5

Families with Children with Disabilities

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"It was ability that mattered, not disability, which is a word I'm not crazy about using."

—Marlee Matlin (as cited in Miserandino, 2004)

"Having [a child with a disability] has taught me not to judge others who are different . . . rather find their strengths."

—Parent (as cited in Hanson, 2003b, p. 358)

"He's definitely been a blessing over and over and over again. He's always had a positive attitude. He's taught me what unconditional love is."

—Parent (as cited in Hanson, 2003b, p. 358)

Disability is a part of our lives. A report jointly released by the World Health Organization and the World Bank estimated that 15% of the world's population has a significant physical or intellectual disability, including about 5% of children (Brown, 2011; World Health Organization, 2011). Although the incidence of disability increases with aging, a large number of children also have disabilities. Trends in prevalence data for the United States reveal that approximately one in six children have developmental disabilities and specific conditions, such as autism and attention-deficit/hyperactivity disorder, have increased in recent years (Boyle et al., 2011).

The experience of families in rearing and caring for their children with disabilities has been the subject of articles in the popular press and in scientific journals. Many have emphasized the possibility for negative repercussions related to the disability and documented the increased struggles faced by families in meeting the health, educational, and social needs of their children. In recent decades, this perspective has been replaced by a more comprehensive and balanced approach that considers both positive and negative outcomes and an analysis of family interaction and adaptation when a child has special needs (Blacher & Baker, 2007; Blacher & Hatton, 2007).

To be sure, the presence of disabling conditions can be challenging. However, the notion of disability is a complex phenomenon. The transactional nature of development

underscores the importance of each person's interaction with her or his environment. A physical or intellectual condition may be deemed a barrier for one person in one context, but it may not be experienced as a difficulty by another person in a different setting. The ability to walk and the reality of whether an individual uses legs or a wheelchair for mobility, for instance, have little bearing on the person's ability to use a computer or function as a productive member of society.

Current international perspectives on health and disability, as articulated through the International Classification of Functioning, Disability and Health of the World Health Organization (2012), now reflect this more complex and transactional outlook. The revised classification system for describing health status has shifted away from the sole emphasis on a particular physical condition to a broader view of how individuals are able to function and socially participate in their environment. Health and disability factors are viewed from a more social perspective and account for the contexts in which individuals live.

The family is typically the primary context of importance for the child with a disability. This chapter examines the context of the family and the experiences of families as they adapt and adjust to circumstances associated with the disability. The focus is on understanding families' abilities to meet the needs of all family members including the child with disabilities, as well as service delivery models that support and enhance families' strengths and resources in addressing their own family goals and functions.

The cultural and community contexts in which families reside and interact may profoundly influence their abilities to approach challenges posed by their children's health and disability conditions. Developmental disabilities occur in all socioeconomic and ethnic groups. However, a family living in poverty that is struggling to meet the most basic health, safety, and sustenance needs of their children may need more supports and assistance outside the family to address their concerns. Families' living contexts in which disabilities are met with acceptance and community support, on the other hand, may experience different types of needs to meet their families' goals. As we have discussed throughout this text, families' societal contexts can play pivotal roles in supporting or limiting the family's ability to function.

The experiences of families and the opportunities and options that are available to them in rearing and supporting a family member with developmental disabilities or risks is deeply embedded in the values and culture of the society within which the family resides. Race, culture, social class, and language are variables integrally linked to how developmental disabilities are defined and the opportunities provided to children and families (Klingner, Blanchett, & Harry, 2007). Families' interactions with the various contexts in which they are nested (e.g., neighborhood; community; health, education, and social service agencies; government) deeply affect how they adapt to circumstances surrounding disability. As such, the service delivery system must offer a variety of options that are flexible and can be tailored to the variable needs of families in this diverse world. Contemporary options for service delivery reflect a shift away from earlier service models that were primarily professionally driven. Today, service systems typically are more family based and designed to support and enable families to function effectively.

Societal mores have varied over the years and across cultures depending on attitudes and perspectives on the meaning of disability (Berry & Hardman, 1998; Klingner et al., 2007; Safford & Safford, 1996). In ancient times, individuals with disabilities in some societies were cast out or even killed because they were viewed as burdens or

nonproductive members of that society. In other societies, they were seen as possessing special powers and links to higher spiritual powers. Although the industrial age gave rise to more humanitarian perspectives and reforms, disability typically was viewed as a disease. Greater focus was given to intervention through medical and/or education regimens, but attempts to "cure" the disability were generally unsuccessful. Societies that placed high value on the economic contributions of its citizenry showed a lack of acceptance toward individuals with disabilities because they doubted the productivity of these individuals. In time, most cultures have embraced social and educational programs for individuals with disabilities. The participation or self-determination of those individuals and their families in defining their own needs and supports has increasingly become the priority.

Societal values and mores also influenced service practices and scientific investigation by clinicians and researchers. For many years, parents—particularly mothers—were blamed for their children's disabilities such as intellectual and developmental disabilities, emotional disturbances, and health problems. For instance, mothers of children with autism were characterized as cold and unresponsive and were viewed by some as being responsible for their children's disorders. Notions promulgated during the eugenics movement (1880–1930) undoubtedly fueled this view of parents as causing their children's disabilities (Turnbull & Turnbull, 1990).

Fortunately, contemporary viewpoints have led to a more informed and just, less linear, and more transactional approach to understanding the nature of human development and to promoting models that support optimal outcomes. They recognize the dynamic nature of the interplay between the child and the family, between the family and the larger world or community, and the importance of interactions among family members. This focus leads to interventions that more closely address family priorities and concerns and identify appropriate points of support.

INITIAL FAMILY EXPERIENCES WHEN A BABY IS BORN WITH A DISABILITY

Most expectant parents have developed a picture in their minds of the child they will have. Wrapped up in these mental images are all the hopes and dreams, cultural values and expectations, family histories, and personal preferences of each parent. When a child is born with or subsequently acquires a disability or disorder, these images, as well as the hopes and expectations, must be revisited and adjusted.

Parents who give birth to a child with a disability often describe their initial reaction as one of feeling shattered, overwhelmed, or devastated. These adjectives underscore the shock, the suddenness, and the comprehensive impact this event can have on the family. They also highlight the sadness and the violation of expectations that the event precipitates. Families may experience trauma when this discrepancy occurs between the ideal or fantasized child and birth experience and the actual child and less optimal birth situation (Bruce & Schultz, 2001; Solnit & Stark, 1961). When the reality of the circumstances does not match parents' hopes and expectations, parents are faced with an altered course for their family.

