



# FOCAL POINT



## FAMILIES AND PROFESSIONALS WORKING TOGETHER Issues and Opportunities

*Improving collaboration between parents, family members and professionals has recently become a central theme in efforts to improve services for children and adolescents with emotional and behavioral disorders. In this issue, conceptual issues and practical applications of parent-professional collaboration are presented. Here, we examine the rationale for collaboration, some common barriers to effective partnership and key elements that enhance a collaborative relationship. Accompanying articles describe a broad array of activities occurring throughout the country to promote collaboration, support parent organizing efforts, and enhance family support policy and practice.*

Interest in promoting parent and professional partnership stems from recognition that effective intervention with children suffering from emotional disorders is enhanced by a close working relationship between professionals, parents and other family members. Such a relationship allows the unique perspectives and knowledge of parents concerning the condition and needs of their child and family to be joined with the specialized skills and resources of helping professionals. A collaborative relationship between parents and professionals will help ensure that services provided to the family are based on a thorough understanding and response to family-identified needs and priorities, support family strengths in meeting needs, and promote the family's ability to acquire and sustain resources for problem solving.

Despite the practical and philosophical appeal of developing collaborative relationships between professionals and parents of children with emotional disabilities, the success of such efforts appears uneven at best. While the variety and nature of individual characteristics that may interfere in the establishment of any particular partnership are numerous, several

overarching factors may be identified as influencing or inhibiting the process of collaboration. These factors include perceptions of the cause and nature of mental illness and emotional disabilities in children, the history and experiences of professionals and of parents with children who have emotional disabilities, cultural differences, and socioeconomic influences.

• **Perceptions of Mental Illness and Emotional Disabilities.** The beliefs of professionals and parents regarding the etiology or cause of mental illness or emotional disability can



*Elizabeth Newhouse of the Texas Respite Resource Network spoke at the October 1989 national conference on respite care services for families whose children have emotional disabilities (see article on page 9).*

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on Family Support and Children's Mental Health

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be very significant in shaping their attitudes concerning the possibility and even desirability of forming a partnership. Professional perspectives that view the parental role in the development of emotional disabilities in children as primarily pathological will clearly affect and limit the extent to which parents will be perceived as helpful or capable. Likewise, parents who believe that their child's emotional disability was somehow the result of bad or inadequate parenting, or who are burdened by the stigma of being the parent of a child with a disability, may feel inadequate as (or lacking the power to be) a partner in the treatment process.

• **Experiences of Parents and Professionals.** Given the complex nature of emotional disabilities in children and the lack of a cohesive and coordinated system to deliver services, it is not unusual for a family to receive services from a number of agencies and private providers simultaneously. In the absence of a coordinated approach, these services may be a source

of added stress for the family. Contradictory service goals, frequent meetings with various providers, lack of clear expectations, and confusing or unclear communication between parents and providers may all serve to influence parents to view professionals with suspicion or anger.

The daily demands of family life and caring for a child with a serious emotional disability may also present barriers for parents. The physical and psychological toll of this twenty-four hour caretaking may tap the emotional and physical ability of parents to engage in active partnership with professionals.

Professionals also face barriers not dissimilar to parents. The multiple needs presented by some families, large caseloads and limited resources place great demands on the time and energy of professionals. The level of time and commitment needed to develop a close partnership with parents may seem unrealistic. Agency policies and regulations that limit the type, location and extent of contact professionals can make with families may also frustrate attempts at collaboration.

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Regional Research Institute for Human Services  
Portland State University  
P.O. Box 751  
Portland, Oregon 97207-0751  
(503) 725-4040  
National Clearinghouse  
(800) 628-1696

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*We invite our audience to submit letters and comments.*

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*"Collaborate . . . to work jointly with others or together . . . to cooperate with an agency or instrumentality with which one is not immediately connected"*

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• **Cultural Differences.** Cultural factors and the extent to which professionals recognize and honor cultural difference are a vital component for effective collaboration. Cross, Bazron, Dennis and Isaacs (1989), in a review of the literature demonstrate the differential treatment that non-white children with serious emotional disabilities and their families receive in mental health, education and juvenile justice systems. Higher rates of out-of-home placement of minority children, inappropriate placements, and inappropriate diagnoses are but some of the problems encountered by minority families. The ability of professionals to recognize cultural differences, knowledge and resources, and to provide services that are congruent with the family are essential ingredients of parent-professional collaboration.

• **Socioeconomic Influences.** Socioeconomic status and educational levels of parents may also influence the ability or extent of collaboration. The ability to locate and secure resources for their child and family, the extent to which parents have access to or the ability to obtain information on their child's condition, and the level of informal social support available to the family may help or hinder the collaborative process. Additional caretaking and financial burdens may be felt by single parents, limiting the time and energy they can realistically expend in interactions with professionals.

#### ELEMENTS OF COLLABORATION

Webster's Ninth New Collegiate Dictionary (1985) defines "collaborate" as "To work jointly with others or together. . .to cooperate with an agency or instrumentality with which one is not immediately connected" (p. 259). Clearly, the ability to work together requires a relationship in which two or more people are bound together by common purposes or goals. A successful relationship is one in which partners not only share a common goal, but in that partners share joint responsibilities and rights, are seen as equals, and can jointly contribute to the process.

Over the past three years the Family As Allies Project has been involved in a number of research and training efforts on the nature of collaboration and the attitudes, behaviors and skills that enhance parent-professional partnership. Based on these activities and experiences, a number of key elements emerge that appear central to developing a collaborative relationship.

• **Mutual Respect for Skills and Knowledge.** Central to the establishment of any relationship is the recognition that all members of the relationship have equal value and worth. Parents and professionals need to recognize and acknowledge the strengths and expertise that each possesses. By virtue of their status, parents are indeed experts on their child and family. Parents have a vast repertoire of skills and wisdom concerning what 'works' and what does not work with their child, how services help or hinder the family, and what needs the family have. Likewise, professionals, using specialized skills obtained through training and experience, offer parents opportunities to obtain new knowledge about their child's condition and behavior, adapt or change methods and behaviors to be more successful, and try new ways to assist family functioning.

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• **Honest and Clear Communication.** In many ways, respect is the result of partners being honest in their feelings and expectations, and clear and open in how they communicate their thoughts. Parents and professionals need to examine the biases and preconceptions they have towards each other and how those biases may inhibit honesty in communication. Truthful input and feedback is essential for both parties to be able to understand the needs of the family, generate strategies for help, and evaluate progress.

Clear and open communication, when conducted in an atmosphere of respect and sensitivity to the other person, will provide a basis for mutual understanding and action between parents and professionals. Accurate and timely information sharing, openness to questioning and clarification, and a desire to share knowledge will help overcome many barriers in working together.

• **Two Way Sharing of Information.** The extent and nature of information that is exchanged between parents and professionals is extremely important. Parents seek as much information as is available that can help them understand their child's condition, the nature and course of the disability, treatment strategies, and its long term consequences for the child and family. Information on how systems work, tips on how to negotiate with and between agencies, and information about where to obtain a broad range of resources needed by the family are also a common desire. A professional's sensitivity and responsiveness to the information needs of families and the family's reciprocal sharing of important information will greatly facilitate the collaborative process.

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• **Mutually Agreed Upon Goals.** Too often, parent and professional relationships are characterized by a dominant professional role and a passive, recipient role for parents. Parents typically provide information to the professional who then, often after consultation with other professionals, develops a plan of action for the parent or family. The goals of the plan or the rationale for them may not be made explicit or clear to the family, and may or may not be seen of any value by the family. Parents may then follow the prescribed actions, regardless of their helpfulness, or fail to complete the assigned task, risking the perception of being "resistant" or "non-compliant." Whatever direction the family may go, the likelihood is that neither the family nor the professional will feel fully satisfied with the process.

By working together to set goals, parents and professionals can be better assured that their efforts will represent a shared commitment that has made use of the knowledge and expertise each can provide. Such efforts not only recognize the priority of the family in deciding what is most helpful to them, it relieves the professional of the unrealistic expectation and burden of "having all the answers."

