



Developing a Needs Assessment Process to Address Gaps in a Local System of Care

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Abstract

Early diagnosis and access to behavioral health services can improve the health outcomes for young children suffering from mental illness. Often, children and their families' behavioral health needs are not met due to a broken local system of care. Developing a deep understanding of the situation by exploring all stakeholders' needs across a community in conjunction with a comprehensive review of the existing scientific literature prepared one rural midwestern county to build a better local system of care. This study's unique aspects include visual mapping using art in focus groups and close collaboration between a public mental health board, academic faculty, student researchers, local behavioral health organizations, and schools. Major themes found about the existing barriers were dysfunctional patterns in families, lack of resources, reliance on the school system, and lack of access to healthcare professionals. Other communities can use this approach as a model for a local needs assessment.

Keywords Children · Community-based participatory research · Mental illness · Parent support · Visual mapping · Qualitative research

Introduction

When a state-required needs assessment revealed the need to increase access to behavioral health services for young children, the DeKalb County Community Mental Health Board responded by setting goals and objectives to address the issue immediately. Together in partnership with Northern Illinois University, they developed a 360-degree view of the problem through community-based participatory research that involved in-person focus groups, an online survey, and telephone interviews with each targeting various stakeholders. By taking an academic-oriented path seeded by a systematic review of the literature and multiple novel approaches like visual mapping to capture the community views, this pursuit to increase access went beyond a traditional community plan. Such community and academia collaboration for behavioral health services may also have

wider reaching benefits as health sciences student researchers can take their knowledge and skills from this project to other communities in need post-graduation.

Research shows that taking a population health approach to caring for the behavioral health care needs of young children in a community can enhance overall care (Jason & Aase, 2016; Purtle et al., 2020). This involves coordination between the various individuals and organizations that interact with young children and their families such as early childhood educators, social services, the school system, primary care physicians, mental health care providers, and other community groups (Jason & Aase, 2016; Foy et al., 2010). Parents often do not receive education about behavioral health care for their young children early enough. They may endure months or even years of struggling to understand their situation before learning about specific behavioral health conditions and available resources (Cormier et al., 2020; Frauenholtz et al., 2015). Such parent education may come from schools, health care providers, social media, and community groups (Aciri et al., 2017; Arimura et al., 2011; Stroever et al., 2011).

Parents may also learn from their peers, and a successful strategy to help parents learn about behavioral health care resources and providing support is by establishing

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parent peer support. Parents may support each other through online networks, face-to-face groups, telephone calls, or individual meetings (Substance Abuse and Mental Health Services Administration, 2017; Niela-Vilén et al., 2014). Besides offering hope and camaraderie, parents can help their peers navigate the health care system and exchange ideas and information about local medical providers and community resources (Substance Abuse and Mental Health Services Administration, 2017). Parent peer support groups can also help parents gain skills and feel empowered to deal with challenging issues they face (Law et al., 2002). In a systematic review, Niela-Vilén et al. (2014) found that parents were satisfied with online peer support and that it was accessible despite geographic or time constraints. However, it's important to point out that online support may not be accessible to all as it depends on access to the Internet (Parra-Cardona & DeAndrea, 2016).

When an educator or primary care provider identifies a young child as needing mental health evaluation, that child is often referred to a behavioral health care provider (Substance Abuse & Mental Health Services Administration, 2019; Williams et al., 2010). This process can break down when there is a shortage of psychiatrists, psychologists, and other behavioral health care professionals in a geographic area (Chandra, 2020). A shortage of behavioral health care professionals in the U.S. is all too common, particularly for caring for children (McBain et al., 2019; Thomas et al., 2009) and for people living in rural locations (Guerero & Roberts, 2017; Merwin et al., 2003). Even when there are behavioral health care providers in the area, parents often face an insurance barrier (Rowan et al., 2013). Bishop et al. (2014) found that acceptance rates of all types of insurance were significantly lower for psychiatrists than for physicians of other specialties.

Some strategies communities and health care systems employ to help overcome the behavioral health care shortage barriers include financially incentivizing mental health care providers to shortage areas and utilizing telepsychiatry (Health Resources and Services Administration, 2021; Myers et al., 2007; Thomas et al., 2018). Financial incentives may include loan forgiveness or signing bonuses in exchange for a provider's service in an area in need of health services (Health Resources & Services Administration, 2021; U.S. Department of Education, 2021). Telepsychiatry is the process of "providing a range of services including psychiatric evaluations, therapy (individual therapy, group therapy, family therapy), patient education and medication management...from a distance through technology, often using videoconferencing (American Psychiatric Association, 2020)." Research shows that telepsychiatry can be an effective strategy for delivering effective care to children and expanding access to care in

underserved communities (Myers et al., 2007, 2008; Thomas et al., 2018).

