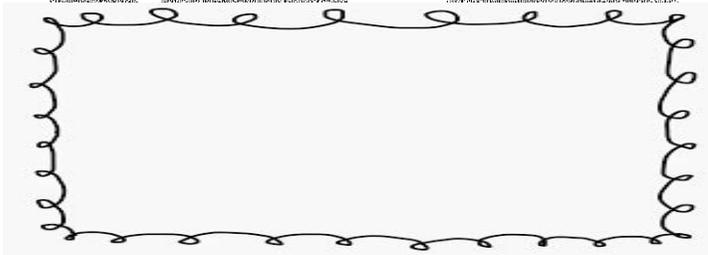


Children with Disabilities



edited by

Mark L. Batshaw, M.D.

Children's National Medical Center
The George Washington University
School of Medicine and Health Sciences
Washington, D.C.

Louis Pellegrino, M.D.

SUNY Upstate Medical University
Syracuse, New York

Nancy J. Roizen, M.D.

Cleveland Clinic
Cleveland, Ohio

2007

· P A U L · H ·
BROOKES
PUBLISHING CO[®]

Baltimore • London • Sydney

- evaluate drugs in pediatric populations. *Pediatrics*, 95, 286-294.
- American Academy of Pediatrics, Committee on Hospital Care. (2003). Family centered care and the pediatrician's role. *Pediatrics*, 112, 691-697.
- Bach, J.R., & Campagnolo, D.I. (1992). Psychosocial adjustment of post-polio myelitis ventilator assisted individuals. *Archives of Physical Medicine and Rehabilitation*, 73, 934-939.
- Bartholome, W.G. (1995). Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*, 96(5, Pt. 1), 981-982.
- Beauchamp, T.L., & Childress, J.F. (1994). *Principles of biomedical ethics* (4th ed.). New York: Oxford University Press.
- Brown, R.H., & Truitt, R.B. (1979). Rights of minors to Medicaid treatment. *De Paul Law Review*, 28, 290-295.
- Carter, B.S., & Levettown, M. (Eds.). (2004). *Palliative care for infants, children and adolescents: A practical handbook*. Baltimore: The Johns Hopkins University Press.
- Cassidy, R.C., & Fleischman, A.R. (1996). *Pediatric ethics: From principles to practice*. Amsterdam, The Netherlands: Harwood Academic Publishers.
- Cesire, V.R., Blustein, J., & Fleischman, A.R. (2000). Urban bioethics. *Kennedy Institute of Ethics Journal*, 10, 1-21.
- Code of Federal Regulations. (2001). 45 CFR 46; 21 CFR 50.56.66 FR 20598, April 24, 2001.
- Crichton, J. (1998). Balancing restriction and freedom in the care of people with intellectual disability. *Journal of Intellectual Disability Research*, 42(Pt. 2), 189-95.
- Dresser, R. (1996). Mentally disabled research subjects: The enduring policy issues. *Journal of the American Medical Association*, 276, 67-72.
- Engelhard, Jr., H.T. (2003). The bioethics consultant: Giving moral advice in the midst of moral controversy. *HEC Forum*, 15, 362-382.
- Fedder Kitay, E. (1998). *Love's labor: Essay on women, equality and dependency*. New York: Rutledge.
- Field, M., & Behrman, R. (Eds.). (2004). *Ethical conduct of clinical research involving children*. Washington, DC: National Academies Press.
- Ford, C., English, A., & Sigman, G. (2004). Confidential health care for adolescents: Position paper for the Society for Adolescent Medicine. *Journal of Adolescent Health*, 35, 160-167.
- Fost, N. (1999). Access to IVF. *Pediatrics in Review*, 20(8), e36-e37; discussion e38-e39.
- Fost, N.C. (2004). Conception for donation. *Journal of the American Medical Association*, 291, 2125-2126.
- Gerhart, K.A., Koziol-McLain, J., Lowenstein, S.R., et al. (1994). Quality of life following spinal cord injury: Knowledge and attitude of emergency care providers. *Annals of Emergency Medicine*, 23, 807-812.
- Glover, N.M., & Glover, S.J. (1996). Ethical and legal issues regarding selective abortion of fetuses with Down syndrome. *Mental Retardation*, 34(4), 207-214.
- Health Insurance Portability and Accountability Act (HIPAA) of 1996, PL 104-191, 42 U.S.C. §§ 201 et seq.
- Hoehn, K.S., & Nelson, R.M. (2004). Advising parents about children's participation in clinical research. *Pediatric Annals*, 33(11), 778-781.
- Kodish E. (Ed.). (2005). *Ethics and research with children*. Oxford, Oxford University Press.
- Lee, S.K., Penner, P.L., & Cox, M. (1991). Comparison of the attitudes of health care professionals and parents toward active treatment of very low birth weight infants. *Pediatrics*, 88, 110-114.
- Levine, R.J. (1988). *Ethics and regulation of clinical research* (2nd ed.). New Haven, CT: Yale University Press.
- Loewy, E.H. (1994). Limiting but not abandoning treatment in severely mentally impaired patients: A troubling issue for ethics consultants and ethics committees. *Cambridge Quarterly of Healthcare Ethics*, 3, 216-225.
- MacIntyre, A. (1999). *Dependent rational animals: Why human beings need virtues*. New York: Open Court.
- Mappes, T., & Degrazia, D. (Eds.). (2000). *Biomedical ethics* (5th ed.). New York: McGraw Hill Higher Education.
- Miller, P.S. (1998). Genetic discrimination in the workplace. *Journal of Law and Medical Ethics*, 26(3), 178, 189-197.
- Monat-Haller, R.K. (1992). *Understanding and expressing sexuality: Responsible choices for individuals with developmental disabilities*. Baltimore: Paul H. Brookes Publishing Co.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1983). *Seriously ill newborns: Deciding to forgo life-sustaining treatment* (pp. 197-229). Washington, DC: U.S. Government Printing Office.
- Rapp, R. (1999). *Testing women, testing the fetus: The social impact of amniocentesis in America*. New York: Routledge.
- Ross, L.F. (2004). Should children and adolescents undergo genetic testing? *Pediatric Annals*, 33(11), 762-769.
- Ross, L.F., & Moon, M.R. (2000). Ethical issues in genetic testing of children. *Archives of Pediatrics & Adolescent Medicine*, 154(9), 873-879.
- Savage, T.A. (1998). Children with severe and profound disabilities and the issue of social justice. *Advanced Practice Nursing Quarterly*, 4(2), 53-58.
- Sigman, A.S., & O'Connor, C. (1991). Exploration for physicians of the mature minor doctrine. *Journal of Pediatrics*, 119, 520-525.
- Silber, T.J. (1981). Amniocentesis and selective abortion. *Pediatric Annals*, 1981, 31-34.
- Silber, T.J., & Batshaw, M.L. (2004). Ethical dilemmas in the treatment of children with disabilities. *Pediatric Annals*, 33(11), 752-761.
- Society for Health and Human Values-Society for Bioethics Consultation. (1998). *Task force on Standards for Bioethics consultation, Core competencies for Health Care Ethics Consultation: The report of the American Society for Bioethics and Humanities*. Glenview, IL: American Society for Bioethics and Humanities.
- Streeter, K., Ashcroft, R., Henderson, J., et al. (2000). The decision making process regarding the withdrawal or withholding of potential life-saving treatments in a children's hospital. *Journal of Medical Ethics*, 26(5), 346-352.
- Terrenoire, G. (1992). Huntington's disease and the ethics of genetic prediction. *Journal of Medical Ethics*, 18, 79-85.
- Walsh-Kelly, C.M., Lang, K.R., Chevako, J., et al. (1999). Advance directives in a pediatric emergency department. *Pediatrics*, 103(4, Pt. 1), 826-830.
- Woodstock Theological Center. (1999). *Ethical issues in managed health care organizations*. Washington, DC: Georgetown University Press.
- Yang, E.Y., Flake, A.W., & Adzick, N.S. (1999). Prospects for fetal gene therapy. *Seminars in Perinatology*, 23(6), 524-534.

