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ORIGINAL PAPER

Family Advocacy, Support and Education in Children's Mental Health: Results of a National Survey

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Abstract In conjunction with the national survey of mental health service organizations (Schoenwald et al. this issue), a separate but complementary national survey was conducted of family advocacy, support and education organizations (FASEOs). Directors of FASEOs within the same localities as the mental health agencies responded to a survey and provided information in four areas: (1) structure and funding; (2) factors influencing advocacy decisions about children's mental health; (3) types of services provided by FASEOs and factors perceived as related to improved outcomes; and (4) the types of working relationships between FASEOs and local mental health clinics. Findings from a total of 226 (82% response rate) portray a network of family advocacy, support and education organizations that are strategically poised to effect substantive change and characterized by significant fiscal instability. Results from this survey and implications for delivery of family-based services are provided.

Keywords Family advocacy · Family-based services · Children's mental health · Education organizations

Since approximately the mid-1980s, when the System of Care (Stroul and Friedman 1986) monograph first outlined principles for improving the coordination of children's mental health services, the role of organized advocacy and support for families of children with mental health issues has expanded dramatically. This development has signaled acknowledgement of families as important partners in service delivery. Today at least five major national organizations, with hundreds of state and local chapters, exist to support and advocate on behalf of families whose children have mental health needs. Among the organizations that have both national and state or local affiliates are the National Alliance for the Mentally Ill (NAMI); the National Mental Health Association (now called Mental Health America (MHA); the Federation of Families for

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Children's Mental Health; Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD); and the Child and Adolescent Bipolar Foundation (CABF). International chapters are beginning to be formed, particularly for families of children with specific disorders, such as ADHD, autism, and bipolar disorders (Hoagwood et al. 2006).

The advent of family advocacy and support in children's mental health follows a long history of advocacy about pediatric illnesses, including autism, AIDS, cancer, diabetes, asthma, and developmental disabilities (Palfrey 2006). Sociological studies of advocacy organizations have suggested that the focus of the questions about advocacy have shifted since the 1970s away from macro-level analyses about the distribution of power among agencies, government and families (e.g., Mills and Wolfe 1999) towards more micro-level issues of individual participation and behavioral activation (Andrews and Edwards 2004). What might be thought of as mid-range analyses—studies of networking among advocacy groups or studies of community mobilization, for instance—are relatively underdeveloped, although likely to emerge more substantively in the next decade because local organizations appear to be highly influential in some aspects of service delivery (Gruen et al. 2004). In the area of pediatric health advocacy, the number of international organizations is spreading rapidly, spurred in large measure by AIDS activism and now, more recently, by international attention to the impact of war and terrorism on pediatric trauma (Palfrey 2006).

In the United States, the growth of family support and advocacy in children's mental health can be traced to the late 1980s and its development has closely paralleled expansion of community-based services for families and children. In fact, the numbers of national organizations with a specific focus on children with mental health needs has doubled during this time. Federal funding contributed to this growth through stipulation of family involvement in service expansion. The growth has been largely visible through the establishment of organizations focused around specific childhood psychiatric diagnoses, such as attention-deficit disorders, bipolar disorders, autism, or depression.

Expansion of family advocacy and support in children's mental health is coming at a time of increased national momentum among nonprofit policy organizations for improving the active participation of consumers in health care (Institute of Medicine (IOM) 2001). At the same time, federal and state government agencies, spurred in part by the series of Surgeon General's public health reports (e.g., U.S. Public Health Service (USPHS) 1999, 2000, 2001a, b) are urging greater attention to the use of evidence-based assessment and intervention practices for children and adults with mental health problems. This convergence of policies to encourage attention to the quality of services, growth in family support and advocacy, and international attention to both pediatric health and mental health raises a number of opportunities for considering expanded roles for family organizations. Understanding the current structure and function of these organizations is a first step.

Information about the infrastructure and roles of family advocacy, support and education organizations for children's mental health in the US, however, is nonexistent. Consequently, the Child STEPS project of the MacArthur Foundation Youth Research Network, with funding from the Robert Wood Johnson Foundation, launched a national survey of family organizations providing education, support or advocacy to families of children with mental health needs that would parallel and complement the Clinic System Study (as described by Schoenwald et al. this issue).

Together with the national organizations mentioned above and other advocacy and policy organizations involved in children's mental health (e.g., Bazelon Center, Kansas Keys, National Wraparound Initiative, National Center for Children in Poverty, Portland's Research and Training Center on Family Support and Children's Mental Health), a subgroup of the Clinic Systems Project (CSP) designed a survey to assess the role of family advocacy, support and education organizations (FASEOs) in community-based services in children's mental health.