• **Shared Planning and Decision-Making.** Joint decision-making between parents and professionals affirms the primary role of the family in what services they receive and how they are provided. A commitment to shared responsibility implies that parents should be involved in all phases of service provision, including direct services provided to families and involvement in the policy-making process of agencies. This commitment helps to ensure that services are responsive to family and community needs and that gaps in services can

be identified.

While certainly not the only factors involved in achieving collaboration, the above elements — mutual respect for skills and knowledge, honest and clear communication, open and two way sharing of information, mutually agreed upon goals, and shared planning and decision-making — are basic building blocks upon which a collaborative relationship will develop and flourish. To put these building blocks together requires patience, desire and, commitment. Collaboration can only occur when both parents and professionals believe their joint efforts can make a difference in helping the child, when they follow through on decisions for joint action, and when they remain committed to the process over the long run.

#### References

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*Adapted from "Changing Roles, Changing Relationships: Parent-Professional Collaboration on Behalf of Children With Emotional Disabilities." This monograph is available through the Resource Service.*

**Richard W. Vosler-Hunter, M.S.W.,** is the Director of Training for the Research and Training Center and is on the staff of the Families As Allies, Families in Action, and Cross-Disciplinary Professional Training Projects.



## Recent Parent Support, Advocacy And Collaboration Activities

*Focal Point* readers were invited to submit material for a review of parent-professional collaboration activities and training, parent support, and advocacy activities and training conducted throughout the United States during the last two years. We would like to thank those who responded with copies of conference or training announcements, agendas, and other related information. The activities described reflect the many common concerns shared among the states.

**Delaware.** In August 1989 CASSP sponsored a regional Families as Allies *Train the Trainers'* conference in Wilmington. All of the states in the Northeastern region were invited to send two training teams to participate in the conference.

**Georgia.** CASSP sponsored a statewide Families as Allies Conference in June 1988. "Mini" Families as Allies workshops were subsequently held in eight regions. As an outgrowth of the Families as Allies trainings, several parent support groups have begun. An organizational meeting was held in July 1989 by a group of parents interested in developing a statewide organization, the Georgia Parent Network.

**Hawaii.** Hawaii Families as Allies held their first statewide conference in April 1989. Two support groups meet regularly on the island of Kauai. Support groups also meet in Honolulu, on Molokai, and in Hilo. A support network for parents of children with emotional disabilities has been established on Maui and efforts have been undertaken to develop a network in the Kona area.

**Idaho.** Idaho parents prepared a parent information packet for distribution to parents as their children enter intensive treatment facilities. The packet addresses immediate concerns on such topics as the cost of care, children's and parental rights,



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suggested reading materials, and additionally includes a description of treatment programs and facilities. Fall conferences included the *Integrated Services Within a Family-Centered Model* Conference, sponsored by the Divisions of Family and Children's Services and Community Rehabilitation; the *Third Annual Parents Conference*, sponsored by Idaho Parents Unlimited; *A Tapestry of Tomorrow: Weaving Healthy Patterns into Idaho's Future*, the *Youth 2000* and *Governor's Task Force on Children at Risk* conference; and the *Early Childhood* conference.

**Illinois.** Three *Parents as Partners for Mental Health Services* workshops for parents of children with emotional disabilities, designed to help families find and build needed support, have been held. One of the workshops was conducted in Spanish for Hispanic families. Additional workshops include the following: *Developing and Maintaining Parent Self-Help Groups*, *Parents and Professionals as Partners for Children's Mental Health Services*, *Working Together-Parents and Professionals as Partners*, *Bridging Racial and Cultural Differences in Working With Children and Families*, four *Family Partnership Project Workshops*, *Assessing Mental Health Needs of Children and Adolescents*, and the *Interagency Symposium to Improve Services for Emotionally Disturbed Children*.

**Indiana.** In June 1989 the Child and Adolescent Committee of the Indiana Council of Community Mental Health Centers sponsored their annual *Child and Adolescent Services Conference*. In July 1989 a training program for parents, *Building Partnership With Protection and Advocacy Agencies*, was presented by the Beach Center on Families and Disability in Nashville, Indiana. A pamphlet describing available respite services has been prepared.

**Iowa.** A Families as Allies train-the-trainer conference was held in September 1988 that produced eleven parent-professional teams. These teams have conducted workshops on collaboration, advocacy, and peer support. In addition to the parent delegation, professional attendees included clinical psychologists, special educators, social workers, residential treatment providers, and local CASSP project coordinators.

**Kentucky.** The innovative Break Away Respite Program has been launched within a community mental health center operated by the Bluegrass Regional Mental Health-Mental Retardation Board, Inc. The continuum of services includes summer and after-school therapeutic recreation programs, scheduled brief respite care, emergency brief respite services in or out of the home for up to twenty-four hours, and emergency out-of-home respite care for up to five days. The *Kentucky Integrated Delivery System (KIDS) Conference* was held in September 1989.

**Louisiana.** Close to one hundred parents of children with emotional disabilities serve on Louisiana CASSP teams, representing about one-third of these teams' memberships. Their participation is supported by the CASSP Parent Involvement Specialist. Six parent support groups have been established through CASSP. The *Parents and Professionals Together: For A Change* conference was held in October 1988. Additional meetings have included a one day workshop for parents on building positive self-esteem and the *Raising Good Kids in Bad Times* conference. Every issue of the CASSP newsletter has a page devoted solely to parent information and news. Efforts are underway to acquire a parent as editor. Activities of the Winn-Grant Community Level Demonstration Project have included a seminar introducing the strengths model of case management, a regional eight parish *Parents and Professionals Working Together: For a Change* conference, and parent workshops on such topics as hyperactivity and active parenting.

**Maryland.** Two groups, Parents Supporting Parents and the Alliance for Mentally Ill Children and Adolescents, have been working collaboratively with CASSP staff. The Parent Assistance Network has been established. The Network's activities include assisting parents in their role as primary caregivers and case managers for their children, empowering parents to advocate for appropriate services, creating opportunities for parents to share experiences and participate in training, sensitizing professionals and the community to issues faced by families whose children have emotional disabilities, and providing information on available resources and services. CASSP co-sponsored *Reaching Children. An Inter-professional Workshop and Course on System Principles and Practice Skills* and *The Art of Intervening. Understanding the Problems: Setting the Goals*. A parent organizer was a featured speaker at both of these events and shared a parental perspective with the professionals in attendance.

**Mississippi.** CASSP staff are developing a Families as Allies educational curriculum to provide a formal structure for encouraging family empowerment and parent/professional collaboration. Three teams of parents and professionals participated in the Southern Regional Parent/Professional Collaboration Training held in July 1989. Meetings held within the state include a series of *Families as Allies* conferences and a series of *Services to Preschool Children With Handicaps: A Parent/Professional Partnership* workshops and the *Lookin' to the Future* conference which focused on the independent living issues facing the older adolescent in out-of-home care. CASSP Region III Task Force members met for over two hours with representatives of the Governor's Office and discussed the needs of children with emotional disabilities.

**Missouri.** Parent support groups are meeting in St. Louis,

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St. Charles, and Springfield. A newsletter is published bi-monthly and sent to parents and professionals throughout the state as part of the CASSP effort. Coalitions of parents and professionals are meeting in the St. Louis and Springfield areas to develop parent support groups and to address other goals that the coalitions have individually established. The St. Louis coalition assisted in planning a fall conference and resource fair for parents and professionals from throughout the state entitled *Parents and Professionals: Partners for Change*. A model for parent support and advocacy has been developed that will be used throughout the state to replicate the coalitions and support groups currently meeting.

**Nebraska.** A *Train the Trainers for Parent/Professional Collaboration* workshop was offered to sixteen professionals and sixteen parents in November 1988. *Special Education Rights for Children With Severe Emotional Disabilities: A One-Day Workshop for Parents and Other Persons Caring for Children with Severe Emotional Disabilities* was held in December 1988. In June 1989, Nebraska hosted the *Administrator's Conference: Family Focused Intervention*. The overall goal of the conference was to develop an awareness among legislators and administrators from key agencies of family-focused intervention and its impact on the professionals who staff those agencies.

