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ABSTRACT

This bulletin reflects the commitment of Syracuse University's Center on Human Policy to the idea that children belong with families. The bulletin contains a policy statement which recommends; that all children, regardless of disability, belong with families and need enduring relationships with adults; that families with severely disabled children should be supported as needed; and when children cannot stay with their families due to family crises or other circumstances, efforts should focus on (1) reuniting the family; (2) adoption; and (3) foster care in that order. Efforts of public and voluntary agencies to apply the statement are documented. An article by Sue Lehr illustrates the need for family support services from a parent's perspective. Following the article, the purpose of family support, its costs, and its funding sources are reviewed. Legislation and innovative programs providing family support are described, including the Michigan Family Subsidy Act and programs in Wisconsin, Montana, Maryland (Calvert County), and New York (Syracuse). The concept of permanency planning is presented, and Michigan's efforts to implement the concept are described, specifically the experiences of the Macomb-Oakland Regional Center in permanency planning, specialized foster care, and respite care. (JDD)

FOR THE STUDY & PROMOTION OF OPEN SETTINGS

The Center On Human Policy

Community Integration Project and Research and Training Center on Community Integration, Center on Human Policy
Division of Special Education and Rehabilitation, School of Education, Syracuse University. September 1987.

FAMILIES FOR ALL CHILDREN

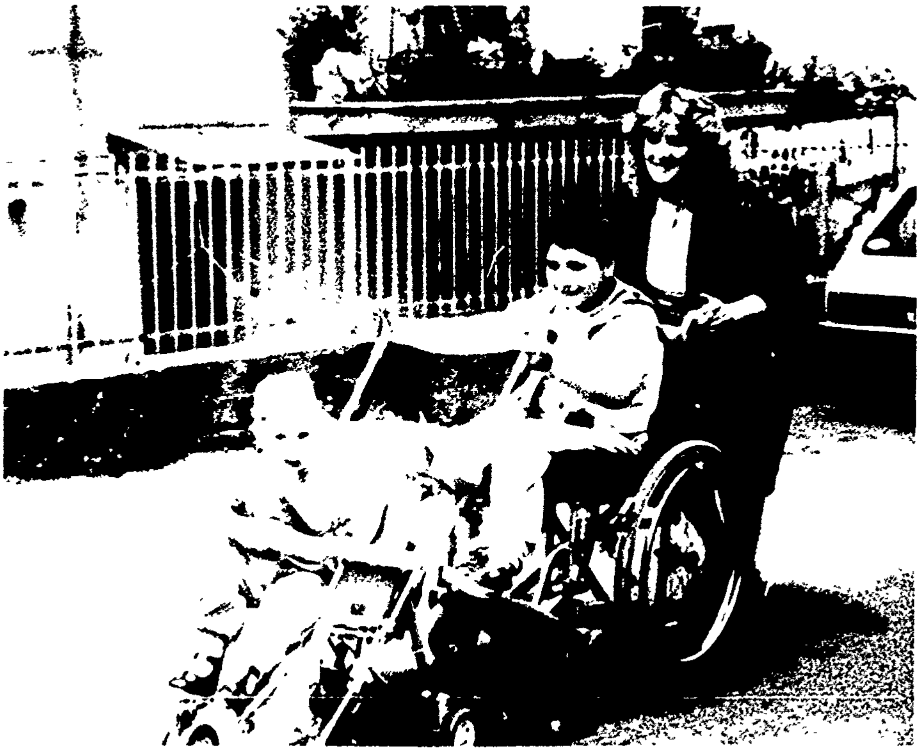
EDITOR'S NOTE

The Center on Human Policy has studied services for children with severe disabilities for the past two years, and has become even more committed to the idea that children belong with families — that families whose children have severe disabilities should be supported in as many ways as they need, and that children who cannot stay with the families into which they were born deserve to live with other families.

This issue develops this theme. We offer, first, a policy statement on families and their children, a statement that has been endorsed by many individuals, organizations, and states around the country. Readers who would like to endorse the statement may write to Steve Taylor, Director of the Center on Human Policy, to do so.

Other articles in this issue look at family support, taking a parent's perspective and a broad look at family support nationally. We present ways in which family supports are being provided in Wisconsin, Michigan, New York, and Montana.

Some children, no matter what supports are available, cannot remain with the families into which they were born. Should they be placed in group settings with other children with severe disabilities, or in temporary foster homes, where they are moved from home to home throughout their childhood? We present the concept of permanency planning, and describe the experience of one state that has committed itself to this concept. Michigan is developing its services so that all children with disabilities, no matter how severe, can live with families and experience consistent, enduring relationships with adults.



INTRODUCING A STATEMENT IN SUPPORT OF FAMILIES AND THEIR CHILDREN . . .

In 1979, the Center on Human Policy released "The Community Imperative" declaration, which supported the right of people with mental retardation to community living. We asked professionals, parents, and concerned people to endorse this statement.

While we remain deeply committed to community living for people with mental retardation, we have a clearer vision today of how best to support adults and children with developmental disabilities in the community.

We believe that *all children* with developmental disabilities, regardless of the severity of disability, *belong with families*.

Yet, thousands of children with developmental disabilities remain in public institutions, while thousands of others have been placed in nursing homes, group homes and other facilities. In most states, families still do not receive the supports necessary to keep their children at home.

In order to advocate for the right of children with developmental disabilities to live with families, we developed the following position statement, **A Statement in Support of Families and their Children.** This statement grew out of a meeting we held in 1985 that included representatives from states, universities, parent and consumer associations, and agencies from around the country.

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A STATEMENT IN SUPPORT OF FAMILIES AND THEIR CHILDREN

THESE PRINCIPLES SHOULD GUIDE PUBLIC POLICY TOWARD FAMILIES OF CHILDREN WITH DEVELOPMENTAL DISABILITIES...AND THE ACTIONS OF STATES AND AGENCIES WHEN THEY BECOME INVOLVED WITH FAMILIES:

All children, regardless of disability, belong with families and need enduring relationships with adults. When states or agencies become involved with families, permanency planning should be a guiding philosophy. As a philosophy, permanency planning endorses children's rights to a nurturing home and consistent relationships with adults. As a guide to state and agency practice, permanency planning requires family support, encouragement of a family's relationship with the child, family reunification for children placed out of home, and the pursuit of adoption for children when family reunification is not possible.

