

**STATEWIDE PARENT ORGANIZATION  
DEMONSTRATION PROJECT**

**FINAL REPORT**

**1989-1990**

**Research and Training Center on Family Support  
and Children's Mental Health  
Portland State University**

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## INTRODUCTION

The Statewide Parent Organization Demonstration Projects exist as a result of the Families as Allies Conferences which were held around the country in the mid 80's. Parents were struggling to organize and form networks of support. As a result the National Institute on Disability and Rehabilitation Research and the National Institute of Mental Health jointly allocated monies to be awarded to states for the development of statewide parent organizations. The Research and Training Center on Family Support and Children's Mental Health served as the administrator for funding and provided technical assistance and evaluation services to the demonstration projects. In the first year of funding, grants were awarded to five states to develop Statewide Parent Organizations. In the second year, three states received grants to develop Statewide Parent Organizations.

## PURPOSE AND OBJECTIVES

The Statewide Parent Organization Demonstration Project has two major goals: 1) to stimulate and support the development of model statewide parent organizations that have the capacity to provide technical assistance, information, support, and networks to parents and parent organizations within states; and 2) to evaluate the conceptualization, implementation, and outcome of these models to inform decision-makers about the most effective approaches in promoting such activity within states.

Specific objectives were identified that each of the funded parent organizations were expected to meet. These objectives provided a framework for project evaluation. The objectives were stated as follows:

By the end of the project year, each Statewide Parent Organization will develop the following capacities:

1. A mechanism for inexpensive, accessible two-way communication with parents on a statewide basis;
2. A resource service for disseminating print and visual media accessible on a low cost basis to parents, professionals and parent groups statewide. If appropriate, an existing resource service may be expanded to include materials specifically relevant to parents of children with emotional disabilities; and
3. Support services, resources, information and visibility to develop and maintain ties with diverse groups and individuals throughout the state.

These capacities represent the essential framework within which the Statewide Parent Organizations provide the following services:

1. Referring parents to existing parent groups or to individual parents in their geographic area;
2. Directing parents to existing agencies able to answer questions and make referrals within the service delivery system;

3. Strengthening the network of parents and parent organizations by making a sustained effort to increase formal and informal contacts among individuals and groups;
4. Providing technical assistance and support to newly forming or ongoing parent support groups, including the latest information regarding services for emotional disturbances in children and adolescents and the range of community-based services to meet their needs;
5. Developing or enhancing a statewide parent organizational structure to provide information regarding pending legislation, state planning processes, and opportunities for public comment and testimony at relevant legislative and administrative hearings on a timely basis; and
6. Providing special outreach to underserved groups of parents, such as low income parents, minority parents, etc.

It was recognized that the amount of money in this contract was not sufficient to build new parent networks where nothing existed. Successful applicants were those that had the capacities identified above at least partially in place. The limited resources provided through the grant needed to be supplemented and applicants were encouraged to pursue other sources of support (both monetary and in-kind). Applicants needed to describe what was currently in place and how they intended to achieve adequate support for developing capacities and providing services.

#### **ORGANIZED PROJECT ACTIVITIES**

Between October 1989 and September 1990, the Statewide Parent Organization Demonstration Project funded three parent organizations to develop statewide parent networks and organizational structures. Eligible applicants were existing parent organizations that could demonstrate the capacity to fulfill project objectives. Each project addressed a common set of expectations, but had great flexibility in developing creative approaches to achieving them. Forty-seven proposals were received from 38 states and the District of Columbia in response to the 1988-89 request for proposal. Proposals were reviewed by a panel of national experts, a local panel of parents and professionals, and staff. Five states were chosen to receive a grant for the 1988-89 year. For the 1989-90 year the three states with the next highest rating from the 88-89 list were chosen to receive \$20,000 each: Kentucky, Indiana, and New Jersey. The parent coordinators from Indiana and New Jersey came to the Research and Training Center in Portland for two days of orientation and technical assistance in December 1989. At the last minute, Kentucky's parent coordinator was unable to attend the training.

During the following months telephone contact was maintained between the Research and Training Center staff and the parent coordinators. During Summer 1990, the project evaluator from the Research and Training Center made a site visit to each of the three statewide organizations. The purpose of these visits was to observe the functioning of the statewide parent organization and collect data by interviewing the persons most involved in the organization's development.

## DESCRIPTION OF STATE ACCOMPLISHMENTS

This section of the report examines the development of a statewide parent organization within each of the three states selected as a demonstration site. The situation varies according to the unique political and social conditions of the state. Several distinct approaches to the organization of parents have resulted. These unique models of organizational development will be explored along with the development and utilization of some of the services required in the contract.

### INDIANA FAMILY SUPPORT NETWORK

#### Background

Indiana Parent Task Force was formed as a result of a 1987 Families as Allies Conference sponsored by Indiana's CASSP project. Several parents as well as staff of the state and local Mental Health Associations attended the conference. Following the conference the CASSP project began to work with the Mental Health Association to establish at least five parent support groups which would be geographically distributed throughout the state. CASSP provided financial support to start up the program and the Mental Health Association provided the staff to facilitate the support groups. The Mental Health Association and CASSP worked with local Mental Health Association chapters to develop orientation and training materials to assist in the implementation of these parent support groups.

The Indiana Parent Task Force was organized for the purpose of applying for one of the first NIMH grants being offered through the Research and Training Center at Portland State University. While Indiana was not one of the first states to receive the grant, the Indiana Parent Task Force was one of three proposals funded the second year. The Task Force director was hired in December 1989. At a Task Force organizational meeting where representatives from the eight known support groups were in attendance, it was decided to change the name of the organization to Indiana Family Support Network (IFSN). The support group representatives decided this change would be more inclusive of extended family members who care for children with severe emotional disorders.

The Mental Health Association of Indiana was the fiscal agent for this project. Their goal of working towards the improved care and treatment of children with emotional disabilities coincided with IFSN's mission of promoting a statewide organization of parents who would provide technical assistance, information, support and networking to parents and parent support groups. The Mental Health Association of Indiana provided IFSN with office space, part-time staff support, phone use, and postage for mailings.

In addition to the Mental Health Association of Indiana, CASSP has been instrumental in promoting IFSN's activities. They have provided scholarship money for parents to attend statewide conferences as well as sponsoring advocacy training for 45 parents. IFSN has received a lot of recognition from professionals in the state due to the exposure CASSP has helped bring to the organization.

## **Support Group Activity**

A major focus of IFSN was to establish support groups that would serve the needs of Indiana's 92 counties. The five support groups, which originally were run by the Mental Health Association with MHA staff acting as group facilitators, were eventually encouraged to be parent-led. Parents decided early on that mixed disability support groups did not work. In Indiana parents wanted the groups to be specific to the needs of families who have children with emotional disabilities. By the end of the grant period eleven parent groups were meeting on a regular basis (see Table 1). Some of the barriers to getting new groups going in Indiana included the stigma of having a child with an emotional disability and the isolation introduced by the school system. This isolation was felt by parents who did not have access to other parents either because of confidentiality issues or because there were no special classes or services available for children with emotional disabilities where parents were likely to meet each other.

## **Building the Statewide Organization**

The Indiana Family Support Network determined that in order to develop their statewide organization they needed to involve parents in the Network's activities. One way of doing this was involving parents on statewide task forces, advisory boards, and joint projects with other agencies. The Indiana Family Support Network provided scholarships to parents to assist them financially to attend meetings and conferences which were related to the organization (see Table 2, Section III-C). Also, families were encouraged to submit their long distance phone costs to IFSN for reimbursement, however most families did not take advantage of this opportunity.

In the early development of IFSN information about the statewide organization was disseminated through the Mental Health Association's newsletter. During the final year of the grant several parents assumed total responsibility for putting together IFSN's own newsletter, from layout to copying, with a mailing list of 495 entries (see Tables 1 and 2, Section III-A).

The Indiana Family Support Network has established relationships with other statewide organizations. Agencies and organizations such as Indiana Advocacy Services, the Task Force on Education for the Handicapped, and the Family Service Association have presented educational topics at IFSN's support groups meetings. Also at the local level IFSN has established networking relationships with the local Mental Health Centers, Special Education Agencies, Welfare Departments, Probation Offices, Special Education Parent Advisory Councils, Psychiatric Hospitals, and with parent groups of children with different disabilities.