**New Hampshire.** Three parent-professional teams attended the Delaware train-the-trainer program in August 1989. In addition to training other teams in New Hampshire, these teams will provide leadership in maintaining an active regional parent support group, identify and recruit parent-professional teams to participate in regional Families as Allies conferences, and provide training for a statewide Families as Allies conference in 1991.

**New York.** In 1988, CASSP funded five parent support groups. In 1989, there were thirteen groups. The Mental Health Association in Ulster County has conducted a training program on how to facilitate parent support groups and has prepared a manual for distribution entitled *Parents Together: A Manual for Leaders of Support Groups for Parents of Children Experiencing Emotional and Behavioral Disorders*. Their facilitator training for new parent support groups will be repeated and a respite training component will be added. Two parent/professional teams attended the Delaware train-the-trainer program and will conduct similar workshops in New York and provide technical assistance to the state on parent support. In collaboration with the Mental Health Association in New York State, CASSP funded a statewide newsletter for parents. In June 1989 the Northeast Cluster of CASSP states and local projects sponsored the *Implementing A System of Care for High Risk Black and Latino Children and Youth Conference* held in New York.

**Oregon.** CASSP sponsored a parent-professional team to attend the Covington, Kentucky national respite conference in October 1989. CASSP's assistant director has assumed primary responsibility to work with parents to develop a parent support network. CASSP staff are also working with parents, advocates and professionals to help parents and other family members identify ways to increase their involvement in planning for services.

**South Carolina.** The third annual child and adolescent services training conference, *Assessing Families: South Carolina's Most Valuable Resource*, was held in April 1989.

**Virgin Islands.** Three parents sit on the Virgin Islands CASSP Planning and Management Board. The parents represent the two incorporated parent groups in the Territory. The November 1988 *Virgin Islands' Mental Health Conference* included workshops for parents on advocacy, empowerment, and parent/professional/community collaboration. The CASSP budget includes funds to recruit the parent of a child with an emotional disability to serve as a part-time CASSP project assistant. Additionally, the budget includes funds to cover the cost of a minimum of four trips to the mainland for parents to attend relevant workshops or trainings and share the information with other parents.

**Washington.** In June 1989 the Mental Health Division hosted the *Children's Mental Health Conference: Building Community Capacity* conference. The purpose of the conference was to promote stronger roles for families, further the improvement of services for children with emotional disabilities, and disseminate technical information on serving children and families. The South King Family Resource Network is a community-based, family-focused resource brokerage. The network is a collaborative effort by state mental health, education, child welfare and developmental disabilities agencies. The three major areas of emphasis are working in partnership with families to respond to their requests for support and assistance with problem solving, fostering community awareness of families' need and stimulating activities to respond to those needs, and working with service providers to expand their collaborative involvement with both parents and other professionals.

**Wisconsin.** Legislation entitled "The Children Come First" has been enacted in Wisconsin. Funds amounting to \$200,000 were appropriated to enable participating counties to develop multi-categorical coordinated community-based service programs for children with emotional disabilities. Joint service plans for children and families with complex treatment needs will permit efficient allocation of resources and help ensure that children with atypical treatment needs do not fall between the cracks among single-category providers.

## Why Not?

Why collaborate? (1) To more fully involve families in the care of their loved ones; (2) To use the experience and knowledge gained through caring for a child with an emotional disability; (3) To provide families with practical information useful in the care of their child; (4) To increase the levels of trust and respect between family members and professionals; (5) To use the family's strengths in treatment; (6) To enhance communication between families and professionals; (7) To increase family satisfaction with service provision; (8) To develop treatment plans that consider the family's needs and life situation; (9) To include both family and professional concerns in the formulation of treatment goals; (10) To help families and professionals understand that there are limits to what each can do; (11) To reduce the sense of guilt often experienced by families; (12) To provide the most efficacious and sensitive service possible to families and children.

Family-professional collaboration is a classic example of a synergism in which the action of two entities combine to produce an effect of which neither is capable individually—an instance where the whole is greater than the sum of the parts.

Why not collaborate? N.D.

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

## NATIONAL CLEARINGHOUSE ON FAMILY SUPPORT AND CHILDREN'S MENTAL HEALTH

The Research and Training Center is launching the first clearinghouse designed to serve families of children with serious emotional disorders as well as professionals, policy-makers and other interested persons. The National Clearinghouse on Family Support and Children's Mental Health includes a national toll-free telephone service, a computerized data bank, a series of fact sheets on issues pertaining to children who have emotional disabilities and their families, a state-by-state resource file, and the addition of a family resource coordinator to the Center's staff.

Available fact sheets address the following topics: children's mental, emotional, and behavioral disabilities; resources (books, journals, newsletters, and films) addressing children's mental health issues; starting parent/family support groups; financing; early intervention services; and descriptions of specific children's emotional disabilities including childhood depression, attention deficit hyperactivity disorder, and childhood schizophrenia.

Clearinghouse hours of operation are 8:00 A.M. to 12:00 P.M., Pacific Time. When staff are not available, callers may leave their names, addresses, telephone numbers and inquiries on an answering machine. The Clearinghouse may be reached by telephoning (800) 628-1696 or by writing the National Clearinghouse on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751.

## Statewide Parent Organizing Efforts Garner Financial Support

Support for the development of statewide parent organizations for families of children with emotional disorders continue to grow across the country. In 1988, the Portland Research and Training Center funded five, twelve month demonstration projects to develop model statewide parent organizations in Hawaii, Minnesota, Montana, Virginia and Wisconsin. Building upon the continued success of these organizations since their original funding, three additional one-year projects were added this past October. Parent organizations in **New Jersey, Indiana and Kentucky** will each receive funding of \$20,000 during 1989-90.

The Statewide Parent Organization Project has two major goals: (1) to stimulate and support the development of model statewide parent entities that have the capacity to provide technical assistance to parents and parent organizations within

states; and (2) to evaluate the conceptualization and implementation, and outcome of these projects. The purpose of the evaluation is to examine the issues that arise during the process of establishing a statewide parent organization and to track the impact of their activities. Understanding what does and does not work will help policy-makers better anticipate the supports needed by parent organizations in other states as they extend services to a wider geographic area and a greater variety of parents.

Currently funded organizations and contact persons are: (1) Gail Lincoln, Executive Director, Kentucky Coalition of People With Handicaps, Inc., 1375 Clearfork N., Morehead, Kentucky 40351-9514, (606) 784-7580; (2) Jean Gaunt or Pat McGuffey, Indiana Parent Support Network, Indiana Mental Health Association, 433 N. Meridian St., Indianapolis,



Indiana 46202, (317) 638-3501; and (3) Carolyn Beauchamp, Executive Director, Mental Health Coalition for Children's Rights to Services in New Jersey, New Jersey Mental Health Association, 61A Carol St., Ramsey, New Jersey 07446, (201) 646-3099.

In addition to activities sponsored by the Research and Training Center, the following are examples of the accelerated state and foundation support of parent organizations during the past year. The Parent Advocacy Coalition for Educational Rights (PACER Center, Inc.), a statewide organization in Minnesota, received a grant this past December from the McKnight Foundation to support a current project for parents of children with emotional or behavioral disorders. The one year grant will assist the project in ongoing activities, including continued statewide organizing of parents and development of local parent support groups, training of advocates, sponsorship of workshops for parents, and production of a videotape concerning children with emotional and behavioral disorders. PACER Center was the recipient of a one year grant from the Research and Training Center's Statewide Parent Organization Project in 1988. Information on PACER can be obtained by contacting: Dixie Jordan, PACER Center, Inc., 4826 Chicago Avenue South, Minneapolis, Minnesota 55417-1055; (612) 827-2966.

In Washington, D.C., the Family Advocacy and Support Association (FASA) has received funding from the District of Columbia Child and Adolescent Service System Program (CASSP) to enhance its activities to improve services for families of children with serious emotional disorders. FASA works to support families of children with emotional disorders, educate professionals and parents about their needs; provide information on available resources for parents; and advocate for improved services. Recent activities have included co-sponsorship of a city-wide conference, *Strengths of Black Families—Coping in a Time of Stress*, participation in production of a video on mental health needs and services in the District of Columbia, and development of a parent produced quarterly newsletter. More information on the activities of FASA are available through: Velva Spriggs, Family Advocacy and Support Association, 3649 New Hampshire Avenue, N.W., Washington, D.C. 20010; (202) 291-4967.

