

Family-Centered Care



A module designed to introduce primary health care providers to the principles of family-centered care and how the family plays a central role in the provision of care for their child with disabilities and/or special health care needs.

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INTRODUCTION

The philosophy of family-centered care is the basic foundation for the Children with Disabilities curriculum. As a physician working with children, it is essential to have an understanding of the impact disabilities and/or special health care needs can have on a family. This module is designed to inform you, the pediatric resident, of this impact and to support you in gaining an appreciation of the central role a family has in the provision of care for their child. You will learn the nine principles of family-centered care and how their implementation assists and supports the needs of families in the delivery of services to children. The importance of cultural competence and its elements will be discussed as well as family systems theory and the medical home model. You will gain first-hand knowledge of the impact of disability on the family when you visit two families in their homes, one being a patient from your own continuity clinic.

ORGANIZATION OF MODULE

The Family-Centered Care module is divided into four components. The first is a didactic component about the principles of family-centered care. During this didactic, a panel of parents will discuss the impact of having children with special health care needs and their perspectives on the health care system. The second component requires you to conduct two home visits with families whose children have disabilities and/or special health care needs. One of these visits will be with a family chosen by the project coordinator and the other will be to one of your own continuity clinic patient's home. (This patient must have disabilities and/or special health care needs.) The third component requires you to interview a family attending a specialty clinic to learn about a child's care from the family's perspective.

Summary of organization of module:

- ❖ One half day/evening didactic
- ❖ One half day home visit arranged by University of Connecticut A.J. Papanikou Center for Excellence in Developmental Disabilities
- ❖ One half day home visit with child from continuity clinic (to be arranged by resident)
- ❖ One half day specialty clinic visit

OBJECTIVES

At the completion of the Family-Centered Care module, you will be able to:

1. Learn and apply the nine principles of family-centered care to the health care delivery system and to interactions with families and patients.
2. Describe cultural competence and how cultural differences impact one's work with children and families.
3. Explain how the family systems theory relates to family reactions to disability, father and child interactions, and sibling interactions.
4. Describe how life span issues can be especially difficult for children with disabilities and their families.
5. Define the medical home and describe the benefits for children with special health care needs and/or disabilities.

COMPONENT ONE: INTRODUCTION TO FAMILY- CENTERED CARE

Location and Times:

These will be established by the project coordinator in conjunction with the chief residents. You will be notified by either the coordinator or a chief resident with as much advanced warning as possible.

Format:

Information will be presented through discussion, reading materials, case studies, and panel presentation. Videos are optional.

Resident's Responsibilities:

Please arrive on time and come prepared to participate in the conversation. It will be a more productive session if you have read the materials beforehand. Be prepared to critique the session afterwards.

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RELATED VIDEOTAPES:

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PHILOSOPHY OF FAMILY-CENTERED CARE

Family-centered care is a philosophy of care (developed by the former Surgeon General, C. Everett Koop, M. D., Sc. D) that encompasses family-centered, community-based, coordinated services for a child with special health care needs and his or her family. A major premise of this approach is that the child is part of a family, and that the family has great impact on the development and well-being of the child. A family-centered approach to providing services to a child and his or her family requires a relationship based on mutual trust and respect to be established and maintained between professionals and the family. There are nine principles of family-centered care with the underlying premise being to develop a system that 1) assists in the delivery of services to children with special health care needs and 2) supports the needs of the family.

The family-centered approach may represent a shift in orientation for some physicians and professionals in other fields. It is important that health care professionals become familiar with the family-centered principles to ensure that the services being provided meet both the child's and the family's needs.

NINE PRINCIPLES OF FAMILY-CENTERED CARE

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

As a child grows and moves through the service delivery system, he or she will be involved with many professionals, specialists, and agencies.

However, the family will be the constant in the life of the child. It is essential that professionals recognize and respect the central role that the family plays in the care of their child. Ultimately, each family must assume

responsibility for their child's life. Professionals must learn to work in partnership with each family, valuing their judgment, and respecting their values.

2. Facilitation of parent/professional collaboration at all levels of health care.

Successful care plans must be developed through meaningful collaborations to reflect each family's strengths and be tailored to each family's needs. The ultimate success of this process depends on the ability of parents and professionals to work together in partnership.

3. Sharing of unbiased, complete information with the parents about the child's care on an on-going basis.

A true partnership between parents and professionals requires that parents have access to information which is communicated in an understandable way and in the family's primary language. This information includes diagnosis and prognosis, available resources, such as funding for services, and current research data.

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

Every family is unique. Each family's need for support reflects unique values, strengths, coping styles, and hopes for the future. Family support protocol suggests that families have access to information and resources to enable them to maintain the integrity of their family system. Family needs

may include funding, respite, child care, service coordination, parent-to-parent support, transportation, adaptive equipment, assistive technology, housing modifications, and advocacy.

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

Each family has its own strengths and sources of support. These may include neighbors, extended family, friends, and community associations. Professionals should work with the family to identify support networks and develop strategies to strengthen and reinforce them. In addition, each family is defined differently and may include friends, as well as grandparents, brothers, sisters, aunts, and uncles. Services must be tailored to fit around this unique family system with its own specific goals, visions, values, culture, and coping style.

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

A medical plan must address other issues in addition to each child's health care needs. Each family system should have access to opportunities for socialization and community support. The medical home allows each family member to fulfill his or her role and support each child with opportunities to be a part of family and community life. Please see Appendix A for a fact sheet on how to communicate with people with disabilities and a list of common acronyms and abbreviations.

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

Support from other families is valuable in developing successful coping strategies. Parent-to-parent support may involve matching experienced or veteran parents with a parent newly referred into the service delivery system. The veteran parents receive training in their roles as parent-to-parent support group volunteers, and each parent-to-parent support group is coordinated by a parent. Family supports can also include parent groups led by professionals.

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

It is critical that service providers be able to respond to the ever-changing needs of each child and family with a flexible, accessible, and responsive system of services. Families often report that inflexible service systems and friction between parents and professionals are greater sources of stress than the daily care of their children. They report stresses such as rigid and conflicting eligibility criteria; confusing application forms; turf battles among agencies and service providers; and a fragmented, difficult-to-access system of services.

9. Honoring the racial, ethnic, cultural, and socioeconomic diversity of families.

Each family has its own beliefs, values, strengths, and needs. Professionals need to guard against imposing their own values or cultural expectations upon the family. Care plans must enhance the family's strengths and address only those needs which the family itself has identified, rather than those which professionals believe exist.

Providing Family-Centered Care

Questions To Ask Yourself

Topic	Questions
Family is Constant	<ul style="list-style-type: none">◆ Have I identified the family's needs?◆ What can I do to help meet their needs?◆ Have I solicited the family's input?◆ Have I taken the family's needs into account when making recommendations?
Collaboration	<ul style="list-style-type: none">◆ Have I met with or contacted other professionals serving this family?◆ Have I let the family and other professionals know how to contact me?
Information	<ul style="list-style-type: none">◆ Have I been honest in providing the family with information about their child's condition?◆ Have I been supportive to the family, helping them to adjust to the needs of their child?◆ Have I presented all information in a clear and understandable way and in the family's primary language?

Topic	Questions
Policies and Programs	<ul style="list-style-type: none"> ◆ Have I informed the family of agencies and services that can help assist them with issues related to the care of their child (e.g., funding, education, service coordination, parent-to-parent support, transportation, adaptive equipment, housing modifications, and advocacy)?
Strengths and Individuality	<ul style="list-style-type: none"> ◆ Have I helped the family identify its strengths? ◆ Am I aware of the individual needs of this family?
Developmental Needs	<ul style="list-style-type: none"> ◆ Does the treatment I prescribed support the more “typical” developmental and life span needs of the child and family?
Support	<ul style="list-style-type: none"> ◆ Have I encouraged the family to seek out the support of other families and agencies?
Health Care	<ul style="list-style-type: none"> ◆ Have I clearly informed the family of the services for which they qualify? ◆ Have I collaborated with other professionals involved with this family to make sure the family is aware of all possible services that they qualify for? ◆ Have I responded to the family’s needs?
Values	<ul style="list-style-type: none"> ◆ Have I considered the family’s culture and values when prescribing the treatment?

