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ABSTRACT

This newsletter issue focuses on the theme of fostering collaboration between parents and professionals in meeting the mental health needs of children. Structured group interviews (focus groups) were held with both parents and professionals who have been members of decision making boards and committees. Interview excerpts illustrate findings that participating parents had a strong commitment to system level change and were often motivated by personal painful experiences. Parents offered tips for effective participation on boards and committees especially for learning to communicate with professionals. Briefly described are sample sites of the Families in Action Project which conducted the study. Other brief articles in the newsletter address: the importance of family participation, a Wisconsin program of political advocacy by parents, new legislation supporting Maine families, parent involvement and the Vermont system of care for children with emotional disorders, a Mississippi program for families of children with emotional or behavioral disorders, a foster parent's advocacy experience, and an account of a trying day in the life of one family. (DB)

FALL 1991/WINTER 1992

FOCAL POINT®

PARENTS AS POLICY MAKERS: CHALLENGES FOR COLLABORATION

In recent years the nature of the relationship between professionals and parents of children with emotional disorders has been undergoing substantial change. A major feature of this change has been the concept of partnership or collaboration among professionals and family members as an essential element in the effective treatment of children. Efforts to enhance relationships between professionals and parents to meet the mental health needs of children have been a major priority for the Child and Adolescent Service System Program (CASSP) of the National Institute of Mental Health and state and local initiatives funded by CASSP.

Initial attention to the concept of collaboration has often focused upon improving individual working relationships between family members and professionals and the development of skills and methods of promoting such partnership. Increasingly, however, family members and family support/advocacy organizations have both sought and been invited to become involved in the development of public policy and programs serving children with emotional disorders. While offering great promise, the inclusion of family members on national, state, and local advisory committees, planning boards and other decision-making bodies that shape mental health services for children and their families may also seriously test the limits of collaboration.

As professionals and family members meet in the board room instead of the office, new challenges and questions arise. Can family members be accepted and treated as equal decision makers? How can parents and professionals best work together on policy- and decision-making bodies? What changes in roles and relationships occur? What barriers to this form of collaboration exist? Are there particular skills and strategies that can enhance family member participation?

The Families in Action Project of the Research and Training Center on Family Support and Children's Mental Health is examining these and other issues related to the effective participation of family members on such policy- and decision-making boards and committees. Project staff are working with parents and professionals at several demonstration sites throughout the country to develop and evaluate strategies to promote family participation. To assist in developing these strategies, project staff conducted a number of focus groups (structured group interviews) with both parents and professionals who have been members of decision-making boards and committees. These interviews asked participants to describe their experiences; to identify attitudes, behaviors and skills of parents and professionals that affect participation; discuss common barriers to effective participation; and propose strategies to overcome those barriers.

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PARENTS AS POLICY MAKERS CONT.

Setting the Stage. Among parents participating in the focus groups, their commitment to improving services for their children and the children of other families was foremost in their decision to move into the policy-making arena:

> *The one thing that's kept me going is the fact that I'm armed now with so much information that I can share with so many other parents...*
>
> *There is so much support that has come to me, and I can't let it stop there. It has to keep flowing...and being able to see that my presence is making at least some difference.*

This commitment to make change at the system level, tempered with what one parent described as "tenacious patience," was most frequently described by focus group participants as stemming from their belief that parents and other family members were equal experts on the nature of services their children receive and what service systems need to look like to provide effective services. As one parent commented on the impact of this belief upon policy makers,

> *"So our role switched...from one of saying, 'Well, you just happen to be a parent,' to one of saying 'You have an expertise that nobody else there has.' And none of the professionals have it. Because they don't see the people, they don't see the kids on a regular basis."*

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We invite our audience to submit letters and comments.

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Undergirding this commitment, parents in the focus groups discussed the importance of their personal, and often painful, experiences in seeking help for their child as a major reason for their participation in the public arena:

> *I think our involvement has evolved from being so overwhelmingly angry at a system that wouldn't serve our child to deciding how could we vent our anger in an appropriate way that will change services...so that other parents and other children don't have to suffer the same way.*
>
> *I look at people I've seen in other parts of the country who are effective at this, and it's an attitude. It's the biggest single contributing factor to being successful in the job...an attitude, which starts with the old Howard Beale syndrome, 'I'm mad as hell, and I'm not going to take it anymore' but it progresses far beyond that.*

The above statements from two parents illustrate a general theme expressed in the focus groups concerning the important aspect that anger often plays in the motivation and decision of consumers to become publicly and politically active. Many parents, when discussing their early motivation for becoming involved in the decision-making process talked about their frustration with obtaining appropriate services for their child and family, wading through confusing policies and regulations, and dealing with service providers and administrators who appeared unaware or insensitive to the impact of an inadequate service system upon them. For these parents, feelings of frustration and anger served as a proactive catalyst for change.

> *When I first came into the system trying to get services for my child, I was extremely angry. I took that anger and I started networking with other parents, trying to take that and put it more in a positive way of how I could become effective...when you can go in with what I call 'calm anger' you can tend to become effective in working with systems and in trying to get the services.*

Similarly, professionals echoed the legitimacy of anger among parents and the need for professionals to acknowledge and affirm these feelings:

> *I think the most important trait is self-confidence followed by a tempered degree of anger. I think the anger is necessary to maintain the commitment to work through the barriers, to work through the bureaucracy, to work through the frustration associated in dealing with a system like a board...and so I think anger is terribly important but it has to be a controlled, directed form of anger.*

FOCUS GROUP COMMENTS

Policy Making Skills for Parents

- group process skills
- public speaking
- time management
- focus on long term vs. short term goals
- trust your expertise as a parent
- be willing to take risks
- know the rules of order
- maintain your objectivity
- stick to the issues until you are satisfied
- get support from other parents

Surviving on the Board: Tips for Parents

- patience/tenacity
- have a sense of humor
- regular attendance (mere presence is power)
- resiliency (expect some rejection)
- optimism
- assertiveness
- willingness to compromise when appropriate
- realistic expectations
- commitment
- get support from other parents

Recruiting Family Members: Strategies for Boards

- develop a written outreach plan
- educate members on the importance of family representation
- provide an orientation training for new members
- provide convenient meeting times/locations for parents
- offer reimbursement for parents' costs of attendance
- one parent on the board is not enough!
- ensure diversity among the membership
- overtly recognize the value of family members
- combat stigma and stereotyping
- rotate board leadership, including family members

ON THE BOARD: PARENTS' EXPERIENCES

> *After a while we learned when we're sitting on a committee the terminology that professionals use, such as, 'I have some concerns,' which translates into, 'I'm madder than blazes!' You learn the lingo, you learn the dress. Carry a briefcase whether there's anything in it or not.*

The process of transition for parents in becoming members of boards and committees stimulated a a diverse

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PARENTS AS POLICY MAKERS CONT.

number of comments concerning both positive and negative experiences. Many parents noted the challenges inherent in being a board member. One major challenge described by parents was dealing with the tasks and duties of being a board member. Learning to understand budgets, interpret agency organizational charts, and translate the "legalese" of agency policies and regulations were often cited as initial barriers to effective participation. Many parents reported that basic information, such as an orientation to their roles and responsibilities, or even a list of other board members or represented agencies, was often not provided to them.

Logistical issues, such as the location and times of board meetings also presented practical problems for family members. Parents reported that often board meetings are held during working hours, convenient for professionals who can attend as part of their employment, but difficult for parents who must lose time at their jobs or those who do not receive reimbursement for their travel costs. The related problems of finding child care during meetings and reimbursement for the care were also cited as major barriers to participation. The physical location of meetings also was mentioned by parents as important, including the convenience of the meeting site and access to public transportation.

Perhaps more important as a key to effective participation, parents in the focus groups directed most of their comments towards dealing with the informal "culture" of the board and the challenges parents face in being accepted by other—mostly professional—board members as partners in the decision-making process:

> *[U]sually the committee has been in operation for a long time before you had come into it...where everybody else knows the beginning. They know the script and you don't, and you're the parent to represent all parenthood.*

THE FAMILIES IN ACTION PROJECT

The goal of the Families in Action Project is to develop and test strategies that address skills and knowledge needed by family members to participate effectively in decision- and policy-making boards, committees and other bodies that affect services to children with emotional disorders and their families.