Clinicians have likened parents' responses to those of people who experience the terminal illness or death of a loved one. Parental response has been described as mourning the loss of the expected child. Using stage models, typically based on the stages of grief described in the work of Kubler-Ross (1969), clinicians have speculated that parents

go through a series of responses to the traumatic event that begins with shock and disorganization or disequilibrium (including feelings of denial, anxiety, guilt, anger, depression, fear, blame, and bargaining or shopping for another option or cure) and is followed by acceptance and reorganization.

Although such models can be useful for understanding the range of emotions and feeling states that family members may experience as they grapple with the new knowledge of the child's disability, significant caveats are in order. Some family members may experience these feeling states, whereas others may not. Some may pass through these states, but in a different order. Some individuals may experience these states, but each may take varying amounts of time to go from state to state; for example, individuals may dwell in an emotional state for a long time or for a day. Categorizing family members' responses as lodged in a particular stage based on a limited interaction can be disrespectful, overly simplistic, and poor clinical practice. Rather, service providers must appreciate the tremendous variation in parental reactions as well as the other stresses, strains, and supports that are brought to bear on the situation.

Furthermore, cultural backgrounds and values play a significant role in defining the meaning families place on having children with disabilities (Hanson, Lynch, & Wayman, 1990; Lynch & Hanson, 2011). Just as different cultures stress different child-rearing practices, roles for family members, and family values, the meaning and causation ascribed to disability or risk also vary according to cultural history and background. In some cultures, disability may be attributed to chance, whereas in others it may be seen as a punishment for a sin committed or a taboo violated by one of the parents (e.g., eating the wrong food) or an ancestor (e.g., committing a wrongdoing or crime). In some cultures, the individual with a disability may be seen as virtually possessed by an evil spirit, whereas in other cultures the individual with a disability may be seen as a gift from God and as imbued with special powers or perceptions. The interaction of disability and gender may play a role as well. In some cultures, the birth of a male child is more highly prized than that of a female; in these cultures, if the boy is born with a deformity or disability, the reaction may be particularly adverse. Given the diversity among the families and the variability of cultural responses to the meaning of disability, care must be taken by family service professionals not to jump to rapid conclusions about the family's interpretation or behavior with respect to the meaning of the birth event or disability. Service providers are cautioned not to make assumptions about family responses or the stages that the family will encounter. Stage theories simply do not account for diversity among families, nor do they respect individual differences in responses. They do not acknowledge the transactional nature of family responses and adjustment.

IMPACT OF DISABILITY ON FAMILIES

The preponderance of clinical and research attention has been directed to the negative impact on the family of having a child with a disability. Today, those in the scientific and clinical communities typically incorporate a more balanced perspective, considering the potential positive impact as well as the strengths and resilience of families (Blacher & Hatton, 2007; Blacher, Neece, & Paczkowski, 2005; Hastings & Taunt, 2002; Risdal & Singer, 2004; Summers, Behr, & Turnbull, 1989).

The addition of any new member to the family usually brings not only joy and hope but also some trepidation and stress. Although stress is a part of human existence for all individuals and families, families of individuals with disabilities may be subject

to additional stressors created by the risk or disabling conditions (Singer & Irvin, 1989). Families are typically thrust into new interactions with a myriad of professionals in the medical and health care fields, education, and social services. Some of these interactions may relate to highly emotional and draining life and death decisions. Families also are met with increased bills and financial burdens for these services. Parental employment and child care arrangements often are affected by the child's disorder, and the family's routines and activities may be dramatically altered in response to the child's needs. The challenges of caregiving may be overwhelming to primary caregivers, not to mention their impact on interactions with other family members, friends, and acquaintances. The disability, like a rock thrown into a pond, has repercussions that reverberate throughout the elements and routines of the family's life. As one father related, "Adam's our cruise, our new home, our boat. You know over the years, we laugh because every time we would get a down payment [for a house], it would go for Adam" (as cited by Hanson, 2003b, p. 360). Although this family realistically appraised their situation and lamented some of their sacrifices, they also added that they "wouldn't have had it any other way."

A number of research studies have examined stress in relationship to families of children with disabilities. In general, findings comparing these families with those of children who are typically developing find increased stress and greater demands on family functioning and well-being for families with children with disabilities (Beckman, 1991; Dodd, Zabriskie, Widmer, & Eggett, 2007; Dyson, 1991, 1993; Palfrey, Walker, Butler, & Singer, 1989; Winkler, 1988). The type of disability also has been linked to amount of stress and family functioning. Greater stress has been associated with severe physical disabilities (Sloper & Turner, 1993), autism, conduct disorders and behavior problems (Noh, Dumas, Wolf, & Fishman, 1989; Orr, Cameron, Dobson, & Day, 1993; Sanders & Morgan, 1997), intellectual disabilities (Fidler, Hodapp, & Dykens, 2000), and neurological disorders (Hanson & Hanline, 1990). Although it is noteworthy that characteristics and types of disability appear to play a role in the degree to which families experience stress and demands (Hodapp, Ly, Fidler, & Ricci, 2001; Sanders & Morgan, 1997), most studies have not addressed how perceptions may vary by gender and cultural group. Some studies have noted different predominant types of stress for mothers (e.g., caregiving) and fathers (e.g., financial), as well as the effect of family structure (e.g., being a single parent versus having a partner) on stress levels (Bailey, Blasco, & Simeonsson, 1992; Beckman, 1991; Trute & Hauch, 1988). The research studies, as a whole, do establish that many families of children with disabilities encounter additional stressors or demands necessitating changes and reorganization in families' expectations for their children, in the roles and relationships among family members, and in the routines and priorities of the family.

Investigations also have documented the more positive impact on families of having children with disabilities. Reviews have examined these dimensions of positive experiences on family life related to parenting and sibling experiences and have identified factors such as pleasure and satisfaction in caring for and relating to the child, personal growth, and greater purpose in life (Dykens, 2005; Hastings & Taunt, 2002; Stoneman, 2005). These studies have attempted to identify the full range of family experiences; other studies have included families from various cultural groups. Blacher and Baker (2007), for instance, studied families of children with disabilities from both Anglo and Latino backgrounds. They inferred positive impact from the lack of negative views, the fact that parents experienced many of the same joys of child rearing as did families of

children without disabilities, and the reports that families experienced unique or special benefits from their parenting experiences, such as greater sensitivity and tolerance. They found positive impact was inversely related to children's behavior problems and that positive impact moderated the relationship between parenting stress and behavior problems. Differences between cultural groups were noted in that Latina mothers reported higher positive impact.

