

# Parent Advocates in Children’s Mental Health: Program Implementation Processes and Considerations

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**Abstract** Children’s mental health service systems are increasingly utilizing peer support services to support families experiencing serious child mental illness. The literature provides few detailed accounts of such peer-based approaches. This study qualitatively examined the approaches and processes of “parent advocate” programs implemented in two Ohio counties for children served through publicly funded mental health services. Descriptions of each county’s program, the background and roles of parent advocates, reasons families decline advocate services, and challenges to advocates’ work with families are provided. Implications for the field in developing clear and effective administrative and practice structures for peer support services are discussed.

**Keywords** Children’s mental health · Parent advocate · Family-centered services · Family advocacy · Family support services

The need to develop more effective mental health systems for children with serious emotional disturbance and their families in the United States has been well documented over the past half a century. A key challenge for families dealing with child mental illness is that these complex emotional and behavioral challenges often require families to interact with multiple child service systems to obtain needed resources. Historically families have been encouraged to rely on the recommendations of professional providers to ensure that their children received the most appropriate treatment. However, individual providers generally function within one specific service system, and thus adhere to that single system’s policies and regulatory provisions. As such, these providers operate with limited and often disjointed knowledge of other systems. As a result of these fragmented children’s service delivery systems, families often languish in long waits and experience a quagmire of “red tape,” duplicative service processes and, ultimately, may “fall through the cracks” and not receive the most appropriate and efficient treatment.

Understanding the nature of each child serving system and concurrently how to effectively pull together their respective resources demands a unique set of knowledge and skills. Faced with multiple systems and the resultant fragmented reality, children’s mental health service systems and the families of youth being offered treatment are exploring alternative mechanisms for ensuring that the mental health needs of children and youth are being met. One such mechanism is the inclusion of peer-based providers who can offer a variety of supports to families with children experiencing serious mental health issues. However, as recently noted by Hoagwood et al. (2008), very little is known about the makeup, processes, and impact of such peer-based approaches, especially in the realm of children’s mental health. The purpose of this study was to

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examine how one Midwestern state utilizes one such peer-based approach—hereafter discussed as “parent advocates”—in delivering services to families that are served through publicly funded children’s mental health services. More specifically, the researchers partnered with the National Alliance on Mental Illness (NAMI) Ohio in order to qualitatively explore the approaches and processes of its Parent Advocacy Connection (PAC) program as implemented in two metropolitan regions of the state.

## Literature Review

Adults who themselves or whose children have experienced a range of personal challenges often in turn provide a range of services across fields that can be classified as peer support services. While the use of peer support service approaches over the past several decades is particularly observed in the education and health care literature, our review of the literature uncovered a variety of peer-based services across many additional disciplines. Interestingly, most accounts of such approaches were noted outside of the realm of children’s mental health.

### General Use of Peer-Based Nonprofessionals

Various titles are used to identify peer support providers that are devoid of the respective discipline-related formal education and training. Such titles include, but are not limited to, “parent advocate,” “parent liaison,” “parent advisor,” “parent mentor,” “parent coach,” “peer mentor,” and “peer advocate.” Though these titles and the disciplines in which they function may differ, peer support roles seem to be more similar than different. Peer support providers are ultimately intended to serve as a bridge between professional providers and the individuals, children and families served by provider systems.

The use of peer-type providers was noted in several areas of health care, including aural rehabilitation (Bally and Bakke 2007); diabetes (Sullivan-Bolyai et al. 2004); HIV/AIDS (Cabral et al. 1996; Fogarty et al. 2001; Gielen et al. 2001); pediatric hematology/oncology (Carpenter et al. 1992); socio-economically disadvantaged first-time mothers (Murphy Cupples et al. 2008); and violence-related spinal cord injuries (Hernandez et al. 2001). Common elements were noted across the health care programs. For instance, peer support providers were all adults who had experienced challenges similar to persons they served. Additionally, programs were mixed in whether peer support providers were paid or served as volunteers, and all of the health related programs reported varying levels of success. Further, with one exception, peer support providers across health care specialties assumed like roles and

provided similar activities. Roles and activities, to varying degrees, included providing social, emotional, educational, and resource support to adults (often times parents) through regular face-to-face or telephone contacts, helping to obtain needed resources, attending care team meetings, facilitating support groups, and serving as a liaison between adults and health care providers. Peer support providers received some level of training in all of the health care programs that were reviewed. Manualized training curricula were identified in all but two of the programs (exceptions included Carpenter et al. 1992 and Murphy et al. 2008). Only the aural rehabilitation program reviewed here differed from other programs in that its peer mentor curriculum is a graduate-level program that requires a college degree of its participants (Bally and Bakke 2007).

In systems specific to serving children, special education is at the forefront of the movement to include an advocate on behalf of children with serious emotional and behavioral challenges. Accounts of education-related efforts include advocates working both directly with the child, or on the child’s behalf, and with the child’s caregiver. Hardin and Littlejohn (1994) discuss a variety of programs designed specifically to increase parent involvement in their children’s education. The models described include paid and volunteer “parent mentors” who are caregivers of a child with disabilities. The mentors’ duties vary, but generally include activities such as providing support and multiple levels of information to parents around resources, rights, and system processes; support to special education staff; training parents, education staff, and professional service providers; and work to improve communication between parents and staff. However, even with its long history of including peer support paraprofessional providers, the field of education still lacks “compelling outcome data and conceptually sound models for the work of paraprofessionals” (Walter and Petr 2006, p. 462).

More recently, the child welfare field began exploring the use of peer-type providers. In a paper resulting from the 2007 Best Practices for Mental Health in Child Welfare Consensus Conference, Romanelli et al. (2009) focused on the role of parents and youth when mental health issues were of concern. “Peer family mentors” (also called family advocates, advisors, associates, or specialists) were identified as a key approach to ensuring consumer involvement in care. Romanelli et al. credit the Annie E. Casey Foundation’s Family-to-Family Initiative for the increasing use of parent advocates in child welfare services. The authors suggest that, given the success of adult peer mentors in other fields, utilizing trained adult peer mentors in child welfare to “advocate *with* and assist families in seeking care” (Romanelli et al., p. 195) would help to alleviate

workforce shortages, bring family voice to child welfare, and provide services in a way that would address issues of access, family involvement, and family distrust of child welfare.