CULTURAL COMPETENCE

Best practices in working with families call for open, supportive, and responsive environments in which differences are valued and encouraged. Cultural competence requires awareness, appreciation, and respect for diversity and the capacity to recognize and respond to the needs of those who are different from oneself. Cultural competence requires one to adapt and accommodate their work to the values, behaviors, and expectations of others' cultural beliefs and practices. Optimally, professionals should view intercultural interactions as learning opportunities and use cultural resources in their intervention practices.

The term cultural describes the patterns of behavior, communication, customs, beliefs, values, and institutions of a specific racial, ethnic, religious, social, or even professional group. Cultural identity exerts a strong influence on how people live. However, other factors also shape the ways in which individuals and families live and how they identify themselves. These additional factors include:

- ◆ Socioeconomic status
- ◆ Educational level
- ◆ Age
- ◆ Gender
- ◆ Premigration and migration experiences
- ◆ Vocational or professional status
- ◆ Language proficiency
- ◆ Physical characteristics
- ◆ Sexual orientation
- ◆ Family composition
- ◆ Proximity to other members of their cultural group
- ◆ Disability or health care status

The elements of cultural competence include:

- ❖ Self-awareness and awareness of the “dynamics of difference” (including understanding “culture” and its function in human behavior).
- ❖ Knowledge of culture-specific information pertaining to various ethnic groups.
- ❖ Skills necessary to engage in successful cross-cultural interactions with culturally diverse populations.

Developing cultural self-awareness

An understanding of how one’s own cultural beliefs and practices impact behavior, motivation, and opinions can be developed by exploring one’s own cultural heritage. Discussions with older family members about their memories of past events; examining family albums, journals, and documents; and gathering information about activities, customs, celebrations, and events are helpful in painting a picture of what values and beliefs make up an individual’s cultural heritage. Once an individual has discovered the values and beliefs that make up his or her cultural heritage, it is important to reflect on them to understand how they influence one’s behavior, motivations, and opinions. Having a clear understanding of the way in which one’s own values and beliefs influence behavior helps the individual understand how the behaviors of others reflect their cultural values and beliefs.

GATHERING CULTURE-SPECIFIC INFORMATION

Professionals need to become familiar with the cultural values, beliefs, traditions, and customs of families from diverse backgrounds. In particular, they need to gather culture-specific information related to a family's views of children and child rearing practices; its structure and the roles of its members; disability and its causes; health and healing practices; and views of change and intervention.

There are four ways to gather culture-specific information:

- ❖ Learn by studying and reading about a culture, including history, geography, poetry, biography, and fiction.
- ❖ Talk and work with individuals from a particular culture who can act as cultural guides and mediators.
- ❖ Participate in the daily activities of another culture through celebrating holidays, community projects, or joining in worship practices.
- ❖ Learn the language of that culture.

Acquiring knowledge about specific cultural practices, beliefs, and customs is a large undertaking that requires a great deal of observation, study, and reflection. Learning information about a particular culture, including its values and beliefs, behaviors, and customs, should not lead one to conclude that all people who belong to that culture fit into that particular stereotype.

Rather, cultural competence involves recognizing, understanding, and respecting cultural differences that impact any individual's behavior,

thoughts, beliefs, and practices. Professionals should not make assumptions about a family's concerns, priorities, and resources based on their cultural identity.

FAMILY SYSTEMS THEORY

The family is not simply a collection of individuals but a complex system. To understand a family, it is not enough to know who the members are. The experience of living in a family involves the emotional bonds and interaction patterns that exist among family members. It also includes the family's history, values, goals, dreams, and belief systems. Finally, it involves interactions outside the family.

Family systems theory is a transactional theory in which each of the components of a system have an effect on any or all of the other components in that system.

Five concepts basic to a family systems perspective include:

- ❖ The family as a system is more than the sum of its parts.
- ❖ Change in one part of the family affects the entire family system.
- ❖ Subsystems are embedded within the larger family system.
- ❖ The family system exists within a larger social and environmental context.
- ❖ Families are multigenerational.

FAMILY REACTIONS TO DISABILITY

Reactions to the diagnosis of disability or chronic illness are as varied as families themselves. These reactions can be impacted by cultural beliefs, religious practices, socioeconomic status, and the availability of and comfort with using support systems, both formal and informal.

Common feelings experienced by family members are fear, anger, loneliness, resentment, embarrassment, and guilt. These feelings often occur at the time of initial diagnosis or recognition of the illness or disability. They can also resurface at other transitional times, for instance, when a child reaches a milestone. A mother's initial excitement and joy at the sight of her five-year-old child walking may be tempered by her observation of her sister's five-year-old child beginning to read. At this moment her joy may be mixed with a resurfacing of disappointment and sadness. A father who has just witnessed his six-year-old throw a ball with good aim may be saddened when observing other six-year-olds march in the Memorial Day parade with their little league teams.

Not all feelings are negative, however, and many families share stories of courage, personal growth, happiness, and joy when they discuss their children with disabilities and/or special health care needs. They point out how the family has emerged stronger, closer, and wiser; more accepting and tolerant of differences. Parents point with pride to their other children who have learned to celebrate diversity. The mother of an infant with Down Syndrome rejoices as her child survives major heart surgery that had threatened to end her life. The parent of the honor student beams as his son sits with a peer who uses a wheelchair in the cafeteria.

All families go through adjustment and adaptation periods with the addition and growth of their members. Families of children with disabilities and/or special health care needs experience these challenges in different ways. Each family finds its own way of adjusting to the change in lifestyle required by the child with extraordinary needs and gifts. However, the typical periods of adjustment may be more difficult, often involving significant changes or, at times, crises. This may lead to an increase in the normal stresses associated with parenting. Most families adjust well to these changes and continue to grow as unique family systems. However, some families may feel overwhelmed at particular times. They may need additional assistance to increase their capacity to use their unique skills and resources in coping with change.

Protective factors which promote comfortable adjustments include the availability of support systems chosen by the family. These may include formal systems (professionals, therapists, doctors) and informal systems (neighborhood groups, parent-to-parent support, churches, friends, family, community service groups), as well as access to economic resources, information networks, and recreational opportunities.

In order to understand why families vary so dramatically in their responses to having a child with a disability, it is important to understand how resilience, vulnerability, and risk factors can influence the probability of potential problems. For instance, if a family's vulnerability is high (living in poverty, no health insurance, history of alcoholism) and the risk factor is high (conflicts with extended family members, poor community resources), then the probability for a problem to occur is high. Preventative interventions for families should be designed to 1) reduce vulnerability or increase resistance to

stressors and 2) decrease environmental risks or add protective factors from outside the family system. Knowing about vulnerability and risk can help service providers to avoid common, unjustified assumptions about certain kinds of families and their resilience.

FATHER AND CHILD INTERACTIONS

Fathers have a tremendous influence on a child's development, particularly in the areas of cognitive, personal and social development, and the development of gender identity. When fathers interact with their children, it is most often spent in play activities. Fathers may not directly be involved in the health care issues concerning their typically developing children. This may be even more true for children who have developmental delays or special health care needs.

Because of work schedules and the lack of flexible work hours for many fathers, the tasks of managing educational and health care systems are delegated to the mother. As a result, pediatricians have more direct contact with the mother of a child with a disability than with the father. This is also true for other service providers, including home health aides, nurses, therapists, and teachers. Fathers must often rely on second hand information provided by the mothers. It is easy to overlook the roles of fathers and their importance in enhancing the overall quality of life for children with disabilities and/or chronic health care needs.

