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Provider Perspectives of Mental Health Needs and Services Among Children in Nebraska

Prepared by:

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TABLE OF CONTENTS

Authors/Research Team	1
Executive Summary	2
Acknowledgements	5
Introduction	6
Background	6
Approach and Methods	10
Ethical Considerations	11
Analysis and Results	12
Key Informant Characteristics	12
Key Informant Perceptions of Populations Served	13
Key Informant Perceptions of Pediatric Mental and Behavioral Health Issues	18
Services and Referrals	19
COVID-19 Pandemic	21
Telehealth Services	22
Future Directions	23
Strengths and Limitations	26
Recommendations	27
Conclusions	29
References	30
Appendix	31

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EXECUTIVE SUMMARY

In the United States, up to 20% of children will experience some emotional or behavioral issues at any given time. These issues have become even more pressing during the current COVID-19 pandemic, when many children have resorted to remote learning and become isolated from each other. As part of the Nebraska Partnership for Mental Healthcare Access in Pediatrics (NEP-MAP) Project, the present study aimed to assess provider perspectives on unmet needs in the screening, treatment, and referral associated with mental and behavioral health disorders among children of 18 years or younger, and to evaluate the impact of COVID-19 on the clinical practices of participating pediatricians. In addition, the study team sought to identify effective coping strategies, including any use of telehealth services.

To meet this study's aims, we adopted a qualitative phenomenological approach in our data collection by conducting semi-structured interviews with 18 key informants from different clinical settings in Nebraska. Study participants included pediatricians, nurse practitioners, physician assistants, licensed counselors, psychologists, and clinical social workers from various clinical and hospital settings. Interview questions were developed to elicit participants' perspectives, context, and experiences of serving children of racial and ethnic minorities, screening and referral processes, COVID impact and responses, and recommendations related to the future of serving children with mental and behavioral health issues. Of the 18 key informants, one-third were from rural regions throughout Nebraska.

Highlights of Findings

- All of the participating key informant providers identified anxiety, depression, and ADHD as the primary mental and behavioral concerns expressed in their populations.

- All Key Informant providers identified working with racial and ethnic pediatric populations at various levels of their patient caseloads (from 5% to 100%).

- Providers reported the major barriers to receiving effective care experienced by minority populations include transportation, language interpretation, and financial constraints. Providers identified several internal barriers to serving minority populations, including lack of training in specific cultural areas, and lack of evidence-based practices.

- Providers described acting as the “bridge” oftentimes, specifically to find children long-term care. This included providing pharmacotherapy and in-clinic therapy services until a child can be seen by a more specialized provider. Providers named limitations they face including lack of age-appropriate mental health providers, long wait times, and lack of insurance reimbursement.

- During the COVID-19 pandemic, providers reported cases of pediatric anxiety, depression, and family stress have been increasing both in quantity and severity. In an effort to mediate barriers, many providers were offering telehealth services. A related survey by the study team also showed families have increased their use of telehealth during the pandemic. While these findings suggest increased accessibility in some populations, other populations may be missing or delaying key treatments due to lack of internet and phone accessibility.

Recommendations

While the sample size was small, the study team found significant insights as a result of the depth of the interviews. Key Informants were forthcoming not only in articulating barriers and challenges, but also in their perceptions of ways to improve access to mental health care for families. Through our study, we found providers able to assess areas where they and their practices could improve, as well as observations on the impacts of inadequate or inflexible systems and infrastructure. In sum, the findings of this study provide the basis for five recommendations for further action.

1. Prioritize professional development for pediatric providers on culturally- and linguistically-appropriate services to all families, including best practices in working with qualified interpreters in patient interactions; and evidence- and trauma-informed approaches to treatment for children with mental and behavioral health problems, including non-English-speaking children and families and children with disabilities. Providers are aware the lived experiences of some of their patients, leading to mental and behavioral health issues, including trauma, adversity, and displacement, need to be considered in addressing mental distress or behavioral maladaptation. Some providers expressed concern regarding the appropriateness of current evidence-based practices and the lack of research into their effectiveness in minority populations. Further research and funding into this area is crucial for the development of appropriate therapeutic treatments for patients from diverse backgrounds.

2. Link primary care providers to child-serving community referral systems in Nebraska, in order to create a validated, standardized, seamless approach to screening and referral throughout the state. Providers express concern about finding timely and effective referrals once concerns are identified. Children and adolescents often experience different levels of screening and interventions in different settings within the community, which may or may not be communicated with the child's primary care provider. Overall physical health and development, trauma history, parent/caregiver mental health, and social needs of the family may or may not be considered when evaluating behavior. An evidence-based, standardized approach to screen, refer, and develop interventions would create a more rigorous intervention plan.

3. Mobilize community resources and primary care linkages to provide coordinated care and to improve referrals. Key informants expressed a strong interest in improved coordination of services and improved communication between providers, in order to meet children's needs and support families. In addition to identifying the role of care coordinator as a member of the clinical team, several providers mentioned it would be helpful to have parents more permissive of releasing information about their children. Also identified was the need for schools to have more formalized relationships with primary care providers, in order to improve referrals and support children and families.

Recommendations (Cont.)

4. Improve the quality, availability, financial sustainability, and utilization of medical interpreters in order to support the ultimate aims of health care access: effectiveness, cost containment, satisfaction, and equitable outcomes.

5. Continue to monitor children and adolescents for developing mental and behavioral health issues as the COVID-19 Pandemic continues. There is a continual need to monitor and screen kids for mental and behavioral health issues as children are isolated from the school system during the pandemic lockdowns and to continue to monitor children for emerging issues as the pandemic continues. Both access and outcomes must be measured through an equity lens.