The impact of a child with a disability in the family will vary from family to family. The presence of a disabling condition may add to family demands and necessitate adjustments in family life. However, like any factor, the impact will be enacted differently by different families and will vary over time. Service providers are encouraged to keep this more balanced perspective in mind. Global generalizations about family reactions and needs fail to take into account differences in personal characteristics of family members, including dimensions such as personality dispositions, coping styles, and cultural values and beliefs.

FRAMEWORKS FOR UNDERSTANDING FAMILIES' EXPERIENCES AND OUTCOMES

To fully appreciate the range of family responses and the circumstances faced by families as they adjust to challenges posed by a disabling condition, it is useful to reflect on the conceptual models (family systems, ecological, and coping/adaptation models) described in Chapter 3. These models all emphasize the dynamic interaction between families and their environment in the processes of adaptation and adjustment to change. Assumptions that the presence of a disabling condition will lead to negative repercussions are not supported. Moreover, emphasis is placed on how families use their resources to adjust and adapt to their altered circumstances (McCubbin & Patterson, 1982; Patterson, 1988, 1989, 1993) and how the family as a unit and individual family members may grow personally from the experience. These changes are deeply influenced by and embedded in the social relationships among family members and their relationships with others, including service providers. Families have different types and amounts of resources, and the meaning they ascribe to challenges and resources will vary. Service providers will be well served to appreciate this diversity in family response and appreciate the individual and unique characteristics of each family's set of circumstances.

SERVICES AND SUPPORT FOR FAMILIES OF CHILDREN WITH DISABILITIES

All service delivery systems in the fields of health care, education, and social services face challenges related to how best to serve and support families as they adjust to the different or increased demands associated with raising a child with a disability or developmental risk. As discussed throughout this text, service delivery philosophies have shifted away from linear or medical models that directly link the individual's outcome to a disease or disorder to more dynamic approaches aimed at capitalizing on the resources and strengths that individuals and families bring to their situations. It is likely that families have not suddenly developed new strengths and resources. Rather, service providers have made a shift into new roles and relationships with families.

These philosophical shifts and concomitant changes in service delivery models are directly linked to societal values and mores and to beliefs about families. As service providers travel this road of working with families in various capacities, it is important

to remember that these values and philosophies drive services. Service providers have personal choices to make along this path with respect to how they behave with families.

Historically, when a child was diagnosed with a disability, parents and other family members were given a prescribed set of activities or directives for where and how to care for their child. Specialists in the various helping professions (i.e., health, education, and social services) functioned as experts and, like orchestra conductors, they assessed the child's difficulties and needs and provided guidance and direction to families.

The importance of parents' involvement in the care and education of their children with disabilities has long been understood, and the roles and relationships of family members in their children's intervention regimens have been paramount. Over the years, parents of children with disabilities have functioned as their children's advocates, political advocates, organization members, teachers, assistant staff members in intervention programs, and program catalysts. Many parents still actively participate in their children's services through these roles. Although parents historically have been seen as crucial to their children's development, they have often been relegated to the role of recipients of services rather than decision makers. These service philosophies can be contrasted with more contemporary program philosophies that emphasize partnerships between parents and professionals, placing the family at the core of the decision-making process (Sandall, McLean, & Smith, 2000).

Family-Centered and Relationship-Based Approaches

Two terms have entered the early intervention service delivery lexicon and best describe the goals of contemporary service philosophy: *family-centered* and *relationship-based* interventions or service delivery models. Both stress the importance of acknowledging the child as living within the context of the family, the family members as the primary decision makers for the child, and the relationships among family members and among family members and professionals as being essential to the intervention and support processes. Family-centered (also referred to as family-focused or family-based) approaches place emphasis on the following (Bailey et al., 1986):

- Helping the family to care for and raise their child with a disability and cope with unique needs
- Helping the family understand the development and needs of the child both as an individual and as a family member
- Promoting parent–child interactions that are sensitive and warm, mutually enjoyable, and appropriate to the child's developmental level
- Preserving and reinforcing the dignity of the family by responding to their needs and desires in all phases of service–assessment, planning, and evaluation

Family-centered models can be contrasted with more traditional approaches in that the focus is on the child within the context of the family, not just on the child. The child's and family's *strengths* and *resources* are highlighted and form the basis for the intervention. Again, this is in contrast to previous approaches that focused on the disability as a pathology or difficulty. Families are placed in the role of decision makers rather than merely as the recipients of decisions made by experts or specialists. This orientation represents a shift in power in the relationship.

The implementation of family-centered services often involves new roles and relationships and "ways of doing business" for professionals who have been trained as experts only. Professionals must continue to maintain and update their knowledge and special expertise and share this information with families. The goals, styles, and methods they use in their delivery of services may be modified somewhat from traditional approaches, however. The following key elements for professional behavior have been identified as essential to the implementation of family-centered services and remain strong underpinnings of clinical service (Edelman, Greenland, & Mills, 1992):

- Recognizing the family as the constant in the child's life, whereas other caregivers and service systems may come and go
- Facilitating collaboration at all service levels between parents and professionals
- Honoring and respecting family diversity in all dimensions–cultural, racial, ethnic, linguistic, spiritual, and socioeconomic
- Recognizing family strengths and the different approaches that families may use in coping
- Sharing unbiased and honest information with family members on an ongoing basis
- Encouraging family-to-family support and networking
- Acknowledging and incorporating the developmental needs of the child and other family members into the service
- Implementing policies and services that promote emotional and financial support for families
- Designing and implementing services that are accessible, culturally and linguistically respectful and responsive, flexible, and based on family-identified needs

The centrality of the relationship between parent and child is emphasized in the expanded concept of relationship-based service approaches. Although typically applied to clinical approaches in infant mental health and early intervention, the relationship-based model underscores the crucial importance of services aimed at supporting and nurturing sensitive and satisfying parent–child interactions and relationships (Mahoney, 2009; Weston, Ivins, Heffron, & Sweet, 1997; see also Chapter 8 in this text). This approach advocates and incorporates partnerships between parents and professionals in the planning and implementation of appropriate services for the child and family.