The Family Advocacy, Support and Education Organizations (FASEO) survey instrument collected information in four areas: (1) the infrastructure and funding sources for FASEOs; (2) the major factors influencing advocacy decisions about children's mental health; (3) service delivery within FASEOs and factors perceived as related to improved outcomes for children; and (4) the types of working relationships among FASEOs and local mental health clinics. These areas of inquiry parallel the domains of the community-based mental health services infrastructure assessed in the CSP Director's survey (see Schoenwald and colleagues, this issue), thus providing points of comparison on the fiscal, governance, and operational aspects of mental health organizations and FASEOs serving children and families in the same locales. The data obtained from the FASEOs were thus expected to illuminate the nature of family support efforts and organizations pertinent to children's mental health and suggest additional, family-based leverage points for the improvement of children's services potentially relevant to the implementation of evidence-based practices.

This paper describes the sample, sample selection, methods and findings from this national survey, the first to our knowledge, of FASEOs.

Methods

The sample consisted of 226 directors of FASEO that explicitly promoted children's mental health services. The sample was identified from the 200 clinic directors participating in the provider survey (see Schoenwald et al. this issue). The executive directors of the 226 FASEOs responded to a 1-h semi-structured telephone interview. Initial contact information was received for 349 family organizations from the directors of the provider organizations. After examining the contact information and speaking with the identified agencies, we determined that only 275 (78.8%) actually met our criteria for a family organization and were thus eligible to participate in the survey. Seventy-four organizations were not eligible for the following reasons.

- Twenty-two organizations could not be identified based on the information received from the informant for the CSP Director's Survey (e.g., did not have telephone numbers that were in service; internet searches did not turn up anything with a similar name)
- Twelve organizations were comprised of providers whose purpose was not family advocacy or support
- Ten were duplicative
- Eight were not specific to mental health
- Eight were government agencies
- Five were confirmed to be no longer in operation
- Five were direct MH service providers, not education, support or advocacy organizations
- Four organizations served adults only

Of the 275 agencies that met our criteria, we completed the survey with 226, yielding a response rate of 82.2%. Ten family organizations actively refused to participate when contacted, while an additional 39 were passive refusals. Each passive refusal received a minimum of nine contacts (email, fax, and/or phone message) and was not able to be reached, even though we had confirmation that we had correct contact information.

Semi-structured interviews were conducted by staff from one of the Network sites (Children's Hospital of San Diego (J. Landsverk, PI) from November 2005 to July 2006. The survey instrument included items modified from the CSP provider survey (Schoenwald, et al. this issue), such as infrastructure of the organization (e.g., affiliation status, structure, size), and sources of funding. Based on feedback from the advisory board, the survey included items specific to family advocacy, support and education, including techniques employed, how decisions are made about advocacy, types of issues that are most salient for advocacy, and factors that influence advocacy. Also included were questions related to types of direct services offered by the FASEOs, roles of family members in mental health services, and factors related to improved outcomes. Finally because the types of working alliances that existed with local mental health providers were of interest, questions were included about the types of formal and informal professional relationships with the largest local mental health service providers in their community. A copy of the semi-structured interview is available from the corresponding author.

Results

Infrastructure

Three categories of information were collected about the infrastructure support within FASEOs: information related to affiliation status (i.e., whether the FASEO was or was not affiliated with a national organization); size of the organization's membership; and base of funding support.

Affiliation

Figure 1 indicates the range of affiliation status among the sample of local FASEO and the parent (national) organizations. About 76% of the FASEOs were affiliated with a national advocacy group (NAMI, FFCMH, NMHA—now Mental Health America, or CHADD). The majority of those with a national affiliation represented NAMI chapters. About 23% of FASEOs were independent—that is, they were not affiliated with any national organization.

Size

The size of the FASEO varied widely in terms of number of active members and number of persons served (i.e., population base directors reported their organization served). The mean number of active members was 193, with a range of 1 to 3, 082 members. About 13% of the FASEOs had 500 or more members. About 50% had 60 or fewer members and 27% did not have any members. The number of persons served by the FASEOs also varied. The mean number was 20,998 members, with a range of 1–1.8 million. About 33% served 100–499 members and 32% served more than 2,000 persons. About 50% served fewer than 500 persons.