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INTRODUCTION

Optimal health and wellness begin during childhood and include the components of mental, behavioral, psychosocial, and physical health. The importance of mental health for children and adolescents cannot be overstated, as childhood is a critical time for their development. Mental health disorders affect as many as one in five children across America and can be chronic or transitory (Centers for Disease Control and Prevention [CDC], 2021). The most frequently diagnosed mental health disorders in children include anxiety, depression, attention deficit hyperactivity disorder (ADHD), behavioral disorders, and autism spectrum disorder (CDC, 2021). Due to the magnitude of the COVID-19 pandemic impacting nearly all aspects of life since March of 2020, children's mental health may be more at risk than before the onset of the pandemic. With this increased risk of poor mental health outcomes, it is now more important than ever for care providers to be equipped to identify and address mental and behavioral health conditions in children and youth as quickly and effectively as possible.

BACKGROUND

Parental awareness of mental health is a salient component in maintaining the overall wellbeing children and adolescents, reinforcing positive mental health throughout the lifespan. Primary care providers may assist families through developmental and mental health screening, anticipatory guidance for families, and providing resources to families on child development. Glascoe (2003) reported that children who had difficulties with social skills or behavioral issues, as documented by parents, were more likely to experience mental health disorders. This research suggests that parents should continue to report concerns about behavior or social skills to their child's primary care physician (Glascoe, 2003), as this may be a reliable way to identify mental health issues early in childhood through screening and diagnosis. Older children experiencing mental health issues may benefit from their providers ensuring a proper transition between pediatric care and their adolescent physician (Leeb et al., 2020).

Many healthcare providers have adapted to the evolving communication demands due to COVID-19. There is evidence that uptake of telehealth by primary care providers lags behind uptake by behavioral health providers. Telehealth services help maintain social distancing and quarantine from COVID-19. Children are typically dexterous with technology, able to navigate Zoom, FaceTime, and other means of virtual interaction with their healthcare providers. Connecting online can be a great convenience to tech-savvy parents. However, fast and affordable internet connectivity is not currently available in all areas of the state. "Zoom fatigue" has set in for many users. Not enough is understood about the implications of telehealth utilization for health disparities and unequal access to care. Children of color, rural children, and children living in poverty may be disproportionately left out of technology-driven improvements in access to care (Sen & Tucker, 2020; Fortuna et al., 2020). As a result, we see an ongoing need to consider equity impacts in internet and telehealth policy decisions, as well as the need to implement culturally relevant training in the healthcare system (Betancourt et al., 2003).

Telehealth Services

The benefits of telehealth services are vast. Residents of rural communities, particularly in Nebraska, may find telehealth services preferable to commuting miles to visit a provider in person. Using telehealth may be perceived as more affordable than seeing a provider in urgent care or an emergency room. In Nebraska, policy development for reimbursement of the provider for a telehealth visit at an equivalent rate as an office visit has increased acceptance. The pandemic has further increased the availability of providers by telehealth for consumer convenience and safety. Despite recent advancements in telemedicine services, there are barriers that persist. 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. According to Smith-East and Starks (2021), "until more disadvantaged youth, especially low-income minority youth, have internet access and either computers or smartphones, they will continue to be left out of the fast-paced technological changes occurring in U.S. healthcare settings, and this will undoubtedly result in deteriorating mental health outcomes."

Despite hesitations with transitioning to telehealth medicine, many healthcare providers have reported benefits to the sudden upheaval of traditional, in-person medicine. A mix-methods study found that 82% of childcare providers surveyed felt positively about transitioning to telehealth services for parent-child interaction therapy, noting their mutual willingness to continue telemedicine in the future (Barnett et al., 2021). Pollard and colleagues (2021) found that children with autism experienced similar outcomes during the early transition from in-person to telehealth services. Additionally, Ferguson et al. (2020) found that children with autism who transitioned to telehealth from in-person appointments were successful in managing their goals. Longitudinal research is needed to assess the ongoing response of telehealth services; however, this early research suggests some children may experience continuity of care via telemedicine.

Unmet Needs in Nebraska

In addition to lacking consistent and reliable internet and computer access, other unmet needs for children persist across America. One of the most glaring unmet needs since the onset of the COVID-19 pandemic has been lack of affordable healthcare. With millions of parents losing their jobs throughout various periods of the pandemic, the rate of uninsured has skyrocketed (Strane, Rosenquist, & Rubin, 2021). This leaves parents with the challenging decision to forgo important healthcare appointments due to lack of insurance and affordable healthcare. On the other hand, with the Nebraska Medicaid Expansion in October 2020, more than 56,000 newly enrolled members are now covered with Medicaid services. This may help bridge the insurance instability gap created by the pandemic.

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.

Navigating the complex healthcare system, including screening and referral services for children with mental health concerns, can also be a burden for parents. Long wait times to receive health care is frequently cited, especially since the onset of the COVID-19 pandemic (Bebinger, 2021). The behavioral health care system has not been traditionally integrated with primary or physical health care, in the same way dental health care has not been traditionally available at the doctor's office. Families may lack experience in navigating, much less be equipped to be informed consumers, when they first 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. Johansson and colleagues (2019) proposed expanding dual-diagnosis facilities, increased medical training, and collaboration amongst public health organizations in Nebraska in order to address these unmet mental health needs.

Role of NEP-MAP

NEP-MAP is the Nebraska Partnership for Mental Health Care Access in Pediatrics, Nebraska's Pediatric Mental Health Care Access Program, funded by the US Department of Health and Human Services, Health Resources and Services Administration, through a cooperative agreement with the Nebraska Department of Health and Human Services. The primary intervention model of the Pediatric Mental Health Care Access Program is to offer provider-to-provider consultation services, with pediatric behavioral health experts offering consultation to primary care providers. As a result, the goal is to improve the capacity of primary care providers in rural and underserved communities to screen, refer, and treat children and youth with mild-to-moderate mental and behavioral health conditions. In addition, NEP-MAP has launched several additional strategies to improve equity and access to care for all families statewide.

