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ABSTRACT

This paper profiles nine model programs for supporting families who care for a child with a severe illness or one or more disabilities and discusses current trends as they emerged from interviews with key persons in the field. Core components examined include self-help, advocacy, parent education, respite care, family-centered case management, and cash assistance. The following programs are described: Family Impact, Grand Rapids, Michigan; Family Support and Resource Center, Dane County, Wisconsin; Give Families a Break, Allegheny County, Pennsylvania; The Family Support Project, Butler County, Pennsylvania; Family Support Network of North Carolina, Chapel Hill; Parents Organization Supporting Special Education, Georgetown, Kentucky; Parents Involved Network, Philadelphia, Pennsylvania; Clinical Case Management, Tampa, Florida; and The State of Alaska--Services for Children and Youth. After a final section considering the future of such programs, contact information is given for all programs described. Three references listed. (PB)

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THE STATE OF THE ART**

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**FAMILY SUPPORT PROGRAMS FOR FAMILIES WHO
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THE STATE OF THE ART**

BACKGROUND

This monograph was written as part of a three year project funded by the National Institute on Disability and Rehabilitation Research. The intent of this project is to identify and explore various approaches to supporting families who care for a child with a serious illness or severe disability at home. The purpose of this monograph is to profile some model programs and discuss the current trends in family supports as they emerged from interviews with persons who have been leaders in formulating the direction of these innovative programs.

Our concept of a comprehensive family support program was developed, in part, as a result of meetings at the "Next Steps" Conference sponsored by the Portland State Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families which took place in Washington, D.C. in December, 1988. The purpose of this conference was to establish a national family agenda for families with children with emotional or behavioral handicaps. A national organization, The Federation of Families for Children's Mental Health, was created as a result of this conference.

The family support working group at the conference was composed of parents of children with emotional or behavioral disabilities and professionals connected with serving such children and their families. The mission statement for the group reads as follows:

Every family has a basic right to an appropriate, available and accessible support base to meet family identified needs.

The objectives identified for this mission read as follows:

1. The service system should build on empowering and utilizing the strengths of families, insuring that families are equal partners in planning, implementing and evaluating programs.
2. Policy, legislation and funding will provide incentives to develop innovative programming, choices, family involvement, service integration and collaboration.

The working group assembled a lengthy list of components of family support that they believed could and should be coordinated in some way to provide adequate support to families in order to care for their children at home. As a result of this discussion, there is an assumption that in the model programs described below, home-based services are valued and viewed as integral to service provision when appropriate.

For the purposes of this monograph, the core components of family support have been identified as:

- Self-help
- Advocacy
- Parent education
- Respite care
- Family centered case management
- Cash assistance

The structure of this monograph will be to 1.) define the population, 2.) profile model programs that coordinate in some systematic fashion all or most of the core components listed above, 3.) profile any one or cluster of components which are delivered in a particularly creative fashion, and 4.) present a discussion of the future of family support programs.

Methodology

Phone interviews were conducted with persons knowledgeable about existing family support programs at both state and local levels. The Child and Adolescent Service System Program (CASSP) contact list, the State Mental Health Representatives for Children and Youth (SMHRCY) active members list, and the Next Steps Conference participant list were the primary sources of contacts around the country. Persons on these lists were contacted regarding family support programs in their states. The core components of family support programs (listed above) were mentioned and the respondents were asked if they were aware of any programs existing in their state which encompassed all of the components or clusters of components that were available to families in innovative programs. Contacts were also asked if they knew anyone else in their state who may know of other programs.

The greatest advances in the area of family support have arisen from the fields of Mental Retardation and Developmental Disabilities. Even in MR/DD, efforts in family supports are barely ten years old. (Cohen, Agosta, Cohen and Warren, 1989). Contact persons responding to the data collection often stated or were aware that more was available to families with children who have mental retardation/developmental disabilities than to families of children with emotional, behavioral or mental disorders. Programs which offer

comprehensive family supports are very rare. These findings are consistent with a recent survey of family supports in all fifty states (Knoll, Covert, Osuch and O'Connor, 1989).

Any program which included all or almost all of the components is described in this paper. The cluster programs included were all felt to have provided services in an unusual or innovative manner. All programs described must serve families of children with emotional, behavioral or mental disorders or be open to such families. Programs whose primary focus was intensive home-based treatment were not included unless several other components were also present. Programs in the planning stage were not included, although operational programs were included in certain cases even though new program features were currently being developed.

