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ABSTRACT

The book defines and discusses eight key elements of a family-centered approach to care for children with chronic illnesses and special health care needs: (1) recognition that the family is the constant in the child's life, while the service systems and personnel within those systems fluctuate; (2) facilitation of parent/professional collaboration at all levels of health care; (3) sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner; (4) implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families; (5) recognition of family strengths and individuality and respect for different methods of coping; (6) understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care delivery systems; (7) encouragement and facilitation of parent-to-parent support; (8) assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs. The document also offers the following: (1) a brief review of selected research studies; (2) a series of checklists for professionals and parents, states, communities, professional training programs, hospitals, and research investigations; (3) lists of selected technical organizations, audiovisual and written materials, and family-centered programs; and (4) a list of over 70 references. (JW)

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FAMILY-CENTERED CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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Family-Centered Care for Children with Special Health Care Needs: An Overview

During the last thirty years, systems of care for children with chronic illnesses and disabling conditions have evolved that have not recognized adequately the support needs of families whose children have special health care needs or the essential roles that parents play in the lives of their children. There is, however, a growing recognition on the part of professionals that the approach to health care for these children and their families must be changed—that health care must be family-centered.

> ◆ *"Not only is the family the primary unit for the delivery of health services to infants and children, but the family environment is probably the greatest influence on a child's health . . . a child is dependent upon his or her mother and other family members not only for the physical necessities of life . . . but also for the emotional support and intellectual stimulation needed for healthy growth and development. . . . Our growing recognition of the psychological and social components of health has enhanced our awareness of the family's importance. . . . The family is not only the principal influence upon a child's development, it is also the intermediary between the child and the outside world, including the health care system. . . . Health providers can support, encourage, and enhance the competence of parents in their role as caregivers . . ." (Schorr, Chair of the Select Panel for the Promotion of Child Health, 1980).*

Although we believe that all children who encounter the health care system would benefit from a family-centered approach to care, it can be especially beneficial to the seven to ten million children in the U. S. who have special health needs (Ireys, 1981).

But what is family-centered care? Can we agree, as parents and professionals, on a common definition of the term? Can we determine what attitudes, policies and practices support a family-centered approach? It is as a response to these and other questions about family-centered care that this publication was developed.

While it is impossible to define all the ways in which care can become family-centered, this publication presents eight components that have been identified by parents and professionals across the country as key elements of a family-centered approach to care. Each element is defined, and specific examples of family-centered approaches are presented. Statements of parents whose children have chronic illnesses or disabling conditions and professionals who work with them help to clarify in personal terms what family-centered care is and what it is not. A consideration of each component individually reinforces the multifaceted nature of this approach and can be helpful to individuals who are developing, implementing, or monitoring programs and policies for children and families. To further facilitate the implementation of family-centered care, concrete examples of programs and policies are presented. These examples are by no means exhaustive. They, and the checklists, and other resources listed in the appendix can be used by parents and professionals to generate ideas for initiating or enhancing family-centered approaches to care.

While it is important to discuss the individual components of family-centered care, it is equally important to consider all the elements as a whole. Family-centered care is not just one component. Each element reinforces and facilitates the implementation of the others. Together the elements convey a new *philosophy* of care—moving from an institution/agency oriented approach, to a child-centered approach, and most recently to a family-centered approach. We are approaching what Turnbull and Summers (1985) have called a "Copernican Revolution" in the care of children with special needs.

> ◆ *"Copernicus came along and made a startling reversal—he put the sun in the center of the universe rather than the Earth. His declaration caused profound shock. The earth was not the epitome of creation; it was a planet like all other planets. The successful challenge to the entire system of ancient authority required a complete change in philosophical conception of the universe. This is rightly termed the 'Copernican Revolution.'*
>
> *Let's pause to consider what would happen if we had a Copernican Revolu-*

tion in the field of disability. Visualize the concept: the family is the center of the universe and the service delivery system is one of the many planets revolving around it. Now visualize the service delivery system at the center and the family in orbit around it. Do you see the difference? Do you recognize the revolutionary change in perspective? We would move from an emphasis on parent involvement (i.e., parents participating in the program) to family support (i.e., programs providing a range of support services to families). This is not a semantic exercise—such a revolution leads us to a new set of assumptions and a new vista of options for service" (Turnbull & Summers, 1985, p. 12).

As with other "revolutions," this one demands a great deal of the participants. Neither parents nor professionals are fully prepared for the new roles they must play in developing programs that are truly family-centered. It is hoped that this publication along with thoughtful discussion and a positive commitment to change can make family-centered care a reality. ■

1 Recognition that the Family Is the Constant in the Child's Life While the Service Systems and Personnel Within Those Systems Fluctuate

■ INTRODUCTION

This is the most crucial component of family-centered care. It is essential for health care professionals to recognize, respect, and support the pivotal role that families play in the care of their children. ■

WHAT DOES IT MEAN?

Because the ultimate responsibility for managing a child's health, developmental, social, and emotional needs lies with the family, health care systems must enable families to function as primary decision makers, caregivers, teachers, and advocates for their children.

> ◆ *"It is the parents of a child who are the link among the specialists and the only people who see the child in all settings over time. Therefore, parents must be prepared to assume the role of providing the overall management to coordinate the efforts of those many specialists and the needs of the child within the context of the family" (Anderson, 1985, pp. 3-4).*

As one mother of a child with special health care needs emphasized, "I'm not just a member of the team, I'm the captain of the team." While not all parents may wish their role to be one of "captain," they all have a vitally important role to play. An appreciation of the importance of the family's role, the unique contribution they make, or the constant responsibility they assume in the care of their children may not always be reflected in professionals' attitudes, policies or practices.

> ◆ *"Many professionals realize full well that parents are the ones who implement the therapy the professionals teach them. Yet others, observing the progress of a disabled child may still say, 'Early intervention is doing a wonderful job.' " (Cetroni, 1985, p. 2).*

Not only do families have the responsibility for the daily implementation of their child's therapeutic program, they do this in addition to addressing their child's other daily needs. This means balancing professional recommendations with their own priorities for their child. While the physical therapist may feel that range of motion exercises and an appointment with an orthopedic surgeon are of vital importance, and the speech/language pathologist asserts that time must be spent in working on total communication skills, the parents may be primarily concerned with daily, ongoing activities such as "When will my child be able to feed himself?", "When can I start toilet training?", or "How can I help him get along better with his older brother?" A study by Goldstein, Strickland, Turnbull, and Curry (1980) indicated that the topic most frequently addressed by parents in Individualized Education Plan (IEP) conferences was personal family life, not goals, objectives, evaluation levels, or placement.

Professionals and families must work together to balance professional recommendations with the priorities of families so that programs truly meet family needs and goals. Without this balance, programs may be developed that place unrealistic expectations and demands on parents; home care plans can become unmanageable and, therefore, are not implemented; and then families may experience enormous feelings of guilt and frustration.

> ◆ *"Although I tried to sound reasonable . . . this new demand appalled me. . . . Jody, I thought is blind, cerebral palsied, and retarded. We do his physical therapy daily and work with him on sounds and communication. We feed him each meal on our laps, bottle him, change him, bathe him, dry him, put him in a body cast to sleep, launder his bed linens daily, and go through a variety of routines designed to minimize his miseries and enhance his joys and his development. . . . Now you tell me that I should spend fifteen minutes every day on something . . . directed at the health of his gums. . . . Where is the fifteen minutes going to come from? What am I supposed to give up? Taking the kids to the park? Reading a bedtime story to my eldest? Washing the breakfast dishes? Sorting the laundry? Grading students' papers? Sleeping? Because there is no time in my life that is not spoken for" (Featherstone, 1980, pp. 77-80).*

Recognizing that parents play a central role in their child's life also involves valuing their judgement and respecting the unique contributions that they make. Because parents are the only ones who see their child in *all* settings, they really are the "experts," and their observations and recommendations must be taken seriously if the health care plan is to be family-centered.

Recognizing and supporting the family's role also means evaluating whether programs and policies address the long-term needs of the total family rather than just the immediate needs of the child. For example, the medical needs of a young child on a ventilator may be adequately addressed in a hospital setting, but is this an appropriate long-term solution for the child and family? If not, if home care is a better option, are there mechanisms to provide the respite care and other supports that are necessary for the child to live at home?

Professionals may also need to be certain they are actually supporting and not supplanting the family's role. A family-centered approach involves supporting families without undermining their confidence in their ability to care for their children.

> ◆ *"Often times because they [parents] have relied on the professional to 'make their child better' they feel they no longer can add anything to the child's life. Help them to realize that this isn't so, that they make the 'educated' decisions—that the child is their child—this will only help to strengthen them through the years to come" (Beckett, 1985, p. 11).* ■

MAKING IT A REALITY

Once we begin to understand and recognize the parents' role, how can this element be reflected in health care programs and policies? What should be our philosophy of care?

> ◆ *"The philosophy we believe should be operative in planning and delivering our services can be summarized in the following statements. Parents and families are the durable thread in the life of a handicapped child. Public agencies and private agencies are transitory, dropping in and out based upon the condition, the complication, or the chronological age of the child. If this previous statement is true then it is necessary for us to structure our activities in such a way to take this reality into account and to make provisions for parents as active participants in planning and in policy development" (Freedman, 1986).*

The following program is an example of how services can be provided in a way that recognizes the pivotal roles of parents in their children's lives.

Program

■ Family-Centered Planning Program

The Family-Centered Planning Program at the Kennedy Institute for Handicapped Children, Baltimore, Maryland is a home- and community-based program for families of children with developmental disabilities between birth and 21. The Planning Coordinator and family work together to establish a community interdisciplinary team that plans child and family support services. Family decisions are the primary consideration in how services are planned and provided. These plans are based on the strengths as well as the needs of the family. Parents are encouraged to take a leadership role in this interdisciplinary team process. Though professional recommendations are critical to the service plan, the parents greatly influence how, when, and where these services are provided. This program includes several features which ensure that the strengths and individuality of children and families are respected and supported.

— Visits are made in the family home or preferred location at a time convenient to them.

— Staff complete a needs assessment based on the parents' concerns, desires, and needs.

— Parents are the key to the development of the annual service plan. They determine who will attend, where, and when it will be held, and what role they want to assume, (i.e., chair or active participant).

— The service plan is comprehensive and addresses all areas of need (i.e., services to the child, family supports, financial assistance, recreation, and emotional needs).

— When requested, staff are available to assist the family in enhancing their individual skills as their child's advocate and coordinator. ■

2 Facilitation of Parent/Professional Collaboration at All Levels of Health Care

INTRODUCTION

If "recognition of the family as the constant in their child's life" is at the *heart* of a family-centered approach, then "parent/professional collaboration" is the *spirit* of family-centered care. Parent/professional collaboration and an appreciation of the parents' role has been evolving in health care and in policies and educational programs since the 1960's. It has been furthered by the enactment and implementation of P.L. 94-142, the law that addresses the educational needs of children with disabling conditions. This law explicitly states that parents have a right to basic information about their children and "that they can participate meaningfully in planning and decision-making" (Anderson, 1985, p. 3). This level of parent participation requires that professionals think carefully about their relationships with parents. As one participant at a recent national meeting expressed, "If we are going to be successful with families . . . we are going to need to reorient as professionals. . . . We are going to need to ask them to join us cooperatively as equals in this partnership so that we create a reality out there that matches what all of us want to see" (Vincent, 1985, p. 40).

WHAT DOES IT MEAN?

For many years, health professionals have functioned in an environment in which they provided care, made the decisions, and controlled the flow of information to families. Professionals, not parents, were in control. As one professional notes,

> ◆ *"For a number of years, the attitudes of professionals working with families have seemed to say, 'Tell us what your problem is, and we'll fix it.' The professionals were in a sense in control. We professionals need to change our orientation. We need to reframe that question to ask simply 'How can we help you?' We need to begin to view our work with families as a partnership in which we are the consultants but the families are in charge, and it is on the care of their child that we are in fact consulting them" (Barnard, 1985, p. 4).*

The change in orientation must be reflected at all levels of health care: in providing care for an individual child; in developing community and hospital services; and in the charting of policy. Meaningful parent/professional collaboration at all levels is the driving force to ensure quality health care for children and their families.

Collaboration in Providing Care for the Individual Child

Parent/professional collaboration is vitally important in planning and providing services for an individual child. "Parents can and should be a part of the . . . health care-giving team, not bystanders" (Kaufman, 1985, p. 3). Though different, the perspectives of both parents and professionals are needed. While professionals can offer the expertise of their discipline and knowledge gained from working with a number of children, parents are the only ones who can contribute information on their particular child in all settings. Parent/professional collaboration can lead to more comprehensive and appropriate care plans that are individually tailored to both the child's and family's strengths and needs.

Despite the benefits of collaboration at this level, "parental involvement" may be more rhetoric than actual practice. There are still too many incidents where parents' opinions and expertise have not been considered in their child's care . . . or were included only after great persistence on the part of the parent.

> ◆ *"By the end of the day, Zack had improved and wanted to run around. When the respiratory therapist came around, I suggested it was time to disconnect the 0_2-CO_2 monitor so that Zack would be free to move. He agreed. To get the order took much discussion, explanation, and arguing. The resident on duty was resistant. He finally admitted knowing absolutely nothing about Zack's condition other than what he saw in the chart, threw up his hands and said let's write an order 'Per Mom'! . . . One small step for man, but a giant leap for parents." (Kaufman, 1985, p. 8).*

Not all professionals are this resistant to parent input. And yet, there can be many reasons why both parents and professionals have difficulty working effectively with each other on the care of an individual child. For many, the problem may be a lack of experience in working in a collaborative way. Whatever the barriers, when parents and professionals are able to combine their expertise, the benefits for the child far outweigh the initial difficulties.

Collaboration in Developing Community and Hospital Services

At this level of collaboration, numbers of children with special needs benefit from the ability of parents and professionals to work together to develop, implement, and evaluate programs. The importance of this type of collaboration is evident in other fields. Major manufacturers spend millions of dollars soliciting consumer input to ensure that their products are designed and packaged in a way that reflects the desires and needs of the public. Parents of children with chronic illnesses or disabling conditions are consumers as well—consumers of vital services for their children. This type of "consumer participation is a vital process and is an important component in quality health care" (Anderson, 1985, p. 18). A family-centered approach to care encourages parents to exercise their rights as consumers.

Family-centered care also involves creating opportunities that allow both professionals and parents to contribute their knowledge and experience in the development of services. Because of their "hands on" experience, parents can offer a valuable perspective on the range of services that are needed and how to make them more accessible and supportive for families. Because their perspective is different from those operating within an agency, parents often bring fresh, innovative, and creative solutions to long-standing service delivery problems. Multidisciplinary, parent/professional advisory committees in hospitals, in community agencies, and in state health departments exemplify the type of cooperative endeavor that can lead to more responsive programming

Collaboration at the Policy Level

Family-centered care can also be achieved through parent/professional collaboration at the policy level. Policies that are developed through the joint efforts of parents and professionals have benefits for all involved.

For families, "being regarded as capable of participating is an important message. . . . Typically, families or individuals begin with little knowledge of the health care system or sense of their own competence. This is an area where growth is particularly important" (Anderson, 1985, p. 17). Being involved in the decisions also affords a much needed overall sense of the health care system.

For children, the result of parent/professional collaboration at the policy level not only results in more comprehensive and better coordinated services, but more importantly, "parents [also] serve as important role models for their own children. By taking active roles as partners with health and other professionals, parents help prepare children for their own roles later in life" (Anderson, 1985, p. 17).

For professionals, parent/professional collaboration at the policy level can lead to a "greater understanding of the issues . . . and lead to better questions and better answers." It provides a forum for "feedback from individuals with disabilities and chronic illnesses and their families" and can "improve services . . . and serve as important reinforcement to professionals for the jobs they do" (Anderson, 1985, p. 17).

MAKING IT A REALITY

What is needed in order to make parent/professional collaboration a reality at all levels of care?

Collaborative Skills

One thing that is necessary is the skill to work collaboratively with another person . . . whether that person is a professional or a parent. Just as parents have been thrust into new roles without adequate emotional or educational support, so, too, have professionals been ill prepared for this new collaborative relationship with parents.

- *"Health care providers have in the past been granted uncontested control over children as critically ill*

> *as these children. The survival of these children long enough for family adaptation to occur is a recent phenomenon. . . . The prolonged intensive interaction between health care providers and family members . . . is relatively new. Health care providers have not previously had an opportunity to experience family competency in the care of medically fragile children" (Thomas, 1986a).*

Further, professionals have not learned how to develop working relationships with other disciplines or with community support agencies. As recently as twenty years ago, pediatric residents were taught how to arrange for the institutionalization of newborn infants with Down Syndrome, not how to encourage care for the child at home or how to identify available community support services for the child and family. Educational programs have not taught health professionals how to encourage families in their natural caregiving roles. And thus many professionals may inadvertently foster dependence in families rather than encouraging independence and confidence.

New approaches to preservice training for professionals are needed. This fact was recognized almost ten years ago by the Task Force on Pediatric Education. In 1978 the Task Force concluded that greater attention must be directed to the family and psychosocial aspects of health care for children including those with chronic illnesses and disabling conditions (Task Force, 1978). "Borrowing one of the fundamental principles of developmental disability services, appropriate experiences [for health care professionals] in the beginning years could be viewed as 'early intervention' for this 'high risk' group of professionals" (Shonkoff, 1983, p. 80).

The need for additional training in this area is true for all professions, not just pediatrics, and for parents as well. Training curricula developed by parents and professionals from all disciplines will greatly enhance the collaborative relationships that can lead to quality care.

Opportunities for Interaction

Collaborative skills alone will not be successful without opportunities to use them. There must be formal and informal mechanisms that increase the opportunities for parents and professionals to work together. In the care of the individual child, this could mean involving the parent directly at each stage of the child's care. Or it may mean that an agency schedules fewer patients during a clinic in order to allow professionals time to discuss more fully with the parents their priorities for their child.

In developing community and/or hospital services, advisory committees are one mechanism where professionals can elicit feedback from parents as to the range of services that are needed. Other factors must also be considered if these opportunities are to be a reality. Reimbursement for parents' time, their transportation and child care costs, and scheduling meetings at a time that is convenient for parents will greatly facilitate the success of collaboration at this level.

Opportunities for parent/professional interaction are even more important at the policy level where they may be less likely to occur without some planning. Governor's task forces, state health department advisory committees, and working conferences, with each composed of equal numbers of parents and professionals, are just a few of the ways opportunities can be created. As with collaboration at the community or agency program level, collaboration at the policy and state level must be ensured by considering those factors that enable parents to participate. Parents must be reimbursed for their participation—whether it is for travel, for consultation or for full time employment. As Gene Judge, a parent from Maine noted,

> ◆ *"True involvement of parents at the state level will come when a parent is paid full time—that's not going to happen soon, but it should be possible to subsidize parents' participation. Reimbursement for child care expenses, time off given to a parent by an employer would allow effective parents to participate in state initiatives" (Judge, 1985, p. 1).*

An Examination of Attitudes

Perhaps the most important factor in making this aspect of family-centered care a reality is that parents and professionals come to the relationship with attitudes which are open to a collaborative approach. First there must be an awareness of each other's perspective. While it is certainly understandable that both parents and professionals may come to this relationship with some degree of cautiousness and even anger, it is important for all to try to interact in nonadversarial ways.