Families should receive the supports necessary to maintain their children at home. Family support services must be based on the principle "*whatever it takes.*" In short, family support services should be flexible, individualized, and designed to meet the diverse needs of families.

Family supports should build on existing social networks and natural sources of support. As a guiding principle, natural sources of support, including neighbors, extended families, friends, and community associations, should be preferred over agency programs and professional services. When states or agencies become involved with families, they should support existing social networks, strengthen natural sources of support, and help build connections to existing community resources. When natural sources of support cannot meet the needs of families, professional or agency-operated support services should be available.

Family supports should maximize the family's control over the services and supports they receive. Family support services must be based on the assumption that families, rather than states and agencies, are in the best position to determine their needs.

Family supports should support the entire family. Family support services should be defined broadly in terms of the needs of the entire family, including children with disabilities, parents, and siblings

Family support services should encourage the integration of children with disabilities into the community. Family support services should be designed to maximize integration and participation in community life for children with disabilities.

When children cannot remain with their families for whatever reason, out-of-home placement should be viewed initially as a temporary arrangement and efforts should be directed toward reuniting the family. Consistent with the philosophy of permanency planning, children should live with their families whenever possible. When, due to family crisis or other circumstances, children must leave their families, efforts should be directed at encouraging and enabling families to be reunited

When families cannot be reunited and when active parental involvement is absent, adoption should be aggressively pursued. In fulfillment of each child's right to a stable family and an enduring relationship with one or more adults, adoption should be pursued for children whose ties with their families have been broken. Whenever possible, families should be involved in adoption planning and, in all cases, should be treated with sensitivity and respect. When adoption is pursued, the possibility of "open adoption," whereby families maintain involvement with a child, should be seriously considered.

While a preferred alternative to any group setting or out-of-home placement, foster care should only be pursued when children cannot live with their families or with adoptive families. After families and adoptive families, children should have the opportunity to live with foster families. Foster family care can provide children with a home atmosphere and warm relationships and is preferable to group settings and other placements. As a state or agency sponsored program, however, foster care seldom provides children the continuity and stability they need in their lives. While foster families may be called upon to assist, support, and occasionally fill in for families, foster care is not likely to be an acceptable alternative to fulfilling each child's right to a stable home and enduring relationships.

APPLYING THE STATEMENT

The Statement in Support of Families and their Children has been endorsed by individuals, organizations, and states around the United States, and endorsements are continuing to come in. We believe that the momentum is building, that family support and permanency planning are ideas whose time has come. We asked a few individuals to describe ways in which the statement has been useful to them or ways its concepts have been applied in their states or organizations.

The Department of Mental Retardation in Connecticut has adopted the statement and uses its concepts to guide public policy decisions about children with disabilities. Linda Goodman, a representative of that Department, says, "the policy of permanency planning has been adopted on an informal level in the training of the staff of our specialized foster homes and of other agencies with regard to special needs adoption. We organized a parents' conference ently in Connecticut to publicize your policy of family support services, and help in its implementation in existing services."

Describing Connecticut's new public policy initiative on family support, she says, "We are trying to consolidate our family support services in each of the six regions we administrate by establishing family support coordinators. Each family support coordinator will be responsible for supervising respite coordinators and other staff appointed for providing any other support service that would require them to go into a home and work with the family household as a team.

"We have funding for transportation, for the adaptive devices program, and for the services of a case manager to whom families receiving support services are assigned. We are also providing early intervention services for 650 families of children with severe disabilities of ages birth to three years.

"We are trying to procure budget allocations of $100,000 a year for minor home alterations and for implementing the Lekotek program, a Scandinavian-based program which offers educational materials and toys for children with severe disabilities. Families would make monthly appointments to discuss their child with the Lekotek leader and take some toys home with them. They would also be offered referral services whenever necessary."

Jeff Strully, Director of the Association for Retarded Citizens in Colorado, describes its potential impact in Colorado as follows. "We are using the concept of family support to help us generate support from the state in terms of a commitment towards funding for providing services. Our long range plan is to keep families together, and the policy statement helps us to solidify our position. We are not directly involved in providing services, our primary goal being advocacy. The family support policy statement, which we fully endorse, supports our position towards this purpose

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and serves as a critical leverage that we use to procure the commitment of the bureaucracy and the state government."

The Association for Retarded Citizens of the United States (ARC-US) has adopted a policy statement that is a modified version of the Center's statement in support of families and their children. According to Sharon Davis, Director of Research and Program Services of the ARC-US, "the Children's Services Committee modified the original statement slightly to represent the ARC-US philosophy and presented it to the Board of Directors, which adopted it in May 1987." The fall, 1987 issue of *the arc*, the ARC-US newsletter, focuses on the statement and some of its implications, and will reprint the ARC-US version of the statement. ARC-US President Warren Tashjian's column will discuss the ARC's historical philosophy and position on family support and how that has culminated in adoption of the ARC-US "Statement in Support of Families and their Children." The issue also discusses policy implications of the Board's adoption of the statement.

Nebraska's legislature recently adopted what has become known as the "Family Policy Act (LB 637)." According to Dave Powell, ARC-NE Director, "it appears that the Center on Human Policy's statement in support of families and their children influenced the legislation, which reflects the philosophy and some of the language in the statement. I feel this is potentially the most important piece of legislation adopted this year by the Nebraska Legislature. It is unclear yet as to how the legislation will be implemented, but I feel that it will have many possible uses by advocates. The Family Policy Act applies to all children, including those with disabilities; we hope that it will prevent institutional placement of children, and if such placement continues to take place, the courts may be asked to interpret the legislative intent."

The Center on Human Policy is interested in learning about other states' and organizations' responses to the Statement. Readers with such information may call or write to Steve Taylor or Bonnie Shoultz at the Center.