There are limitations to this type of data collection method. It is quite possible that innovative family support programs exist that were not discovered by this data collector. The purpose of this paper is to provide an overview of programs, not a complete catalogue.

Description of the Population

There exists significant controversy in the field regarding a definition of severe emotional disturbance in children. It is beyond the focus of this monograph to tackle the issue of a precise definition which would be acceptable to the field. For our purposes, we will rely on portions of the definition of the population as presented in the Child and Adolescent Service System Program RFP. This population description focuses on the following characteristics:

- Age: 18 or under, with some exceptions
- Lack of ability to perform in the family, in school and in the community
- Multi-agency need, service needs in multiple agencies
- Disability/disorder, presence of a mental or emotional disorder and/or disability which must be present for at least one year or is expected to last more than one year.

Model programs coordinating most or all of the critical components of family support:

Family Impact, Grand Rapids, Michigan.

The purpose of this program is to provide services to children with severe emotional and behavioral disabilities who are in group care or who are at risk for out of home placement and their families. The aim of this county funded agency is to prevent out of home care and provide families with needed services to allow the return of a child from out of home care back to the family. In 1988, Family Impact received approximately 430 referrals, served 260 families, and placed 11 children in out of home placements. Referral sources are as follows:

14% from schools

22% from parents

49% from residential providers and agencies providing only outpatient mental health services who recommend more intense levels of services

15% from other state agencies such as Child Welfare

The budget of the agency is \$1.1 million. Family Impact is under contract with a county community mental health agency which in turn receives its funding from the Michigan Department of Mental Health.

Family Impact offers the following services:

1. **Case management and in-home therapy services provided by a master's level family intervention specialist.** Services are not only available to families whose children are at risk for out of home placement, but are available as well to families whose children are currently in an out of home placement. This provides an important continuity of care component that is often lacking when a child is placed in group care. The family intervention specialist also provides advocacy services in dealing with schools and other agencies and provides a case management function. The agency is currently developing an Assertive Community Treatment Team which will function in a more intensive way than the regular in-home therapy program described above.

The Assertive Community Treatment Team will provide services to children, most of whom, have been in out of home placements. Children accepted into this program are those whom the system has been unsuccessful in treating. There may be no family members around. The team provides treatment and supervision seven days per week if necessary. All the children involved are in day treatment facilities in the public school. The team will meet every day to discuss cases. There will be more money available per child in this program than in the regular in-home therapy program.

2. **Parent education in the form of parenting classes offered throughout the year.** The agency is in the process of producing video tapes as educational resources that cover issues such as attention deficit disorder which provide concrete information regarding how parents can more effectively deal with children displaying such disabilities.
3. **Establishing a strong relationship with the local parent run support group.** Parent support groups have not been terribly successful within the agency. As a result of this, Family Impact is working with the local parent run support and advocacy group to help the agency develop more successful groups. Critical to this effort is the plan to create a formal mechanism through which families are systematically referred to the parent group for self help and advocacy services. In addition, Family Impact's advisory panel has always

included parents, and the parent who is the president of the local support group is on this panel.

4. Family Impact currently has four **respite care** models available to families. These include:

- Foster care respite
- Access to a county run short term respite facility for protective service referrals for up to 30 days
- One-to-one respite care in which a trained professional spends from 6 hours up to a few days with a child
- Crisis hospitalization, on a short term basis, for suicidal or homicidal children.

The agency is currently in the process of proposing a weekend retreat respite program on a farm owned and operated by Franciscan nuns.

Respite models in the process of development include:

- In home respite provided by volunteers.
- Crisis respite care available on an on call basis, usually for a weekend in a locked residential facility. This is run by a private group care agency. This service is usually available over a weekend.

5. **Cash assistance** in the form of a discretionary fund has been utilized by families. These monies are available to families on the basis of a treatment team decision and cover such things as reestablishing fuel delivery which has been cut off, down payments for apartments, groceries and other essentials. When the Assertive Community Team is established, there will be approximately \$10,000 cash assistance pool available to cover the needs of 24 children and families.

Family Support and Resource Center, Dane County, WI.

This agency provides family support services to families whose children have a wide range of disabilities. The disabled person must be age 21 or younger. The agency began as a pilot program funded through the state Developmental

Disabilities Planning Council in 1983. Though this model has not been implemented on a statewide basis yet, the budget for the agency is now provided through a county contract via the state Department of Health and Social Services. The model may be instituted statewide by 1991.