Fathers may have little direct contact with the physician and other service providers. They may at times feel left out and lacking in the necessary expertise to promote a comfortable relationship with their children. The

reluctance some fathers appear to have is often attributed to “distancing” or a “lack of bonding” by professionals, when in reality it may be the result of the way medical and educational systems interpret the actions of fathers. A father who appears to be uncomfortable holding his small, crying child diagnosed with cerebral palsy may be uncomfortable for a number of reasons. He may not be used to small babies or have difficulty understanding why the baby is crying. He may not know how to hold his infant or how to provide security or comfort to the infant.

Professionals need to be cautious in interpreting a father’s lack of motivation to engage with the child or participate in an intervention activity. Open communication between the father, the pediatrician, and other professionals may elicit more information from the father. For fathers, an indication from the service provider that their input and participation is desired can provide the invitation needed for them to become more active participants.

The priorities and preferences of fathers should be considered as part of any intervention program. Too often service delivery is scheduled around the mother’s daily routines without attempting to include the father. Time preferences, availability, and parenting styles should be solicited from the father, as well as the mother, in planning and implementing service delivery. Fathers tend to prefer verbal interaction, physical involvement, and games requiring problem solving when playing with their young children. Fathers should be provided opportunities to learn about the ways young children communicate and be supported in their interactions with their children.

SIBLING INTERACTIONS

Perhaps one of the longest bonds that a person will develop is with a sibling. Sibling interactions affect the entire family, and family decisions concerning the child with a disability can affect sibling relationships. There are many factors that can influence the sibling relationship, for example, age, family characteristics, type of disability, and characteristics of the siblings without disabilities. Depending upon these and other factors, the reactions and behaviors of the siblings will vary.

A child's adjustment to a sibling with a chronic health care need or disability depends upon a variety of economic, personal, emotional, and social factors. Among them are several of the following:

- ◆ Nature and severity of the sibling's disability
- ◆ Parents' feelings and reaction to the child with a disability
- ◆ Availability of both formal and informal support systems
- ◆ Age span between children
- ◆ Age of the child with a disability
- ◆ Extent that the child's disability impacts the home environment and family functioning
- ◆ Amount and type of responsibility placed on the other children
- ◆ Financial status of the family
- ◆ Ready access to services
- ◆ Size of the family

Siblings experience both positive and negative feelings and concerns about having a brother or sister with a disability. These feelings may involve self perceptions, perceptions of the child with the disability, their relationship to their parents, and their interactions in the community. Some of the most common feelings are highlighted below:

Positive feelings:

- ◆ Pride in the accomplishments of their sibling
- ◆ Appreciation for their intelligence
- ◆ Compassion
- ◆ Enhanced sense of responsibility
- ◆ Acceptance of diversity in others
- ◆ Appreciation of their own good health
- ◆ Closer, warmer relationships with their parents
- ◆ Pride in their ability to help
- ◆ Maturity
- ◆ Patience
- ◆ Increased protection of the sibling
- ◆ Awareness of the needs of others

Difficult feelings:

- ◆ Misunderstandings about the disability
- ◆ Jealousy of differential treatment by parents
- ◆ Anger at the demands the child places on the family and its resources
- ◆ Embarrassment
- ◆ Resentment when rules and expectations differ
- ◆ Fear of the disability and the way others perceive it
- ◆ Isolation/loneliness from peers, school, community
- ◆ Guilt at their good fortune

Siblings need opportunities to talk about and share their feelings. They need to be listened to and respected. Their opinions should be willingly solicited and accepted. They need honest, direct, and understandable information across the life span of their sibling, as well as education and training in dealing with the specific challenges of the disability. Suggestions that help parents support their children include providing information, accepting feelings, helping them develop strategies for balancing responsibilities, and enhancing their own sense of competence.

Siblings of a child with disabilities may need support for any of the following questions or concerns that may be expressed:

With their friends:

- ◆ How to tell them
- ◆ How to handle their own negative feelings
- ◆ How to make them understand
- ◆ How to gain acceptance for themselves and their sibling
- ◆ How to handle taunting and teasing

In the community:

- ◆ What to say when people stare
- ◆ What to do if the sibling embarrasses them
- ◆ How to help their sibling behave
- ◆ Responsibility for their sibling at school
- ◆ How to help their parents in public
- ◆ Responsibility for their sibling in community places (parks, schools, stores)

In adulthood:

- ◆ Their own genetic make-up
- ◆ Acceptance by a spouse/spouse's family
- ◆ Continued emotional, social, medical, and financial responsibility for their sibling
- ◆ Community acceptance
- ◆ Starting a family

LIFE SPAN ISSUES

All families face life span issues which may present challenges, including families of children with disabilities and/or special health care needs.

However, families whose children have disabilities and/or special health care needs often face unique challenges based on the individual strengths and needs of their children. Physicians who are aware of these issues can play an important role in acknowledging them and providing information and guidelines about issues which may inevitably arise.

It is important for the physician to be aware of life span issues and ways in which they can be addressed. It is especially important to adapt information to meet the changing needs of the individual and family. In addition, just as it is essential that the physician understand how families are impacted by having a child with a disability and/or special health care needs, it is important to consider how our society as a whole perceives and treats individuals with disabilities. The pediatrician treating the child with a disability must focus on the physical needs of the child and also on the emotional and social issues associated with having a disability in our society.

There are points in the lives of families that present opportunities for children to transition into new levels of awareness and learning with concurrent increases in responsibility and independence. These natural transition times may vary for families with children who have disabilities or special health care needs. They may also present significant logistical, emotional, social, and financial challenges to such families. These transition times can include initiating the child into formal school programs (e.g., kindergarten, middle school, high school or college) or the working world. Transitions require adjustments not only on the part of the child but also on the part of the parents.

Transitions are not the only life span challenge that parents of children with disabilities and/or special health care needs face. In addition, these families experience “off-time transitions” and “the prolongation of parenting stages” that other families move through more quickly. Thus, the mother of an individual with physical and cognitive challenges may find herself providing basic personal care to her child when she is fifty years old, well past the time other parents have attended to these needs.

An overview of some of the life span issues faced by families with children with disabilities and/or special health care needs include:

- ❖ **Childhood:** From the time that a child is diagnosed with a disability and/or special health care need, the family must cope with the impact the diagnosis will have on their lives as a family. The family will have to deal with changes in almost every aspect of what they might have thought would be the normal social progression of the child’s life. What might have been a time for settling into parenthood, may turn into a time of developing coping strategies, lifestyle adaptations, and redefining of

family roles. The pediatrician for the family whose child has a disability can better help the family through difficult situations by being sensitive to family dynamics and being knowledgeable about sources of support.

Many parents express a need for guidance and suggestions from the pediatrician early on in the child's life. They may be especially interested in learning about methods for addressing behavioral problems. Middle childhood (ages 5 to 10) seems to be a time for the permanence of the child's disability to become much more evident to the child's family members. Parents have expressed that this is the point during which they shift their focus from basic survival needs to planning for their child's future. They also begin to address issues such as social interactions, friendships, and independence.

- ❖ **Adolescence:** The second major transition time for families of children with disabilities occurs during adolescence. The onset of puberty often raises serious concerns and fears for the caregiver. It is important not to assume that just because a child has a disability, that he or she will not encounter such milestone issues as sexual desire, concerns about peer relations, or learning to drive a car. Adolescents with disabilities often are overlooked in their right to learn to do things that everyone else does. Issues such as dating, menstruation, sexual activity, and other adolescent concerns need to be addressed sensitively with the family and the adolescent. The pediatrician may be called to mediate or explain such issues to those involved.

- ❖ **Adulthood:** Life span issues such as parent illness, reproduction, and vocation are part of the lives of persons with disabilities. Because of the increased dependence of a child with a disability on the parent/caregiver, issues such as parent illness and parent death are of paramount importance. As the pediatrician, it is important to begin fostering the personal independence of children with disabilities early in their childhood. Pediatricians can assist families in learning about ways in which they can facilitate their children's independence by providing information about adult issues well before their onset and encouraging parents to foster independence during childhood and adolescence.