Enabling and Empowering Families

The family-centered and relationship-based service approaches focus on the child within the context of the family, rather than on the child alone. The family is part of a social system and all parts of the system are interconnected. Empowerment is a helpful concept for guiding service practices with families; empowerment may include a person's access to and control over needed resources, decision-making and problem-solving abilities, and abilities to interact effectively with others to gain the resources they need (Dunst, Trivette, & Deal, 1988). In examining the early intervention context and analyzing the roles of help seekers and help givers, Dunst et al. highlighted the importance of service providers (help givers) in creating opportunities for families (in this case, help seekers) to

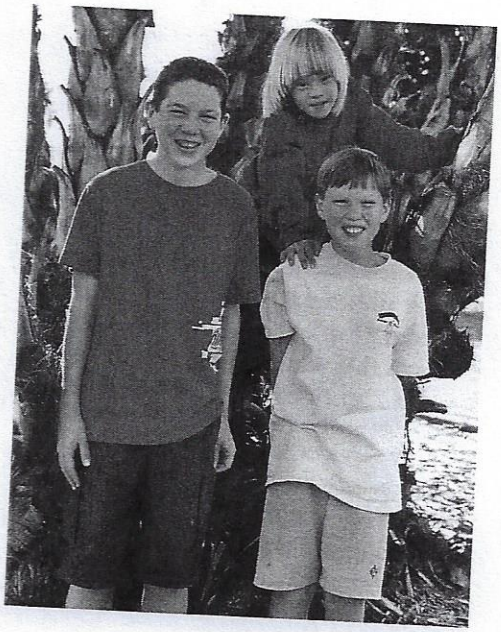
experience and display their competence. They referred to these experiences as *enabling.* Thus, the major thrust of these family-centered services is to help families become more competent and mobilize their resources.

The assessment and intervention model advocated by Dunst et al. (1988) described four components. The first component is the identification of family needs and aspirations–what the family's priorities are and where the family wants to expend their efforts and resources. The second component is the family's style and functioning–in other words, the unique ways in which that family operates. Third, the family's social network is mapped to identify resources for meeting the family's needs. Finally, the help-giving behavior of the professionals facilitates families' aligning their needs and resources to implement their goals.

Support for families may come from many sources including both formal and informal networks. Formal networks typically include professionals and helping agencies (i.e., education, health, and social services) that are formed to provide assistance to families needing services. Informal networks refer to family members, friends, neighbors, social groups, spiritual leaders, and so forth. Although these informal networks are not formed to provide assistance, they often serve that purpose. For many years, these informal sources of support were often overlooked or underrated. As services have been implemented with a social systems perspective in mind, the importance and power of these informal social support resources to family well-being has come to be recognized (Dunst, Trivette, Gordon, & Pletcher, 1989).

Family Experiences and Service Options

Families of children with disabilities, like all families, face an inordinate number of daily demands. When the child (or any family member) has extra or extraordinary needs for care, the family may be faced with even more challenges. The discussion that follows highlights some of the resources and personal characteristics that have been described



by families as useful or as outcomes of their experiences in parenting a child with a disability. These issues are directly, forcefully, and eloquently described by parents themselves in a number of publications (e.g., Harry, 2010; Naseef, 2001; Spiegle & van den Pol, 1993; Turnbull et al., 1993; Turnbull & Turnbull, 1985).

Growing Personally Families often describe their own personal growth and that of their immediate family members as a result of raising a child with disabilities. It is common for parents to note increases in their abilities to advocate for their children and their own sense of self-reliance and self-esteem. They often take great pride in the challenges they have effectively met and express confidence in their abilities to continue to address the needs of their child and family. Family members also mention the growth they have experienced in terms of helping others and being more receptive to other people who may be different. One mother of a (now adult) child with Down syndrome described her experience of returning to study at a community college. She related with pride that she went out of her way to help foreign students find their way around the college because she understood what it was like to be treated as different and what it was like to be fearful of new challenges. These experiences do not minimize the many difficulties that families may encounter, but they do illustrate the opportunities for personal growth and satisfaction that many family members report.

Developing New Skills and Resources Families of children with disabilities may need and receive a variety of services from formal networks. Caring for a child with a disability typically demands that the parents develop a certain degree of expertise in complex medical jargon and procedures, therapy techniques, and educational protocol. A major goal of most helping agencies is to provide information, education, and training in caring for and educating children with disabilities. Through the use of these informational and education/training resources, family members often become quite knowledgeable in and adept at working with children with that particular disability. They use these skills and expertise to improve their own children's circumstances and also to help other families of children with similar challenges. Increasingly, parents and other family members have become teaching partners in in-service and preservice training programs for professionals in the helping fields. Parents' input and perspectives are highly valuable to new and continuing professionals in training.

Supporting Parent–Child Interactions and Relationships A child with a disability may present many caregiving challenges. Some young children, for example, are hard to soothe. Others, due to their physical disabilities, may remain in rigid postures or fail to make eye contact with their parents. All of these characteristics can affect the way that parents feel about their children and can hamper parents' feelings of competence and enjoyment when interacting with them. Professionals can assist parents to more effectively read and understand their children's signals or cues and respond in a fashion that will enhance interaction and their children's development (Hanson, 1996).

Reducing Stress Family services may be aimed at reducing the family's stress and demands. This may be as simple as a professional being more attentive to the stress of a family and showing care not to pile on programs, services, or appointment demands. It may come in the form of helping parents procure needed services such as respite care, child care, or community programs that will include the child with special needs. In some cases, formal counseling or stress reduction workshops may be useful for the parent, and the professional can assist him or her in finding such services.

Linking to Parent-to-Parent and Community Resources Some families may choose the opportunity to get to know other parents in similar circumstances or parents who have "gone before" them and have experiences to share. Numerous parent-to-parent networks and family resource centers are found throughout the nation, and professionals may help families to link to these networks in their communities (Santelli, Poyadue, & Young, 2001). Similarly, a variety of national, state, and local organizations that range from disability rights organizations to city recreational programs may be useful to families. For more information, visit the National Dissemination Center for Children with Disabilities web site (http://www.nichcy.org).

Again, the role of the professional is to provide parents with the information they need to be able to gain access to these services if they wish. Some parents desire active participation in parent networks and/or other community organizations; others prefer to remain more contained within their immediate family or ethnic, cultural, or spiritual communities. Although information and service options should be made available and accessible to all families in the modality and language of their choice, professionals must respect families' decisions regarding whether or to what degree they wish to participate in these organizations.

Focusing Services on Family Priorities and Strengths

Services that are truly family centered are culturally sensitive and respectful. Implementing these services typically requires a shift in perspective or point of view for most service providers. Rather than starting with professional assumptions about what the family needs or should have based on the challenges posed by the disability, professionals must begin with identifying the family's own priorities and concerns. This focus precludes an a priori view of what impact the disability may have or what services the family may need or desire. Working with families in creating strategies and mapping their resources puts the family in the position of power and responsibility. This perspective emphasizes the strengths and resources that families bring to the table rather than the problems created by the child's disability. The experiences of one family, Gennifer and Demiko, help demonstrate family experiences and service models.