NEP-MAP commissioned the present study in order to gain insight into the experiences, attitudes, and needs of primary care providers in Nebraska. In developing the survey methodology, the study team was informed by the contributions and suggestions of NEP-MAP Technical Workgroup #2, for Culturally- and Linguistically-Appropriate Services (CLAS) and equity practices in primary care and mental health care. The Technical Workgroup (TWG#2) charged the study team with helping identify areas for data-driven intervention and investment by NEP-MAP.

Presently, limited research is available regarding how the COVID-19 pandemic has affected the mental wellbeing of children in the United States, particularly from the perspectives of child healthcare providers. This study seeks to understand the ways in which healthcare providers across the State of Nebraska have observed changes in children's mental health, notably in rural and underserved areas, since the initial COVID-19 pandemic impacted American life. By mutual agreement with NEP-MAP, Study Aims were articulated as follows:

- Assess provider perceptions of unmet needs in the screening, treatment and referral associated with mental and behavioral health disorders among children of 18 years or younger;

- Evaluate the impact of COVID-19 on clinical practices of participating primary care providers and identify effective coping strategies, such as any use of telehealth services;

- Collect feedback on barriers and practical ways via which tele-behavioral health consultation can be integrated into current pediatric primary care in rural and underserved areas of Nebraska.

APPROACH AND METHODS

Study Design

The qualitative approach in our data collection was conducted through semi-structured interviews (Zoom or telephone) with key informants including pediatricians, nurse practitioners, physician assistants, clinical social workers, psychologists, and licensed professional counselors across the state of Nebraska. This multi-perspective approach made it possible for us to assess similarities and differences in 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.

Development of questions for the semi-structured interviews with primary care providers was influenced by participation 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.

The key informants entered the interview process by responding to an email inviting participation. The qualitative phenomenological approach was chosen in order to comprehensively understand participant feelings, opinions, and experiences and to interpret the meaning of their actions, which quantitative studies usually cannot capture. Our methodology focuses on an iterative process that seeks to understand and contextualize a participant's point of view by listening and purposeful questioning. The interpretation of results in the form of key findings and recommendations is intended, with limitations, to illuminate understanding of the experiences of primary care providers in addressing pediatric mental health issues during the COVID pandemic.

Study Participants

We used purposive and snowball sampling to recruit diverse participants involved in the primary care of children and youths in Nebraska in various clinical settings. With the support from Nebraska DHHS, various healthcare systems, and professional organizations across the state, we recruited 18 key informants representing care providers of children and youth in different regions across Nebraska. We sought to make sure the sample would represent various clinical settings across geographic regions in Nebraska and reflect experiences with children and youth at different ages. To be eligible, the participant was required to be 19 years of age or older and be able to effectively communicate in English.

Data Collection

Before the data collection, training was provided to two interviewers, encompassing commonly used interview skills, technical issues related to Zoom or phone interviews, how

to record the conversations, and ethics in conducting qualitative research. An interview guide was developed to facilitate the training. Informed consent was emailed to potential participants before each interview to explain the study purpose, what participation in the study incurs, and foreseeable risk and benefit. Informed consent was collected from those who were willing to participate. Interviews were conducted via Zoom or over the phone according to the convenience of participants on a pre-arranged day and time, with each interview on average lasting approximately 30 to 45 minutes.

During the interview, the interviewers asked participants a series of questions using the semi-structured interview guide with open-ended questions and additional probes when needed (Appendix A). The questions were developed to elicit participants' perspectives, context, and the provision of mental and behavioral health services for children in Nebraska. We also sought to understand the perspectives of care providers across the state as they respond to the COVID-19 pandemic and try to figure out how to grow their capacity to meet the increasing demand for pediatric mental and behavioral health services.

Each interview was audio- or zoom-recorded and later transcribed for qualitative data analysis. The data were collected between July 2021 and September 2021. A gift card of $60 was mailed to participants who completed the interview as compensation for their time.

Data Analysis

A thematic analysis was conducted to illustrate the principles of framework analysis and broadly follow the five steps of familiarization: identifying a thematic framework, indexing, charting, mapping, and interpretation (Gale et al., 2013). The analysis consisted of multiple steps, including reading the transcript of participants several times to acquire a feeling for the participants and their responses, identifying significant phrases and restating them in general terms, formulating meanings and validating meanings through research team discussions to reach consensus, identifying and organizing themes into clusters and categories, and developing a full description of themes. The rigor of the study was established by using robust qualitative research strategies to ensure credibility and trustworthiness. Each transcript was independently coded using thematic content analysis.

ETHICAL CONSIDERATIONS

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

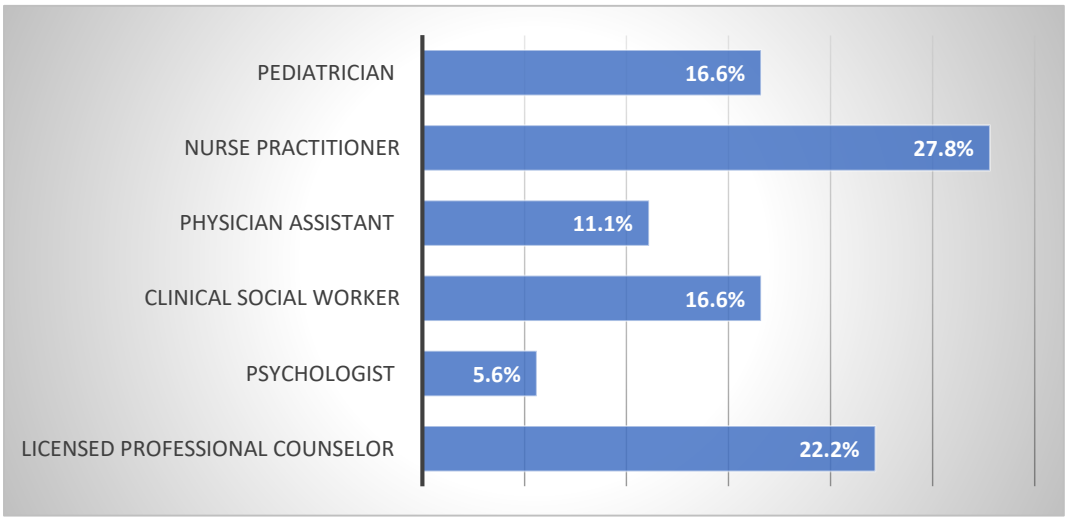
Only de-identified data were used in the final project report and related dissemination of project findings.