Caring and Coping

Helping the Family of a Child with a Disability

Symme Wilson Trachtenberg, Karen Batshaw, and Michael Batshaw

Upon completion of this chapter, the reader will

- Understand the impact of having a child with a disability on family development during the life cycle of the child
- Learn the principles of family-centered care
- Be knowledgeable about strategies and resources to help families cope with a disability
- Recognize the influence of societal attitudes on the outcome of children with disabilities

The preceding chapters have focused on the medical, rehabilitative, and educational supports for various developmental disabilities. Equally important is the impact of these disabilities on the function of the child-family unit. How the family handles the day-to-day stresses, concerns, and needs of its members influences to a great extent the outcome of the child with disabilities (Green et al., 2005). Traditionally, professionals offered only those resources they believed were "appropriate" or "best" for the child and family, and they focused exclusively on their area of perceived responsibility. It is now recognized that to be effective in working with these families, professionals must take a holistic, family-centered care approach. This chapter focuses on the issues that families face through the life of a child with a disability and the approaches professionals can take to help them. For the purposes of this chapter, the term *family* is used to refer to children and their parent(s) or family member(s) who are primary caregivers. Families today have many different structures: traditional two-parent families, single-parent families, adoptive families, stepfamilies, gay and lesbian families, foster families, and intergenerational families (Farber & Maharaj, 2005; Han-

son & Lynch, 2004). Each family is a culture unto itself (Arrango, 1999). The family unit, regardless of its composition, transmits traditions, values, ethnic heritage, religious beliefs, and personal spirituality. The family's traditions provide members with stability, support, comfort, strength, guidance, and strategies for coping with the difficulties of daily life (Harry, 2002; Ochieng, 2003). These family cultures and belief systems must be respected and incorporated into the care plan.

SAMANTHA

Samantha (Sam) is an 8-year-old with Down syndrome and the daughter of Monica and Sean. When Sam was born, her parents were excited by the arrival of their first child, a healthy and active baby. Shortly after birth, however, they were told that Sam had Down syndrome. They were devastated. Khandra, the social worker from the Down syndrome clinic, met with Monica and Sean as well as Sam's grandparents. They were all distressed by this diagnosis that was so unexpected, especially as Monica was just 25 years old. The grandparents had visions of Sam needing to be institutionalized, while Monica and Sean were over-

whelmed with sadness. Khandra answered questions about what they could do to help Sam. She was very encouraging, noting that most children with Down syndrome have a long and productive life. She supplied information about Down syndrome and resources available to support the family. She also helped the family contact the early intervention program in order for Sam to begin receiving weekly home visits from the early intervention specialist. Khandra continued to meet with the family each time they came for follow-up to the Down syndrome clinic. She noted that Monica was very loving and appropriate in her care for Sam and that her sorrow had been replaced by commitment. Khandra helped Monica become involved with the local Down syndrome support group, where Monica eventually became an officer. Sean became involved in the Special Olympics, where Sam excelled in track and field. The grandparents, however, have had a hard time accepting Sam, and this has created tension. Monica would call Khandra when she needed advice or just when she needed to talk a bit. When interviewed by a local newspaper, Monica said "Khandra is like part of the family. We feel blessed to have her."

HOW FAMILIES COPE WITH THE DIAGNOSIS

Individuals and families differ widely in their initial responses to being told they have a child with a disability. Their responses may depend on the severity of the disability and the health care professional's manner of delivery of the news. Oftentimes it is the timing, the words used, the time spent, and the emotional support provided by the professional that has a great deal of influence. The impact on the family also depends on past life experiences, religious and cultural backgrounds, and age of the child at diagnosis (Leiter et al., 2004). Other factors that may influence familial reactions include their attitudes about individuals with disabilities; knowledge about health care practitioners; and receptiveness to accepting help from professionals, friends, and other family members (Sullivan-Bolyai et al., 2003). Some individuals with a strong religious faith may believe that God has chosen them to care for a child with a disability. Others may be able to adjust more easily because of previous experience with a family member with a disability. If the diagnosis has been delayed, parents may be relieved to finally

receive answers and help for their child. Yet, they also may be angry with health care professionals, friends, or family members who previously reassured them that their child would "grow out of it." It is difficult to predict how a particular family member will react to the news that a child has a disability. Furthermore, what one family considers a mild disability may be a major disability to another family.

The most common initial response of parents who are told that their child has a severe disability is some combination of shock, denial, disbelief, guilt, and an overwhelming sense of loss. Some parents initially deny their child's diagnosis and visit various professionals looking for a more optimistic diagnosis or prognosis (Ho & Keiley, 2003; Sullivan-Bolyai et al., 2003).

Families with a child who initially developed typically but later acquired a disability as a result of an illness or an injury have some additional challenges. They often have a difficult time accepting that aspirations for their child must be adjusted and that family relationships may be altered. After the initial period of shock and denial, some family members experience depression (Rolland, 2003). This can result from emotional stress combined with the physical strain of following through on the many appointments; procedures, recommendations, and care required for their child (Ello & Donovan, 2005). Other factors contributing to depression may be spousal disagreement over acceptance of the diagnosis, assignment of blame, choice of treatment options, and/or responsibility in caring for the child (Singer & Powers, 1993). The mother, usually the primary caregiver, is more often affected. Symptoms of depression include extreme fatigue, restlessness or irritability, insomnia, changes in appetite, and/or loss of sex drive. Professionals should screen for depression and refer the family member for further evaluation and treatment if concerned.