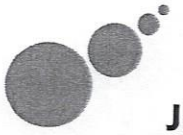
Gennifer and Demiko

Gennifer is a 19-year-old high school dropout and single mother raising her 3-year-old son, Demiko. Demiko was born prematurely and hospitalized for a prolonged period of time at birth. Medical personnel suspect that the premature delivery was related to Gennifer's lack of prenatal care and drug use during pregnancy. Demiko has multiple disabilities including cerebral palsy, speech delays, and visual impairments. Gennifer lives in a large urban area on very little income from her part-time job.

If the story ended here, it would be easy to predict that the outcome for Demiko and Gennifer would not be a very positive one. Many professionals would be tempted to blame Gennifer for Demiko's poor developmental prognosis and prescribe an intensive regimen of therapy and education outside of the home. However, the story does not stop here. Gennifer lives with her mother and her grandmother in her mother's home. All three women love Demiko dearly and spend countless hours tending to him. A

home-based early intervention teacher visits their home weekly to help teach them strategies for caring for Demiko and enhancing his development. Together, these women are looking for preschool programs in their local community so that Demiko can begin school. Furthermore, Gennifer no longer uses drugs and has been clean since Demiko's birth. She is also working on her high school general equivalency diploma so that she can get a better job. To be sure, Gennifer and Demiko face many challenges, but they have many resources and strengths even though they are living in poverty and Demiko has severe disabilities.

The outlooks and options available to families are quite different depending on whether the focus is placed on their difficulties and what they lack, or whether the lens is aimed on the strengths and resources that families bring to meet their challenges. All families have strengths and resources; service providers should assist families in identifying these and accessing the supports that they need.



Justin

Justin is an extremely active 6-year-old boy who is passionate about trains and cars. His parents, Lily and Evan, try to capitalize on his interests by filling the house with books and toys about things with wheels. Because Justin is such a picky eater, his parents have continued the "wheel theme" at the dinner table with train placemats and plates; they even try to tempt Justin to eat by cooking wheel-shaped macaroni. Justin attends a local public school in his neighborhood and has been provided special education and related services since he was diagnosed as having an autism spectrum disorder when he was 2½ years old. His first school experience was an early intervention program. Once a week, an early interventionist visited Justin's family home and helped Justin's parents organize family routines to enhance Justin's communication and social skills as well as address his eating difficulties. When he was 3 years old, Justin attended a half-day preschool program where an itinerant special education teacher worked with his parents and the preschool teachers to modify the preschool and home environment to best meet Justin's educational and developmental goals. Evan also took off work for an afternoon each week to take his son to a local playgroup. Now, in his local neighborhood elementary school, Justin continues to receive special education services. Justin's parents are thankful for the expertise and assistance of teachers and other specialists who have taught them how to support Justin's development so that he can participate in school and have friends.

NATIONAL POLICIES FOR CHILDREN WITH DISABILITIES AND THEIR FAMILIES[1]

Children with disabilities, like Justin and Demiko, typically need educational and developmental services that are specifically tailored to meet their individual needs. Their families also need support to learn how to address their youngster's own special needs. This

[1]A portion of the discussion on disability policy is adapted from Hanson (2003a).

section provides an overview of primary policies in the United States that are designed to address the needs of individuals with disabilities. These laws and policies have their foundation in years of experience and advocacy by professionals and parents of children with disabilities. Prior to the 1970s, some children in the United States were denied a public school education because they had disabilities. Family and advocate-initiated litigation, court decisions, national legislation, research studies, and family grassroots advocacy efforts all served to change this perspective dramatically. The 14th Amendment to the U.S. Constitution guarantees equal protection for all citizens under the law and establishes the right to not be discriminated against for an unjustifiable reason such as race or disability. This amendment was central to establishing a legal remedy for this inequity in educational opportunities for children with disabilities. For a historical discussion and review of public polity related to developmental disabilities, the reader is referred to Turnbull, Stowe, Turnbull, and Schrandt (2007).

Several key laws have provided far-reaching guarantees and rights for individuals with disabilities. This legislation charted policies and services to ensure that individuals with disabilities received equal protection under the law and public education. They also have ensured that families are active participants in educational programs. These laws are briefly reviewed, with special emphasis given to IDEA and its components for family involvement in children's educational planning and implementation.

Americans with Disabilities Act

ADA of 1990 is a landmark piece of legislation with crucial implications for access and education for children with disabilities. The ADA is a federal civil rights law that ensures that people with disabilities have access to all entities (including child care for young children). It gives individuals with disabilities civil rights protection like those provided to people on the basis of race, sex, national origin, and religion, and it requires that reasonable accommodations be made to allow everyone to participate in the services and opportunities offered.

Section 504 of the Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973 is a civil rights law that prohibits discrimination on the basis of disability. In education, it continues to play an important role because it also applies to students with disabilities who may not be eligible for special educational services under other laws, such as IDEA. The definition of disability is defined more broadly and applies to those that have a physical or mental impairment that substantially limits one or more major life activities.

Assistive Technology Act

The Assistive Technology Act of 1998, amended in 2004 as Public Law 108-364, ensures that individuals with disabilities have access to assistive technology devices and services. The use of assistive technology for people with disabilities can improve individuals' access and the ability to function in school, home, work, and the community.

Individuals with Disabilities Education Act and Amendments

Access to public education and special education services and supports were realized for school-age children through another piece of landmark legislation, the Education for All Handicapped Children Act of 1975 (PL 94-142; see Braddock [1987] and Turnbull [1986] for reviews of federal policies and the development of this law in the United States). This law subsequently was modified to apply to all preschool-age children with disabilities and, through state discretionary programs, to children with disabilities from birth through 2 years. This legislation was retitled as IDEA of 1990 (PL 101-476) and was subsequently amended in 2004 (PL 108-446).

IDEA Foundational Core Principles IDEA provides the framework for educational policies and services for children with disabilities and their families. Six principles are core to this framework:

1. *Free and appropriate public education.* This provision requires that special education and related services be provided to children at public expense and that these services meet the standards of the state educational agency. A policy of "zero reject" is inherent in this law that precludes public schools from excluding children with disabilities. Furthermore, services are to be "appropriate" to the individual needs of each child.

2. *Appropriate evaluation.* This law stipulates many conditions related to evaluation: a "full and individual initial evaluation," the requirement of parental consent for the initial evaluation, evaluation by a team of professionals, assessment in the child's native language or mode of communication, the use of multiple measures rather than a single instrument to determine eligibility, and the provision for reevaluations. Furthermore, evaluation activities are to include data gathering information pertinent to the child's involvement and progress in the core general education curriculum, and evaluation procedures must be nondiscriminatory.