The Family Support Program and the Respite Care Program are the two components which comprise the agency. The Family Support Program links home based service coordination (case management) with cash assistance, and the Respite Care Program provides a pool of 125 respite workers available to families.

In 1983, the Family Support Program served 100 families and the Respite Care Program served 310 families. A percentage of these families received services from both programs. Referrals come from other types of agencies such as day care, early intervention programs, schools, hospitals, parent support groups, and generally by word of mouth. Although the majority of families served by the agency have a child with a developmental disability or physical illness or disability, a small number of families are served whose children suffer from an emotional or behavioral disability or are dually diagnosed with mental retardation and an emotional/behavioral disability.

The 1989 budget allotments are as follows:

Family Support Program

\$81,000 - operations budget

\$129,000 - cash assistance budget

Respite Care Program

\$90,000 - operations budget
\$50,000 - respite subsidy budget

The Family Support Program offers or provides linkages to the following services:

1. **Service Coordination.** This service takes place in the family home or in the community. It consists of a family advisor working with the family to examine the needs of the family in terms of services and tangible items, to provide referrals to obtain these, and to provide informal advocacy and parent education. The family advisor helps the family gain access to community resources to provide for various needs, including the needs of other family members besides the identified disabled family member.
2. **Cash Assistance.** Once it is established that a family is in need of cash assistance because the needs of the family cannot be met through any other resource, a family plan is written by the family and the family advisor indicating priorities for the use of the cash funds. Some families are given a one time cash subsidy to pay for a particular item or service, and others are given a monthly check. Families are eligible for up to \$3,000 per year per disabled family member. Families are asked to keep receipts or records of purchases, but are not asked to justify expenditures.

There are 16 categories for the use of the cash subsidies:

- architectural modifications
- child care
- counseling/therapeutic resources
- dental/medical care not otherwise covered
- specialized diagnosis and evaluation
- specialized diet/nutrition/clothing
- specialized equipment/supplies
- homemaker services
- in-home nursing services/attendant care
- training or parenting courses
- recreation activities
- respite care
- transportation
- specialized utility costs
- vehicle modification
- other (i.e. legal fees)

3. Parent Education, Advocacy, and Self-Help. As stated above, family advisors provide informal parent education and advocacy services. The agency has a resource file available to parents on a number of topics. There is a strong referral relationship with several local self-help groups. Within these groups parents are able to obtain support, advocacy and educational resources. Many parents active in these self-help groups are also recipients of services from the Family Support Program and the Respite Care Program.

The Respite Care Program offers a pool of 125 respite workers. These respite providers are composed of a diverse group of people including students from the local university and nurses. There is an orientation process for respite workers provided by the agency. In addition, respite services may be purchased from a natural provider connected with the family such as a neighbor, friend or relative. Thus, the provider is not always known to the agency. Respite providers connected with the agency are matched to family needs, so for example, a person with some medical experience would be chosen to provide respite for a medically fragile child over someone who had no medical experience. Unfortunately, this program is available only to those families with a child who has a developmental disability or a dual diagnosis of developmental disability and an emotional or behavioral disorder.

Respite is provided in either the family's home, the community or in the worker's home. The family's must contribute \$1.25 per hour for respite care plus \$.50 for each additional child per hour, although there is a waiver available for this fee. The total cost for in-home or community respite is \$3.70 per hour and \$3.35 per hour for respite in the worker's home. Many families supplement the \$3.70 per hour with money from their cash assistance allotments so as to be able to offer a more competitive wage to respite providers.

GIVE FAMILIES A BREAK, Allegheny County, PA.

GIVE FAMILIES A BREAK (GFAB) is a program administered by the United Mental Health Inc., a mental health association located in Allegheny County. This program began in 1987 with a grant from the Developmental Disabilities Planning Council. United Mental Health is an advocacy and public education organization, and began the program as a demonstration project. The project intent was to provide support services to families with children with emotional, behavioral or mental disorders and was funded for 5 components:

1. Develop an advisory council composed of professionals and family members of emotionally or behaviorally disordered children;
2. Establish a self-help group run by parents;
3. Provide respite care;
4. Develop a telephone support line;
5. Provide financial assistance.

