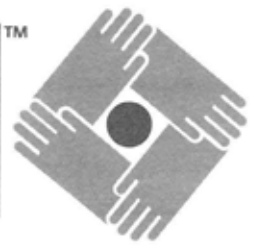




FOCAL POINT™



Families as Allies Conference

The Families as Allies Conference was held in Portland, Oregon, on April 28 and 29, 1986. The mission of the conference was to promote collaborative working relationships between professionals and parents of seriously emotionally handicapped children and adolescents. Designed as a working conference, parents and professionals from thirteen western states were invited to attend. Representatives from the following states participated: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington and Wyoming.

While the composition of each state delegation varied, the goal was to assemble state delegations composed of:

- (1) policy-making, administrative and service delivery professionals from the major public systems that serve emotionally handicapped children and youth, i.e., mental health, child welfare, juvenile justice, education and vocational rehabilitation;
- (2) private service providers; and
- (3) parents of emotionally handicapped children and adolescents.

Each delegation was encouraged to meet prior to the conference.

The keynote address was given by Susan DeConcini. Ms. DeConcini is a practicing social worker in the mental health field and is a child care advocate. The keynote speaker's theme of mutual respect helped set the tone for parent-professional collaboration and for much of the work that occurred during the rest of the conference. She noted, "It really is a partnership--a joining of hands together so that everybody wins." Parents of emotionally handicapped children are desperate for information about emotional problems and are eager to learn coping skills. Open communication between parents and professionals is essential. Subsequent

speakers, panelists, and workshop leaders provided conference participants with both thought-provoking commentary and with ideas they could adapt to their own circumstances.

Obstacles to parent-professional collaboration were explored during the first day of the conference. Theories of etiology of mental illness often unwittingly cast parents as villains and are a serious obstacle to parent-professional collaboration. These beliefs lead to professionals blaming parents, holding them responsible and viewing them as pathogenic agents. Similarly, parents often also believe they are to blame for their children's problems. This belief may lead to guilt, shame, fear and avoidance of mental health professionals, teachers, and others.

Professionals tend to view children's needs and problems from within the context and capacities of the agency in which they are employed and within a relatively short time frame.

Continued on page 3



Keynote speaker Susan DeConcini. (Photo by Tom Young.)

FROM THE EDITOR

This issue of *Focal Point* features the Families as Allies Project, which is designed to promote collaboration between families of children with emotional handicaps and the professionals who serve them. Project objectives include conducting relevant research, developing training curricula and other written materials, and designing and presenting workshops and other training events.

Included in this issue is a report about an April, 1986 conference held in Portland that involved equal numbers of parents and professionals from thirteen western states. This meeting was one of the first public explorations of our project concepts, and we were very gratified by the positive response of most participants.

As a part of our research program, we are currently conducting a survey in which we ask parents about their experiences seeking and obtaining services for their children. We are also involved in a search for innovative programs and faculty within professional schools that encourage professionals to work collaboratively with parents.

Curriculum development activities of the Families as Allies Project are also featured. Among these, we are happy to announce the availability of training materials developed by two parent organizations through an agreement with the Research and Training Center.

Because one purpose of *Focal Point* is to provide a forum for various points of view about important issues regarding children and their families, we are pleased to include an essay by Ira Lourie, M.D. and Judith Katz-Leavy, M. Ed., of the Child and Adolescent Service System Program (CASSP) Branch at the National Institute of Mental Health (NIMH). The essay constitutes a response to an article by Thomas Young, Ph.D., published in our last issue entitled, "Re-Thinking Emotional Disturbance." We hope that other readers will be stimulated to express their ideas regarding these and other important issues related to the mental health needs of children and their families.

RESEARCH AND TRAINING CENTER

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We invite our audience to submit letters and comments.

RESEARCH AND TRAINING CENTER

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Parents, on the other hand, have an ability to see the many needs of the child and the family, and thus the need for a wide range of services over a longer time span. Parents, however, may lack the knowledge and skills to put together a long term comprehensive plan unassisted.

Professionals and parents are further constrained by the requirement that professionals operate within agency policy and within the limitations imposed by funding sources. Agency policies and funding requirements are often impediments to the delivery of appropriate services to emotionally handicapped children.