Depression may be accompanied or followed by anger, which may be directed at a person, an event, God, or life in general. If directed at a person, it may be the doctor, other professionals caring for the child, the other parent, one of the other children in the family, or even the child with the disability (Tunali & Powell, 1992). Alternately, the anger may be self-directed. A parent may ask, "What did I do or not do that contributed to or caused the disability?" Regardless of where the anger is directed, it is important to recognize that such expressions are part of a coping strategy. Anger may well be an appropriate expression of frustration

when parents feel their opinions are not being heard or respected. However, it may be inappropriately directed at a "safe" target (i.e., the spouse) rather than at the person for whom it is felt (i.e., the professional who communicated the diagnosis). Counseling and advocacy training can help parents or other family members channel their anger into productive interactions, so they can learn how to obtain the resources they need for their child and find ways to express their feelings more effectively (Banks, 2003). Support from family members and friends is critical. Families who have strong relationships are better able to meet the challenges they encounter. However, at a time when the parent(s) are most in need of support, family and friends may be unable to provide it. The extended family may not accept the diagnosis or may assign blame to one of the parents, most commonly to the one unrelated to them. Friends may feel uncomfortable in the presence of the child with a severe disability or not know what to say in consolation; as a result, they often stay away. In addition, parents may be embarrassed by their child's disability or behavior and rarely venture into the community with the child. Parents may find it difficult to see their friends' typically developing children, knowing their own child will follow a different trajectory. All of these factors can lead to social isolation. Even if parents want to maintain social contacts, their child's physical, behavioral, and medical challenges may be so complex that simply going shopping and/or finding a skilled baby sitter becomes a major production.

Finances also play a role. Families come from a wide range of educational and socioeconomic circumstances. Some families are very knowledgeable about their choices and can afford to obtain multiple expert opinions and services. Other families have neither a good understanding of the health care and educational systems nor the means to obtain private fee-for-service programs. These disparities can directly affect the outcome of the child. Family-centered care involves educating all parents about their child's condition, resources, and entitlements. Parents who learn advocacy skills in the individualized education program (IEP) process (see Chapter 34) are better able to meet their child's needs.

Most parents are eventually able to cope with their child's disability and recognize positive outcomes from the experience. This leads to improved family cohesion and hardiness, increased understanding and compassion among

family members, and, for some, a more enriched and meaningful life (Ho & Keiley, 2003). Parents become experts in meeting their children's needs. They learn to ask for and obtain what is needed. This strength and ability in many cases benefits the child, who may achieve more than what was originally expected at the time of diagnosis. For example, in some communities, families who receive a prenatal diagnosis of Down syndrome are immediately connected with the Down syndrome parent group in their area. Positive experiences are shared and families immediately begin to receive the help they need. After birth, the child and family are welcomed into the community of Down syndrome families, which creates a supportive environment of hope and positive expectation throughout the life span (Bittles & Glasson, 2004).

For most families, the sadness lessens as members develop a routine of care, gain access to early intervention and respite care services, and begin seeing progress in the child's development (Turnbull et al., 1993). The need for support and/or therapy, however, may recur at various developmental stages. Support from friends, extended family, and other parents of children with disabilities also can be (re)established over time. Parenting networks, in which parents educate and support one another, are often very powerful and may be even more effective than professional information and support (see Appendix D for examples of such resources).

LONG-TERM EFFECTS ON THE PARENTS

The problems engendered by having a child with a disability may include physical and time demands for in-home care that interfere with employment; requirements for medical, educational, and therapy appointments; financial burdens; added stress level; and specialized needs for recreational programs, legal services, and transportation (Trachtenberg & Lewis, 1996). Parents or partners often react differently to these problems, perhaps as a result of their separate roles within the family unit or gender-specific issues.

In most families, women continue to carry most child care responsibilities, although men often are participating more than in the past. This responsibility carries both potential risks and benefits. A mother caring for a child who will remain dependent in daily living skills throughout life is at high risk for developing

stress, depression, and burnout over time (Johnson et al., 2005). If the mother can efficiently and effectively master the child's care, however, she may feel a sense of accomplishment and competency that is positively reinforcing (Leiter et al., 2004). Meanwhile, the traditional father who focuses on financial issues and long-term planning rather than taking part in the child's daily living activities may be avoiding having to deal with the reality of the child or the disability (Green et al., 2005). In contrast, he may find that by participating actively in the child's care, he not only provides relief for the mother but also experiences pleasure from an enhanced role in daily family life (Willoughby & Glidden, 1995).

Gender-specific differences also are found in communication styles. Although men tend to talk in order to impart information, women talk to communicate feelings as well. This can lead to miscommunication. The husband may think his wife is complaining when she is actually just sharing her feelings and experiences of the day. The wife may think her husband is insensitive when he imparts information without emotional content. This difference in communication styles is not unique to families of children with disabilities, but it is often accentuated in an environment of increased stress and inadequate financial and emotional resources. Fathers may also feel that they must keep their emotions internalized and be the strong partner.

Given these stresses, it has been found that strong marital relationships, good parenting and problem-solving skills, financial stability, and supportive social networks are predictors of a good outcome for parents who have a child with a disability (Power, 2004; Rolland, 2003). For families who lack these supports, professionals need to be available to provide advice and support to ensure the child's optimal growth, development, and safety. Although some marriages are strengthened by the challenge, others deteriorate, especially if the relationship had previous troubles (Banks, 2003). Strong religious and community affiliation and effective behavioral interventions in the home are also associated with an increased likelihood of effective family functioning (Hanson & Lynch, 2004; Power, 2004; Rolland, 2003). Related life experiences may have sometimes unpredictable effects. For example, a parent who has dealt with a chronic illness or disability in another family member may feel more competent in handling this new disability. Alternatively, a previous difficult caregiving experience may

leave the parent burned out and unable to cope with this new responsibility.

