

https://dspace.org/

Challenges and supports for families of youth with behavioral health needs

D M R DAGENHARDT; Melinda Kavanaugh; T FREIBURGER

SPRINGER
https://hdl.handle.net/10539/47346
WOS

Downloaded from a DSpace repository. https://dspace.org/

Community Mental Health Journal (2025) 61:682–692
https://doi.org/10.1007/s10597-024-01386-0

ORIGINAL PAPER

Challenges and Supports for Families of Youth with Behavioral Health Needs

Danielle M. Romain Dagenhardt[1] · **Melinda Kavanaugh**[2] · **Tina Freiburger**[1]

Received: 29 March 2024 / Accepted: 24 October 2024 / Published online: 21 November 2024
© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2024

Abstract

As mental health needs increase for youth across the United States, little is known about how these youth engage with emergency psychiatric services (EPS) and how accessing of these services is experienced by the family caregivers. This study utilized interviews with 19 youth and their adult caregivers, detailing their experiences with EPS and community needs. Interviews were conducted in-person and over the phone, lasting approximately 45 min. Qualitative data were analyzed following grounded theory to elicit a potential new theoretical view of youth and family experiences and needs associated with EPS. Themes elicited included: (1) family and school challenges, (2) challenges for caregivers, (3) structural and system challenges exacerbate issues, (4) family and friend supports, (5) community supports. Families in this study struggled with numerous family, school, and community barriers, indicating a need for targeted supports that address the family and community systems.

Keywords Youth psychiatric services · Youth behavioral health · Community behavioral health · Family caregiver

Introduction

Estimates from the Center for Disease Control (CDC) demonstrate that a sizeable proportion of youth experience mental health issues. Data from 2016–2019 show that the most commonly experienced issues are ADHD, anxiety, and behavioral problems (i.e., oppositional defiant disorder, conduct disorder), which impact roughly 9–10% of youth between 3–17 years of age (CDC, 2023). Further, anxiety, depression, and behavioral problems often co-occur among youth, and are frequently combined with self-harming behaviors such as suicide or self-mutilation (Merikangas et al., 2011). For the adolescent population (defined as those 10–19 by Center for Disease Control) specifically, suicide and depression are particularly concerning. Data from 2018–2019 demonstrate that over one-third of adolescents experienced symptoms of depression (e.g., hopelessness), while almost 20% had considered suicide and just over 15% had made a suicide plan (CDC, 2023).

Although mental health issues are relatively common among youth, many do not receive treatment. In one study, only about one-third of youth received treatment for mental illness (Kalb et al., 2019; see also Merikangas et al., 2011; Chitiyo, 2014). Factors that were found to predict treatment included symptom severity, illness type, co-occurring disorders, and race/ethnicity. While youths receiving outpatient mental health services increased 13.3% in 2010–2012 (Olfson et al., 2015), services remain well below the need. Individuals who do not receive treatment or disengage from treatment often faced increased symptoms and in-patient hospitalizations (Dixon et al., 2016).

While there is a large body of research that examines use of treatment more generally, fewer studies specifically examine families' experiences with youth that enter emergency psychiatric services (EPS) (Janssens et al., 2013). This paper specifically examines the nexus of youth enrolled in a Wraparound care program who also have had emergency psychiatric visits while engaged in treatment. Wraparound is a community-based program with a team-based approach that provides a care plan individualized to the youth's specific needs and family support (Olson et al., 2021). Understanding the challenges that this population faces is particularly

✉ Danielle M. Romain Dagenhardt
dmromain@uwm.edu

[1] Department of Criminal Justice and Criminology, University of Wisconsin-Milwaukee, PO Box 786, Milwaukee, WI 53201, USA

[2] Department of Social Work, University of Wisconsin-Milwaukee, Milwaukee, WI, USA

important to improving systems of care that utilize Wraparound programs.

Types of Services in Systems of Care

Emergency psychiatric services, often called emergency mental health departments or psychiatric crisis systems, are often the first touchpoint to the mental health systems of care for families of youth with mental illness. Common pathways to use of EPS include school referrals (Molteni et al., 2021) and family members calling for law enforcement during a crisis (Hirschi, 2022). Community-based treatments, such as Wraparound programming, may be recommended depending on the severity of symptoms, yet not all youth who visit emergency services engage in these treatments. Other research suggests that use of EPS for those engaged in community-based treatment may be due to receiving inadequate lower-level services (Janssens et al., 2013; Leon et al., 2017; Walter et al., 2006). In fact, this research further finds that these youth tend to have a significant history of mental health treatment (Leon et al., 2017; Walter et al., 2006; Worsley et al., 2019). While many youth who visit emergency psychiatric service have not previously received treatment, others have been frequent users of community-based treatment, yet that treatment was inadequate.

One of the key components to systems of care for youth with behavioral health needs is Wraparound programming. Developed in the 1980s as part of the systems of care approach to severe behavioral health needs of youth, Wraparound utilizes a teams-based approach to coordinate community-based care, support families, and provide individualized treatment plans with a strengths-based approach (Olson et al., 2021; Winters & Metz, 2009). The goals of this program include reducing reliance on in-patient treatment, negative mental health symptoms, school problems, and juvenile justice contacts. A recent meta-analysis of 17 empirical studies demonstrates that the program is effective at achieving these outcomes, while fidelity to best practices increased the magnitude of impact (Olson et al., 2021).

Factors related to use of community-based treatment include access, types of programming available, stigma, recognition of symptoms, and family support (e.g., Barksdale et al., 2010). Although there are multiple components to treatment in systems of care for youth, research has demonstrated differences in utilization of community-based treatments like Wraparound compared to relying on emergency psychiatric treatment. Specifically, several studies have demonstrated Black youth are less likely to utilize community-based treatment due to negative perceptions of services and providers and restricted access to these services (Lindsey, et al., 2013); reliance on emergency psychiatric treatment alone diminishes the underlying principles of systems of care and continuity of care (Barksdale et al., 2010; Das et al., 2020). Additionally, research has demonstrated that Black youth are more likely to re-enter emergency psychiatric treatment after disengagement with treatment (Snowden et al., 2009). Further, some research specific to Wraparound programming has found that Black youth are more likely to disengage with programming (Yohannan et al., 2017) and that Black families report negative perceptions with how staff treat them (Stenersen et al., 2022). Taken together, prior research suggests challenges in access and engagement with community-based treatment lead to continued reliance on emergency psychiatric crisis services, with poorer outcomes.

