



Uplifting  
community  
voices

## Parent and caregiver experiences with barriers to child and youth mental health care

This brief focuses on the experiences of parents and caregivers in Ohio when accessing mental health care for their children, providing important perspectives on the considerations described in the [Access to mental health care for Ohio children and youth policy brief](#).

Given increasing rates of mental health challenges amongst children and youth in Ohio<sup>1</sup>, there is a substantial level of unmet need for mental health care.<sup>2</sup> A variety of factors may impede access to mental health services for children, including cost, workforce shortages and social stigma.<sup>3</sup> Understanding the barriers to mental healthcare access for this population is a critical step in identifying potential policy solutions.

To further explore these and other barriers, HPIO conducted two focus groups with Ohio parents and caregivers of children with mental health needs. Key issues from these conversations are described throughout this brief, including difficulties navigating the mental health care system, issues with service availability and finding the right provider, and compounding burdens for parents and caregivers.

### Navigating the mental healthcare system

The child mental healthcare system is highly complex to navigate, potentially requiring familiarity with insurance models, providers at each level of care, the child welfare system and more.

Difficulties with understanding the intricacies of this coverage and delivery system stood out across all the specific barriers that parents and caregivers experienced when accessing mental health services for their children. Many caregivers described feeling lost when trying to get their children the care they needed.

*"When I first got my grandchild, I didn't know anything about a child with autism. And so, I needed some help. And it's like everybody I asked, it was like, you can try this or you can try that. I mean, nobody really gave me a definite answer. So I had to wiggle through this whole thing to try to find, to get some kind of help. You know, so it's been a lot. It's been hard for me."*

Others described facing "red tape" when trying to figure out the necessary steps to getting their child mental health care.

### Parent and caregiver focus group methodology

Two focus groups with Ohio parents and caregivers of children with mental health needs were conducted in the fall of 2025 with 10 total individuals via Zoom. The parents and caregivers selected for participation in these focus groups cared for children of various ages with diverse mental health needs and represented different regions of the state.

During the focus groups, participants were asked to describe their experiences, including the barriers they encountered during the process of accessing mental health services for their children. From these conversations, HPIO identified key issues that caregivers face when attempting to get their children mental health care. Participants were compensated for their time.

**"I feel like I spend more time talking about forms than I do about what my kids actually need."**

Many participants responded to these difficulties with navigating the mental healthcare system by turning to a trusted case worker or care coordinator. For example, one caregiver described the long-term assistance she received from a case worker at a local children's hospital, noting how, "she has been a godsend to me. I have a problem like [the insurer] isn't paying for something, she will reach out for me. All I have to do is leave a message with them."

Another critical resource for some parents and caregivers were other parents with children who had similar needs, with one parent explaining, "I also get our information from a kinship, foster, and adoptive support group. The parents share information and that's how we navigate it."

## Mental health service availability

Parents and caregivers described major challenges when attempting to find mental health care providers for their children. They most prominently encountered lengthy waitlists, with multiple participants saying they had to wait over two years for services at some points. These findings align with research that describes mental and behavioral health workforce shortages in Ohio and nationally.<sup>4</sup>

**"I would probably say the biggest barrier was the wait. Like the waitlist just to get in to be assessed. That's not even counting them assigning an actual therapist to them to get in to see a psychiatrist. And I guess it's because the need, I guess the need is so great that it's just a really long wait list process."**

While data on waitlists for mental health services are limited, experts agree that they represent a major barrier to care access for children, especially those who are younger or require specialized services.<sup>5</sup>

Parents and caregivers also described how insurance coverage impacted their ability to find mental health treatment, including outdated or inaccurate provider lists as well as limited in-network provider availability. One parent, for example, explained the many difficulties they faced with their insurance company.

*"When they send you a list of providers, sometimes you'll call [the provider] and, you know, they'll deal with anxiety, but it's not in children, but they're on the list of providers that are covered by the insurance. And it's extremely frustrating to get lists where ADHD, impulsivity and like the other stuff, like you might be able to find a provider, but they're either not taking clients and you get waitlisted through the insurance, or you wind up with an inappropriate counselor and the list is useless of what's going to be covered by the insurance."*

## Mental health services in schools

Some participants described how their children's schools bridge the gap with not only direct mental health support but also helping parents and caregivers access services for their children. For instance, one participant described how the clinic at school, which provided both physical and mental health care, allowed her children to, "have that ability to access services in school and not have to constantly be missing school or me not having to constantly be missing work, [which] has been fantastic. And I need them to continue with that."

Another caregiver explained how her grandchild's school helped them find mental health services:

**"I would say my granddaughter's school has really helped me through quite a few things. They've directed me to resources that helped."**

## Provider alignment with child and family needs

Even after identifying a mental healthcare provider who was covered by insurance and had appointments available, some parents and caregivers described difficulties with ensuring that the provider met the specific needs of the child and family and fostering a long-term clinical relationship. For instance, one caregiver struggled to find a provider who could connect and communicate with their child.