Project staff are currently working with four organizations in three states to develop site specific targets for intervention, strategies for intervention, and expected outcomes. Four additional sites will be selected during the current year. Preliminary information on each of the current sites was collected through telephone interviews with participants and key informants, a written, structured questionnaire completed by participants, and site visits by project staff. The current sites include:

- **Rhode Island Parent Support Network**, a statewide family organization, in cooperation with the Rhode Island Department of Children, Youth and Families. Interventions will focus statewide upon a number of regional boards responsible for advising the state children's mental health system, and include skill building for family members in policy-making, enhancing the organization's capacity to recruit and support members in the policy-making process, and promoting public awareness of children's mental health issues;

- **Parents Helping Parents**, a local family support group in Kingston, New York, in collaboration with the Mental Health Association of Ulster County, New York and the New York State Office of Mental Health. Interventions are focused upon developing mechanisms for parent involvement, recruitment of family members on decision-making bodies, training in policy-making skills and public education on the needs of children with emotional disorders and their families;

- **Children and Youth Subcommittee of the New York State Regional Planning Advisory Committee** in Rochester, New York, a regional planning body for mental health policy. Interventions are focused upon enhancing the functioning of the committee with the inclusion of consumers and possible expansion of consumer involvement in local areas; and

- **Parents Supporting Parents of Maryland**, a statewide family organization, in cooperation with the Maryland Child and Adolescent Service System Program. Interventions will focus on skill-building in policy-making arenas, recruitment and maintenance of family member participants, and strategic planning for organizational influence.

Persons interested in additional information concerning the project may contact Nancy Koroloff, Principal Investigator, or Richard Vosler-Hunter at the Research and Training Center on Family Support and Children's Mental Health.

Most of the people who are there are professionals in that field, and if you don't feel that you can communicate at their level, you're going to be too intimidated to speak up or come. And, you know, our children are not only stigmatized, but so are we as parents.

Many of the parents in the focus groups pointed out that they and other consumers on boards are often out of the informal "loop" of professional members who see and talk to each other on a regular basis as part of their work, thus making it difficult to form satisfying relationships with other board members. Often, the parents reported they were the only member representing parents, and frequently felt like "outsiders" in the meetings. While crossing these relational bridges is a large challenge, parents in the focus groups reported that it could be accomplished—counseling patience, resiliency, a willingness to take risks, and a sense of humor.

Parents also reported that their role as the sometimes "identified parent" on a board could be turned into a powerful voice:

[T]he fact of the matter is that when you're talking about how the agency provides a service, the only expert in that room is going to be that parent because they're the ones who have to live with that service on a day to day basis...So they have a role that to some extent is much more important and much more valuable than all the experts on finances and everything else on that board.

There's power in numbers, and if there's two [parents] sitting around a table of professionals, then you have a little more of a backbone to speak out and say what you feel, what really needs to be said.

DOES IT MAKE A DIFFERENCE?

While the focus group participants discussed numerous and very real barriers and difficulties that parents face in becoming effective, accepted participants in the decision-making and policy-making process, nearly all indicated that participation by parents was possible and necessary. Participants in the focus groups stressed that both parents and professionals must learn new skills and adopt new attitudes to work in partnership in the public arena. For parents and professionals alike, it requires the patience and commitment to form a shared vision, recognize and balance personal and public responsibilities, develop an atmosphere of openness and inclusion in the decision-making process, and careful attention to the differing needs, roles and expectations of board members. Both parents and professionals in the focus groups stressed that such collaboration could and does make a difference in promoting change and improving the lives of children.

I'm still the parent at home at 11:00 at night when somebody calls and says, 'I'm in trouble.' I'm still the parent that goes to the school. I'm still the parent that is there when they need the psychiatrist and who do we see and how do we fire him. I'm still the parent that they call. And I'm still that mom that says you love them no matter what...Seeing the changes take place within the system...That's kept me going longer, and my kid is no longer a little person, but I'd do that for any little person. So it's the changes within the system.. and I've come down the pike a long way, and I've seen lots of change. It has not been anything fast, and it's not going to happen all tomorrow, and we still have big problems. But little bits at a time we've chiseled away at this rock.

***Richard Vosler-Hunter, M.S.W.**, is the Director of Training for the Research and Training Center and is on the staff of the Families in Action Project. **Susan Hanson**, B.S., is a staff member of the Families in Action Project and a student in Portland State University's Graduate School of Social Work.*

FAMILY PARTICIPATION: ONE MORE TIME

Recent experiences have led me to wonder whether Richard Vosler-Hunter's description of progress in the area of parent-professional collaboration and family participation in decision-making is "useful fiction"—optimistic rhetoric designed to change behavior by asserting that our goals have become standards of practice.

I have recently been involved in discussions with professionals in which family participation is embraced as a clinical practice strategy but devalued as a system design requirement and where assertions that parents are experts about the needs of the families are countered with examples of families' choices that do not agree with professionals' judgments. Perhaps the most troubling thing is a tendency to treat three central principles of the system of care—individualized service, family participation, and cultural competence—as if they are just three more items in a long list of service components or activities associated with the Child and Adolescent Service System Program (CASSP).

For a number of complicated reasons, family participation is still treated as a "side issue" in many states and communities—a nice but not necessary part of changing the system for the better. And the belief that the system belongs to the professionals who are employed by it is tenacious.

We have made tremendous progress over the last decade. Great amounts of energy and creativity have been mobilized to fundamentally change the ways we think about, plan, and deliver services for children with emotional disorders and their families. But we are no longer a small intimate family with a shared vision and the luxury of face-to-face debate to explore and articulate our differences. We are now part of a social movement vulnerable to the developmental landmines of such phenomena: goal displacement, or loss of a common vision through a gradual focus on means rather than on ends; co-optation, or being captured by elements of the system we would change; and loss of flexibility and adaptive capacity due to obstacles to effective communication associated with growth.

Given the current phase in the change effort, I believe that family participation in all aspects of service planning, delivery, and evaluation is more important than ever. We need a strong and vigorous family movement to support the gains that have been made and to keep the system grounded in reality. I offer the following questions in the hope that they will stimulate thought and discussion:

> Families have long-term emotional, social and legal bonds with their children. Society also shares some social and legal responsibility for the care and protection of all children and the preservation of families. But individual service providers, administrators and public officials come and go. *On any given day, who but family members are most likely to be concerned about the welfare of individual children and to be able to serve as their advocates?*
>
> *Is it possible to have truly individualized care without family participation in planning?*
>
> *If families are centrally involved in case-level service planning and their needs and preferences are taken into account, does it not follow that services designed for them are more likely to be culturally appropriate than in instances where families are not involved in planning?*
>
> Children with emotional disorders have great difficulty adjusting to change, and are likely to have strong emotional ties to their families, no matter what their circumstances. *Why don't we put as much energy into supporting families and keeping children in their own homes as we do maintaining a foster care system that reinforces childrens' experiences that life is unpredictable and unstable?*

Family organizations as well as individual family members need the respect and support of committed professionals. Let's work together to remove the barriers to meaningful family participation and to assure that today's exciting experiments in family involvement are tomorrow's common practice, taken for granted because it's hard to imagine operating any other way.

Barbara J. Friesen, Ph.D., is Director, Research and Training Center on Family Support and Children's Mental Health

NEXT ISSUE: CASE MANAGEMENT

The next issue of *Focal Point* will report upon the March 1992 **Building on Family Strengths** conference that will address case management for children with emotional, behavioral and mental disorders and their families. We will describe various models of case management, provide program examples, and discuss financing options. Service implementation, monitoring and research issues will also be addressed.