ANALYSIS AND RESULTS

I. Key Informant Characteristics

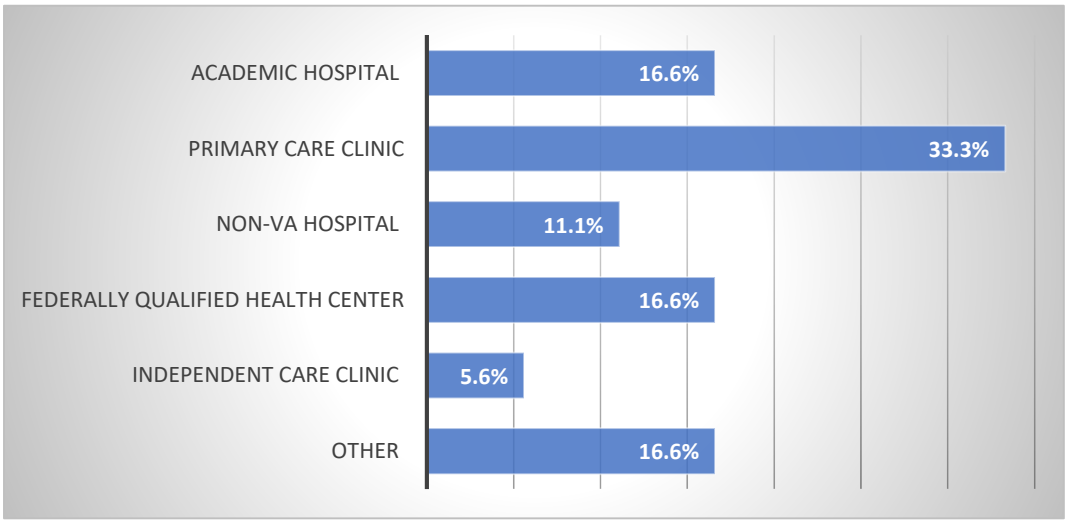
Eighteen key informants participated in semi-structured interviews between July and September 2021. Of these key informants, the majority were nurse practitioners (APRN) (27.8%), followed by licensed professional counselors (22.2%) (Figure 1). Three of the four licensed counselors were licensed independent mental health practitioners (LIMHP), while the remaining counselor was a licensed mental health practitioner (LMHP).

Figure 1: Job titles of Participating Key Informants



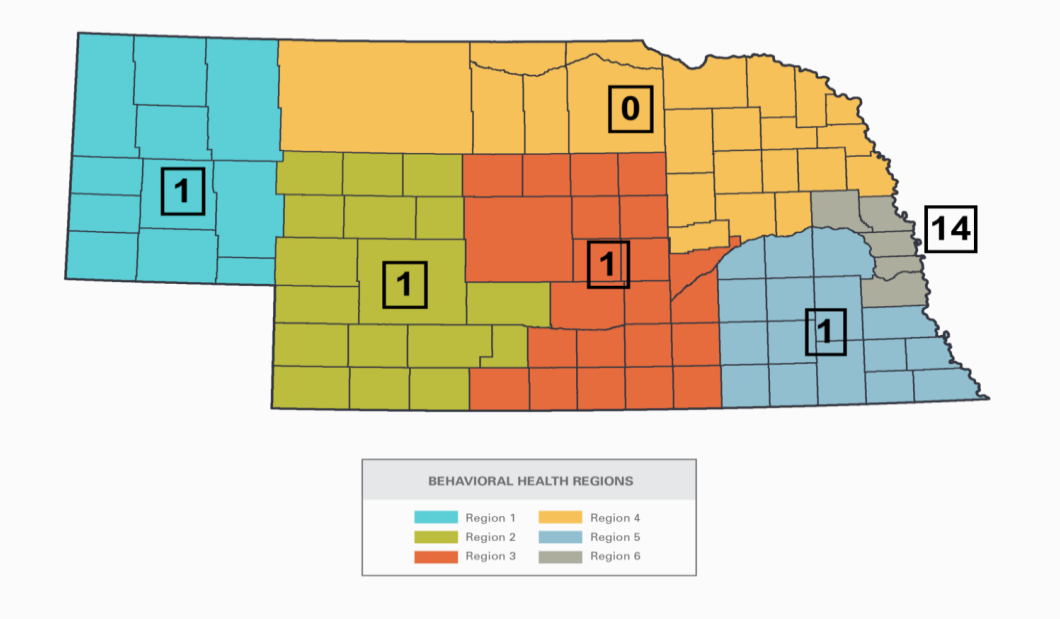
The majority of respondents worked at primary care clinics (33.3%) (Figure 2). Approximately 28% of providers worked in a hospital setting (either academic or non-VA associated). Almost all of the providers were associated with a healthcare organization (83.3%) and worked in a clinic or other ambulatory care setting within the last 30 days (94.4%).

Figure 2: Employment Setting of Key Informants



Fourteen (78%) key informants were located within Behavioral Health Region 6, with one Key Informant (5.5%) from each of Behavioral Health Regions 1, 2, 3, and 5 (Figure 3). There were no respondents from Behavioral Health Region 4.

Figure 3: Distribution of Key Informants by Behavioral Health Region



Predominantly, the key informants identified as Caucasian/White (77.7%), Asian (5.6%), or Hispanic (16.7%).