Family Challenges in Supporting Youth with Mental Illness

Caregivers play a central role in youth accessing and engaging in treatment, yet they often experience challenges in navigating systems of care. Research has demonstrated that caregivers often face barriers in access to care, such as financial burdens (e.g., insurance coverage, Medicaid, treatment costs and co-pays) (Barker et al., 2012; Mendenhall & Mount, 2011; Song et al., 2018; van Vulpen et al., 2018; Walter et al., 2006), waitlists (Markoulakis et al., 2020), and limited availability of services (Walter et al., 2006). Further, transportation challenges may create additional barriers in access and engagement (Walter et al., 2006). Even for those youth already engaged in treatment, caregivers continue to experience challenges within care systems. They express negative experiences in navigating these systems, with the lack of information provided, poor interagency communication, and disconnect in the continuity of care (Champlin, 2009; Hirschi, 2022; Walter et al., 2006). Caregivers often feel like their concerns are not taken seriously, listened to, or validated—particularly for those who utilized EPS (Hirschi, 2022; Walters et al., 2006).

In addition to barriers in accessing care for their youth, caregivers often face additional challenges in their lives that can be compounded by caring for a youth with mental illness. Some are involved in the child welfare system (Duong et al., 2021), have housing instability (Copeland & Heilemann, 2011), and additional legal issues (Hirschi, 2022). Others face employment and financial concerns due to the increased time commitment in providing care and responding to crises for these youth (Markoulakis et al., 2020; Song et al., 2018). The emotional toll of caregiving can create and exacerbate mental health concerns for caregivers (Champlin, 2009; Farinelli & Guerrero, 2011; Green et al., 2019; Hirschi, 2022; Mendenhall et al., 2011; Molteni et al., 2021) and lead to physical health concerns (Song et al., 2018). Finally, family relations are often strained, whether between partners or with other children in the household (Barker et al., 2012; Hirschi, 2022; Katz et al., 2015; Mendenhall et al., 2011). Taken together, the research demonstrates that

caregivers face a myriad of challenges in seeking treatment for their youth, and that caregiving for this population creates additional challenges for caregivers to navigate.

Youth Challenges in Access and Engagement in Treatment

Less research has focused on challenges youth experience in accessing and engaging in treatment, as well as other broader challenges they experience. Some of the key factors that foster or hinder access to treatment are family recognition of mental health concerns and initiating contact with treatment providers (Cohen et al., 2009; Hall et al., 2016; Markoulakis et al., 2020; van Vulpen et al., 2018). Further, family involvement and commitment to treatment is central to continued engagement in treatment (Green et al., 2019; Hall et al., 2016; Richardson et al., 2007). As such, Wraparound care is a community-based treatment that utilizes a team-based approach to break down silos between different social services in supporting youth and their families (Bruns et al., 2010; Olson et al., 2021). It involves incorporating strengths-based approaches for building family and youth support systems, while also developing individualized care plans and continued contacts for monitoring and adjusting plans as needed (Bruns & Walker, 2010; Olson et al., 2021).

Youth who are aware of their mental health symptoms may avoid seeking help for mental health concerns, or prolong treatment (Cohen et al., 2009). When they do seek help, they often seek out informal services (e.g., family, peers, church leader, etc.), rather than professional care (Hall et al., 2016). Further, prior poor experiences with mental health professionals reduces the likelihood they will seek formal help (Hall et al., 2016), as well as family members' negative perceptions or prior experience with mental health treatment (Cohen et al., 2009; van Vulpen et al., 2018). Finally, stigma surrounding mental health and treatment creates an access and engagement gap (Hall et al., 2016; Markoulakis et al., 2020).

Youth with serious, complex mental health issues often face additional challenges in obtaining access and engagement in treatment. These youth are often involved in other social service systems, such as child welfare and juvenile justice systems (Duong et al., 2021; Miller et al., 2012). Further, these youth often have issues at school, such as limited peer support, bullying, and externalizing behaviors (Lee & Korczak, 2010). In fact, school referrals are one of the most common referrals for EPS (Molteni et al., 2021; Walter et al., 2006). Involvement in juvenile justice and school systems of care often stems from underlying symptoms and behavioral disorders (Lindsey et al., 2010; Zajac et al., 2015). These youth who are involved in multiple systems of care have more difficulty accessing care. This may be the result of poor transitions and lack of communication among the various systems (Markoulakis et al., 2020), as well as long wait times, contingencies in access to certain treatments (e.g., receiving an additional type of care, completing one level of treatment, insurance restrictions).

The Current Study

Although there is some research that examines barriers in accessing treatment for youth with severe behavioral health needs, there is less research that focuses on strengths for this population. Further, prior research is limited on qualitive descriptions of the characteristics of youth with significant mental health needs, and how these needs impact their families. This is a critical gap given the high level of involvement by family caregivers in youth mental health care, coupled with the lack of services and program targeting family caregivers. The current study seeks to fill this gap by providing a thick description of the lives of this under-examined and uniquely vulnerable population—identifying the needs, challenges, and supports. It examines the following research questions that broadly assess the challenges and supports experienced by families of youth with significant behavioral health needs: (1) What are the needs and challenges that caregivers and their youth face across the domains of school, family, and the community? (2) What supports do these families have in navigating mental health challenges and building resilience?

Methods

Sample

The population of interest included families of youth enrolled in Wraparound, a community mental health program, who also received services though a county emergency psychiatric facility. This county's mental health division offers behavioral health services, and is located in an urban, Midwestern County. Families with youth served by the emergency psychiatric facility who were also actively enrolled in Wraparound between January 2019 and June 2020 and between the ages of 8 and 22 were eligible for interviews. The research team was provided with a list of eligible families by staff from the mental health division; caseworkers from Wraparound assisted in the recruitment process, referring clients served through their organizations. Research oversight was provided by the authors' university Internal Review Board (IRB). All participants under 18 signed assent, while all parent/guardians signed consent for youth under 18 participation.