Keys for Networking, a statewide parent support and advocacy organization in Kansas has helped develop seven local support groups throughout the state. During the past six months, the organization has also responded to over 200 calls from parents, providing information, referral and advocacy services, and conducted a number of training workshops for parents and professionals on issues related to parent support, parent-professional collaboration, and improved services for families. In addition, the organization is strongly advocating for passage of legislation that would provide reforms in the

state's mental health system and improve support services for families whose children have emotional disorders. Activities of Keys for Networking are partially supported through funds from the state's Division of Youth Services and the Division of Mental Health and Retardation.

In Vermont, Judith Sturtevant, the parent representative on Vermont's State Interagency Team, has been active in efforts to promote the development of a statewide parent network. In 1988, she submitted a grant proposal to the Portland Research and Training Center to establish a statewide parent support network. The grant proposal, one of 43 submitted from around the country, was not one of the five successful applications; however, the Department of Mental Health used federal funds and contracted with Sturtevant to implement her original grant.

Sturtevant has begun to facilitate the project's goals through the following objectives: (1) to develop an inexpensive information, referral, and support system; (2) to develop and distribute a parent/professional resource guide; (3) to establish ties with diverse groups and individuals throughout the state, and link such groups with the Public Law 99-660 Planning Council and other relevant groups; and (4) to strengthen the statewide network of parents and parent support groups. For further information, contact Judith Sturtevant at RD 2, Box 770, Morrisville, Vermont 05661; (802) 888-3231.

The Iowa CASSP office has sub-contracted with the Alliance for the Mentally Ill of Iowa (AMI) to stimulate the development of local parent support groups in the state, coordinate information and organizing efforts with existing, cross-disability parent organizations, and provide information and resources to parents of children with serious emotional disorders. AMI has employed a parent, Deb Capaldo, to carry out these tasks. For additional information contact: Deb Capaldo, 133 Lillian, Ottumwa, Iowa 52501, (515) 682-6467; or AMI, P.O. Box 495, Johnston, Iowa 50131; (515) 225-8666.

Information about other statewide parent organization efforts will be included in future issues of *Focal Point*. Please send summaries of statewide activities to Marilyn McManus, *Focal Point* editor.

### **Next Issue: Focus on Barriers to Accessing Services—Part Two**

The next issue of *Focal Point* will continue the Summer 1989 *Focal Point* discussion of the barriers families whose children have emotional disorders encounter in locating and obtaining appropriate services, including the requirement in some states that parents transfer legal custody to the state for the sole purpose of obtaining necessary out-of-home services at public expense. We will report the results of a recent survey of states regarding custody transfer, highlight additional barriers to the provision of services to children that relate to custody, and describe efforts parents have undertaken to address this issue.



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## National Conference Addresses Respite Care Services For Families Whose Children Have Emotional Disabilities

The Research and Training Center on Family Support and Children's Mental Health, in collaboration with the Child and Adolescent Service System Programs (CASSP) in a number of states sponsored a national conference, *Respite Care: A Key Ingredient of Family Support*. The conference, held October 28-30, 1989, in Covington, Kentucky was attended by families whose children have mental, emotional, or behavioral disorders and by professionals interested in facilitating and implementing respite care and family support programs for these families. Hosts for the conference were the Kentucky and Ohio CASSP projects; co-sponsors were CASSP projects in Indiana, Illinois, Kansas, Kentucky, Ohio, Oklahoma, West Virginia, and Wisconsin.

The goals of the conference were to provide participants with information about respite care concepts, programs, and issues and to help participants develop plans for designing, financing, and implementing respite programs in their states and communities.

Approximately 200 people attended the two-day conference representing 36 states; 40 percent of those in attendance were family members. Most participants attended as members of state delegations organized through state mental health programs. Program directors, service providers, policy-makers, advocates, and others interested in learning about and promoting respite services for families whose children have mental, emotional, or behavioral disorders also attended.

Barbara Friesen, director of the Research and Training Center on Family Support and Children's Mental Health and Catherine Staib, a Kentucky parent, made opening and welcoming remarks. The program included a panel discussion of respite care issues for this population. William Scott, former CASSP director in Kentucky who presently works at a mental health center in New York, was moderator for this panel. Panel members were Terry Butler, formerly on the staff at the Portland Research and Training Center and the author of an annotated bibliography and a monograph on respite care, and three family members: Barbara Huff (Kansas); Creasa Reed (Kentucky); and Judy Sturtevant (Vermont). The luncheon address, "Enhancing Treatment for Children and Families Through Provision of Respite Services," was presented by Richard Donner. A second panel looked at respite care from a national perspective. This panel, moderated by Ellen Kagen from the Georgetown CASSP Technical Assistance Center in Washington, D.C. included Ted Boyden from the U.S. General Accounting Office and Milton Cassidy and Elizabeth Newhouse, both from the Texas Respite Resource Network.



*West Virginia representatives at the respite conference: (left to right) David Majic, West Virginia CASSP Coordinator; Rachel Stewart, Outreach Program Director, Beckley Child Care Center; J. Michael Geary, Department of Health; and Gwen Bridges.*

Workshops were offered in the areas of training respite care providers, financing, building advocacy, and presentation of existing program designs and operations. Two workshops dealt with training: Richard Donner and Barbara Huff described the Rest A Bit curriculum they developed in Kansas based on parent-defined competencies, and Phyllis Tarrant of the Oklahoma Department of Vocational and Technical Education presented her instructional packages with a focus on selecting and adapting elements to meet individual training needs. There was one workshop (presented twice) on issues of financing respite care programs. This workshop was led by Ted Boyden of the General Accounting Office, who is conducting a national study for Congress on respite care programs, and Bill Underwood from Arkansas who has developed a program using Title IV-E funds for respite services. Three workshops were held that addressed issues of advocacy and building community support for respite care programs. Susan Failing discussed a statewide model developed in Maine; Judith Wagner of the Center for Handicapped Affairs in Lansing, Michigan presented a program whereby parents can join together to create new community services; and Milton Cassidy and Elizabeth Newhouse of the Texas Respite Resource Network described a step-by-step approach to develop a community-based respite care program.

Seven workshops were presented that described existing programs and models in Indiana, Texas, Tennessee, Michigan, West Virginia, Kentucky and Vermont. Issues included family-directed programs, rural respite care, support groups and their relationship to respite, in-home care, recreationally-oriented programs, and the use of parent-professional teams to implement programs. Following the workshops, state delegations met in work sessions to identify barriers and develop

*Continued on page 14*

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## Overview Of Research And Training Center Projects In The Next Five Years

The Research and Training Center on Family Support and Children's Mental Health has been funded for the 1989-94 five year period by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, and the National Institute of Mental Health (NIMH), U.S. Department of Health and Human Services. The new grant will continue the work of the Research and Training Center, which was originally funded from 1984 through 1989. During the next five years, faculty and staff from the School of Social Welfare at the University of Kansas will join the Research and Training Center effort through a contract with Portland State University. The research program of the Research and Training Center includes eight projects and the addition of a national clearinghouse.

**Family Caregiver Survey.** This project will develop a comprehensive model of family caregiving for families of children and youth with a serious emotional disability. The model to be tested ultimately seeks to identify the determinants of family functioning, child well-being, and caregiver well-being in these families. In doing so, the project will consider a range of factors, some of which are given characteristics of the family, child, or community (e.g., sex of the child, marital status of caregiver, and population density), and other changeable characteristics that may vary as families attempt to deal with their child's disability (e.g., perceptions of disability, availability and use of community services).

The identification of both given and changeable characteristics that impact on these families and their children are important for administrators, practitioners, family advocates and the families themselves. The given characteristics can be used to identify unmet needs and for the targeting of special intervention efforts. Changeable characteristics can be manipulated to maximize positive outcomes for these families and children. In this way it is expected that the development and testing of a comprehensive family caregiving model can contribute to the well-being of children with severe emotional disabilities and their families.