Parents may also fear for the safety of their child, especially as the child attends preschool or school outside of the home environment. An ever-present concern is that their child will be injured, teased, or bullied by other children or physically/sexually assaulted by other children or by adults. For children who are violent, with or without intent, the concern is that they may injure themselves, other children, or staff. This fear is heightened when a child has a disability that interferes with communication skills. The parents may also face increasing behavior problems, new health care and physical needs, mounting financial concerns, or feelings of inadequacy in meeting the needs of other family members. Parents of children with the most severe developmental disabilities and/or medical fragility—for example, requiring prolonged technology assistance such as a ventilator—are at greatest risk for caregiver burnout and decreased family functioning (Ello & Donovan, 2005; Trachtenberg & Trachtenberg, 1996). Many families, however, do well and thrive at home with children who have technology dependence (O'Brien, 2001). Some parents have difficulty finding or accepting respite care or other assistance for their child. As a result, they continue to experience chronic stress, which can lead to depression or physical illness and ultimately render them incapable of continuing to meet the demands of care. Parents whose children have mild disabilities may also experience recurrent episodes of sadness and feelings of despair, which, in some instances, become a condition called chronic sorrow (Wickler, Wasow, Hatfield, 1981). When the feelings of sadness and grief become chronic and interfere with the parent's ability to function, psychological intervention is indicated.

EFFECTS ON SIBLINGS

The siblings of a child with a disability have special needs and concerns that vary with gender, age, birth order, and temperament (Burke, 2004; Stalker & Connors, 2004). Coleby (1995) found that older male siblings had an increased appreciation for children with disabilities, whereas older female siblings showed increased behavior problems (perhaps because of being overburdened with child care responsibilities). The same study showed that near-age siblings had less contact with peers, and younger siblings showed increased anxiety. Sibling con-

cerns also appeared to reflect such situational variables as whether their own needs were being met, how the parents were handling the diagnosis emotionally, what the children were being told, and how much they understood.

In addition to recognizing age and gender differences, it is important to acknowledge that children, in general, have mixed feelings about their siblings with or without disabilities. They may be glad that they do not have a disability yet feel guilty about this fact as well. They may worry that they will "catch" the disability or fantasize that they actually caused it by having bad thoughts about their sibling. Adolescents may question whether they will pass a similar disability on to their future children. Furthermore, because of the extra care and time required by the child with a disability, the typically developing children may think that their parents love their brother or sister more than them. As a consequence, they may act out in order to get attention, or they may withdraw, not wanting to ask for attention from their overly burdened parents (Williams, Williams, & Graff, 2003). Care must be taken to balance the parenting efforts so that the typically developing sibling(s) continue to feel appropriately supported. When the siblings reach adolescence, it may be the appropriate time for a family discussion of planning for the future. This discussion should include the eventuality of the parents' death and/or the parents being unable to continue providing care for the child with a severe disability. The discussion should include the participation of the affected child to whatever extent possible. Getting assistance from professionals who have training in self-determination or person-centered planning may be useful for some individuals (DePoy & Gilson, 2004). There may also be a need for an attorney to set up an estate plan and a special needs trust and guardianship, as well as an evaluation to determine the person's competence to make financial and/or medical decisions for him- or herself (see Chapter 41).

Despite these concerns, having a child with a disability in a family does not necessarily adversely affect the typically developing siblings. In fact, there is some evidence that these children demonstrate increased maturity, a sense of responsibility, a tolerance for being different, a feeling of closeness to the family, and enhanced self-confidence and independence. In one study, siblings ages 3–6 years showed more involvement in social play and nurturing activities than children in a control group (Lobato, Miller,

Barbour, et al., 1991). Many siblings of individuals with disabilities ultimately enter helping professions (Lobato, 1990).

Siblings fare best psychologically when 1) their parents' marriage is stable and supportive, 2) feelings are discussed openly, 3) the disability is explained completely, and 4) they are not overburdened with child care responsibilities (Lobato, 1990; Pilowsky et al., 2004; Williams et al., 2003). Parents must remember that children take their lead. If the parents are upset, so too will be the children, even if they do not understand why. In contrast, parents who acknowledge their pain while being proud of the accomplishments of all their children show their ability to adapt to the increased emotional and physical demands of having a child with special needs. This sets the tone for the entire family. Parents also should avoid burdening siblings with caregiving responsibilities. It has been shown that mothers of children with disabilities are more likely to put child care demands on the siblings and reprimand them more (Lobato et al., 1991).

Parents must recognize that their other children often feel torn between protecting and caring for their brother or sister with a disability and being accepted by children outside the family who may tease them and their sibling. Siblings should be informed at an early age about their brother or sister's disability so their knowledge is based on fact, not misconception. This must be done in an age-appropriate fashion, with the siblings feeling free to ask questions. These sessions will need to be repeated as the children grow older and require more information. By the time siblings have reached adolescence, the parents may be ready to share with them information about genetics, estate planning, guardianship arrangements, and wills. It is helpful for siblings to know what resources and options are available. Some siblings will choose to have their sibling with a disability live with them in the future or they may promote their sibling's independence by finding living arrangements and/or the available systems of care in their community (Rivers & Stoneman, 2003). The family should stay current with services offered in their community as well as be aware of any waiting lists for those services.

EFFECTS ON THE EXTENDED FAMILY

Having grandchildren creates strong feelings in most people. These include feelings of satisfaction, connectedness, fulfillment of life's pur-

pose, joy, and comfort. Learning that a grandchild has a disability leads to more mixed feelings. To the extent that the grandparents have or do not have a quality relationship with their own children further affects their own coping with the disability and with their support of the child. Typically, when a grandchild is born with a disability, grandparents grieve for their own loss as well as for their child's loss. They may experience denial more strongly than do the parents of the child with the disability, and this can interfere with the family's adaptation to the disability. Yet, grandparents can be extremely helpful to the family as a strong source of emotional support. They also may provide respite care and financial assistance that may be crucial for having a child with a severe disability live at home (Sandler, Warren, & Raver, 1995). Counseling, support groups for grandparents, and/or information given via the parents can help them deal with the reality of the child's disability and lead them to become more involved in supporting the family.

Other extended family members and friends also can help or hinder the parents' ability to cope. Some family members may have their own issues that will interfere with their ability to be supportive. For example, parents' siblings may be concerned about their own risk for having a child with a genetically based condition, in addition to experiencing sadness or discomfort with the diagnosis. Professionals can suggest ways to discuss these issues with family and friends and should encourage parents to utilize support groups and community service agencies that fully include people with disabilities.

EFFECTS ON THE CHILD WITH A DISABILITY

Some effects on the child with a disability vary across the life span. Issues common at particular ages are discussed next.

Preschool Age

Prior to school age, the child with a disability may not recognize that he or she is different from other children. During this period parent-child interactions and child-peer interactions are crucial to prepare for future school-age interactions. Referral to early intervention and special preschool services is very important at this stage (see Chapter 34). This will lead to interactions between parents and professionals to set up the individualized family service plan

(IFSP), setting the tone for dealing with the disability.