FAMILY SUPPORT...OR IS IT?

by Sue Lehr

Support for families of children with disabilities is taking a new direction, and to reflect this there is a movement to promote a strong family support public policy initiative. As a parent of a youngster with severe disabilities, I gladly welcome this new initiative with a shout of "Hooray!"

In the past, family support services have tended to be determined by the agency or professionals rather than the family itself. Why is this? In an article in the *Coalition Quarterly* (1984, vol.4, no 1, pp.3-7), Gunnar Dybwad prods us to look to history for the answer. He describes how, over the years, but especially after World War II, parents became tired and resentful of society's discrimination against their children. Finally, parents rebelled. They wanted services for their children where none were available, and so they created them. They started their own schools, recreation programs and in some communities, they began sheltered workshops.

It did not take them long to realize that this was no easy task — they needed help. Recognizing their own limitations, the parents sought help from educators and other professionals. They were the experts, and parents turned to them for expert guidance and information. However, in the process, authority passed from parent to expert, a pronounced shift that left the family lost and forgotten. "For many years, we (the professionals) essentially ignored and devalued the family as a focal point of helping children with severe handicaps" (Dybwad, ibid.).

In essence, the family became convinced by the experts that they were not equipped to cope with their child and his/her extreme needs. Though they may not have intended to undermine the role of the family in the life of their child, the professionals began to tell the families what the families needed, and agencies began to develop services and programs to meet these needs. In many places, including my own area (Central New York), parents found that their child had to fit the program, not the other way around. I'll give two personal examples.

Jane and Carl (fictitious names) are friends of mine and parents of Alicia, a 13 year old girl who has been labeled autistic and emotionally disturbed. Alicia is by everyone's description a "tough kid." She hits, bites, scratches herself and others. Although she can speak she rarely utters intelligible words anymore. Alicia is Jane and Carl Baker's youngest daughter; they have two other children. But those of us who

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know the Bakers know that they love Alicia and try to do what they think is right. Despite her aggression toward others and her constant attempts to hurt herself, Alicia is lovable. But the Bakers are tired, they are getting older, Carl's health is poor, and Alicia is getting tougher.

Alicia was refusing to go to school in the morning. She refused to bathe, dress, or get on the bus Carl would literally drag her out of bed, forcefully dress her and drive her to school The Bakers had tried everything, but each morning had become a greater confrontation than the day before. Exhausted and frustrated, the Bakers requested "family support" services from a local agency. Specifically they asked for someone to come in the morning for about an hour to help get Alicia up, dressed and off to school In addition, they saw the need for a psychologist or social worker to help figure out what the real problem was, do some problem solving with the family, and provide some on-going support for Jane and Carl.

> **"Professionals have assumed the role of telling the parents not only what they need, but what they can have...To me, this is not family support."**

Both requests were processed by the agency, a procedure that took several days. Both requests were denied. It seemed the agency was unable to find someone who could go into the home during the morning hours, and their psychological services were not equipped to deal with people at home who had disruptive behaviors. Instead, the agency recommended placement for Alicia in an institution or, if there was space available, placement in a group home which was geographically located in another town. Was this, I wondered, family support?

My own experiences, while certainly less traumatic, have been equally frustrating. As a working mother, I have called several "family support" agencies seeking help in finding after-school care for my adolescent son. One agency which provides respite services sent me an eight page application form before they would even speak to me. (It came with $.48 postage due, too.) Later, I was informed they could not help me because I live in a rural part of the county and the few trained care givers in the general area only accepted preschool children. Without after-school care, I would be forced to quit my job. Is this family support?

I have talked with many other families over the years and the story is often the same. The agency worker listens as the family outlines their needs, or the family responds to a survey, questionnaire or checklist Then the agency describes what services they have available, who is eligible to receive the services, and at what cost. From this array, ideally, the family can choose what they need. In actuality, they often have to accept whatever the agency can offer. In some cases, families are put on waiting lists, referred to other agencies or simply denied services. From my experience, families who have children with severe disabilities or challenging behaviors are frequently the most needy and the least served.

> **"Family support services have tended to be determined by the agency or professionals rather than the family itself."**

In other words, the main problem seems to be that the professionals have assumed the role of telling the parents not only what they need, but what they can have. Families can say what they need, but the professionals will then tell them what they can have. To me, this is not family support. Families know best what will make their life easier, more productive, and secure for their child. But, unfortunately, professionals usually feel they know better what the family should have and often make decisions accordingly.

Hence my joyful response to the movement toward a public policy initiative for a new direction in providing family support services How will this initiative impact on families and agencies? Certainly, the obvious impact will be to truly make services and programs respond to the expressed needs of families As a parent, I believe firmly that this is how it should be. If "family support" is to be just that, it must be determined and directed by the family, with the assistance of the professionals, not the other way around.

Agencies should be the case managers, not the family managers Professionals need to stop telling the families that they, the professionals, know better what is needed. Their role should be to help the family identify what long and short term support services they need and assist them in accessing these services. If the services do not exist, then the professionals should be compelled to find or provide the technical assistance to generic community based agencies to create the service or augment already existing services. Let us support the initiative to ensure that family support will be just that: support for the family.

> **"If 'family support' is to be just that, it must be determined and directed by the family, with the assistance of the professionals, not the other way around. Agencies should be the case managers, not the family managers."**

TIMELY ANSWERS: WHAT ARE FAMILY SUPPORTS?

What is the purpose of family support? Family supports have two major goals: 1) to support families caring for their developmentally disabled infants, children, and dependents; and 2) to reduce costly out-of-home placements Without family supports, families are more likely to have to seek out-of-home placements for a family member with a developmental disability. By providing the right service at the right time, family supports can make a substantial difference in the quality of life for a family In some areas of the country, the availability of family supports has encouraged a family to bring a member home from an out-of-home placement. Appropriate family supports can also be a factor in adoption or permanency planning for a child with a severe disability.

