

NEBRASKA CONNECTING FAMILIES PROJECT

CAREGIVER FOCUS GROUP REPORT



MUNROE-MEYER
INSTITUTE

Participant Information



26 total participants
in August and
September of 2024



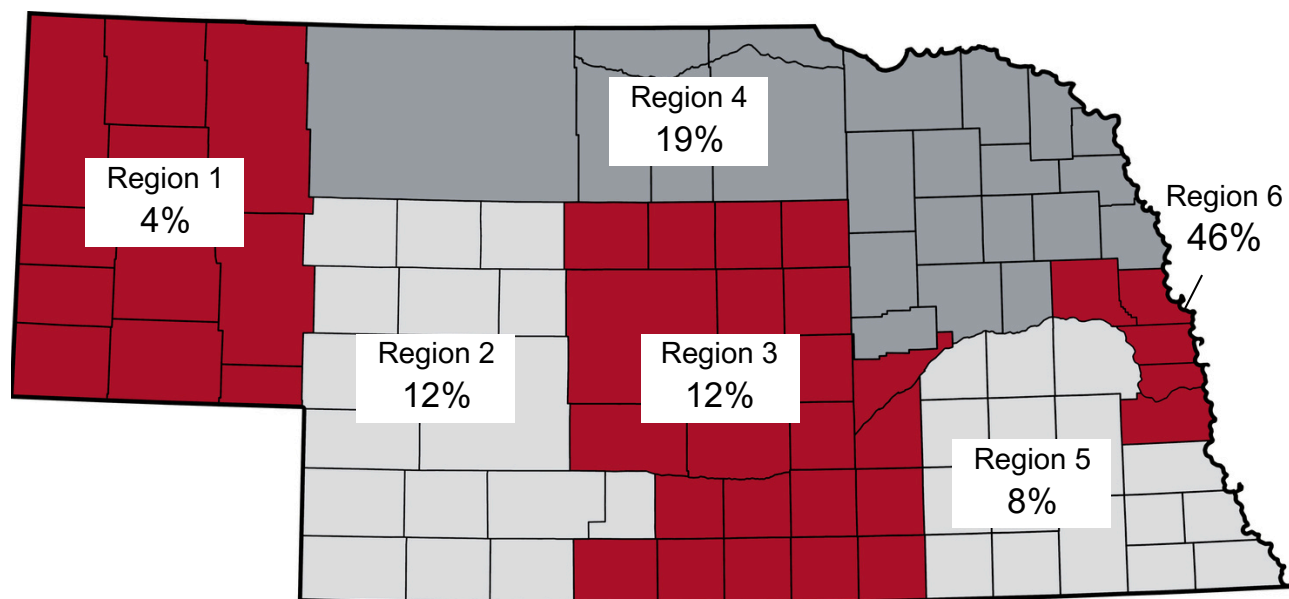
22 caregivers participated in English
4 caregivers participated in Spanish



6 focus groups: 5 fully virtual groups on Zoom and 1 hybrid group
with in-person attendees and an online moderator

4 caregivers participated in virtual interviews

PARTICIPATION BY NEBRASKA BEHAVIORAL HEALTH REGION



COMMUNITY TYPE



RACE



■ White ■ Hispanic/Latino ■ Native American/Alaska Native

Identifying and Accessing Resources

IDENTIFYING THE NEED FOR SUPPORTS

Many participants sought help after noticing the **impact of their children's behaviors**, whether on the children themselves or on others. Noted impacts on the children included distractibility, emotional extremes (e.g., strong reaction, high anxiety, and withdrawal), self-injury, and suicidal ideation or attempts. External impacts included school disciplinary actions (e.g., suspensions or classroom removals), changed or canceled plans and routines, and physical or emotional harm to family members.

"I guess we decided—or I decided—when it became bigger than what we could manage or what I could manage in our home. It did kind of start to affect school, and my kids are much older. So when it started to come out at home, it was one thing. But when it started to affect schoolwork and things like that, it is when we decided it was probably time to was bigger than we could deal with on our own."

"She was starting to self-injure herself, and she'd get really upset. And so we knew she needed to talk to somebody and see if we could help her kind of process her emotions a little bit better."

Some caregivers sought help after receiving a **referral or request**. Medical professionals referred children for testing or specialist services based on comparisons to typical developmental milestones or in response to caregivers' concerns. School personnel suggested evaluation through the school, the Educational Service Unit (ESU), or a medical provider based on their observations. Some children requested mental health support, including counseling and hospitalization.

"One of my children, we were told by his speech and occupational therapist that we needed to pursue a psychologist. And then another one of my children during the pandemic just started to become really anxious and really worried. And it was something that was that she was talking about and she was really worried. And so I knew that I needed to [get help]."

