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ABSTRACT

This monograph articulates eight key elements of a family-centered approach to policy and practice for children needing specialized health and developmental services. An introductory section reviews the development of the first edition of the monograph in 1987 and its widespread dissemination and acceptance since that time. Each of the following eight chapters then addresses one of the following elements: (1) recognition that the family is the constant in the child's life, while the service systems and support personnel within those systems fluctuate; (2) facilitation of family/professional collaboration at all levels of hospital, home, and community care; (3) exchange of complete and unbiased information between families and professionals in a supportive manner; (4) respect for cultural diversity within and across all families including ethnic, racial, spiritual, social, economic, educational, and geographic diversity; (5) recognition of different methods of coping and promotion of programs providing developmental, educational, emotional, environmental, and financial supports to families; (6) encouragement of family-to-family support and networking; (7) provision of hospital, home, and community service and support systems that are flexible, accessible, and comprehensive in meeting family-identified needs; and (8) appreciation of families as families, recognizing their wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support. Checklists for evaluating these elements are attached. (Contains 160 references.) (DB)

FAMILY-CENTERED CARE FOR CHILDREN NEEDING SPECIALIZED HEALTH AND DEVELOPMENTAL SERVICES

by
Terri L. Shelton
and
Jennifer Smith Stepanek

Association for the Care of Children's Health

with support from
The Maternal and Child Health Bureau
U.S. Department of Health and Human Services

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The Association for the Care of Children's Health (ACCH) is an international education and advocacy organization that promotes family-centered care policies and practices addressing the comprehensive needs of children and youth, and their families, in hospital, home, and community program settings. The ACCH Community of family members, multidisciplinary providers, administrators, educators, and researchers, is dedicated to defining a better way of providing health and developmental services for children and their families . . . with a distinctive human touch.

For information about ACCH's many educational and advocacy resources, as well as membership in the ACCH Community, contact:

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The content of this publication was subject to extensive peer review. Every attempt was made to accurately describe the policies, programs, and practices presented.

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ACCH
Humanizing Health Care
for Children and Families

Family-Centered Care for Children Needing Specialized Health and Developmental Services

Third Edition*
September, 1994

by

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and
Jennifer Smith Stepanek

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*Formerly titled *Family-Centered Care for Children with Special Health Care Needs*

Foreword

by William Sciarillo, ACCH Executive Director

The 1987 publication of *Family-Centered Care for Children with Special Health Care Needs* (Shelton, Jeppson, & Johnson, 1987), the initial edition of this current update — *Family-Centered Care for Children Needing Specialized Health and Developmental Services*, marked:

> *. . . the beginning of a new era in the delivery of health care services to children and their families . . . they delineated eight elements of care that, taken together, constitute a philosophy about how health care practices, policies, and systems would need to change if they were to become family-centered (Trivette, Dunst, Allen & Wall, 1993, pp. 241-242).*

In large part through the leadership and support of former Surgeon General C. Everett Koop and the U.S. Maternal and Child Health Bureau, much has happened in the family-centered care movement since then. Our hope in 1994 is that all children throughout North America will benefit from a standard comprehensive health benefits package. However, universal coverage and other proposed health care reforms will not necessarily assure quality care for children who require specialized health and developmental services. Quality care for such children requires something more than access and financing strategies . . . it requires the synergy that's possible when service administrators, multidisciplinary providers, and families work together for change — with respect to the individual child, as well as at the program and policy levels. Simply stated, that's what this book is about.

As discussed in the Introductory Chapter, this updated edition of a landmark resource has slightly revised and reordered the *Key Elements of Family-Centered Care*, with each succeeding element building on the previous one. Consequently, the Key Elements taken together represent a conceptual framework, rather than simply a listing or checklist approach, which can guide us in our practice, teaching, and research.

Inevitably, one must raise the critical issue as to the place of family-centered services in a managed care environment. Although there is a paucity of research examining the specific effects of family-centered care on health care costs, a growing body of research documenting the effect of family factors on the health of its members provides a strong rationale for managed care systems to recognize that consideration of a family's values, resources, and needs within the context of providing services to a child may be an effective cost containment measure (Consortium of Family Organizations, 1994). In fact:

> *. . . cost-saving measures which do not provide the education and supportive services required by the family/caregivers and do not take into account the specific needs and resources of individual families may result in a rigid, inflexible system and result in poor, ineffective and cost-inefficient treatment (p. 17).*

References:

Consortium of Family Organizations (1994) Principles of family-centered health care A health care reform white paper The ACCH Advocate, 1(2) 13-20

Trivette, C., Dunst, C J., Allen, S., & Wall, L. (1993). Family-centeredness of the Children's Health Care journal. Children's Health Care, 22,(4) 241-256.

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This monograph represents the collaborative effort of many family members and professionals with diverse backgrounds and experiences. The heart and spirit of family-centered care in practice is truly evidenced by their valuable input and assistance, and their clear commitment to the total health and well-being of children with illnesses and physical, mental, or emotional disabilities. These individuals have formally or informally reviewed, advised, encouraged, supported, or otherwise helped to make this a better resource for others who are also striving to incorporate into policy and practice the philosophy of family-centered care for children needing specialized health and developmental services and supports and their families.

The *Maternal and Child Health Bureau (MCHB)* of the U.S. Department of Health and Human Services has provided national vision and leadership for the family-centered care agenda since the mid-1980s. MCHB has supported this publication through a grant to the *National Center for Family-Centered Care* (NCFCC, #MCJ 115039) at the *Association for the Care of Children's Health (ACCH)*. Across the years, MCHB has created many opportunities for family/professional collaboration, which have been critically important to our understanding of family-centered care and to the writing of this publication. We are grateful to **Merle McPherson**, **John Shwab**, and **Diana Denboba**, in the Division of Services for Children with Special Health Care Needs.

We are also grateful to **William Sciarillo**, Executive Director of ACCH, for his leadership in ensuring the total commitment of ACCH to the completion of this monograph, and for his own commitment to comprehensive services for children and families with a distinctive human touch — the hallmark of ACCH.

The revision of this monograph would not be possible without the talent, time, and effort put forth by **Sue Sandmeyer**, Publications Manager at ACCH. We greatly appreciate her hours and hours of input and work on both the design and the content of the monograph, and her dedication to the goal of "best practice" in children's health and developmental care.

Karen Lawrence, Project Coordinator of the NCFCC, and **Sandra Newcomb**, Project Coordinator of the Project Assist Family Support Group, have exceeded the standards as professionals practicing family-centered care, and as friends. We are very grateful for their energy and motivation, and for all of their skillful guidance and assistance in ensuring that the content of this monograph in fact delivered the message we intended. We are also grateful to **Arlene Kiely**, a lay-minister, parent, and former staff member of the NCFCC, whose skills in consultation and training were valuable to this publication.

The chapter exploring the fourth element of family-centered care — honoring the diversity of families — was largely adapted from an unpublished manuscript contributed by **David Allen Jones**, President of the Institute on Cultural Dynamics and Social Change. We appreciate his time and effort on this project and his endeavor to ensure that family-centered care is a reality for all families.

Many colleagues were involved in the field review process of the manuscript as it was developed for publication. They brought a diverse mix of expertise and experience, representing: family members of children needing specialized health or developmental services and supports; physicians and nurses; professionals in early intervention, early childhood education, and special education; social workers; project coordinators and program directors; support personnel; and, other disciplines. We appreciate the time and energy of **Nan Nelson** who proofread the entire monograph for content and editing comments, and the input and insights offered by field reviewers, including:

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Thank you to **Tyler, Arthur**, and **Mom**... who taught me what it means to be a family.
— Terri

Thank you to **Greg**, for your patience and support, and for all those 2 a.m. pots of coffee. And especially, thank you to **Katie, Stevie**, and **Jamie** — my three little angels — and to **Mattie** — my brave and very wise little trooper — for your love and inspiration, and for your clear message that *every* child is an unrepeatable gift to be treasured for life.
— Jeni

Contents

The Key Elements of Family-Centered Care

- Incorporating into policy and practice the recognition that the *family is the constant* in a child's life, while the service systems and support personnel within those systems fluctuate.

- Facilitating *family/professional collaboration* at all levels of hospital, home, and community care:
  - care of an individual child;
  - program development, implementation, evaluation, and evolution; and,
  - policy formation.

- *Exchanging complete and unbiased information* between families and professionals in a supportive manner at all times.

- Incorporating into policy and practice the recognition and *honoring of cultural diversity*, strengths, and individuality within and across all families, including *ethnic, racial, spiritual, social, economic, educational, and geographic diversity.*

- Recognizing and respecting *different methods of coping* and implementing comprehensive policies and programs that provide *developmental, educational, emotional, environmental, and financial supports* to meet the diverse needs of families.

- Encouraging and facilitating *family-to-family support* and networking.

- Ensuring that *hospital, home, and community service and support systems* for children needing specialized health and developmental care and their families are *flexible, accessible, and comprehensive* in responding to diverse family-identified needs.

- *Appreciating families as families* and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support.

Shelton, T.L. & Stepanek, J.S. (1994). Family-centered care for children needing specialized health and developmental services, Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, Maryland 20814, 301/654-6549.

Family-Centered Care for Children Needing Specialized Health and Developmental Services

Photo courtesy of Children's Memorial Hospital, Chicago. Photographer: Mark Batrell

An Historical Perspective

The term family-centered care has been used in various contexts for nearly 30 years (e.g., Wiedenbach, 1967). However, it was the publication of the first edition of this monograph in 1987 (Shelton, Jeppson, & Johnson, 1987) that articulated how key elements of family-centered care should be reflected in policy and practice for children needing specialized health and developmental services. The monograph was part of many groundbreaking initiatives in family-centered care funded by the Maternal and Child Health Bureau (MCHB), U.S. Department of Health and Human Services.

This publication, and the ongoing work in family-centered care, reflected the driving force of several movements at that time including the emergence of family support programs, early intervention practices, and previous family-centered care practices found in maternity care (Dunst, Johanson, Trivette, & Hamby, 1991). In terms of legislation, Public Law (P.L.) 99-457, Amendments to the Education of the Handicapped Act, (1986), had just been passed, with many professionals wondering how to implement the cornerstone of the legislation — the Individualized Family Service Plan (IFSP) — which mandated a family-centered approach and family/professional collaboration. The Children's Justice Act (P.L. 99-401, 1986), which provided for temporary non-medical respite services for families of children with disabling conditions or chronic illnesses, had been enacted but no funds were yet appropriated.

In terms of finances, the care of children needing specialized health and developmental services and supports, particularly home health care, was at that time a confusing array of waivers and state plan amendments. Alternatives to hospital care were being explored actively, but comprehensive community-based systems and transition services were not well-established to provide these alternatives. Reflecting advances in medical technology, the specialized health and developmental needs of children were becoming more acute or chronic in nature, and health care reform was just a dream.

Within this context, a group of parents and professionals were brought together in 1986 for the expressed purpose of defining the critical characteristics of an emerging philosophy of care. Based on the collective wisdom of those individuals, the original eight elements of family-centered care were articulated and a brief description of these elements was developed. The text for the final monograph was then sent to the initial group of individuals, and to additional parents and professionals across the United States in various service delivery settings, for review. The review was to ensure that the authors had indeed captured the prevailing thinking about what family-centered care should encompass. The final monograph, often referred to as *"Big Red"* because of the color of the cover, was then published (Shelton et al., 1987).

These original elements served as the basis for then U.S. Surgeon General C. Everett Koop's agenda that year: to provide services to children needing specialized health care that were family-centered, community-based, and well-coordinated (Koop, 1987). His efforts, along with the continuing work of MCHB, provided the impetus for the initial dissemination of this "best practice" philosophy — family-centered care.

The intent of the original authors was to incorporate the recognition and respect of cultural diversity into the design and delivery of services as reflected in the original elements. While it was clear that services did not necessarily reflect this sensitivity at that time, there was some discussion that the addition of a separate element might result in professionals looking at cultural diversity as something separate, rather than attending to diversity as integral to aspects of all services. That notwithstanding, it later became apparent that this aspect of family-centered care did need to be highlighted. As a result, a ninth element was added in 1990: "Honoring the racial, ethnic, cultural, and socioeconomic diversity of families" (National Center for Family-Centered Care, 1990). With the current 1994 revision of the monograph, the wording of this element has been refined to reflect more comprehensively the importance of honoring *all* diversity within and across all families beyond the concepts of ethnicity and race.

Since the initial publication of the monograph, more than 30,000 copies have been distributed to various professionals and family members in community-based programs, government agencies, hospitals, schools, and other facilities throughout the health, education, and social service arenas. Much has happened since 1987 in the developing field of family-centered care. Programs attempting to operationalize the elements of family-centered care into practice have grown, largely as a function of the supportive funding of MCHB. Also, organizations such as the *Family Resource Coalition*, which has grown to more than 2,000 family support programs dedicated to the development of community-based programs for supporting and strengthening family functioning (Weissbourd & Kagan, 1989), have been integral in the transition of family-centered care from an ideal into a reality.

Formal and informal examples of family/professional collaboration are more numerous now, as are family support and advocacy organizations. Articles in professional journals and texts on family-centered care have increased (Trivette, Dunst, Allen, & Wall, 1993). Although more is needed, research examining the benefits of family-centered care for children and their families and the cost-effectiveness of this approach for families, facilities, and financial providers has also grown.

The family-centered philosophy has been incorporated into several landmark pieces of legislation including: the Omnibus Budget Reconciliation Act (OBRA, 1989) which mandated states to develop family-centered systems of care as part of their Title V MCH services block grants; Part H of the Individuals with Disabilities Education Act (IDEA, 1991), which is the reauthorization of P.L. 99-457; the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 101-496); and the Mental Health Amendments (P.L. 101-639).

Thus, in many ways, our understanding of family-centered care has increased immensely since the publication of the original monograph. As a result of this growth, many texts have picked up where *Big Red* left off (e.g., Bishop, Woll, & Arango, 1993; Dunst, Trivette, & Deal, 1988; Johnson, Jeppson, & Redburn, 1992). Such writings have taken up the charge of articulating more fully the family-centered philosophy. Most importantly, these efforts have begun to examine what truly constitutes family-centered care — to go beyond merely using the "words" in one's program description to weaving the "threads" of the philosophy into every fiber of the services. Efforts must continue and are invaluable to advancing this philosophy of care, not only for children needing specialized services and supports, but also throughout physical health, mental health, and developmental care in general, where systematic approaches beyond the medical/technical aspects are surely lacking.

Despite these publications, there still appears to be an important role for "*Bigger Red,*" this updated version of the original monograph. This monograph will continue to serve as a dictionary of terms, providing an initial introduction to family-centered care for individuals and agencies just beginning to consider a family-centered approach. In addition, it can serve as a benchmark against which to assess progress for services and providers that are working to become more family-centered. Because of this continuing need, the revision of the 1987 monograph was commissioned by MCHB through the work of the National Center for Family-Centered Care (NCFCC) at the Association for the Care of Children's Health (ACCH).

This revision is guided by several purposes. First, the original elements were re-examined for clarity and found to vary in their specificity and in their focus. Some elements were quite practical and easily operationalized; others were more abstract and philosophical. Because the elements alone are often published without accompanying explanations, it is important that the intent of each element be as clear as possible. So for clarity, some of the elements have been slightly reworded, but the intent of each remains the same.

Second, the order of the elements has also been revised. The updated elements again begin with the essential recognition of the family as the constant in a child's life. Then, each of the succeeding elements builds on the previous one, with communication being the strong thread that weaves the elements together. The second element, collaboration — the ultimate key to incorporating the central role of the family in family-centered care, is made possible by the third element, an exchange of information, which cannot be well-accomplished without the fourth element, recognition of family diversity. The fifth through seventh elements address recognizing, respecting, and providing for the diverse strengths and needs within and across families through appropriate, flexible, and accessible services and supports. Finally, the eighth element brings the process full circle, by remembering that families are families and children are children first and foremost, with strengths and concerns beyond their need for and participation in specialized services and supports.

Third, without lengthening the document considerably, attempts have been made to explain the elements as clearly as possible. However, while taking advantage of the advances that have been made in our understanding of family-centered care, we are also keeping the monograph's purpose as an introductory resource to family-centered care in the forefront.

Fourth, the program examples have been updated. These examples are by no means exhaustive (nor were those in the first edition). In addition, while certain programs may have been chosen to illustrate a particular element, the same programs may illustrate other elements as well. Using the paradigm developed by Dunst and colleagues (Dunst et al., 1991), attempts have been made to illustrate programs which most closely reflect the philosophy of family-centered care as distinct from family-focused, family-allied, or system-centered.

Finally, while it was believed that family-centered care was essential to quality care, there was little research to support these "gut" feelings (although most of us would readily acknowledge that such an approach would be preferable where our own loved ones are concerned). Since 1987, however, a number of informal program evaluations as well as more systematic studies of the benefits of family-centered care have been conducted. As a result, examples of studies and program evaluations providing empirical support for family-centered care are also included in this revision. While not as "revolutionary" in concept as nearly a decade ago, the philosophy of family-centered care is no less important. In fact, the progress that has been made and the research that has been conducted since the initial publication of this monograph highlight the "evolutionary" nature of the family-centered care approach.

Although each key element of family-centered care can be examined individually, it is the integration of all of the elements into a cohesive philosophy of care that makes the difference. When taken together, the elements of family-centered care result in policies and practices in which the pivotal role of the family is recognized and respected. Families are supported in their caregiving roles by building on their unique strengths as individuals and as families. Opportunities are created for families to make informed choices for their children, and more importantly, these choices are respected. Family-centered care results in policies and practices that promote normalized patterns of living. Family-centered care also results in policies and practices where family/professional partnerships are clearly evident.

Achieving family-centered care "is not a final destination, but a continual pursuit" (Edelman, 1990, p. 4). Our hope is that this updated edition of the monograph will help families and professionals meet the ongoing challenge for establishing "best practice," understanding that family-centered care is not just "doing things right," but rather, "the right thing to do."

The First Element

Incorporating into policy and practice the recognition that the family is the constant in a child's life, while the service systems and support personnel within those systems fluctuate.

Photo courtesy of Children's Memorial Hospital, Chicago. Photographer: Peter Kiar

The Family As The Constant

This first element represents the driving force behind family-centered care. Encompassed in this element are two critical aspects. The first relates to the word "family," and the diverse definition of the word. The second relates to the degree to which services are "centered" around the family members who play a pivotal role in the life and care of the child.

What Does This Mean?

The family-centered philosophy represents a significant change from typical neonatal, pediatric, and adolescent practice. In fact, some have likened it to the radical change in thinking that was the result of Copernicus' discovery centuries ago.

Listening to and understanding how the family defines itself is the first, and most critical, step to providing family-centered care. If we define a child's family in narrow terms based on stereotypes or our own limited experiences, on the "caseload" demographics of an agency, or even from research, then we have already jeopardized the possible achievement of family-centered services.

The *House Memorial 5 Task Force on Young Children and Families* (1990) in New Mexico suggests a definition of family that highlights the dimensions along which families may differ or share commonalities. More importantly, it is a definition that is both broad and flexible:

> *Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support . . . A family is a culture unto itself, with different values and unique ways of realizing its dreams; together, our families become the source of our rich cultural heritage and spiritual diversity . . . Our families create neighborhoods, communities, states, and nations (p.1).*

By creating opportunities that enable us to learn who is important in a child's life and why, we have the best chance of providing services that are family-centered. Such an approach also lays the groundwork for the other elements of family-centered care, and for truly honoring the diversity of families.

The second assumption requires an acknowledgment of the pivotal role that families play in the lives of their children:

> *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 (Select Panel for the Promotion of Child Health, 1981, p. 53).*

Because of this unique and critical role, the priorities and choices of the family must drive the delivery of services if they are to be family-centered.

The family-centered philosophy represents a significant change from typical neonatal, pediatric, and adolescent practice. In fact, some have likened it to the radical change in thinking that was the result of Copernicus' discovery centuries ago:

> *Copernicus came along and made a startling reversal — he put the sun in the center of the universe rather than the Earth . . . Let's pause to consider what would happen if we had a Copernican Revolution in the field of disability: The family is the center of the universe and the service delivery system is one of the many planets revolving around it . . . Such a revolution leads us to a new set of assumptions and a new vista of options for service (Turnbull & Summers, 1985).*

As Turnbull and Summers (1985) suggest, these assumptions are not merely a semantic exercise. Their point is well articulated by Dunst and others (Dunst, 1988; Dunst et al., 1991; Trivette, Dunst, Gordon, Hamby, & Starnes, 1993) who have identified a continuum of four models of service delivery in early intervention which have bearing on pediatric service delivery: professionally-centered, family-allied, family-focused, and family-centered. All four acknowledge a role for the family and use systems frameworks for understanding how the family influences and is influenced by events within its community and culture. However, the degree to which families have an active part or "drive" the services varies considerably across the four models. Additionally, a child-centered approach to care, in which the needs of the child are the driving force of service delivery, has been identified (e.g., Bailey, McWilliam, & Winton, 1992).

Models of Service Delivery

In *professionally-centered* or *system-centered* models, families are viewed as needing the help of professionals to function in a less dysfunctional manner. Interventions are planned and implemented by professionals, who are the experts, with families viewed as incapable of solving their own problems. The needs of, or benefits to, the agency drive the delivery of services. In *family-allied* models, families are given (by professionals) a more active role in their child's care, but as agents of the professionals. Families may be given the responsibility to implement interventions, but they have little role in articulating their choices, in designing how and when the services are to be delivered, or in evaluating their effectiveness.

In *family-focused* models, there is increased collaboration between parents and professionals. Families are viewed as consumers of services, but are generally viewed as needing professionals for advice and guidance. Professional networks of support may be more encouraged than existing or normative networks within the family or community. Family-allied and family-focused models, however, clearly represent an improvement over professionally-centered or system-centered models, or even child-centered services where the strengths and needs of only the child drive the service choices without input from the family.

In *family-centered* services, however, families are not just the consumers of services, t the ones who dictate practices as well:

> *That is, families' needs and desires determine all aspects of service delivery and resource provision. Professionals are seen as the agents and instruments of families, and intervene in ways that maximally promote family decision-making, capabilities, and competencies (Dunst et al., 1991, p. 118).*

In addition, while professional networks and supports are seen as helpful in family-centered care, efforts are focused on developing supports and resources for children and their families that are more likely to be continued once professional services end. They are also similar to supports that are more likely to be used by others in the family's community or culture. Family-centered care relies on true partnership, where family members and professionals are of mutual benefit to each other as integral members of the child's care team through the sharing of information from their unique perspectives.

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Family-centered care has also been compared to *child-centered* care (e.g., Bailey et al., 1992). However, Beckman and colleagues (in press) say that this is an unfortunate contrast, implying that the needs of the child are not consistent with the concerns of the family. While it is important to attend to the needs of the child, it is essential to remember that the child is an integral part of a family system. Most often, families incorporate the needs of the child within the context of the concerns and priorities of the family as a unit.

The differences between these models, though sometimes subtle, are powerful. Differences become evident in the assumptions about the importance of families in the lives of their children and about the inherent strengths of families. Differences are also evident in how families are perceived regarding their capability in making decisions about their children's care, in their use of professional versus community supports, in their choice of where and how services are delivered, and in their role in collaborating with service providers to provide their child's specialized care and support.

Families as Decision-Makers

Family-centered care means recognizing, respecting, and supporting the pivotal role that families play as decision-makers, caregivers, teachers, and advocates for their children. One way to do this is to respect and respond to the unique contributions that families make. Instead of viewing parents' input as "suspect" and "not objective," family-centered care practices view parental input as the cornerstone of quality in neonatal, pediatric, and adolescent services. Because families are the ones who see their child on a continuous basis, and in a variety of settings, through different developmental stages, they really are the "experts:"

Because families are the ones who see their child on a continuous basis, and in a variety of settings, through different developmental stages, they really are the "experts."

> *It is the parents [or family/caregivers] of a child who are the link among the specialists and the only people who see the child in all settings over time (Anderson, 1985, p.3).*

Their observations, recommendations, and choices must be taken seriously if pediatric care is to be family-centered. As a former director of state services noted:

> *Parents and families are the durable thread in the life of a . . . 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 (Freedman, 1986).*

Professional recommendations are not always developed based on the priorities and wishes of families. Also, professionals sometimes incorporate only part of a family's input, still not respecting the ultimate and continual responsibility they have for being the primary mediator in their child's health, developmental, social, and emotional needs. Without a full collaborative balance, service plans may be developed that place unrealistic expectations and demands on the family. Home care plans can become unmanageable and therefore cannot be implemented, and families may be thrust into roles that they do not choose.

Helen Featherstone illustrates this point in her book, *A Difference in the Family* (1980):

> *Although I tried to sound reasonable . . . this new demand appalled me . . . Jody, I thought* [is blind, and has cerebral palsy and mental retardation.] *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 else . . . Where is that 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 (pp. 77-80).*

If crucial choices must be made, family-centered care demands that the families make these choices. Family-centered care requires that professionals provide information and create opportunities for choices and options. Just as all families differ in the way they define themselves, so do they differ in their priorities for their children and in the roles they choose to play over time. 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." However, other mothers or fathers may not wish to be the "captain," instead wishing to be a team member incorporating a "professional captain." The true challenge of family-centered care is that we create options, and that we respect each family member's choices.

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Family-Centered Care for *All* Families

It is important to bear in mind that family-centered care is best practice for all families, as they provide a unique perspective to care, that encompasses the child's past, present, and future, within the family context. The greatest barrier to family-centered care is not a lack of services, or financial constraints, or even knowledge of the key elements of a family-centered approach. The greatest impediment to the practice is believing that family-centered care is only appropriate for certain families. Family-centered care is not a "privileged option," nor is it a "when convenient" service for families who are "easy to work with" or who have values consistent with those of the professionals.

Families who are struggling with extra stresses of life and their child's condition, who may not agree with the treatment recommendations, who have coping strategies that differ from professionals, or who have other traits that may be viewed as undesirable (e.g., substance abuse problems), should not be excluded from family-centered care simply because of these characteristics. Every child's family has the right to be listened to, to be informed, to be respected and supported in their strengths and concerns, and to be involved in their child's care.

> *Family-centered care does not mean that the 'family gets whatever the family wants, whenever the family wants it.' To do so would be an abdication of professional responsibility, and would be an inappropriate way out of comprehensive health care by those who don't truly understand the intent behind such care. Rather, this philosophy advocates that the family is the constant in a child's life, and therefore, the family should be central to decisions . . . whether simple or complex . . . made concerning the care of their child (Stepanek, 1994, p. 2).*

This first element really defines the *vision* of family-centered care: the family is the constant in a child's life, and therefore central to the child's care and decisions made concerning the care. As Peters and Austin (1985) noted, visions chart the course and are essential to success. They show where you are heading and why. While visions are not goals, they generate goals and can be empowering in and of themselves. Recognizing that the family is the constant nurturing factor in a child's life and that services must therefore be family-driven is the vision. The subsequent elements of family-centered care represent the goals to meet this vision of best practice.

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Making It A Reality

Recognizing and respecting the central role of the family in a child's life is the heart of family-centered care Incorporating this first element into policy and practice is then the essential core step to providing specialized health and developmental services that embody this philosophy. Since the inception of family-centered care as a formal and organized approach to services and supports in 1987, the number of programs and resources exemplifying the elements has spiraled tremendously. This section lists a few of the many programs and resources that illustrate how services and providers can reflect this best practice, integrating the diverse needs of children with the concerns and priorities of their families. These examples were chosen to represent programs and resources embracing the family-centered philosophy across various levels and settings of care.

Organizations

Association for the Care of Children's Health (ACCH)
Bethesda, MD

For nearly 30 years, the *Association for the Care of Children's Health (ACCH)* has been making a difference in health care for children and families through its leading role in promoting comprehensive services for children consistent with the principles of family-centered care. This international non-profit membership organization is a community of multidisciplinary professionals and family members working together to ensure that the unique needs of children and the central role of the family are not overshadowed by the inevitable issues relating to financing and to medical and technical advances in health care.

ACCH offers a multitude of publications and other media for and by families and professionals on topics that include: implementation of family-centered care in hospital, home, and community settings; psychosocial services; information and support for children, families, and staff, in a variety of hospital units/settings; early intervention and education; working and/or living with a child who is ill or has a disability; supports for children, families, and professionals; environment and design of pediatric facilities; and, creating resources for children, families, and professionals. The organization also hosts an annual conference and provides consultation on psychosocially sound, developmentally supportive, family-centered policies and programs exemplifying their motto: *Kids need more than medicine to get well.* **For more information, contact ACCH, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814 (PHN: 301/654-6549 or 1/800/808-ACCH; FAX: 301/986-4553).**

Family Voices
Algodones, NM

Family Voices is a grassroots organization of families and professionals speaking on behalf of children needing specialized health and developmental care. Working through voluntary State Coordinators throughout the U.S., this organization works to ensure that the needs of children who are ill or who have disabilities will be met in health care reform. *Family Voices* is based on the premise that all children deserve quality physical, mental, and developmental health care. The members of this large and growing group believe that families of children needing specialized services and the professionals who work with them have an expert understanding of the inadequacies of current health care systems, and direct experience with a set of tested principles and practices that can provide insight to significant improvements in the health status of all children and families. This organization has at least one volunteer Coordinator in each state who informs families and professionals about health care systems through meetings and monthly newsletters. The Coordinators and other representatives are included in health reform dialogues at local, state, and national levels. **For more information, contact P.O. Box 769, Algodones, NM 87001 (PHN: 505/867-2368; FAX: 505/867-6517).**

Federation for Children with Special Needs
Boston, MA

The *Federation for Children with Special Needs* is a parent-staffed organization representing children with disabilities. Organized in 1975, the Federation operates a Parent Center which offers a variety of services to families, family organizations, professionals, and others who are concerned with children needing specialized services and supports. Believing that families are experts when it comes to identifying their own children's needs, the Federation provides information, training, and support that may be needed to help families carry out the responsibilities associated with their children's needs.

Some of the projects and programs that have been developed across the years to reflect the diverse interests and concerns of families and the professionals who work with them include: the Parent Training and Information (PTI) Project, the Agent Orange Parent Network, the Parent/Professional Advocacy League (PAL), the Technical Assistance for Parent Programs (TAPP), the CAPP/National Parent Resource Center, MassCARE, and the parent component of the National Early Childhood Technical Assistance System (NEC*TAS). **For more information, contact the Federation for Children with Special Needs, 95 Berkeley Street, Suite 104, Boston, MA, 02116 (PHN: 617/482-2915).**

National Association of Children's Hospitals and Related Institutions (NACHRI)
Alexandria, VA

The *National Association of Children's Hospitals and Related Institutions* (NACHRI) is another organization recognizing that *"one size won't fit all"* in health care. The members of NACHRI believe that every child should receive health care through an "integrated child health network." Such networks should consist of multidisciplinary professionals who work with children and their families to provide expert and organized care and who are accountable to the public for children's health. This non-profit association is concerned with children's health care. Founded in 1968, NACHRI advocates for children in the public policy arena and maintains extensive data on children's health and medical centers across the U.S. **For more information, contact the National Association of Children's Hospitals and Related Institutions, 401 Wythe Street, Alexandria, VA 22314 (PHN: 703/684-1355; FAX: 703/684-1589).**

Programs, Policies, and Practices

Beach Center on Families and Disability
The University of Kansas, Lawrence, KS

The *Beach Center on Families and Disability* at The University of Kansas is an outstanding resource that provides training, technical assistance, and research with practical applications for supporting families and professionals. They also provide numerous publications, including a free quarterly newsletter funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education, Office of Special Education and Rehabilitative Services. Activities of the Beach Center support the essence of all the elements of family-centered care, with programs encouraging graduate students with disabilities, special educators, and other professionals to pursue doctoral studies in Family Studies and Disability. According to the co-directors, Ann and Rud Turnbull, the Beach Center aims to fulfill the commitment of its namesakes, Marianna and Ross Beach of Kansas, "to help others to be effective and achieve beyond their own expectations" through educating and informing families and professionals about the philosophy and best practice of family-centered care. **For more information, contact Beach Center on Families and Disability, The University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045 (PHN: 913/864-7600; FAX: 913/864-7605; Internet: BEACH@DOLE.LSI.UKANS.EDU).**

Rainbow Babies and Children's Hospital
University Hospital of Cleveland, Ohio

Rainbow Babies and Children's Hospital is "literally changing the culture" in which they deliver care to exemplify comprehensive family-centered services at all levels of care and in all departments throughout the hospital. According to Leslie Clark, Vice President of Nursing and Patient Care Services, staff members are "looking at [their] current practice, establishing new standards, envisioning the future, and creating systematic change." Integrally involved with ACCH for many years, various Rainbow Babies and Children's Hospital staff members have served on the organization's Board of Directors, Editorial Advisory Board, and Hospital Leadership Advisory Council. They also provided consultation on ACCH's 1994 Annual Conference for 1,200 family members and professionals. The hospital has also purchased and distributed dozens of copies of ACCH's publication detailing the guidelines for implementing comprehensive family-centered care in hospitals. As a result, departments are regularly developing new awarding-winning and nationally recognized programs responsive to the needs of the children and families they serve, such as:

- *The Prenatal Special Care Program* is an innovative support program for families anticipating the birth of a high risk infant. Designed to prepare families for their experience in the neonatal intensive care unit (NICU), the program includes a prenatal interview and visit, a NICU tour, a video about parenting in the NICU, and follow-up support as needed;

- *The All in the Family Room*, which brings families together in the hospital, aims to provide hospitalized children with a homelike environment which affords privacy, promotes normalcy, and incorporates all family members in their care and support. Individual families determine which members of their family will comprise the four members staying in the room each night, including supervised children. Put together on a shoestring budget, the program is a concept which involves a liberalized mind set, a focus on staff inservice education, and a respect for the diversity of families;

- *The Sibling Sitter Program* in the NICU has a hospital volunteer available at different times from week to week in the NICU Family Center to care for brothers and sisters of a child in the NICU while a parent is visiting; and,

- The *Professional/Assistant Partnerships: A Work Redesign* program that enhances family-centered care through effective utilization of human resources. An "assistant" permits a nurse to have greater availability and flexibility which facilitates collaboration with families in both general and acute care units. Care is negotiated among the family, the nurse, and the assistant based on the families' individual needs, strengths, and coping mechanisms. The goal is to maintain as much of their home routine as possible while in the hospital.

For more information, contact Rainbow Babies and Children's Hospital, 2974 Abingdon Road, Cleveland, OH 44106 (PHN: 216/844-1964).