> ◆ *". . . before a partnership can genuinely exist, there must be give-and-take, mutual respect, and some-*

> *thing like moral and cultural equality. Both the parent and the professional must attempt to understand the other's point of view. . ." (Gleidman & Roth, 1980, p. 145).*

There also must be balance. Given that there need to be more instances of parents and professionals working together in a collaborative fashion, it is easy to insist on full participation of every parent at every step. However, care must be taken that in the move to become more family-centered the pendulum does not swing the other way. Parent/professional collaboration must not become "one more thing" for parents to do as they care for their children. Parent/professional collaboration is a continuum. The aim in family-centered care is a balance. It is achieved by giving the family the option of being anywhere along that continuum . . . depending upon the strengths and needs of the child, the family, and the professionals that are involved.

Finally, for parent/professional collaboration to truly succeed, professionals must be committed to this approach. They must be careful that the appointment of a "token parent" to an ineffectual advisory committee does not become the way to satisfy a family-centered "conscience" or that parent participation is used as a solution to staff shortages or to avoid taking responsibility for difficult decisions. Collaboration is crucial because it leads to better care for children with special health needs.

The following are examples of parent/professional collaboration at all three levels of health care.

In Planning for the Individual Child

Project Dakota

This is an early intervention program serving children with special needs from birth to four in Dakota County, Minnesota. The name "Dakota" means "alliance" in the nation of the Sioux, and this program employs a transdisciplinary service delivery model in which parents and professionals form an alliance to assist the family and community in promoting the optimal development of the child. As Linda Kjerland, the project's director has noted,

> ◆ *"We've thrown away the words 'parent involvement' and instead in their place put in 'what is the appropriate staff involvement with families.' We recognized that we are an extension of a family system and they are not an extension of us . . . that they exist and will exist long after our services to them will cease, and we need to be supportive of their efforts through our efforts" (Kjerland, 1986).*

The design, implementation, and evaluation of the child's program are the result of a collaborative effort of the parents and the service providers. The pivotal role of the parents is clearly evident in the project's goals:

- focus on the child's and family's needs that are considered essential by parents,
- provide parents with direct and meaningful participation throughout the intervention process,
- promote the acquisition of knowledge, skills, and confidence by parents to describe their child's strengths and needs and to identify and carry out goals for their child,
- encourage the transmission of these strategies by parents to other caregivers and settings, and
- increase the child's ability to function in the least restrictive environment.

The family-centered approach is particularly evident in the assessment component of the program. The parent is an active participant in the assessment, facilitating the child's responses and in some cases, administering the test items. Because all disciplines are present during the evaluation, the child does not have to experience the usual grueling day of multiple assessments. It also eliminates the necessity of parents having to answer the same questions from multiple professionals. The parents are present for the discussion of the results. The focus of the evaluation is to identify not only the child's needs but their strengths as well, and the discussions and recommendations are focused on the parents' priorities. For more information contact Linda Kjerland, Project Director, Dakota, Inc., 680 O'Neill Drive, Eagan, MN 55121, (612) 455-2335.

In Developing Community and Hospital Services

Parent Advisory Committee—Children's Medical Program, Jackson, Mississippi

Established in 1986, this committee provides recommendations to the general

Advisory Board of the Children's Medical Program (formerly Crippled Children's Services). The goal of the committee is threefold:

1) to educate the Board as to the needs of children with chronic illness and disabilities in order for CMP to develop programs and policies that are responsive to their needs;
2) to increase public awareness of the benefits of the services provided by CMP; and,
3) to advocate for state legislation that is supportive of these programs.

- Children's Case Resolution System—South Carolina

  This commission was created by the South Carolina Children's Coordinating Cabinet to review cases of children not being served adequately, collect data, and identify gaps in delivery of services. Most of the commission's members are parents of children with special needs.

- Community Advisory Board—Children's Hospital Child Health Centre of Alberta, Canada

  Begun in 1973 the Community Advisory Board represents parents and community associations. Its purpose is to provide direction and to give advice on an ongoing basis to the Board of Trustees and to ensure that the concerns of parents are solicited and channeled directly to the board.

- Parent Advisory Committee—Children's Hospital, Boston, Massachusetts

  This committee was formed to assist the planning team on construction of the new hospital facility and to provide the perspective of children and families. The committee has grown beyond its original role on the planning team and continues to serve an advisory capacity in the development of hospital policies.

- Parent Advisory Committee Survey

  In the spring of 1987, the Federation for Children with Special Needs completed a survey examining parent/consumer participation in advisory committees within the state departments of Maternal and Child Health (MCH) and Children with Special Health Needs (formerly Crippled Children's Services—CCS). Consumer participation exists in 34 states with 20 states having more than one committee with parent representation.

  In this survey, the state Directors were also asked to comment on the perceived difficulties and benefits of this form of parent/professional collaboration. The difficulties largely related to factors affecting parents' ability to attend the meetings such as needed reimbursement for travel and child care expenses. The other major difficulty was that professional terminology and parents' lack of information often became a barrier to communication and understanding.

  The benefits were many. The most frequent comment was that the participation of parents on the committees provided a broader understanding of parents' needs, and they were able to provide alternative solutions to service delivery problems. One director noted,

  > ◆ *"Operational policies are examined in light of parents' and family's needs, not agency convenience and legislative action. It helps to remind professional staff and agencies that they really serve people and not 'clients.'"*

  For information on this survey or a similar survey examining consumer participation on committees in children's hospitals and hospitals with pediatric residency programs, contact Betsy Anderson, Federation for Children with Special Needs, 312 Stuart Street, Boston, MA 02116 (617) 482-2915.

At the Policy Level

- Arizona Consortium for Children

  The Consortium consists of parents, professionals, organizations, hospitals, and state agencies concerned with improving the quality of care for children with special needs through a collaborative process. Because of its multifaceted nature, the Consortium is seen as an important resource. For example, when the state's Children's Rehabilitative Services was interested in developing grant guidelines for the delivery of new services, the Consortium was consulted. As a result of their identifying a need for increased psychosocial services and greater coordination of care, four full time positions were created, two psychologists and two special educators, to ensure the coordination and continuity of care as the children go from home to hospital to community.

  The Consortium has been particularly effective in the legislative process. In 1986, two pieces of legislation were passed supporting children with special needs and their families. One required school districts to develop a homework policy for children with chronic illnesses. This policy enables these children to keep up with school work and to remain in a regular classroom placement despite frequent absences. The second piece established a statewide information and referral system for children with chronic illnesses which can be accessed through a toll free number. For more information contact Barbara Hopkins, P.O. Box 2128, Phoenix, AZ 85001 (602) 838-9006.

In Education and Training Programs

Education and training programs are also needed in order to provide both parents and professionals with the skills necessary to enter into a collaborative partnership. The following are organizations and programs which address this need:

- **Federation for Children with Special Needs—Boston, Massachusetts**

  The Federation has received funds from the U.S. Department of Health and Human Services, Division of Maternal and Child Health for the project entitled CAPP—Collaboration Among Parents and (Health) Professionals. The overall purpose of the project is to increase and encourage parent involvement in the health care of their children who have disabling conditions or chronic illnesses. The goals of the CAPP Project include:

  - the preparation of parents to assume an integral role in the health care of their children,
  - the promotion of communication and collaboration among parents and health care providers, and
  - the development of a national system to ensure parents access to information and peer support.

  The activities of this project include the development of written materials, training packages, workshops, and presentations. Models of collaboration with other parent and professional agencies and groups will be designed, field tested, and replicated. For more information, contact Betsy Anderson, CAPP, Federation for Children with Special Needs, 312 Stuart Street, 2nd Floor, Boston, MA 02116 (617) 482-2915.

- **The Association for the Care of Children's Health (ACCH)—Washington, D.C.**

  ACCH has a three year grant from the Division of Maternal and Child Health which began January 1, 1986. The overall goal of the project is to promote parent/professional collaboration and a family-centered approach to care for children with special health care needs. A key component to the implementation of this grant is ACCH's parent network. This growing network consists of approximately 400 parents of children with special needs across the country who are leaders in their own communities and states. This network provides ongoing input in the development of publications and media, in providing consultations, and in the general activities of ACCH. The Parent Network Meeting, which has been held concurrently with ACCH's Annual Conference over the past five years, provides another invaluable opportunity for the exchange of information and resources among parents and between parents and professionals. For more information on ACCH's activities, contact Beverley Johnson, Executive Director, Ibby Jeppson, or Terri Shelton, ACCH, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016 (202) 244-1801.

- **The Chronic Illness Teaching Program—Michigan State University**

  Michigan State University offers a primary care pediatric residency program that focuses on the developmental and behavioral aspects of children with chronic illness and their families. The specific objectives of the program are:

  - to obtain an understanding of the impact of chronic illness on the child, the family, the service providers, and society,
  - to acquire skills in the primary-care management of chronic illness,
  - to understand the process of coordinating care with the family and with other health, education, and community professionals,
  - to develop attitudes and values associated with the support of the child and family autonomy, and
  - to evaluate the effectiveness and success of their efforts based on improvement or stabilization of function rather than cure.

A critical component of the program is the three-year, indepth experience with a child who has a chronic condition and his or her family. The purpose is to enable the resident to understand more fully the social, financial, educational, and psychological impact of the child's condition and, with the assistance of the family and other professionals, to develop the skills to address the child's and family's needs in a comprehensive fashion. The first group of residents will complete the program in June of 1987 and the program has plans to conduct a longitudinal study of the graduates' involvement with children with special health care needs. For a more detailed description of the program see, B. W. Desguin (1986), *American Journal of Diseases in Children, 140,* 1246-1249.

- Roundhouse Conference on Children with Disabilities—Grand Junction, Colorado

The initial concept of the conference was jointly developed by a pediatrician, a parent, and an educator from Grand Junction. Their hope was to design a conference where parents and professionals could meet together to "educate" each other, to share information and feelings on issues surrounding children with disabilities, and to leave with renewed vigor and insight. The railroad term "Roundhouse" seemed appropriate: "a center where locomotives turn around and head in a different direction." For the past seven years, the main objective of the conference has been to provide a "safe" atmosphere for parents to interact with professionals. At the conference, no one uses a professional title, and service providers have an invaluable opportunity to develop a new understanding and sensitivity to the issues of parents. The conference is held in a retreat setting that encourages informal interaction where participants can receive not only information on current and future trends in the field of disabilities but also have "free time" where they can share ideas and feelings. For information on this conference, contact Effective Parents Project, Inc., 930 Ute Avenue, Grand Junction, CO 81501, (303) 241-4068. ■

3 Sharing of Unbiased and Complete Information with Parents About Their Child's Care on an Ongoing Basis in an Appropriate and Supportive Manner

INTRODUCTION

The sharing of information between parents and professionals is an integral part of any family-centered care approach. If what we are aiming for in the care of children with chronic illnesses or disabling conditions is for "parents to join us cooperatively as equals in this partnership" (Vincent, 1985, p. 41), then parents must have ready and complete access to information.

WHAT DOES IT MEAN?

At first glance, this element appears to be the most simplistic and easily attainable of all the aspects of family-centered care. "Of course, we pass on information. Why my developmental evaluation report was over five pages long" may be heard from professionals. "I've told all of them about his developmental milestones. Don't they talk to each other?" is a frequent complaint of parents. While perhaps the most tangible of the elements, the sharing of information between parents and professionals and among professionals is akin to trading a fragile and precious commodity. The sharing must be carefully nurtured.

What Are the Barriers?

Perhaps the greatest barrier to the exchange of information between parents and professionals is what Robin Thomas (1986) has termed as a difference in "paradigms." In her interviews with families, she became aware of a very real difference in the way health care providers and families see the world. "It was, in many cases, like a Martian speaking to an Earthman" (Thomas, 1986). Parents and professionals must find ways to understand each other's "language." Sometimes the use of undefined or vague terms can be the problem. One parent reports, "When they said 'delayed' I thought of all the trains going from New Jersey to New York. Jeff's on a slower train, but he's going to get to New York. They knew all along he was never going to get to New York. Their 'delay' was my 'off the track' " (Healy, Keesee, & Smith, 1985, p. 38).

Sometimes the difficulty arises when a parent, who is new to the health care system, tries to articulate his or her needs. As illustrated by Rubin and Quinn-Curran (1983),

> ◆ *"Parents new to the search for services may not be clear about how to label the service they are seeking. All they may know is that a family member needs assistance. There are three steps a parent must go through to gain access to services. First, parents need to identify what their needs are—e.g., someone else to take over for awhile so they can get some rest. Second, they need to translate their needs into the proper service label—e.g., 'respite care.' Third, they need to contact the appropriate agency that delivers that service. Only the first step in this process is familiar to the average parent. In the second and third steps, parents must rely on the knowledge they have acquired, their memory, resourcefulness, and persistence" (Rubin & Quinn-Curran, 1983, p. 71).*

Why Is the Sharing of Information Important?

For professionals who are accustomed to receiving information and having access to each other and to resources without difficulty, the importance of sharing information with parents may be underestimated and the difficulty families have in accessing information, overlooked. Knowledge is power and ". . . knowing what's going on, and participating in whatever way you can, reduces anxiety" (Kaufman, 1985, p. 3).

Not only does the provision of information have an emotional impact, it is a critical factor in enabling parents to participate fully in the decision-making process. It is important for ongoing and daily decisions about the child's care. It is critical for more basic decisions regarding the provision of medical treatment.

> ◆ *"We have been asked to make decisions, sometimes life-or-death decisions, on the basis of scanty or outdated information. How can one possibly make a decision for or against surgery needed to save the life of a child with Down's Syndrome twenty minutes after her birth when one's only 'information' is inaccurate myth?" (Duffy, McGlynn, Mariska, & Murphy, 1984).*

All parents, even those who have had professional training in related areas prior to the birth of a child with special needs, require information. The speed with which medical knowledge and developmental interventions are changing further highlights the need for up to date information in these areas for both parents and professionals.

◆ *"Parents themselves need adequate knowledge of the range of support and treatment facilities for the disorder in question. It is a rare parent who has even the slightest knowledge of where to go or how to obtain the necessary resources to get help for this youngster. Although we were a professional family, used to dealing with the helping professions, many years passed before we felt we fully knew the range and kind of services that could be available to our son on a community, state, and federal level" (Gallagher & Gallagher, 1978, p. 208).*

What Information Should Be Shared?

In a word . . . EVERYTHING . . . from medical information, to community resources, to support groups, to pros and cons of treatment choices.

◆ *"The more you know, the less scary the future looks. Parents need to have both concrete information about their child's condition and prospects and what I will call emotional information. The hospital social worker gave us two books to begin with, one explaining what Down's Syndrome is and how early intervention helps and the other written by parents which let us know that the emotions we were experiencing—even the ones we were ashamed of feeling—were not abnormal and that we could and would move beyond them" (Duffy, 1984).*

Often the information needed to provide adequate care for children with special needs can be very technical. It is important for this information to be provided in understandable terms. It is equally important to link these explanations with medical terminology. Each profession develops a vocabulary that makes it easier to communicate with other professionals. However, this technical "shorthand" may impede the exchange of information between parents and professionals. Parents need both the layman's terms to help them understand as well as the technical language that allows them to communicate with professionals and to research their child's condition on their own.

Information can also bring a sense of power and control to a family who may feel "more hostage than partner to a gang of powerful professionals" (Oster, 1985, p. 27). It can also help to minimize the development of a dependent relationship between parents and professionals that can undermine the competence of parents.

◆ *"Almost universally, the parents of at-risk and disabled children express, early in their experience, a sense of powerlessness in the face of their child's special condition. A habit of deferring to professionals for everything can easily develop in response to this sense of powerlessness. Such deference can be not only flattering to professionals, but its acceptance can be justified in the belief that it is taking some load of decision making from already burdened parents. . . . Dependence is encouraged when professionals unilaterally make decisions which could more appropriately be made by the parents in the light of individual family styles, and this dependence is not compatible with the goal of building parental competence" (Healy et al., 1985, p. 39).*

Sharing information can enable parents to operate more independently, as partners with professionals and in some cases, in their absence.

◆ *"One of the first things Jan, our home trainer, told us was that her goal was not only to show us how to teach our daughter specific skills, but to teach us how to teach her so that if we ever found ourselves without services we would still know how to facilitate progress. After three and a half years of working with Jan and my daughter, I know I would hate to see Jan go—she has become a good friend as well as someone whose professional abilities I respect tremendously—but she has come close enough to her goal that if we were suddenly shoved out of the nest to fly on our own, I think we could. In these times of uncertain and shrinking funding for human services, it's a real comfort to know we've learned well" (Duffy, 1984).*

How Is Information Shared?

The way information is shared is perhaps the most important factor that ensures that the *giving* of information is truly the *sharing* of information. How much information is shared and the timing of the communication are critical factors in the parents' ability to use the information most effectively.

Sometimes professionals share too little information.

◆ *"I gave the neurologist a list of questions I had," said one mother, "including the fact that Angie's muscle tone didn't seem to be anywhere near what it should be. He ran a bunch of tests and then sat down with me and said, 'She has hypotonia, which means she has underdeveloped muscles.' That was it. He got up and left. My pediatrician gave me a copy of the report, and the neurologist really did have a lot to say. He just didn't want to say it to me" (Healy et al., 1985, p. 40).*

Sometimes information is exchanged between parents and professionals but not with other individuals who interact with the child. If we recognize that the child does not exist in a social vacuum and that extended family and other individuals have important perspectives and provide care for these children, information must be shared with brothers, sisters, grandparents, and other family members, and when appropriate, with the child as well.

Sometimes in an effort to be responsive to the families' need for information, professionals may give too much. Because the information isn't just about any child, but about their child, the ramifications of each statement, prediction, silence, or facial expression take on greater importance for parents. Because of this, even apparently innocuous questions and explanations can take on overwhelming proportions. Information, particularly disturbing information, is difficult for anyone to absorb fully. A family-centered approach facilitates an atmosphere where ideas and questions can be exchanged between parents and professionals and where the amount of and manner in which the child and family wishes to receive the information can be understood.

Sometimes it may not be possible to share information because there are no "answers" to the "questions." The admission of "I don't know" can be a very important piece of information as well.

◆ *"Professional behavior must be tempered by humility. It is impossible to have all the answers in regard to the diagnosis and treatment of problems associated with handicapping conditions. It was shocking and humbling to me to come face to face against how much I did not know. I often wondered what my professional colleagues would think of me if I admitted to them that I needed help in solving particular problems. It was important, albeit difficult, for me to learn to acknowledge my weaknesses without apology or shame. Honesty and openness can be the keys to genuine professional behavior. Learning to say 'I don't know' can be the beginning point of refining one's skills" (Turnbull, 1978, p. 136)*

Sometimes professionals feel they must resort to "mind reading" in order to provide information at a time when they feel the parents are ready. Because each family is different, however, this approach may not be an effective one. A family-centered approach would suggest that the best way to find out what families want is to ask them . . . but to ask them in a way that is supportive.

◆ *"Every time another professional interviewed me about them [my children]—how I took care of them, and why, and wrote all this down—I felt more unsure. If they didn't comment, I felt it must be because they couldn't think of anything good to say, so I must really be failing as a parent" (Weyhing, 1983, p. 126).*

Here a potentially good exchange between a parent and a professional has not been a positive one, particularly from the perspective of the parent. Communication can be improved if professionals explained more fully why they are asking certain questions and if they are sensitive to parents' reactions. Parents can enhance the communication process by helping professionals to understand how best to ask questions—what is supportive and helpful, and what is intrusive.

While it is understandable that parents may feel uncomfortable telling a professional directly that the way he or she asked a question was intrusive or not helpful, a parent can still encourage professionals to use more successful strategies by telling them about what they did like. Learning directly from parents through their participation in professional training programs and by reading parent produced materials on these subjects can help professionals understand how best to share information. Sharing of information does not involve just a one time brief discussion. It is an ongoing process with both parents and professionals having responsibility for the success of that process.

Why Share Information In This Way?