WISCONSIN PARENTS UNDERTAKE POLITICAL ADVOCACY EFFORTS

Wisconsin Family Ties (WFT), a statewide support, education, and advocacy organization for families of children with emotional and behavioral disorders, came into being in June 1987. Coincidentally, this was within one month of when *Kids in Crisis*, an important analysis of the status of mental health services for children in the state, was published. Two years later, an innovative piece of legislation was passed. S. 46.56, the **Integrated Services Program for Children with Severe Disabilities Act** (commonly referred to as the **Children Come First Act**), was designed to remedy chronic problems in integrating the systems that serve these children, to provide for case management, and to require the development of innovative services to support families' efforts to keep their children at home and out of costly long-term institutional care.

From the time the legislative proposal was undergoing development to the time it became law, our fledgling organization had a wonderful opportunity to help parents get their voices heard. In Fall 1987, parents were invited to participate in a working conference that was called to conceptualize a collaborative mental health system for Wisconsin's children. Program models were presented and issues were raised. A follow-up meeting was held in early Spring 1988 to consider a draft proposal that had subsequently been developed. Comments were solicited and parents once again had input.

Between this conference and Fall 1988, the proposal was refined. Parents testified about children's mental health issues at several legislative hearings. They related experiences they had had with "the system" as it currently existed. Fortuitously, at the same time, WFT was awarded a Statewide Family Organization Demonstration grant that enabled us to open an office, hire staff, and develop a communication system, which helped us greatly in our efforts to involve parents throughout Wisconsin. Early in 1989 WFT sponsored the first of five regional conferences that featured speakers on the proposal, including the legislator who eventually sponsored the bill. In Spring 1989, WFT also began including information about the pending legislation in its newsletter *Family Ties* which was distributed to over 2000 parents and professionals statewide.

Also in Spring 1989 the **Children Come First** legislation was introduced as an amendment to the state budget bill, which was then before the Legislature. Working closely with our state's protection and advocacy agency, we developed strategies that promoted parent involvement with legislators. We sent information on the pending legislation to parent leaders in affiliate support groups and included information to help parents write letters or contact their representative on the legislative hotline. We learned the importance of correct timing. Most parents had never been involved in this kind of advocacy, but willingly participated.

Late in June of that year, we received news that the legislature had passed the budget bill unanimously and that the **Children Come First** proposal had been included as a budget amendment appropriating $200,000 to enable five counties to begin integrated services programs. The funding proposal was accompanied by language establishing the legislative framework so that all counties could develop similar programs.

Work then began to convince the Governor not to veto the provision (in our state, he has broad line-item veto power). Much to our amazement (let's be honest here), it was included in the budget signed by the Governor. Those legislators who took leadership roles during the deliberations reported that calls and letters from constituents provided the crucial factor in its inclusion. Parents advocating for better mental health services for children were a new and powerful voice in our state capitol. We have not been allowed to rest on our laurels, however, because now we face the challenge of urging continuation of funding for existing programs and expansion to other counties (only 66 left to go!).

Advocacy exists on many levels, and little battles need to be fought constantly. These include insisting on being treated as a partner with professionals, and with respect as worthy experts on our children. Winning those battles gives one courage to take on the big system, which is especially important when it is not always possible to see any direct benefit for one's own child or family.

Quick results followed our advocacy efforts, and the victory was good for our self-esteem. We learned first-hand that our system of government can be responsive, and were especially gratified that those in positions of power confirmed in law our desires for our children. For further information on Wisconsin's parent political advocacy efforts contact: Maggie Mezera, Wisconsin Family Ties, Inc., 16 N. Carroll Street, Suite 410, Madison, Wisconsin 53703; (608) 267-6888.

Maggie Mezera is Executive Director, Wisconsin Family Ties.

MAINE FAMILIES ACHIEVE NEW STATUTORY SUPPORTS

On December 12, 1991, the Governor of the State of Maine signed Law L.D. 1481, **An Act to Facilitate the Delivery of Family Support Services.** This landmark legislation was the culmination of several years of successful advocacy by parents of children with developmental disabilities. The Act establishes several fundamental principles of family support and gives families a voice in the planning and policy development of the state agency responsible for mental health and developmental disability services.

Community-based Respite Program. In 1985, responding to a lack of community-based respite care services, the Maine Department of Mental Health and Mental Retardation was awarded a federal demonstration grant from the Administration on Developmental Disabilities, U.S. Department of Health and Human Services. One key component of the pilot program was the establishment of a Respite Advisory Board. Consumers, parents and agency directors from state and private programs met monthly to discuss the development of programs and policies to promote respite services in Maine.

The Advisory Board experience provided a forum for coalition building. It soon became apparent that a major barrier to providing community-based respite services was the lack of adequate liability protection for providers. Representatives from major insurance companies and the State Bureau of Insurance revealed that current homeowner policies would not protect respite providers who used their homes as the site for services. They argued that payments to providers constituted a business; therefore, homeowner policies were not responsible for injuries. The insurance agencies argued that a business policy would be required to fully protect the homeowner from possible liability. After additional investigation, the insurance providers indicated no company currently offered such coverage and, due to the anticipated liability, no company could offer an affordable plan.

Liability Protection. The Respite Advisory Board turned to the State Legislature for assistance. In 1987, L.D. 380, **An Act to Provide Liability Protection for Respite and Foster Care Providers** was introduced. Concerned by the growing family advocacy movement in support of L.D. 380, the insurance carriers offered to develop a "pooled risk coverage" for respite and foster care providers. This voluntary policy was made available in 1988 and, to date, has protected over 500 respite providers and 300 foster families.

Funding for covering the cost of liability insurance premiums and expanded respite support was added in 1989. Families testifying before the legislature made convincing arguments for state human service policies to be supportive of families caring for their members with disabilities. The legislature responded by incorporating fiscal and statutory language related to family support policy in the statute that addresses the Bureau of Children with Special Needs.

Empowered Respite Services. During the 1989 second regular session of that same legislature, L.D. 943, **An Act to Fund Respite Services** was introduced. The family movement had found its advocacy footing and pressed for additional appropriations to expand respite care statewide. Legislators from every district found they had constituents who could significantly benefit from this funding increase. During the budget hearing before the State Appropriations Committee, parents offered graphic testimony that described the significant benefits of respite services, and asked legislators to "walk a mile in our shoes." Powerful testimony was given by one mother who described her struggle to care for her teenage daughter who continues to "behave like a four year old." "Until the respite project, nobody would baby-sit for me and I just needed a break," the mother stated. The chairperson of the Committee, usually anxious to move the countless witnesses along, interrupted, "I remember what it was like when my kids were four years old. I can't imagine what it is like for you." The state respite budget was increased 200% that session. In addition to the new appropriation, L.D. 943 was carried over into the next session for consideration of funding additional family supports.

Buoyed by the success of this early advocacy movement, the Maine Advisory Committee of Developmental Disabilities sponsored legislative advocacy training for families during the Summer and Fall of 1989. Families discovered they had empowered themselves and could bring the attention of state lawmakers to issues affecting Maine families. L.D. 943 called for the development and funding of a broad range of family supports, and increased funding for state respite services.

One key member of the State Appropriations Committee described the groups' efforts as "the most effective grassroots effort I have seen in my 20 years of legislative service." Unfortunately, the growth of family support advocacy in Maine met head on with the largest budget deficit in state history. In the closing morning hours of the legislative session, key leaders of both parties let it be known that if any money could be found, L.D. 943 was the only outside bill that would be funded. Finally, it was announced that no money could be found.

Family Support Council. The set-back did not leave the family support movement in shambles. Instead, leaders discussed the need to become part of the regular channels of policy and budget development. This meant forging a closer partnership with the state mental health/developmental disabilities agency responsible for services. In 1991 with the support of department officials, L.D. 1481, **An Act to Establish the Maine Family Support Council** was introduced.

The statute outlines services and principles of family support for the Department of Mental Health and Mental Retardation. An appointed twelve member family support council covers each of the states' six regional offices. The elected chairs of each council also serve on the state level Family Support Council. The councils are empowered to participate in the planning and development of services, including any state/federal planning requirements. In addition, the councils advise regional and state officials on the development of family support policies. Finally, the state council is required to issue an annual report to the legislature on the status of family supports in Maine.