School Age

By school age, most children with disabilities are aware of their abilities and challenges and may need help in dealing with feelings of being different. If the child is given proper supports, he or she can learn to cope with the disability effectively. Full acceptance must first come from the home. If the child is seen as being worthwhile by parents and siblings, the child's self-image is usually good. This acceptance includes being part of family activities (e.g., attending religious services, taking part in recreational programs, going on vacations), participating as much as possible in developmentally appropriate family responsibilities, and being permitted to discuss the disability openly.

Discussing and modeling how to handle different situations at home improves the child's ability to cope with social situations in the community as well. This is very important because acceptance outside of the home can be difficult to achieve. Classmates may tease the child, and schoolwork may prove difficult in an inclusive setting. Furthermore, if the child's communication or social skills are limited, this may interfere with interpersonal interactions. If others do not accept the child, he or she may develop a poor self-image and exhibit behavior problems. In order for inclusion to work, teachers and school personnel must be adequately informed and trained about the specific physical and cognitive needs of the child (Ross-Watt, 2005).

Planning for the child's entry into school should begin while the child is in preschool and with the help of professionals. The transition to school also can be eased by preparing the class for the child's entrance (Cutler, 1993). The child's parents must be included in this planning. They can help explain the child's disorder and the necessary adaptations to both the teacher and students. They also can share with the school staff their hopes and fears for their child's education and future during the IEP meeting (see Chapter 34). It should be noted that in the case of a recent disability (e.g., a traumatic brain injury [TBI], Chapter 30), as opposed to a congenital disorder (e.g., meningomyelocele; see Chapter 28), the parents may be less able to take such a proactive role, because they may be coping with their own adjustment to the disability. Professionals from the treating hospital can assist in school reentry.

The child with disabilities gains self-confidence through participation in activities in which he or she can be successful. These can be either general or special activities. The philosophy of inclusion is that children who are differently challenged are accepted in general activities with appropriate adaptations or assistance. This, however, should not preclude either participation in segregated programs, such as the Special Olympics, or development of friendships with children who have similar disabilities.

Some children with disabilities will need encouragement and assistance in socializing and developing friendships. Summer camps (be they inclusive or special) that welcome children with special needs provide an avenue for children to develop important socialization skills and experience independence from parents. This not only encourages personal growth for the child but also for his or her parents and camp mates as well. In camps with inclusive programs, the typically developing children learn to appreciate people with differences. This will prepare them for a future where they will live, work, and befriend people with disabilities (Davern & Schnorr, 1991).

Adolescence

Adolescence is one of the most difficult periods for both children and their families, not only because of the many biological and social changes taking place but also because society does not have a well-developed support system for adults with disabilities in education, employment, and socialization (Kim & Turnbull, 2004). For parents, adolescence signals their child's proximity to adulthood and adult responsibilities. It quite naturally elicits anxieties and fears about independence, self-sufficiency, and maturity. Adolescents may become preoccupied with comparing themselves with their peers (Orsmond, Krauss, & Seltzer, 2004). Yet, the desire for sameness and peer approval in areas of physical and intellectual development may be unattainable because of the developmental disability. This will be less of an issue if the adolescent with a disability has a strong peer group or has already come to terms with being "different." If the adolescent has just acquired a disability (e.g., from TBI) or is having emotional or behavior difficulties, counseling may be helpful in working through his or her concerns and learning effective behavioral strategies. There are specific interventions that are effective to assist adolescents as they move to-

ward becoming productive adults (White et al., 2002).

It is important to use this time to start developing a reasonable plan for enhancing the adolescents' capacity for independent behavior and self-sufficiency as they make the transition to young adulthood. As an example, they should be acknowledged as sexual beings. They should be given appropriate material about intimate relationships and "safe sex" and encouraged to discuss issues of sexuality with parents, peers, and professionals in a way and at a level they feel comfortable with and can understand. Although promiscuity or sexual exploitation is sometimes an issue, social isolation is a far more common problem during adolescence. This can result either from limitations imposed on the child by the disability or by attitudes and reactions of peers and family (Hill, 1993). For some developmental disabilities (e.g., autism spectrum disorder), social skills impairments are an integral part of the disability. These adolescents may act in an odd manner in social interactions, often making peers feel uncomfortable in their presence. They may benefit from social skills training that entails modeling appropriate social interactions and learning to participate successfully in group activities. They also can learn to enjoy individual recreational activities, such as listening to music, watching movies, and participating in sports activities (e.g., swimming, horseback riding) (Orsmond et al., 2004).

Adolescence is a critical time for predicting future independence; individuals who remain dependent through adolescence tend not to move from this stage in later life (Powers, Singer, & Sowers, 1996). Adolescents who have the potential for independence but face difficulties with issues of separation and individuation need assistance with these developmental tasks. Parents should be encouraged to give them the necessary freedom to become independent. At times, this requires taking certain reasonable risks and providing psychosocial intervention. If parents persist in managing their child's life and the disability, however, they are giving the adolescent the message that he or she is not competent to manage independently. This can have long-term adverse consequences.

Young Adulthood

The transition to adulthood is both important and difficult for parents and children with disabilities (see Chapter 41). It must be viewed as a dynamic lifelong process that meets individual

needs by providing developmentally appropriate services that continue uninterrupted as the individual moves from adolescence to adulthood (White et al., 2002).

The young adult's ability to cope and become as independent as possible depends on the degree of the disability and the effectiveness of the family in planning and managing this transition emotionally and financially (Hallum, 1995). The individual may be ready to move out of the family home and into an independent living arrangement. If he or she is affiliated with an agency focused on the needs of young adults with disabilities, the support offered can provide important socialization opportunities within the community, contributing to personal development, competency, maturity, and adaptive functioning. It also can be a very difficult time, however, disrupting the established family structure. The family may need assistance in successfully supporting the young adult at this point.

PRINCIPLES OF FAMILY-CENTERED CARE: ROLE OF THE PROFESSIONAL

Table 40.1 lists principles of family-centered care. The goal of family-centered care is to facilitate the best possible outcome for a child with a developmental disability. To achieve this goal, the professional must establish a relationship with the family based on mutual respect and open communication. This means that the family sees the professional as someone who is nonjudgmental, open to constructive feedback, respectful of cultural diversity, and able to listen empathically (Arrango, 1999; Johnson, 2000; see also <http://www.familycenteredcare.org>). Once this relationship has been established, both parties will be in a strong position to receive and appreciate the unique expertise that each contributes.