MEDICAL HOME MODEL

A lifetime of intensive, supportive health care is often necessary for a child with special health care needs. Multiple specialty providers, innumerable hospitalizations, and changes of service providers often leave both families and providers confused about who is responsible for coordinating care. This confusion may lead to poor or inadequate information sharing among the many individuals serving the family. To avoid this, parents often assume the role of updating medical information for everyone involved with the child. This frustrating task of coordinating ever-changing information among specialists, combined with the difficulty of meeting the financial demands, poor availability of qualified, competent child care, and coping with the high degree of responsibility in the daily care for a child with chronic health care needs, creates enormous stress for the family.

To help alleviate some of the family's stress, a child with special health care needs should be cared for within the context of a medical home. A medical home is an approach to providing health care services in a high-quality and cost-effective manner. It is not a building, house, or hospital. The ideal source of a child's medical home is a primary health care provider (defined as a pediatrician, hospital clinic resident, nurse practitioner, specialty pediatrician, family practitioner, or specialist) working in partnership with the child's parents. Together, they identify and access all of the medical and non-medical services needed to help the child and their family achieve their maximum potential.

The American Academy of Pediatrics (AAP) presents the medical home concept as a way of delivering accessible, continuous, comprehensive, family-centered, coordinated, and compassionate medical services to children.

SERVICES WITHIN THE MEDICAL HOME

The medical home model promotes opportunities for effective collaboration among physicians, other health care providers, and the community and educational agencies involved in providing services to children with disabilities and special health care needs and their families. The ideal medical home encompasses the following services:

- ⊕ Provision of preventive care including, but not restricted to, immunizations, growth and development assessments, appropriate screening, health care supervision, anticipatory guidance, and patient and parental counseling about health and psychosocial issues.

- ⊖ Assurance of ambulatory and inpatient care for acute illnesses twenty-four hours a day, seven days a week, during the work day, after hours, on weekends, fifty-two weeks a year.
- ⊖ Provision of care over an extended period of time to enhance continuity.
- ⊖ Identification of the need for subspecialty consultation and referrals, and knowing from whom and where these can be obtained; provision of medical information about the patient to the consultant; evaluation of the consultant's recommendations, implementation of recommendations that are indicated and appropriate, and interpretation of these to the family.
- ⊖ Interaction with school and community agencies to be certain that the special health needs of the individual child are addressed.
- ⊖ Maintenance of central record and data base containing all pertinent medical information about the child, including information about hospitalizations. This record should be accessible, while maintaining confidentiality.

The AAP Medical Home Program for Children with Special Needs also provides support to physicians to enhance their health care practices for children with disabilities and/or special health care needs. This program provides information about strategies and educational materials as well as technical assistance to physicians for developing a medical home program within their practice. For more information about support for physicians using the medical home model, contact:

Elizabeth Osterhus
AAP Department of Community Pediatrics
1-800-433-9016, ext. 7621

BENEFITS OF THE MEDICAL HOME

The medical home creates a partnership between the family and the child's primary health care provider, encouraging collaborative decision making, continuity of care, and family support in times of need. The medical home model provides many benefits to children and families as well as to health care and other service providers. These benefits are described below:

- ❖ **Continuity of care:** A child with special health care needs often has medical problems that may develop suddenly and require the expertise of a pediatric primary health care provider who is familiar with the child's history. The medical home guarantees the availability of medical support around the clock. This assurance of appropriate medical care by a health care provider who knows the child's history provides great comfort for the family.

- ❖ **Effective communication:** The multiplicity of specialists and providers for the child with special health care needs presents many challenges to the family. In the medical home model, a family has one primary contact for the child. The medical home encourages effective communication among specialists and the primary health care provider. This accessibility to the child's medical information relieves the burden on the family for understanding and disseminating information about technical procedures, treatment protocols, and new findings to the various specialists caring for the child.

- ❖ **Family-centered care:** Family-centered care supports families as the center of the decision-making process. This value is also the foundation of the medical home model. Collaboration among families, primary health care providers, medical specialists, and the staff of the medical offices creates problem-solving partnerships and strengthens the sources of support for families and their children with special health care needs. A medical home encourages this partnership by defining a common goal and vision. A relationship is often formed between the family and a member of the medical provider's office staff (i.e., a nurse or physician assistant). This staff person becomes an important contact for the family and gains an understanding of the family's expertise and insight. This type of relationship makes access to the physician's office easier for the family.

- ⊞ **Appropriate documentation:** Frequent regulation and monitoring of medications, treatments, and assistive devices are quite commonplace for families whose children have special health care needs. Often, medical interventions must be changed or modified to achieve an optimal level of care. Additionally, medical supply companies, public assistance programs, and insurance providers require documented approval of medications, medical supplies, assistive technology, and nutritional supports as modifications occur. The medical home model minimizes the frustrating red tape that can overwhelm families as they deal with confusing funding issues. The medical home provides a family with a primary health care provider and support staff, who are easily accessible and able to provide this documentation in a timely manner.

- ❖ **Record keeping:** The medical home model maintains an accessible, confidential medical record that merges all specialties and integrates them into one comprehensive resource. If it is necessary for the child to be referred to another medical center or if the child needs to be hospitalized, this complete and concise medical record can readily provide a wealth of medical information and recommendations.

The medical home concept emphasizes that the primary health care provider acts as the coordinator of all aspects of pediatric care and supports the child and family as they attempt to address the health care needs in the school and community settings. The medical home model provides the necessary supports to ensure that these children get the care and educational opportunities they deserve. Through the establishment of the medical home, families can more confidently address the educational and medical needs of their children.

FAMILY STUDY

JP is about to be discharged from the newborn intensive care nursery after a twenty-week hospitalization following his premature birth. Shortly after birth (at 72 hours), he developed seizures which were subsequently controlled by medication. He required ventilation for three weeks. He also had difficulty feeding by mouth. His mother, Pilar, is a seventeen-year-old single parent in good health. Pilar is from the Philippines. She works an average of 30-40 hours a week, with no insurance benefits, as a secretary for a temporary employment agency. Pilar must continue to work after JP comes home and would like to find a permanent position with benefits. She worries about how she will pay for all of JP's needs.

Pilar lives alone and JP's father is not involved with the family. She has no family living nearby to assist her with JP's care; however, Pilar does have a few close friends here from her country who have visited her and JP at the hospital. Pilar will need support in making decisions about and providing care for JP. It is a custom in the Philippines for parents not to question a physician's opinion about medical care.

When Pilar was able to visit JP, she often sat and rocked him for hours. She missed some visits which made it difficult for the hospital staff to adequately train Pilar in JP's care. In addition, Pilar's English is not clear and there exists a language barrier. However, toward the end of JP's hospitalization, Pilar arranged for two days and one overnight at the hospital so she could learn JP's care plan and participate in the discharge planning process.

Pilar lives in a one-bedroom apartment across town from the hospital. She does not have a telephone, so maintaining contact with the hospital is difficult. JP has a number of ongoing medical concerns, including the need for seizure medication and assistance during feedings. Because his muscle tone is poor, he is unable to suck for long periods. His caloric intake must therefore be monitored to make sure he gains enough weight.

Pilar is committed to having JP with her but has a number of questions she would like answered before she takes JP home. The hospital social worker is concerned about Pilar's ability to adequately care for JP. As the community pediatrician who will be caring for JP, you are responsible for making sure the transition to home goes smoothly.

FAMILY STUDY--REVISITED

DISCUSSION QUESTIONS

As JP's primary pediatrician, evaluate the following:

What do you see when you look at this family?

What staff member and/or health care professional should explore the issues affecting Pilar's ability to visit JP in the hospital and to participate in his care? How should these issues be addressed? What is the family's role in discharge planning?

What should be included in JP's discharge plan?

How will you ensure JP's discharge plan is being implemented?

How might your own cultural beliefs, values, and customs influence your behavior and thus your interactions with JP, his family, and other professionals?

How can you effectively communicate with individuals of different cultures?

