And it was very difficult for them to access care.” [HKI]

“I don't enjoy using it for any services (for) children, especially with severe behavioral mental health disorders. It's very difficult to get (them) to engage and then being able to continue treatment.” [HKI]

“I don't do it (telehealth) for things like anxiety and depression, but especially with the pandemic part of helping is getting to see someone face-to-face and listening to them. I found that direct interaction has helped students so much, versus that kind of detached interaction that you get from online.” [HKI]

“Telehealth is not the long-term answer.” [P/C]

“Some of the people who help with telemedicine problems are not very good, and I don't think they have a lot of experience with children.” [P/C]

“Doing a zoom meeting for mental health is not building relationships with patients.” [P/C]

All of the key informants agreed that telehealth services were most likely going to be incorporated into the standard of care for mental health services in the future, even after the pandemic has abated. However, there are several areas that will need further discussion to incorporate these services effectively into the current healthcare system, especially in the treatment of pediatric mental and behavioral health .

B. Social and Academic Concerns

Within the educational setting, many professionals are expressing concerns with the isolation and academic issues that emerged due to school shut-downs and the implementation of online schooling. 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, which was related to some rural schools remaining open throughout the first phases of the pandemic. Overall, parents and caregivers reported that 18.4% of the sample did not handle the changes to the school safety protocols well or found it very difficult.

Specific issues emerged across all geographic locations and age groups equally. For younger children, several providers noted a diminishing of social skills that are achieved in early education settings. Emerging concerns included issues with language development, social skills, and behavioral issues.

For example, one early education provider stated:

“The children’s social skills have almost completely diminished... She doesn’t really know how to interact other than the people that she knows, and she doesn’t know how to respond. She doesn’t know what is appropriate. Because she hasn’t had those opportunities.” [EKI]

For school-aged children and adolescents, social issues, learning disabilities, stress and anxiety, behavioral issues, and loss of established healthcare services were major concerns.

“We know just on the remote learning that we had done, and data we collected, we saw a big loss in knowledge and skills amongst the kids who cannot be in in the classroom.” [EKI]

“We saw a lot more kids coming in with like stress from not doing well in school; their families weren’t doing well with dealing with virtual school. So, there was a lot more school failures and stress in the family.” [HKI]

“COVID definitely impacted referrals. We had students without services for so long a period of time that we’re definitely seeing the remnants of that now that we’re having increased behavior.” [EKI]

“I think it’s been a huge barrier and a struggle as several of my students were receiving, you know medication and therapeutic services pretty regularly.” [EKI]

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.

C. Concerns Developing within The Home or with The Family

A large number of parents/caregivers and key informants detailed the increase in familial strife and home-life disruptions. A large percentage of parents adjusted their lives to better accommodate the many changes that occurred during the pandemic shut down. Some of these accommodations include:

- Worked from home
- Finding alternative childcare
- Finding reliable internet
- Cutting or changing hours at work
- Quitting work or taking unpaid leave
- Female departure from the workplace

Other identified home-life disruptions were due isolation, lack of economic security, food insecurity, and stress. Academic professionals and community members that screened or assessed for these disruptions found the following to be major concerns in their pediatric populations:

- Abuse
- Involvement of child protective services
- Exacerbation of paternal mental health
- Unsafe childcare situations
- Neglect
- Maternal depression
- Parentification of older siblings
- Isolation

Some examples of this include:

“They don't have that in-person interaction. So, I mean, that alone affects their mental health.” [EKI]

“...and I think we haven't necessarily identified this directly yet, but I'm sure we've been having some issues along the lines of maybe some neglect and abuse that has occurred. You know, you're unemployed and how do I pay the bills and you want me to teach my kid at home too, and all of that becomes overwhelming for most people.” [EKI]

“Availability of where their child can go so that they could work or have some respite some time apart. I've seen it, it's gotten difficult because it's more time to spend together. Maybe they're trying to help school their older children.” [EKI]