3. *Development of an individualized education program (IEP).* IDEA requires that an IEP be developed for each child with a disability. IEPs must state the child's current level of educational performance; measurable child goals; specified special education and related services; the dates, frequency, location, and duration of services;

and transition services to the next educational environment. The IEP is developed through a team approach that includes the child's parents and appropriate professionals. The child's strengths and the parents' concerns for enhancing the child's education are taken into consideration. For children from birth through 2 years of age, the individualized plan is termed the individualized family service plan (IFSP). These plans are described in greater detail in a subsequent section.

4. *Education provided in the least restrictive environment (LRE).* Children with disabilities must be provided an appropriate education designed to meet their individual needs in environments in which the children are educated with their peers without disabilities to the maximum extent possible. The intention of the law is to maximize the opportunities for children with disabilities to be educated with their peers and in their neighborhood communities. The emphasis is on creating services and supports that allow children to have access to and participate in the general education curriculum. For young children, the LRE is typically referred to as *natural environment* and may include the children's homes, as well as other settings in which children received care, such as child care programs.
5. *Parent participation in decision making.* Parents have the right to review their child's educational records, and parental informed consent is required for children's initial evaluation and placement. Parents can actively participate in all aspects of the evaluation, placement, and education process, and they have the right to challenge or appeal any decision related to the identification, evaluation, or placement of their child.
6. *Procedural safeguards to protect the rights of parents and their child with a disability.* IDEA outlines safeguards to ensure that the rights of children with disabilities and their parents are protected, including parents' access to educational records, right to request a due process hearing, and right to appeal the hearing decision and bring civil action to appeal a hearing decision. Rights and requirements related to discipline are specified in the law as well.

Family Roles and Services for Children IDEA essentially establishes a national policy and infrastructure for a system of service delivery across the United States. Central to this service system is the recognition of the unique role that families play in children's development. Two primary components or parts of IDEA are reviewed: the Early Intervention Program for Infants and Toddlers with Disabilities, Part C of IDEA, which covers services to children from birth through age 2, and Part B of IDEA, which covers services to children from ages 3 through 22 years.

Early Intervention Program for Infants and Toddlers with Disabilities In 1986, the U.S. Congress established the Early Intervention Program for Infants and Toddlers with Disabilities. The law was based on the recognition of "an urgent and substantial need" to enhance the development of infants and toddlers with disabilities, reduce education costs by minimizing the need for special education through early intervention, minimize the likelihood of institutionalization of individuals with disabilities, maximize independent living, and enhance the capacity of families to meet their children's needs.

The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal discretionary grant program that assists states in planning, developing, and implementing a statewide system of early intervention services for infants and toddlers with

disabilities, ages birth through 2 years, and their families. The statute and regulations for Part C stipulate state requirements for implementing this comprehensive, coordinated, multidisciplinary, and interagency service delivery program.

For states to participate in the program, they must ensure that early intervention will be available to every eligible child. The law defines an eligible infant or toddler with a disability as follows (IDEA, 2004, 20 U.S.C.):

> An individual under 3 years of age who needs early intervention services because the individual (i) is experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the areas of cognitive development, physical development, communication development, social or emotional development and adaptive development; or (ii) has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay.

States may, at their discretion, also serve children who are at risk of experiencing substantial developmental delay as defined by that state. Thus, definitions of eligibility vary considerably across states.

In implementing the program, the governor of each state designates a lead state agency to administer the program. A variety of agencies may function as the lead agency including education, health, human services, social services, developmental disabilities, and rehabilitation service agencies. Despite state differences with respect to child eligibility criteria and the state's lead agency of administration, several elements must be stipulated in each state's plan. These common elements are the minimum components required of a statewide comprehensive system for early intervention for infants and toddlers with special needs (IDEA Part C, 20 U.S.C. §1435[a], as cited by National Early Childhood Technical Assistance System, 2012a):

- Definition of developmental delay
- Appropriate early intervention services based on scientifically based research
- Timely and comprehensive multidisciplinary evaluation of needs of children and family-directed identification of the needs of each family
- Individualized family service plan and service coordination
- Comprehensive child find and referral system
- Public awareness program
- Central directory of services, resources, and research and demonstration projects
- Policies and procedures for personnel standards and development
- Single line of authority in a lead agency designated or established by the governor for carrying out 1) general administration and supervision, 2) identification and coordination of all available resources, 3) assignment of financial responsibility to the appropriate agencies, 4) development of procedures to ensure that services are provided in a timely manner pending resolution of any disputes, 5) resolution of intra- and interagency disputes, and 6) development of formal interagency agreements
- Policy pertaining to contracting or otherwise arranging for services
- Procedure for securing timely reimbursement of funds

- Procedural safeguards
- System for compiling data on the early intervention system
- State interagency coordinating council
- Policies and procedures to ensure that, to the maximum extent appropriate, early intervention services are provided in natural environments

The range and types of services that are funded through this program are varied and represent services from many different disciplines. These services may include the following (20 U.S.C. §1400):

> (i) Family training, counseling, and home visits; (ii) special instruction; (iii) speech-language pathology and audiology services and signed language and cued language services;(iv) occupational therapy; (v) physical therapy; (vi) psychological services; (vii) service coordination services; (viii) medical services only for diagnostic or evaluation purposes; (ix) early identification, screening, and assessment services; (x) health services necessary to enable the infant or toddler to benefit from the other early intervention services; (xi) social work services; (xii) vision services; (xiii) assistive technology devices and assistive technology services; and (xiv) transportation and related costs that are necessary to enable an infant or toddler and the infant's or toddler's family to receive another service.

Family-centered services are to be provided in the child and family's natural environment. Thus, services may be provided in a range of environments that include the child's home and community locations, such as a child care or infant/toddler program.

A description and overview of this law and its components is provided by the National Early Childhood Technical Assistance Center (2012a). Updates to regulations and state services also are available (Danaher, Goode, & Lazar, 2011).

Part B of IDEA Children and youth from 3–22 years receive special education and related services under Part B of IDEA that are administered through state and local education agencies. The provisions of due process, nondiscriminatory testing and evaluation, IEP, and placement in LREs that were reviewed earlier are applied to educational services. Important provisions of the law also acknowledge the role of parent involvement, particularly in programs for young children with disabilities, highlight strengthening the role of parents, and ensure meaningful opportunities for parents to participate in their child's education at school and home.

