Voices of parent advocates within the systems of care model of service delivery

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ABSTRACT

A growing body of research suggests that the "systems of care" approach to children's mental health can be effective in improving children's behavior and reducing stress on their families. What is less understood is how systems of care achieve these improvements. Through a series of focus groups, this study examined parent advocates, a key but understudied element of systems of care. Focus groups were conducted with parent advocates to examine how they themselves perceive their role within the systems of care model of service delivery. A research team identified several consistent themes from the focus group transcripts: unique role of parent advocates; similarities and differences between advocates and care managers; and, the value of having personal experience. For example, parent advocates saw themselves as navigators for families, helping them understand the system and access traditional and non-traditional services. Because of their own experiences with mental health services, parent advocates also believe they can communicate with family members in ways that professionals cannot. Results from this study can help strengthen the role of parent advocates by clarifying their contributions to service delivery. Future research should measure the extent to which parent advocates can produce the benefits identified in this study.

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1. Introduction

Children's mental health shifted its focus toward a model aimed at strengthening families, drawing on their capacities, and letting parents lead with the introduction of the "systems of care" philosophy in the 1980's (Stroul & Friedman, 1988). This philosophy, or movement, has strengthened the role of families in their children's mental health care and it continues to dominate the field today. The philosophy is based on a core set of principles suggesting that services need to be family focused, parent led, and strengths-based. These principles are thought to lead to higher quality services, particularly for those at risk for removal from home and those engaged in multiple child-serving systems of care. Practitioners working within the systems of care model bring together, or wraparound, formal and informal supports to empower families in times of need. Focusing on family support has been a cornerstone of the systems of care movement. Family support takes many forms, including advocacy, education, support, respite, information and referral to needed services. Kutash and Rivera (1996) summarized definitions of family support, which included doing whatever it takes for families to just be families and keeping families together and helping them achieve balance. Parent advocates, a key form of family support, straddle the roles of paraprofessional and peer. They are a felt presence in family

case conferences. This study presents the voices of parent advocates themselves regarding their roles in helping families.

2. Systems of care movement in Cuyahoga County, Ohio: Tapestry

The Cuyahoga County system of care initiative, entitled Tapestry, is one of the largest wraparound training and service delivery initiatives in the country. Tapestry was set up as a partnership between county child-serving systems of care and neighborhood provider organizations (Cuyahoga Tapestry System of Care, n.d.). Ten neighborhood collaboratives, which are made up of neighborhood provider agencies, utilize wraparound strategies (Burchard, Bruns, & Burchard, 2002) to work together with parent advocates and system professionals in order to improve access to mental health services and non-traditional supports for children and families affected by mental illness (Bruns et al., 2004). Parent advocates working with families involved in Tapestry are working within the "High Fidelity" wraparound model (Bruns, Burchard, Suter, Leverentz-Brady, & Force, 2004). Parent advocates contribute to family-driven services (National Federation of Families for Children's Mental Health, 2008) within the wraparound model by providing supports and encouraging parents to partner with professionals in making decisions about the services received by their children. When conducting or observing team meetings, which are planning meetings that are structured to bring together the multi-system professionals serving the family and their natural supports, the value of having a parent advocate present is apparent; however, little

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systematic research has been conducted with parent advocates directly regarding their perceptions of how it is that their presence impacts the lives of families (see Robbins et al., 2008 for a review).

A recent qualitative study interviewing family members, parent advocates and system administrators directly addressed this gap, reporting that family empowerment within the children's mental health system was positively impacted by "greater family 'voice and choice' (Scheer & Gavazzi, 2009, p. 370)." Through focus groups, they found that caregivers, advocates and administrators similarly reported that non-traditional services, such as respite, along with arts and recreation programs, were critical to helping families. When discussing indications of success in helping families, however, stakeholder groups varied in their views; caregivers reported increased confidence as success, advocates reported accessing respite as success and administrators reported the ability to fund traditional mental health services, such as family therapy as success. The present study aims to further understand the roles parent advocates play in helping families cope with mental illness from their point of view.