What is meant by family support? In many places across the country, family support services are limited to the provision of respite care. While families benefit a great deal from access to respite services, family support can encompass much more Family-centered supports can be designed to aid the families who wish to keep a member with a disability at home, but who need assistance to do so In this way, family supports can be the most individualized of all services, built on the assumption that families themselves are the experts on what services they will need to support their son or daughter with a disability in their own home.

How are these services paid for? Currently over 25 states across the US offer something that they call family supports. There is wide variation in the types of services and there are several different ways that money for family supports can be spent. In general, states spend family support resources in some combination of three methods: direct payment to the provider of the needed service, reimbursement to the family upon receipt of appropriate documentation, and provision to the family of a direct cash subsidy. The funding for these services usually comes from state general funds and federal funds such as Medicaid, although some programs rely extensively on United Way donations as well. Of these three methods, the most controversial is that of cash subsidy. States such as California, Michigan, Nebraska, and Wisconsin offer a combination of specific services and an outright cash subsidy to be spent as the family sees fit. Clearly this method offers the greatest flexibility for the family, and allows the greatest amount of control to remain with the family.

How much is being spent on family support? Unfortunately, what is available for family supports depends a great deal on where you live. Approximately half of the states in the US have no family support program at this time Of those states that do operate family support programs, there is great variation in the amount of money being spent and the numbers of people being served In some states, pilot programs serve as few as eight to twelve families In other states, thousands of families receive supports.

Similarly there is great variety in the size of state budgets for family supports Some states have only a few thousand dollars earmarked for these activities, while others spend millions. The amount of money spent on family support can be placed in perspective by comparing it to the amount spent on institutional placements. To evaluate the extent of your state's commitment to family supports, you need to ask not only how much is spent on family supports, but also what services are provided for those dollars and what percentage of the total state mental retardation budget is dedicated to family supports.

What are the public policy lessons that we have learned? After looking at family support projects across the country, we have reached a few conclusions.

1) Family supports are working. Sometimes they prevent institutionalization, sometimes they only postpone the need for an out-of-home placement. But family supports are very effective at reducing the need for out-of-home placements, and they improve the quality of life for the people who use them.

2) Currently, there is no equal access to family supports. A family's ability to gain access to the needed supports depends a great deal on the developmental disability system in the state where they live.

3) Even where substantial resources are being spent in family support programs, in most states the family support budget constitutes only one percent or less of the total developmental disabilities budget.

4) There is a need to create policy and funding mechanisms for family supports to provide support on an equal basis as needed for families across the country.

THE MICHIGAN FAMILY SUBSIDY ACT

The policy of deinstitutionalization and, more important, community integration has achieved support on a state level in Michigan. As articulated by the Governor and the Department of Mental Health, Michigan adopted a goal of returning all children from state institutions and specialized nursing homes to local communities by 1986. Towards this purpose, Michigan established an innovative family subsidy program that provides direct cash subsidies to families with severe disabilities. The program was piloted in a single region prior to the passage of the **Family Subsidy Act** to provide subsidies on a statewide basis

The subsidy is designed to help parents pay for the extra expenses incurred in having a child with severe disabilities (for example, equipment, respite, home renovation, diapers, and other services and materials). The subsidy amounts to $255 per month, an annual subsidy of $2,700 for eligible families. The eligibility criteria for the family subsidy program are: 1) the family's annual income must be less than $60,000; 2) the child must be 0 to 18 years of age (after that age, they are eligible for Supplemental Security Income), and 3) the child must have a severe disability.

Support for the Act was gained by appealing to philosophical and economic grounds. As a philosophical rationale, supporters pointed to the needs of children with severe disabilities and their families As an economic measure, they argued that the passage of the legislation would result in cost savings to the state by preventing out-of-home placements and encouraging families to take their children home from institutions and other alternative placements

By encouraging, rather than discouraging, families to maintain their children at home, reversing the traditional pattern of developmental disabilities services, and placing increased control over services in the hands of direct consumers, the Michigan Family Subsidy Act is an important step in the right direction.

WISCONSIN'S FAMILY SUPPORT PROGRAM

Wisconsin has one of the most innovative family support programs in the country. While many states have begun to establish respite and other programs for families, the Wisconsin Family Support Program stands out for its responsiveness to the needs of individual families. Unlike many other schemes, the program is flexible, individualized, and "family-centered." Like other Wisconsin community services, it is administered by counties. Counties either provide services directly or contract with local agencies.

The Family Support Program provides up to $3,000 in services for families of children with severe disabilities. The state is authorized to approve additional funds to families upon the request of the local administering agency. Under state legislation, 10% of the funds allocated to a county may be used to pay for staff and other administrative costs; the rest must be spent directly for family support services.

Services families may need The Family Support Program can be used to pay for a broad range of services families may need. As Linda Brown, one of the parents participating in the program in Dane County, has stated, families of children with severe disabilities can have a variety of extraordinary expenses. "Along with the stress that arises from living much of the time on the edge of life, we families deal with things most families never have to consider: occupational, physical and speech therapy; special feeding techniques, utensils and foods, special equipment like wheelchairs, bolsters, wedges, seats, splints, braces, and hearing aids; life support equipment like oxygen, apnea monitors, ventilators, nebulizers and compressors, various tubing, trachs, trach masks, and suctioning equipment. There are even special dressings for all of the tubes inserted and sterile water for all the special techniques. On top of these are countless medications, diapers, usually far past the normal toilet training stage and often special clothing."

The Family Support Program lists 15 specific categories of services a family can receive: 1) architectural modifications to the home; 2) child care; 3) counseling and therapeutic resources; 4) dental and medical care not otherwise covered; 5) specialized diagnosis and evaluation; 6) specialized nutrition and clothing; 7) specialized equipment and supplies; 8) homemaker services; 9) in-home nursing and attendant care; 10) home training and parent courses; 11) reation and alternative activities; 12) respite care; 13) transportation; 14) specialized utility costs, and, 15) vehicle modification. In addition, the program can pay for the costs of other goods or services as approved by the state.