#### Parent Involvement in Children's Mental Health

In the not-too-distant past, the role of parents in ensuring receipt of appropriate mental health care for their children seemingly was regarded as secondary and of little consequence. These increasingly antiquated notions are slowly shifting with the emergence and integration of "family-centered" practices across the child serving sectors. Systems of care for children's mental health (Stroul and Friedman 1986) and its predecessors have contributed greatly to such changes in the children's service delivery environment in the U.S. over the last two decades, such that families increasingly are seen as a vital resource for their children. It is now widely acknowledged that families should be full partners in the planning and delivering of services for their own child (Burns et al. 1999; Worthington et al. 2001) and in planning and overseeing services at the system level (Friesen and Stephens 1998; Koroloff et al. 1996; U.S. Department of Health and Human Services 1999).

Systems of care for children's mental health generally incorporate *wraparound* as the primary service delivery approach. The wraparound approach (Burchard and Clarke 1990; VanDenBerg and Grealish 1998) requires practitioner knowledge at many levels of service implementation. For example, the wraparound practitioner must know how to access a vast array of resources, including flexible service funds and a vast array of community resources; effectively collaborate with and manage care teams that include the child, family members, natural family supports, and professional providers across child serving systems; individualize culturally responsive care; and gather and utilize outcome data. Service planning requires the wraparound facilitator to work with the entire family, keeping the family centrally involved in the care planning and implementation processes. The model focuses on developing a service plan that centers attention on the strengths and natural supports of the child and family. Some communities implementing wraparound include a peer support provider, typically the parent of a child with serious emotional disturbance, who serves in a non-professional capacity as a part of the wraparound process. Although there is nothing that could be found in the published literature, a review of conference materials and training manuals leads to the conclusion that children's mental health systems of care seem to readily engage advocates due to the family-focused nature of this work.

#### Peer Providers as Parent Supports in Children's Mental Health

Though the use of peer support paraprofessionals in mental health is documented in the broader literature, related research literature has been markedly intermittent and often tangential to the primary focus of programs reported; thus, empirical efforts focused on increasing caregiver involvement began emerging only recently (cf., Bickman et al. 1998; Reich et al. 2004). In 1997, Heflinger et al. noted that "The parent advocacy movement in children's mental health services has learned from its counterpart in special education, but achievements still lag behind those in general education" (p. 185). Despite the increasing use of formal peer supports or advocates to increase family involvement in children's mental health services, the literature contains few accounts of specific models and related processes (Hoagwood 2005; Hoagwood et al. 2008). Similar to other recent reviews (cf. Hoagwood et al.; Walter and Petr 2006) we found limited peer-reviewed mental health literature describing parent advocate services or how such services are linked to individualized care or improved child and family outcomes. In fact, a 10-year gap appears to exist between the first such studies and what has been published most recently.

In the 1990s Evans et al. (1994, 1996) conducted a randomized study in order to compare family-based treatment (FBT) with family-centered intensive case management (FCICM) in rural communities of New York. Along with the same support services provided through FBT, the FCICM added the use of a parent advocate as a key element of individualizing care with families (Evans et al. 1996). As part of an advocate-case manager team with a small case load of families, peer-based advocates worked primarily with the adults, and case managers worked with the children (Evans et al. 1994). The advocates, who were parents of a child with serious emotional disturbance, provided direct support to parents via telephone and home visits and advocated on the families' behalf with professionals. The advocates helped parents prepare for meetings, accompanied them to meetings, and worked with parents to advocate for their children. However, early published accounts indicated that these parent advocates did not appear to significantly contribute to the observed gains in outcomes measured (Evans et al. 1996).

Koroloff et al. (1994, 1996) conducted a comparison study across multiple sites to examine the role of "family associates" in supporting "low-income families" with children referred to mental health services through Oregon's Early and Periodic Screening, Diagnosis and treatment (EPSDT) program. The majority of children in the study were White and between the ages of 4 and 12. The intervention was intended to reduce barriers to service

access (individual and systemic), increase continued service utilization, and increase caregiver empowerment (Koroloff et al. 1994, 1996). Three family associates, two of whom were parents of children with mental health issues and one who had worked as a line staff in the mental health system, provided three primary types of time-limited assistance: emotional and social support; general information (e.g., system processes, mental health disorders, services, etc.); and resource linkage (e.g., locating and securing resources, transportation, child care). Families who received services from these family associates were more likely to initiate mental health services than families in the comparison group, but were just as likely to miss appointments and terminate service prematurely. Hence, while greater gains in family and service system empowerment were achieved by families with associates, there was no difference between groups in community/political empowerment gains (Koroloff et al. 1996). That is, families gained a sense that they could effectively identify problems and manage the appropriate services, but they did not indicate a perceived ability to advocate for and effect macro-level change.

More recent work completed by Walker and Schutte (2005) reported on the effect of parent advocates in wraparound team planning across 7 states and 11 different communities. While geographically diverse, 97% of team meetings in the sample were for White children. Parent advocates from a family support organization were included as members in 43% of 26 wraparound teams. Walker and Schutte found that the presence of these paid peer support providers during team planning was not associated with higher degrees of treatment plan individualization. Debriefings with team members, including advocates, suggested that the finding may be due to a lack of clarity about the advocate's role. The authors did not provide a description of expected advocate roles and activities.

Recognizing the paucity of available advocacy-related research, Hoagwood et al. (2008) conducted a national survey study of 226 directors of family advocacy, support, and education organizations directly affiliated with children's mental health. The study examined organizations' structures and funding, influencing factors on the organizations' children's mental health related decisions, types of services provided and perceived impact on outcomes, and relationships between the organizations and mental health clinics. Findings related to the roles directors believe are important for families to play are specifically relevant to the current study.

Hoagwood et al. found that over 90% of the directors believe the most important roles for families are educating other families, advocating for mental health services, and peer-to-peer support. Further, over 80% indicated leading support groups, training other families, and serving as a

direct liaison with mental health providers as other key roles. Finally, 79% of directors included direct advocacy on behalf of individual families as a key role for families. Interestingly, when asked what services they would name as important for improving children's mental health outcomes, directors did not indicate the aforementioned family service provider roles. It is unclear from the information provided whether family roles were included among the choices available. Hoagwood et al. concluded that formally expanding the roles of families in providing care to other families should be considered given the existing insufficiencies of the mental health system for children and families. They offer the caveat, however, that any such action must include equitable financing modifications, both to the family support provider and the organization providing the family support service.

#### Parent Advocacy in Ohio

Influenced by the system of care literature and in partnership with other child and family focused agencies, the State of Ohio Department of Mental Health developed the access to better care (ABC) Initiative in order to improve care to families and children with behavioral health challenges. Fundamental to ABC was family-centered practice that both strengthens and empowers parents to have voice and choice in the treatment of their children and youth. As such, ABC required that parent advocacy services be offered to all families receiving family support services for their children with behavioral health needs. Local funding and programming entities implementing a specialized funding stream were responsible for providing these services. Each county had the option of utilizing the Parent Advocacy Connection (PAC), the program designated to provide assistance to counties in meeting this requirement, or, alternatively, providing parent advocates via the local mental health board. The PAC is the statewide, NAMI Ohio-administered program collaboratively developed by four Ohio advocacy organizations, including NAMI Ohio, the Ohio Federation for Children's Mental Health, Ohio Family Care Association, and Ohio Citizen Advocates for Chemical Dependency, Treatment and Prevention. Regional coordinators were hired across the state to coordinate the recruitment, training and assignment of the local parent advocates.

