ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

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This chapter explores the adolescent period for individuals with developmental disabilities and their families. The inclusion of this chapter in a volume that focuses predominantly on typically developing adolescents attests to the increased visibility of and concern for persons with various types of disabilities in our society. Although the research base studying the adolescent period among children with developmental disabilities is comparatively sparse, there is a considerable public policy interest in maximizing the developmental potential of children and adolescents with developmental disabilities, as is evident by the mandates of the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act. In addition, although longitudinal studies of the development of children with developmental disabilities are few in number, there are yielding important theoretical and applied knowledge regarding the utility of mainstream developmental theories, such as developmental systems theory (Lerner, 2002b), to our understanding of the relation between biological and environmental influences on their development. Thus, there is an increased interest in integrating the unique and common concerns of youth with developmental disabilities in scholarly reviews of adolescent development, such as the present volume.

The period of adolescence is traditionally defined not in terms of a specific span of years, but rather in terms of what occurs during this life phase: the transition from childhood to adulthood (Modell & Goodman, 1990). As noted by Zahn-Waxler (1996), adulthood is characterized by the internalization of societal norms, economic independence, formation of viable family units, and acceptance of responsibility for oneself and for others. For individuals with developmental disabilities, there may be notable constraints on the extent to which some of these adult roles are achieved, particularly with respect to economic independence and formation of family units. The biological, cognitive, psychological, and social changes that characterize the transition from the adolescent period to adulthood, however, are as challenging for individuals with developmental disabilities (and their families) as they are for typically developing individuals. Unlike typically developing adolescents, however, adolescents with develop-
mental disabilities may chronologically reach adulthood without the same degree of personal independence and autonomy that generally defines the adult stage of development. However, as Graber and Brooks-Gunn (1996) note, “understanding how individuals navigate developmental transitions is at the crux of understanding risk and resilience across the life span” (p. 768).

Our review of the adolescent period for individuals with developmental disabilities addresses four main topics: (a) a discussion of developmental theories with applicability to persons with developmental disabilities, (b) an analysis of the literature on the major developmental tasks associated with adolescence and how such tasks are affected by developmental disabilities, (c) a discussion of the role and functioning of the families of adolescents with developmental disabilities, and (d) a proposed research agenda required to fill in the many missing pieces of our understanding of this critical life stage. We begin with a brief description of the definition of developmental disabilities.

**DEFINITION OF DEVELOPMENTAL DISABILITIES**

The term developmental disabilities was codified in Public Law (PL) 95-682, the Developmental Disabilities Bill of Rights Act of 1978. It is defined as a condition attributable to a mental or physical impairment that begins before age 22, is likely to continue indefinitely, and results in substantial functional limitation in three or more areas of major life activity. The scope of major life activities include self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Among the most common conditions included within the label of developmental disabilities are autism, cerebral palsy, epilepsy, mental retardation, and other neurological impairments. The rates of documented disability during childhood and adolescence have increased substantially over the last decade (Fujiura & Yamaki, 2000); current estimates indicate that approximately 12% of youth receive special services because of a developmental disability (U.S. Department of Education, 2001).

**THEORETICAL MODELS OF ADOLESCENT DEVELOPMENT: IMPLICATIONS FOR ADOLESCENTS WITH DISABILITIES**

Developmental theories about adolescence for typically developing children have been fundamental to the construction of a knowledge base about this life phase, yet few theorists have applied their models explicitly to adolescents with developmental disabilities. Such application would provide empirical information that could assist in constructing appropriate services as well as expand our knowledge about the extent to which developmental theories apply broadly. In this section, we discuss three theoretical perspectives with regard to their potential application to adolescents with developmental disabilities: psychosocial models, developmental compensation models, and developmental systems models.

Perhaps the most cited work on adolescent development is Erikson's psychosocial model (Erikson, 1950, 1968). Although he delineates stages in the development of the
ego from infancy through the elder years, identity and its epigenetic development forms the core of this theory applied to the adolescent period. Accordingly, Erikson features the adolescent period as a time of strife in which the individual ideally constructs an identity formed through the development of a set of personal ideals and belief systems while developing an orientation toward a future role deemed appropriate by society. The next period—the transition from adolescence to young adulthood—is also marked by strivings but focused on forming intimate relationships. This life phase is characterized by the engagement in mutual interchanges, which provide the individual with a deeper understanding of the emotions, psychological processes, and belief systems of a partner.

Although clearly generated from a psychoanalytic framework, Erikson based his view of the epigenetic model on principles of interaction between the individual and the society. He considered that individuals interact with a widening “social radius” (Erikson, 1950, p. 270)—that is, adolescents increasingly relate to a variety of social systems as they respond to society’s expectations. Society, according to Erikson, ideally both safeguards and encourages transitions at appropriate times in the individual’s life cycle.