The benefits of a family-centered approach to the sharing of information are many. First, information that is shared in manageable doses, with all family members, and with adequate time for follow-up conversations is information that is more readily used. While this may not eliminate the need for repeating questions or answers, it does facilitate a quicker understanding of both the parent's and the professional's perspective. This type of sharing can lead to clarification of misunderstandings which, in turn, will enhance the quality of care for the child. It is the quickest way to determine if programs and policies are truly responsive to the needs of the child and family. And finally, it is the cornerstone of effective parent/professional collaboration. ■

MAKING IT A REALITY

The sharing of information between parents and professionals can be facilitated in a number of ways. As mentioned, the manner and timing of the communication is critical to the degree to which the information is absorbed and subsequently used. Given that all individuals process information differently and considering the "charged emotional states" under which most families and professionals meet, the sharing of information can be maximized by providing it verbally, in written form, through media, and if possible by demonstration. Other mechanisms that facilitate the sharing of information include the following.

Libraries

Both public and hospital libraries can be a powerful mechanism for facilitating the sharing of information. Including information about parent-to-parent support groups, community services, resources that assist the family as they care for their child, and specific information on chronic illnesses and disabling conditions for adults as well as for children would be very helpful for both parents and professionals.

In addition to special collections within existing libraries, the establishment of a family resource library can further the exchange of information. This type of library contains specialized materials for adults and children to help them understand and cope with health and family concems. It can augment existing hospital, community, and state services by informing families and professionals about important resources such as care for a child with special health needs, available community resources and how to access them, training in child growth and development, and assistance in finding an appropriate school replacement. For those interested in establishing such a library, the publication *Guidelines for Establishing a Family Resource Library* provides suggestions on planning and staffing the library, selecting materials, considerations when distributing medical information, selected bibliographies, and sample forms. The publication is available from the Association for the Care of Children's Health (ACCH), 3615 Wisconsin Avenue, N.W., Washington, DC 20016 (202) 244-1801.

- The Community Health Information Network (CHIN)

  This service is an example of public libraries in cooperation with a community hospital providing access to medical information for families. Families request information on medical topics at the public library in five participating communities in Massachusetts. The CHIN program can provide a listing of available articles on requested topics and copies of articles from publications in the Mount Auburn Health Sciences Library. For further information, contact Ms. Cherie Haitz, Director, Mount Aubum Health Sciences Library, 330 Mount Auburn Street, Cambridge, Massachusetts 02238, (617) 492-3500, extension 3121.

Medical Records

Parent access to their child's medical records is another important way that information can be shared between parents and professionals. The Federal Privacy Act governs and allows all patients access to medical records held by Public Health Service facilities, Veterans Administration hospitals, and military hospitals run by the Defense Department. In other facilities, access to medical records depends on the state where the families live. Only 11 states allow complete access to medical or mental health records (Public Citizens' Health Research Group, 1986). For more information on a specific state's laws concerning access or for assistance in reading medical records consult the following publication, *Medical Records: Getting Yours* available from the Health Research Group, 2000 P Street, N.W., Suite 708, Washington, D.C. 20036.

Information Services

- **National Information System for Health Related Services (NIS)**

This is a three-year project funded by the Division of Maternal and Child Health. Through these funds, NIS has compiled information on state programs, community and hospital services, and parent support resources related to children with special health needs. The information can be accessed by consumers and professionals through a toll free number. The NIS currently serves eight southern states: Alabama, Kentucky, Mississippi, Tennessee, Florida, Georgia, North Carolina, and South Carolina. During the second year of the project, information from an additional twelve states and the District of Columbia were added with complete implementation in all 50 states to be completed by the end of 1987. The types of agencies listed on the NIS include University Affiliated facilities programs, State Crippled Children's Programs, state level human services agencies, children's hospitals, national support groups and their local chapters, and novel or exemplary model programs. Each listing includes the agency name, address, telephone number, contact person, services provided, eligibility criteria, reimbursement accepted, and information about agency operations. This information can be accessed through a toll free number: (800) 922-9234.

- **AUNT FABS**

This is an electronic bulletin board sponsored by the National Resource Center on Family-Based Services. Designed to provide an exchange of current information on family-based services and access to the Resource Center's library, AUNT FABS can be accessed by any individual with a computer, a modem, and a communication software package. For more information, call (319) 335-4130.

Education and Training Programs

- **Better Ways (of Breaking News to Parents)**

This is a workshop for professionals conducted by Parents Helping Parents, Inc. (PHP), a non-profit, resource center and support group in San Jose, California. The workshop uses parents as teachers and covers a number of topics including: "When to Tell", "What to Tell", and "Discussing Institutionalization" along with an extremely helpful list of "Do's and Don't's" when communicating with a parent of a child with a disabling condition. For more information on this workshop, contact Florene Poyadue, PHP, 535 Race Street, Suite 220, San Jose, CA 95126 (408) 288-5010.

- **Parent Training and Information Centers (PTI's)**

The U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS), funds these centers (PTI's) in 38 states and the District of Columbia. They are designed to provide information and training to parents about the special education laws and services for children with special needs. Parent centers receive technical assistance from Technical Assistance to Parent Programs (TAPP). The contact information for the Central Office and the four regional offices of TAPP is included in the chapter on Resources. For information regarding any of these programs contact: U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS), Office of Special Education Programs, Division of Personnel Preparation, Switzer Building, Room 4620, 400 Maryland Avenue, S.W., Washington, D.C. 20202 (202) 732-1032. ■

4 Implementation of Appropriate Policies and Programs that Are Comprehensive and Provide Emotional and Financial Support to Meet the Needs of Families

■ INTRODUCTION

In her book *A Difference in the Family,* Helen Featherstone (1980) talks about the four ways that professionals can assist families who have children with special needs In addition to providing information, respecting the child and the family, and providing emotional support, Featherstone mentions providing services. If the philosophy of family-centered care is to be translated into practice, then programs and policies must be developed that are comprehensive and that provide support to meet the changing needs of families.

> ◆ *"Families have responsibilities for meeting many different needs These needs are in the areas of economic, personal, physical care, domestic care, rest and recreation, socialization, self-definition, affection, and educational/vocational. Children vary in the extent to which they influence a family's ability to meet these needs; the primary variables are the type and severity of the disability and the availability or unavailability of community and family resources" (Turnbull & Turnbull, 1985)* ■

WHAT DOES IT MEAN?

The first step toward implementing this element is understanding what "providing comprehensive, emotional, and financial support" means. The impact of a child's chronic illness or disability can be seen in a number of areas including the psychosocial adjustment of the child, the parents, the brothers and sisters, and other family members; the parents' marriage; the family's finances; and even the parents' careers. Likewise, the ways in which these care and family support needs are addressed are not one dimensional. The support needs of families are diverse and varied and change over time. These needs include but are not limited to: respite care, home care management, equipment loan, sibling support, transportation to health services, greater coordination of services, and parent-to-parent support. (Because so many parents have attested to the overwhelming importance of parent-to-parent support in their efforts to care for their children, it will be discussed in more detail later in this publication.) Unfortunately the programs that address these needs are frequently unavailable. Consider the following examples:

> ◆ *"Without a respite care program, the only relief is an institution. It is a high price for our Andrew to pay so that we may have a vacation from the worries of looking after him and spending time with our other three children. It is a price we are unwilling to ask him to pay. Yet the need to recoup is getting more desperate and, as a result, the institutions loom closer" (Lukas, 1975, pp 2-3).*
>
> *"Do we ruin ourselves financially or place our child before he is ready?" (Bertaina, 1985).*
>
> *"Like most other families, we were left alone to sort out these complicated emotional issues. Two things would have helped: emotional support and information" (Oster, 1985, p. 31).*

All three of these parents reflect some of the stress and frustration they have experienced in caring for their children. Stress sometimes has been defined as an imbalance between the demands placed on an individual and the available resources. While it may not always be possible to reduce some of the demands faced by these parents and their children, family-centered care policies and programs can provide resources that support existing family strengths and that balance the demands of care.

For example, hospital policies that maintain family relationships and support the parent's role during hospitalization can reduce stress. In one study, Miles and Carter (1985) asked parents to identify staff behaviors and policies that were helpful to them during their child's hospitalization in a pediatric intensive care unit. The policy reported as most important by the largest number of parents was being permitted to stay with their child as much as possible. Not only do family-centered policies ease the parents' stress, they also can improve the ease with which medical procedures are completed. For example:

> ◆ *"I was told that parents were absolutely not allowed to participate (in the X-ray process). The baby, age about fifteen months, was, without any warning,*

> *strapped down tightly to a cold hard board. Imagine how you'd feel if a stranger came up, grabbed you without warning or explanation and tied you down. Of course, Zack screamed and turned very blue for lack of oxygen. He had enough lung problems as it was. That never happened again. Either my husband or I always went with him and held him and there never was any problem with the X-rays coming out well, which was the justification for using boards and straps. We never had to repeat an X-ray" (Kaufman, 1985, pp. 5-6).*

The implementation of this element can also be reflected in the creation of options to institutionalized care. Caring for children at home and in their community can help to minimize the disruptive impact of the child's condition and can maximize the growth and development of the child and his or her family.

> ◆ *"When Katie's doctors told us we could take her home it seemed as if our prayers were answered. All the learning processes seemed minute compared to the joy of having us together" (Beckett, 1985, p. 6).*

To do this, however, the growing trend toward home care and deinstitutionalization must not exceed the availability of necessary support programs such as in-home nursing and respite care that make this care at home possible. Financing mechanisms to provide this care must also be available.

> ◆ *"It is an amazing paradox that institutional care for Adam would cost $35,000 to $65,000 per year but the federal and state governments are willing to spend only $2-3,000 per year to help us keep Adam at home" (Bertaina, 1985).*
>
> *"If I said to the state, 'Take her, she's yours,' it would cost the taxpayers $50,000 per year to put her in an institution. I don't want $50,000 or even $5,000. I would be satisfied to have the part-time homemaker back so the wife and children can get out for a few hours" (Cohen cited in Cina & Caro, 1984, p. 45).*

Creative and coordinated approaches to financing these support and health services are needed. Having the "child follow the money," where the family must attempt to meet varying agency eligibility criteria in an effort to procure the services needed, can lead to frustration and fragmentation of services. In contrast, having the "money follow the child," where available sources of funding can be pooled to address the child's needs, could lead to better coordinated and more supportive services. ■

MAKING IT A REALITY

The ways in which states, communities, and institutions can address the support needs of families are varied. The following are examples of programs and policies that address family support needs.

Financial Policies

■ Individual "Katie Beckett" Waivers

Created in 1982, this individual waiver program is named after the first child to receive one. These waivers provided states an option for addressing the problems of individuals who remained institutionalized because returning home for less costly medical treatment would result in the loss of SSI and Medicaid eligibility. These waivers permitted states to provide regular state Medicaid services by waiving income "deeming" or eligibility rules on a case-by-case basis. States applied to an HHS review board on behalf of a child for a waiver of the "deeming" rules provided that deinstitutionalization would result in Medicaid savings and that the quality of care would be maintained. "Katie Beckett" waivers approved or applied for prior to December 31, 1984 continue to be funded; no new applications are accepted after that date.

■ Regular 2176 Waivers

The "regular" Section 2176 Waivers established by the Omnibus Budget Reconciliation Act in 1981, allow states to offer a wide array of home- and community-based services for individuals who would otherwise require care in a skilled nursing facility, intermediate care facility, or hospital. States must specify a projected number of people to be served from one of the following three categories of Medicaid recipients: aged or disabled, or both; mentally retarded or developmentally disabled or both; or mentally ill. The objective of the waiver is to prevent or delay treatment in institutions by substituting less costly home- and community-based services. States must provide assurances that average per capita Medicaid costs will not increase as a function of the waiver. The waivers are for a three year period and can be renewed for five year periods. There is no limit to the number of waiver requests a state may submit.

■ Model 2176 Waivers

In December of 1982, the Health Care Financing Administration (HCFA) developed a "model" 2176 waiver. The waiver was specifically developed to provide home- and community-based care for individuals who otherwise would have been eligible for Medicaid only if they received care in an institution. It is similar to the regular waiver except that it can serve no more than 50 individuals with disabilities or visual impairments at any given time and that the Social Security Income (SSI) eligibility requirements must be waived to allow Medicaid to cover noninstitutional services. States may designate specific groups of individuals with disabilities to receive services but are required to offer only one home- or community-based service in addition to those provided by regular Medicaid programs. States can admit only those eligible individuals whose estimated home care costs are below the estimated costs for institutionalization.

■ State Plan Amendment

States also have the option of amending their state plans to provide regular Medicaid coverage to children with disabilities under the age of 19 living at home who, because of the SSI eligibility rules, would only be eligible for Medicaid if they were institutionalized. Only the normal range of covered Medicaid services in that state are available under this option. Special services cannot be added solely for this particular group. States must determine that home care is appropriate and less costly than a similar level of care at an institution. Once the plan is amended, all children meeting the eligibility criteria are allowed to participate whether or not they are receiving care in an institution

Thirty-three states were serving children dependent on technology or with physical disabilities through a waiver as of April, 1986. Eight states were providing home care services under a regula. ·76 waiver with 14 states providing benefits through 19 separate Model 2176 waivers. Nine states (with one pending) had amended their state plans and 14 states have individual "Katie Beckett" waivers. Together these options have been serving 938 children who include those dependent on technology, those with central nervous system disorders (e.g., cerebral palsy or spina bifida), those with congenital, metabolic, or immune disorders or injury-induced trauma.

Individuals interested in obtaining additional information on waiver programs may contact their state Medicaid agency, Services for Children with Special Health Needs (formerly Crippled Children's Services-CCS), or their State Department of Health. State personnel interested in more information on the process of developing a waiver program should contact the Health Care Financing Administration, Department of Health and Human Services, Washington, D.C.

State Programs

■ Michigan Family Subsidy Program

This program is designed to pay for special expenses the family incurs while caring for a child with significant disabilities. This financial support may prevent or delay institutionalization or may enable a child to return home. The program recognizes that each family has differing and unique needs that often cannot be met by specific agency services. Thus, every family that meets the eligibility criteria receives $225.00 per month to use as they wish Families may use the money for physical therapy for their child, for alterations to their home to accommodate medical equipment, or for a much needed family vacation. Not only is the family allowed this flexibility but the program saves money for the taxpayer by avoiding and/or reducing the need for more costly out-of-home placements. For additional information contact the Michigan Department of Mental Health, Lewis Cass Building, Lansing, MI 48926 (517) 373-3740.

■ Medically Fragile Children's Program

MFCP is an innovative family-based support program established in 1984. This program provides in-home nursing and other health services to families with children who have both a life-threatening medical condition and a developmental disability. The program enables families to care for their children at home rather than in a hospital or institution. It was through the advocacy efforts of a statewide coalition of parents of children with special needs, called Parents Reaching Out (PRO), that legislation was enacted which allocated state matching funds thus establishing MFCP through a federal Medicaid Waiver. For more information contact: Georgia Cleverley, Coordinated Community In Home Care (CCIC), PERA Building, Room 516, P.O. Box 2348, Santa Fe, NM 87504-2348. (505) 827-4923.

- Texas Respite Resource Network

The Texas Council for Developmental Disabilities initiated the Texas Respite Resource Network (TRRN). TRRN is a clearinghouse with information for parents and professionals on respite care services in Texas as well as in other areas of the country.

TRRN also is

- — examining existing services to determine the components of successful programs and to make recommendations regarding the types and range of services that should be available to families;
- — developing two directories, one that documents services statewide and one that documents services nationally; and,
- — delineating guidelines for model respite care programs and developing a series of training materials for respite care providers.

For more information on the network or on the directories of state and national respite care programs contact: Jennifer Cernoch, Ph.D., P.O. Box 7330, Station A, San Antonio, TX 78285, (512) 228-2576.

Community Programs

- Family Friends

This project, developed by the National Council on the Aging, Inc., is an unique intergenerational project that uses senior citizen volunteers to work one-on-one with children with chronic illnesses and disabling conditions and their families.

Family Friends:

- — provide emotional support through talking and listening;
- — offer educational activities such as helping with school work;
- — assist parents in providing some limited daily care for the child such as feeding and dressing,
- — help parents in teaching their children about self-care; and
- — act as advocate for the child and family in obtaining services or information they need.

For more information on this project contact: Meredith Miller, Ph.D., Project Director, or Jane Diao, M.S.W., Program Associate at Family Friends Project, National Council on the Aging (NCOA), 600 Maryland Avenue, S.W., West Wing 100, Washington, DC 20024, (202) 479-1200.

Legislative Policies

- Children's Justice Act

In August, 1986 Congress enacted legislation to initiate temporary non-medical child care (respite) services for families of children with disabling conditions or chronic illnesses. The act, known as the Children's Justice Act, incorporates temporary respite care for children with special needs to alleviate social, emotional, and financial stress among the families of such children.

Pending the appropriation of funds, the Children's Justice Act would establish a demonstration program of grants to states to assist private and public agencies and organizations in providing in-home and out-of-home respite care for children with special needs. Such care would be provided on a sliding fee scale with hourly and daily rates.

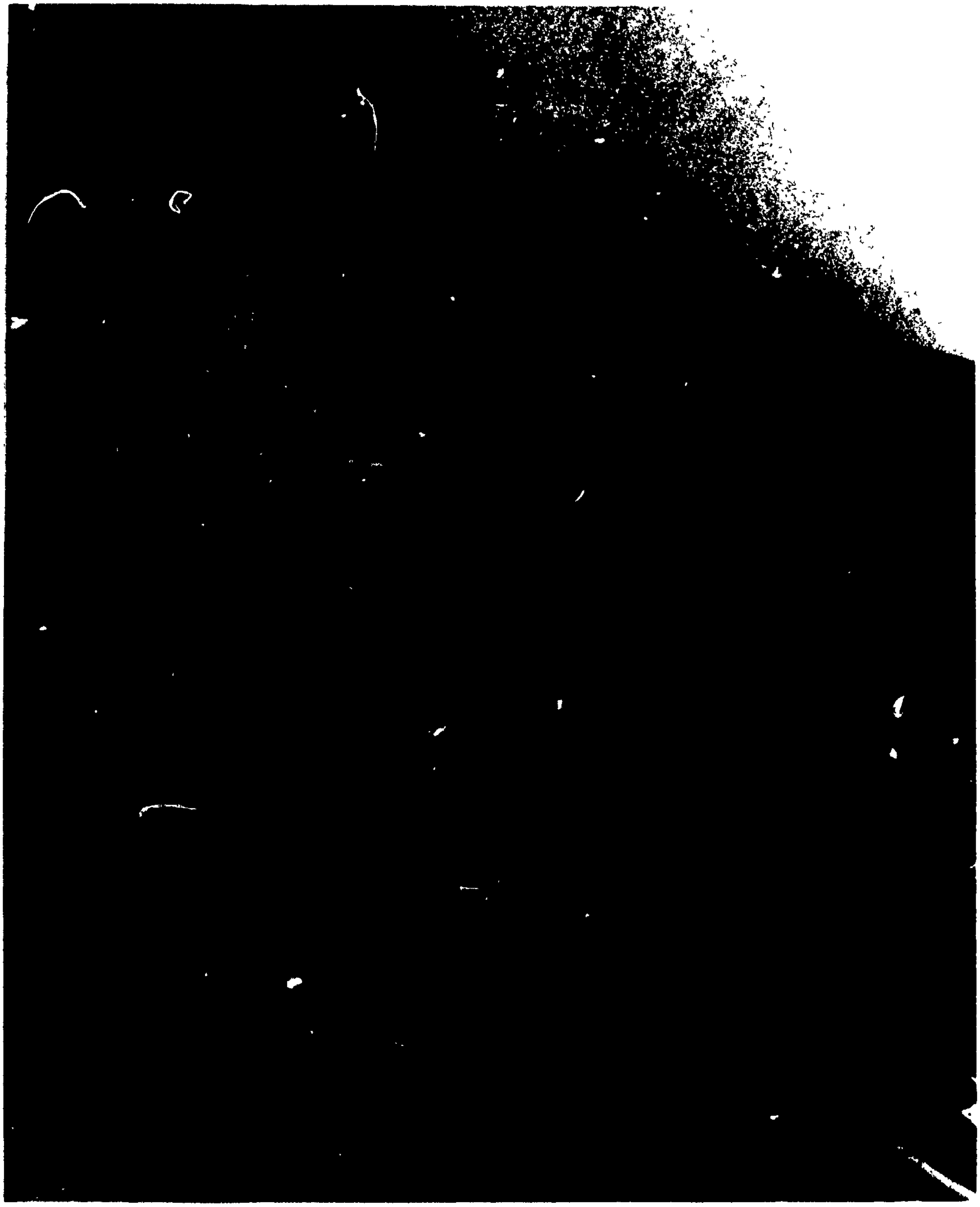
The legislation was developed by the Select Committee on Children, Youth and Families of the U.S. House of Representatives, Congressman George Miller, Chairman. For additional information about this legislation, contact Jill Kagan at the Committee, Room H2-385, House Annex 2, Washington, D.C. 20515, (202) 226-7660.