The second day of the conference was devoted to developing strategies to overcome barriers to parent-professional collaboration. Panelists emphasized the importance of parent empowerment, the necessity for professionals to examine their attitudes toward parents and to view them as equals, and the value of parents' equipping themselves with the knowledge and skills needed to function as equal partners. One presenter urged that we re-examine the theories about the causes of emotional disturbance that lead us to blame parents.

Additionally, a multicultural project that trains parents to serve as trainers and that assists parents to assume leadership roles, as well as a project to develop parent support groups and services for military families were presented by panel members.

Following the presentations, members of state delegations met together to develop action plans and strategies for implementation upon return to their home states. Planned activities include efforts to better coordinate the activities of existing statewide advocacy groups, commitments to establish parent support groups in specific cities or regions, development of resource directories, establishment of parents-training-parents capabilities, development of parent handbooks, publishing newsletters, and engaging in legislative advocacy.

Nationally, four regional Families as Allies conferences have been scheduled. For more information, contact the following:

GREAT LAKES/APPALACHIAN REGIONAL CONFERENCE

Illinois, Indiana, Kentucky, Michigan, Minnesota, Ohio, Tennessee, West Virginia, Wisconsin
June 27 and 28, 1987

Bloomington, Indiana

Jim Killen (317) 232-7888 [IN]

Dagmar Plenk (608) 266-2712 [WI]

William Scott (502) 564-7610 [KY]

Donna Simonson (217) 785-2561 [IL]

MIDWEST REGIONAL CONFERENCE

Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, South Dakota, Texas

May 13 and 14, 1987

Overland Park, Kansas

Rock Richardson (405) 521-0044 [OK]

(Arkansas, Oklahoma, Texas)

Art Sands (913) 296-3774 [KS]

Kansas, Missouri, North Dakota)

Jose Soto (402) 471-2851 [NE]

(Iowa, Nebraska, South Dakota)

NORTHEAST REGIONAL CONFERENCE

Connecticut, Delaware, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, Virgin Islands

May 20 and 21, 1987

Albany, New York

Mary Armstrong (518) 474-8394 [NY]

Lenore Stern (717) 783-8335 [PA]

Joyce Wale (609) 987-2005 [NJ]

SOUTHEAST REGIONAL CONFERENCE

Alabama, District of Columbia, Florida, Georgia, Louisiana, Maryland, Mississippi, North Carolina, South Carolina, Virginia

June 12 and 13, 1987

Mobile, Alabama

Donna Glass (205) 271-9261 [AL]

Lucy Leslie (601) 359-1301 [MS]



Panelists Glenda Fine, Richard Donner and Cindy Boatman. Topic: Obstacles to Parent-Professional Collaboration. (Photo by Tom Young.)

Update of States Involved in the Families as Allies Conference

Alaska - Post-conference activities in Alaska have addressed two areas:

- (1) parent involvement and support at a residential treatment facility; and
- (2) governmental lobbying efforts.

A bi-weekly parent support group has been established at a residential treatment facility in Juneau. Parents of children served by this residential treatment facility will serve on the agency's board of directors on an ongoing basis. One member of the Alaska delegation has met with the state's CASSP project manager on several occasions, and has worked with legislators on an upcoming bill to establish an Alaskan children's trust fund, and also met with many candidates prior to the November election to discuss issues affecting children and youth.

Arizona - Members of the Arizona delegation have not met on a formal basis. The coordinator of the Arizona delegation did, however, meet with the state hospital's youth coordinator and discussed the goals of the Families as Allies Conference. The governor's representative on children, youth and families, as well as other gubernatorial staff members, will be included in future efforts to improve parent and professional collaboration.

California - California was unable to send a formal delegation to the Portland conference because of scheduling conflicts. The relevant professionals in the state were meeting at the same time as our conference to work on issues of interagency collaboration in delivering services to emotionally handicapped children and their families. This same group plans to meet again in the Spring of 1987, at which time the issues of parent-professional collaboration will be discussed. California has funded a demonstration project in Ventura County to develop a model of service delivery to seriously emotionally handicapped children and their families.

Colorado - The group representing Colorado at the conference has not met on a formal basis. However, the Department of Mental Health is

initiating the planning meetings for a forum to be held in the Spring of 1987. The planners are seeking to identify people throughout the state who share an interest in advocacy efforts and children's issues. These individuals will be invited to attend the forum. The objectives are to:

- (1) share information on advocacy efforts;
- (2) identify children's and families' needs;
- (3) identify obstacles to parent-professional collaboration;
- (4) plan for establishment of a broad-based constituency; and,
- (5) form task groups to work on establishing state and local advocacy groups.