To better understand the community's needs regarding behavioral health services for young children and determine a targeted plan that includes some of the above strategies for developing a local system of care, this study employed multiple qualitative research methods. Through visual mapping using art, surveys, and interviews, the researchers collected data across the rural county to determine unmet needs for children and families and construct evidence-based recommended strategies and provide resources for community entities going forward.

Methods

Northern Illinois University's Institutional Review Board declared this study was not "human subjects research" and therefore exempt from review.

Focus groups

Focus group participants were recruited by emailing flyers to behavioral health-related organizations, publishing information in local newspapers, advertising through local chambers of commerce, and posting flyers in public facilities around DeKalb County, IL. All individuals aged 18 or older who either lived or worked in the county were eligible. The focus groups were held at three different times in three different public locations around the county. At the beginning of the focus group, the facilitator explained the purpose of the focus group and randomized the participants into small groups consisting of about four people. Each of the groups received a different fictional persona about a child and his/her circumstances and mental health issue. Each persona included details about the child's life (e.g., struggling in school, having tantrums) as well as his/her family members (parents fighting, parent depressed). The persona also included an image of the child created using artificial intelligence (Nvidia, 2021). The groups met and discussed their assigned persona for 20 min.

After the small group discussions, the facilitator brought the participants together for a larger discussion about the personas. An artist drew images and wrote keywords on a large sheet of white paper reflecting what the participants were saying and visually created "stories" for each of the personas. The facilitator or artist probed further when participants made comments about behavioral health problems that existed in the community. At one point, the artist said, "What happens next in this story?" The personas were used as prompts, but often the discussion addressed the problems for people who lived in the community facing issues similar to those of the characters in the fictional scenarios.

For the focus group analysis, the two researchers (MCH & ES) viewed the three storybooks (one from each focus group) in their entirety to immerse themselves in the content and flow of the focus groups before developing a codebook and independently coding the focus groups. The structure of the focus groups and main question elements guided the beginning list of codes. After comparing coded storyboards, the researchers resolved discrepancies through discussion and developed a detailed codebook. The researchers used the qualitative data management software, ATLAS.ti, to perform a limited content analysis, including identification of themes and representative images. Quantitative analysis was limited to tabulation of responses without statistical testing to keep with the exploratory nature of this study. The chosen images represented the nature of other images of the same theme.

Surveys and interviews

For the surveys, we recruited behavioral health care organizations serving DeKalb County by sending an invitation email to take a short survey about children's mental health services in the county. The survey consisted of 12 questions (see Table 1) based on our literature review and guided by our focus group data and research questions. We made revisions to our survey, mainly to add additional questions or answer choices based on feedback from members of the DeKalb County Community Mental Health Board.

For the interviews, we recruited student services directors in the county by first emailing superintendents for public school districts and head of schools for private schools asking if they would be willing to have their school district/school participate in an interview. Our introductory email explained that Northern Illinois University was collaborating with the DeKalb County Community Mental Health Board to help improve access to mental health care services for children ages 0–7 in DeKalb County. We included that we wanted to hear from the area schools to understand better their role and any resources (existing or needed) to assist families dealing with mental health issues. We developed the written interview guide and protocol based on our literature review and guided by our focus group data and research questions. The interview explored the process of identifying children in need of behavioral health services, behavioral health-related training received by faculty and staff, resources provided to children and families, resources needed by children and families, and collaborations schools may have with community organizations in the area of behavioral health. The interviews were conducted by a graduate student with a background in mental health care and by a study co-author (ES), both trained in qualitative data collection. The survey and interview data were analyzed by two researchers (ES & MCH) using cross-tabulations, categorization, and graphs to generate themes. MCH and ES received consulting fees from the DeKalb County Community Mental Health Board for their time to administer the survey and