**“[My biggest difficulty was] finding a provider that’s appropriate for my 17-year-old. He has level 2 autism and finding one that could talk to him in a meaningful way was very challenging. Even though we were told by many that they had experience with autism, there was a very large disconnect between their communication and his communication.”**

Another common barrier was the frequency of provider turnover at an agency or facility. After parents and caregivers found a provider who connected well with their child and had a positive impact, they sometimes needed to start over because the provider moved or changed practices. One caregiver explained finding a home-based specialist for her children that was working well, only to discover that, “the therapists have such a high turnover rate that once our kids get connected, the therapist is no longer working for the organization.”

Parents and caregivers were often left feeling like they needed to rotate through providers to find an adequate fit, a challenging task given the widespread availability issues within the mental health workforce.

## Compounding burdens for parents and caregivers

The access issues that parents and caregivers face intersect with their own lives in many impactful ways. This includes having difficulties managing transportation needs for their children’s care, lacking support or respite as a caregiver and experiencing stress associated with financial strain or uncertainty.

Figure 1. **Burdens experienced by parents and caregivers**

What parents and caregivers had to say

### Transportation and travel time



*“I live in Cincinnati, but I am about 30 minutes away from downtown Cincinnati. So technically I’m in Harrison, Ohio. But location, I cannot find a therapist without driving 30, 45 minutes away in rush hour traffic, which leads, you know, to me having to miss work, because I have to leave to go get her [and] pick her up early from school.”*

### Lack of backup, support or respite as a caregiver



*“I mean, it’s kind of scary with the respite situation. There is none. And it is kind of like what do you do then? What happens if we get sick? Like, I’m supposed to go and do stuff. It worries me and it takes my stress level up, you know?”*

### Financial strain and stress



*“And then when you start looking at paying for stuff out of pocket and the costs are adding up, it’s like, where do we start cutting corners? How much credit card debt can we take on, get a loan, consolidate something to find the appropriate level of care for the issues that we are having?”*

## Support for kinship caregivers

While all parents and caregivers described facing difficulties, some participants highlighted the lack of support that kinship caregivers (relatives who take over full-time care of a child) face in particular. While specific resources do exist for kinship caregivers in Ohio<sup>6</sup>, participants who served as kinship caregivers described the difficulties they experienced in this role.

**"I have shut down my whole life, which I'm glad I did, to take care of her, but I get nothing... I just, you know, it's just not right. You know, I'm a family member. They should be with their family members. I love her, you know, and I'm going to do the best by her. And it's like I get nothing, no help."**

## Caregiver experiences with OhioRISE

Multiple focus group participants had children who were covered by Ohio Resilience through Integrated Systems and Excellence (OhioRISE), a specialized Medicaid managed care program for children and youth (ages 0-20) with complex behavioral health and multisystem needs. OhioRISE is designed to coordinate care across systems and improve access to mental health services.

Participants discussed their experiences with the program, including benefits such as getting connected to care sooner and the availability of different care approaches like in-home therapy. Participants also described some challenges with the program, with the most common being navigating the program's complexity. Some caregivers mentioned not understanding all the supports that were available and encountering some delays with getting the necessary screenings and assessments.

### Helpfulness:

**When I found out about the OhioRISE program, I immediately got excited because it's like, oh my gosh, we finally get to have behavioral health for help with young children in elementary age up until age of 21. That did not exist when my adult daughter was three, four years old. And she's got borderline personality disorder. And I think things would be different today for her if what we know today was provided back then.**

### Difficulties:

**"So yeah, there's a lot to it and it can be confusing, and you got to know who to turn to to get your questions answered."**

## Notes

1. Health Policy Institute of Ohio, "Mental Health Conditions among Ohio Children and Youth," December 2024.
2. Health Policy Institute of Ohio, "Access to Mental Health Care for Ohio Children and Youth" December 2025.
3. Jerica Radez et al., "Why Do Children and Adolescents (Not) Seek and Access Professional Help for Their Mental Health Problems? A Systematic Review of Quantitative and Qualitative Studies," *European Child & Adolescent Psychiatry* 30, no. 2 (2021): 183–211, <https://doi.org/10.1007/s00787-019-01469-4>.
4. Nathaniel Counts, "Understanding the U.S. Behavioral Health Workforce Shortage," *Commonwealth Fund*, May 18, 2023, <https://doi.org/10.26099/5km6-8193>.
5. Anderson, Joanna K., Emma Howarth, Maris Vainre, Peter B. Jones, and Ayla Humphrey, "A Scoping Literature Review of Service-Level Barriers for Access and Engagement with Mental Health Services for Children and Young People," *Children and Youth Services Review* 77 (June 2017): 164–76, <https://doi.org/10.1016/j.chidyouth.2017.04.017>; see also "Access to Mental Health Care for Ohio Children and Youth." Health Policy Institute of Ohio. December 2025.
6. "OhioKAN: Connecting Kinship Caregivers to Resources," Ohio's Statewide Family Engagement Center, 2025, <https://ohiofamiliesengage.osu.edu/resources/ohioKANconnecting-kinship-caregivers-to-resources/>.

## Ohio Child Mental Health Project

Led by the Health Policy Institute of Ohio and informed by a **multi-sector advisory group**, this project includes a series of policy briefs exploring child and youth mental health in Ohio.

<https://bit.ly/3MdgVQx>



Support for this project was provided by the Harmony Project, the Woodruff Foundation and HPIO's **core funders**