Additionally, the Department of Mental Health is formulating plans to replicate the Families as Allies Conference for Colorado parents and professionals.

Hawaii - Hawaii is a CASSP state with a strong interagency network in place. The group attending the conference included an equal number of parents and professionals. This group continues to meet monthly and planned a December Hawaii Families as Allies Conference. The conference was modeled on the Portland effort, and encouraged participants to attend as parent-professional teams. In addition, the CASSP project has hired a Parent Coordinator, Ginny Wright.

Idaho - Idaho's CASSP staff has taken numerous steps to improve parent-professional collaboration within the state. These efforts include:

- (1) the identification of parents of emotionally handicapped children;
- (2) parent and professional participation in regional needs assessment surveys to identify the essential components of an Idaho treatment delivery system;
- (3) coalition building meetings held in each of Idaho's seven regions with parents, mental health professionals, teachers and service providers;

-
- (4) a statewide CASSP conference involving administrators, parents and professionals held in Sun Valley in October; and
 - (5) publication of the first two issues of a statewide newsletter. One page of each issue of the newsletter will be devoted to an editorial written by a parent or to the discussion of parent issues.

Montana - The Montana delegation to the Conference formed their own organization called Montana Families as Allies. Since Montana is a large state geographically, and each of the five parents were from different cities, the group has not been able to meet. However, the state coordinator is in communication with local coordinators to encourage local efforts, perhaps in conjunction with existing groups or organizations. The state coordinator (a parent) is the only consumer on a state task force charged with devising a legal definition of emotional disturbance for presentation to the state legislature. She has also written an article for the Montana Mental Health Association Newsletter.

Nevada - The members of the Nevada delegation disseminated a brief press release to key state and local professionals in which they described the Families as Allies Conference. The statement identified the lack of interagency coordination as the most pressing problem hampering the provision of services to the state's emotionally handicapped children. Delegation members have not formally met since the conference.

New Mexico - The New Mexico delegation has maintained contact with each other. They are working on two projects designed to help create a statewide network for parents. The first is the production of a videotape created by a parent group. The videotape will be used for outreach to parents living in rural areas of the state. The second project is the purchase of space in the New Mexico Alliance for the Mentally Ill newsletter dedicated to children's issues. Both projects are funded by the Mental Health Bureau.

Oregon - Three support groups for parents of children with emotional handicaps have started since the April conference. These groups are

located in Portland, Lake Oswego, and Monmouth. The Monmouth group has named itself Families and Children Together (F.A.C.T.) and is seeking support from the Mental Health Association of Oregon. The Oregon Mental Health Division (OMHD) has recently named Faye Lindemann-Tayler as the Coordinator of Programs for Children and Adolescents. This appointment should increase the emphasis given to children's mental health issues in the state. This is the first time in many years that an OMHD position has been devoted exclusively to children's issues.

Utah - One member of the Utah delegation met with the state's Interagency Commission and thereafter arranged for the director of the Utah Parent Center to meet with the Commission. As a result of these meetings, agencies will now refer parents to the center. The center will serve as the focal information center and will direct parents to the appropriate resource.

Washington - A follow-up meeting to the Portland conference was held in the Fall of 1986. The action plan developed by the state delegation was updated and revised. The plan includes a statewide parent-professional conference in the second or third year of Washington's CASSP activities. The Washington CASSP staff is conducting ongoing discussions with established advocacy groups in the state to assist with their advocacy efforts and to develop strategies for working together. Three parents serve on the state's CASSP Coordinating Council. In addition to the experience and skill he brings to the position, the newly appointed assistant CASSP Project Director is the parent of a psychiatrically disabled child.

Wyoming - The Wyoming delegation has not met as a group. One member of the delegation, who has since moved out of the state, made a public presentation in which she discussed the conference.

A Perspective on Rehabilitative Services Within the Child and Adolescent Service System Program

by

Ira S. Laurie, M.D. & Judith Katz-Leavy, M.Ed.

