

PARENTS AND PROFESSIONALS AS ADVOCACY PARTNERS

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In this article we discuss how parents, other family members, and professionals can work together as advocates on behalf of children and youth with emotional, mental or behavioral disorders. The development of such efforts during the last five years at the local, state and national levels are addressed. We also examine some pitfalls that may be associated with parent-professional collaboration in advocacy, and present recommendations about how parents and professionals can work together to support each other and maximize the impact of advocacy efforts.

Why Parents As Advocates? The effectiveness of parents and other family members as advocates for children with a variety of disabilities is well known. Parents have the social and legal responsibility as well as an emotional investment in their children's welfare that is far beyond that which can be hired. For most children, their parents are the only constant in their lives, while they may have contact with many professionals and programs over the years.

Parents are persuasive advocates because they have direct, first-hand experience and a "consumer's eye" view of the service system that legislators and other policy-makers can relate to and understand. Parents' motivations are less likely to be suspect than those of professionals, who may be seen as self-serving when they ask for increased and improved services. Parents are also freer than many professionals to speak out. They do not have the legal and institutional constraints on their advocacy activities that many professionals have, especially those who are paid with public funds.

In order to be most effective, however, collaboration between family members and professionals is necessary. While parents have an emotional investment and "first-hand" experience with their children and their needs, professionals have information about existing services and often have relationships with service

providers that improve access to needed services for individual children and families. At the system advocacy level, professionals can help to identify important issues and have access to facts and figures that are important to building a case or preparing a presentation. Professionals can also provide an understanding of how the system works and why it stays the way that it is.

In the mental health field, relatives of adults with long-term psychiatric disabilities have worked for reforms and increased resources through organizations such as the National Mental Health Association and the National Alliance for the Mentally Ill. Parents of children and adolescents with serious mental or emotional disorders have not been an organized advocacy force, however, until recently. And the reasons that parents of children with serious emotional disorders have been slower to organize than other groups have important implications for their involvement in advocacy efforts.

Barriers to Parent Advocacy. Probably the biggest impediment to advocacy and other public action for parents of children with emotional disorders has been the stigma attached to mental and emotional problems. Because they have often been held responsible and even blamed for their children's problems, family members have been reluctant to identify themselves, to speak out, and to demand the services and accommodations that their children need. Some parents have even felt that could not ask for more because they themselves thought that they must somehow have caused their children's problems and unhappiness. When professionals share these views, they may not see parents as a resource, or as potential allies or advocates. Considerable effort to educate professionals, parents and the general public is needed to overcome the counter-productive attitudes and beliefs that still prevail in many quarters.

Other barriers to parents' involvement in support groups and advocacy activities have to do with the nature of their children's problems. When their

children's behavior is strange or very difficult, many families are unable to locate appropriately trained child care or respite care providers, so can't leave home to attend meetings. Many families also experience crisis situations that absorb their attention, place a severe strain on the family, and make their participation in outside activities impossible or unpredictable at best.

Families are also often isolated and may not have information about opportunities for involvement or they may simply lack the confidence or experience they need. Finally, of course, there are more concrete barriers to participation: lack of transportation, meetings scheduled during parents' working hours, financial constraints, and other considerations. The volunteer nature of parent participation on advisory committees, boards, and as advocates prohibits the involvement of many families and limits the involvement of others.

The problems faced by children with emotional disorders and their families are also very complex, and the "right answers" may not be readily apparent. Children and their families often receive services from several agencies: mental health, education, child welfare, juvenile justice, and health, among others. Because the system is very complicated, choosing an advocacy agenda is not easy. Until recently, efforts were also hampered by a lack of vision about what was needed. During the last five years, however, developments at the local, state and national levels have occurred which have helped family members and professionals develop a clearer vision of an "ideal system."

Recent Developments. In 1984 a national program to improve services for children with serious emotional disorders and their families was authorized by the U.S. Congress. This program within the National Institute of Mental Health (NIMH), is called the Child and Adolescent Service System Program (CASSP). The program includes grants to states for system-building and demonstration activities and a national Technical Assistance Center at Georgetown University Child Development Center. The CASSP program also funds, along with the National

Institute on Disability and Rehabilitation Research (NIDRR), Research and Training Centers in Florida and Oregon.