"And I knew it was time for care because I noticed he wasn't talking as much as his peers. He was in Early Head Start. And, you know, he had just had delayed speech. So he was just too young to have [an autism] diagnosis then. Because around four, I kind of felt like I knew. And then, when he was six, I felt like I knew. But I had to wait until he was in first grade to get that diagnosis."

Multiple participants discussed **feelings of guilt or regret** for waiting to get services. Often, they noticed less frequent or intense behaviors at first and sought help once those behaviors grew beyond the level they felt they could manage alone.

"I feel like it took longer than necessary to recognize that we probably needed some professional intervention. And I think what it finally took was when my son started pre-K and his teachers were insightful in pointing out that that he was having difficulties and that, you know, that there were interventions out there that that he would benefit from."

"It was when the behaviors in the home were to a level that I couldn't manage. I finally accepted that they were outside of the scope of normal childhood levels of behavior and that I needed outside help. There's a lot of shame involved in that, and I would have gotten help sooner if I could have gotten over the shame."

STARTING POINTS

Participants discussed their initial resources for seeking assistance. Many turned to medical professionals, such as family doctors. Others looked to children's schools, often seeking out school counselors, school psychologists, or administrators for guidance. Some participants reached out to family members or friends who had lived experiences seeking help for their own children. Various agencies, like the Early Childhood Development Network, Nebraska Autism Network, Boystown, and NAMI, provided resources and support to families. Because of legal restrictions, caregivers with children in foster care typically contacted the agency or caseworker first.

"I have a large family, so I'd probably reach out to one of my sisters or put it on Facebook sometimes, or I've got some friends who also are foster adopt families, like us. So I do a lot of reaching out to people in our situation who can understand our struggles and then give suggestions like that."

"I reached out to the Early Childhood Development Network. And from there it was to her doctor. And now I'm trying to work with a therapist to figure something."

Many participants turned to the Internet in their initial searches for information. Facebook groups facilitated connections with other parents, allowing for shared experiences and support. Some participants used Google to find information about support groups, services, and potential providers. One participant noted that a general search led them down a "rabbit hole" and said they would use a more targeted approach like the Nebraska DHHS website if they could do it over again.

Participants' first attempts for help and information **often connected them with medical professionals** (e.g., provider lists to call, diagnosis and referral to specialists, and starting new

services). Some caregivers reported a lack of success from their first outreach attempts, citing overwhelming information, low or no response, lack of available services, or dissatisfaction with providers or outcomes.

“Have I reached out for help on grieving? Yes, I have reached out for help with mental health services with the school, but none of the programs within 20 miles offer the help we need.”

HOW FAMILIES LEARNED ABOUT AVAILABLE RESOURCES

The methods by which caregivers learned about the services and supports available in Nebraska varied widely. Teachers, advocates, healthcare providers, and lawyers played a part in disseminating knowledge about available resources, and multiple participants cited their professional or volunteer roles as significant sources of information. **Schools** served as a common avenue for information, with many caregivers highlighting the importance of Individualized Education Programs (IEP) and school-based services, including those provided by Educational Service Units (ESU). Counselors and social workers provided referral lists and recommendations, and early childhood providers and groups shared information regarding Individual Family Service Plans (IFSP), evaluations, milestones, and school-based services (e.g., home visits). Opinions were mixed regarding the level of support received from schools in helping families navigate and access these resources. Some participants felt the schools were vital to their search, while others felt frustrated.

“My son, in his early years, I got lots of supports from the early child intervention. He's 12 now, and so then, when he began the public school kindergarten, he had an IEP, and then I was just using different information that they were providing for us.”

In addition to school-based supports, many respondents turned to **other families** and parent groups, leveraging in-person and virtual connections to gather information. **Vetted directories and lists** were also mentioned as valuable resources, such as those from Medicare providers, the Nebraska Department of Health and Human Services (DHHS), as were handouts from organizations like Immanuel. A few participants named social media, in-person meetings with emerging service providers, and advertisements (e.g., billboards) as sources of information. Some participants noted that they had not learned much about the supports available in Nebraska, with a few stating, “I haven’t.”

“Two years ago when, you know, I felt like I was at the end of my rope. I'm driving home from work and I'm at an interchange...and there is this huge billboard and it says, ‘Parents, do you need help? Call us. We can help you.’ And I took a picture of that and I came home and I called it. It was BoysTown, and thank God for BoysTown.”

COMMUNICATING INFORMATION TO FAMILIES

Looking toward the future, respondents voiced their preferences for how best to receive information about services and supports for their families. **Trust in professionals** emerged as a key theme. Participants expressed a desire for a **consolidated and easily accessible source of information** from vetted professionals, assuring them that the information is current. Suggestions included a unified and regularly updated portal or website designed for this purpose. Doctors, legal representatives, social service offices, trusted websites (e.g., UNMC and Boystown), and schools were also identified as critical information-sharing channels. Native American participants noted the importance of Tribal government and community spaces for sharing information.