Needs assessment and family plan. As the first step in participating in the program, families receive a needs assessment and family plan. To be eligible, families must have a child with a severe disability according to state criteria, which parallel the federal definition of developmental disabilities. While there is no income test for the program, families may be expected to share some of the costs of services. Under state legislation, a child is defined as a person under the age of 24. In practice, however, the program is directed at families of children in school. The state must approve services for families of children ages 21 through 23.

The needs assessment looks at the family's existing formal and informal support networks and the family plan attempts to build upon these. For example, a neighbor may be looked to to provide transportation for a child. The plan specifies what services a family will receive through the program. These services may be paid for directly by the agency or the family can be given a grant to pay for them (families must keep receipts).

In addition to providing support services, the Family Support Program is intended to help coordinate other services a family receives. According to documents describing the Family Support Program, "an important role for the family support coordinator or case manager is to act as a kind of service broker assisting the family through the bureaucratic maze of available programs and services. The worker can also act as an advocate in helping the family to make maximum use of community services, such as community recreation programs, medical and dental services, public transportation, and other generic service providers."

Family Support and Resource Center. In Dane County, family support services are provided by the Family Support and Resource Center, a private agency with a board composed of 50% consumers. The center has a range of funding sources and administers the state's Family Support Program. It provides three types of services to families. The first is information and referral for which purpose it maintains listings of services in Dane County. The second type of service is the family support program, which pays for services families need.

The final type of support offered through the center is respite. This is provided above and beyond other family supports. Families can receive 14 days or 140 hours of respite care per year; but this arrangement is flexible. The center offers both in-home respite and out-of-home respite in foster homes. It also has foster care providers on call for emergencies. The center's respite workers recruit and train all respite providers.

FAMILY SUPPORTS IN MONTANA

Through the Specialized Family Care (SFC) program in Montana, STEP (Specialized Training for Exceptional People), a regional service agency, is providing individualized, flexible supports to families of children with severe and multiple disabilities. Currently funded through both the Medicaid waiver and state funds, the SFC program serves families of children 0-22 years of age, who are "at-risk" of institutionalization. The range of supports provided includes: "habilitation aides," "home teachers," respite, and many sorts of adaptive equipment, materials, toys, and so forth.

Tim is 9 years old and lives in a small city in Montana with his parents and younger brother and sister. He has cerebral palsy, severe mental retardation, cannot walk, and needs assistance in most all daily activities and routines. His family was considering out-of-home placement, but as an alternative decided to keep him at home with support from SFC.

A "hab aide" comes to the home 15 hours per week (3 hours a day, 5 days a week). She is at the house when Tim comes home from school. During her time there, she assists Tim in self-help and communication skills. For example, when he has an after-school snack, he participates in feeding himself. They are also working on a "yes/no" response (i.e., "want more juice?"). She stays through the family dinner to assist Tim with eating.

Once a week, a "home teacher" comes to Tim's house both to discuss any concerns with his parents and to observe and give technical assistance to the hab aide if necessary. Tim's family can use up to 48 hours of respite per month (it can be used by the hour, or by the day): they choose to have the "hab aide" provide this respite. The family enjoys going for evening bike rides; Tim can now join them, since, through STEP, they have acquired a cart that attaches to the back of a bicycle.

Mark, who is 7 years old, is diagnosed as having spastic athetoid cerebral palsy and mental retardation. In addition, just recently he was found to have a degenerative condition of undetermined origin. Since December he has lost most of the control of his upper extremities, and needs assistance to walk. Mark lives with his mother, who just recently had another child. They live in a small trailer park in the foothills on the outskirts of a small city in Montana. His father drinks heavily, and is often not at home.

The hab aide, who comes 3 hours a day (5 days a week), assists Mark in bathing and in potty training. They are working on his communication through a recently acquired "communiclock," on which one presses a switch to move the clock hand to the desired symbol or word. Mark and his hab aide also spend time reading stories, going swimming, or other recreational activities.

In addition, the "home teacher" comes once a week to visit. She has assisted them in obtaining adaptive equipment such as the communiclock, a travel chair, and a bath chair, and in arranging evaluations and other services before he was in a school program (PT, OT). With the presence of the combined family supports of the hab aide and respite (in addition to Mark's time at school each day), Mark's mother has been able to maintain a full-time job and go to school to become an LPN, something she has wanted to do for a long time.

Tim and Mark provide just two examples of many children and their families who are being supported through the SFC program throughout Montana. There are a number of strengths of the program. First, it begins by asking families what they need to keep their child at home. Second, "home teachers" and "habilitation aides" are doing much more than just teaching or habilitation; they are assisting to coordinate services for the family, and to support families in whatever ways are needed. A few parents commented on the tremendous "moral support" they have received from STEP. Although hab aides are STEP employees, the families can hire (and fire) them.

"(The Specialized Family Care Program in Montana) takes a 'family-centered' approach, asks families what they need, and provides individualized, flexible supports to meet these needs as well as is possible."

Third, families can choose a friend or neighbor to provide respite—someone they are comfortable with in the care of their child. In addition, however, STEP also has an active list of people who are willing to provide respite. These people are trained in CPR, and would be oriented to the needs of the individual child prior to actual respite care. Fourth, the STEP program utilizes a combination of many sources of funding (Medicaid, state DD funds, respite funds, state education funds, and so forth) to provide supports to families. Funds can be pooled (i.e., the state DD funds for the allocated number of "slots"), providing significant financial flexibility at the regional level. Overall, the program's success can be attributed to the fact that it takes a "family-centered" approach, asks families what they need, and provides individualized, flexible supports to meet these needs as well as is possible.

THE CALVERT COUNTY FAMILY SUPPORT PROGRAM

The Calvert County, Maryland, Association for Retarded Citizens (CARC) operates a Family Support Services program. The intent of this program is to prevent any person 21 years of age or younger from being institutionalized. The program provides respite, specialized family support, and integrated day care to approximately 50 people with developmental disabilities and their families. The specialized family support component attempts to help parents obtain any service or piece of special equipment which the family sees as needed in order to maintain a disabled member at home

"As needed" basis. The staff at CARC are always conscious of the fact that different families have different needs In response to this recognition, they provide service to families on an "as needed" basis Frequency of contact, therefore, depends on families' needs. 1) *one time or time limited intervention.* Some families come in for help, they get it and they leave; 2) *come and go* These are families that do not need the day-to-day intervention that other families do, but their need does not go away, and, 3) *on-going need.* These families are in regular contact with project staff, and receive a variety of services regularly from financial support, to respite care, to just a friendly person to discuss problems over a cup of coffee.