Key informant providers served a variable proportion of pediatric patients in their caseloads, depending on the nature of their practice and the type of facility in which they predominantly worked. For example, pediatricians saw 100% pediatric patients, with upwards of 2,000 visits per month in a busy specialty facility. On the other hand, those located in generalist clinical settings such as physician assistants, nurse practitioners, licensed counselors, psychologists, and clinical social workers, may only have between 10% to 50% of their case load dedicated to pediatric populations.

II. Key Informant Perceptions of Populations Served

Key informant providers identified several characteristics of the pediatric populations they serve, including the ages and the proportions identified as a racial or ethnic minority.

Overall, 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.

The proportion of children from non-white racial and ethnic minority groups was also dependent on the Key Informant and their respective location, ranging from 5% of the total pediatric population to 100% of the pediatric population served. The proportion of minority population was often reflective of the general population in which the clinic or facility was located. Thirteen providers currently provide services to refugee children from various countries, with the majority of them coming from Somalia, Burma, and Afghanistan.

All key informants reported some experience providing services to children from non-white racial and ethnic minorities. Overall, barriers identified by key informants that prevent families from receiving the care they need fall into three thematic areas: those external to the clinical setting, those within the clinic, and those specific to the individual provider.

A. Barriers external to the clinical setting.

These identified barriers are often experienced by children and families seeking professional help for mental and behavioral health issues, prior to entering the clinical setting. Examples of these barriers include, but are not limited to:

- Transportation
- Insurance instability
- Lack of qualified providers
- Stigma towards mental health
- Lack of insurance coverage

In particular, one key informant stated:

"The biggest issue that I see with families is that, okay, they (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)."

"We have tried to set the appointments at the school because those students and parents cannot get to the larger cities. There are no local providers whatsoever."

B. Barriers within the clinical setting.

Once within the clinic environment, key informants identified different and new barriers that children and families may experience within the clinical setting. These include:

- Language barriers with lack of interpretation services
- Provider offers limited hours of availability
- Providers perceive patients need more time than allowed in schedule.
- Provider does not have resources at the patient's health literacy level.

Specific examples of these “internal” issues include:

“It (cultural differences) makes it more challenging and more difficult (because) appointments take longer. People tend to be late. Or there's a miscommunication, and they show up at the wrong time. So, it definitely makes clinic less efficient.”

“We don't always have the time in each appointment to address some of the social determinants of health for that patient. There are some of the barriers that they have so we don't know what we don't know kind of thing.”

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.”

“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.”

Key informants discussed the issues associated with in-person interpretation versus using video or phone interpretation. The majority of key informants preferred in-person interpretation. However, still some issues or hurdles occur. For example, the client may be uncomfortable with an interpreter in the room and limit the openness of the session. An interpreter from the local community may inhibit disclosure by a patient. An interpreter may not be trained to be fully accurate. A provider is not always in the position to control the quality or training of the interpreter. Key Informants also noted that culturally, it is sometimes difficult to interpret the body language and minor language nuances that are so important when discussing sensitive topics.

All key informants stated there was a lack of qualified in-person interpreters to assist with any language presented within the clinical setting, 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 but was an issue in every location.

C. Barriers unique to the individual provider.

- Lack of appropriate training in cultural competence or cultural humility.
- Cultural congruence/incongruence with patients.
- Differential willingness of providers to receive referrals.

Remarks from key informants regarding provider characteristics include:

"I am probably not as well versed. I personally have taken and tried to learn more about the culture by just reading but I haven't done anything formal. And (I've) tried to learn more about the history of their country and learn more about some of their cultural practices to help be a more effective provider."

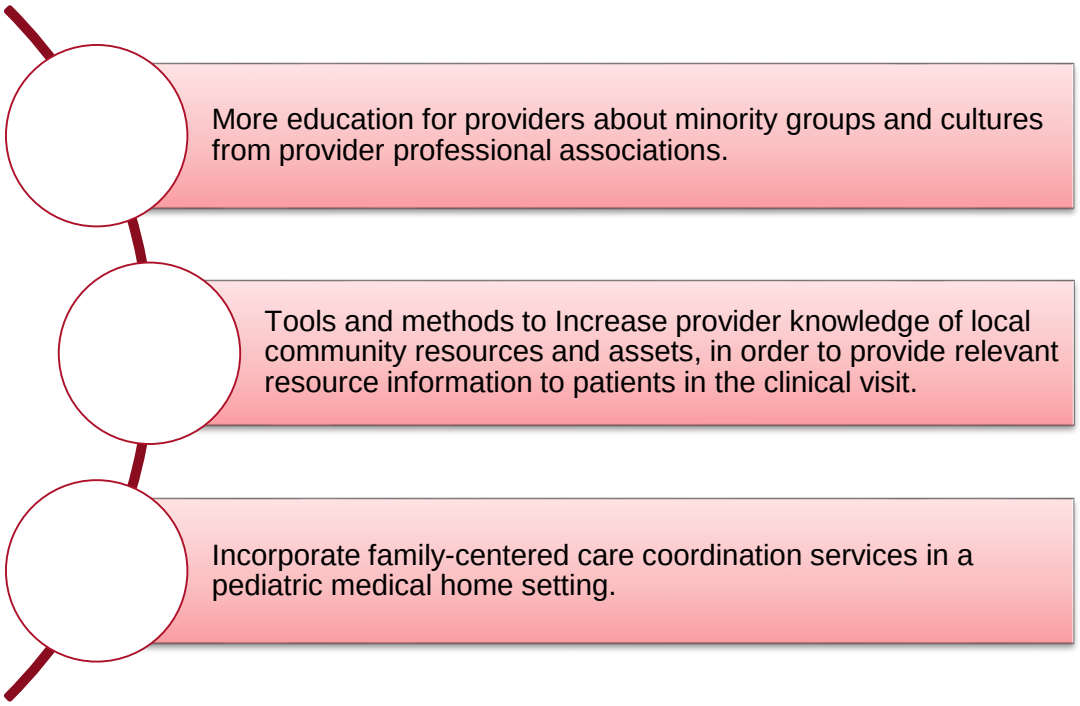
"We struggle to get staff kind of ethnic and diverse backgrounds, which then I think kind of hinders on implementation of some of those strategies (that might help families)."