Families of children with disabilities come into contact with a bevy of professionals (e.g., physicians, nurses, teachers, physical and occupational therapists, psychologists, social workers). Individually and as a group, they are responsible for explaining the results of the initial evaluation and testing, presenting various treatment options, and teaching intervention and advocacy strategies. The initial contact the family has with professionals generally sets the tone for future interactions (Miceli & Clark, 2005).

Professionals need to be flexible and responsive while recognizing the importance of

coordinating efforts with the family and other professionals. As a result of their training, experience, and expertise, professionals often have strong opinions about what is best for the child and family. However, people with disabilities and their families have the right to choose their own path. If a family encounters difficulties along the way, it can always turn to a professional for further assistance to accomplish its goals. It is important to remember that families who make their own choices are empowered to continue making decisions that best meet their needs (Miceli & Clark, 2005).

The overall approach of the professional toward the family should be one of respect and support, promoting decision making and mastery of care by the family. This family-centered practice leads to a true partnership between parents and professionals (Cavet & Sloper, 2004; Singer & Powers, 1993). Families who find programs consistent with their personal needs and cultural values are much more likely to follow through, to their child's advantage (Banks, 2003; Hanson & Lynch, 2004; Harry, 2002; Ochieng, 2003). Professionals should pro-

Table 40.1. Principles of family-centered care

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 building on strengths of each child and family, even in difficult and challenging situations
4. Supporting and facilitating choice for the child and family about care and support
5. Ensuring flexibility in organizational policies and procedures, and providers 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 on-going basis and in ways they find useful and affirming
7. Providing and/or ensuring formal and informal support (e.g., family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood
8. Collaborating with families at all levels of health care, in the care of the individual child and in 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

From Johnson, B.H. & Eichner, J.M. (2003). Family-centered care and the pediatrician's role. *Pediatrics*, 112(9), 692; reprinted by permission.

vide self-determination by encouraging families to become actively involved in understanding the disability, setting goals, and making decisions. Families often use the Internet for information and guidance, and professionals need to understand that it contains a wealth of both information and misinformation. Therefore, they need to be proactive in helping families evaluate the quality of the information and its appropriateness for their child.

A consequence of feeling empowered is that families are more likely to make decisions on their own and challenge the advice of professionals (Sullivan-Bolyai et al., 2004). A family may request additional information or referral for a second opinion. Families may not follow advice because of specific child-rearing and medical care practices advanced by ethnic and religious affiliations, specific cultural values, family authority figures and communication patterns, or decision-making practices (Trachtenberg & Hale Sils, 1996). Professionals should work within the family's system of beliefs, if at all possible. Collaboration with another colleague, often a social worker or psychologist, may clarify the family's perspective, and compromises may be reached that provide good care for the child and are acceptable to both family and professionals. If the professional is persistent and uncompromising in pushing his or her approach, the likely result is that the prescription will not be filled, the therapeutic intervention will not be followed, and the family will not return to the professional for further care.

The professional must take action, however, if the choices the individual or family makes are perceived as inappropriate. For example, a family may decide to pursue treatment that has not been proven scientifically valid, is potentially harmful, and/or costs the family a great deal of time and money. It is the professional's responsibility to inform the family of the risks of nonvalidated interventions while respecting the family's autonomy. This action should not be performed in a demeaning or controlling manner. The decision must always remain in the family's hands. The one exception is if it is believed that the family's actions may be harmful to the child. The professional must then contact the local child welfare agency (or other authority) to report suspected child abuse or neglect.

Sometimes isolation and depression are experienced by one family member or the entire

family. In these situations, the professional can suggest several proven methods of psychotherapy to assist the family. At the present time, the two most validated time limited therapies are cognitive-behavioral therapy (CBT) and interpersonal psychotherapy (IPT). CBT uses cognitive approaches to problem solving (Dobson, 2002). Professionals can help families deal with isolation, depression, and discord, especially if these feelings are interfering with the parents' ability to care for their child. These cognitive therapies provide family members with an opportunity to examine feelings and develop solutions. IPT is helpful in identifying the places of interpersonal discord in the family that have led to the depressive symptoms. This therapy helps individuals understand and change interactions that cause strife in the family. The therapy usually lasts for 4 months at the most and has been shown to be effective in treating a variety of interpersonal issues (Blanco, Lipsitz, & Caligor, 2001; Stuart, 1999; Weissman, Markowitz, & Klerman, 2000). Although CBT and IPT are the most rigorously proven psychological therapies, there are other modalities that can be helpful to a family. These include supportive therapies and family therapy (Carr, 2000; Serkerich & Dumas, 1996).

THE ROLE OF SOCIETY AND COMMUNITY

The family's social context plays an important role in determining the outcome of its members. Fortunately, in today's society there is greater appreciation for people with disabilities. There are more educational, vocational, and housing services, as well as entitlements, available. Federal funding provides for a protection and advocacy system for people with disabilities in each state.

Federal legislation also guarantees equal opportunities for all members of society. The Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004; PL 108-446) mandates free educational and rehabilitative services for school-age children (see Chapter 34). Reaching citizens of all ages with disabilities, the Americans with Disabilities Act (ADA) of 1990 (PL 101-336) focuses on the establishment of rights regarding access to employment, transportation, telecommunications, and public accommodations. The effects of the ADA are increasingly visible. City sidewalks now have direct curb access so that wheelchairs

can be used, and buses are equipped with wheelchair lifts. Buildings have wheelchair access ramps, and theater and sporting events are able to accommodate individuals with disabilities. Public telephones have adjustable speaker volumes, and many offices have teletypewriter (TTY) capability. More, however, needs to be done.

As a result of these and other laws, people with disabilities and their families and friends are guaranteed the same civil rights as people without disabilities. Parent advocates have paved the way for the current focus on family-centered care, with parents acting as true partners with professionals to enable the child to function at the highest possible level.

Although laws are important, they need to be accompanied by a change in the public's perception and attitudes toward individuals with disabilities. This too seems to be happening, perhaps as a consequence of "mainstreaming" that began in the mid-1970s. Young adults who have grown up in schools with children with disabilities are more sensitive to their needs and more cognizant of their abilities. Individuals with disabilities are in the workforce and are productive members of society. They are seen in movies, on television shows, in television commercials, and in magazine advertisements. Although society has made itself more accessible to and supportive of individuals with disabilities, the future remains challenging.