Regardless of the frequency of the service needed, CARC sees three global benefits to the program: 1) to prevent out-of-home placement; 2) to postpone out-of-home placement; and, 3) to make life more pleasant while a family waits for an out-of-home placement

Major types of service. As part of the family support service, CARC operates several types of services to meet families' needs. 1) *Companions come to the family home.* In this type of respite, a worker comes to the family home to provide respite and personal attendant assistance. Most of the families have a regular structured amount of in-home respite, such as 20 hours per week However, this support is also available on an "as needed" basis for specific situations.

2) *The child/adult goes to the respite worker's home.* In other situations, individuals have agreed to provide respite care for families, but prefer to work in their own home. By offering families respite services in another home, families can stay at home for some privacy, or can go away from home knowing that their child is in a caring environment.

3) *Respite at the integrated day care center.* CARC operates a day care center for the children of their employees. They feel this is part of being a good employer. They also reserve six "slots" at any time to be used by children with handicaps and families in the family support program for a "drop-in" respite center. Nonhandicapped siblings are invited as well. For the staff and parents, the respite center has a number of positive aspects. a) it is parent-need responsive, b) it is cost-effective, c) it is integrated, d) it makes a difference, and e) it is a good environment for all the kids who come.

4) *Parent counselor.* Essentially, the family support services to an individual family are coordinated by the parent counselor, that is, a person who is herself the parent of a child with a disability who works as a counselor for the project Most of the parents say they find it easier to communicate with another parent A major part of what the counselor does is to check in with families as frequently as needed.

5) *Parent support group* (Share Our Support). SOS is a parent group that currently involves some forty families, although not all of them come to every meeting.

6) *Financial support.* For many families, the extra costs involved in supporting a child with a disability can be a major force for an out-of-home placement. CARC offers financial support to families who are interested in keeping their children at home. Based on financial need, families can be reimbursed for up to 100% of the costs of the disability related expenses of items ranging from adaptive equipment to diapers.

7) *Information referral and coordination.* The CARC staff provide information about educational rights of children with handicaps, referral to existing services, and coordination of the various services being used. By giving information, referral, and coordination to existing services, the project saves its own limited resources, and involves the family in more generic services in the community.

Cost information. While families do make a financial contribution toward the services they receive, based on their ability to pay, most of the families in the program have low income so they do not pay any of the costs. The same holds true for financial support. Families receive assistance in paying for diapers, medicine, and the like. The family buys the supplies, and they are reimbursed for up to 100% of the costs. At the drop-in respite program there is only a cost to the families who use the service for full time child care.

EXTENDING FAMILY SUPPORT SERVICES: THE DUNBAR COMMUNITY CENTER

Family support services can extend beyond the immediate environment of the family group too. Integrated recreation can serve as a type of respite care, and at the same time, give a child with disabilities the chance to spend time and make friends with people outside the family.

The Dunbar Community Center, a private, nonprofit neighborhood center located in an inner-city section of Syracuse, New York, provides such an opportunity. Here, 40-50 neighborhood children and teenagers participate in a variety of recreational, educational, and cultural activities. Among them are three girls with disabilities, all of whom are labeled mentally retarded and attend special education classes, who come to Dunbar on a regular basis. For Tracy, this includes arts and crafts, games, browsing in the library, going on field trips to community sites such as museums and swimming pools, movies, and being in a poetry group. For Michelle and Pam, too, this is a time to make friends as they join their nondisabled peers in making ceramics, in the playground, or in the game room.

Participation by Tracy, Pam, and Michelle, at Dunbar is made possible by the presence of a support person, Bertha Jones. Bertha is paid, through respite funds provided by the New York State Office of Mental Retardation and Developmental Disabilities, to work part-time assisting the girls. Bertha continually makes efforts to involve them in activities with other nondisabled children. For instance, she will help engage them in activities that are of interest to others also, and invites others to participate. She assists other staff at the Center to get to know them and learn to assist them.

At Dunbar, these girls are forming friendships and acquaintanceships with other children from their neighborhood. Pam's mother commented, "it's really great that she can come here. She comes here every day."

PERMANENCY PLANNING

Permanency planning provides a policy context for the various programs that support families with a child who has a severe disability. It reflects a conscious decision to abandon the policies of the past that essentially required that a child be placed outside of a home to receive specialized services. As applied in the field of developmental disabilities a permanency planning perspective also represents a realization that the presence of a disability does not affect a child's basic right to a home and family.

At bottom, permanency planning is no more than a policy affirmation of the basic fact that children develop best in a secure nurturing environment—what we usually call a family home. The fact that the birth home, for any number of reasons, is not able to provide a child with this nurturing climate does not alter this fact nor obviate a child's right to a home, positive enduring relationships with adults, and an individual advocate who is solely committed to his or her best interests.

"A permanency planning perspective represents a realization that the presence of a disability does not affect a child's basic right to a home and family... (It) is a policy affirmation of the basic fact that children develop best in a secure nurturing environment—what we usually call a family home."

In child welfare, permanency planning has been the dominant perspective for many years. It is required in any program receiving assistance under Public Law 96-272, The Adoption Assistance and Child Welfare Act of 1980 which redirected "...current federal fiscal incentives away from out-of-home care and towards alternatives to placement, and. .provide(d) protection for children to insure they enter care only when necessary, are placed appropriately, provided quality care, reviewed periodically, and provided permanent families in a timely fashion." Since most children with developmental disabilities have received services from a different funding stream, this concept has not had an impact in their lives until recently.

The last few years have seen numerous states reorder their priorities in services to children with developmental disabilities. Increasingly, the emphasis has shifted from services that focus exclusively on the disability to a more holistic perspective that sees the child first. The State of Michigan has been in the forefront of states that have used the permanency planning process as a vehicle for giving expression to this change in priorities.