A class action lawsuit on behalf of families from two of the three regions of the state who were demanding services for their children while not directly involving IFSN, helped to promote the awareness of IFSN and the services they provided to families. The lawsuit kept Indiana families who have a child with an emotional disability in the limelight via radio, television news, talk shows, and newspaper coverage.

The IFSN Advisory Board, consisting of 15 members, has been meeting monthly. In the future they will move to quarterly meetings with subcommittees meeting in between regular advisory board meetings.

IFSN began with a limited supply of materials for their Resource Center. Due to the fact that they shared the office of the Mental Health Association they were able to also share printed materials and resources with them. The parent coordinator put together resource packets for each support group leader which the leaders would then share with members of their group. There was not a big demand from parents for books. Most parents preferred purchasing their own copy and requested copies of book lists instead (see Table 2, Section II).

### **Outreach to Underserved Families**

There were a number of efforts to reach underserved families through IFSN. Three of the eleven parent support groups included families from diverse cultures and were located in major metropolitan areas of Indiana. One very successful support group was developed through a local school district in Gary, in the northernmost part of the state. This group consisted of predominantly African-American families. The local school district supported and funded the activities of the group which was led by three parents. The group met once a month and at times included up to 100 parents.

### **Future**

Since the conclusion of the contract the IFSN board continued to meet every three months. Through a contract with the Mental Health Association IFSN did receive \$10,000 from CASSP. This allowed several parents to attend the 1991 Federation of Families Conference in Washington, D.C. There are plans to use the remainder of the \$10,000 for an IFSN newsletter, parent leadership conference, and to support 12 support groups. The IFSN board plans on meeting monthly for a period of time to refocus their efforts towards the implementation of these plans.

## **KENTUCKY FAMILIES AS ALLIES**

### **Background**

Kentucky Families as Allies (KFAA) began as a parent planning group providing technical assistance to existing parent support groups. After meeting for one year, the parent planning group submitted the grant proposal to create a statewide family project in Kentucky. The Kentucky Coalition for People with Handicaps (KCPH), a statewide coalition of parent, consumer and advocacy groups, served as the fiscal agent for Kentucky Families as Allies.

### **Building the Statewide Organization**

KCPH provided Kentucky Families as Allies with office space and supplies, telephone access, and technical support. Other in-kind supports were provided by Kentucky CASSP, including: access to a Watts line, newsletter expenses, photocopying, and resource materials. A parent coordinator was hired part-time (.8 FTE) to guide the development of the statewide project. Her primary goals for the project were: 1) to evaluate the status of existing support groups and provide technical assistance where needed, 2) to organize family members and service providers of children with serious

emotional disorders for legislative events, and 3) to provide information and referral services, as time allowed. Kentucky Families as Allies and the Kentucky Coalition for People with Handicaps co-sponsored a legislative breakfast, which 200 people attended, to discuss issues related to children with serious emotional disorders with state legislators (see Table 3, Section VIII-C). The parent coordinator's participation on a respite task force for Kentucky ensured that the interests of parents and family members of children with serious emotional disorders were represented for inclusion in this vital service. Several conferences were held throughout the year. In August of 1989, 48 parents and 14 professionals attended a conference on collaboration. Conferences that took place later in the year were, "Understanding the Individual Education Plan (IEP)" held in response to the many requests by parents of children with serious emotional disorders for information related to this topic, and "Understanding Medical Income Waivers". Parent scholarships were provided by Kentucky state CASSP for low-income family members for the IEP and Medical Income Waiver trainings.

A statewide advisory council was developed and met regularly, including 18 parents and 3-4 professionals from regions throughout the state. Various minority community members were asked to serve on the advisory committee, which eventually included an African-American council member. Parent stipends and travel reimbursements were offered for each advisory council meeting to assist low-income and rural parents in participating. Outreach for potential members of the advisory council was undertaken through the school systems and children's mental health service systems throughout the state. The functions of the advisory council included assisting new parent support groups to grow, organizing and conducting workshops and trainings for parents, as well as fund raising.

Access by telephone has been very important in Kentucky, where rural and mountainous areas are the norm. KFAA shared an (800) number with the agency DIRECTIONS, a statewide information and referral assistance for people in Kentucky with special needs. The parent coordinator of Kentucky Families as Allies assisted DIRECTIONS in developing a comprehensive, statewide database for serious emotional/behavioral disorders. A "client-tracking" system utilized by DIRECTIONS was used for recording incoming calls according to type of disability, region and unmet needs. The KFAA parent coordinator developed an identical system for tracking calls coming to her house or to the KFAA office. A TDD was available for the hearing impaired through the (800) number. An average of 26 calls from parents were received each month by the Kentucky Families as Allies office during the demonstration year.

The (800) number, as well as the KFAA office number, were distributed through a variety of mechanisms. A letter with the numbers was sent to all of the regional mental health centers, the 13 parent resource centers, all of the chapters of the Kentucky Alliance for the Mentally Ill, existing parent support groups, and numerous advocacy and social service agencies throughout the state. The numbers were printed in the KFAA and the KCPH newsletters, and distributed to parents already in the service system across the state. In addition to these mechanisms, the parent coordinator: was interviewed by *Ironton Press*, a regional news source; was a member of a panel on a regional radio show; and was a guest on a one-hour statewide television program on mental illness. The telephone numbers were given out during each of these media events. The parent coordinator's business cards were also distributed across the state with the KFAA and the (800) telephone numbers.

The Kentucky Families as Allies project did not develop a centralized resource library. Due to the rural and mountainous geographic nature of the state it was felt that a centralized office would not be utilized as highly as a more regionalized resource service. The resource libraries of the 13 regional

sites of the Kentucky Office of Education for Exceptional Children were offered as resources, as well as CASSP resource materials and the Kentucky Coalition for People with Handicaps office resource materials. The KFAA parent coordinator spent time researching print and video materials pertinent to serious emotional disorders to be given out to each of the existing support groups as she visited them, as well as the 13 regional resource centers. Materials were collected relating to existing parent support groups, services at the comprehensive care centers, respite services, the IEP process, legislation, advocacy and parent empowerment. A Kentucky Families as Allies newsletter, with a readership of 1,700 statewide, was edited by the parent coordinator and provided communication to the various regions in the state. The cost of distributing this newsletter was supported by Kentucky CASSP. The KCPH brochure included a description of the statewide project as well as the office and (800) telephone numbers. Flyers describing the project were distributed by teachers and through the behavioral disorders units in the schools.

At the time of the project, only 2% of the population in Kentucky under age 18 had been identified as having serious emotional problems, compared with an average of 5% nationally. In most rural areas of Kentucky this percentage was zero. Furthermore, Kentucky has the highest illiteracy rate of any state in the nation, and includes many families living in extreme poverty in Appalachia and other rural areas. Because of under-identification, diagnostic and support services were important focal points for the statewide project. Education and support for families in the form of groups, especially in rural areas, was one mean to this end.

### **Outreach to Underserved Families**

In the state of Kentucky it is important to consider cultural minorities, as well as racial minorities. Appalachian people are a cultural minority in the state due to low economic status and rural isolation. The state's public education system has been found to be unconstitutional because of the poor school districts in these regions. The residents have traditionally been grossly underserved and are in need of services and trainings. Nearly 100 parents attended a training in Appalachia that developed into a needs assessment and outreach project and created a forum for parents to express their needs and concerns related to services for their children. Four more trainings were held in this area to follow-up on the needs identified in the initial meeting.

### **Support Group Activity**

By the end of the project year, 20 parent support groups with 115 participants were meeting regularly throughout the state of Kentucky (see Table 1). Initially, support groups were clustered in the eastern part of the state. Later in the year, groups were developed in western Kentucky, a 6-8 hour drive from the parent coordinator's office in Lexington. Parents calling the (800) number from rural regions were referred to existing group leaders and participants nearest to them. The advisory council consisted of many members of parent support groups, keeping the KFAA office informed on developments in different parts of the state. These regional council members were also able to bring support and information from the council meetings back to their regions.

## **Future**

Kentucky Families as Allies received no funding to continue its project at the capacity it had attained over the demonstration year, although application was made to a variety of sources. One obstacle to refunding was an issue related to unemployment compensation for an employee of KFA which caused turmoil and confusion during the time of the search for funding. Although the Advisory Committee is no longer meeting, the Mental Health Association of Kentucky continues to provide technical assistance to existing parent support groups.