As a part of this effort, we now have an outline for a comprehensive system of care for children and families (Stroul & Friedman, 1986), and materials that describe a variety of community-based services (Butler & Friesen, 1988; Goldman, 1988; Stroul, 1988).

In addition, efforts have been directed toward helping parents to define their agendas, and to encouraging the development of parent support and advocacy groups around the U.S. Some of these activities include:

- o A series of Families as Allies conferences designed to promote collaboration between parents and professionals. These conferences were held in every region of the country during 1986 and 1987. At these meetings, state delegations of equal numbers of parents and professionals worked together to identify needs and develop plans to improve services in their states. For many parents, these conferences were their first opportunity to meet parents with similar problems and experiences;
- o In 1987, Oklahoma CASSP and Positive Reflection, an Oklahoma parent advocacy organization, sponsored a meeting where parents from across the country provided consultation about the content of training for respite care providers. Parents provided valuable advice which is being implemented in the states of Oklahoma and Kansas, among others;
- o In October, 1987 the Portland Research and Training Center trained 10 teams, each composed of a parent and a professional, to teach parents and professionals how to work together at case, agency and systems levels. Since that time, more than 50 additional parent-professional teams have been prepared to provide training in many parts of the U.S.;
- o In January, 1988 a group of parents met in Washington, D.C. to address issues involved in organizing family support systems at the local, state and national levels. They presented a set of recommendations to officials from the U.S. Department Education and the CASSP program;
- o During 1988-89 NIMH funded five statewide parent organization demonstration projects in the states of Hawaii, Minnesota, Montana Virginia, and Wisconsin. Three more projects are scheduled for 1989-90;
- o In December, 1988 a group of parents and professionals met in Washington, D.C. at a conference entitled "Next Steps: A National Family Agenda for Children Who Have Emotional Disorders."

Participants at this working conference addressed four major issues: family support services, access to education, relinquishing parental custody to obtain services, and case coordination;

- o During the Next Steps meeting, parents voted to establish a steering committee to "develop a plan to establish a parent run coalition to address the needs of children with emotional problems, to promote their healthy development as children and in their transition to adulthood." At subsequent meetings, members of the steering committee have established a new national organization to address these goals. The new parent-run organization is called "The Federation of Families for Children's Mental Health."

Statewide Parent Organization Advocacy Efforts: The Kansas Experience.

The Midwest Regional Families as Allies Conference in May, 1987, brought families together who identified their needs and began to organize at the local level to provide support and case advocacy for families. In 1988 a statewide organization, Keys for Networking, was formed for the purpose of providing information, training and technical assistance to local parent support groups, assistance to families in crisis, case advocacy, and representation of Kansas families at state-level advisory and policy-making meetings. These activities are carried out either by the executive director or by other family members who serve as volunteers.

During the last two years, a number of important activities have been undertaken by the executive director and parent volunteers with the support and involvement of the organization's board members and other interested citizens. These efforts have included serving in a liaison role between the parents of Kansas and professionals and policy makers. In this role, the executive director and other representatives educate parents and professionals alike, promoting the vision of a comprehensive, coordinated system of care for children and adolescents with emotional and mental disorders. Promoting this vision often includes advocating for system change. Some accomplishments that can be at least partially attributed to these efforts include the establishment of a state-funded position devoted to the mental health needs of children and adolescents in the

Kansas Mental Health Division. Through the executive director, Keys for Networking is represented on the Governor's Kansas Mental Health Services Planning Council. The organization was also involved in successfully adding children and adolescents to a bill establishing mental health boards throughout the state. This bill previously focused entirely on adults.

The Kansas experience is only one example of exciting developments occurring throughout the country. In addition to the Statewide Parent Organization Demonstration projects in Hawaii, Minnesota, Montana, Virginia and Wisconsin, local parent groups are operating in almost all states, and statewide efforts are developing in many others. In many places, parent groups have joined with professionals to strengthen and refine their advocacy efforts.