General Emergency Psychiatric Service (EPS) Population
A total of 1521 youth had an emergency psychiatric service visit in 2019, representing 2357 unique visits within the county emergency psychiatric facility. The average age of youth in this population was 16.15 years (SD = 3.45); 51% identified as female, and the most common racial/ethnic groups were Black (approximately 59%), followed by White (approximately 25%), and Hispanic (approximately 11%) with less than 5% identifying as Asian, Alaskan Native/American Indian, or Native Hawaiian/Pacific Islander. Most youth were residents of the county where the emergency psychiatric facility is located, with the highest density residing in north-central areas of the county, which is known to have higher concentrations of socioeconomic disadvantage. Finally, approximately 51% of youth with an emergency psychiatricvisit in 2019 did not have a previous admission in 2019; a small subset of the population had three or more visits within 2019 (approximately 10%).

Wraparound EPS Population A total of 212 youth enrolled in Wraparound had an emergency psychiatric visit in 2019 within the county emergency psychiatric facility. The average age of youth in this population was younger than the general EPS population, 14.13 years (SD = 2.72), approximately half identified as female, and the most common racial/ethnic groups were Black (approximately 75%), followed by White (16%), and Hispanic (approximately 11%) with less than 1% identifying as Asian. Most youth were residents of the county where the county emergency psychiatric facility is located, with the highest density residing in north-central areas of the county, which is known to have higher concentrations of socioeconomic disadvantage. Finally, a substantial subset of the Wraparound population had three or more visits within 2019 (i.e., high-utilizers, approximately 32%).

Study Sample A total of 19 participants were interviewed, including 11 youth and eight caregivers. The average age of youth interviewed was 15.9. The race/ethnicity/gender distribution included eight Black and three White youth. The sample was predominately female (n = 7), with most youth (n = 8) having only one visit to the emergency psychiatric crisis facility in the last year. Finally, caregivers who participated were most commonly mothers (n = 6), with one grandmother and one grandfather also participating.

Interview Process As part of a larger study, the interview guide, developed in collaboration with the EPS and Wraparound staff, included questions on three overarching areas: (1) experiences in the emergency psychiatric department setting, (2) Wraparound care and team communication, and (3) challenges and supports that youth and caregivers have within school, family, and the community. Participants were also asked about psychiatric crisis plans and what could be helpful or improved for current services. The focus of this study is on the challenges and supports that these families face.

Interviews were conducted in the community, with no set period of time after experiencing the EPS visit. The interview process was forced to undergo changes as the result of COVID-19. Initially, interviews were conducted within the community at preferred locations of the participants (e.g., homes, libraries, fast food restaurants). In March 2020 interviews transitioned to telephone. The research team interviewed caregivers and youth separately, often simultaneously, if needed. Interviews were typically 30–60 min long, with breaks offered if the participant expressed emotional discomfort. Adult caregivers and youth were compensated in the form of gift cards. All interviews were audio recorded to ensure participants' responses were accurately preserved and transcribed by research assistants. Transcriptions were reviewed for accuracy before being imported to Max-QDA software for qualitative analysis.

Analytical Procedure Based on the principles of grounded theory (Glaser & Strauss, 1967), the coding process was iterative in developing categories and refining until themes emerged. Analysis for each group of participants occurred simultaneously. The researchers developed a coding scheme through an iterative process, reviewing the transcripts for codes before beginning the coding process. Initial coding was conducted line-by-line, while also examining sections of text for keywords based on the interview questions as well as commonly occurring phrases. Next, the authors used axial coding to identify initial patterns in phrases and terms used, as well as relationships between codes. Finally, themes were identified from creating axial codes and superordinate ideas from the existing categories (e.g., community support, family disruption). The researchers examined connections between themes and categories to identify commonalities among participants' perceptions and experiences with challenges and supports in their lives, as well as experiences with behavioral health services. Additionally, the researchers assessed commonalities and differences between youth and caregivers.

The authors undertook several steps to enhance methodological rigor. First, the authors identified their own positionality to increase awareness of any bias and engaged in reflexivity throughout the analysis (Padgett, 2016). Second, the authors met to discuss any possible discrepancies in the interpretation of the data, finding congruent interpretations. Lastly, negative cases, or a lack of consensus on ideas, were compared to overall emerging patterns, and are acknowledged in the findings below.

Results

Youth in our study described a mix of mental health concerns including anger, depression and suicidal ideation, and schizophrenia and/or psychosis. Behaviors that triggered an emergency psychiatric crisis facility visit included self-harm and suicidal ideation, violence or property damage, and less commonly psychosis. Youth reported facing considerable challenges with respect to family and school, while caregivers articulated the impact of their youth's mental health concerns on employment, family functioning, and overall health. Further, several families reported structural and system stressors that compounded with these challenges. Youth and caregivers identified family and friends as key sources (or lack thereof) of support, while community organizations were also offered at times as supports for both parents and youth. This section delineates the ways in which challenges are intertwined for many families and youth, as well as the varied types of supports in their lives.

School Challenges

One of the most common sources of conflict for youth was school problems, which often escalated into triggering an EPS visit. Some youth engaged in self-harming behaviors or suicidal attempts in response to bullying, including the youth above, while others would act out at school, creating further school-related problems. One female youth demonstrated this response to bullying, noting, "Like if a boy mess with me or something. Or if somebody want to fight me. Or if I'm skipping or something like that." Other youth described school problems related more toward handling anger, such as fighting with classmates, while others resisted following directions from authority figures (i.e., teachers). This is particularly true for some of the male youth in the study who were characterized by their caregivers has having anger issues. One parent described her child as exhibiting this type of school-related problem, "He walks the hallway and he's been suspended a couple of times because he refused to go into the classroom and stuff like that. So, he has been suspended. Other than that, he gets into small fights—it's what he do. He get angry and he walk out the classroom."