Referrals are generated mostly through the public relations efforts of the agency. These efforts consist of media publicity and dissemination of information to local service providers about the existence of the program. GFAB also quarterly publishes PARTNERS, a newsletter aimed at parents and professionals which promotes the partnership ideology between parents and professionals. The most recent issue of this newsletter featured articles on such issues as: educational rights for children, the development of a parent to parent telephone support line, mutual help groups, and a listing of summer activities for children. There is no formalized or structured referral process. There are currently 250 families on the mailing list who receive the agency's parent newsletter and 200 - 275 families have been in touch with the program either through the telephone support line, the self-help meetings or direct advocacy services. Sixteen families are currently registered in the day care center and 80 families are registered with the in-home respite program, Take a Break. Sixteen families have received homecoming grants, which provides cash assistance to families who have a child returning to the family from a long term psychiatric facility.

The total program budget is \$394,916 and this covers the period 4/1/88 through 3/31/90. In addition to the Developmental Disabilities Planning Council grant, matching funds were received from the Allegheny County Mental Health/Mental Retardation program, the Howard Heinz Endowment. In-kind matches were provided by United Mental Health and PLEA, the day care/respice care provider.

GIVE FAMILIES A BREAK provides the following services to families:

1. **Parent Education.** The agency is currently developing a family resource center with literature and materials on emotional/behavioral/learning disabilities which will be staffed by a parent consultant knowledgeable in these areas as well in systems and advocacy. Informal meetings will be held and there will be a play area provided for children. In addition, the support group has speakers on various issues as well as a newsletter, P.S. which provides practical information to parents and PARTNERS, which addresses issues pertaining to parents and professionals working together.
2. **Parent Support.** A parent run self-help group was established and meets in Allegheny Co. twice per month. The agency has also developed and implemented a telephone support line which is used mostly by parents who are not attending the self-help group. The line is staffed by four parent volunteers from the advisory council. They were trained to be effective supportive listeners.
3. **Respice Care.** GFAB offers two models of respice which were developed with PLEA, an established therapeutic pre-school/respice care provider in the community.
 1. **Take a Break** is an in-home specialized babysitting service which is paid for out of the project's respice fund. This program has been successful and continues to grow. The agency is currently working on developing an overnight respice model in a provider's home, and plans to match 10 care givers with 3 families each. Care givers and consumers will be trained together.
 2. **Center-based day care center.** The original intent of this program was to provide a drop-in center which would free families up to do errands, go to appointments, etc. The agency envisioned that of the 20 slots, 10 would be used for full-time day care and 10 would be used as

needed for respite. The agency has found this program to be costly and that transportation is a problem for many families. It is being used more for ongoing day care than for a respite day care/drop-in center.

A goal for the agency is to provide a continuum of respite care and staff are working on developing a training package to be used by any agency for overnight respite and will include evaluation tools.

4. **Cash Assistance.** The project has a \$10,000 financial assistance fund to provide one time grants to families whose children are being discharged from psychiatric facilities. These are "no strings attached" funds, usually for approximately \$250.00, which have been used for such things as clothes, food, furniture, lessons, and welcoming home parties.

5. **Advocacy.** United Mental Health is an advocacy organization. Advocacy is provided by staff on both individual case and system levels. Staff will help individual families advocate for services in the school, for example, as well as represent parent interests in such forums as state Board of Education hearings on educating children at risk.

GFAB does not have a case management component. It does not provide any direct clinical services.

GFAB has an evaluation component coordinated by the University of Pittsburgh School of Public Health.

The Family Support Project, Butler County, Pa.

The Mental Health Association of Butler County received a grant in 1987 through the state Developmental Disabilities Planning Council to provide family support services to families who have children with emotional, behavioral or mental disorders. This demonstration project was funded from 10/87 through 3/90 to provide four major components:

1. Establish a parent support group.

2. Provide parent education and advocacy.
3. Provide cash assistance.
4. Develop an advisory council of parents and community volunteers to participate in the decision making process for the organization.

The Family Support Project serves a rural area approximately one hour north of Pittsburgh. Referrals are obtained primarily through school districts, private therapists, clergy, self-help groups and pediatricians. The agency sends out flyers to service providers in the area to alert them to various programming offered by the support group and other services. The agency reports that it has been difficult to get the local community mental health clinic and the state and local hospitals to refer families to the program, though some gains have recently been made.

The parent education, advocacy and support group services have served approximately 125 families. Twelve families have received cash assistance and eighteen families have received significant individual case advocacy services such as staff persons going to meetings at schools, etc. The grant from the state Developmental Disabilities Council is \$65,900 and the agency provides an in-kind match of \$22,800. These figures represent a 2 1/2 year budget.