While years in the making, the family support movement in Maine has continued to demonstrate tremendous energy and enthusiasm for moving state human service policy toward community supports and family friendly services.

Robert E. Durgan, Ph.D., Director, Bureau of Children with Special Needs, Department of Mental Health and Mental Retardation, State House Station #40, Augusta, Maine 04333; (207) 289-4250.

PARENT INVOLVEMENT AND THE VERMONT SYSTEM OF CARE FOR CHILDREN & ADOLESCENTS WITH SERIOUS EMOTIONAL DISORDERS

The Vermont strategy for developing a family-focused community-based system of care was two-fold by design. First, we needed to create the mechanisms at the state and local level that would provide children and their families access to the needed service systems. Secondly, we needed to develop an array of services such as intensive home-based services, respite care, crisis outreach, therapeutic case management, and enhanced regular school programs, within each catchment area of the state so that a child could be served within the context of their family and community. Central to both aspects of building our system was the involvement of families.

Family involvement at the beginning of our effort was easy to verbally promote; yet very difficult to realize. It was not uncommon for many professionals to doubt—out loud—that parents could be equal partners in our system of care efforts. Early on we brought in Glenda Fine, a wonderful articulate parent from Pennsylvania, to help us begin the process of breaking down the myths and stereotypes attached to parents who had a child experiencing a severe emotional disorder. Glenda's and other Vermont parents' work was slow to progress; yet, the parents' early impact on planning for our system of care was tremendous. Consistently, they would make recommendations that kept the focus on the family as a viable partner in determining and providing services for their children. When it became time to propose legislation to set in motion the interagency team process, it was clear that parent involvement at all levels had to be legislated if parents were going to sit on local and state interagency teams with any consistency. Looking back, we made the right decision.

In 1988, the Vermont legislature passed and the Governor signed into law the legislation that created the structures that many child advocates thought necessary to ensure that children and adolescents who are experiencing a severe emotional disorder did not fall through the proverbial cracks in the system. This law, Act 264, created twelve Local Interagency Teams that brought together a parent of a child experiencing a severe emotional disorder, the child welfare district director, the children's mental health agency coordinator, a special education administrator (who represented all the special education administrators within the catchment area), and other child-serving agencies. Also present at these meetings would be the child and his or her parents who needed a coordinated treatment plan.

At the state level, a State Interagency Team was created that brought together policy and program level administrators along with a parent. This team of eight people from the Agency of Human Services; the Departments of Education, Social and Rehabilitation Services, Mental Health and Mental Retardation; and families were brought together to back up the twelve Local Interagency Teams. Experience has shown us that approximately 85% of the cases reviewed at the local level are resolved at the local level.

VERMONT CONTINUED.

Act 264 was similarly responsible for the appointment of a fifteen member Governor-appointed advisory board. Membership is divided into five parents, five advocates, and five professionals. This group watchdogs the system, making recommendations to the various departments on priorities and needed policy revisions.

As an outgrowth of parent involvement in all the collaborative efforts in the state, the Vermont chapter of the Federation of Families for Children's Mental Health was born. In fact, the Board of Directors for the Federation are the parents who serve on each of the local interagency teams and the Advisory Board. Judy Sturtevant, who serves as the parent on the State Interagency Team is the Director of the Vermont Federation. The Federation has helped develop parent support groups throughout the state, produces a quarterly newsletter for parents and offers an 800 telephone line service to provide assistance to parents on a variety of issues.

The question must be asked, "What impact has parent involvement had in Vermont and the implementation of our system of care?" In short, the answer is, "Simply phenomenal!" On the interagency teams, parents have added a family sensitivity and child and family advocate piece that has in real ways changed how a treatment plan looks at individual children. With regards to program development, it was the parents on the Governor-appointed advisory board that made respite care the system of care priority in both 1991 and 1992. That prioritization helped the state pickup respite care services that were threatened to terminate due to a federal grant ending. The Board's strong advocacy for respite services also positioned us for eventual success in receiving another federal grant devoted to respite care for families with children with severe emotional disorders.

Time after time parents have turned a good idea into a good proposal. Their experience and understanding of the needs and strengths of families has been an immeasurable help to everyone involved in our efforts to build a family-focused community-based system of care for children and adolescents who are experiencing severe emotional disorders and their families. For additional information contact: Gary De Carolis, Deputy Commissioner, Vermont Department of Mental Health and Mental Retardation and Director, Child, Adolescent and Family Unit, Waterbury Complex, 103 South Main Street, Waterbury, Vermont 05676; (802) 241-2650. ***Gary De Carolis.***

WHY NOT?

You probably didn't plan to have a child with an emotional disability. If it had been up to you, you probably would have chosen a different scenario. That's one of the most difficult challenges of parenting a child with an emotional, behavioral, or mental disorder; it appears there is no choice. That's why it is so important to become involved in family support and advocacy for better children's mental health care.

Why not arrange to be part of your child's treatment team and insist that the planning provides your family with the support your individual situation requires? Or...you can choose to let the professionals make all the decisions based on what they think is best for you.

Why not reach out to other parents with similar difficulties and share your mutual successes and frustrations? Or...you can choose to go through your day feeling isolated, angry, sad, and helpless.

Why not help your local government plan for appropriate and adequate services for these special children? Or...you can choose to remain inactive and lament the lack of alternatives available to your child.

Why not educate your state legislators about the need for good community-based mental health services so that we can avoid placing children in more expensive residential facilities? Or...you can sit at home and read the newspaper articles about state funds being allocated elsewhere for something the lawmakers understand.

Why not join national parent organizations such as the Federation of Families for Children's Mental Health or NAMI-CAN and add your voice to the ones demanding support and understanding for children with emotional disabilities and their families instead of scorn and blame? Or...you can choose to continue being hurt, oppressed, stigmatized, and abandoned.

Advocacy heals the wounds of disappointment, restores self-esteem, gives a positive focus for frustration, and enlightens the ignorant. Why not see that you really do have a choice?

Linda Reilly, Portland, Oregon. Ms. Reilly is the parent of a child with a serious emotional disorder.

Editor's Note: Readers are invited to submit contributions, not to exceed 250 words, for the *Why Not?* column.

MISSISSIPPI LAUNCHES DEVELOPING FAMILIES AS ALLIES PROGRAM

Developing Families as Allies (DFAA) is a psychoeducational curriculum for families of children or adolescents with serious emotional, behavioral or mental disorders designed to empower families through sharing support and knowledge. Supported by funding from Mississippi's Child and Adolescent Service System Program (CASSP), the curriculum is part of an array of services provided by the Mississippi Department of Mental Health's Division of Children and Youth Services in collaboration with our statewide parent support network, Mississippi Families as Allies.

Developing Families as Allies grew out of a variety of experiences including my own family's struggle to adapt to the mental illness of our child. Our journey of discovery, love, pain and growth, was a struggle that left me determined to find a way to give other families truly useful information and support for their own journeys. What I learned on my journey was confirmed when I began my own search of the literature. Surveys of families of adults with long term psychiatric disability and of families of children and adolescents with serious emotional disorders reveal that families need: (a) information; (b) coping skills; (c) emotional support; (d) help in locating resources; (e) respite services; (f) involvement in treatment planning; (g) help in time of crisis; (h) acknowledgement by professionals of parents' expertise; (i) help with managing assaultive behavior; and (j) assistance with long range planning. The content and design of *Developing Families as Allies* are based on these stated needs of families.

I also reviewed other research that focused on providing information about mental illnesses and upon teaching concrete "here and now" focused behavioral techniques to families of adults with psychiatric disabilities. This research has had positive outcomes related to maintaining individuals in the community. We believed this approach could be used with younger families and, accordingly, adopted the philosophy of psychoeducation as our own and used its definition and characteristics to guide us in content development.

