Barriers to and Supports of Family Participation in a Rural System of Care for Children with Serious Emotional Problems

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Abstract

Researchers have not adequately addressed the unique characteristics of rural areas that influence the accessibility of services for families with children who have serious emotional problems. Understanding rurality is particularly important to "systems of care" grant sites because these grants are intended to restructure mental health service delivery by building upon the strengths of a community and addressing the community's needs. This qualitative study examines the barriers to and supports for participation in services within a rural system of care site through the reported experiences of eight caregivers and nine staff. Findings indicate families face many challenges related to rurality, including stigma, transportation, isolation, poverty, and service availability. In addition to these challenges, however, participants reported many meaningful supports such as the religious community and the close-knit community of families and service providers. We present implications for planning, implementing, and evaluating systems of care in rural areas.

Keywords

children; mental health; rural; barriers; supports

Introduction

The Comprehensive Community Services for Children and their Families Initiative (hereafter referred to as the "system of care") is the largest children's mental health project ever conducted by the US federal government. Between 1993 and 2007, the Substance Abuse and Mental Health Services Administration (SAMHSA) funded 126 system of care community grant sites at a total cost of $1.1 billion (SAMHSA Systems of Care, 2008). These grants represent an attempt to restructure local children's mental health systems so they incorporate system of care values and principles into all service providers working with families with children with serious emotional problems. This includes agencies such as mental health, juvenile justice, education, and child welfare. The system of care philosophy emphasizes community-based, culturally competent, integrated, comprehensive services provided in the least restrictive environment and with the full participation of the child's family and natural supports in planning and delivery of services (Stroul & Friedman, 1986).

To help reach these goals, many grantee communities engage in some sort of collaborative service planning, such as wraparound. Wraparound refers to a process of organizing and coordinating service delivery with children and families with complex needs who are involved with multiple services, such as therapy, special education, medication, employment services, and transportation. The principles of wraparound include such things as conducting a team-driven treatment planning process that includes caregivers, children, agencies, and community services; prioritizing family voice and choice; and utilizing natural supports such as friends, extended family, and neighbors (Bruns, et al., 2004; Goldman, 1999).

As illustrated above, the system of care philosophy and the principles of wraparound both emphasize the community context. Because the community context is highly important within systems of care, it makes sense to consider the salient aspects of communities. One of these aspects may be rurality. Rural areas, and the mental health systems within them, are part of a particular ecological context not often studied in social science, which has been historically urbancentric (Heflinger & Christens, 2006). This is somewhat incongruent, as people living in rural areas make up a large portion of the United States' population. More than one in five (21%) children or adolescents in the United States live in rural areas (U.S. Census Bureau, 2000).

Rural areas have unique characteristics that are likely to contribute to the type of coordination and collaboration necessary in system of care sites and wraparound planning. Similarly, people living in rural areas may have unique needs in regards to systems of care. The specific relationship of rurality—and its corresponding physical, cultural, and relational characteristics —to the supports and barriers in accessing services in system of care sites has not been systematically studied.

In general, the prevalence of psychiatric disorders in children and young adults in rural areas in the United States is understudied. There has been no national study comparing rural and urban prevalence rates, although some evidence indicates that these rates are comparable. One of these studies was conducted using data from system of care grantee communities: children served through systems of care sites in rural areas were found to have comparable levels of functioning to children served in urban sites, after controlling for demographic variables (Walrath, et al., 2003). Similarly, Costello, Keeler, and Angold (2001) found roughly equivalent prevalence rates for children aged 9 to 11 living in four poor rural counties in North Carolina when compared to national prevalence rates. Another study found that young adults in the rural Midwest had rates of mental health disorders comparable to or higher than certain urban communities (Rueter, Holm, Burzette, Kim, & Conger, 2007).

Rates of service utilization may or may not be equivalent. At least one study found comparable rates of service utilization between rural and urban young adults (Rueter et al., 2007). However, studies have generally found that adult residents of rural areas are less likely to receive mental health treatment than residents of urban areas (Hartley, Agger, & Miller, 2002; Lambert & Agger, 1995; Wang, et al., 2005). Rural mental health utilization rates have been shown to be lower than urban rates for both outpatient and inpatient care (Hartley, et al., 2002; Lambert & Agger, 1995). While these studies were conducted with adults, there is reason to believe that these concerns are similar for children and adolescents. Furthermore, children and adolescents are often more reliant on others for assistance in accessing services. This can be both an enabling factor and a barrier to use of mental health services. On one hand, it is possible that children have more "built-in" supports such as families and schools. Conversely, when these supports fail, or are themselves part of the problem, children and adolescents may have little recourse.