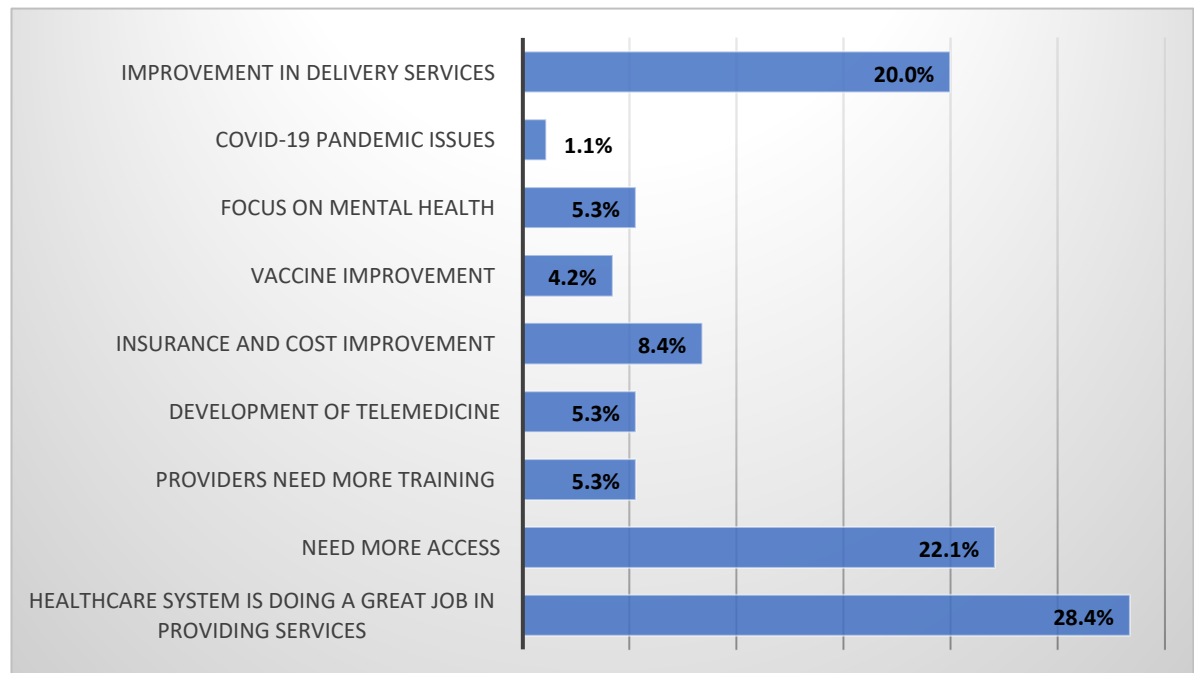
“A lot of parents that we work with do have also ongoing mental health issues. And I feel like it's probably sparked more of that for the parents trying to deal with kids being at home full time and trying to just create some kind of routine for kids and, you know, keeping learning ongoing. I feel like it's probably impacted the parents more than the kids that I've seen.” [EKI]

Suggested Changes to the Nebraska Healthcare System for Improvement

Key informants and parents/caregivers were all asked to provide insights into improving the current healthcare system to better serve children with behavioral mental and behavioral health issues in Nebraska.

Of the 373 parent/caregiver respondents, 25% gave specific improvement strategies to help serve their child/children better (Figure 13). Among these respondents, 28.4% believed the healthcare system was doing a great job and no further improvements were needed. Among the other respondents, eight key themes were developed to provide suggested improvements, with improvement to access to care being the most predominant suggestions, followed by improvement to delivery services, and insurance or cost improvements.

Figure 13: Parent/Caregiver Suggested Improvements to Healthcare System



Similarly, professionals from the educational and healthcare system have identified similar areas of improvement. Areas of concern that key informants have identified as areas that need improvement are depicted in Table 4.