Using **social media and the online communication** for information dissemination also garnered significant interest. Participants discussed using electronic communication in different ways depending on the audience. For general messages or information, social media (e.g., through parent information or support groups) was the preferred method of sharing information. If participants had registered to receive information from a specific group or service, they preferred receiving personalized information through email or text.

"I kind of feel overwhelmed when there's like all kinds of, like, pamphlets, emails, advertising, stuff. So really, honestly, if it was to come through a recommendation through the therapist that I've already built a relationship with or through the family care provider that I've already built the relationship with. Essentially, this place would have to make their case to the family care provider that I trust in order for me to want to see what other additional services there are."

"The one thing I found is if there's one trusted location like UNMC or whatever, university or educational institution. If they have a trusted website that has all the links as good as they can to these different groups, that would be so helpful for me."

"If it's something that pertains specifically to me, an organization that I already know about, then text or email is preferred, but if it's something that's new to me, social media is probably the the best way that I connect with new organizations or new people."

RESOURCE FORMATS

Regarding the resource formats that would be most useful, **web- or tech-based options** were favored, including websites, social media platforms, podcasts, and videos. However, traditional paper resources were still deemed valuable, particularly in high-traffic areas or clinical settings and for older caregivers. There was a strong emphasis on understanding the audience's needs to ensure the information reaches its intended recipients. Caregivers discussed the time constraints and stress they regularly experience, and some participants also noted they have personal behavioral or mental health concerns (e.g., ADHD) that affect their engagement.

"I like websites just because I feel like moms with children with behavioral issues don't have a lot of time."

"So videos are nice, but I don't often have time for videos, so that's why the podcasts come in, even though sometimes I have to listen to them or like back it up because I mentally have zoned out. They are an efficient use of my time, I guess, driving back and forth a lot for school, for the kids school."

Respondents emphasized the need for resources to be **concise and accessible**, suggesting that initial communications should be short and to the point, with options to explore further if desired. Participants suggested including **filtering options** (e.g., by child age or need) to increase usefulness and make information less overwhelming. Including **visuals** was also recommended to enhance understanding, and web-based resources were favored for their capability to offer translations, text readers, and other modifications for accessibility.

A common theme among respondents was **trust in other parents and caregivers**. Participants wanted more opportunities to hear from other families who had already engaged with the system in Nebraska so they could learn from their experiences.

"I think short and sweet. So it's not real detailed where you have to sit there for a long time and read because you're going to lose interest. But you know, like short and sweet. Pictures even are helpful."

"I just go back to that one main hub where we can go and we can trust and and have it in a variety of ways. Because if it's on the web, we can have it do audio for us if we have disabilities as parents ourselves or as older children trying to go figure this out."

"Other parents who have lived it."

Barriers

Caregivers perceive a significant **shortage of mental and behavioral health providers** in Nebraska—particularly in rural areas—leading to long waitlists and difficulties in obtaining consistent care. Finding in-network providers can be challenging, and low-cost services often have **long wait times**. Caregivers have difficulty identifying approved providers with availability to see new patients. Appointment information is typically only shared via telephone, and approved medical groups may only accept their insurance for certain providers. The **lack of pediatric beds** for emergency mental health care was a concern, as multiple participants discussed long waits and extensive travel to access emergency care.

“I believe that mental health is not something that should be left for two months. It seems illogical to me that one has to wait two months to make an appointment with a psychologist.”

“I have good private insurance and I still have problems accessing services. When I started looking for my daughter... I find the reviews, and I find, okay, this one looks good, and this one's not, probably, what I want. Then I have to call the place or message the place and I have to figure out whether or not they take the insurance. And a lot of times, [their] website will say, ‘Oh, we take this insurance,’ ... and then they're like, ‘It's only with these providers, and these providers are full.’”

Families new to navigating the system often face challenges that further delay access to services. For example, caregivers who call only one provider and join one waitlist may wait significantly longer than those who get on multiple providers' waitlists or know how to join a provider's appointment cancellation list.

Some families experienced **barriers in communication with providers**. Participants discussed frustration with delayed or lack of responses to their phone calls and voicemails, as speaking directly with office staff was essential for clarifying accepted insurance, services offered, and availability. Some participants also noted communication issues during appointments, such as limited time for providers ignoring or dismissing families' concerns about child behaviors, treatment plans, or medication side effects.

“And I went to my call log and I said, ‘I've reached out to 147 places this week. I haven't talked to anybody. I've been leaving messages trying to get help.’”