Families living in rural areas may experience service barriers that are more numerous, more difficult, more pervasive and different from barriers experienced by families living in urban areas (Hartley, Bird, & Dempsey, 1999). The most significant disparity between urban and rural areas is the presence of resources. In general, people living in rural areas have inadequate access to physicians (Ricketts, 1999), mental health services (Hartley, et al., 1999), and emergency psychiatric services (McCabe & Macnee, 2002). One study with adolescents in rural Iowa found that even after admission to a treatment center, only 36% of those with a dual diagnosis of mental health and substance use disorders received both mental health and substance use treatment (Anderson & Gittler, 2005), possibly due to the unavailability of resources. In addition, people living in rural areas may experience increased stigma about

receiving mental health services (Boydell et al., 2006; Ekeland & Bergem, 2006; Hoyt, Conger, Valde, & Weihs, 1997), which some studies have associated with the interconnectedness of rural communities and mistrust of health professionals (Sawyer, et al., 2006). A qualitative study of rural caregivers of children with mental health problems in Canada found personal, environmental, and systemic barriers and facilitators to receiving care (Boydell et al., 2006). In this study, personal barriers included stigma, a lack of awareness of services, and financial difficulties, while personal facilitators included word of mouth and personal advocacy. Systemic barriers included a lack of human resources, policy and funding issues that prevent collaboration and flexibility, long waiting lists, and the invisibility of mental health problems. Systemic facilitators included delivery of personal services and offering services in local communities. Distance from providers was mentioned as an environmental barrier, while the small size of rural communities was mentioned as an environmental facilitator of services (Boydell et al., 2006).

As the field of rural mental health research moves forward, it is important to also explore local contexts, the ways in which facilitating and disabling factors interact to create complex situations, and the creative and resilient strategies that caregivers, service providers, and community agencies develop to deal with unmet need. This research is especially needed in the context of systems of care efforts. The system of care emphasizes policy and practice within local contexts, focusing on community-based services, community involvement in planning and delivery of services, and cultural competency at all levels. A major goal of the system of care is to reduce the barriers to care for families, including barriers related to community context.

Qualitative research on barriers to and supports of service utilization in rural systems of care is lacking. For instance, a published review of all of the qualitative research presented at one of the leading system of care research conferences (the University of South Florida's Research and Training Center for Children's Mental Health) from 1988 to 2003 did not mention the rural context as an issue or topic of research (Hodges, Hernandez, Pinto, & Uzzell, 2007). An additional review, conducted by the present authors, of the conference proceedings from this conference between 2003 to 2007 found only three presentations that specifically addressed the rural context (Dean, Wiens, Liss, & Stein, 2007; Gilford & Walrath, 2008; Thomlinson, Maples, & Rimel, 2005). Only two of these were empirical, each were quantitative, and only one of these (Thomlinson, et al., 2005) used data from a system of care grantee site. None of these studies examined barriers to care. The purpose of the current study was to address this gap in the system of care research by qualitatively examining barriers to family participation in a rural system of care for children and adolescents with serious emotional problems and to provide information that could be used to improve service delivery in a rural context.

Methods

This study employed a community-based participatory design (Minkler & Wallerstein, 2003). As a university-based research team, we were invited to conduct this research by members of a rural system of care site (including the director of the statewide family support agency, the research manager of the participating mental health agency, and the project director of the program created by the system of care site). This was due to concerns by the research manager, the director of the statewide family support agency, and the executive committee of the site regarding a lower rate of family engagement and retention in their system of care program than they wanted.

Study Context

The system of care grantee community that served as the location for this study, which we will call the "Community of Care" program in order to preserve anonymity, is located in a rural

county in the southeastern United States. There are an estimated 78,000 residents in the county (U.S. Census Bureau, 2006). Population density for the county (113 persons per square mile) is considerably less than the state average (138 PSM). In the center of the county, there is a micropolitan area (defined as an area with at least one urban cluster between 10,000 and 50,000 people) with 38,000 residents (U.S. Census Bureau, 2006). There is a metropolitan area located outside of the county, approximately an hour's drive away. Most employed persons living in the county work in the county itself, often in one of the local large manufacturing plants. Important to our study, the limited availability of health and mental health services is matched by lower incomes for health and human service professionals working in the county. In 2000, the average income for health and human service professionals in the county was approximately $30,000, while the average income for similar professionals in other parts of the state was $39,000 (U.S. Census Bureau, 2000).