Table 1 Survey questions

1. What is the name of your organization?
2. Please choose the best answer for each row about your organization's services for *children ages 7 & under and their families*
 - a. *Column headings* We do not provide service; Underutilized service we provide; Demand is roughly equal to supply of service we provide; Overutilized service we provide
 - b. *Rows* Mental health assessments; Case management services; Child psychiatry services; Community living support; Day program or activity services; Emergency or crisis services; Home-based services; Family counseling services; Individual services; Play therapy
3. Name any services (from those above or others) that your organization does NOT provide but that the *public shows interest in* from your organization
4. In what ways do you communicate information to the public? Check all that apply. (Choices: Newspaper, Website, Facebook, Flyers, Instagram, Twitter, Snapchat, Mobile app, School distribution channels, Other—please describe)
5. Which of the following do you provide at no extra cost or low-cost for your clients? Check all that apply. (Choices: Transportation, Child care; Your services outside of normal weekday hours; Referrals, Financial assistance—please describe; Other—please describe)
6. What are the names of other organizations where you often refer children and/or their families?
7. What are the names of organizations that refer children and/or their families to your organization?
8. Please list any organizations with which you collaborate to provide services and indicate what services you collaborate with them to provide
9. What kind of support, resources, or training do you need to enhance your organization's support of young children?
10. What else would you like us to know about your organization's mental health services and/or the accommodations that you offer for children and their families?
11. Do you have any other thoughts you would like to share about mental health services for young children and their families in DeKalb County?
12. What is your name and contact information? (*optional*)

analyze the focus group data. All authors certify responsibility for the manuscript.

Results

Focus Groups

There were 31 individuals who attended the focus groups. The focus groups were held in three different locations and at three different times of day across the county. The participants’ affiliations varied and are described in Table 2. Only one participant in the focus groups was male.

Theme 1: Dysfunctional Patterns in Families

Dysfunctional patterns in families were observed in all focus groups and was central to playing a large part in the occurrence and reoccurrence of various pain points. In each of the focus groups, the trigger for taking action about the child’s mental health usually involved family conflict. In many cases this included absence of a family member (e.g., a parent) and/or hostility toward the child. Throughout the process of pursuing help and obtaining care and treatment for each persona, family-related struggles permeated the discussion. A mother’s mental health status revealed itself as a pain point during a part of the discussion moving from pursuing help to focusing on care and treatment. The child’s potential trauma was also mentioned at this time.

Theme 2: Lack of Resources

A lack of resources was an ever-present concern for all of the focus groups. Transportation was mentioned multiple times. Not having childcare resources was another concern repeated throughout the day of focus groups (Fig. 1). A lack of time was another concern for dealing with child and family behavioral healthcare. Oftentimes, the parent works outside the home and finds it difficult to manage the additional

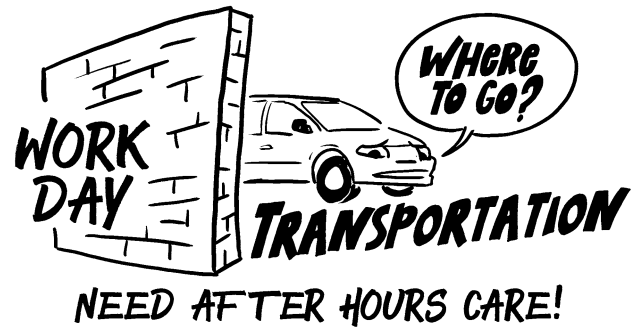


Fig. 1 Lack of transportation and childcare resources were discussed in the focus group

needs required when there are child mental health issues. For example, it can be hard to schedule appointments with mental health care professionals during working hours when the parent is also working and cannot afford to take time off work. Participants often mentioned knowledge as a resource that was lacking. While information exists online or from friends and family, too often it is bad or conflicts with other information.

Theme 3: Reliance on the School System

The importance of the school system surfaced throughout the focus groups. Most of the time poor behavior in school and/or poor performance was an early indicator of a child needing mental health assistance (Fig. 2). This was mentioned for children of various ages, from daycare to preschool to early elementary school. The schools are a resource for parents to learn more about their child’s condition and obtain help.

Theme 4: Lack of Access to Healthcare Professionals

The participants brought up the difficulties in gaining access to healthcare professionals. Concerns about an overall lack of qualified professionals were apparent. In many cases, there are long waitlists, and participants said that children

Table 2 Participant affiliation

Affiliation	No. of participants
Community residents	6
Education providers	7
Medical	1
Nonprofits	8
Northern Illinois University professors	3
Therapists	5
Unknown	1



Fig. 2 Poor behavior in school: early indicator of a child needing mental health assistance

often aren't seen by medical professionals for a long time. Relating to getting visits with healthcare professionals was the importance of help navigating the health care system, in general.

Surveys and Interviews

Of the 43 behavioral health organizations invited, 19 completed the survey. The response rate for school interviews was lower, with nine superintendents or heads of schools agreeing to have their school district/school participate out of the invited 24. Eight student services directors were interviewed because there was one who could not be reached.