The Family Support Project provides the following services:

1. **Self-Help.** Two support groups meetings are held each month. The first meeting has an educational format with speakers. Child care is offered at these meetings at no cost. The second meeting has a sharing format where parents take the lead in initiating various issues. There are currently 2 facilitators who do publicity and other leg work. A goal is for this group to be a free standing parent group solely run by parents by the end of the project.

2. **Parent Education.** In addition to the self-help meeting with an educational format described above, there are five week parenting courses run by a mental health professional held on a quarterly basis. An Education Rights Workshop run by an attorney is held in different places throughout the county and is available at no charge.
3. **Advocacy.** In addition to the Education Rights Workshop described above, the agency offers individual case advocacy services. This may entail a staff member attending IEP meetings at schools with parents and other intensive efforts aimed at attaining appropriate services for children and families.
4. **Cash Assistance.** Cash assistance of up to \$1000 per year per family is available through the project. The families choose how to spend these monies. These grants have been spent on such services as in-home therapy, recreation, medication and evaluations. Respite may also be purchased with these funds, although there is a significant lack of availability of respite in the area. The strong family self-empowerment philosophy of the program has translated into a policy of not requiring families to keep receipts on what they have purchased.

There is no formalized case management component to the project, though in the process of providing advocacy services, staff members often provide the essentials of case management in terms of referral to services. The project embraces the concept and practice of family self-empowerment. Staff members view these efforts at service liaison as important, and emphasize that they must be provided in a way which sustains an alliance with families and which supports decision making within the family.

The Developmental Disabilities Council will fund a grant to do independent evaluations for their model projects.

Model Programs Coordinating a Cluster of the Critical Components of Family Support

Family Support Network of North Carolina, Chapel Hill, NC.

This organization provides support and information to families with children across disabilities and chronic illness. It operates out of the University of North Carolina and started in 1985 with a grant from the state Developmental Disabilities Council.

FSNNC is now a state budget item, and has an operating budget of \$200,000 from state and private foundation monies. It gives approximately \$40,000 per year to some of its local parent to parent programs, of which there are 15 around the state. Activities with local parent to parent programs are funded in part by state monies.

There are three major activities in which the organization is involved:

- 1. Developing and promoting a statewide network of local parent to parent support groups.** These groups are non-categorical, meaning that they are open to parents independent of the child's disability or illness. Since 1985, 15 groups have formed and many have a paid parent coordinator. The Chapel Hill staff are responsible for providing technical assistance, site visits, telephone conferences, regional meetings and other development and supportive activities. The groups are usually located at another host agency such as a center serving children with developmental disabilities. 225 persons have been trained as support parents by local groups and may be called upon by other parents in need.

- 2. Central Directory of Resources - Family Information Network.** FSNNC is responsible for developing a computer data base which has information on disabilities and illness and where available services can be found. Funding is being sought to place these data bases in the local agencies where the parent to parent support groups are located. Printed materials, video tapes and materials on training, conferences and workshops are also available and may be on line in the data base. Parents and professionals who have agreed to be resource persons are also listed in the data base.
- 3. Promoting parent and professional collaboration.** The Chapel Hill staff and parent program representatives give presentations to professional groups in order to educate professionals on the needs of families and to promote professional participation in parent to parent support groups. Staff also work to recruit parents for panels, boards, and advisory groups upon request.

FSNNC is promoted or publicized through press releases to newsletters, posters, its own quarterly newsletter, presentations, word of mouth, University Hospital social services and Duke University. Many consumers report hearing about FSNNC through other parents and/or professionals.

Through close collaboration, group coordinators are able to notify each other of families needing to go to various cities around the state for their children to receive treatment. Support group families are notified in those cities and are connected up with the traveling families. Traditional groups involved with this population have not often been actively involved in non categorical programs. Staff members are beginning to explore means for outreach to those interested in families of children with emotional, behavioral or mental disorders such as CASSP.

*Parents Organization Supporting Special Education (POSSE),
Georgetown, KY.*

The purpose of this organization is mainly to provide an opportunity for parent self-help in tandem with a parent initiated respite program. The parent

support group began in 1987 as a non-funded and independent group. In 1988 the group began a joint initiative designed by parents with the local community mental health center. Together they received a grant from the state for \$25,000 plus matching funds of \$16,732 from the CMHC and \$3,588 from Georgetown College. This local college provided students to work in the after school and respite programs as well as in recreational activities. In addition to the college students, other persons in the community are recruited as respite providers and are trained by both the parents and CMHC staff.