The "Community of Care" program was a collaborative initiative of the state mental health department, a statewide family advocacy organization, and a mental health service agency, and had been operating for a year and a half when interviews with staff were conducted, and 21 months when caregivers were interviewed. However, no families were enrolled during the first year of the program, which was dedicated to hiring, training, and community-relations building. Therefore, the program started serving families about six months prior to the time of the staff interviews and about nine months prior to the time of the caregiver interviews. One innovative aspect of the initiative was that family members of children with mental health problems were hired as paid family support providers. They worked alongside the mental health agency staff, called community liaisons, in shared office space in order to improve collaboration and communication between the two groups. At the time we conducted the interviews, the organization employed several community liaisons and family support providers, a public relations specialist, a project director, and support personnel. The role of the family support provider is to extend emotional and practical support, often by helping the family prepare for meetings, accompanying them through court proceedings, and checking in with caregivers on a regular basis. The family support provider is available 24 hours a day, 7 days a week. The community liaison works to locate or create services and supports, and to coordinate the various service providers that are involved with the family. In general, then, the family support providers work on the more informal needs of the family, while the community liaisons manage and coordinate the family's professional services. However, these roles sometimes overlap depending on the individual strengths and needs of the families and the service providers.

At the time of the study, the management information system (MIS) used by the agency contained information on 72 families who had been referred. Of these 72 families, 26 (36%) were recorded as currently enrolled in services, 8 (11%) were recorded as closed but previously enrolled, 19 (26%) were recorded as having been referred to services or meeting with agency staff but were never formally enrolled in services, 6 (7%) were new clients and had not yet been formally enrolled in services, and 13 (18%) were recorded as closed, with no information on whether they had ever been formally enrolled in services. Hence, from 26% to 51% of referrals had never engaged in services enough to be formally enrolled. There was no information in the MIS on the reasons why families did not engage in services. This study was conducted, in part, due to this relatively high rate of non-engagement and a lack of detailed information on the barriers to services.

Data Collection

Because of the interest in the many different individual, family, community, and service level factors that shape and are shaped by mental health service provision, we conducted qualitative semi-structured interviews with staff members and family caregivers of the children who had been referred. Qualitative research is particularly useful when the topic being studied is one

that incorporates many different and intersecting factors and allows researchers to explore the contexts and processes of complex phenomena such as the provision of child mental health services (Hodges, 2007). Over the course of several meetings, emails, and phone calls, the research team, the project director of "Community of Care," the research manager of the mental health agency, and a representative of the family support agency worked together to determine the purpose of the research, create a research protocol, develop and edit interview questions, and discuss recruitment methods. Additionally, nine "Community of Care" staff members presented ideas for additional interview questions and research topics during one-on-one interviews. The qualitative interview guide included open-ended questions that elicited information on the referral, engagement, and service process at the "Community of Care" program, and family experiences, benefits, challenges, and satisfaction with the process. This study received approval from institutional review boards of the university where researchers were employed, the state mental health administration, and the participating mental health agency.

Participants

We interviewed nine staff members of various roles, representing two-thirds of the active staff at the time of the study, including 3 family support providers, 3 community liaisons, a program evaluator, a program marketer, and a support staff. Two of the FSP's and one CL had worked in the program for its duration, one and a half years. Two of the CL's had one year of experience. One FSP had been employed for six months. The marketer had been employed for one year and the support staff had 3 months of experience.

Due to human subjects research protections, we were unable to directly contact families to invite them to participate, so the agency mailed letters to 85 families who had been referred to the agency by that time, briefly describing the research and requesting that they contact us if they were interested in participating. Ten family caregivers contacted us, two were unable to be interviewed after repeated contacts, and eight participated in the study. All eight were female, six were biological mothers, one was an adoptive grandmother, and one was a stepmother. Seven caregivers were white and one was African-American. The target children were three girls and five boys, fairly evenly distributed between the ages of 4 to 17 years old. Half of the families were engaged in services with the "Community of Care" program at the time of the interview and half met with the "Community of Care" program but had not engaged, due in part to the barriers to services discussed below. According to the caregivers, three of them had been enrolled in the program for approximately nine months, and one had been enrolled for three weeks.