Table 4: Key Informant Identified Areas for Improvement

	Educational Setting	Healthcare Setting
Training	X	X
Communication techniques	X	X
Culturally appropriate training	X	X
Evidence-based treatments	X	X
Knowledge of community resources	X	X
Family-centered care coordination		X
Improved interpretative services		X
Increased care providers	X	X
Improved telehealth infrastructure		X

Examining the suggested improvements from the educational and healthcare professionals, as well as parents/caregivers, the most significant improvement needed is the increase of trained and accessible mental and health providers. Sample statements of this sentiment are as follows:

“We need more mental health providers. I think myself and my partners are all very comfortable with dealing with things like ADHD, depression, and anxiety. A lot of our families need coaching on how to change their kid’s behavior. We just don’t have the resources, or the time (especially if there are)multiple visits that have to occur over time.” [HKI]

“For kiddos, Monroe Meyer has a six-month waitlist, Boy’s Town has four plus months waitlist. Most of the places that are specialized in any services, (have) months long waits.” [HKI]

“I also feel like my school staff, my teachers especially, are frustrated with the number of things that they’re being asked to be the experts on.” [EKI]

“We need more specialists. Waiting months-years for my son to get the help he needs is frustrating and unnecessary. I am sure that if I was not pushing, he would have slipped through the cracks.” [P/C]

“The wait times are out of control and the time the providers can spend with you is not long enough. It often feels like a band-aid. We shouldn't have to fight to get supports for our children. It was also almost impossible to find a male LMHP in the panhandle.” [P/C]

One component of the accessibility of providers is the provision of providers that are trained with evidence-based, effective treatments. Key informants were specifically asked to provide training suggestions to help improve their practice. These included:

- Trauma-informed care
- Mental health first aid
- Motivational interviewing
- Community resources
- Evidence-based treatments via telehealth
- Suicide and self-harm identification
- Conflict resolution
- Culturally appropriate training
- Cultural competency/humility

“Both mental and physical healthcare providers in rural areas need a lot more education and training on pediatric care if they are not going to support actual pediatric specialists in their clinics. Training should include trauma-informed care, co-regulation, implicit bias and other more recent advancements.” [P/C]

“I don't think I am as prepared as I should be. I don't think I have enough tools in my toolbox to really help.” [EKI]

“I kind of had a personal paradigm shift that changed my perspective on that. Recognizing that most evidence-based practices and mental health are really whitewashed has been a game changer.” [HKI]

“Already mental health is something we don't have enough resources of, and it takes so long for kids to get needed help. As a primary pediatrician, especially during the pandemic, it pushed me to where I realized that I needed to be comfortable at least beginning an initial anxiety or depression medication when there was a positive screen.” [P/C]

Despite the acknowledgement that further training is required, there is concerns adding more responsibilities to an already overstretched system.

“I do not (have time to get training or identify resources). Because personally, when you're trying to see 20 plus patients a day, it's hard.” [HKI]

Other suggested improvements include the improvement of care coordination services, improving interpretative services, and improving telehealth infrastructure.

- ❖ Regarding Care Coordination: Providers acknowledge that improved care coordination would improve patient care overall and create a wrap-around service model to help prevent overlooking children in need of services. This would include the inclusion of key care providers, such as social workers and community health workers, as well increased

communication with other organizations (such as between the health care and school systems).

“We need more support; they need more care coordination. But oftentimes, especially in private practice, we put a lot of it on the parent.” [HKI]

“Communication with the school system has been very limited but not from lack of trying.” [HKI]

“I don't think there's a real streamlined process in our clinics. We rely on a lot of patient and parents' self report.” [HKI]

“I think it would be really helpful to include care coordination, and potentially social worker who could kind of help with connecting some of our families to those resources, or transportation or financial issues, how we can receive financial support, or just know of any additional resources that would be helpful that kind of add into treatment. I definitely see the benefit of care coordination with social worker.” [HKI]

- ❖ Regarding interpretive services: One key area of improvement is the ability to provide consistent and reliable interpretation services for families in need of language assistance at all contact points of treatment.

