

Pediatric Physical Therapy

FIFTH EDITION

JAN S. TECKLIN



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Health

PEDIATRIC PHYSICAL THERAPY

FIFTH EDITION

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*With deep love, affection, respect and thanks to my
wife who has loved and supported me through almost fifty years of our lives*

I love you Randee Lynn

and

in memory of my dear friend

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The 5th edition of *Pediatric Physical Therapy*—“whooda thunk it” 27 years ago, in 1987, when the 1st edition was conceived. That this text is so well received and regularly adopted by many entry-level physical therapy programs in the United States and abroad is a testament primarily to the contributors. Two contributors, Dolores Bertoti and Elena Tappit-Emas, have been with the text through each of its five editions, and have always met deadlines and written and updated chapters in a very timely manner. The continuing goal that has guided the editor and many contributors through each edition is to provide a current description of major areas of practice in pediatric physical therapy for entry-level students and novice practitioners. Each edition has attempted to prepare entry-level students and new practitioners to begin pediatric care with a content that is supported by evidence, provides knowledge and insight within the diagnostic areas, and offers the tools by which to initiate and continue sound practice for the children with whom we work.

Organization

The book is organized into several sections based on the more common groups of disorders seen in infants and children. Chapter 1 stands alone and presents the issues of cultural sensitivity and family-centered care, to enhance understanding of these issues because the family is virtually always involved and we depend so often on a family’s support and adherence with interventions. Chapter 2 focuses on the basics of chronologic motor development with a strong emphasis on the biomechanical aspects of that development. An entirely updated chapter on tests and measures of development, written by Kirsten Malerba, follows.

Neurologic and neuromuscular diseases and injuries are the focus for the next section of the text. The eight chapters in this section include one addition and one new group of authors. Jason Beaman and his associates have performed the daunting task of developing a completely new chapter about Cerebral Palsy with a strong section on gait. The new chapter, written by Anjana Bhat and colleagues, offers current information and discussion about autism spectrum disorders and is an important and current addition.

Chapters 13 through 15 discuss common musculoskeletal disorders and include two major revisions. Michael DiLenno

revised the chapter on major orthopedic disorders in children for Chapter 13. Elliot and Eric Greenberg (no relation) have updated and increased the evidence provided in Chapter 14 on sports injuries.

The final six chapters include several important and diverse groups of disorders. This section of the book includes one new chapter and a new author. Chapter 18 discusses a very contemporary topic—Obesity in Children—and was written by Kathy Coultres. Chapter 19, on Cardiac Disorders, was written by Heather Hansen, who is new to the book. The other chapters in this last section include updates to the previous edition.

Features

We have included extensive **Chapter Outlines** to help the student and the instructor focus on specific areas of information in the chapter. **Displays** have been included in an effort to provide greater depth of information, allowing information to be more inclusive without necessarily lengthening the text of the chapters. **Chapter Summaries** encapsulate and recapitulate the major points of information presented in each chapter. **Case Studies** help students hone their clinical decision-making skills with real-world situations.

Ancillaries

An interactive website is also included with this edition of *Pediatric Physical Therapy*. Instructors will have access to an Image Bank and PowerPoint lecture outlines. All of these resources are available at thePoint.lww.com/Tecklin5e.

The 5th edition of *Pediatric Physical Therapy* is much more than a timely update. It includes two chapters new to the book on autism and obesity, four entirely new chapters, and major updates for virtually all other chapters. In addition to the updates, the new authors in this edition have extensive experience in clinical care and regularly teach at the full-time faculty level or as an associated faculty member, and most have participated in clinical research. The authors represent the best in pediatric practice.

Jan Tecklin

As in each previous edition, I would like to acknowledge the skill, creativity, knowledge, determination, and *generosity* of each of the authors who have contributed chapters to this 5th edition. Elena Spearing, a friend and former boss, updated Chapter 1, Providing Family-Centered Care in Pediatric Physical Therapy. Elena again, with her usual grace and agreeableness, coauthored Chapter 8, Traumatic and Atraumatic Spinal Cord Injury in Pediatrics, along with Heather Atkinson. Emilie Aubert authored two chapters despite, even more than most of us, dealing with a very stressful period of time. Her work under stress was, as in the past, outstanding and complete. Emilie updated her Motor Development chapter and again authored Chapter 12 on Adaptive Equipment and Environmental Aids for Children with Disabilities. Diane Versaw-Barnes and Audrey Wood completely rewrote Chapter 4 The Infant at High Risk for Developmental Delay. As I told them after the 4th edition, this extraordinarily comprehensive chapter could serve as a textbook on its own. Jason Beaman, a new author, along with his colleagues, dove in and completed the daunting Chapter 5 on Cerebral Palsy. We spoke regularly, and Jason was clearly up to the task and expanded the gait section of that chapter. Chapter 6, Spina Bifida, represents the fifth version of this comprehensive chapter by Elena Tappit-Emas who, along with Dolores Bertoti (coauthor of Chapter 10 with Mary Schreiner), has been with the text since the first edition in 1989, as noted in the Preface. Amy Both again updates her chapter, which discusses children with Traumatic Injury to the Central Nervous System: Brain Injury in Chapter 7, just as she did so successfully in the 3rd and 4th editions. Alan Glanzman, and Jean Flickinger coauthored and updated Chapter 9, Children with Myopathy and Related Disorders. I already mentioned Dolores Bertoti and the fifth version of Chapter 10 on Children with Mental Retardation written with Mary Schreiner. A new chapter to the 5th edition on Autism Spectrum Disorders by Anjana Bhat and colleagues Deborah Bubela and Rebecca Landa is an overdue and needed addition, and I appreciate the three coauthors' eagerness to participate. Emilie Aubert also updated Chapter 12, as noted above. Chapter 13, Orthopedic Management, has been completely written and revised by Michael DiLenno a new author to the 5th edition. Mike completed the chapter on time despite becoming a new dad and taking on a major increase in professional responsibilities, and I appreciate his ability to juggle several daunting projects. Chapter 14 about Sports Injuries in Children and Adolescents by Elliot Greenberg and Eric Greenberg is a

great update that adds much evidence to support the interventions discussed about a multitude of injuries to young athletes. Susan Klepper has again presented the Juvenile Idiopathic Arthritis chapter (Chapter 15) which updates the 4th edition. Victoria (Tori) Marchese offers an update of her Pediatric Oncology in Chapter 16. Rehabilitation of the Child with Burns, by Suzanne Migliore revises and updates the discussion of the acute and long-term rehabilitation following serious burn injuries in Chapter 17. Heather Hanson, a new contributor, eagerly revised and updated Chapter 19 on Cardiac Disorders. I say "eagerly" because Heather's was the first completed chapter I received for review. I updated the Pulmonary Disorders chapter (Chapter 20) and attempted to focus on contemporary issues. Karen Lunnen, a friend since the early days of the Section on Pediatric Physical Therapy in the 1970s, and Rita Geddes have revised Physical Therapy in the Educational Environment, Chapter 21, with a focus on the clinical relevance of the topic.