Both the schools and organizations reported the need for more social services support for families in areas like childcare and transportation. They also reported inadequacies in the health care system regarding providing enough services and support. The lack of child psychiatry services particularly stood out for organizations. Education about behavioral health for children for parents was another reported unmet need. The school interviews also brought to light the need for behavioral health information for adult services that parents might need. Overall, there is considerable overlap in the data collected from the community, organizations, and schools. Table 3 summarizes

Table 3 360-degree view of community behavioral health service needs for young children and families

Need	Viewpoint		
	Community (focus groups)	Organizations (surveys)	School (interviews)
Childcare	Overall lack	Connects with lack of transportation	Limited to after school care available only in some school districts
	Reliant upon family members		Lack of quality (e.g., emotional regulation before kindergarten)
	Availability conflicts with work schedule		
Healthcare system	Not enough behavioral health providers	Lack of psychiatrists	More rural schools have very low to almost no providers
	Waitlists	Need psychiatry services in schools	Long wait times
	Lack of long-term relationships with providers	Need for infant and early childhood consultation	Families lack understanding of the system
	Red tape	Lack of autism support services	More partnerships needed
	Need assistance navigating	Need more home-based services for young children	
	Inefficient Referral after referral		
Identification of problem	Rely on schools for screenings	Need better understanding of how to engage and work with "high risk" families	Rely on schools for screenings
	Bad information		Schools becoming front lines for many problems School staff has limited training in behavioral health care
Insurance	Reliant upon who takes Medicaid	Many children are under-insured or not insured	Families lacking insurance coverage issues for behavioral health
Parent education	Look online	Need groups	Lack of resources
			Funding behavioral health education is an issue
			Parents need behavioral health care education for themselves, too Some parents are disinterested
Transportation	Lack of Transportation	Major barrier to obtaining services	Need more for services provided outside of school
	Reliant on public transportation		
	Public transportation is unreliable and inconsistent		
	Lack of time for transportation		

the community behavioral health services needs for young children from all perspectives examined in this study.

Discussion

The comprehensive community study used a variety of qualitative methods from multiple stakeholder angles to reveal major needs related to behavioral health services for young children in the County. Increasing access to behavioral health services for children and education to parents along with helping to meet the social needs of children and their families were salient themes from the data. The need for better communication and information exchange between parents, schools, health care providers, and behavioral health organizations was also apparent.

When communities identify behavioral health services needs in their locale, it can be helpful to know what works in other communities. For example, other communities have developed and implemented creative strategies to address dysfunctional patterns in families. One such initiative, *Handle with Care*, implements a trauma-informed response coordinating law enforcement, schools, and behavioral health providers (West Virginia Center for Children's Justice, 2021). In this program, if a law enforcement officer encounters a child during a call, that information is relayed to the school before the start of the next school day. The school immediately implements its trauma-sensitive curricula and has behavioral healthcare available if the child needs it. Another community approach is offering trauma-informed events such as fairs, educational sessions, and film screenings. See Table 4 for strategies developed and implemented in U.S. communities to

address dysfunctional patterns in families and the other major study themes.

Parent education and peer support regarding young children's behavioral health needs stood out as lacking yet desired by stakeholders across the County. Information for parents not only can help their children but can also help ease the stress for the parents. Past research has shown success in implementing peer outpatient support (Pasold et al., 2010), peer support specialists (Byrne et al., 2018; Daniels et al., 2017), and parent-led groups (Law et al., 2002; Niela-Vilén et al., 2014). Local public health organizations, schools, and community organizations can help facilitate parent education and peer support by providing internet links to behavioral health education, starting online peer support groups, and managing an online database of parent reviews of providers.

This study highlighted the heavy reliance on the school system. With that reliance comes an opportunity for the school system to help positively impact the behavioral health of students and families. A recent initiative by schools includes offering mental health days to students (Caron, 2021; Franklin, 2021). The need for this measure has been more apparent during the COVID-19 pandemic when young children have exhibited anxiety about their parents getting sick and separation from their parents and caregivers (Franklin, 2021). Schools are also increasing suicide awareness with middle schools and high schools printing suicide prevention information on students' identification cards (Guerrero, 2021).