Supplemental Security Income, medical assistance, and food stamps all currently provide financial support for parents and eventually for children with disabilities when they turn 18. Many of these entitlement programs are being challenged, however, and may not exist in their current form in the future (Chapter 42). For example, managed care plans may not cover all long-term medications, rehabilitation therapies, and technologies that are presently funded by mandated programs (Giardino et al., 2002). New cost-effective care models must be developed to promote quality and outcome-oriented services that build on the strengths of the children, their families, and the professionals who serve them.

SUMMARY

As a family journeys through its life cycle, its members face many challenges and changes. This trip is particularly challenging for the family of a child with a disability. The child, parents, siblings, extended family members, and

friends are all affected and may initially undergo a period of grieving for their loss of a "normal child." Over time, the family's coping strategies generally improve. Parents learn to master the child's care and to advocate effectively for necessary medical, educational, and other services. The child learns to cope with the disability at school and in the community and to become a self-advocate. Working closely with the parents and child in a family-centered approach, the social worker, therapists, teachers, and physicians can play a crucial role in promoting these adjustments and may be instrumental in determining the prognosis of the child and the outcome of the entire family.

REFERENCES

- Americans with Disabilities Act (ADA) of 1990, PL 101-336, 42 U.S.C. §§ 12101 et seq.
- Arrango, P. (1999). A parent's perspective on family-centered care. *Journal of Developmental and Behavioral Pediatrics, 20*(2), 123-123.
- Banks, M.E. (2003). Disability in the family: A life span perspective. *Ethnic Minority Psychology, 9*(4), 367-384.
- Birtles, A.H., & Glasson, E.J. (2004). Clinical, social, and ethical implications of changing life expectancy in Down syndrome. *Developmental Medicine and Child Neurology, 46*, 282-286.
- Blanco, C., Lipsitz, J., & Caligor, E. (2001). Treatment of chronic depression with a 12-week program of interpersonal psychotherapy. *American Journal of Psychiatry, 158*, 371-375.
- Burke, P. (2004). *Brothers and sisters of disabled children*. Philadelphia: Jessica Kingsley Publishers.
- Carr, A. (2000). Evidence-based practice in family therapy and systemic consultation I. *Journal of Family Therapy, 22*, 29-60.
- Caver, J., & Sloper, P. (2004). Disabled children's participation in decision-making. *Children and Society, 18*, 278-290.
- Coleby, M. (1995). The school-aged siblings of children with disabilities. *Developmental Medicine and Child Neurology, 37*, 415-426.
- Cutler, B.C. (1993). *You, your child, and "special" education: A guide to making the system work*. Baltimore: Paul H. Brookes Publishing Co.
- Davern, L., & Schnorr, R. (1991). Public schools welcome students with disabilities as full members. *Children Today, 20*(2), 21-25.
- DePoy, E., & Gilson, S.F. (2004). *Rethinking disability: Principles for professional and social change*. Belmont, CA: Brooks/Cole.
- Dobson, K.S. (Ed.). (2002). *Handbook of cognitive-behavioral therapies* (2nd ed.). New York: The Guilford Press.
- Ello, L.M., & Donovan, S.J. (2005). Assessment of the relationship between parenting stress and a child's ability to functionally communicate. *Research on Social Work Practice, 15*(6), 531-544.
- Farber, M.L., & Maharaj, R. (2005). Empowering high-risk families of children with disabilities. *Research on Social Work Practice, 15*(6), 501-515.
- Giardino, A.P., Kohrt, A.E., Arye, L., et al. (2002). Health care delivery systems and financing issues. In M.L. Batshaw (Ed.), *Children with disabilities* (5th ed., 707-724). Baltimore: Paul H. Brookes Publishing Co.
- Green, S., Davis, C., Karshmer, E., et al. (2005). Living stigma: The impact of labeling, stereotyping, separation, status loss and discrimination in the lives of individuals with disabilities and their families. *Sociological Inquiry, 75*(2), 197-215.
- Hallum, A. (1995). Disability and the transition to adulthood: Issues for the disabled child, the family, and the pediatrician. *Current Problems in Pediatrics, 25*(1), 12-50.
- Hanson, M.J., & Lynch, E.W. (2004). *Understanding families: Approaches to diversity, disability, and risk*. Baltimore: Paul H. Brookes Publishing Co.
- Harry, B. (2002). Trends and issues serving culturally diverse families of children with disabilities. *Journal of Special Education, 36*(3), 131-138.
- Hill, A.E. (1993). Problems in relation to independent living: A retrospective study of physically disabled school leavers. *Developmental Medicine and Child Neurology, 35*(12), 1111-1115.
- Ho, K.M., & Keiley, M.K. (2003). Dealing with denial: A systems approach for family professionals working with parents of individuals with multiple disabilities. *The Family Journal: Counseling and Therapy for Couples and Families, 11*(3), 239-247.
- Individuals with Disabilities Education Improvement Act of 2004, PL 108-446, 20 U.S.C. §§ 1400 et seq.
- Johnson, B. (2000). Family-centered care: Four decades of progress. *Families, Systems & Health: Special issue on consumers and collaborative care, 18*(2), 137-156.
- Johnson, C.P., Kastner, T.A., & Committee/Section on Children with Disabilities. (2005). Helping families raise children with special health care needs at home. *Pediatrics, 115*(2), 507-511.
- Kim, K., & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and Practice for Persons with Severe Disabilities, 29*(1), 111-124.
- Leiter, V., Krauss, M.W., Anderson, B., et al. (2004). The consequences of caring: Effects of mothering a child with special needs. *Journal of Family Issues, 25*(3), 379-403.
- Lobato, D.J. (1990). *Brothers, sisters, and special needs: Information and activities for helping young siblings of children with chronic illnesses and developmental disabilities*. Baltimore: Paul H. Brookes Publishing Co.
- Lobato, D.J., Miller, C.T., Barbour, L., et al. (1991). Preschool siblings of handicapped children: Interactions with mothers, brothers and sisters. *Research in Developmental Disabilities, 12*(4), 387-399.
- Miceli, P.J., & Clark, P.A. (2005). Your patient—my child: Seven priorities for improving pediatric care from the parent's perspective. *Journal of Nursing Care Quality, 20*(1), 43-53.
- O'Brien, M.E. (2001). Living in a house of cards: Family experiences with long-term childhood technology dependence. *Journal of Pediatric Nursing, 16*, 13-22.
- Ochieng, B.M. (2003). Minority ethnic families and family-centered care. *Journal of Child Health Care, 7*(2), 123-132.
- Ormond, G., Krauss, M., & Seltzer, M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 34*(3), 245-256.
- Pilowsky, T., Yirmiya, N., Doppelt, O., et al. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry, 45*(4), 855-865.
- Power, P.W. (2004). *Families living with chronic illness and disability: Interventions, challenges, and opportunities*. New York: Springer Publishing Co.
- Powers, L.E., Singer, G.H.S., & Sowers, J.-A. (Eds.). (1996). *On the road to autonomy: Promoting self-competence in children and youth with disabilities*. Baltimore: Paul H. Brookes Publishing Co.
- Rivers, J., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders, 33*(4), 383-394.
- Rolland, J.S. (2003). Mastering family challenges in illness and disability. In E. Walsh (Ed.), *Normal family processes: Growing diversity and complexity* (3rd ed.). New York: The Guilford Press.
- Ross-Watt, F. (2005). Inclusion in the early years: From rhetoric to reality. *Child Care in Practice, 11*(2), 103-118.
- Sandler, A.G., Warren, S.H., & Raver, S.A. (1995). Grandparents as a source of support for parents of children with disabilities: A brief report. *Mental Retardation, 33*, 248-250.
- Serketich, W., & Dumas, J.E. (1996). The effectiveness of behavioural parent training to modify antisocial behaviour in children: A meta-analysis. *Behaviour Therapy, 27*, 171-186.
- Singer, G.H.S., & Powers, L.E. (Eds.). (1993). *Families, disability, and empowerment: Active coping skills and strategies for family interventions*. Baltimore: Paul H. Brookes Publishing Co.
- Stalker, K., & Connors, C. (2004). Children's perceptions of their disabled siblings: 'She's different but it's normal for us'. *Children and Society, 18*, 218-230.
- Stuart, S. (1999). Interpersonal psychotherapy for postpartum depression. In L. Miller (Ed.), *Postpartum psychiatric disorders* (pp. 143-162). Washington, DC: American Psychiatric Press.
- Sullivan-Bolyai, S., Sadler, L., Knaf, K.A., et al. (2003). Great expectations: A position description for parents as caregivers: Part I. *Pediatric Nursing, 29*(6), 457-461.
- Sullivan-Bolyai, S., Sadler, L., Knaf, K.A., et al. (2004). Great expectations: A position description for parents as caregivers: Part II. *Pediatric Nursing, 30*(1), 52-56.
- Trachtenberg, S.W., & Hale Sills, N. (1996). Collaboration with parent and child. In L. Kurtz, P.W. Dowrick, S.E. Levy, et al. (Eds.), *Children's Seaboard House handbook of developmental disabilities: Resources for interdisciplinary care* (pp. 526-533). Gaithersburg, MD: Aspen Publishers.
- Trachtenberg, S.W., & Lewis, D.F. (1996). Case management. In L. Kurtz, P.W. Dowrick, S.E. Levy, et al. (Eds.), *Children's Seaboard House handbook of developmental disabilities: Resources for interdisciplinary care* (pp. 203-208). Gaithersburg, MD: Aspen Publishers.
- Trachtenberg, S.W., & Trachtenberg, J.I. (1996). Prevention of burnout for parents and professionals. In L. Kurtz, P.W. Dowrick, S.E. Levy, et al. (Eds.), *Children's Seaboard House handbook of developmental disabilities: Resources for interdisciplinary care* (pp. 593-596). Gaithersburg, MD: Aspen Publishers.
- Tunali, B., & Power, T.G. (1992). Creating satisfaction: A psychological perspective on stress and coping in families of handicapped children. *Journal of Child Psychology and Psychiatry, 34*(6), 945-957.
- Turnbull, A.P., Patterson, J.M., Behr, S.K., et al. (Eds.). (1993). *Cognitive coping, families, and disability*. Baltimore: Paul H. Brookes Publishing Co.