"As a philosophy, permanency planning endorses children's rights to a nurturing home and consistent relationships with adults."

In Michigan, permanency planning for children with developmental disabilities expands on the basic concept and recognizes the special demands which a child with a disability can place on a family. The state regulations describe the process as supporting both children and families. The first priority is to provide what is needed to *maintain* the child with the birth family. If this fails, the service system begins working towards *reunifying* the family. If reunification is not possible, and there is no active parental involvement, services focus on facilitating the *adoption* of the child. When these other goals cannot be achieved a plan is developed for a permanent *foster family*, with arrangements for on-going involvement with the birth family (if appropriate) and a guardian or advocate to keep an eye on the best interest of the child. Institutionalization is not considered for *any* child and, in practice, children are no longer placed in any group setting in Michigan.

Implementation of the permanency planning program requires not only changes in policy and procedure, but also changes in staff attitudes toward birth families. It requires a change in the purposes for which out-of-home placement is provided, i.e., utilizing placement as a temporary support to families, not a long-term answer for children whose families are experiencing stress and difficulty in parenting their developmentally disabled child. It also requires a goal-directed casework practice that assumes children ought to be with their families.

"Implementation of the permanency planning philosophy requires not only changes in policy and procedure, but also changes in staff attitudes toward birth families...It also requires a goal-directed casework practice that assumes children ought to be with their families."

The Permanency Planning Project, which is now in its fourth year, has provided extensive training to mental health staff of those agencies involved in the project about such topics as the permanency planning philosophy and concept, the importance of the parent child relationship, how to maintain and reunite children with their families, the impact of the pyscho-sociological processes of attachment and separation, and adoption proceses and procedures. Permanency planning casework activity has also been initiated for those children in care with the project agencies, 250 children in foster care with three agencies in metropolitan Detroit were screened and permanency objectives identified. As a result of efforts initiated through the project, 45 individuals have returned to their families from out-of-home placements and 18 children have been adopted.

Permanency planning cannot work without having concrete services and resources to support children being with their families. As Gerry Provencal, Director of the Macomb-Oakland Regional Center, put it, "we don't believe in giving lip-service to the concept of family support, the important thing is to make good the concept. Our purpose is to help families re-establish contact with a member of the family with whom they may have lost contact, and to give them whatever support they may need to enable the member with disabilities to return home permanently as a full member of the family. So we ask families what *they* need to keep their son or daughter with disabilities at home or to help them to return home. The shopping list may include anything like help with getting on and off the bus, constructive use of leisure time, or assistance at mealtimes."

"If reunification with the birth family is not possible, and there is no active parental involvement, services focus on facilitating the adoption of the child."

Concurrent with the development and implementation of the Permanency Planning Project, three other major initiatives were developed. The first of these is the family support program. This program provides funds to local community mental health boards to develop services to support families such as respite care, case management, and other services. The second program is the family support subsidy program. This program, which was signed into law in 1983, provides a subsidy of ap-

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proximately $2,700 a year to families whose child is at home and is either severely mentally impaired, severely multiply impaired or autistic. The third program is the individual Medicaid Waiver program for 50 children.

All of these programs, however, are just the first steps in meeting the goal of redirecting funds away from out-of-home placement and toward support of families through a variety of services and resources like "as needed" respite care, in-home aides, adaptive equipment, assistance with physical plant modifications to the home, and training to deal with their child. Certainly helping families to keep their developmentally disabled child at home is, over all, a less costly alternative to out-of-home placement, but more importantly, for the child, home is the best place to be.

PROVIDING STABLE HOMES FOR CHILDREN: ONE AGENCY'S EXPERIENCE

Macomb-Oakland is a state agency located in the two suburban counties north of Detroit. The Macomb-Oakland Regional Center (MORC) is one of a number of state regional centers within Michigan. Macomb-Oakland has developed community living arrangements for over 1,100 people. Each of these is operated by a private nonprofit contract agency, with case management and professional services provided by MORC.

Permanency planning. MORC has embraced the concept of permanency planning for all children with developmental disabilities, including those requiring ongoing medical care. Families of these children are offered support services to maintain the child in their home. If these services are not enough and the child must live outside the family, a foster home is offered. Families are not given other options, such as group living facilities, nursing homes, or institutional care. Instead, they are helped to accept the idea of foster care as a temporary placement, with the goal of returning the child to natural family.

When this is not possible, the agency tries to find an adoptive home for the child. The natural families of some children are no longer involved in their lives. For these children, Macomb-Oakland looks for adoptive families who will take over all of the parenting of the child. In other cases, families want to stay involved. Then Macomb-Oakland explores "open adoption," where the child's natural family can visit frequently and maintain the affectional ties they have with the child. Sometimes a child cannot be freed for adoption. Then the agency pursues options such as "shared care" and "permanent foster care." Shared care is an arrangement in which the natural and foster parents agree to share responsibility for the child; permanent foster care is a nonlegal agreement by foster families to serve as primary parents for children until adulthood

Specialized foster care. Like many service systems, Macomb-Oakland has turned to foster families to provide homes for people with developmental disabilities. Nearly one-fourth of the people served by MORC live in foster homes; over half of these are children. What distinguishes MORC from most service systems is that it has placed people with severe disabilities in foster homes. Indeed, MORC is finding foster homes for children with the most severe multiple disabilities and medical involvement, and does not place children in other forms of care.

MORC's foster homes are referred to as Community Training Homes and this creates an expectation about what foster families are supposed to do. Community Training Homes serve from one to three people. In addition, MORC contracts with families to operate "alternative family residences" for four people. These families are provided with a separate budget to hire staff to come into the home. All of the homes are licensed by the Department of Social Services.

Ensuring good foster homes. MORC employs specific techniques to ensure the recruitment of good foster homes. First of all, it makes foster home recruitment an agency priority. It employs three full-time community training home specialists who recruit, screen, and train foster parents. Second, Macomb-Oakland pays families relative-

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One Agency's Experience

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ly well. Community training homes receive between $25 and $35 per person per day ($9,125 to $12,775 per year) and higher in some instances. The amount depends on the needs of the person in the home. MORC looks for sensitive and caring families, but it doesn't mind if they become foster families for the extra money.