Funding Base

Figure 2 displays the range of funding sources for the FASEO. The majority of directors of FASEOs (78%)

Fig. 1 Affiliation with national organizations (*N* = 226)

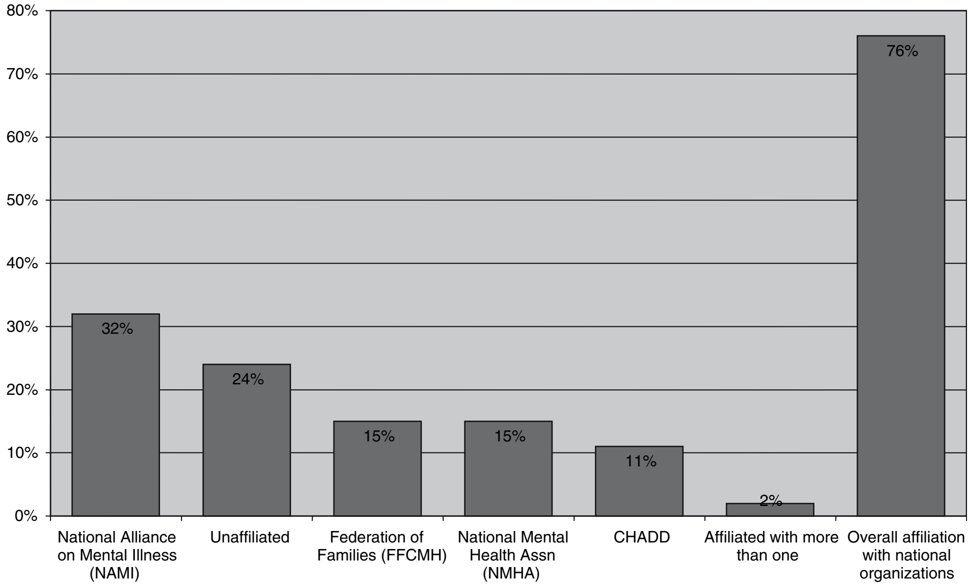
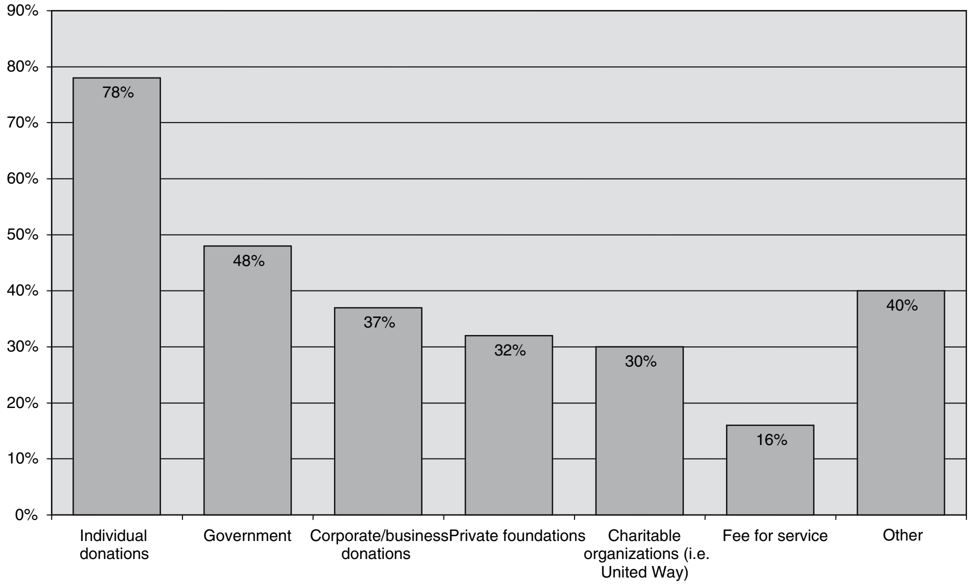


Fig. 2 Major sources of funding (*N* = 226)



reported that their organizations are supported through individual donations. About 48% of the directors reported that their organization receives at least half of their revenue through private funding sources (individual and business donations, charitable organizations, and private foundations). Approximately one third receive support through corporate sources, private foundations, or charitable organizations (37, 32, and 30% respectively). In contrast to the mental health service organizations, only 16% receive support through fee for service mechanisms.

Among the sources of public funding directors were asked to identify specific sectors that contributed to FAS-EOs funding base (see Fig. 3). Not surprisingly, the largest contributory source of public funding is from mental health (35%). The other sectors (i.e., education, child welfare, health, mental retardation or developmental disabilities) contribute between 5% and 10% to the total funding support for the organizations.

