

Nebraska Connecting Families Project

CAREGIVER FOCUS GROUP EXECUTIVE SUMMARY

Collection Methods and Participation

METHODS

- **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**.
- Groups and interviews were conducted in August and September of 2024.

PARTICIPANTS

- **26** total participants: 22 caregivers participated in English and 4 participated in Spanish.
- **54%** of participants were from rural areas of Nebraska and **46%** were from urban areas.
- Racial self-identification: **62%** White, **19%** Native American/Alaska Native, and **19%** Hispanic/Latino.

Findings

Focus group questions were designed to gain information around five topics related to families' needs and their experiences engaging with Nebraska services for mental and behavioral health support.

IDENTIFYING AND ACCESSING RESOURCES

Many caregivers sought help due to the negative impacts of their children's behaviors, such as emotional extremes, self-injury, and school disciplinary actions. They often reached out to medical professionals, schools, family members, and support agencies for guidance. Many also turned to the Internet and social media (e.g., online support groups) for information about available resources. Trust in professionals emerged as a key theme, with a preference for a centralized, easily accessible source of current information on available services. Multiple participants suggested a unified portal or website, noting that families were more likely to use it if doctors, legal representatives, and trusted organizations supported the portal by recommending it at appointments, providing information about it through brochures or newsletters, or linking to it on their websites.

BARRIERS

Families in Nebraska face numerous barriers when accessing youth mental and behavioral health services, particularly in rural areas. Key issues include a perceived shortage of providers, long waitlists, and difficulties finding in-network options. Communication problems with providers, such as delays or lack of responses, hinder timely access to care and frustrate caregivers. Traveling for appointments poses additional challenges, as many are scheduled during traditional working hours, which conflicts with families' schedules. Newcomers often lack systemic knowledge that could reduce their wait times (e.g., contacting multiple providers and joining cancellation lists). Social stigma surrounding mental health and a lack of culturally competent providers add to the challenges in accessing care.

Age-related obstacles are a concern, especially for adolescents transitioning from pediatric to adult services. Caregivers also noted a need for more providers to receive training in trauma-informed counseling for youth and play therapy to support young children. More than 75% of caregivers reported discontinuing services for various reasons, including financial burdens, dissatisfaction with treatment outcomes, and negative experiences with provider interactions.

SUCSESSES

Participants described success in accessing services as having a readily available provider and consistent appointments. Collaboration among providers within the same agency was highlighted as beneficial for managing appointments and billing. Success also meant services tailored to the child's specific needs and easily covered by insurance. Effective communication, timely callbacks, and bilingual providers were essential for Spanish-speaking caregivers.

Participants recognized success during appointments through consistent relationships and trust between the child and provider, measurable goals, and regular progress reports. They appreciated providers who personalized services, listened to families, and made appointments enjoyable for children. Effective professionals advocated for children, connected families to specialists, and reduced the stigma around mental health support. Some caregivers noted significant growth in their children, including measurable progress, discharge from services, and observed changes in child behavior, mood, or functioning.

TRAINING NEEDS

Participants evaluated the knowledge of school staff and primary care providers regarding support for children's behavioral and mental health needs. Participants rated school staff's knowledge as 2.99 out of 5, indicating a moderate level of understanding. Caregivers who rated staff highly appreciated effective communication, specialized services, and personalized strategies, while concerns were raised about inadequate communication, dismissed concerns, and compliance with accommodation plans. Caregivers called for training to increase staff's knowledge of mental health, particularly in trauma-informed care and recognizing signs of mental health disorders. Recommendations for improvement included lowering staff-to-student ratios and growing outreach to foster relationships.

Caregivers rated primary care providers' knowledge as 3.67 out of 5, also reflecting a moderate level of understanding. Positive feedback focused on strong relationships with healthcare teams, validation from providers, and support navigating services. Communication issues and instances where provider responses felt dismissive were noted as concerns. Suggestions for training topics included techniques for rapport with patients and caregivers, cultural competency, trauma-informed care, and increasing providers' awareness of the available resources and supports in Nebraska.

ESSENTIAL INFORMATION

Focus group participants emphasized the role of caregivers as advocates for their children. They encouraged caregivers to persist despite barriers, ask questions, contact multiple providers, and stay informed about their family's legal rights. There was a call for greater connection among caregivers, and many participants emphasized that caregivers are more willing to trust information from other families who have already navigated the system. Participants highlighted barriers to accessing support, including the impact of bias and racism in behavioral and mental healthcare, additional legal obstacles for children in the foster care system, lack of providers—particularly in rural areas—and social stigma around seeking help. Multiple participants wanted other caregivers to know that many families are already taking their children to supportive services and that it is ok to ask for help.

Caregivers called for better communication with families and providers about supports and services in the state. Several emphasized the need for a centralized hub to help families find resources.