The lack of child psychiatry services reported by the community and organizations was not surprising given national shortages of providers (McBain et al., 2019; Thomas et al., 2009). With about 20% of Americans living in non-urban

Table 4 Recommendation strategies that have been developed and implemented in U.S. communities to improve a local system of behavioral health services for children

Theme	Strategies	Examples
1. Dysfunctional patterns in families	Schools or community organizations implementing trauma-informed events	<i>Handle with Care</i> (West Virginia Center for Children's Justice, 2021)
	Trauma-informed community events	Community screening film, <i>Paper Tigers</i> (KPJR Films, 2021; Redford, 2015)
2. Lack of resources	Assemble and share an online database of parent reviews of local mental health care providers accessible to other parents	The Parent List (Messana, 2020)
	Online mental health education for parents	NAMI Basics OnDemand (National Alliance on Mental Illness, 2021)
3. Reliance on the school system	Offering students mental health breaks	Allowing mental health days off school (Caron, 2021; Franklin, 2021)
	Increase suicide awareness in schools	Printing suicide prevention information on student IDs (Guerrero, 2021)
4. Lack of access to healthcare professionals	Offer teletherapy in schools	(Smith et al., 2020)
	Take advantage of education scholarships or loan repayment	National Health Service Corps (Health Resources & Services Administration, 2021)

areas (U.S. Census Bureau, 2021), finding methods to increase behavioral health professional access to these locations, which often lack child psychiatrists (Centers for Disease Control & Prevention, 2018), is paramount. One potential method for increasing provider access in areas with a lack of psychiatrists is telepsychiatry, a mode of service delivery that can be especially useful in emergencies (Hughes et al., 2019; Thomas et al., 2018). Additionally, communities can take advantage of education scholarships or loan repayment offered to mental health care providers (Health Resources & Services Administration, 2021).

The need to address children's and families' social needs was highlighted by all the groups of stakeholders in the study. Research shows that addressing social determinants of health like access to health care and transportation can positively impact health outcomes (Office of Disease Prevention and Health Promotion, 2021). Using a life-course approach, the adverse effects of not having social needs met in childhood can have a cumulative impact on both mental and physical health throughout the lifespan (Allen et al., 2014). To help improve the social situations of the poor and underserved, a 2019 report of the National Academies of Science, Engineering, and Medicine recommends that health care and social care become more integrated, and that social workers and other social care workers be reimbursed by health care payers as if they were health care providers (National Academies of Sciences, Engineering, and Medicine, 2019). States are increasingly taking such action by implementing strategies to address social determinants of health for their Medicaid population. Its enrollees are low-income and, thus, more likely to struggle to meet basic needs. Some of these strategies include integrating social support and health care, covering nonmedical services, and evaluating the impact of social determinants of health interventions (KFF, 2018).

DeKalb County Community Mental Health Board is now following up this study with a community-wide survey to elicit any additional barriers to receiving behavioral health services and gain community member expertise about possible strategies to address the care gaps. In disseminating this survey, they have asked community leaders and other trusted individuals to endorse and support survey completion. One of the goals is to capture information from community members represented as personas in the focus group process. Following this step, the DeKalb County Community Mental Health Board will determine and implement strategies to improve the local system of care.

This study had both strengths and limitations. One strength is the access it provided to community members', behavioral health organization administrators', and school student services personnel's viewpoints regarding behavioral health services for young children. Another strength

is the use of visual mapping and persona stories to capture stakeholders' thoughts, emotions, and concerns throughout the community. A limitation of the study is that the data is dependent on self-reported information. There is a possibility that the respondents answered in ways they thought would please the researchers. Furthermore, this study examines one county. Though there are not any apparent aspects of this county that make it that different from other rural U.S. counties, there is a chance that local factors exist that impacted the data.

Early diagnosis and access to behavioral health services can improve the behavioral health outcomes for young children with mental illness. This study highlights the needs and opportunities for improving the local system of care in one midwestern county by engaging stakeholders countywide using various qualitative research methods. This model of county mental health workers collaborating with academic researchers to more deeply understand the barriers and facilitators to providing child behavioral health services for families most in need can be replicated in other locations throughout the country. Furthermore, the knowledge and skills acquired by student researchers assisting with data collection and analysis will potentially benefit future communities where these individuals work after graduation. With limited public mental health resources available and competing needs for those resources, developing a thorough and holistic understanding of the gaps in services and potential evidence-based strategies is critical to ensuring future success in meeting children's and families' behavioral health needs.

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Author Contributions MCH conceived and supervised the study. MCH, ES and DC performed data collection. ES and MCH coded and analyzed the data. All authors contributed to the article writing.

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Declarations

Conflict of interest M. Courtney Hughes and Ethan Spana received consulting fees from the DeKalb County Community Mental Health Board for their time to administer the survey and analyze the focus group data.

Ethical Approval MCH and ES received consulting fees from the DeKalb County Community Mental Health Board for their time to administer the survey and analyze the focus group data. Northern Illinois University's Institutional Review Board declared this study was not "human subjects research" and therefore exempt from review.

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