In addition to an emphasis on practical management and problem-solving techniques that have a "here and now" focus versus an insight-oriented, interpretive approach, the curriculum provides current information about serious emotional disorders, treatment, and community resources; an emphasis on the strengths versus deficits of the family and child; and the message that families have the power to influence the course of the rehabilitation process for the better. Most beneficial was my collaboration with Dr. Brenda Hankins, a specialist in adult learning and training curricula, made possible through the support and funding of the Division and Mississippi CASSP.

PROGRAM CONTENT. Designed for a minimum of ten meetings, curriculum content falls into the two main domains in which families must operate—home and community. The meetings are divided just that way, in a sequential building process using topics that arise from the program's two main goals: (1) providing information; and (2) providing the opportunity for skill development—information and skills that can improve the life of the family and the ability to access and support community-based services.

Thus the program provides information about emotional and behavioral disorders, child development, medications, tests, treatment strategies, system of care model, and joint parent/professional development of community service/support networks. Skill development is offered in coping and adaptive strategies, behavior management strategies, effective communication, assertiveness, community interviews, and parent/professional collaboration. Because *Developing Families as Allies* is firmly grounded in adult learning techniques, the program emphasizes hands on activities, practice and feedback, family action plans, and structure for future plans.

One of the several unique aspects of the curriculum is the section on child development. The concepts of cognitive and social development, life stages and developmental tasks are explained. Social cognition and the role of empathy and role-taking in the child's interaction with peers, and strategies to improve such interaction are introduced and practiced. In addition, an experiential exercise on the perspective of a seventh grader with serious emotional disabilities helps participants "walk in the shoes" of the child experiencing such difficulties.

Another unique aspect of the curriculum calls for teams of parents to interview representative helping professionals in their local communities, and then invite these new contacts to one of the final meetings. During this meeting parents share the Families as Allies perspective and give the professionals an overview of what they have been learning and discussing. The second purpose of the meeting is to engage the professionals in a discussion of their thoughts on a collaborative network of services and supports. Because the co-leaders of the program, a parent and a professional, have modeled a collaborative relationship throughout the meetings, this structured plan for a collaborative, supportive network with the helping

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MISSISSIPPI CONTINUED

professionals in their community is a natural development.

DISSEMINATION. In March 1991 Dr. Hankins and I trained the first five teams of parent and professional group leaders in both curriculum content and adult learning techniques. These teams subsequently conducted the Developing Families as Allies program at five community mental health center sites in the state. Patty Appleton, the coordinator of our statewide parent network, Mississippi *Families as Allies* (one of the fifteen parent organizations to receive funding from NIMH) was also trained to lead the curriculum. With the cooperation of Dr. Brenda Scafidi, Director of the Division of Children and Youth Services, Mississippi Families as Allies applied for and received funding from a regional utility company's Stay-in-School Challenge grant to conduct the program in the Jackson metropolitan area. The curriculum is also spreading across state lines; in December 1991 I trained six teams of co-leaders in Louisiana and they began their programs in February 1992.

A recent and exciting development is the collaboration between the Division of Children and Youth Services and the Mississippi State Department of Education Special Services Division to train special education teachers and to disseminate the curriculum in school systems throughout the state. This process will reach many more families and children and will complement the network building efforts of Mississippi Families as Allies.

CHANGE PROCESS. The effect of the *Developing Families as Allies* curriculum can be observed on several different levels. As the program is identified both with Mississippi Families as Allies and the Mississippi Department of Mental Health and as a concrete product associated with our specific disability population, it is regarded as a tool for quick and easy education and publicity in the corporate, media and school arenas. On a practical level, as we had hoped, parents who have participated in the program are remaining together in cohesive groups after the close of the initial educational programs. The majority of these groups are affiliating with the Mississippi Families as Allies parent network as we had planned. In addition, *Developing Families as Allies'* role in promoting change among the attitudes and techniques of the mental health professionals who have been trained as group leaders cannot be over-estimated. Further, families have gained both emotional support and experienced positive change on the personal and system levels. Data are being kept at all sites in order to measure the impact of the program on coping and adapting, collaborative service development and the expansion of the Mississippi Families as Allies affiliated parent groups across the state.

Today, fifteen years since my family was first entering crisis, years since I began my initial attempts to support other families like ours, Dr. Hankins and I have made what I hope will be a useful gift to all our families. What a joy it is to see good things happen for them as well as for our professional colleagues! Out of pain—joy; out of struggle—gift. There's the mystery, there's the grace.

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Tessie B. Schweitzer, M.S.W., a program planner in the Division of Community Services, Mississippi Department of Mental Health, is on the Board of Directors of Mississippi Families as Allies, and serves as a speaker, consultant and trainer on issues related to service system needs of children and adults with psychiatric and chemical dependency disorders.

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ADVOCACY: *ONE FAMILY'S STORY*

My involvement in advocacy began in 1986 when I requested and received a grant from the Catholic religion community of sisters to which I belong, to open a home for children whose lives had been affected by family drug and alcohol abuse. Another sister joined me in this effort. We agreed that I would be the parent at home and she would continue to work outside the home. Our plan was to provide a stable home for children while their parents received treatment for chemical dependency and work toward reuniting families. We were excited about the prospect of assisting children and their parents in building happier lives. My background is in nursing and my sister's is in education and finance. We anticipated short stays for the children.

In November 1986 our first two children (siblings ages 8 and 7) arrived through our state child welfare agency. The plan was to return them to their mother in two weeks. Maggie and Alex (now ages 13 and 12) never did return to live with their mother and we four have become a family. We have been named by the court as their psychological parents and their placement is a permanent foster home. We continue to belong to our religious community, which in its founding 125 years ago was to educate and care for children. Our community supports us and continues to place a priority on serving women and children.

The children's special emotional needs have led us to become involved in advocacy efforts on their behalf. We began our advocacy for Maggie and Alex with the state child welfare agency. Next we requested help from the school counselor. We were told that parenting children with special emotional needs is very difficult and she offered to help. Without the help of the teachers and school counselor we would not have made it through the first six months. Many a day we felt overwhelmed with the tasks of parenting. Over the years the children have improved and we have grown as parents.

The schools have provided the children and us with the best services and we have felt partners in their education. The mental health system has provided us with traditional services, but what is lacking are alternatives to the traditional mental health model of therapy. We need respite care in and out of our home. We need after-school structured programs. We need structured group settings to build socialization skills. These services are not available even if one can pay for them. Families with children who have special emotional needs require improved and individualized services. That is why we chose to advocate.

At this time I am struggling with my role in advocacy. I have much personal advocacy to do in working with my own children. Trying to coordinate teachers, doctors, dentists, mental health professionals, maternal visitations and caseworkers into a planned treatment of care for the children is a full-time job. While I know th [illegible] am helping two children, there is a constant gnawing [illegible] ve beyond my own situation. There are several reasons for this. I am encouraged by professionals to speak our story and represent parents on boards and committees. I am told I have something to offer decision-making groups. This builds my self-esteem and confidence. It gives me a vehicle to move beyond my own situation and renews my energy for life. It puts me in contact with other parents. Listening to each other's stories offers us hope and humor.

It is difficult for me to narrow my focus for advocacy. I sometimes want to jump on every band wagon. I think my advocacy needs a time of exploration. I would encourage any parent before making a commitment to advocate on a certain board or committee to shop around. Have a mentor who keeps you informed on what is happening with your advocacy issues. Set your own criteria for advocacy. I have set down this criteria and try to use it in my own decision-making for board involvement: Will I be respected and valued for who I am and for my experience on this board? Will I be reimbursed for my time on the board and for work done as a board member (such as attending parent groups or conferences or interviewing parents)? Am I viewed as a professional peer with members of this board? Will I be reimbursed for travel and childcare? Do I feel that this group has the potential to bring about change? and) Are there other family members or consumers on this board? I have set-up this criteria because of my own trial and error experience. Sometimes in my enthusiasm I have said "Yes" all too quickly and then end up on a board and have to backtrack and advocate for myself to be a viable board member and not a token parent.

In making a proactive choice to become involved in public advocacy I need to include my family and coordinate our focus. At the present time we are on a mental health board and a child and youth services board. Our common commitment to build neighborhoods of support for families is what we represent on advisory committees.