3. Previous research

3.1. Family support/parent advocacy

In recent years, parents and family members have increasingly been employed as service providers, supports, and advocates for families of children with emotional and behavioral disorders. Parents that have been in similar situations with their own children, sometimes referred to as "veteran parents" (Santelli, Turnbull, Marquis, & Lerner, 1995, p. 48), provide a particularly distinctive type of help navigating complex and fragmented systems of care, meaning they have a sense of how things are done and they know what it feels like to be the parent of a child with emotional and behavioral problems from personal experience. One study reported, "parent-to-parent programs offer supports to these parents by matching them with parents who understand the stress by virtue of shared experience" (Robbins et al., 2008, p. 1). They also provide an example of hope, as they have often been in similar situations as parents with newly diagnosed children and they have survived. Growing numbers of communities are relying on families, parents and caregivers to develop peer advocacy and support networks. The roles parents take on in the process of advocating and supporting are diverse and can be extensive, including facilitating access, case management, resource linkage, training, empowering and coaching to name a few. A recent study of directors of family advocacy, support and education organizations (FASEOs) ($N = 226$) reported that the directors viewed family as valuable team members in delivering services in local mental health communities; services such as education, advocacy, peer support, training, and working as liaisons between families and providers (Hoagwood et al., 2008).

Reviewing the parent advocacy and family support literatures is not without challenges. There are numerous definitions to grapple with and a variety of ways in which parent-to-parent support is implemented (Robbins et al., 2008). Recently, two review studies have been published that inform this area of scholarship. Robbins et al. (2008) examined 31 studies on parent-to-parent support, with 11 of the reviewed studies focusing on mental health. The authors concluded that parent-to-parent support is "helpful and valuable" (p. 6), while suggesting that the field needs conceptual refinement in order to better understand the underlying mechanisms of effective parent support. Further, in a comprehensive review of family-based services in children's mental health, Hoagwood (2005) reported that family support has not been rigorously examined, but has been described and evaluated through pre–post studies. Hoagwood's review (2005) highlights some of the processes of family support, such as empowerment, which has been shown to improve service use, retention, parent self-efficacy, and parent knowledge. More research is

needed to understand parent support, with particular attention to the processes or mechanisms that are thought to make a difference when helping families.

3.1.1. Roles: facilitating access

Recent literature suggests that family, or peer, advocacy addresses public health concerns, such as access to care, engagement in care and improvements in functioning and quality of life. In a national survey ($N = 834$) Koroloff and Friesen (1991) found that parents that attended support groups reported a greater need for information and services, along with increased service use, when compared to those that did not attend parent support groups. The Parent Partners model, which utilizes peer family members to facilitate wraparound teams, was also successful at engaging families (Becker & Kennedy, 2003). A review of family peer advocacy programs suggests that there are other models that likely increase access to care, such as the Kansas model in which family peers explain care options and interpret policies and regulations for families (Osher, deFur, Nava, Spencer, & Toth-Dennis, 1999). Through the processes of interpretation and navigation advocates facilitate initial access, while also enhancing engagement among families once services are accessed.

3.1.2. Roles: providing social support

Peer advocacy is also believed to be an effective social support mechanism to reduce caregiver stress and strain that may be a result of a child's emotional problems, including the "carry-over" of stress that can translate from one role domain to another (Thoits, 1995). This is particularly true in roles performed outside of the home, such as employment, because caregivers with special needs children have to make adjustments in the amount of time they spend at home compared to the amount of time they spend at work. A number of recent studies found that caregivers had to reduce their labor force participation to find time to care for their child living with emotional difficulties (Brennan & Brannan, 2005; Rosenzweig & Huffstutter, 2004). Further, a qualitative study on work-family fit among parents of children with emotional and behavioral disorders reported that parents experience a "serious lack of community-based services and resources necessary to support work and family obligations in a meaningful way" (Rosenzweig, Brennan & Ogilvie, 2002, p. 415). There is encouraging evidence that suggests systems of care and peer advocacy can have a positive impact on the economic outcomes of families. Krivelyova, Stormann, King, Hussey and Montgomery (2006) studied the labor force outcomes of caregivers in systems of care communities funded by the Center for Mental Health Services. They found that of the 16.5% of caregivers ($N = 784$) who directly attribute their unemployment status to the behavioral and emotional problems of their child, 24.3% of these caregivers found employment six months after the start of services. They attribute the services and social supports connected to systems of care services, such as parent advocates, as responsible for helping them cope and for giving them the confidence and skills necessary to obtain employment.