I am deeply indebted to each author for the untold number of hours, moments of aggravation, and requests for the chapters to have been submitted "yesterday." I have incredible respect for each of these learned individuals, whom I think of as friends, who are also outstanding clinicians, mentors, scholars, and caregivers to children.

On a personal note:

I acknowledge the help over the past 27 years of the 41 colleagues across the United States who have been contributors to one or more editions of *Pediatric Physical Therapy*. Several of them I have not met face-to-face, but I have tried to mentor them using telephone, email, texts, and other modes in preparing chapters as best as I've been able. The most enjoyable parts of editing and compiling the 5th edition was to have the pleasure of including as authors five former students from Beaver College, which is now Arcadia University. These five include Diane Versaw-Barnes, Heather Baj Atkinson, Kathy Coultres, Elliot Greenberg, all graduates of the entry-level program, and Kirsten Hawkings Malerba, a graduate of our post-professional program.

I would be remiss if I did not acknowledge the support of the staff at Lippincott Williams & Wilkins. Notable among these folks has been Mr. John Larkin, our Managing Editor, who has nudged, pushed, cajoled, encouraged, but never nagged—and been largely responsible for the ultimate production of this book. To each and all of the folks above I offer my heartfelt appreciation and thanks.

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Providing Family-Centered Care in Pediatric Physical Therapy

Elena M. Spearing

Family-Centered Care

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Cultural Desire

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Benefits to Providing Family-Centered Care

Summary

Family-centered care

The notion of family-centered care was first presented in the 1980s. It began in children's hospitals and pediatric units. This philosophy of care then spread to cancer units, maternity wards, mental health units, and various adult health care practices, where it is referred to as patient-centered care. Family-centered care is a philosophy recognizing that the family plays a vital role in ensuring the health and well-being of its members. Family-centered care also empowers the family to participate fully in the planning, delivery, and evaluation of health care services. It supports families in this role by building on the family members' individual strengths.^{1,2}

Family-centered care is the foundation of pediatric physical therapy. Because a child is dependent on a caretaker, we must address both the child and the caretaker when we interact with a child receiving physical therapy.

The definition of family, in today's society, respects the notion that each family has unique characteristics and variables. Today, the family unit consists of "those significant others who profoundly influence the personal life and health of the individual over an extended period of time."² Families today come in all configurations and sizes and are not all traditional, married, two-biologic parent families. The 2010 U.S. Census reports that the number of husband-wife-own

children family households has decreased over the past 20 years despite increases in the total number of family households. The number of single-parent families, dual-income families, adoptive families, same-sex-parent families, and intergenerational families has steadily increased.³

Additionally, there is a "melting pot" of various cultural identities represented in the United States. The U.S. Census Bureau reported that the minority population continues to grow to an all-time high in 2012, with more people speaking languages other than English outside the home. The three fastest growing racial categories continue to be Asian and Pacific Islander, Hispanic, and "other."³ This cultural factor presents additional challenges to health care providers who care for people with varying cultural and ethnic backgrounds.^{4,5}

Historically, there has been a change in the developmental theory behind how pediatric physical therapy is provided (Display 1.1). This change has resulted in a shift from a reflex hierarchy model where a child develops on the basis of a set of primitive reflexes to one where a child develops as a result of the dynamic interaction of different systems that affect one another in the development of the child. In this dynamic system's model, all systems' components interact to produce meaningful, functional behavior.⁶ The child's family is one of those systems. Similarly, pediatric care has shifted from being child focused, as in the 1980s, to currently being family focused.^{1,7} Also, many center-based physical

DISPLAY

1.1 The Change in Structure of Pediatric Service Delivery Motor Learning and Function

Reflex Hierarchy Model	→	<i>Systems Model</i>
Child-Centered Services	→	<i>Family-Centered Service</i>
Center-Based Delivery	→	<i>Natural Environment</i>

therapy service delivery models have been replaced by physical therapy service in the natural environment of the home and school. These initiatives help to promote family-centered care practice by the physical therapist.

Physical therapists who practice in the early intervention setting are mandated by law to provide care that respects a family's individualism. Those therapists have been charged with providing family-centered care since the initiation of Public Law 99-142 in 1975, Public Law 99-457 in 1986, and Public Law 102-119 in 1991.¹ Public Law 107-110 of 2001—No Child Left Behind (NCLB) and PL 108-446 of 2004, The Individuals with Disabilities Improvement Act—have similar mandates.^{7,8} These laws placed the focus on revising and enhancing parents' involvement in the habilitation and education of the child.^{1,9} Early studies showed that it was difficult to achieve this role on the basis of white middle-class families, and little attention was paid to social or ethnic differences. Additionally, enhancing parents' involvement is based on the assumption that the parents can participate in formal processes and, when necessary, draw on the availability of due process of the law. Family-centered care processes are also central to the development of the individualized family service plan (IFSP) and individualized education program (IEP), the required documentation for early intervention and educational services.

Physical therapists who practice in other pediatric settings, including the medically based inpatient and outpatient arenas, may be bound by health care accreditation standards, which recognize the importance of family-centered care. The Joint Commission on the Accreditation of Health Care Organizations has standards of care initiatives in place to address the needs of the family.¹⁰ The Joint Commission has also developed publications to assist hospitals with meeting these standards.¹¹

Collectively, the vision for family-centered care has included increasing support for the emotional and developmental needs of the child. Strategies for this include prehospitalization visits, presurgical education and preparation, 24-hour parental visitation and sibling visitation guidelines, and home care services. These initiatives have shifted from placing the family central not only to the child, but also to the child's plan of care.^{12,13} Ultimately, this type of care results in a respect and a value for the parents as the ultimate experts in caring for their child.

Family-centered care involves the following themes^{14,15}:

1. Respecting each child and his or her family
2. Honoring racial, ethnic, cultural, and socioeconomic diversity and its effect on the family's experience and perception of care

3. Recognizing and facilitating the choices for the child and family even in difficult and challenging situations
4. Facilitating and supporting the choices of the child and family about approaches to their care
5. Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family
6. Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
7. Providing and ensuring formal and informal support for the child and parent and/or guardian during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood
8. Collaborating with families in the care of their individual child at all levels of health care, including professional education, policy making, and program development
9. Empowering each child and family to discover their own strengths, build confidence, and make choices and decisions about their health care

Barriers to Providing Family-Centered Care

Role conflict between families and health care professionals can impede the implementation of family-centered care. Often, this is very evident in the acute care setting. In the past, parents were expected to hand over the care of their children to the professionals and remain separate from them. Today, parents are expected to stay with their child and participate in their care. This example is also seen in the home care environment where parents are not afforded the respite care that they once were.