Resources

Caring for Children and Families: Guidelines for Hospitals

B. Johnson, E. Jeppson, & L. Redburn (1992)

Caring for Children and Families: Guidelines for Hospitals, is a comprehensive guide discussing the process of change in hospitals committed to organizing and delivering pediatric health care in ways that support children and families. Each chapter in *Guidelines* contains resources to be reproduced and used for initiating, supporting, and evaluating family-centered policies and practices. Published by ACCH, this book helps hospitals: identify values and resources; evaluate strengths, needs, and priorities; develop a systematic plan for change; and, collaborate and network with others to achieve goals. *Guidelines* helps hospitals understand the subtleties of family-centered practice and the integral connections between such seemingly disparate areas as administration and governance, architecture and design, personnel policies, and family support. **For more information, contact ACCH, Publications Department, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814 (PHN: 1/800/808-ACCH, ext. 327, or, 301/654-6549, ext. 327; FAX: 301/986-4553).**

Delivering Family-Centered, Home-Based Services
Kennedy Krieger Institute (1991)

This videotape and facilitator's guide is helpful for educating both professionals and families in the principles and practices of family-centered care. Available through ACCH, the resource presents core principles for delivering family-centered, home-based services, and realistic situations for analysis. **For more information, contact ACCH, Publications Department, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814 (PHN: 1/800-808-ACCH, ext. 327 or 301/654-6549, ext. 327; FAX: 301/986-4553).**

Guidelines and Recommended Practice for the Individualized Family Service Plan, (Second Edition)
B. Johnson, M. McGonigel, & R. Kaufman (Eds., 1991)

Published by ACCH, this book presents a growing consensus about best practices for comprehensive family-centered early intervention services as required by Part H of the Individuals with Disabilities Education Act. It includes extensive samples, forms and procedures, and instruments that integrate federal rules and regulations with recommendations and guidelines for sound psychosocial practice. **For more information, contact ACCH, Publications Department, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814 (PHN: 1/800-808-ACCH, ext. 327, or, 301/654-6549, ext. 327; FAX: 301/986-4553).**

Taking Charge: A Parents' Guide to Health Care for Children with Special Needs
C. Takemoto, C. King, K. Maggio, & K. Granath (1993)

Published by the Parent Educational Advocacy Training Center (PEATC) and The Arc of Northern Virginia in 1993, *Taking Charge* is a resource that recognizes the demands on a family related to managing and coping with a child needing specialized physical or mental health care. This guide, written by a group of professional parents who have children with disabilities, provides much needed information for families about the unique and diverse needs of children needing specialized services and their families in an easy to use format. Included for reference are a glossary, a resource list, charts to help maintain a chronology of a child's specialized services, and an organized way to plan questions for care conferences or appointments with professionals. **For more information, contact PEATC, 10340 Democracy Lane, #206, Fairfax, VA 22030 (PHN: 703/691-7826).**

Working Toward a Balance in Our Lives: A Booklet for Families of Children with Disabilities and Special Health Care Needs
E. Barlow (Ed., 1993)

This small book, published by Project School Care at Children's Hospital in Boston, offers guidance for families transitioning from hospital care to home care. Covered topics include home nursing, respite care, financing health care, equipment, education, vocational training and planning for adulthood, and recreation and travel. The book contains a comprehensive listing of state public health agencies, federal and private resources, and suggested readings. **For more information, contact Judith Palfrey, Director, Project School Care, Children's Hospital, 300 Longwood Avenue, Boston, MA 02115 (PHN: 617/735-6714; FAX: 617/735-7940).**

Facilitating family/professional collaboration at all levels of hospital, home, and community care:

- care of an individual child;
- program development, implementation, evaluation, and evolution; and,
- policy formation.

Photo courtesy of Children's Medical Center of Dallas. Photographer: Skeeter Hagler

Family/Professional Collaboration

If the first element is the vision or heart of family-centered care, then collaboration between and among families and professionals is the spirit behind this movement. Not only does working together make sense, it is also a respectful way to humanize the delivery of health and developmental services, and it improves the outcomes for children needing specialized care and support. A commitment to collaboration in hospital-, community-, and home-based health and developmental care settings represents the only means to achieve the vision of family-centered care.

What Does This Mean?

For many years, in what was thought to be in the best interests of families, professionals provided the care, made the decisions, and controlled the flow of information to families. As Kathryn Barnard (1985) noted:

> *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 (p. 4).*

The relationships between families and professionals are slowly changing. This has been spurred in part by educational and early intervention mandates, such as P.L. 94-142 in the 1970s (Education for All Handicapped Act), and more recently in the amendments to this act, P.L. 99-457, in 1986 (now reauthorized as P.L. 102-119. the Individuals with Disabilities Education Act). This law mandates aspects of family/professional collaboration, as part of family-centered practices in intervention programs for very young children.

But finding what Lisbeth Vincent (1985) terms "equals in this partnership" (p. 40) is illusory. At the heart of the collaborative process is the relationship that is established between those seeking assistance and resources and those creating opportunities for the assistance and resources to be acquired. The nature of this relationship affects not only whether this "help" is actually viewed as helpful, but also whether parents and families are likely to have their expertise and essential role recognized, supported, and nurtured.

After reviewing the "help seeker/help giver" research of Brickman and others (1982, 1983; Karuza, Rabinowitz, & Brickman, 1982; Rabinowitz, Karuza, & Zevon, 1984), Dunst and colleagues (1988) concluded:

> *It is not just an issue of whether needs are met, but rather the manner in which mobilization of resources and support occurs that is a major determinant of enabling and empowering families (p.44).*

Moreover, this "manner" is determined by the degree to which a professional views parents and families as being responsible for their circumstances, as well as the degree to which they are viewed as responsible for or capable of acquiring the skills or resources to meet these challenges.

Models of interaction in which professionals are viewed as the only "experts" and the only ones capable of making decisions and solving problems result in lowered self-esteem, guilt, and dependence on the part of those seeking professional services. These types of interactions may in fact create barriers that discourage families from using valuable services. The "professional as expert" view may also result in temporary professional networks being used as opposed to an emphasis on more permanent, community-based networks of resources, services, and supports.

At the heart of the collaborative process, is the relationship that is established between those seeking assistance and resources, and those creating opportunities for the assistance and resources to be acquired.

In contrast, Dunst and colleagues (1988) have articulated a model for family-centered collaboration which they term an *enablement model*. In this model, those seeking assistance are not viewed as responsible for the conditions that led them to seek assistance or resources. Instead, they are viewed as responsible and capable of solutions. As a result, changes are more likely to be attributed to the individual and not to the professional, and positive coping abilities are reinforced.

The professional's role in this model is to create opportunities for necessary skills and resources to be acquired, or ones that exist to be used. Families are assumed to be competent, or at least capable of being so. Services are aimed at promoting growth and independence. The professional says in effect "How can I help you?" rather than "Do what I say," and mobilizes needed resources and supports until the family can determine and direct their own services (Brickman et al., 1982).

Implicit in this enablement model is the assumption that those providing help or assistance acknowledge the strengths of those seeking their help, and that help-givers assist families in seeing, developing, and using their capabilities

Implicit in this enablement model is the assumption that those providing help or assistance acknowledge the strengths of those seeking their help, and that help-givers assist families in seeing, developing, and using their capabilities:

> *This is all done in a cooperative, partnership approach that emphasizes joint responsibility between the help-seeker and help-giver. The goal is to make help-seekers better able to deal effectively with future problems, needs, and aspirations, not to make them problem- or trouble-free (Dunst et al., 1988, p. 44).*

Furthermore, this model relies on professionals acknowledging what they do or not know, and what can or cannot be predicted:

> *Admitting the limit of one's knowledge and skill is hard for everyone to do. Yet truth-telling. . . must be central to a professional's set of values. For children [needing complex health care], no one professional or parent has sufficient knowledge or skill to provide the best care. Instead, good care has to evolve out of different persons working together, each at the limits of their own knowledge and skill (Ireys, 1987).*

Benefits of Collaboration

To be family-centered, a collaborative partnership must be integrated into the decision-making process at all levels of health and developmental care. Whether they be decisions about the care of an individual child, about the design of programs or of broader service systems, or about the development of public policy, family/professional collaboration is the cornerstone of family-centered care for infants, children, adolescents, and their families.

That collaboration makes a difference at the individual care level has been well established in the field of early intervention (Shonkoff & Hauser-Cram, 1987). Empirical support for the effectiveness of collaboration exists within other service arenas as well. For example, in a study examining parental anxiety and discomfort in the pediatric intensive care unit, Curley (1988) reported that the development of collaborative relationships between nurses and families actually decreased parental anxiety.

Collaboration is an integral part of effective communication between professionals and parents, and likewise, open communication is essential to building trusting, collaborative relationships. A number of authors have pointed out that disproportionate power relationships tend to restrict the communication flow between members (e.g., Knafl, Breitmayer, Gallo, & Zoeller, 1992). Collaborative interviewing or goal setting as illustrated by Bailey (1987) and Dunst and his colleagues (Dunst et al., 1989) is associated with better family and child outcomes, jointly held perspectives, and a reduction of perceived role conflicts (Pomeranz, 1984).

Furthermore, a lack of collaboration can contribute to discrepant working relationships and destructive struggles for control. Robinson (1987) documented the importance of collaboration through a qualitative analysis of the experience of parents of children with chronic illness during their hospitalization. Problems arose in relationships because the families' frames of reference were oriented toward their experience with long-term illness, whereas the frames of reference of the professional health care providers in the hospital were oriented toward acute disease.

Parents cited this and other discrepancies related to their child's illness, goals, and family involvement as roadblocks to family-centered care. Parents also viewed themselves as experts on their own child and expected collegial relationships founded on negotiation and trust. When professionals did not respond with the same view, partnerships were impeded. Parents reported feeling that collaboration was often hampered by a lack of information, and that:

> *They could be involved if it did not interfere with professional care, and that they would be told what they needed to know. Of course, what health care professionals thought parents needed to know was often different than actual parental request (Robinson, 1987, p.190).*

Similar results are reported when professionals are interviewed. In one study, 25 pediatric nurses were interviewed and asked to select and describe relationships that they had with parents of hospitalized children that were either satisfying or dissatisfying. Qualities that differentiated satisfying from nonsatisfying relationships included communication patterns, issues of control, the lack of awareness of the impact of their own behavior in their relationships with parents, the lack of training in communication and family-centered care, and the degree to which the organizational structure of the hospital encouraged or discouraged family involvement in care (Brown & Ritchie, 1989).

Developing Partnerships

For collaboration to be a reality, there must be an understanding that families will vary in the degree of responsibility and control they wish or are able to exercise over time. Without communication though, it cannot be determined what is desired, what is practical, and who can take best responsibility for what actions. This may present a challenge for professionals, to adapt to the diversity of strengths and needs within and across families in caring for a child needing specialized care. However, this challenge can result in a more satisfying role for the professional who moves beyond the traditional role of dominance, and develops trusting bonds and partnerships with families.

Benefits of family/professional collaboration have been documented. For example, with regard to anesthesia induction, having parents participate results in children feeling more prepared and less anxious and in families reporting greater satisfaction with care (Hannallah, Abramowitz, Oh, & Ruttimann, 1984; Hannallah & Rosales, 1983; Schulman, Foley, Verson, & Allan, 1967; Smerling, Lieberman, & Rothstein, 1988; Vessey, Caserza & Bogetz, 1990).

Another example is in care-by-family units. In such units, family members adopt a more active formalized role, being trained to provide functions such as routine caretaking as well as more complicated medical procedures. These units have been associated with cost savings of 13.5 to 33 percent compared to traditional units (Evans & Robinson, 1983), as well as increased parent satisfaction (Caldwell & Lockhart, 1981), and positive ratings from third-year medical students (Lerner, Haley, Hall, & McVarish, 1972).

Family/professional collaboration is vitally important when planning and providing services. *"Parents* [and family members] *can and should be a part of the. . . health care-giving team, not bystanders"* (Kaufman, 1985, p. 3). However, while professionals may acknowledge the benefits of collaboration and shared decision-making, this partnership may not happen in practice (King, 1992). At times, family/professional discussions may be more *"to educate* [families] *about the complexities of the* [child's] *condition and to meet legal requirements rather than to engage them in meaningful decision-making"* (Rushton, 1994, p. 64).

Collaboration is essential beyond the care of an individual child. Family-centered policy formation, program development, implementation, evaluation, and evolution rely on collaborative efforts from both families and professionals. Opportunities for program and policy enhancement are created when both family members and professionals are encouraged to share their valuable insights and experiences. The results of collaborative program development and policy formation are more accessible and supportive services for families, that ultimately better meet the needs of the children being served.

Opportunities for program and policy enhancement are created when both family members and professionals are encouraged to share their valuable insights and experiences.

In 1992, the Collaboration Among Parents and Health Professionals (CAPP), a Project of the Federation for Children with Special Needs in Massachusetts, surveyed the Title V Children with Special Health Care Needs (CSHCN) programs in all 50 states and the District of Columbia as to the existence and benefits of family participation in program and policy development (Wells. Anderson, & Popper, 1993). One of the most frequently mentioned benefits of family/professional collaboration was improved planning and policies resulting in services more directly responsive to needs expressed by families.

Quality psychosocial care and family/professional partnerships should not be compromised in the name of cost-savings; in fact, they may lead to long-term cost-effectiveness in care.

The Institute for Family-Centered Care (1994) provides a checklist which can be used to evaluate progress toward incorporating family expertise in policy and program development in hospital-, home-, and community-based systems. The items on the self checklist include:

- Recognizing and respecting the expertise of families;
- Ensuring timely and regular feedback from families about policies, programs, and practices;
- Involving families in developing responses to this feedback;
- Hiring experienced family members as consultants and advisors;
- Making experienced family members available as a source of information and support for other families;
- Including family memberes as educators for staff orientation and inservice sessions;
- Creating opportunities for family members to share their expertise in ways consistent with their cultural practices and individual personalities;
- Compensating families for their time, expertise, and expenses;
- Ensuring that families participating as staff consultants. advisors, and teachers reflect the cultural diversity of the program's service area;
- Publicly acknowledging and rewarding family members for their contributions; and,
- Including family members on advisory boards, professional education committees, policy committees, planning committees, ethics committees, quality improvement committees, and other decision-making bodies.

We must open the door to collaboration — not just a crack, but widely, and without judgement.

While the goal of family/professional collaboration is becoming more of a reality in some hospital-based settings, it is essential that this same goal be extended into home-based and community-based care as well. Barriers to effective communication and collaboration may be even greater in these settings, where professionals may not have available as many resources or means of support to address the concerns of the family. It is also important to be aware of the impact of financial constraints as a potential barrier to collaboration. Quality psychosocial care and family/professional partnerships should not be compromised in the name of cost-savings; in fact, they may lead to long-term cost-effectiveness in care.

Opening the Door to Collaboration

Collaboration requires a common vision, and results from open and effective communication, which involves active listening. It also requires a common language, which is free from overly technical terminology and jargon. We must not only examine what we are saying, but also, how we are saying it. It should never be assumed that a family member comprehends what a professional is discussing with them. For many people, a nod of the head does not mean "yes, I understand," but rather, it is merely a reflexive response to a speaker. Questions should be asked by both professionals and family members; important concepts and information should be repeated in various ways; and the necessary time should be taken to ensure that all members of a child's health care team — family and professional members — understand the issues, concerns, and decisions relating to care, services, and supports.

Family-centered care is not something that can be done behind closed doors; it cannot become a reality with a room full of well-intentioned providers, nor only family members. Collaboration, as the spirit of family-centered care, can likewise never be achieved when there remains exclusion — of family members, of multidisciplinary professionals, or of other significant individuals with valuable input. We must open the door to collaboration — not just a crack, but widely, and without judgement.

Though different, the perspectives and expertise of both families and professionals are essential to quality care. Professionals can offer the expertise of their particular discipline and knowledge gained from working with many children and their families. Parents and families are the ones that know their child the best overall. They, alone, can examine the choices related to their child's care in the context of what will best promote the life goals and values they seek. By combining both perspectives, it is more likely that health and developmental services and supports will be designed and delivered in ways that are individually tailored to both the child's and family's strengths and desires.

Collaboration does not mean that differences will not exist or that everyone must come to the same conclusion about how and when and which services will be provided or used. Nor does it mean that all families and professionals, or each individual within a family or discipline, will have the same skills, abilities, or preferences. Rather, collaboration is a process whereby these differences can be discussed; where opinions, though differing, can be valued; and, where ultimately, the care will be better.

Personal style, clinical experience, education, families' unmet expectations or needs for information, lack of support for professionals collaborating with families, and a less than positive outcome for the child can all contribute to difficult interactions between families and professionals. Nevertheless, family-centered care can, and should, occur. Collaboration in care and decision-making may look different for different families and for different professionals, depending on the desire of the families to participate in care, on the skills and expertise of professionals, and on the child's specific needs. Differences between professionals' recommendations and families' decisions relating to a child's care can be a consequence of friction, but should not lead to a breakdown in communication:

> *Attempts to focus on solutions to the problems at hand — what can be done; how parent and professional can pool their energy and skill — may help to build a working relationship and move beyond the boundaries of dislike.*
>
> *Locking horns with [family members] is of little value. Honestly accepting the . . . distress and trying to understand . . . the pain may open gates to improved communication (Leff & Walizer, 1992, p. 246).*

Incorporating Collaboration Into Policy and Practice

How collaborative agreements are developed may vary, and achieving a comfortable partnership may not be easy for all families with all professionals. But nevertheless, family-centered care provides the primary basis for building the type of trusting relationship upon which quality health and developmental services and supports must be based, and it is best practice for all families:

As developmental pediatrician Robin Blitz reflected on a particularly challenging situation she encountered while caring for a young child with Down syndrome, she offered insight on the process of collaboration when the values of the family and the values of the professional differ:

> *Because of the mother's stated religious beliefs, the child did not have surgical correction of [a] congenital heart defect. Also, after the first set of immunizations resulted in a fever and fussiness, [the child] did not receive any further immunizations . . . and [therefore, could] not receive any early intervention services . . . Through all of this, the child's mother was not very compliant with most of the medical profession. However, she was always compliant with [our] High Risk Infant program, and we had a certain rapport. This little [child] recently died of heart failure, and [although I had advocated for the corrective surgery], I was the one professional the mother notified.*
>
> *Perhaps because our program strived to be family-centered by recognizing and respecting cultural and religious differences; perhaps because we researched [the child's] caloric needs in accordance*

. . . collaboration is a process whereby these differences can be discussed; where opinions, though differing, can be valued; and, where ultimately, the care will be better.

. . . family-centered care provides the primary basis for building the type of trusting relationship upon which quality health and developmental services and supports must be based, and it is best practice for all families.

> *with [the] mother's religious and vegetarian diet; perhaps because we frequently spoke of [the child's] strengths, is why [the] mother felt more comfortable with us as professionals. Most importantly, we — myself, the High Risk Infant program, and [the child's] mother — all had the child's well-being as a priority, but with different definitions of 'well-being.' Striving to be 'family-centered' and collaborate with a family means not judging a family's values. It means working with a family within the family system, and it sometimes means accepting situations that are out of context with one's own value system, being non-judgmental, and working towards a common goal (Blitz, personal communication, July 27, 1994).*

Professionals who embrace and practice the philosophy of family-centered care will more than likely face a paradox in which their values and preferences are discordant with those of the family. Yet through collaboration, these professionals can still help the family to make difficult decisions with the ultimate shared goal of doing what is in the best interest of the child within the family context. According to Karen Lawrence, Director of the National Center for Family-Centered Care:

> *Perhaps, some professionals can take comfort in the recognition that had the family been coerced into consent or other decisions that compromised their lifestyles and values, their strength and solidarity which the professionals have strived to enhance would have suffered. As a professional, of course in many cases I want to have families make the decisions I would make, and this confirms my knowledge. [However,] I am reaffirmed also when a family makes a different decision than I would make, but we continue to collaborate and respect each other's position (personal communication, April 28, 1994).*

Making It a Reality

Children, families, and professionals all benefit from true collaboration at all levels of service delivery and evaluation. Collaboration should exist between and among families, professionals, and service systems. Family-centered care rests on the assumption that families are involved not just with the immediate care of their child, but also with the ongoing development and improvement of hospital-, home-, and community-based policies, practices, and programs that meet the short- and long-term needs of children and families. The examples listed in this section represent programs and resources illustrating family/professional collaboration in a variety of service settings.

Programs, Policies, and Practices

ENable Program

Learner Managed Designs, Inc., Lawrence, KS

The *ENable Program* is a curriculum developed to guide primary health care providers, particularly those who must share painful information with families of children with severe disabilities. This training resource helps health care teams communicate with parents and family members during the time when an acute or chronic diagnosis is being made. The program materials, which include a concise and informative video, provide a necessary service in health care instruction. **For more**

information, contact Learner Managed Designs, Inc., 2201 K West 25th Street, Lawrence, KS 66047 (PHN: 913/842-9088).

The Family Advocacy Committee
Johns Hopkins Children's Center, Baltimore, MD

The Family Advocacy Committee at the Johns Hopkins Children's Center was created to be an advisory group for the Chair of Pediatrics and other administrative staff and departments. The purposes of the Committee are: to advocate for improvements in organization and communication between and among families and professionals to facilitate better outcomes for children and their families; to work in partnership with administrative staff in areas of program development and facilities planning, policies, and services; to develop strategies that encourage and facilitate family-to-family support and networking; to work with staff to make education and orientation of staff and students more inclusive of families; and, to identify and address families' concerns and needs for information about resources and processes.

Membership of the Committee is composed of up to 15 parents of children whose health care experiences represent the diverse needs and services provided in the Children's Center. Non-voting members of the Committee include a physician who has clinical responsibilities, a nurse, a member of the child life or social work staff, and an administrative person (the Coordinator of Family-Centered Care). The Committee plans goals and activities aimed to meet informational and networking needs of children and families, and reports directly to the Chairman and Deputy Chairman of Pediatrics. **For more information, contact Pat A. Johnson, Family-Centered Care Coordinator, Johns Hopkins Children's Center, Department of Pediatrics, 600 North Wolfe Street, CMSC 2-125, Baltimore, MD 21287 (PHN: 410/614-1548; FAX: 410/955-0761).**

Family-Centered Care Program
Memorial Miller Children's Hospital
Long Beach Memorial Medical Center, Long Beach, CA

In 1990, Memorial Miller Children's Hospital formally developed their *Family-Centered Care Program* which has produced anticipated improvements in satisfaction reflected in surveys of families, professionals, and other staff members throughout the hospital. The need for the program was approached as a concern by the Parent Advisory Board at the hospital (now a component of the Family-Centered Care Program), to address issues faced by patients and families, particularly families of children with chronic illnesses or frequent admissions. By improving communication and collaboration between families and staff in workplaces such as administration, admitting, billing, and accounts receivable systems, the hospital has been able to address concerns such as streamlining the billing of frequently admitted patients.

The Family-Centered Care Coordinator, now a full-time staff member, reports directly to the vice president of the hospital. The primary purpose of the coordinator and of the program is to serve as a resource to both families and staff, to help them develop good family relations through collaboration. The program also encompasses a family resource library, a sibling care program providing activities for brothers and sisters of patients while parents are visiting, a hospital grandparent program providing volunteer social and emotional support for the children, a parent advisory board, and a children's advisory board composed of former patients. **For more information, contact Linda E. Williams, Family-Centered Care Coordinator, Memorial Miller Children's Hospital, Long Beach Memorial Medical Center, 2801 Atlantic Avenue, Long Beach, CA 90801 (PHN: 310/933-2331; FAX: 310/933-3440).**

Family Participation in Resuscitation

Fort Foote Hospital, Jackson, MI

More than ten years ago, Fort Foote Hospital in Jackson, Michigan began a family-centered program of planned participation of family members in the resuscitation of their loved ones. "Participation" means that the family becomes part of the team by providing support to the patient during the periods that they are present in the resuscitation room. The program has evolved from fears expressed by some staff members (of uncontrollable grief by family members or emotions by the professional team) to acceptance by both staff and community and has been very successful in both pediatric and adult situations. **For more information, contact Cheryl Hanson, Emergency Department, Fort Foote Hospital, 1266 E. Southfield, Jackson, MI 49203 (PHN: 517/788-4811).**

Guiding Appropriate Pediatric Services (GAPS)
The Pediatric Family Service Plan

Worcester, MA

Funded by the U.S. Maternal and Child Health Bureau, the GAPS project is designed to operationalize the elements of family-centered care in primary pediatric care settings. To facilitate collaboration between families and professionals, the *Pediatric Family Service Plan (PFSP)* was developed. Modeled after the Individualized Family Service Plan mandated in early intervention laws, the PFSP is developed between families and primary care pediatricians, based on information provided by the parents, pediatricians, subspecialists, and in some cases, the child. The plan includes short- and long-term goals for the child as prioritized by the family — the individuals responsible for carrying out those goals. **For more information, contact Ellen Perrin, Project Director, or Janet Stanton, Project Coordinator, GAPS, Department of Pediatrics, University of Massachusetts Medical Center, 55 Lake Avenue North, Worcester, MA 01655 (PHN: 508/856-6295).**

The Medical Education Project at the University of Vermont

Parent-to-Parent of Vermont, Winoski, VT

A growing area for family/professional collaboration is in medical education. Professionals involved in preservice and inservice physician training are recognizing the need for a "fundamental reordering" of education to include parents as partners in training professionals to work with children and families. The *Medical Education Project* is designed to improve medical students' knowledge and perceptions of children needing specialized care and their families as part of a required course during the pediatric rotation of the third year at medical school.

Family members from the Parent-to-Parent of Vermont organization involved in the curriculum development offer an "inside look" at the perspectives of families, and serve as volunteers for home visits. During the home visits, students have an opportunity to observe a child participating in typical family routines, and an opportunity to talk with family members about some of the positive and negative experiences that can result from having a child who needs specialized services. Qualitative and quantitative evaluations of the program indicate a positive shift in students'attitudes towards children with disabilities and their families, and confirm the value of informal, experiential interactions between students and families. **For more information, contact Parent-to-Parent of Vermont, 1 Main Street, Champlain Mill, Winoski, VT 05404 (PHN: 802/655-5290).**

National Center for Youth with Disabilities
University of Minnesota, Minneapolis, MN

The *National Center for Youth with Disabilities,* a collaborative project of the Society for Adolescent Medicine and the Adolescent Health Program at the University of Minnesota, is supported by an Maternal and Child Health Bureaugrant. The mission of the organization is: to raise awareness of the needs of youth with disabilities; to foster coordination and collaboration among agencies, professionals, families, and youth in planning and providing services; and, to provide technical assistance, publications, and consultation about family-centered care and collaboration. **For more information, contact NCYD, Box 721, 420 Delaware Street, SE, Minneapolis, MN 55455 (PHN: 612/626-2825, 800/333-6293).**

The School of Medicine, Department of Pediatrics
The University of New Mexico, Albuquerque, NM

The *Department of Pediatrics*, an affiliated program at The University of New Mexico, has developed an excellent care conference model. The model illustrates how families and service providers can work in collaboration, and offers guidelines for facilitating care conferences, strategies to enhance communication between families and professionals, and tips for family members. Materials and information about the program are available in both Spanish and English. **For more information, contact Catherine McClain, The School of Medicine, Department of Pediatrics at The University of New Mexico, Albuquerque, NM 87131 (PHN: 505/272-5551).**

When Home is the Hospital: Collaborative Care for the Chronically Hospitalized Child
The Children's Hospital of Alabama, Birmingham, AL

When Home is the Hospital is a program that encourages family-centered care for children in acute care or transitional care facilities whose families are not present for any number of reasons. It offers guidelines for staff members from all disciplines to take on the roles of advocate, caregiver, disciplinarian, and gatekeeper for children who are medically ready for discharge, but reside in acute or transitional care settings. The guidelines address issues such as continuity of care, primary care, preventive health maintenance, routine orders, outings off the hospital unit or out of the facility, daily care and teaching, personal grooming, free play, common goals across therapists, and behavior and discipline. They also address special considerations, such as volunteer male role models for male toddlers, space for personal belongings, a system for washing clothes, scrapbooks to record personal history, keeping in touch with the family, and plans for education through the public school system. **For more information, contact Claire Lenker, Medical Social Worker, The Children's Hospital of Alabama, Suite ACC-620, 1600 7th Avenue South, Birmingham, AL 35233 (PHN: 205/939-9583).**

Resources

Building the Healing Partnership: Parents, Professionals, & Children with Chronic Illnesses and Disabilities
P. Leff & E. Walizer (1992)

Building the Healing Partnership sensitively portrays the concerns of both parents and professionals dealing with children who are chronically or acutely ill. It weaves together brief vignettes and personal experience to provide practical, specific approaches and recommendations for both parents and professionals. **Available through ACCH, this book is published by Brookline Books, Cambridge, MA.**

Families, Disability, and Empowerment: Active Coping Skills for Family Interventions
G. Singer & L. Powers (1993)

Families, Disability, and Empowerment is a comprehensive resource that gathers expertise from individuals involved in social work, health care, early intervention, family-to-family programs, counseling, and education to present strategies for building strong partnerships between service providers and the families of individuals with disabilities. These support strategies equip professionals to empower families, as well as enable families to empower themselves. The book discusses difficult family issues and challenges that practitioners face daily, and offers specific strategies for assertive, yet sensitive, communication and collaboration to solve problems. **Published by Brookes Publishing Company, Baltimore, MD.**

Families in Program and Policy
N. Wells, B. Anderson, B. Popper, & the Collaboration Among
Parents and Professionals (CAPP) National Resource Center (1993)

Families in Program and Policy summarizes the results of a 1992 survey of family participation in State Title V programs for children needing specialized health care throughout the United States. The monograph analyzes the reported types and amounts of participation by family members in Title V programs, such as membership on committees or task forces, involvement in inservice training for professionals, or participation in the Title V Block Grant process. The types of support provided to family networks and organizations, the addition of family members as staff or consultants for programs, input sought from adults with disabilities, and the efforts of Title V programs to include underrepresented and underserved populations are also detailed. **This report is available through the National Maternal and Child Health Clearinghouse, 8201 Greensboro Drive, McLean, VA 22102 (PHN: 703/821-8955, ext. 254/265; FAX: 703/821-2098).**

Family/Professional Collaboration for Children with Special Health Needs and Their Families
K. Bishop, J. Woll, & P. Arango (1993)

This monograph "celebrates more than ten years of dialogue, debates, and collective thinking between many parents, family members, and professionals," that led to the development of a comprehensive guide detailing the principles of family/professional collaboration. The text details each of the established seven elements of collaboration, and addresses the behaviors, beliefs, attitudes, and values that must be present in a collaborative relationship. The authors state that this monograph "represents a conscious struggle with language and ideas to represent the shift in thinking required to collaborate . . . In no way do we believe these words represent the final description of collaboration, but we hope it is a good beginning." **Available through ACCH, this resource was published by the Family/Professional Collaboration Project, Department of Social Work, University of Vermont, 499B Waterman Building, Burlington, VT 05405 (PHN: 802/656-8800).**

Exchanging complete and unbiased information between families and professionals in a supportive manner at all times.

Photo courtesy of St. Mary's Hospital Medical Center, Madison, WI. Photographer: Bruce Fritz

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Chapter Three

Exchanging Information

Effective communication, a thread that weaves together all of the elements, is essential to the family-centered process and to the third element of family-centered care — an unbiased and ongoing exchange of information between and among families and professionals. True collaboration demands that families and the professionals they work with openly exchange information, ideas, and concerns. This type of communication is the cornerstone of quality health and developmental services and supports for children and their families.

What Does This Mean?

. . . while professionals generally achieved the legal requirement for informed consent, few, if any, engaged in meaningful and collaborative decision-making with the families involved.

When families of children needing specialized care are asked what they want most from physicians and other professionals, their answers are consistent: information and communication. Surprisingly, medical competence is seldom mentioned in the "most important" category. Perhaps this knowledge base is assumed, and parents thus wish for those qualities that enhance the application of scientific knowledge and technical skill. When experienced physician educators are asked about the skills and abilities needed to provide family-centered care, they answer similarly. While the essential core knowledge of child development, diagnoses, and treatments are important, this group recognizes that attitudes and behaviors determine how well the knowledge will enhance the quality of care. Both groups agree that the ability to elicit and communicate information in a supportive manner is critical to the family-centered care process.

Information and Decision-Making

Nowhere is communication more important than in the decision-making process concerning an individual child's need for specialized health or developmental services. In family-centered care, decisions are shared between families and professionals. The process involves professional expertise, but it also involves the "expertise" of the family regarding what choices are consistent with their life circumstances and goals and the values they have and aspirations for their child. As King (1992) noted, this process should go far beyond the legal requirement for informed consent. Rather, the goal should be to fully engage families in the process of decision-making to ensure that they understand the range of possibilities for treatment and its consequences. Equally important is the opportunity for families to share information, goals, values, and aspirations with professionals.

In a recent study examining the decision-making process among professionals and families who have an infant with a life-threatening condition, Rushton (1994) reported that while professionals generally achieved the legal requirement for informed consent, few, if any, engaged in meaningful and collaborative decision-making with the families involved. Although information was provided to families, the goal appears to have been more to educate families about the infant's condition and to meet legal requirements than to have true collaboration in the decision-making.

Collaboration can be particularly difficult to achieve in settings where the choices are limited. However, the way in which options are presented or framed seems to be a critical factor in determining whether families perceive the process as collaborative or not. As stated by a parent in The National Center for Family-Centered Care's program brochure:

> *We hold the most complete understanding of (our) child's past, present, and future. To make decisions, we need complete and unbiased information about our child's care — from bathing and playing to therapy and treatment. Lack of understanding and experience leads to anxiety, which interferes with collaboration on*

important issues. Professionals should not be hesitant of our knowledge, our need to be involved, or our right to decision-making. Family empowerment through ongoing support, sharing of information, and involvement in care, builds mutual trust, and makes the philosophy of family-centered care a reality (Stepanek, 1993).

Effective communication does not necessarily require inordinate amounts of time. In fact, skillful time spent in mutual collaboration is a prevention strategy, as it is more likely to lead to satisfactory results for all concerned. It builds partnerships through cooperative definitions of the challenges to be solved and the strategies and commitments required. And when it is successful, the satisfaction from mutual problem solving is a powerful antidote to both parent and professional burnout (Beckman & Boyes, 1993).