"I think one of the things that is helpful for for families and minority and 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."

"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."

There is an acknowledgement that to be effective providers, clinics and organizations need to take steps to become more accessible to diverse families. During interviews, key informants were asked not only about perceptions of barriers to care, but also about their recommendations for quality improvement approaches. Some approaches identified by Key Informants are shown in Figure 4.

Figure 4: Improving Provider Capacity to Serve Diverse Families: Key Informant Recommendations.



Support for these identified areas of improvement include:

"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."

"Outside of (financial services), I've been a little disappointed, especially because, the social determinants of health is a big thing that's being pushed…(yet) we really aren't screening. And then like, once you start screening, you've got to have resources for people."

"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."

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

III. Key Informant Perceptions of Pediatric Mental and Behavioral Health Issues

Providers identified several mental and behavioral issues as present in the pediatric populations they serve. The most common pediatric mental and behavioral issues included anxiety, depression, and ADHD. Every Key Informant identified at least one of these issues as the prevalent cause for seeking professional help.

Other conditions that emerged were specific to the population served in their clinics or facilities. These included:

- Oppositional Defiant Disorder
- Stress-related disorders
- Behavioral disruptions
- Post-traumatic stress disorder
- Substance use
- Autism
- Learning disorders
- Eating disorders

Providers that worked with in-patient and out-patient pediatric populations stated:

"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."

"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."

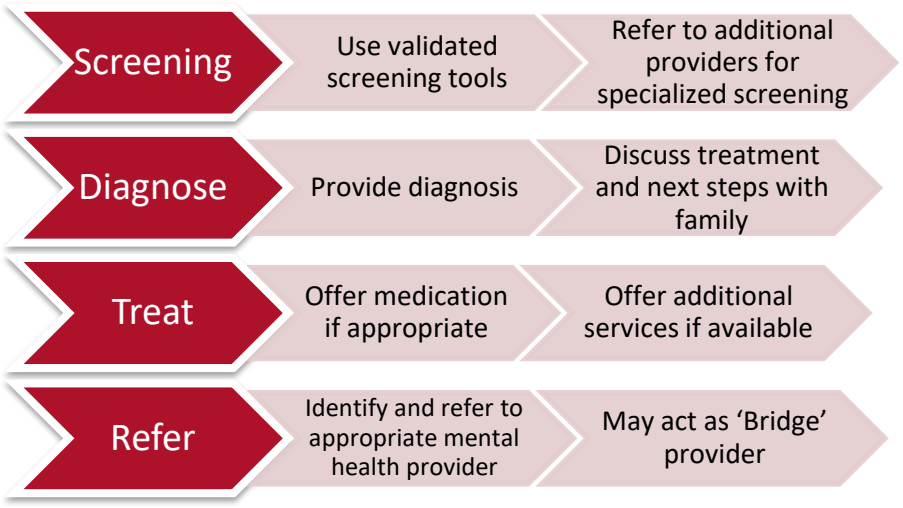
IV. Services and Referrals

The key informants provided mental and behavioral health services at different points of patient contact, and therefore have variable roles in providing screening, treatment, and referrals for mental and behavioral health issues among children. For the purpose of this assessment, Key Informants were broken into two categories: those that provide care at the time of initial evaluation and diagnosis, and those who work with the pediatric patient and family to manage treatment and identify other areas of care.

A. Initial Screening and Diagnosis

For pediatricians, nurse practitioners, and physician assistants serving as primary care providers, and primary points of contact for the medical system, parents often make appointments to address mental health issues due to a recommendation from the school or personal observations. The following (Figure 5) is an amalgamation of the process of evaluating, diagnosing, and treating patients with behavioral and mental health issues as described by the the 9 (50%) Key Informants that fell into this category:

Figure 5: Process Diagram, Pediatric Mental Health Care



B. Secondary Contacts of Pediatric Patients after Diagnosis of Mental or Behavioral Health issue

Other key informant providers treat children and adolescents following the initial screening by the primary care provider. For example, several licensed counselors, psychologists, and clinical social worker are secondary or tertiary points of contact for children with potential issues. These providers may be located within the primary care clinic, associated clinic, or completely outside of the current health clinic. These providers working with a child with an established mental health diagnosis identified the following roles in the management and treatment of children with mental or behavioral health issues:

- Temporary or bridge provider
- Care coordinator
- In-patient care provider
- Short-term counselor
- Long-term service provider

Key informants observed several barriers and struggles faced by families in the ongoing management of a child with a mental health concern. These include:

- Long wait time for an appointment,
- Forced transition plans when a child must transition to adult care,
- Lack of provider training in mental and behavioral health of children
- Insurance limitations on care
- Lack of culturally and linguistically appropriate services from providers
- Need for more sliding-scale providers or options for uninsured families
- Lack of knowledge about and availability of community resources.
- Factors influencing family comfort and confidence with the system of care, possibly not understanding the significance of failing to get treatment.

An example of these barriers is as follows:

"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."

V. COVID-19 Pandemic

Key informants expressed concerns about increases in mental and behavioral health issues among children and youth during the onset of the COVID-19 Pandemic, and the potential long-term effects as the pandemic continues. 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. 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."

"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."

Other mental health issues identified by the key informants during the pandemic included:

- Anxiety resuming in-person school
- Fear of going back to virtual school
- Self-harm tendencies
- Suicidal ideation
- Family stress
- Lack of available mental health resources

Some comments regarding these additional issues are as follows:

"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."

"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."

"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."

VI. Telehealth Services

Key Informants expressed variable views about increasing utilization of telehealth services. No Key Informants discussed the use of telehealth for their own education, or for the purposes of their own consultation with another provider with specialized expertise to enhance care.