Role conflict contributes to role stress. Role stress is defined as "a subjective experience that is associated with lack of role clarity, role overload, role conflict, or temporary role pressures."¹² This stress can affect the communication process between health care provider and parent by causing one or the other to focus on the source of the stress as opposed to the underlying issues. Parents can be subjected to role stress owing to their child being ill, with exacerbation of that stress being associated with the child being hospitalized (Display 1.2).¹² The hospitalization of a child can be

DISPLAY

1.2 Stress-Limiting Strategies

Newton defines strategies that health care providers can do to limit stress for a family by using the acronym LEARN¹²:

Listen sympathetically and with understanding of the family's perception of the situation.

Explain your perception of the situation.

Acknowledge and discuss the similarities and differences between the two perceptions.

Recommend interventions.

Negotiate an agreement on the interventions.

extremely stressful for even the most well-organized family. Many studies show that a professional can ease this stress by helping the parents understand the illness, help provide familiarity and comfort with the hospital setting, and encourage negotiating care of the child with health professionals.¹² Building a relationship with families and adapting styles to the individual learning styles, emotional stresses, and culture can lead to more effective intervention.⁶ This has also been reported to improve developmental outcome and lead to enhanced cognitive and socioeconomic development in premature babies in the neonatal intensive care unit.⁶

The purpose of this chapter is to provide a framework for understanding the principles of family-centered care in order to enable the physical therapist to incorporate principles of family-centered care into their examination, assessment, and intervention techniques regardless of the pediatric practice setting. Themes of family-centered care cross not only practice settings, but also age and diagnosis. As these themes are threads across the pediatric spectrum of care, they are also threaded throughout the chapters of this textbook.

Families' response to medical illness and disability

When parents are faced with the fact that their child has an illness or disability, their lives must change immediately. Some changes include readjusting the family's expectations and dealing with financial difficulties and health care systems and professionals. The most common initial responses include shock, disbelief, guilt, a sense of loss, and denial. After the period of denial, some parents may experience anger because of the stress of the medical issues as well as spousal disagreement or individual feelings of fault and guilt.¹⁶

As a result of these responses and concerns, there are many stresses for families with a child with a disability. Families raising a child with a disability will have different responses and means of adaptation. Factors that affect how a family responds include past life experiences, familial reactions to the child and the disability, and knowledge about health care and support systems. Supports can also vary. Sometimes there is a lack of understanding of the medical implications from those outside the family. There can also be feelings of embarrassment for the family. Professionals can use a cognitive approach to problem solving to help families examine their feelings and develop solutions for their own needs.

The effects of having a child with a disease or disability can not only affect the parents' relationship, but it can also have varied effects on siblings who also have individualized needs based on gender, birth order, and temperament. Siblings can also have mixed feelings toward their disabled sibling.¹⁷ Some siblings may feel or be expected to have increased responsibility for the care of their siblings. Some siblings may have feelings of jealousy toward the sibling who has special needs.

A child with a disability may experience different effects as a result of his or her disability. By school age, most children are aware of their disability and may need help dealing with their feelings as they transition to school. The transition to school can be eased with education to the classmates prior to the disabled child entering school. Parents and professionals can assist with this planning. During adolescence, there may be particular new issues that emerge for a child with a disability. Feelings of comparing themselves and being part of a peer group are important for all adolescents and can present new challenges for those with chronic or new disabilities. Adolescents should also be acknowledged as having sexual interests. They should be educated on these feelings as well as trained in social skills. They should also be exposed to age-appropriate recreational skills, such as dancing, listening to music, and sports activities. Programs of inclusion help children to develop socialization skills and a good self-image.

Children with disability or illness may also have varying levels of understanding about their disease process or disability.¹³ More recent data in the medical literature demonstrate that children with sickle cell disease provide their parents with information about their pain and assist with decision making. This should be kept in mind with children even as young as 5 years old.

The transition to adulthood is both important and difficult for patients and parents. Those individuals who remain dependent through adolescence tend to remain dependent through adulthood.¹⁸ Adolescents who have the potential for independence but are having difficulties with separation may need assistance. Likewise, the family members may need assistance in supporting their child during this difficult time. Professionals should be partners with the family members and empower them to make decisions.

Disability as defined by the Americans with Disabilities Act is "physical or mental impairment that substantially limits one or more of the life activities of an individual, a record of such an impairment, or being regarded as having such an impairment."¹⁹ Advances in medical technology, diagnosis, and treatment have resulted in decreased mortality rates for children with life-threatening conditions to survive well into adulthood.¹⁸ The diagnosis of chronic illness or disability clearly impacts a family. How families respond to the diagnosis is a function of their adaptive capabilities.¹⁶ What makes some families reorganize and become stronger, while others decline in function, become symptomatic, and sometimes disintegrate depends on family resilience according to Ferguson.¹⁶ He describes eight aspects of resilient family processes as:

1. Balancing the illness with other family needs
2. Developing communication competence
3. Attributing positive meaning to the situations
4. Maintaining clear family boundaries
5. Maintaining family flexibility
6. Engaging in active coping efforts
7. Maintaining social integration
8. Developing collaborative relationships with professionals

A family's ability to be resilient or the extent of its resiliency is largely defined by society, time, place, and culture.¹⁶

Additionally, in studies dealing with disability, when looking at reaction to disability, there are three issues considered to be universal. They are as follows²⁰:

1. The culturally perceived cause of a chronic illness or disability will play a significant role in determining family and community attitudes toward the individual. (This will be discussed later in this chapter.)
2. The expectations for physical survival for the infant or the child with a chronic disability will affect both the immediate care the child receives and the amount of effort expended in planning for future care and education.
3. The social role(s) deemed appropriate for disabled or chronically ill children and adults will help determine the amount of resources a family and community invests in an individual. This includes issues of education and training, participation in family and social life, and the long-range planning done by, or undertaken for, the individual over the course of a lifetime. In the history of literature on family reactions to having a child with a disability, there has been a shift in thinking. In the 19th century, with the flourish of specialization, the moral blame for disabilities was often placed on the parents. This set of beliefs most often placed the blame on poor mothers who made bad judgments. Reform schools, asylums, and residential schools all became apparent in the 19th century. This movement also led to special education schools after the turn of the century. The only way to deal with children that weren't "normal" was to turn the parenting over to professionals within the walls of these facilities.¹²

There was a major shift in thinking throughout the 20th century that included a reversal of the above assumptions. Professionals shifted to focusing on the damage that children with disabilities caused their families. The medical model began to analyze the family unit with terms such as *guilt*, *denial*, and *grief* and *role disruption*, *marital cohesiveness*, and *social withdrawal*.