Barriers to Information Exchange

In speaking about his experiences as the father of Josh, a child born with a rare metabolic disorder, Charlie Alfero (1987) comments that families want two things from professionals — information and respect. It is only through ongoing and shared communication that these goals can be achieved. Professionals hope to honor the family's individuality, diversity, and values. How information is provided, how information is obtained, and the ultimate decisions that are made are affected by a family's culture, previous life experiences, and general philosophy of life (Pueschel, 1986). Therefore, it is imperative that the sharing of information be a "two way street."

Families need as much information, knowledge, and understanding as possible about their child's condition, treatments, probable outcomes, and overall prognosis to make decisions (Zaner & Bliton, 1991). For many reasons, however, including attempts to protect families' feelings, information often is cloaked in half-truths or colored by euphemisms that inaccurately depict the child's condition in the context of overall development.

In some instances, professionals may share too little information. In others, professionals may give too much, or give information in a way that is not very useful. Because the information is not about just any child, but about their child, the ramifications of each statement, prediction, silence, or facial expression take on greater importance for families. Information, particularly upsetting information, can be difficult for anyone to absorb fully. A family-centered approach facilitates an atmosphere where ideas can be exchanged between families and professionals, and where the amount of information and manner in which the child and family wishes to receive the information can be understood.

Sometimes professionals feel they must resort to "mind reading" to provide the right amount of information. Not only is this not necessary, it is dangerous and defeats the collaborative process. As one professional commented *"Never assume you know what's going on with a family. Ask. Listen"* (Stanton, 1991). Likewise, families should never assume that professionals know of their strengths, needs, nor their concerns and priorities for their children. An exchange of information is essential to the collaborative team process, and to the collaborative decision-making that best meets the child's needs.

Sometimes professionals feel they must resort to "mind reading" to provide the right amount of information. Not only is this not necessary, it is dangerous and defeats the collaborative process.

Benefits of Information

Effective communication and information exchange is critical for families to be able to access services. 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. According to Rubin and Quinn-Curran (1983), parents need to identify their needs (e.g., someone else to take over for awhile so they can get some rest). They need to translate their needs into the proper service label (e.g., respite care), and they need to efficiently and effectively contact and communicate with 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.

Developing ways to help families share information is one way to ensure that services are delivered in a coordinated, flexible, accessible, and competent manner. A physician in the Picker/Commonwealth Study Group commented that:

> *One of the fascinating paradoxes of medicine is that if you look at most service industries, they learned long ago to go to the customer to find out what's going on. Medicine has been extraordinarily slow to do that (Delbanco, 1992, p. 2).*

Developing ways to help families share information is one way to ensure that services are delivered in a coordinated, flexible, accessible, and competent manner.

In an attempt to remedy this, Delbanco, along with a team of researchers at Beth Israel, Harvard Medical School, and the Massachusetts Department of Public Health, developed a survey examining the key elements of patient-centered care. Although applied to adult health care, there are striking parallels to the elements of family-centered care. In the 1989 survey of almost 6,500 adult medical and surgical patients, satisfaction with care was directly related to the quality of information and patient education received. Difficulties that were noted included: not being told about daily routines; not being told whom to ask for help; not getting understandable answers from doctors and nurses; and, not being given enough privacy while receiving important information (Cleary et al., 1991).

Literature provides additional empirical support for the importance of effective communication. Several studies have reported that effective communication between parents and professionals results in reduced levels of upset among parents and children and is linked to greater satisfaction with care. For example, in a study of parents with children who had genetic disorders, parents cited information as one of their greatest needs and attributed much of their anxiety from not knowing the truth about their child's condition (Darling, 1977). In a more recent study of the dynamics of parent and health care provider communication in the intensive care nursery, parental anxiety was identified as a result of a lack of information. Parents noted that information that was honest, constructive, related to follow-up resources, and provided in lay person's terms was necessary for them to participate effectively in the decision-making process (Able-Boone, Dockeki, & Smith, 1989).

In another study, Diehl, Moffit, and Wade (1991) examined the perceptions of parents of children needing complex medical care and found that satisfaction with care was directly associated with the provision of adequate information about home care and planning for the future. Dissatisfaction resulted from the need to be constantly vigilant and assertive to get the information and services they needed.

Providing information and eliciting and listening to families' priorities also has a direct influence on the child's ability to cope. After reviewing nearly 2,000 sources, Schwenk and Hughes (1983) concluded that the way in which a family perceives an illness or accident (e.g., the way that the family's beliefs and cultural history affect their interpretation of a stressful event) was directly related to the eventual level of family stability and child and family coping. Furthermore, effective communication related to preparing families to care for their children facilitates effective long-term coping for both the child and the family (Robinson, 1987).

Types of Information Needed by Families

Information regarding a child's condition needs to be balanced with how an individual child and family responds. Some families may understand information regarding their child's diagnosis and care very quickly. Other families may need to hear the same information repeatedly or presented in a variety of ways. Families need information that will allow them to adapt the overall care plan to the child's individuality and to family needs and choices. As a result, professionals must collaboratively exchange and elicit information about both the child and the family.

Asking what information families want and need is a good place to start. In addition, there are general categories of information that are likely to be helpful for most families. These include:

- Information about diagnosis;
- Information about treatment options and probable outcomes;
- Information in the child's medical records; and,
- Information about community resource referrals.

How Information is Exchanged

The location and events surrounding communication say as much as the actual information provided. For example, standing at the door with hand on the handle doesn't communicate that someone is eager to listen. Several aspects of communication have been cited as critical to the sharing of information. Listening is one of the most essential skills. Professionals are taught to ask, assess, prescribe, and do or fix. However, professionals who fail to listen risk proceeding from an incomplete knowledge base. The diagnosis may be correct, but essential information about the child and the family's concerns and priorities may be missing. The absence of this information can negate the professionals' competence to collaborate with and help the child and family. As a result, both professionals and families experience disappointment over such failures to communicate productively.

To be useful, the information must be up to date, complete, and unbiased. Multiple sources should be considered as well, including medical and lay literature and community resources provided through a family resource library. Also important is the information that can be provided by other families who have had to make similar decisions. Using these strategies can result in a more complete and balanced base from which families can make more informed decisions.

Common courtesy helps. This includes returning phone calls, acknowledging written correspondence, listening to people, and treating people with respect. Communication should be clear so everyone knows what is happening and can explain the process to others outside the collaborative process.

The ability to ask open-ended questions, to encourage discussion of psychosocial issues, to speak in plain language, and to elicit the child's and family's hopes, dreams, concerns, and priorities are also critical to the information exchange process. Asking the family for feedback about their satisfaction with care and making all records and information readily available to families are other ways to facilitate effective communication. Questions such as the following may help:

- How are things going;
- Has anything different or unusual happened to you, your child, or your family since the last visit;
- Is there anything else you need to know;
- Is there anything else we need to know;
- Do you have all the information you want about your child's clinical status, test results, and treatment options;
- Do you have all the information you want about hospital, home, and community resources;
- Do you have the information you need to manage on your own to the extent that you wish and are able to do so;
- What needs to be changed;
- What needs to be maintained; and,
- Who or what is helpful?

Other strategies are also helpful. These include:

- Schedule additional time for discussion when it is not possible to talk at the moment;
- Use understandable language but explain the jargon as well, as it will enable the family to communicate effectively with other professionals and agencies;
- Develop fact sheets with information about diagnoses, family-to-family support networks, and community resources;
- Establish a call back time and/or call-in time; and,
- Schedule conferences when there is adequate time, in a quiet place that provides privacy, and when key family members and professionals can all be present.

When exchanging information in a family-centered manner, it is important to accommodate both family members and professionals so that information from all valuable perspectives can be shared and the child's needs can be best met. It is also important to balance an unbiased exchange of information between and among families and professionals with the maintenance of confidentiality. Irrelevant information, particularly statements that can lead to inappropriate and preconceived negative or value judgements about a child or family can be detrimental to the collaborative process, and

The ability to ask open-ended questions, to encourage discussion of psychosocial issues, to speak in plain language, and to elicit the child's and family's hopes, dreams, concerns, and priorities are also critical to the information exchange process.

therefore, to the decision-making process regarding the care of a child. Collaboration is not competition for information or participation. If the ultimate goal is collaboration and family-centered care, there can be no exclusions when exchanging information — no exclusion of professionals across disciplines or of the child and family. There can be no exclusions when exchanging information about a child's need for specialized services and supports or of professionals across disciplines or of the child's family members.

Making It a Reality

The exchange of information between families and professionals can be facilitated in a number of ways. Verbal communication can take place through personal contact, such as individual or group conferences, or meetings, workshops, and seminars. Written communication can be made available through open medical records that reflect input from all members of a child's health care team, including parents and multidisciplinary professionals. Fact sheets, brochures, and other written resources are also helpful.

Family resource libraries, as well as public and other private libraries, can offer a great wealth of information for both families and professionals on topics ranging from specific diagnoses, to legal and financial concerns, to implementation of psychosocial care and family support. Audio and video resources can also provide valuable information in these areas. As families and professionals become aware of information about local and national resources (e.g., newsletters, information clearing-houses, and phone networks), they should share this with each other, so that other families and professionals can also benefit. This section identifies a few of the immense number of programs and resources that illustrate a collaborative exchange of information, as well as examples of the vast wealth of information available about disabilities (general or specific) across a variety of settings.

Organizations

National Organization for Rare Disorders, Inc. (NORD)
New Fairfield, CT

The *National Organization for Rare Disorders, Inc.* provides information, help, and hope to families and professionals seeking knowledge about rare diagnoses. NORD's Rare Disease Database can be accessed through Compuserve or at many drug stores or hospital waiting areas. NORD also links families with other families with the same disorder through its Networking Program, and sponsors a Medication Assistance Program for financially stressed individuals needing life-saving medicines. NORD publishes a newsletter and other resources for families and professionals, and sponsors an annual Patient/Family Conference. **For more information, contact NORD, P.O. Box 8923, New Fairfield, CT 06812 (PHN: 203/746-6518; FAX: 203/746-6481).**

National Pediatric Trauma Registry (NPTR)
Research and Training Center in Rehabilitation and Childhood Trauma, Boston, MA

Founded in 1985, the *National Pediatric Trauma Registry* has information on more than 28,000 children with traumatic injuries who were hospitalized at one of 61 specialized pediatric units across the United States. The organization primarily answers questions from policy planners and advocacy organizers related to specific serious injuries. Fact sheets, written to emphasize critical information in a simple, accurate form, have been developed to respond to the most commonly requested information. Goals of the NPTR include evaluating the effectiveness of the medical care provided to children and understanding the needs of children for rehabilitation services. **For more information, contact Publications, Research and Training Center in Rehabilitation and Childhood Trauma, 750 Washington Street, #75K-R, Boston, MA 02111 (PHN: 617/956-5036).**

Parent Training and Information (PTI) Centers
Office of Special Education and Rehabilitative Services (OSERS)
U.S. Department of Education, Washington, DC

Designed to provide training and information to families about special education laws and services for children needing specialized care and support, *Parent Training and Information Centers* receive technical assistance from Technical Assistance Parent Programs (TAPP). All states, as well as the District of Columbia, Palau, and Puerto Rico, now have PTI funding through OSERS. **For information regarding any of these programs, contact the 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 (PHN: 202/732-1032).**

Programs, Policies, and Practices

Child Life Services
Children's Hospital of Vanderbilt University Medical Center, Nashville, TN

The *Child Life Services Department* at the Children's Hospital of Vanderbilt University Medical Center provides inservice training for staff members across all disciplines on the developmental and psychosocial needs of children and families. Child Life is a professional service designed to help children and their families through specific programming on various age levels. The program aims to promote typical growth and development, minimize stress and anxiety associated with hospitalization, provide opportunities to help children enhance their self-esteem and retain appropriate independence, advocate for non-medical needs of children and families, increase families' understanding of hospital experiences, and encourage family-centered care. **For more information, contact Child Life Services, Children's Hospital of Vanderbilt University Medical Center, D-2120 MCN, Nashville, TN 37232 (PHN: 615/322-0358).**

Introduction to Hospitals: School Outreach Program

Sutter Children's Center at Sutter Memorial Hospital, Sacramento, CA

Introduction to Hospitals is a program that visits Head Start programs on a weekly basis through the Sutter Children's Center at Sutter Memorial Hospital. For preschool, kindergarten, and first-grade students, there is an upbeat hands-on discussion using a doll, real medical equipment, and large pictures. Children review what they have learned about health care and hospitals by creating a medical collage art activity. For elementary students (grades two through six), the program presents an interactive slide show with role playing, real medical equipment, and lively discussions during which students make finger casts and use stethoscopes. Students in grades five and six also focus on careers in health care. Once each month, the program is taken into homeless shelters. **For more information, contact the School Outreach Program, 5151 F Street, Sacramento, CA 95819 (PHN: 916/451-KIDS).**

The National Information Clearinghouse for Infants with Disabilities and Life-Threatening Conditions (NIC)

Center for Developmental Disabilities, Columbia, SC, and
Association for the Care of Children's Health, Bethesda, MD

The *NIC* is a national information and referral system that provides free assistance to meet the informational needs of family and professional caregivers, and to protect the rights of infants with disabilities and life-threatening conditions. When an individual calls the NIC, an Information Specialist discusses the situation to determine the service needs. The Specialist then searches the database and other information and services to make a referral to local and/or national resources.

The NIC responds to questions about parent support and training, early intervention resources, community and financial resources, disability resources, adoption and advocacy agencies, and other information. The NIC also provides education, technical assistance, fact sheets, and bibliographies on topics including: disability terminology, language, and acronyms; ethics; Infant Care Review Committees; Child Abuse Amendments; family involvement in the decision-making process; and, the impact of culture, disability, and socioeconomic factors in decision-making. **For more information, contact NIC, Center for Developmental Disabilities, University of South Carolina, Benson Building, 1st Floor, Columbia, SC 29208 (PHN: 1/800/922-9234).**

National Information Center for Children and Youth with Disabilities (NICHCY)

U.S. Department of Education, Office of Special Education, Washington, DC

An information and referral center that provides free information on disabilities and disability-related issues, *NICHCY* addresses the informational needs of families and professionals dealing with children and youth from birth to age 22. One of four clearinghouses established by Congress to provide specialized information on disabilities, NICHCY is a project of the Academy for Educational Development. The information available relates to specific disabilities, early intervention, special education, family issues, disability organizations, professional associations, legal issues, transition to adult life, and multicultural issues.

Services available through NICHCY include: personal responses to specific questions through information specialists; free publications and fact sheets on specific disabilities, state resources, parent guides, and relevant bibliographies; referrals to other organizations and sources of help at the state and national level; information searches of databases and libraries for unique concerns and needs; and, technical assistance to parent and professional groups through workshops, presentations, and consultations. Materials are available in Spanish and alternative formats. **For more information, contact NICHCY, P.O. Box 1492, Washington, DC 20013 (PHN: 1/800/695-0285).**

National Insititute on Deafness and Other Communication Disorders (NICDC) Clearinghouse

National Institutes of Health, Washington, DC

The *NICDC Clearinghouse* is a national resource center mandated by legislation guiding the National Institutes of Health. Established in 1991, it collects and disseminates information on typical and atypical processes of hearing, balance, smell, taste, voice, speech, and language for health professionals, families, industry, and the public. The Clearinghouse is developing a subfile of the Combined Health Information Database (CHID) available to the public, citing numerous health information and health education resources which are not referenced in any other computer system or printed material. **For more information, contact NICDC Clearinghouse, P.O. Box 37777, Washington, DC 20013 (PHN: 1/800/241-1044; TDD: 1/800/241-1055).**

The National Pediatric HIV Resource Center

Newark, NJ

The *National Pediatric HIV Resource Center* offers a range of services to families and professionals caring for children with HIV infection. The goals of the Resource Center are: to promote the development of family-centered, coordinated, community-based systems of care for children and families; to improve access of service providers to state-of-the-art information about management and treatment of children with HIV infection; to provide education and training to health care providers; and, to increase providers' understanding of and sensitivity to the diversity of families and the impact of diversity on individual family strengths and priorities.

The Resource Center provides consultation, educational materials, standards of care, technical assistance, and training, and it serves as a forum for exploring public policy issues related to the care of children with HIV infection. The Resource Center is a project of the University of Medicine and Dentistry, New Jersey Medical School and The Children's Hospital of New Jersey, and is funded in part by a project of the Maternal and Child Health Bureau, U.S. Department of Health and Human Services. **For more information, contact The National Pediatric HIV Resource Center, Children's Hospital of New Jersey, 15 S. 9th Street, Newark, NJ 07107 (PHN: 201/268-8251 or 1/800/362-0071).**

The National Training Center

Kennedy Krieger Community Resources, Baltimore, MD

The National Training Center is a collaborative organization of diverse individuals and programs whose shared goal is to develop, disseminate, and provide training, publications, and consultation to assist individuals with disabilities, their families, and service providers. The activities of the Center promote inclusion and independence of individuals with disabilities, and encourage service delivery practices that are community-based, coordinated, knowledgeable and respectful of family diversity, family-centered, and based on the practice of positive approaches.

The Center offers technical assistance, books, videos, and training services on a variety of topics of interest to individuals with disabilities of all ages and to the families and professionals who work with these individuals. **For more information, contact The National Training Center, Kennedy Krieger Community Resources, 2911 East Biddle Street, Baltimore, MD 21213 (PHN: 410/550-9700; TDD: 410/550-9758; FAX: 410/550-9766).**

Resources

1994 ACCH Resource Catalogue

Association for the Care of Children's Health

The *Association for the Care of Children's Health* annually updates this Resource Catalogue which contains an expansive inventory of books, journals, videos, pamphlets, guides, and other materials available through the organization's Publications Department. The resources are designed for and by professionals and family members, and provide comprehensive information and guidelines about: illness and disability; family-centered health and developmental care; hospital-, home-, and commmunity-based settings; training and services for children, families, and professionals; educational, financial, environmental, and emotional supports for children, families, and professionals; and, facility architecture and design. **For more information, contact ACCH, Publications Department, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814 (PHN: 1/800/808-ACCH, ext. 327 or 301/654-6549, ext. 327; FAX: 301/986-4553).**

Central Directory of Resources

Family Support Network of North Carolina

The *Central Directory of Resources* is a single number to call for computerized information about any disease, disability, or services for children needing specialized care and their families. The Directory is funded by the North Carolina Department of Human Resources and the North Carolina Department of Public Instruction in conjunction with the Individuals with Disabilities Education Act (IDEA). The types of information available are related to: public and private agencies and services; printed information about specific health problems, diagnoses, and disabilities; family support and advocacy programs throughout the state and nation; and, assistive technology. **For more information contact the Family Support Network, Campus Box 7340, University of North Carolina at Chapel Hill, NC 27599 (PHN: 1/800/852-0042).**

Children with Disabilities: A Medical Primer, 3rd Edition

M. Batshaw & Y. Perret (1993)

This resource provides important clinical information for families and professionals about disabilities, but personalizes facts with a sensitive look at the needs of individuals. Specific disabilities include Down syndrome, autism, sensory impairments, cerebral palsy, AIDS, learning disabilities, and more. This reference guide provides information about various causes, prognoses, and development. It includes illustrations, charts, case studies, and an extensive glossary. **Published by Paul H. Brookes Publishing Company, Baltimore, MD.**

Deciphering the System: A Guide for Families of Young Children with Disabilities

P. Beckman & G. Boyes (1993)

This book, co-authored by a parent and a professional, is a comprehensive guide for families (and professionals) who want to learn how to understand and negotiate the early intervention and educational service delivery systems. While reviewing and addressing feelings and concerns expressed by families across the years, *Deciphering the System* also provides basic information strategies that enable families to know, and therefore exercise their rights, as a part of their children's care team. **Available through ACCH, this book is published by Brookline Books, Cambridge, MA.**

A Handbook for Parents, Life Support Unit

Minneapolis Children's Medical Center

When a child needs to spend time in an intensive or critical care unit, the new sights, sounds, terminology, and roles in care can initially seem overwhelming to parents and family members. It is only when professionals take the time to orient families to the critical care environment that parents get the information and education they need to assume new ways to care for their child. Minneapolis Children's Medical Center is one of many hospitals that offers a handbook for families that deals specifically with the life support unit in their facility. The book explains the meaning of the unit, why children need such intense care, why critical care units seem overwhelming, how to get information about their child and his or her condition, how to help their child adjust to the unit, and general unit and hospital policy information. **For more information, contact Minneapolis Children's Medical Center, 2525 Chicago Avenue South, Minneapolis, MN 55404 (PHN: 612/863-6100).**

HIV Treatment Information Exchange (HTIE)

National Hemophilia Foundation

This publication is designed to provide information on advances in the treatment of HIV. The articles chosen for this newsletter are drawn from a wide scope of other newsletters and bulletins. HTIE is produced at least four times per year. **For more information, contact The National Hemophilia Foundation, 110 Greene Street, Suite 303, New York, NY 10012 (PHN: 212/219-8180).**

LINCS-BBS™

PHP, The Family Resource Center for Children with Special Needs

Hundreds of resources are available to families and professionals caring for children needing specialized care through *LINCS™*, a free electronic Bulletin Board System. Callers access LINCS-BBS with a computer and modem, making available an expansive local and national resource directory, information files, and an events calendar. The 24-hour BBS number is 408/294-6933, settings are N-8-1, up to 14,400 baud. **For more information, contact PHP, 535 Race Street, Suite 140, San Jose, CA 93126 (PHN: 408/288-5010; FAX: 408/288-7943).**

The Medical Home Newsletter
Hawaii Medical Association

This newsletter is designed to provide important information about creative strategies that promote the medical home concept for children with illnesses and disabilities. This concept aims to promote medical homes for children needing specialized services by outlining practical methods for providing primary care that ensures early detection of problems, supports parents as partners, and coordinates with support services needed by the child and family. The newsletter is disseminated both locally and nationally to offer strategies promoting family-centered care through collaboration and an ongoing exchange of information. **For more information, contact The Medical Home Project, Hawaii Medical Association, 1360 South Beretania, Honolulu, HI 96814 (PHN: 808/536-7702).**

Nurses, Physicians, Psychologists, and Social Workers Within Statewide Early Intervention Systems: Clarifying Roles Under Part H of the Individuals with Disabilities Education Act
D. Von Rembow & W. Sciarillo (Eds., 1993)

This monograph provides critical information that better defines the roles of discipline-specific professionals in the early intervention process. A joint endeavor of the Association for the Care of Children's Health (publisher) and the Maryland Infants and Toddlers Program, the four resource documents contained in this monograph were developed by multidisciplinary groups of parents and professionals, and provide a general framework and specific guidance. **For more information, contact ACCH, Publications Department, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814 (PHN: 1/800/808-ACCH, ext. 327, or, 301/654-6549, ext. 327; FAX: 301/986-4553).**

Reaching Out
U.S. Maternal and Child Health Bureau

A Directory of national organizations related to Maternal and Child Health. **For more information, contact the National Center for Education in Maternal and Child Health, 38th & R Street, NW, Washington, DC 20057 (PHN: 202/625-8400).**

Understanding Title V of the Social Security Act
U.S. Department of Health and Human Services

Understanding Title V of the Social Security Act is a brief guide to the provisions of federal Maternal and Child Health Services legislation after enactment of the Omnibus Reconciliation Act (OBRA) of 1989 (P.L. 101-239). The information in this pamphlet offers an overview of the amended Title V for individuals who are new to the concept, as well as updated information for those who have been involved with Title V Programs across the years. Sections provide information related to authorization and appropriation, funding and allocation, Block Grants to states, and discretionary grants, such as Special Projects of Regional and National Importance (SPRANS) grants. **For more information, contact The Maternal and Child Health Bureau, Parklawn Building, Room 18-05, 5600 Fishers Lane, Rockville, MD 20857 (PHN: 301/443-2170).**

Incorporating into policy and practice the recognition and honoring of cultural diversity, strengths, and individuality within and across all families, including ethnic, racial, spiritual, social, economic, educational, and geographic diversity.

Photo courtesy of Shriner's Hospital, Los Angeles, CA. Photographer: David D. Hatter

The Diversity of Families

The fundamental idea of family-centered care is that children are best served when they are understood as inextricably linked to a larger living unit, the family. Disability and illness can affect any family, crossing all cultural, ethnic, racial, spiritual, social, economic, educational, and geographic lines. Family-centered care requires that each family be approached anew, with a recognition of and a respect for such diversity within and across each family. Decisions about care must be made by a collaborative exchange of information, not by predetermining child or family needs, strengths, concerns, or priorities based on assumptions about their culture, about their ethnicity and traditions, about their religious beliefs, about the way they dress or talk, about how much money they make or what they eat, about how much formal education they have had, or about where they live.

What Does This Mean?

Honoring diversity involves a recognition of individual differences, with the understanding that by differentiating ourselves, we define ourselves.

All human cultures recognize and support the predominance of the family in protecting, nurturing, and socializing the developing child. The family provides the essential context of life, directing a child toward meaningful participation in the larger community. Yet, until recently, this natural bond of children to parents, siblings, grandparents, and others within the circle of family, had not been well-recognized nor supported by modern human service delivery systems. Nor have services traditionally been designed, provided, and evaluated with respect to the diversity inherent within and across families. In the past, it was the specific characteristics of the individual child toward which all of the medical and educational technology and knowledge was aimed. If the disease was cured, or the condition stabilized or ameliorated, the intervention was considered successful, and the child was "given back" to the family.

The family, whether or not it is formalized through legal marriage, and whether it brings up children through birth, adoption, foster placement, or another arrangement, is the basic unit of community. To the family falls the primary responsibility of bringing the child into a successful adulthood within the framework of the family's individual values and definitions. Honoring the diversity within and across families is then essential to the collaborative process that drives family-centered care.

Practicing this element goes beyond merely recognizing that differences in culture and in families exist. Rather, in looking at diversity, it is important that differences not only be recognized and defined by each family's expressed needs, but also by each family's inherent and expressed strengths that arise from individual experiences, abilities, values, attitudes, and beliefs. Honoring diversity involves a recognition of individual differences, with the understanding that by differentiating ourselves, we define ourselves.

Incorporating this element into practice also requires a broadening of the typical definition of family differences commonly referred to in the catch phrase "cultural diversity." Honoring and incorporating the diversity of families into practice involves going beyond ethnic and racial differences, and viewing "culture" as the sum total of a specific groups' customs, habits, beliefs, and values (Hayes, in press; Leninger, 1970; Wilson, 1978). Culture directs the actions and thoughts of a group of people with commonalities. In addition to ethnicity and race, culture can be influenced by any combination of factors, such as spiritual convictions, social or educational experiences, or economic and geographic living conditions. Cultural differences have an impact not only on the definition

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The majority of this chapter is adapted from an unpublished manuscript, *Exploring and Honoring Family Diversity* (July, 1994), contributed by David Allen Jones, President of The Institute on Cultural Dynamics and Social Change, Rochester, MN, and member of the Advisory Committee, National Center for Family-Centered Care, ACCH, Bethesda, MD.

and interaction of families, parenting, behavior patterns, traditions, and language, but also on how illness and disability are viewed across families, and on how decisions are made by individual families regarding the care of their children.

Understanding the Diversity of Culture

The family both shapes culture and is shaped by culture. Culture serves as a mitigating force, a kind of shock absorber, between the family and the world. Yet culture is never static. Even as it gives families a sense of place, a sense of belonging, and a sense of values and meaning, it is constantly, though slowly, changing to meet the actual needs of the community, and to be relevant to real people's real lives.

Culture plays a strong role in defining the structure and function of the family itself. To a great extent, it is culture that defines whether the family will be nuclear or extended, mobile or rooted, small or large, matrilineal or patrilineal, and whether it will be part of a larger kinship group or clan. Culture also determines the role of the family in the larger community.

Culture provides families with a variety of ways of coping with the world. While the basic task of every family is to provide food, shelter, companionship, and a framework for physical, intellectual, spiritual, social, and emotional growth, it is culture that colors and flavors the diverse ways that families will respond to these fundamental needs. Other aspects of culture encompass personal hygiene, celebrations and rituals, conceptions of time and space, definitions of wellness and illness, and a framework for death and dying. For example:

- *Food* — What kind? How will it be prepared? How will it be eaten? When will it be eaten? How often will it be eaten?;
- *Shelter* — Will it be permanent or temporary? What will it look like? How many will live there? How long will they live there?;
- *Relationship* — Who will live together? Will they share beds, rooms, meals? How is their relationship defined? What are their specific roles in the family? What rules will guide their behavior (deference to age and authority, how close to stand to each other, how much touching is allowed, meaning of eye contact, volume of speech, value placed on vocal interchange)? Is greater value placed on individuality, or on group cohesiveness (family/clan/community)?;
- *Physical growth* — What activities are allowed, for whom, and under what circumstances? Is scarification required, encouraged, condoned, or condemned (pierced ears, tattoos, circumcision, clitorectomy)? To what degree is ornamentation controlled and defined (clothing, hair style or covering of hair, jewelry, lip painting)?;
- *Intellectual growth* — Who is allowed to study? What is to be learned? How, when, and where will it be learned? Is a written or oral form of learning preferred?;
- *Emotional growth* — How will pain be perceived? Will suffering be expressed or repressed? To what degree is anger allowed, and how is it permitted to be resolved? Are individual feelings solicited?; and,
- *Spiritual growth* (a concept broader than religion) — Why are we here? Where did we come from? Where are we going? By what rules shall we live? What formal structures of belief and worship will we share? Will our world-view be optimistic or fatalistic? (Jones, 1992)

Understanding the Effects of Diversity

It is important to remember that within any community or cultural group will be found a wide range of individual family values, beliefs, and behaviors. In this sense, each family is a "culture" unto itself, and must be understood within its own context. One way of describing culture is to say that a particular group has developed those beliefs, values, and behaviors — and a metaphysical framework — that enable it to successfully sustain itself (Jones, 1985). Interestingly, the family itself can be described in much the same way.

Each family exists in a specific environmental and social context, and each family adjusts to

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try and survive and thrive in its given world. We have to be very careful not to succumb to the temptation to fit each family into neat little preconceived categories based on their ethnicity, race, religion, economic or educational level, geographical habitat, or any other generality. Let each family define itself, must be our guiding principle. As Goodman (1993) has stated:

> *It seems to me that each family forms its own chorus and sings its own song, taking the meter, rhythm, tone, lyrics and melody from cultural, religious, social and economic variables, while themes may come from family history or intrapsychic sources. Some choruses sing harmoniously, others are discordant. All aspire to make celestial music; none ever succeeds. It is the practicing/refinement that really matters most (p. 11).*

Educational level should never be confused with intelligence, and no research has ever correlated education or intelligence with wisdom.

Key components to understanding the music of each family unit include: familiarity with cultural variations; respect for differences; sensitivity to nuances of meaning; willingness to consult and learn; creativity in our interventions; and, an openness to hear and respond to each distinct voice in the chorus of the family song (Goodman, 1993).

Effects of the "culture" of poverty have sometimes been misperceived as racial or ethnic characteristics, which can easily lead to unwarranted negative stereotypes about communities or entire groups, "blaming the victims" for circumstances over which families have little control (Ryan, 1971). Families living in poverty, for instance, may by necessity be forced into a reactive, day-by-day, survival-oriented way of life:

> *They may live in multi-generational households where age-defined roles differ greatly from the middle class, and they may not share the same self-assurance that they can affect their world in positive ways (Jones, 1991b, p.10).*

Educational level should never be confused with intelligence, and no research has ever correlated education or intelligence with wisdom. Families know themselves, and they understand what it takes to survive, sometimes against huge odds. When parents choose to look for outside assistance with certain issues regarding their children, it should be assumed that they want the best for their children, and that they are the best source of information regarding their child's and family's needs.

One of the challenges for service providers is to locate the family within its own story, the dramatic sequence that tells us where they have been, and where they see themselves going. It is within their story, as much as they are willing to share it, and to the extent we are willing to really hear it, that we will truly begin to build a partnership with the family, as we share a time when both our stories intertwine for awhile.

Honoring Diversity in Principle

To begin to understand the power of culture in shaping the lives of children and families is to start on a path that begins with *awareness.* Awareness manifests itself as an *attitude* toward life and all people. Attitude is translated into *behavior* which changes our lives and the lives of the children and families with which we work. Awareness begins with self-awareness, an examination of our own beliefs and values and how they have been shaped by our family, cultural background, and experiences. Self-awareness grows as we begin to realize how our values and beliefs affect our interactions with others.

Awareness also means learning about others — about the history, values, child-rearing practices, health beliefs, and other insights regarding the families and communities we serve. This learning may take place through articles, books, and other media, but is certainly solidified through respectful and sincere relationships with individuals, families, and communities different from ourselves.

Without this growing awareness of ourselves and others, we will often be misjudging the actions and motivations of those we work with and those we serve. According to Cross (1988), both sides of any cross-cultural interaction bring:

> *. . . their own unique history with the other group and the influence of current political relationships between the two groups.*

Both will bring culturally prescribed patterns of communication, etiquette and problem solving. Both may bring stereotypes with them or underlying feelings about working with someone who is "different" (p.4).

In changing our awareness, we can begin to assume a new attitude in our interactions with others, which is marked by respectfulness, empathy, open-mindedness, flexibility, tolerance of ambiguity, desire to learn, and the ability to laugh at life and oneself (Lynch, 1992). This new attitude can become a cornerstone for forming partnerships with parents and other family members. It also reminds us that recognizing, respecting, and honoring diversity within and across families is a natural and integral part of family-centered care, and cannot be separated from it:

> *. . . A provider must come to the therapeutic relationship with humility, respect, and a willingness to learn — characteristics that are implicit in the concept of family-centered care . . . Humility means that the provider will accept the fact that only the family can provide the understanding of what constitutes the problem. A sincere attitude of humility allows one to truly respect the personhood of another, and such respect precludes any behavior suggesting elitism, racism, ageism, or other biases . . . Humility and respect open an individual to readiness to accept others as being of equal value with oneself, and a willingness to learn about their beliefs (Jones, 1991a, p. 10).*

To honor the diverse values, beliefs, customs, and traditions of families is the ultimate sign of professional competence and a necessary foundation for family/professional partnerships and collaboration. In recent years, the term "cultural competence" has come to encompass this new level of provider/agency capability. Competence has been defined as:

> *. . . a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or professional and enable that system, agency, or professional to work effectively in cross-cultural situations (Cross, 1988, p. 1).*

Cross (1988) has delineated a cross-cultural interaction continuum representing provider behaviors ranging from cultural destructiveness to advanced cultural competence:

- *Cultural destructiveness* actively carries out activities that destroy or disrupt cultural beliefs or practices;

- *Cultural incapacity* represents cross-cultural ignorance, often characterized by support of the status quo;

- *Cultural blindness* refers to well-meaning but misguided "liberal" policies and practices based on the belief that if only the dominant cultural practices were working properly, they would be universally applicable and effective for everyone;

- *Cultural pre-competence* reflects a movement toward the recognition that there are differences in individuals, families, and communities, and a willingness to begin to try different approaches to improve service delivery;

- *Basic cultural competence* is characterized by acceptance and respect for difference, continuing self-assessment regarding culture, careful attention to the dynamics of difference, continuous expansion of cultural knowledge and resources, and a variety of adaptations to service models to better meet the needs of minority populations;

- *Advanced cultural competence,* at the most positive end of the scale, is characterized by actively seeking to add to the knowledge base of culturally competent practice by conducting research, developing new therapeutic approaches based on culture and publishing and disseminating the results of demonstration projects . . . Such an agency advocates for cultural competence throughout the system and improved relations between cultures throughout society.

