INTRODUCTION

A comprehensive understanding of adolescent development requires investigation into both normative patterns and individual differences in the full range of developmental domains. Extensive research in adolescent development has focused on delineating trajectories of typical development and understanding how those vary based on gender, culture, and socioeconomic context. Very few studies, however, consider such trajectories in adolescents with developmental disabilities (i.e., biologically based delays or impairments in one or more areas of development). Investigations of individuals with developmental disabilities usually require cross-disciplinary collaboration among such fields as psychology, sociology, biology, medicine, public health, special education, social work, and psychopathology, and therefore the study of adolescents with developmental disabilities has not found a primary home. Indeed, some researchers point out that adolescence is not even considered an actual subdiscipline within the field of intellectual impairment (Hodapp, Kazemi, Rosner, & Dykens, 2006). Cross-disciplinary work, however, can provide critical insight into such investigations.

For example, current research emanating from the fields of molecular biology and behavioral genetics has stimulated thinking about the complex interplay between genetic disorders (such as Down syndrome or fragile X syndrome) and developmental changes in individuals with those disorders (Inlow & Restifo, 2004). Such work is essential to mapping the variation within typical development, locating biological differences in atypical development (e.g., in the synthesis of proteins), and forming testable hypotheses about gene-environment interaction and potential therapeutic interventions (Gardiner, 2006). Currently, the growing knowledge base on the confluence of gene-environment complexity along with the biological changes and psychosocial demands that typically occur during the adolescent period makes the study of this developmental phase for individuals with developmental disabilities essential to a full understanding of adolescent development. For example, studies on those with fragile X syndrome, the most common form of hereditary intellectual disability, indicate that the disorder is due to a mutation of the FMRI gene on the X chromosome, a condition that has been simulated in mice. Restivo et al. (2005) conducted a study on such mice (termed knockout mice since the FMRI gene is deleted) comparing those reared in enriched and standard caged environment. They reported that the transgenic mice raised in the enriched environment showed fewer behavioral abnormalities (such as hyperactivity and lack of habituation) and displayed
postmortem morphological advantages in dendritic length and branching in the visual cortex. Such studies on transgenic mice combined with growing knowledge on changes in the adolescent brain of humans, especially synaptic pruning and reorganization (Blakemore & Choudhury, 2006), suggest that investigations on adolescent development in those with developmental disabilities may lead to a greater understanding of gene-environment-development interactions during the adolescent phase of life.

In this chapter, we center on the current theoretical and empirical knowledge base about the adolescent period for individuals with developmental disabilities and their families. Although adolescents with developmental disabilities by definition display atypical trajectories with regard to some aspects of development, most still encounter life challenges and embark on life tasks typical of this developmental phase. In addition, like most parents of adolescents, their parents face issues about the adolescent’s current and future well-being. The need to understand the way in which typical developmental issues emerge for these adolescents and those supporting them is increasingly highlighted both in discussions about daily practice as well as in policy discourse. Despite the accelerating public attention on developmental disabilities and current federal mandates, including the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA), empirical information, while rich at the early childhood phase, is only slowly gaining momentum about the development, strengths, and needs of adolescents with disabilities and their families.

This chapter has five main sections. The first offers a description of developmental disabilities and current U.S. federal policies and statistical information relevant to adolescents with developmental disabilities. In the next section, we discuss special concerns related to adolescents with developmental disabilities, with attention to their health and well-being. We then provide a discussion of the applicability of current developmental theories and related empirical work to adolescents with developmental disabilities. Relationships within families often change in adolescence, and in the fourth section we review theory and research on the role and functioning of families, including siblings, of adolescents with developmental disabilities. In a concluding section, we discuss the implications of current work and offer directions for future research.

DEVELOPMENTAL DISABILITIES: DEFINITIONS AND FEDERAL POLICY

In this section, we present a definition of developmental disabilities along with data on the increasing incidence of such disabilities. As legislation affects the lives of adolescents with disabilities in critical spheres including education, employment, and health, we also review the major federal policies that are specific to those with disabilities in the United States.

Definition and Incidence of Developmental Disabilities

The term developmental disabilities is codified in Public Law (PL) 106-402, the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000. It is defined as a condition attributable to a mental or physical impairment (or combination) that manifests before age 22 and is likely to continue indefinitely. It results in substantial functional limitation in three or more areas of major life activity, including self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency, and reflects an individual’s need for ongoing care and/or services. Among the most common conditions included under the umbrella of developmental disabilities are autism, cerebral palsy, epilepsy, intellectual disability (formerly termed mental retardation), and other neurological impairments. Current estimates indicate that, in 2005, about 17% of U.S. youth receiving special education services did so because of a developmental disability (U.S. Department of Education, 2007c).
The rates of documented disability during childhood and adolescence have increased steadily over the past decade (U.S. Department of Education, 2007c). This trend appears to be particularly strong for adolescents. For youth aged 12–17 years, the U.S. Department of Education reported a disability prevalence rate of 9.77 per 10,000 in 1995; by 2005, this rate had increased to 11.69. This increase appears to be due, in some part, to an increase in the number of youth who are diagnosed with autism spectrum disorders (ASDs). While the prevalence of children and adolescents with an intellectual disability has decreased slightly, the identification of autism and its related disorders has seen a marked increase. In 1995, only 6,648 adolescents nationwide received special education services because of a primary diagnosis of autism; however, this number had increased to 71,889 in 2005 (U.S. Department of Education, 2007c). There has been some debate around whether this increase in prevalence actually reflects an increase in the incidence of autism in the population, an increase in the rate of identification, or an effect of changing diagnostic criteria. Based on a review of 37 studies, Fombonne (2005) concluded that existing epidemiological data were insufficient to support the hypothesis of a secular increase in the rate of autism. Rather, the available evidence suggests that increases in the prevalence of autism are largely attributable to changes in diagnostic criteria and broadened definitions (Fombonne, 2005). Shattuck and Grosse (2007) suggested that because special education data are based solely on primary classifications, the growing enrollment prevalence of autism might also reflect the increasing proportion of youth with dual diagnoses who are being classified as having an ASD, rather than by a coexisting disability.

Federal Legislation Related to Developmental Disabilities

The rights of youth with developmental disabilities are protected by a range of federally legislated mandates and policies. In this section, we discuss three areas of legislation that are particularly salient for adolescents with developmental disabilities. First, we will briefly discuss the federal legislation that protects the civil rights of individuals with disabilities in the United States. Next, we will talk about educational legislation and policies that are relevant to youth with developmental disabilities. Finally, we will discuss programs enacted under the Social Security Act that have been put in place to assist individuals with disabilities and their families.

Civil Rights Legislation

In 1973, the Rehabilitation Act (PL 93-112) was passed, making it the first federally enacted legislation that addressed the rights of people with disabilities. Section 504 specifically stated that no federally funded program or institution may exclude individuals from access or participation based solely on their disability status. In 1990, the Americans with Disabilities Act (PL 101-336) extended these protections, providing comprehensive civil rights protection for people with disabilities. It mandated that local and state, as well as federal, programs must be accessible; that businesses make reasonable accommodations for workers with disabilities; and that various aspects of public life, such as transportation and communication, be accessible. Thus, by ensuring these protections and rights, the ADA has guaranteed a variety of opportunities for youth with developmental disabilities, such as competitive employment, independent living, and a high level of community involvement, that were not available two decades ago.

Educational Policy and Legislation

In 1975, the Education of All Handicapped Children Act (PL 94-142) mandated a free, appropriate public education for all children with disabilities. Aside from guaranteeing the education of all students, this act established regulations governing the terms of “Special Education.” For example, it mandated that all students receiving special education services have an individualized education program...
(IEP) that specifies current level of performance, annual goals, and services to be provided. More recent amendments also mandate that an IEP specify the extent to which the student will be included in the general education curriculum. In 1990, this act was amended and renamed the Individuals with Disabilities Education Act (IDEA; PL 101-476). Since then, the IDEA has been amended and reauthorized twice, in 1997 (PL 105-17) and, most recently, in 2004 (PL 108-446).

Since 1990, the IDEA has included specific language that addressed the preparation of students for the transition from school to adulthood. Specifically, it mandates that schools must provide adolescents with disabilities with instructional and experiential opportunities that foster the skills necessary to function successfully after high school. Transition services, as detailed in IDEA 2004, encompass a broad set of coordinated activities and services, including both academic instruction and community experiences, which are tailored to prepare students to meet their goals for adult life. For youth with developmental disabilities, primary transition goals most frequently include maximizing functional independence, enhancing social relationships, living independently, and working competitively in the community (National Longitudinal Transition Study 2, 2007a). A transition plan is developed in consideration of each child’s individual strengths, interests, and preferences and must be included in the IEP by age 16.