Data Analysis

We transcribed each interview and entered it into qualitative analysis software. We chose a grounded theory approach to analysis because it allowed us to rely on the data to inform the creation of concepts, categories, and themes, as opposed to relying on predetermined analysis schemes (Miles & Huberman, 1994). We created a codebook for the data, first reading interview data for themes in participant responses that cohered because they dealt with the same topic, and then dividing these into sub-topics. Once the codebook was developed, two different researchers independently coded the interviews.

In all stages of research, we used methods consistent with the principles and process of naturalistic inquiry as endorsed by Guba and Lincoln (1989) and Erlandson, Harris, Skipper, and Allen (1991). In naturalistic inquiry, the "trustworthiness" of the research is earned through a different process than is common in prevailing research methods. Naturalistic inquiry accepts multiple constructions of reality, each construction valid to the person who holds it. Therefore, our methods established credibility of the research without an assumption of single "truths" to

be uncovered, as opposed to traditional methods such as establishing high rates of interrater reliability of analytical codes. Our methods included: triangulation of viewpoints by purposefully interviewing people in various roles within and external to the agency; frequent meetings among the team members to discuss, refine, and assign analytical codes, sometimes assigning multiple codes per statement; peer debriefing with professionals outside the context of the study; and member checking, or presenting findings to respondents, seeking their feedback, and incorporating that feedback into a more refined analysis.

Human Subjects Review and Conflict of Interest Statement

Participant protections for this study were reviewed and approved by institutional review boards at Vanderbilt University, the participating state mental health department, and the participating mental health service provider agency. There were no known conflicts of interest in this study.

Results

Seven primary themes emerged and are discussed below. First, however, it is important to consider the overall context of the interviews.

Initial Impressions

Our family interview questions were focused on the caregiver's report of her experience accessing and, in some cases, receiving services through the system of care site. Hence, we were surprised at the extent to which caregivers described their family's problems, generally ranging far beyond children's mental health services. Most commonly mentioned was a history of physical and emotional abuse within the family. Without any direct questions about abuse, seven of the eight caregivers reported that they, their child, or both had been subjected to physical or emotional abuse, usually from the child's father. In one case a grandmother had custody of a child who she reported had been abused by both parents. Correspondingly, many caregivers talked in great depth about custody battles and dealing with the ongoing strain of maintaining a parental relationship in the midst of an ended romantic relationship. Several cast considerable blame on fathers and described fathers' behavior as destructive for their child's mental health. Caregivers talked at length about resource difficulties, including unemployment, poverty, lack of transportation, and inadequate housing. Additionally, some caregivers struggled with alcohol and drug addiction.

Emergent Themes

Common themes emerging from staff and caregiver interviews were both convergent and divergent, with each group describing unique and shared themes (see Table 1). Similar to findings from other rural research (Boydell et al., 2006), many of these themes are closely interrelated—for instance, a sense of stigma was often connected to a description of the close knit nature of a smaller community. Living in a small town meant that many people would be aware of anything in which the family was involved, including mental health services, and this public surveillance was considered to be potentially embarrassing. Additionally, some themes were paradoxical in that they were reported as both barriers to and supports of service access depending on the context of the situation.

Stigma—Stigma of mental health and mental health services was frequently mentioned as a barrier to accessing services in rural areas. Stigma included embarrassment or "humiliation," a sense of shame from not being able to take care of a problem without help, and a fear of mental health services. This perceived or actual stigma was mentioned by several staff members and a few caregivers.

Caregiver: I feel like that makes people question whether they're thinking I'm a bad parent or something like that. Which, you know, it makes me sad because this is a very small town. And I just wonder, you know, I don't want to be looked at in those eyes, when I'm just trying to do the best for my son. But that's the least of everything…. My humiliation is the least of anything.

However, the sense of stigma was not universal among caregiver interviews. Several expressed that they had no negative feelings about public knowledge of their child's mental health problems.

Caregiver: No. I have no concerns about [people knowing about my family], nope. I would love to have meetings with whole families who are having problems like this, so we would know that hey, there is someone out there.