To honor the diverse values, beliefs, customs, and traditions of families is the ultimate sign of professional competence and a necessary foundation for family/ professional partnerships and collaboration.

Honoring Diversity in Practice

One of the greatest challenges in providing family-centered care is in letting each family determine the parameters of the care that is offered and of the care that is utilized. The spirit of collaboration between family members and professionals must be tempered by the recognition and honoring of diversity, strengths, and individuality within and across families:

> *If a family subscribes to traditional Chinese beliefs, communication between them and a medical provider will need to reflect the provider's understanding of the fact that she may be held in high esteem both as a physician and as an authority figure. This will make an approach based on an 'equal partners' model very awkward at the least. The family may feel overwhelmed, confused, and perplexed as they try to maintain decorum and provide due respect, against a flood of information, framed by leading questions by the provider intended to solicit family input and leadership in the relationship (Jones, 1994b).*

This element of family-centered care requires a reinforcement of attitudes and behaviors that reflect respect for differences across families, both in principle, and in practice.

Additionally, false attributions and stereotypes can have a negative impact on the collaborative process:

> *I think of my work in the NICU and how things were said about single, teenage mothers who had no prenatal care, who smoked, and who delivered their babies prematurely. In some ways, they were blamed for the birth, and they clearly were not seen as being capable of participating in any active way in the design or delivery of [their infant's] care. Their role was to follow directions. When they didn't, the attribution of irresponsibility was just reinforced (Shelton, personal communication, July 17, 1994).*

This is an example of the "medical model" of service delivery, which according to Dunst and colleagues (1994a), results in conflict, and when treatment is followed, can result in dependency.

Parents and caregivers with a high level of education or who are professionals themselves may also have a difficult time developing collaborative partnerships with service providers. Frequently, it is assumed that highly educated parents understand everything when it is first told to them, even though the information may relate to a different field of professional work than that in which the parent is trained. Additionally, family members with a high level of education are often seen by service providers as a "threat" to their own expertise and role in the child's care team, rather than appreciated for their strengths and contributions.

Developing Attitudes of Respect for Diversity

This element of family-centered care requires a reinforcement of attitudes and behaviors that reflect respect for differences across families, both in principle, and in practice:

> *No human being is born with racist, sexist, and other oppressive attitudes. As children, (when) we learned about the world and about people, we were often misinformed about people who were different from ourselves. That misinformation was acquired involuntarily, usually through a process of conditioning. We received some of those messages overtly from our parents, friends, teachers, and others . . .*
>
> *These early learned stereotypes became mental tapes or cultural software that affected what we thought and what we felt about [other] people . . . who were different from us . . . Through training and sustained efforts, however, it is possible to get off automatic and become conscious of our reactions to difference, make choices about how we wish to respond and begin to respond to difference in a clear-headed, rational manner without fear and apprehension, without bias (Hays, in press).*

The following list reflects some of the characteristics of a family-centered approach to services and supports which recognize and honor the uniqueness and diversity within and across families:

- Approaching families with no judgements or preconceptions;
- Meeting each family on its own terms;
- Allowing each family to define itself;
- Avoiding a "pathology" approach to non-mainstream families;
- Recognizing culture, and the great diversity of cultural characteristics (e.g., ethnic, racial, spiritual, social, economic, educational, geographic) as a deep well of strength from which families can draw;
- Understanding that many families carry scars from personal and community experiences with the human services system;
- Focusing on the strengths of each family, and building on them;
- Examining continuously one's own values, beliefs, and behaviors as a lifetime process of personal development;
- Developing and practicing professional skills of openness and flexibility; and,
- Letting each family, in its turn, define the meaning of the collaborative process that guides family-centered care.

Laws and guidelines can be written to gain equity for the few and to alter the behavior of the many, but their ultimate success depends almost entirely on changing awareness and attitudes, and these cultural variables are often difficult and slow to change. It is not reasonable to expect that any one single approach to providing specialized services and supports will be appropriate for all families. Diversity in the definition or composition of a family, and in the cultural differences and commonalities within and across families, calls for flexibility in approaches to health and developmental care for children and families.

Laws and guidelines can be written to gain equity for the few and to alter the behavior of the many, but their ultimate success depends almost entirely on changing awareness and attitudes, and these cultural variables are often difficult and slow to change.

To be most effective, services for a child must be consistent with the preferences of the individuals making up the child's family. These preferences, which are influenced by ethnicity and race, spirituality, social and educational experiences, economics, geographical residence, and other factors, must be recognized, respected, and honored when planning for or delivering the child's care.

Making It A Reality

Providing health and developmental services in a family-centered way requires that systems of care be competent in recognizing and honoring the diversity within and across families. Becoming competent in understanding the unique contributions of cultural strengths and differences involves an ongoing examination of one's own values, attitudes, and behaviors. It also involves both preservice and inservice training and research, and evaluation and evolution of programs, policies, and practices serving children and their families. Core curricula about different cultural characteristics for professionals can help diminish the myths and stereotypes which interfere with understanding, acceptance, respect, and collaboration.

Mentoring and encouraging individuals of diverse backgrounds to become health and developmental professionals, thereby increasing the number of multilingual/multicultural staff, is another way to bridge cultural barriers for families. Diverse representation of a wide range of consumers — children and families — on governing bodies and advisory councils to participate in the evaluation of hospital-, home-, and community-based services *can also help ensure that this element of family-centered care can become a reality. This section presents examples of some of the many policies, programs, practices, and resources that consider the diversity of families when planning and delivering services, and that strive to meet the unique and varied needs associated with cultural characteristics.*

Programs, Policies, and Practices

The Center for Children with Chronic Illness and Disability

The University of Minnesota, Minneapolis, MN

The Center for Children with Chronic Illness and Disability has a special focus on the needs and concerns of children with chronic and disabling conditions and their families who are African American, Southeast Asian American, Hispanic American, and Native American. The collaborative work style of the Center relies on and facilitates guidance from consumers, respect and desire for diversity, focus on resilience, empowerment of families, integration into communities, and changing policies and systems. Their national invitational conference brought together professionals, families, and individuals with disabilities representing diverse multicultural heritages and resulted in several published papers.

The Center collaborated with PACER Center to lead a demonstration project providing support to African American fathers and siblings of children with disabilities. This project was replicated with Southeast Asian American families. They have also collaborated with La Rabida Children's Medical Center to pilot a longitudinal study, Project Resilience, which analyzes and support the strengths and needs of African American children with disabilities and their families to improve collaboration and participation in care. **For more information, contact The Center for Children with Chronic Illness and Disability, The University of Minnesota, Box 721, 420 Delaware Street SE, Minneapolis, MN 55455.**

The Chapel Hill-Carrboro Transition Project

Chapel Hill Training-Outreach Project, NC

The Chapel Hill-Carrboro Transition Project is one of 32 federally funded programs nationwide which are studying the benefits of providing family support and developmentally appropriate programs for "at-risk" children as they enter kindergarten and progress through elementary school. An evaluation of the effectiveness of these support services is being conducted by the Frank Porter Graham Center at the University of North Carolina. The data collected will be compiled with research data from other national sites.

Transition services include: a Home Teacher, who visits families and serves as a bridge between the classroom and the home; a Family Service Coordinator, who addresses the concerns of the family in areas of nutrition, health, child care, and parenting; and, information and training, which is provided to the public school, day cares, and teachers in the community. Among its many services, the Transition staff assists families with accessing medical care, helps families secure social services, and helps families develop preventive health routines for their children. **For more information, contact Chapel Hill-Carrboro Transition Project, Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514 (PHN: 919/490-5577).**

The Chicago Family Support Project (CFSP)

Family Resource Center on Disabilities, Chicago, IL

The Chicago Family Support Project, funded by the Illinois Department of Mental Health and Developmental Disabilities, is a program of the Family Resource Center on Disabilities. The project, run by the parent of a child needing specialized services and support, serves primarily low income families of color who have children with severe disabilities. The project employs Family Resource Workers, who are parents who come from the same communities the project serves, to help other families learn how to be effective care coordinators for their children. The staff and families are also assisted by a team of Parent Mentors, trained volunteers who formerly participated in CFSP as service recipients. **For more information, contact The Family Resource Center on Disabilities, 20 E. Jackson, #900, Chicago, IL 60604.**

Family Development Training

National Resource Center on Family-Based Services, Iowa City, IA

Family Development Training is a model of family-based intervention designed to help all families, but especially families with low income, to improve family functioning and achieve economic independence. Participation in family development programs is voluntary, and programs may be sponsored by social services, mental health, or educational organizations. Sessions can occur in the family's home, in groups, or through center-based activities. Family Development Specialists are problem-solvers, allies, and advocates who are skilled in helping families to review their needs, their stresses, and their strengths. **For more information, contact The National Resource Center on Family-Based Services, The University of Iowa, School of Social Work, 112 North Hall, Iowa City, IA 52242.**

Healthy Mothers, Healthy Babies Coalition (HMHB)

Washington, DC

The *Healthy Mothers, Healthy Babies Coalition* is made up of more than one hundred national, professional, voluntary, and governmental organizations with a common interest in maternal and infant health. The purpose of the Coalition is to foster educational efforts for pregnant women, new mothers, and their families through collaborative activities and sharing of information and resources.

HMHB's Minority Outreach Initiative, funded by a grant from Metropolitan Life Foundation was conceived in 1991 as a response to the urgent need to gain ground in the battle to reduce infant mortality, morbidity, and low birth weight in communities of color across the U.S. **For more information, contact Lori Cooper, Executive Director, HMHB Coalition, or Claudia Morris, Director, Initiative for Communities of Color, HMHB Coalition, 409 12th Street SW, Washington, DC 20024 (PHN: 202/863-2458).**

Kaleidoscope, Inc., Changing Patterns in Child Care

Chicago, IL

Kaleidoscope, Inc., Changing Patterns in Child Care, is a licensed, not-for-profit child welfare agency in Illinois that specifically serves children and youth considered to be most in need of support. They serve children regardless of the severity of their behavioral problems, mental health challenges, or disabling conditions. The agency is supported largely by general grants and individual contracts with the state's Departments of Mental Health, Child and Family Services, and Corrections. Corporate and foundation grants supplement these funds. Kaleidoscope's philosophy is based on the concepts of normalization and unconditional care. The organization believes that children best learn to become competent adults if they live in and learn from a typical environment — family, neighborhood, or community.

Kaleidoscope, Inc., offers "WrapArounD" services, which are community-based, unconditional, centered on the strengths of the child and family, culturally competent, and include the delivery of coordinated, highly individualized interventions in three or more life domain areas of the child and family (e.g., residential, family or surrogate family, social, educational/vocational, medical, psychological/emotional, legal, safety, cultural/ethnic). Kaleidoscope Training Institute provides on-site training, consultation, needs assessment, technical assistance, and conference workshops. **For more information, contact Karl Dennis, President, 1279 North Milwaukee, Suite 250, Chicago, IL 60622 (PHN: 312/278-7200; FAX: 312/278-5663).**

Making It Work for Children with Special Needs: The Family, the Community, and the State

W.G. Klingberg Center for Child Development, Morgantown, WV

This program, funded by a SPRANS grant from MCHB, is a joint project of West Virginia University's Klingberg Center for Child Development and the West Virginia Division of Handicapped Children's Services. The goals have included providing coordinated, comprehensive family-centered evaluations and care coordination to children in rural areas who need specialized health services and their families. A key element of the success of the interdisciplinary teams in this project is the involvement of parents as part of the staff, as members of an advisory board, as care conference planners, as writers of the project's newsletter, and as consultants for other families at clinic visits. **For more information, contact Chet Johnson, Director, Making It Work for Children with Special Needs, W.G. Klingberg Center for Child Development, Robert C. Byrd Health Sciences Center, Department of Pediatrics, West Virginia University, P.O. Box 9216, Morgantown, WV 26506 (PHN: 304/293-4337; FAX: 304/293-4337).**

New Alternatives for Children (NAC)

New York, NY

New Alternatives for Children provides services for children with chronic illnesses or disabilities who are living in hospitals, to help these children leave the hospital and live in the community. In addition to foster care and adoption programs, NAC offers a prevention program which serves biological families in their own homes. NAC also provides individual and family counseling, care coordination, medical services, respite, educational services, transportation, and recreation. Group services include parent support groups, parenting skills groups, and sibling groups. NAC is committed to keeping families together, works with an extremely underserved population, and combines health and social services, offering a Food and Clothing Bank, a Diaper Co-op, a 24-hour hotline, and a substance abuse prevention program. The project is funded by the New York City government, foundations, and private donations. NAC estimates it saves over $207,000 annually, by keeping the child out of the hospital — even at the cost of the highest level of service for NAC. **For more information, contact Joy Freville, New Alternatives for Children, Inc., 37 West 26th Street, New York, NY 10010 (PHN: 212/696-1550; FAX: 212/696-1602).**

LINKS: Linking Networks for Kids
Bazelon Center for Mental Health Law, Washington, DC

LINKS is a national consortium of key organizations in the fields of early care and education, health, development, and disability. Each LINKS member plays a role in promoting optimal child and family development and preventing serious developmental harm to children. Through LINKS, early childhood providers, advocates, policy-makers, and families collaborate in overcoming lack of knowledge, categorical funding, turf issues, and other barriers to the delivery of critical services and supports to children and families who live in poverty. In addition to enhancing collaboration and increasing knowledge, awareness, and access to relevant programs and resources, LINKS aims to identify and disseminate successful strategies for utilizing resources and to promote policy changes at the federal, state, and local levels LINKS provides a number of resources, including a newsletter dealing with issues such as child care and comprehensive health and developmental services for young children who are homeless, community networking, funding, and health care reform. LINKS is coordinated by the Judge David L. Bazelon Center for Mental Health Law, with support from other foundations. **For more information, contact LINKS, Judge David L. Bazelon Center for Mental Health Law, 1101 15th Street NW, Suite 1212, Washington, DC 20005 (PHN: 202/223-0409; FAX: 202/467-5730).**

Pathways to Understanding: Culturally Sensitive, Coordinated Care for Indian Children with Special Health Needs
Bernalillo, NM

Pathways to Understanding addresses the need to develop and improve statewide systems of family-centered, culturally sensitive, community-based, and coordinated care, that will enhance the coordination between the New Mexico Maternal and Child Health agency and the Early Intervention program. It also provides information and technical assistance to increase the effectiveness of health care professionals working with Native American families by increasing their understanding of providing appropriate services to Indian children and families and of the cultural barriers faced by Indian families. **For more information, contact Randi Malach, Project Director, Pathways to Understanding, P.O. Box 788, Bernalillo, NM 87004 (PHN: 505/867-3396).**

Saskatchewan Institute on Prevention of Handicaps
Saskatoon, Saskatchewan

Since 1980, the *Saskatchewan Institute on Prevention of Handicaps* has promoted the Wellness Model of health by providing public health education and by working within the community to educate people on how to prevent handicapping conditions in children. Program initiatives include research, program planning, interagency coordination, program implementation, and program evaluation. Information is provided in the form of displays, talks, workshops, professional seminars, publications and videos, and tours of the Institute, covering topics such as prenatal care, child safety, injury prevention, and healthy lifestyles. **For more information, contact the Saskatchewan Institute on Prevention of Handicaps, 1319 Colony Street, Saskatoon, Saskatchewan, Canada S7N 2Z1 (PHN: 306/966-2512; FAX: 306/966-2511).**

Southeast Asian Developmental Disabilities Project (SEADD)
San Diego, CA

The *Southeast Asian Developmental Disabilities Project* aims to reduce barriers to and enhance the availability and use of genetic and other maternal and child health services for Southeast Asian refugee families in San Diego, California. The goal of the project is to improve the health of infants and children who are at-risk, have developmental disabilities, or have genetic disorders in the local Asian communities. Outreach, prevention, intervention, and education services for these children and families are the main strategies used to achieve this goal. Funded by a SPRANS grant from MCHB, this project has developed several publications related to the competent delivery of services to diverse cultures. **For more information, contact James Cleveland, Project Director, San Diego Imperial Counties Developmental Services, Inc., San Diego, CA 92101.**

Resources

Center for Children with Chronic Illness and Disability Newsletter
University of Minnesota

This newsletter contains a wealth of information about children with chronic illnesses and disabilities and their families, focusing on the strengths and resiliency of these individuals. The theme of each newsletter is well-presented, with articles exploring the philosophy and practice of issues related to family-centered care. Volume 2, Number 1, published in 1993, explores the diversity of families, and how culture contributes to values, attitudes, beliefs, and roles and decision-making in health and developmental care. **For more information, contact C3ID, Box 721, University of Minnesota, 420 Delaware Street SE, Minneapolis, MN 55455.**

Culture and Chronic Illness: Raising Children with Disabling Conditions in a Culturally Diverse World
N. Groce & I. Zola (1993)

Culture and Chronic Illness: Raising Children with Disabling Conditions in a Culturally Diverse World is the resulting publication from an invitational conference addressing community, culture, and chronic illness. Three key issues are discussed in the paper: the culturally perceived cause of a chronic illness or disability; the expectations of survival for an infant or child with an illness or disability; and, the social roles deemed appropriate for children and adults with disabilities as such relates to the amount of resources a family and community will invest in an individual. **This paper is published by the American Academy of Pediatrics, in the *Journal of Pediatrics*, Volume 91, Number 5, Part 2, Supplement.**

Developing Cross Cultural Competence
E.W. Lynch & M.J. Hanson (1992)

Developing Cross Cultural Competence is an important resource on cultural sensitivity and competence, that provides extensive information on families of various ethnic backgrounds. **Available through ACCH, this resource is published by Paul H. Brookes Publishing Company, Baltimore, MD.**

Empowering Adoptive Families
D. Lakin (1992)

Empowering Adoptive Families was developed to help families who have adopted children needing specialized services and supports. The resource addresses central issues in adoption, assessment and intervention with adoptive families, and models for post adoption services. It also contains a reference and resource guide, and basic information about emotional, cognitive, social, and moral development. Produced by the National Resource Center for Special Needs Adoption through a grant from the U.S.

Department of Health and Human Services, this resource is available from the Baltimore City Department of Social Services. **For more information, contact Baltimore DSS, 1510 Guilford Avenue, P.O. Box 17259, Baltimore, MD 21203 (PHN: 410/361-5519; FAX: 410/361-4395).**

Journal of Religion in Disability and Rehabilitation
The Haworth Press, Binghampton, NY

The *Journal of Religion in Disability and Rehabilitation* is a new quarterly publication that brings religious professionals and those in other helping professions greater knowledge and kinship, so they might join alongside each other with confidence and assurance, to help individuals with disabilities by better understanding their unique and diverse strengths, needs, and values. **For more information, contact The Journal of Religion in Disability and Rehabilitation, The Haworth Press, Inc., 10 Alice Street, Binghampton, NY 13904.**

Mental Health Services for Minority Children and Youth: An Introductory Training Manual
Department of Social and Health Services, State of Washington

The *Mental Health Services for Minority Children and Youth: An Introductory Training Manual* was designed to assist mental health service providers increase their knowledge of: minority cultures, including child-rearing practices and other values; minority children; the relationship between racism and children's struggles; and, the implicit assumptions of traditional counseling practices and necessary modifications to provide culturally appropriate services to diverse ethnic groups. This resource was developed by the Ethnic Minority Mental Health Consortium and the Mental Health Division of the Department of Social and Health Services from a workshop held by the Consortium, which is a statewide coalition of minority and non-minority people who are committed to working toward the development of a mental health system that will effectively address the needs of minority communities. **For more information, contact Special Programs, Mental Health Division, DSHS OB-42F, Olympia, WA 98504 (PHN: 206/ 753-5414).**

Strategies for Working with Culturally Diverse Communities and Clients
E. Randall-David (1991)

Strategies for Working with Culturally Diverse Communities and Clients provides principles that can be effectively used by a variety of community groups engaged in a broad range of educational, medical, and social service outreach efforts. The guide offers definitions related to the terms culture and ethnicity, and guidelines for assessing one's own cultural heritage, for working with diverse community groups, for using interpreters, and for analysis of sociocultural factors related to health. **This resource is published by and available through ACCH.**

That All May Worship: An Interfaith Welcome to People with Disabilities
National Organization on Disability (1994)

That All May Worship is a coaching manual, interfaith in scope, written to "encourage, prod, and prayerfully push religious leaders and their congregations to change the ways people with disabilities are, or are not, included in their congregations." The Religion and Disability Program at the National Organization on Disability encourages national denominational groups, seminaries, and local churches, synagogues, and congregations, to remove the obstacles to worship that may alienate people with disabilities, and to welcome people with all disabilities into all aspects of worship and religious life. The organization works to enlighten all people about the strengths and needs of individuals of all ages with disabilities and their caregivers. Materials available through the program help religious communities identify and remove architectural, communications, and attitudinal barriers. Copies of *That All May Worship* are also available on tape. **For more information, contact Ginny Thornburgh, National Organization on Disability, Religion and Disability Department, 910 16th Street NW, Suite 600, Washington, DC 20006 (PHN: 202/293-5960; TDD: 202/293-5968; FAX: 202/293-7999).**

Towards a Culturally Competent System of Care

T. Cross, B. Bazron, K. Dennis, & M. Isaacs (1989)

Towards a Culturally Competent System of Care is a monograph discussing effective services for minority children with severe emotional disabilities. Funded by the National Institute of Mental Health, Child and Adolescent Service System Program (CASSP), this resource was developed to ensure that service systems meet the unique needs of diverse children and families in appropriate ways. It gives special attention to African American, Asian American, Hispanic American, and Native American sociocultural groups. It contains information about barriers to and the continuum of cultural competency, citing program examples useful to policy-makers, service providers, and administrators of public and private child-serving agencies. **For more information, contact the CASSP Technical Assistance Center, Georgetown University Child Development Center, 3800 Reservoir Road NW, Washington, DC 20007 (PHN: 202/687-8635).**

Unity Through Diversity

The National Maternal and Child Health Clearinghouse (1993)

Unity Through Diversity is a report sharing the insights of 20 invited leaders in communities of color and authorities on maternal and child health issues about problems unique to their communities related to infant morbidity, poor prenatal care, poor nutrition, and tobacco and other drug use. The report provides recommendations to maternal and child health programs across the country that are feasible and lay the groundwork for the process of inclusion of communities of color at every level of health care, from program planning to service delivery. The report, made possible by the Healthy Mothers, Healthy Babies Coalition, also includes a listing of selected projects representative of diverse children and families as a resource. Single copies of this publication are free. **For more information, contact the National Maternal and Child Health Clearinghouse, 8201 Greensboro Drive, Suite 600, McLean, VA 22102 (PHN: 703/821-8993, ext. 254).**

Recognizing and respecting different methods of coping and implementing comprehensive policies and programs that provide developmental, educational, emotional, environmental, and financial supports to meet the diverse needs of families.

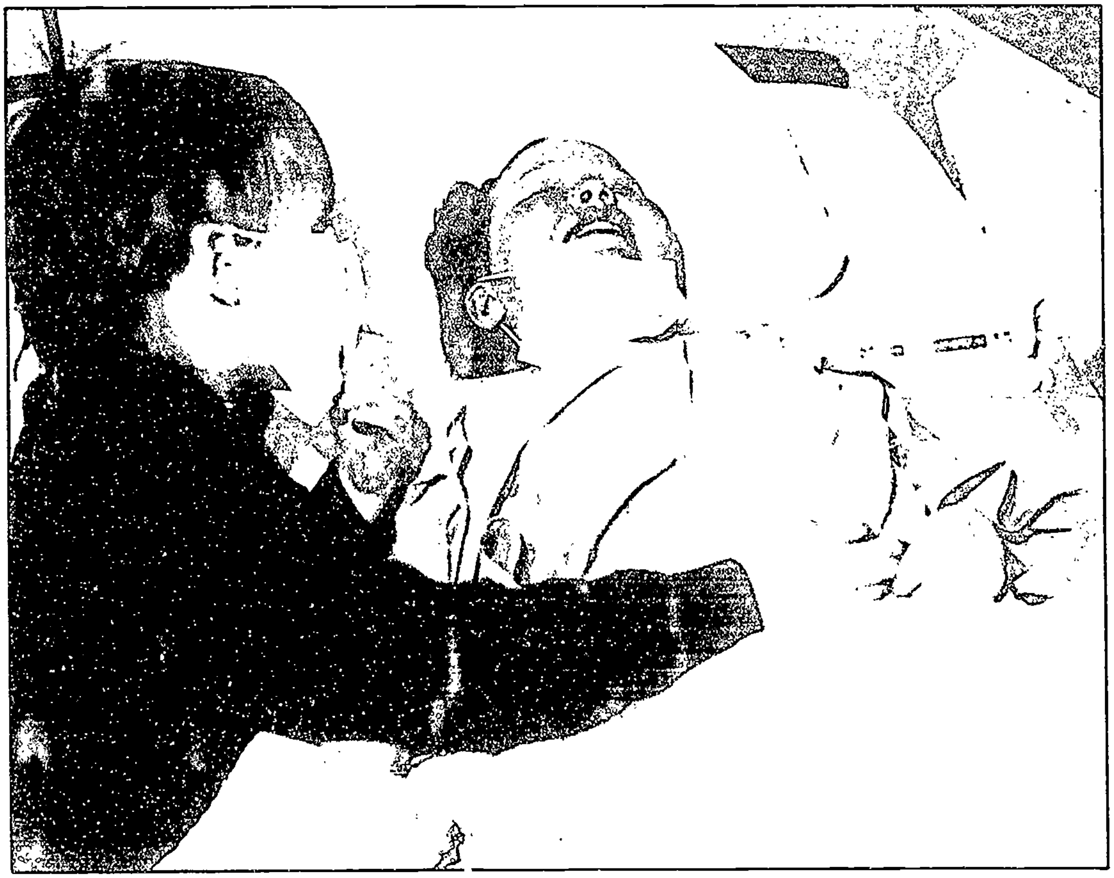

Photo courtesy of Kitchener-Waterloo Hospital Children's Out-Patient Clinic, Kitchener, Ontario

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Coping and Support

One critical aspect of honoring family diversity is recognizing and respecting the different ways in which families approach their child's illness or disability — the meaning they ascribe to it, the impact it has on family members, and the way they choose to meet the new challenges brought by it. While there are many issues that are common to families whose children need specialized services, care must be taken to respect each family's individuality in their adaptation to their child's needs, and to address the specific goals expressed by each family.

What Does This Mean?

The ability to accept differences in coping is important not only for professionals, but also for families to consider as well. Even various members of the same family may react differently, cope differently, and need different kinds of support from within and outside of the family.

In well-meaning attempts to understand the myriad of feelings experienced by families and to support the way families cope, professionals have sought to identify predictable patterns and stages of adaptation (e.g., Kubler-Ross, 1983; Wurzbach, 1985). However helpful these theories can be, more recent research has suggested that the large body of literature identifying distinct "stages" of adaptation may inadvertently ignore, and thus not support, the individuality of a family's style of coping:

> *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).*

Affleck and Tennen (1991) concluded that family coping cannot be accurately categorized into stages, nor can assumptions be made about either family stress or feelings of ability to cope and participate in care. Furthermore, when professionals hold stereotyped expectations of parental adjustment, their efforts to provide support are jeopardized and their relationships with the parents suffer. Theories that detail stages of adjustment do have their place and can be helpful to professionals and to families as they attempt to anticipate and address the changing needs of families; however, a family-centered approach involves using these theories as a framework while approaching each family anew. This style better enables families to articulate their needs and priorities, rather than attempting to "fit" them into a preexisting scheme.

A family-centered approach also means taking the time to find out what has worked for individual families in the past, and what different choices and decisions mean for individual families. For example, if a family seeks a second opinion, instead of interpreting this as "doctor shopping" or "denial," professionals should listen to what the family may be needing — more information to make an informed decision. Disagreement over a treatment plan may reflect a less than effective explanation of the reasons for the recommended treatment on the part of the professional, and/or a family's misunderstanding of the plan.

The ability to accept differences in coping is important not only for professionals, but also for families to consider as well. Even various members of the same family may react differently, cope differently, and need different kinds of support from within and outside of the family. One mother described the distinctly different reactions between herself and her husband as they first began dealing with their daughter's disabling condition:

> *When Annie was diagnosed with a disability at four months of age, we embarked on a whole new set of challenges in our relationship. After years of fairly open communication, we found we couldn't talk about this situation. It was too painful. We had no comfort to offer*

> *each other. We protected each other from our deepest, darkest fears. We managed crises together, made medical decisions together, but we didn't discuss our feelings about what was happening to Annie, to us, and to our family. Our male/female roles became more polarized. With the level of care Annie required — weekly doctor appointments, physical tests, medications — I became consumed by my role as her mom. I felt David had the luxury of not dealing with her disability 24 hours a day because he got to go to work. As a result, it didn't seem to impact him to the extent it did me . . . He thought I was obsessed. I thought he was in denial (Isett, 1993, p. 2).*

Another parent commented on her need for support beyond her immediate family:

> *I found it an enormous relief to talk to friends rather than to family. Jay and I shared much . . . Yet our fates were so bound up together that I hesitated to tell him how close I sometimes felt to despair. With many parents it was almost the same. They needed to believe I was strong, was coping: my despair would have fed theirs. Friends were different. They loved us, felt sad for us, cared and helped in many ways. But they did have their own lives, and I could speak to them of my anguish without worrying that I struck at a faith essential to their survival (Featherstone, 1980, p.62).*

Types of Supports

The second part of this element recognizes that sometimes children and families may need additional amounts and more varied types of support, and that the types of supports needed across families may differ. Although personal strengths and methods of coping may have been successful in the past, the new demands and constraints that come with the child's illness or disability may make it difficult to use these coping strategies effectively. Or, it may be that the "tried and true" ways are not sufficient alone ring the extremely stressful, complex, or chronic situations encountered as families realize and respond to their child's illness or disabling condition.

Comprehensive family support encompasses many services. Family support can be broadly defined to include services such as those designed to help a family meet its basic needs (e.g., housing, food, job skills training, or finances). But when supporting children who are ill or who have a disabling condition and their families, family support takes on additional realms. Families need traditional health and developmental supports (e.g., medical and developmental evaluation/intervention, home and hospital health care, speech therapy, occupational therapy, physical therapy, dental, and nursing services), as well as informational and emotional supports. Researchers (e.g., Beckman, Newcomb, Frank, Brown & Filer, 1993; Dunst, Trivette, & Deal, 1994a; Knoll, Covert, Osuch, O'Connor, Agosta, & Blaney, 1990; Newcomb, Stepanek, Beckman, Frank, & Brown, 1994) have identified several major areas of family support services:

- *Educational, informational, and instructional support* (e.g., early intervention and special education, behavior management, information related to the child's disability and related care, advocacy, systems change, service coordination, outreach, guardianship/future planning, group homes, rehabilitation and vocational programs);

- *Financial support* (e.g., government or private cash subsidies, insurance coverage, allowances, utilities assistance, vouchers for meals or parking, transportation assistance, reimbursement);

- *Environmental and material support* (e.g., adaptive equipment, home modifications, special clothing or diet, lounges or sleeping accommodations for family members during hospitalization); and,

- *Emotional, recreational, and respite support* (e.g., counseling, family support groups and networks, recreation programs, respite and child care programs).

Although personal strengths and methods of coping may have been successful in the past, the new demands and constraints that come with the child's illness or disability may make it difficult to use these coping strategies effectively. Or, it may be that the "tried and true" ways are not sufficient alone during the extremely stressful, complex, or chronic situations encountered as families realize and respond to their child's illness or disabling condition.

Ideally, these supports should be available within the community. Furthermore, the principles underlying family support services should: enhance a sense of community with shared concerns, mobilize resources to assist children and families, be a shared collaborative responsibility of families and professionals, protect family integrity and traditions, strengthen family functioning, and be exemplary of proactive human service practices (Dunst et al., 1994a).

In seeking to provide comprehensive support, the mandate for family-centered care becomes clear: endeavor to provide comprehensive support services that maintain, bolster, strengthen, sustain, endure, and even finance the enabling and empowering of the family's ability to cope. In doing so, programs can not ignore the reality that medical care, education, and community are inextricably linked. The child's health cannot be addressed in isolation from these factors. Comprehensive support does not mean that a single program or professional must provide all of these services. Rather, there should be a range of options available, which together encompass a comprehensive system of supports to meet the needs of the family, so that they are better able to meet the needs of the child.

Comprehensive support does not mean that a single program or professional must provide all of these services. Rather, there should be a range of options available, which together encompass a comprehensive system of supports to meet the needs of the family, so that they are better able to meet the needs of the child.