Eligibility criteria for a child with a disability under Part B of IDEA include the following conditions: intellectual disabilities, hearing impairments (including deafness, speech, or language impairments), visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, specific learning disabilities, deaf-blindness, or multiple disabilities. For children from ages 3 to 9 years, the state and local educational agency may, at their discretion, also serve children with developmental delays as defined by that state; this may include delays in the areas of physical, cognitive, communication, social or emotional, or adaptive development.

A wide range of services may be considered in special education service delivery systems. These types of services include assistive technology devices and services, audiology, counseling services, early identification and assessment, medical services of diagnosis or evaluation, occupational therapy, parent counseling and training, physical therapy,

psychological services, recreation, rehabilitation counseling services, school health services, social work services in schools, special education, speech pathology, and transportation.

Educational environments are typically more broadly construed for young children than they are for school-age children. For children younger than kindergarten age, educational environments may include child care and Head Start programs as well as school programs. Head Start is a key environment for services. The Head Start program was established in 1965 through provisions in the Economic Opportunity Act of 1964 (PL 88-452). A primary focus was to provide early educational and social services for young children from low-income families in an effort to provide them with a head start and to break the cycle of poverty. The Economic Opportunity Act subsequently was amended to require that at least 10% of the enrollments in Head Start be children with disabilities and that their specialized services be provided in these programs. As such, these Head Start service options have had a major impact in expanding inclusive services for young children. Head Start also has had, from its inception, a strong family and community focus, and it has emphasized multidisciplinary service provision and coordination. These are crucial components of services for children with disabilities.

Key Education Service Delivery Concepts Under IDEA IDEA addresses a number of key concepts and components. The primary elements are outlined and briefly discussed.

Individualized Education Programs for Children Under the law, all children with disabilities are required to have an IEP/IFSP. The IEP consists of a written statement that includes the child's present level of academic achievement and functional performance; measurable annual goals and a description of how the child's progress will be measured; special education and related services, supplementary aids and services, and program modifications or supports needed to enable the child to meet educational goals and participate with other children; an explanation of the extent, if any, to which the child will not participate with nondisabled children in the regular classroom; individual accommodations that may be needed to measure achievement and performance; the date for beginning services and the frequency, location, and duration of those services and modifications. An IEP team includes the child's parents, general education teacher, special education teacher, representative of the local educational agency, and other individuals who may have knowledge of or expertise regarding the child.

Under Part C, infants and toddlers and their families receive an IFSP. The IFSP includes written statements of the infant's or toddler's present levels of physical, cognitive, communication, social or emotional, and adaptive development; the family's resources, priorities, and concerns relating to enhancing the development of the child; the major outcomes expected and the criteria, procedures, and timelines used to determine progress; specific early intervention services; the natural environments in which early intervention services will be provided, including a justification if services will not be provided in a natural environment; the time, place and duration of the services; who pays for the services; the identification of the service coordinator who oversees the implementation of the IFSP; and the steps to be taken to support the transition of the toddler to preschool or other appropriate services. A model form for the IFSP is provided by the U.S. Department of Education (http://idea.ed.gov/part-c/search/new).

These individualized plans are fundamental to services for children with disabilities. Education plans and the delivery of services are designed to meet each child's unique needs, and systems of accountability are stipulated. Challenges have centered around the

provision of appropriate and meaningful assessments, establishing parent–professional partnerships for planning and implementation, ensuring parents' meaningful roles while individualizing for each family's cultural and linguistic background and preferences, and exercising professional teamwork in developing and providing services.

Family-Centered Service Delivery Models In family-centered service delivery models, the full and active participation of parents and family members is encouraged, particularly in early intervention service delivery systems for infants, toddlers, and preschoolers. IDEA and its regulatory procedures formalized due process procedures and requirements for involving families in decisions regarding their child's assessment, placement, and education program planning and implementation.

The roles of families and the many ways in which families can be involved in their children's education programs have taken various forms and shifted over the years. At times, emphasis has been placed on notions of parents as teachers, parents as advocates, and parents as assistants in classrooms. Of course, one size does not fit all. Families differ in terms of their family membership or structure, family roles, culture and linguistic background, faith backgrounds, values and belief systems, resources, and the family's priorities and concerns for their children. So too do they differ in the roles and preferences for their involvement.

Family-centered or family-focused services refer not only to a philosophy of services, but also to a set of recommended practices in the field of early intervention (Bruder, 2000; Sandall, McLean, & Smith, 2000). These services describe a cluster of practices, including providing respectful and culturally sensitive family services, identifying families' concerns and priorities for their children, obtaining families' informed consent and participation in the decision-making process regarding service decisions for their children, and implementing practices that empower families and support and enhance families' development and competencies.

Inclusion, Least Restrictive Environments, and Natural Environments The law specifies that services should be provided to the maximum extent possible in educational environments in which children with disabilities are educated with children who do not have disabilities. It further stipulates that children should be removed from such an environment only when the nature or severity of the child's disability is such that the education cannot be achieved adequately in the general education environment with supplemental aids or services. This provision is often referred to as education in the least restrictive environment. Different terms, such as *mainstreaming* and *integration,* have been used over the years to describe the participation of children with disabilities in educational environments with their typically developing peers. Today, the practice is typically termed *inclusion.*

The intent is similar for infants and toddlers, although the language of the law differs somewhat. The Part C program for infants and toddlers states that services should be provided to the maximum extent appropriate in natural environments. Such environments include the child's home and community environments in which children without disabilities participate.

The provision of the children's individualized and specialized services within their homes and community and school programs requires careful planning, teamwork, administrative support, flexibility, and family involvement. Learning opportunities abound in daily routines and family and community activities. Particularly in the early years, interventionists are challenged to adapt activities, curricula, and environments

and forge new working relationships to meet the needs of children with disabilities in a range of environments (Bruder & Dunst, 2000; Dunst, 2007; Guralnick, 2001; Odom, 2002; Sandall, McLean, & Smith, 2000; Sandall & Schwartz, 2008).

Transitions A child's life is characterized by crucial transitions, particularly for children born at risk. These transitions are defined as "points of change in services and personnel who coordinate and provide services" (Rice & O'Brien, 1990, p. 2). The first transition may occur as the child moves from care in the hospital to the family's home. Subsequent transitions for children with disabilities include the transitions from home into infant/toddler services, from infant/toddler services into preschool, and from preschool to kindergarten to elementary school and so forth. Transitions can be stressful for families under the best of circumstances. Because in many states different agencies are responsible for early intervention services for infants/toddlers than for preschool/school-age education services, these transitions may be particularly challenging. Interagency agreements and transition procedures, support for families from key personnel, preparation of children for the transition, information exchange procedures between the sending and receiving services and personnel, and staff training and preparation for transition are but a few of the areas targeted for careful planning and support in order to ease transitions for children and their families (Hanson, 2005; Rosenkoetter, Hains, & Fowler, 1994).