Lessons for Advocates. Although we have addressed some of the benefits of collaboration between professionals and family members in advocacy efforts, we have also encountered some potential pitfalls or dilemmas for both parents and professionals. We share some of these here so that others can learn from our experience.

Pitfalls for Parents. One important concern for parents is that of cooptation. There is a fine line, in our experience, between trust and cooperation, on the one hand, and cooptation on the other. The cooptation of parents and parent agendas by professionals range from deliberate attempts to weaken and neutralize the advocacy efforts of parents to an apparently benign, but still alarming, lack of understanding of issues from the perspective of families. The mechanisms of cooptation include such problems as (1) parents' feeling reluctant to disagree with professionals whom they perceive as having more expertise or power, especially when they have been friendly and cooperative; (2) parents' agendas and concerns being distorted by professionals' keeping minutes of meetings or preparing other written reports without building in mechanisms for parent review; (3) professionals' appropriating parents'

agendas and then changing the priorities.

The problem of cooptation is of course, complicated when parent organizations are dependent for funding on the very systems that need to be changed. The important word here is "dependent," in our opinion. Some advocates advise that parents groups should accept no such funds, in order to avoid conflicts of interest and/or coercion. However, a careful look will reveal that many organizations that engage in advocacy activities do accept money from a variety of sources, including local, state and federal governments. Especially when funding is diversified, we think that it is possible to accept any funding that does not compromise the ethics and principles of the organization.

Another problem for parent advocates is that of not having enough information, or not having information in a form they can understand. In particular, complicated pieces of legislation, technical budget or other documents may require translation by specialists--lawyers, budget analysts, accountants or other experts--in order to make information accessible. Parent advocates are also often confronted by very large amounts of written and verbal material that needs to be summarized before it becomes useful information.

The expectations that some professionals have of parents may also constitute a problem. Chief among these is lack of sensitivity to the volunteer status of parents. Issues include scheduling meetings at times parents cannot attend, or expecting them to take time off work without reimbursement, and expecting parents to bear the cost of transportation and child care.

There are often too few parent advocates in any given community. The result is that a few parents are "overused;" they are invited to serve on a multitude of committees, asked to review plans and proposals, and often called upon to organize or arrange the participation of other parents in meetings. When focused on just a few parent leaders, these requests may become overwhelming.

Responding to many requests for participation may also seriously limit the time available for advocacy efforts.

A final dilemma faced by many parent advocates, especially those associated with a formal parent group or organization, is that of choosing between demands that compete for the parent advocate's time. They must often balance the immediate need for case advocacy, building organizational capacity, and the agenda for systems change. The strain of having to choose between responding to families who are in urgent need of crisis intervention and organizational or systems change agendas is common to parent organizations around the country. The problem is not usually conflicting values or agendas; it is most often one of over-burdened parent advocates having to choose how to use their precious time.

Pitfalls for Professionals. The legal and organizational constraints faced by professionals constitute an ongoing dilemma; it is not always clear which activities are allowed and which are not. These constraints may cause serious value conflicts for professionals who speak publicly on behalf of their agencies. Official communication often only presents facts that are favorable to the organization, because professionals have learned that to expose problems may have the unintended consequence of losing resources, even when their problems result from lack of resources. This problem also can create serious misunderstandings between parents and professionals unless the difference between the professional's public stance and private opinions are clearly understood. Even then, professionals' lack of candor serves to maintain distance and create misunderstanding between parents and professionals who seek the same goals.

Another dilemma that causes great consternation among well-meaning professionals is the situation where parents who have been encouraged to be more assertive and supported in the development of leadership skills express anger and impatience with their "professional mentors." It often appears that the more family members learn about what services should look like, what their rights are,

and how their children might have been helped, the more frustrated and angry they may become. And it is not infrequent that their targets become the very professionals who encouraged them to "get involved and make a difference." Friesen (1989) discusses these dilemmas in a recent book focused on advocacy for improved children's mental health services.