Traveling to appointments is time-consuming, particularly in rural areas. Most appointment times are during the traditional workday, which conflicts with families' work and school schedules. Some caregivers shared negative feedback they received from their employers or their children's schools,

despite having medical documentation for the absences. Others discussed the **difficulty in finding reliable, affordable childcare** for their other children while they travel to and attend appointments.

“There's a two-year waitlist for most of our speech therapists in town. And so we took every sick appointment for a year because little kids get sick a lot. But then driving, they're a 30-minute drive for us. So you're doing that four times a week.”

“Most providers are Monday through Friday, 9 to 5, and last year we got a lot of pushback from school as far as attendance. Even though all of our appointments were documented, that they were for medical reasons.”

Caregivers experienced **additional barriers based on the children's ages**. Participants shared experiences of providers dismissing or minimizing their concerns because their children were too young for diagnosis. Participants also mentioned the need for more child-focused mental health providers in Nebraska, such as play therapists. Adolescents with mental and behavioral health needs typically diagnosed in childhood may struggle with transitioning from pediatric to adult services, often losing access to necessary support as they age. For example, a participant mentioned the limited availability of community events and support groups for adolescents with Autism compared to the options for younger children. Participants discussed the difficulty of finding mental health services for adolescents, as they may need a blend of pediatric and adult approaches. A few participants suggested that perceptions of adolescents as moody or difficult may deter some providers from working with that age range.

“I had no trouble finding someone who would talk to my ten-year-old. She was seven at the time. No trouble finding somebody who was willing to talk to her because trauma was more understandable at that age. It was they were a gentler approach to it. With my teenagers, it was more I think they were viewed as like... maybe part of the problem was them. Like maybe it's just a phase kind of thing because of some of the ways that it was manifesting in their lives.”

Caregivers of children in the foster care system shared about **legal barriers** to accessing services and communicating with providers, as a child's caseworker is responsible for behavioral and mental health care decisions. One participant noted that their child had been through four caseworkers and that there were often delays in getting responses because caseworkers have large caseloads.

Social and interpersonal factors were also barriers, with multiple participants discussing the impact of **social stigma** around mental health and seeking therapy. Participants discussed pervasive mental health struggles and bullying in their communities as a result. Some participants struggled to find providers who spoke their language or understood their cultural norms and values. **Child-provider relationship** issues were a barrier for some families. One participant compared finding a good-fit therapist for their child to finding a partner through online dating.

WHY FAMILIES DISCONTINUE SERVICES

When asked if they had ever discontinued mental or behavioral health services for a child in their care, 77% of participants (n=20) said they had. Families discontinued using services for various reasons. Two participants shared positive reasons for discontinuing, which included the provider or caregiver determining that the child no longer required the service and the family accessing a better-fitting alternative with availability. Conversely, several caregivers shared negative factors that influenced their decisions. These included financial concerns, the time required for travel and attending appointments, and dissatisfaction with outcomes, whether due to ineffective service or poor results. Provider-related issues also played a role, such as a poor fit between the provider and the family's needs or negative incidents. Participants' examples of major incidents included inappropriate comments about caregivers' parenting, singling out a child in ways that made them a target for peers, and ethical breaches by the provider.

77% of participants reported that they stopped using a behavioral or mental health service for a child in their care.

"He was getting behavioral therapy. But we decided that a different type of behavioral therapy would be more appropriate for him. And so we we stopped. And his therapist actually agreed with us."

"Another reason is that it was too much. Too many therapies. Do you get tired? It's too much for the family. We spent like two or three years, three or four times a week. Even on Saturdays, we went to therapy."

"I still don't like calling the police because of the things that have been said to me. After therapists and Region 6 professional partners have said, 'This is what you need to do,' and then getting talked to by the police like, just making me feel this big."

"No. No. I am willing to take any [services] that I can get."

SERVICES STILL NEEDED

Participants highlighted several gaps in support for children and families related to mental and behavioral health needs. They emphasized the **need for more available providers statewide** to reduce initial waiting times for appointments, allow for more regular scheduling, and ensure they have enough time to understand and diagnose children properly. Additionally, there were requests for **specialized services and knowledge**, such as play therapy, self-esteem support, and transition services for older youth. Caregivers also saw a need for medical providers and school staff to receive more training to support children who have experienced trauma. Some participants noted the need for more Spanish-language materials and bilingual providers.

"We just started with a play therapist, but apparently there was a shortage of those in [our community]. So it's like it seems like there could be more of those for the younger children. And there need to be more trauma-informed therapists because that is severely lacking. You think that you're going to somebody who understands early childhood trauma and different things that come up with that and you're like, 'Oh, your experience is nothing.' ...Unless somebody really has a solid experience with some of these things, they're not able to help us. And you think that they're prepared and they're not. We've seen that more than once."

"For me it's all the same whether it's English or Spanish, but if I think about all this information, it's all just English for English, there's almost no access in Spanish. And I do know of many families where the parents can't speak enough English to understand."