Peer advocacy can also reduce caregiver strain by providing a support person that has been through similar experiences. These relationships can assist in decreasing difficult emotions, such as shame, guilt and embarrassment that can be associated with children getting in trouble with the school, the community, or law enforcement. A person to compare their situation with and find support from also can decrease the isolation that parents often describe accompanying raising a child with emotional difficulties. Ireys, DeVet and Sakwa (1998) describe social support as one of the areas commonly underlying parent support programs. They suggest that veteran parents bring information, empathy, and connections to the community, which are important types of support for parents raising children with emotional difficulties. In a later study, Ireys and Sakwa (2006) again discuss the foundation of family-to-family support as support through "intensive personal attention and information-sharing

opportunities" (p. 11) that builds mutuality among parents. They also highlight components of family support, such as phone contact, educational workshops, informational support, support offering affirmations (i.e., enhancing confidence in parenting) and emotional support. Programs such as Family Connections and "Keys for Networking," also referred to as Keys, work to decrease the isolation level that is often felt by parents of children with emotional and behavioral difficulties (Adams, Edwards, Westmoreland, & Adams, 2006).

3.1.3. Roles: empowerment

Advocates have also been increasingly playing a role in empowering families to gain a sense of control over their experiences within the mental health system. Ramos, Burton, Hoagwood, and Jensen (2008, p. 5) discuss the "parent empowerment framework," which is based on both practical experience of parent advisors and scientific evidence to improve engagement of families. This framework includes ten principles that are cornerstones of parent support, including individualized and tailored support for each family, facilitating linkages, being respectful and culturally competent, and providing information, to name a few. This approach acknowledges the value of parent advisors having been there and experienced similar situations as the families they are empowering. Adams et al. (2006) describe how Keys has conceptualized the process parents go through on a continuum from "seeking help to emerging as a problem solver to becoming a systems change agent" (p.15). This process, which empowers parents to become advocates themselves, is an important part of the work of advocates within systems of care models of service delivery.

3.2. Outcomes of parent-to-parent support programs

To date, there have been three randomized control trials of parent support programs in mental health and two qualitative studies that illuminate some of the effects of parent support programs. Ireys and Sakwa (2006) reported that among over 250 families a larger percentage of the mothers in the group that received Parent Connections, as compared to those that did not, moved from high levels of anxiety to lower levels (22% versus 12%). Mothers in the family support programs also reported significantly higher mean levels of perceived social support than the comparison group. Elliott, Koroloff, Koren, and Friesen (1998) reported that mental health services with Family Associates in Oregon ($N = 239$) was associated with increased initiation and follow through of mental health services, increased empowerment, and decreased barriers to service use. In a study of parent-to-parent support for families battling anorexia nervosa, Rhodes, Baillee, Brown, and Madden (2008) reported that after completing 20 parent-to-parent sessions there was a significant difference in weight restoration between those receiving family consultations and those that did not receive consultations. As stated earlier, Scheer and Gavazzi (2009) found successes, such as increased confidence and access to services occurred when working with parent advocates. Finally, Slowik, Willson, Chun-Chong, and Noronha (2004) reported that among 10 parents attending a support group on an in-patient adolescent ward the most effective aspects of the group for parents were a sense of relief when allowed to talk openly about family experiences, a sense of no longer feeling alone, and the education process about mental health issues in adolescents, which they perceived as a mutual process between parents and providers.

Together, these studies suggest parent-to-parent support is a promising way to intervene with families of children with mental health needs. More research is needed to better understand the effects of parent support on a variety of outcomes, along with the specific processes that occur between parent supports and families that create change. The present study aims to further this area of scholarship by systematically examining the role that parent advocates themselves perceive that they play within a system of care model of service delivery in a large urban city in one Midwestern state. Four focus

groups were conducted with parent advocates ($N = 16$) to examine the broad research question: What is unique about the role of parent advocates within the systems of care model of service delivery? This study aims to shed light on the unique role of parent advocates by highlighting the statements of parent advocates and discussing these data within the context of previous research.