Advocacy Decision-making

Because of theory and mixed findings from the diffusion of innovation literature about the impact of public education, outreach, and passive dissemination strategies (e.g., of print material) on consumer awareness and behavior (Bero et al. 1998; Greenhalgh et al. 2004; IOM 2002), four areas of advocacy decision-making were selected for specific focus. These were types of dissemination/communication techniques employed; types of issues identified as salient to

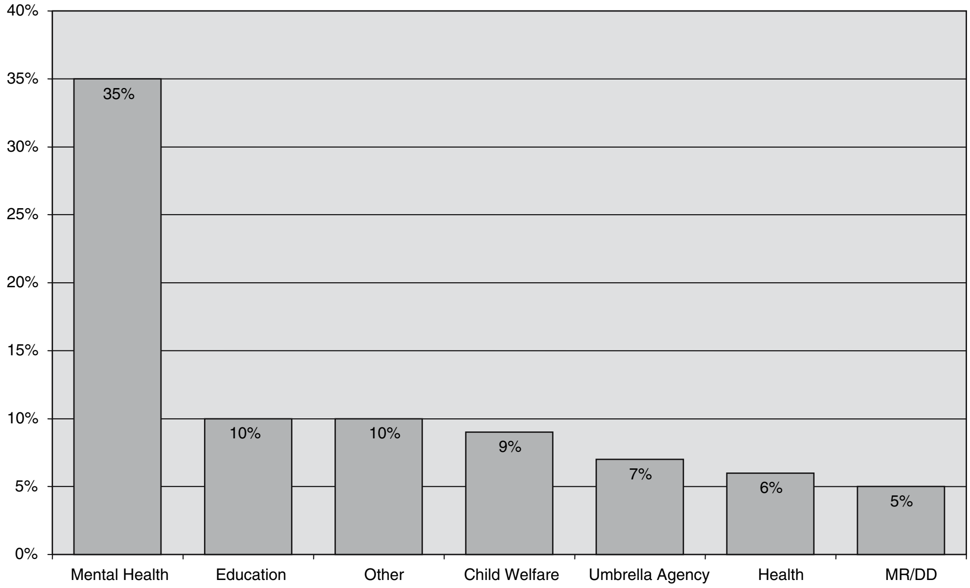


Fig. 3 Source of Public Funding ($N = 226$)

FASEOs; how advocacy decisions are made; and factors that influence advocacy decisions.

Among the advocacy techniques employed, 95% of respondents indicated that they use print materials; 79% used outreach; 73% used workshops; and 71% used the web. Only 38% used a listserv. Thus the FASEOs use a variety of mechanisms to reach their membership, including both grass root approaches and electronic means of information transmission.

Directors indicated that the two top issues for which they advocate are public awareness of mental health and family involvement (90 and 89% respectively) (see Fig. 4). Screening and assessment issues, evidence-based practices, and cultural competence issues were endorsed by slightly over half of the directors (56% each). Advocacy around specific clinical practices, which in general are closely aligned with evidence-based approaches, were endorsed by only 26% of the directors. Thus the advocacy issues that FASEO directors see as most important to their organization involve the public face of mental health and the role of family members within it. See Fig. 4.

Directors indicated that advocacy decisions are largely made by the board (69%) and by informal member meetings (59%). See Table 1. Other ways in which advocacy decisions are made include requests from state or local chapters (48%), requests from national chapters (49%) and decisions by the director (49%). Relatively infrequent are requests from legislative bodies or policymakers (29%).

When asked to indicate on a scale of 1–7 the factors that are most important in influencing advocacy decisions, the factor that received the highest rating was families' attitudes towards the issue (6.4), followed by the board's