In the lead article of the premier issue of *Focal Point*, Dr. Thomas Young challenges some of the basic concepts of the Child and Adolescent Service System Program (CASSP). Dr. Young feels that the terminology of "severely emotionally disturbed" children and adolescents will focus too strongly on the mental health aspects of the child's service needs and will lead to the development of a narrow system of care and a focus on behavior as perceived by parents and teachers. He does this in face of the reality that "severely emotionally disturbed" (SED) is an educational term that is not found in the mental health literature. This term has been adopted by CASSP as an alternative to the concept used in mental health to describe this population of chronically mentally ill children and adolescents. The national work group brought together to develop CASSP chose this definition in an attempt to demonstrate the need for a broad based continuum of care similar to the one that Dr. Young suggests is needed.

Dr. Young implies that only by adopting a rehabilitative model will CASSP be able to create the appropriate continuum of care. In the service of this conceptualization he states that the Portland R&T Center has changed its own terminology from "emotionally disturbed" to "emotionally handicapped," as he states, "because we believe it helps us shift our focus from the child-as-problem to the context-as-solution." On one hand, it seems that this is just a semantic quarrel which will not prove to be particularly useful to the field in the long run. On the other hand, Dr. Young urges a focus on "rehabilitation" which we feel may well prove detrimental to the promotion of developmentally focused corrective services.

The use of the term "severely emotionally disturbed children and adolescents" by CASSP comes from the same concerns addressed by Dr. Young. CASSP originally selected the term "seriously emotionally disturbed" (SED) to provide as much consistency as possible with the categories of eligibility used in the Education of

the Handicapped Act, P.L. 94-142. This initial decision was indicative of CASSP's commitment to taking a total system-wide approach to service delivery and to our acknowledging that mental health services take many different forms and are provided in a variety of community-based settings by a broad range of agencies and providers.

In the 1983 Concept Paper on the Child Adolescent Service Systems Program prepared by Beth Stroul, in the CASSP grant guidelines published annually, and again in the July 1986 monograph, *A System of Care for Severely Emotionally Disturbed Children and Youth*, by Stroul and Friedman, CASSP presented a set of five basic parameters for defining the target population. The first parameter addressed age limitations, and was immediately followed by the following two parameters:

- "The target population should include children whose emotional problems are disabling based upon social functioning criteria. Level of functioning is a critical variable for children and adolescents, determining the nature and level of care that is appropriate. Degree of disability or level of functioning in family, school and community contexts is often more meaningful than mental health diagnosis in planning and delivering services."
- "Children and adolescents included in the target population should have a multiagency need. Severely emotionally disturbed youngsters require a range of services which necessitates the involvement of multiple agencies including mental health, health, education, child welfare, juvenile justice, and others."

Dr. Young proposes a system-wide approach to service delivery which emanates exclusively from the rehabilitation model. We, at CASSP, feel very strongly that it should not. We contend that there are specific problems in apply-

ing the rehabilitation model to severely emotionally disturbed children and adolescents which should not go unaddressed. Rehabilitation is a concept that has traditionally applied to adults and physically handicapped children. In discussing the World Health Organization's perspective on disabilities, Dr. Young states that the Portland R&T Center is "concentrating on research and training activities designed to help parents, teachers, employers and the helping professions find ways of modifying living, learning and working environments to accommodate, adjust to and compensate for children with emotional disabilities." Further, he refers to "modifying environments so that children are no longer handicapped by their emotional disabilities in those contexts." Dr. Young appears to view the disabilities of these youngsters as static, disregarding the concepts of growth and development as well as the possibility of corrective change.

While rehabilitation, as used in the context of the Portland R&T Center, should be a vital component of any service system, a total focus in that area will necessarily deny appropriate options to those children and adolescents who have the capacity to decrease their disabilities through growth and psychological therapy. Our view of intervention with severely emotionally disturbed/handicapped children and adolescents is based on the concept of habilitation or posi-

tive change. Orthopsychiatry describes the process of corrective intervention. This has been the traditional rallying point for child mental health professionals, special educators, juvenile justice specialists and child welfare workers for years, and there is no indication that we should give up on it now.

While rehabilitation, as discussed by Dr. Young, serves an important role in the services system defined by CASSP, the practice of current rehabilitation agencies has not been child and adolescent oriented to this time. For rehabilitation to take its proper role, there must be adjustments in how these principles are applied to children. This is especially true in regard to how the needs of adolescents are met as they progress from the child to the adult service systems.