- Weissman, M.M., Markowitz, J.C., & Klerman, G.L. (2000). *Comprehensive guide to interpersonal psychotherapy*. New York: Basic Books.
- White, P.H., Schuyler, V., Edelman, A., et al. (2002). Future expectations: Transition from adolescence to adulthood. In M.L. Batshaw (Ed.), *Children with disabilities* (5th ed., 693-705). Baltimore: Paul H. Brookes Publishing Co.
- Wickler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs. professional depiction of

the adjustment of parents of mentally retarded children. *American Journal of Orthopsychiatry*, 51, 63-70.

Williams, P.D., Williams, A.R., & Graff, J.C. (2003). A community-based intervention for siblings and parents of children with chronic illness or disability: The ISEE study. *The Journal of Pediatrics*, 143(3), 386-393.

Willoughby, J.C., & Glidden, L.M. (1995). Fathers helping out: Shared child care and marital satisfaction of parents of children with disabilities. *American Journal on Mental Retardation*, 99, 399-406.

41

Future Expectations

Transition from Adolescence to Adulthood

Nienke P. Dosa, Patience H. White, and Vincent Schuyler

Upon completion of this chapter, the reader will

- Be aware of the importance of planning for the transition to adulthood for youth with disabilities
- Understand the relationship between self-determination and health outcomes and social participation
- Understand the resources and mandated laws available to assist youth with disabilities
- Know the role of employment and postsecondary education in the transition process
- Understand the role health care providers play in promoting successful transition to adulthood of youth with disabilities

Individuals with developmental disabilities encounter the same life transitions as typically developing people do. Perhaps the most challenging of these is the transition to adulthood, a period of complex biological, social, and emotional change. This transition involves learning to move from 1) school to work, 2) home to community, and 3) pediatric- to adult-oriented health care. This chapter focuses on the steps involved in the successful transition of an individual with developmental disabilities from adolescence to adulthood.

BRYAN

Bryan is a 23-year-old former premature infant who has cerebral palsy and intellectual disability. Since he completed his public school education 2 years ago, Bryan has worked in a supported employment position at a local supermarket. He receives support and guidance from co-workers who were trained by a local job placement program to provide natural supports in the workplace. After work he participates in many recre-

ational and leisure activities with friends. With his increasing job satisfaction and financial independence, this past year Bryan expressed a desire to live on his own. He and his parents contacted the local United Cerebral Palsy Association chapter and with assistance from the staff found an apartment and a live-in personal care attendant. Bryan still goes to his parent's house for family dinners and events at least once per week and spends additional time with his two younger siblings, ages 16 and 18, who come to visit him frequently in his apartment. Bryan has recently started dating a young woman he met at his job.

GENERAL PRINCIPLES OF TRANSITION

There are three basic tenets of successful transition. First, transition is a process, not an event. Planning should begin as early as possible on a flexible schedule that recognizes the young person's increasing autonomy and capacity for making choices. Transition to adult services should occur prospectively rather than during a crisis