## **NEW JERSEY - THE STATEWIDE PARENT ASSOCIATION FOR THE CHILDREN'S EFFORT (S.P.A.C.E.)**

### **Background**

The Statewide Parent Association for the Children's Effort (SPACE) was established following a 1988 statewide conference titled "Parents and Professionals in Partnership." This conference, sponsored by the Mental Health Association of New Jersey (MHANJ), served as the impetus for a statewide agenda for families of children with emotional disorders that included the development of six on-going parent support groups throughout the state. MHANJ later authored the proposal for the demonstration grant, and acted as fiscal agent for SPACE from the program's inception. The demonstration grant employed one part-time Parent Outreach Coordinator, and was housed within the MHANJ office in Montclair. SPACE received in-kind support in the form of word and data processing and duplicating from its MHA sponsor.

### **Building the Statewide Organization**

Two parent volunteers and a part-time (.25 FTE) parent coordinator comprised the core staff for SPACE. The part-time coordinator of SPACE also held a full-time position at a social service agency. This fact limited the amount of time that was dedicated to SPACE and inhibited the development of the project as a statewide organization. An informal network of parents supporting parents regionally characterized the state prior to the inception of SPACE. Mailing lists and resources were fragmented by region, and parents contacted local chapters of the MHA for information and referrals. Due to this fragmentation, it became a primary goal of the project to unite families statewide, secondarily to unite them around agreed upon issues and goals. This fragmentation also created barriers for accurate tracking and record keeping systems as calls and inquiries remained within their local areas. SPACE shared a statewide (800) number with the Self-Help Clearinghouse, however this resource was discontinued after only a short period due to a Department of Mental Health and Human Services funding reduction. SPACE estimated receiving 75% of its calls from parents and 25% from professionals throughout the year (see Table 4, Section I-B). The Parent Coordinator reported the number of calls received from parents began at six per month early in the demonstration year, and jumped to over 100 calls per month by the end of the year (see Table 1).

SPACE shared the resource center of the Mental Health Association of New Jersey, developed a mailing list of over 560 (see Table 1), and distributed 2,250 project brochures to mental health agencies, advocate organizations, legislators, conference participants, libraries and clinics statewide.

In May of 1989 the SPACE Executive Committee met, and officers were elected in July. Regional representatives were invited to join the meetings, and a loose knit group of 12 parents comprised the core of this committee. Meeting announcements were sent to case managers and hospitals statewide. In June a Legislative Subcommittee was formed and a wish list for children's mental health was developed and sent to the Commissioner of Human Services.

During the year, SPACE assisted with 4 statewide children's mental health conferences, as well as a regional family based services training (see Table 4, Section III-C). The parent support group participants coordinated a training in March titled "Serving Troubled Children." A sponsorship of \$500 was provided by SPACE for parent training on issues of returning children to their homes. Scholarships were provided for three parents to attend conferences throughout the year.

In December of 1989 a quality of care crisis at Arthur Brisbane, the New Jersey children's psychiatric hospital, created a situation in which parents statewide were asked to participate in an assessment of the services provided by this facility. Out of this statewide crisis grew greater parent and family cohesion, a renewed focus on networking, the practice of solicitation of family concerns, as well as on-going parent contact with the State Commissioner of Human Services.

### **Support Group Activity**

Thirteen parent groups, and over 100 participants, were active throughout the demonstration year (see Table 1). Much of the parent coordinator's time was spent visiting existing support groups offering technical assistance and needs assessments. These groups were located primarily in the central region of the state, including East Orange and Trenton, and were usually facilitated by MHANJ professionals. Due, in part, to this professional facilitation these groups served more as education groups rather than parent to parent support and discussion groups. The potential for growth of family support groups in New Jersey was set back due to a number of events. Mental Health budgets were cut during the grant year by 4% statewide. Four counties running support groups received significant monies for planning for services to children, no actual dollars were tied to family support groups. Two urban locations, Newark and Jersey City, had identified potential locations for groups but had not met by the end of the grant year. Newark's efforts had been focused on the high number of urban foster parents caring for state placed pre-school children.

### **Outreach to Underserved Families**

The demographics of New Jersey are unique in that it is the most densely populated state in the nation. Many of the northern and central regions act as bedroom communities to New York City. Many ethnic minority members live in these densely populated areas, as well as persons who are economically unstable. Many families in these areas are struggling to meet basic needs, and have not accessed the service system for their children with serious emotional disorders. The demonstration

project was written to serve these northern and central regions. A \$500 grant from New Jersey state resources provided a needs assessment for families in the southern parts of the state, a more rural and isolated population with needs that differ from the family members in the urban areas.

## **Future**

In 1990, SPACE was awarded a two year contract from NIMH to continue the work of building a Statewide Family Organization. The Mental Health Association of New Jersey continues to serve as its fiscal agent. The parent who was elected President of the Executive Committee in 1989 also took on the position of Parent Coordinator. Under her direction the organization has continued to grow and the Executive Board has expanded. SPACE produces a newsletter and provides parent-to-parent support on a regular basis. The number of support groups remains about the same.

New Jersey has recently adopted a policy that mandates family member participation in regional and state planning groups for children's mental health. SPACE has been a major supporter of this shift in policy and has been instrumental in the implementation effort. The Parent Coordinator/President is active on a number of state level advisory bodies.

## HYPOTHESIS/METHODOLOGY

The research design was developed to carefully document the issues arising during the process of establishing a statewide family organization. Understanding these issues will contribute to our knowledge about the supports needed by family organizations to extend their services to greater geographic areas and a greater variety of parents. The evaluation involved case studies of each statewide family organization demonstration project and analysis of certain variables across all projects.

Two general research questions guided the analysis of the data:

1. Did the three family organizations attain the goals identified in their individual proposals? Did the three family organizations develop the capacities and deliver the services outlined in the project objectives?; and
2. What issues and barriers impeded implementation of a statewide family organization? What resources and supports are needed to facilitate effective implementations of these organizations?

Several methods of data collection were employed in this study. Because conditions and plans were unique to each state, qualitative methods were most appropriate. However, quantitative data was collected wherever possible. The following sources of data were used:

1. Quarterly reports with narrative descriptions of the implementation process and activities;
2. A set of seven common data elements collected from each state for the month prior to beginning the organization effort and for the last month of the project;
3. Regular telephone contacts with staff of each family organization; and
4. A site visit including unstructured observation and a structured (taped) interview with principal staff and related professionals.

## RESULTS

### **1. DID THE THREE PARENT ORGANIZATIONS ATTAIN THE GOALS IDENTIFIED IN THEIR INDIVIDUAL PROPOSALS? DID THEY DEVELOP THE CAPACITIES AND DELIVER THE SERVICES OUTLINED IN THE PROJECT OBJECTIVE?**

Each family organization was responsible for developing and implementing a plan for evaluating their activities and outcomes. Technical assistance was provided in developing these evaluation plans and data regarding these plans was to be reported quarterly. Thus, two sets of data are relevant to the first research question. The first set of data is based on the individual evaluation plans developed for each state and exhibited in Tables 2, 3 and 4. The second set of data is derived from the pre- and post- measurement of common data elements and is found in Table 1.

The individual evaluation plans were re-ordered so that the indicators reflect the three capacities and six services outlined in the objectives for the projects. By reading each Table horizontally, the progress of the family organization can be followed over the year. By comparing Tables, it is apparent that the activities and indicators have some common elements, but are unique to each state for the most part.

#### **Capacity 1: Two-Way Communication with Family Members (Tables 2, 3, and 4; Section-I)**

Each of the three statewide projects utilized the phone systems at the office of their sponsoring organizations, augmented by home phones of volunteers and the Parent Coordinators. This lack of a single, centralized phone system frustrated efforts at a comprehensive data collection of phone contacts with family members.

Several of the projects developed (800) numbers for the demonstration year, however, personing these phones during office hours proved to be difficult. Parents often reached message machines or the receptionists of sponsoring organization rather than actual parent volunteers or the parent coordinator. New Jersey (S.P.A.C.E.) temporarily shared an (800) number with a self-help clearinghouse for Children's Mental Health, which was discontinued mid-year. Indiana Family Support Network utilized the (800) number of Indiana which relayed messages to the Parent Coordinator of the project.