Some parents described school staff as helpful and receptive to the challenges their youth face, while others noted that teachers and administration were unhelpful, particularly in response to bullying and peer interactions. One parent describes the challenges of working with school staff, "the interaction in the various schools have been kind of like worse, and then a little better, a little better, a little better, but they were still pretty bad because she would struggle with peer interaction. She [the youth] would struggle with staff interaction. She would struggle with just how to handle stuff or how to deal with stuff when she was feeling unsafe or when she was feeling like she might be unsafe towards others." This parent went on to state that the virtual nature of schooling during COVID helped alleviate some of the challenges her child faced with peer interaction, isolation, and self-harm. Given that many youths experienced problems with bullying or fighting at school, it is not surprising that several youths attended multiple schools over the past few years, as described by this parent, "in the past year and a half she's gone through four different school scenarios based on her need." Some parents reported that some of these school transitions were due to finding better care for their child, while others were due to fighting and safety concerns. One parent noted it was difficult to keep her child enrolled in a school setting due to fighting, "we have been strapped for schools, as a matter of fact; for him and the other students because he likes to put people in head locks and choke-a-holds and things of that nature when he fights."

Family Challenges

In addition to school-related problems, both youth and their caregivers often discussed family problems. For some youth, these issues were characterized by resistance to parents (and other authority figures) and fighting with siblings. One youth noted his history of fighting with siblings ended after his mother died, "I haven't had a crisis since the last time I fought my brother. Since the last time I fought my brother. I was trying to kill him, [my brother]. […] But ever since my momma pass, we haven't fought. It stopped when she pass, 'cause it ain't worth it." Some caregivers felt the fighting was related to anger issues, while others described it as resisting authority as their youth "don't listen to nobody," including their caregiver. Others, however, noted that parental absence and death of a family member prompted some of the problems at home or school. One parent noted that her youth's acting out at home increased due to parental separation, "So I even let her go live with Dad for a couple months because that's what she kept screaming, like she was missing that bond with Dad. It got worse."

Caregivers often described family dynamics as strained by the youth's mental illness. Parents felt other siblings were unable to receive the attention they needed, often due to increased time spent addressing their youth's symptoms and crises. One parent describes, "It's been ages—his behavior is outrageous. If every day, he can't get what he wants he wants to holler and throw things. Everybody else's things—he wants to tear them up. And everybody's sick and tired of it. It get very old for the whole family."

Another observed that she took her frustration out on the other children, "Now I'm yelling and taking it out on other kids. And then I wasn't even paying attention that my older daughter has issues, you know." Others described concern for siblings' or family members' safety within the home, particularly with youth who engaged in violent behaviors. One caregiver describes:

> That was when him and my niece got into it. I had my niece with me. She is 18 or 19 now. Basically, I had both fighting for my attention. And she was throwing it in his face, 'Well, I was here first. I was born first so, I come first.' […] That's when he pulled a knife on her. He ended up not getting what he supposed to get for his birthday (he was supposed to go to Dave and Buster's). He ended up not getting that for his birthday. And so, she came, and he felt threatened by her. And she had something in her hand or something or she was in his face or something. There was a knife at the sink, and he took that kitchen. And at that point, I called the police. He's acting up. And there's no way I'm going to kind with that. And I mean he pushed on me too. He didn't put the knife on me, but he pushed on me too. He pushed me down and onto the ground.

In situations similar to the one described here, parents described feeling helpless, particularly if law enforcement and the county behavior health services division would not take their youth away from the crisis.

Some families reported youth experiencing family and school challenges that compounded on one another. One youth with multiple prior visits discussed this phenomenon, in particular bullying and parental absence that exacerbated their depression symptoms:

> "Well, I guess, I had some kids that used to bully me and stuff, and I just got upset. And really, my dad was not there. Really, my dad wasn't there to save the day or do anything, because he was barely by my side. He was barely there even to stand next to me. And I just got really… and they said I had anti-depressant disorder, so I guess I just had some thoughts, and they took over me. I just let loose. I just try to take advantage of myself and just take myself out."

Caregiver Employment Challenges

Some caregivers also experienced employment issues, which were often exacerbated by the strain of caregiving for their youth. A couple of caregivers reported employment strain in adjusting work schedules or employment to fit youth appointments and needs. One parent noted that putting her child's needs first meant changing employment, "I did have to quit my employment and find something else that could work more around her schedule, be more flexible with what she needed." Another noted that school problems often meant common phone calls to pick up her child, which led to work absences and frustration, "Meanwhile still trying to work a full-time job, but I can't, because I keep getting phone calls saying come get your daughter, come get her."

Caregiver Health Challenges

Some caregivers reported having behavioral health concerns themselves, while others reported physical health concerns made worse from stress. Those reporting behavioral health concerns noted that the stress of caring for their youth left them overwhelmed and anxious, often because they felt they had few formal or informal supports (e.g., friend or family member). One parent expressed frustration over lack of county behavior health division support and few informal supports, "I'm crying out for help here, like I'm the parent, I'm breaking down. I'm starting to look at myself different, like what am I doing wrong? If I do this this way, she still don't get it. I do this, she still don't get it. And I'm starting to blame myself here, like is it me? Maybe I need some mental help now, because you know, it's taking a toll on me." Others with existing mental health concerns described the stress of caregiving for their youth as exacerbating their own illnesses. One parent describes seeking out help for her own mental health concerns, "I'm looking to get evaluated to just get my own counseling going through [the county behavior health division service] as an adult. But that's partially connected to her and partially just separate issues."

Structural and System Challenges Exacerbate Issues

Some families experienced external challenges, including housing insecurity and system involvement, which often compounded with family, employment, and school concerns. Three families mentioned housing insecurity as a broader challenge. One parent stated, "we've been homeless for about three months now," and that obtaining housing assistance was the greatest barrier she faced. Adult youth, by contrast, faced housing instability when caregivers no longer wanted to support them. One adult youth described homelessness in response to his actions with smoking marijuana and spending time with a girlfriend, "I got kicked out because I was finna go to my girlfriend's house, and he had a problem with it so he say he was done. And then like, I was like jumping from—nope, I slept at the park for a couple of days. And then I was jumping from hostels for two weeks and then I moved in with my sister, and then I came [to the group home]."

Finally, some families report justice and child welfare system involvement, which at times created additional barriers in caring for their youth. Two families reported juvenile

justice system involvement of their youth, often with youth placed in group homes if families are unable to address school truancy or other behavioral issues with their youth. One parent stated, "[She] was took and put in a group home. Since the date of September 28th, she's been in like 30 different group homes. And now, she's in the juvenile detention center. Between those group homes she's been in detention for like a month or two weeks. She's been there like four different times."