Parent advocates affiliated with NAMI Ohio PAC must submit an application, references and pass a comprehensive criminal background check. Advocates approved by NAMI Ohio are eligible for small stipends and mileage reimbursement designed to offset the cost of volunteering their time and talents. Parent advocates selected and utilized by counties outside the NAMI-administered program do not receive NAMI stipends or reimbursement, though other

local mechanisms may provide alternative arrangements. However, all individuals acting as parent advocates may access the training and support offered through NAMI. Aside from basic data required for financial accountability, little else was known at the time of this study about the advocates or the county-level processes for implementing parent advocacy services.

Funded by a grant from the Ohio Department of Mental Health's Office of Program Evaluation and Research, the research team sought to better understand the role of parent advocacy in serving family caregivers. The research team worked with NAMI Ohio to systematically examine the processes of linking families to parent advocates affiliated with its Parent Advocacy Connection (PAC) and to document the actions and services PAC advocates provided. Variations of the PAC program were implemented in each Ohio County. This research gathered descriptive information about the parent advocacy approaches and processes used in two of these counties. The main objectives of this research as reported here were to (1) document current advocacy roles and advocate characteristics (experience level, prior training, etc.), and (2) examine the processes and procedures in place by which families were offered (or were not offered) advocacy services and, where appropriate, to document the reasons why families chose not to utilize the services of parent advocates when they were offered.

## Methods

Meetings were held among the research team, NAMI Ohio, Regional PAC Coordinators, parent advocates, and other stakeholders affiliated with the Ohio ABC initiative to discuss the research. Stakeholders provided an overview of parent advocacy as it was intended within the specialized funding stream. Two metropolitan communities were collaboratively selected for the study's focus. Each community was uniquely implementing parent advocacy services and thus it was believed they would offer two different approaches to implementing the PAC program. One was selected because it was implementing parent advocacy as part of its wraparound service delivery approach. The other was selected because it was in fact not using any sort of wraparound approach, but rather was implementing a "standard and usual" form of parent advocacy based on training conducted by NAMI Ohio.

Focus groups and individual interviews were conducted with parent advocates in each county to provide rich grounding for contextualizing parent advocacy efforts. The sample description, in part, emerged from the interviews and is further described within the findings. The range of information collected includes background information on

parent advocates (PAs); advocate perceptions of families' decisions around engaging a PA; step-by-step processes used and services provided by PAs in their work with families; processes by which PAs determine service needs of families; PA perceptions of their service effectiveness; and PA perceptions of administrative support for their work. The focus group and interview open-ended question guides are included in appendices A and B, respectively.

All parent advocates actively serving families in each county were invited to participate in the study. A total of 11 parent advocates participated in the study. Of these, five were from a county in southeast Ohio (hereinafter referred to as Southeast) and represented all active advocates. The other six were from a county in central Ohio (hereinafter referred to as Central) and reflected all but one active advocate. One Central advocate did not respond to multiple requests for participation in the study. The lead author and a research associate together conducted both focus groups, each consisting of five participants. The Southeast focus group was held at the local Educational Service Center. The Center's facility houses the PA Coordinator and county's wraparound program, and it serves as the regular PA meeting place. Central's focus group was held at a public library meeting room occasionally used by the parent advocates for group meetings. Central PAs did not have an affiliated facility with office or regular meeting space. Each focus group discussion lasted approximately 1.5 h.

Because the individual interviews aimed to gather information specific to the work of each parent advocate versus the broader scope of the focus group questions, the participation of all advocates was additionally sought for the interviews. All five Southeast focus group participants also volunteered to engage in individual interviews. Southeast interviews were conducted at the Educational Service Center. In Central, four of the five focus group participants plus one additional PA were interviewed. Central interviews were held at locations of interviewee choice and included two public library meeting rooms and one local restaurant. All interviews were conducted by the lead author. Interviews lasted an average of 1 h each.

The focus groups and interviews were audio recorded and transcribed verbatim. Individual interviewees received \$10.00 for their participation. A research associate analyzed each focus group separately using content analysis (Krippendorff 2004) and coded the data for recurring patterns and themes related to the respective questions. Except for information related to program specific procedures, data across the two focus groups were summarized into overall categories and themes. The lead author compared these findings against extensive flip chart notes taken to record participants' key ideas during the focus groups to ensure consistency.

The lead author followed a grounded theory approach to analyzing the interviews, using open coding (Padgett 1998; Strauss and Corbin 1998) combined with content analysis processes (Krippendorff 2004). Atlas.ti 5.2 qualitative software was used to assist in organizing and structuring the data during analysis. Transcripts were coded using chunks of text, beginning with phrases and moving to sentences and then paragraphs, to identify patterns and streams of thought. Open coding schemes were developed and the nature of the interview questions led to codes and categories that reflected responses both directly related to the questions and more general advocate experiential dialogue. Each interview was analyzed and coded individually with the coding scheme continuing to build across interviews. Using constant comparative analysis codes were refined during the iterative process of returning to previously coded interviews to compare emerging categories and themes. Interview findings were checked against related focus group findings for consistencies and potential discrepancies where relevant. No notable discrepancies were found. The lead author's iterative process, familiarity with language and concepts used by families and professionals within children's mental health systems of care, and grounding in the data served as additional measures for reliability of interview coding. Findings from the focus groups and interviews were subsequently synthesized and are reported accordingly.

## Findings

### Advocate Experience and Training

While participants' in both counties reported providing advocacy services with their current affiliation for an average of 2 years ( $SD = .73$ ), their individual total years of advocate experience spanned 2–42 years ( $SD = 13.96$ ; median = 5). The form of experience, however, varied greatly among advocates. Several PAs had moved from voluntary to paid advocacy positions; others moved from formal work experience to volunteer advocacy. PAs described examples of formal (paid and unpaid) experiences ranging from foster parenting to providing case management to setting up and running programs.