Although schools in the United States have made significant progress in their ability to implement transition plans for their students with disabilities (National Center on Secondary Education and Transition, 2004), their success in helping students with more severe impairments has been marginal. Recent findings from the National Longitudinal Transition Study 2 (2007b) report that, for youth with intellectual disabilities, less than 25% are described as making “a lot of progress” toward transition goals, as compared to 50% of youth with learning disabilities.

No Child Left Behind Other federal education legislation that has had particular relevance for youth with developmental disabilities is the No Child Left Behind Act of 2001 (NCLB; PL 107-110). The NCLB established a state accountability system that is monitored through standards-based testing for all students, including those who receive special education services. This act also gave the states flexibility to use alternate and/or modified methods of assessment (based on alternate and/or modified standards of achievement) to assess the progress of students with disabilities, thus aligning the NCLB with existing IDEA regulations that require all students to have access to the general education curriculum and to be included in general assessments. The inclusion of students with developmental disabilities under NCLB has placed additional emphasis on special education in the United States, providing both increased opportunities and increased challenges for students and teachers (Wakeman, Browder, Meier, & McColl, 2007).

Social Security Additional federal programs that significantly impact the lives of youth with developmental disabilities are those of the Social Security Administration, specifically, Supplemental Security Income (SSI) and Medicaid. SSI is an income assistance program for people with disabilities whose income and assets are sufficiently low to meet eligibility requirements. A significantly larger proportion of individuals with developmental disabilities than in the general population experience economic hardship, including children and youth with developmental disabilities and their families (e.g., Parish, 2003). In 2005, over 2 million children and youth received SSI payments, and about half of these were adolescents (U.S. Social Security Administration, 2007). In most states, those who apply for and are eligible for SSI are automatically enrolled in Medicaid, the federal program providing medical benefits to people with disabilities; however, in some states, individuals must apply separately.
Although both SSI and Medicaid are designed to reduce poverty and offset disability-related expenditures, neither program provides sufficient support (Parish, 2003). In 2006, the maximum federal SSI payment fell several thousand dollars short of the national poverty threshold (U.S. Department of Health and Human Services, 2006). Furthermore, the linking of SSI and Medicaid programs has created additional challenges and barriers for many parents of youth with disabilities. Because eligibility is linked to asset and income criteria, parents who are employed but have low-paying jobs risk losing comprehensive Medicaid benefits for their children, regardless of whether their employers offer health care benefits (Parish, 2003; Turnbull et al., 2007). Moreover, children and youth with developmental disabilities often have complex health problems (Lotstein, McPherson, Stickland, & Newacheck, 2005), and some of these health concerns may increase or worsen during the adolescent years due to hormonal changes, making this a particularly challenging and stressful time for parents. To address this problem, the Deficit Reduction Act of 2005 (PL 109-171) included the Family Opportunity Act, which authorized states to offer families of children with disabilities who do not meet SSI income eligibility requirements to buy-in to Medicaid. The act allows states to offer this opportunity to families with incomes up to 300% of poverty, and it is projected that by 2010, all children under the age of 18 that meet eligibility requirements will be covered.

Although clearly there are policies in place to aid and support adolescents with disabilities and their families, accessing and coordinating these services can be a significant responsibility and a source of stress (Schneider, Wedgewood, Llewellyn, & McConnell, 2006). It is striking that presently there is little to no interagency collaboration, and therefore the integration of these rights and resources is left to the adolescent and his or her parents, many of whom may already have limited resources. A recent study found that this was one of the greatest challenges faced by families; parents spoke of the complexity of navigating multiple service delivery systems that was exacerbated by a dearth of available information and the lack of coordination between agencies and schools (Timmons, Whitney-Thomas, McIntyre, Butterworth, & Allen, 2004). Indicating that this is not a situation unique to families in the United States, an Australian study concluded that, “the frustrations, difficulties, and delays typically encountered in accessing many services appeared to add to, rather than alleviate, the pressure and workload of families” (Schneider et al., p. 932).

HEALTH AND WELL-BEING OF ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES

Although health and well-being are important areas of concern for anyone focusing on adolescent development, they have increased salience when considering those with developmental disabilities. Particular health concerns emerge for adolescents with specific disabilities. For example, among adolescents with autism, the risk for the onset of seizure disorders during adolescence is at least 20 times that of the general population (Spector & Volkmar, 2006). Due to scientific advances in medicine, many children with developmental disabilities now have much longer survival rates, and some of their adolescent health care needs are only beginning to be understood (Bittles, 2002). Notably, children with Down syndrome now have a life expectancy well into the adult years, primarily due to major changes in surgical treatment of cardiac anomalies during early life and better health care services overall (Glasson, Sullivan, Hussain, Pettersson, Montgomery, & Bittles, 2002).

Sleep disruption is an area of increasing attention for those with intellectual disability (Sajith & Clarke, 2007), and obesity and obesity-related secondary conditions tend to be a concern for many adolescents with developmental disabilities (Rimmer, Rowland, & Yamaki, 2007). There is also evidence that the symptoms of particular developmental
disabilities change during the adolescent period. Shattuck et al. (2007) report that there is a gradual pattern of improvement in the core symptoms of autism during adolescence and adulthood, although residual levels of impairment remain clinically significant. The American Academy of Pediatrics (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians–American Society of Internal Medicine, 2002) has called for pediatricians and other health care providers to become better educated about the population of children with special health care needs as increasing numbers are moving into the adolescent and emerging adult periods.

**Transition to Adult Health Care Services**

The entry into the late-adolescent period brings with it a transition in health care services from the pediatric, family-focused system to the adult, specific-care system. The American Academy of Pediatrics and other medical professional organizations recommend that all adolescents with special health care needs have a written health care transition plan by the age of 14 years (American Academy of Pediatrics et al., 2002), yet empirical studies indicate that this rarely occurs (e.g., Scal & Ireland, 2005). Although all adolescents or young adults need to move from the pediatric to the adult health care system, those with special health care needs or with developmental disabilities and their parents experience more disruption with this transition at least partially because the pediatric and adult systems of care represent different subcultures (Reiss, Gibson & Walker, 2005). Some find the more fragmented services available for adults to lack a necessary focus on the well-being of the adolescent as a developing person. Others find it difficult to leave a pediatrician who has known the child and family since birth. Mitchell and Hauser-Cram (2008) reported that satisfaction with the health care of their adolescent with developmental disabilities predicted maternal psychological well-being. Consistent with family systems theory (Minuchin, 2002), the adolescent is not the only one affected by the relationship with the health care system providing services to him or her.

One indicator of an adolescent’s readiness to make the transition to adult services is his or her knowledge of sexual health (Ledlie, 2007). Sexuality, however, is an area of well-being that has been neglected in the study of adolescents with developmental disabilities. This neglect may be due to societal discomforts and misperceptions (Gordon, Tschopp, & Feldman, 2004); but like all adolescents, those with developmental disabilities are sexual beings (Committee on Children with Disabilities, 1996). Some disabilities, such as cystic fibrosis, are associated with slower-than-typical pubertal development whereas others, such as spina bifida, are associated with precocious puberty (Holmbeck, 2002). Although parents, health providers, and, most importantly, the adolescents themselves need information on changes to expect during puberty, little syndrome-specific information is available and even less is known about the behavioral correlates of those pubertal changes.

A few studies, however, indicate that parents are concerned about sexual abuse of their adolescent with developmental disabilities (Wilgosh, 1993). Prevalence rates of being abused are higher among those with developmental disabilities, although rates vary widely (Hodapp et al., 2006). In particular, girls with Williams syndrome may be at increased risk for sexual abuse given their tendency toward social disinhibition, and at least one study indicates that abuse rates may be higher for this group (Davies, Udwin, & Howlin, 1998).

**Mental Health and Behavior Problems**

The study of children and adolescents with developmental disabilities is sometimes placed within the field of developmental psychopathology. Generally, those who have developmental disabilities can be classified by the system detailed by the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition
and intellectual disability (formerly termed mental retardation) is included in the DSM-IV categorization of psychiatric diagnoses. Adolescents with intellectual and other developmental disabilities do not necessarily, however, have mental health issues. Therefore, the presumption of psychopathology as an inevitable correlate of having a developmental disability is unwarranted.