Educational Supports

It is impossible to describe supportive services without also considering the child's educational needs. Federal and state legislation have gone a long way in laying the groundwork for educating children needing specialized health and developmental care. Individualized education or family service plans, in-home tutoring, and the concepts of inclusion and least restrictive environment can provide the mechanisms whereby a child's educational development is encouraged, even in the face of a chronic illness or disability. But as Larry Bell, Parent Delegate from Delaware, commented at the 1992 conference *Healthy Children Ready to Learn:*

> *Being ready to learn is more than making our children ready for the schools. We need to make the schools ready for our children.*

This means creating coordinated programs that result in a community environment that supports the child and the family:

> *For me, integration is more than just ensuring that children with disabilities are included in neighborhood schools with their peers without disabilities. It is a movement that seeks to build a society that recognizes and accepts diversity, seeks out people's abilities and contributions, and is committed to equality (Abderholden, 1991).*

More importantly, addressing these needs in a family-centered way requires that families be given information and choices in achieving this aspect of their child's care plan. Penny McPhail, an ACCH Parent Network Regional Representative and a coordinator for early intervention services, adds an essential point when considering inclusion:

> *While I believe that full inclusion is the optimal educational environment, I also believe that for people with disabilities to be fully included in our communities, as well as in our schools, they must be given the option of choice. It would be a giant step backward if in our leap to implement full inclusion, we exclude the right of families to choose the educational option they view as most appropriate for their child and family (1994, p. 3).*

In attempting to provide supportive educational services in a family-centered way, the following suggestions can be used as a checklist to evaluate school policies and practices and to create a more supportive environment for students needing specialized services:

- Document the student's health management needs and goals and a plan for the services and accommodations necessary to meet the standard for a free and appropriate education in the least restrictive environment;
- Provide training, information and assistance to staff that enable them to support

the student's educational, health management, and social goals, to individualize and modify curriculum, to build effective teacher-parent partnerships, and to be responsive to changing needs;

- Provide medication in a timely, convenient manner and in a way that promotes the student's independence, self-care, and social interaction;
- Consider the impact of a student's condition, treatment, medications, or side effects on learning, behavior, or attendance when assessing performance or setting standards for grading and promotion;
- Develop individualized guidelines that allow the student to adapt participation in vigorous exercise, gym, or outdoor play;
- Anticipate the need for tutoring or make-up assistance to maintain academic and social continuity during periods of frequent and/or intermittent absences and to facilitate transitions between hospitals home, and school;
- Provide peers with education and sensitization; and,
- Consider appointing a school-based liaison to facilitate coordinated health management and service monitoring and evaluation (adapted from Goldberg, 1993).

Financial Supports

Resource-based supports, such as those addressing financial concerns, go beyond the provision of specific services (e.g., respite care or therapies) to encompass the range of resources that can be mobilized to meet specific needs (Dunst, Trivette, Starnes, Hamburg, & Gordon, 1993). Facilitating financial support for families can be a difficult task. Often, families suddenly find their resources rapidly exhausted as they struggle to meet the overwhelming costs associated with their child's illness or disability. Some families are forced into a position of having to choose whether to spend each dollar on something related to their child's need for specialized care, or to spend it on basic necessities for the child or other members of the family. This can be even more pronounced when the illness is catastrophic and/or chronic, or the disabling condition is complex, requiring multiple long term intervention services.

Many insurance companies impose annual or lifetime spending caps, or deny payment for indicated services related to the child's condition. Even for families with seemingly adequate health insurance benefits, the burden of repeated co-payments, out-of-pocket expenditures, and non-covered services quickly adds up, leaving many families who were heretofore appreciating financial security seeking public and/or private assistance.

Some families are forced into a position of having to choose whether to spend each dollar on something related to their child's need for specialized care, or to spend it on basic necessities for the child or other members of the family.

Frequently, families struggle longer or more than necessary because the system and professionals providing their child's care are either unaware of the family's needs, or unaware of the many sources of assistance that are available in the community, or at the state and national levels. Patience, persistence, and creativity are frequently essential during the process of accessing and securing various sources of financial support, but help is available. According to Rosenfeld (1994):

> *. . . a number of public and private programs provide care directly or help American families to pay for medical and related care. Some programs require that a child's family has limited income and 'resources.' Other programs require that a child fit a certain category of need. However, some programs can provide emergency or periodic help for any child or family in need (pp. 107-108).*

Nan Nelson, the mother of a child needing specialized services wrote of the difficulties she and her husband encountered when attempting to collaborate with professionals on the financial aspects of their daughter's care:

Our daughter was facing complicated eye surgery involving the removal of her right eye. Since we were paying out of pocket (pre-existing condition), we decided it was only fair to level with potential surgeons ahead of time so they could turn us down if our

> *financial circumstances were unacceptable to them. We also needed to know what we could expect to pay for this surgery, which meant that coupled with the anguish of having a child about to lose an eye was the burden that it was up to us to initiate awkward discussions about money. More than once we expected to be politely shown the door, and during these agonizing conversations we felt like we were being viewed as consumers looking for the best deal, as though we were negotiating medical procedures the way we'd consider an options package on a new car.*
>
> *Asking a doctor to talk about money feels like a breach of etiquette; it just isn't done. Perhaps the line 'if you have to ask what it costs, you can't afford it' typifies the medical profession's attitude. Whatever the reason, critical details about major medical expenses shouldn't be so difficult for families to come by (personal communication, September 1, 1994).*

. . . it cannot be expected that everyone be an expert, but it can be expected that professionals know where the experts are and how to access them and the available supports.

The key to providing financial support to children and their families is to keep informed of essential information: what the family needs in the way of supplements and supports, what local and national sources of support are currently available for meeting the varied financial needs of families, and the changing guidelines for eligibility. Additionally, it is important to keep informed of legislative policies that affect children needing specialized care and their families, that may in turn directly affect financial resources and programs. Individual professionals and programs may not always be the providers or support, but they should be aware of available resources:

> *It is important to remember that [when] a health care bill passes . . . a number of these programs may be changed. You will have to check with the agencies administering the programs . . . to see whether their roles have been affected (Rosenfeld, 1994, p. 109).*

The array of available resources changes so quickly and frequently that it cannot be expected that everyone be an expert, but it can be expected that professionals know where the experts are and how to access them and the available supports.

Environmental Supports

Another type of support that families frequently need, particularly as they are learning new skills necessary to adjust to an infant or young child's illness or disabling condition, is environmental or material support at home or in the hospital. Even for families whose children are older, when hospitalization is necessary, the environment is different and intimidating, and the situation can alter familiar roles and coping strategies. In these instances, institutions and individuals practicing sound psychosocial policy can facilitate family coping by identifying and eliminating physical barriers that detract from family-centered care (Rushton, 1990). Environmental and material supports can range from lounges for family members to adequate parking facilities to adaptive equipment or diets for a child.

Just as professionals need physical and environmental supports to meet the demands of the health care setting, families also have similar, basic needs that when met, would enable them to participate more fully as a member of the health care team (Stepanek, in press). These needs include such things as a place to sleep, and a place to take a break from the demands of the situation, especially when the setting is a critical care environment.

More and more hospitals are providing accommodations for parents to room-in with their children on general units. While it is not always possible for parents to room-in in all critical care environments, hospitals can provide other close by accommodations for sleeping and personal needs (Johnson et al., 1992). Family lounges can be both inviting and informing, with comfortable seating and nearby snack or meal preparation areas, as well as bulletin boards stocked with relevant information about the hospital, and community and national resources and services.

Emotional Supports

Families have many natural capabilities, but they may also need emotional support to affirm their positive contributions, and to enable them to act on choices and participate as a member of their child's care team (Families and Disability Newsletter, 1989). In recognizing the need for emotional support, it is essential to understand that a high level of stress is not necessarily a factor of psychological dysfunction; it may actually be the absence of appropriate support systems (Lipsky, 1985). Families of children needing specialized care are faced with reacting to an abnormal situation; but, they do not necessarily react abnormally (Graves & Ware, 1990).

The most common types of structured emotional support available for families are some type of individual counseling and support groups. These services can be provided by either a professional or another family member. While there are pros and cons to each type, both are well-documented and valued by families and professionals when provided in a non-judgmental way that promotes realization of family empowerment. Support groups may also vary in terms of which families they serve: some are very broad in scope, encompassing any family with a child needing specialized care, while others are very specific with regard to such characteristics as location, child's age, or nature of disability.

Regardless of leadership or focus of support, there are several basic strategies which when implemented, foster a truly supportive environment for families (Beckman et al., 1993; Newcomb et al., 1994). These include:

- Allowing the family to define "family," so that support services are available to anyone providing care to the child (e.g., biological parents, foster parents, grandparents, aunts and uncles, siblings, and other care providers):

- Allowing the family to decide the content to be discussed during support sessions so that specific individual and group needs are addressed;

- Ensuring that no family is declined the opportunity to receive individual or group support based on financial restrictions;

- Making support services truly accessible. This may involve holding sessions or groups during both evening and daytime hours to accommodate as many family members as possible; being flexible about the location of service delivery (e.g., hospital, home, community building) so that it is convenient to as many families as possible; and providing transportation for all members of the family, and/or providing child care for the child with a disability and any siblings when necessary so that all members of a family who would like to participate can receive support;

- Ensuring confidentiality, so that members of a family feel free to discuss a full range of emotions and concerns without fear of any negative effect on the ultimate care of their child or their standing as a team member; and,

- Providing multiple ways for families to evaluate support services so that they can be sustained or improved to meet the needs of families.

Providing families with emotional support can reduce feelings of isolation, increase self-esteem and feelings of acceptance, and be a valuable source of information and resources (Newcomb et al., 1994). Particularly with chronic illness and disability, when there may be little chance of a cure, there can still be individual, family, and even community healing (Jones, 1988). There needs to be in place a coordinated array of policies and programs which can support families, that focus on "human healing" beyond the concept of "disease curing" (Jones, 1994a). These services can act as a buffer for intrusion on personal and cultural values by those outside the family. And, they can be designed with the goal of providing *"a community of caring"* (DiVenere, 1988) and *"whatever it takes to maintain and enhance the family's capability to provide care"* (Knoll et al., 1990, p. 5).

Recognizing, respecting, and meeting individual and varied needs for support is a vital part of a comprehensive system of providing services to children needing specialized care and their families. It is important to recognize that there is not a single "right" way to support a family. Families are diverse in composition, and in their strengths and needs, and concerns

In recognizing the need for emotional support, it is essential to understand that a high level of stress is not necessarily a factor of psychological dysfunction; it may be actually the absence of appropriate support systems.

and priorities. Some families need very little formal support, and other families need a great deal of support in many areas.

In providing family-centered services, families need choices with regard to the type of support services that are available, and choices of which programs they would like to access to meet their needs. When professionals and service systems are able to support families and meet the needs associated with the specialized care of their children, they can truly achieve comprehensive family-centered services. This, in turn, can improve the quality of life for children and their families, and enhance family coping and functioning.

Making It A Reality

If the philosophy of family-centered care is to be translated into practice, then comprehensive programs, policies, and resources must be developed that meet the individual and changing support needs expressed by family members. Creative and coordinated approaches are necessary to address diverse educational, financial, environmental, and emotional concerns. This section lists examples of some of the many ways in which facilities, communities, and states can offer support for all family members, and for professionals working with families, in hospital-, home-, and community-based settings.

Organizations

ABC for Health, Inc.
Madison, WI

ABC for Health, Inc. is a non-profit public interest law firm dedicated to ensuring that families have equal access to health care that is coordinated, community-based, culturally-competent, and family-centered. This organization fosters opportunities for consumer participation in shaping the health care system through a variety of activities and publications. Current projects include the Rural Health Outreach Project (KIDS CARE) and the Legal Assistance in Health Care Financing Project. ABC for Health provides direct health benefits counseling and legal services free of charge, and is funded by grants from the government and private foundations, and by individual contributions. **For more information, contact ABC for Health, Inc., 152 West Johnson Street, Suite 206, Madison, WI 53703 (PHN: 608/251-2323).**

The Children's Resource Center
Children's Hospital and Medical Center, Seattle, WA

The Children's Resource Center at the Children's Hospital and Medical Center provides a Children's Resource Line staffed by registered nurses to address specific and general health concerns of families in the community, a Community Education Program about children, families, and health care, and a Family Resource Center. The Family Resource Center is a quiet and relaxing place for parents and family members, with a play area for children. Its purpose is to provide various types of information to families, such as books and pamphlets about parenting, growth, and development, and also about childhood illnesses and disabilities.

Open 24 hours a day and staffed by a health educator, a program coordinator, and trained volunteers during typical working hours on weekdays, The Resource Center also has magazines, paperback books, daily newspapers, and information about local resources and events, and hosts lockers, showers, and private spaces for family members of children in the hospital. A chapel, open 24 hours a day, is located in the Resource Center wing. **For more information, contact The Children's Resource Center, Children's Hospital and Medical Center, 4800 Sand Point Way NE, P.O. Box C5371, Seattle, WA 98015 (PHN: 206/526-2201).**

Family Resource Coalition
Chicago, IL

The *Family Resource Coalition* is a national leader in the family support field. A not-for-profit membership organization, it develops resources for programs, provides information for developing public policies, and works to increase public understanding of and commitment to families. The Coalition: manages the National Resource Center for Family Support Programs; provides technical assistance and training services for programs, schools, and government agencies; publishes research and how-to materials on family support issues; and, sponsors national and regional conferences. **For more information, contact the Family Resource Coalition, 200 S. Michigan Avenue, Suite 1520, Chicago, IL 60604 (PHN: 312/341-0900).**

Institute for Family-Centered Care
Bethesda, MD

The *Institute for Family-Centered Care* promotes understanding and practice of family-centered care to ensure that the needs of children and families receiving specialized health, education, mental health, or social services or supports are appropriately met. In partnership with families and professionals from many disciplines, the Institute develops and disseminates research and publications, and provides consultation, training, and technical assistance. Projects include training seminars for parent/professional hospital teams, promoting excellence in design in child health facilities, technical assistance on family-centered care to Ryan White Title IV programs, and an annual seminar on family-centered care for physicians. **For more information, contact The Institute for Family-Centered Care, 7900 Wisconsin Avenue, Bethesda, MD 20814 (PHN: 301/652-0281; FAX: 301/320-0048).**

National Early Childhood Technical Assistance System (NEC*TAS)
The University of North Carolina, Chapel Hill, NC

Through a contract with the Office of Special Education Programs, U.S. Department of Education, *NEC*TAS* assists states and other designated governing entities in developing multidisciplinary, coordinated, and comprehensive services and supports for children needing specialized care and support, birth through eight years of age, and their families. NEC*TAS is coordinated by the Frank Porter Graham Child Development Center at the University of North Carolina, and collaborates with a variety of other universities and national organizations of families and professionals. **For more information, contact CB# 8040, Suite 500, NCNB Plaza, Chapel Hill, NC 27599 (PHN: 919/962-2001).**

North Carolina Assistive Technology Project
Raleigh, NC

The *North Carolina Assistive Technology Project* is creating a statewide system that will benefit children and adults with disabilities across all aspects of their lives — education, employment, recreation, and independent living, by coordinating assistive technology services. Assistive technology is any piece of commercial or customized equipment or device that is used to increase the independence of individuals with disabilities (e.g., wheelchairs, augmentative communication devices, prostheses, computers, visual aids, adapted toys and sports equipment). The activities of the Project include technical assistance, information and referral service, awareness and training, expansion projects, consumer groups, statewide networks, systems change, and interagency collaboration. Four demonstration projects located throughout the state display a variety of assistive technology devices for demonstration and "hands-on " activities. The Project, which works collaboratively with the Family Support Network, also publishes a quarterly newsletter with articles from consumers and others. **For more information, contact The NC Assistive Technology Project, 1110 Navaho Drive, Suite 101, Raleigh, NC 27609 (PHN: 919/850-2787 or 1/800/852-0042).**

Programs, Policies, and Practices

Access to Respite Care Help (ARCH): National Resource Center for Crisis Nurseries and Respite Care Services
The Chapel Hill Training-Outreach Project, NC

The *ARCH National Resource Center for Crisis Nurseries and Respite Care Services* provides support to service providers and families through training, technical assistance, evaluation, and research. ARCH is a consortium that includes the North Carolina Department of Human Resources, the Chapel Hill Training-Outreach Project, the Texas Respite Resource Network, and the Frank Porter Graham Child Development Center. ARCH conducts an annual national conference, regional conferences, presentations at other conferences, quarterly newsletters, bi- monthly resource packets, and a national crisis nursery and respite care directory. **For more information, contact ARCH, 800 Easttowne Drive, Chapel Hill, NC 27514 (PHN: 1/800/473-1727 or 919/490-5577; FAX: 919/490-4905).**

The Advocacy Center
Rochester, NY

The Advocacy Center helps individuals with disabilities and their families by providing information, linkages, support, and representation that can turn "visions into realities." Primarily serving individuals with developmental disabilities or brain injuries and their families, this organization offers support through newsletters in two languages, workshops, conferences, resources, and advice about the rights of individuals with disabling conditions. They also provide referrals to other programs, family-to-family connections, service coordination, legal assistance and advocacy, support groups, and emotional and financial assistance and preparation. Funded by the Monroe Developmental Disabilities Service Office, their "Resource Line" provides up-to-date information and guidance on issues including education, health care, respite, legal rights, recreation, training, finances, and other support services affecting individuals with disabilities and their families. **For more information, contact The Advocacy Center, 242 Andrews Street, Suite 205, Rochester, NY 14604 (PHN: 716/546-1700; Spanish: 716/546-6757).**

The Caregiver's Resource Company
Bellevue, WA

The Caregiver's Resource Company offers life and disability insurance, trust funding, and employee benefits planning for individuals needing specialized care. They also produce a caregivers' guide to assist families in planning for the future. This resource tool helps families organize the way they inform others about their children's specialized needs, medical history, daily living requirements, strengths, weaknesses, likes and dislikes, as well as individual families' concerns and priorities for their children. The guide is divided into sections which address family, medical, daily living, personal, legal, and financial information, and is designed to allow families to duplicate and update information as needed. **For more information, contact John Leitch, President, Warren and McGinnis Company, P.O. Box 3734, Bellevue, WA 98009 (PHN: 206/455-1603).**

The Children's House at Johns Hopkins
Baltimore, MD

The Children's House at Johns Hopkins provides a family-centered, supportive residence for children receiving care at the Johns Hopkins Children's Center or at the Kennedy Institute, and their families. The facility provides a way to keep families together in the midst of medical crises, to reduce stress, and to promote self-help and mutual support. Part of the Children's House is used to promote a Care-By-Parent program for families whose children have had major surgery (e.g., an organ transplant). This program provides families with a place to stay after their child's hospital discharge, offering them the opportunity to learn how to meet their child's specialized needs in a comfortable setting close to the hospital. The Children's House also has a resource library, and serves as a center for educational, support, and therapeutic groups within the community. Individual and corporate donations have made the Children's House a reality, and the construction was coordinated by the Grant-A-Wish Foundation with donated services and materials. **For more information, contact National Headquarters, P.O. Box 21211, Baltimore, MD 21228 (PHN: 410/242-1549; FAX: 410/242-8818).**

The Children's Oasis Project
Children's Hospital of New Mexico and Carrie Tingley Hospital

The Children's Oasis Project provides family members of children with critical or chronic illness, a short break from the demands of being at the bedside. Parents designate which family members will receive the respite. After approval, family members are given a gift certificate from a selected restaurant and/or tickets to a movie or other special events. The project is funded by the Grant-a-Wish Foundation. **For more information, contact Kim Schwartz, Children's Oasis Project, University of New Mexico Health Science Center, 2211 Lomas Boulevard NE, Albuquerque, NM 87106 (PHN: 505/843-2671).**

The Family Empowerment Network (FEN)
Madison, WI

The goal of *The Family Empowerment Network* is to provide support, education, and training to families affected by Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE), and to the professionals working with these families. The FEN networks nationally with families, family support groups, and professionals, coordinating activities that include: an annual family retreat; a toll-free family advocacy line; a monthly educational teleconference; an annual national conference; a quarterly newsletter; and, other resource materials, technical assistance, and educational workshops throughout the year. **For more information, contact The Family Empowerment Network, 610 Langdon treet, Room 521, Madison, WI 53703.**

Healthy Kids: The Key to Basics
Newton, MA

Healthy Kids: The Key to Basics is an information and consulting service promoting medical and educational equity for students with chronic illnesses or disabilities. They offer a pamphlet on educational planning and other resources. **For more information, contact Ellie Goldberg, M.Ed., Educational Rights Specialist, 79 Elmore Street, Newton, MA 02159.**

Help Encourage Advocate Resources Training Support (H.E.A.R.T.S.) Connection
Kern Infant Council, Bakersfield, CA

The *H.E.A.R.T.S. Connection* is a family resource center founded in 19[illegible] by parents of children needing specialized care and by service providers involved with the Kern Infant Council. The mission of H.E.A.R.T.S. Connection is to enhance the quality of life for children needing specialized care and their families through: sharing resources, experiences, and information between families; providing education and training at meetings and workshops; offering family and sibling support; maintaining a central resource library; improving collaboration between families and service providers; networking families with children needing specialized care; providing public awareness and outreach activities; and, referring families and service providers to other available resources.

H.E.A.R.T.S. Connection was originally part of a nationwide federal early intervention grant project, aimed at working in collaboration with regional centers, schools, hospitals, and various agencies and organizations. The program is now funded by a federal grant under Public Law 102-119 (IDEA), along with individual and corporate donations. **For more information (in English or Spanish), contact H.E.A.R.T.S. Connection, Family Resource Center, 3200 North Sillect Avenue, Bakersfield, CA 93308 (PHN: 805/327-8531).**

My Other Me (MOM): Doll Play Therapy Dolls
Ontario, Canada

My Other Me (MOM): Doll Play Therapy Dolls assist health care workers in demonstrating medical procedures by allowing children to repeat the procedures that have been done on them on the soft-bodied, featureless dolls. These activities offer children a developmentally-appropriate outlet for concerns, fears, and emotions. Children are allowed to keep the dolls, whose faces and "specialized supports" are individually designed for or by each child. Funds for the project are donated from community groups and local service groups. **For more information, contact Darlene Dupe (PHN: 519/462-1066) or Sharon McConnell (PHN: 519/623-1019), 9 King Crescent, Hickson, Ontario, Canada N0J 1L0.**

The Psychosocial Team
Pediatric Emergency Department
Children's Hospital Medical Center, Cincinnati, OH

The Psychosocial Team in the Pediatric Emergency Department provides education and support for families and staff dealing with medical crises, traumatic injury, psychiatric emergencies, the death of a child, and abuse and neglect. One of the activities of the team is conducting a "critical incident stress debriefing" for staff members — a structured, confidential group meeting focusing on ventilation of thoughts and feelings related to a critical event. The debriefings have been found to decrease job-related stress and enhance coping, thus enriching staff members' abilities to provide holistic family-centered health care. **For more information, contact Jenifer Varhola or Kathleen Zink, Children's Hospital Medical Center, 3333 Burnet Avenue, Cincinnati, OH 45229.**

Respitality Program
The Radisson Hotel and The United Cerebral Palsy Association

The Radisson Hotel Chain and the United Cerebral Palsy Association (UCPA) have teamed up to give parents of children with disabilities a break. Through the *Respitality Program*, Radisson offers parents a free weekend away from home while the UCPA coordinates and pays for respite care for their child with a disability at home. There are no income guidelines to participate, and any family of a child with a disability between ages one and 18 is eligible, although priority is given to children with cerebral palsy or related disabilities. The program is operating nationwide, with a goal of at least one weekend per hotel each month being offered. **For more information, contact UCPA of Minnesota at 612/646-7588 or UCPA National at 1/800/872-5827.**

The Washington Area Wheelchair Society (WAWS)
Silver Spring, MD

The WAWS Annex is a clearinghouse for donated medical equipment needed by individuals with disabilities and their families. This program: accepts all donated durable medical equipment (e.g., manual and power wheelchairs, shower chairs, van lifts, walkers, corner seats, sidelyers, and standers); provides storage, parts, and repairs using volunteer labor; and, loans the equipment to families in need at no charge. WAWS offers information about medical equipment and about resources available from other volunteer wheelchair clubs run by community organizations such as Kiwanis, Jaycees, American Legions, local churches, and employee groups. There is also a Make-a-Memory program of WAWS, structured to provide practical and social experience outside of the home for individuals with life-threatening illnesses and chronic disabilities. This is done by: submitting individual referrals to programs such as Make-A-Wish. Ronald McDonald, and Sunshine Foundations; providing specialized recreational equipment to structured therapeutic programs in local institutions; and, coordinating all-day picnics at recreational and theme-park locations with WAWS volunteers providing specialized assistance to individuals with disabilities. **For more information, contact The Washington Area Wheelchair Society, 912 Thayer Avenue, #108, Silver Spring, MD 20910 (PHN: 301/495-0277).**

Resources

Candlelighters Childhood Cancer Foundation Quarterly Newsletter, and Youth Newsletter
American Cancer Society

The mission of *Candlelighters* is to educate, support, serve, and advocate for children with cancer and their families, survivors of childhood cancer, and the professionals who care for them. The information provided by the organization enables families to make educated decisions concerning their child's illness, and to play a more active, informed role in treatment and care. Support is available to children, families, and professionals through a variety of resources, including: newsletters for and by children with cancer and their siblings; newsletters with articles and poetry for and by parents and professionals; handbooks, pamphlets, resource guides, and other media; a Speakers Bureau; and, a toll-free hotline. More than 400 peer support groups are available through this worldwide network, which provides information, problem-solving, socialization, bereavement support, emergency funding, recreation, transportation, and guidance at regional and national levels. **For more information, contact The Candlelighters Childhood Cancer Foundation, 7910 Woodmont Avenue, Suite 460, Bethesda, MD 20814 (PHN: 301/657-8401 or 1/800/366-2223; FAX: 301/718-2686).**

Family Assessment in Early Intervention

D. Bailey & R. Simeonsson (1988)

Family Assessment in Early Intervention examines issues related to the systematic assessment of family strengths and needs — a crucial component of the Individualized Family Service Plan process federally mandated in the early intervention system. The book provides necessary information to design and implement a comprehensive assessment and to collaborate in goal-setting with families. **Available through ACCH, this resource is published by MacMillen Publishing Company, Philadelphia, PA.**

Helping Children By Strengthening Families: A Look at Family Support Programs

Children's Defense Fund

Helping Children by Strengthening Families is a book on family support and education programs with three major goals: to help every child get the best possible start in life; to prevent problems before they become serious and require costly treatment; and, to prepare and support families to best meet the physical, emotional, and intellectual needs of their children. This book provides child advocates, community leaders, policy-makers, and others who work for children's well-being a clearer idea of what family support programs do, how they operate, and why they are effective for all families. Published by the Children's Defense Fund, it also describes a variety of family support and education programs in action. **For more information, contact The Children's Defense Fund, 25 E Street, NW, Washington, DC 20001.**

Paying the Bills: Tips for Families on Financing Health Care for Children with Special Needs

New England SERVE (1992)

Paying the Bills is a booklet written by parents who have children needing specialized services and supports. The authors have tapped their own experiences, as well as those of other families and professionals, to share information and strategies for getting payment for children's health and developmental care. This resource encourages families to ask questions, to learn about the health financing system, and to be persistent in attempts to make the system work to meet the needs of their family. **For more information, contact New England SERVE, 101 Tremont Street, Suite 812, Boston, MA 02108 (PHN: 617/574-9493).**

Supporting and Strengthening Families, Volumes 1 and 2

C. Dunst, C. Trivette, & A. Deal (Eds., 1994)

Supporting and Strengthening Families is a collection of papers that builds on the thoughts, models, and practices described in the authors' previous books on enabling and supporting families. This book addresses theory, practice, and outcomes of adopting an empowerment and resource-based approach to supporting families and strengthening individual and family functioning. **Available through ACCH, this resource is published by Brookline Books, Cambridge, MA.**

Therapeutic Play Activities for Hospitalized Children
R. Hart, P. Mather, J. Slack, & M. Powell (1992)

This resource details play activities for children who are hospitalized in any hospital unit. Organized according to subject, the format provides at-a-glance information on intended age of participants, staffing ratios, and time required to complete an activity. **Available through ACCH, this resource is published by Mosby Publishing Company, St. Louis, MO.**

Understanding Your Health Insurance Options: A Guide for Families Who Have Children With Special Health Care Needs
M. McManus (1988)

This small easy-to-use consumer guide can help families who have children needing specialized services and supports better understand their health insurance options, and select plans most suited to their needs. **Supported as a Special Project of Regional and National Significance (SPRANS) from Maternal and Child Health Bureau, this resource is available through ACCH.**

Whispers of Hope: A Hospital-Based Program for Bereaved Parents and Their Families
T. Rose & E. Stewart (1993)

Whispers of Hope is a resource guide that serves as a model family-centered approach to supporting bereaved families through a hospital program. The book details a variety of ways to support families through letters, educational material, family conferences, personal communications from staff, an Annual Day of Remembrance, and a Family Lending Library. Appropriate record keeping and evaluation information is also discussed. This resource was funded with assistance from the Duke Children's Miracle Network Telethon. **Available through ACCH. For more information, contact Duke Pediatric Brain Tumor Family Support Program, DUMC 2916, Duke University Medical Center, Durham, NC 27710 (PHN: 919/684-5301).**

You and HIV: A Day At A Time
L. Baker (1991)

Written for children and adolescents with HIV and their family members, *You and HIV: A Day At A Time* is an easy-to-read, illustrated book. Children and families reading the book are guided through the medical and psychological "what's and why's" of HIV — transmission, diagnosis, treatment, home care, and emotional responses. This resource strongly emphasizes positive approaches to living with the disease, and provides space for personal notes and other information. **Available through ACCH, this book is published by Harcourt, Brace and Company, Troy, MO.**

Encouraging and facilitating family-to-family support and networking.

Photo courtesy of Project Assist Family Support Group, The University of Maryland, College Park, MD.

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Peer Networking

Most families establish individual networks of friends, relatives, or professionals such as clergy, on whom they rely for support as they encounter challenges of life. Ironically though, the birth of a child with a chronic illness or disability, or the diagnosis of a condition, may isolate families from the very sources of informal support that could be most helpful. Family-to-family support — from informal discussions with other parents in hospital lounges to membership in groups that meet regularly and consistently across many years — is very powerful. In fact, one of the most effective ways to provide comprehensive support to children and families is by encouraging and facilitating family-to-family support.

What Does This Mean?

In recounting her own experiences and those of many other parents of children needing specialized care, Helen Featherstone (1980) noted that a disability or chronic illness may isolate families in a variety of ways. Some may feel shut out by the physical limitations that an illness or disability may impose. Others may feel isolated because of a lack of understanding they encounter in the wider world, or even among family and friends.

Because some people feel awkward with pain and difference, the child and his or her family as well may be avoided — even by other family members (Ferrari, 1986; Friedrich & Friedrich, 1981; Gabel & Kotsch, 1981). This is particularly evident among certain families such as those who have children who test positive for the Human Immunodeficiency Virus (HIV) infection which can lead to Acquired Immune Deficiency Syndrome (AIDS). Many fear the withdrawal of support and empathy, even by other individuals in their own families, precisely at the time that it is most needed (Spiegel & Mayers, 1991). Still others may feel a sense of isolation from within because of a personal sense of their own family's uniqueness. Their consciousness of difference can make them feel very much alone on occasion. Failures of others to understand their special concerns can intensify the problem. In July, 1988, at the *Family Meeting on Pediatric AIDS*, families reported that having access to support groups made up of other families of children with HIV infection was a primary source and support.

Having contact with another family that has a child who is ill or has a disablility can make all the difference. Formal family support groups, whether led by a family member or by a professional, can result in improvements in parenting satisfaction (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983), personal health and well-being (Cohen & Syme, 1985; Wallander et al., 1989), and feelings of well-being in the family (Patterson & McCubbin, 1983). These improvements are more likely to occur when programs provide support and information that match the needs identified by individual families.

While formal groups can be helpful, there is something unique about family-to-family support.

While formal groups can be helpful, there is something unique about family-to-family support. The instant connection that can be formed between families is eloquently expressed by a father attending a support group for the first time, who after observing the discussion for 20 minutes commented:

> *'You guys must know each other really well to talk this openly.' 'Not really,' [another] man said, 'it's just that we have so much in common' (May, 1992, p. 1).*

It is this power of shared experience that uniquely characterizes family-to-family support.

Benefits of Family-to-Family Support

Family-to-family support may actually be more effective than professional support in developing the informal supports (e.g., friendships, knowledge of community programs, local resources) that can sustain a family long after a particular group has stopped meeting. In fact, there are consistent findings that the benefits to families from informal support can often be greater than that attributable to formal support sources (Beckman et al., 1993; Dunst et al., 1988). As Vincent, (1988) notes:

> *Families are succeeding because they are able to build support networks which they can call upon when their individual resources are not enough to solve their problems. Parents are most likely to rely upon family members, friends, neighbors, or co-workers for support when confronting problems in raising their children . . . Only as a last resort do they consult professionals . . . We need to focus more of our attention on helping families develop and strengthen their own support networks (p. 3).*

Family-to-family support is a means of: helping parents and families feel less isolated; receiving and providing empathy between those who truly understand; being able to share similar experiences; gathering and sharing information, resources, and problem-solving strategies; exploring ways to improve systems; building friendships; and, sharing, developing, and nurturing hope.

Whether providing mutual support and friendship, information gathering and sharing, or advocacy and improving the health care system (Nathanson, 1986; Rawlins & Horner, 1988; Smith, Gabard, Dale, & Drucker, 1994), contact with another family can be supportive in varied ways, and at different times, and can serve different purposes depending on an individual's relationship to a child. As Ellie Valdex-Honeyman, Parent Delegate from Colorado said at the 1992 *Healthy Children Ready to Learn — The Critical Role of Parents* Conference:

> *Parent to parent — that can mean a lot of things. But, parents, I suggest that we need each other. No matter whether we're a step parent, a foster parent, single parent, the birth parent, adoptive parent, grandparent — we need each other. And we can help each other by supporting, mentoring, role modeling, whatever it is that links us together — we need each other.*

Through participation in such groups, families report having a chance to develop supportive relationships with other families that transcend any specific goals of the program.

The importance of family-to-family support has been supported not only in the research literature, but it is also highlighted in policy. When former Surgeon General C. Everett Koop pledged a national commitment to children needing specialized care in 1987, he declared that parent-to-parent support must be encouraged and facilitated by health care providers as a complement to professional support, and incorporated as a key element of family-centered care (U.S. Department of Health and Human Resources, 1987). Family-centered care requires that the changing needs of the family be viewed not in isolation, but within the context of its social support system (Mitchell & Trickette, 1980).