All advocates in Southeast were parents of children with emotional and/or behavioral problems. Most advocates in Central did not express such personal experience. Rather, they described their general experiences as parents, grandparents, or people experienced in working with children and families struggling with child emotional and behavioral challenges. While advocates who had not parented children with mental health needs may not consider themselves peers in this sense, as one advocate stated,

*"I think as a parent we have all had situations that have gone on with our families, whether they are actually labeled mental health or not, as a parent I think we've just had challenges with our children."* As such, they believed their own experiences allow them to relate to the parents with which they work. A commonly expressed notion was that responding to the needs of others is something many PAs recollected doing for most of their lives. It appeared to be a natural extension of how they saw themselves as individuals. Several participants even indicated that they often informally worked with families who were not a part of their current PA "caseload." Advocates described rich backgrounds of experience from one-to-one work with families to extensive involvement with teams of people working with families.

...working one-on-one – I do a lot of that, but I've always done a lot of that – it comes very naturally and normally. Like I said even when I was little that was the kind of thing I did, you know there was a kid in class or school that didn't get what they needed and I would help advocate for that kid.

...the service team is about 20 people – a parent advocate, here, you have to make sure you are heard.

Participants similarly described an abundance of experience working across the multiple public and private systems serving children and youth. While the extent of PA interaction with the different systems varied, it would be difficult to name a system untouched by a parent advocate. Only a couple of advocates indicated experience in any form of advocacy at a legislative level.

The training received by parent advocates is as varied as their levels of experience. Advocates were asked to describe their training background which they believed prepared them to serve as a PA. Some PAs described work experiences; others described their own family experiences. The following excerpted quote captures the spirit of what seemed at the core of PAs whose training was described as "been there done that" with their own children:

In the beginning giving me that base was quite frankly having a child that I was told was going to be potentially removed from [school]...and so that took my life in the path that it has gone. And so I ended up navigating the school system myself and came to recognize that I had a lot of challenges and barriers working with that system. I walked out of my son's first IEP meeting with a signed IEP, did not know for sure what I had signed, got outside the front of the building and finally looked at the document long enough to process a piece of it...Once it sank in...that very day I knew in my heart that I had to

learn what this document was, what I had signed – the fact that I had signed something of which I was not knowledgeable about or comfortable with. Also I don't know, I just had some feelings of anger in a way because I felt ganged up on. I was at the meeting alone...there were 10 school people and I was alone. So that was the beginning...

PAs were also asked to describe any formal training received. Only two PAs indicated formal education as contributing to their preparatory background. Most described various trainings, workshops, and conferences attended over the years. Hand-to-Hand was a frequently cited NAMI training attended by PAs. Southeast PAs more consistently referred to trainings received since beginning their current affiliation than Central PAs, who cited little consistency in formal training from their current organization. A couple of Central PAs referred to learning how to do their PA work after getting involved as a PA; that is, they learned from doing it and learned from other advocates.

#### County Approaches to Parent Advocacy

As previously indicated, parent advocacy is intended to be offered to all families with children served through Ohio's ABC initiative. NAMI Ohio's Parent Advocacy Connection (PAC) is designed to provide a basic structure for guiding the training of parent advocates, setting boundaries for the types of service activities expected of advocates,

and paying small stipends and travel reimbursement to PAs for their meetings with families. While all Ohio counties are able to access the NAMI-PAC infrastructure for their respective advocacy efforts, each county is free to design its own parent advocacy program. Thus, implementation of parent advocacy, and ultimately utilization of advocacy services, looks very different across counties.

The focus groups and interviews conducted for this research centered on examining the specific approaches to advocacy implemented in two counties in an effort to understand the utilization of advocacy services and to get inside the "black box" of advocacy service provision. That is, we wanted to document the step-by-step processes involved in each program and learn about the specific actions parent advocates take as a function of their engagement with families. The implementation structures and processes of each program are detailed below with a contrasting summary provided in Table 1.

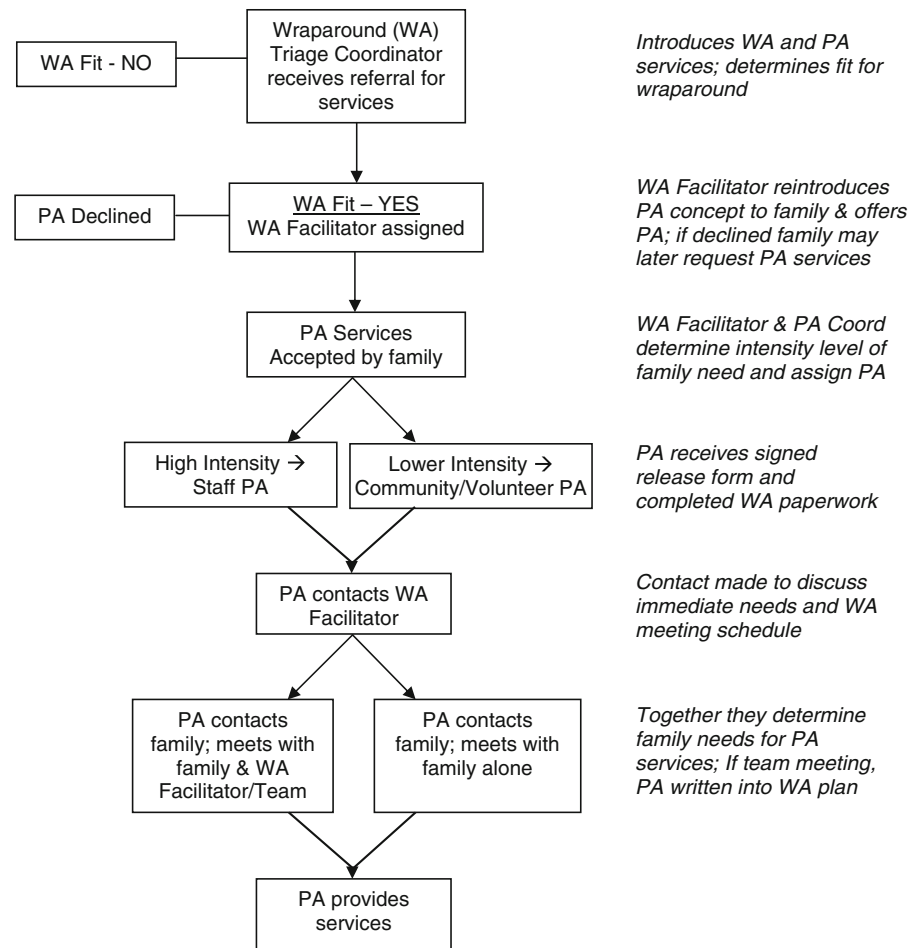
#### *Southeast County*

Figure 1 illustrates the referral and decision processes followed in Southeast as described and understood by the parent advocates themselves. NAMI parent advocacy in Southeast is embedded within its county-wide structure for implementing a wraparound service delivery approach. Implementing parent advocacy within the existing wrap-around structure eventually led to an approach which consists of both paid staff advocates and volunteer