Nevertheless, the likelihood of behavior problems is known to be increased in this group. Some individuals have specific genotypic disabilities that are associated with specific behavior problems. For example, Prader-Willi syndrome is associated with extreme hyperphagia (i.e., overeating). In contrast, those with Down syndrome have fewer difficulties with mental health in comparison to individuals with other forms of intellectual disability (Mantry et al., 2007). Longitudinal studies of behavior problems in children and adolescents with developmental disabilities indicate a prevalence rate around 40% (Einfeld & Tonge, 1996; Stromme & Diseth, 2000). That rate is notably higher than reported for the typical population of adolescents (Roberts, Attkisson, & Rosenblatt, 1998). In reviewing prior longitudinal studies of children with developmental disabilities, Chadwick, Kusel, Cuddy, and Taylor (2005) note that although stability of behavior problems remains fairly strong across developmental periods, a decrease in such problems tends to occur during the adolescent years. Lounds, Seltzer, Greenberg, and Shattuck (2007) reported that nearly half of their sample of 140 adolescents and adults with autism decreased in the number of behavior problems manifested over a 3-year period. In results from their longitudinal study of those with severe intellectual disabilities, Chadwick et al. (2004) found that the rates of some behavior problems decreased, especially in areas of overactivity. Two longitudinal birth-cohort samples were used in the Dutch Mental Health Study, allowing comparisons to be made between those with and without intellectual disabilities. In one such comparison, de Ruiter, Dekker, Verhulst, and Koot (2007) concluded that children with intellectual disabilities had higher rates of problem behaviors across all ages but showed greater decreases in these behaviors during the adolescent period in comparison to other adolescents. Problems with aggression and attention showed notable decreases in the adolescents with intellectual disabilities, but problems in social-relating areas increased. Given the importance of peer relationships during the adolescent period, such findings underscore the importance of considering distinct types of behavior problems rather than an aggregation of problem behaviors or a division into the general categories of internalizing and externalizing problems.

As in studies of typically developing adolescents, investigations of those with developmental disabilities indicate that behavior problems are not entirely biologically based. Emerson, Robertson, and Wood (2005) found higher levels of behavior problems among those adolescents with intellectual disabilities living in low-income areas; this relation was stronger among those with relatively higher intellectual functioning than in those with more severe intellectual disabilities. The levels of psychological distress experienced by parents as well as the management strategies used by parents (Emerson, 2003) are also correlates of behavior problems in children and adolescents with intellectual disabilities. The sociocultural factors associated with increased likelihood of behavior problems, such as aggression, in typically developing youth (Watson, Fischer, Andreas, & Smith, 2004) appear also to be operational among those with developmental disabilities, although such factors may possibly operate differently among those with low levels of cognitive skills.

For adolescents as a group, an increased rate of psychiatric disorders has been noted to occur during the adolescent period, particularly depression among females and specific mental health conditions, such as schizophrenia, which have their onset during the adolescent
or early adult period (Rutter, 1990). The extent to which such disorders emerge during adolescence among those with developmental disabilities is not known. Based on only a few studies, an increased risk of psychiatric disorders has been found for adolescents on the autism spectrum. Tantam (2000), for example, reported that such adolescents were more likely to experience depression. In a longitudinal study of adolescents with severe intellectual disabilities, however, Chadwick et al. (2005) found only a few cases (<10%) of individuals developing psychiatric disorders de novo in adolescence. The reliability of psychiatric diagnosis in those with intellectual disabilities is uncertain, however, and concerns about individuals with a dual diagnosis of intellectual disability and a psychiatric disorder are mounting (Sturmey, Lindsay, & Didden, 2007). One basis for such concerns is the increasing awareness that the emotional needs of those with intellectual disabilities may have been overlooked by a focus on their cognitive limitations. A related concern, however, is the lack of strong evidence about productive interventions for this population of adolescents, although pharmaceutical, behavioral, and, to a lesser extent, other therapies are increasingly common and have met with some success (Hodapp et al., 2006; Lounds et al., 2007).

In summary, it would be erroneous to assume that all adolescents with developmental disabilities have psychopathological problems. Although the likelihood of behavior problems is clearly much higher in this population than in typically developing youth, over half of adolescents with developmental disabilities do not exhibit high levels of problematic behaviors. The risk of having psychiatric disorders is somewhat elevated; however, we know less about the onset and course of such disorders among adolescents with developmental disabilities. The importance of diagnosing and treating behavior problems and psychiatric disorders should not be diminished, as such concerns are likely to affect the adolescent’s sense of self, interaction with peers and family, and ultimate well-being.

THEORETICAL MODELS OF ADOLESCENT DEVELOPMENT: APPLICATIONS TO ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES

Several current themes in the scholarship on adolescent development have particular relevance to, and raise provocative questions about, adolescents with developmental disabilities. Adolescence is a time of identity exploration and the development of a deeper and more complex understanding of self. It is also a period of establishing greater connection to others, especially peers, while reconfiguring relationships with parents and siblings. Finally, integral to these psychological changes and concomitant challenges and accomplishments is the sense of personal agency that can promote or dampen positive developmental change. Given the cognitive and often social challenges of many adolescents with developmental disabilities, what do we know about their development of a sense of self, their construction of a peer network, and their enactment of agentic behaviors?

Development of a Sense of Self

Adolescence is traditionally seen as a time of identity formation, developing a coherent sense of self based on values and ideological commitments (Erikson, 1950). Although Erikson originally depicted a stagelike progression in the development of the ego, with identity formation as a core event in the life of the adolescent, current theory places such formation within a developmental systems model in which the individual attempts to “make meaning” of his or her experiences (Kunnen & Bosma, 2000). From the perspective of developmental systems theory, identity development is not independent of other developmental transitions as identity emerges in part from transitions in cognition and metacognition, likely corresponding with neurodevelopmental changes.
in the brain that result in an integrated, reflective consciousness (Keating, 2004). Much research reviewed in this volume indicates that adolescence is a time when strength in executive processing emerges, not just for cognitive tasks but also for social challenges. Gaining a perspective of oneself (albeit a changing one) is a hallmark of adolescence; yet research on self-perception among adolescents with developmental disabilities is extremely limited. How do adolescents with developmental disabilities "make meaning" of their experiences and view themselves?

In one of the few investigations on this topic, Davies and Jenkins (1997) conducted interviews with 53 young adults with intellectual disabilities and their caregivers. They found that only eight participants understood the terms traditionally applied to their disability (e.g., mental handicap) and that most parents and other caregivers reported choosing not to discuss the meaning of such terms with the young adults. Nevertheless, many of these young adults incorporated a sense of diminished personal agency and of many societal limitations into their view of self, created through their daily experiences with adults, including caregivers, parents, and employers, who had authority over them.

Given current policies in the United States, especially IDEA, that mandate the rights of adolescents to participate in meetings involving their educational future, parental decisions about whether or not to discuss an adolescent's disability with him or her may not limit the adolescent's actual knowledge of that disability. Gildden and Zetlin (1992) suggest that part of the identity struggle for adolescents with developmental disabilities is related to the need for and resistance to awareness of their differences, especially if they perceive such differences as likely to have an immediate effect on their daily lives. Examples of these differences—such as driving a car, leaving home to live elsewhere, and having a job—all contribute to social comparisons for adolescents with developmental disabilities, especially during mid and late adolescence.

There are indications, however, that genotypical variations exist in self-concept. For example, Begley (1999) found that the self-concept of individuals with Down syndrome appears to be more positive than those with other intellectual disabilities and to increase between middle childhood and adolescence. She further found that such students differentiated their sense of competence and their sense of acceptance, as they tended to rate themselves relatively lower on scales measuring the latter. Glenn and Cunningham (2001) also reported positive ratings of general self-worth for adolescents and young adults with Down syndrome with more discriminative distinctions among domains of self-perception with increasing mental age. Shields, Murdoch, Loy, Dodd, and Taylor (2006) conducted a systematic review of self-concept in children and adolescents with cerebral palsy in comparison to other children and found that adolescent females with cerebral palsy (in comparison to typically developing adolescent females) had a lower self-concept in the domains of social acceptance, physical appearance, and athletic and scholastic competence. As found for typically developing adolescents, social acceptance and physical appearance appear to be areas that relate heavily to overall sense of self (Harter, 1986).

Ironically, as Glenn and Cunningham (2001) note, if adolescents with developmental disabilities have immature levels of cognitive processing (i.e., below the mental age of 6–7 years), they tend to be more positive in their views of themselves. For example, in a study of children with spina bifida, Mincham et al. (1995) reported that children with lower cognitive performance gave themselves higher ratings in the area of self-worth. This may be because those with lower cognitive performance, like preschool-age children, lack the skills required to make social comparisons and tend to describe themselves based primarily on physical attributes (Selman, 1980). Moreover, traditional measures of self-esteem and self-concept require making fine distinctions, often
on a Likert scale, that are not always apparent to those with intellectual disabilities.

Given the difficulties in using quantitative measures of self-concept, several studies have employed qualitative methodologies to describe the multiple tasks involved in developing a sense of self when one has a disability. In a study by Olney and Kim (2001), college students with cognitive or emotional disabilities explained the complex processes involved in self-definitions that included their limitations but did not simultaneously pathologize their differences. Unlike those with physical disabilities, they wrestled with whether and how to disclose their disabilities to others. Like others with disabilities, however, they worried about stigmatizing and patronizing attitudes of peers.