- P.L. 99-457

Depending on how states choose to participate, Public Law 99-457, the Education of the Handicapped Amendments Act of 1986, has the potential to be a policy that will be very supportive of families of young children with special needs. Signed into law on October 8, 1986, P.L. 99-457 provides incentives to states to serve an additional 70,000 children ages three to five years with disabling conditions and creates a new program to address the special needs of infants and toddlers, birth through age two, with disabling conditions and their families.

Of particular interest is Title I of the bill which establishes a new discretionary program for infants and toddlers. Included in this program is a comprehensive list of services that could be offered such as family training, counseling, and home visits; special instruction; speech pathology and audiology; occupational therapy; physical therapy; psychosocial services; care coordination (case management) services; medical services only for diagnostic or evaluation purposes; early identification, screening, and assessment services; and health services necessary to enable the infant or toddler to benefit from other early intervention services. Section 677 of the Act also requires that the family of each infant and toddler have an Individualized Family Service Plan (IFSP). The IFSP must consist of a multidisciplinary assessment of the child's and family's needs and a written family service plan developed by a multidisciplinary team, which includes the parents or guardian, that lists the major outcomes expected and recommendations for needed services. This law has the potential to be very supportive of families by addressing the issues of the entire family and by providing more comprehensive and better coordinated services. ■

5 Recognition of Family Strengths and Individuality and Respect for Different Methods of Coping



INTRODUCTION

This element embodies two complementary concepts. The first is that family-centered care must reflect a balanced view of the child and family. That is, in assessing and attempting to address the child's problems, the child's and the family's strengths and resources must be considered as well. Secondly, the individuality of the child and his or her family and their different methods of coping must be respected and supported.

◆ *"Exceptional parents are not just mothers and fathers. We are paraprofessionals, physical, feeding and occupational therapists. We are program designers, service coordinators, nurses and advocates. In addition, we are husbands and wives, sons and daughters, home makers and breadwinners, parents of healthy children and creative budget managers. Most importantly, we are individuals" (Downey, 1986, p. 8).* ■

WHAT DOES IT MEAN?

Recognition of Child and Family Strengths and Individuality

Too often, the focus of assessment and program planning has been on the child's health or developmental problems alone. Ignoring strengths in the planning process often creates an inaccurate picture. Many children with special needs and their families possess far more strengths than needs and experience more successes than failures. Furthermore, focusing only on the needs may result in a "self-fulfilling" prophecy.

Professionals can play an important role in identifying a child's strengths. This approach can make a positive difference in the interaction between professionals and parents, and more importantly in the parents' interaction with their child.

> ◆ *"Sometime after Nicholas had started nursery school I saw a grainy, black and white videotape that demonstrated what Dr. Brazelton calls the 'irresistible responsiveness' of a premature baby. I almost cried while I watched as a 3 lb. preemie slowly followed a ball with his eyes, looked for the sound of his mothers's voice, and with heroic effort, finally turned his head and even reached for her. A nurse practitioner had taught that mother to read the subtle cues that could have drawn me to my son so much earlier. It was a piece of information, a teachable skill, that might have changed the course of our lives" (Oster, 1985. p. 31).*

Recognizing and supporting the parents' strengths and resources is just as important as recognizing them in the child. The emotional and educational benefits of this approach are reflected in Ann Oster's comments.

> ◆ *"The individuals stand out who helped me begin rebuilding a sense that I was worth something· the nurse who sat and talked with me when she had time, and loaned me a nursing text when I was frustrated by my ignorance; the child life teacher who asked how was I doing and then sat down to listen as I told her; the physical therapist who celebrated Nick for what he could do instead of defining him by his disabilities" (Oster, 1985, p. 27).*

Respect for Different Methods of Coping

Becoming more aware of a child's and family's strengths is a crucial step in recognizing their individuality and respecting their methods of coping. Sometimes though, well-intentioned professional efforts that are aimed at understanding and supporting families may result in just the opposite. This is particularly evident with respect to the issue of labeling. The use of labeling is often justified as necessary because it facilitates a child's placement into pre-existing programs or enables financial resources to be allocated. While it is impossible to totally eliminate the use of labeling, a family-centered approach encourages the use of flexible categories and when necessary, the use of diagnostic terms in as sensitive a manner as possible. By not "categorizing" children to fit those services or programs that already exist in the community, comprehensive services can be more easily tailored to the child and family and new and creative programming may be established as the result of the identification of new service needs

Sometimes families may be labeled.

> ◆ *"Parents of developmentally disabled children have been ascribed many roles. They have been perceived as tragic victims and advised to institutionalize their child at once. They have been seen as silent observers of their child's professional treatment and given a spot on the other side of the one-way window. They have been viewed as patients with disabling emotional sequelae, and have been invited into therapy for themselves" (Baker, 1983, p. 55).*

They have been viewed as "noncompliant," which may be as much a result of inappropriate or poorly explained recommendations rather than a conscious desire to ignore recommendations or an apathetic response (Cadman, Shurvell, Davies, & Bradfield, 1984). Recognizing and respecting the individuality and strengths of families will only serve to strengthen their self-confidence and to provide a strong framework for parent/professional collaboration.

While there are issues that are common to families whose children have special needs, care must be taken to respect each family's individuality in their adaptation to their child's needs and to address their goals for their child. For example, some have suggested that the large body of research identifying discrete "stages" of adaptation may inadvertently ignore the individuality of a family's coping responses.

> ◆ *"Many writers invoke the notion of stages to describe parents' changing responses to a child's handicap. Certainly these stage models tell a part of the story: people do change; many follow rather similar paths; for the most part, life improves. I think, however, that most stage theories oversimplify a complex and diverse process. Just as not all dying people pass through Elisabeth Kubler-Ross' well-known stages—denial, anger, bargaining, depression, and acceptance—mothers and fathers of the disabled travel in many different directions when they move beyond despair. This is presumably why theorists argue about the number and the character of the stages" (Featherstone, 1980, p. 10).*

These theories have their place and can be very helpful to professionals as they attempt to anticipate and address the changing needs of families. A family-centered approach to care involves using these theories as a framework while approaching each family anew—listening to their individual needs and strengths rather than attempting to "fit" them into a pre-existing scheme.

> ◆ *"Although we may be able to generalize to the extent of predicting the likelihood of parental anger or fear or denial, the specific manifestations of these emotions are as varied as the individuals who feel them. The only way to discover what any collection of human beings needs is by listening to each one" (Oster, 1985, p. 27).*

A family-centered approach also involves respecting cultural and socioeconomic differences. Understanding, respecting, and incorporating a family's values into the planning for their child is as critical to the success of the child's care as a consideration of the child's level of development or medical diagnosis. This may become very difficult when programs designed to assist families unwittingly conflict with prevailing values within the families' community. Cleveland (1983) makes the following observation of Asian families.

> ◆ *"There is a high degree of shame associated with receiving charity medicine and welfare. One of the largest social problems confronting the Chinese family, particularly with regard to obtaining health care, is the cultural value of family pride and personal face. This value influences the elderly Chinese and inhibits their ability to reveal their immediate needs to the public agencies of social service and health care. The loss of face is translated as subjecting one to embarrassment and shame but it is more than an individual shame—it reflects not only on the individual but also on the entire family. It is connected with failure, a loss of respect, trust, and a loss of integrity" (Cleveland, 1983, p. 17).*

Similar conflicts in values can exist with respect to differences in religious beliefs and/or socioeconomic differences. As one upper middle class father whose son has cystic fibrosis said,

> ◆ *"When we finally realized that we were going broke, we had to face the fact that we needed help from someplace, and that someplace was going to be the government. My family? On welfare? No way. But eventually I had to do it; I had to accept public monies for my son's hospital costs. It was a long time before I could tell my neighbor about that" (Shayne & Cerreto, 1981, p. 13).*

While it may be difficult for all programs and policies to be specifically tailored to each individual child's and family's needs, when parents and professionals collaborate it facilitates the development of programs that respect individual strengths and values.

MAKING IT A REALITY

This aspect of family-centered care can be encouraged by examining public awareness of the terminology that is used when referring to children with disabilities and their families While some may say it is merely semantics, using the term "child with cerebral palsy" as opposed to the "cerebral palsied child" may help parents and professionals to remember that a child with a chronic illness or disabling condition is a *child first*. A recent article by Carol Jefferson (1986) entitled "Disabilities—The Language We Use" addresses this issue.

> ◆ *"People with disabilities are commonplace in our lives and it is our [professionals] responsibility to do something special to sensitize the general public to their uniqueness and worth by the language we use in our everyday communication. There needs to be a change in negative attitudes about people with disabilities into positive thoughts and actions" (Jefferson, 1986, p. 5).*

The article goes on to suggest some alternatives to phrases that are often used. For example, she suggests "using a wheelchair" as opposed to "wheelchair bound" and replacing the words "victim" or "afflicted" with "a person who has." Jefferson concludes, "by changing our attitudinal barriers, and using a more positive communication style we can eliminate the myths and misconceptions about people with disabilities" (Jefferson, 1986, p. 6).

Programs

It is important to offer a *variety* of support programs so that *families* can decide what would be of the most help to them The following are examples of programs that are designed to provide a range of options to families.

■ Candlelighters

This national support organization for families whose children have cancer, feels that not every parent wants to attend a regularly scheduled parent-to-parent support group. Yet, they still may want access to another parent from time to time. To address this need, some regional groups have set up a hotline where parents can call anonymously.

"The Connecticut Candlelighters have a telephone lifeline which has become a daily vehicle for the emotional support of families in their area. It is a credit card number funded by a local foundation. The line has been used heavily for information. . Most commonly it is used to let out pent-up emotions, and to share good news when a child has successfully completed surgery or chemotherapy" (Pizzo, 1983, p. 97).

For more information contact: Candlelighters, 2025 Eye Street, N.W., Suite 1011, Washington, DC 20006 (202) 659-5136.

■ Iowa Health Care Guidelines

Funded by the Federal Division of Maternal and Child Health, the Iowa Health Care Guidelines Project is one example of how this element of family-centered care can be encouraged. Originally, the purpose of the project was to develop model guidelines to assist physicians who provide services to children with chronic illnesses or disabilities. However, the project staff quickly recognized that these children and families interact with so many professionals that additional guidelines for nurses, social workers, and therapists were developed. Similar guidelines were developed by and for families to assist them in the selection, implementation, coordination, and evaluation of services for their child. The development of the guidelines and the "Principles of Health Care," which provide the philosophical basis for the guidelines and are intended to promote optimal health care for all children and their families, reflect the joint contribution of families whose children have special needs and professionals from multiple disciplines.

Specific guidelines are included that stress the importance of recognizing the child's and family's strengths and respecting their individuality. The following suggestions are listed in the family guidelines:

"Look at family members' individual strengths, and your strengths as a unit. Use these strengths, which have helped you before, in this new situation. You may want to seek assistance from a counselor or parent-support person to evaluate objectively and follow the emotional and mental health of the family."

"Help professionals understand your family's particular set of circumstances. Your relationships, beliefs, emotional status and style of life, as well as your financial situation are relevant to setting up an effective and workable care plan for your child" (Healy & Lewis-Beck, 1987a, p. 17).

Similar suggestions are found in the guidelines for professionals:

"Ask about parents' goals and priorities for their child. Emphasize a positive outlook, noting the child's strengths and abilities."

"Consider each family's circumstance on a case-by-case basis. Assist the family in evaluating how many areas of their lives may be affected by their child's condition such as their employment situation, relationships with other family members, their financial status. Allow parents to explain their individual family circumstances: Do they have an elderly parent at home? Another child at home with a chronic condition? An uncertain employment situation? Transportation problems? A need for respite care?" (Healy & Lewis-Beck, 1987b, p. 17).

Copies of the guidelines may be obtained by contacting: Campus Stores, 208 G.S.B., The University of Iowa, Iowa City, Iowa 52242. Ask for the publication by authors (Alfred Healy, M.D. and J. Arline Lewis-Beck, Ph.D.) and by specific guidelines (i.e., for families, physicians, nurses, social workers, or therapists). ■

6 Understanding and Incorporating the Developmental Needs of Infants, Children, and Adolescents and Their Families Into Health Care Systems

INTRODUCTION

Embodied in this statement is the idea that family-centered care goes beyond the child's health care needs. It strives to recognize and to promote healthy family functioning by enabling the child and family to meet "normal" developmental tasks.

The fields of health, medicine, social work, psychology, education, and others have made great strides in the treatment of chronic illnesses and disabling conditions. However, these advances may have unwittingly encouraged a type of professional specialization that may interfere with a comprehensive approach to helping the child and his or her family to meet day-to-day developmental challenges. The importance of this consideration is clearly stated by a mother of a child with a rare genetic disease.

> ◆ *"Regardless of handicapping conditions, our children have the same needs as able-bodied children. Handicaps and mental retardation do not cripple their innate desire to grow, to develop, to be accepted, to belong, to be loved and to love" (Downey, 1986, p. 1).* ■

WHAT DOES IT MEAN?

For the child, this approach means planning a developmentally appropriate program that incorporates individual strengths and needs.

> ◆ *"A major gap in our health system is a model that will also help families understand and support their child's emotional and social development, while taking into account his or her specific physical, neurologic, and cognitive capacities. It is only by placing emphasis on the full scope of the child's needs—emotional, developmental, and intellectual, as well as physical—that realization of the child's full potential can be assured" (Nover, 1985, p. 9).*

For example:

- — How do you safely encourage body movement and activity in a toddler with hemophilia?
- — How can the effects of a child's separation from a parent during hospitalization be minimized?
- — How can you encourage a ten-year-old child with asthma to take his medication at school when he is concerned it interferes with his ability to establish peer relations?
- — How do you address the concerns of independence and sexuality in an adolescent with cerebral palsy?
- — How can you help a child or adolescent with special needs celebrate the transitions that are important in his or her life?

All aspects of a child's development are integrally related. This is true for children with special needs as well as for healthy children. And yet, our methods of delivering and designing services may not reflect this reality. This compartmentalized approach can lead to a fragmentation of services (e.g., the physical therapist takes the legs, the speech therapist takes the mouth, the cardiologist takes the heart) or to a lack of attention to other important areas of development. At times, ". . . the child's emotional and social development have taken a back seat to his more easily detectable disabling condition" (Nover, 1985, p. 3).

While it is important for parents and professionals to work together to address the child's specific health care needs, parents and professionals must also collaborate on facilitating other areas of the child's development.

> ◆ *"The parents' capacity to interpret their child's behavior, to understand his developmental needs and to be able to participate actively in facilitating his social and emotional development—given his handicaps—may, in certain cases, be more important than providing motor exercises to encourage physical development. The emotional milieu of the family, for example, will affect the child's interests, motivation, and the degree to which he practices emerging skills" (Nover, 1985, p. 4).*

Attending to the "developmental" needs of the other family members is just as important as it is for the child with special needs. Parents, in their roles as adults, as professionals, as partners in a marriage have developmental needs as well. Often the parents may be so involved with carrying out recommendations, in caring for the child, and attending to his or her health and therapeutic needs that they have little spare time to enjoy being a family . . . to just be parents.

◆ *"The vast majority of services for these children directly and extensively involve the child's mother as therapist, teacher, trainer, or, at the least, transporter. . . . There is little time, money, or energy for the development of normal interpersonal relationships between or among the family members, much less outside of it" (Doernberg, 1978, pp 107-109).*

A family-centered approach addresses these issues, both directly through program planning and indirectly by creating an atmosphere where parents feel comfortable addressing these issues themselves.

◆ *"The speech therapist says, 'Do half an hour of therapy after dinner.' The physical therapist says, 'Do 30 minutes of therapy in your spare time.' What spare time?! I have two other kids and a husband! I finally said 'no' to all that therapy. I had to choose between being my child's extension therapist and being his mother. And I chose being his mother.*

There are times when even an acceptable amount of therapy becomes too much— When your child needs time just be a child, or when you need time to be with the rest of the family. It's O.K. to say 'no' at those times, for a while. Your instinct will tell you when" (Simons, 1985, p. 51).

Brothers and sisters of a child with a chronic illness or disabling condition also face special challenges as they grow and develop and adapt to having a family member with special needs. Although each brother and sister is unique, many of them no matter what the disability their brother or sister has, share a number of concerns and needs.

Like parents, brothers and sisters need information about their brother's or sister's condition. Featherstone (1980) and others have written about the anxiety that comes from the fear of "catching" the disability or the guilt that somehow an "evil thought" about the brother or sister caused the illness. This normal, magical thinking, especially characteristic of younger children, can cause problems without appropriate information.

As more children with special needs are cared for at home and in the community, brothers and sisters are increasingly involved in their care. While this role has some advantages, it also may be a role that at times they are ill prepared to assume. As a result of this increased involvement, brothers and sisters may not have adequate opportunities to meet the developmental challenges so necessary for normal growth.

These typical developmental challenges can seem insurmountable at times for brothers and sisters.

◆ *"Siblings are caught between two worlds. the outside world and the world at home. These worlds place very different demands on them, and they want to do well and be loved in both. Outside the home, a premium is placed on normalcy. All children, through their adolescent years, want to be as much like other children as possible They want their families to be as much like other families, too.*

Within the family, children want almost the opposite. They want to stand out—to feel special in their parents' eyes. Having to compete with a brother or sister who really is 'special' is difficult" (Simons, 1985, p. 34).

Sibling rivalry and feelings of anger, worries about who will care for their brother or sister in the future, competition for parents' time and attention, and what to tell friends are just a few of the issues that parents and professionals can help brothers and sisters address. There is no way to avoid the changes that take place in a family following the birth or diagnosis of a child with special needs. However, with support, brothers and sisters can be helped to be a part of the family's adaptation to those changes.

◆ *"It is also frustrating and maddening when she messes up a room I just tidied up, or when she gets into my school art work that I have just spent the evening on. There are many incidents like these that bring negative feelings. They are small and perhaps silly, but they still exist and bother me. But, who is perfect? Besides, when Kim comes along and lays a big, wet kiss on my cheek and says 'I love-a-love-a-love-a-love Melissa,' it is easy to forget the anger that just took place" (Hanson, 1986).* ■

MAKING IT A REALITY

The following are some concrete examples of programs as well as some suggestions of ways to assist children and families as they face developmental tasks.