Whether we refer to disabled children as "disturbed" or "handicapped" will not deter our joint efforts to provide the most appropriate intervention along a continuum of care that includes corrective therapies as well as rehabilitative solutions.

Dr. Lourie is the Assistant Chief of the Community Service Systems Branch of the National Institute of Mental Health. Ms. Katz-Leavy is the Program Director of the Child and Adolescent Service System Program of the National Institute of Mental Health.

Parent Organization Survey

From July, 1985, to February, 1986, a national survey was conducted of organizations for parents of children with serious emotional handicaps. This telephone survey was carried out by regional centers of the Technical Assistance for Parents Program (TAPP) and by staff of the Research and Training Center. We gathered information about the history of the parent groups, the activities and services provided by them, their views of the current service delivery system, and their plans for the future. An immediate practical use of the information gathered was to publish a national directory of parent organizations which is available through our Resource Center.

Some highlights of the findings include:

- 207 (100%) **parent organizations** in 47 states were included in the survey. No parent groups were found in Iowa, Missouri and Wyoming.
- 60 (29%) of the organizations have an **exclusive focus on emotional disturbance** and do not serve or include other disabilities. Many of the remaining organizations developed in response to P.L. 94-142 and serve families representing a wide range of childhood disabilities.
- 205 (99%) **provide education/information services** to parents. Of these, more than three-quarters provide specific information about emotional

- disturbance and the rights of children and families under P.L. 94-142.
- 184 (89%) **provide parent training** in such areas as coping with the needs of emotionally handicapped children and developing effective case and systems advocacy skills.
- 177 (86%) **engage in advocacy activities.**
- 131 (63%) **sponsor support groups** that are available to parents of emotionally handicapped children and adolescents. Only 52 organizations (25%) provided support groups exclusively for parents of this population.
- 164 (79%) **provide some type of direct assistance to parents.** These services include assistance in dealing with agencies or the public schools, child care, transportation, respite care, assistance with food, money or shelter, and homemaker services.
- 196 (95%) **provide training or other services for professionals.** Most frequently mentioned were information designed to help professionals understand the needs of families and services aimed at improving the working relationship between family members and professionals.

Asked about future plans, respondents identified the following areas as those in which they would like to expand (as one of three choices):

Education/information for parents	109
Skills training	102
Advocacy	84
Support groups	70
Services to improve parent-professional relationships	63
Direct assistance	61
Other services to professionals	29
Counseling for parents	25

Respondents were also asked about a number of service delivery system issues. Three issues identified by a majority of respondents as extremely important were:

There are not enough services for all children who need them;

Low income or lack of insurance prevents families from obtaining services; and

Services are not available to children and families regardless of location, i.e., geographical barriers and maldistribution of services create an uneven system of care for this population.

A full report of the findings of the Parent Organization Survey is available through the Resource Center.

Parent Produced Training Materials

The Families as Allies Project has funded two parent organizations to produce training materials designed to promote parent-professional collaboration. Using videotape and a workbook format, each product takes an informative, educational approach.

The PACER (Parent Advocacy Coalition for Educational Rights) Center in Minneapolis, Minnesota has produced a professional quality videotape entitled *Parent's Voices: A Few Speak for Many*. Intended for viewing by professionals, the tape features a narrator and three parents (all of whom have children with diagnosed emotional handicaps) discussing the experiences they have had seeking help for their children. The parents discuss their feelings of frustration

in their efforts to communicate with helping professionals and their belief that they are often left out of the treatment process. They describe how poor coordination between agencies, as well as the differing perspectives of schools and various treatment workers, added to the problems they were already experiencing. Although the program is designed with a professional audience in mind, it should also be useful for groups composed of parents or other interested persons.

PLUK (Parents, Let's Unite for Kids), affiliated with the Montana Center for Handicapped Children, has drafted *Parent Information Workbook on Emotional Handicaps*. Designed as a self-teaching workbook for parents, it covers a

range of topics and seeks to increase parents' awareness and decision-making capabilities on important issues. One section, "Being the Parent of an Emotionally Disturbed Child," discusses thoughts and feelings parents often must face about themselves, their children, and the people around them. Many of the comments come from parents who have children with emotional handicaps. Also included are information on various diagnoses, types of professionals and treatments, and legal aspects of the treatment and special education systems.