Over the past few decades, a new approach has developed regarding the impact of a child's disability on the family. The recent approach includes models of stress and coping (adaptation) and models of family life course development. The adaptive family describes X—the potential family crisis—as an interaction of three factors: (1) an initial stressful event, combined with (2) a family's resource for dealing with the crisis and (3) the family's definition of the stressor.¹⁶ This approach has allowed researchers to focus on the resiliency of the family and its ability to cope with a potentially stressful situation. There is a level of consensus today that identifies the varying ways that families with children with disabilities deal with stressful situations. There is great similarity to the way that families with children without disabilities deal with similar issues. There are also varying responses to how some deal with stressors. Sometimes, others can view stressors as

benefits. Also, the response to stressors is cyclic and cumulative. Each stressor response affects others' responses.¹⁶

The evolving family concept also accepts that families evolve over time and tries to identify where they are in their developmental process. Similarly, families need to be considered across the continuum of care. This is especially true as their younger children age and approach adulthood. This line of thinking has allowed researchers to look at how and why some families are more resilient than others and also how extended coping with chronic disabilities affects families over time.

The supported family members look at internal and external resources that are available to them. How family members respond to difficulties depends on their supports. This also has root in societal and cultural assumptions. Recent research on family adaptation shows the following key themes¹⁶:

- There is a dominant body of literature that shows patterns of adjustment and well-being to be similar across groups of families of children with and without disabilities. This does show, however, that there are some developmental differences over the family life course.
- Additionally, there is an increasing recognition and growing research that a significant number of parents actually report numerous benefits and positive outcomes for their family associated with raising a child with a disability. These include coping skills (adaptability), family harmony (cohesiveness), spiritual growth or shared values, shared parenting roles, and communication.
- There are, obviously, stressors associated with having a child with a disability. The research continues to refine our understanding of why some families are more resilient than others in adapting to stress. Some research has suggested that the level of disability or family structure may not be as crucial as other factors (income, self-injurious behaviors, etc.). There are also differing patterns of adaptations along ethnic and cultural lines.¹⁶

Culture

Culture affects how others view disability, how people with disabilities view themselves, and how people with disabilities are treated. The cultural context within which a disability is perceived is important to understanding the meaning of disability for a person or his or her family. It is also important to know the kinds of services to be provided to families and people with disabilities.

Culture can be defined in many ways. O'Connor defines culture as "the acquired knowledge people use to interpret experience and generate social behavior."²¹ Other definitions include "the ever changing values, traditions, social and political relationships and a world view shared by a group of people bound together by a number of factors that can include a common history, geographic location, language,

social class and/or religion.”²² An analysis of the various studies of culture yields the emergence of various similar themes²¹:

1. Culture is not innate or biologically inherited but, in fact, learned patterns of behavior.
2. Culture is transmitted from the older people to the young, from generation to generation.
3. Culture serves as a group identity and is shared by other members of the group.
4. Culture provides the individual or the members of a group with an effective mechanism for interacting with each other and their environment.

Diversity versus Sensitivity

There are many terms that are used today to refer to the impact of culture on health care. It is necessary to describe the two most common terms and their fundamental differences. *Cultural diversity* refers to having a range of cultures represented in an organization. This leads to a workforce that is more representative of the general population. In health care, diversity in the workplace leads to the increased potential of having similar cultures represented. By comparison, *cultural sensitivity* and effectiveness is a process of becoming “culturally competent” and striving toward the ability and availability to work effectively within the cultural context of a client, individual, family, or community regardless of the cultural background.²²

Cultural sensitivity refers to the understanding that cultural differences exist. These differences are not necessarily better or worse, right or wrong, or more or less intelligent, but rather simply differences.²³ It is necessary to examine, in detail, attitude, behavior, and communication, which directly affect health care. It is important to realize that each person within a culture is an individual and should not be characterized or stereotyped on the basis of his or her cultural association. It is only through generalizations that one can gain a frame of reference and become more culturally aware.

Influences on Cultural Identity

There are various things that influence who we are and how we view illness and disability. These include our nationality, our race, and our ethnicity. Similarly, our socioeconomic status and education also play a role. Our society’s view of illness and disability also influences our perception of the same. Other things like age, religion, and past experience shape our beliefs.

In addition to these, health care providers who were brought up in the U.S. culture are finding that their medical views are in conflict with the views of their patients from differing cultural backgrounds. Care provided in the past was monocultural and suited for the Euro-American culture. Traditionally, in medicine we have functioned under a

“medical culture,” one that values a “cure” and the expertise of those in the medical profession.⁹

This traditional model, however, is not as appropriate or relevant for those who are not of that “medical” cultural identity.⁹ When this cultural disconnect occurs, the consequence is often disparities in the quality of care received by racial and ethnic minority populations. One example of this is the Tuskegee Syphilis Research Experiment, which occurred between 1932 and 1972. Three hundred and ninety-nine poor African American sharecroppers who were identified as having syphilis were told that they were being treated for the disease when they were unaware that they were control subjects.²⁴ This legacy has continued to affect the credibility and reputation of the medical industry for many African Americans who believe there are continuing racial and ethnic disparities in the health care system and mistrust the medical community.²⁴ Fortunately, these disparities are evolving with time but they still exist. Guerrero et al. found that black children have similar experiences as white children on overall family-centered care in models that adjust for socioeconomic factors. In contrast, there were still differences found on dimensions of overall family-centered care between white children and Latino children, irrespective of interview language and even with multivariate adjustment.²⁵

Cultural and Parental Expectations

Many studies reveal that culture and acculturation are strong predictors of parental expectations of cognitive and social development. Most studies point to ethnic origin as the differentiating factor. More contemporary literature has determined that Western education and socioeconomic status were more predictive of differential beliefs than ethnic origin. This demonstrates that acculturation has a powerful effect on parenting styles and on parental beliefs about child development. What is even more profound is the difference between the description of mildly retarded, behaviorally disordered, and learning disabled between the parents and the professionals. Ethnographic studies have shown that there are sometimes differences related to culture, which emphasized that for some parents, a child’s cognitive and social functioning has to be more limited for the concept of handicap or disabled to be applied. These statements are then interpreted by the professional as families being in “denial.”²³ The following themes occur in a review of the literature on culturally appropriate services in the special education literature⁹:

1. There are cultural differences in definitions and interpretations of disability.
2. There are cultural differences in family coping styles and responses to disability-related stress.
3. There are cultural differences in parental interaction styles, as well as expectations of participation and advocacy.