Periodically we sit down and evaluate the advocacy we are doing and renew our choices or terminate some involvement. Our public advocacy efforts are measured by our responsibilities to the children—when their needs increase, our advocacy drops; when they are in a period of relative stability, our advocacy efforts increase.

I have come to appreciate the value of parent and

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ADVOCACY CONTINUED

consumer advocates. There is great power in listening to a parent speak from the heart about the pain and hurt families and children experience on a daily basis. Stories from these families must be heard so there will be changes in attitudes, care and services for families. Support groups provide a place to share our stories and build a network for advocacy. In writing letters and presenting our stories we educate policy-makers and boards. Our presence at board meetings makes it uncomfortable for professionals to blame parents.

I wish that I did not have to work with so many "systems" to advocate for and coordinate services for my children. I would like to sit back and enjoy watching them grow and develop without having to deal with the persons in the various systems that impact their lives. I relish the times when I can just enjoy their presence and their successes without interference from the various "systems" that direct our lives and make so many decisions for us. As an advocate for Maggie and Alex I walk with them today as they mature into a world where they not only have to make their own choices, but must also learn how to advocate for themselves. I am proud of Alex when he brings home recognition awards from school. I am proud of Maggie when she accepts love from us and enjoys being a teenager. I am proud of us as a family as we learn to advocate personally and publicly for ourselves and our society.

Judith A. Mayer, B.S.N., is on the staff of the Research and Training Center's Families in Action Project and is currently completing her master of social work degree at Portland State University.

HAVING OUR SAY

This column features responses to questions posed to readers. In this issue we feature responses from parents to the question: "What has been the greatest benefit to you or your child as a result of your activism?"

Networking with individuals on federal, state and local levels in my efforts to obtain information and quality services for my child. *Kansas.*

Because I am outspoken and involved in my child's education, he has been able to benefit from more creative programs and has been successful and able to graduate. Because he's been successful, he's not afraid to try and not afraid of failure. *Kansas.*

Services. Our cup has gone from being half-empty to half-full. *Kentucky.*

I became more educated about the mental health system for children and adolescents. I was completely ignorant when I began. As I began to read about it, I couldn't believe how neglected children are. I've really been educated about bureaucracies. *Maryland.*

Probably the most important thing I have gotten out of my involvement is a feeling that Nicholas is important. The only real help to Nicholas has come from the fact that my involvement has given me a relationship with those who make the decisions that effect Nicholas, that I wouldn't otherwise have, giving me some influence on those decision-makers. *Oklahoma.*

The greatest benefit has been the healing process for our family—doing something positive to get professionals to realize there really is something wrong with children with serious emotional disorders. As far as our son is concerned, my activism has gotten him into some programs that he otherwise would not have been able to get into. *Oregon.*

PARENTS' PERSPECTIVE: A DAY IN THE LIFE

When first you see us, we look like your normal average family—a father, mother and three young sons. Please, step a little closer. Let me take you into our home for one day. Maybe you might gain a little more understanding. Have a little more compassion.

Our three sons are handsome boys. Bright, willing to learn. Extremely active and mischievous as boys are. Our middle son has attention deficit hyperactivity disorder, learning disabilities, a serious seizure disorder and has a serious emotional disability with oppositional conduct behavior disorder. Big words. But what do they mean? His attention span is very limited and he acts completely on impulse. Disciplining him takes imagination, trial and error. What worked today may not work tomorrow. He also is heavily medicated for these disorders.

Our mornings begin at 6:00 A.M. On this morning, he awoke in a very aggressive state. He refused to get dressed. He was combative, violent, defiant and led off with a string of obscenities that would make a sailor blush. His older and younger brothers had to fend for themselves while all of my energies and time were spent getting him ready for school. His bus comes at 7:10 A.M. as his school starts at 7:50 A.M. And, although his bus stop is just two doors down from ours, I must walk him to the stop and stay with him until the bus comes. This morning, he decided to go into the neighbors' yard and antagonize their dog. It was all I could do to get him back to the street for the bus. When it arrived, it was as if he became a different child. I had barely succeeded in getting his morning medications into him. When he arrived at school, all seemed to be going well. He had to stay in at recess to complete his homework and the teacher said he understood why.

Then, after lunch, no one seems to know what happened. He lost it. He became violent, abusive and aggressive. I was called. I called our mental health worker but he was unable to meet me at the school. So, I went by myself. When I arrived he was calmer, but refused to talk to me, the assistant principal or his teachers. He came home willingly. But when we got home, he took off and refused to come into the house.

His younger brother was crying when he got home. Something had happened at the bus stop. My younger son needed mom's attention, but my middle son became violent and aggressive towards the neighbor boy and became abuse to him.

Immediately, my attention was directed towards the second son again. The neighbors saw a child out of control, violent, abusive and cursing. I was called a psychotic, neurotic, negligent mother who could not control her son. After a tremendous struggle in which a neighbor did come and help me restrain him, he came in and decided to watch a movie. He seemed to have calmed down. I was able to give him his medication. And, I felt, maybe, until dad got home from work things would be okay. And they were—for awhile.

I had started to fix dinner, when he grabbed a knife (which I had put away and he had found), ran outside and was cutting on our tree. I heard the kids all screaming and ran to see what was happening. After another struggle, in which the same neighbor assisted me, I got him inside.

Dad got home shortly after this. He came into a home that was disruptive and in complete disarray. Dinner only half started and laundry strewn all over. Since our son had had his afternoon medications, he was calming down. Maybe with dad home, things would quiet down?

Dad took over fixing dinner and tending to the boys in the hopes of giving me some respite. But that was not to be because we weren't fixing what he wanted, and I was trying to help the older boy with his homework. He began to physically attack me. Dad had to physically restrain him, and I fixed what he wanted, just to gain some peace.

Dinner is done, baths are taken, evening medications are given. He has fallen into an exhausted sleep. It is 10:30 P.M. I have taken my medication and am too exhausted to pick up a single dish to wash or to fold the clean laundry. So, I too, go to bed for tomorrow is another day. And, prayerfully, things will go better.

I've written this story because I know there are other families who go through the same kind of days to let them know they are not alone. Together we can help each other and maybe educate our neighbors.

And to my neighbors, the next time you see me struggling with him, maybe, instead of stares and condemnation, you will feel just a spark of compassion, for our son is ill. He didn't ask to have these problems and, with medication, counseling and support we know he will get better.

Diana Matthews. This article is excerpted from the Merced Sun-Star, *December 9, 1991. Ms. Matthews has launched a support group for parents who have children with serious emotional disorders in Merced, California.*

Editor's Note: Parents are invited to submit contributions, not to exceed 250 words, for the *Parents' Perspective* column.

NOTES & COMMENTS

Summer CASSP Training Institutes Scheduled

An important upcoming event will provide an intensive training opportunity for a wide range of participants. The biannual CASSP (Child and Adolescent Service System Program) Training Institutes are scheduled for July 18-22, 1992 and will be held in Breckenridge, Colorado. This year's Institutes are entitled *Developing Local Systems of Care for Children and Adolescents Who Are Severely Emotionally Disturbed.*

The Training Institutes will offer a timely opportunity to obtain in-depth, practical information on how to develop, organize, and operate comprehensive, coordinated, community-based systems of care for children and their families. The faculty will be comprised of representatives of communities that have made substantial progress toward developing systems of care, and participants will be able to choose four separate Institutes presenting different approaches to system development. Communities that will be highlighted at the Institutes range from rural to small cities to urban environments to ensure relevance and usefulness to all participants. Additional Institutes will focus on research on local systems of care, systems of care for early intervention, financing systems of care, and individualized services within systems of care. General sessions will focus on such topics as changing systems, roles for parents in systems of care, and creating culturally competent systems of care, with featured speakers including Douglas Nelson, Executive Director of The Annie E. Casey Foundation, and Samuel Betances, Ed.D., Professor of Sociology at Northeastern Illinois University. Opportunities for consultation with Institute faculty will be offered as well as informal discussion groups on a variety of topics.