**Minority Cultural Initiative Project.** This project will focus on culturally appropriate services for children and youth with serious emotional disabilities and their families. The project will use existing knowledge in the published literature and unpublished program examples as a foundation for developing models that will allow agencies to identify and deliver culturally appropriate services.

The project will consist of two major phases: (1) the model development phase; and (2) the demonstration phase. In the

model development phase, two parallel activities will occur. The first entails a comprehensive review of the literature concerning culturally appropriate services and service delivery approaches for each of the four major sociocultural groups of color in the United States (i.e., African-American, Asian/Pacific Islander American, Latino- or Hispanic-American, and Native American peoples). The second activity in the first phase consists of identifying existing programs and practices that embody aspects of cultural competence. The second phase of the project, the demonstration phase, will involve consultation and training with agencies to help them address their ability to provide culturally appropriate services to children and their families. Activities may take several forms including providing training, brokering training, identifying alternative models, recommending literature, and generally facilitating a given agency's or system's self-help process with respect to cultural competence.

**Supporting Families: A Strengths Model.** The focus of the project is the evaluation of the Family Advocacy Model with families of Head Start children who have been identified as having mental health needs. This project helps families identify their strengths and needs, and locate and obtain services through a specialized case management approach. The hypotheses are that as a result of participating in the Family Advocacy Project caregivers will increase their ability to: recognize their caregiving strengths; recognize their child's strengths; recognize the child's special caregiving demands; increase their knowledge of strategies to meet the child's special needs; increase their ability to acquire educational services to meet the child's special needs; and increase their social supports as well as use of concrete services.

The evaluation is designed to determine the impact of the Family Advocacy Model on both caregivers and children served. This will be accomplished through the use of a quasi-experimental design that will permit in-program and post-program comparisons of families and children receiving the services of the Family Advocacy Model with a cohort of similar families and children identified in the system in the year prior to implementation of the Family Advocacy Model.

**Families as Allies Project.** The major endeavor of this project will build on the accomplishments of the previous five years by testing the effectiveness of the collaboration training curriculum developed by the Portland Research and Training Center. The evaluation will use an experimental design and include professionals and family members. The professional sample will include workers from mental health, child

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welfare, and special education. A unique feature of the study will be the assessment of collaboration from the perspectives of both family members and professionals. Additional measures will include the assessment of attitudes and behaviors relating to collaboration before and after training. Three and six month follow-ups will also be conducted to examine the relationship of collaboration to multi-dimensional outcome measures.

In addition to the empirical assessment of the impact of the model training curriculum the project will also: (1) collect data on different aspects of collaboration in order to develop and refine an instrument for measuring the construct within the evaluation described above; (2) provide consultation and technical assistance to the existing national network of parent-professional trainees; (3) update and refine an annotated bibliography on parent-professional collaboration; (4) refine the training handbook for parent-professional collaboration based upon the literature review and survey of parents and professionals; and (5) disseminate project materials, including research findings, to family and professional audiences.

**Families in Action Project.** The purpose of this project is to develop and test strategies that will encourage the involvement of family members in policy and decision-making processes affecting services for children with emotional disabilities. The project will focus on parent participation in community-based services at the community and state level. The Families in Action Project will develop and test strategies for family involvement through a three-phase process.

Phase I is an extensive literature review on citizen and consumer participation and structured data collection from selected family members and professionals active in state and community level decision-making processes. This information will be used to refine conceptual models and strategies for effective family participation. Phase II is the development of strategies for working with family members and professionals in selected demonstration sites. Project staff will work with individuals in the demonstration sites to identify opportunities for participation both by project staff and family members. Plans will be developed to facilitate family involvement in the identified opportunity. This plan may include training and technical assistance as well as other approaches. Phase III includes an evaluation of the strategies employed by both project staff and parents and each strategy's general applicability.

**Empowering Families: A Policy Analysis.** This project will develop a training intervention in policy analysis skills designed to help empower families to become effective participants in the planning and delivery of services. Specifically, a framework for policy and program analysis will be adapted for use by family members and taught to them as a training

intervention. This intervention will be designed for use by family support groups and will be initially piloted in Kansas and Oregon. Evaluation of these pilots will occur using a mixture of qualitative measurements, including participant feedback, and quantitative measurements of individual psychological empowerment, personal advocacy, and representative advocacy. Long-term follow-up measurements will assess the impact of the training intervention on systems change. After the initial pilots, the intervention will be made available to other states, based on criteria such as geographic diversity, the existence of parent groups, and interest expressed by parents or professionals.

The initial product from this project will be a training intervention in policy analysis that is designed for family groups. This study has the potential of corroborating some of the initial work that has been done on empowerment for citizen participation.

**Cross-Disciplinary Professional Training Project.** This project provides an opportunity to influence professional education through the development of standards of "exemplary training," and dissemination of information and program examples to faculty and students in professional schools. The project will locate, develop and test, and disseminate materials in two major areas: (1) enhancing the responsiveness of professional interventions to family needs (including promoting partnerships between professionals and family members); and (2) promoting collaboration among professions on behalf of families whose children have serious emotional disorders.

The project will include four phases. Phase I consists of three major activities: (1) conducting literature reviews of materials in the broad areas of cross-disciplinary training, parent-professional relationships, and consumer satisfaction; (2) convening a cross-disciplinary panel of experts to assist in developing criteria for identifying "model" programs; and (3) preparing a concept paper outlining principles of good cross-disciplinary education. Phase II involves identifying exemplary programs and gathering information through site visits, telephone calls and mail. Phase III includes analyzing information from Phase II and preparing written materials for dissemination, or where they do not exist, suggesting curricula and/or program approaches to be developed. Phase IV includes dissemination of information through written curriculum materials and articles and papers for presentation at major professional conferences.

**Statewide Parent Organization Demonstration Project.** See discussion on pages 7 and 8.

**National Clearinghouse on Family Support and Children's Mental Health.** See article on page 7.





Board members and officers of the Federation of Families for Children's Mental Health were installed by Barbara Friesen, director of the Portland Research and Training Center, at the first annual meeting in October 1989. Left to right seated: Judith Sturtevant, Glenda Fine, Jane Walker, Creasa Reed. Left to right standing: Carol Freebairn, Chris Koyanagi, Barbara Huff, Danny Amrine, Bonnie Shoultz, Naomi Karp, Chris Petr, Barbara Friesen, Marilyn Henry, Marge Samels, Ann Ince, Dixie Jordan, Al Duchnowski.

## Federation Of Families Holds First Annual Meeting

Approximately 75 persons from 26 states attended the inaugural meeting of the Federation of Families for Children's Mental Health. The meeting, held on November 11-12, 1989 at the Sheraton National Hotel in Arlington, Virginia, was the first annual meeting of the newly formed national organization focusing on the needs of families whose children have emotional, behavioral or mental disorders.

Members of the Federation Steering Committee opened the meeting by sharing their visions of the future for children and their families. Barbara Huff, Interim President (Kansas), invited members to work together to develop goals and strategies for the next year and beyond. Naomi Karp (Virginia) presented a history of events and activities beginning in 1983 that led to the development of the Federation of Families for Children's Mental Health, and presented her vision for the year 2000. Bonnie Shoultz (New York) urged a shift from defining the issues facing children and families as "private troubles," where families are isolated and expected to solve their problems without support to "public issues," where the needs and circumstances of children and families are seen as critical public concerns.

Peter Jensen, M.D., Chief of the Child and Adolescent Disorders Research Branch of the National Institute of Mental Health (NIMH) provided a professional's perspective. He called for a partnership between parents and professionals and suggested that professionals have much to learn from family members. Dr. Jensen stated that placing blame on families is totally inappropriate, especially since the causes of emotional disorders in children are largely unknown. Despite this, he said, many professionals still use theories that blame families for the problems of their children, and many parents blame them-

selves. Dr. Jensen also discussed the challenges of understanding emotional disorders of children, citing factors such as the complexity of children's development and their natural tendency to respond differently across environments such as home, school, and with peers. Dr. Jensen described positive developments within NIMH related to children's issues such as a national plan for research on children and a consortium of NIMH divisions that will focus on children's issues.