Mpofu and Harley (2006) propose that determinants of disability identity are similar to those of racial identity in that both types of identity are socially constructed phenomena. They maintain that those with a healthy disability identity view their disability difference as a resource for growth. Like resilient racial identity described by Spencer (2006), resilient disability identity might serve valuable protective, compensatory, and self-enhancement functions. Racial identity, as described by Cross (2001) and Helms (1995), however, is a staged process and the extent to which children and adolescent with disabilities emerge through different life phase understandings of themselves in relation to having a disability is not known.

Moving beyond a psychological approach to the question of identity development in adolescents with developmental disabilities to a philosophical one offers a different and provocative perspective. Much work in this area is based on Foucault’s (1994) themes of power, knowledge, and subjectivity as activities that produce and maintain the concept of disability as an “impaired body.” Even the term disability implies its opposite—ability—and, according to this social theory, establishes unnecessary dichotomies that impose on the self-surveillance of individuals as they construct an identity and a sense of self (Reeve, 2002). By shifting the emphasis on the phenomenon of identity development from the individual to the societal level, the adolescent need not accept the larger social model and instead can replace it with a view of self as a social actor (Block, Balcazar, & Keys, 2002). Empirical research is lacking, however, on whether and how such shifts occur for adolescents with developmental disabilities in their understanding of self.

Development of a Peer Network
Adolescence is a time when social networks often change both in breadth and in depth. During the adolescent period, friendships typically change from being activity oriented to being relationships with strong emotional ties (Buhrmester & Furman, 1987). Friendships during adolescence provide companionship but also promote important social cognitive advances in areas such as conflict resolution, reciprocity, intimacy, and dimensions of trust and loyalty (Hartup, 1993). Friendships, therefore, are important to an adolescent’s sense of well-being but also serve to advance development in significant ways.

Because of federal mandates, adolescents with developmental disabilities are now included with typically developing adolescents in many school classes and activities. Nevertheless, research on social interaction between students with and without a disability, although extensive for the preschool age group, is lacking for the secondary school level. The few studies that have been conducted report similar findings and point to the small and often inadequate social networks of adolescents with disabilities.

In a comparison of adolescents with and without intellectual disabilities, Zetlin and Murtaugh (1988) found that those with intellectual disabilities not only had fewer friends but also tended to have more relatives in their friendship group. Moreover, their friendships tended to be less stable and to have more conflicts than those of typically developing adolescents. A study by Heiman (2000)
indicated that high levels of "feeling alone" (three to four times higher) were reported by students with intellectual disabilities in comparison to other students. They also were less likely to meet their peers out of school. Orsmond, Krauss, and Seltzer (2004) reported that almost half of their sample of 235 adolescents and adults with autism were reported not to have any reciprocal peer relationships with same-aged persons.

The nature of friendships of adolescents with developmental disabilities has been explored in a few studies. Bottroff et al. (2002) conducted a small-scale study of adolescents and young adults with Down syndrome and classified their friendships according to Selman's (1980) model of developmental stages of friendship formation. They found that only 25% of their sample could be classified at a friendship level that indicated mutual trust and reciprocity, whereas more friendships were classified at the lower levels based on simple proximity. Several participants, however, reported having imaginary friends, possibly a compensation strategy for such adolescents. In an ethnographic study of friendship among adolescents with developmental disabilities, Matheson, Olsen, and Weisner (2007) found that participating in shared activities and being perceived as similar were common themes in determining friendships, as was an ability to be available over time. Unlike typically developing adolescents, however, the adolescents with disabilities stressed that attributes of friendships often involved mere proximity and being in a group together, whereas notions of trust and reciprocity were mentioned less frequently.

One reason for the lack of strong reciprocal friendships found among adolescents with intellectual disabilities is likely related to individual levels of social cognitive processes. Interpreting social cues, developing strategies for approaching and responding to peers, and self-evaluation and monitoring are all central processes required for productive social interaction. Research indicates that in each of these areas individuals with intellectual disabilities exhibit more difficulties than those developing typically (Leffert & Siperstein, 2002). Syndrome-specific patterns of relative strengths and weaknesses in areas of social cognition also exist. For example, children with Williams syndrome often orient to and prefer social stimuli and are relatively successful in identifying others, seeing others as approachable, and imitating their affective states (Bellugi, Adolphs, Cassady, & Chiles, 1999), whereas they are less successful in perspective taking and decision making based on affective cues (Fidler, Hepburn, Most, Philofsky, & Rogers, 2007).

In a review of studies of children and adolescents with Down syndrome, Wishart (2007) speculated that their heightened sociability may be misunderstood as having good interpersonal understanding. Highly sociable behavior may, in fact, distract those with Down syndrome from developing more complex social cognitive skills necessary to collaborate with and learn from others using joint engagement on tasks. Studies on children and adolescents with autism spectrum disorders indicate that they have pronounced difficulty in social perspective taking, and thus tend to be limited in their ability to perceive the world through the eyes of others (Spector & Volkmar, 2006). This deficit has been attributed to impairment in the "theory of mind," that is, the ability to impute mental states to oneself and others, and thus make inferences regarding the thoughts of others (Baron-Cohen, 1995). In general, the growing literature on syndrome-specific disabilities is likely to lead to a greater understanding of the various aspects of social cognition necessary for the development and sustenance of friendships during the adolescent years as well as guide the field toward more productive interventions for adolescents with developmental disabilities who lack specific skills and are either rejected or ignored by their peers.

Development of Self-Agency
From a developmental systems perspective, the individual is an instrument of self-agency and,
therefore, to some extent promotes his or her own development (Lerner, 2002). The action psychology model of Brandstädter (1998) and the agentic model of Baltes (1997) are relevant to the development of all adolescents, but have especially important implications for those with developmental disabilities. Agency is indicated in an adolescent's motivated approach to problem-posing tasks and situations, and is revealed by the adolescent's overture to others, including family members, engagement in the world of work or further schooling, and attempts to develop self-sufficiency to the extent possible. Those whose agentic actions are intruded upon or usurped by others risk developing behaviors indicative of learned helplessness, a pattern that has been found to be typical of many young adults with developmental disabilities (Jenkinson, 1999).

Autonomy implies the ability to act according to one's preferences, interests, and abilities, and therefore requires knowledge of self (Wehmeyer, 1996) but also involves the opportunity for choice. The importance of self-agency, which is required for autonomous behavior, is a continuing theme in the literature on children with developmental disabilities. In our longitudinal study of children with Down syndrome, motor impairment, or developmental delay (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001), we found that children's early strivings for agency predicted their adaptive skill development over a 10-year period. From a systems perspective, positive skill development is likely to provide children and adolescents with additional opportunities for self-determination, which in turn compounds the positive effects of agency.

Wehmeyer has conducted a series of studies on self-determination in individuals with developmental disabilities. In an investigation of adolescents, he reported both a positive relation between self-determination and age as well as higher scores for typically developing adolescents in comparison to those with disabilities (Wehmeyer, 1996). Considering only individuals with intellectual disabilities, Wehmeyer and Garner (2003) reported a low correlation between level of intelligence and self-determination scores with only opportunities for choice (not intellectual performance) predicting membership in a high self-determination group. Wehmeyer and Schwartz (1998) reported that adolescents with developmental disabilities who had higher levels of self-determination had more positive adult outcomes, including higher rates of employment.

Employment offers one opportunity for increased autonomy, since through employment adolescents often develop a sense of responsibility, increased self-reliance, and expanded social networks. The employment of adolescents and young adults with developmental disabilities has received more attention than any other aspect of this phase of life. Findings from the National Longitudinal Transition Study 2 (Wagner, Newman, Cameto, Levine, & Garza, 2006), a longitudinal survey-based study of adolescents with a wide range of disabilities, indicated that at the time of the survey more than 40% of youth were employed, compared to 63% of the same-age out-of-school youth in the general population. These rates of employment varied considerably, however, based on type of disability, with highest rates among those with learning disabilities and far lower rates among those with intellectual disabilities. Rates also varied based on ethnicity, with highest rates among whites and lowest rates among African Americans and Native Americans. These figures indicate generally more positive trends than found in data collected two decades ago, but they still accentuate lower rates for those with disabilities than for the typically developing population, and they mimic the social inequities by ethnicity. Wagner et al. (2006) found that the reliance on low-paying caregiving jobs for females has decreased and the percentage of jobs in the trades has increased among males. Despite such generally positive trends in engagement in employment for adolescents and young adults with disabilities, students with cognitive disabilities report that...
they have few opportunities to work in paid
jobs in career areas of their choice (Powers
et al., 2007).

One of the greatest changes over the last
decade has been an increase in opportunities
for youth with developmental disabilities to
attend postsecondary education programs.
Wagner et al. (2006) found that about 30% of
youth with disabilities were enrolled in some
type of postsecondary school. Although this
rate is still lower than that among typically
developing youth (41%), this figure illustrates
the potential role of community colleges and
other institutions in increasing their services to
adolescents and young adults with disabilities.
Howlin (2000) notes the expanding number
of higher functioning adolescents with autism
spectrum disorders who now attend college,
especially smaller colleges, supported by
a range of mental health and peer mentoring
services. The need for such postsecond­
ary programs is likely to continue to grow as
adolescents with developmental disabilities
who have experienced education under the
support of the IDEA emerge from high schools
and push for a range of future educational and
employment training opportunities.