Several caregivers identified **concrete supports** they lacked. These included affordable insurance options, better and more transparent access to Medicare waivers, and improved transportation solutions, particularly in areas with limited bus access. Participants also suggested assistance with gas to help families get to appointments. Other support areas mentioned were financial aid and childcare options to support caregivers during appointments or when they needed a break.

"I made a request for a waiver, which they told me no, that I did not qualify. Well, why? But they don't say what the reason is. They don't tell me why? They just say that I don't qualify for a waiver. Okay. And then I don't understand. Why not?"

"She's on probation and transportation has been the biggest issue. Her probation officer continues to say they can only transport her one way. And there have been times where I've been at work and I can't just leave to transport her. She understandably doesn't want to get into a Lyft with a stranger."

Finally, some caregivers discussed the need for additional resources and community involvement. They wanted better access to resource information, such as local health fairs or mobile resources to visit rural communities. Participants also stressed the necessity of community acceptance for individuals with mental or behavioral health challenges, aiming to reduce stigma around seeking help and ultimately prevent other families from going through what they had experienced.

Successes

ACCESSING SERVICES

Participants were asked to describe success in accessing services. They discussed having a system where **services are readily available** and where **appointments can be obtained quickly and consistently**. One participant noted that it is particularly beneficial when providers within the same agency collaborate to streamline the process, making it simpler for families to manage appointments and billing. Additionally, caregivers said success means services are tailored to meet the specific needs of the child while remaining covered by their insurance without significant hurdles. **Effective communication and timely callbacks** were also discussed as vital components of creating a supportive environment for families navigating the system of care in Nebraska. Spanish-speaking caregivers considered it a success to find bilingual providers and office staff.

"The child's need is identified, the service that matches that is identified, and you just get it. Without fighting or advocating. It not being an issue. It just happens. The kid just gets what they need."

"I had a meeting with her and she said, 'Do you want someone who knows how to speak Spanish?' Yes, because I'm the one who's going to be in charge of talking and contacting them. So, we were talking. 'Oh. Do they speak Spanish?' 'No, no.' In several places they said no until one said 'Yes, we do speak.' And I grabbed that one there... I've been with them for two years now."

"Getting callbacks. I mean, and even if it's a service that's like, 'We can't provide a service,'... Because then I know. Move on. Move on to another. Or maybe refer me. Like, can you tell me who can provide the service?"

Some participants discussed what they could see during appointments that let them know they had achieved success in accessing services. Some looked for **consistency** and a **relationship** between the child and provider, noting how a strong connection and sense of trust can significantly enhance a child's experience. They discussed **measurable goals and regular progress reports**, which gave them confidence in the quality and level of care the child received. Caregivers also appreciated the times when the providers educated them on additional resources and services.

"And the lady that ended up being my kids' counselor was born and raised [nearby], so she was very familiar with the area and my kids had a very good vibe with her, which I think is crucial when you're when you're a mental health counselor. Like, if you don't feel right with your counselor, I think we're going to kind of pull back."

POSITIVE OUTCOMES

When asked about services and supports that led to positive outcomes for their child, many participants discussed times when providers had **worked to meet their family's or their child's needs**. This included personalizing services around their child's needs or interests, creating goals unique to the child, and considering the best fit for the child and family when making referrals. Participants complimented providers who listened to them and their children, made appointments enjoyable for children, and worked to build rapport and trust.

"We had a really great OT and team and coordinator through the EDN, IFSP process and they evaluated progress super well. We developed a really good relationship... We could trust each other and they taught me things that I didn't know. Like different tips and tricks and taught me as much as—probably even more than—they did my son. And then they evaluated the progress. They set goals. He was discharged at different times from speech, physical, occupational. It wasn't like a guessing game, like, why are we even going to therapy? It was like, these are the goals. They're measurable. And then here's progress reports and just kind of comparing like, here's what an age-appropriate child is. And here's where your child is."

"The speech language pathologist that our son sees at school. It was the third in three years, but we finally got a good thing going. And she has tailored her services so well to what he needs. They had tried [services in the classroom]. They tried pull out. Nothing was working. And finally she designed a whole group, social emotional class so he doesn't feel like he has something wrong with him."

"Our schools counselor for both of our kids thinks outside of the box. She supports them, is always there whenever they get overwhelmed in class or whatever. They can always go down and see her and talk to her."

Some participants pointed to providers' actions during the diagnosis and referral process. They appreciated professionals who took the time to get to know their children, **advocated for the child** to receive needed services, and guided them through the process (e.g., connecting with specialists, applying for waivers, or working with insurance and billing). Participants also noted professionals who **worked to reduce stigma and guilt** around needing mental or behavioral health support. A few caregivers noted the **growth** they had seen in their children. This included measurable gains toward goals, discharge from services, and observation that the child was doing better than before.