Kentucky shared an (800) number with the agency DIRECTIONS, a statewide information and referral assistance for people with special needs. Plans to work with DIRECTIONS to do referrals were only partially implemented, however. A TDD for persons with hearing impairments was available at this (800) number. Kentucky also had access to a watts line to return phone calls to family members with no long-distance charge. This line was provided by the Kentucky CASSP. Each of the statewide projects had various means for distributing their telephone numbers to family members throughout the state. New Jersey printed 2,250 project brochures that were then distributed to mental health agencies, advocate organizations, legislators, conference participants, libraries and clinics statewide. The Kentucky Families as Allies number was distributed through a variety of mechanisms, including a letter to each of the thirteen resource centers, and to existing support groups and service providers throughout the state. New Jersey printed 2,250 project brochures that were then distributed to mental health agencies, advocate organizations, legislators, conference participants, libraries and clinics statewide. The Kentucky Families as Allies number was distributed through a variety of mechanisms, including a letter to each of the thirteen resource centers, to each of the regional mental health centers, and to existing support groups and service providers throughout the state.

#### **Capacity 2: A Resource Service (Tables 2, 3, and 4; Section-II)**

Developing a resource service was not a high priority for the three states, consequently there was a limited amount of activity in this area. Most of the states utilized the existing resource centers of their sponsoring organizations or other organizations that provide services for children's mental health. These resource centers were then augmented with materials related to children with Emotional-Behavioral Disorders. In Kentucky, thirteen regionalized resource libraries of the Kentucky Office of Education for Exceptional Children, as well as the Kentucky Coalition for People with Handicaps, were offered as resources to family members. The Kentucky Parent Coordinator

then supplemented these resources with materials related to parent support groups, comprehensive care centers, respite services, the IEP process, legislation, advocacy and family member empowerment. The Indiana Family Support Network, and the Statewide Parent Association for the Children's Effort (S.P.A.C.E.) of New Jersey shared the print and video materials of their respective Mental Health Associations. Indiana and Kentucky each developed resource packets that were distributed to each of the existing support groups across their states.

Data regarding utilization of the various resource services was incomplete during the demonstration year. Printed or video materials were not commonly requested at this time. The Indiana Parent Coordinator reported that parents preferred to buy rather than borrow books, and that a comprehensive listing of available print and video materials was extremely useful.

### **Capacity 3: Ability to maintain ties with diverse groups (Tables 2, 3, and 4; Section-III)**

All three states published a statewide newsletter. This proved to be an effective method for reaching parents in all parts of the states. The number of names on the mailing lists continued to increase over the year (Table 1). Two states (Indiana and New Jersey) printed their own brochure about their organization and the services they provide. The brochures were mailed statewide and distributed at various statewide conferences. Each parent coordinator reported attending several statewide advisory committees, governmental committee meetings and other meetings with diverse groups throughout the year.

### **Service 1: Refer family members to existing parent groups (Tables 2, 3, and 4; Section IV)**

A major focus for all three states was linking parents to existing support groups and to individual parents who had agreed to provide individual support. In two of the states (New Jersey and Indiana) Mental Health Association staff did much of the information and referral for the part-time parent coordinator since the parent organization shared office space with the Mental Health Association. New Jersey reported that the greatest increase over the year had come from the neediest part of the state (north and central regions). All three parent coordinators noted the difficulty in collecting data from support groups on the group's activities.

### **Service 2: Direct family members to existing referral agencies (Tables 2, 3, and 4; Section V)**

In all three states this service was a difficult one to deliver in a consistent manner. The Mental Health Associations in Indiana and New Jersey provided this information to family members in the absence of the part-time parent coordinator. Parents' requests included services for respite care, in-home care, recreational programs, residential placements and help with IEP's. Being connected with a sponsoring organization proved to be a definite advantage for all three states.

**Service 3: Strengthen the network of families and family organizations in the state (Tables 2, 3, and 4; Section IV)**

There are several ways the three states' parent coordinators communicated with families across the state. Information about the statewide organizations were disseminated through newsletters; parent coordinator's contacts with support groups and individual parents; statewide conferences in Indiana and New Jersey; and advisory committee meetings in all three states.

**Service 4: Provide technical assistance to family groups (Tables 2, 3, and 4; Section-VII)**

This was an area of emphasis for all three states. It was reported by the parent coordinators that the technical assistance took many forms. Parent coordinators made regular telephone contacts to support group facilitators as well as visits to support groups to assist in providing group direction, problem solving, starting groups, and increasing membership. All three states increased the number of parent groups over the year (see Table 1).

**Service 5: Developing of a statewide family organization structure (Tables 2, 3, and 4; Section VIII)**

Kentucky, Indiana, and New Jersey experienced little progress with building a statewide organization even though there was an attempt. Several factors may have contributed to this slow progress. There had been little effort at building statewide organizations prior to the demonstration project. A few loosely connected parent support groups was not enough to build a statewide effort. To develop a statewide focus a core group of parents is needed. It was difficult for the part-time parent coordinator in all three states to devote any time to developing this statewide effort. This was not a priority for the states.

**Service 6: Provide special outreach to underserved groups (Tables 2, 3, and 4; Section-IX)**

This continues to be a struggle for the demonstration projects. All three states made some effort towards reaching this population. Kentucky has been successful in reaching the people of Appalachia who are a cultural minority due to their low economic status and isolation. A training was held for parents who live in this region of the state. Indiana was able to reach families who are predominantly African-American in the northern part of the state through a group supported and funded by the local school district. The demographics of New Jersey in the northern and central areas include many families struggling to meet basic living needs. They are not yet ready to seek assistance from the project for their child.

**2. WHAT ISSUES AND BARRIERS IMPEDE IMPLEMENTATION OF A STATEWIDE PARENT ORGANIZATION? WHAT RESOURCES AND SUPPORTS ARE NEEDED TO FACILITATE EFFECTIVE IMPLEMENTATION OF THESE ORGANIZATIONS:**

The conceptual framework for studying the implementation process is adapted from the framework developed by Van Meter & Van Horn (1975). This framework examines components of six general areas and posits that each can hinder or contribute to successful implementation.

1. **Characteristics of the proposal.** For example, how clear and specific were the parameters of the proposed statewide organization? How well were these parameters understood? How much change was required?
2. **The resources available.** What monetary and in-kind resources became available during the year for this proposal? Who provided these resources?
3. **The characteristics of the primary implementing agency.** For example, what is the size, orientation and stability of the organization responsible for implementing the statewide parent network?
4. **The characteristics of the individual primarily responsible for implementing the statewide family network.** What was this individual's background, power base, personal resources, etc.?
5. **Interorganizational relationships.** How strong were relationships with other important agencies? What needed to be done to ensure their cooperation?
6. **Social, political and economic conditions.** What is the economic condition of the community and state? Were there social or political issues that might intervene in implementation efforts?

Using primarily qualitative data each of these will be examined. The presentation of results in this report will be in summary form. More detailed examination of conditions in specific states will be published in monograph form at a later date.

1. **Characteristics of the proposal.** All of the proposals were overly broad and ambitious. This was due in part to expectations the request for proposals placed on writers encouraging them to include a wide array of services in the proposal. This was very overwhelming to the parent coordinators who were not involved in writing the grant. It was difficult to sort out the priorities of the grant among the stakeholders. There were not a lot of good role models for these states to follow in the process.
2. **The resources available.** All states relied on this federal grant and in-kind contributions from generous sponsoring organizations. Those organizations included the Mental Health Associations for New Jersey and Indiana and, The Kentucky Coalition for People with Handicaps, a coalition of parent, consumer, and advocacy groups for all disabilities. CASSP monies were available in Kentucky and Indiana but not in New Jersey.
3. **The characteristics of the primary implementing agency.** The demonstration projects in New Jersey and Indiana were implemented by their sponsoring organizations, the Mental Health Association, which were large, stable organizations. Kentucky was implemented by a mixed

disability organizations. There were no funds available prior to these demonstration projects specific to parents of children with emotional disorders. All three states lacked strong parent members who were associated with the sponsoring organization and were also involved in writing the grant which would have provided consistency in implementing the proposal.