**Table 1** Summary contrast of program implementation structures and processes

| Focus Area                     | Central   | Southeast  |
|--------------------------------|---|--|
| Structure and Administration   | No designated facility provided for advocate activities<br>Advocates are volunteer with limited stipends<br>Advocates not required to be caregivers of children who experienced emotional or behavioral problems  | County facility houses staff advocates and provides meeting space for general advocate activities<br>Community advocates are volunteer with limited stipends; Staff advocates are paid and serve dually as wraparound facilitators<br>Advocates required to be caregivers of children who experienced emotional or behavioral problems |
| Referral to Advocate           | Family linkage to advocates depends on local service providers making referrals to referring youth service coordination agency  | Referrals and ongoing work with advocates occurs within established county Wraparound Service Delivery/service coordination structure<br>Referral to paid/volunteer advocate depends on level of family need   |
| Advocate Linkage to Family     | Advocates provided with family contact information<br>Advocates matched with families based on race, ethnicity, types of advocate experience with families, their individual areas of expertise, past professional experience, perceived needs of families, and geographic location | Advocates provided with detailed family information<br>Beyond level of need, additional factors considered in matching advocates to families include advocate experience with different types of family issues, compatibility and preferences of advocate and family, and geographic area  |
| Supervision                    | Supervision/Monitoring provided as requested by advocates   | Regular supervisory/monitoring meetings held with advocates  |
| Training Provided to Advocates | Little formalized training arranged by regional coordinator; Advocates cited on-the-job learning as primary form of training  | Formal trainings consistently scheduled by affiliated agency; Advocates kept informed of other training opportunities  |

**Fig. 1** Southeast parent advocacy referral and decision process. WA wraparound, PA parent advocate, Coord coordinator



community advocates. It was believed that staff advocates would be more immediately accessible when needed to meet the needs of families in the midst of serious crises upon entering services. A more scheduled approach could be used with community advocates for families not entering services in serious crisis. Southeast employs two staff PAs; both serve in dual capacities splitting their time as advocates and wraparound facilitators. One of them additionally serves as the Parent Advocate Coordinator.

After families are admitted into wraparound and accepts the services of a parent advocate the assigned wraparound facilitator and the PA coordinator work together to triage families and determine their intensity level of need. Families initially determined to have a high level of need are typically assigned a staff advocate. Families with perceived lower needs are typically assigned a volunteer community advocate. The assumption is that the staff advocates have more hours available and can more readily respond to the immediate needs of families than a community volunteer advocate. This assignment may later switch to a community advocate (and vice versa) upon agreement by the

family if family level of need is determined to be either greater or lesser than originally assessed. The PA coordinator considers additional factors of family need in assigning PAs to families such as PA experience with different types of family issues, compatibility and preferences of PA and family, and geographic area.

While family and PA circumstances may necessitate some process variations upon PA assignment, PAs generally receive a copy of the family's release of information along with information already gathered from the family. Specifically the wraparound plan documents, including the Strengths, Needs and Culture Discovery (VanDenBerg and Grealish 1996) are shared with the PA if already completed by the wraparound facilitator and family. The PA then contacts the wraparound facilitator to determine where the PA will first meet with the family, at a scheduled wraparound team meeting or with the family alone at a mutually agreed upon location. If it is determined the PA and family will meet alone to begin the PA service process, the PA uses available information and works with the family to plan PA involvement. If the PA is to first meet with the

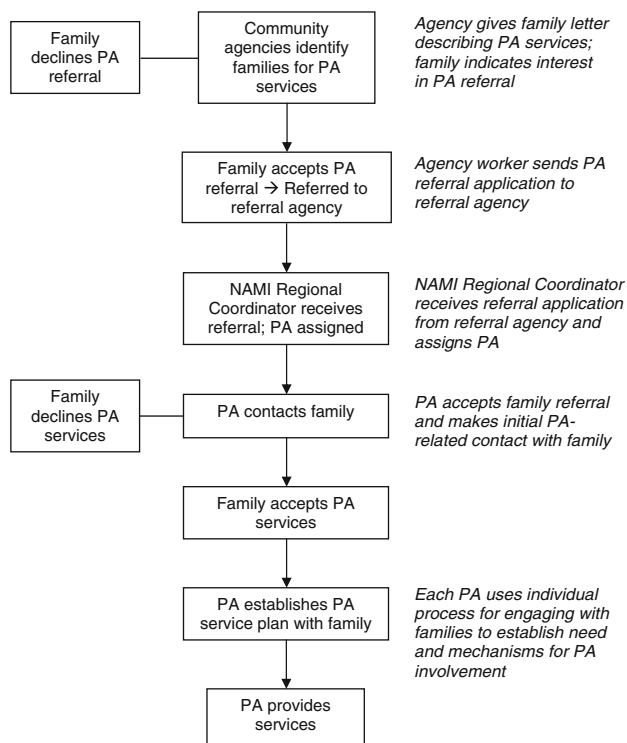


wraparound facilitator and family together, the PA calls the family to make an initial introduction but planning for PA involvement begins at the scheduled meeting. If the family situation is such that the strengths, needs, and culture discovery and wraparound planning can wait until the first meeting with the wraparound team, the PA is often able to participate in the wraparound team planning process. Sometimes PAs are written into the wraparound plan. In any case, the PA is often viewed as a member of the family's wraparound team and participates as a member of the team accordingly.

The parent advocates meet as a group with the PA coordinator on a monthly basis, where the coordinator checks in with the PAs to determine their status with current families and their availability to take on additional families. PAs are provided program information and updates relevant to their work as NAMI PAs. Meetings occasionally include brief trainings specifically for parent advocates.

### Central County

Figure 2 illustrates the implementation processes followed in Central County as described and understood by the parent advocates themselves. In the midst of this research the NAMI Parent Advocacy in Central went into transition.



**Fig. 2** Central county parent advocacy referral and decision process. PA parent advocate

Personnel and structural changes were occurring in the agency responsible for providing referrals to parent advocacy services. In addition personnel changes were made to the NAMI Regional Coordinator serving Central. Both the referral agency and Regional Coordinator historically played significant roles in Central's parent advocacy program; thus, the findings reflect the processes as understood by PAs during the time period of the study. However, it is important to note that PAs reported very mixed levels of understanding about the parent advocacy program processes overall, even before the changes in personnel. Parent advocates described varying ideas about how families are identified and referred for PA services, with some indicating little if any knowledge of these processes. Figure 2 reflects a picture of the advocates' combined understanding and presentation of ideas offered about how parent advocacy works in Central.