"[He] has been incredible for our family. He's a psychiatrist. He does my daughter's med management. He makes sure that we get what we need. He helps us get into services and understands the system and how to advocate."

"I don't know if we are succeeding, but we are doing the best we can. And she is home."

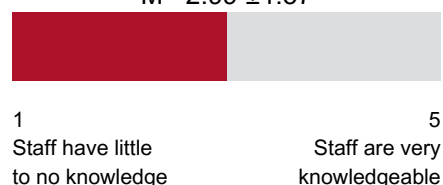
Training Needs

SCHOOL STAFF

Participants were asked to rate school staff's knowledge of how to support their children with behavioral or mental health needs. (1=Little to no knowledge, 5=Very knowledgeable). Provided examples of staff included classroom teachers, administrators, school counselors, school psychiatrists, and special education teachers. On average, participants (n=25) scored school staff knowledge as 2.99 ± 1.37 , indicating a moderate level of knowledge. Responses ranged from 0 to 5. Ratings below the baseline of 1 were coded as 1 for calculating the mean and standard deviation.

Level of Knowledge Rating: School Staff

M= 2.99 ± 1.37



Caregivers who rated their child's school staff highly discussed effective communication, the **availability of specialized services** within the school, and teachers or other staff who employ strategies tailored to their child's unique needs. Caregivers felt their children were supported when accommodation plans were followed, and that staff showed a **genuine investment in their child's success**. Staff efforts to build relationships with children also left a favorable impression.

"We meet every year for his IEP and as needed. But the staff that I work with, we communicate really well."

"We've had meetings about my son and his autism. There are people who go to the entrance for him, the personnel takes him to get breakfast. They pay attention."

"At this point now I'm really content with the efforts made to help get him in place. But again, I know there's so much they have on their plate to not just attend to my son's unique needs."

Conversely, many caregivers shared concerns about the level of knowledge among school staff. Many parents discussed **communication issues**, such as infrequent updates or a lack of information from non-homeroom teachers and specialists. In larger schools, this communication gap can become even more pronounced. Caregivers expressed frustration when their concerns regarding behavior challenges and mental health needs were dismissed or ignored, and some shared examples of staff **treating their child differently** than peers (e.g., lower thresholds for calling home or suspension, leaving children out of class or school activities). A few caregivers shared comments from school staff that indicated the staff member had "written off" their child. There were also allegations of **procedural non-compliance**, with reports of individual education plans (IEPs), 504 plans, and intervention plans not being read, adequately followed, or consistently implemented across environments. Some participants reported that they had to fight for compliance from staff (e.g., with medication management) or encountered a lack of necessary personnel.

Participants indicated a **lack of preparation** among staff in **recognizing mental health issues**, a need heightened in the post-COVID landscape. There were calls for better training, particularly in trauma-informed care and signs of mental and behavioral health disorders. Because the term “school staff” encompasses many positions, some caregivers distinguished ratings for different staff members or types. Specialized staff (e.g., ESU providers or school-based special education providers) were sometimes called out as having higher levels of knowledge.

“I think the specialized staff from the ESU do a pretty great job with our son. But the regular school staff, I just don't think they have the education. I don't think they understand autism. And so they're not really able to see situations from that perspective, from that informed perspective. That's my biggest struggle.”

“Our schools aren't trauma-informed. We have moved her schools, and she's in a much better place in her current school. We also have an attorney. We're also filing federal complaints. So that's an area where I think a lot of support for kids struggling with mental health is needed.”

Participants suggested strategies to improve school staff knowledge, such as lowering staff-to-student ratios, establishing more alternative schools in larger rural communities, and increasing outreach to foster better student relationships and community connections. A systematic review for compliance with relevant laws, such as the Individuals with Disabilities Education Act (IDEA), was also recommended. Suggested professional development topics included **trauma-informed care**, teaching social-emotional skills, and **recognizing the signs of mental and behavioral health disorders** (e.g., anxiety, schizophrenia, and bipolar disorder).

“Monthly audits from the Educational Rights Council lawyers. Maybe like their continuing ed has to be in special ed would be nice. They could get in trouble instead of just talked to if they're blatantly violating IEP rules. Have the resource director or counselor actually take some classes in special ed and stay up to date with that.”

“More outreach so that the kids felt more comfortable just knowing who the counselors are, who your outreach people are. Because as it is with Native American children, they have trust issues. So right then and there, before you even walk into a school on the reservation, you already got these barriers in front of you.”

“More recognition of symptoms that people kind of overlook. Just being aware of those. And then obviously not overtaxing [school counselors] because, you know, if you have 300 students you're trying to keep an eye on, you're going to miss stuff. You're absolutely going to miss stuff.”