A related problem for professionals is finding parent advocates with whom they usually have a collaborative relationship on the opposite side of issues. For example, in some states professionals have been disappointed when parent organizations would not support the expansion of residential treatment beds; parents in this case were providing leadership for achieving community-based services. On the other hand, professionals in other states who are working to increase the number and quality of community programs have encountered some family members who want more residential treatment beds. Or, family members may not disagree about the contents of a "wish list" of services, but may have different priorities.

A third problem in which professionals become involved, is that of dealing with conflicting agendas among parent groups. The occurrence of serious differences of opinion is often a surprise to professionals who may assume that parents will represent or at least adopt a unified agenda. This state of affairs, of course, reduces the effectiveness of advocacy efforts and saps the energy of dedicated parents and professionals alike.

How Parents and Professionals Can Work Together as Advocates.

Advice for Professionals:

- o **Work as partners with parents in advocacy efforts.** This involves trusting that parents are capable of knowing what they need and can use the information you provide to them.
- o **Listen carefully to what parents tell you and be open to new perspectives.** A large problem reported to us by parents around the country is that of professionals' appearing to agree or understand, but then ignoring or distorting parent input.

- o **Be candid about barriers to change.** Share your professional knowledge of the system, including private opinions, when you can.
- o **Be a resource to parents.** Be available to answer questions and share information, use your contacts to help parent groups get media attention, or give concrete help such as providing mailing lists, assistance with preparing newsletters, paying for postage, or providing meeting space. Your professional expertise is also an invaluable resource to parent groups, e.g., helping them analyze a piece of legislation, or using your knowledge of group dynamics to help understand the interpersonal and political processes within a parent organizations.
- o **Invest in the development of parents as advocates.** In particular, include parents in training opportunities, and provide funds for family members to attend conferences and workshops where they will gain new information about the service system, learn new skills and gain confidence.
- o **Insist on family participation** within your organization and in all meetings and task forces you attend. Ask, "Where are the family members?" and be prepared to help locate family participants.

Advice for Parents:

- o **Recognize that professionals need support, too.** Parents often think that professionals are stronger, tougher and more powerful than they really are. Working as partners involves mutual support and assistance between family members and professionals.
- o **Acknowledge the constraints that professionals may face as advocates, especially those who work within "the system."** Do not expect them to put their jobs on the line. They may make that choice, but it unfair to demand it of them.
- o **Be a resource to professionals.** They need to understand the perspectives of family members and they need information about the total needs of families who cope with their children's emotional problems. Written information is particularly useful, especially information about the results of studies or surveys you have done, or vignettes or stories about the situations faced by families who are willing to have their circumstances made public.
- o **Foster a collaborative attitude within your organization.** Do not engage in "professional bashing" without initiating positive action. Help to create situations where professionals can be constructively involved with family members in the spirit of partnership.

Parents and professionals can work effectively together as advocates on behalf of children and adolescents with emotional, mental, or behavioral disorders. Key to a successful collaborative relationship is an understanding that

some conflict is likely to occur because of differences of opinions and preferences between professionals and family members as well as differences within the two groups. These differences may involve issues such as what constitutes the "ideal" system and how to achieve it, as well as less substantive issues such as struggles for control. Parents and professionals can learn how to negotiate their differences and work together productively by focusing on the overall goal of improving services and the quality of life for children with emotional disabilities and their families.

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RESOURCES

Research, Training & Technical Assistance Centers

CAASP Technical Assistance Center, Georgetown University Child Development Center, 2233 Wisconsin Avenue, N.W., Washington, D.C. 20007, (202) 338-1831.

Research and Training Center for Children's Mental Health, Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, FL 33612-3899, (813) 974-4500.

Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute, Portland State University, P.O. Box 751, Portland, OR 97207-0751, (503) 725-4040.

National Organizations

Federation of Families for Children's Mental Health, 1021 Prince Street, Alexandria, VA 22201, (703) 684-7710.

National Alliance for the Mentally Ill Child and Adolescent Network (NAMI CAN), 2101 Wilson Boulevard, Suite 302, Arlington, VA 22201, (703) 524-7600.

National Mental Health Association, 1021 Prince Street, Alexandria, VA 22314-2971, (703) 684-7722.

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