Transition in Relationships with
Parents
One of the hallmarks of adolescence is a
reconfiguration of relationships with parents
from one of dependency toward one of greater
mutuality. Although such reconfiguration often
involves struggles on the part of both the ado­
lescent and the parent, national data indicate
that most adolescent–parent relationships are
positive (Moore, Guzman, Hair, Lippman, &
Garrett, 2004). Such close and positive adoles­
cent–parent relationships are related to a wide
range of benefits for adolescents, including
better academic outcomes and fewer problem
behaviors (Moore et al., 2004).

Most adolescents with disabilities also
report having strong and positive relationships
with their parents (Wagner et al., 2006). They
differ from other adolescents, however, in that
they report receiving a great deal of attention
from their families, more so than that reported
by other adolescents (Wagner et al., 2006).
Although such attention may indicate high lev­
els of protection, resulting in less development
of autonomy, it may also be a response to the
adolescent’s need for support from a trusted
adult. Collins and Laursen (2004) propose that
adolescent–parent relationships often serve
to modify the impact of deleterious sources
of influence, such as difficulties at school or
destructive peer relationships. Although this
proposition has not been tested explicitly in
relation to adolescents with disabilities, survey
data from parents of adolescents or young adults
with disabilities leaving high school indicate
that parents are well aware of the dilemmas they
face regarding their dual role in the promotion
of independence and the protection from harm
of their child (Thorin, Yovanoff, & Irvin, 1996).
Protection may limit immediate opportunities
for independence but may serve an intermediate
function that, in turn, promotes autonomy. For
example, Dixon and Reddcliff (2001) found
that parental behaviors aimed at protecting their
adolescent with developmental disabilities from
difficulties and exploitation also led to more
successful employment outcomes.

Current trends in the United States indicate
that many young adults return to reside with
their parents during some periods of their
young adult life (Arnett, 2004; DaVanzo &
Goldscheider, 1990). In contrast to returning to
the family home for brief periods of time, many
adolescents with developmental disabilities
live with their parents consistently for many
years (Fujiura & Braddock, 1992; Seltzer &
Krauss, 1984). Seltzer, Greenberg, Floyd,
Pettee and Hong (2001), using data from the
Wisconsin Longitudinal Study, found that 57% of
the sons and daughters with a developmental
disability and 41% of those with multiple
mental health problems continued to live with
their parents, in contrast to only 16% of sons
and daughters without disabilities. In a study
of individuals with developmental disabilities
who had attended special education programs,
Scussimarra and Speece (1990) found that the majority resided with their parents, although over 75% of those individuals said they would prefer to live independently. Kraemer and Blacher (2001) investigated the living situations of young adults with low levels of intellectual functioning and found that the majority lived at home; furthermore, their parents did not identify leaving home as a primary goal for their child. Thus, the reasons that the young adult with developmental disabilities most likely continues to live at home appear to be multiply determined, based on a confluence of parental choice, whether living options are available, and the extent and the desire of the adolescent or young adult to advocate for such change.

Parents and other family members serve as a potentially strong support network for individuals with developmental disabilities but may also substitute for friends. In a study of young adults with mild to severe disabilities, McGrew, Johnson, and Bruininks (1994) reported that an inverse relation occurs between the number of family and non-family members in their social networks. Therefore, the parent–child relationship, although always complex, becomes increasingly so for adolescents with developmental disabilities, especially those who rely on parents for many aspects of their daily living and social activities.

FAMILIES OF ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES

Although early studies of parents of children with disabilities focused on issues such as “chronic sorrow” of parents (Olshansky, 1962), and assumed deleterious functioning of the parents, current research provides a more nuanced view of families. Drawing from several perspectives, a broad understanding of the family and its tasks and functioning over time have guided current investigations.

Conceptual Perspectives in Family Research

There has been a surge of research in the past several decades on the influence of children with developmental disabilities on their families and the influence of families on the development of children with developmental disabilities (e.g., Greenberg, Seltzer, Hong & Orsmond, 2006; Hauser-Cram et al., 2001; Keogh, Garnier, Bernheimer, & Gallimore, 2000; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Mink, Nihira, & Meyers, 1983; Parish, 2006; Seltzer & Heller, 1997). This body of research has roots in transactional theories of human development (Lerner, 2002; Sameroff & Fiese, 2000), models of the ecology of human development (Bronfenbrenner, 1979), family systems theory (Minuchin, 2002; Olson, Russell & Sprenkle, 1983), and family life cycle theory (Carter & McGoldrick, 1980). Common to all these theoretical roots are three core propositions:

1. Individual development is shaped by both the biological attributes of the individual and the multiple and complex environmental contexts over the life course in which the individual exists.
2. Changes in the individual and his/her environment affect other members of the individual’s environment in reciprocal and iterative ways.
3. There are predictable stages in human and family development that shape the tasks, functions, and behaviors of individuals and other family members.

Although this chapter focuses on a particular life stage for individuals with developmental disabilities and, by extension, of their families, much of what conditions the development of the adolescent and his/her family during this protracted period is linked to prior periods of individual development and family patterns, and is affected by the anticipated outcomes for the adolescent during adulthood.

In order to provide a context for considering the family environment of adolescents with developmental disabilities, a brief discussion of family life cycle theory is provided. Family life cycle theory posits that just as
individuals have stages of development, families as a collective unit pass through predictable stages over the life course. These stages are typically defined by the employment status of the head of the household, the entry into and exit of family members from the family, and the age of the oldest child in the family. Theorists of the family life cycle posit a variable number of stages, from as few as seven (Duvall, 1957) to as many as 24 (Rodgers, 1960). The most commonly used set of stages include the following: couple, childbearing, school age, adolescence, launching, postpubertal, and aging (Olson, McCubbin, Barnes, Larsen, Muxen, & Wilson, 1984). Within each stage, there are specific tasks and functions that families perform, including economic, physical, rest and recuperation, socialization, self-definition, affection, guidance, educational, and vocational (Turnbull, Summers, & Brotherson, 1986). For each stage, the priorities of these different functions vary and the roles that individual family members assume in the conduct of these functions reflect their individual developmental capabilities and needs. Particular functions may be heavily influenced by the age of the child.

For example, during the adolescent period, there is usually less emphasis by parents on the physical care of their child and greater emphasis on the child's vocational preparation. In contrast to the childbearing stage, when physical affection and contact is a dominant feature of the parent–child relationship, the adolescent stage is characterized by an emphasis on "letting go" and on reducing child dependency.

**Contemporary Perspectives on Family Impacts**

While there is scant research on the reciprocal influences of parents on their adolescents with developmental disabilities, there is a broader literature available on the life-span impacts on families of having a child with a developmental disability (Seltzer, Greenberg, Floyd, Pettee & Hong, 2001; Seltzer, Krauss, Osmond, & Vestal, 2001). Research on the role of the family for individuals with developmental disabilities acknowledges that the family occupies a central and enduring role over the life course and that taking a life-span perspective reveals undeniable stresses on parental well-being and health, as well as positively regarded accommodations to family life and values (Blacher & Baker, 2007; Heller, Hsieh, & Rowitz, 1997; Krauss & Seltzer, 1994).

Over the past several decades, there also has been a shift in perspectives on the impacts on families of having a son or daughter with a developmental disability. Decades ago, the common view among professionals and society at large was that having a child with a developmental disability was a burden on the family and was associated with deleterious outcomes for the parents and siblings (Hodapp, Ly, Fidler, & Ricci, 2001). Indeed, out-of-home placement of the affected child was commonly recommended (Seltzer & Krauss, 1984). With the advent of the parents' movement and changes in social policies ensuring educational and social services for persons with developmental disabilities since the 1960s, the role of and impacts on the family have been viewed from new perspectives that acknowledge the complex and multifaceted ways that families adapt to their caregiving responsibilities.

Helff and Glidden (1998) reviewed research on family impacts over a 20-year period (from the 1970s through the 1990s) and found that while there was a decrease in the "negativity" of the research, there was not a concomitant increase in perceived positivity of family impacts. Blacher and Baker (2007) provide an interesting three-level conceptual scheme for identifying positive impacts on families. The first is that positive impacts may be inferred by the absence of negative impacts (the "low negative" level). The second, called the "common benefits" level, refers to families experiencing the same joys and frustrations with their child as is typical of all families. The third, called the "special benefits" level, implies that there are unique benefits associated with having a child with a developmental disability.
Indeed, there is a growing body of literature that focuses on the resilience found among many families who have a child with a developmental disability. The concept of resilience implies more than just coping with a situation—it includes the capacity to withstand hardship and rebound from adversity. Scorgie and Sobsey (2000) examined parental views on the transformations they have experienced because of having a child with a developmental disability and found evidence of three major areas of transformational change: personal growth, improved relations with others, and changes in philosophical or spiritual values. Bayat (2007) surveyed 175 parents of children and adolescents with autism regarding factors contributing to “family resilience” and found evidence of family resilience such as family connectedness and closeness, positive meaning-making of the disability, and spiritual and personal growth. Grant, Ramcharan, and Flynn (2007) reported three core elements associated with resilience at the individual level—search for meaning, sense of control, and maintenance of valued identities.