Parent advocates reported that agencies serving children with mental and behavioral health needs in Central were the sources of family referrals for advocacy services, though they believed referrals came primarily, and inconsistently, from a few private agencies. The referral process begins with the individual "counselors" or "therapists" identifying families who might benefit from advocacy services. The therapist introduces the idea to families by presenting them with a letter about parent advocacy. Families are asked to let the worker know of their interest in being referred to the program. If the families indicate interest, an advocacy application is completed and sent to the designated referral agency. In turn the referral agency sends names and contact information for selected families to the NAMI Regional Coordinator who serves as the coordinator of Central's PAC program.

The NAMI Regional Coordinator is responsible for linking families with parent advocates. The criteria for matching families with advocates were understood differently among participants. Types of criteria expressed by advocates included matches based on race and ethnicity, types of advocate experience with families and their individual areas of expertise, past professional experience, perceived needs of families, and the match between advocate and family geographic locations.

Parent advocates indicated that they initially receive little information about the families assigned to them. The PA typically receives the family's contact information and calls to introduce her/himself to the parents. The parent(s) may choose to decline the PA involvement or meet with the PA for further introduction. Advocates described times when it seemed they were making "cold calls" to parents who did not seem to remember requesting a PA. Advocates described a range of family understanding of the role of a PA and the effort that is often involved in helping families understand the services a PA can offer. In this specific

regard, PAs suggested families be introduced to the PA concept and the PA him/herself much earlier in the process so that families clearly understand the PA role and can more fluidly engage with the PA.

Once families and PAs establish a connection, the PA works with the family to develop a plan for PA involvement based on the needs expressed by the family. At this point PAs may also actively seek information from formal providers working with the family. However, Central PAs appeared to work fairly independently with their assigned families. While they described occasional group meetings with the Regional Coordinator their accounts of these meetings were inconsistent with regard to content and utility in providing direction and support to advocates.

While service plans reflect the role of PAs as described below, Central advocates often discussed services of parent mentoring or parent coaching. In attempting to distinguish among parent advocacy, mentoring, and coaching services it was learned that several PAs were also involved in separate parent mentoring and coaching service roles. Some families appeared to receive “educational” mentors and/or coaches paid through Ohio’s specialized funding stream. It remained unclear how many, if any, of the PAs were actually paid as mentors and coaches, how many engaged in such activities voluntarily, or how many simply defined their PA services as often requiring them to move into a role of mentoring or coaching with parents.

#### Role of Parent Advocates across Counties

Parent advocates in both counties reported engaging with families in a variety of capacities. In general PAs indicated they primarily interact with systems on behalf of families, engage in one-on-one work with families, engage in indirect family advocacy in the community, and provide transportation for families. Among their many roles, advocates reported spending an extensive amount of time in meetings with families, particularly school-based meetings.

...in all honestly in the short time that I have officially been a parent advocate under wrap around most of my work has revolved around school related meetings.

I’ve been to I don’t know how many school meetings this year...I’ve been to school meetings I think almost every week.

Thus, we further explored the specific roles PAs take on while in the various meetings. Table 2 provides a snapshot of the kinds of support PAs reported providing to families during meetings. As evidenced by the list, advocates indicated a variety of roles. Their specific role depended upon the needs of the families.

**Table 2** Parent advocate roles in meetings

|   |
|---|
| Ask questions   |
| Broker/negotiator   |
| Debriefing with families  |
| Ensuring consumer voice   |
| Help create service plan  |
| Help families understand information/process/translate any jargon           |
| Help families complete forms  |
| Help prepare family for meetings  |
| Intervening between families and systems                                    |
| Listen  |
| Seek clarification from providers   |
| Take notes  |
| Talk on behalf of families/advocate for families/communicate family’s needs |

A few examples from the dialogue with PAs illustrate the commitment they offer to providing whatever the families need in the way of support around meeting with professionals.

I call the parent first and ask what issues do you want brought up in the team meeting, or I make a home family visit. What type of resolution would you like to see? We will talk about that and I will say what do you feel comfortable bringing up yourself? We will decide then what they will bring up and what I’m going to bring up. Now in the meeting if something comes up, something that is being said outside what we talked about, and I see that there may be an issue there, then I will just go ahead and bring it up. I don’t bring up any surprises for my parents. I do not take over their parenting role. I do not take away from their authority.

Basically, I listen, and if I see something like in IEP meetings, I want to make sure that the parent’s voice is heard, and if I hear something, and I know the law and I know that the school isn’t doing it, then, I bring up questions.

...the person might not have heard what was said and so when you get home and talk to them the next week or something... I clarify what they said....

I empower that family to come to that meeting and that they will be heard and as a parent advocate I am with the family and I let them know that you don’t have to be afraid of all of the professionals because you have a parent advocate that is here for you.

#### Reasons Families Decline Parent Advocate Services

The reasons parent advocates offered for why they believe some families decline the services of a PA echoed findings

from other evaluations of the specialized funding stream (Scheer and Gavazzi 2009). The reason most often cited by advocates in the current study was that they believe parents simply did not have adequate information or an accurate understanding of parent advocacy and how it could support them. Interestingly, even with the more structured processes in place in Southeast County, PAs in both counties indicated this as a primary reason for families declining services.

Because they don't know what it is...So if they could understand that the person isn't telling them what to do and also probably most importantly that the parent advocates are people who have been through all of this stuff, that would help them enormously. That never, in my opinion, has come across the strongest...When you hear the words parent advocate, it doesn't mean safety. So to get that idea across would be essential.

The second most cited reason across both counties for why parents decline advocacy services is that PAs believe parents are overwhelmed with the number of people already involved in their lives and just do not want to include another person in their family.

...Because they just don't want another person in their lives. They are so overburdened with doctor appointments and counseling appointments and school appointments and just trying to keep it together on their own. Many of the parents are working parents so they have a lot to juggle.

Advocates in both counties also suggested that some families may feel they have enough support and do not need the services of a PA. Additional potential reasons cited for families declining PA services included families' sense of embarrassment about the chaos of their lives, families' sense of hopelessness, language barriers, fears related to undocumented immigrant status, or concerns related to non-acceptance of people who are gay.

#### Challenges and Needed Supports for Parent Advocates

The collaboration with NAMI Ohio also resulted in a desire to better understand how NAMI Ohio and other stakeholders might support PAs in their efforts with families. Thus, PAs discussed challenges they encounter and offered ideas for how they could be further supported by stakeholders. Advocates offered the following as noted challenges:

- It is often challenging to work around personal needs like child care and professional commitments to do advocacy work

- Advocacy work sometimes takes time away from advocates' own families
- Documentation of PA activities—advocates sometimes feel undervalued since their time on the phone and certain other expenses they incur are not reimbursable; some advocates find the documentation burdensome
- There is sometimes a lack of follow through on the part of the clinical workers
- Transporting families is not permissible as a NAMI PAC service; advocates see transportation necessary to their work

One final recurring theme related to marketing and recruitment. As noted above, advocates believed that families were not adequately hearing about the PA program, either in terms of the program itself or with regard to the specific role of a PA. Advocates in Central attributed this in large part to a lack of understanding on the part of the agency professionals.