Another two reported child welfare involvement and out of home placement. For these parents, the stress of dealing with their youth, often coupled with additional challenges, led to a child welfare case. One parent describes the feeling of helplessness and lack of support, which culminated, in her opinion, in the removal of her children:

> when I say, hey, I need a break? I need a break. You know I don't want to be crying out for help and then I say, hey, this is going on, you guys need to remove her temporarily from the home. And they tell me, oh no, she's fine. Then I'm messing around having a mental breakdown and I snap out, and here they come, taking all my kids, and I'm like oh okay, see, so I asked you for help and now… When I ask you for help, I don't get help, but then when something happens, that's when they wanna come and say, oh now, you're gonna help.

Youth removed from home had varying experiences with separation from a parent. One youth described living with her grandmother as helpful, noting her parent had her own mental health concerns and was unable to provide the care she needed. Another youth described being teased and bullied at school for being in the child welfare system. Her mother responded, "I'm like, don't mind that, just tell them how you not in foster care, you know." For this youth, school problems with bullying and truancy compounded when she entered the child welfare system.

Family and Friend Supports

Both youth and caregivers discussed ways in which family and friends acted as informal supports in navigating stressors. Several parents mentioned family as a main source of support in dealing with the stress of caregiving for their youth. One parent mentioned that family is helpful to talk to, vent, or get perspective when her youth was escalating, "Yeah, I definitely have the ability to lean on my sister who is sometimes a much more level head." For others, tangible aspects of family support were viewed as more important, whether helping financially, offering to watch children, or providing transportation. One parent stated, "I'd like if they helped me with my rent since I don't have a job [laugh]. But I been getting by, my mom, she helps me a lot, but yeah. I need help like that." For this parent, unemployment and housing insecurity were key challenges faced in addition to caring for their youth. Having family support with these external factors may help alleviate some of the added anxiety and stress that caregivers experience. Some caregivers, however, had limited family and friends to call on for support, expressing frustration at dealing with their youth alone. One parent expressed, "It's just really hard, my life is hard. I feel like I ain't got no support, and it's just me in this world by myself, dealing with this." Although she mentioned that she does have a sister, "she got her own family too."

Similarly, some youth felt they had support—discussing the role of family in helping during emotional escalation. One youth stated, "I've always had my mom and my dad there for me. It's always been—they've always been really supportive." Only one youth mentioned that friends are supportive; instead, several youth described self-isolation and limited interaction with friends or peers at school. One youth noted, "I barely even talk to the kids in my class."

Community Supports

The role of the community, whether through churches or local organizations, as a support system for parents and youth was less commonly mentioned. Although one person mentioned religion more as relying on personal faith, two caregivers discussed how church involvement was helpful to them in dealing with stress and offering support. One caregiver stated, "we talk to our pastor, our church family about it and our friends about it. They give us advice and everything." Another mentioned that with churches closed during the initial part of the COVID-19 pandemic, she missed the support and the sense of community.

Another source of community support that a few parents mentioned is structured programing for youth. Caregivers reported summer camp and a church community service program as helpful for their youth. One parent mentioned that summer school was helpful in a previous year to keep her youth from fighting and having frequent contact with law enforcement due to behavior. She stated that the summer school provided structure for her youth, which was lacking and contributing to his triggers, "Little bit more structure; he went to summer school, he had his parenting person, the [crisis] stabilizers.".

Some caregivers report having limited community support systems, expressing frustration on caring for their youth alone. One parent stated that she and her children kept to themselves in the community, noting that she did not want her children involved in "stuff that's been going on" in her neighborhood. This is an important caveat for the role of community—many of the families served by this behavioral health system are located in areas of concentrated socioeconomic disadvantage, high crime rates, and limited community resources for mental health (Clancy et al., 2022).

Finally, some caregivers noted that the system was unsupportive at addressing the needs of their youth. One parent, whose child had attempted suicide in response to name-calling by a sibling expressed her frustration over lack of support, "I just didn't know what to do at that point, because I'm just a parent here and I have been crying out for help. It was just real disturbing to me." One parent suggested a peer support group or specialist could help show caregivers that they are not alone and provide a source of support if family and community are lacking. She felt that others too would be helped having "somebody to talk to, so I can know that I'm not in this boat alone by myself."

Discussion

Community-basedpsychiatric services are critical to youth with mental health issues, particularly youth in low socioeconomic areas, with high crime and few additional supports. Services like Wraparoud programming are built upon the systems of care model, with the goal of connecting families with the variety of needs they may have around child welfare, mental health, juvenile justice, and substance use treatment (Stroul et al., 2021). While there have been empirical studies identifying challenges to access and engagement with treatment, few studies have examined the lived experiences of families of youth with severe mental health needs in navigating these systems of care and the strengths they draw upon.

This study highlighted the high need for psychiatric crisis services in this population, how and why youth engage with these services, and how their family caregivers either receive or do not receive support in dealing with the complexity of mental health. While much of the literature on community psychiatric care focuses on the youth alone (e.g., Lindsey et al., 2013), the inclusion of the adult caregiver in our study is critical towards a broader understanding of the needs and future development of community-based programming. Indeed, Miller et al. (2012) noted the importance of addressing the family unit in providing systems of care for youth with mental illness. Although a common component in Wraparound programming, family supports may not always be present or function as intended (Olson et al., 2021). Given the additional challenges in our study sample caregivers' lives, referrals and assistance that is applicable to their needs is timely and necessary.

Data from this study highlighted the often-extreme need for services, yet underscored the gaps in providing them, particularly in the school setting. Many youths experienced bullying, which was a major contributor to continued mental health issues. Bullying by classmates often affected youths' academic performance and at times led to truancy, which had an unintended domino effect for parents. Parents discussed being pulled from work, missing appointments, and sometimes losing their jobs because they had to intervene in situations at school. In fact, bulling sometimes exacerbated situations that had been manageable, into crises. Prior research supports our findings, with school-related problems affecting caregiver employment (Stefanidis et al., 2023).