4. **The characteristics of the individual primarily responsible for implementing the statewide parent organizations.** Each demonstration project was led by a part-time, paid staff person who was the parent of a child with a serious emotional disorder. New Jersey's parent coordinator worked full-time at another job and could only respond to calls at night. This seriously limited the effectiveness of providing services to families. In each demonstration project, the parent coordinator attended night meetings, traveled overnight to out-of-town locations, and responded to parent calls on their home telephones. In all three states the parent coordinators received low pay for high stress work that required skills for which they were not trained, yet each was dedicated and committed to meeting the needs of families who have a child with an emotional disorder.
5. **Interorganizational relationships.** The strength and consistency of relationships with other organizations varied from project to project. Generally, networking with organizations was minimal and only a few strong, coordinated relationships existed. Emerging from the project data is an increased emphasis on the nurturance of a supportive, reciprocal network with a selected group of family and mental health organizations. It is increasingly clear that the development of a statewide organizational must include a strong network of related organizations that provide information and input to one another, coordinated planning efforts, and group and organizational advocacy.
6. **Social, political and economic conditions.** This project year was typically a year of cut-backs and fiscal turbulence. Kentucky, with a history of chronic poverty and struggling social services for children and families, experienced the least cut-back during this year. In New Jersey and Indiana, lawsuits against state agencies on the part of family members of children with serious emotional disorders created a forced attention to the needs of this population, as well as the lack of sufficient resources to meet their needs. In New Jersey this lawsuit focused on the state hospital for children and had the outcome of greater coalescence for family members in support of their children and each other. Out of such political and social turbulence developed a more unified group of family members, as well as a more knowledgeable and attentive general population.

Table 1  
 Results of Pre- and Post- measurement of  
 Common Data Elements

|   | INDIANA |       | KENTUCKY |       | NEW JERSEY |          |
|---|---------|-------|----------|-------|------------|----------|
|   | 10/89   | 10/90 | 10/89    | 10/90 | 10/89      | 10/90    |
| # of entries on mailing list            | 150     | 495   | 1200     | 1700  | 50         | 560      |
| # of parent groups                      | 5       | 11    | *        | 20    | 6          | 13       |
| # of group participants                 | 55      | *     | *        | 115   | 45         | over 100 |
| # of telephone calls from parents/month | 24      | 37    | *        | 26    | 6          | over 100 |

\* data not available

Table 2

Indiana Family Support Network - 1

| Evaluation Indicators   | Progress Report - 1  | Progress Report - 2  | Progress Report - 3   |
|---|--|--|---|
| I. Number of Calls<br>A. Services requested<br>B. Services provided   | I. 84 total calls<br>A. no data<br>B. no data                    | I. 188 total calls<br>A. ??<br>B. ??   | I. 188 total calls<br>A. no data<br>B. no data  |
| II. Resource service<br>A. 1. New acquisitions<br>2. Types of acquisitions<br>B. 1. # of requests for resources<br>2. Types of resources<br>3. Who made requests  | II.<br>A. no data<br>B. no data                                  | II.<br>A. 1. 44<br>2. mag. sub., manuals, booklets, videos, newsletters<br>B. 1. 42<br>2. print, video<br>3. 25 parents, 12 prof.                      | II.<br>A. 1. 151<br>2. manuals, books, audio/video tapes, newsletters<br>B. 1. 31<br>2. magazines, newsletters, books<br>3. 25 parents, 6 prof. |
| III. Ties w/diverse groups & individuals<br>A. Newsletter<br>1. # of newsletter issues<br>2. # mailed<br>3. Geographic dispersion<br>4. # of new names<br>B. Brochure<br>1. # mailed<br>2. Geographic dispersion<br>C. Trainings/workshops<br>1. # held<br>2. # of participants<br>3. participant evaluations | III.<br>A. none, (column in MHA's newsletter)<br>B. none<br>C. 0 | III.<br>A.<br>1. 3<br>2. 150<br>3. statewide<br>4. no data<br>B.<br>1. 50<br>2. distributed at a statewide conf.<br>C.<br>1. 2<br>2. 163<br>3. no data | III.<br>A.<br>1. 1<br>2. 495<br>3. statewide<br>4. no data<br>B.<br>1. 200<br>2. statewide<br>C.<br>1. 2<br>2. 78<br>3. none                    |

Table 2

Indiana Family Support Network - 2

| Evaluation Indicators   | Progress Report - 1  | Progress Report - 2   | Progress Report - 3   |
|---|--|---|---|
| <p>D. Presentations</p> <ol style="list-style-type: none"> <li>1. # requests</li> <li>2. # given/topics</li> <li>3. # participants</li> <li>4. whom</li> </ol> <p>E. Meetings</p> <ol style="list-style-type: none"> <li>1. #</li> <li>2. whom</li> </ol> | <p>D. 0</p> <p>E. 1. 15<br/>2. MHA, parents, CASSP, Governor's board meeting</p> <p>F. 0</p> | <p>D. 1. no data<br/>2. 11, no data<br/>3. 248<br/>4. MHA, CASSP, MHA, support groups, Gov's Interdepartmental Brd.</p> <p>E. 1. 30<br/>2. Juv. Just. Task Force, Respite Ad. Comm, MH Task Force, Childhood MH Comm, MHA/ Invisible Child Com, Sp. Needs Adoption, Gov's Inter Dept. Brd. on Human Services</p> <p>F. 1. no data<br/>2. 0<br/>3. 0</p> | <p>D. 1. no data<br/>2. 5, no data<br/>3. 71<br/>4. support grps., Gov's Task Force, Gov's Interdepartmental Brd.</p> <p>E. 1. 13<br/>2. Children's Agenda Task Force, MHA/ Staff mtgs., Ind. Sp. Needs Adopt.</p> <p>F. none</p> |
| <p>F. Use of media</p> <ol style="list-style-type: none"> <li>1. # posters/flyers</li> <li>2. # radio/TV PSAs</li> <li>3. # radio/TV press release</li> <li>4. # times database used in contacts</li> </ol>   |  |   |   |
| <p>IV. Referrals to parents/parent groups</p> <ol style="list-style-type: none"> <li>A. # requests</li> <li>B. # parents to parents grps.</li> <li>C. # parents to other parents</li> </ol>   | <p>IV. A. no data<br/>B. 4<br/>C. no data</p>  | <p>IV. A. no data<br/>B. 21<br/>C. no data</p>  | <p>IV. A. no data<br/>B. 45<br/>C. no data</p>  |
| <p>V. Referring parents to other agencies</p> <ol style="list-style-type: none"> <li>A. # requests</li> <li>B. # parents referred</li> </ol>  | <p>V. A. 12<br/>B. no data</p>   | <p>V. A. no data<br/>B. no data</p>   | <p>V. A. 89<br/>B. no data</p>  |

Table 2

Indiana Family Support Network - 3

| Evaluation Indicators  | Progress Report - 1  | Progress Report - 2   | Progress Report - 3   |
|--|--|---|---|
| <p>C. nature of info.</p> <p>D. geog. diversity of requests</p> <p>E. geog. diversity of referrals</p>   | <p>C. speaker for par. grp., TA, print material, sharing info.</p> <p>D. all from central Ind.</p> | <p>C. no data</p> <p>D. No., Central, So.</p>   | <p>C. respite, TA, supp. grp., newsltr.</p> <p>D. statewide</p> <p>E. no data</p>   |
| <p>VI. Formal/Informal Contacts</p> <p>A. 1. # Staff contacts w/parent groups</p> <p>2. nature of contact</p> <p>B. # mtgs. w/ parent grps.</p> <p>C. # Informal connections between parent grps.</p> <p>D. # parent scholarships</p> <p>E. 1. # statewide mtgs.</p> <p>2. nature of mtgs.</p> <p>3. # parent participants</p> <p>F. 1. # trngs./wkshps. attended by parents</p> <p>2. nature of trngs.</p> <p>3. # parent partic.</p> | <p>VI.</p> <p>A. 1. 6</p> <p>2. no data</p>  | <p>VI.</p> <p>A. 1. no data</p> <p>B. 3</p> <p>D. 25</p> <p>E. 1. 3</p> <p>2. org. advs. board, advs. brd. mtgs.</p> <p>3. 37</p> <p>F. 1. 1</p> <p>2. MHAJ Annual Conf.</p> <p>3. 25</p> | <p>VI.</p> <p>A. 1. 5</p> <p>B. 3</p> <p>D. 25</p> <p>E. 1. 3</p> <p>2. advs. brd. mtg.</p> <p>3. 37</p> <p>F. 1. 2</p> <p>2. Child and Adoles. Conf.</p> |
| <p>VII. TA to support groups</p> <p>A. 1. # requests</p> <p>2. nature of TA</p> <p>3. # times TA provided</p>  | <p>VII.</p> <p>A. 1. 2</p> <p>2. Increasing membership, problem solving</p> <p>3. 2</p>            | <p>VII.</p> <p>A. 1. 8</p> <p>2. mthly. advs. bd. mtgs, trng., telephone contact</p> <p>3. no data</p>  | <p>VII.</p> <p>A. 1. 3</p> <p>2. mthly. advs. bd. mtgs., lunches, respite funds, transp. to mtgs.</p> <p>3. 3</p>   |