“In those situations (using interpretation lines), we do have to use a phone. And I just think that families actually see that as an undignified way of accessing health care.” [HKI]

- ❖ Regarding telehealth services: It is important to further develop the telehealth system as a means to address disparities in pediatric mental health care access and help combat stigma against mental health services in vulnerable populations.

“When the entire care system went online, part of the reason they need those services (or many times the reason they need those services) is because they're not wealthy or affluent, things aren't easily accessible. So (we) just created another layer of barrier to getting them the care they needed.” [HCI]

“I think the biggest thing that I saw in our clinic and our patient population is most of the mental health care visits went virtual. And a lot of our families didn't have great internet or an ability to access that. And it was very difficult for them to access care.” [HCI]

STRENGTHS AND LIMITATIONS

Several strengths and limitations of this study are worth noting, as detailed below. The significance of findings from this study and their implications for developing future strategies and programs to expand and improve access to pediatric mental and behavioral health services should be understood in the context of these strengths and limitations.

Strengths

To our knowledge, this is the first statewide assessment of perspectives on pediatric mental and behavioral health in Nebraska based on systematic data collection from three groups of key stakeholders including educators, parents, and health care providers. These data have made it possible for NEP-MAP to assess current mental health trends, disparities, unmet health needs, screening and referral processes, gaps in service coordination, as well as how the ongoing COVID-19 pandemic has impacted pediatric mental and behavioral health and access to related services among children from diverse background in Nebraska. The integration of qualitative and quantitative data further enhanced our understanding of the topics of interest and concerns.

Most importantly, the simultaneous presentation and examination of findings from three separate data sources represent a rare opportunity to evaluate whether and the extent to which parents, educators, and health care providers perceive unmet mental health needs among children similarly, the areas or topics they would agree, as well as the areas or topics whereby their perspectives might be different or not resonating with each other. These findings go beyond what has been revealed in previously released NEP-MAP reports.

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. Another strength of the study is that we have interviewed a fairly large number of key informants from various agencies across Nebraska, which provided us with the rich data to comprehensively assess screening and referral practices, how these issues have incurred more unmet needs in both screening and referral services under the current pandemic, and access to mental and behavioral health services for children in Nebraska.

Limitations

There are several limitations regarding the study that we would be remiss to mention. One limitation is the use of convenience sampling, which calls for caution in generalizing our findings to various community settings in the whole state of Nebraska. Another limitation is that the interviews conducted via Zoom or phone may have elicited different responses than those performed in person or may restrict the interpretation of non-verbal responses by the interviewer. The use of purposeful and snowball sampling may also lead us to a wide range of participants representing various agencies across geographic regions in Nebraska

who might hold similar views or experiences, although this strategy also facilitated our recruitment of participants beyond our networks. The survey and interviews were also only provided in English, which may have limited the responses received.

Finally, the data used in this report were collected throughout various stages of the COVID-19 pandemic. Community members from the educational system were interviewed during the school shut-down in Spring 2020, while families and primary care providers were assessed later in the pandemic, as systems and vaccines were beginning to become available. This may provide a skewed point of view, as some members of the assessments may have struggled with recall bias, or the needs of children may have changed as the pandemic continues to evolve.