The issue of job loss and stressors for the caregivers was described throughout the interviews as a major issue. Among other social needs, these families live in low social economic areas, with few employment opportunities. Moreover, work at home options are not available to many of these families who work low pay service industry jobs. Thus, missing shifts, showing up late or constantly being called to the school burdens the families and exacerbates the potential for further involvement with the county services, including removal from home into foster care. These findings are consistent with a larger body of literature on the impact of children with mental health needs on employment stability (e.g., Sellmaier, 2022; Sellmaier et al., 2020).

The potential for removal of children from the home loomed large for many families, underscoring the tenuous nature of their everyday life in living with mental health issues of their youth. While removal can be healthful for some families, other families described how traumatic foster care was for the youth and the family, and how foster care became an added stressor to their already overwhelming experiences. The fear of removal prohibited some families from asking for help, or prevented them from asking for help until mental health issues became severe, leaving them isolated in their attempts to care for their youth.

The desire for youth to have their parents involved in their care was found in all interviews yet was particularly poignant in the interviews where the youth had lost a parent. For some, the grief of loss caused them to retreat further into mental health issues. Underscoring the positive role parents can play, parents must be supported in mental health services, but critically, services must be offered which address grief and loss in youth. None of the youth interviewed stated they had received such services, yet the amount of grief was clear as was the role grief played in exacerbating many mental health issues.

Support from both family and community is inconsistent and often fraught with stigma and inaccessibility, particularly community-based mental health services. Although extended family may be near, they offered limited help, lessening the opportunity for support. The lack of consistent and effective community support was pointed, again given the low social economic areas and extreme need. Thus, targeted community-based services, culturally relevant to the often-single family homes where parents have limited work flexibility, are critical to improved mental health for these youth and their caregivers.

Moreover, support must be flexible. These families are some of the most stressed and least supported, with little ability to adjust work schedules and with few other adults to rely on. Therefore, it is crucial that community support be conveniently located, provide flexible hours, and provide an environment safe from neighborhood crime. For some caregivers, crime in the community led to isolation and decreased support systems, limiting youth engagement with community programming for fear of crime. These findings are consistent with literature utilizing the National Survey of Children's Health, demonstrating that neighborhood safety and support systems for caregivers are important aspects for youth with special health needs (Radel & Bramlett, 2014). Community activity combined with flexible programming and behavioral health support services are crucial to keep these youth busy and receiving support, which can affect any emotional dysregulation which may occur. Finally, for those youth over 18, services drop off dramatically, including assistance with housing. Nationwide, housing is a growing issue, with costs skyrocketing, requiring high paying jobs to often afford any housing (Quigley & Raphael, 2010). Yet, in this study many youths were struggling with employment and were receiving limited support from family, making housing instability a threat to stability with mental health—with few places to turn. Thus, as with many areas, housingis critical to building better mental health in these youth.

Limitations and Future Research

This study is not without limitations. Given the nature of this hard-to-reach population, gaining participation was a challenge. Although Wraparound staff were helpful in recruiting participants, competing priorities may have meant some families were not approached or given full information during the recruitment process. The smaller sample size may limit our understanding of this population as a whole, yet many of the families interviewed did reside in the areas that have higher concentrations of psychiatric care consumers, suggesting that many of the challenges identified here would extend to other families served by this mental health division in diverse, similar low sociogenic communities. Second, our population included youth involved in Wraparound that had at least one emergency psychiatric crisis visit. Families who are not involved in Wraparound yet also have visits to this hospital setting may be vastly different from those in Wraparound, particularly on informal and formal supports. Future research should examine this subgroup of families to determine what challenges and supports they have, as well as draw comparisons between groups to better inform policy and programming for youth with mental health issues.

Future research also is needed on caregiver and youth experiences with community-based mental health services. Given that most of the youth in this population receive treatment or services within the community, it is imperative to understand caregiver and youth experiences with these services to better inform social work and mental healthcare practice in providing holistic care and reducing the need for emergency and inpatient treatment.

Policy Implications

Although this study focused on caregivers in an urban, diverse, Midwestern County, the challenges they experience likely extend to other areas, particularly in urban settings with concentrated socioeconomic disadvantage. Therefore, we make several recommendations for mental health divisions that serve youth. Although Wraparound programming incorporates systems of care approaches, the findings from this study found gaps in a well-functioning system of care. To better serve youths and there families, we recommend key components that are identified as best practices within systems of care approaches to working with youth with severe behavioral health needs (Stroul et al., 2021).

First, community based, culturally relevant formal supports are needed for these families, which can be built into mental health programming using family connection social workers, peer guides, and an overall holistic approach. Dedicated social workers can provide connections for these families to programming as well as connections and referrals for additional challenges that experience, such as housing referrals and food pantry contacts. Further, by having community-based and flexible family connection staff, involvement in programing may increase, as these staff are better able to share available programs, answer questions and speak to hesitations, and facilitate intra-agency referrals to increase follow-through by families.

In addition to family connection staff, community peer guides can be a particularly useful formal support for caregivers and youth. Older youth and caregivers who have successfully navigated mental health issues are best suited to serve as these social supports, modeling successful coping strategies and resilience, while also demonstrating empathy and shared experiences. Further, they can provide a source of connection to community resources and services to address broader challenges that families face (Najavits et al., 2014; Repper & Carter, 2011; Solomon, 2004).

Given that some caregivers expressed concern over a lack of community or family support, informal support systems are also needed. Stroul et al. (2021) highlight respite care as an example of addressing some of the needs highlighted in our findings by offering short periods of supervision for the youth while parents engage in self-care practices. One avenue of caregiver programming that could be particularly helpful is peer support groups for caregivers to share their frustrations and experiences, offering a sense of community and support from adults who can empathize with one

another based on similar experiences. This programming may assist with the feelings of isolation for caregivers who have limited natural supports from family, friends, and the larger community (see Stroul et al., 2021). This support must be offered at various times, so as not to interfere with work, and it must be offered in the community—easily accessible leading to higher engagement. These community-based support groups, whether funded by county mental health divisions, churches, or community centers, could be offered as an outside resource for caregivers who may not want system-involvement. Attention to the location of these groups and where most consumers reside is necessary to reduce transportation challenges and other barriers to access.