4. There are differences in cultural groups' access to information and services.
5. There are negative professional attitudes to, and perceptions of, families' roles in the special education processes.
6. There is dissonance in the cultural fit of educational programs.

There are traditional cultural patterns associated with particular cultural groups. One example is that Asian groups attribute disability to spiritual retribution or reward. Similarly, there is an emphasis on the wholeness of the spirit within a disabled body. This is powerfully described in the novel *When the Spirit Catches You, and You Fall Down* by Anne Fadiman. It is demonstrated throughout the novel that this Hmong family attributed epilepsy to spiritual phenomena within the individual.²⁶

The Cultural Response to Illness

How one views and responds to health, illness, and death is largely defined by his or her cultural values. Before detailing this, a distinction between disease and illness must be made.

Physicians diagnose and treat diseases, which can be defined as abnormalities in the structure and function of body organs and systems. Illnesses, on the other hand, are experiences of disvalued changes in states of being and cultural reactions to disease or discomfort.²⁷

How a person understands and responds to illness is determined by what Kleinman calls “explanatory models.” These are defined as “notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process.”²⁷ Explanatory models address five major issues:

1. Etiology of the problem
2. Time and mode of onset
3. Pathophysiology of illness
4. Course of illness and degree and severity
5. Type of treatment that should be sought²⁸

“Illness is culturally shaped in how we perceive, experience, and cope with disease based on our explanations of sickness, explanations specific to the social positions we occupy and systems of meanings we employ.”²⁷ The role of traditional medicine and folk healing is based on cultural values. An estimated 70% to 90% of self-recognized episodes of sickness are managed outside of the formal health care system.²⁷ As Kleinman states, “folk healers deal with the human experience of illness.” They seek to provide meaningful explanations for illness and respond to personal, family, and community issues surrounding illness.²⁷ Illness referred to as “folk illness” (i.e., illnesses that are recognized within a cultural group) may sometimes conflict with the biomedical paradigm.²⁹

It is important to understand folk illness because people who experience “folk illness” may present to a medical practitioner and a “folk healer.” Additionally, some “folk

treatments” may be potentially hazardous. Finally, folk illness may be cultural interpretations of states of pathophysiology that may require medical attention. For many chronic problems, patients have reported greater improvement with marginal folk healers than with medical physicians. Kleinman attributes this improvement to folk healers' increased emphasis on “explanation” and a greater concordance of explanatory systems between healer and patient.²⁷

For more serious illness, values and beliefs become even more crucial to understanding. Although the biologic manifestations of diseases are the same among cultural groups, individuals differ in the way they experience, interpret, and respond to illness. Explanatory models as well as coping styles have been shown to influence perceptions of illness.²⁷ Some have suggested that meanings are assigned using characteristic themes resulting from individual coping styles, knowledge, beliefs, and cultural background.²⁷ Viewing illness as a challenge regards the illness as something to be approached internally and mastered. The proper authorities are consulted, advice is followed, and life goes on. Illness as “God’s will” is often perceived as beyond human control and may result in passive acceptance and resignation of what cannot be changed. This set of beliefs may result in less interest in aggressive procedures and may produce depression. Illness as a “strategy” describes using illness to secure attention or nurturing from parents, family, or health care professionals. Illness as a “value” may be the “highest form” of coping, where illness is viewed as an opportunity that can result in important insight into the meaning of life. Although meanings may be influenced by culture, they are not culture specific.²⁷

Our expectations and perceptions of symptoms, as well as the labels we attach to sickness behaviors, are influenced by environment, family, and explanatory models. In addition, the way in which problems are communicated, how symptoms are presented, when and who is visited for care, how long one remains in care, and how care is evaluated are all affected by cultural beliefs.³⁰ Likewise, culture dramatically influences the reaction to and expression of pain, which has been learned throughout childhood.³⁰

The Cultural Response to Disability

Research gives strong support to the argument that definitions of disability are socially constructed.^{9,23} When disability is severe, studies show that although all groups recognize gross developmental, behavioral, or sensory impairments, their attributions differ widely as does the extent of stigma or value associated with that condition.^{9,31} Responses to impairments vary through time, place, and culture. Over the course of history, societies have defined what did and did not constitute a disability or handicap. The past decade has seen changes in the conceptualization of the meaning of disability and the interplay between the possibility that an impairment becomes a physical handicap. Even more than physical limitations placed on the individual with a disability,

attitudinal concepts and images affect treatment of an individual with a disability. The sources of concepts and images they produce are found in literature and art, television and movies, religious texts, and school books. Since these sources are all artifacts of culture, it is impossible to separate culture from attitudes toward disability.

For children with disabilities, the culturally perceived cause of a chronic illness or disability affects aspects of a family and community's attitudes toward that child.²⁰ In some cultures, disability is viewed as a form of punishment. Depending on the belief system, the individual with a disability, the family, or an ancestor has been targeted by God, or a god, for having sinned or violating a taboo. Witchcraft may also be strongly linked to disability as well as associated with that person who has been bewitched.²⁰

Similarly, inherited disorders are frequently attributed to "running in the blood" or caused by a curse.^{20,27} Closely related to this is the traditional belief that a disabled child may be the product of an incestuous relationship. In societies where there is a belief in reincarnation, disability may be seen as the result of a transgression in a previous life by parents of a child with a disability or the child itself. Some belief systems may emphasize the imbalance of humoral elements in the body as the cause of disability.²⁰

All of these perceived causes identify the individual with the disability as responsible for that disability and suggests likely consequences on the person's place in the family. Additionally, where disability is seen as a punishment, the presence of a child with a disability may be a source of embarrassment to the family. Various types of neglect may be apparent, including isolation. In many cultures, the idea of early intervention is not in the mindset for medical and educational professionals.²⁰ There may also be strong social pressures placed on the family in these instances. Families may be reluctant to participate in therapeutic programs, fearing that these will call attention to their family member's physical and intellectual limitations.²⁰

An understanding of traditional expectations for survival is also important. For some cultures, the belief that severely disabled children will simply not survive makes the allocation of medical and parental attention to healthy children more practical. Either neglecting a disabled child or overprotecting him or her because he or she is alive for only a short period of time can have serious implications for both health care services and psychological development. Moreover, how one is believed to be restored to health can have implications on long-term planning or arranging for special care, with members of some cultures feeling that "maybe God will make your baby all better on its own."²⁰