Close-knit community of families—Staff and family caregivers described the close-knit community of families in this rural area as both a barrier to and support of service access. Closely tied to the sense of stigma described above, some respondents felt that they would be or were judged harshly for their family's problems. This sense spread beyond mental health and into aspects of domestic violence, substance use, and poverty. However, some respondents also felt that this close-knit community created a supportive environment for resources and service access. They described how friends, extended family, and church members engaged in several helpful roles, including participating in service coordination planning/wraparound teams, providing practical support such as transportation and domestic assistance, and providing emotional support. The religious community was frequently mentioned as a source of practical and emotional support, but at the risk of an increased sense of stigma and embarrassment. Some staff described a desire to engage churches in their work in order to improve service access, participation, and retention.

The paradox of the close-knit community is summarized by one caregiver, who had mixed feelings knowing people were talking behind her back, even though it was with the intention of help.

Caregiver: I had been suffering from bad bouts of high blood pressure, and then my son had a broken ankle, and he really needed me to take care of him, and everybody knew that my ex-husband would cause a problem for me anytime and anyway he could. So my ex-case manager from [mental health center], talked to her best friend, who is also my best friend, from the church, and I'm like, 'Oooh! I don't know that I really wanted to go there!' So, at first my feelings got kind of hurt, but I'm assuming from perspective and everything, that the conversation was based more on love and concern, than, you know, maliciousness or anything like that.

Close-knit community of service providers—Service providers described close connections among the various family-serving agencies as a factor specific to rural communities and as an important ingredient of the system of care effort. Some of the staff at the "Community of Care" program had previously worked for the child welfare agency or a mental health agency within the county and maintained connections with their previous colleagues. They said that having personal connections among the agencies assisted with the coordination and delivery of services.

Service provider: I do think that a lot of the agencies in this county really want something like this and that's a good thing. It's a close-knit community, there's a lot of people in the community that care about others, and I think that's one thing we've got on our side. We have people from juvenile justice that are just willing to do whatever, they'll go on these system of care conferences, and I think that's awesome.

Lack of resources—Caregivers and staff described several resources that would have been helpful. Most particular for rural areas was a lack of public transportation, especially given the long distances rural families have to travel for services. Three of the eight caregivers either did not have a car or a driver's license. They relied on friends, family, and church vans for transportation. These created added difficulties of burdening friends and family, hassles associated with scheduling and paying for the church transportation service, and the long distances required when traveling in sparsely populated rural areas.

> *Caregiver*: It's expensive when you're on a limited income…. I mean their hours aren't very flexible, and you have to give them 48 hours notice, so there's no spontaneity—it's like your whole life has to be scheduled around transportation. It was costing me one hundred and sixty dollars a month to get my child back and forth to Head Start, plus three hours of my time a day, and I was like, 'Y'all don't understand how much of my time this is eating up.'

Caregivers and staff also described high rates of poverty, which made it difficult to pay for specialized programs.

Staff reported that there was a lack of certain service-related resources due to rurality. Specialist care such as neurology was located in the next largest city, approximately an hour drive from the county. This barrier was compounded by the transportation problems in getting to these distant services.

Isolation—Six out of the eight caregivers described some feelings of isolation. In a few of these interviews, which were conducted in the caregivers' homes, the sense of isolation and loneliness was almost palpable to the interviewer. Living in a rural area, compounded by a lack of transportation and dealing with a messy divorce or separation left many caregivers feeling alone, despite several caregivers' comments about the sense of tight-knit community. One caregiver, who lived in the country and did not have transportation, reported, "I'd get lonely if it wasn't for my dog. But he follows me everywhere I go." Other caregivers reported having friends but no real sense of a supportive community that understood the problems they were experiencing.

Lack of mental health knowledge—Several staff responded that there was a lack of education and understanding in the community at large in regards to mental health issues. They believed this lack of education contributed to stigma, a reluctance to ask for help, and a misunderstanding of what kind of services the "Community of Care" program provided. Some also believed that this presented an added challenge to working with families in a way that everyone could relate to.

> *Staff*: I find myself, how to say this carefully, when talking to somebody who might be more rural and less educated, to kind of alter my speech pattern to where they can relate a little bit better. A lot of times you find that on the clinical side, people have a hard time doing that and they talk to someone who may be less educated and everything goes right over their head. So I really try to adjust to who I'm speaking with, how I talk to them, the words that I choose.