4. Method

In defining the sample, we sought to include parent advocates with various levels of experience working within systems of care. The sample includes parents with over twenty years of experience in advocacy and parents that have worked as advocates for six weeks. Advocates were excluded if they had not been working within the children's mental health system of care for over one month. Names of potential participants were suggested by the parent lead for Tapestry. Sixteen parent advocates volunteered to participate in the study: 100% ($N = 16$) were female and 75% ($N = 12$) identified as Black/African American.

An interview guide was developed with five questions: What do you think is unique about what parent advocates do in wraparound meetings?; What are parent advocates responsible for within the systems of care model of service delivery?; How are parent advocates different (and similar) to care managers, system professionals, and parents that are working within the systems of care model?; Can you share a specific example of a situation when you made a difference in the life of a child/family involved in Tapestry?; And, what have been some of the positive approaches or solutions of helping that you perceive that families and children find particularly helpful? Additional probes were utilized to elicit more information, including their perceptions of negative aspects of their role. Informed consent was completed before groups began. Case Western Reserve University's human subjects committee approved all study procedures and documents.

Data were generated between 2006 and 2008. Focus group meetings lasted between 60 and 90 min. Interviews were audio taped and professionally transcribed. Members of the research team reported that data had reached a point of saturation and that the amount of data was adequate (Morse, 1994).

Grounded theory coding techniques were utilized to construct content categories and identify relationships among categories (Glaser, 1965). Three investigators independently read transcripts from the first three focus groups, labeling text that was found to be pertinent to the research question. Investigators then grouped data elements together on the basis of content similarity and assigned higher level labels. This procedure yielded three sets of content categories. Next, investigators came together to compare and contrast the sets of data, reducing them into a single set. Categories were assembled into a codebook. Two investigators coded the final transcript and then came back together and discussed discrepancies. Coders agreed upon the best code for each passage. Investigators examined and discussed the data again. This led to further understanding of the meaning of participant responses. Also, relationships between categories were examined and discussed. Through this iterative process, investigators confirmed categories, or constructs from previous literature, while adding new categories to the literature to further explicate the views of parent advocates on their unique role within the systems of care model of service delivery.

5. Results

There were three main categories that emerged from the data: 1) Unique role of parent advocates; 2) Similarities and differences between advocates and care managers; and, 3) Value of personal experience. These categories and the relationships between them make up the results of this study.

5.1. Unique role of parent advocates

5.1.1. Translator of the content and process of meetings

Advocates discussed their unique role within the systems of care model of service delivery. Comments such as "a lot of the language or some of the wording might be a little confusing to them and to be able to let them know 'this is what they really mean' and to help them define what is going on and what has been said" and "we're telling them the real deal…" suggest that advocates help to translate the content of discussions in meetings with professionals. Also, advocates commented on translating to minimize miscommunication. "…A lot of what the problem is miscommunication and misunderstanding of perceptions of the other side and I think a big part of our role is to help alleviate those misunderstandings…parents have misperceptions about the professionals…and vice versa…and I see a big part of our job as staying on the fence and being able to help each side understand the other's perspective…" Finally, advocates revealed that they often help translate difficult to understand paperwork and/or policy, "Well let's just take it home and maybe when we get home we could break it down to you what this paper says." With regard to translating the process of meetings, one advocate stated, "I had a client who needed to ask for more money from the District, and I said…'Let's talk about how we want to communicate. Now you know your child's needs, but how do we want to communicate this to the District person so that they understand that this is what this child needs to be successful?'" These statements reveal that the advocates in the present study perceive that an important part of their role is translating the content and process of meetings for families and children.

5.1.2. Navigator

Similar to previous studies (i.e., Scheer & Gavazzi, 2009), advocates in the present study reported acting as a navigator for parents and children by providing direction during meetings or direction for work between meetings. One advocate reported, "I was the main information person. I had to manage all the information. I had to make sure everybody was on the same page, everybody had a copy of the IEP [Author Added: Individualized Education Plan], everybody had a copy of the ISP [Author Added: Individual Service Plan], everybody had a copy of the medication list, and everybody knew what was going on." Another advocate reported, "…one of the things we can do ahead of time is set up a little sign with them that if they're getting to the point where they think they're going to lose it or get angry or say something that they'll regret later…they can give you a little signal and you can say 'You know, I can see this is getting really difficult for mom. Can we take a five minute break?' That's something that she would not be comfortable doing on her own…we understand how emotional parents can get and we can help allow them to take a break for a few minutes to recollect themselves…" The role of navigating was discussed in each focus group.