...the professionals I don't think understand what a PA is...and what we can do because they have been trained to be social workers and there is a difference between their thinking and what we can do for them and we are there to support them as well. I have had some of them from the agencies say to me, well can you do this for me? Well sure we can do a lot of leg work for them, and this takes the pressure off of the worker in general.

Along with improved program marketing and recruitment, Advocates also identified a number of other supports needed to address some of their concerns. Several ideas related to the need for more direct supports, such as regular meetings, backup coverage, documentation assistance, child care, and more learning and training opportunities for PAs. Central PAs in particular noted that improvements to the program structure itself were warranted. Some advocates also indicated that monetary support to use in their work with families would be helpful.

Overall PAs expressed remarkable commitment and dedication to their advocate work with families. This was evidenced not only by their continued involvement in the research itself, but by their voiced expressions of belief in the work they do. Parent advocates appear motivated not by money but by a genuine desire to engage with families in a way that provides relief and hope in some very challenging times for their families.

Without the parent advocate I just believe a lot of families would not be heard. I don't think that they would get that empowerment. I don't think that they would get knowledge of what is going on, they get frightened. So without the parent advocate there to encourage them and to put love into it, to let them

know that we are concerned about their household, so without the parent advocate there to educate them on what is going on and what their needs are for that family, to keep the kids intact, to keep the house and family intact, it wouldn't work without the parent advocate being there.

## Discussion

The use of parent advocates as peer support paraprofessional providers continues to expand in the realm of children's mental health services without a corresponding base of research to support such rapid development. This study is one of few to have examined the program approaches, processes, and roles of parent advocates in children's mental health services. Considerations of key policy and practice implications related to implementing parent advocate services emerged from this study's findings, including more specifically the need to establish supportive administrative structures and clear practice structures.

Additionally, findings from this study add new information to the literature about such peer support provider topics as parent advocacy roles, county-level approaches to parent advocacy, reasons for why families decline parent advocate services, and challenges expressed by parent advocates. These findings, to our knowledge, are the most recent published accounts of parent advocacy approaches in children's mental health, and are the first to detail the precise structure and process of referral to parent advocates, initial contact, and ongoing parent advocacy engagement. It is exactly this type of detailed research that is needed in order to understand parent advocacy, support, and education in children mental health (Hoagwood et al. 2008).

## Administrative Structures

The findings suggested that a variety of administrative structures are needed to support effective parent advocacy programs. These structures include the provision of initial and ongoing training, supervision, and support for advocates; clear and understandable parent advocate job descriptions; the availability of parent advocate incentives; and the accessibility of flex funds to support advocacy services. In turn, the most pressing indirect administrative support discussed by study participants involved marketing and recruiting efforts for parent advocate programs.

The existing literature provides no consistent accounts or recommendations for the level of training or education peer support providers need to effectively serve children

and families. However, such providers typically bring personal experience in dealing with their respective circumstances. Training received by PAs in this study varied greatly, ranging from work or volunteer-based training to family experiences. Where PAs in one county were required to have personal experience with a child challenged with mental health issues, this was not the case for PAs in the other county. Few PAs had formal human services related education for preparing them as PAs; most PAs indicated trainings, workshops and conferences as the educational formats they experienced.

Research by Walter and Petr (2006) that examined the use of paraprofessionals for attendant care in children's mental health suggested that training and supervision are key components to effectively serve children and families, as well as helping to maximize the retention of these individuals. The level of supervision provided to PAs differed greatly between the two counties in this study. In fact, inadequate supervision was a specific point of concern for those PAs who were not receiving high levels of contact with individuals who retained a managerial role in their county. Interestingly, however, even in the county experiencing less supervision, this fact did not appear to deter PAs from providing their volunteer service as a parent advocate.

Two unique approaches to providing parent advocate services were clearly identified through this investigation. On the one hand, the Southeast PA system was embedded in its county wraparound structure with both paid and unpaid staff (two PAs had responsibilities as both advocates and Wraparound facilitators). On the other hand, Central county involved community agencies in identifying families for PA services with involvement of a NAMI regional coordinator. At the same time, PAs in both counties engaged in similar activities with or on behalf of families. These comparable actions ranged from individualized attention (one-to-one support) and education to advocacy and transportation. As well, the PAs in both systems took on many similar roles such as asking questions, listening, and ensuring family voice when they were present in family meetings with providers. Interestingly, though one county required advocates to be parents of a child with mental health needs and the other did not, the ultimate work of advocates did not seem to vary. All of the advocates believed they could effectively support, mentor, and coach parents in advocating for their children. What did differ between the counties were the tools and supports the advocates themselves were provided by the system of care to aid in their service to families. Clearly, advocates were more fully engaged with the overall intervention processes in the county embedding the PAs in its wrap-around structures.

Hence, though 15 years have passed since the inclusion of parent advocates was first described as being part of a family-focused model of intensive case management (Evans et al. 1994), the roles of parent advocates appear fairly unchanged since that time. Parent advocates continue to support families in obtaining needed services for their children through direct modeling and teaching families to self-advocate. As noted earlier, Hoagwood et al. (2008) found similar evidence of this consistency in their national survey of family advocacy organizations, whereby family advocates in general were described largely in terms of serving as peer educators, peer supports, and peer advocates.

### Practice Structures

The findings also suggested a need to establish clear practice structures to provide guidance and boundaries for programs utilizing parent advocates. Some specific areas of need identified by advocates in these two counties included defining consistent referral processes to advocacy services, including criteria both in terms of family eligibility and what constituted the most appropriate family conditions and characteristics for advocacy services; obtaining a comprehensive child and family assessment; and determining specific child and family information to be provided to advocates prior to and throughout their work with families. If family or peer providers are to be considered a critical resource that can help to address the mental health workforce shortage (Hoagwood et al. 2008; Romanelli et al. 2009), then considering each of these practice issues will be of vital importance as parent advocate service programs are developed.

This study also sought to determine why some families declined PA services. The data revealed a variety of common responses, including: family members' lack of understanding PA services, family members feeling too many people were already involved in the lives of their families; and family members believing that they already were receiving enough support. Comparably, in a study of parent mentors with families raising young children with Type 1 diabetes, similar evidence was found for those who declined parent mentor involvement (Sullivan-Bolyai et al. 2004), whereby parents who refused parent mentors cited hectic family schedules and expressed the belief that they had enough support already. These results suggest the importance of adequately educating family members about the nature and role of parent advocates as they decide whether a parent advocate would be beneficial for them.