The Institutes are designed for a variety of individuals including state and local administrators, planners, providers, parents, and advocates. A primary target group consists of agency administrators, managers, providers, and parents from local areas, representing mental health and other child-serving agencies. These individuals, ideally attending as a team, are the ones who can take the knowledge and skills developed at the Institutes and begin to apply them in their home communities. This training can be an invaluable experience for a community planning a system improvement initiative.

The Institutes are sponsored by the CASSP Technical Assistance Center at Georgetown University and are funded by the National Institute of Mental Health, Child and Adolescent Service System Program. For more information contact the CASSP Technical Assistance Center at 2233 Wisconsin Avenue, N.W., Washington, DC 20007; (202) 338-1831.

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Multicultural Initiative Project Holds Advisory Meeting

The Research and Training Center's Multicultural Initiative project convened its first National Research Advisory Meeting on September 10 and 11, 1991. The meeting provided an opportunity for professionals with recognized cross-cultural expertise to provide consultation and feedback to project staff. Invited consultants included: Marva Benjamin, M.S.W., Chair, Georgetown CASSP Technical Assistance Center Minority Initiative Committee; Steven Lopez, Ph.D., University of Southern California; Mareasa Isaacs, Ph.D., The Isaacs Consulting Group (Washington, D.C.); Holly Echo-Hawk Middleton (Vancouver, Washington); and Bruce Bliatout, Ph.D., International Health Center, Joseph Gallegos, Ph.D., University of Portland, David Wagner, M.S.W., New Dynamics, and Garfield de BardeLaben, Ph.D., of Portland, Oregon.

The major areas of discussion centered on: (1) refining the Cultural Competence Self-Assessment Questionnaire and key informant assessment processes; (2) utilizing the reviews of literature conducted by project staff; and (3) developing and disseminating materials and products for use by professionals in the field. An important benefit of the meeting was the identification of other researchers, professionals, and consumer and family organizations who have engaged in efforts to enhance services to ethnic groups of color and various ethnic and non-ethnic minority populations.

The two-day meeting culminated in a reception hosted by project staff that was attended by professionals, providers, and consumers interested in the subject of cultural competence. The reception provided an opportunity for project staff and members of the local community to talk informally with the consultants while enjoying ethnic food, art, and music.

NOTES & COMMENTS

Connecticut CASSP Hosts Northeast Parent-Professional Meeting

Psychodrama organized around the theme, "Parent-Professional Collaboration: The Inner Struggle," kicked off the conference *Partners for a Change* on November 22-23, 1991 when more than 150 parents and professionals convened in Madison, Connecticut. The conference, sponsored by the Child and Adolescent Service System Programs (CASSP), involved seven northeastern states and was designed to stimulate planning for state and local system improvement.

Plenary presentations introduced the themes of parent-professional collaboration and family support. "Partners for a Friendly System" featured Beth Dague, a parent and children's coordinator for the Stark County (Ohio) Mental Health Board, Sandra Corcoran, a parent and vice-chair for the Coalition for Children with Mental Health Needs in Connecticut and Barbara Friesen, director of the Portland Research and Training Center. Family empowerment through involvement in the development of a family support program was central to a presentation by Bill Scott, Project Coordinator, Debbie Wahlers, Parent Consultant, and Jim Wahlers, who spoke from a parent's perspective about the Fingerlakes Family Support Program in New York state.

Members of the Teen Theatre group "Looking In," gave conference participants a glimpse of the challenges and struggles faced by youth. They addressed issues of peer relationships, teenage suicide, substance abuse, adjustments to parents' divorces and remarriages and other issues of concern to teens.

Workshop topics included a description of a family advocacy effort in Maine, "Families First," a discussion of how family support services can be empowering, multicultural considerations in supporting families in urban settings, development of the Fingerlakes Family Support Program, parent-professional partnerships, and building local interagency teams.

During state caucus meetings state delegations composed of parents and professionals developed action plans for system change. These were shared during a wrap-up session facilitated by Judith Katz-Leavy, Child and Family Support Branch, National Institute of Mental Health, and Barbara Friesen.

Statewide Family Organization Demonstration Project Holds Fall Meeting

The Research and Training Center hosted the Fall 1991 meeting for the parent coordinators from fifteen statewide family organization demonstration projects that receive funding through the National Institute on Disability and Rehabilitation Research and the National Institute of Mental Health. This funding supports the development of model statewide organizations that have the capacity to provide technical assistance, information, support, and networking structures to family members and family organizations within states. The October meeting included representatives from four additional states (New York, Utah, Louisiana, and Oregon) who are also developing statewide family organizations.

The three-day meeting included specific workshops on future funding for statewide projects, reaching underserved families, organization building and board development, office management, time management, working with sponsoring organizations, and using humor to cope with the stresses of coordinating a statewide project.

Future funding was the most pressing issue for the parent coordinators in this second and final year of their funding. They developed a plan to pursue future funding through a private foundation so that they may continue to serve families throughout their respective states who have children with serious mental health needs.

Federation of Families for Children's Mental Health Awarded Funding from the Annie E. Casey Foundation

Through the Annie E. Casey Foundation's Community Initiative for Children's Mental Health program, the Federation of Families for Children's Mental Health has contracted to receive $300,000 each year for three years. The Community Initiative for Children's Mental Health program takes a comprehensive approach to children's mental health issues in inner city neighborhoods. Key cornerstones of the Initiative include a commitment to address issues of poverty, minority status, prevention, and service delivery. The Casey Foundation's contract with the Federation of Families for Children's Mental Health will support the development of the organization's capacity to assist with advocacy efforts, organize families, and provide training. The Federation office in Alexandria, Virginia will have full-time staff beginning in mid-April 1992.

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Pennsylvania Establishes Children's Research and Advocacy Center

Pennsylvania Partnerships for Children (PPC) is a newly-founded statewide advocacy group formed to ensure that by the beginning of the 21st century, Pennsylvania's children will have appropriate health care, child care and early education. The formation of PPC marks Pennsylvania's first statewide research, resource and advocacy center for children, a structure proven successful in other states including Illinois, California, New York and New Jersey.

PPC has been funded for the first three years of operation by grants of $450,000 each from The Pew Charitable Trusts, based in Philadelphia, and The Howard Heinz Endowment, based in Pittsburgh. According to Marge Petruska, program officer at the Howard Heinz Endowment, "PPC will begin to bridge the information gaps between advocacy groups and legislators, policymakers, and the media that lead to ineffective programs and a lack of understanding for the problems facing our children." For additional information contact: Lucy D. Hackney, President, Pennsylvania Partnerships for Children, 3812 Walnut Street, Philadelphia, Pennsylvania 19104; (215) 387-2707.

Federation of Families for Children's Mental Health Holds Third Annual Meeting

Approximately 130 parents and mental health professionals attended the Federation of Families for Children's Mental Health third annual meeting entitled *Family Support: Whatever It Takes* in Arlington, Virginia on November 9 and 10, 1991. Creasa Reed, secretary of the Federation, set the stage for the rest of the conference in her opening address "Family Support: A Parent's Perspective." A highlight of the conference was a luncheon speech by Jane Knitzer, co-author of *At the Schoolhouse Door: An Examination of Programs and Policies for Children with Behavioral and Emotional Problems*, on education and mental health systems' roles in providing support for families.

Workshops addressed a variety of topics including reaching out to families of color, transition planning, and facilitating support groups. Other workshop topics addressed model family support projects, developing family support policies for states, respite care and accessing Supplemental Security Income. A high point of the conference was a general session with a panel of siblings who described their experiences growing up with a brother or sister with an emotional disorder.

Outgoing President Barbara Huff was honored for her contributions during her three years service as the Federation's first president. Creasa Reed of Kentucky has been elected to serve as the organization's second president. The first "Claiming Children Award" was given to Velva Spriggs for "outstanding efforts on behalf of children with emotional/behavioral/mental disorders and their families."