5.1.3. Empowerment

Previous research has shown that parent advocates empower parents and their children as they struggle with the difficulties surrounding living with a serious emotional disturbance (Scheer & Gavazzi, 2009). In the present study, advocates voices further this assertion. Responses such as, "…we're supposed to make sure the parents' voices are heard…" and "You empower the parents to speak themselves. You let them know that they're not alone, that others have gone through it and have made it through…so you make sure you decrease that isolation…but I think the most important thing is that if you can empower them to educate themselves on their rights and responsibilities and they start doing that even in baby steps…it makes the parent feel good like, 'I actually did this for myself' and then they start building more self-confidence in themselves and it just snowballs all the way down in the rest of their lives" reveal that parent advocates in Tapestry perceive empowerment as an important

function of their work within the system of care model in Cuyahoga County. One advocate shared an example that illustrates advocates helping parents find their voice. She stated the following about a parent she worked with, "…she's sitting there looking at them like, 'I can't understand this, because I can't read' but no one asks her if she can read. They just say, 'Here, this is your IEP Plan…Sign it' and not knowing you know, that she can't read…And I think a parent advocate will be in there like, 'Okay…'" This advocate illustrates that there are times parents need to be empowered to speak up and voice their concerns, as professionals can be forceful and at times, intimidating. In sum, one advocate simply stated, "…we become that mouthpiece for that parent."

5.1.4. Networking agents

Parent advocates reported, "Linking them with one another is a big part of our role, too, if that's something they desire" and "…we always do try to help them hook up with other supports besides us to meet those needs, not just because of time constraints or that we don't want to do it, but we're always trying to make sure that our families will have something in place for when we're not in their lives." This networking role is particularly important as one worker noted, "We're [Author Added: Tapestry] a short-term intervention." Thus, helping to link parents with other parents may serve as an instrumental part of long term success navigating the systems of care for their children.

5.2. Similarities and differences between parent advocates and care managers

5.2.1. Medicaid billing

Advocates voiced a difference between their role and that of care managers with regard to Medicaid and billing stating, "We're not so fixated on the Medicaid piece" and "…we don't have to worry about whose being billed…" One advocate stated, "I hope we don't get to a point where we become a billable service" suggesting that some advocates prefer to remain distinctive from care managers with regard to billing for their services.

5.2.2. Flexibility and range in work

Advocates comments suggested they perceive that they have more flexibility in their work, when compared to care managers. One advocate stated, "They're under the gun more often about where their time is divided…we're a little more comfortable in what we do for the family and how long it takes, but theirs has to be broken down into hourly increments and who and where it's directed in order to be paid…parent advocates don't have to worry about that now…" Another reported, "…we're not on a time schedule…we're not fixated on, you know, the Medicaid piece or anything…so we might see a need that the family has that the care manager might not see…" Finally, one advocate illustrated the flexibility in stating, "If I can spend an hour on the phone trying to find some place where this child could go horseback riding because it helps him…I'll spend an hour and a half on the phone…" Advocates perceived a great deal of flexibility in their role helping families and children involved with Tapestry, flexibility they perceive care managers do not have, as they struggle to document their time and justify their work so that it is Medicaid billable. Parents perceive this limits care manager's ability to help.

5.2.3. Non-traditional services

Parent advocates reported that they are engaged in developing strategies or solutions with families that involve non-traditional or non-medical services. With regard to this sentiment, one advocate stated, "A big barrier in the mental health field itself as a whole is the belief that treatment, clinical treatment is the answer and they don't put a lot of stock in the non-medical, non-clinical stuff that families need to survive and remain intact and stay resilient." An example of using a more non-traditional strategy was discussed by one advocate

stating, "Like with a young girl who is being reintegrated back into public school, her father is very musical. Her mother is very theatrical. She has always wanted to try out for plays, and we encouraged her when she gets back into high school to try out, and she actually got a small part…this was something that really builds her self-esteem…" Advocates viewed alternative, or non-traditional, services as an important component of an overall recovery plan to help families and children live full lives.