Table 2

Indiana Family Support Network - 4

| Evaluation Indicators  | Progress Report - 1  | Progress Report - 2   | Progress Report - 3  |
|--|--|---|--|
| <p>4. a. # requests for forming new group<br/>                     b. nature info. provided</p> <p>5. # mtgs. to dev. statewide parent org.</p>  | <p>4. a. 0</p> <p>5. 0</p>   | <p>4. a. 8</p> <p>b. no data</p> <p>5. 1</p>  | <p>4. a. 2</p> <p>b. how to begin a new group</p> <p>5. 2</p>  |
| <p>VIII. Develop Statewide parent org.<br/>                     A. # participant members<br/>                     B. # mtgs. re: legis.<br/>                     C. types of mtgs.<br/>                     D. # calls to parents<br/>                     E. # legis. bulletins<br/>                     F. # times testimony given<br/>                     G. # times media contacted<br/>                     H. types legis. activity<br/>                     I. # legis. activ.</p> | <p>VIII.</p> <p>A. no data<br/>                     B. 3<br/>                     C. trng.<br/>                     D. 0<br/>                     E. 4</p> | <p>VIII.</p> <p>A. 150+<br/>                     B. 1<br/>                     C. advls. bd. mtg.<br/>                     D. 0<br/>                     E. 5</p> | <p>VIII.</p> <p>A. 250<br/>                     B. 1<br/>                     C. policy mtg. of MHAI<br/>                     D. 0<br/>                     E. 3<br/>                     F. 1</p> |
| <p>IX. Outreach to underserved parents<br/>                     A. # efforts to reach<br/>                     B. nature of efforts<br/>                     C. # new groups<br/>                     D. # parents in new groups<br/>                     E. # minority parents in supp. group<br/>                     F. feedback from parents</p>   | <p>IX.</p> <p>A. none</p>  | <p>IX.</p> <p>A. 3<br/>                     B. parent scholarships, transp. to mtgs &amp; conf<br/>                     E. 50</p>                                 | <p>IX.</p> <p>A. 0</p>   |

Table 2

Indiana Family Support Network - 5

| Evaluation Indicators  | Progress Report - 1   | Progress Report - 2  | Progress Report - 3   |
|--|---|--|---|
| X. Expenditures, Resources & Donations<br>A. Money raised<br>B. In-kind<br>C. # volunteers<br>D. vol. time<br>E. summary of expenses | X.<br>A. 0<br>B. no data<br>C. 0<br>E. expense summary included | X.<br>A. 0<br>B. \$1200<br>C. 5<br>D. 183 hrs.<br>E. no summary included | X.<br>A. no data<br>B. no data<br>C. no data<br>D. no data<br>E. summary included |

Table 3

Kentucky Family As Allies - 1

| Evaluation Indicators   | Progress Report - 1  | Progress Report - 2  | Progress Report - 3   |
|---|--|--|---|
| I. Number of Calls<br>A. Services requested<br>B. Services provided   | I. A. no data<br>B. no data  | I. 206 total calls (134 parents, 72 profs)<br>A. 336 requests<br>B. 181 provided   | I. 176 (94 parents, 82 prof)<br>A. no data<br>B. 92   |
| II. Resource service<br>A. 1. New acquisitions<br>2. Types of new acquisitions<br>B. 1. Requests for resources<br>2. Types of requests<br>3. Who made requests  | II. A. no data<br>B. no data   | II. A. 1. 13 new<br>2. print - 13<br>B. 0  | II. A. 1. 2 new<br>2. print-2<br>B. 1. 1<br>2. access-guide<br>3. parent  |
| III. Maintain ties with Diverse Groups & Individuals in State<br>A. Newsletter<br>1. Newsletter issues<br>2. # mailed<br>3. Geographic dispersion<br>4. # new names<br>B. Brochures<br>1. # mailed<br>2. Geographic dispersion<br>C. Trainings/wkshps.<br>1. # held<br>2. # participants<br>3. partic. evals.<br>D. Presentations<br>1. # requests<br>2. # given/topics<br>3. # participants<br>4. whom | III. A. 1. no data<br>2. 1,500 (Fam as Allies newsletter)<br>1,200 (KCPH newsletter)<br>3. statewide<br>4. no data<br>B. None<br>C. 1. 1<br>2. 70<br>3. no data<br>D. 1. same as training above<br>2. sp. education<br>3. 70<br>4. parents | III. A. 1. 1<br>2. 1,600<br>3. statewide<br>4. 157<br>B. None<br>C. 1. 4<br>2. 103<br>3. no data<br>D. 1. 10<br>2. 10, (parent empowerment IEP, services for EBH)<br>3. 91<br>4. parents | III. A. 1. 2<br>2. 3,200<br>3. statewide<br>4. 67<br>B. None<br>C. 1. 1<br>2. 62<br>3. no data<br>D. 1. 0<br>2. KAMI/Blended Families<br>3. no data<br>4. parents |

Table 3

Kentucky Family As Allies - 2

| Evaluation Indicators  | Progress Report - 1  | Progress Report - 2   | Progress Report - 3  |
|--|--|---|--|
| <p>E. Meetings</p> <ol style="list-style-type: none"> <li>1. #</li> <li>2. with whom</li> </ol>  | <p>E.</p> <ol style="list-style-type: none"> <li>1. 6</li> <li>2. providers, legislators, parent supp. grps</li> </ol> | <p>E.</p> <ol style="list-style-type: none"> <li>1. 10</li> <li>2. Kentucky Resp. Task Force Blended Fam. of K, MH Instit. of K, MH Coal, KAMI, K Dept. - MH (Child's Branch), K. Coalition for People with Handl., CASSP, DIRECTIONS, KY SPIN</li> </ol> | <p>E.</p> <ol style="list-style-type: none"> <li>1. 19</li> <li>2. Kentucky Resp. Task Force, Blended. Fam of K, PUSH, Unit. Par., K. Coal. for People with Handl., K. DD Plan. Council, K. Dept. MH, Pathway - ReAct Comm.</li> </ol> |
| <p>F. Use of Media</p> <ol style="list-style-type: none"> <li>1. # posters/flyers</li> <li>2. # radio/TV PSAs</li> <li>3. # radio/TV press releases</li> <li>4. # times database used in contacts</li> </ol> | <p>F.</p> <ol style="list-style-type: none"> <li>1. no data</li> <li>2. 1</li> <li>3. 3</li> <li>4. no data</li> </ol> | <p>F.</p> <ol style="list-style-type: none"> <li>1. 0</li> <li>2. 0</li> <li>3. 1</li> <li>4. 2 - mailing newsltr &amp; info to parent res-ctrs</li> </ol>  | <p>F.</p> <ol style="list-style-type: none"> <li>1. 0</li> <li>2. 0</li> <li>3. 1</li> <li>4. no data</li> </ol>   |
| <p>IV. Referrals to parents/parent grps.</p> <ol style="list-style-type: none"> <li>A. # requests</li> <li>B. # parents to parent grps.</li> <li>C. # parents to other parents</li> </ol>                    | <p>IV.</p> <ol style="list-style-type: none"> <li>A. no data</li> <li>B. no data</li> <li>C. no data</li> </ol>        | <p>IV.</p> <ol style="list-style-type: none"> <li>A. 19</li> <li>B. 10</li> <li>C. 5</li> </ol>   | <p>IV.</p> <ol style="list-style-type: none"> <li>A. 4</li> <li>B. 4</li> <li>C. 0</li> </ol>  |
| <p>V. Referring parents to other agencies</p> <ol style="list-style-type: none"> <li>A. # requests</li> <li>B. # parents referred</li> <li>C. nature of info.</li> </ol>                                     | <p>V. no data</p>  | <p>V.</p> <ol style="list-style-type: none"> <li>A. 69</li> <li>B. 15</li> <li>C. respite, IEPs, laws &amp; rts, summer/rec. prog., in-home support, resid/non-resid. prog., counseling &amp; MH services</li> </ol>                                      | <p>V.</p> <ol style="list-style-type: none"> <li>A. 19</li> <li>B. 19</li> <li>C. respite(7), rec.prog. (9), IEP(3)</li> </ol>   |
| <p>D. geographic divers. of requests</p> <p>E. geographic divers. of referrals</p>   | <p>D. Geog. diverse</p> <p>E. Geog. diverse</p>  | <p>D. Geog. diverse</p> <p>E. Geog. diverse</p>   | <p>D. northeast</p> <p>E. northeast</p>  |