Programs

■ The Adolescent Autonomy Project

Funded by the Department of Health and Human Services. Division of Maternal and Child Health, this project is designed to promote independence in adolescents who have a physical disability or chronic illness. Using structured interviews and a variety of exercises focusing on assertiveness training and health education, the program hopes to increase the adolescent's knowledge about normal puberty, his or her disability, and to enhance his or her ability to plan for the future. For more information contact: Sharon L. Hostler, M.D., Children's Rehabilitation Center, 2270 Ivy Road, Charlottesville, VA 22901 (804) 924-8184.

■ Camps

Camps specifically designed for children with special needs offer supervision of the child's medical regimen while providing an important opportunity for children to interact with other children, to gain independence from parents, and to have an experience in common with able-bodied peers. Examples of some of these camps are:

— Camp Ozawizeniba in Minneapolis, Minnesota for children and youth with epilepsy. For further information contact: Vicki Florine, 2701 University Avenue, S.E., Suite 106, Minneapolis, MN 55414 (612) 376-5031.

— Camp Glyndon in Baltimore, Maryland for children with diabetes and their families. For further information contact: Dan Markowitz, Camp Glyndon, 3701 Old Court Road, Executive Park, Suite #20, Baltimore, MD 21208 (301) 486-5515.

— Camp Sunshine in Portland, Maine for children with cancer and their families. For further information contact: Julie Russem, Childhood Cancer Support Program, 1921 West Street, Portland, ME 04102 (207) 775-5481.

— Camp Latgawa in Eagle Point, Oregon for children with spina bifida and their families. For further information contact: Theresa Schneider, 1664 Hammel Road, Eagle Point, OR 97524 (503) 826-6194.

— Camp Kaleidoscope in Durham, North Carolina for children with chronic illnesses who share space and activities with well children attending Girl Scout Camp. For further information contact: Thomas K. Kinney, M.D. or Alex Gordon, M.Ed., P O. Box 2916, Duke University Medical Center, Durham, NC 27710.

The *1987 Parents' Guide to Accredited Camps* includes listings of camps for children with special needs as well as children without disabilities or health impairments. The directory is available from the American Camping Association, 100 Bradford Woods, Martinsville, IN 46151, for $8.95.

■ Chronic Health Impaired Program (CHIP)

CHIP is a federally funded program in Baltimore, Maryland. Its purpose is to provide special services for children who have frequent, extended, or intermittent absences from school and who need to keep up with classroom work. Referrals are made by community or hospital-based physicians and social workers. Children from elementary grades through high school are included in the program.

The CHIP program involves the parent as an active partner in initiating services. When a child is ill, the parent calls the school and home instruction begins at once. If the child falls behind because of periodic problems, the CHIP teacher may provide extra tutoring at home even after the child has returned to school. It is important to note that many of the children enrolled in the CHIP program are not in need of special education, but rather continuity of regular programming. CHIP also includes counselors who work with the families and the children on psychosocial issues. For more information contact: Joan Cace or Sylvia Matthews, CHIP, Baltimore City Public School System, Baltimore, MD 21217.

■ Let's Play to Grow

Established in 1979 by the Joseph P. Kennedy, Jr. Foundation, Let's Play to Grow is a program developed by Mrs. Eunice Kennedy Shriver. In her words, "it is a program dedicated to bringing the physical and spiritual delights of play to all families who have a member with special needs. Through play, mothers, fathers, sisters, brothers, relations and friends come to share a close and creative relationship."

The organization consists of family clubs across the country that provide opportunities for all family members to get together with other families who have a child with special needs to enjoy adapted recreational activities and support. The national office offers a variety of resources including a series of play guides showing parents how to adapt recreational activities for their child. For more information contact Lisa Morris, Program Coordinator, Let's Play to Grow, 1350 New York Avenue, N.W., Suite 500, Washington, D.C. 20005, (202) 393-1250.

General Suggestions for Meeting Developmental Needs of Children

Other ways this element can be implemented include:

- primary nursing care that encourages consistency in caregivers,
- community vocational rehabilitation programs,
- providing age appropriate activities for children who are hospitalized through child life programs and hospital school programs,
- providing discipline and setting limits for a child with special health care needs.
- setting aside time and learning ways to best facilitate play, and
- encouraging independence by letting go ■

7 Encouragement and Facilitation of Parent-to-Parent Support

■ INTRODUCTION

There are numerous ways in which public and private agencies can support families in their efforts to care for their children This support can take many forms, such as care provided by professionals, financial assistance, respite care, and transportation to health services. However, an important complement to these services is the support that can come only from other families parent-to-parent support ■

WHAT DOES IT MEAN?

During the 1986 ACCH Parent Network Meeting over 80 parents representing 31 states were asked to consider the concept of family-centered care. These parents stressed that parent-to-parent support is one of the *key* elements of family-centered care. It is one of the most important forms of support for families of children with special health needs and at the same time, one that is the least understood and least supported by the professional community. While professionals certainly provide support to families in many formal and informal ways, the support that another parent offers is unique. *Both* types of support are needed.

> ◆ *"What parents offer other parents, through literature and friendship and organized peer support, is respect—with empathy—and without the burden of clinical assessment—a precious resource for families in crisis. Ideally, the survival skills that only parents know are added to the rich expertise of professionals, who cure and teach and understand in a different way" (Oster, 1985, p. 28).*

Why is this form of support so important to parents? Consider the following statements of two mothers.

> ◆ *"When my third daughter, Sara, was born with Down's syndrome, isolation is what I felt. I had what seems to have been a unique experience in that I was surrounded with supportive people at the time of Sara's birth and diagnosis. The medical people who dealt with us were very sensitive; my husband and close family were incredibly helpful; our friends were trying desperately to understand what had happened. Yet, through the first few weeks I felt isolated . . . almost as if I were insulated from the very people who were trying to reach me the hardest. In those first agonizing days, I felt desperately that no one, absolutely no one, knew what I was going through" (Mariska, 1984).*
>
> *"Family and friends fell by the wayside in a fantastic pattern of despair . . . like a chain of dominoes. Many of these friends were professionals that I had the utmost confidence in. Pillars of strength and guidance drifted away like straws in the wind . . . . I knew then that from that day forward my whole life must change if Matthew were to survive. His vulnerability frightened me. I knew what I must do. I could no longer go it alone. I needed other mothers, other fathers to relate to" (Pizzo, 1983, p. 25).*

In one case, the mother was surrounded by supportive individuals, in the other, the mother was abandoned by both friends and professionals. In both cases, the parent felt isolated. To combat this sense of isolation, "talking with another person who actually understands is invaluable" (Mariska, 1984). It is this power of shared experience that uniquely characterizes parent-to-parent support.

> ◆ *"Parents can share feelings and experiences with another parent who has been there, one who can empathize (not merely sympathize), and one who can validate what is being said. In some cases, these support parents, who have been total strangers and may have very little else in common with the new parents, may be even more important for a time than the extended family or friends" (Gould & Moses, 1985, p. 16).*

What are the roles that parent-to-parent support can play? They are varied. In her book on organizing and maintaining support groups, Minna Nathanson (1986) outlines three important functions:

— mutual support and friendship;

— information gathering and sharing, and

— improving the system.

Mutual Support and Friendship

This function creates important social networks and provides parents with the opportunity to help others. Much of the emotional support comes from listening. As Helen Featherstone aptly observed, "listening is supportive . . . therapeutic insight is part and parcel of the opportunity to hear oneself" (Featherstone, 1980, p. 210). The opportunity for parents to listen and share in a nonjudgmental atmosphere can lessen the isolation that many parents experience.

> ◆ *"Many people have discovered that they can receive more help and enlightenment from strangers who have the same problem than they can from those closer to them. . . . Through a . . . mutual help experience they are discovering additional or alternative ways of coping with . . . crises in their lives . . . . Mutual help provides people with: information on how to cope with their problems; material help, if necessary; a feeling of being cared about and supported . . . and is very effective because participants find other people 'just like me'; they learn that other people have similar feelings and that these feelings can be normal in their circumstances; they are encouraged by the observation that they too, in turn, can become helpers rather than clients" (Silverman, 1980).*

Information Gathering and Sharing

Parent-to-parent support provides an opportunity to exchange skills gained from invaluable "on the job training." Information and ideas range from identifying babysitters who are skilled and comfortable in caring for a child with special health needs, to locating places which sell clothes for an infant born prematurely, to choosing the best health care providers. A formalized group can enable its members to have access to professionals in the community who can provide needed technical information.

> ◆ *"Because many members of our group have children with genetically based problems but may wish to have further children, there is a great deal of interest in amniocentesis. Although none of us on our own would have asked our obstetricians to spend two hours discussing amniocentesis with us, as a group we were able to ask in an obstetrician who did spend that much time with us. And in the group setting we felt secure enough to ask all the questions we wanted answers to" (Mariska, 1984).*

Improving the System

> ◆ *"By identifying and relaying information on their needs, by fund raising, and by supporting research on their children's diseases and conditions and on their effects on children and families, parents contribute to the development of psychosocial programs for children and families; to improvements in the medical treatment, control and cure of their children's conditions; and to changes in institutional and public policies which benefit their children and families. . . ." (Nathanson, 1986, p. 5).*

As Minna Nathanson illustrates, parent-to-parent support can improve the system in a number of ways. First and foremost, as consumers, parents have an unique and invaluable perspective on the advantages and disadvantages of existing programs, gaps in services, and existing difficulties in accessing and coordinating services. Furthermore, they may have the most creative and innovative ideas for remedying the deficits in the services. Because there is "strength in numbers," the collective expertise of a group of parents can be a powerful tool to improve the system.

> ◆ *"One parent, alone, can do a lot . . . if determined enough and willing to work hard enough . . . . But that same parent can do so much more, working with other parents, through an organization that is effective, an organization that is not afraid to use its power" (DesJardin, 1971).*

Structure and Organization

Parent-to-parent support can take many forms. While most easily identified as the formal support group that meets at a regularly scheduled time, parent-to-parent support can take place in informal ways as well . . . a conversation in the grocery store check-out line, talking to other parents through a newsletter in rural areas where transportation is difficult, reading a story written by another parent, or a nonverbal expression between parents . . . a sigh, a nod, a look that says "I've been there." As one parent noted, "Parent-to-parent support is two parents, who aren't married to each other, talking together" (Poyadue, 1986).

Whatever its form, parent-led and parent/professional-led support groups do differ from professional-led groups. Yoak and Chesler (1983) have noted that parent-led or parent/professional-led groups are more likely than professional-led groups to

— develop a system of one-to-one parent contact;

— work for changes in the system; and

— organize opportunities for socializing.

Many parent-to-parent groups, especially those that are organized nationally, have as their focus a specific condition or disability. These groups have been particularly successful advocating for programs, raising funds, and organizing local chapters. Recently, however, there has been an increase in the number of groups that are organized across disabilities. In cases where the child's condition is rare or where it may be difficult to identify a number of children with the same illness such as in rural areas or small communities, a parent-to-parent support group that is organized across disabilities may be the only option. More importantly, however, is the fact that families of children with special needs have many common concerns. When the emphasis is shifted away from a medical model, from the disease to the family, the common issues far outweigh the differences. Financial concerns, the need for respite care, and difficulty in coordinating medical care are as characteristic of a family whose child has cerebral palsy as it is of the family whose child has cancer.

The notion that the specific diagnosis is not the overriding concern in the management of the child's condition is one of the main ideas behind what has been called the generic or noncategorical approach to chronic illness in childhood (Stein & Jessop, 1982). The "noncategorical" parent-to-parent support groups, together with the more disease specific groups, all have a role in providing emotional, educational, and programmatic support for parents whose children have special needs. For parent-to-parent support to be most effective, programs must have clear goals and structure. However, it is important that they remain flexible enough to address those issues specific to a disability as well as those that are common to all families. ■

MAKING IT A REALITY

Despite the fact that parents of children with special needs consistently testify to the importance of parent-to-parent support, this type of support for families has not always been adequately encouraged. A consideration of some of the potential barriers to parent-to-parent support may lead to strategies for encouraging further implementation of this element of family-centered care.

Barriers and Strategies

Sometimes the problem may lie in parents' difficulties in identifying other parents on their own.

> ◆ *". . . it can be a complicated task for families of disabled and at-risk babies to find their peers—particularly during the first few months or years when the future is a list of unimaginable possibilities rather than a clear diagnosis. Nick was nine months old before I met a mother whose baby had similar problems. I will never forget the incredibly intense feeling of recognition and kinship that I experienced during that hour long talk in a hospital cafeteria. And later, as our parent group flourished, I saw so many other mothers and fathers experiencing the remarkable sense of connection that had kept a group of strangers talking in a hospital parking lot until midnight after our first meeting" (Oster, 1985, p. 32).*

Professionals can help parents overcome this barrier by being aware of support groups in their area and by providing this information on parent-to-parent support to parents as soon as possible, either at diagnosis or as part of the discharge plan. How this information is conveyed, however, is critical.

> ◆ *"If you have a patient who's been to surgery, and you as a professional know the benefit of having this patient cough after surgery so that his lungs don't get clogged, you don't go in and suggest to him that he cough, or hand him a flyer on the benefits of coughing and expect him to do it. And here is a parent who has a child. This is the most devastating thing that can happen to you, and you give them a flyer. You put one out in the waiting area and hope maybe they accidently glance at it and see that there is parent support around" (Poyadue, 1986).*

While a start, just giving the name of a support group may not be enough. Often a parent may not be able, for a variety of reasons, to make the contact. And yet, as the following comment illustrates, they may be just as in need of this type of support as the family who actively seeks or organizes a support group.

> ◆ *"Another healing factor was meeting other parents of handicapped children. We did not feel ready for this at first. Sometimes parents who have lived many*

> *years with this situation pose the same sorts of problems for parents receiving a new diagnosis as do professionals—the lack of synchrony about acceptance The experienced parents may be dealing with what is, while the new parent has no wish to belong. Nevertheless, when we were ready, it was good to have contact with other parents and their children, people who understood us in a special way. It was encouraging to see people who had survived for a long time; it aided us in our belief that we could too" (Weyhing, 1983, p. 129).*

Often policies designed to protect the rights and privacy of families may work against the use of parent-to-parent support. For example, important concerns about breaching confidentiality may also result in a reluctance on the part of professionals to give a parent-to-parent support group the name of a parent whose child has special health needs. As noted earlier, merely giving parents the name of the group or resources may not be the most effective way to encourage this type of support. The parents may not contact the group. They may be overwhelmed with a new diagnosis or are concentrating on their child's discharge. For a variety of reasons, parents may not have the physical or emotional energy to make the initial call. Nevertheless, these parents may be very interested in receiving, and could benefit from, this type of support. This potential barrier may be overcome easily by simply asking the parents' permission to give their names to a parent support group or resource center. That way, the group can contact the parents, and when the parents are ready, that support will be available.

Sometimes professionals and parents seek to match families on the basis of their child's condition. While this is helpful when possible, the provision of support should not be delayed because a "match" is not available. As mentioned, there are many issues that parents, whose children's conditions vary, have in common. Sometimes parents may not feel in need of "emotional support" or may not feel comfortable acknowledging their need. To prevent this from interfering with their accessing the other important benefits of parent-to-parent support, it is important that professionals be knowledgeable about the variety of roles these support groups can fill. As Florene Poyadue, Executive Director of Parents Helping Parents (PHP), points out, this is why she refers to PHP as a *resource center*. A parent-to-parent "resource center" can be suggested in a positive way that truly supports the family rather than conveying the impression that they are not coping adequately.

Another reason that parent-to-parent support may not be encouraged by professionals is because of territorial struggles. Professionals who offer support to families may feel in competition with parent support groups Parent-to-parent support should be seen as complementing rather than competing with the type of support and services offered by professionals

> ◆ *"Our group does not intend or pretend to replace physicians, therapists, or other professionals. We function in the belief that many of our needs go beyond the bounds of formal service. What we can offer each other is uniquely ours, because we all have paid our dues We all have 'been there,' and we all know how it feels to have a child who is way less than perfect" (Mariska, 1984).*
>
> *"As parents and professionals we can best accomplish the difficult job of meeting families' needs by utilizing each other as practical human resources. Parents developing literature or programs containing medical or educational information must turn to professionals for guidance. Professionals developing services for families must draw on the special expertise of families" (Oster, 1985, p. 32).*

Organizing parent-to-parent support requires time and resources. In these days of federal, state, and institutional budget cuts, providing tangible support to parent groups may not seem feasible. And yet there is mounting evidence that "judged on the basis of cost effectiveness, family support programs may be the biggest bargain this country has ever had" (Zigler, 1986).

The professional community can facilitate the organization and maintenance of parent-to-parent support groups in the following ways:

— making referrals to the groups;

— providing parents a place to meet;

— providing access to a copy machine;

— mailing or typing a newsletter;

— being available to provide inservice training (at no cost) on a particular professional topic,

— facilitating access to important sources of information such as medical records, hospital libraries, and research on new treatment approaches;

— conducting research documenting the benefits of this type of support;

— reimbursing parents for transportation and child care costs;

— providing access to telephones,

— having a paid parent position within the institution specifically designed to provide support, information and advocacy; and

— having parents stress the importance of parent-to-parent support through their participation in educational training programs for health care professionals.

The following are examples of programs that provide parent–to-parent support.

Programs

■ Parents Helping Parents (PHP)

PHP is a non-profit resource center composed of parents, professionals, and lay counselors in San Jose, California, whose goal is to offer support and information to families of children with special needs and to help children with disabilities to receive the care, services, love, respect, and acceptance they need to enable them to become all they can. PHP is composed of several divisions that concentrate on a particular disability, problem, or need; and a large "general" division for all other disabilities including those undiagnosed. The divisions include parents of near drowning victims, parents of children with Down Syndrome, parents whose children have been hospitalized in an intensive care nursery, parents suffering a neonatal death, parents of autistic children, and parents of children with learning disabilities. The flexibility of the group allows it to address the needs of these specific groups as well as the issues common to all. A comprehensive array of supportive programs, an information packet on available community resources, and a quarterly newsletter are available for all divisions. Among its many activities, PHP offers a Visiting Parent Program that provides information about special education laws and a sibling program that addresses the psychosocial needs of brothers and sisters of children with special needs.

PHP also provides training programs for professionals. Conducted by parents, these workshops include information on how professionals can improve the psychosocial care of families, communication strategies such as better methods for presenting the child's diagnosis, and information on local resources for families. PHP also provides training for parents interested in becoming peer counselors. Both the professional workshops and the peer counseling training program involve the joint participation of parents and professionals. This provides an invaluable opportunity for increasing parent/professional understanding and collaboration. For more information, contact: Florene Poyadue, PHP, 535 Race Street, Suite 220, San Jose, CA 95126, (408) 288-5010.

■ Nurse Clinician/Parent Consultant Duke University Medical Center

An important and innovative approach to offering parent-to-parent support is found at Duke Medical Center. Through a grant from Ronald McDonald Children's Charities, Beth Stewart is employed as a Nurse Clinician/Parent Consultant on the Pediatric Hematology-Oncology team. In this role Ms. Stewart combines her nursing expertise with the knowledge, understanding, and compassion from her experience as the mother of a child with cancer. As she says, "I am in a unique position to represent and present both sides, that of a health professional and a parent of a child with cancer."

She provides support to the families in many ways. One-to-one, she shares their concerns and fears about what the diagnosis of cancer means, how it will affect the child, and what it means for his/her future and the rest of the family. She uses her nursing knowledge to assist parents by interpreting medical terminology, explaining treatment protocols, and enabling them to participate more fully in discharge planning. She also provides support by matching a trained, experienced Support Parent with the parent of a newly diagnosed child within or near the same community.