Recommendations

Based on major findings from this study, it is recommended that the following steps should be taken to better identify and address the behavioral, mental, and emotional health needs among children and adolescents in Nebraska:

- 1. Develop family-centered care coordination for children with complex mental or behavioral health needs.** Providers in the educational and healthcare settings know that children and families with mental and behavioral health care needs are going to be involved with systems of care for a long time. Primary care providers and education professionals often provide short-term or bridge services until a child can find a long-term, mental health medical home. Families themselves usually cannot sustain the inter-provider communication that needs to occur for adequate planning and a continuum of care. Individual providers may have limited awareness or connection with other providers involved with a family. Children with unmet health needs would be better serviced if there was more coordinated and ongoing, even facilitated, communication amongst primary care providers, schools, therapists, and psychiatrists.
- 2. Improve care providers' knowledge of community resources for family support.** A major area of concern is that pediatric care providers usually lack the time to learn and stay current about local community resources that can be utilized for family support. For some providers, having the capacity to make community referrals is outside of their traditional role and there is evident discomfort. Other providers think that having a Community Health Worker or Parent Resource Coordinator as a member of the clinic team allows them to make a "warm hand-off" to a clinic worker who will spend needed time with a family.
- 3. Strengthen the pediatric mental health system and infrastructure.** This includes decreasing the pediatric mental and behavioral health provider medical deserts, utilizing established or newly developed telehealth services, such as the Tele-Behavioral Health Consultation for Providers implemented at the UMMC Munroe-Meyer Institute (MMI), and implementing evidence-based strategies to improve telehealth access and utilization. For sustainability purpose, it would help to assess the cost and return on investment of established tele-behavioral health programs (See Appendix B).
- 4. Develop a streamlined and efficient referral system to mitigate the burden of families as they navigate a complex healthcare system for access to mental health services.** Children and adolescents with mental health needs are often screened multiple times in the educational and healthcare systems. This can create unnecessary and redundant barriers for parents who are struggling to find proper care. A streamlined system may reduce barriers and enhance the efficiency of referring.

CONCLUSIONS

The rising prevalence of pediatric mental and behavioral health issues amid COVID-19 has posed a serious challenges to families, schools, and health care systems in the U.S. Similar to national trends, children in Nebraska are experiencing an increase in ADHD, anxiety, and depression. The negative effects of the pandemic on pediatric mental health are further exacerbated by an overwhelmed, understaffed, and underfunded mental healthcare system, especially in medical deserts like those found in rural Nebraska. Increasing service and care provision in these underserved areas becomes more urgent under COVID-19. Part of the solution lies in expanding and refining tele-mental or tele-behavioral health services.

Children identified with a mental or behavioral health issue are often screened multiple times, with different screening tools, and by professionals in various settings (school, primary care, and specialist). Findings from this report highlight the current fragmentation in the provision of mental health services and how the fragmentation might have hampered community efforts in addressing pediatric mental health issues. A more streamlined and coordinated approach, simultaneously involving parents, schools, and health care providers, to the screening, referrals, and treatment of mental and behavioral health issues is needed to better serve children and their families with different mental health needs.

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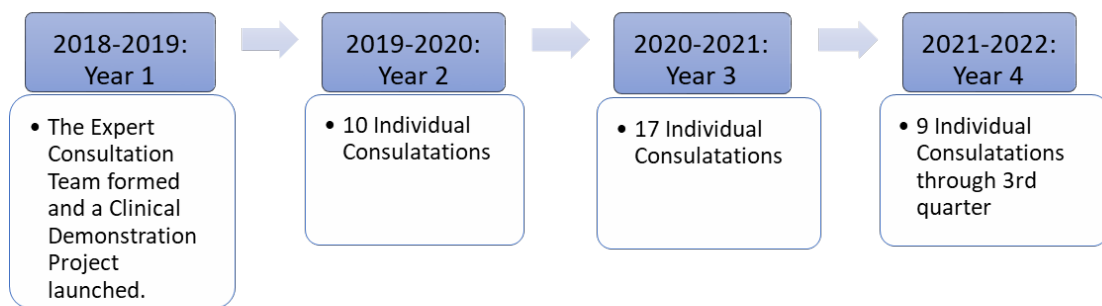
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APPENDIX A – Sample Demographics of Parents or Caregivers