Table 3

Kentucky Family As Allies - 3

| Evaluation Indicators   | Progress Report - 1 | Progress Report - 2   | Progress Report - 3  |
|---|---------------------|---|--|
| <p>VI. Formal/Informal Contacts</p> <p>A. 1. # staff contacts w/parent grps.</p> <p>2. Nature of contact</p> <p>B. # mtgs w/parent grps</p> <p>C. # infomal connections between parent grps.</p> <p>D. # parent scholarships</p> <p>E. 1. # statewide mtgs.</p> <p>2. Nature of mtgs.</p> <p>3. # parent partic.</p> <p>F. 1. trngs/wkshps attended by parents</p> <p>2. nature of</p> <p>3. # parent partic.</p> | <p>VI. no data</p>  | <p>VI.</p> <p>A. 1. 52</p> <p>2. info &amp; referral, TA</p> <p>B. 13</p> <p>C. no data</p> <p>D. 3 - for respite, travel to statewide advis. comm. meetings</p> <p>E. 1. 2</p> <p>2. parent empowerment, par. advis. comm.</p> <p>3. 66</p> <p>1. 4 F.</p> <p>2. parent empowerment, IEP</p> <p>3. 103</p> | <p>VI.</p> <p>A. 1. 26 (5 in person, 21 telephone)</p> <p>2. info, referral, coord. mtg., TA</p> <p>B. 4</p> <p>C. no data</p> <p>D. 3 - respite, travel</p> <p>E. 2. PAC</p> <p>no data</p> |
| <p>VII. TA to support grps.</p> <p>A. 1. # requests</p> <p>2. nature of TA</p> <p>3. # times TA provided</p> <p>4. a. requests for forming grp.</p> <p>b. nature of info. provided</p> <p>5. # mtgs. to dev. statewide parent org.</p>  | <p>VII. no data</p> | <p>VII.</p> <p>A. 1. 15</p> <p>2. providing group direction</p> <p>3. 11</p> <p>4. a. 1</p> <p>b. how other grps. are org.</p> <p>5. 1</p>  | <p>VII.</p> <p>A. 1. 20</p> <p>2. help plan mini conf.</p> <p>3. no data</p> <p>4. 0</p> <p>5. 4</p>   |

Table 3

Kentucky Family As Allies - 4

| Evaluation Indicators  | Progress Report - 1  | Progress Report - 2  | Progress Report - 3   |
|--|--|--|---|
| <p>VIII. Develop Statewide parent org.<br/>                     A. # parent members<br/>                     B. # mtgs. regarding legislation<br/>                     C. types of mtgs.</p>   | <p>VIII.<br/>                     A. no data<br/>                     B. 1<br/>                     C. Legislative breakfast</p> | <p>VIII.<br/>                     A. 18 parents serve on advs. comm.<br/>                     B. no data<br/>                     C. no data</p>                         | <p>VIII.<br/>                     A. 18 parents<br/>                     B. no data<br/>                     C. no data</p>   |
| <p>D. # of calls to parents<br/>                     E. # legis. bulletins</p>   | <p>D. no data<br/>                     E. 1</p>  | <p>D. 21 calls re: (pending legislation)<br/>                     E. no data</p>   | <p>D. 0 calls<br/>                     E. no data</p>   |
| <p>F. # times testimony<br/>                     G. # times media contacted<br/>                     H. types legis. activ.<br/>                     I. # legis. activ.</p>  | <p>Note: Parent Coordinator assists KCPH in legis. efforts informally.</p>   | <p>Note: Legis. meets ea. 2 yrs. (met 1 mo. this quarter.) Parent coord. worked with KCPH for EBH legis. Incl. alerts to parents &amp; personal contacts with legis.</p> | <p>Note: K. legislature met in Spring. Efforts this 1/4 focussed on Nov. elections</p>  |
| <p>IX. Outreach to underserved parents<br/>                     A. # efforts to reach<br/>                     B. Nature of efforts<br/>                     C. # new grps.<br/>                     D. # parents<br/>                     E. # minority parents in supp. grp.<br/>                     F. Feedback from parents</p> | <p>IX. no data</p>   | <p>IX.<br/>                     A. 26<br/>                     B. recruit minorities for statewide ad. brd, info. re: scholarships to parents to attend mtgs.</p>        | <p>IX.<br/>                     A. 32<br/>                     B. Contact racial minorities for statewide advs. comm., provide scholarships to low income par. to attend mtgs., travel to Appalachia to personally assist parents</p> |

Table 3

Kentucky Family As Allies - 5

| Evaluation Indicators  | Progress Report - 1                                       | Progress Report - 2  | Progress Report - 3  |
|--|---|--|--|
| <p>X. Expenditures, Resources &amp; Donations</p> <p>A. Money raised</p> <p>B. In kind</p><br><p>C. # volunteers</p> <p>D. vol. time</p> <p>E. Summary of expenses</p> | <p>X.</p> <p>E. Budget summary, list of expenditures.</p> | <p>X.</p> <p>A. attempts made</p> <p>B. 1,000 from CASSP</p> <p>E. Budget summary included</p> | <p>X.</p> <p>B. supplies, photocopying, newsletter, office space, phones, materials - CASSP &amp; KCPH</p> <p>E. Budget summary included</p> |

Table 4

Statewide Parent Association for the Children's Effort - 1

| Evaluation Indicators  | Progress Report - 1   | Progress Report - 2  | Progress Report - 3   |
|--|---|--|---|
| I. Number of calls<br>A. Services requested<br>B. Services provided  | I.<br>A. about 100<br>B. about 100<br>(est. 75% parents, 25% prof.)   | I.<br>A. about 300<br>B. about 300   | I.<br>A. about 50<br>B. over 100  |
| II. Resource Service<br>A. 1. New acquisitions<br>2. Types of acquisitions<br><br>B. 1. Requests for resources<br>2. Types of requests<br><br>3. Who made requests   | II.<br>A. 1. 1<br>2. cable show<br><br>B. 1. 3<br>2. printed material, videos<br><br>3. professionals   | II.<br>A. 1. 10<br>2. print material<br><br>B. 1. 26<br>2. req. for services, I&R info, support grp info<br>3. parents and ?                   | II.<br>A. 1. 1<br>2. video, parent workbook<br><br>B. 1. 0  |
| III. Ties w/diverse grps & individuals<br>A. Newsletter<br>1. # of newsletter issues<br>2. # mailed<br>3. Geographic dispersion<br><br>4. # of new names<br>B. Brochure<br>1. # mailed<br>2. Geographic dispersion<br>C. Trainings/Workshops<br>1. # held<br>2. # participants<br>3. participant evaluations | III.<br>A.<br>1. (inside MHANJ)<br>2. 300<br>3. Statewide (to all vol. & prof. MHANJ staff)<br>4. about 10<br>B. none--at printer<br><br>C. N/A | III.<br>A.<br>1. none, plans for summer<br>2.<br>3.<br>4. 400 on mailing list<br>B.<br>1. 2250<br>2. Statewide<br>C.<br>1. 4<br>2. 360<br>3. 0 | III.<br>A.<br>1. 2<br>2. 400<br>3. statewide<br><br>4. 200<br>B.<br>1. 2000<br>2. no data<br>C.<br>1. 0 |