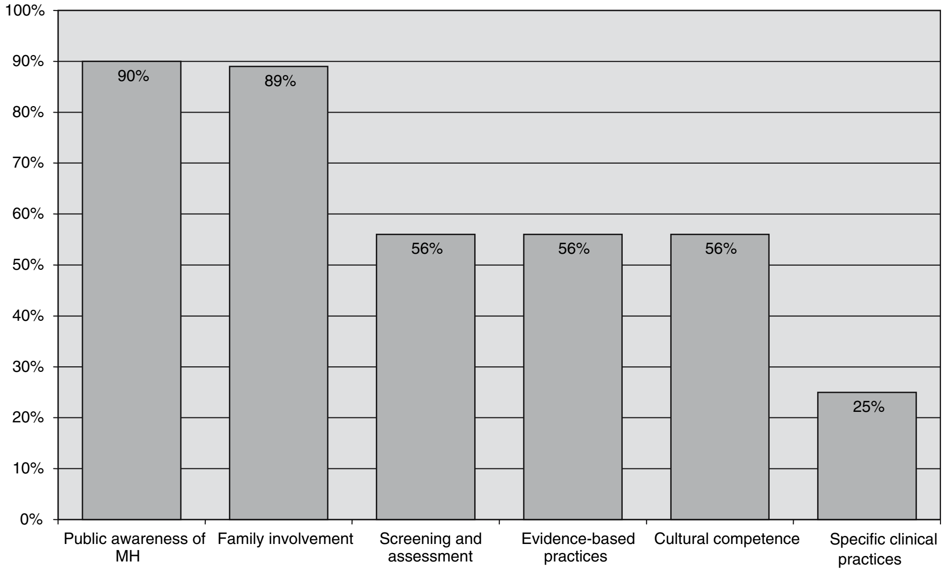


Fig. 4 Advocacy Decisions: What do they advocate for? ($N = 226$)

Table 1 How are advocacy decisions made? (*N* = 226)

How	Percent	*N*
Decision by board	69	226
Informal member meetings	59	226
Request from state/local chapter	48	226
Request from national chapter	49	226
Decision by director	49	226
Formal member meetings	46	226
Request from legislature/policymakers	29	226

attitude towards the issue (5.8). Thus the selection of advocacy issues is seen as directly related to family member's endorsement of the issue. Other factors that were rated as highly important included the existence of scientific evidence for the issue and the director's attitude towards the issue. Each of these factors received ratings of 5.5. See Fig. 5.

Services, Family Roles, and Outcomes

The survey asked directors about issues related to service delivery within their organization and within their mental health community, including types of services provided, the kinds of roles that family members are able to provide, and the service factors that they believe to be most important to improving child and adolescent outcomes.

Services Provided

Directors reported the types of services provided by their organizations. The majority (93%) indicated that they provide information and referrals to family members. This appears to be the primary function of the FASEO. In addition, however, 85% indicated that they provide support groups and 81% provide training or technical assistance, 76% newsletters, 75% website services, and 69% public advocacy and legislative or policy advocacy. Thus the range of services is broad and is primarily related to information dissemination, direct family support, and policy advocacy.

Roles for Families

Directors identified the most important roles for family members within their local mental health community. Table 2 displays the results. The overwhelming majority (97%) identified educating other families as the most important role for families. Advocating for mental health services and peer-to-peer support was also identified as key roles for families (94 and 91%). Leading support groups, training other families, and being a direct liaison with mental health providers were also identified as key roles by 88, 88 and 81% of the directors of the FASEOs. This suggests that community leaders of family advocacy, support and education organizations see families more able to play a much more active role in service delivery than is typically afforded families by provider organizations.

Improving Mental Health Outcome

Directors were asked to rate on a scale of 1 (unimportant) to 7 (important) mental health services that they believe are most important for improving children's mental health

Fig. 5 What influences advocacy (1—unimportant to 7—very important)

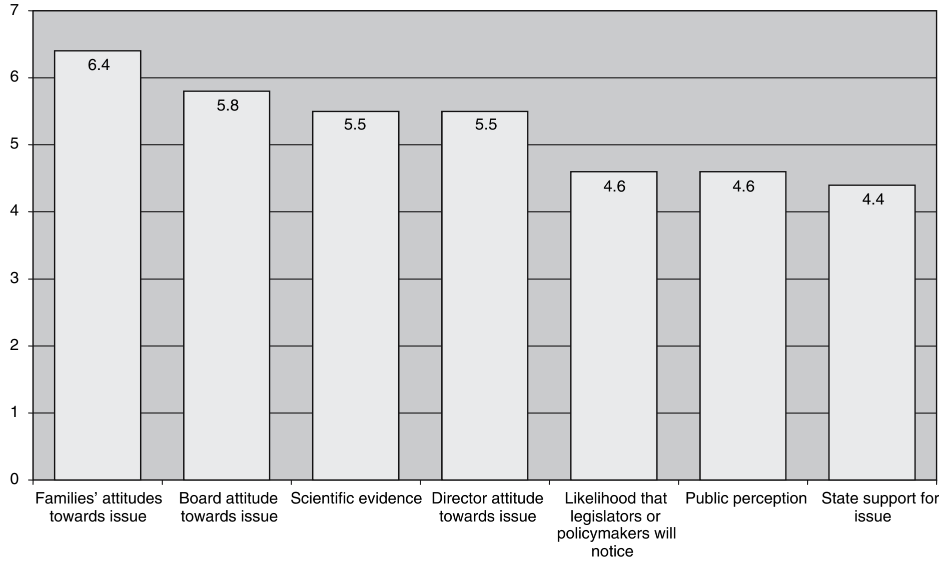


Table 2 Most important roles for families in mental health service delivery

Roles	Percent	*N*
Educating other families	97	226
Advocating for MH service delivery	94	226
Peer-to-peer support	91	226
Leading support groups	88	226
Training families	88	226
Liaison with MH, other professionals	81	226
Direct advocacy on behalf of individual families	79	226
Outreach	73	226
Crisis intervention	61	226
Respite	56	226
Case manager	52	226
Research collaborator	50	226
Consultation	49	226
Home visitation	43	226
Co-therapy	39	226
Conducting screening/assessments	35	226