Needed services in this rural community—Caregivers and staff were asked about what services they felt were needed in this rural community and their answers mirrored some of the barriers to care provided above. Both staff and caregivers mentioned transportation most frequently. Both also mentioned a need for financial support for material resources, as well as to provide for specialized programs and activities such as recreational sports. Caregivers, but not staff, described a need for family and child emotional support in the form of a supportive community of understanding peers. Staff, but not caregivers, said there was a need for respite

care to give caregivers a rest. Staff also mentioned a need for more outreach and family support from the local churches and religious groups.

Limitations

The agency mailing approach to recruitment no doubt had a negative impact on the number of family participants in the study, as mailed requests for research participation generally have a lower response rate than other methods of solicitation (Babbie, 2005). Another likely cause of low response is that letters were sent to all families ever referred to the agency, regardless of whether they actually received services or were currently receiving services. Later reports from some of the interviewees confirmed that they were hesitant to contact the researchers because they had never received services. This low response rate no doubt impacted our findings, especially considering the unique and complex life circumstances of each of the families in our study. However, it did allow us the opportunity to more fully examine and interpret the lengthy interviews and complex circumstances of the families who did participate. Naturalistic researchers argue that true generalizability is not possible because all contexts are in a constant state of flux (Erlandson, et al., 1993); likewise, we make no assertions that our findings are representative of the barriers and supports to service provision in all rural areas, or even this specific area in a different temporal context. However, we do feel that these interviews bring to light possible issues of concern for systems of care in rural areas, with transferability to areas with shared contexts, such as difficulties in transportation in sparsely populated, poor regions, or the importance of religion in the rural south. This is why our study describes the context in such detail above.

Similarly, one-third of the staff were unavailable to interview. It is uncertain if the staff who were interviewed were representative of the staff as a whole. However, by interviewing staff representing five different roles and finding convergent themes among those staff, we feel that the most salient staff concerns are likely represented in our findings.

Discussion

This study provides information from one rural community on the barriers that influence families' use of mental health services. The themes, however, mirror that of other communities and the available literature (Boydell et al., 2006). During a conference presentation on this work, the attending family members and staff from rural communities and system of care grantee sites shared similar experiences and concerns. Many of the concerns raised here correspond with those reported by Starr, Campbell and Herrick (2002), who identified negative outcome expectations toward mental health services as a barrier for rural families with children who were receiving services, including concern about others finding out and mistrust of mental health professionals. Our results are also strikingly similar to those of Boydell and colleagues (2006), who interviewed caregivers of youth with mental health problems in rural Canada and found that stigma, financial difficulties, a lack of resources, and distance were barriers to services, and that services were facilitated by word of mouth and personalized service providers. Most notably, both studies found that certain aspects of rural areas can simultaneously and paradoxically act as barriers and supports to service delivery. The close-knit community can provide information via word-of-mouth and it can be a source of emotional and practical support. However, it can also be a barrier because of fears of public surveillance, gossip, and stigma.

Acknowledging the Most Pressing Concerns of Families

The most pressing concerns to most of the caregivers we interviewed were not mental health services and coordination for their child. These families were overwhelmed by issues of abuse, custody, relationships, poverty, and isolation. In an ecological context, all of these issues impact

children's mental health, and the ideal system of care should help address these issues. However, these concerns contributed to the fact that half of the caregivers had not engaged with the agency at all. Similarly, transportation problems were widespread, affecting their lives in general as well as being a barrier to participating in services. Other studies in rural areas have also reported that difficulty finding transportation, a lack of public transportation, the long distances one might have to drive to receive services in a rural area, and resulting isolation are often mentioned barriers to service (Arcury et al., 2005; Boydell et al., 2006; Gamm, Stone, & Pittman, 2003; McCabe & Macnee, 2002; Nicholson, Hinden, Biebel, Henry, & Katz-Leavy, 2007; Sawyer, Gale, & Lambert, 2006; U.S. Surgeon General, 1999). Systems of care, particularly in rural areas, need to address these contextual issues.