In the matter of telehealth utilization by families to access mental health care, Key Informants expressed views ranging from highly positive to far more reserved.

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.

On the other hand, some providers felt that telehealth services were creating or exacerbating existing gaps in mental health access. For example, one provider 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."

Telehealth presents challenges to effective engagement. Some providers utilizing play therapy found it difficult to gain attention or understanding with children on-line. Some settings do not provide privacy, or freedom from distraction. For example, some providers commented:

"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."

"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."

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. These include:

- Insurance reimbursement
- Research into the effectiveness of treatment via telehealth
- Internet access for patients
- Provider training in CLAS, use of technology, and mental health, and
- Consistency of availability among various provider types.

VII. Future Directions

In addition to key informant suggestions on how to increase the capacity of the provider workforce to serve diverse patients and families (Figure 4), deep analysis of key informant interviews led to three themes of practice improvement and two themes pointing to overall infrastructure and systems improvement, to benefit families' access to care in effective and equitable ways reaching all families.

A. PRACTICE IMPROVEMENT STRATEGIES

1. Improve family-centered care coordination for families with complex needs.

Providers 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, such as pediatricians, physician assistants, nurse practitioners, and in-clinic counselors often provide short-term or bridge services until a child can find a long-term, mental health medical home. Families alone 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 would be better serviced if there was more open and ongoing, even facilitated, communication between primary care providers, schools, therapists, and psychiatric services.

"Communication with the school system has been very limited but not from lack of trying."

"Once they leave our program, we can't connect with them anymore. I mean, we can do like a basic phone call. But once they're discharged, then you have to start the whole process over again."

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

2. Improve provider knowledge of community resources for family support.

A major area of concern is that providers lack the time to learn about 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 are discovering a Community Health Worker or Parent Resource Coordinator as a member of the clinic team allows the provider to make a "warm hand-off" to a clinic worker who will spend needed time with a family.

"People are designated as health coaches, but they really don't do any of the pediatric stuff. I reached out once, and it wasn't very helpful. I think that's kind of one of the downsides of our hospital is that it's very like adult medicine heavy. So, the pediatric aspects are overlooked."

"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."

3. Improve the availability, quality, and utilization of interpreter services to benefit families and their complex care needs.

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. Key informants identified the need for consistent, in-person, medically trained interpreters offered for all patients or families that need interpretation services. While the participants discussed how this is not always feasible, more research and examination of the effectiveness of phone or internet services should be conducted to determine the effectiveness.

In addition, qualified interpreters do not materialize out of thin air. Looking at interpretation services as a practice-level issue places the provider in the role of employer or facilitator of the service. In order to do this, health insurance payors must recognize and accommodate the business expense this service involves.

"In those situations, yeah, we do have to use a phone. And I just think that families actually see that as an undignified way of accessing health care."

B. SYSTEMS/INFRASTRUCTURE IMPROVEMENT STRATEGIES

1. Strengthen the pediatric mental health care workforce.

Repeatedly, key informants expressed concern with the lack of mental health providers available to the pediatric population, especially among younger children. Where providers are present, there may be long wait times.

"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."

"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."

2. For telehealth to improve equitable access to care, all families must have access to reliable, affordable internet, in all areas of the state, both for health care and education.

Concerns regarding equal access to telehealth services for all families extends past the services of the provider and into the area of affordable internet for all families. One major concern among key informants was the ability of some families to be able to access internet through the home use of a computer or cell phone.

"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."

STRENGTHS AND LIMITATIONS

This study has several limitations and strengths that are noteworthy. The size of the study sample small, and the use of convenience sampling limits generalizing our findings to various community settings in Nebraska. 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. 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.

Despite these limitations, the strengths of the present report include the systematic approach used in sampling, data collection, and analysis to improve the reliability and validity of the analysis, checking of transcripts against audio-recordings and field notes taken, and triangulation among coders by consensus to ensure rigor and consistency. Another strength of the study is that we have interviewed a variety of different providers, including pediatricians, nurse practitioners, physician assistants, clinical social workers, licensed counselors, and psychologists from across the state of Nebraska. This data allowed us to learn about access to mental and behavioral health services for children in Nebraska from the perspectives of care providers across the state as they respond to the COVID-19 pandemic and grow their capacity for meeting the increasing demand for mental and behavioral health services.

RECOMMENDATIONS

While the sample size was small, the study team found significant insights as a result of the depth of the interviews. Key informants were forthcoming not only in articulating barriers and challenges, but also in their perceptions of ways to improve access to mental health care for families. Through our study, we found providers able to assess areas where they and their practices could improve, as well as observations on the impacts of inadequate or inflexible systems and infrastructure. In sum, the findings of this study provide the basis for five recommendations for further action.

1. Prioritize professional development for pediatric providers on culturally- and linguistically-appropriate services to all families, including best practices in working with qualified interpreters in patient interactions; and evidence- and trauma-informed approaches to treatment for children with mental and behavioral health problems, including non-English speaking children and families and children with disabilities. Providers are aware the lived experiences of some of their patients, leading to mental and behavioral health issues, including trauma, adversity, and displacement, need to be considered in addressing mental distress or behavioral maladaptation. Some providers expressed concern regarding the appropriateness of current evidence-based practices and the lack of research into their effectiveness in minority populations. Further research and funding into this area is crucial for the development of appropriate therapeutic treatments for patients from diverse backgrounds.

2. Link primary care providers to child-serving community referral systems in Nebraska, in order to create a validated, standardized, seamless approach to screening and referral throughout the state. Providers express concern about finding timely and effective referrals once concerns are identified. Children and adolescents often experience different levels of screening and interventions in different settings within the community, which may or may not be communicated with the child's primary care provider. Overall physical health and development, Trauma history, parent/caregiver mental health, and social needs of the family may or may not be considered when evaluating behavior. An evidence-based, standardized approach to screen, refer, and develop interventions would create a more rigorous intervention plan.