Societies that limit occupational roles and social roles for individuals with disabilities can affect the time, energy, and expense invested in educating a child with a disability. Additionally, a gender bias, common in some cultures, may affect the degree to which a family is willing to spend money in order to obtain medical care. In these cultures, it may be perceived less justifiable to expend vast amounts of

family resources on disabled female children than disabled male children.²⁰

Failure to fully understand cultural beliefs and values toward disability may influence a family's care toward its disabled child. Consider the family members whose cultural beliefs lead them to feel that it is their responsibility to provide complete and total care for their disabled child. They may prefer to keep their child at home, unseen by even neighbors. They may hesitate to come forward for aid or advice, for various reasons, which may include poverty, fear, language barriers, or faith in traditional medical practices. When not viewed in a cultural context, this may be construed as neglect—the failure of parents to nurture and provide adequate ongoing education and emotional support.²³

The Cultural Response to Death and Dying

The number of children with severe and complex neurodevelopmental disabilities and complex medical conditions who are surviving is increasing owing to advances in medical care and technology.³² There can be conflict between palliative care at the end of life and cure-oriented treatment. Death and the customs surrounding it need to be addressed as they are highly influenced by cultural values. Expressions of grief and coping mechanisms vary from person to person but are related to cultural background.³³ The meaning of death, family patterns, including family roles during periods of grief, and the family's expectations for professional health care need to be understood. Professional attitudes regarding quality of life and appropriateness of care, the uncertainty of prognosis and the unique role of the child with a chronic disability, and the codependence between caregiver and child may all contribute to barriers to end-of-life care in this patient population.

The loss of a child with a chronic disability signifies not only loss of the child but loss of a lifestyle. Again, respecting the family's expertise when it comes to their child will assist with effective advanced care planning and implementation.³²

► Providing family-centered intervention

The nursing literature has explored the process of cultural competence in the delivery of health care service, including a model for providing culturally competent interventions. This model for cultural competence includes cultural desire, cultural awareness, cultural knowledge, and cultural skill.³⁴

Cultural Desire

The first requirement for cultural competence is "cultural desire." This is the motivation to "want to" engage in the process of becoming culturally aware, becoming culturally knowledgeable, becoming culturally skillful, and seeking cultural encounters.³⁴ Rather than doing it because it is required, cultural desire involves doing it because it is

personally desired. It includes a genuine passion to be open and flexible with others, to accept differences and build on similarities, and to be willing to learn from others as cultural informants.

Cultural Awareness

Cultural awareness is the next step in achieving cultural competence and has been described as the self-examination and in-depth exploration of one's own cultural background.³⁴ This awareness involves recognizing one's biases, prejudices, and assumptions about individuals who are different. Without this self-awareness, there is a risk of imposing one's own beliefs, values, and patterns of behavior on one from another culture.

Cultural Knowledge

Cultural knowledge is the process of seeking and obtaining a sound educational foundation about diverse cultural and ethnic groups.³⁴ Obtaining this information does not refer to learning generalizations but to learning individual differences. Learning generalizations about specific cultural subgroups leads to the development of stereotypes. Understanding that there is as much intracultural difference and intercultural difference due to life experiences, acculturation to other cultures, and diversity within cultures will prevent us from imposing stereotypic patterns on our patients and families.

Cultural Skill

Cultural skill is the ability to collect cultural data regarding the patient's problem as well as performing a culturally based physical assessment.³⁴ There are many tools available to help collect this information via questions. One must also remember that it is a developmental skill to ask questions in a way that does not offend the patient or family. Listening and remaining nonjudgmental are effective and sensitive ways to obtain information. Additionally, having multiple cultural encounters is the way to refine or modify one's own belief about a cultural group and prevent stereotyping. Linguistic assessment is necessary to facilitate accurate communication. The use of specifically medically trained interpreters is important to the assessment process. Untrained interpreters, family members, and specifically children and siblings may pose a problem owing to lack of medical knowledge.

We must provide care that is not only culturally competent, but that also provides for low literacy skills. It is documented that people who have limited English proficiency experience obstacles when accessing health care.³⁵ They may experience delays in making appointments, and are also more likely to have misunderstandings regarding time, place, date, and location of appointment. People with low literacy skills may have difficulty communicating

with the health care professional and employees in the health care institution. These issues are more likely to exacerbate medical problems that require timely treatment or follow-up.³⁵

In 1999, the U.S. Department of Health and Human Services (HHS) office of Minority Health developed standards of care within these areas. These standards were revised in 2007 (Display 1.3). In addition, the Office of Civil Rights and HHS enforce federal laws that prohibit discrimination by health care providers who receive funding from the HHS. Antidiscrimination laws are established by Section 504 of the Rehabilitation Act of 1973, title VI of the Civil Rights Act of 1964, title II of the Americans with Disabilities Act of 1990, Community Service Assurance provisions of the Hill–Burton Act, and the Age Discrimination Act of 1975. The laws mandate that providers who accept federal money must “ensure meaningful access to and benefits from health services for individuals who have limited English proficiency.”³⁶ Using an interpreter and translating materials into languages and levels that can be read by those who have literacy deficiencies are important mandated tools.

Adults who have literacy deficiencies face many problems in understanding written and verbal materials that are provided to them. It is important to remember that while some readily admit their limitations regarding understanding verbal and written information, others may feel shameful and use strategies to hide their limitations. In these situations, one can use oral explanation and demonstration. Pictures, photographs, and visual cues also help to reinforce the information. Some people will also use family members to assist them with reading, and these family members may be important in the education process.

One can identify people with low literacy skills by looking for clues. An example is someone who gives excuses for not being able to read something or who cannot read back information that is provided. Some other strategies to providing information to those with low literacy skills include³⁷:

- Remaining nonjudgmental
- Involving the patient/family
- Asking the patient simple questions
- Simplifying instructions
- Repeating the information many times
- Finding various ways to give the same message
- Organizing information so that the most important information is provided first
- Using audio-visual information
- Involving family and friends in the learning and reinforcing of information
- Asking the patient to recall the message in his or her own words or demonstrate the skill that is being taught
- Empowering individuals and families and fostering independence in their programs

Health care professionals and physical therapists should promote the sharing of information and collaboration

DISPLAY

1.3 National Standards on Culturally and Linguistically Appropriate Services (CLAS)

The CLAS standards are primarily directed at health care organizations⁴⁰; however, individual providers are also encouraged to use the standards to make their practices more culturally and linguistically accessible. The principles and activities of CLAS should be integrated throughout an organization and undertaken in partnership with the communities being served.

Standard 1

Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and in preferred language.

Standard 2

Health care organizations should implement strategies to recruit, retain, and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area.

Standard 3

Health care organizations should ensure that staff at all levels and across all disciplines receive ongoing education and training in CLAS delivery.

Standard 4

Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation.

Standard 5

Health care organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language assistance services.

Standard 6

Health care organizations must assure the competence of language assistance provided to limited-English-proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer).

Standard 7

Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.