outcomes. The issues that received the highest rating (6.8) were availability of services, family's relationship with the clinical staff (6.8) and appropriate diagnostic assessment (6.6). Several other issues received high ratings (of 6.5) as well, including respect for families, inclusion of the family, therapist training, and working with other agencies. These findings suggest that the kinds of factors that from a family perspective are most closely related to improved outcomes include service availability, relationships with providers that are respectful, and high quality services, including assessments, well trained clinicians, and strong linkages to other agencies.

Working Relationships

Since the FASEO survey was linked to the CSP Director's Survey and because the shared goal of the two surveys was to identify effective locally based supports for children's mental health service implementation, we also included questions about the types of working relationships that had been formed between local FASEOs and their local mental health clinic. Specifically, we asked about five potential areas of connection: (a) whether the FASEO had a governance (i.e., decision-making) role in their local mental health clinic; (b) whether the FASEO was involved in the acquisition or allocation of outpatient clinic resources, such as the development of grants or budget decisions; (c) whether the FASEO had representation at meetings convened by their local mental health clinic that resulted in noticeable changes in the policies or practices of the clinic; (d) whether their local mental health clinics shared specific information about outcomes (e.g. retention, utilization, satisfaction, improvements, etc.) with the FASEO; and (e) whether staff of their local outpatient mental health clinic worked formally with the FASEO. See Fig. 6.

About 24% of FASEO directors reported that their organization had a governance role within their local mental health clinic; 26% reported involvement in acquisition or allocation of resources; 68% reported representation of their FASEO at clinic meetings and of those, 77% indicated that their representation resulted in noticeable changes. Forty-seven percent of the FASEO directors reported that their local clinic shared information about child or family outcomes; and 43% indicated formal working relationships by clinic staff with their FASEO. We then grouped the responses into three categories of working relationships: close, moderate, or no working relationship.

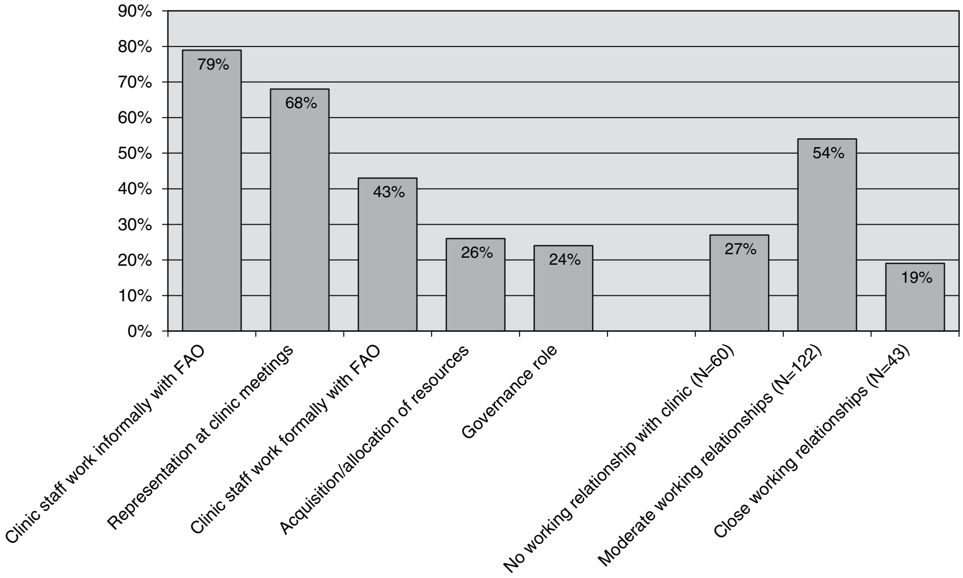


Fig. 6 Types of working relationships with local mental health clinics

We defined a close connection as one that had at least four or five affirmative responses to the questions identified above; a moderate connection as one having between one and three affirmative responses; and no connection as the absence of any of these items. We found that 27% of respondents ($N = 60$) reported no working relationship whatsoever with their local clinics (i.e., no affirmative response to any of these items); 54% ($N = 122$) reported some degree of connection (between one and three affirmative responses); and 19% ($N = 43$) reported a close working relationship (i.e., four or five affirmative responses). See Fig. 6.