3. Mobilize community resources and primary care linkages to provide coordinated care and to improve referrals. Key informants expressed a strong interest in improved coordination of services and improved communication between providers, in order to meet children's needs and support families. In addition to identifying the role of care coordinator as a member of the clinical team, several providers mentioned it would be helpful to have parents more permissive of releasing information about their children. Also identified was the need for schools to have more formalized relationships with primary care providers, in order to improve referrals and support children and families.

4. Improve the quality, availability, financial sustainability, and utilization of medical interpreters in order to support the ultimate aims of health care access: effectiveness, cost containment, satisfaction, and equitable outcomes.

5. Continue to monitor children and adolescents for developing mental and behavioral health issues as the COVID-19 pandemic continues. There is a continual need to monitor and screen kids for mental and behavioral health issues as children are isolated from the school system during the pandemic lockdowns and to continue to monitor children for emerging issues as the pandemic continues. Both access and outcomes must be measured through an equity lens.

CONCLUSIONS

The rising awareness and prevalence of mental and behavioral health problems among children and youths dwarfs the capacity of primary care providers in underserved communities to meet these needs. The COVID-19 pandemic has exacerbated needs and access to care issues. It is vital to prepare providers to identify and effectively respond to the mental and behavioral health needs of children, including those from minority groups, and those with trauma-inducing life experiences.

In the eyes of key informant providers, besides the increasing burden of mental and behavioral health issues during the COVID-19 pandemic, families also face a host of barriers to care including unmet social needs, such as transportation, financial barriers, lack of services in their language of choice, lack of care coordination services, and unmet needs for referral to community resources.

Significant barriers faced by providers include lack of training to address the specific mental and behavioral health needs of children; lack of access to reliable and effective interpreter services for patient encounters where needed; and lack of mental health professionals to meet patients' referral needs. While telehealth has become more widely adopted by care providers to engage and serve children during the pandemic, developing more effective and equitable telehealth services requires reliable and affordable internet access in all communities of the state.

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APPENDIX

Questions for Provider Interview

Provider Interviews

The Nebraska Partnership for Mental Health Access in Pediatrics (NE-MAP) worked with UNMC Center for Reducing Health Disparities to collect data to learn about access to mental and behavioral health services for children in Nebraska from the perspectives of care providers across the state as they respond to the COVID-19 pandemic and to grow the capacity of care providers for meeting the increasing needs for mental and behavioral health needs. The provider interview focuses on 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.

I. Demographic Questions

1. Could you describe the healthcare facility where you work and your role in it?

a. What type of health care facility do you work in?

1. Academic Hospital
2. Primary care clinic
3. Non-VA Hospital
4. VA Hospital
5. Federally Qualified Health Center
6. Healthcare system
7. Independent care clinic
8. Other: _____

b. What is your profession?

1. Pediatricians
2. Nurse practitioners
3. Physician assistants
4. Clinical social workers
5. Family practitioners
6. Psychologists
7. Licensed Professional Counselors *(Includes both licensed counselors (LPCs) and licensed professional clinical counselors (LPCCs)*
8. Other: _____

c. **What is the zip code of your primary practice? _____**

d. Are you an independent practitioner or part of a health care organization?

e. In which setting did you work the most hours during the last month?

1. Temporary site or structure set up for COVID
2. Home health care
3. Long-term care facility
4. Remote location (treating patients via telemedicine)
5. Clinic or other ambulatory care
6. Hospital
7. Other: _____

2. What ethnicity and race do you identify as?

1. Hispanic
2. Non-Hispanic
3. Black/African American,
4. White,
5. American Indian/Native American,
6. Asian/Pacific Islander,
7. Multiracial
8. Prefer not to Answer

II. Interview Questions

Now we want to ask you about your clinical practices.

1. Based on your best estimates or knowledge, how many children is your program/facility currently serving each month? _____ proportion of children among your patients?

2. What is the age range of the children you serve? From age____ to age____

3. Based on your best estimates or knowledge, what is the proportion of children served by your program/facility who are racial and ethnic minorities? _____

    a. On a scale of 1 to 10, with 1 denoting "not prepared at all" and 10 denoting "fully prepared", (Likert Scale?) how well prepared do you think your program/facility is for serving racial/ethnic minority children? _____

        - In what ways has your program adapted to serve patients of diverse backgrounds?

    b. Could you explain why you gave the score you just noted down?_____

    c. What barriers have you experienced related to serving diverse families?

4. Does your program/facility offer any interpretation services to immigrant children or families with limited English proficiency?

5. How does serving patients from other cultures influence your practice as a primary care provider?

Questions for Provider Interview

6. Based on your best knowledge or estimates, how common do children served by your program/facility have mental or behavioral health issues such as attention deficit hyperactivity disorder (ADHD), autism, learning disorder, oppositional defiant disorder (ODD), depression, anxiety, conduct disorder, or substance use? (What are the some of most frequent mental/behavioral health issues you see?)

    a. Did you see any increase or decrease in these issues during the COVID-19 pandemic?

7. What is the typical procedure when a child is identified with a potential mental or behavioral health issue in your program/facility?
    a. Screening
    b. Referral

8. Do your patients currently receive care coordination services? If so, how are these services provided?

9. Do you think there would be value in including care coordination services for your patients and families at your clinic? If yes, what advantages or values do you see? If no, why not? What barriers?

10. Does your program/facility have a strategy to offer additional support to families who may struggle to address basic social needs such as housing and food security? Are you aware of any resources in the community that help your patients address some of these unmet social needs?

11. How has the COVID-19 pandemic impacted your ability to meet the needs of children with mental/behavioral issues?

12. How often are you using telehealth such as emails, texting, phone, Zoom/Skype, remote patient monitoring to provide care to your patients now? Did you encounter any issues when providing care through telehealth?

13. Based on your observation and knowledge, what should be done to better support you in your capacity ?

14. Any other comments on issues we discussed today?