Personnel Preparation and Interdisciplinary Team Models Professional standards and personnel licensure, certification, and credentialing requirements may differ by state and also across professions based on the standards set by each professional discipline. Thus, considerable variability can be found across states, although all must adhere to provisions for a comprehensive system for professional development.

Most professional groups have expanded curricula at both the preservice and in-service levels to address competencies related to serving young children and their families, and many have separate certification or add-on training programs in pediatric or early care. Creative and cross-disciplinary approaches are needed, however, for personnel development across health, education, and social service fields (Winton, McCollum, & Catlett, 2008).

The range of service needs experienced by children with disabilities and their families bridge professional disciplines. Only through collaborative team models can these service needs be fully addressed. In early intervention, the transdisciplinary team model is considered the most optimal for service delivery. The transdisciplinary team model highlights a team approach through which "role release" is practiced, in that one or a few professionals are the primary individuals responsible for implementing a child's program with assistance, consultation, and continuous skill training and development from the full spectrum of team members representing various disciplines. This team approach requires careful collaboration across professional service providers and requires time and resource allocation for training and planning, as well as commitments and effective working relationships among professionals (Hanson & Bruder, 2001).

Parents and other family members are crucial members of any intervention/education team. Including families in a respectful, culturally sensitive, and family-centered way has necessitated adaptations and shifts in preservice and in-service personnel preparation for professionals. Most programs now actively seek and involve families in these training regimens.

Service Coordination and Interagency Collaboration Service coordination is a mandated service under Part C of IDEA, and it is to be provided at no cost to families.

It is defined as an "active, ongoing process that assists and enables families to access services and assures their rights and procedural safeguards" (National Early Childhood Technical Assistance Center, 2012b). Early intervention team members must jointly provide assessment, intervention, and evaluation activities in a partnership with the child's family and enable families to obtain the various services they need (Bruder & Bologna, 1993). Active and collaborative cross-disciplinary working relationships and interagency coordination are needed regardless of the child's age and special needs. Such collaboration forms an important element in providing support to families.

Benefits of IDEA The passage of IDEA has provided an unprecedented opportunity in the United States to establish a unified service delivery system to address the complex needs of children with disabilities and their families. A child's individualized service needs and goals and the active inclusion and participation of the child's family are at the core of policies and procedures. The legislation has provided the necessary infrastructure for developing a system that spans the United States and incorporates the full range of service delivery agencies, structures, and professional disciplines that deliver education services. It has afforded the means to cross boundaries of agencies and professions in order to serve the diverse needs of children and their families. By the same token, the comprehensive nature of this legislation also has produced tremendous challenges related to interagency coordination, teaming and collaboration, and the provision of full and meaningful participation options for families in a manner that is congruent with family priorities and needs.

SUMMARY

Although having a family member with a disabling condition may have a great impact on a family, many of the challenges these families face are the same or similar to those of other families. In other words, parents of children with disabilities should be viewed as parents first, just as their children with disabilities should be viewed as children first. When the child has a disability, however, it may create the need for more supports or specialized services to enable the child and family to participate in normative family events and routines.

As service providers reflect on their views about families and families' perspectives on parenting children with disabilities, they must be vigilant and keep in mind the impact of cultural and societal values in shaping these service priorities and approaches. Families are nested within the contexts of their neighborhoods and communities as well as the larger society in which they live. The policies, laws, values, and priorities of these communities help shape the experiences that families will have and the services and supports that will be available to them and desired by them.

Most individuals and families readjust and adapt to the new challenges presented to them by the presence of a disability. As the literature previously reviewed has suggested, families who have a member with a disability are often even inspired to reach out to others and develop a sense of their roles in the "greater good" of their communities. For instance, as one mother reflected, "I guess the hardest part has been to figure out what his little niche is. And I think maybe it's just that he's a teacher [of others]" (as cited by Hanson, 2003b, p. 364). Regardless of a family's goals, professionals can best help families by engaging in practices that facilitate the family's sense of competence and confidence and the family's abilities to determine the services and resources that they will need throughout their journey.

"Once we got over the dismay and shock at the hospital and picked up our shattered dreams and hopes, we began the slow process of reorienting and reorganizing those dreams and hope into a different set of rules, a different lifestyle. No, maybe our little boy with Down syndrome wouldn't be able to realize some of those high dreams we had composed before his birth, but with a little reshuffling (and a lot of hard work) he will be able to realize other dreams that we are composing day by day. So the song will have different words and a different melody, but will still be a masterpiece."

—Timothy and Marilyn Sullivan (as cited in Hanson & Harris, 1986, p. 8)

ACTIVITIES TO EXTEND THE DISCUSSION

1. **Mapping supports.** Identify a difficulty or issue of significance with which you or a family member is grappling. Develop a map or outline of the resources and supports that you have for addressing this concern. Try to consider the broad range of resources and supports that are available to you and the ways in which they are interconnected. Sketch out or display your "map" of these resources and supports much as you would an organizational chart for a business or corporation. Draw lines to show how they may be interconnected.
2. **Imagine how it feels.** To envision the experience for families as they encounter new stresses in their daily lives, try this activity with a friend or colleague. Ask your partner to make a list of all the stressors the family may encounter (e.g., car breaks down, child care provider moves away, illness in the family, parent loses job). With each stressor or demand, have your partner place a balloon in your arms. Before long you will find it difficult to manage or juggle the many balloon "stressors." Suddenly the balloons will start to drop or pop, creating even more chaos and instability for you as you struggle to keep them in order and afloat. While this task graphically displays the juggling act, it cannot possibly do justice to the emotional experience of coping with these issues, especially with a loved one such as one's child.
3. **Mapping supports and resources for a family in your clinical practice.** If it is comfortable and appropriate, work with a family in your clinical practice to map out the supports and resources that they have to address identified needs. For example, they may have extended family members and/or neighbors and friends who help out with child care, errands, and picking up children after school. Professionals may provide valuable services with respect to medical needs and educational needs. A local agency may provide information on housing options. As the discussion continues, professionals and families can identify and appreciate the many formal and informal supports that may be available to families.

TO LEARN MORE: SUGGESTED WEB SITES

National Dissemination Center for Children with Disabilities
http://www.nichcy.org

National Early Childhood Technical Assistance Center
http://www.nectac.org

Office of Special
http://www2.ed.g

U.S. Department
http://www.ed.go

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