Third, Macomb-Oakland uses a range of aggressive recruitment techniques: ads, public service announcements, newspaper articles, radio and television appearances, community presentations, newsletters, flyers, posters, and referrals from other people. Finally, MORC provides a lot of support to Community Training Homes, including respite, professional consultation (nurses, occupational therapists), home aides, and financial assistance for special equipment and supplies and making necessary modifications in the home. MORC case managers also maintain close contact with foster homes, making at least monthly visits. They also make unannounced visits to all homes.

Respite care. Macomb-Oakland is also looking to community training homes to provide respite for natural and foster families. Families are paid the community training per diem for each day of respite. MORC is working on one arrangement for respite care whereby families would receive four weeks of pay for providing three weeks of respite. This arrangement carries a "no-reject" clause. In other words, families would have to agree to accept anyone sent to them for respite.

USEFUL RESOURCES ON FAMILY SUPPORT

Agosta, J.M., & Bradley, V.J. (Eds.) (1985) *Family care for persons with developmental disabilities: A growing commitment*, Boston: Human Services Research Institute. (Available at. Human Services Research Institute, 120 Milk Street, 8th Floor, Boston, MA 02109; $19 00)

Agosta, J , Bradley, V , Rugg, A., Spence, R., & Covert, S. (1985) *Designing programs to support family care for persons with developmental disabilities: Concepts to practice* Boston: Human Services Research Institute. (Available at: Human Services Research Institute, 120 Milk Street, 8th Floor, Boston, MA 02109; $12.00)

Bates, M.V. (1985). *State family support/cost subsidy programs.* Madison, WI: Wisconsin Council on Developmental Disabilities.

Bradley, V.J., & Agosta, J.M. (1985). Keeping your child at home: The case for family support. *Exceptional Parent.* November, pp.10-22.

Cohen, S., & Warren, R.D (1985). *Respite care: Principles, programs, and policies.* Austin, TX· Pro-ED. (Available at: Pro-ED, 5341 Industrial Oak Boulevard, Austin, TX 78735; $18.00)

Nelson, K.A. (1985) *On the frontier of adoption: A study of special-needs adoptive families.* New York: Child Welfare League of America

Rosenau, N., & Provencal, G (1981). Community placement and parental misgivings. *Mental Retardation*, 31(2), 3-11. (Available at: G. Allan Roeher Institute, Kinsmen Building, York University Campus, 4700 Keele Street, Downsview, Ontario, M3J 1P3, Canada)

Salisbury, C.L , & Intagliata, J.(Eds.) (1986). *Respite care: Support for persons with developmental disabilities and their families*, Baltimore: Brookes. (Available from· Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624; $23.95)

Tingey-Michaelis, C. (198) *Handicapped infants and children: A handbook for parents and professionals.* Austin, TX. Pro-ED. (Available at. Pro-ED, 5341 Industrial Oak Boulevard, Austin, TX 78735, $14.00)

Upshur, C.C. (1982). An evaluation of home-based respite care *Mental Retardation*, 20, 58-62.

Wisconsin Department of Health and Social Services. (1985). *Family support program: Guidelines and procedures.* (Contact person: Beverly A. Doherty, Family Support Program Coordinator, Division of Community Services, 1 West Wilson Street, P.O. 7851, Madison, WI 53707)

This is one of a series of bulletins, reports, and resource materials on community integration from the Center on Human Policy. People who receive this bulletin are c . our mailing list and will continue to receive information; those wishing to be removed may write to Bonnie Shoultz, Center on Human Policy, 724 Comstock Ave., Syracuse, New York 13244-4230.

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CENTER RESOURCES AND REPORTS ON COMMUNITY INTEGRATION

The Center on Human Policy, through its Community Integration Project and Research and Training Center on Community Integration, has developed a variety of reports and resources on the integration of people with severe disabilities into community life. The following reports deal with services and supports to children and families and are available for the cost of copying and postage. To get the full list of publications, please write Center on Human Policy, Syracuse University, 724 Comstock Avenue, Syracuse, New York 13244-4230. Orders may also be sent to this address to the attention of Rachael Zubal, remittance should include 10% of the total amount of your order for postage and handling. All orders $15.00 or more must be prepaid unless an official institutional order form is submitted. Orders will not be accepted on the phone. Checks must be made payable to the Center on Human Policy.

1. *The Nonrestrictive Environment: On Community Integration for People with the Most Severe Disabilities* outlines some basic principles of community integration, critiques the "continuum concept," describes homes and supports for children and adults with severe disabilities, discusses integrated vocational services, looks at what makes community integration work and covers the emerging controversies in community integration. (Now available through Human Policy Press, P.O. Box 127, Syracuse, NY 13210 for $9.95 plus 10% of the total or $1.50, whichever is greater, for postage and handling. *Please order separately*, check must be made payable to Human Policy Press.)

2. *Report on the State of Michigan* provides information concerning that state's innovative family support program. (46 pages) $2.75

3. *Report on Macomb-Oakland Regional Center, Michigan* discusses the approach to residential and support services in two counties north of Detroit, Michigan. (30 pages) $2.30

4. *Community Living in Three Wisconsin Counties* highlights Wisconsin's family support services program, their Medicaid-waiver Community Integration program, innovative community living arrangements, county leadership and setting priorities for case management services. (52 pages) $3.25

5. *Report on Calvert County ARC, Family Support Services* describes a program providing respite, specialized family support and integrated day care to approximately 50 people with developmental disabilities and their families in Maryland. (20 pages) $1.95

6. *Report on Seven Counties Services* reviews the residential and support services in the region around Louisville, Kentucky. (9 pages) $1.25

7. ***Programs demonstrating model practices for integrating people with severe disabilities into the community*** describes the results of a national search for programs which demonstrate "model" practices for integrating people with severe disabilities. (22 pages) $2.00

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