Discussion

This is the first national survey of family advocacy, support and education organizations that has explicitly sought to characterize grassroots, locally based support agencies that serve families of children and adolescents with mental health needs. As the structure, capacity and availability of the current mental health system has been vigorously called into question in recent reports (National Advisory Mental Health Council's Services Research and Clinical Epidemiology Workgroup 2006; President's New Freedom Commission Report on Mental Health 2003; USPHS 1999), family-based organizations are frequently asked to fill gaps created by the absence or inadequacy of local mental health services. Therefore having a more complete picture of the structure, function, and roles of the national network of family-based organizations is advantageous. The findings from this survey both underscore the fiscal fragility of the local family-support system and point to its membership strengths and to its potential for further expanding the roles of families in children's mental health service delivery. They also contribute to the emerging "mid-range" literature on networking and connectedness among advocacy and support groups both vertically (i.e., among local and state affiliations) and horizontally (i.e., among FASEOs and local clinic providers).

The findings from our survey suggest that ¾ of FASEOs are affiliated with national organizations but that size of membership and numbers of individuals served vary considerably. Fifty percent of the FASEOs had fewer than 60 members and 50% served fewer than 500 persons. Thus our sample was essentially comprised of small locally operated organizations likely to be affiliated with a national organization.

Funding support for the FASEOs is largely driven by private donations. Private support was identified as a primary source for 78% of the FASEOs whereas government support was available for 48%. Fee for service support contributed only a fraction of the total funding sources (16%). Insofar as the FASEOs receive public funds, it is likely to come from state or local mental health agencies rather than other health, education, or human service agencies. Together the findings suggest that most FASEOs are faced with fiscal fragility and uncertain sources of revenue, painting a picture of a national family advocacy network that contains significant elements of instability.

The findings about advocacy decision-making depict a network that uses a variety of approaches to communicate information to its membership and to the public at large. Print media, outreach, workshops and the web were among the communication mechanisms used. It is interesting to note that although we did not assess the perceived impact of these different methods of communication, evidence from studies about the dissemination of public health information using these kinds of approaches suggests that they typically have limited impact (Bero et al. 1998; Greenhalgh et al. 2004). In fact, systematic reviews by Gilbody and colleagues (2003) found that educational strategies were generally ineffective and similar findings have been reported in efforts to implement guidelines (IOM 2002). The implications are that the primary mechanisms for communicating information by FASEOs to their membership may be inefficient if not ineffective.

The existence of a national network of FASEOs with a clear commitment to public outreach, however, is a powerful social-political starting point for widespread public health change. It would be valuable to examine the relative advantages of different types of communication strategies in accomplishing public awareness goals, reducing stigma, or effecting behavior change.

The kinds of issues that are most salient for FASEOs involve public awareness of mental health and family involvement, issues that have historically been the grist of grass-roots advocacy for families of children with other disabilities. Interestingly, screening, assessment, cultural responsiveness, and evidence-based practices were each endorsed by 56% of the directors. Given the criticisms that have been leveled against both mental health screenings and evidence-based practices by some groups (United Advocates for Children in California 2005), it is interesting that among this group of directors, positive advocacy about both of these issues were seen as important to their mission.

With respect to the drivers of decision-making, directors indicated that advocacy decisions are largely made by their advisory board (69%) and by informal member meetings (59%). This responsiveness to membership and board interests is historically a common element found among grassroots advocacy organizations. Consistent with this was the finding that family attitudes and board attitudes towards an issue were rated as the most important factor influencing selection of the issue for which to advocate.

Since the capacity of the mental health system to provide an adequate supply of providers, professionals, and of services has been emphatically criticized (Annapolis Coalition on Behavioral Health Workforce 2007), directors' perspectives about types of services provided within their own organizations, types of roles that family members are able to provide, and factors perceived as important to improving child and adolescent outcomes are of particular interest. The majority of directors (93%) indicated that information and referrals to family members constituted their primary form of service delivery. However, a range of other services were also mentioned by the majority of FASEOs, including support groups for families, specific training or technical assistance workshops, and legislative or policy advocacy. Thus an array of direct services (e.g., peer-to-peer and group support, training, public advocacy) combined with an emphasis on dissemination of information to their constituencies constitute cornerstone functions for these organizations.