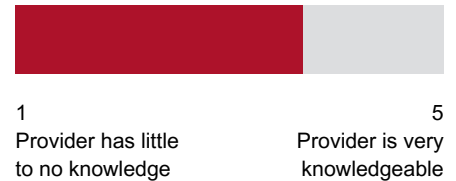
“I feel like there needs to be more social-emotional teaching and stuff in schools, and I know that's a big thing lately, but I think that it would help all students if there was more of it in the schools.”

PRIMARY CARE PROVIDERS

Participants were asked to rate their primary care provider's knowledge of how to support their children with behavioral or mental health needs. (1=Little to no knowledge, 5=Very knowledgeable). On average, participants (n=23) scored primary care provider's knowledge as 3.67 ± 1.45 , indicating a moderate level of knowledge. Responses ranged from -5 to 5. Ratings below the baseline of 1 were coded as 1 for calculating the mean and standard deviation.

Level of Knowledge Rating: Primary Care Provider

M= 3.67 ± 1.45



Many participants noted positive relationships with their child's healthcare team. Some participants shared examples of **validating comments** from providers that made them feel seen and supported. Caregivers valued **long-term relationships** with primary care providers and said it was helpful when they could access multiple services or specialists through one provider group or agency. Participants appreciated primary care providers who recognized the limits of their scope of expertise, and they praised those who **provided support** in navigating insurance, referrals, and obtaining necessary services. A few caregivers noted that their family doctor provided medication management while the family waited for specialist availability. The **collaboration between primary care providers and school support teams** was another positive aspect noted by parents.

"Our doctor actually helped us get on the Medicaid AD waiver. Like, we had no idea because we don't qualify through foster care or income-wise. And we were like, this is bleeding us dry. So he helped us provide the paperwork for that."

"And like just to have a doctor that says, 'You know, you are doing really hard things and I acknowledge that and that what you're doing is harder than most families go through in a lifetime.' And to hear that from her, like it was like so impactful to me, I just felt seen and recognized. And I know that I can just talk to her about any of the struggles that we're facing in our home, and that's nice to feel like that's a safe place."

"[She] goes to the same clinic that I go to and they've taken her since she was 11, and she also goes to counseling there and they all work together. So they've known her for a long time. And, yeah, it's a very strong [score of] five. I feel blessed to have the caregivers that we do."

Some participants shared negative sentiments. **Communication issues** were a common concern for participants who gave low ratings. A few participants encountered language barriers. Others shared examples of providers **ignoring caregiver or child concerns** about medication side effects, interventions, or symptoms. A few participants shared about seeking second opinions and diagnostic testing from other providers, sometimes traveling to other counties or states. Some participants felt that providers attempted to diagnose or treat issues **beyond their expertise** rather than collaborating with other professionals. Some caregivers also discussed that providers might be unwilling to admit they don't know the answer or may not refer out because they are unaware of available supports and services in the state.

"I go there to see if I need to sign some paperwork. Come to find out she never put the referral out. She also never used to listen to anything I'd say about my daughter's possible diagnosis."

"I think that a lot of times with health care providers, if they don't have an answer to a problem, they're afraid to say, 'I don't know the answer.' And I think that that's kind of been a barrier with our primary care. Like, it's not their specialty and they don't know what direction to send you in a lot of times."

"They kind of were almost offstandish to us, like they didn't know what to do until we took her to Immanuel for the first time."

Participants suggested training topics to increase primary care providers' level of knowledge. A common theme was **patient rapport**, with participants wanting providers to demonstrate openness to their concerns and their ideas about testing and treatment. Participants also wanted providers to put families at ease, as caring for children with mental or behavioral health needs can be stressful and confusing. Professional development included **cultural competency** (e.g., maintaining high standards of care for all patients regardless of race and understanding of diverse cultural values), **trauma-informed care**, and improving access and care for state wards. Participants also wanted providers to be better informed of the providers and supports in Nebraska, including lesser-known or region-specific options.

"Well, and then trauma-informed care. Are you familiar with that? I really think we need to focus on that community-wide, not just at the hospital. But I think it would help everybody to understand what that is. Sensitivity, you know. Cultural."

"They're looking for something within their scope of knowledge without the multidisciplinary idea that other professionals might have insight into what is going on. And so they don't have the training. But with communication between the professions, that might happen. But it does not happen. The communication doesn't happen."