DISCUSSION QUESTION ANSWERS

- ❖ What do you see when you look at this family?
 - ◆ Does your description include the following family strengths and resources?
 - a) Pilar loves JP.
 - b) Pilar's strong determination to provide care for JP at home.
 - c) Pilar took time off from work to participate in the planning process for JP's discharge.
 - d) Pilar visited JP despite transportation difficulty.
 - e) Pilar has some friends for emotional support.
 - f) Pilar has kept her job throughout the stress and trauma of JP's hospitalization.
 - g) Pilar's customs and beliefs may differ from the teams.
 - ◆ Does your description include family needs and concerns, such as insurance benefits, child care, and transportation? Other family needs and concerns include assistance in coordinating JP's doctor appointments, support for Pilar to help her understand JP's needs, employment counseling for Pilar, the language barrier, and securing a telephone.
- ⊖ What staff member and/or health care professional should explore the issues affecting Pilar's ability to visit JP in the hospital and to participate in his care? How should these issues be addressed? What is the family's role in discharge planning?

- ◆ Pilar, JP's pediatrician, primary care nurse, discharge planner (nursing), and social worker should be involved in identifying the issues affecting Pilar's ability to visit JP in the hospital and participate in his care. The early intervention service coordinator should be involved if a referral to Birth to Three takes place prior to discharge.
- ◆ These issues should be addressed in a team meeting of the above individuals in a collaborative, family-centered manner. They should all work toward the goal of JP being cared for at home with his mother.
- ◆ The family's role should be as an equal team member in the discharge planning.
- ❖ What should be included in JP's discharge plan?
 - ◆ Referral to a visiting nurse.
 - ◆ Medical equipment from a home health supply vendor.
 - ◆ Medication for seizures.
 - ◆ Referral to Birth to Three, early intervention services.
 - ◆ Referrals for medical follow-up appointments.
 - ◆ How the discharge planning team feels the following issues should be addressed: Pilar's need for a telephone; health care financing; transportation; Pilar's ability to get JP to multiple appointments without losing her job; Pilar's support needs; and child care.

- ❖ How will you ensure JP's discharge plan is being implemented?
 - ◆ Maintain regular communication with the family, other health care providers, and the child's service coordinator if referred to early intervention services.
- ❖ How might your own cultural beliefs, values, and customs, influence your behavior and thus your interactions with JP, his family, and other professionals?
 - ◆ The answer will be different for each physician.
- ❖ How can you effectively communicate with individuals of different cultures?
 - ◆ Understand and appreciate one's own culture.
 - ◆ Understand and appreciate other individual's cultural identity.
 - ◆ Seek out information specific to individual cultures, focusing on the cultures of the families you work with, including styles of interaction, communication, and values.
 - ◆ Recognize and continuously develop your own interpersonal skills when interacting with people.
 - ◆ Recognize that not all people of one cultural background are the same.
 - ◆ Respect the individuals from a different culture.
 - ◆ Make continual efforts to understand the issues and situation from the family's point of view.
 - ◆ Be open to new approaches and learning what people of different cultures may bring your way.

- ◆ Be flexible.
- ◆ Have a sense of humor.
- ◆ Tolerate uncertainty and seek clarification.

RESOLUTION

Pilar was committed to caring for JP at home. Despite limitations in transportation, she did manage to visit JP and was very nurturing towards him, spending hours in the hospital rocking and hugging him. Prior to his discharge, she learned how to care for JP, including how to operate all of his medical equipment. Pilar had a few friends who provided her with emotional support. She had managed to keep her job despite the stress and trauma of JP's hospitalization and was struggling to meet both of their needs.

Using a family-centered model, the following people began discharge planning for JP after the sixth week of his hospitalization, when his health stabilized:

- ❖ Pilar
- ❖ Primary NICU physician
- ❖ Primary nurse
- ❖ Discharge planner (nursing)
- ❖ Social worker (hospital-based)
- ❖ Visiting nurse (community-based)
- ❖ Community pediatrician
- ❖ Translator

The discharge planning included three team meetings: at 8 weeks, 16 weeks, and just prior to discharge. Pilar was able to attend only one of these meetings but met with JP's primary nurse before and after each meeting to discuss the plans and her own concerns. Pilar also met with the hospital social worker on four other occasions. The visiting nurse made one visit to Pilar's home before discharge and assessed JP's home care needs. During the discharge planning process, Pilar identified several of her concerns, including a lack of insurance benefits. She would need to find child care for JP and expected that this would be difficult because of his medical and developmental needs. She did not have a car of her own and worried about being able to return for medical appointments with JP. She was also concerned about taking too much time off from work. She also had questions about JP's long-term care needs and prognosis. She felt that she had no one to support her and assist her in understanding these issues.

With Pilar's input relayed by the primary nurse, the team wrote the discharge plan at their last meeting. Afterwards, the nurse met with Pilar to explain the plan. A referral for early intervention was discussed with Pilar and she said she would think about it. Her copy of their discharge summary included telephone numbers and appointments and information on the following medical needs:

- ❖ The medical equipment needed and the home health supply vendor phone number.
- ❖ Proper dosages and administration of medications for seizures.
- ❖ Referral to early intervention services for developmental follow-up and physical therapy.

- ❖ Referrals for follow-up in the following specialties: ophthalmology, neurology, pulmonary, audiology, and developmental follow-up clinic.
- ❖ Referral for eight hours of home nursing per day.

In addition to JP's medical/developmental needs, Pilar's other concerns were addressed through the discharge plan:

- ❖ Pilar's need for a telephone. The hospital social worker secured a donation from a local charitable foundation to have a phone installed; Pilar understood that ongoing bills would be her responsibility.
- ❖ Health care financing. Pilar was assisted in applying for Medicaid (Title XIX) and WIC (food supplement for pregnant women, infants, and children). At the time of JP's discharge, she had met the eligibility requirements: JP's care, as well as her own, was covered.
- ❖ Transportation. Medicaid would pay for transportation to medical appointments.
- ❖ Multiple care providers and appointments. The visiting nurse agreed to act as a service coordinator and would assist Pilar in coordinating appointments on the same day so her time away from work and transportation needs would be eased.
- ❖ Support needs for Pilar. Prior to JP's discharge, Pilar was offered support through Parent-to-Parent, a network of trained veteran parents who have children with disabilities. She was matched up with another mother who visited her several times at the hospital, and they planned to continue

meeting after discharge. The discharge plan also contained a referral to an employment counseling agency which would help Pilar find permanent work.

- ❖ Child care needs for JP. JP would receive eight hours a day of home nursing while Pilar was working; this coverage would continue as long as JP needed skilled care. Should his condition improve, Pilar would again need to find child care. The Visiting Nurse Association would assist her in training a child care provider, but Pilar was aware that this care may be costly and difficult to secure.

With the appropriate support, including a good relationship with JP's primary care pediatrician, Pilar and JP can eliminate barriers to implementing a successful discharge plan and effectively deal with the challenges they face in the future.

COMPONENT TWO: HOME VISITS WITH TWO FAMILIES

Location and Times:

You will meet with two families with children with disabilities and/or special health care needs in each family's home.

We will attempt to schedule visits according to the block schedule, however, in some cases it may be necessary to meet with families during evening hours or on the weekend.

Format:

The goal of the visits is to find out how having a child with special needs has impacted the family and their perceptions of the health care system, etc.

Please refer to *Guidelines for Home Visits*.

Resident's Responsibilities:

- ❖ **First home visit:** You will be assigned a family that is participating in this project by the project coordinator. The project coordinator will contact the family and arrange the home visit.

- ◆ The *Resident Self-Evaluation: Home Visit* should be completed and returned to the University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities. The *Performance Rating by Parent* form should be completed by a family member and also returned to the University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities.

- ❖ **Second home visit:** You should identify a child from your continuity clinic for the home visit. Please refer to *Guidelines for Identifying Children with Disabilities and/or Special Health Care Needs within the Continuity Clinic* in Appendix B. You should then obtain permission from the parents and arrange the home visit at a mutually agreed upon time.