PLUK has also produced two complete workshop formats in the areas of parent-professional collaboration and systems advocacy. The first workshop, *Working Together: The Parent Professional/Partnership*, includes activities designed to increase the understanding professionals and parent's have for each other's feelings, needs and limitations, an examination of roles,

and strategies to promote cooperation. *Making the System Work: An Advocacy Workshop for Parents*, addresses topics such as the importance of advocacy, power and problem-solving techniques and strategies for making effective demands. Each set of materials includes a guide for trainers, copies of exercises, handouts and workshop evaluation forms. The materials are designed to provide a complete set of information and materials needed for a day long workshop in each area. Topical modules from each workshop can also be adapted for shorter training sessions, when needed.

These four new products should help enhance understanding and cooperation between parents of seriously emotionally handicapped children and the professionals working to help them. Information about the workshop materials can be obtained from the Resource Service.

NOTES & COMMENTS

SEARCH FOR INNOVATIVE PROGRAMS. CAN YOU HELP?

We are in the process of identifying innovative programs and materials designed to help professionals learn to work collaboratively with families of emotionally handicapped children. Many professional training programs focus on families as the target for change (placing family members in the role of patient) or stress the provision of services to family members (placing families in the client role). Our focus in this search is on programs that feature the role of parents as partners, or allies in the process of assessment, planning, implementation and evaluation of services. We want to identify programs and approaches that can be shared with faculty members in professional schools, and with professional organizations, parent groups, and other interested individuals and organizations.

Some interesting programs we have unearthed so far include a child psychiatry training program that uses parents as guest lecturers; several parent-professional workshops that use role play and role reversal to increase the empathy of parents and professionals for each others' perspective; and a number of written materials that re-examine or re-interpret traditional ways of thinking about families.

While we are most interested in programs and materials pertaining specifically to parents of children with emotional problems, we know considerable development has occurred in relation to groups such as adults with long term psychiatric disabilities, or children with conditions such as mental retardation or developmental disabilities, chronic health problems, autism, or learning disabilities. We welcome information from any quarter that will help us promote professional training that includes a broad definition of "help" for families, and encourages future professionals to work with family members in collaborative ways.

If you know of programs, materials, or people we should know about, please let us know. Thanks for your help!

NIHR NAME CHANGE

As of October 21, 1986, the National Institute for Handicapped Research (NIHR) changed its name to the National Institute on Disability and Rehabilitation Research (NIDRR). NIDRR and the National Institute of Mental Health (NIMH) are the two funding sources for the Portland Research and Training Center.

PARENT-PROFESSIONAL TRAINING PROGRAM LAUNCHED

A program to prepare parent-professional teams to provide training to help other parents and professionals learn to work effectively together will begin Spring, 1987. Through a contract with the Georgetown CASSP Technical Assistance Center, the Families as Allies Project will prepare curriculum materials and provide training to participants from throughout the country.

The trainees will be parents and professionals identified through the regional Families as Allies Conferences scheduled for May and June, 1987. During an initial week of intensive training in Portland, participants will increase their training skills as well as learn to present specific content related to parent-professional relationships, parent support groups, and advocacy strategies.

When they return to their own states and communities, the parent-professional training teams will be available to conduct workshops, provide consultation, and to teach others interested in becoming trainers. They will also assist in following the progress of the state delegations as they work to implement the state action plans developed during the Families as Allies Conferences.

HAWAII FAMILIES AS ALLIES CONFERENCE

On December 6, 1986 the Hawaii Families as Allies Conference was held in Honolulu. Approximately 130 parents and professionals worked productively together, and accomplished a great deal in the short time available. The conference was instrumental in increasing the awareness of public officials and the public-at-large. Portions of the general session were televised by the local CBS affiliate later that evening with an estimated viewing audience of over 42,000. An assistant to Hawaii's new governor, John Waihee, attended most of the conference and participated in a small group session that was very active in identifying issues and needs. Conference participants drafted a letter to the governor requesting a meeting with a delegation of parents and professionals.

Pursuant to their request, the Governor's Administrative Director met with conference representatives in January. The delegation was composed of representatives from the CASSP of-

fice, the Mental Health Association, the state Children's Mental Health Services Branch and two parents. The conference representatives urged the recognition of children's mental health as a state priority, discussed the need for a continuum of care and offered themselves and their agencies as resources to the Governor's office.