Ms. Stewart also educates the medical team, hospital staff, and other health professionals about the needs and concerns of parents. Such opportunities occur formally and informally in daily rounds, patient-care conferences, staff meetings, inservice classes, administrative meetings, and in the community setting. The establishment of this position at Duke reflects a growing trend that recognizes the importance of parent-to-parent support. For more information contact: Beth Stewart, R.N., M.S.N., Nurse Clinician/Parent Consultant, Department of Pediatrics, Division of Hematology-Oncology, Box 2916, Duke University Medical Center, Durham, NC 27710 (919) 684-3401.

■ Parent Consultants Rhode Island Hospital

Since 1975, the pediatric oncology unit at Rhode Island Hospital has had a parent consultant position. In 1977 the position became full time, funded through pediatric oncology. Since 1980, the position has been divided between two parents each working half-time.

The parent consultants are fully participating members of the pediatric oncology staff. They attend staff meetings and have ready access to all other staff members Their primary responsibilities are to assure that the needs of patients and their families are identified and met. Their involvement with a family can extend from the time of diagnosis through the entire treatment period and even beyond, depending upon family needs and desires. As advocates for the families and liaisons between the families and staff, the parent consultants attempt to make the health care system more responsive to the needs of families. Examples of these activities include organizing meetings with brothers and sisters, and members of the extended family, arranging for transportation and babysitting, providing emotional and psychosocial support where appropriate, and helping to resolve difficulties with hospital administrative departments such as billing. The parent consultants perform administrative and leadership functions in helping support the local parents' self-help group. They conduct formal and informal teaching sessions for various hospital staff and community organizations, as well as represent the pediatric oncology service at local and national meetings of professional organizations.

Parent consultants play a crucial role in educating families about the functioning of the pediatric oncology service, answering basic questions about the diseases, and supporting active parent/professional collaboration. For more information contact: Joy Benson or Helena G. Richards, Rhode Island Hospital, Pediatric Oncology Service, 593 Eddy Street, Providence, RI 02902, (401) 277-5497.

■ Project HOPE (Helping Other Parents Through Empathy)

Project HOPE, a special part of the Family, Infant, and Preschool Program in Morganton, North Carolina, is a parent-to-parent support program for families of children with disabling conditions living in rural counties of western North Carolina. Due to the distances between families in the nine county area served by Project HOPE, the telephone is the primary helping service utilized.

Project HOPE began in 1981 with a core group of 25 volunteer parents. These volunteer parents offer support to families not only at the time of diagnosis, but also in dealing with concerns and problems that develop as the child matures. With that in mind, attempts are made to match families as closely as possible with regard to the specific disabling conditions of the child, the child's level of functioning, the age of the parent, the age of the child, and similarities in family structure. The training program for volunteer parents is a major component of Project HOPE. Parents participate in approximately sixteen hours of training. In addition to providing information on a range of disabling conditions, training sessions focus on accessing community resources, effective counseling techniques, and advocacy and networking skills.

Training materials that facilitate replication of the program, a 30-minute videocassette, and a paper describing the project are available upon request. For more information, contact: Angela Deal, Coordinator, Project HOPE, Family, Infant and Preschool Program, Western Carolina Center, 300 Enola Road, Morganton, NC 28655, (704) 433-2674. Parents interested in HOPE services can call the HOPEline collect at (704) 433-2684 from 8:00 a.m. to 5:00 p.m. Monday through Friday.

Support Programs for Other Family Members

■ Sibling Information Network

The Sibling Information Network was formed to support brothers and sisters as well as to assist professionals, researchers, and parents caring for persons with disabilities. The major product of the Network is the *Network Newsletter*. Published quarterly, the newsletter is an extremely informative resource covering such topics as available literature/media for brothers and sisters, letters from family members seeking to contact others related to a child with special needs, and current research and journal articles. Those interested in receiving the newsletter may do so by sending $5.00 to: Sibling Information Network, School of Education, Department of Educational Psychology, U-64, The University of Connecticut, Storrs, CT 06268.

■ Helping Grandparent Program

Sponsored by the King County Advocates for Retarded Citizens (ARC) and the University of Washington's SEFAM (Supporting Extended Family Members) Program, this program provides a core of trained "helping grandparents" who offer mutual support to grandparents of newly diagnosed grandchildren. The volunteers receive training in interpersonal communication skills, available community resources, and referral procedures.

During a series of six Grandparent Workshops, grandparents meet as a group with a professional team to share their concerns and to learn about their grandchild's needs. The workshops offer grandparents opportunities to discuss the impact of the child's disability on the entire family and to obtain up-to-date information about the child's special problems and needs. Most important, grandparents have a chance to meet other special grandparents who share their concerns.

Their quarterly newsletter entitled *Especially Grandparents* is written by and for grandparents of children with developmental disabilities. Additional training manuals and curricula are also being developed to enable other organizations to develop programs to meet the needs of grandparents. All of the programs are free. For more information or to receive the newsletter contact Elaine Schab-Bragg at the King County ARC, 2230 8th Avenue, Seattle, WA 98121, (206) 622-9292.

■ Other Support Groups

There are numerous groups that are organized around a specific disability. Local chapters can be identified by contacting the national organizations. Most of the major national organizations are identified in the following publication:

Reaching Out—available from: National Center for Education in Maternal and Child Health, 3520 Prospect Street, N.W., Washington, DC 20057, (202) 625-8400.

There are also a growing number of national organizations that are organized across disability at the national or regional level. Some of these are:

ACCH Parent Network
Association for the Care of Children's Health
3615 Wisconsin Avenue, N.W.
Washington, D.C. 20016
(202) 244-1801

The Federation for Children with Special Needs
312 Stuart Street
Boston, MA 02116
(617) 482-2915

Pilot Parents
2005 North Central, Suite 100
Phoenix, AZ 85004
(602) 271-4012 or (602) 969-8209

SKIP—Sick Kids (Need) Involved People
216 Newport Drive
Severna Park, MD 21146
(301) 261-2602

Alliance of Genetic Support Groups
38th & R Streets, N.W.
Washington, DC 20057
(202) 625-7853 ■

8 Assurance that the Design of Health Care Delivery Systems is Flexible, Accessible, and Responsive to Family Needs

■ INTRODUCTION

If anything can be anticipated in the life of a child with a chronic illness or disabling condition, it is that the child and his or her family will have a variety of needs that require a myriad of services; that they will interact with hundreds of professionals; and that their needs will change over time In order to serve these children appropriately, the health care system must be flexible, accessible, and responsive to family needs. ■

WHAT DOES THIS MEAN?

Flexibility

Lack of "consumer input," turf issues between agencies and professionals, financial and staff cutbacks, and complicated and differing agency eligibility criteria are a few of the factors that may diminish the flexibility of programs. In a family-centered approach to care, programs must be designed with the individuality of families in mind, and with the flexibility to tailor services to each child's and family's unique strengths and needs. Clearly an agency, institution, or program that offers a variety of services and uses these options flexibly will be more able to support children and families than one that determines programming based on agency concerns and availability alone rather than the child's and family's priorities.

> ◆ *"We need to look at new approaches to families. We need to recognize the resilience of the American family, even though it may be different than ours, and we need to realize that we are not going to be able to have one approach or one program or one set of parents' meetings or one manual that fits every parent" (Vincent, 1985, p. 35).*

Even when the program offers a variety of services, the manner in which it is determined if a child or family can qualify for these services must be flexible as well. Services tied to narrow diagnostic categories may penalize those children whose complex conditions either overlap several disease categories or fall between them, and may prevent families from obtaining needed services.

Sometimes this issue of flexibility becomes a point of contention between parents and professionals. From the parents' perspective, they aren't asking professionals to do anything more than they do everyday in having to respond to their child's changing needs. For professionals, however, achieving this flexibility may be very difficult. Professionals may be caught between responding to the needs of families and financial cutbacks or program requirements over which they have little control. Only through increased collaboration among parents, professionals, and policy makers can each begin to understand the other's perspective, and with that knowledge, begin to work effectively for the design of more flexible programs and policies.

Accessibility

In addition to flexibility, a family-centered approach to care encourages programs to be accessible.

> ◆ *"It is remarkably difficult for parents to locate the services that do exist. The state funds some programs, while counties and towns sponsor others. A third group owe their existence to private philanthropic organizations, to church groups or to hospitals. No one seems to know exactly what is available for whom under what circumstances" (Featherstone, 1980, p. 184).*

As was noted in the Vanderbilt University Institute of Public Policy landmark study of children with chronic illnesses in America, "diversity and fragmentation characterize the organization of services for chronically ill children" (Ireys, Moynihan, Perrin, & Shayne, 1983, p. 11). This applies not only to specialized medical and surgical services but also to educational, psychosocial, and community support services.

> ◆ *"Because Jody had turned seven I needed to find a new school for him. The head of his current program gave me two possible names and suggested I call the special education department in my town for further suggestions. The preschool coordinator there gave me two more names, while pointing out that I should actually be talking to another woman in an office across town. When I called this lady she offered two sugges-*

tions of her own. I noted with interest that my three lists did not overlap at any point" (Featherstone, 1980, p. 184).

Many of the same factors that impede the development of flexible programs, affect the degree to which programs are accessible. However, the combined experience of both parents and professionals can be very productive in relocating or expanding hospital services to community settings, in clarifying eligibility criteria, and in educating service providers and parents about available services.

Responsiveness

Family-centered care involves the design of services that are responsive to the priorities of the child and the family. Being responsive may involve arranging for follow-up services to be provided at a facility in the child's community rather than at a tertiary care center, including comprehensive psychosocial and educational services in the care plan, or coordinating scheduled appointments.

◆ *"Especially for children with multiple handicaps, arranging to be Monday morning in the cardiology clinic, Tuesday afternoon in the neurology clinic, and on Thursdays in the orthopedist's office becomes itself a major management problem" (Ireys, et al., 1983, p. 11).*

This type of situation forces the parent to either cancel a much needed appointment for their child, lose multiple days of employment placing further financial stress on the family, or attempt to coordinate the appointments themselves—something even professionals or agencies may not be able to do as the following story illustrates.

◆ *"Agency A may recommend a genetic evaluation . . . by Agency B, which is in another town . . . . Agency A may fail to coordinate the appointment (seeing that as the family's responsibility), fail to arrange for defraying the cost (Agency C has the money for such evaluations), fail to understand the implications of travel for the family (Agency D is responsible for travel expenses while Agency E is the only group that can provide respite care for the family's other children), and fail to share the resulting information with other agencies (since Agency B did the evaluation, it's B's responsibility). What seemed like a simple, reasonable recommendation from A's point of view can become an enormous undertaking for the family if A does not follow through" (Duffy, 1984).*

By making systems of care more flexible and accessible and most importantly by asking families more directly what types of services they want, programs and policies will be more responsive. ■

MAKING IT A REALITY

What are the ways in which programs can be more flexible, accessible, and responsive to the needs of the children and their families? Recognizing where the organization of services runs counter to the goals of the child and family is a start. This point is thoughtfully addressed by Kohrman and Diamond in a 1986 article. The authors suggest a need for a reorientation of values which include:

- — growth in community- and home-based approaches to care;
- — greater coordination and management of care between professionals and between agencies; and
- — a shift from specialty-centered approaches to "noncategorical" approaches centered around the functional capabilities of children.

The following are examples of approaches to program development and technical assistance that reflect this needed shift.

Program Development

One way to ensure that a program is responsive to the families it serves is to ask them directly about their priorities for services. The following are examples of programs that have sought consumer input.

■ Children's Home Health Network

Funded through the Division of Maternal and Child Health, the purpose of the network is to develop models of discharge planning for ventilator-dependent children in Illinois. In order to gain a better understanding of the health care and support needs, stress experienced, and methods of coping used by these children and families, project personnel are interviewing children, parents, siblings, respiratory therapists, equipment vendors, insurance companies, nursing agencies, in-home nurses, and public aid agencies. At present, 35 families caring for their children who are dependent on ventilators at home are participating in the program. The data from the project will be used to improve the quality of services provided to families, and to address service gaps, the discharge planning process, and family support needs. For more information contact: Kathleen Murphy, MSW, CSW, Children's Home Health Network, Division of Services for Crippled Children, 1919 W. Taylor Street, Chicago, IL 60612 (312) 966-6380.

■ Project Serve

In 1983, three agencies, the Division of Family Health Services within the Massachusetts Department of Public Health, the Developmental Evaluation Clinic within Boston Children's Hospital, and the Department of Maternal and Child Health within the Harvard School of Public Health, joined in this public/private collaboration. The purpose of the project was to improve the statewide public health service programs for children with a chronic illness or disability. Nine hundred ten parents of children with special needs along with hundreds of state agency personnel, direct service providers, other state programs, and providers of health care coverage were surveyed in order to document existing services for children with special needs with the goal of developing recommendations for the reorganization of services and service delivery systems.

The parent survey was developed with the help of parents from various parent organizations and a paid parent consultant from the Federation for Children with Special Needs. While some of the parents' answers did vary depending on the condition of their child, in many cases there were no differences among families whose children varied in their particular disability or health condition. Included in the survey were questions about the importance of services, the availability of services, insurance coverage and out-of-pocket expenses.

The services that were ranked as most important by the parents included: parent education on rights and entitlements and training for child's health needs; help in getting needed services including parent support, specific therapeutic services, and early intervention; financial help; information on community resources; social/recreational opportunities; and transportation to medical services. Regarding the availability of services, parents reported the following as least available: support groups for siblings; work opportunities for their child; help in making physical house changes; financial help; day care; transportation to medical services; information on community resources; and social/recreational opportunities.

Regarding insurance coverage and out-of-pocket expenses, only four percent of the parents reported having no public or private insurance of any type. Yet only 48 percent said they felt confident that their child had and would have adequate health insurance now and in the future. Services for which the parents reported out-of-pocket expenses included: travel, parking fees, drugs and medications, bills after insurance payments, physician charges, lost wages due to child's hospitalization or medical visits, special equipment, and babysitters for other children.

The results of the parent survey along with the responses of the professionals interviewed led to the following conclusions and recommendations:

- — a need to recognize and support the significant role of families in the delivery of care;
- — a need for increased coordination in service planning, program development, and provider communication;
- — a need for additional support services for families and expanded services for children;
- — a need for improved interagency coordination; and
- — a need for additional protection for families in their ability to secure and maintain affordable health insurance.

For more information or a copy of the report contact: Project Serve, 101 Tremont Street, Room 615, Boston, MA 02108, (617) 574-9493.

Technical Assistance

Project NEXUS

Project NEXUS (which means to link or connect) is developing a technical assistance manual to assist individuals in developing a coordinated and responsive system of care for children with special needs and their families. Funded by the National Institute of Handicapped Research with the Department of Special Education and the Bureau of Child Development at the University of Kansas, the project is based on the premise that agencies must be coordinated in such a way so the family does not have to function as a "switchboard operator" trying to link a multitude of unconnected agencies. The manual suggests ways to involve a cross section of the community in planning that go beyond the typical interagency collaboration. Families as well as citizens-at-large are involved in the development of interagency agreements, the reduction of fragmentation of services, and the identification of gaps in service availability. The participation of parents of children with special needs helps service providers keep family issues in the forefront. The citizens-at-large bring a fresh approach to service delivery and may be able to raise the awareness of the total community as to the services needed. Together, they can assist service providers in developing systems of care that meet the priorities of families. For more information contact: Robin Hazel, Project NEXUS, Kansas University Affiliated Facility, 377 Haworth Hall, University of Kansas, Lawrence, KS 66045, (913) 864-4954

Network Project

The Center for Networking Community-Based Services is based at the Georgetown University Child Development Center (GUCDC). Through the Network, GUCDC provides technical assistance and training to states to enhance interagency collaboration and to improve services to children with chronic illnesses or severe emotional disturbance and their families. The Network consists of leaders in health, mental health, and education in over 35 states, as well as a national level task force with representation from key federal agencies and departments in each of these areas. The Network also includes the CASSP (Children and Adolescent Service System Program) Technical Assistance Center, a special NIMH initiative focusing on children with severe emotional problems in 24 states. For more information contact: Phyllis Magrab, Ph.D., Georgetown University, 3800 Reservoir Road, N.W., Washington, D C. 20007, (202) 625-7033

Programs

Home-Based Support Services for Chronically Ill Children and Their Families

The New York state health department has received funds from the Division of Maternal and Child Health to develop community-based services for children with chronic health conditions and their families in New York City through a network of respite care providers. Program components include home-based care, community cooperatives, training curricula, program evaluation, and the development of self-help support groups. For more information contact Barry Sherman, Ph.D., New York State Department of Health, Tower Building, Empire State Plaza, Albany, NY 12237.

Coordination of Care for Chronically Ill Children Program

This project, funded by the Division of Maternal and Child Health, brings together a wide range of services for children with special needs and their families through four regionally-based demonstration sites in New York State. For more information contact Thomas Nattell, M S.W., New York State Department of Health, Tower Building, Empire State Plaza, Albany, NY 12337.

The Child and Family Support Project

The project, at Children's Hospital Medical Center in Seattle, Washington, is a pediatric hospital discharge program for children dependent on ventilators and their families. Flexibility, accessibility, and responsiveness are encouraged through parent/professional collaboration (e.g., Parent Advisory Board, family support groups) at all phases of the project. For more information, contact Robin Thomas, R.N., Ph.D., Children's Hospital Medical Center, 4800 Sand Point Way, Seattle, WA 98105.

Research

INTRODUCTION

An important resource for the implementation of a family-centered approach to care is research. Research studies that further define family-centered care or that examine its effectiveness can be very influential in increasing an overall awareness of this approach and in establishing programs and policies that exemplify this philosophy of care.

Because the family-centered care movement is in its infancy, the number of research investigations in this area is somewhat limited. What follows is a brief review of selected studies that focus on family-centered care and related issues along with suggested areas for additional investigation.

Research Investigations

An important factor in providing care that is truly family-centered is a better understanding of the daily experiences of children with special needs and their families and the support services that would be most desirable to them. Not only is this topic of great importance but the manner in which this information is obtained is equally important.

> ◆ *"The best way to find out about the special concerns of families with a chronically ill or disabled child is to ask parents themselves" (Horner, Rawlins & Giles, 1986, p. 40).*

The critical importance of how one asks, and how one interprets the information, is reflected in the following studies.

In 1981, Wikler, Wasow, and Hatfield conducted a study examining "chronic sorrow" experienced by parents of children with mental retardation. As part of the study, parents were asked whether raising a child with developmental disabilities had made them stronger or had resulted in negative consequences. While most parents reported feelings of sadness, they also indicated they had become much stronger people because of their experiences. Unfortunately, the authors chose not to report these more positive findings. Because the results so contradicted their prior assumptions about parents of children with special needs, they thought these findings were not valid but rather a result of methodological problems in the study.

In a courageous second article published in 1983 the authors "now consider this initial dismissal to be another example of a pervasive stance adopted among professionals, in which problems instead of strength and instances of coping are concentrated on in dealing with families of developmentally disabled children" (Wikler, Wasow, & Hatfield, 1983, p. 313). The authors go on to report the original results which reflect a more balanced view, identifying not only stresses experienced by these families but also their strengths and coping strategies. The authors also offer several recommendations which will be helpful to others in researching the experiences of children with special needs and their families. For more information see *American Journal of Orthopsychiatry*, 1981, *51*, 63-70 and *Social Work*, 1983, *28*(4), 313-315.

The following studies reflect another innovative approach to gaining a better understanding of the strengths and service needs of these children and families.