Standard 8

Health care organizations should develop, implement, and promote a written strategic plan that outlines clear goals, policies, operational plans, and management accountability/oversight mechanisms to provide CLAS.

Standard 9

Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction assessments, and outcomes-based evaluations.

Standard 10

Health care organizations should ensure that data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected in health records, integrated into the organization's management information systems, and periodically updated.

Standard 11

Health care organizations should maintain a current demographic, cultural, and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.

Standard 12

Health care organizations should develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS-related activities.

Standard 13

Health care organizations should ensure that conflict- and grievance-resolution processes are culturally and linguistically sensitive and capable of identifying, preventing, and resolving cross-cultural conflicts or complaints by patients/consumers.

Standard 14

Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS standards and to provide public notice in their communities about the availability of this information.

among patients, families, and health care staff. Offering places such as a family resource center will give families opportunities to educate themselves around their child's needs. Also, developing programs that provide support to families in the community is an important related activity.

Some institutions have instituted family faculty.³⁸ These families have often been in similar situations and can act to encourage and facilitate parent-to-parent support. They also

provide a network for families. Additionally, one must support family caregiving and decision making and help give them the tools to do so, even if one does not agree with the decision that is made. Institutions must involve patients and families in the planning, delivery, and evaluation of health care services. They should take feedback from families and incorporate that into program planning. They should also consider the family needs as well as the child's needs.

In summary, one provides culturally competent intervention by asking the right questions.²²

► Benefits to providing family-centered care

Health care practitioners who practice family-centered care are aware that it can enhance parents' confidence in their roles and, over time, increase the competence of children and young adults to take responsibility for their own health care, particularly in the anticipation of the transition to adult services.³⁸ Family-centered care can improve patient and family outcomes, increase patient and family satisfaction, build on the child and family strengths, increase professional satisfaction, decrease health care costs, and lead to more effective use of health care resources, as shown in the following examples from the literature³⁸:

- Family presence during health care procedures decreases anxiety for the child and the parents. Research indicates that when parents are prepared, they do not prolong the procedure or make the provider more anxious.
 - Children whose mothers were involved in their posttonsillectomy care recovered faster and were discharged earlier than were children whose mothers did not participate in their care.
 - A series of quality improvement studies found that children who had undergone surgery cried less, were less restless, and required less medication when their parents were present and assisted in pain assessment and management.
 - Children and parents who received care from child life specialists did significantly better than did control children and parents on measures of emotional distress, coping during the procedure and adjustment during the hospitalization, the posthospital period, and recovery, including recovery from surgery.
 - A multisite evaluation of the efficacy of parent-to-parent support found that one-on-one support increased parents' confidence and problem-solving abilities.
 - Family-to-family support can have beneficial effects on the mental health status of mothers of children with chronic illness.
 - Family-centered care has been a strategic priority at children's hospitals all over the country. Families participated in design planning for the new hospital, and they have been involved in program planning, staff education, and other key hospital committees and task forces.
- Staff satisfaction also improves with family-centered care initiatives. The following points have been found:
- Staff report valuable learning experiences.
 - A Vermont program has shown that a family faculty program, combined with home visits, produces positive changes in medical student perceptions of children and adolescents with cognitive disabilities.
 - When family-centered care is the cornerstone of culture in a pediatric emergency department, staff members have more positive feelings about their work than do staff members in an emergency department that does not emphasize family-centered care.
 - Coordination for prenatal care in a manner consistent with family-centered principles for pregnant women at risk of poor birth outcomes at a medical center in Wisconsin resulted in more prenatal visits, decreased rate of tobacco and alcohol use during pregnancy, higher infant birth rates and gestational ages, and fewer neonatal intensive care unit days. All these factors decrease health care costs and the need for additional services.
 - After redesigning their transitional care center in a way that is supportive of families, creating 24-hour open visiting for families, and making a commitment to information sharing, a children's hospital in Ohio experienced a 30% to 50% decrease in their infants' length of stay.
 - In Connecticut, a family support service for children with HIV hired family support workers whose backgrounds and life experiences were similar to those of the families served by the program. This approach resulted in decreases in HIV-related hospital stays, missed clinic appointments, and foster care placement.
 - King County, Washington, has a children's managed care program based on a family participation service model. Families decide for themselves how dollars are spent for their children with special mental health needs as long as the services are developed by a collaborative team created by the family. In the 5 years since the program's inception, the proportion of children living in communication homes instead of institutions has increased from 24% to 91%. The number of children attending community schools has grown from 48% to 95%, and the average cost of care per child or family per month has decreased from approximately \$6,000 to \$4,100.
- Benefits to the health care professional include³⁸:
- A stronger alliance with the family in promoting each child's health and development
 - Improved clinical decision making on the basis of better information and collaborative processes
 - Improved follow-through when the plan of care is developed by a collaborative process
 - Greater understanding of the family's strengths and caregiving capacities
 - More efficient and effective use of professional time and health care resources
 - Improved communication among members of the health care team
 - A more competitive position in the health care marketplace
 - An enhanced learning environment for future pediatricians and other professionals in training

- A practice environment that enhances professional satisfaction
- Greater child and family satisfaction with their health care
- Involving patients and families in change efforts in health care institutions helps deliver improvements in care processes, gains in health literacy, and more effective priority setting as well as more cost-effective use of health care and better outcomes.³⁹

SUMMARY

It is important for us to examine our own belief systems to provide family-centered culturally competent care.

First, we need to recognize the vital role families play in ensuring the health and well-being of its family members. It has been proposed that family members are equal members of the team.

Next, we need to acknowledge that emotional, social, and developmental supports are integral components of health care. Third, we need to respect the patient's and the family's choices and their values, beliefs, and cultural backgrounds. This can be accomplished by asking questions.

Finally, we can assume that families, even those living in difficult circumstances, bring important and unique strengths to their health care experiences.

"Family-centered care is a service delivery model that includes the manner in which the services match the needs identified by the family."¹ Although many people practice family-centered care, it is not widespread. Health care professionals must adopt new practices and policies, and families and patients must learn new skills.

Today there are many government agencies that have been instituted around family-centered care initiatives. The Agency for Healthcare Research and Quality (AHRQ) (www.hhs.gov) and the Institute for Patient and Family Centered Care (www.ipfcc.org) are two examples. These organizations provide recommendations that include training programs to educate professionals both pre- and post-professionally about their role in fostering family-centered care. Historically, these agencies began in an attempt to educate professionals around principles of family-centered care. In 1998, then Vice President Al Gore held a conference in Nashville regarding families and health. This conference set the stage for initiatives nationwide for recognizing the value of family-centered care in our health system. A Family Bill of Rights was originally developed by President Clinton. This Bill of Rights is posted in public areas in health care practices in multiple languages and made available to families as necessary.¹⁴ At the family reunion conference, Vice President Gore also outlined a five-step action plan for bringing the powers of families into our health care system. This action plan can be used as a summary for this chapter. The plan is SMART. Its principles are as follows¹⁴:

Support families with information, education, understanding, and resources. Some examples of this are family resource centers, family advocacy groups, and family faculty.