Informal support networks are not meant to replace formal resources. Rather they are a unique resource, and an addition to the wealth of resources available to meet the varied needs that exist within and across families. The support that another family can provide cannot be underestimated (Arango, 1990; Johnson, 1990; Newcomb et al., 1994; Rushton, 1990;). Family-to-family support is a means of: helping parents and families feel less isolated; receiving and providing empathy between those who truly understand; being able to share similar experiences; gathering and sharing information, resources, and problem-solving strategies; exploring ways to improve systems; building friendships; and, sharing, developing, and nurturing hope:

> *From the first word our conversation was unguarded. . . . We communicated in an insider's language, a vocabulary scoured, for once, of gloss or apology or subterfuge. Among ourselves, we didn't need to temper our sentiments. . . but had the liberty of telling each other the truth as we had come to know it. For two hours we opened the doors to our secret rooms, merged the parallel universes each of our families inhabited (Dorris, 1989, p. 202).*

Barriers to Networking

Family-to-family support works. However, even when the value of family-to-family support is recognized, there are many potential barriers which not only limit its use, but sometimes lead to discouraging this type of communication and support (Stepanek, in press). Often policies designed to protect the rights and privacy of families may work against linking families with families. For example, it is vitally important to respect the confidentiality of information families have shared, asking their permission to send reports or to share details with another professional. However, concerns about breaching confidentiality may also result in a reluctance on the part of professionals to give the name of a family to a support group. As one parent noted:

> *Finding them [other parents] was surprisingly difficult. Through policies of confidentiality and professional territorality, the system impeded our access to each other instead of encouraging this crucial human contact (Oster, 1985, p. 30).*

This potential barrier may be overcome easily by providing families with information about family-to-family support before the family asks. However, even this may not be enough. Featherstone, (1980) and others have noted that during the initial period following the birth or diagnosis of a child with a disability or chronic illness, families may be so swamped by emotions, information, the day-to-day care and decisions, and changes in their vision of the world and their own future, that there is little time to worry about loneliness. In the months, years, and even decades that follow, however, many families feel isolated at times. A parent commented:

> *There is no worse feeling than thinking you are the only one out there with the problem. I wasn't able to make the call for two years. I wish someone had linked us. Never assume that folks with lots of support don't need a support group. Ask, and offer to make the call (Parent quote from videotape Empowering Parents, Parent Advisory Council, Phoenix Children's Hospital).*

To make sure that these families could have access to this very important form of support, simply ask the family's permission to give their names to a family support group or resource center. That way, the group can contact the family and when they are ready, support will be available.

Sometimes support is delayed when attempts are made to match families on the basis of their child's condition. While having the opportunity to talk with another parent whose child has the same illness or disability can be extremely supportive, particularly in sharing information about the particular diagnosis, the provision of support should not be delayed because a "match" is not available. Family-to-family support can be just as effective across diagnostic categories as within a specific illness or disability.

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Families of children needing specialized care have many concerns in common. When the emphasis is shifted away from a medical model, from the disease to a consideration of the child and the family, the common issues far outweigh the differences. Financial concerns, the need for respite care, difficulty coordinating services, and wanting someone to talk to can be as important to a family whose child has cerebral palsy as it is to the family whose child has cancer. The "non-categorical" family-to-family support groups, together with the more disease specific groups, all have a role in providing emotional, educational, and programmatic support for families whose children need specialized health and developmental care.

There are other potential barriers to the development of strong formal or informal family-to-family support networks. Oftentimes, the families who most need and want support are unable to attend networking meetings because of logistical issues such as the lack of transportation or child care (e.g., Newcomb et al., 1994; Smith et al., 1994). Problems such as these can be remedied by incorporating family input about specific concerns and needs related to support in the design, evaluation, and evolution of support programs.

Furthermore, professionals sometimes are unaware of the value of support groups, unaware of the options that exist, or unaware of the importance of including this as a standard offer when making discharge plans or telling families of their child's diagnosis. A professional spoke of genuine concern when other professionals do not appreciate the value of this support, which can be conveyed in the manner in which this information is offered:

> *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. . . and you give them a flyer. You put one out in the waiting area and hope maybe they accidentally glance at it and see that there is parent support around (Poyadue, 1986).*

. . . it is essential to recognize the diversity of family needs and desires, to provide broad-spectrum systems of support, and to encourage and facilitate family-to-family support for all family members.

Incorporating Family-to-Family Support Into Policy and Practice

Thus, an essential component of family-centered care is that professionals do whatever they can to link families together. There are a number of ways to facilitate this special type of support, including:

- Make referrals to the groups;
- Provide places for families to meet or help groups find a place in the community;
- Facilitate access to transportation (e.g., program vehicle, organizing carpools, or reimbursement for buses, taxis, and cars);
- Facilitate access to important sources of information such as medical records, hospital libraries, and research on new treatment approaches;
- Provide inservice training or speakers (at no cost);
- Conduct research documenting the benefits of this type of support;
- Offer concurrent groups, which can give brothers and sisters the opportunity to get together, and offer the option for fathers and mothers to meet separately and together;
- Offer child care during meeting times (e.g., facilitate respite care, train volunteers, pay older siblings to provide supervised care);
- Make program services available such as typing, photocopying, and mailing services; and,
- Submit grant proposals to fund support groups.

Different people perceive stress in different ways. What individual supports are needed will vary across and within families. How support and information is conveyed to a family — by whom and in what manner, can have a significant impact on how each will be received by that family (Poyadue, 1988). To ensure that comprehensive family-centered support is available for children needing specialized care and their families, it is essential to recognize the diversity of family needs and desires, to provide broad-spectrum systems of support, and to encourage and facilitate family-to-family support for all family members. While many programs recognize that the child must be viewed in the context of his or her family, services often imply that the "family" consists only of the "mother." However, as detailed at a conference on family leadership training:

> *A family is a group of people who are important to each other and offer each other love and support, especially in times of crises . . . To be sensitive to the wide variety of life styles, living arrangements, and cultural variations that exist today, the family. . . can no longer be limited to just parent-child relationships . . . Family involvement must reach out to include: mothers, fathers, sisters, brothers, grandparents, neighbors, and other persons who have important roles in the lives of people with disabilities. (OSERS Family Leadership Conference, 1991).*

Options for support should be extended to all members of the child's "family" as defined by the family. This might include biological, adoptive, foster, or surrogate parents, as well as grandparents and other relatives, or even close friends directly involved in some aspect of the child's and family's care. In providing comprehensive family-centered support then, it is important to be open-minded, creative, respectful, and accepting in designing, facilitating, and maintaining family-to-family support, so that the needs of all family members be addressed.

Peer Support for Fathers

Historically, support groups have been attended primarily by mothers, and in many ways, geared more toward mothers. Yet, if one considers the child's family as a whole, support must be available for fathers as well, and that support should be specifically tailored to the needs of fathers. The reasons fathers attend support groups — a chance to express oneself in confidence, to learn new information, to share feelings, to relax, to be understood — are not really different from the reasons mothers may attend. However, the ways to support those needs may be quite different from other family members.

Parenting models for fathers, at least in Western culture, include: having an active and physical relationship with their children, particularly in play; being in control; protecting one's family; being the problem-solver; and, being self-sufficient (May, 1991). When a child is born or diagnosed with a chronic illness or disability, these roles may be difficult to fulfill (Gallagher, Cross, & Scharfman, 1981; Price-Bonham & Addison, 1978; Pruett, 1987). Fathers may not be able to "protect" their child from the illness or disability. Many decisions may be out of their hands, or appointments are made at times when fathers may be unable to attend, particularly when collaboration between professionals and families is less than ideal. They may have difficulty learning about new or different ways to play and parent their son or daughter. And finally, being self-sufficient may take its toll. As a result, fathers of children needing specialized care need support.

Similar to the research on the effectiveness of family-to-family support in general, research on the effectiveness of support groups for fathers has also been confirmed (Markowitz, 1984; May, 1991; Vadasy, Meyer, Fewell, & Greenberg, 1985). Enhanced self-esteem, decreased stress, depression, and fatigue, and improvement in their relationships with their children are just some of the outcomes that have been documented. In addition, as support helps fathers to be more active in the care of their children, benefits for the whole family result as well. As physical and emotional stress and tension decrease, families report improved communication, increased sharing of chores and responsibilities, and increased family harmony (Frey, Fewell, Vadasy, & Greenberg, 1989).

In his book, *Circles of Care and Understanding* (1992), James May noted that support programs may not be available locally, nor will all fathers use this type of group. However, if one respects an individual's choice of coping, this means that support must be available for those fathers who do choose to attend such a group. May, (1992) outlines some important ways in which other family members and professionals can be supportive of fathers as they define their goals for themselves in relationship to their families, and as they strive to meet those goals, such as:

- Demonstrate a willingness to involve the men that emotionally touch a child's life in a positive way, including grandfathers, stepfathers, extended family members, neighbors, and friends;
- Involve them by valuing a father's perspective as different from a mother's. Create opportunities for fathers to share this information and their skills;
- Ensure that men are offered the opportunity to learn the skills necessary to share in the responsibilities of caring for and advocating for their child;
- Support men in finding ways in which they can share their feelings, especially their "fears," in a comfortable way;
- Provide fathers with the needed places to grieve their losses and to celebrate their joys. Relegating all the "feeling" to women in the family is just as unfair to men as it is burdensome to women; and,
- Create opportunities for fathers to learn new roles, expand their knowledge of children, and explore their own conception of parenting including their relationship with their own fathers.

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Peer Support for Siblings

Sibling support is equally important for the brothers and sisters of a child with a chronic illness or disability. While they share many of the concerns expressed by their parents, children have questions and worries that are specific to their age, their sibling, and their personal situation and means of coping. They may be uncertain about the nature and extent of the disability. They may be worried that they might have caused the illness, or concerned that they, too, will get sick. Concerns about helping to care for their brother or sister, guilt about having negative feelings, feeling a pressure to achieve to "make up" for the illness, as well as concerns about their own and their sibling's future can all have a negative impact on other children in the family, and may lead to feelings of isolation. Just as with their parents, sibling-to-sibling support can help children cope, and provide a safe haven for addressing their concerns.

For many years now, children with illnesses or a disabling condition have been called children "with special needs." After hearing well-meaning professionals and others refer to their brother or sister as "special," many siblings wonder where that leaves them. Aren't siblings, and their unique and diverse needs special too? In addition to a shift in language labeling the care and services a child needs as specialized, rather than a child and his or her needs as being special, sibling support groups can fill this need to feel special without having an illness or disability. It is very important for children, as well as parents and other family members, to have an understanding that they are not alone.

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Despite the many concerns, questions, emotions, and fears related to their sibling's illness or disability, research has documented that there are also positive outcomes as a result of having a brother or sister with a disability or chronic illness (Carlson, Leviton, & Mueller, 1993; Turnbull & Turnbull, 1986). Sibling groups can reinforce some of the positive outcomes that have been identified such as pride, loyalty, insight, appreciation of good health, and family bonds. Providing services to the brothers and sisters of children with disabling conditions is not only sound practice, but its benefits can also lead to improved relationships and outcomes for the family and child needing specialized services.

Peer Support for the Child

In providing family support, it is important not to overlook the needs of the child with a chronic illness or disability. Children, like their parents and families, are not always comfortable and familiar with the environment or the information they must face during hospitalizations. They may have their own fears, concerns, and questions. Many children, especially younger children, do not always know what is happening to them, or why.

These children need information; they need an opportunity to talk and to share experiences with other children; and, they need an opportunity to talk about their disability. Children needing specialized care also need an opportunity to express their concerns about their own health and future. Although these types of things are often discussed with parents and other family members, children need peer support, and an opportunity to talk about their concerns without fear of worrying their parents.

Peer Support for Professionals

Another area of support that fosters the development and implementation of true family-centered practices, yet is easily overlooked, is that of facilitating peer support for the professionals who care for children who are ill or have disabling conditions. Professionals may be well-trained in their field and discipline, as well as in psychosocial care, family perspectives, and recognizing and meeting the diverse needs of children and their families. But in addition to skill, experience, and sensitivity, motivation of personnel is also a significant factor in meeting the needs of children and their families.

Professionals are more likely to treat families with respect and support if they, too, are treated with respect and support. Studies report that there is greater staff cohesion when supervisors of hospital units express strong support for their staff, and are willing to listen to and advocate for them (e.g., Browner, 1987).

Although professionals working with children who are ill or who have disabling conditions make a conscious decision to do so, they are still subject to the same types of human emotions as the children and families who face the related stress and challenges of each situation. Children and their families benefit from peer support because it helps them be able to express fears, angers, sadness, hopes, dreams, and a host of other emotions with others who have "been there" — who can empathize with what they are going through and be a part of a mutually supportive team. Professionals, too, need this reciprocal support, from peers in their field, who can understand the frustrations and joys that come with their work. Social and peer support can actually help reduce job-related stress, particularly in "high-stress" areas such as intensive and chronic care units (Johnson et al., 1992), where levels of staff turnover and "burn-out" can be elevated. These authors go on to say:

> *Developing personnel policies and practices that support the needs and priorities of children and families and the staff who serve them is an investment in family-centered care (p.134).*

Peer-to-peer support is important, whether it is between mothers, fathers, siblings, children with disabilities, other family members, or professionals involved in the care of a child. This type of support can be accomplished in a variety of ways, both formally and informally, and barriers to such support can be overcome when identified by the individuals receiving the support.

It has been said that the greatest gift a professional can give a parent is access to another parent. In providing comprehensive support for children and families, it should be understood that family-to-family support networks are not intended to replace other forms of informal or formal support, self-help supports, or the delivery of health and developmental services in a family-centered environment, nor are they interchangeable with other services and supports. Because these systems should be mutually supportive, they may overlap in their functions, creating a comprehensive system of support to meet the diverse and individual needs of children and families.

. . . the greatest gift a professional can give a parent, is access to another parent.

Making It A Reality

Family-to-family support is unique, and different from the types of support children and families can be provided by professionals and friends. Networking with a peer who has shared similar experiences (e.g., intensive care unit, specific illness or disability, early intervention, home health care, bereavement) or who has played a similar role in the life of child with an illness or disability (e.g., mother, father, child, sibling, grandparent, caregiver) is a powerful experience. Peer support can be informal or formal in structure, and it can be very specific in membership or open to any family member. Being knowledgeable about regional and national resources and facilitating family-to-family support is essential to family-centered health and developmental care. This section explores a few of the abundant myriad of peer support programs and resources that encourage family-to-family support through groups, individual networking, and training and employment of parents to provide services to other parents.

Programs, Policies, and Practices

Ability On-Line Support Network
Ontario, Canada

Ability On-Line Support Network provides a free, public forum where children, teens, and young adults with and without disabilities can discuss ideas, opinions, and knowledge electronically. This is a bulletin board system for callers across North America, as well as around the world. **For more information, contact Ability On-Line, 919 Ainess Street, North York, Ontario, Canada, M3J2J1 (PHN: 416/650-6207; FAX: 416/650-5073; Modem: 416/650-5411; Internet: info@ablelink.org).**

The Family Support Network (FSN) of Michigan
Michigan Department of Public Health

The Family Support Network of Michigan is a statewide family-to-family network for families with children who have any type of illness or disability. The program is directed by volunteer parent coordinators at the county level and parents on staff at the Parent Participation Program, Children's Special Health Care Services, Michigan Department of Public Health. The FSN offers one-on-one peer support by experienced family members who are trained to listen and offer information about available resources at the local, state, and national levels. Local coordinator teams take the lead in coordinating parent support groups, family social events, and an information and referral service, depending on the needs of the community. The Network also provides information and workshops for parents and professionals concerning special issues of grandparents, siblings, fathers, and accessing health care services in urban areas. Ongoing training for FSN coordinators is provided through quarterly regional meetings and an annual conference. **For more information, contact The Family Support Network of Michigan, DSCC/Children's Special Health Care Services, Michigan Department of Public Health, 1200 Sixth Street, 9th Floor, North Tower, Detroit, MI 48226, (PHN: 1/800/359-3722; TDD: 1/800/788-7889).**

Mothers United for Moral Support (MUMS), Inc.
Green Bay, WI

Mothers United for Moral Support is a national family-to-family organization for parents or care providers of a child with any disability, disorder, chromosomal abnormality, or health condition. The main purpose of MUMS is to provide peer support to parents in the form of a computerized networking system that matches parents with other parents whose children have the same or similar condition. Their database contains more than 4,300 families and covers more than 1,000 disorders. Funded only by the generosity of its members and small grants from charitable organizations, MUMS connects parents with each other and with other support groups dealing with their child's specific disability, assists them in forming a group, and offers a quarterly newsletter. **For more information, contact Julie Gordon, 150 Custer Court, Green Bay, WI 54301 (PHN: 414/336-5333).**

Parent Partners Program
George Washington University, Washington, DC

The *Parent Partners Program* has been initiated at George Washington Hospital and at Greater Southeast Community Hospital (Washington, DC) and at Arlington Hospital (Arlington, VA) to provide listener support for families experiencing the birth of an infant who is premature or critically ill or the loss of a newborn. Parent Partners matches an experienced volunteer parent with a new parent experiencing a neonatal crisis. The veteran parents are trained to provide support through a free, four-session course offered at George Washington University. Upon completion of the course, which covers listening skills, high risk pregnancy, prematurity, specialized care for infants, teenage parents, substance abuse, newborn loss, developmental intervention, and available resources, volunteer parents receive 1.0 Continuing Education Units from the University. A Train-the-Trainer course is also available to other hospitals who would like to develop a similar program. **For more information, contact Marian Jarrett, Program Director, Parent Partners, George Washington University, Department of Teacher Preparation and Special Education, 2134 G Street, NW, Washington, DC 20052 (PHN: 202/994-1509).**

The Pen Pal Program
The Children's Hopes and Dreams Foundation, Dover, NJ

The Pen Pal Program matches children with life-threatening or chronic illnesses with other children (with and without disabilities) of similar age and sex in a different state or country. More than 3,000 individuals and agencies worldwide currently participate in this program. **For more information, contact 280 Route 46, Dover, NJ 07801 (PHN: 201/361-7366; FAX: 201/361-6627).**

Project Assist
University of Maryland, Department of Special Education, College Park, MD

Project Assist originated in 1989 as a parent support project for local families with infants or young children with disabling conditions. Now, in addition to family support, the project staff provides preservice and inservice training for professionals in early intervention throughout the state of Maryland. They have developed a number of training materials and publications, and offer classes and presentations on family perspectives, family support, personal values and attitudes, and service coordination in early intervention, consistent with the philosophy of family-centered care. Project Assist continues to facilitate support groups for families who have or have had children in the local early intervention program, and provides transportation, child care, and day or evening group and/or individual support. The project staff consists of early childhood special education faculty, a social worker, and a family member who was formerly a participant in the project. **For more information, contact Paula Beckman, Director, or Sandra Newcomb, Coordinator, Project Assist, 1308 Benjamin Building, Department of Special Education, The University of Maryland, College Park, MD 20742 (PHN: 301/405-6476 or 301/405-6492).**

Sibling Support Project
Seattle, WA

The primary goal of the *Sibling Support Project* is to increase the number of national peer support and education programs for brothers and sisters of children with illnesses or disabilities. Project staff create awareness and curricular materials; conduct workshops for family members and professionals on sibling issues; provide training, technical assistance, and demonstration to agencies wishing to create programs for siblings; and, maintain a database of services for siblings throughout the United States. Supported by the Maternal and Child Health Bureau, Department of Health and Human Services, the Sibling Support Project collaborates with agencies nationwide to create project outreach sites. **For more information, contact Sibling Support Project, Children's Hospital and Medical Center, 4800 Sand Point Way, NE, Seattle, WA 98105 (PHN: 206/368-4911).**

Peer Networks, Newsletters, and Clearinghouses

AboutFace: A Support and Information Network Concerned with Facial Difference
99 Crowns Lane, 3rd Floor
Toronto, Canada M5R 3P4
PHN: 414/944-FACE or 1/800/665-3223
FAX: 414/944-2488

Alliance of Genetic Support Groups
A Coalition of Voluntary Organizations and Professionals
35 Wisconsin Circle, Suite 440
Chevy Chase, MD 20815
PHN: 301/652-5553 or 1/800/336-GENE
FAX: 301/654-0171

ARC-Capital Pilot Parents Program
215 Centennial Mall South, Suite 410
Lincoln, NE 68508
PHN: 402/477-6925

Children With AIDS: The Newsletter of the Foundation for Children With AIDS, Inc.
1800 Columbus Avenue
Roxbury, MA 02119

Family CARES Network of The Comprehensive Pediatric AIDS Project Children's Diagnostic & Treatment Center of South Florida
417 South Andrews Avenue
Fort Lauderdale, FL 33391
PHN: 305/779-1400

The Family Support Clearinghouse
Epilepsy Foundation of New Jersey
2150 Highway 35, Suite 207C
Sea Girt, NJ 08750
PHN: 908/974-1144 or 1/800/FSC-NJ10
FAX: 908/974-0940

Family Support Network of North Carolina:
A Program for Families, Physicians, and Service Providers
CB #7340
University of North Carolina
Chapel Hill, NC 27599
PHN: 1/800/852-0042

In Touch with Kids
The National Spinal Cord Injury Association
600 West Cummings Park, Suite 2000
Woburn, MA 01801
PHN: 1/800/962-9629

Just for Us: A Newsletter For and By Bereaved Siblings
St. Mary's Hospital for Children
29-01 216th Street
Bayside, NY 11360

National Family Caregivers Association (NFCA)
9621 East Bexhill Drive
Kensington, MD 20895
PHN: 301/942-6430
FAX: 301/942-2302

National Fathers' Network
Merrywood School
16120 N.E. Eighth Street
Bellevue, WA 98008
PHN: 206/747-4004 or 206/282-1334

Sibling Information Network
The University of Connecticut
A.J. Pappanikou Center on Special Education and Rehabilitation
1776 Ellington Road
South Windsor, CT 06084
PHN: 203/648-1205

Resources

Exceptional Parent

Brookline, MA

Exceptional Parent is a monthly magazine filled with articles, information, and resources for families with children who have disabilities. In addition to a column written by and for fathers, this magazine regularly publishes a resource section with regional and national organizations, and provides a readers exchange column for parents to request and provide information from and for other parents. **For more information, contact Exceptional Parent, 209 Harvard St., Suite 303, Brookline, MA 02146.**

Fathers of Children with Special Needs: New Horizons

J. May (1991), and,

Circles of Care and Understanding: Support Programs for Fathers of Children with Special Needs

J. May (1992)

Fathers of Children with Special Needs: New Horizons focuses on the special concerns of fathers of children with disabilities. This book highlights research, strategies for effective service delivery, and guidelines for promoting fathers' involvement in their children's care. It is a wonderful companion to *Circles of Care and Understanding*, a comprehensive book useful for establishing and developing support groups for fathers. **Both books are published and available through ACCH.**

Parent Resource Directory, 3rd Edition

K. Lawrence, G. Johnson, J. Stepanek (Eds., 1994)

This directory lists the interests, experiences, and expertise of more than 450 parents of children with illnesses and disabilities who have volunteered to be a resource for other families and professionals. The book is well-organized and indexed by state/province, names of families, types of conditions, and topical areas. **It is published by and available through ACCH.**

The Special Needs Project

Santa Barbara, CA

The Special Needs Project sells books about physical and mental disabilities by mail. The coordinator of the project is experienced as a parent of a child with cerebral palsy and the project is about books as tools which are "crystallized experience." The project offers information about thousands of books which have to do with issues that include disabilities, disability rights, adaptive equipment, parenting, health, and education. **For more information, contact Hod Gray, The Special Needs Project, 1482 East Valley Road, #A-121, Santa Barbara, CA 93108 (PHN: 805/565-1914; FAX: 805/969-4321; for orders: 1/800/333-6867).**

What About Me?: When Brothers and Sisters Get Sick

A. Peterkin, (1992)

What About Me? is a book for children of all ages coping with the serious illness or hospitalization of a sibling. Information is presented in the form of a story about a young girl with a brother who is sick. **Available through ACCH, this resource is published by Brunner/Mazel, New York, NY.**

Ensuring that hospital, home, and community service and support systems for children needing specialized health and developmental care and their families are flexible, accessible, and comprehensive in responding to diverse family-identified needs.

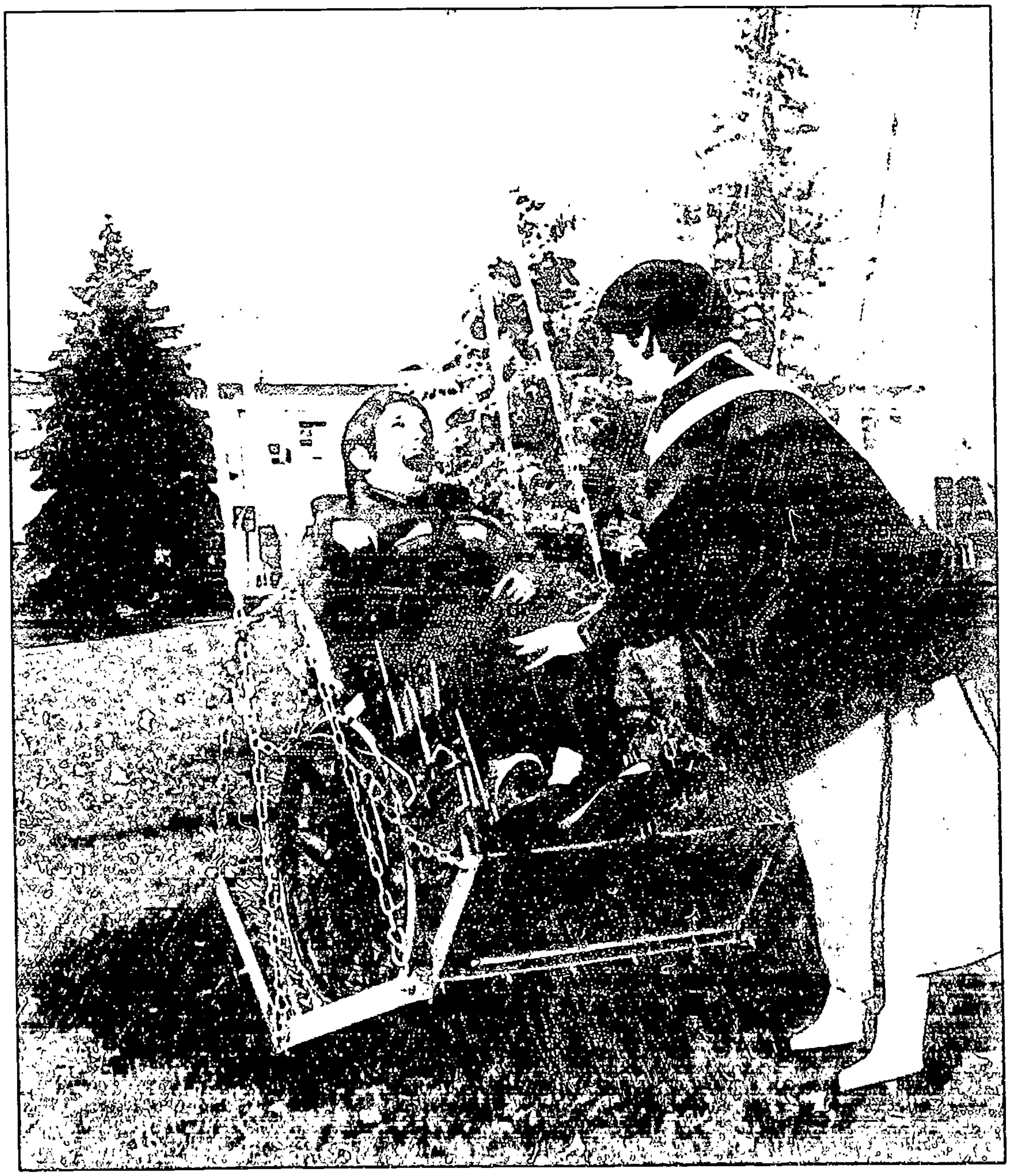

Photo courtesy of Child and Parent Resource Institute, London, Ontario. Photographer: Doug Sutherland

Chapter Seven

Coordinated Services and Supports

If anything can be anticipated in the life of a child with a chronic illness or disability, it is that the child and family will have a variety of needs that will require a myriad of services, that they will interact with a multitude of professionals and service systems, and that their needs will change across time. Furthermore, because one of the goals of service provision should be to prepare caregivers to deal effectively with future concerns, needs, and aspirations, service provision is not just an issue of whether or not specific needs are met. Rather, it also involves the manner in which the mobilization of resources occurs, and whether or not resources contribute to the enablement and empowerment of families to collaborate fully as equal partners in their children's care. The provision of services and supports must therefore be flexible, accessible, and comprehensive in responding to the wide array of family-identified needs.

What Does This Mean?

. . . Although professionals tend to focus on child and family characteristics as sources of stress, there are a variety of aspects of the service system that also create stress.

There is substantial evidence in the literature suggesting that families of children who are ill or have disabling conditions often report higher than usual levels of stress and isolation (e.g., Beckman, 1993; Beckman & Boyles, 1993; Kazak & Marvin, 1984). However, there are considerable individual differences in the extent to which stress is experienced by families. Moreover, while these families often have higher degrees of stress than other families, they do not always differ in family functioning, and they tend to be very resilient in adapting to the demands of the child (Dyson, 1991). Therefore, while remaining aware that there is a potential for increased stress, it is important not to assume that the effect of having a child with a disability is necessarily negative (Beckman, 1993; Newcomb et al., 1994; Stepanek, in press).

Beckman (1993) reported that much research has been done to examine the various factors which are associated with increased stress for families. Well-researched factors contributing to family stress include: the characteristics of the child; the characteristics of the family (e.g., socioeconomic status, race, education); the presence of additional or unusual caregiving needs on the part of the child; and, the lack or presence of adequate social support. She notes, however, that while researchers have typically been interested in factors within the family system related to the child and the informal sources of support, less attention has been focused on the impact of the more formal, organized systems of support on stress levels.

The result has been a general failure to examine the extent to which the service systems which are presumably designed to support the child and family are in fact supportive, or the extent to which the service delivery system may actually contribute to stress. Beckman (1991) has argued that although professionals tend to focus on child and family characteristics as sources of stress, there are a variety of aspects of the service system that also create stress.

Families have expressed concerns and frustrations about the difficulties created by various aspects of the service system including: funding for services; obtaining desired and/or appropriate services; accessibility and availability of formal supports; family involvement and rapport with service providers; obtaining accurate and adequate information; the number of systems and providers needed by children and families; and, a lack of coordination of and communication between service systems (Beckman, 1993). Yet, such factors are rarely considered as sources of stress by researchers investigating the issue. Researchers tend to focus on characteristics of the child and family when asking about sources of stress, while features of the service system are typically listed on various measures as potential sources of support, rather than as potential stressors. The assumption is that since the systems were created as supports for families, that they function in that way. In implementing policies and practices exemplifying family-centered care, it is critical to be aware of all of the factors — child, family, informal support, and formal systems of service and support — which contribute to the stress experienced by families who rely on formal support systems and related services for their children with disabilities.

Components of Coordinated Services

This element highlights the variety of locations in which resources should be available: the hospital, the home, and the community, as well as the need for coordinated systems of care. In most cases, there are not systems of care but a fragmented, patchwork quilt of confusing eligibility requirements and shrinking resources. The following observation made by Helen Featherstone more than a decade ago (1980) is still applicable:

> *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 owes 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 (p. 184).*

The essential characteristics of family-centered services — that they be flexible, accessible, and comprehensive — are also highlighted in this element. This requires changing one's perspective from a service-based approach to one that is resource-based (Dunst, Trivette, & Deal, 1994b; Dunst et al., 1993). In distinguishing these two approaches, Dunst and colleagues note three critical differences which speak to the issue of developing service systems in a family-centered manner.

In service-based practices, services are professionally-centered. Because services are provided to certain people under certain conditions, accessibility becomes a problem. Complicated eligibility requirements must then be established and must change frequently to meet the programming needs of the agency. In contrast, resource-based practices result in developing community-based systems. They encourage one to look to the wide array of individuals and organizations in the community for services. This can result in: increased flexibility as families are not tied to one service provider; greater accessibility as eligibility requirements can become more relaxed; more comprehensive programming; and, the establishment of a more permanent support system.

In service-based approaches, professional services are viewed as quite scarce (Katz, 1984). This results in limited accessibility as services can be given only to those most in need, as determined by professionals. For example, a family who has had in-home nursing may find it abruptly discontinued because their child no longer has the most critical health care needs among those families in the agency's "case load." The "need" is determined from the point of view of the agency, not the family. This is what Dunst and colleagues (1994b) refer to as a "scarcity" paradigm.

In contrast, resource-based practices are based on a "synergistic" paradigm. That is, community resources that are expandable, flexible, and renewable. In this model, families might have access to a number of home care agencies and be able to collaborate with those who provide care in a way that is most consistent with their family's needs, concerns, and priorities.

Finally, service-based and resource-based interventions differ in the ways in which they offer help and assistance. In service-based practices, the emphasis is on formal supports, provided solely by professionals. Just as in family-to-family support, resource-based interventions are not in lieu of professionally-based supports. Rather, they are broader — linking families with, and facilitating the growth of, informal community networks. These networks can include: family members, friends, clergy, and co-workers; community associations such as neighborhood groups, PTA/PTO,

In most cases, there are not systems of care but a fragmented, patchwork quilt of confusing eligibility requirements and shrinking resources.

churches, charitable organizations, veteran groups, and civic groups; community organizations such as schools, libraries, legal assistance, recreational camps; and, many more creative networks.

Importance of Coordinated Services

In 1991, Kay Marcel, then Chairperson of the Louisiana Developmental Disabilities Planning Council (DDPC) and the mother of two sons, one with Down syndrome, commented:

> *What families have told us is that they need a flexible menu of services from which they can choose to support their child at home. A flexible and individualized family-driven system of support is the key to meeting the wide variety of needs that families have, depending on the type of disability that their child has, their own family situation and the support available in their community. For example, one family needed a fence for their yard so that their son could play outside without constant supervision, allowing the mother much needed relief from her continuous caregiving responsibilities (p. 5).*

In some cases, where the system itself is complicated, the family may wish to have a "pathfinder" to help them articulate their wants and identify needed services.

Even when services are flexible, accessible, and comprehensive, there must be some way for the resources to be coordinated:

> *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 (Duffy, 1984).*

As this mother's comments illustrate, a child's needs often do exceed any one person or agency, resulting in a confusing array of service providers or a a duplication of services; but more often than not, it results in fragmentation and gaps in care. As a consequence, coordination becomes imperative. But the way in which this coordination is accomplished becomes essential. Coordination can occur through more systematic and community-based resources. In some cases, where the system itself is complicated, the family may wish to have a "pathfinder" to help them articulate their wants and identify needed services. In any event, it is the:

> *. . . case in need of management; not the family or the child . . . systems are best managed by communities and families are best managed by themselves (Magrab, 1987, p. 4).*

* * * * *

> *No one professional or parent has sufficient knowledge or skill to provide the best care. Instead, good care has to evolve out of different persons working together, each at the limits of their own knowledge and skill . . . In the best of circumstances, family-centered [care coordination] is a process, not a procedure. It evolves out of a continuing relationship between professionals and families. This relationship must rest on a mutual respect and a shared commitment to working together in an imperfect world (Ireys, 1987).*

Thus, effective coordination can only occur if systems are family-centered and community-based.