Essential Information

Participants were asked to share the information that they most wanted others to know about services and supports in Nebraska. They stressed the important role of **caregivers as advocates** for their children and in improving access to services for Nebraska's children and families. Participants emphasized that caregivers are the best advocates for their children and urged them to keep trying when they encounter barriers. Participants advised other caregivers to keep asking questions, reach out to multiple providers, and consistently follow up on requests. They also emphasized the power in demonstrating to children that their caregivers will always be there for them and are willing to keep fighting for their needs. Participants discussed the need to stay informed. Specific topics to research included children and families' legal rights; the processes for requesting, administering, and reviewing support plans (e.g., Individualized Education Program (IEP), Individualized Family Service Plan (IFSP), and Section 504 Plan); the Family and Medical Leave Act (FMLA), and sick leave policies at work. Some caregivers recommended documenting of all communications and meetings.

"I would like to quickly comment what I learned in a parenting program: We are also the best advocates for our children and we are the voice of our children, and if we don't make it count and listen, they will be left without that voice."

"Parents should know that they should not give up. Ask, ask, ask, ask. And that they should not settle for the pediatrician, or the school, or the person who is giving their child mental health assistance until they find what [they] are truly looking for."

"You are your kid's biggest advocate, or should be. And also, you know your kid better. So if somebody...suggests something you know is not going to work or the kids are not going to go for it, it's okay to say, 'Oh, let's move on.'"

Participants asked for more **opportunities to hear from other caregivers and families**, seeking connection with peers who can provide support and share invaluable information. They emphasized that caregivers are more likely to trust the information they get from other caregivers who are willing to share their experiences.

"We're going to trust other parents better than we're going to trust the teachers and the staff at the school."

"I wish that there was some sort of support group because parents, I feel, struggle as much, if not more than the child does."

Multiple participants pointed to systemic issues that prevent access to services and supports in Nebraska, saying that many individuals seek services but cannot get past the hurdles. They emphasized that there is a **pressing need for more providers, particularly in rural areas**. Participants noted how difficult it can be to find appropriate services outside metropolitan regions, with some even advising others to leave rural areas if their child needs mental or behavioral support. One participant suggested finding ways to incentivize providers to practice in rural areas.

“You have to be available first. I mean, when you can’t even find that and then on top of that, you’ve got transportation, you can’t afford it and you don’t have child care to get there. I mean, it’s almost impossible. And then we’re waiting for our kids to be treated like, unfortunately, a lot of times, like after suicide attempt, it’s awful.”

“I don’t want anybody else to have to go through this or have to jump through this many hurdles just to get some counseling and some support.”

“We need more providers. We need some incentives to get them to come out here to a rural area. Educational reimbursement, you know. There’s the whole reason professionals don’t practice in rural areas. They get burnt out. You’re practicing with your neighbors and your family and you don’t get paid enough.”

“I think we’re super lucky that we live in this little area. But if you live in a rural part of the state and you have a child going through this. Sadly, my only advice would be to move.”

Some participants highlighted the **impact of racism and bias** on behavioral and mental health care. Their examples included misdiagnosis, stereotyping, and policies that don’t account for cultural or physical differences. Caregivers also recognized the unique challenges faced by families with children in foster care, as caseworkers are often overwhelmed by high caseloads. Several participants discussed the **impact of stigma** around seeking support and sought to normalize asking for help. They wanted other families to know that many caregivers are already taking their children to therapy and that families throughout the state are in need of supportive services for their children. One participant encouraged other caregivers to sit down and meet with the relevant providers or schools if approached about starting services.

“I think I would put out there how real systemic racism is. I question if my child has gotten the right diagnoses. I also think at times, I’m pretty confident some of the situations that happened to her would maybe not have happened the same way.”

“They don’t need to feel that it’s shameful and that it’s embarrassing, that it’s going to hurt the child, that you’re being a baby or too emotional or too sensitive, too gentle of a parent. I think other parents need to know that there’s lots of other parents out there that take their kids to therapy. They’re just not talking about it.”

"If you're approached by someone like the special education services, really just take the time to sit down with them and figure out a plan, too. Because I didn't even know until my son was in kindergarten that there was a psychologist at the school. And they had speech therapists coming in and like occupational therapist coming in... And I was like, 'I don't even know you guys had all this.'"

Caregivers expressed a need for a **consolidated hub to find resources**. They called for better communication with families and providers about the supports available in Nebraska, noting that communities often offer various resources that might not be widely known unless families actively seek them out or learn from one another. Participants wanted other caregivers to know that places and organizations like the Nebraska Children and Families Foundation (NCFF), the University of Nebraska Medical Center (UNMC), the National Alliance on Mental Illness (NAMI), Behavioral Health Region offices, and local hospitals may provide newsletters or lists that help families identify available support. Additionally, schools and Educational Service Units (ESUs) can be valuable resources that families can access for assistance.

"What I've experienced is that there is great resources here in the community. Sometimes they're like little special treasures that are hidden and if you make the right connection then you get informed."

"Most of everything I found out was through my job and I feel like, if the mental health community of professionals, if they knew more about what type of services are available, they could help a lot more patients."

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