In a study designed to have families teach health care providers about their experiences with their children who are dependent on ventilators, Thomas (1986b) of Children's Hospital Medical Center, Seattle, Washington, used both structured data and quantitative analyses to examine the in-depth information gathered during a one-week period where Dr. Thomas lived with families of children dependent on ventilators during a SKIP (Sick Kids [Need] Involved People) sponsored Family Learning Retreat Camp in Miami, Florida Although a small sample, the information gained from these parents was very similar to the comments obtained during an earlier study with seven families with children on ventilators (Thomas, 1986a). According to Dr. Thomas, the families in both studies "developed an impressive ability to cope with their exceedingly stressful experiences . . . they demonstrated a remarkable adaptation, a balance in living." Another finding common to both studies is that the families identified the struggle for control between families and health care providers as a consistent major strain in their lives. This struggle for control was evident not only in relationship to the child's care but with regard to the families' lifestyle as well. Part of this struggle may very well be due to the fact that both parents and professionals may not be accustomed to the new roles each must assume now that these children with chronic health impairments are living longer. For more information contact, Robin Thomas, R.N., Ph.D., Children's Hospital Medical Center, 4800 Sand Point Way, Seattle, WA 98105.

The next investigation provides another illustration of how a research study can serve as a valuable needs assessment. Horner, Rawlins, and Giles (1986) surveyed parents of children with chronic health impairments in Kansas to determine their needs. The authors mailed a questionnaire to a sample of 493 families whose names were obtained through State Services for Children with Special Health Needs, local Head Start programs, and local parent support groups. Of these, 164 were returned. These families identified a number of needs including: help with medical bills, recreation for the child, appropriate educational opportunities, child care, more information on their child's condition and support services, family counseling, parent-to-parent support, training in home therapy techniques, in-home nursing, and out-of-home placement. While the authors specifically discussed how these needs could be addressed by nursing personnel, their conclusions can be very helpful in identifying ways that other professionals and agencies can better support families and their children with special needs. For more information see M. M. Horner, P. Rawlins, and K. Giles (1987), *American Journal of Maternal/Child Nursing, 12*(1), 40-43.

Other research investigations have supported family-centered care by documenting a need for support/community services and as a result may influence the establishment or expansion of services. This function is illustrated in the Project Serve Study conducted in Massachusetts that was described earlier as well as in the School-Age Child Care Project of the Wellesley College Center for Research on Women. This one year study, begun in September, 1986, will examine after-school care programs for children with special needs ages 5 to 16. The Project's past research suggests that very few communities have considered children with special needs in designing before-and-after-school programs. While some have suggested that "latchkey" children may learn valuable self-care and "survival" skills, there is little debate that children with physical disabilities, emotional problems, or other disabling conditions need appropriate supervision. This study will assess the degree to which these needed services are now available and will identify model programs demonstrating creative and effective approaches which can be replicated. The findings will be disseminated at professional conferences and in a booklet entitled, "School Age Children with Special Needs: What Do They Do When School's Out?" For more information or to advise the project of an innovative program serving children with special needs contact: Dale B. Fink, Director, School-Age/Special Needs Study, Center for Research on Women, Wellesley College, Wellesley, MA 02181, (617) 235 0320, extension 2542.

Once the need for family-centered services is identified, and in those cases where they are then provided, it is important to examine the effectiveness of such programs. There are a number of studies that provide solid evidence that the degree and quality of social support affects such variables as family functioning (Bronfenbrenner, 1977), child development (Cochran & Brassard, 1979), and the security of infant-mother attachment (Crockenberg, 1981). It is not surprising that similar relationships would be identified among parents whose children have special needs. Iscoe and Bordelon (1985) examined the benefits of a parent-to-parent support program organized across disabilities. The study was based on questionnaires and personal interviews completed by new parents of children with varying disabilities, experienced parents, and program directors and staff in 13 Pilot Parent Programs in the U.S. and Canada. Among the many findings were that most new parents were very satisfied with the support. The experience was just as positive for the 20 experienced parents. The benefits included, "giving hope . . . sharing information and experiences . . . helping new parents avoid frustrations." The professionals and parents agreed that the program was "an addition to, rather than a replacement or circumvention of, medical, therapeutic, or social service intervention." With very little money (no yearly budget exceeded $35,000) and minimal salaried staff, the programs provided the "one thing that is beyond the ability of professionals in any field: another parent who understands" (p. 107). For more information see L. Iscoe and K. Bordelon (1985), *Children's Health Care, 14*(2), 103-109.

In another study, Pless and Satterwhite (1972) evaluated the benefits of a parent-to-parent support program for families of children with special needs. A total of six counselors participated, four of whom had one or more children with a chronic illness themselves. Each counselor was responsible for eight families and worked an average of ten hours per week. They received an annual stipend of $1,000 plus travel expenses (46 percent of their time was spend in home visits). At the end of the year the success of the program was evaluated.

Significantly more of the children whose families received support improved their "psychological status" in comparison to those who did not receive the support. (The authors did not delineate what specific "psychological" variables were studied). The parents receiving the support also rated the program so positively that 84 percent indicated that they would be willing to pay for the service. (The average amount offered was $60 per year).

The total cost of the project, including the counselors' stipends, travel costs, and administrative costs averaged $15.50 per month for each family. If all families had paid $60 per year (the average amount offered), the cost to the institution would have been only $126 per family for the entire year. Even if professionals could have provided the same support and resources as the parent counselors, the cost for the parent counselors would be considerably less that the equivalent amount of staff time. For more information see T. B. Pless and B. Satterwhite (1972), *Clinical Pediatrics, 11*(7), 403–410.

The importance of information to parents of children with special needs was discussed earlier. In an answer to this need for information, the PACER (Parent Advocacy Coalition for Educational Rights) Center was begun in 1976 as the parent training program of a coalition of eighteen disability organizations concerned about the education of children with disabling conditions and their families. Members of the PACER Coalition recognized that if parents of children with special needs were to fulfill roles provided in P.L. 94-142, they would need systematic information about the major provisions of the special education laws. To examine the effectiveness of this education program PACER conducted a major evaluation study with funds from the Department of Education. Parents reported increasing not only their knowledge of their rights and responsibilities in the care of their children, but also their confidence. They also reported a decreased sense of isolation and increased interaction and sharing of knowledge with other parents. For further information about this study or to receive a copy of the evaluation report, contact PACER, 4826 Chicago Avenue, South, Minneapolis, MN 55417, (612) 827-2966.

The option of caring for children with special health needs at home is one way in which a family-centered approach to care has been implemented. Both parental satisfaction and the cost effectiveness of this care must be investigated in order to improve and to promote this option for children and families.

In a study reported by Stein and Jessop (1984), the effectiveness of pediatric home care was examined. The study was conducted over a one and a half year period. Two hundred nineteen children with various chronic conditions participated. Children were randomly assigned either to the Pediatric Home Care (PHC) program at the Albert Einstein College of Medicine—Bronx Municipal Hospital Center or to the traditional hospital-based program. The PHC program is based on the assumption that care must:

1) address issues of concern to families of children with chronic conditions that cross disease categories;
2) be oriented to the health of the child while focusing on the whole family and its needs;
3) foster the independence and maximize rehabilitation and adjustment of the child and family; and
4) actively involve the family in the management and decision-making process.

Services are provided in the child's home by an interdisciplinary team that includes the child's family. The results of the study indicated that pediatric home care was effective in improving the satisfaction of the family with the care provided, in improving the child's psychological adjustment, and in reducing maternal anxiety, depression, anger toward the child, somatization, and potentially abusive parent-child interactions. For more information see R. Stein and D. J. Jessop (1984), *Pediatrics, 73*(6), 845-853.

The specific issue of the cost effectiveness of home care for 18 children dependent on ventilators in Illinois was examined by Goldberg and associates in 1984. From the findings, the authors conclude that the initial reduction in health care costs associated with transfer to home was 70 percent or more. This fact, in addition to the "unanticipated improvement in medical conditions and psychosocial development" of the child, supports this type of approach to care for certain children. For more information see A. I. Goldberg, E. A. M. Faure, C. J. Vaughn, R. Snarski, and F. L. Seleny (1984), *Journal of Pediatrics, 104*(5), 785-795.

In order to provide home care and other family-centered care services, it may be necessary to develop innovative and creative approaches to financing these services. The Health Sciences Research Institute (HSRI) in Massachusetts has a three year grant to identify exemplary models for designing and financing home care for children with severe disabilities and chronic illnesses. The goal of this project is to define flexible, yet effective mechanisms to support and to sustain family care for these children as follows:

- — to identify the costs of providing home care and the factors which contribute to these costs;
- — to develop alternative models for financing home care; and
- — to evaluate the effectiveness and feasibility of alternative financing models following implementation at demonstration sites.

The project will review the available literature on home care; interview families caring for children at home; solicit opinions of health care experts; and identify those variables that are critical to financing the costs associated with providing home care for children with different chronic illnesses and disabilities. HSRI will develop a network of representatives from national organizations serving families and children with severe disabilities and chronic illnesses. Two to five representatives will be selected from each state depending on the size of the state and available organizations. For additional information about this project contact: Governmental Activities, United Cerebral Palsy Associations, 1522 K Street, N.W., Suite 1112, Washington, D.C. 20005, (202) 842-1266 or Valerie Bradley, President, Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140, (617) 876-0426.

Areas in Need of Further Investigation

Not only is additional research examining family-centered care needed, but greater attention needs to be directed toward conducting research in a "family-centered" way. An excellent resource that can assist individuals in conducting research is an article by Turnbull, Blue-Banning, Behr, and Kems at the University of Kansas. This article, entitled "Family Research and Intervention: A Value and Ethical Examination" (unpublished manuscript available from the University of Kansas) highlights some of the negative bias that exists in current research about families. The authors note that there seems to be a lack of attention to the positive attributes and contributions of children with special needs, a point well illustrated by the Wikler et al. (1981, 1983) articles. The authors suggest alternative philosophical approaches along with two major recommendations for conducting research.

> ◆ *"First, we challenge . . . researchers conducting family research to form partnerships with families and organizations representing their interests. . . . By mutual prodding of each other's thinking, academicians and parents can enable research to have its best chance to fulfill the promise. Second, we recommend increasing the emphasis in graduate education programs on the philosophy of science. Focusing on how to do research is necessary but not sufficient. It is equally important to know why to do research, to know what questions are important to ask, and what to do with the results of the research" (Turnbull et al., p. 10).*

In the same article, the authors recap the types of questions families of children with special needs would like to see researched.

- — How can the first encounter between parents and professionals be improved?
- — What are potential successes we can have with our children?
- — How have other families coped well?
- — What makes the difference between successful and unsuccessful families?
- — What is the economic impact of disability on the family and how can money be spent proportionally?
- — How can one get employment without losing government benefits?
- — How can persons with disabilities develop relationships with persons of the opposite sex? (Turnbull et al., p. 9)

Other areas in need of further research include the following.

- ■ Additional studies are needed that provide a greater understanding of the strengths as well as the needs of children with chronic illnesses and disabilities and their families. This approach to research can be facilitated by reviewing the available literature (e.g., Crnic, Friedrich, &

Greenberg, 1983; Longo & Bond, 1984; Sherman & Cocozza, 1984) to learn more about the range of responses and coping strategies.

- Similar to Dr. Thomas' research, additional investigations are needed that take a more comprehensive approach to research rather than an examination of a small slice in the lives of these children and their families. Longitudinal studies would be very helpful in identifying the changing needs of children and families and in reflecting the pivotal role that parents play in the lives of their children. This information will greatly enable program developers and policy makers to design services that are more responsive to the needs of families.
- Research can play a powerful role in identifying needed services. Additional studies that ask parents directly about their service needs, their goals for their child, and the most effective ways of delivering them as well as studies that examine the availability of these services are needed.
- Once needs are identified and services provided, the effectiveness of family-centered care services, in terms of support as well as cost effectiveness, needs to be examined along with innovative mechanisms for financing this care. This research can be very instrumental in establishing and maintaining quality family-centered care. ■

Implementing Family-Centered Care

A Checklist for Effective Parent/Professional Collaboration

☐ Are there formal and informal mechanisms for ensuring effective parent/professional collaboration at all levels of care?

  ☐ Collaborative meetings scheduled at convenient times for families?

  ☐ Reimbursement for parent's time, services, transportation, and child care expenses?

  ☐ Formal and informal ways to encourage parent participation during meetings?

☐ Are parents attending collaborative committees representative of a variety of cultural, economic, educational, and geographic backgrounds?

☐ Do the parents participating in collaborative meetings include those whose children have been newly diagnosed, those who are experienced in identifying services, and those representing parent organizations?

☐ Are collaborative meetings composed of equal numbers of parents and professionals?

☐ Are there mechanisms for including parents along with professionals in inservice programs to build skills necessary for this collaboration on an ongoing basis?

☐ Are there mechanisms for preservice and inservice training for professionals in working collaboratively with parents?

☐ Are there effective mechanisms for receiving information from parents and parent groups and for disseminating information to them?

A Checklist for States

☐ Does the health department have a written philosophy of care that clearly reflects the pivotal role of parents?

☐ Do parents participate collaboratively with professionals at all levels of decision making and policy formation within the state?

☐ Is there a statewide coalition of parents and parent support groups across disabilities?

☐ Are there effective mechanisms for receiving information from parents and parent groups and for disseminating information to them?

☐ Is there an up-to-date statewide information and referral system that is easily accessible to parents and professionals?

☐ Do parents have complete and ready access to their children's records?

☐ Are there effective mechanisms for coordinating services for individual families?

☐ Is there a single individual who can assist the family in coordinating the care plans?

☐ Are there mechanisms within the state's funding system that support the family's efforts to care for their child at home?

☐ Are services organized in ways that allow for flexibility to address the changing and varied needs of children and families?

A Checklist for Communities

☐ Are there services available that support families as they care for their children with special health needs?

- ☐ Parent-to-parent support programs and networks
- ☐ Parent education programs
- ☐ Sibling support programs
- ☐ Family resource libraries or parent information centers
- ☐ In-home health care services
- ☐ Care coordination services
- ☐ Equipment loan or exchange programs
- ☐ Transitional care facilities
- ☐ Hospice care
- ☐ Respite care programs
- ☐ Mental health services
- ☐ Transportation assistance
- ☐ Financial planning assistance
- ☐ Day care and babysitting services
- ☐ Recreational programs and camps
- ☐ Toy lending libraries

☐ Are there mechanisms for addressing the educational needs of children with special health needs and their families?

  - ☐ Early intervention programs
  - ☐ Special education from the time of diagnosis until 21 years of age
  - ☐ Transitional vocational rehabilitation programs
  - ☐ Hospital school programs and home tutoring, particularly for children with frequent hospitalizations and/or long term health problems
  - ☐ Community libraries containing resources on developmental disabilities and chronic conditions and available services
  - ☐ Parent Training and Information Centers or other formal or informal networks for parents about educational issues

☐ Are available community services flexible, accessible, and responsive to the strengths and needs of children and families?

  - ☐ Mechanisms to ensure effective communication and continuity of care among home, hospital, primary care settings, school, and community
  - ☐ Regionally coordinated planning among community-based services, local hospitals, and tertiary care centers
  - ☐ Easily accessible buildings
  - ☐ Information on community health care and support services available through the media, in clinic and physicians' offices, schools, and libraries
  - ☐ Inservice training involving parents to educate community service providers about the strengths and needs of children and the pivotal role played by their families

A Checklist for Professional Training Programs

- ☐ Are there opportunities for professionals to learn directly from parents about their perspectives and support needs?
- ☐ Do parents participate in the development of training programs for professionals?
- ☐ Do preservice and inservice training programs provide instruction in the following areas?
    - ☐ Effective communication skills and methods for working collaboratively with families
    - ☐ Skills in working collaboratively as a team member with professionals of other disciplines
    - ☐ Service delivery models that provide a mechanism for coordinating care among agencies in the community and for developing linkages to and from primary, secondary, and tertiary care settings
    - ☐ Planning care in the home and community
    - ☐ Financing options for families
    - ☐ Normal and atypical child development
    - ☐ Support needs of families
    - ☐ Family dynamics
    - ☐ Effectiveness of parent-to-parent support
    - ☐ Advocating for comprehensive community resources
    - ☐ Research methodology examining the cost and emotional effectiveness of family-centered care policies and programs
    - ☐ Techniques for conducting research in a way that respects the rights of the children and families and reflects a balanced approach, focusing on family strengths as well as needs

A Checklist for Hospitals

☐ Does the hospital have a written philosophy or standards of care that clearly reflect the pivotal role of parents?

☐ Are there mechanisms for facilitating parent/professional collaboration in the design and implementation of hospital policies and programs?

☐ Is there a Parent Advisory Committee which reports to the Board of Directors?

☐ Are there established policies that encourage parent participation in child health care?

  - ☐ 24-hour open visiting for parents
  - ☐ Rooming-in facilities
  - ☐ Liberal sibling visiting
  - ☐ Presence of parents during anesthesia induction, a stay in the recovery room, radiology examination, and emergency room treatment

☐ Does the hospital provide programs and staff that support the developmental and emotional needs of children and families?

  - ☐ Preadmission preparation program
  - ☐ Preparation for patients and parents during and after medical and surgical procedures
  - ☐ Professionally staffed child life programs and appropriately equipped playrooms
  - ☐ Hospital school program
  - ☐ Family Resource Library
  - ☐ Readily available parent-to-parent support
  - ☐ Primary care nursing particularly for young children in need of consistent caregivers
  - ☐ Support staff such as paid parent consultants, patient representatives, social workers, child life specialists, psychologists, chaplains, and trained volunteers

☐ Are there mechanisms for informing parents about hospital policies and programs?

☐ Are there mechanisms for receiving feedback from parents regarding their satisfaction with hospital policies and programs?

☐ Are there mechanisms for coordinating care among the hospital, community clinics, community support services, and primary community-based health care providers?

☐ Does the architectural and interior design of the hospital and allocation of space meet the developmental and support needs of children and families?

☐ Are mechanisms available which enable families to care for their children at home, or in a home-like environment?

  - ☐ In-home health care services
  - ☐ Respite care programs
  - ☐ Transitional care facilities
  - ☐ Linkages to community services

A Checklist for Research Investigations

☐ Does the research design and data analysis reflect a balanced approach, focusing on a family's strengths as well as needs?

☐ Is participation presented in a way that families feel they will not jeopardize the quality of the services they receive if they do not wish to participate?

☐ Are consent forms easy to understand?

☐ If a number of research studies are being conducted in one facility, is there a mechanism to ensure that families are not overwhelmed with requests?

☐ Is there a mechanism to ensure that the results of the research are communicated to families who participate?

Family-Centered Care Resources

INTRODUCTION

To assist parents and professionals who are interested in implementing a family-centered approach to care for children with special health needs, this section includes selected examples of technical assistance organizations, audiovisual and written materials, and programs currently utilizing a family-centered approach to care. ■

Technical Assistance

Through funding from the Division of Maternal and Child Health (DMCH) and their previous ongoing activities, the following organizations are in the position of offering assistance to individuals interested in implementing family-centered care.

Association for the Care of Children's Health (ACCH), 3615 Wisconsin Avenue, N.W., Washington, DC 20016 (202) 244-1801

ACCH is a multidisciplinary association of professionals and parents which promotes quality psychosocial health care for children and their families in all health care settings through education, research, advocacy, and networking. ACCH has available written and audiovisual materials as well as consultation services to assist those interested in implementing a family-centered approach to care for children with special health needs.

Federation for Children with Special Needs, 312 Stuart Street, Boston MA 02116 (617) 482-2915

The Federation has received funds from MCH for the Collaboration Among Parents and (Health) Professionals (CAPP) project. This project is designed to increase and encourage parent involvement in the health care of their children who have a chronic illness or disability. CAPP also promotes partnerships between parents and health care professionals.