- ◆ The *Resident Self-Evaluation of Second Home Visit* should be completed and returned to the University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities. The *Performance Rating by Parent* should be completed by a family member and also returned to the University of Connecticut A.J. Pappanikou Center for Disabilities.

GUIDELINES FOR HOME VISITS

Purpose:

- ❖ To gain an increased understanding of a child within his or her home environment, including the family's strengths, concerns, priorities, and resources as they relate to the child's disability and/or special health care needs.

Family Interview--Suggested Outline:

- ❖ Identify the positive experiences the family members have had in their home, community, school or child care program(s), and with the health care system.
 - ◆ What factors have contributed to making these experiences positive?
- ❖ Identify challenges the family members have experienced in their home, community, school or child care program(s), and with the health care system.
 - ◆ What factors have contributed to these challenges?
 - ◆ How might these issues be addressed?
 - ◆ What role could the physician play in addressing these issues?
- ❖ Identify the family's current concerns and needs with regard to the home environment, school or child care program(s), and health care system.

- ◆ What are this family's major concerns, priorities, and resources?
- ◆ What supports might be offered to this family?
- ◆ How are extended family members involved with this child?
- ◆ How do siblings interact with the child? What are the positive aspects? Challenges?
- ◆ How are friends and neighbors involved with this family?

- ❖ Discuss the components of the child's current school or child care program.
 - ◆ Is the child receiving early intervention or special education services?
 - ◆ Is the child included in a class or other setting with children who do not have disabilities, a mainstream or inclusive environment? Describe the process in place for successful inclusion.
 - ◆ Does the child receive related services such as occupational therapy, physical therapy, speech and language therapy, and counseling? Where are these services provided? How?
 - ◆ Does the child use any assistive technology at school, such as a computer, an assistive language device, a modified spoon, or Velcro on a writing tool?
 - ◆ Who is responsible for implementing technology? How is this accomplished?

- ❖ How do the child's health care needs impact his or her ability to participate in the program?

COMPONENT THREE: SPECIALTY CLINIC VISIT

Location and Times:

You will be scheduled to attend a specialty clinic for one half day based on your interests and schedule.

Format:

There are two formats for specialty clinic visits:

- ❖ Accompany a family you have met through your continuity clinic to a scheduled visit in a specialty clinic (please refer to *Guidelines for Identifying Children with Disabilities and/or Special Health Care Needs within the Continuity Clinic* in Appendix B).

OR

- ❖ Attend a specialty clinic for one half day and observe what takes place. The focus will be on understanding the family's perspective of the experience. During this time you will interview at least one family. See *Guidelines for Specialty Clinic Visit Family Interview*.

Resident's Responsibilities:

- ❖ Prior to attending the specialty clinic, you should complete some independent reading about the medical issues associated with the disability or condition treated in this clinic.

- ❖ During the clinic visit, please follow these procedures:
 - ◆ Inform the preceptor/family support person that you are there to observe and learn about that specialty from the family/child point of view as part of the Children with Disabilities curriculum experience.
 - ◆ Be introduced (by the preceptor or family support person) to one or two families that you will follow during the half-day experience.
 - ◆ Follow at least one family throughout its entire appointment. For example, you should stay with the family as they wait to be seen by the clinic team, during the evaluation, and as they receive feedback from the team.
 - ◆ Observe and interact with the family (see *Guidelines for Specialty Clinic Visit Family Interview*).
 - ◆ Participate in a debriefing session with the preceptor, family support person, or specialty clinic team.
 - ◆ Complete the *Resident Self-Evaluation: Specialty Clinic Visit*. (Certain clinics have different evaluation forms, the project coordinator will provide you with the appropriate form.)

- ◆ Provide the clinic preceptor with the *Performance Rating by Preceptor: Specialty Clinic Visit* form.

GUIDELINES FOR SPECIALTY CLINIC VISIT FAMILY INTERVIEW

Purpose:

- ❖ To gain a better understanding of how to provide care for children with disabilities and/or special health care needs, including recognizing the impact of disabilities and special health care needs on childhood development; obtaining knowledge of the array of services available for children with special needs; and learning how to coordinate comprehensive medical care for children with special health care needs.
- ❖ To learn how issues specific to a child's disability may impact the child and family in terms of their ability to participate in typical routines within the home, school, and community.
- ❖ To gain an in-depth awareness of how clinic visits are viewed through the eyes of the child and family.

Family Interview--Suggested Outline:

- ❖ Find out about the family composition, including who lives in the home, where they live, language spoken at home, sources of income, etc.
 - ◆ What is a typical day/week like for this child and family?

- ◆ Identify the family's perceptions of the child's needs with regard to the home environment, school or child care program, and health care system.
- ◆ Does the family feel that these needs are being adequately addressed?
- ◆ What types of changes can be made, if any?
- ◆ If appropriate, ask for the child's input about this clinic visit. What are his or her concerns, questions, priorities, things he likes about coming, dislikes, feelings, etc.?
- ◆ What types of social supports does the family have?
- ◆ How was this child referred to the clinic? Is this an initial visit or follow-up visit?
- ◆ How did the family get to the clinic? Is transportation an issue?
- ◆ What does the family feel is the purpose of today's appointment?
- ◆ What types of questions do the family members have for the medical team?
- ◆ How comfortable does the child appear to be? The family?

APPENDICES

- A: Communicating with People with Disabilities: Acronyms and Abbreviations
- B: Guidelines for Identifying Children with Disabilities and Special Health Care Needs within the Continuity Rotation
- C: Reprint Of: American Academy of Pediatrics, Committee on Children with Disabilities (1993). Families Recommendations for Improving Services for Children with Chronic Conditions. Arch Pediatrics Adolescent Med., 98 (152), 440-448.

APPENDIX A

Communicating with People with Disabilities: Acronyms and Abbreviations

APPENDIX B

GUIDELINES FOR:

Identifying Children with Disabilities and Special Health Care Needs
within the Continuity Clinic

GUIDELINES FOR IDENTIFYING CHILDREN WITH DISABILITIES AND/OR SPECIAL HEALTH CARE NEEDS WITHIN THE CONTINUITY CLINIC

While this list is not all inclusive, the following are possible factors that may indicate a disability and the need for referral to early intervention (birth to age 3) or special education (ages 3 to 21) services.

❖ **Prenatal history:**

- ◆ Maternal illnesses: e.g., infectious diseases, conditions such as diabetes or PKU
- ◆ Abnormal prenatal test results: triple screen (AFP), amniocentesis, ultrasound
- ◆ Exposure to teratogens
- ◆ Substance abuse: alcohol, cocaine, heroin, other controlled substances
- ◆ Pedigree: family history of learning disabilities, mental retardation, specific inherited disorders

❖ **Birth history:**

- ◆ Complications to newborn: e.g., meconium aspiration, intrauterine growth retardation, neonatal sepsis, prematurity, postmaturity, respiratory distress, low birth weight
- ◆ Admission to Neonatal Intensive Care Unit (NICU)
- ◆ Congenital abnormalities

❖ **Newborn period:**

- ◆ Failure to thrive
- ◆ Need for medication or medical intervention: e.g., ventilation, NG feeding
- ◆ Oral motor difficulties: e.g., poor feeding or sucking
- ◆ Regulatory difficulties: e.g., temperature regulation
- ◆ Abnormalities in muscle tone: hypertonia, hypotonia
- ◆ Involvement of any specialty medical care

❖ **At any age--functional delays in combination with any one of the following complications:**

- ◆ Need for adaptive devices or assistive technology: e.g., ankle-foot orthosis, communication board, wheelchair
- ◆ Child abuse
- ◆ Chronic condition or illness: e.g., congenital heart disease, cancer, HIV
- ◆ Exposure to toxins: e.g., lead
- ◆ Gastroenterology: reflux, need for G-tube
- ◆ Congenital, genetic, or inherited disorders
- ◆ Hospitalization or surgeries
- ◆ Neurologic disorders or dysfunctions: seizure disorder, traumatic brain injury
- ◆ Recurrent ear infections, cleft palate