The grant has enabled the following services to be provided:

- an after school program from 2:30 - 5:00 is available on a sliding scale.
- 5 hours of in-home respite per week is provided free of charge.
- special baby sitting is available on a pre-arranged, sliding fee scale basis.
- short term (up to 5 days) emergency out of home respite is available in a transitional group home free of charge.
- a 24 hour Comprehensive Care Crisis Hotline is available and staffed by CMHC staff.
- a summer program within the community from 8:00 am to 5:00 pm on a sliding fee scale.

The importance of recreational activities is central to the POSSE families. A priority has been to involve the children in community activities which encourages the community to be responsible for providing integrated activities. POSSE holds fund raising activities to support scheduled camping trips which

can accommodate twenty children and a "family day" outing which provides a pot luck meal and recreation for families.

Parents Involved Network (PIN), Philadelphia, PA.

The purpose of this parent run organization, based at the Mental Health Association of Southeast Pa. located in Philadelphia, is to provide families with support, advocacy and education. There are PIN groups located across Pennsylvania.

PIN assists parents in the following ways:

- Provides parents with support, telephone counseling, training, education, case advocacy, organizational assistance, linkages between parents and other parent organizations, and promotes parent professional collaboration.
- Seats members on state and national program planning and advisory committees.
- Offers a self-help advocacy group based out of the children's state hospital, and provides statewide telephone network to disseminate information about hospitalization including obtaining contacts of other parents whose children have been hospitalized and are willing to be contacted.
- Publishes a statewide newsletter for parents with a circulation of 1800.
- Provides a parent resource center staffed by parents which has various materials including literature on emotional and behavioral disabilities.
- Contracts with counties to hire parent coordinators to organize self-help advocacy groups and provide other family support assistance.
- Provides technical assistance to counties on family support issues through a Pennsylvania CASSP contract.

- Organizes self-help advocacy groups, including the provision of technical assistance to such groups.

Clinical Case Management, Tampa, FL.

This program is based out of the local mental health center and is aimed at serving children through age 18 in out of home placements or who are at risk for out of home placements. It is an intensive case management program which uses flexible dollars to provide families with needed services. The total operating budget is \$155,000, \$30,000 of which are flexible funds set aside for wrap around services. This program was first contracted through the Florida Department of Health and Rehabilitation Services in 1984.

Program staff have limited caseloads of 10 to 20 and function in the following ways to assist families:

- Provides a clinical assessment of the child and of family strengths and helps families clarify goals. Meetings are held at the family home.
- Arranges regular Planning Linking Conferences with all service providers and family to monitor progress and appropriateness of services.
- Staff act as family advocates and as service brokers and hire consultants to provide families with services.
- Staff are available 24 hours per day and can provide crisis intervention in the home or at any other setting when necessary.
- Provides linkages to support groups.

The philosophy of the program is to attempt to provide families with whatever it is they may need to keep their children at home. Cash assistance is available to families to purchase therapeutic services, recreational opportunities, items

for the home which aid in the child's adjustment such as punching bags, a gym membership and respite services ranging from 6 to 60 hours per week. The program is strictly voluntary and takes families from all over the county. If a child must leave the home and go into an out of home placement, the program continues to work with the child and the family. Flexible dollars have been used to help in transitioning a child to a less restrictive setting. This has been done by paying for extra staff time so someone familiar can be with the child as he moves to the new setting.

The State of Alaska: Services for Children and Youth

The following is a partial description of a service system in place in Alaska, and not a description of a particular local program. Specific facets of the system are described because they are inherently supportive to families in their own environments.

Alaska is unique in characteristics of size, geography and population. Citizens live far apart precluding the existence of local programs in many areas of the state. Planners and administrators had to envision and create a system of care for children and adolescents with emotional, behavioral or mental disorders which addressed the needs of persons living in remote areas. Previously, most children considered "severely mentally ill" were sent to treatment facilities in the lower 48 states at a prohibitive cost to the state. State mental health administrators wanted to eliminate the pattern of sending children out of state and instead provide services to children and families in their own communities.

The following are characteristics of the state system which support families:

The state pays for a yearly conference for parents and professionals to come together to discuss the needs of children and families and to problem solve. This conference is put together and run by parents.