A panel of family members presented their hopes and visions for the future and for the Federation of Families. Dixie Jordan (Minnesota) envisions an organization that will provide hope and information for families. Glenda Fine (Pennsylvania) stressed the importance of accessible information for families in all parts of the country. Creasa Reed (Kentucky) spoke of her hope that the Federation would continue to improve the public image of families whose children have emotional disorders and reduce the blame that parents feel. Jane Walker (Maryland) discussed the need for community-based services, and emphasized the importance of supporting all families, regardless of where their children live.



Dr. Peter Jensen

During the remainder of the conference, Federation members turned their attention to developing goals and plans for the future. Workgroup reports presented in the final plenary session included the following priorities: (1) To reduce stigma through education of family members, professionals, and



the public at large; (2) To promote a full range of family support strategies and services; (3) To support local family groups through information exchange, education and advocacy; (4) To promote strong involvement of representatives of racial and ethnic minority groups; (5) To develop and articulate a public policy agenda; (6) To identify the ideal service system, including standards for quality; (7) To promote high quality, accessible educational services; and (8) To develop the people and resources to articulate the organization's vision.

Conference participants also made recommendations concerning ways to increase the Federation's capacity to meet its goals. These strategies address the areas of organizational structure, recruitment and membership, funding, communication between national and state levels, collaboration with other organizations that share the philosophy of the Federation, leadership development and services to members.

The meeting concluded with the installation of officers and members of the Board of Directors for the Federation of



Bonnie Shoultz

Families for Children's Mental Health: President: Barbara Huff; First Vice President: Bonnie Shoultz; Second Vice President: Naomi Karp; Secretary: Creasa Reed; Treasurer: Danny Amrine. Elected to two year terms on the Board of Directors were: Al Duchnowski, Glenda Fine, Marilyn Henry, Ann Ince, Chris Koyanagi, Marge Samels and

Judy Sturtevant. Members serving one year terms are Marva Benjamin, Kevin Dwyer, Carol Freebairn, Dixie Jordan, Chris Petr and Jane Walker. For more information about the annual meeting or the purposes, activities, and services of the Federation, contact: Federation of Families for Children's Mental Health, 1021 Prince Street, Alexandria, Virginia 22314-2971; (703) 684-7710.

## CASSP Project Directors' Meeting Features Community Services For Children With Serious Emotional Disorders and Their Families

Developing local systems of care for children with serious emotional disorders and their families was the focus of a recent meeting of Child and Adolescent Service System Program (CASSP) state and local level grantees in Washington, D.C. March 13-15, 1990. In her opening address Dr. Jane Knitzer highlighted findings from her recent study on mental health services and schools entitled *Beyond Compliance: The Role of the Schools and Children with Behavioral and Emotional Problems*. Dr. Knitzer is the author of the 1982 book, *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services* which helped to focus public attention on the problems of children with emotional disorders and their families.

CASSP project directors, staff, parents and other participants heard an overview of local system development presented by Connie Dellmuth, Director of the Bureau of Children and Youth Services, Pennsylvania Office of Mental Health and Robert F. Cole, Deputy Director of the Mental Health Service Program for Youth, Prudential Insurance Company. A variety of workshops addressed approaches to local system development currently used around the country, featuring programs in Pennsylvania, Ohio, Vermont, Illinois, Alaska and Louisiana.

The important role of research in improving services for children with mental and emotional disorders was emphasized. Kelly Kelleher, M.D., Division of Biometry and Applied Science, National Institute of Mental Health (NIMH), presented

highlights of the NIMH *National Plan for Research on Child and Adolescent Mental Disorders* and past research and future plans of the Research and Training Center on Children's Mental Health in Tampa, Florida and the Portland Research and Training Center on Family Support and Children's Mental Health were discussed. Conference participants also engaged in work sessions designed to help CASSP project staff use evaluation to improve child mental health services. Mike Hendricks, evaluation consultant to the NIMH was the featured speaker. New research opportunities available in the children's mental health field were also described (see related story, p. 16).

Other highlights of the meeting included a two-day orientation session for states with new CASSP projects, and a graduation ceremony for state and local projects at the end of their funding periods.

### Telephone Number Change

The prefix for all Portland State University telephone numbers has changed. The Research and Training Center's new telephone number is (503) 725-4040.

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## PARENTS' PERSPECTIVE

Before respite care my days were filled with havoc. There wasn't a minute (literally) of relaxation from my four year old. I would envy other families whose children would sit in stores or restaurants for more than two minutes. I found myself explaining my son's diagnosis to strangers in an effort to solicit their understanding.

Weekends were especially difficult as I was alone and had little help. I heard about a local respite program and soon had a skilled worker helping me a couple of times each week. I was able to receive some peace and spend quality time with my oldest child. We would go to a movie or out for brunch. It definitely gave my special child something to look forward to and made a difference in my psychological well-being. A bond was formed between the respite worker and our family, and we remained in contact when she went away to college.

I am excited about Tompkins County Mental Health Association's new Family Support Services Program. I was honored when asked to attend a national respite care conference in Kentucky with the program director as a parent representative. My conference and flight fees were paid by Portland State University. The conference proved to be both a consciousness raising and informative experience. I hope to carry the knowledge I gained with me to help others.

The most significant point I learned at the conference is the importance of educating parents, mental health professionals, and teachers that respite care for parents whose children have emotional disabilities is an *entitlement*—not a luxury—as these parents do not get the “natural breaks” most parents receive. Conference speakers also emphasized the importance of lobbying in order to continue to get funding for programs. Parents' descriptions of their situations to legislators has made the difference in whether programs were funded.

As a volunteer working with the Family Support Services Program, I am involved in an outreach plan to educate the community about families' entitlement to respite care for their children with emotional disabilities. We have some distance to go, as this new concept will take time, but my utmost goal as a parent advocate is for children and youth with emotional disabilities and their families to live healthy and harmonious lives together. *Gail Creighton, Tompkins County Mental Health Association, Family Support Services Program. Ithaca, New York.*

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

### Respite Conference cont. from page 9

strategies for implementing respite care programs in their states and communities. Some states had large delegations at the conference. In some cases, however, there were only one or two people in attendance from a state. These people were grouped together and were encouraged to begin to develop strategies to share with others when they returned home. Contact with various individuals since the conference indicate that in some states follow-up meetings of the delegation were held (Ohio), that at least one state is planning its own respite care conference (Indiana), and that planning is progressing rapidly in some local communities (Tompkins County, New York). The delegation work session members produced plans that listed needs, resources, funding sources, and strategies for implementation.

One continuing theme throughout the conference was that respite care services are just one component of a broader system of family support services. Speakers and panel members encouraged participants to view respite care services in this way when designing and developing services in their own states

and communities. Some panelists suggested that respite care programs cannot succeed unless they are nested within the broader context of family support.

The Portland Research and Training Center on Family Support and Children's Mental Health will publish conference proceedings. This publication is currently being prepared and includes the conference agenda; complete text of the opening remarks, both panel sessions, and the luncheon address; the results of the evaluation; all state delegation work session plans; and a conference summary. For further information, write Publications Coordinator, Research and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751.

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## Survey Of Parents Whose Children Have Serious Emotional Disorders: Report Of A National Study

The report of a study that explored families whose children have serious emotional disorders and family members' perspectives of their problems, needs, and experiences has been released by the staff of the Research and Training Center's Families as Allies Project. Areas addressed by the study included family members' experiences with seeking and receiving information and services for themselves and their children, sources of formal and informal support upon which they rely, and their perceptions of the effect of their child's disability on family life. The study is based on responses from nearly 1000 parents from 45 states and the District of Columbia collected between May 1987 and September 1988.

The initial analysis of the data from the parent survey suggest a number of areas that merit attention from parents and advocates, planners, service providers, and researchers:

*One-fourth of parents in the study said that it had been suggested that they relinquish legal custody of their children to gain access to services.* A re-examination of both mechanisms for mental health financing and child welfare policy is needed, since they each contribute to this problem. Further examination of the effects on children and families of this phenomenon is also sorely needed.