Rethinking Stigma and Social Networks

Two other issues that were particularly salient in our data and call for further exploration and attention in rural areas were the roles of social networks in influencing stigma, and the importance of social networks in providing informal support for children and families with behavioral health needs. With regards to stigma, we noticed that the behavioral health issues of one person (in this case, usually the target child) would often result in experiences of stigma for the person him- or herself, *and* for the people charged with providing care for that person, which is similar to other research on relatives of people with disabilities (Birenbaum, 1992; Gonzalez-Angermeyer, Schulze, & Dietrich, 2003). While the stigma that is experienced by the child is often felt as isolation and shame about how one "is," the stigma that is experienced by caregivers is more likely to be felt as isolation and shame about how one "has done" – how one has failed as a caregiver, or what others think about the caregiver's abilities and resources for managing the child's behavior (Corrigan, Watson, & Miller, 2006; Hinshaw, 2005). This distinction is important because it calls for different approaches to dispelling the stigma associated with mental illness. It is important that the appropriate social institutions and networks understand the difficulty and burden of caring for a child with serious emotional problems as well as the difficulty and burden of personally experiencing mental illness.

Social networks were critical to the participants in this study. Many people described the close-knit relationships of their rural community as both a support and a source of distress. On one hand, being part of a small community meant children and caregivers tended to have an established and localized network of people with whom they interacted on a consistent basis for multiple reasons, including, but not limited to, provision of care for the child. Conversely, these networks also proved to be detrimental in some cases, in particular when parents feared they were being judged or shunned by those on whom they otherwise relied. Thus, we find that the role of close-knit social networks to be something of a double-edged sword. This paradox has been found in other studies of barriers to mental health services in rural areas (Boydell et al., 2006). In the field of rural health care, researchers and ethicists have described this dilemma as "the problem of overlapping roles" (Roberts, Battaglia, & Epstein, 1999). It is possible that this problem has gone somewhat unexamined because social support is typically conceptualized as relationships between care-receivers, caregivers, and those who might support them. This conceptualization has been challenged in the literature by Felton and Shinn (1992), who claim that a more systems-level approach to social support might be more fruitful and beneficial.

Implications for the Planning, Implementation, and Evaluation of Systems of Care

System of care sites are uniquely situated to help with the kinds of multiple issues expressed by families in our study. However, in our study, system-level constraints having to do with existing community structures interfered with service access and delivery. As one example, transportation is an issue that must be addressed at both the family and community level. Existing transportation services through churches and Medicaid systems are not always

responsive to the individualized schedules and needs of these families. When families have their own vehicles, the cost of gasoline may prohibit them from pursuing anything but basic activities.

Related to the need to broaden the community focus, systems of care work to link mental health services with other child serving agencies, including child welfare and juvenile justice. While the involvement of these institutions is essential and should not be underestimated, their highly structured nature may limit the type of services and supports that they can provide. However, our data revealed a strong need in rural system of care sites to incorporate not only public or private transportation options, but also churches, and abuse intervention programs other than child welfare.

For systems of care to be effective in rural areas, community stigma must also be addressed. Most antistigma campaigns (including the awareness-raising initiatives of the "Community of Care" program) are aimed at understanding mental illness with illness itself as their focus. While this awareness is, in many ways, tremendously important, it also acts to reify mental illness as a concrete and individual experience, as opposed to a socially and culturally contingent phenomenon. Our interviews with caregivers clearly illustrated that their experience of their child's mental health problems was firmly situated in social contexts, including poverty, geographic isolation, physical abuse, family drug and alcohol abuse, and peers. Furthermore, an illness approach to stigma all but ignores the experiences of caregivers. Interventions aimed at dispelling stigma, therefore, should involve actionable and practical initiatives for raising awareness of caregiving activities, as well as initiatives to improve the ways that communities define and support those who suffer from mental illness and their caregivers.

Systems of care aim to bring formal and informal community-based networks of support into the lives of families with children who have serious emotional problems, in order to help address problems throughout the multiple domains of their lives. Rural communities have unique aspects which act as both strengths and weaknesses in service access and provision. An understanding of these aspects will potentially assist the development of the system of care in positive ways. This study is one step in beginning to discover, interpret, and understand these unique aspects and how they relate to the system of care.

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Table 1

Emergent Themes from Caregiver and Staff Interviews

	Caregiver responses	**Staff responses**
Existing Barriers	Stigma / Close knit community	Stigma / Close knit community
	Lack of transportation	Lack of transportation
	Lack of money	Lack of money
	Isolation	Lack of resources
		Education
Existing Supports	Religious community	Close knit community of service providers
	Close knit community of families (emotional support)	Close knit community of families
	Close knit community of service providers	Religious community
Needed Services	Transportation	Transportation
	Financial support	Financial support
	Family and child emotional support	Outreach by the religious community
		Respite