Directors were also asked to identify the most important roles for family members within their local mental health community. It was interesting that the range of roles identified spanned far more responsibilities than are generally acknowledged as pertinent family roles by the provider community. Almost all of the directors reported that educating other families in a peer-to-peer format was the most important role for families. In addition, four out of five directors cited leading support groups, training other families, and being a direct liaison with mental health providers as key roles for families. The range of roles identified by these FASEO directors suggests that the significant shortages of workforce capacity in mental health services might be addressed by greater use of family members in professional roles within provider organizations.

Issues that FASEO directors rated as ultimately important for improving mental health outcomes for children included availability of services, including use of diagnostic assessments and availability of well trained clinicians, quality of the relationship with clinicians, and having strong linkages to other agencies. These three issues—availability of quality services, personal relationships with clinical staff, and service sector linkages—have been consistently identified as components of high quality systems of healthcare delivery since the inception of the public mental health service system for children (Davis et al. 1982; Knitzer and Olson 1982; Stroul and Friedman 1986).

Finally, the linkages between FASEOs and local mental health clinics were examined with a particular eye toward identifying models of working relationships among local mental health providers and family-run organizations that may help reduce the fragmentation of child mental health care. Survey results suggested that the connectedness among FASEOs and mental health clinics is complicated in a number of ways. First there are many different ways a family run organization might develop a working relationship with a local provider. These include simple attendance at meetings, fiscal exchange of resources, exchange or sharing of staff, or even official representation on each other's boards. More than a quarter of our sample had no relationship with their local clinic whatsoever. In contrast close to 20% had a very strong connection involving fiscal sharing of resources, formal representation on a board, sharing of outcomes information, and having a governance role. The remainder—about 54%—had some of these types of connections with their local provider.

Second, circumspection is warranted about assuming that connectedness itself has either a positive or a negative valence. In meetings with the project's national family advisory board, the advisors pointed out that strong connectedness may or may not be desirable given a particular policy or advocacy agenda. In other words, a less formalized or even weaker connection with a local mental health provider could result in positive improvements in clinic services if this more distant relationship, for example, enables a local family-run organization to advocate at a federal, state or county level for quality improvements or enhanced fiscal rates for the clinic. On the other hand, a strong and close working alliance among a FASEO and a provider could improve the responsiveness of the provider organization to family-centered issues. So the extent to which linkages among FASEOs and local mental health clinics are likely to yield delivery of higher quality mental health services for families and youth is unknown and is complicated by a host of structural and political factors that affect the relationship. Future studies of these issues around linkages among FASEOs and providers are being planned and are likely to be increasingly important as the family movement in children's mental health strengthens.

The results of this survey raise bigger issues, however, about the growing role of FASEOs and their capacity to manage and deliver a broader range of services for families. The well-acknowledged failures of the current mental health system for children and families (President's New Freedom Commission Report 2003), in combination with the clear inadequacies of the mental health workforce (Annapolis Coalition 2007), suggest that there may be opportunities to expand the roles of families within the workforce and expand the service capacities within FASEOs. This would require of course that reimbursements for these services be equitable and fair, and that these family-run services are billable. There are some states (i.e., New York) that are providing certification for professional family advisors and advocates, as well as manualized training and consultation specifically in support of the roles of family advisors (Hoagwood 2005). New York City's Department of Mental Hygiene is restructuring its family support programs to provide expanded professional roles for family members through a network of Parent Resource Centers. The opportunities for further expansion of and more active participation in services by family members are clearly on the horizon.

In summary, the survey findings from our study describe a network of local grassroots organizations across the country that are comprised of relatively small groups with a fiscally fragile funding base, yet a network with strong personal commitments to educating and strengthening family involvement in services and disseminating information about mental health services broadly. Contrary to expectations, this survey found that directors of family-based organizations believe that improvement of mental health services requires attention to the front end processes of screening and appropriate diagnostic assessments as well as use of effective clinical practices, in addition to service availability and quality of the therapeutic relationship. This finding holds promise for the alignment of consumer advocacy interests, and of consumer collaboration, in the development and larger-scale implementation of evidence-based engagement, assessment, and intervention practices.

The extent to which connectedness among FASEOs and their local providers will improve services in general, and use of evidence-based practices specifically, is currently unknown. However the existence of a widespread, locally based network of family advocacy, support and education organizations with a strong commitment to change, if coupled with well-established information dissemination strategies, and an interest in improving delivery of effective services for children, bodes well for creating more substantive and diversified roles for families and FASEOs in the quest to improve children's mental health care.

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