Barbara Huff

Velva Spriggs

Research and Training Center Resource Materials

☐ *Annotated Bibliography. Parents of Emotionally Handicapped Children: Needs, Resources, and Relationships with Professionals.* Covers relationships between professionals and parents, parent self-help, support and advocacy groups, parent participation, parents' problems and guidelines. $7.50 per copy.

☐ *Annotated Bibliography. Youth in Transition: Resources for Program Development and Direct Service Intervention.* Transition needs of adolescents: educational and vocational issues, programs and curriculum, research overviews, interpersonal issues, skills training. $6.00 per copy.

☐ *Brothers and Sisters of Children with Disabilities: An Annotated Bibliography.* Addresses the effects of children with disabilities on their brothers and sisters, relationships between children with disabilities and their siblings, services and education for family members. $5.00 per copy.

☐ *Changing Roles, Changing Relationships: Parent-Professional Collaboration on Behalf of Children With Emotional Disabilities.* The monograph examines barriers to collaboration, the elements of successful collaboration, strategies for parents and professionals to promote collaborative working relationships, checklists for collaboration, and suggested resources for further assistance. $4.50 per copy.

☐ *Child Advocacy Annotated Bibliography.* Includes selected articles, books, anthology entries and conference papers written since 1970, presented in a manner useful to readers who do not have access to the cited sources. $9.00 per copy.

☐ *Choices for Treatment: Methods, Models, and Programs of Intervention for Children With Emotional Disabilities and Their Families. An Annotated Bibliography.* The literature written since 1980 on the range of therapeutic interventions used with children and adolescents with emotional disabilities is described. Examples of innovative strategies and programs are included. $6.50 per copy.

☐ *Developing and Maintaining Mutual Aid Groups for Parents and Other Family Members: An Annotated Bibliography.* Topics addressed include the organization and development of parent support groups and self-help organizations, professionals' roles in self-help groups, parent empowerment in group leadership, and group advocacy. $7.50 per copy.

☐ *Families as Allies Conference Proceedings: Parent-Professional Collaboration Toward Improving Services for Seriously Emotionally Handicapped Children and Their Families.* Held in April 1986 and attended by delegates from thirteen western states. Includes: agenda, presentation transcriptions, biographical sketeches, recommendations, worksheets, and evaluations. $9.50 per copy.

☐ *Gathering and Sharing: An Exploratory Study of Service Delivery to Emotionally Handicapped Indian Children.* Findings from Idaho, Oregon, and Washington, covering current services, successes, service delivery barriers, exemplary programs and innovations. $4.50 per copy.

☐ *Glossary of Acronyms, Laws, and Terms for Parents Whose Children Have Emotional Handicaps.* Glossary is excerpted from the *Taking Charge* parents' handbook. Approximately 150 acronyms, laws, and words and phrases commonly encountered are explained. $3.00 per copy.

☐ *Interagency Collaboration: An Annotated Bibliography for Programs Serving Children With Emotional Disabilities and Their Families.* Describes local interagency collaborative efforts and local/state efforts. Theories of interorganizational relationships, evaluations of interagency programs, and practical suggestions for individuals contemplating joint programs are included. $5.50 per copy.

☐ *Issues in Culturally Competent Service Delivery: An Annotated Bibliography.* Perspectives on culturally-appropriate service delivery; multicultural issues; culturally specific African-American, Asian-American/Pacific Islander, Hispanic-Latino American, Native American sections. $5.00 per copy.

☐ *Making the System Work: An Advocacy Workshop for Parents.* A trainers' guide for a one-day workshop to introduce the purpose of advocacy, identify sources of power and the chain of command in agencies and school systems, and practice advocacy techniques. $8.50 per copy.

☐ *The Multnomah County CAPS Project: An Effort to Coordinate Service Delivery for Children and Youth Considered Seriously Emotionally Disturbed.* A process evaluation of an interagency collaborative effort is reported. The planning process is documented and recommendations are offered. $7.00 per copy.

☐ *National Directory of Organizations Serving Parents of Children and Youth with Emotional and Behavioral Disorders.* The 344 U.S. organizations in the second edition provide one or more of the following services: education and information, parent training, case and systems level advocacy, support groups for parents and/or brothers and sisters, direct assistance such as respite care, transportation and child care. $8.00 per copy.

Next Steps: A National Family Agenda for Children Who Have Emotional Disorders Conference Proceedings. Held in December 1988. Includes: development of parent organizations, building coalitions, family support services, access to educational services, custody relinquishment, case management.

☐ Conference Proceedings: $5.00 per copy.

☐ Conference Proceedings and Companion Booklet: $6.00 per set.

Next Steps: A National Family Agenda for Children Who Have Emotional Disorders (booklet). Briefly summarizes Next Steps Conference and recommendations made by work groups. Designed for use in educating administrators, policymakers and advocates about children's mental health issues.

☐ Single copy: $2.50.

☐ Five Copies: $7.00

☐ **NEW!** *Organizations for Parents of Children Who Have Serious Emotional Disorders: Report of a National Study.* Results of study of 207 organizations for parents of children with serious emotional disorders. Organizations' activities, program operation issues, training programs described. $4.00 per copy.

☐ *Parents' Voices: A Few Speak for Many* (videotape). Three parents of children with emotional disabilities discuss their experiences related to seeking help for their children (45 minutes). A trainers' guide is available to assist in presenting the videotape. Free brochure describes the videotape and trainers' guide and provides purchase or rental information.

☐ **NEW!** *Respite Care: A Key Ingredient of Family Support.* Conference proceedings. Held in October 1989. Includes speeches and panel presentations on topics such as starting respite programs, financing services, building advocacy, and rural respite care. $ 5.50 per copy.

☐ *Respite Care: An Annotated Bibliography.* Thirty-six articles addressing a range of respite issues are summarized. Issues discussed include: the rationale for respite services, family needs, program development, respite provider training, funding, and program evaluation. $7.00 per copy.

☐ *Respite Care: A Monograph.* More than forty respite care programs around the country are included in the information base on which this monograph was developed. The monograph describes: the types of respite care programs that have been developed, recruitment and training of respite care providers, the benefits of respite services to families, respite care policy and future policy directions, and a summary of funding sources. $4.50 per copy

☐ *Statewide Parent Organization Demonstration Project Final Report.* Describes and evaluates the development of statewide parent organizations in five states. $5.00 per copy.

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☐ *Taking Charge: A Handbook for Parents Whose Children Have Emotional Handicaps*. The handbook addresses issues such as parents' feelings about themselves and their children, labels and diagnoses, and legal issues. The expanded second edition includes post-traumatic stress disorder and mood disorders such as childhood depression and bipolar disorder. $7.00 per copy.

☐ *Therapeutic Case Advocacy Trainers' Guide: A Format for Training Direct Service Staff and Administrators*. Addresses interagency collaboration among professionals in task groups to establish comprehensive systems of care for children and their families. $5.75 per copy.

☐ *Therapeutic Case Advocacy Workers' Handbook*. Companion to the *Therapeutic Case Advocacy Trainers' Guide*. Explains the Therapeutic Case Advocacy model, structure of task groups, group process issues, evaluations. $4.50 per copy.

☐ *Transition Policies Affecting Services to Youth With Serious Emotional Disabilities*. The monograph examines how state level transition policies can facilitate transitions from the child service system to the adult service system. The elements of a comprehensive transition policy are described. Transition policies from seventeen states are included. $8.50 per copy.

☐ *Working Together: The Parent/Professional Partnership*. A trainers' guide for a one-day workshop for a combined parent/professional audience. Designed to identify perceptions parents and professionals have of each other and obstacles to cooperation; as well as discover the match between parent needs and professional roles, and practice effective listening techniques and team decision making. $8.50 per copy.

☐ *Youth in Transition: A Description of Selected Programs Serving Adolescents With Emotional Disabilities*. Detailed descriptions of existing youth transition programs are provided. Residential treatment, hospital and school based, case management, and multi-service agency transition programs are included. Funding, philosophy, staffing, program components, and services information is provided for each entry. $6.50 per copy.

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