> *Coordinating, generally thought of currently as some form of a case management system, that is not designed to be family-centered or community-based is likely to become yet another unsupportive and unhelpful service that families must deal with. On the other hand, if there are*

> *service systems — schools, health care providers, county programs, etc. — who are truly respectful of family needs, goals, and values and are committed to complete integration of children with special health care needs and their families within the community, we then can find that improved coordination of services whether by enhanced inter-agency collaboration or with the support of a designated care coordinator, can truly be a powerful way of helping. . . . Coordination must be a way to support children and their families and not be designed with the primary intent of managing them, or monitoring costs, or meeting some other agenda (Schwab, 1988).*

Barriers to Coordinated Services

There are, however, many potential barriers to providing such comprehensive services. One is the fear that *all* of the needs identified by a family must be provided by one program or professional. Therefore, it's better not to ask what families want, but to deliver what the agency has to offer. However, services are not provided in isolation from each other, nor in isolation from the family's experience.

While it is unreasonable to expect one program to provide all services, it is reasonable to listen to what families want, and then consider how best to provide those wants. This is essential to care that is coordinated. For example, no one expects pediatric subspecialty clinics to provide transportation to clinic visits. However, knowing that transportation is a problem for a family could result in more coordinated office visits, such as scheduling several visits on one day or minimizing the number of visits.

It also means recognizing that a single agency or professional is not the only resource. Family-centered care means developing *systems* of support, linking agencies with families, as well as families with other families and with community resources. In the previous example, this could mean: having bus schedules available for families at clinic; linking the family with a family-to-family support group that could help with transportation; or, establishing a relationship with a community or volunteer group that might provide transportation. Communication within an agency or system, as well as between multiple agencies and systems, becomes essential for the provision of comprehensive family-centered services.

The third, and most important, aspect of this element is that services must respond to family-identified needs. Dunst and colleagues (1994a) comment on the potential misconceptions that can arise from using the term "needs-based." One potential problem is that these services may be perceived as deficit-oriented because they only address problems. If a professional identifies what a family needs, that can result in a negative or deficit-oriented approach. However, if a family articulates its needs, desires, and aspirations, and if interventions are responsive to the family's concerns and goals, then this becomes a strength-oriented approach:

> *The ability to recognize needs, and take actions to meet needs, represents an important subset of intrafamily resources (Dunst et al., 1994a, p. 96).*

Communication within an agency or system, as well as between multiple agencies and systems, becomes essential for the provision of comprehensive family-centered services.

This element reminds us that providing family-centered care goes beyond one-to-one interactions; it must be reflected in institutions and systems from the local schools and hospitals to the state legislature. It is only through families and professionals working together that appropriate services will be provided in an accessible and affordable manner.

Providing Coordinated Services

One way to accomplish the goal of providing accessible, flexible, and comprehensive services is to change from a service-based to a resource-based approach to care as outlined above. Another is to look for ways to provide care in a coordinated way, doing what some might call "permanency planning," a term borrowed from the social service field. This could address the need for continuity of care during transitions between hospital units and between hospital and home. Permanency planning, a concept traditionally used in foster care, helps keep families central in their child's care and in decisions made about the care. It does this by ensuring smooth transitions between service units, systems, agencies, or locations, and by keeping the family informed, involved, and supported as they care for their child. Family members could then have the opportunity to choose and work with what will become a community-based team of professionals.

Another way to accomplish the goal of providing comprehensive services that are flexible, accessible, and family-driven is to look to the world of business. How do successful businesses stay on the cutting edge? Tom Peters and colleagues in their series of books, *In Search of Excellence* and *A Passion for Excellence*, state quite clearly that success begins with the customer. Peters and Austin (1985) talk about the shift from "management-oriented" to "consumer-oriented" to "consumer-obsessed." The parallel to the shift from professionally-oriented to family-focused to family-driven/family-centered pediatric care is obvious.

This shift includes: listening to the wants and needs of customers; assessing customer satisfaction; responding quickly to information from these evaluations; being sensitive to cultural diversity and providing a "product" that fits with the culture; and, "total customer responsiveness." Thus, this element becomes inextricably tied to family/professional collaboration — the way to provide flexible, accessible, and comprehensive services is by asking families directly.

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Benefits of Coordinated Services

Providing services in this manner is effective in so many ways. Dunst, Boyd, and Trivette (1994) summarize five studies, looking at which program and service delivery characteristics resulted in families' perceived control over receiving and procuring needed services and resources. Specific demographic characteristics of the parents, the child's condition, or the family were only minimally related. In contrast, the characteristics of the program or agency and the manner in which help was provided was quite important. Those programs providing services in a family-centered way resulted in greater feelings of empowerment. Accepting and supporting families' decisions, active family/professional collaboration, offering help that matches family-identified needs, offering resources that decrease the need for help, and making the family more independent in their ability to access needed services are just some of the characteristics related to positive outcomes.

There are benefits for professionals as well. Several surveys (U.S. Maternal and Child Health Bureau, 1993) have shown that providing services in this manner, through family/professional collaboration results in:

- Greater depth of professional skills due to increased sensitivity to clients;
- Improved, appropriate communication skills with families;
- Greater ease on the part of providers working with families;
- Stronger provider/family relationships; and,
- Greater job satisfaction.

An understanding of the way in which formal support systems function for families is essential to providing family-centered care and enhancing the effectiveness of services provided for children needing specialized care and their families. The examination of formal support systems is a complex task, but a very worthwhile one. It is only through carefully assessing factors contributing to both the stressors and the empowerment of families with children who have illnesses or disabling conditions that service implementation can be improved, and that providers within systems can exemplify best practice that includes comprehensive intervention and psychosocial care (Beckman, 1993).

For systems to exemplify family-centered care, families need to be respected as partners in decision-making — not just decisions related directly to their child, but also decisions related to the how the systems that serve their children provide care. Families should be involved in the training of professionals, with respect to family diversity, family strengths and needs, and family perspectives. Families should also be involved in the evaluation and effectiveness of the professionals and systems serving their children.

To ensure that hospital, home, and community service systems are flexible, accessible, and comprehensive in responding to diverse family-identified needs, children must be viewed within the context of their family, and there must be a sense of shared responsibility and collaboration between and among families, professionals, and service systems. Systems must become proactive in their human services, responding to the needs of families across all socioeconomic levels. By recognizing the resilience and adaptation of families, yet being sensitive and responsive to their diverse needs related to accessing services and systems for their child needing specialized care, resources and supports can be mobilized to strengthen family functioning and protect family integrity (Dunst, Trivette, Gordon & Starnes, 1993).

Making It A Reality

Ensuring that programs and policies are flexible, accessible, and comprehensive in meeting the diverse needs of children and families is a crucial component of family-centered care. The needs of children who require specialized health and developmental services change over their lifetimes, as do the needs, strengths, concerns, and priorities of their families. Children with chronic illnesses and disabling conditions and their families typically interact with a multitude of service providers and programs in their homes, in hospital and tertiary care facilities, and in school and other community settings. The delivery of services must respond to the evolving needs of these children and families.

Flexible, accessible, and comprehensive services require much more than ramps and elevators and adequate parking. They also necessitate the elimination of barriers such as strict eligibility requirements, lack of coordination between and among service providers and service systems, and insensitivity to the emotional and logistical struggles encountered by many families. Consumer input at all levels of care and across all settings is one important way for both existing and developing services and systems to begin to meet the goals of family-centered care. In addition to traditional post-service evaluations, consumer input should be elicited by including family members on planning boards and on advisory committees, not just as tokens, but as full voting members. This section contains examples of some of the many other programs and resources currently available that address this seventh element of family-centered care.

Organizations

ACCH Design Resource Network
Bethesda, MD

The *Design Resource Network* at the Association for the Care of Children's Health is a national organization for individuals concerned with the architecture, design, and planning of children's health care environments. Newsletters, meetings, conferences, and a networking resource directory offer creative ideas and opportunities to ensure that facilities are consistent with the principles of family-centered care, by bringing together designers and health care decision-makers. **For more information, contact ACCH, Membership Department, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814 (PHN: 1/800/808-ACCH, or, 301/654-6549; FAX: 301/986-4553).**

The Federation of Families for Children's Mental Health
Alexandria, VA

The Federation of Families for Children's Mental Health is a national parent-run organization focusing on the specialized needs of children and youth with emotional, behavioral, or mental health disorders and their families. The mission of the Federation is: to provide leadership in the field of children's mental health; to develop necessary human and financial resources to meet the unique needs of children, birth through transition to adulthood; to ensure rights to full citizenship and access to community-based services; and, to provide information and advocacy regarding research, prevention, early intervention, family support, education, transition services, and other services needed by these children and their families.

Family participation and support are fundamental to the work of the Federation which strives to ensure that every family has a right to an appropriate, available, and accessible support base to meet family-identified needs. They strongly advocate that policies, legislation, funding mechanisms, and service systems utilize the strengths of families by involving parents as equal partners in the planning, implementation, and evaluation of services, and by empowering families to make decisions about their lives and the lives of their children. **For more information, contact the Federation of Families for Children's Mental Health, 1021 Prince Street, Alexandria, VA 22314 (PHN: 703/684-7710).**

National Parent Network on Disabilities (NPND)
Alexandria, VA

The *National Parent Network on Disabilities* (NPND) is an organization that was established to provide a presence and national voice for children, youth, and adults needing specialized care and their families. The NPND shares information and resources that promote and support the power of families to influence and affect policy issues concerning the needs of individuals with disabilities and their families. It includes organizations of families with children needing any type of specialized care and with any type of disabling condition, and believes that access to appropriate health care is a right, not a privilege.

The Network's location (near Washington, DC) provides an on-the-scene presence to speak on issues and act on plans or activities affecting programs and services for individuals with disabilities. The NPND can provide up-to-date reporting on governmental policy and planning, a strong advocacy voice to communicate needs and priorities of children with disabling conditions and their families, a system of sharing experiences to develop effective policy recommendations, and a link between parent organizations to share the expertise of effective parent leadership. The Network can also help organizations become more effective at the local level and collaborate to address the concerns of families across the country. **For more information, contact NPND, 1600 Prince Street, Suite 115, Alexandria, VA 22314 (PHN: 703/684-6763).**

New England SERVE
Massachusetts Health Policy Research Institute, Inc., Boston, MA

New England SERVE is a planning and technical assistance network of families, health care providers, and State Title V Programs for Children with Special Health Care Needs (CSHCN) in the six New England states. All project activities assist the efforts of families, providers, and policy-makers to move health care systems in each of the six states toward the goals of family-centered, community-based, and coordinated care. The project focuses on building state leadership networks based on family/professional collaboration, dissemination and implementation of standards of quality care, and increasing effective advocacy for adequate health care financing. They also provide publications with criteria for judging health care financing systems from the perspective of children needing specialized services and their families. **For more information, contact New England SERVE, Massachusetts Health Policy Research Institute, Inc., 101 Tremont Street, Suite 812, Boston, MA 02108 (PHN: 617/574-9493).**

Programs, Policies, and Practices

Children's Support Systems (CSS)

La Rabida Children's Hospital and Research Center, Chicago, IL

Children's Support Systems is a community-based program that helps families care for children with chronic illnesses or disabilities. CSS helps link families with the unique and essential medical, social, and financial network of resources that they need to provide their children with the best possible care. With the help of CSS, families often find they are able to better keep scheduled medical appointments, reduce the number of school days their children miss, and cut down on their children's emergency room visits. CSS serves any family in their region needing coordination and support in the care of their child, birth to 21 years of age, at no cost to the family. Funded by federal and local grants, the work of CSS is guided by an advisory board of community representatives and health and human services professionals. **For more information, contact Children's Support Systems, Woodlawn Social Services Center, 950 E. 61st Street, Room 263, Chicago, IL 60637 (PHN: 312/324-9495; FAX: 312/324-3571).**

CHOICES

Shriners Hospitals for Crippled Children

CHOICES is a state program serving children needing specialized care by improving coordination of services and access to health care. The goals of this program include providing more health care options for children, helping families and professionals work collaboratively on behalf of children, and making families full participants in the health care team. CHOICES helps provide improved access and facilitated referral to services of both Shriners Hospitals and participating state programs, as well as coordinated care planning and open communication among all care providers. Jointly funded by a federal grant from the Maternal and Child Health Bureau and by Shriners Hospitals (which neither seek nor accept federal, state, or local government funding), the CHOICES program helps multiple service systems work more collaboratively by promoting a cooperative team approach to services for children needing specialized health care. **For more information contact one of the three CHOICES Care Coordinators at 606/266-2101 (Kentucky); 513/872-6000 (Ohio); or, 803/271-3444 (South Carolina).**

The Family Child Care Integration Project (FCCIP)

Alexandria, VA

The Family Child Care Integration Project prepares family child care providers to include children with disabilities in their home programs. Grounded in the belief that quality, developmentally-appropriate practice is best for all children, the FCCIP unites the staff of a center-based program that includes children with disabilities with a group of home-based child care providers in a unique partnership to promote inclusion for children, and an opportunity for choice by families. Workshops offer simple and affordable strategies for creating adaptive environments, toys, and learning materials for all children. **For more information, contact Mary Ellen Hoy, Director, FCCIP, The Danny Chitwood Early Learning Institute, 2280 N. Beauregard Street, Alexandria, VA 22311 (PHN: 703/820-6461).**

The National Resource Center on Family-Based Services

University of Iowa, School of Social Work

The National Resource Center on Family-Based Services offers an eight-day training program for professionals and paraprofessionals to become family development specialists. Family development is a model of family-based intervention designed to help all families, especially low-income families, improve family functioning and achieve economic independence. Family Development Specialists are skilled in helping families: review their needs, their stresses and their strengths; enhance family relationships; set goals; use developmental community resources; and, develop competencies they need for economic independence. This program was designed as a family-based equivalent to the Head Start Child Development Associates training. It also offers follow-up and refresher courses, and supervisor training and organizational development training for administrators and managers. **For more information, contact the University of Iowa School of Social Work, 112 North Hall, Iowa City, IA 52242 (PHN: 319/335-2200; FAX: 319/335-2204).**

Parent Advisory Council

Children's Healthcare and Pediatric Services of America, Inc.
Charlotte, NC

Children's Healthcare (which recently merged with Pediatric Services of America, Inc.), operates as an extension of hospital teams around the country to provide neonatal and pediatric home health care to children needing specialized and complex health care. To help ensure that their philosophy of respect for the dignity of children and families is a reality and best practice, the organization has a very active Parent Advisory Council. The *Parent Advisory Council* meets monthly, and all parents who have children being served by the home health care agency are welcome to attend. In addition to addressing current topics, the Council schedules speakers to address issues related to health and developmental care, and plans social events (e.g., Easter Egg Hunt, Teddy Bear Clinic) for the children, their families, and their service providers.

A monthly newsletter from the Council keeps families and service providers up-to-date on concerns and priorities, and shares special information about some of the families being served (e.g., birthdays, developmental milestones). Pediatric Services of America, Inc. also provides a newsletter for families and providers, with information on the organization and on issues related to pediatric health and home care, and with fun activities and puzzles related to current topics. With input from families and the Council, the organization is better able to take all aspects of the family environment and needs into account when making a plan of care. **For more information, contact Carolyn Mullins, Regional Director of Operations, 2101 Sardis Road North, Suite 207-D, Charlotte, NC 28227 (PHN: 1/800/725-5611; FAX: 704/845-1501).**

Partnerships for Inclusion (PFI)

University of North Carolina

Partnerships for Inclusion is a statewide project providing technical assistance to support the inclusion of young children with disabilities, birth through five, in community child care programs in North Carolina. Inclusion Specialists work with a variety of individuals and groups, including early interventionists, preschool coordinators for children with disabilities, child service coordinators, parents, teachers, developmental day programs, local interagency coordinating councils, and resource groups.

PFI collaborates with state agencies to develop policy and program initiatives. They facilitate full community integration of children with disabilities and their families by raising public awareness and preparing personnel. They have developed innovative models of delivering technical assistance to a variety of groups serving children with disabilities, and offer intensive on-site consultation, community forums about inclusion, a statewide lending library, train-the-trainer activities, a course for child care providers about how to integrate children needing specialized care into child care programs, and videos featuring the perspectives of both families and service providers about inclusion. Funding for PFI comes from North Carolina's Department of Human Resources through the Division of Child Development and the Division of Mental Health/Developmental Disabilities/Substance Abuse, and from the Department of Public Instruction through the Division for Exceptional Children's Services. The project also receives support from the North Carolina Council on Developmental Disabilities and the University of North Carolina. **For more information, contact PFI, 300 NationsBank Plaza, 137 East Franklin Street, The University of North Carolina, Chapel Hill, NC 27514 (PHN: 919/962-7359 or 7356).**

Resources

After High School...? Building on Today for Tomorrow
Chicago Family Resource Center on Disabilities (1993)

After High School? is a 20-page text providing step-by-step information for designing and implementing a community-based, family-centered, transition planning program. Transition-related legislation, listings of regional and national transition resources, forms, and other materials are included in the appendices. **For more information, contact Family Resource Center on Disabilities, 20 E. Jackson, #900, Chicago, IL 60604.**

Bridging Early Services for Children with Special Needs and Their Families
S. Rosenkoetter, A. Hains & S. Fowler (1994)

This is a comprehensive book for families and professionals, offering step-by-step advice for the process of planning coordinated, uninterrupted transition services for children with disabilities and their families. The goal of the book is to lessen the stress children and families typically feel as they must leave one service system and enter another one. This manual describes guidelines for meeting federal requirements, and offers strategies to ensure successful transitions, consistent with a family-centered philosophy of care. **Published by Paul H. Brookes Publishing Co., Baltimore, MD.**

Child Health Care Facilities: Design Guidelines — Literature Outline
A. Olds & P. Daniel (1987)

Child Health Care Facilities offers guidelines for overall issues related to design and to specific spaces, focusing on the psychosocial impact of design on children and families. The resource contains an annotated review of selected literature organized in outline form by topic, and includes photographs, floor plans, and illustrations. **This resource is published by and available through ACCH.**

Developing Community Networks: A Guide to Resources and Strategies
B. Steele (1991)

Developing Community Networks is a guide that offers models, examples, and strategies for improving community support networks for children needing specialized services and their families. This resource addresses issues that include defining networks and communities, forming advisory councils, funding network organizations, assessing needs and setting goals for community resources, and networking strategies that are collaborative and family-centered in practice. **This resource is published by and available through ACCH.**

Enhancing Quality: Standards and Indicators of Quality Care for Children with Special Health Care Needs

New England SERVE (1989)

Enhancing Quality provides generic standards defining family-centered care, and identifies critical policies and practices that determine quality related to collaboration, training, program assessment, and advocacy necessary for meeting the needs of children with disabilities and their families. **For more information contact, New England SERVE, 101 Tremont Street, Suite 812, Boston, MA 02108 (PHN: 617/574-9493).**

National Health/Education Consortium (NHEC) News

Institute for Educational Leadership

The *National Health/Education Consortium News* is a newsletter that "crosses the boundaries between health and education." It addresses issues related to the efforts of federal and state governments to improve interagency cooperation on school-based services and health education. **For more information, contact Silvia Holschneider, Chris Shearer, IEL, 1001 Connecticut Avenue NW, Suite 310, Washington, DC 20036 (PHN: 202/822-8405; FAX:202/872-4050).**

Physician Education Forum Report

National Center for Family-Centered Care (1990)

The *Physician Education Forum Report* is the summary of a forum that brought together professionals and parents to discuss how family-centered approaches to care can be integrated into all aspects and levels of medical education, including medical school, residency, and continuing education. Forum participants discussed issues that included: the skills, abilities, and attitudes of family-centered service providers; barriers in professional education that need to be overcome for professionals to learn family perspectives; and, core curriculum content for family-centered preservice and inservice training. **This valuable resource is published by and available through ACCH.**

Together We Can: A Guide for Crafting a Profamily System of Education and Human Services

A. Melaville, M. Blank, & G. Asayeh (1993)

This book was developed jointly by the U.S. Department of Education and the U.S. Department of Health and Human Services to help communities improve coordination of health, education, and human services for children and families. A five-stage collaborative process is detailed, to assist communities in the difficult process of creating a more responsive service delivery system. **This resource is available from the U.S. Government Printing Office, Superintendent of Documents, Mail Stop: SSOP, Washington, DC 20402.**

Universal Access to Outdoor Recreation: A Design Guide
U.S. Forest Service (1994)

This guide details how facilities (from toilets to bridges to fishing piers to picnic tables) can be made more accessible for use by all individuals, including those with disabilities, without "paving over the outdoors." It allows primitive areas to remain with a "degree of challenge," but usable by people with temporary or long-term disabilities. **For more information, contact MIG Communications, 1802 Fifth Street, Berkeley, CA 94710.**

Your Child and Health Care: A "Dollars and Sense" Guide for Families with Special Needs
L. Rosenfeld (1994)

Your Child and Health Care is a book that gives straightforward, practical answers to questions about the full range of services available to children needing specialized health and developmental services and their families, and how to pay for them. This resource is filled with empowering ideas on how to make the most of financial resources, while securing the quality of services provided by federal, private, and community programs and organizations. Helpful for both families and professionals, **this book is published by Paul H. Brookes Publishing Company, Baltimore, MD.**

Your Child With Special Needs at Home and in the Community
Association for the Care of Children's Health (1989)

This is a thoughtful booklet for families offering practical information on family life, and on managing medical care, school, and finances. It includes an extensive listing of books, organizations, and other resources. **This resource is published by and available though ACCH.**

The Eighth Element

Appreciating families as families and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support.

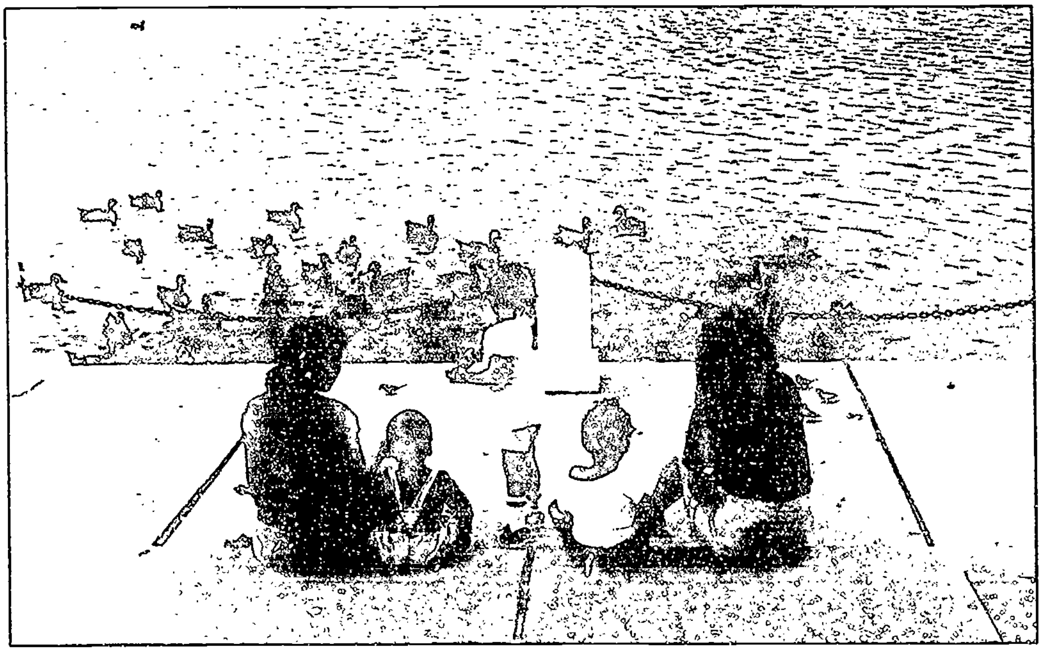

Photo courtesy of Kennedy Krieger Children's Hospital, Baltimore, MD. Photographer: LeRoy Marrow

Appreciating Families as Families

The previous elements each highlight the need for collaboration and communication between and among families and professionals, as well as between and among the formal and informal service and support systems that meet the diverse needs of children who are ill or who have disabling conditions. But in understanding and respecting the family's central role in their child's care, it is also essential for professionals to understand, accept, and support the fact that the child's health condition may not always be the family's only or most central priority. Furthermore, the concerns and priorities of children and families change across time.

What Does This Mean?

In providing quality health and developmental care, it is vitally important to attend to families as they define themselves. However, while recognizing and respecting the family members as a full partners in children's health and developmental care teams, it must also be recognized and respected that they also are members of a family, before, during, and beyond the present and future specialized needs of their children. One of the participants at the Seventh Annual National SPRANS Workshop remarked:

> *sometimes the family becomes more of a service provider and may experience less parenting, less normalization of their role. There's an irony in that what is usually viewed as family-centered care may be very disruptive to the essence of 'family' (SPRANS, 1993, p. 9).*

In discussing her concerns related to recognizing children and their families beyond the dimension of their health, developmental, and related needs, Judy Heumann (1994), Assistant Secretary of the Office of Special Education and Rehabilitation Services (OSERS) and an adult with a disabling condition, said that it is important for families to be able to see their children with disabilities simply as children. Interactions with hospital and community service systems though, can cause parents to have difficulty recognizing that their child with a disability, in many ways, is just like a child without a disability.

Children needing specialized health and developmental services need the same kind of love and support and direction as other children. In addition, parents need to have goals, aspirations, and expectations for their children, regardless of their illness or disabling condition. While moving towards respecting the strengths associated with various aspects of diversity within and across individuals (e.g., cultural, spiritual, geographical), our society does not yet acknowledge disability as a type of diversity, also with inherent strengths. This is evidenced by the tendency to include people with disabling conditions in society, yet in "separate" or "token" ways:

> *There is a big move in this country for diversity — being sensitive to racial and cultural differences, making sure that boys and girls are treated equally. But often in the case of children and adults with disabilities, we're not appropriately reflected in textbooks or in the media. When we show up in books or on television, we are treated as special. Personally, I don't like the word 'special'. All children are special! It is important that people with disabilities are reflected more accurately in children's literature. That's not just something children [with disabilities] need to see; children [without disabilities] need to see it, too. We need to help children accept the fact that people with disabilities are becoming a larger and more influential part of society (Heumann, 1994, p. 59).*

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Appreciating the Child as a Child

In planning care, it is important to keep in mind how to support the whole child:

> *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).*

Providing services in a family-centered way demands that families be viewed in a context much broader than the health care encounter.

The lives of children and families can continue to grow and develop beyond a diagnosis or condition.

As one mother remarked:

> *Many professionals seem to forget sometimes that Laura is not only a little girl with Turner Syndrome or congenital health disease or malformed kidneys or complications of surgery or multiple orthopedic problems . . she is also a horse lover, a fish breeder, a Girl Scout, a student of the viola, a reader of great books, a sister who comforts a crying brother, a daughter who sweeps the kitchen, a granddaughter who crafts homemade Valentines, a niece who tickles a cousin — all of the things that are more important about her than the string of diagnoses that we can choose from (Leff & Walizer, 1992, pp. 209-210).*

This comment not only highlights the importance of recognizing the child as unique and as an individual, but also the many family connections that a child has — the multiple relationships both within and outside of her family. Maintaining and supporting these connections and providing a supportive environment in which children can learn the skills necessary for daily life, where they have the opportunity to succeed, and to fail, becomes as essential to any care plan as the most advanced medical technology. As one nurse commented:

> *I am reminded again — children grow and thrive best if they are seen first as children of their families and then are recognized as having . . . needs which require [specialized] care (Huggens, 1994, p. 1).*

Appreciating the Family as a Family

Family-centered care recognizes the many roles that parents, families, and caregivers play — as experts, nurturers, advocates, decision-makers, coordinators of care, and partners in developing, implementing, and evaluating care. Yet it is vitally important that in recognizing these new roles, one does not lose sight of their role as parents, as grandparents, as other family members, and as individuals themselves. Being the parent of a patient should never overpower the fact of being a parent.

Providing services in a family-centered way demands that families be viewed in a context much broader than the health care encounter. Recognizing this has at least two implications for care. First, decisions about therapy and intervention can be made only in the context of the family's finite time, resources, and energy. This consideration, in turn, demands that goals for the child and family be set in collaboration with the family. Furthermore, these decisions should only be made while recognizing the aspirations of the parents, the interests of the child, and the consideration of brothers and sisters, and with respect for the family's desires.

Respecting a family's priorities may mean temporarily, or indefinitely, foregoing a particular intervention if it is not life-threatening, and possibly, delaying progress in one area of a child's life. It also means respecting the family's decision to do just that — acknowledging their authority on what is right for their family at that particular time:

> *There are times when even an acceptable amount of therapy becomes too much . . . When your child needs time just to be a child, or when you need time to be with the rest of the family. It's okay to say 'no' at those times (Simons, 1985, p. 51).*

It also means that in planning care, for the child or for the family, that parents' needs as adults, as professionals, and as partners must be supported:

> *Please remember that you see our family in only one dimension — the medical. We have husbands and wives, other children, grandparents, friends and neighbors, jobs, school, mortgage payments, chicken pox and a dozen other things to juggle every day (Leff & Walizer, 1992, pp. 212-213).*

In reviewing the research on effective help-giving practices, Dunst and colleagues (Dunst et al., 1994) extend support for the importance of this element. First:

> *Help-giving is most effective if the help-giver offers aid and assistance that is normative in terms of the family's own culture (p. 178).*

That is, services and resources must be provided in a way that does not interfere any more than necessary with the way other families in that culture or social network would deal with the same problem or need (Gross & McMullen, 1983). In addition:

> *Help-giving is most effective if it assists the help seeker to identify, clarify, and prioritize aspirations as well as needs (Dunst et al., 1994a, p. 178).*

The family's goals and aspirations must be integrated within any plan that addresses the child's health care needs. Family preferences will be influenced by their diversity, their family traditions, and their previous experience with prioritizing the needs of their child. When the values and outcomes chosen by the family are not consistent with those of the professional, friction and negative judgements by both parties can result, particularly when the decision involves a lack of treatment or an ethical issue. It then becomes a challenge for the professional to understand the philosophy of family-centered care. Even when the outcomes and care plans embraced by families and professionals appear very different, they are quite often ultimately pursuing the same goal — to do what is best for the child — but each within their own set of beliefs and values. And in the end, it is still the family that knows and has the right to decide what is best for their child in their unique family context.

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Incorporating Appreciation into Policy and Practice

How can respect and appreciation for families as families be exemplified? One way is improving the language we use when speaking to or referring to children and families. In addition to being sensitive to the family's need for explanations of discipline-specific health and developmental terminology and jargon, awareness of how we communicate with children and families, and of the words that we use, is one way to advance this aspect of family-centered care.

Respect and appreciation can start in the initial encounter with a family. As Leff and Walizer (1992) note, professionals often introduce themselves by title and surname, but fail to address anyone else by name except the patient. It is important to learn and use proper names and titles. This conveys a message of respect for families and the critical role they play in the lives of their children. As Newcomb (1993) stated:

> *For a physician to introduce himself as 'Dr. A,' and then proceed to call the child's mother 'mom,' is a sign of disrespect, and an indication that the family is not an equal partner on the child's health care team. The child's mother is not the physician's mother. She has a first name, and a last name. Either is okay to use, but it should reflect how all members of the team are addressed. Either everybody is comfortable being called by their first names, or everybody is called by their title and their last name.*

Similar considerations are needed when referring to the child's disability or health condition. Inadvertently, outdated language and words contribute to perpetuating old stereotypes and highlight the condition rather than the individual. Some guidelines for updating language when talking to or about a child with a disabling condition include:

- Use "disability" rather than "handicap" to refer to the child's condition or disability. Never use "crippled," "defective," or "damaged" in any reference to the child. For example, it is better to say "congenital disability/birth anomaly" than to say "birth defect;"

- When referring to a person's disability, try to use "people first" language. It is better to say "child with cerebral palsy" or a "child with a disability" rather than the "CP child" or "disabled child;"

- Avoid referring to individuals with disabilities as "the autistic, the deaf, the preemie." Descriptive terms should be used as adjectives, not as nouns such as the "child with Down syndrome" as opposed to the "Down's child," and never "the mongoloid." Say the "child with quadriplegia," "medically involved/has chronic illness," or "child with speech/ communication disability," not the "quadriplegic," "diseased/sickly/invalid," or "dumb/ mute;"

- Don't say "wheelchair-bound" or "confined to a wheelchair." People who use mobility or adaptive equipment are, if anything, afforded freedom and access that otherwise would be denied them;

- Avoid negative or sensational descriptions of a person's disability. Don't say "suffers from," "a victim of," or "afflicted with." Don't refer to people as "patients" unless they are receiving treatment in a medical facility;

- Don't portray people with disabilities as overly courageous, brave, special, or superhuman. It may imply that it is unusual for people with disabilities to have talents or skills; and,

- Don't use "normal" to describe people who don't have disabilities. It is better to say "people without disabilities" or "typical," if necessary to make comparisons (ACCH, 1994).

Families should have the right to feel guilty, even if they are not at fault, and they should have the right to be angry, sad, and confused, and express these feelings without any negative consequences.

Respect for families as families can also be exemplified in recognizing that it is not typical for families to have to share so much personal information, time, responsibility and care, and decision-making processes with professionals and service systems — not just about their child, but also about the needs, concerns, priorities, and resources of the entire family. Henry Ireys (1987) said during a conference on issues for professionals:

> *. . . the child with chronic illness and the family is treated by dozens of different strangers who may, according to their specialty or their agency affiliation, regard the child as a malfunctioning organ rather than a whole person, as a sickly school child rather than someone desiring to learn, as a third-party payment problem rather than a child and family struggling to cope. Distance and the alienation of helper and helped have led to professional values that conflict with the helping function by creating dependency rather than collaboration, [and] distrust rather than respect.*

The Central Role of the Family

As families come under the watchful eye of professionals who teach them how to provide the specialized care their child needs, they are often put in a position of being "observed" by other members of the health or developmental care team as they also try to play, nurture, bond, or be intimate with their child. Furthermore, the full range of typical human emotions, life events, struggles, and achievements that families experience and show — both related to the child's condition as well as to other things that are going on in the family's life beyond the child's illness or disability — are often witnessed by professionals involved in the child's care.

As parents participate in their child's care, it must be recognized that caring for a child who is ill or who has a disabling condition can create unique strains on family systems. Understanding the naturalness of their feelings can lead to a better sense of acceptance, and of peace of mind. Families should have the right to feel guilty, even if they are not at fault, and they should have the right to be angry, sad, and confused, and express these feelings without any negative consequences.