The families in this study are likely similar to many other families across the United States with a youth who has mental health concerns. Therefore, we expect that the need for community supports to cope with the daily struggles and stresses these families experience are widespread. As the United States focuses more on mental health, the needs of the most vulnerable, under resourced, and high poverty families need to be at the forefront in developing targeted, community-based mental health services. It is through these types of services that families can begin to build support and a long-lasting ability to manage mental health issues within their family and community.

Author Contributions DRD assisted with methodology and data collection, conducted analysis, conceived of paper, led paper writing. MK wrote grant, co-led methodology, assisted with data collection, assisted with paper writing and editing. TF wrote grant, co-led methodology, assisted with data collection, assisted with editing.

Funding This was funded by SAMSHA Grant No. MIL115362.

Declarations

Conflict of interest There are no conflicts of interest to disclose.

Ethical Approval This study was approved by the University of Wisconsin-Milwaukee Institutional Review Board.

References

Barker, E. T., Greenberg, J. S., Seltzer, M. M., & Almeida, D. M. (2012). Daily stress and cortisol patterns in parents of adult children with a serious mental illness. *Health Psychology, 31*(1), 130.

Barksdale, C. L., Azur, M., & Leaf, P. J. (2010). Differences in mental health service sector utilization among African American and Caucasian youth entering systems of care programs. *The Journal of Behavioral Health Services & Research, 37*(3), 363–373.

Bruns, E. J., & Walker, J. S. (2010). Defining practice: Flexibility, legitimacy, and the nature of systems of care and wraparound. *Evaluation and Program Planning, 33*(1), 45–48.

Bruns, E. J., Walker, J. S., Zabel, M., Matarese, M., Estep, K., Harburger, D., Mosby, M., & Pires, S. A. (2010). Intervening in the lives of youth with complex behavioral health challenges and their families: The role of the wraparound process. *American Journal of Community Psychology, 46*(3), 314–331.

Center for Disease Control. (2023). Data and statistics on children's mental health. Retrieved from https://www.cdc.gov/childrensmentalhealth/data.html

Champlin, B. E. (2009). Being there for another with a serious mental illness. *Qualitative Health Research, 19*(11), 1525–1535.

Chitiyo, J. (2014). The wraparound process for youth with severe emotional behavioural disorders. *Journal of Research in Special Educational Needs, 14*(2), 105–109.

Clancy, K., Chudzik, J., Snowden, A. J., & Guha, S. (2022). Reconciling data-driven crime analysis with human-centered algorithms. *Cities, 124*, 103604.

Cohen, A., Medlow, S., Kelk, N., & Hickie, I. (2009). Young people's experiences of mental health care: Implications for the headspace national youth mental health Foundation. *Youth Studies Australia, 28*(1), 13–20.

Copeland, D. A., & Heilemann, M. V. (2011). Choosing "the best of the hells": Mothers face housing dilemmas for their adult children with mental illness and a history of violence. *Qualitative Health Research, 21*(4), 520–533.

Das, A., Singh, P., & Bruckner, T. (2020). Racial disparities in pediatric psychiatric emergencies: A health systems approach. *Journal of Psychiatry and Brain Science*, *5*(2).

Dixon, L. B., Holoshitz, Y., & Nossel, I. (2016). Treatment engagement of individuals experiencing mental illness: Review and update. *World Psychiatry, 15*(1), 13–20.

Duong, M. T., Bruns, E. J., Lee, K., Cox, S., Coifman, J., Mayworm, A., & Lyon, A. R. (2021). Rates of mental health service utilization by children and adolescents in schools and other common service settings: A systematic review and meta-analysis. *Administration and Policy in Mental Health and Mental Health Services Research, 48*(3), 420–439.

Farinelli, L., & Guerrero, L. K. (2011). Associations between caregiving and health outcomes among parents of children with mental illness: An attachment perspective. *Health Communication, 26*(3), 233–245.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory. Chicago: Aldine.

Green, A. L., Lambert, M. C., & Hurley, K. D. (2019). Measuring activation in parents of youth with emotional and behavioral disorders. *The Journal of Behavioral Health Services & Research, 46*, 306–318.

Hall, A., McKenna, B., Dearie, V., Maguire, T., Charleston, R., & Furness, T. (2016). Educating emergency department nurses about trauma informed care for people presenting with mental health crisis: A pilot study. *BMC Nursing, 15*(1), 1–8.

Hirschi, M. (2022). Understanding the family perspective in police responses to individuals living with mental illness. *Social Work in Mental Health, 20*(1), 107–127.

Janssens, A., Hayen, S., Walraven, V., Leys, M., & Deboutte, D. (2013). Emergency psychiatric care for children and adolescents: A literature review. *Pediatric Emergency Care, 29*(9), 1041–1050.

Kalb, L. G., Stapp, E. K., Ballard, E. D., Holingue, C., Keefer, A., & Riley, A. (2019). Trends in psychiatric emergency department visits among youth and young adults in the US. *Pediatrics*, *143*(4). https://doi.org/10.1542/peds.2018-2192

Katz, J., Medoff, D., Fang, L. J., & Dixon, L. B. (2015). The relationship between the perceived risk of harm by a family member with mental illness and the family experience. *Community Mental Health Journal, 51*, 790–799.

Lee, J., & Korczak, D. (2010). Emergency physician referrals to the pediatric crisis clinic: Reasons for referral, diagnosis and disposition. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 19*(4), 297.

Leon, S. L., Cloutier, P., Polihronis, C., Zemek, R., Newton, A. S., Gray, C., & Cappelli, M. (2017). Child and adolescent mental health repeat visits to the emergency department: A systematic review. *Hospital Pediatrics, 7*(3), 177–186.

Lindsey, M. A., Chambers, K., Pohle, C., Beall, P., & Lucksted, A. (2013). Understanding the behavioral determinants of mental health service use by urban, under-resourced Black youth: Adolescent and caregiver perspectives. *Journal of Child and Family Studies, 22*(1), 107–121.

Lindsey, M. A., Joe, S., Muroff, J., & Ford, B. E. (2010). Social and clinical factors associated with psychiatric emergency service use and civil commitment among African–American youth. *General Hospital Psychiatry, 32*(3), 300–309.