Measure the effectiveness of programs. This can be done with outcome measures, qualitatively and quantitatively.

Ask the right questions. Determine the individual needs of the patient and family. This will decrease the tendency to make generalizations based on culture.

Respect that individual differences do occur and that they may be different from our own.

Train early on in the health care profession. Recognize that training is lifelong and ongoing.

Training programs should be in place to educate health care workers both pre- and postprofessionally about their role in fostering family-centered care. There is an urgent need for preservice training in multicultural practices.¹⁴ Coursework for special educators and health professionals should be part of the preprofessional curriculum. There has been much published about specific cultural groups. This type of approach is promising for professionals who are being trained to work with specific groups of people. There is danger, however, in this method of training. It risks the development of stereotypes and assumptions that are not true. No individual training program can possibly address all the differences that are possible within groups. More effective methods of teaching cultural effectiveness include processes for a much broader conceptual approach. Many programs have developed their own methods. All have common themes: self-assessment, culturally effective knowledge of language, and the ability to apply the knowledge at both interpersonal and systems levels. Harry recommends an approach that is a habit of reflective practice that will lead to effective parent-professional collaboration without having a great deal of culturally specific information.¹⁴ The approach includes developing culturally appropriate observation and interviewing skills, including asking questions that are open-ended. The federal government will continue to look at funding systems for programs and enact legislation to ensure that principles are being respected. If these principles are in place with our delivery of Physical Therapy Examination, Assessment and Intervention, it will serve to improve all aspects of the patient experience.

CASE STUDIES

CASE STUDY 1 **Roselyn** Roselyn is an 8-year-old girl with cerebral palsy. She lives with her mother, father, two brothers, one sister, grandmother, aunt, and four cousins in a small home in an urban environment. Roselyn's parents moved to the United States when they were teenagers. They have learned

to speak English, but it is not their primary language spoken at home. Roselyn is unable to walk and does not attend school. Her family takes care of her every need. She rarely leaves the house except to go to church, where she is carried and doesn't have many friends her own age. She has a close family and enjoys many visits from friends and neighbors. Her family takes her regularly to the major medical center for all her medical care.

The professionals have recommended a special educational setting for Roselyn, where she would receive all her educational needs and therapies. The family has declined such a placement and prefers to homeschool her. She is not receiving any therapy at this time.

Many professionals who have seen Roselyn have tried to get the family to agree to outside help for Roselyn. They have stressed the importance of teaching her how to function independently. The family members insist that she does not need to do anything, because they will take care of her. They do not even want to get any type of special equipment to help them to take care of her. Roselyn has not had any acute medical issues; however, the team feels that Roselyn could do more for herself.

After many years of team recommendations not being followed by Roselyn's family, a new physical therapist offered to make a visit to the family's home to assess the situation. When she arrived, she found a very crowded living arrangement within a very small home. As she stayed to "visit," she observed a typical day in the life of Roselyn. She was amazed to see the whole family involved. One family member bathed and dressed her. Another family member fed her along with the rest of the family. When the other children went off to school, Roselyn's mother spent a few hours teaching her math and reading and doing "exercises" to make her strong. After lunch, Roselyn was carried outside and taken for a walk around the neighborhood and accompanied her father to the store for some groceries in a homemade wagon. After the children returned from school, Roselyn sat outside on the porch and watched the children as they played. They all included her in their games.

The physical therapist realized that Roselyn's family and neighbors had embraced her care as a team. They had developed strategies to care for her and included her in the family's activities. When speaking to Roselyn's mother, she sensed an enormous amount of sense of responsibility for Roselyn's disability, even referred to "punishment for sins that had been committed by her parents." It was obvious that Roselyn's family took great pride in her caretaking.

When the physical therapist returned from her visit, she shared the information that she received with the team. She took photos and video of the house and the equipment that the family used. All agreed that Roselyn was being cared for, but that perhaps they were going about helping her in the wrong way. They decided to have a social worker, who was of the same ethnic group, to work with the family on changing its understanding of the disability. Instead of focusing on changing what the family was doing, the team worked to support the family members in what they were doing. Very soon, the family accepted some help from the team. The team was able to give the family members suggestions to make it easier for them to care for Roselyn and

gave them suggestions for how she could play a more active role in the family and the community.

Clinic visits were not frustrating anymore as the team took a new approach to making recommendations to the family.

Points to Ponder

Was the team being family centered when they first worked with Roselyn and her family?

How did the therapist's visit change the perception of the team?

Why was the family so resistant to the recommendations that they made as a team?

How should the team proceed with their recommendations as Roselyn gets older?

CASE STUDY 2 Daniel

Daniel is a 4-year-old boy who was admitted to the hospital for "a bad cough." His parents were not born in this country and spoke little English. There was no other family member with Daniel who spoke English, so the nurses and doctors attempted to get information to complete their assessment using gestures, pictures, and simple English. It appeared from the examination that Daniel had been ill for quite some time, without medical care. He was malnourished and had a severe productive cough with bloody sputum. He also had marks on his chest that appeared to be caused by a small object being rubbed on it. The professionals who examined Daniel felt that he had been neglected and discussed whether the authorities should be notified. The attending physicians decided to admit Daniel to the hospital for a workup. He called Social Services because of his concerns about the family and refused to allow the parents to accompany Daniel to his room. The family was left in the emergency room while Daniel was wheeled away, and security was called to restrain them there until Social Services arrived.

The social worker arrived to the situation and first went to speak to the doctor. The doctor said that he felt the parents neglected Daniel's needs and he was very concerned for Daniel's welfare. He added that Daniel had signs of abuse on his chest and was malnourished. It was his duty to call child protective services. In the meantime, Daniel was undergoing tests to determine what was wrong with him. The physician left to attend to Daniel as the social worker returned to the emergency room to speak with the parents.

The social worker met the parents and found out by simple cards with different languages what language they spoke. She was then able to get an interpreter through a language service. She collected basic facts about the boy and his current medical situation. She was also able to get a phone number to a neighbor of the family who was bilingual. She was able to convey to the parents that their son was going to have some medical tests to determine why he is sick and how to make him better.

The family's neighbor was able to come to the hospital to help to communicate with the family. It turned out that the boy had been sick for a few weeks and the family members were using traditional means to care for their son. "Coining," where a coin is rubbed on the ailing part of the body, was performed by the mother to "drive out the cough." The family also believed that a