- ◆ Pulmonary: asthma, cystic fibrosis
- ◆ Rheumatology: juvenile rheumatoid arthritis, Ehlers-Danlos syndrome
- ◆ Sensory impairments: hearing, vision
- ◆ Sociocommunicative disorders: autism, pervasive developmental disorder

- ❖ **General concerns in child development:**
 - ◆ Any concerns raised by parents, family members, day care providers, or teachers
 - ◆ Attention and concentration
 - ◆ Behavioral or emotional difficulties, including reactivity to changes in environment, stress
 - ◆ Child abuse
 - ◆ Cognitive development/thinking skills
 - ◆ Communications skills, including speech/articulation, understanding language, expressing self
 - ◆ Fine and gross motor skills, coordination
 - ◆ Learning disabilities
 - ◆ Processing sensory information: e.g., hypersensitivity to sound, hyposensitivity to pain (increased threshold)
 - ◆ Self-care and daily living skills
 - ◆ Social skills and play skills

❖ **Involvement with:**

- ◆ Birth to Three/early intervention services
- ◆ Special education services through the public school system

❖ **Involvement with other agencies:**

- ◆ Board of Education and Services for the Blind (BESB)
- ◆ Children with Special Health Care Needs (Title V)
- ◆ Department of Children and Families (DCF)
- ◆ Department of Mental Retardation (DMR)
- ◆ Department of Social Services (DSS), including any medical waiver programs
- ◆ Psychotherapists, family therapists, social workers
- ◆ Supplemental Security Income (SSI)
- ◆ Visiting Nurse Association (VNA)

APPENDIX C

REPRINT OF:

American Academy of Pediatrics, Committee on Children with Disabilities (1993). Families' Recommendations for Improving Services for Children with Chronic Conditions. Arch Pediatrics Adolescent Med., 98 (152), 440-448.

APPENDIX D

FORMS FOR SPECIALTY CLINIC VISIT: ADAPTIVE EQUIPMENT SPECIALTY
CLINIC

SPECIALTY CLINIC VISIT: ADAPTIVE EQUIPMENT

Location and Times:

You will be scheduled to attend the Adaptive Equipment Specialty Clinic for one half day based on the block schedule. Adaptive Equipment Specialty Clinic takes place at Connecticut Children's Medical Center, Rehabilitation Department, on the fifth floor.

Format:

Attend the Adaptive Equipment Specialty Clinic for one half day and observe what takes place. The focus will be on understanding the family's perspective of the experience. During this time you should use any opportunity to talk with the patients, families, and team members. See *Specialty Clinic Experience: Guidelines for Observation*.

Resident's Responsibilities:

- ❖ Prior to attending the Adaptive Equipment Specialty Clinic read the attached summary of medical issues associated with the disabilities or conditions treated in this clinic and any other related readings.

- ❖ During the clinic visit follow these procedures:

- ◆ Inform the preceptor/family support person that you are there to observe and learn about the family's/child's point of view as part of the Children with Disabilities Rotation experience.

- ◆ Be introduced (by the preceptor) to each family that is attending the clinic on this day.
- ◆ Follow the patients throughout their entire appointment. For example, you should stay with the patients as they wait to be seen by the clinic team, during the evaluation, and as they receive feedback from the team.
- ◆ Observe and interact with the patients, family members, and team members. See *Specialty Clinic Experience: Guidelines for Observation*.
- ◆ Complete the *Resident Self Evaluation of the Specialty Clinic Visit*.
- ◆ Provide the clinic preceptor with the *Performance Rating by Preceptor: Specialty Clinic Visit* form.

SPECIALTY CLINIC EXPERIENCE GUIDELINES

Purpose:

- ❖ To gain an understanding of adaptive equipment needs and concerns for various patients.
- ❖ To learn how adaptive equipment needs may impact the patient and his or her family in terms of their ability to participate in typical routines within the home, school, and community.
- ❖ To gain an in-depth awareness of how clinic visits are viewed through the eyes of patients and family members.

Observation of Specialty Clinic - Suggested Outline:

During this specialty clinic, the resident should consider the following questions.

- ❖ What difficulties are patients having with their adaptive equipment?
 - ◆ How do these difficulties impact their functioning in home, school or work, and community settings?
 - ◆ Who is the person most likely to identify or describe the problems?

- ❖ What is the quality of communication between the professionals, the family members, and the patient?
 - ◆ Is the patient addressed directly?
 - ◆ Are suggestions for improvement elicited from the patient and family?
 - ◆ Are treatment options offered?
 - ◆ Are the patient and family involved in decision making?

- ⊖ Do patients encounter any difficulties getting to the clinic (i.e., transportation, parking)?

- ⊖ Does the adaptive equipment appear age appropriate?
 - ◆ Are there attempts to enhance the patient's independence?

- ⊖ Are there any financial difficulties that could interfere with the patient's ability to acquire appropriate adaptive equipment?
 - ◆ Is insurance coverage adequate?
 - ◆ Are there restrictions, limitations, or timing issues imposed by the insurance company?

- ❖ What are the patients' and families' perspectives about the adaptive equipment clinic?
 - ◆ What are the perceptions of patient needs in home, school or work, and community environments?
 - ◆ Are the needs identified by patients being adequately addressed?
 - ◆ What types of social supports do the patients and their families have?
 - ◆ Do the patients and families appear to be at ease in this clinic?

- ❖ What role should a physician assume regarding a patient's adaptive equipment needs?
 - ◆ How can a physician be an effective team member?
 - ◆ How can a physician communicate with the treatment team?

ADDENDUM*

ADAPTIVE EQUIPMENT

Below are descriptions of the primary diagnoses carried by most patients who are seen in the Adaptive Equipment Specialty Clinic. This is offered as a brief overview of these diagnostic categories; you are urged to do additional reading as needed.

CEREBRAL PALSY

Cerebral palsy is a disorder of movement and posture due to damage to areas of the brain that control motor function. Cerebral palsy can occur before, during, or after birth and typically becomes evident in infancy or early childhood. The motor impairment may affect different parts of the body and may include:

- ◆ Hemiplegia - involving the arm, leg, and trunk on the same side.
- ◆ Paraplegia - legs only (rarely seen in cerebral palsy).
- ◆ Quadriplegia - both arms and legs, as well as the trunk and neck.
- ◆ Diplegia - legs more involved than arms.

- ◆ Double hemiplegia - arms more involved than legs, and one side more involved than the other.

**Adapted from: J. L. Bigge (1991). Teaching individuals with physical and multiple disabilities. New York: Macmillan Publishing Company.*

Involvement ranges from severe to mild. Factors include: a) level of independence in meeting physical needs; b) level of head control; c) amount of deformities that limit functioning or produce pain; and d) level of perceptual and sensory-integrative ability as they impact achievement of academic and age-appropriate motor skills.

In addition to the neuromotor impairment in cerebral palsy, there may be abnormalities of sight, hearing, speech, and sensation. Mental retardation and seizures may also occur with this condition.

In cerebral palsy, though the brain lesion does not progress with time, deformities can develop in the spine and extremities as the child gains length and weight. The most common descriptions of cerebral palsy include the area of injury within the central nervous system (pyramidal or extrapyramidal tracts); the muscle tone (hypertonia or hypotonia); the quality of muscle control (athetosis, dyskinesia, or ataxia); or mixtures of these.

Hypertonia is evident in approximately 60% of all cases of cerebral palsy. The motor cortex and spinal cord (pyramidal tract) are affected. Hypertonia is an increased stiffness that gradually causes limitation in range of motion and the development of muscle contractures. Deformities of the spine also develop with scoliosis (side-to-side curves) and/or kyphosis (posterior

prominence; hip dislocation; and/or elbow, hand, knee, and foot contractures).