*Nearly half of the parents reported that they had been physically threatened by their children.* While much more study into the nature and extent of this problem is needed, it is apparent from parents' comments that many currently face serious injury or worse. Information about how to deal with assaultive children, as well as concrete assistance should be provided to families now.

*Parents provided much rich information about their expectations of professionals, along with their actual experiences.* This information should be used in the development and revision of professional education programs.

*Specific services identified as particularly difficult to gain access to included financial assistance, support groups for parents as well as brothers and sisters and respite care.* More attention might be given to including these services in new or existing programs. In general, our findings lend support to the commonly accepted need for improvements in the quantity, quality, and variety of service options for families.

*Information needs identified by families include a better understanding of the causes of emotional disorders as well as specific information about the nature and appropriate treatment of their children's problems.* Parents need better access to existing information and, perhaps, more direct consultation with professionals about their own circumstances. While much remains to be learned about childhood emotional dis-

orders, improvements can be made by sharing what is known. Both improved access to information and additional research are needed.

*Parents also identified the need for better information about coping for themselves and for their children.* Transition services is an area where information appears to be especially sparse and sorely needed.

*Many effects of childhood emotional disability on family life were identified by parents.* The findings support current practice impressions that many families experience heavy caregiving burdens with insufficient relief. Family support programs that specifically address the needs of families who have children with serious mental or emotional disorders and that include respite care, parent support mechanisms and help for brothers and sisters should be developed and carefully evaluated.

*Parents reported that they received support from a variety of informal sources, especially relatives and friends.* Overwhelmingly, emotional support was seen as the most important aspect of help from these informal sources. The important contribution of informal support to the well-being of families should be emphasized in professional training programs, as well as through information and training opportunities for family members and their support systems.

*Involvement with other parents was identified by a large number of parents as the most important source of help in coping.* This finding confirms and supports current efforts to expand the availability of parent groups and other parent support systems. Additional study is also needed to understand the most effective forms of parent-to-parent support.

*Religion as a source of coping for family members was identified as important by a large number of parents across all income and educational levels.* This finding suggests a need for further research in this area as well as program development aimed at increasing the awareness and involvement of churches and other religious organizations in addressing the needs of families.

There is much interesting and useful information yet to be extracted, examined, and reported. Some studies are in progress and several others are planned. Staff are currently looking more closely at the experiences of minority families and comparing the responses of parents who are members of parent support groups with those who are not. In the coming months we will examine in depth the data about the characteristics of professionals and the effects of the child's disability on family life. The current report is available through the Research and Training Center's Resource Service.



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## NOTES & COMMENTS

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### **Materials On Children With Emotional Disabilities Available From The University Of Kansas School Of Social Welfare**

Faculty and staff from the School of Social Welfare at the University of Kansas are participating in the activities of the Portland Research and Training Center during the 1989-1994 period. Materials on children with emotional disabilities available from the School of Social Welfare are described below.

*Training Manual for Family Advocacy In Home Services.* This case management model seeks to identify and use family strengths to assist families to meet their needs and the needs of their children within the home and school. \$7.00.

*Resource Training Manual for Family Advocacy Case Management With Adolescents With Emotional Disabilities.* The goal of the model is to assist adolescents to remain in school and other community programs and develop independent living skills. \$10.00.

*What You Need to Know About Your Child With an Emotional Disability and the Individualized Educational Plan.* This booklet is a resource for parents and other advocates in working with schools to obtain an individualized educational plan for a child with an emotional disorder. \$3.00. (The first three resources were developed in collaboration with the Kansas Department of Social and Rehabilitation Services, Division of Mental Health and Retardation.)

*Together to Self-Sufficiency: Independent Living Lifebook: Employment; Health.* These two lifebooks (one on employment; the other on health) are for use by youth and an adult caregiver. Each contains exercises that enable youth to assess, document, and develop their independent living skills. \$10.00 per book.

*Assessing Child and Adolescent Service System Program (CASSP) Information Transfer Performance.* This monograph presents a model for evaluating information transfer projects and is applied to the CASSP program. \$10.00.

The following manuscripts are available at no charge: (1) *Beyond the Continuum of Care: Day Treatment for Youth with Emotional Disabilities* (draft); (2) *Effective Therapeutic Foster Care: The Foster Parents' Perspective* (draft); (3) "Services for Children with Emotional Disorders: Historical Perspectives and Contemporary Opportunities for Social Work," *Social Work*, in press; (4) "Protection and Advocacy for the Mentally Ill. New Hope for Emotionally Disturbed Children?" *Community Mental Health Journal*, 25(2), Summer 1989, 156-163; and (5) "Services for Children Returning to School After Brief Psychiatric Hospitalization," *Social Work in Educa-*

*tion*, 9(3), Spring 1987, 169-179.

Send requests to: John Poertner, Twente Hall, School of Social Welfare, University of Kansas, Lawrence, Kansas 66045.

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### **Service and Research Demonstration Grants Available**

Two new Requests for Applications (RFAs) present funding opportunities for service system improvement for children with serious emotional disorders and their families. The RFAs are issued through the Child and Family Support Branch of the National Institute of Mental Health. Two classes of demonstration grants may be funded: (1) service demonstrations at both the state and community levels (these include the traditional state level Child and Adolescent Service System Program (CASSP) grants); (2) research demonstrations in two priority areas. These are (a) presently ongoing service system development efforts and (b) comprehensive services for homeless adolescents who have, or are at risk of, severe emotional disorders. Eligibility for application is restricted to State Mental Health Authorities or a coordinating agency designated by the Governor. States may apply for more than one grant. Each grant must be applied for in coordination with local service agencies, a university and/or another research organization.

Grant applications are due on June 18, 1990. For more information contact: Ira S. Lourie, M.D., Chief, Child and Family Support Branch, Division of Education and Service System Liaison, National Institute of Mental Health, Parklawn Building, Room 7C-14, 5600 Fishers Lane, Rockville, Maryland, 20857; (301) 443-1333.

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### **NIDRR Seeks Peer Reviewers**

Both family members of children and adolescents with serious emotional disorders and professionals serving these families and youth are invited to participate in the peer reviews conducted by the National Institute on Disability and Rehabilitation Research (NIDRR). The purpose of these reviews is to make recommendations about proposals submitted to NIDRR. The peer review meetings are held in Washington, D.C. Family members or professionals interested in participating in the agency's peer review process should have familiarity, knowledge, and skills in one or more of the following areas: (1) parent training; (2) special education, mental health, or social welfare systems; (3) grant or project man-



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agement; and/or (4) systems, psychosocial/developmental research in the area of children's mental health. Send resumes to Naomi Karp, Program Specialist, U.S. Department of Education, National Institute on Disability and Rehabilitation Research, Room 3060 Switzer Building, 330 C Street, S.W., Washington, D.C. 20202-2702; (202) 732-1196.

### **Search To Identify Transition Programs**

The Research and Training Center for Children's Mental Health at the University of South Florida and the Boston University Research and Training Center for Psychiatric Rehabilitation are interested in identifying transition services for youth with serious emotional disabilities. The primary focus is on identifying programs that (1) serve youth from mid-adolescence to young adulthood and (2) prepare and support them for employment, education, and/or independent living. The Centers will survey all suggested programs and select eight to twelve to site visit. The project is designed to build upon a two year study conducted by the Portland Research and Training Center that identified 53 transition programs serving adolescents with emotional disabilities and resulted in the publication of a monograph entitled *Youth in Transition: A Description of Selected Transition Programs Serving Adolescents with Emotional Disabilities*. Please submit information on transition programs and organization names, addresses, telephone numbers, and contact persons to: Dr. Hewitt B. Clark, Research and Training Center for Children's Mental Health (C6-239), Florida Mental Health Institute, University of South Florida, Tampa, Florida 33612-3899.