Each child within the target population has an Individualized Assistance Coordinator who coordinates treatment and education teams and ensures that plans are in place. **At a minimum, team members include:**

parent or guardian;
a school representative;
a representative from the agency responsible for psychological treatment;
a representative from the Division of Family and Youth Services if the child is in state custody.

The cornerstone of the program is the availability and use of flexible funds paired with establishing local individuals to participate in the child's care in whatever way is needed. For example, a neighbor is paid to provide respite and or companionship to the child; a job coach is hired; an account is opened up at the local gas station for the family to be able to purchase gas. The use of flexible funds is based on the decision of the team.

There is a strong emphasis put on evaluation outcome data. This data has shown that children get better with wrap around funding to create needed services rather than trying to fit children into pre-existing services, most of which are out of the child's community. **Parents and administrators have been able to use the results of this data to show politicians and policy makers the efficacy of the flexible funding approach.**

The Future of Family Support Programs

Nationwide and within states, the value of the concept of family support and the development of family support programs is in a process of evolution. Most states have recognized the value of the concept of family support for families with children with emotional, behavioral or mental disorders. The states differ tremendously, however, in the degree to which family support programming exists. CASSP is playing an important role in raising consciousness around family support issues.

It is generally recognized that parents and professionals concerned about children with emotional, behavioral or mental disorders have a good model for organizing based on what parents of children with developmental disabilities have done. Although problems around stigma and blame are still very much alive, parents and professionals can learn from what these parents and professionals have done to effect legislative change, advocacy and coalition building for family issues. As in the field of Developmental Disabilities, parents must be the driving force behind change.

In addition to parents organizing on their own behalf, the family support efforts most likely to succeed will include the following:

- parent self-empowerment including emerging from isolation and the rejection of stigma and blame;
- a parent professional collaborative partnership;
- parents who are members of cultural minorities serving in leadership positions.
- the commitment of adequate funding for programs to meet family needs;
- publicizing of the ultimate cost-effectiveness of the programs in helping families avoid out of home placements for their children;
- increase availability of information to parents about emotional and behavioral disabilities, and the enhancement of the ability to make judgments about the information;

With the emergence of The Federation of Families for Children's Mental Health and other groups, we can hope that the widespread development of family support programming for families of children with severe emotional,

behavioral or mental disorders will be realized in the near versus the distant future.

HOW TO CONTACT MODEL PROGRAMS:

Family Impact - Contact Person: Bill Van Woerkom
1447 Lake Dr. S.E.
Grand Rapids, MI. 49506
616-235-1616

Family Support and Resource Center - Contact Person: Terri Johnson
1045 E. Dayton St. Rm. 308
Madison, WI, 53703
608-256-0400

GIVE FAMILIES A BREAK - Contact Person: Lynn Alms
United Mental Health Inc.
1945 5th Ave.
Pittsburgh, PA. 15219
412-391-1430

The Family Support Project - Contact Person: Sue Simm
Mental Health Association of Butler County
124 W. Cunningham St.
Butler, PA. 16001
412-287-1965

Family Support Network of North Carolina
Contact Person: Maryann Mastrianni
CB #7340
University of North Carolina
Chapel Hill, NC. 27599
919-966-2841

Parents Organization Supporting Special Education (POSSE)
Contact Person: Creasa Reed
2433 Burton Rd.
Georgetown, KY. 40324
502-857-2045

Parents Involved Network (PIN) - Contact Person: Glenda Fine
Mental Health Association of Southeast Pa.
311 S. Juniper St.
Philadelphia, PA. 19107
215-735-2465

Clinical Case Management - Contact Person: Cathy Roberts
Northside Center
13301 Bruce B. Downs Blvd.
Tampa, FL 33612
813-977-8700 or 871-7660

The State of Alaska
Contact Person: John Vandenberg
Coordinator: Child and Adolescent Mental Health
Division of Mental Health/DD
Dept. of Health and Social Services
Pouch H-04
Juneau, AK. 99811
907-465-4950

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Cohen, S., Agosta, J., Cohen, J., & Warren, R. (1989) Supporting Families of Children with Severe Disabilities. Journal of the Association of Severe Handicaps., Vol. 14, No.2, 155-162.

Knoll, J., Covert, S., Osuch, R., & O'Connor, S. (1989) *Family Support Services in the United States: An End of Decade Status Report*. Cambridge, MA: Human Services Research Institute.

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