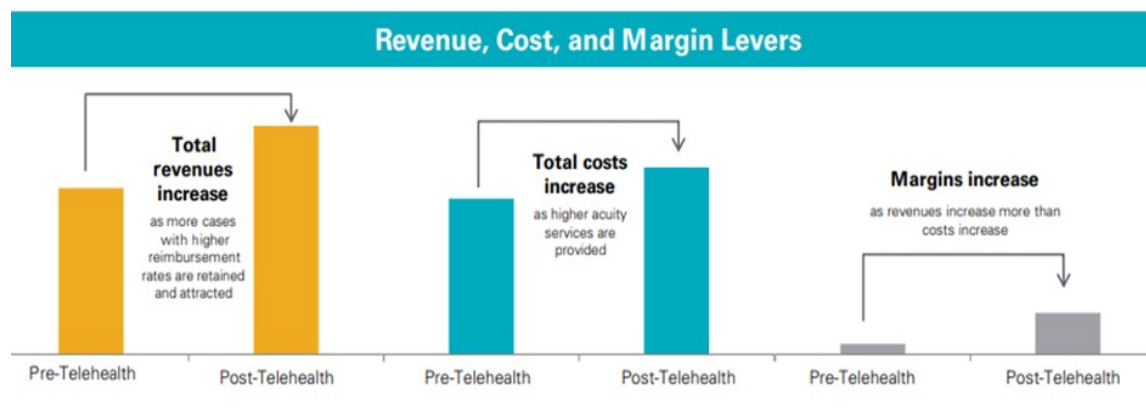
Age (n = 372)	n	%
19-24	18	4.8%
25-34	138	37.1%
35-44	169	45.4%
45-54	45	12.1%
55-64	2	0.6%
Gender (n = 373)		
Female	235	63.0%
Male	136	36.5%
Other	2	0.5%
Ethnicity (n = 356)		
Hispanic or Latino/a	87	24.4%
Not Hispanic or Latino/a	269	75.6%
Race (n = 363)		
White	266	73.3%
Black or African American	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%
Marital Status (n = 366)		
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%

APPENDIX B – Realizing Return on Investment of Tele-behavioral Health Programs

As seen in the assessment of representatives from the school system, healthcare system, and the family, lack of access to care is a one of the largest barriers to seeking and providing treatment for children with mental and behavioral health issues. The Tele-Behavioral Health Consultation Program at UNMC's Monroe-Meyer Institute provides instant access to well-trained and available mental and behavioral health representatives. This will increase access patient access to communities that would otherwise have limited access to services due to medical deserts, lack of trained providers, transportation, cost, time, and other known barriers to receiving care. The following is a framework for assessing the return on investment for incorporating the Tele-Behavioral Health Program into established pediatric primary care clinics in Nebraska. Since its inception in 2019, the Tele-Behavioral Health Program has enrolled 29 pediatric primary care providers in across Nebraska and consulted in 36 individual cases over the course of the program implementation years of program implementation. The course of the Tele-Behavioral Health Consultation Program is depicted in the following figure:



Research has established that telehealth can help organizations save time and money increase patient access and increase patient engagement. In order to determine the effectiveness and long-term maintenance of the Tele-Behavioral Health Consultation Program, a successful return on investment (ROI) needs to be performed. Ideally, an ROI include will conclude an increase in revenue, total costs, and margins.



Source: Marks, J., Augenstein, J, Brown, A., and Lee, Sol. (2019). A Framework for Evaluating the Return on Investment of Telehealth. Manatt Health Strategies, LLC.

In order to accomplish a successful ROI, program management needs to consider several key aspects and determine the overall goals of the program (Gills, 2021; Moore et al., 2013). The following is a basic outline for an ROI:

Define Goals

- The management team needs to identify the goals of the program and the desired outcomes of the program, such as short-term and long-term outcomes

Define Key Indicators

- Based on the identified goals, the management team needs to identify measurable metrics. This may include qualitative and quantitative data from clinicians, program staff, clinic staff, and parents or caregivers.