Markoulakis, R., Chan, S., & Levitt, A. (2020). The needs and service preferences of caregivers of youth with mental health and/or addictions concerns. *BMC Psychiatry, 20*, 1–11.

Mendenhall, A. N., & Mount, K. (2011). Parents of children with mental illness: Exploring the caregiver experience and caregiver-focused interventions. *Families in Society, 92*(2), 183–190.

Merikangas, K. R., He, J. P., Burstein, M., Swendsen, J., Avenevoli, S., Case, B., Georgiades, K., Heathon, L., Swanson, S., & Olfson, M. (2011). Service utilization for lifetime mental disorders in US adolescents: Results of the National Comorbidity Survey-Adolescent Supplement (NCS-A). *Journal of the American Academy of Child & Adolescent Psychiatry, 50*(1), 32–45.

Miller, B. D., Blau, G. M., Christopher, O. T., & Jordan, P. E. (2012). Sustaining and expanding systems of care to provide mental health services for children, youth and families across America. *American Journal of Community Psychology, 49*(3), 566–579.

Molteni, L., Cafaro, R., Varinelli, A., Espa, I., Mora Conde, M., Maria Brambilla, A., Vigano, C., & Dell'Osso, B. (2021). Do adolescents and young adults accessing the Emergency Room with substance use receive poor therapeutic indications at discharge? An observational retrospective study. *International Journal of Clinical Practice, 75*(12), e14890. https://doi.org/10.1111/ijcp.14890

Najavits, L. M., Hamilton, N., Miller, N., Griffin, J., Welsh, T., & Vargo, M. (2014). Peer-led seeking safety: Results of a pilot outcome study with relevance to public health. *Journal of Psychoactive Drugs, 46*(4), 295–302.

Olfson, M., Druss, B. G., & Marcus, S. C. (2015). Trends in mental health care among children and adolescents. *New England Journal of Medicine, 372*(21), 2029–2038.

Olson, J. R., Benjamin, P. H., Azman, A. A., Kellogg, M. A., Pullmann, M. D., Suter, J. C., & Bruns, E. J. (2021). Systematic review and meta-analysis: Effectiveness of wraparound care coordination for children and adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry, 60*(11), 1353–1366.

Padgett, D. K. (2016). *Qualitative methods in social work research* (Vol. 36). Sage publications.

Quigley, J. M., & Raphael, S. (2010). The economics of homelessness: The evidence from North America. *European Journal of Housing Policy, 1*(3), 323–336.

Radel, L., & Bramlett, M. (2014). Children in nonparental Care: findings from the 2011–2012 National Survey of Children's health. *Children*, *3*(01).

Repper, J., & Carter, T. (2011). A review of the literature on peer support in mental health services. *Journal of Mental Health, 20*(4), 392–411.

Richardson, L. P., Lewis, C. W., Casey-Goldstein, M., McCauley, E., & Katon, W. (2007). Pediatric primary care providers and adolescent depression: A qualitative study of barriers to treatment and the effect of the black box warning. *Journal of Adolescent Health, 40*(5), 433–439.

Sellmaier, C. (2022). Physical and mental health of mothers and fathers caring for children with special health care needs: The influence of community resources. *Journal of Family Issues, 43*(11), 2815–2840.

Sellmaier, C., Stewart, L. M., & Brennan, E. M. (2020). Workforce participation of parents of children and youth with mental health difficulties: The impact of community services and supports. *Community, Work & Family, 23*(5), 534–555.

Snowden, L. R., Masland, M. C., Fawley, K., & Wallace, N. (2009). Ethnic differences in children's entry into public mental health care via emergency mental health services. *Journal of Child and Family Studies, 18*(5), 512–519.

Solomon, P. (2004). Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal, 27*(4), 392.

Song, J., Mailick, M. R., & Greenberg, J. S. (2018). Health of parents of individuals with developmental disorders or mental health problems: Impacts of stigma. *Social Science & Medicine, 217*, 152–158.

Stefanidis, A., King-Sears, M. E., & Kyriakidou, N. (2023). School bells are ringing, but can parents attend? Responses from employed parents of children with SEND. *Community, Work & Family, 26*(2), 170–189.

Stenersen, M. R., Kelly, A., Bracey, J., Marshall, T., Cummins, M., Clark, K., & Kaufman, J. S. (2022). Understanding racial-ethnic disparities in wraparound care for youths with emotional and behavioral disorders. *Psychiatric Services, 73*(5), 526–532.

Stroul, B. A., Blau, G. M., & Larsen, J. (2021). The evolution of the system of care approach. *The Institute for Innovation and Implementation, School of Social Work, University of Maryland.* https://www.cmhnetwork.org/wp-content/uploads/2021/05/The-Evolution-of-the-SOC-Approach-FINAL-5-27-20211.pdf.

van Vulpen, K. S., Habegar, A., & Simmons, T. (2018). Rural school-based mental health services: Parent perceptions of needs and barriers. *Children & Schools, 40*(2), 104–111.

Walter, H. J., Gouze, K., & Lim, K. G. (2006). Teachers' beliefs about mental health needs in inner city elementary schools. *Journal of the American Academy of Child & Adolescent Psychiatry, 45*(1), 61–68.

Winters, N. C., & Metz, W. P. (2009). The wraparound approach in systems of care. *Psychiatric Clinics of North America, 32*(1), 135–151.

Worsley, D., Barrios, E., Shuter, M., Pettit, A. R., & Doupnik, S. K. (2019). Adolescents' experiences during "boarding" hospitalization while awaiting inpatient psychiatric treatment following suicidal ideation or suicide attempt. *Hospital Pediatrics, 9*(11), 827–833.

Yohannan, J., Carlson, J. S., Shepherd, M., & Batsche-McKenzie, K. (2017). Exploring attrition, fidelity, and effectiveness of wraparound services among low income youth of different racial backgrounds. *Families, Systems, & Health, 35*(4), 430–438.

Zajac, K., Sheidow, A. J., & Davis, M. (2015). Juvenile justice, mental health, and the transition to adulthood: A review of service system involvement and unmet needs in the US. *Children and Youth Services Review, 56*, 139–148.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.