Hypotonia is a weakness, particularly in trunk and neck muscles. When mild to moderate degrees of floppiness persist through the first year without the emergence of spasticity or extrapyramidal (athetoid) involvement, generalized hypotonia is diagnosed. Many of the postural and movement mechanisms seen in hypotonic children are reminiscent of the infant at 4-8 months of age.

Children with hypotonia are usually late walkers, balancing responses are sluggish, and overall motor activity level is low.

When the brain lesion affects the extrapyramidal tract of the central nervous system, athetosis, choreoathetosis, or dyskinesia results. Extrapyramidal involvement produces involuntary movements. The arms, hands, and facial muscles are typically more involved than the legs. Choreoathetoid movements are wormlike and writhing.

Ataxia is the rarest type of cerebral palsy, occurring in only 1% of cases. The cerebellum is the primary site of injury and the main feature is an inability to achieve coordination in balancing and hand use. The individual bobbles while standing and walking, and "overshoots," often missing the object he or she is trying to reach. Constant efforts to stabilize can result in the eventual development of a rigid quality of movement.

The diagnosis of just one type of cerebral palsy is rarely appropriate. Mixed cerebral palsy is most common because brain damage is often diffuse. Thus, it is typical to encounter a diagnosis such as “mixed spastic/athetoid quadriplegia, with an apparent underlying ataxic component.”

A diagnosis of cerebral palsy generally indicates that a multidisciplinary approach to treatment and physical management is necessary. Services of a physical therapist, occupational therapist, speech therapist, nurse, special education teacher, and classroom aide may be required.

Typically, students with moderate involvement require the greatest proportion of direct therapy time in an attempt to raise the student’s level of independence and to prevent deformity. For students with severe involvement, therapists can train classroom educators and aides in positioning techniques and strengthening activities that can be used daily to prevent deformity and pain, and to enhance participation in classroom activities. Augmentative communication and power-driven mobility devices may also be required. Therapists then continually monitor equipment needs and provide consultation to the teachers. Students with mild impairment can usually be treated in groups with the aid of a physical educator who consults on a regular basis with the therapists and classroom teachers.

MUSCULAR DYSTROPHY

Muscular dystrophy is a hereditary disease characterized by muscle weakness that increases over time. There are several forms, of which the

most common is Duchenne muscular dystrophy. Females usually transmit the condition to their male offspring, but are not affected themselves. The CPK enzyme (creatine phosphokinase) is elevated in the blood of those with muscular dystrophy.

Duchenne muscular dystrophy begins early in life, between the ages of 2 and 6 years, when the child is observed to have trouble climbing stairs and running. Weakness generally begins in the pelvic girdle muscles, but may occur first in the shoulder girdle muscles. Gradual loss of respiratory function is secondary to weakness of the abdominal and thoracic muscles. By age 10 to 14 walking usually ceases and wheelchairs are required. Individuals with muscular dystrophy need increased amounts of physical assistance with some school activities and with most, if not all, activities of daily living as their disease progresses. When children with muscular dystrophy become wheelchair users, severe spinal curvature and contractures in the flexors of the hips, knees, ankles, and feet typically occur. Three months of sitting greatly reduces the likelihood that an ambulating child will walk again. A period of illness that requires bed rest can also reduce the child's functional level.

Individuals with muscular dystrophy often live until adolescence or young adulthood. In the final stages, there is an increased incidence of respiratory infections. Death is usually caused by heart failure due to the weakened heart muscles or respiratory failure caused by the weakness of the chest muscles. Individuals with muscular dystrophy experience the psychosocial difficulties of any terminal illness.

SPINA BIFIDA (MYELOMENINGOCELE)

Spina bifida, a condition present at birth, is a defect in the closure of the vertebral bodies of the spinal column. There are three classifications of spina bifida:

- ◆ Spina bifida occulta - This is the mildest form in which protrusion of the spinal cord or its covering does not occur; only a few vertebrae are effected. The defect is not externally visible other than the occasional hairy patch over the defect.
- ◆ Meningocele - In this form the spinal cord covering protrudes through the open defect in the spine.
- ◆ Myelomeningocele - This is the most common form of spina bifida, characterized by the protrusion of the spinal cord and its covering through the defective vertebral opening. Presence of a myelomeningocele results in varying degrees of paralysis and loss of sensation in the lower trunk and lower limbs. The higher the spinal defect, the more severe the neurologic and functional deficits, including loss of sensation, weakness, loss of bladder or bowel control, joint deformities, and spinal curvature. Many individuals with myelomeningocele have an associated hydrocephalus characterized by head enlargement, brain abnormalities, and seizures. Hydrocephalus is caused by blocked cerebrospinal fluid drainage. It may be congenital or develop later.

Treatment of myelomeningocele is initiated shortly after birth with surgical repair of the bulging sac. Physical therapy is useful for gait training and teaching the use of mobility aids. Patients with myelomeningocele may be able to ambulate independently with the use of braces and crutches or may be nonambulatory, requiring a wheelchair at all times. Perceptual and other learning disabilities, attention deficits, and emotional difficulties are often found in children with myelomeningocele. Students may also have deficits in sensation that impact their ability to process information from touch, movement, position in space, and motor experiences.

APPENDIX E

FORMS FOR SPECIALTY CLINIC VISIT: HOSPITAL FOR SPECIAL CARE

SPECIALTY CLINIC VISIT HOSPITAL FOR

Location and Times:

You will be scheduled to attend the Hospital for Special Care for one half day (morning only) based on your schedule.

Hospital for Special Care
2150 Corbin Avenue
New Britain, CT
Telephone: (860) 827-4868

CONTACT PERSON:

John Pelegano, M.D.
Chief of Pediatrics

Format:

Attend inpatient rounds and observe the care of children with developmental disabilities in an intermediate care facility.

Resident's Responsibilities:

- ❖ Prior to attending the specialty clinic, please read the enclosed articles regarding primary care of children with developmental disabilities.
- ❖ During the clinic visit please follow these procedures:

- ◆ Inform the preceptor that you are there to observe and learn about the long-term primary care of children with disabilities.
- ◆ Follow the attending physician on rounds and discuss acute as well as chronic care issues.
- ◆ Complete the *Resident Self Evaluation of the Specialty Clinic Visit*.
- ◆ Provide the clinic preceptor with the *Performance Rating by Preceptor: Specialty Clinic Visit* form.

SPECIALTY CLINIC VISIT GUIDELINES FOR HOSPITAL

Purpose:

- ❖ To gain a better understanding of how to provide care for children with disabilities and special health care needs, including: recognizing the impact of disabilities and special health care needs on childhood development; obtaining knowledge of the array of services available for children with special needs; and learning how to coordinate comprehensive medical care for children with special health care needs.
- ❖ To learn how issues specific to a child's disability may impact the child and family in terms of their ability to participate in typical routines within the home, school, and community.

Clinic Visit - Suggested Outline:

- ❖ During this clinic visit the following issues should be discussed:
 - ◆ The service delivery model in the Hospital for Special Care Pediatric Unit.
 - ◆ The appropriateness of the physical environment on the unit.

- ◆ The ability of patients to receive early intervention or special education services during their hospital stay. The nature of the relationship between hospital personnel and early intervention or special education service providers.
- ◆ How the developmental (as well as medical) needs of children are being met.
- ◆ How the social and emotional needs of children are being met.
- ◆ How hospital personnel attempt to involve family members in the care of and planning for their children.
- ◆ How hospital personnel interacted with each other during rounds (i.e., “team” behaviors observed).

ADDENDUM*
HOSPITAL FOR SPECIAL

RELATED ARTICLES:

General Principles in the Care of Children and Adolescents With Genetic Disorders and Other Chronic Health Conditions, Pediatrics, Vol. 99 No. 4 April 1997.

Family-Centered, Community-Based, Coordinated Care for Children With Special Health Care Needs, Pediatrics, Vol. 83 No. 6 June 1989.

Community Physician's Role in Case Management of Children With Chronic Illness, Pediatrics, Vol. 84 No. 3 September 1989.

APPENDIX F

PRE-POST TEST:

Family-Centered Care module