The conference was sponsored by Hawaii CASSP, the Mental Health Association in Hawaii, the Office of United Self Help and the Children's Mental Health Services Branch of the Mental Health Division of the Department of Health. Conference planners and participants met with great success. The conference served to stimulate increased activity on behalf of children and families in Hawaii, and shows every sign of being politically effective as well.

NAMI CONFERENCE TO FEATURE PARENT-PROFESSIONAL COLLABORATION

Parents and Professionals: Partners for a Change is the title of a meeting scheduled for September 15-17, 1987 in conjunction with the 1987 convention of the National Alliance for the Mentally Ill (NAMI). At present, there is hope that parent scholarship funding may become available through state CASSP offices. The meeting, which will focus on families of children and adolescents, will be held at the Washington Hilton in Washington, D.C. For more information, call NAMI at (703) 524-7600, or write to them at 1901 North Fort Meyer Drive, Suite 500, Arlington, VA 22209.

PARENT SURVEY

The Families as Allies Project plans to survey parents of children with serious emotional handicaps. The purpose of the survey is to identify parental concerns about services needed and received, about interactions with service providers, and about the helpfulness of various sources of formal and informal support. The results of the survey will be used to develop information and training materials to promote parent-professional collaboration. Although the questionnaire will be completed by parents, the cooperation of state and local organizations will be very important to reaching a cross-section of parents. When feasible, the use of a group setting for administration of the survey instrument

Continued on page 12

Research and Training Center RESOURCE MATERIALS

- ☐ *Annotated Bibliography. Parents of Emotionally Handicapped Children: Needs, Resources, and Relationships with Professionals **
Covers relationships between professionals and parents, parent self-help, support and advocacy groups, parent participation, parents' problems and guidelines.
- ☐ *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.
- ☐ *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. \$7.00 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.
- ☐ *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.
- ☐ *National Directory of Organizations Serving Parents of Seriously Emotionally Handicapped Children and Youth*
The U.S. organizations included provide one or more of the following services: education and information; parent training; case and systems level advocacy; support groups; direct assistance such as respite care, transportation and child care. \$5.00 per copy.
- ☐ *Parent Information Workbook on Emotional Handicaps*
This self-teaching workbook for parents addresses topics such as parents' feelings about themselves and their children, labels and diagnoses, types of professionals and treatments, and legal issues. Single copies free to parents of children with emotional handicaps while supplies last. All others, \$3.00 per copy.
- ☐ *Parents' Voices: A Few Speak for Many* (videotape)
Three parents of children with emotional handicaps discuss their experiences related to seeking help for their children (45 minutes). Brochure describes videotape and provides purchase and rental information.

* One copy free per address while supplies last.

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SURVEY continued from page 10

will facilitate completion of the questionnaire as well as provide help to parents in interpreting the questions. In addition to using the survey results for training curriculum development, the results may augment needs assessment information related to services for seriously emotionally handicapped children in individual states. Parents willing to participate in this survey should contact us directly by writing the Families as Allies Project. Your help will be appreciated.

OFFICE BURGLARY

Our offices were burglarized over the holidays. Five computers were stolen. One computer contained the *Focal Point* mailing list on its hard disk. Fortunately, the bulk of the list was backed up; however, some later changes to the list were lost. We have reconstructed the list to the best of our ability, but some information (such as changes in address) may have been lost. Please bear with us and send any address or personnel changes to us again. We apologize for the inconvenience.

FOCUS: THERAPEUTIC CASE ADVOCACY

The Therapeutic Case Advocacy Project is developing a model to deliver services to seriously emotionally handicapped youth and their families. The model coordinates the efforts of youth serving systems, organizations and agencies as well as the informal supports in the client's environment. Client centered systems of care are established through case advocacy, interpersonal interventions and care management. Collaboration at the case, organizational and inter-agency levels is an integral aspect of the concept.

The next issue of *Focal Point* will feature the Therapeutic Case Advocacy Project. We are interested in hearing about similar models of interagency collaboration at the local level and would like to highlight them in our next issue. If you know of programs or models with similar approaches, please notify: James L. Mason, Therapeutic Case Advocacy Project Manager.

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