Finally, the study examined challenges that parent advocates faced in their work with families, which included dealing with their own family's needs and demands, feeling undervalued by providers, and the issue of not being

permitted by the program to personally transport families. Transportation challenges have been reported in other studies, including one on the role of family associates who helped in connecting mental health services with low income families (Koroloff et al. 1994), where both transportation and distance were identified as two barriers that prevented families from accessing mental health services.

This study was limited by several factors. First, the interview coding process was limited to one researcher. While the researcher was firmly grounded in the data, other researchers may have found different meaning in the words of the respondents and developed alternative concepts for representing the reflections of study participants. The study examined 2 of the 44 Ohio counties with active NAMI Ohio Parent Advocacy Connection (PAC) programs. While elements of the PAC program are becoming more standardized with time, it is unclear how closely the implementation processes examined for this study may approximate those of other counties. In addition, the study gathered perspectives from only one level of system participants, parent advocates. Resources were prohibitive to obtaining additional perspectives, such as caregivers working with advocates or system providers with whom advocates interact. Such perspectives in future studies would provide a broader contextual understanding of how advocates are experienced at multiple participant levels. Finally, no outcome data were available to present with this study. These last two limitations narrow the overall picture of the programs and thus may miss some key aspects of program implementation.

In conclusion, understanding the structures and functions of parent advocates at the program/county level suggest the importance of developing clear and effective administrative and practice structures beyond these local level efforts. Federally funded systems of care for children's mental health both require and support specific efforts at the local level to ensure families are integrated into service and system level processes. Comparable state efforts, such as the Parent Advocacy Connection (PAC) program in Ohio, are similarly attempting new approaches to involve families in their children's care. However, well meaning such efforts may be, moving these family-focused efforts beyond mere "lip service" to a well-supported service system level will require the re-thinking of existing administrative practices and priorities. For example, systems will need to create fiscal arrangements that reimburse for peer-based services (Hoagwood et al. 2008) and administrative supports that can provide adequate peer provider professional training (Romanelli et al. 2009). Romanelli et al. further suggest the development of national training and standards for such peer providers, and some states actually have begun to certify "professional family advisors and advocates" (Hoagwood et al., p. 81).

As the entity responsible for developing and managing Ohio's state-wide parent advocate program, NAMI-Ohio currently is doing what it can to maximize the relatively meager financial support it receives from the Ohio Department of Mental Health in order to implement this mandated program for publicly-funded children's mental health services.

To support these new developments, parent advocate services research is needed to inform the field about the most effective and efficient strategies for assuming the role of parent advocate in children's mental health. In her recent systematic review of family-based services, Hoagwood (2005) found no studies that examined how family-driven care impacts service use, outcomes, retention, satisfaction, or outcomes. This author asserted that such research could help guide administrative and policy decisions around improving both the quality and efficiency of children's mental health services. Information such as that gathered in the current study needs to be made available to aid in the design of future research efforts intended to answer these kinds of impact questions.

Finally, although it is axiomatic to state that further research is needed to determine long-term outcomes of parent advocate providers, at least there seems to be consensus among national leaders that advocates can play an effective role in serving families with children experiencing serious emotional and behavioral challenges. Given the increasing use of peer providers in children's mental health, and in the spirit of integrating families into practice and research enterprises, perhaps future studies should reflect an applied researcher-practitioner model to more immediately maximize the related benefits at all system levels. Lest the most critical point be lost here, we close with the following statement. There is no dispute about parent advocates' desire and efforts to make a positive impact on the lives of children and families, and such aspirations are supported by an overarching theme of this study's findings, whereby parent advocates clearly stated their dedication to and commitment toward the well-being of the families whose lives they are touching.

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### Appendix A: Focus Group Questions

1. How did you first get involved in parent advocacy?
2. What specific model or models of parent advocacy are used in your county?

3. If you had to describe parent advocacy in terms of three specific levels of intensity—low, medium, and high intensity—how would you describe your levels of involvement and the kinds of advocacy activities that occur at each level?
4. Why, in your opinion, do some families decline parent advocacy services when offered?
5. For families that do accept advocacy services, describe their range of responsiveness and willingness to participate in advocacy services. (*Alternate question: What are some differences between families who want a lot of participation with advocate services compared to those who want to participate only a little with advocate services?*)
6. What presents the biggest challenges to you in serving as a parent advocate?
7. What changes, if any, are needed to better support your ability to be an effective advocate?

### Appendix B: Parent Advocate Interview Question Guide

#### Advocate Experience and Training

1. For how many years have you been advocating for families with children who have mental illness? (Overall/In specific county)
2. How did you become affiliated with NAMI/PAC (Parent Advocacy Connection)?
3. How did you become involved with the family or families you are assisting in your current parent advocate role?
4. Describe your experience in advocating for families of children with mental illness. (Descriptive prompts included: Level of experience (e.g., working one-to-one; working with service teams; advocating with agencies; advocating with legislators; etc.); Years and approximate number of families served; Previous advocacy related experience with other organizations/agencies)
5. Describe your specific trainings in advocacy and the agencies that sponsored or provided these trainings.

#### Parent Advocate Involvement and Services

6. List and describe the specific kinds of advocacy services, meetings, assistance, and activities that you provide to families. (Descriptive prompts included: need/purpose of activity; average time spent/month; description of role in activity)
7. What are some examples of how you believe kids and their families are being helped because of your role as a parent advocate? (*Alternative question: describe how*

*you believe your work is helping to support and empower the families with whom you work.)*

8. Why, in your opinion, do some families decline parent advocacy services when offered? [*Probe: what are potential barriers keeping families from accepting advocacy services?*]
9. How do your services vary based on the child's and family's needs?
10. How do you consider and incorporate the culture of families in your parent advocate activities?

*Follow-up probes:*

- (a) How does your approach with children and families differ based on their cultural characteristics (i.e., ethnic and racial background, socioeconomic level, family constellation, religion, family values, other cultural characteristics)?
  - (b) How, specifically, do your services vary by child and family cultural characteristics?
11. Describe the step-by step process that you follow from initial linkage with a family through advocacy planning and action.

Support for Parent Advocates

12. On a scale of 1–5 (1 being not well at all and 5 being very well), how supported do you feel by the following groups for the decisions you make as a parent advocate? (program specific entities; other families)
13. In what specific ways do you feel support by the following groups for the decisions you make as a parent advocate? (program specific entities; other families)
14. In what additional ways would you like to see support offered to Parent Advocates?

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