Measure 'Hard' and 'Soft' Costs

- The management team needs to measure the quantitative and qualitative results of the program

Review Benefits

- They can include a high patient retention rate, high patient volume, cost savings, and increased revenue.

Calculate

- Subtract the expenses from the benefits to see your ROI and know whether you met your goals.
- Use the basic equation:

$$\bullet \text{ ROI} = \frac{[\text{Money Gained} - \text{Money Spent}]}{\text{Money Spent}} \times 100$$

In consideration of defining program and evaluation goals, there are several different aspects of the program to consider. According to one framework on telehealth ROI, it is important to consider eight different aspects of the Tele-Behavioral Health Consultation Program (Marks et al., 2019). The following table identifies the key considerations, definitions of these considerations, and leading questions.

Consideration	Definition	Guiding questions
Patient acuity mix	The measurement of intensity of nursing care needed by a patient	Will the telehealth program impact the average patient acuity level? How will revenue and costs change as the patient acuity levels shift?
Cost savings	The amount of money saved in relation to money spent on the telehealth program	Will the telehealth program result in cost savings (e.g., redistribution of services within a system, delivery of care in a lower-cost setting)?
New-patient volume	The number of new patients seeking care within a selected amount of time	Will the telehealth program result in increased patient volume?
Patient retention	The continuous engagement of patients in care	Will the program result in higher patient retention rates?
Reimbursement	The payment received for a medical service provided	Are these telehealth services reimbursable under: – State Medicaid program and Medicaid managed care organizations? – Fee-for-service Medicare and Medicare Advantage? – Private payers? Will the telehealth program bring in other forms of direct revenue for the institution (e.g., payment from a distant site for a teleconsult)?
Technology	Electronic information and telecommunications technologies to support long-distance clinical health care	What are the hardware and software costs to implement the program?
Program and program management	The process of managing the program, ensuring fidelity, and obtaining the overall goals of the program as it was designed	What are the programmatic costs to design, implement and operate the service?
Staffing	Any staff dedicated to providing and scheduling services, and involved in data collection and reporting	What are the staffing requirements to provide the program? Will there be associated training costs? Can we reduce costs by leveraging mid-level providers to provide the service? Does this program automate existing tasks, thereby reducing professional costs?

For the purpose of an ROI for the Tele-Behavioral Health Program, it would be important to focus on three goals: increasing patient access, increasing patient engagement, and providing overall cost savings. The following key indicators are listed as suggested data collection for the purpose of this ROI:

<p>Saving Time and Money</p>	<ul style="list-style-type: none"> Project Cost Visit volume Reimbursement Rates Referrals to outside providers Hospitalization rates
<p>Increasing Patient Access</p>	<ul style="list-style-type: none"> New patient enrollment Patient retention Patient wait-times Unnecessary referrals
<p>Increased Patient Engagement</p>	<ul style="list-style-type: none"> Physician satisfaction prior to consultation and post-consultation Patient satisfaction prior to consultation and post-consultation Consultation time Accuracy of diagnosis Treatment plan adherence

After the collection of the data, and review of the benefits of the program, the return on investment can be calculated by subtracting the expenses of the program from the total cost of the program. The following table template can be used to guide the calculation of the ROI:

	Prior to Consultation Services	After Consultation Services
Revenue Inputs		
Average number of patients		
Total revenue		
Cost inputs		
Total Care costs		
Technology costs		
Program costs		
Staffing costs		
Budget summary		
Total Direct Margin		
Total technology, program and staffing costs		
Difference between current and future state		\$

Providers can leverage the Tele-Behavioral Consultation Program to optimize pediatric mental and behavioral health delivery of care, reach patients in remote locations, and improve care quality and overall patient satisfaction. This ROI can show that the most significant financial benefits from telehealth programs are likely to be the result of changes to patient acuity levels and increases in new or retained patient volume, as well as increased physician and patient satisfaction, despite limitations in insurance reimbursement.