Table 4

Statewide Parent Association for the Children's Effort - 2

| Evaluation Indicators  | Progress Report - 1   | Progress Report - 2   | Progress Report - 3   |
|--|---|---|---|
| <p>D. Presentations</p> <ol style="list-style-type: none"> <li>1. # of requests</li> <li>2. # given/topics</li> </ol>  | <p>D.</p> <ol style="list-style-type: none"> <li>1. 3</li> <li>2. 3, how to develop support grp., facilitate existing grp., progress. of par. support project.</li> <li>3. 7</li> <li>4. parents, prof., MHA Board members, citiz. ad. comm.</li> </ol> | <p>D.</p> <ol style="list-style-type: none"> <li>1. 6</li> <li>2. 7, MHA Brd Mtg, how to select trmt., support grp.</li> <li>3. 15</li> <li>4. parents, professionals</li> </ol>              | <p>D.</p> <ol style="list-style-type: none"> <li>1. 0</li> </ol>  |
| <p>3. # of participants</p> <p>4. Whom</p>   | <p>E.</p> <ol style="list-style-type: none"> <li>1. 8</li> <li>2. parents</li> </ol>  | <p>E. no data</p>   | <p>E. 0</p>   |
| <p>F. Use of media</p> <ol style="list-style-type: none"> <li>1. # of posters/flyers</li> <li>2. # of radio/TV PSAs</li> <li>3. # of radio/TV press releases</li> <li>4. # of times database used in contacts</li> </ol> | <p>F.</p> <ol style="list-style-type: none"> <li>1. 200 flyers</li> </ol>   | <p>F. no data</p>   | <p>F. 0</p>   |
| <p>IV. Referrals to parents/parent groups</p> <ol style="list-style-type: none"> <li>A. # of requests</li> <li>B. # of parents to parent groups</li> <li>C. # of parents to other parents</li> </ol>                     | <p>IV.</p> <ol style="list-style-type: none"> <li>A. 30</li> <li>B. 30</li> <li>C. 30</li> </ol>  | <p>IV.</p> <ol style="list-style-type: none"> <li>A. 50</li> <li>B. 35</li> <li>C. 30</li> </ol>  | <p>IV.</p> <ol style="list-style-type: none"> <li>A. over 100</li> <li>B. 25</li> <li>C. 60</li> </ol>  |
| <p>V. Referring parents to other agencies</p> <ol style="list-style-type: none"> <li>A. # of requests</li> <li>B. # of parents referred</li> <li>C. Nature of information</li> </ol>                                     | <p>V.</p> <ol style="list-style-type: none"> <li>A. 50</li> <li>B. 50</li> <li>C. partial care for teens lvg. hosp., in-state resid. serving dual diagnosis</li> </ol>  | <p>V.</p> <ol style="list-style-type: none"> <li>A. about 300</li> <li>B. about 300</li> <li>C. services for leavers of state hosp., rts. for out of home plcemnts., sp. ed. serv.</li> </ol> | <p>V.</p> <ol style="list-style-type: none"> <li>A. over 100</li> <li>B. we refer directly</li> <li>C. residential placement, respite care; in-home services</li> </ol> |

Table 4

Statewide Parent Association for the Children's Effort - 3

| Evaluation Indicators   | Progress Report - 1   | Progress Report - 2   | Progress Report - 3  |
|---|---|---|--|
| D. Geographic diversity of requests<br>E. Geographic diversity of referrals   | D. evenly distributed<br>E. referrals as close to home  | D. no data<br>E. greatest #s from North & Central regions, neediest areas: Newark & Jersey City increasing  | D. various<br>E. various   |
| VI. Formal/Informal contacts<br>A. 1. # of staff contacts w/parent grps.<br>2. Nature of contact<br><br>B. # of meetings w/parent groups<br>C. # informal connections between parent groups   | VI.<br>A. 1. 15<br>2. assessments, TA, facilitate<br><br>B. no data<br>C. no data   | VI.<br>A. 1. 10<br>2. TA<br><br>B. 3<br>C. 3  | VI.<br>A. 1. 8<br>2. phone contact, CHADD mtg.<br><br>B. 3<br>C. innumerable   |
| D. # of parent scholarships<br><br>E. 1. # of statewide meetings<br>2. Nature of meetings<br><br>3. # of parent participants<br>F. 1. # of trainings/workshops attended by parents<br>2. Nature of trainings<br><br>3. # of parent participants | D. 3 self-help clearinghouse conf., support group training conf.,<br>E. 1. 2<br>2. advocacy committee<br><br>3. 2<br>F. 1. 1<br><br>2. dv/prmnt. of support group<br><br>3. 3 | D. 0<br><br>E. 1. 5<br>2. SPACE, family-based conf., child & fam. advoc. comm of MHANJ., MH conf.<br>3. 50<br>F. 1. 3<br><br>2. Statewide parent meeting, services for out of home, parent/prof. partnership<br>3. 45 | D. 2<br><br>E. 1. 2<br>2. SPACE mtgs.<br><br>3. no data<br>F. 1. 2<br><br>2. self-help clearinghouse, Assoc. for Children of NJ<br>3. 11 |

Table 4

Statewide Parent Association for the Children's Effort - 4

| Evaluation Indicators  | Progress Report - 1  | Progress Report - 2   | Progress Report - 3  |
|--|--|---|--|
| <p>VII. TA to support groups<br/>                     A. 1. # of requests<br/>                     2. Nature of TA<br/>                     3. # of times TA provided<br/>                     4. a) # requests for forming new group<br/>                     b) nature of info provided<br/>                     5. # of meetings to develop statewide parent organization</p> | <p>VII.<br/>                     A. 1. 16<br/>                     2. Monthly mtg. of coalition planning effort<br/>                     3. 16<br/>                     4. a) 1<br/>                     b) Tech. Assistance<br/>                     5. 3</p> | <p>VII.<br/>                     A. 1. 6<br/>                     2. Starting groups<br/>                     3. 6<br/>                     4. a) 2<br/>                     b) packets for starting groups<br/>                     5. 4</p>             | <p>VII.<br/>                     A. 1. 4<br/>                     2. org. new grps.<br/>                     3. 16<br/>                     4. a) 4<br/>                     b) org. new grps.<br/>                     5. 5</p>           |
| <p>VIII. Develop Statewide parent org.<br/>                     A. # of parent members<br/>                     B. # of meetings re: legislature<br/>                     C. types of meeting<br/>                     D. # of calls to parents<br/>                     E. # of legislative bulletins<br/>                     F. # of times testimony given</p>                | <p>VIII.<br/>                     A. about 150<br/>                     B. 3<br/>                     C. advoc. comm. of MHANJ<br/>                     D. 3<br/>                     E. 30<br/>                     F. no data</p>                            | <p>VIII.<br/>                     A. about 400<br/>                     B. 3<br/>                     C. adv. comm. mtg. of MHANJ, local co. advoc<br/>                     D. 0<br/>                     E. 0<br/>                     F. 0</p>          | <p>VIII.<br/>                     A. 400<br/>                     B. no data<br/>                     C. in dev. stages<br/>                     F. 4</p>  |
| <p>G. # of times media contacted<br/>                     H. types legislative activity<br/>                     I. # of legislative activities</p>  | <p>G. 5<br/>                     H. no data<br/>                     I. no data</p>  | <p>G. 2<br/>                     H. 0<br/>                     I.</p>   | <p>G. 3</p>  |
| <p>IX. Outreach to underserved parents<br/>                     A. # of efforts to reach<br/>                     B. Nature of efforts<br/>                     C. # of new groups<br/>                     D. # of parents<br/>                     E. # of minority parents in support grp.<br/>                     F. Feedback from parents</p>                              | <p>IX.<br/>                     A. no data<br/>                     B. no data<br/>                     C. no data<br/>                     D. no data<br/>                     E. est. 30<br/>                     F. no data</p>                             | <p>IX.<br/>                     A. 3<br/>                     B. mailings, statewide mtg.<br/>                     C. 2<br/>                     D. 15<br/>                     E. approx. 15<br/>                     F. parents want to be included</p> | <p>IX.<br/>                     A. 2<br/>                     B. newsletter mailings<br/>                     C. 4<br/>                     D. 32<br/>                     E. no more than 5<br/>                     F. very positive</p> |

Table 4

Statewide Parent Association for the Children's Effort - 5

| Evaluation Indicators   | Progress Report - 1   | Progress Report - 2  | Progress Report - 3  |
|---|---|--|--|
| <p>X. Expenditures, resources &amp; donations</p> <p>A. Money raised</p> <p>B. In-kind</p> <p>C. # of volunteers</p> <p>D. Volunteer time</p> <p>E. Summary of expenses</p> | <p>X.</p> <p>A. \$2,500 raised for southern region support group</p> <p>B. use MHANJ computer system</p> <p>C. N/A</p> <p>D. tracked next quarter</p> <p>E. Summary available</p> | <p>X.</p> <p>A. 0</p> <p>B. use computer &amp; copying, donation of AT&amp;T PC computer</p> <p>C. 20</p> <p>D. 2000 hrs.</p> <p>E. budget summary incl.</p> | <p>X.</p> <p>A. 0</p> <p>B. no data</p> <p>C. 4</p> <p>D. no data</p> <p>E. summary attached</p> |