Furthermore, families should have the right to enjoy life as much as possible, despite the child's illness or disability, and to be able to express a sense of humor, even as it relates to the child's condition, without feeling guilty or judged. Children and families possess strengths and needs, concerns and priorities, and emotions and aspirations beyond those related to a diagnosis, and beyond those related to their partnership on a health or developmental care team.

While families rely on professionals to provide skilled care for their children, and to teach them how to provide their child's specialized care, they also rely on professionals to respect their needs for privacy and confidentiality. True collaboration and partnership can not be achieved when professionals and families distrust each other, which can often occur when opinions are inappropriately formed on insignificant information. It is essential that attitudes and judgements regarding a child and their family never be based on heresay, on assumptions, or on irrelevant information that may be acquired advertently, or inadvertently, as the family is forced to be in the "public eye" because of their child's needs. This should be true not only in hospital environments, where professionals from all disciplines chart statements about the child's and family's "functioning" in the medical record, but also in home care, where home nurses "live" with families, sometimes 24 hours a day.

For families and professionals to work collaboratively, each discipline must respect the expertise of each of the other professionals and family members integral to the child's team, and also respect their roles as professionals and family members beyond the functions of the team:

> *It is essential for both families and professionals to learn to actively listen to each other, and to use open and honest communication — not just in what is said, but also in how something is said. Preconceived judgements made about the values, abilities, or roles of other team members can be very detrimental to a collaborative process (Stepanek, 1994, p. 2).*

Coming Full Circle

Developing policies and implementing practices that are exemplary of the family-centered care philosophy is not a procedure that can be done, or taught, or acquired all at once. Rather, it is a process, that develops and evolves with an increasing awareness, understanding, and respect of one's own values, that allows for an increasing awareness, understanding, and respect for the diversity of the values other people hold. True family-centered care:

> *. . . evolves out of a continuing relationship between professionals and families. This relationship itself must rest on a mutual respect and a shared commitment to working together in an imperfect world (Ireys, 1987).*

In facilitating the implementation of family-centered practice and policy, we must face the remaining barriers to collaboration with assertiveness and confidence as we encounter them.

Barriers and impediments to family-centered care must be changed from within a system, whether it is a hospital-based, home-based, or community-based system of care. Families frequently feel that they have to "advocate" for their children's rights and care, as well as for their own rights within a system. Parents don't become advocates for their children because too many comprehensive, family-centered services have been provided, because too many professionals have listened to their concerns, or because professionals and systems have been too accurate in their judgements. Parents don't become advocates for their children because they have free time beyond their jobs — professionally or as a family member — and need to stir up the lives of the professionals around them. Parents become advocates because they realize that their children's futures may depend on it, or because they fear they are not getting a particular service that will have a long term consequence for their child. And the reason for this is that the service systems have not always been responsive to family-identified needs; rather, they have been based on determining which needs they can, or will, address, for "qualifying" children and families.

In facilitating the implementation of family-centered practice and policy, we must face the remaining barriers to collaboration with assertiveness and confidence as we encounter them. We must find constructive ways to continue educating individual members of professions, families, and systems about the efficacy and benefits of such care. We must strive to serve children as children within the context of their families, and families as families within the context of their communities.

And so, we come full circle — in appreciating families as families, we must recognize them as the constants in their children's lives, and respect that their children's lives consist of emotions, events, dreams, aspirations, and an existence beyond their need for specialized care. Facilitating the central role of the family, then, relies on collaboration and an ongoing exchange of information, and a respect for the diversity of families and their unique and varied needs, concerns, values, priorities, and ways of coping. In meeting the comprehensive needs of the child and family, services and systems must be accessible and flexible, and responsive to the input of all families. Furthermore:

> *As health care services and funding are reformed, we must work to ensure that the impetus driving the implementation of psychosocial care is not lost in the inevitable financial and logistical struggles. The benefits of family-centered care must be documented through research and other empirical data. Such will provide hesitant policy-makers and service providers with evidence of improved medical and/or psychosocial outcomes for children and their families associated with family-centered care (Stepanek, 1994, p.2).*

. . . professionals caring for children and families must recognize that they are practicing a "human art," that when done well, satisfies both the needs of the patient and of the professional.

However, former Surgeon General C. Everett Koop recently noted (1994), that as research and professional standards are emphasized, we cannot continue to ignore the ultimate purpose of health and developmental services — caring for people. He firmly stated that professionals caring for children and families must recognize that they are practicing a "human art," that when done well, satisfies both the needs of the patient and of the professional. Meeting the specialized health and developmental needs of children and their families through family-centered care then, is not just "doing things right," it is the "right thing to do." As Maya Angelou, renowned author, poet, and speaker on humanity, has often said:

> *At our best level of existence, we are parts of a family, and at our highest level of achievement, we work to keep the family alive.*

Making It A Reality

Embodied in the heart and spirit of family-centered health and developmental care is a respect for families as central in their children's lives, integrated with an appreciation of families as families beyond their need for, and contributions to, their children's specialized services or supports. Family-centered service providers recognize, respect, and appreciate the diverse strengths, needs, concerns, and priorities of children and their families, both related to a diagnosis and participation on a health care team, and also related to their participation in other life roles.

Children and families should be able to work and play, to laugh and cry, to dream and aspire, and to love and grow, whether they spend most of their time receiving services from a hospital-, home-, or community-based program, or very little time in specialized support. Each child and each family should be able to live life to their fullest potential, becoming the best possible child and family they can be, without judgement from any other child, family, or professional. This section lists some of the many programs and resources available that strive to meet the unique needs of children as children and families as families, while also recognizing and addressing individual needs for specialized care.

Programs, Policies, and Practices

The Adolescent Autonomy Program
Kluge Children's Rehabilitation Center
University of Virginia in Charlottesville

The Adolescent Autonomy Program provides exercises to build social skills, such as assertiveness training and peer group activities, during a teen's hospitalization. Peer group counseling enables young adults with disabilities to share their experiences about interviewing for a job or dressing for success in a wheelchair. An Adolescent Apartment enables independence from staff and younger patients and provides an environment to practice independent living skills such as chore delegation, cooking, and cleaning. **For more information, contact Sharon Hostler, Medical Director, Kluge Children's Rehabilitation Center, 2270 Ivy Road, Charlottesville, VA 22903 (PHN: 804/924-2345 or 1/800/627-8596; TDD: 804/982-HEAR).**

The Adolescent Employment Readiness Center (AERC)
Children's Hospital National Medical Center, Washington, DC

The *AERC* offers individual help for teens with chronic illnesses and physical disabilities to prepare for employment and plan for their future. The AERC staff provides educational workshops, and is available to speak to groups about employment issues concerning youth with health concerns. This program is sponsored by the Maternal and Child Health Bureau and a variety of private foundations. **For more information, contact The AERC Office, CHNMC, 111 Michigan Avenue, NW, Room 1301, Washington, DC 20010 (PHN: 202/745-3203).**

The Bear Theatre
The Hospital for Sick Children, Toronto, Canada

The Bear Theatre was conceived in 1992 to be the first ever regularly performing company of health care professionals based in a pediatric hospital. The Bear Theatre's vision is to share with hospitalized children and their parents the humanizing, personal, and non-medical sides of the people caring for them. For that end, an original musical was written which deals with the theme of being different. The Bear Theatre offers the play, the music playback, the pamphlets, and all of the other production instructions without cost to any member of the Association for the Care of Children's Health wishing to establish a similar program. **For more information, contact Dr. Gideon Koren, Division of Pharmacology and Toxicology, The Hospital for Sick Children, 555 University Avenue, Toronto, Ontario, Canada M5G 1X8 (PHN: 416/813-7654, ext. 4204).**

CHEERS
Lucile Salter Packard Children's Hospital at Stanford University
Stanford University, Palo Alto, CA

CHEERS is a special recreation program for teenagers who are patients in the Hematology/Oncology Unit at Lucile Salter Packard Children's Hospital. Originally funded by the Stanford University Public Service Center in 1986, the program is now funded by grants and donations, and a part of the Recreation Therapy Department at the hospital. CHEERS offers many day-long activities throughout the year, including sailing on the bay, white water rafting, concerts, and sporting events. The program provides the opportunity for teenagers to meet each other, to share social experiences, and to spend time together away from the hospital. The staff consists of a physician, a recreation therapist, and several social workers. Some graduates of the CHEERS program are also chosen to become volunteers staffing the program, because of their high energy level, responsibility, and ability to work well with teenagers. **For more information, contact Charlene Mattos, Recreation Therapy Department, Lucile Salter Packard Children's Hospital at Stanford University, 725 Welch Road, Palo Alto, CA 94304.**

Family Friends

Easter Seal Society, Washington, DC

Family Friends is an intergenerational program which matches senior volunteers with families of children under the age of twelve who have chronic illnesses or disabilities. The children receive extra attention, companionship, and love from a "Family Friend," and their families receive the benefits of an extra pair of helping hands, a supportive shoulder, an extra lap, and the gift of time to make the job of raising a child needing specialized health or developmental services easier. Family Friends spend three to four hours each week in a family's home or at a specific program for children and families for at least nine months.

The volunteers who become a Family Friend participate in activities with any or all members of the family, doing things such as reading stories to a child in bed or to a sibling, accompanying a parent to a medical appointment, feeding a child with a disability, or being a good listener to a stressed parent. A Family Friend can make it possible for a parent to run an errand, to take a sibling for a stroll, or to take a break. These services are free to all families in the program. Family Friends was recently honored with the Excellence in Family Support Award designed by the Human Services Research Institute as a program providing high quality supports and services to families of individuals with disabilities. **For more information, contact Family Friends, 2800 13th Street, NW, Washington, DC 20009 (PHN: 202/232-2342; FAX: 202/462-7379).**

The Family Strengths Program

Parent Advocacy Coalition for Educational Rights (PACER), Minneapolis, MN

The Family Strengths Program provides information about family diversity and strengths and offers support for children and families emphasizing that every family is unique and special. The program offers a puppet show featuring large, child-sized puppets that talk about feelings children with and without disabilities may have as their families experience change. Children are given the messages that people live in different kinds of families; that children can talk with trusted adults about family issues; that families can have fun together even when there are challenges; and, that children have strengths that can help their families.

The Family Strengths Program also offers a handbook to help families celebrate and build upon their successes, identify and use their strengths, build family communication skills, take time to be together and have fun as a family, and to enjoy family stories and traditions. A four-lesson curriculum for professionals expands on concepts from the puppet show and handbook, offering service providers information related to recognizing and respecting family strengths and diversity and to stages of child development and their effects on self-esteem. **For more information, contact PACER Center, Inc., 4826 Chicago Avenue South, Minneapolis, MN 55417 (PHN: 612/827-2966; FAX: 612/827-3065).**

National Center for Youth with Disabilities
Adolescent Health Program, University of Minnesota

The *National Center for Youth with Disabilities* works to expand the knowledge and involvement of individuals, agencies, and programs providing services to youth with chronic illnesses and disabling conditions, and to promote the use of strategies which enhance the ability of adolescents and young adults to grow, develop, work, and participate in community life to their fullest capacity. The Center is committed to an interdisciplinary perspective and to fostering collaboration between and among professionals, family members, and youth.

Programs of the Center include: The National Resource Library on Youth with Disabilities; workshops, conferences, and presentations at state and national levels which support the design and implementation of state and community programs for youth and families; publications of monographs, bibliographies, and newsletters on vital issues regarding adolescence and disability; and, technical assistance and consultation. **For more information, contact the National Center for Youth with Disabilities, Adolescent Health Program, University of Minnesota, Box 721 - UMHC, Harvard Street at East River Road, Minneapolis, MN 55455 (PHN: 1/800/333-6293 or 612/626-2825; TDD: 612/624-3939).**

Parent Beeper Program
Children's Hospital Medical Center of Akron

At the Children's Hospital Medical Center of Akron, a number of hospital system beepers are available for use by families with children in the intensive care unit. The beepers allow family members to leave their child's bedside to eat, shower, or take a much needed break, knowing that they can be easily reached in case of an emergency. **For more information, contact Children's Hospital Medical Center of Akron, 281 Locust Street, Akron, OH 44308 (PHN: 216/379-8200).**

Partners for Youth with Disabilities, Inc.
Boston, MA

Partners for Youth with Disabilities is a regional, private, not-for-profit organization that serves youth with physical, sensory, and learning disabilities. The program assists young people to reach their full potential for personal development by arranging one-to-one mentoring relationships between youth with disabilities and adults with similar disabilities. They sponsor training, activities, and events, and provide a newsletter to keep people up-to-date on issues related to the program and to disabilities in general. **For more information, contact Partners for Youth with Disabilities, Inc., Massachusetts Office on Disability, One Ashburn Place, Room 1305, Boston, MA 02108 (PHN: 617/727-7440 or 1/800/322-2020).**

Smarty Pants Audio and Visual, Inc.
Lakewood, OH

Smarty Pants Audio and Visual, Inc. has developed six award-winning videos for use on closed-circuit television in pediatric hospital settings. One of the 30-minute programs helps to normalize the hospital environment for a child who can not get out of the hospital bed or room. These non-violent programs aim: to decrease feelings of isolation; to educate patients about safety, health care, and literacy; and, to boost self-esteem. These programs are currently in use at Rainbow Babies and Children's Hospital in Cleveland, Ohio and are considered a very successful alternative to commercial television. **For more** information, contact Smarty Pants, 15104 Detroit Avenue, Suite #2, Lakewood, OH 44107 (PHN: 216/221-5300; FAX: 216/221-5348).

Special Olympics International
Washington, DC

Special Olympics International is a program that believes that families with children who have disabilities are like other families in many ways, but that having a child who needs specialized services and supports often thrusts families into situations that may make their everyday lives more challenging. Since 1968, Special Olympics has been offering families a chance to be a part of a year-round sports training and competition program which provides the entire family with opportunities for sports, social interaction, and fun. The families involved with the program have an opportunity to help coach, transport, raise funds, officiate, chaperone, and train other volunteers.

The program offers support to the nearly 500,000 participating families through newsletters, brochures, Family Seminars and sports camps, Family Days and Family Committees, Family Receptions at games and special events, Family Hospitality rooms at games, The Family Awards and Recognition Program, a referral system for families seeking professional assistance, and Family Home Training Programs which assist in sports and physical conditioning. **For more information, contact Special Olympics International Headquarters, 1350 New York Avenue NW, Washington, DC 20005 (PHN: 202/628-3630).**

Resources

After the Tears
R. Simon (1987)

In *After the Tears,* parents of children with disabilities share their feelings, their difficulties, and their triumphs. Practical suggestions and ideas are interspersed among very personal vignettes. **Available through ACCH, this book is published by Harcourt, Brace and Company, Troy, MO.**

Baby Book for the Developmentally Challenged Child
Handicapers Company (1994)

This *Baby Book* was designed by the mother of twins who need specialized health and developmental services for parents who have been frustrated trying to complete a conventional baby book for their child with a disabling condition. This book allows a parent to mark the milestones in their child's life in a way that allows for reflective moments and future delights. In addition to the typical information areas (e.g., date of birth, first tooth, first hair cut), this book has areas to record such things as a child's special diet, medical and adaptive equipment, therapists and early intervention goals, and special achievements (e.g., weaned from the ventilator, feeding by mouth). **For more information, contact Handicappers Company, 5323 Sundale Place South, Columbus, OH 43232 (PHN: 614/833-5077).**

Creating a Healthy Camp Community: A Nurses Guide
K. Lishner & M. Bruya (1994)

Creating a Healthy Camp Community is a book designed to help individuals trained in nursing and camp directors to become more familiar with their profession in a camp setting, and more familiar with health care at camps beyond injuries and emergency illnesses. The book addresses issues related to program management, nursing practice, human relations, and the changing way health care is delivered in camps, as more and more children with disabling conditions are beginning to attend camps originally established for children who do not have disabilities. **For more information, contact The American Camping Association, 5000 State Road 67 North, Martinsville, IN 46151 (PHN: 317/342-8456; FAX: 317/342-2065).**

For Families of Children with Special Needs: A Calendar of Resources (Birth to Age Ten)

Adele Warsinski (Undated)

This twelve-month undated calendar was published to provide information and support to families of children needing specialized services and supports. Each month, a theme is presented relevant to living and growing with a child who has specialized health or developmental needs, along with a number of resources related to the theme. Themes in the 1994 edition of the calendar include: caring for a child needing specialized services, family resilience, sibling issues, advocacy, grief related to having a child with a disability, communication development, early intervention, stories and songs, self-esteem and discipline, play, and living and coping with life beyond a disability. This resource also functions as a keepsake and/or a record of appointments, medications, and therapies. **For more information, contact Adele Warsinski, ASW Publishing, 7566 37th Avenue SW, Seattle, WA 98126 (PHN: 206/937-3698).**

Friends of the Family

J. Newton, P. Stookey, & Friends Celebration Shop (1990)

Friends of the Family is an exciting audio tape with a companion coloring book containing activities and lyrics. The materials were created to boost self-esteem of children and young people with chronic health care conditions, while capturing their imagination and entertaining them. These artists have developed several award-winning tapes and compact discs for children and families in both English and Spanish. **Available through ACCH, these resources are produced by The Celebration Shop, Fort Worth, TX.**

Guide for Differently-Abled Kids

Toys R Us & The National Parent Network on Disabilities (1994)

Through a partnership with the National Parent Network on Disabilities, Toys R Us is now sending a specially created *Guide for Differently-Abled Kids* to parents of children with disabilities. The guide contains toys that have met the standards set by the U.S. Consumer Products Safety Commission, have been professionally tested by children with disabilities, and have been specially identified by Toys R Us as deserving of parents' special attention. Through symbols, the guide indicates which skill area(s) each toy addresses (e.g., auditory, creativity, fine motor, language, self-esteem, social skills, thinking, or tactile). **For more information, contact Diana K. Cuthbertson, President, NPND, 1600 Prince Street, #115, Alexandria, VA 22314 (PHN: 703/684-6763; FAX: 703/836-1232).**

"Human Services?... That Must be So Rewarding"

G. Bernstein & J. Halaszyn (1989)

This easy-to-use resource provides practical insights and personal guidance in human services. It offers guidelines and suggestions for: addressing personal motives, goals, and limits; being sensitive to those who receive services; developing effective relationships with consumers, colleagues, supervisors, and professionals from other agencies; planning for professional development; and, identifying long-term professional goals. **Published by Paul H. Brookes Publishing Co., Baltimore, MD.**

The SoonerStart Newsletter
Oklahoma Early Intervention Program

The SoonerStart Newsletter is an innovative and interesting combination of information related to early intervention services for children and families, mixed with other materials related to activities and interests common to many families with young children. This monthly newsletter, written and edited by a parent and grandparent of children needing specialized services and supports, offers articles covering issues from health care reform, educational conferences, and speech therapy, to toy lending libraries, behavior management for toddlers, and baking "Dirt Cups" (a special chocolate cupcake recipe for parents and children to create together). **For more information, contact Penny McPhail, Editor, Regional Coordinator for the Early Intervention Unit, Lawton, OK 73501.**

I Will Sing Life: Voices from the Hole in the Wall Gang Camp
L. Berger, D. Lithwick, & Seven Campers (1992)

I Will Sing Life is an award-winning book of extraordinary hope and inspiration written by seven remarkable children, all of whom attended Paul Newman's Hole in the Wall Gang Camp (for children with life-threatening illnesses and disabilities). This is a book of life, reverberating with voices that are wise, funny, poignant, and triumphant. **Available through ACCH, this book is published by Little, Brown, and Company, Boston, MA.**

Taking Charge: Teenagers Talk about Life and Physical Disabilities
K. Kriegsman, E. Zaslow, & J. D'Zmura-Rechsteiner (1992)

Taking Charge is a book about 15 teenagers with various physical disabilities who talk frankly about self-esteem, relationships, and the future, providing honest advice and creative solutions. This book also contains a resource section covering such issues as assistive technology, legal resources, educational resources, disability organizations, recreation and sports, sexuality and genetics, and disability oriented magazines. **Published by Woodbine House, Mount Ranier, MD.**

Toby Tracheasaurus
Voicing! Inc. (1992)

Toby Tracheasaurus is a special therapy method that teaches children who have had tracheostomies and/or are ventilator dependent how to talk. Using fun activities contained in Toby's Tote, (a colorful kit containing dino bubbles, pinwheels, party horns, dino whistles, and other fun dino toys), children learn how to exhale through their mouth, which is the vital first step in learning how to talk. The producers of this resource also offer a new textbook on talking with or after a tracheostomy, and they conduct two day regional conferences at hospitals in various locations. **For more information, contact Mary Mason, Voicing! Inc., 3857 Birch, Suite 194, Newport Beach, CA 92660 (PHN: 714/833-2710; FAX: 714/833-1005).**

Checklists for Family-Centered Care

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Checklist for Collaboration Between Families and Professionals

☐ How does the philosophy, policy, practice standard, or mission statement of the facility or agency reinforce that family members are essential members of the health or developmental care team?

☐ What steps are taken to ensure that families with diverse backgrounds in culture and experience are well-represented on policy, planning, advisory, and evaluation boards and committees?

☐ How are families invited and encouraged to participate in preservice and inservice training of professionals with regard to family perspectives (e.g., reimbursement for time, child care, or transportation expenses)?

☐ How are all families, regardless of cultural diversity (including ethnic, racial, spiritual, social, economic, educational, and geographic components), invited and encouraged to collaborate in the care of their child and in decision-making processes?

☐ How are families asked to define the composition of their family unit and to indicate who will be included in the collaborative process?

☐ What are the mechanisms that enable families to choose their level of participation in their children's care, and that allow families to change that level as needed or desired?

☐ How are communication and the ongoing exchange of information between and among families and professionals facilitated?

☐ How are families taught necessary skills and encouraged to participate in their children's specialized care?

☐ How is respect for the central role of families, and their expertise on their own children's reactions, temperament, strengths, and needs, facilitated and communicated?

☐ How are the opinions, concerns, and priorities of family members recognized as essential information and incorporated into all care planning and decision-making?

☐ Are meetings/visits scheduled at times convenient for families and are the agenda items developed collaboratively between families and professionals?

☐ What are the mechanisms that ensure families access to their children's medical records, and how is family input incorporated into medical records?

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Checklist for Communities

☐ How are the following resources, supports, and services available for children and families in the neighborhood and community?

- — Primary health care?
- — Specialty medical care?
- — Home health care and/or home nursing?
- — Hospice care?
- — Mental health services and supports?
- — School health care?
- — Early intervention?
- — Care coordination?
- — Special education (from time of diagnosis to age 21)?
- — Vocation, rehabilitation, and habilitation programs?
- — Training for independent living?
- — Hospital school programs including home tutoring?
- — Family resource libraries, centers, and programs?
- — Family-to-family support and networking?
- — Sibling support?
- — Toy and equipment loan or exchange?
- — Play groups?
- — Respite care, child care, and babysitting?
- — Translation and interpretation services, including signing?
- — Transportation assistance?
- — Recreational programs and camps?
- — Financial support?
- — Legal services for estate planning, wills, and guardianships?
- — Spiritual support as the family desires?
- — Home adaptation for health or development equipment needs?
- — Inservice training for families and professionals?

☐ What services are needed that are not available?

☐ What plans are being made to offer needed services?

☐ How do community resources, supports, and services promote integration and full inclusion of all children and families (including a sense of belonging and cohesion, a sense of self-worth and contribution, and a sense of interdependence and reciprocity)?

☐ What plans are being made to achieve improved integration?

Continued, next page . . .

Checklist for Communities, continued

☒ What mechanisms ensure that resources, supports, and services are fully accessible to children and families, and are:

- — Free, low cost, or provided on a sliding scale?
- — Located close to where families live and work?
- — Open at times convenient for all families and all family members?
- — Barrier-free?
- — Welcoming to and supportive of families from all of the cultures within the community?
- — Written or explained so that eligibility criteria are easy to understand?
- — Flexible (e.g., hours, location)?
- — Adequately advertised through media, in clinic and physicians' offices, schools, libraries, and recreation centers?

☒ What plans are being made to improve accessibility?

☒ How are communication and linkages ensured between and among home, hospital, school, community, legislators, and funding sources that promote:

- — Family/professional collaboration?
- — Communication, collaboration, and coordination between and among professionals and agencies that results in efficient communication while preserving confidentiality?
- — Coordinated networks of formal and informal resources, supports, and services including: referrals, public information, record keeping?
- — The accurate identification and description of these resources, supports, and services?
- — Advocacy for new services?

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Checklist for Hospitals

☐ What plans are being made to improve these linkages?

☐ How does the written philosophy of care incorporate standards that recognize and facilitate the pivotal role of families?

☐ How are families welcomed and introduced to the hospital?

☐ How is family diversity honored?

☐ How does the physical environment appeal to children and accommodate the needs of their families?

☐ How is space allocation ensured to provide and support family privacy and developmental and emotional needs?

☐ How are children and families prepared for the hospital experience?

☐ How are the staff trained to become competent in communicating age appropriate explanations?

☐ How are families informed about treatment choices?

☐ How are staff trained to support family participation and decision-making?

☐ How do parents provide input for and easily access their children's medical records?

☐ How are policies encouraging family/professional collaboration at all levels of care and in all hospital units incorporated into practice (e.g., 24 hour open visiting; rooming-in or overnight provisions; liberal sibling visitation; parental presence during anesthesia induction, radiology examination, recovery room, and emergency room treatments; and, comprehensive discharge planning)?

☐ What are the mechanisms to ensure consumer feedback, and to ensure that feedback is incorporated into policy and practice?

☐ How is diverse family representation on boards and committees encouraged and facilitated?

Continued, next page . . .

Checklist for Hospitals, continued

☐ What is the role of the Family Advisory Board, how are their activities supported, do they report to the Boards of Directors and Trustees, and how are their recommendations incorporated into policy and practice?

☐ How are programs developed and staff trained to be available in supporting the developmental and emotional needs of children and families through:

- — Pre-admission preparation programs?
- — Age-appropriate preparation for children and families during and after medical and surgical treatments?
- — Professionally-staffed child life programs and appropriately equipped playrooms?
- — Hospital school programs?
- — Family resource and medical libraries?
- — Readily available family-to-family support?
- — Primary care nursing for children of all ages, in all units?
- — Adequate support staff (e.g., paid family consultants; patient representatives; social workers; child life specialists; psychologists; chaplains; and, trained volunteers)?

☐ How are staff members informed and educated about financial resources that are available to assist families, and how is this information communicated to all families?

☐ How are staff members informed and educated about community services and how families access them, and how is this information communicated to all families?

☐ How is care coordinated between hospital, home, and community systems of service?

☐ How does the hospital support home health care through:

- — Comprehensive and coordinated discharge planning?
- — Training families in their children's specialized care?
- — In-home health services?
- — Respite care programs?
- — Hospice?
- — Transitional care facilities?
- — Linkages to community services (e.g., medical, educational, financial, recreational, social, emotional)?
- — Follow-up programs?

☐ What are the incentives for staff members at all levels of care and in all units to practice family-centered care?

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Checklist for Professional Training Programs

☐ How are the key elements of family-centered care reflected in the training program regarding:

- — Philosophy and conceptual framework?
- — Curriculum?
- — Teaching methods?
- — Standards for evaluation and improvement?

☐ How are family members of children needing specialized health and developmental services and support routinely involved in all areas of preservice and inservice training, including:

- — Curriculum development?
- — Direct teaching?
- — Clinical supervision?
- — Student, faculty, and professional evaluation?
- — Program evaluation and improvement?

☐ How are family members trained, paid, and otherwise supported in these roles?

☐ What mechanisms ensure that professionals at all levels of service and care represent diverse cultural characteristics?

☐ How do instructors, clinical supervisors, and faculty members not only teach the philosophy of family-centered care, but also model family-centered care in practice?

☐ How are professionals recognized and rewarded for family-centered practice just as they are for research and publications?

☐ What mechanisms invite and encourage students and trainees from diverse cultural backgrounds to be a part of the training?

☐ How are the elements of family-centered care reflected in the criteria used to evaluate trainee's performance?

☐ What mechanisms ensure that trainees have multiple and continuing opportunities to interact with children and families outside the clinical or training setting?

Continued, next page

Checklist for Professional Training Programs, continued

☐ How do preservice and inservice training programs provide instruction in the following areas:

- — Effective communication skills and methods for working collaboratively with families?
- — Skills for working collaboratively as a team member with professionals of other disciplines?
- — Coordinating care and developing linkages among families and agencies and institutions?
- — Appreciation of and respect for cultural diversity (including ethnic, racial, spiritual, social, economic, educational, and geographic diversity)?
- — Planning care in the hospital, home, and community?
- — Collaborative goal setting?
- — Financing options for families?
- — Typical and atypical child development?
- — Support needs of families as identified by families?
- — Family systems and diverse family perspectives?
- — Effectiveness and facilitation of family-to-family support?
- — Knowledge and communication of community resources?
- — Advocacy skills?
- — Research methodology examining cost and emotional effectiveness of family-centered care programs and policies?
- — Techniques for conducting research that respect the rights of children and families and reflect a balanced approach, focusing on family strengths and resiliency as well as needs?

☐ How are plans made for improved training?

☐ What are the plans to address the above training needs for professionals and providers working:

- — In hospitals?
- — In community programs?
- — In homes?
- — In schools?
- — In child care programs?
- — In camps?

☐ How are trainees encouraged or required to take advantage of ongoing training opportunities?

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Checklist for Research

- ☐ What are the ways in which families collaborate with professionals in the design of the research?
- ☐ How does the research design and data analysis allow for a balanced approach, focusing on family and child strengths as well as needs?
- ☐ What steps are taken to ensure that families feel they will not jeopardize the quality of services they receive if they do not wish to participate?
- ☐ What are the mechanisms for ensuring that consent forms are easy to understand and are translated into other languages or media as needed?
- ☐ If a number of research studies are being conducted in one agency or clinic, what are the mechanisms for ensuring that families are not overwhelmed with multiple requests?
- ☐ What are the mechanisms for ensuring that the results of the research are communicated and explained to the families who participated?
- ☐ How do families provide feedback to the researchers on their perceptions as participants?

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Checklist for States

- ☐ How does the health department's written philosophy of care reflect the elements of family-centered care?
- ☐ In what ways do families participate collaboratively with professionals at all levels of decision-making and policy formation within the state?
- ☐ How are families informed about statewide coalitions of families and family support groups within and across disabilities?
- ☐ What are the mechanisms for receiving information from families and family support groups and for disseminating information to them?
- ☐ How do statewide information and referral systems that are easily accessible to families and professionals stay up-to-date?
- ☐ What mechanisms ensure that families have complete and ready access to their children's medical records?
- ☐ What are the specific means of coordinating services for individual families?
- ☐ What mechanisms within the state's funding system support the family's efforts to care for their child at home?
- ☐ How are services organized in ways that allow for flexibility to address the changing and varied needs of children and families across time?
- ☐ What are the mechanisms for ensuring that eligibility requirements for state programs are flexible and easy to understand?
- ☐ What are the mechanisms for ensuring family feedback to state policy makers and funding sources?

Shelton, T.L. & Stepanek, J.S. (1994). Family-centered care for children needing specialized health and developmental services. Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814 (301/654-6549).

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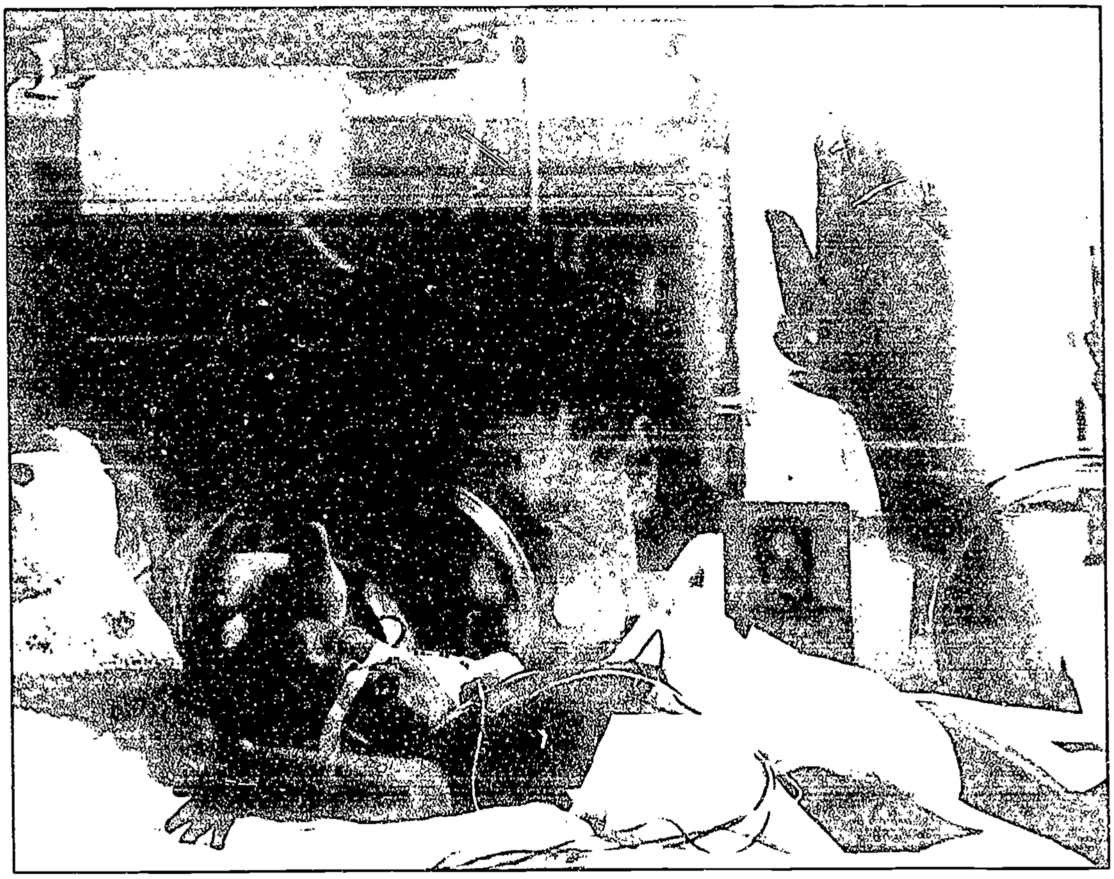

Photo courtesy of Rainbow Babies and Childrens Hospital of University Hospitals of Cleveland

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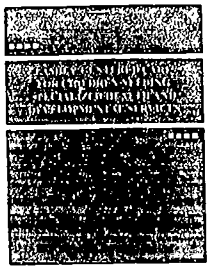

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