5.2.4. Perception of similarity in training

While there was discussion on the differences between parent advocates and care managers, comments also suggested perceived similarities. "I would say right now…the only major difference…is that they have to write notes and have billable time that they have to meet…" "I do very much everything they do…I do write notes based on my contacts with families that go into client records, but I'm not responsible for billable time…" "I don't have the particular pressure on me, but I've done the same paperwork that they've done. I've done the same meetings. I've done the same school visits, transition plans. I've done the same getting the family community needs, clothing, food…I mean I've done all of those things." "I think the similarities are that we all want what's best for the family and we want the family to function as a family again, and I think that's one of the biggest things that is similar."

5.3. Value of personal experience — "That's the key right there"

Advocates discussed their perceptions that having been there themselves is the key to their unique role and their ability to advocate and connect with families. "We've been on the other side of trying to find the services and being so frustrated and getting run around…" "That's the key right there. I think we, having gone through this before, can give other parents the most hope, much more hope than a professional can…" "It gave her so much hope to talk to someone who had been through all of this…" These comments reveal that parent advocates provide hope by being an example of somebody that has been there and come through to the other side.

Together, these data illustrate that parent advocates are instrumental in the wraparound process and overall case management within the Cuyahoga County children's mental health system of care. It is hard to imagine a system of children's mental health existing in this era without close partnership with parent advocates, who clearly possess distinct knowledge and experiences and provide a particularly unique example to families.

6. Discussion

Parent advocates involved in Tapestry view their role as integral and evolving within the children's mental health system in Cleveland. Advocates perceive that their role includes translating content and process, navigating, empowering and being there for families and some of these roles can not be taken on by professionals no matter how much they want to help. Quotes from advocates themselves echo the descriptions of parent-to-parent support programs described earlier, with advocates facilitating access, translating, or interpreting, and navigating the system, alongside families.

The parent advocate's role flexibility contributes to an expanded range and menu of non-traditional supports and services, ultimately blending informal supports with formal mental health services. Advocates see recovery as something that is achieved more holistically with a combination of clinical and non-clinical services. Similar to Scheer and Gavazzi (2009), the parent advocates in the present study highlighted non-traditional services as significant contributors to families overall mental health and well being. This may be particularly important in communities such as Cleveland, where poverty rates are extremely high and access to services is difficult to achieve.

The President's New Freedom Commission (2003) recommended that systems of care "involve consumers and families" (p. 37) in planning, evaluation and service provision. They report that they became convinced of a need to increase engagement with consumers and family members in care through testimony and letters that they received from community members. Our study further suggests the unique type of care consumers and family members can provide. Less social distance (i.e., having been there) and personal credibility with parents may lead to increased levels of client engagement and a greater volume of supportive contacts. Advocates, by definition, have been there and again, this is unique and instrumental to their role. One advocate illustrates the potential impact of less social distance stating, "You know once you build a relationship with somebody you can say what you want to say in a loving manner, and they will receive you, you know." This is critical to reaching parents, which in turn may result in greater exposure to formal mental health services and improved engagement.

7. Limitations

There are limitations to the present study that are important to consider. First, with regard to generalizability, the data are limited, as our sample is from one Midwestern city. It is also important to keep in mind that all of the participants were females, which limits the understanding to women's views of the role of parent advocates within systems of care. As more men become parent advocates, studies can build on the present study to understand, more broadly, how male and female advocates view their role. Last, the study had a modest sample size. More studies examining the role advocates play within children's mental health can build on these results.

8. Implications

The present study has implications for practice, policy and research. With regard to practice, findings suggest that Tapestry System of Care would benefit from including parent advocates in all aspects of the planning process. Their voices represent a perspective that is extremely close to the families that are served in the children's mental health system. And, parents respect and trust the voice of advocates. Thus, their involvement at every level may lead to a more streamline system. Having been there themselves allows advocates to share experiences of barriers and/or particularly helpful services. With their personal experiences of navigating systems and feeling overwhelmed themselves, advocates provide a perspective and a service that most providers cannot provide. Systems of care need to consider developing and adopting policy to financially support additional advocates. The services they provide are critical and need more funding.