Dykens (2005) reviewed contemporary literature with respect to happiness, well-being, and character strengths as outcomes in families, including siblings, of persons with intellectual disabilities. She notes that the “stress and coping” model used in many studies is useful in identifying why some families cope well with the common and unique stresses of having a child with a disability and others do not. Rather than assume that psychopathology is an inevitable outcome for such families, as was common decades ago (Olshtansky, 1962; Solnit & Stark, 1961), studies now focus on why many families cope well and derive valued meanings from their experiences. Indeed, there is considerable evidence that mothers with problem-focused coping styles generally fare better than those with emotional coping styles (Kim, Greenberg, Seltzer & Krauss, 2003).

According to Dykens (2006), the burgeoning interest in “positive psychology” (Seligman, 2000) should be extended to studies of persons with intellectual disabilities (and their families), for whom she argues that emotional states such as happiness, gratifications, and flow are relevant outcomes worthy of empirical investigation. Thus, there is a growing interest within the research community studying impacts on families of having a child with a developmental disability to examine positive contributions of such children (Hastings, Beck, & Hill, 2005), transformational (and positive) impacts on family members (Scorgie & Sobsey, 2000), and factors associated with a “meaningful life.”

Challenges to the Family in the Adolescent Period

The adolescent period is sometimes characterized by heightened turmoil for parents, who must cope with the effects of the biological, cognitive, social, and psychological maturation of their adolescent as well as parental transitions into the midlife period (Seltzer, Krauss, Choi, & Hong, 1996). Part of the transition from childhood to adulthood includes the “push and pull” of relinquishing parental roles of protectiveness, close supervision, and authority while adopting parenting styles that respect the adolescent’s emerging needs for autonomy, independence, and more egalitarian relationships with the parents. When the adolescent has a developmental disability, however, the normative tasks of adolescence and the normative tasks of parents during this period may be experienced in ways that are both similar and distinct in comparison to families of typically developing adolescents. As Zetlin and Turner (1985) note, “although retarded individuals experience the same biological changes and drives as nonretarded youngsters, the issues associated with adolescence—emancipation, self concept, sexuality—are exacerbated by the presence of their handicap” (p. 571).

Turnbull et al. (1986) articulated the major stressors arising from different family life course stages and the transitions across them for families of children with developmental disabilities. With respect to the adolescent period,
they note particular stressors such as the emotional adjustment to the chronicity of the handicapping condition and related issues such as peer isolation. Further, many families remain deeply involved in arranging for leisure-time activities as well as participating in educational and vocational planning tasks. Although some of these stressors are applicable to all families of adolescents (e.g., issues surrounding emerging sexuality, dealing with physical and emotional changes of puberty), some are relatively distinctive features of parenting a child with a developmental disability (e.g., future planning for vocational development, arranging for leisure-time activities, participation in IEP meetings). Indeed, as discussed below, parental roles in the transition of adolescents with developmental disabilities from school to work is one of the major areas of research on parental involvement during this life stage.

There is substantial evidence that the adolescent period has particular and specific stressful content for parents of children with developmental disabilities. The stressful content seems to span various dimensions, including sobering appraisals of the child’s developmental status, awareness of the potential for continued dependence (rather than independence) on the family, parallel parental transitions into their own midlife phase (and its attendant psychological tasks) (Todd and Jones, 2005), and trepidation over the end of federally guaranteed rights to services as children leave the special education system. Schneider et al. (2006) conducted ecocultural interviews with families of adolescents with severe disabilities and found both internal and external challenges to the maintenance of a meaningful family routine. Internally, family roles and relationships underwent change, resulting in various strategies to accommodate these changes (e.g., dividing up family time, protecting some members from too much involvement and engaging others in family activities). Externally, service discontinuities associated with the adolescent period were accommodated by various strategies such as advocacy, coordinating multiple services and forfeiting a desired alternative. Their research illustrates the dynamics within families of managing the needs of and impacts on the family as a unit during the adolescent period.

Baine, McDonald, Wilgosh, and Mellon (1993) conducted quantitative and qualitative research on sources of general and unique family stress among families of adolescents with severe disabilities. The most stressful issues included characteristics of the adolescent (i.e., dependency, lack of autonomy, individual vulnerability, physical size, severity of disability) and aspects of the service systems that support these individuals (i.e., transition from school to adult services, eligibility for government assistance, residential costs). The least stressful aspects related to family interpersonal dynamics (i.e., sibling relationships, parental philosophy). Follow-up interviews with a subsample of the families participating in the quantitative portion of their research revealed a deeper and wider range of concerns than were evident in the numerical ratings of the areas of potential stress. The authors (Baine et al., 1993) summarized parental concerns about individual characteristics of their adolescents with developmental disabilities as follows:

The parents expressed particular concerns about long-term, family life-planning related to chronic dependency of the persons with disabilities; physical management problems related to the increasing size and strength of the individual; concerns related to cleanliness, grooming, aggression, and inappropriate age and gender related behavior (e.g., expression of affection), and the amount of care required (‘we must plan everything around his needs’). (p. 185)

With respect to stressors for the family, the qualitative information revealed concerns about the costs of long-term care, often requiring family sacrifices, parental tension regarding the role or level of involvement of fathers, and the strain on parents of having to organize or create a social, educational, and supportive world for their adolescent child.
Harris, Glasberg, and Delmolino (1998) propose that for families of children with developmental disabilities, adolescence may signify the end of illusion. Parental aspirations and dreams about dramatic changes in their child's functional abilities may be tempered by a clearer awareness of the child's developmental trajectory. Bristol and Schopler (1983), for example, note that parents of adolescents with autism have a greater sense of realism and pessimism about their child's development in comparison to parents of younger children with this disorder.

Wikler (1986) suggests that there is a cyclical quality to family stress over different developmental stages. Her research indicates that stress is highest in families of a child with developmental disabilities who is just entering early adolescence or early adulthood, as compared to stress among families whose child with disabilities is in later adolescence or further into young adulthood. One explanation for the increased stress for families of adolescents with disabilities was attributed to the degree of community acceptance offered to children with developmental disabilities at different life stages.

DeMyer and Goldberg (1983) and Bristol (1984) note that as children with developmental disabilities age, their behaviors are less well tolerated by society and they are less socially acceptable than younger children who, despite their disabilities, may be seen as "cute" or whose atypical behaviors are less different from the range of behaviors of typically developing children. The lack of community acceptance for adolescents with developmental disabilities may translate into greater social isolation of their families, and may instill a greater rigidity of family routines, in comparison to families of typically developing adolescents for whom social acceptance issues are less pressing and for whom more relaxed family routines often emerge as a consequence of the increasing independence of their adolescent.

For many parents of children with developmental disabilities, there is a complex mixture of gratification and frustration encountered in the parenting experience, leading to what Larson (1998) calls the "embrace of paradox." Based on a study of Latina mothers of children with developmental disabilities, Larson (1998) explained this phenomenon as follows:

Despite what would appear as multiple limitations in their daily lives due to the caretaking of a child with disability, these mothers shared hopeful maternal visions and profound personal growth that emerged because of this experience. What surfaced . . . was a life metaphor, the embrace of paradox, that was central to the mothers' maternal work. The embrace of paradox was the management of the internal tension of opposing forces between loving the child as he or she was and wanting to erase the disability, between dealing with the incurability while pursuing solutions, and between maintaining hopefulness for the child's future while being given negative information and battling their own fears. (p. 873)

Parental narratives of their lives with children with developmental disabilities echo Larson's description, particularly during the adolescent period, when the realignment of parental roles in the face of their child's efforts towards independence and autonomy constitutes a compelling family challenge (e.g., Dunsford, 2007; Kaufman, 1999; Park, 2001; Todd & Jones, 2005).