### **Training Institutes On Cultural Competence**

The Child and Adolescent Service System Program (CASSP) Technical Assistance Center at Georgetown University will host *Toward a Culturally Competent System of Care: Effective Services for Children of Color Who Are Severely Emotionally Disturbed* at the Clarion Harvest House Hotel in Boulder, Colorado July 22-26, 1990. The training institutes are designed to provide service providers, family members, state level planners, and policy-makers with state-of-the-art information on the provision of culturally competent services to children and youth with emotional disabilities and their families from the four major minority groups in the United States (e.g., African-Americans, Latino- or Hispanic-Americans, Asian/Pacific Islander Americans, and Native American peoples). For further information call or write: Marva Benjamin, CASSP Technical Assistance Center, Georgetown University Child Development Center, 2233 Wisconsin Avenue, N.W., Washington, D.C. 20007; (202) 338-1831.

### **Arizona Children's Behavioral Health Council Issues Report**

The Arizona Children's Behavioral Health Council issued its first report and recommendations for improved services to children with emotional disorders and their families this past November. The Council, established by the Arizona legislature in 1988, is charged with overseeing the development of Arizona's behavioral health system and making annual recommendations to the legislature. The report recommends and outlines steps necessary to develop a comprehensive, family-focused and community-based system of care for children with emotional and behavioral disorders and their families. The recommendations cover a wide array of direct service, educational, and advocacy issues.

Recommendations include the establishment of a standardized case management system, collaborative interagency service efforts, less restrictive alternatives to residential treatment, intensive short term residential services for children with substance abuse problems, development of support services for families of children and adolescents with emotional disabilities, and a strengthening of the roles of parents in treatment planning and delivery. Further information on the report can be obtained from Miryam Choca, Arizona Department of Health Services, Division of Behavioral Health Services, Birch Hall, 411 North 24th Street, Phoenix, Arizona 85008.

### **Family Support Monograph Published**

Nine programs offering supports to families are profiled in a new publication of the Human Services Research Institute entitled *Family Support Programs for Families Who Have Children With Severe Emotional, Behavioral or Mental Disabilities: The State of the Art*. Six core components of family support are addressed: self-help, advocacy, parent education, respite care, family-centered case management, and cash assistance. Each program offers services to families in creative and innovative ways and promulgates the philosophy of family empowerment and parent-professional partnership. Funding sources, budgets, and family supports are described. The monograph may be obtained for \$6.25 (including shipping) from the following: Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, Massachusetts 02140; (617) 876-0426.

### **Child Mental Health Policy And The 101st Congress**

A non-partisan group of Congressional spouses is working to build broad-based support for children with serious emotional disorders. Members of this Child Mental Health Interest Group and the National Mental Health Association are

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currently presenting a conference series in Washington, D.C. entitled *Child Mental Health Policy and the 101st Congress*. On February 8, 1990, the initial workshop offered an overview of childhood mental disorders. The second workshop, held on March 28th, addressed childhood depression and anxiety as well as childhood schizophrenia and autism. The schedule of future workshops is: "Childhood Learning Disabilities," April 25th, Room 562 Dirksen Senate Office Building; "Childhood Conduct Disorders and Attention Deficit Disorders," May 17th, Gold Room 2168 Rayburn House Office Building; and "Treatment and Service Alternatives for Childhood Mental Disorders," June 7th, Room 562 Dirksen Senate Office Building. Each workshop is scheduled from 9:30 A.M. to 12:00 P.M. Members of the public are welcome to attend. Conference co-sponsors include the Federation of Families for Children's Mental Health, the Georgetown University Child Development Center, the National Alliance for the Mentally Ill, the Florida Research and Training Center for Children's Mental Health, and the Portland Research and Training Center on Family Support and Children's Mental Health. The conference is made possible by a grant from the John D. and Catherine T. MacArthur Foundation.

Tipper Gore (TN) and Ann Simpson (WY) serve as co-chairs of the Group. All members are interested in working on behalf of children's mental health issues in their home states: Lou Beville (AL); Catherine Stevens (AK); Susan DeConcini (AZ); Norma Lagomarsino, Doris Matsui, Gayle Wilson (CA); Claudia Weicker (CT); Nancy Hamilton (IN); Linda Slattery (KS); Lois Breaux (LA); Judy Hoyer (MD); Susan Blumenthal, Corrine Conte (MA); Vicki Levin (MI); Penny Durenberger (MN); Phyllis Burns (MT); Nancy Domenici (NM); Chris Downey, Cathie Mrazek (NY); Alice Lancaster (NC); Sandy Eckart, Shirley Metzenbaum (OH); Carmala Walgren (PA); Kati Machtley (RI); Barbara Johnson (SD); Sharon Archer, Susan Baker (TX); Phyllis Olin (VA); Sharon Rockefeller (WV); and Joan Obey (WI).

### **Proposed New Federal Grant Initiative For Children's Mental Health Services**

A coalition of national mental health and child advocacy groups is proposing a new federal initiative to provide grants to states, on a competitive basis, for the development of comprehensive community-based services for children with serious emotional, behavioral or mental disabilities. Federal funds, which could be used to meet 75% of the expense of local systems of care, would be distributed through the Alcohol, Drug Abuse and Mental Health Administration, (ADAMHA). States would fund the remaining 25% of the cost of services. A recent *Legislative Alert* from the National Mental Health Association

(NMHA) notes that "The inclusion of this program would more evenly balance the service programs funded by ADAMHA, which now allocates more than \$900 million for substance abuse and less than \$300 million for mental health programs."

Based upon the successful Child and Adolescent Service System Program (CASSP) model, a range of community-based services would be offered including: respite care, day treatment, case management, therapeutic foster family care, transition services, and family-based crisis and other emergency services. States receiving funding must demonstrate that the development of local systems of care will: (1) follow CASSP principles; (2) include parents in the planning process; and (3) involve all child-serving agencies (e.g., child welfare, education, juvenile justice) in the implementation of the program.

In addition to the NMHA, a number of other mental health groups have endorsed the proposal including: American Academy of Child and Adolescent Psychiatry, American Psychological Association, Federation of Families for Children's Mental Health, Mental Health Law Project, National Association of School Psychologists, National Association of Social Workers, National Association of State Mental Health Program Directors, State Mental Health Representatives for Children and Youth and National Council of Community Mental Health Centers.

For further information on the proposal contact: Chris Koyanagi, National Mental Health Association, 1021 Prince Street, Alexandria, Virginia 22314-2971; (703) 684-7722.

### **Research Conference On System Of Care For Children Held In Florida**

Speakers at a recent conference agreed that despite increasing research about systems of care for children's mental health, more research is needed. The conference, entitled "A System of Care for Children's Mental Health: Building a Research Base," was sponsored by the Research and Training Center for Children's Mental Health (RTCCMH) at the University of South Florida; this was the third annual research conference organized by the RTCCMH. More than 260 researchers, administrators, clinicians and advocates from 37 states and Canada attended the meeting on February 12-14, 1990 in Tampa, Florida. Presentations were made on a wide variety of topics, including evaluations of large systems of care, minority issues, systems of care and crisis intervention. Conference proceedings are being prepared and conference proceedings from previous years are now available. For further information on the conference or proceedings contact Alissa Algarin, Research and Training Center for Children's Mental Health, Florida Mental Health Institute, Tampa, Florida 33612-3899; (813) 974-4500.

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## Research and Training Center Resource Materials

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- ☐ *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.
- ☐ **NEW!** *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.
- ☐ **NEW!** *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.
- ☐ *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 delegations from thirteen western states. Includes: agenda, presentation transcriptions, biographical sketches, recommendations, worksheets, and evaluations. \$7.50 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 by parents whose children have emotional disabilities are explained. \$3.00 per copy.
- ☐ **NEW!** *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.
- ☐ *Making the System Work: An Advocacy Workshop for Parents.* A trainers' guide for a one-day workshop designed 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.
- ☐ *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.
- ☐ *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.

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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 second edition expands upon emotional disorders of children, including post-traumatic stress disorder and mood disorders such as childhood depression and bipolar disorder. \$7.00 per copy.
- ☐ **NEW!** *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. \$5.75 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.
- ☐ **NEW!** *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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