Finally, there are very few studies that examine parent advocacy and its unique contribution to the systems of care movement. More studies that build on what we know are imperative. For example, studies that examine what advocates do specifically that contributes to better outcomes. Further, studies that utilize these qualitative data to better operationalize parent advocate "services" may improve our ability to quantify what has been an elusive intervention to capture. With this, evaluation studies may be able to determine the relative importance of having a parent advocate involved with a family versus not having one involved with a family. Evaluation studies focused on these questions are essential to further substantiate the value of parent advocates within systems of care. Thus far, most of the support for advocates has come from client testimony, which is important; however, evaluation studies can lead to further understanding of the role of parent advocates and increased empirical support. Based on the findings from this study, research can begin to operationalize and develop measures for things like translation of process and content, navigation of fragmented systems and meetings, and being there for

parents whenever support is needed. With these measures, evaluators can systematically test the effects of parent advocates. Finally, additional qualitative studies that draw out what advocates view as negative aspects of their role can assist in identifying areas that may need to be restructured.

Although only four focus groups were conducted, the data clearly reveal that parent advocates, many of whom had over ten years of experience advocating for families and children living with serious emotional and behavioral problems, play a distinct role in working with families. Systematic evaluation research and policymakers need to closely examine the role of advocates in engaging, empowering, supporting and ultimately changing children and families.

Acknowledgement

References

Adams, J., Westmoreland, E., Edwards, C., & Adams, S. (2006). The "keys for networking": Targeted parent assistance. *Focal Point*, *20*(1), 15—18.

Becker, J., & Kennedy, M. (2003). Tapestry: A wraparound program for families of color facilitated by parent partners. *Focal Point: A National Bulletin on Family Support and Children's Mental Health*, *17*(2), 26—28.

Brennan, E. M., & Brannan, A. M. (2005). Participation in the paid labor force by caregivers of children with emotional and behavioral disorders. *Journal of Emotional and Behavioral Disorders*, *13*(4), 237—246.

Bruns, E. J., Burchard, J. D., Suter, J. C., Leverentz-Brady, K., & Force, M. M. (2004). Assessing fidelity to a community-based treatment for youth: The wraparound fidelity index. *Journal of Emotional and Behavioral Disorders*, *12*(2), 79—89.

Bruns, E. J., Walker, J. S., Adams, J., Miles, P., Osher, T. W., Rast, J., et al. (2004). *Ten principles of the wraparound process.* Portland, OR: National Wraparound Initiative, Research and Training Center on Family Support and Children's Mental Health, Portland State University.

Burchard, J. D., Bruns, E. J., & Burchard, S. N. (2002). The wraparound approach. In B. Burns, & K. Hoagwood (Eds.), *Community treatment for youth: Evidence-based treatment for severe emotional and behavioral disorders* (pp. 69—90). Oxford, England: Oxford University Press.

Cuyahoga Tapestry System of Care, (n.d.). One Community's Journey Retrieved January 15, 2009, from http://www.cuyahogatapestry.org/pdf/OCJbrochure.pdf

Elliott, D. J., Koroloff, N. M., Koren, P. E., & Friesen, B. J. (1998). Improving access to children's mental health services: The family associate approach. In M. H. Epstein, K. Kutash, & A. Duchnowski (Eds.), *Outcomes for children and youth with emotional disorders and their families: Programs and evaluation best practices* (pp. 581—609). Austin, TX: Pro-Ed.

Glaser, B. G. (1965). The constant comparative method of qualitative analysis. *Social Problems*, *12*, 436—445.

Hoagwood, K. (2005). Family-based services in children's mental health: A research review and synthesis. *Journal of Child Psychology and Psychiatry*, *47*, 690—713.

Hoagwood, K. E., Green, E., Kelleher, K., Schoenwald, S., Rolls-Reutz, J., Landsverk, J., et al. (2008). Family advocacy, support and education in children's mental health: Results of a national survey. *Administration and Policy in Mental Health and Mental Health Services Research*, *35*(1–2), 73—83.