National Center for Networking Community-Based Services, Georgetown University Child Development Center, 3800 Reservoir Road, N.W., Washington, DC 20007 (202) 625-7033

The Network consists of state leaders in health, mental health, and education in over 35 states as well as a national task force with representation from key federal agencies and departments in each of these areas. The project provides technical assistance and training to states to enhance interagency collaboration and to improve services to children and families.

National Maternal and Child Health Resource Center, College of Law Building, The University of Iowa, Iowa City, IA 52242, (319) 335-9046

The Center promotes the improvement and expansion of maternal and child health services, including services for children with special health care needs. Center activities include dissemination of information provision of technical assistance, and development of training materials.

Audiovisual and Written Materials

Listed below are several audiovisual and written materials that further define family-centered care by illustrating parent/professional collaboration and/or by providing greater insight into the experiences of children with special needs and their families.

Audiovisual Materials

Only A Breath

This is a sensitive exploration of the lives of five families with children who are ventilator-assisted and living at home. It explores the families support needs through interviews with children, siblings, parents, and health care providers. This film is valuable for both parents of children with special health needs and professionals serving them.

Length: 30 minutes
Format: ½" or ¾" VHS
Contact: Teaching Films, Inc.
Educational Services, Inc.
930 Pitner Avenue
Evanston, IL 60202
(800) 323-9084

Parents To Parents: Grief
Anger
"It's Not True"
"What Did I Do Wrong"

These tapes were developed by parents to present their perspective on four common issues faced by parents of children with special needs. They are excellent tools for encouraging discussion about the emotional needs of families and can be used by both parents and professionals caring for children with special needs.

Length: Approx. 25 minutes each
Format: ½" or ¾" VHS ½" BETA
Contact: West Virginia Advocates for the
Developmentally Disabled
1200 Quarrier Street, Suite 27
Charleston, WV 25301
(304) 346-0847

Seasons Of Caring

This film portrays the strengths and support needs of three families caring for preschool children with special health needs. The film presents some of the stresses experienced by the families as well as the coping strategies they have used. It also shows some of the attitudes, approaches, and services they have found helpful. Parents, educators, and health care professionals are the main audiences for this film. Detailed curriculum materials accompany the film.

Length: 40 minutes
Format: 16mm
½" or ¾" VHS
½" BETA
Contact: Association for the Care of
Children's Health
3615 Wisconsin Avenue, N.W.
Washington, DC 20016
(202) 244-1801

The Family Experience

This film portrays families of infants who are sick or at-risk during their first year of life. In interviews with both families and health and education professionals, the film explores some of the issues facing families of very young children and presents their unique needs. There is an accompanying manual which describes the developmental process of parenting and the disruptions to the parenting process which can occur with prematurity and illness in the infant.

Length: 45 minutes
Format: ½" or ¾" VHS
Contact: Carole Brown
Year One Project
Department of Special Education
The George Washington University
2201 G Street, N.W.
Washington, DC 20052
(202) 676-6170
(202) 994-1510

The Invisible Society

This film was prepared as an informational piece for legislators and community leaders in Arizona but goes beyond its original intent. Families of children with a chronic illness discuss many of the central issues for parents and professionals caring for children with special health needs. The film defines chronic illness and presents national statistics along with those specific to Arizona.

Length: 25 minutes
Format: ½" VHS
Contact: Arizona Consortium for Children
with Chronic Illness
Barbara Hopkins
P.O. Box 2128
Phoenix, AZ 85001
(602) 838-9006

Written Materials

A Difference in the Family: Life with a Disabled Child

In this book, Helen Featherstone provides a mother's sensitive discussion of how parents and families cope with their feelings and demands on the family, and what types of support are most helpful. Available from the Association for the Care of Children's Health, 3615 Wisconsin Ave., N.W., Washington, DC 20016 (202) 244-1801.

After the Tears

After the Tears is a beautifully written book by and for parents of children with disabilities. Interspersed between very personal vignettes are practical suggestions and ideas on the struggles and triumphs of raising a child with a disability; dealing with other people including relatives, strangers, and professionals; meeting the needs of one's self, one's child, and one's family; and growing and coping as part of a special family, A resource section includes a listing of national support groups as well as outstanding printed and visual materials. This book offers support and affirmation to families and provides professionals with a wonderful opportunity to learn from families about their experiences. Available from Harcourt, Brace, and Jovanovich publishers and the Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, DC 20016 (202) 244-1801.

Equals in this Partnership: Parents of Disabled Children and At-Risk Infants and Toddlers Speak to Professionals

This booklet is an outgrowth of a December, 1984 conference jointly sponsored by the Division of Maternal and Child Health, the Office of Special Education and Rehabilitative Services, and the National Center for Clinical Infant Programs. As reflected in the thoughts of seven of the parents and professionals who participated in the meeting, the conference also provided an invaluable opportunity for parents and professionals to learn from each other's ideas and experiences. In a powerful way, this booklet clearly reflects the promise of parent/professional collaboration. Available from the National Center for Clinical Infant Programs, 733 15th Street, N.W., Suite 912, Washington, DC 20005 (202) 347-0308.

Families, Professionals, and Exceptionality: A Special Partnership

This book written by Ann and Rudd Turnbull addresses the important roles played by both families and professionals in the lives of individuals with special needs. An excellent resource for both families and professionals, the authors apply a family systems approach in discussing the needs of an individual with a disability and their family across the life cycle. Specific topics include strategies for improving communication between families and professionals, increasing the advocacy skills of families, improving the educational IEP process, and handling stress. The Appendix includes several useful resources including the Family Preference Inventory. This inventory provides a framework for families to identify the information that they wish to receive about their child as well as the manner in which they wish to receive it. Available from Charles E. Merrill Publishing Company, 1300 Alum Creek, Columbus, OH 43216.

Iowa Health Care Guidelines

Funded by the Division of Maternal and Child Health, the Iowa Health Care Guidelines Project developed four sets of guidelines for professionals involved in the care of children with chronic illnesses or disabilities. In addition to the guidelines for physicians, nurses, social workers, and therapists, additional guidelines have also been developed by and for families of children with special needs to assist them in the selection, implementation, coordination, and evaluation of services for their child. These documents emphasize the need for improved communication and cooperation between families and professional caregivers and recommend the development of individualized service plans for children with special needs and their families. Also included in each set of guidelines are the Principles of Health Care which provide the philosophical basis for the guidelines and are intended to promote optimal health care for all children and their families. The publications reflect the joint contributions of parents and professionals from many disciplines. Available from Campus Stores, 208 G.S.B., University of Iowa, Iowa City, IA 52242.

Let's Play with Our Children
New Directions for Exceptional Parenting

These companion booklets, written by Pat Downey, the parent of a child with severe disabilities, focus on some of the positive ways of coping with the challenges of caring for a child with complex needs. These books are full of ideas for play activities for children and emphasize the importance of playful, nurturant interactions between parents and children. Available from ACCH, 3615 Wisconsin Avenue, N.W., Washington, DC 20016 (202) 244-1801.

Meeting the Challenge of Disability or Chronic Illness—A Family Guide

This book by Lori A. Goldfarb, Mary Jane Brotherson, Jean Ann Summers and Ann P. Turnbull, proposes a supportive model for solving the difficult problems that confront families facing the daily challenges of illness and disability. A deep respect for the uniqueness and resilience of families underlies this book. At the outset the authors state their beliefs that all families have strengths, that there are no answers that work for everyone, that families and family needs change over time, and that families are capable of thriving while responding to the special demands posed by a chronic disability.

The book has two main sections: Taking Stock and Problem Solving. Each section contains a series of practical exercises to help families learn more about their beliefs and values and the ways in which they function both as individuals and as members of a group. In the problem solving section, the authors present a model for step-by-step problem solving that takes into account family needs, priorities and values. Throughout the book the authors use case studies to effectively illustrate their points. The book includes an excellent resource section. Available from Paul Brookes Publishing, P.O. Box 10624, Baltimore, Maryland 21285-0624 (301) 377-0883.

Parent Resource Directory

Developed as part of the Association for the Care of Children's Health (ACCH) family-centered care grant, the directory lists more than 160 parents of children with special health needs from across the United States and Canada. The purpose of the directory is to encourage networking and collaboration among those caring for or providing support services to children with chronic illnesses or disabling conditions. The directory is organized by state and province and includes the parents' name, address, telephone numbers(s), group affiliation(s), and their child's disability. The directory also includes the skills, interests and experiences parents have had in promoting a family-centered approach to health care. The directory is indexed alphabetically and by disability. To receive a copy of the directory, send $3.00 (includes shipping and handling) to ACCH, 3615 Wisconsin Avenue, N.W., Washington, DC 20016 (202) 244-1801.

Raising A Handicapped Child: A Helpful Guide for Parents of the Physically Disabled

This book by Charlotte Thompson is a comprehensive, sensitively written guide for parents of children with physical disabilities. Most of the information is practical and includes several excellent suggestions for further reading as well as anecdotes taken from the author's thirty years of pediatric practice. Available from William Morrow and Company, Inc., 105 Madison Avenue, New York, NY 10016.

Reaching Out—A Directory of Voluntary Organizations in Maternal and Child Health

Developed for health professionals, educators, administrators, and individuals with or caring for a person with a chronic illness or disability, this comprehensive directory lists several hundred voluntary organizations and self-help clearinghouses in the United States and internationally. These organizations provide a variety of services and activities, including publishing educational materials, disseminating general information, making referrals, and furnishing support to assist the professional or individual in coping with a specific need. Available from the National Center for Education in Maternal and Child Health (NCEMCH), 38th and R Streets, N.W., Washington, DC 20057 (202) 625-8400

■ Programs

Below is a listing of all the programs that are described in this publication. Although the programs were presented in this publication as examples of a particular element of family-centered care, in many cases they are illustrative of several of the elements. As was mentioned in the introduction, the implementation of one element often facilitates, or goes hand-in-hand with, the others. The page where the full program description appears is noted in parentheses.

Alliance of Genetic Support Groups
38th and R Streets, N.W.
Washington, DC 20057
(202) 625-7853
(page 43)

Adolescent Autonomy Project
Sharon L. Hostler, M.D.
Children's Rehabilitation Center
2270 Ivy Road
Charlottesville, VA 22901
(804) 924-8184
(page 34)

Arizona Consortium for Children with Chronic Illness
Barbara Hopkins, Parent Representative, Executive Committee
P.O. Box 2128
Phoenix, AZ 85001
(602) 838-9006
(page 11)

AUNT FABS
National Center on Family-Based Services
University of Iowa
Oakdale Campus
Iowa City, IA 52242
(319) 335-4130
(page 19)

Camps for Children with Special Needs and Their Families
1987 Parents' Guide to Accredited Camps
American Camping Association
100 Bradford Woods
Martinsville, IN 46151
(page 34)

Camp Glyndon (for children with diabetes)
Dan Markowitz
3701 Old Court Road, Executive Park
Suite 20
Baltimore, MD 21208
(301) 486-5515
(page 34)

Camp Kaleidoscope (for children with chronic illnesses)
Thomas K. Kinney, M.D. or Alex Gordon, M.Ed.
P.O. Box 2916
Duke University Medical Center
Durham, NC 27710
(page 34)

Camp Latgawa (for children with spina bifida and their families)
Theresa Schneider
1664 Hammel Road
Eagle Point, OR 97524
(503) 826-6194
(page 34)

Camp Ozawizeniba (for children and youth with epilepsy)
Vicki Florine
2701 University Avenue, S.E.
Suite 106
Minneapolis, MN 55416
(612) 376-5031
(page 34)

Camp Sunshine (for children with cancer)
Julie Russem
Childhood Cancer Support Program
1921 West Street
Portland, ME 04102
(207) 775-5481
(page 34)

Candlelighters
2025 Eye Street, N.W.
Suite 1011
Washington, DC 20006
(202) 659-5136
(page 29)

Child and Family Support Project
Robin Thomas, R.N., Ph.D.
Children's Hospital Medical Center
4800 Sand Point Way
Seattle, WA 98105
(page 49)

Children's Case Resolution System
Paula T. Findley
Office of the Governor
State Ombudsman
Edgar A. Brown Building
1205 Pendleton Street
Columbia, SC 29201
(803) 734-0457
(page 11)

Children's Home Health Network
Kathleen Murphy, M.S.W.
Division of Services for Crippled Children
1919 W. Taylor Street
Chicago, IL 60612
(312) 966-6380
(page 46)

Chronic Health Impaired Program (CHIP)
Joan Cace or Sylvia Matthews
Baltimore City Public School System
Baltimore, MD 21217
(301) 396-1611
(page 34)

Chronic Illness Teaching Program
Barbara W. Desguin, M.D.
Department of Pediatrics and Human Development
B-240, Life Sciences Building
Michigan State University
East Lansing, MI 48824-1317
(page 12)

Community Advisory Board
Children's Hospital Child Health Centre
Phyllis Kane
Alberta Children's Hospital
1820 Richmond Road
Calgary, Alberta CANADA T2T 5C7
(page 11)

Coordination of Care for Chronically Ill Children Program
Thomas Nattell, M.S.W.
New York State Department of Health
Tower Building, Room 878
Empire State Plaza
Albany, NY 12237
(518) 473-7163
(page 48)

Family-Centered Planning Program
Audrey Leviton, Director
Department for Family Support Services
Kennedy Institute for Handicapped Children
707 Broadway
Baltimore, MD 21205
(301) 522-5480
(page 5)

Family Friends Project
Meredith Miller, Ph.D., Project Director
Jane Diao, M.S.W., Program Associate
National Council on the Aging (NCOA)
600 Maryland Avenue, S.W., West Wing 100
Washington, DC 20024
(202) 479-1200
(page 24)

Helping Grandparent Program
Elaine Schab-Bragg
King County ARC
2230 8th Avenue
Seattle, WA 98121
(206) 622-9202
(page 42)

Home-Based Support Services for Chronically Ill Children and Their Families
Barry Sherman, Ph.D.
Tower Building, Room 878
Empire State Plaza
Albany, NY 12237
(518) 473-7163
(page 48)

Iowa Health Care Guidelines
Alfred Healy, M.D.
Division of Developmental Disabilities
University Hospital School
University of Iowa
Iowa City, IA 52242
(319) 353-6390
Copies may be obtained from:
Campus Stores
208 G.S.B.
University of Iowa
Iowa City, IA 52242
(page 29)

Let's Play to Grow
Lisa Morris, Program Coordinator
1350 New York Avenue, N.W.
Suite 500
Washington, DC 20005
(page 34)

Medicaid Waiver Programs
State Medicaid Agency or
Health Care Financing Administration
East High Rise Building
6325 Security Boulevard
Baltimore, MD 21207
(page 23)

Medically Fragile Children's Program
Georgia Cleverley
Coordinated Community In-Home Care (CCIC)
PERA Building, Room 516
P.O. Box 2348
Santa Fe, NM 87504-2348
(505) 827-4923
(page 23)

Michigan Family Subsidy Program
Michigan Department of Mental Health
Lewis Cass Building
Lansing, MI 48926
(517) 373-3740
(page 23)

National Information System for Health Related Services (NIS)
Girish G. Yajnik, Project Director
Center for Developmental Disabilities
University of South Carolina
1244 Blossom Street
Columbia, SC 29208
(803) 774-4435
Or access the system directly by calling
(800) 922-9234
(page 19)

Nurse Clinician/Parent Consultant
Duke University Medical Center
Department of Pediatrics
Division of Hematology-Oncology
Box 2916
Durham, NC 27710
(919) 684-3401
(page 41)

Parent Advisory Committee
Boston Children's Hospital
Betsy Anderson
Federation for Children with Special Needs
312 Stuart Street
Boston, MA 02116
(617) 482-2915
or
Barbara Popper
Children in Hospitals, Inc.
31 Wilshire Park
Needham, MA 02192
(617) 444-3877
(page 11)

Parent Advisory Committee
Children's Medical Program
Kathy Olde
Route 1, Box 119
New Site, MS 38859
(601) 728-5121
(page 10)

Parent Consultants
Rhode Island Hospital
Pediatric Oncology Service
Joy Benson or Helena G. Richards
593 Eddy Street
Providence, RI 02902
(401) 277-5497
(page 41)

Parent Training and Information and Technical Assistance Centers Central Office

Technical Assistance for Parent Programs (TAPP)
Martha Ziegler, Director
312 Stuart Street, 2nd Floor
Boston, MA 02116
(617) 482-2915
(page 19)

Regional Centers

New Hampshire Parent Information Center (PIC)
Judith Raskin, Director
P.O. Box 1422
Concord, NH 03301
(603) 224-7005
(page 19)

Parent Advocacy Coalition for Educational Rights (PACER)
Marge Goldberg & Paula Goldberg, Co-Directors
4826 Chicago Avenue, South
Minneapolis, MN 55417-1055
(612) 827-2966
(page 19, 51)

Parents Advocating Vocational Education (PAVE)
Martha Gentili, Director
1010 S. I Street
Tacoma, WA 98405
(206) 272-7804
(page 19)

Parents Educating Parents (PEP)
Mildred J. Hill, Director
Georgia/ARC
1851 Ram Runway, Suite 104
College Park, GA 30337
(404) 761-2745
(page 19)

For more information on these regional centers and the state training centers contact:

U.S. Department of Education
Office of Special Education and Rehabilitative Services (OSERS)
Office of Special Education Programs
Division of Personnel Preparation
Switzer Building, Room 4620
400 Maryland Avenue, SW
Washington, DC 20202
(202) 732-1032
Jack Tringo, Project Officer
(page 19)

Parents Helping Parents, Inc.
Florene Poyadue, Director
535 Race Street, Suite 220
San Jose, CA 95126
(408) 288-5010
(page 19, 41)

Pilot Parents
2005 North Central
Suite 100
Phoenix, AZ 85004
(602) 271-4012 or (602) 969-8209
(page 43)

Project Dakota
Linda Kjerland, Project Director
Dakota, Inc.
680 O'Neill Drive
Eagan, MN 55121
(612) 455-2335
(page 10)

Project Hope
Angela Deal, Coordinator
Family, Infant, and Preschool Program
Western Carolina Center
300 Enola Road
Morganton, NC 28655
(704) 433-2661
(page 42)

Project Nexus
Robin Hazel
Kansas University Affiliated Facility
377 Haworth Hall
University of Kansas
Lawrence, KS 66045
(913) 864-4954
(page 48)

Project Serve
101 Tremont Street, Room 615
Boston, MA 02108
(617) 574-9493
(page 47)

Roundhouse Conference on Children with Disabilities
Effective Parents Project, Inc.
930 Ute Avenue
Grand Junction, CO 81501
(303) 241-4068
(page 13)

Sibling Information Network
Connecticut's University Affiliated Program
Box U-64, School of Education
249 Glenbrook Road
The University of Connecticut
Storrs, CT 06268
(203) 486-4034
(page 42)

SKIP Sick Kids (Need) Involved People
216 Newport Drive
Severna Park, MD 21146
(301) 261-2602
(page 43)

Texas Respite Resource Network
Jennifer Cernoch, Ph.D.
P.O. Box 7330, Station A
San Antonio, TX 78285
(512) 228-2576
(page 24)

Summary of Elements of Family-Centered Care

1. Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.

2. Facilitation of parent/professional collaboration at all levels of health care:
   - care of an individual child;
   - program development, implementation, and evaluation; and
   - policy formation.

3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.

4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.

5. Recognition of family strengths and individuality and respect for different methods of coping.

6. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care delivery systems.

7. Encouragement and facilitation of parent-to-parent support.

8. Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs. ■

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