Zetlin and Turner (1985) conducted an ethnographic study of 25 young adults with mild intellectual disabilities about their adolescence. The study included in-depth participant observation and interviews with the young adults and extensive interviewing of their parents. Their results provide insights into the interactions between parents and adolescents with intellectual disabilities during a stage of life when, for some, the social consequences of their disabilities become painfully manifest. They concluded that:

. . . it appears that both parents and sample members viewed the adolescent experience as more problematic than either the childhood...
period or the adult years and generally agreed on the nature of the adolescent conflicts. For the most part, these retarded adolescents were concerned with the same issues that preoccupy nonretarded adolescents—personal identity and autonomy. They interpreted parental attitudes and practices as nonsupportive and issues of competence and self-definition as sources of frustration and self-conflict. . . . The implications of their handicapped status as well as their limitations were salient concerns for the first time, and many of their experiences—parental restrictiveness, peer rejection, expectancy-performance discrepancies—contributed to their uneasiness and discontent. (p. 578)

There is a growing body of literature that examines changes in the parent–child relationship during the adolescent period. Orsmond, Seltzer, Greenberg, and Krauss (2003) studied the mother–child relationship among 202 adolescents and adults with autism living at home and found that for most of their sample, the mother–child relationship was characterized as positive across multiple measures. They also found that greater positive affect and warmth from the mother to the child was predictive of fewer maternal caregiving strains and greater caregiving gains. In a subsequent analysis from this study, Lounds et al. (2007) reported that during the adolescent period, there was a dominant pattern of improvement in maternal well-being and a closer relationship with their son or daughter with autism. Interestingly, they found that mothers of daughters experienced significantly greater reduction in depressive symptoms and increasing closeness in the mother–child relationship over the 1.5-year study period than mothers of sons.

Planning as a Unique Task for Families of Adolescents
As noted earlier, one of the markers of the end of the adolescent period is the assumption of adult roles, including employment, self-sufficiency, and formation of independent family units. For many individuals with developmental disabilities, these roles are particularly problematic. Because of the ongoing and heightened responsibilities of parents in planning for the future of their adolescents with disabilities, parental involvement in shaping the future may be far more extensive than is the case among families of typically developing adolescents. Thorin, Yovanoff, and Irvin (1996) articulated the six most common dilemmas reported by parents of adolescents with developmental disabilities as wanting to:

- Create opportunities for independence for the young adult, especially in light of health and safety needs.
- Do whatever is necessary to assure a good life for him or her.
- Provide stability and predictability in the family life while meeting the changing needs of the young adult and family.
- Create a separate social life for the young adult.
- Avoid parental burnout.
- Maximize the young adult's growth and potential.

This enumeration of parental dilemmas underscores the fact that for many families of adolescents with developmental disabilities, the parental role intensifies rather than diminishes during the period of transition to adulthood. Parental involvement occurs in regard to fundamental issues of protecting their child’s health and safety, to constructing or arranging environments in which their child’s social and economic life can be supported, and to providing a context in which their child’s capabilities are maximized. These tasks constitute an atypical agenda in comparison to the tasks of parents of typically developing adolescents.

Indeed, the degree of planning that families need to do—repeatedly—over the life cycle has been consistently underscored. Nadworny and Haddad (2007) propose that planning is a lifelong activity, providing opportunities for reassessing goals and roles that various family members (and extended support people) can assume. They also note that planning must take
into account the needs of all family members, not just the member with a developmental disability. Finally, they note that there are specific “pressure points”—transitions in the service delivery system and age-related changes—that punctuate particular planning needs. These pressure points need to include an examination of family issues, emotional needs, financial issues, legal considerations, and government benefits.

One of the unique tasks facing families of adolescents with developmental disabilities is planning for their adolescent’s transition from special education services to adulthood. There is considerable evidence that the prospect of losing the mandated educational and related services guaranteed by the IDEA when a child with a disability reaches the age of 22 is one of the most stressful aspects of the adolescent period for parents (Thorin & Irvin, 1992). Recent estimates suggest that over 2 million students between ages 14 and 21 receive special education services under the IDEA (U.S. Department of Education, 2007a). Of these, approximately 400,000 exit the school system each year and enter the adult world (U.S. Department of Education, 2007b). As indicated in an earlier section, a component of the Individuals with Disabilities Education Act (IDEA) of 1990 requires that an individualized transition plan be crafted as part of a student’s IEP that identifies needed transition services. Parents are expected to be part of that planning process.

Studies of the “transition process” from school to work have found that parents of children with disabilities are significantly less involved in transition planning than they desire to be (McNair & Rusch, 1991), although it appears that parental involvement increases as the severity of the child’s disability increases (Kraemer & Blacher, 2001). Because a hallmark of being an adult is being employed (leading to economic self-sufficiency), and because of the many social benefits attributed to being employed, there is a great deal of attention in the practice and research literature on efforts by parents and service systems to enhance the future employability of adolescents with developmental disabilities. Parental expectations for the future vocational activities of their adolescents with disabilities are an important factor in such transition plans. In a study conducted by Kraemer and Blacher (2001), almost two-thirds of parents of children with severe intellectual disabilities expected their child to work, most commonly in a day activity center or sheltered workshop. Parent roles in achieving desired vocational outcomes were examined in a qualitative study that identified the following important family characteristics: moral support, practical assistance, role models of appropriate work ethic, protection from difficulties and exploitation, and family cohesion (Dixon & Reddickiff, 2001). Clearly, parents occupy a critical position in the lives of youth with developmental disabilities, and parents’ engagement in planning activities for the adult life of their adolescent constitutes a major family task of the adolescent period.

Sibling Relationships

There is very little research that has focused specifically on the sibling relationships of youth with disabilities during the adolescent years. The few studies that have been conducted indicate that these relationships appear to be qualitatively different from those that exist between typically developing siblings. Krauss and Seltzer (2001) reported that siblings of brothers and sisters with disabilities often experience issues that are unique to their family situation and that may set them apart from their friends who do not have a sibling with a disability. The relationships among typically developing siblings are often characterized by two particular dimensions of involvement—affective involvement and instrumental involvement—and these dimensions have been studied, although to a lesser extent, among siblings when one has a developmental disability.

Affective Involvement

Research on the relationships shared by typically developing siblings often focuses on two
affective components: the positive dimension of warmth and the negative dimension of conflict (Bowerman & Dobash, 1974; Furman & Buhrmester, 1985). The relationships between individuals with disabilities and their siblings are frequently characterized by warmth and affection across a range of ages and life-course stages, including adolescence and young adulthood (e.g., Bagenholm & Gillberg, 1991; Begun, 1989; Eisenberg, Baker, & Blacher, 1998; Gath, 1973; McHale, Sloan, & Simeonsson, 1986; Rivers & Stoneman, 2003; Stoneman, Brody, Davis, & Crapps, 1987b). Siblings of individuals with disabilities appear to demonstrate more nurturance, empathy, and emotional support for their brothers and sisters than do comparison siblings of typically developing individuals (Abramovitch, Stanhope, Pepler, & Corter, 1987; Cuskelly & Gunn, 2003; Hannah & Midlarsky, 2005; McHale & Gamble, 1987; McHale et al., 1986). This substantiates the depiction of the more dominant, “parentified” role these siblings appear to adopt in their relationships with their brothers and sisters across the life span.

Siblings of children with a variety of disabilities generally report comparatively low levels of conflict in their relationships with their brothers and sisters (Cuskelly & Gunn, 2003; Eisenberg et al., 1998; Fisman, Wolf, Ellison, & Freeman, 2000; Kaminsky & Dewey, 2001; McHale & Gamble, 1989; Roeyers & Mycke, 1995). They frequently describe the most negative aspect of their relationships in a very different manner: when asked about the negative aspects of having a sibling with a disability, many siblings mention worry (Eisenberg et al., 1998). In a Dutch study, 75% of typically developing brothers and sisters reported that they sometimes worried about the future and/or their sibling’s health (Piten-Cate & Loots, 2000). Moderate levels of worry and concern have been documented in siblings of both adolescents (Kersh, 2007) and adults with developmental disabilities (Orsmond & Seltzer, 2000). Furthermore, meta-analysis has shown that anxiety is one area of psychological adjustment where siblings of children with disabilities and comparison peers do seem to evidence real differences (Rossiter & Sharpe, 2001). It is possible that this documented anxiety is closely connected to feelings of worry about their brothers and sisters, and the future of their families in general.

These relationships may differ from the normative view of sibling relationships in other ways, as well. Dunn (2002) describes intensity and intimacy as dominant themes in the literature on normative sibling relationships. In contrast, there is evidence to suggest that sibling relationships in which one child has a disability are lacking in both those areas. Begun (1989) asked adolescent and adult females to rate their relationships with their siblings both with and without disabilities. Comparisons across 16 dimensions of sibling relationship revealed distinct differences between the relationships these women had with their siblings with intellectual disabilities and their relationships with their typically developing siblings. They described their relationships with their siblings with developmental disabilities as characterized by significantly greater nurturance of and dominance over their siblings and lower levels of admiration. They also rated these relationships as being less intimate, less competitive, and characterized by less perceived similarity between the two when compared to the relationships they shared with their typically developing brothers and sisters. Begun concluded that, despite some strong positive aspects, the relationships that these women shared with their brothers and sisters with disabilities appeared to be more affectively neutral (i.e., less intense) than their relationships with their siblings without disabilities.