Ireys, H. T., DeVet, K. A., & Sakwa, D. (1998). Family support and education. In M. H. Epstein, K. Kutash, & A. J. Duchnowski (Eds.), *Outcomes for children and youth with emotional and behavioral disorders and their families: Programs and evaluation best practice* (pp. 154—175). Austin, Texas: Pro-Ed.

Ireys, H. T., & Sakwa, D. D. (2006). Building family-to-family support programs: Rationale, goals, and challenges. *Focal Point*, *20*(1), 10—14.

Koroloff, N. M., & Friesen, B. J. (1991). Support groups for parents of children with emotional disorders: A comparison of members and non-members. *Community Mental Health Journal*, *27*(4), 265—279.

Krivelyova, A., Stormann, C., King, T., Hussey, D., & Montgomery, E. (2006). Employment outcomes of caregivers in systems of care. *A presentation at The 20th Annual Research Conference—A system of care for children's mental health: Expanding the research base in Tampa, Florida, March 4–7, 2007.*

Kutash, K., & Rivera, V. R. (1996). What works in children's mental health services? *Uncovering answers to critical questions* (pp. 125—147). Baltimore, MA: Paul H. Brookes Publishing Company.

Morse, J. M. (1994). Designing funded qualitative research. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* Thousand Oaks, California: Sage Publications.

National Federation of Families for Children's Mental Health (2008, January). *Working definition of family-driven care.* Rockville, MD: Author.

New Freedom Commission on Mental Health (2003). Achieving the promise: Transforming mental health care in America. *Final Report. DHHS Pub. No. SMA-03-3832. Rockville, MD.*

Osher, T, deFur, E, Nava, C, Spencer, S, & Toth-Dennis, D (1999). New Roles for families in systems of care. *System of Care: Promising Practices in Children's Mental Health*, 1998 Series, Vol. I. Washington, D.C.: Center for Effective Collaboration and practice, American Institutes for Research.

Ramos, B., Burton, G., Hoagwood, K. E., & Jensen, P. (2008). Introduction and background information. In P. J. Jenson, & K. E. Hoagwood (Eds.), *Improving children's mental health through empowerment: A guide to assisting families* (pp. 3—7). New York, NY: Oxford University Press.

Rhodes, P., Baillee, A., Brown, J., & Madden, S. (2008). Can parent-to-parent consultations improve the effectiveness of the Maudsley model of family-based treatment for anorexia nervosa? A randomized control trial. *The Association for Family Therapy and Systemic Practice*, *30*, 96—108.

Robbins, V, Johnston, J, Barnett, H, Hobstetter, W, Kutash, K, Duchnowski, A, et al. (2008). *Parent to parent: A synthesis of the emerging literature.* Tampa, FL: University of South Florida, The Louis de la Parte Florida Mental Health Institute, Department of Child and Family Studies.

Rosenzweig, J. M., Brennan, E. M., & Ogilvie, A. M. (2002). Work-family fit: Voices of parents of children with emotional and behavioral disorders. *Social Work*, *47*(7), 415—424.

Rosenzweig, J. M., & Huffstutter, K. (2004). Disclosure and reciprocity: On the job strategies for taking care of business…and family. *Focal Point*, *18*(1), 4—7.

Santelli, B., Turnbull, A. P., Marquis, J. G., & Lerner, E. P. (1995). Parent to parent programs: A unique form of mutual support. *Infant and Young Children*, *8*(2), 48—57.

Scheer, S. D., & Gavazzi, S. M. (2009). A qualitative examination of a state-wide initiative to empower families containing children and adolescents with behavioral health care needs. *Children and Youth Service Review*, *31*(3), 370—377.

Slowik, M., Willson, S. W., Chun-Chong, L., & Noronha, S. (2004). Service innovations: Developing a parent/carer support group in an inpatient adolescent setting. *Psychiatric Bulletin*, *28*, 177—179.

Stroul, B. A., & Friedman, R. M. (1988). Principles for a system of care: Putting principles into practice. *Children Today*, *17*, 1—15.

Thoits, P. (1995). Stress, coping and social support processes: Where are we? What next? *Journal of Health and Social Behavior*, *35*, 53—79.