Instrumental Involvement

A large body of research indicates that the siblings of children with disabilities spend more time involved in caregiving activities than their peers with typically developing brothers and sisters, regardless of age or birth order.
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(Hannah & Midlarsky, 2005; McHale & Gamble, 1989; Stoneman, Brody, Davis, Crapps, & Malone, 1991). In addition, these siblings are more directive in their interactions with their brothers and sisters when compared to siblings of typically developing youth (Dallas, Stevenson, & McGurk, 1993; Stoneman et al., 1987b). The durability of the sibling relationship has also been noted. In a survey of adult siblings of persons with intellectual disabilities, about a quarter indicated that they planned to coreside with their brother or sister when their parents could no longer take care of the family member (Krauss, Seltzer, Gordon, & Friedman, 1996).

It is generally acknowledged that these sibling relationships appear to follow an atypical pattern of development. In typically developing sibling pairs, the older sibling assumes a dominant role in the family hierarchy, but over time the relationship becomes more egalitarian, as both siblings approach adulthood (Buhrmester & Furman, 1990). In dyads in which one sibling has a disability, the typically developing sibling, regardless of birth order, generally assumes a dominant role that is characterized by high levels of helping and custodial behavior, and these relationships often become increasingly imbalanced over time (Abramovitch et al., 1987; Corter, Pepler, Stanhope, & Abramovitch, 1992; Dallas et al., 1993; Stoneman, Brody, Davis, & Crapps, 1987a).

The patterns of relationship that are evidenced in sibling pairs when one has a disability might be atypical; however, it does not necessarily follow that they are a source of risk. Although it is largely accepted that siblings bear greater responsibility in the home when there is a child with a disability in the family, it is not clear that this heightened responsibility leads to negative outcomes (e.g., Cuskeley & Gunn, 1993). Greater child care responsibilities have also been associated with greater empathy (Cuskeley & Gunn, 2003) and less sibling conflict (Stoneman et al., 1991). McHale and Gamble (1989) found that the amount of time spent in child care activities was positively associated with anxiety, but not with depression, self-esteem, or conduct problems. Since the anxiety reported by this group of siblings did not approach clinical levels, the authors concluded that it might simply represent a normative response to the special care needs of a loved one. In other words, children and adolescents with more severe impairments require greater levels of care and may also simultaneously provoke more impairments in family members.

Kersh (2007) found that the functional level of adolescents with developmental disabilities was a powerful predictor of multiple aspects of sibling involvement. Siblings engaged in greater caregiving and supportive helping behaviors (e.g., providing emotional support) when their brothers and sisters had lower cognitive and adaptive abilities. They also expressed greater warmth and more worry and concern for their adolescent brothers and sisters with developmental disabilities who had lower functional skills. Given that the majority of the siblings in that study were also adolescents, perhaps the overall functional level of a brother or sister with a developmental disability has particular salience for youth at this stage of development. During this stage, teens are often in the process of renegotiating and redefining their roles and relationships within the family (Steinberg, 1990). It may be that the functional skills and level of need of a brother or sister with a disability are particularly instrumental in this process. Indeed, the work of Wilson, McGillivray, and Zetlin (1992) suggests that the predictive power of functionality (with regard to sibling involvement) may dissipate in the adult years.

Positive Impacts

Recently, there has been a greater emphasis on a range of positive outcomes for all family members of individuals with disabilities, including siblings (Dyken, 2005). Many young people acknowledge that they have benefited from having a sibling with a disability (Eisenberg et al., 1998; Kaminsky & Dewey, 2001; Pit-ten Cate & Loots, 2000; Roeyers & Mycke, 1995;
Van Riper, 2000). They have credited their siblings with helping them gain virtues such as patience, tolerance, benevolence, and appreciation of health and family (Eisenberg et al., 1998; Van Riper, 2000). In Grossman’s (1972) landmark study, over half of the college-aged men and women interviewed about having a sibling with an intellectual disability demonstrated increased levels of altruism, idealism, and tolerance. Furthermore, in a survey of adult siblings of persons with intellectual disabilities, the vast majority described their experiences as “mostly positive” and noted the valuable lessons of compassion, tolerance, respect for differences, and patience that they had learned, despite their reflections on interpersonal turmoil during the adolescent period (Krauss et al., 1996).

Finally, there is some suggestion that the presence of a sibling with a disability can profoundly shape individuals’ identity formation. There are a number of anecdotal reports (e.g., McHugh, 1999; Merrell, 1995), as well as several empirical studies (Burton & Parks, 1991; Cleveland & Miller, 1977), that suggest that having a sibling with a disability has played a role in shaping people’s lives, with particular regard to choosing career paths in the helping professions. In a phenomenological case study, a 39-year-old woman with a brother with Down syndrome considered herself a lifelong “surrogate mother” to her brother and chose to enter the field of special education as a direct result of growing up with a sibling with a disability (Flaton, 2006).

FUTURE DIRECTIONS

The years since our last chapter in the Handbook of Adolescent Psychology (Hauser-Cram & Krauss, 2004) are noteworthy for the beginning of the inclusion of the study of adolescents with developmental disabilities and their families into a more comprehensive understanding of development. The inclusion is partially a result of increased work on the genetic origins of some disabilities, such as Down syndrome and Williams syndrome, and the role of gene-environment interactions in human behavior. The inclusion is also a result of researchers discovering that theories applied to those with typical development, such as developmental systems theory, hold much promise for the study of those with developmental disabilities. Core aspects of development, such as agency, identity, and connectedness to peers, also appear to be assets for those with developmental disabilities. Thus, we can derive a deeper understanding of the development of such adolescents through the valuable models applied to the study of typical adolescents.

Despite such promising movement in the field more generally, and the impact of federal legislation on the rights of adolescents with disabilities which has provided more normative opportunities in education, employment, and social interaction, one approach that is notably absent from research on adolescents with developmental disabilities is the model of positive youth development (PYD) (Lerner, 2005). This “strength-based approach” (Lerner, 2005) stands in sharp contrast to more traditional paradigms of adolescent development that view adolescents in general as a group at risk for a variety of maladaptive and/or dangerous behaviors and outcomes (e.g., substance abuse, delinquency, depression). Similarly, this perspective is distinctively different from one that assumes psychopathology based on developmental disability. Predicated on the notion that youth are a resource to be developed, PYD maintains that within each adolescent is the potential for successful, healthy development across five domains: competence, confidence, connection, character, and caring (Lerner, 2005). This is likely to be an effective frame work within which to consider the developmental assets of adolescents with disabilities and offers a cohesive and inclusive model with principles of development that apply to a wide range of adolescents.

In regard to families of adolescents with developmental disabilities, while the volume of research is not large, there is an emergence of several themes from this research that warrant
additional study. Clearly, one of the major tasks for families during their child's adolescence is planning for the future—for the time when the child leaves the educational system and enters the adult services system. Given the increasing variety of employment and postsecondary educational options that are now available in many communities, the choices families and their adolescent have are more varied. Studies should be conducted to elucidate ways in which families and their adolescent make this transition a successful one.

We also noted that the adolescent period brings unique as well as common challenges and stressors to families of children with developmental disabilities. Research on how families manage their caregiving responsibilities has increasingly focused on factors affecting positive outcomes (e.g., maternal well-being, parent–child relationship quality). This shift in attention, from a deficit to a resilience perspective, promises to elucidate new knowledge about the complexity of this developmental period and to offer useful suggestions to service providers and families regarding ways in which family well-being can be supported. While there now is a larger body of research on families of adolescents with developmental disabilities than was available even 5 years ago, more research needs to focus on this critical period in the lives of adolescents and their families.

It is almost commonplace to note that the ethnic and racial diversity of American society is not reflected in the samples included in most research investigations. This situation seriously limits the power of the research base to guide practice for the millions of Americans who have adolescents with developmental disabilities who are not Caucasian (Ali, Fazil, Bywaters, Wallace, & Singh, 2001; Harry, 2002). There is a small but growing literature comparing Latino and Anglo families of individuals with developmental disabilities that focuses primarily on maternal impacts (Blacher & McIntyre, 2005; Eisenhower & Blacher, 2006; Magana & Smith, 2006). Far more research is needed on ethnically diverse samples across the family life span.

CONCLUSIONS

The adolescent period for individuals with developmental disabilities remains understudied but is beginning to emerge in the literature as a critical life phase for both the individuals themselves and for their families. The role of the family does not diminish during this time as developmentally typical challenges occur for the adolescent who has been included in many classroom and school activities but may be struggling for inclusion in social networks, employment, and postsecondary educational opportunities.

Research can serve an important role in articulating these struggles and their moderators but also in locating ways families derive strengths and that the adolescents themselves engage in PYD. Finally, we contend that as a field, we can also understand the science of adolescent development more thoroughly by the study of adolescents with disabilities. It is only through the construction and testing of models that apply to the full range of human development that we will gain comprehensive perspectives on the development of adolescents.

REFERENCES


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