Erikson’s model is presumed to relate to all youth, although he does not address questions about the extent to which these central adolescent developmental transitions—the development of identity and the construction of intimate relationships—apply to adolescents with developmental disabilities. Nevertheless, there is reason to believe that such transitions and the strivings inherent in them occur for all adolescents, including those with disabilities. The strife may be even greater for those with disabilities, however, because of the adolescent’s limited skills (such as in motor skills required to participate in athletic activities with friends) or because of society’s restricted view of appropriate opportunities (in areas such as independent living, employment, post-secondary education). Adolescents with disabilities may also experience a delay in the timing of developmental transitions, so many may confront identity issues at a later chronological age than do their typically developing peers. Additionally, youth with severe levels of cognitive impairment or with particular types of disability, such as autism, may be constrained in ways that make the depth of identity formation and intimacy more compromised than that of typically developing individuals.

In contrast to Erikson’s emphasis on the development of the ego, action psychologists focus on ways in which the individual is an agent of his or her own development. Individuals construct developmental pathways through their unique capacities to have intentions, act on them, and evaluate the intention-action cycle (Brandstädter, 1998). The action perspective is exemplified by Baltes and colleagues (Baltes, 1997; Baltes, Lindenberger, & Staudinger, 1998; Freund, Li, & Baltes, 1999), who delineate three intersecting processes that foster development: selection, optimization, and compensation. These processes include how an individual selects a certain goal, persists in learning the skills or brings resources to bear on that goal (i.e., optimization), and compensates for limitations that prevent goal optimization. Although this model has been applied empirically primarily to development during the aging process, it has value in understanding the development of individuals during other life stages, especially adolescence (Lerner, 2002a). From this perspective, the adolescent is viewed as an agentic being, capable of setting goals and of developing strategies, including ones that compensate for organic or acquired limitations, to achieve those goals.

The importance of compensation for adolescents with developmental disabilities
was addressed specifically by Vygotsky (Rieber & Carton, 1993) in his study of "defec-
tology," the Russian term in the 1920s for the study of disabilities. Vygotsky maintained
that children with developmental disabilities adopt compensation processes along a
"roundabout path" (p. 126); that is, they adapt to developmental challenges by con-
structing different approaches or developing different goals. In this way, the individual
with a disability "transforms the minus of the handicap into the plus of compensation"
(p. 34). Youth vary in the range of compensatory strategies they have available to them,
based only partially on the nature and severity of their disability. According to Vygot-
sky, the reserve of compensatory forces are less a property of the child's motivation or
personality and more a product of the "social-collective life of the child" (p. 127). Thus,
the opportunities provided to those with disabilities are related to the type of compen-
satory behaviors and strategies that can be employed. From this perspective, the avail-
ability of opportunities for the adolescent with developmental disabilities to enhance
appropriate compensatory strategies is central to optimal development.

Developmental systems models expand a view of development beyond the psycho-
social and motivational realms by considering the multiple and changing contexts in
which adolescents develop, learn, act, and are nurtured. According to Bronfenbrenner
and Morris (1998), adolescents are affected by their own psychological processes and
the immediate settings in which they interact, such as the family and the school. More-
over, adolescent development is also affected by systems that influence these proximal
settings, including government policies and cultural ideologies. Lerner's (2002b) depic-
tion of developmental contextualism emphasizes the bidirectional relations among
the adolescent and the multiple interacting systems, each influencing the other in complex
patterns. Such models have important implications for adolescents with developmen-
tal disabilities because they posit that even though particular adolescents may be lim-
ited cognitively, motorically, or both by biological factors, their development influences
and is influenced by sets of interacting and intersecting systems. Some of those systems
affect them directly, such as their family and school, but others influence their immedi-
ate contexts through government policy (e.g., IDEA) and through societal views of
appropriate behavior, goals, and opportunities for individuals with disabilities. Fur-
thermore, the adolescent's own ability to be an agent of change emerges from these ap-
proaches (Brandtstädter, 1998); an adolescent's development may expand beyond that
predicted by societal expectations. Such agency is potentially important to the devel-
opment of youth with developmental disabilities as well, although possibly more diffi-
cult for some adolescents to access.

In summary, all three theoretical perspectives on the development of typical adoles-
cents offer valuable ways of framing research on youth with disabilities. These perspec-
tives are similar in their view that the adolescent's development is promoted through in-
teraction with others and through activities in the social world. According to the psy-
chosocial model, adolescents are striving to understand their own identity and to
develop intimate relationships with others. Developmental compensatory approaches
emphasize the way that adolescents with disabilities can promote the development of
alternative pathways to goal attainment. The developmental systems perspective offers
a broad model of adolescents engaged in and affected by multiple interacting systems,
which determine the opportunities they are provided, the way others perceive them,
and their own sense of agency. All three approaches have similarities in their assump-
tions about the importance of social interaction and family-community contexts to the promotion of optimal development but differ in terms of emphasis of one feature over another. All three also assume that the adolescent acts to varying extents as an agent of his or her own development.

In this chapter we maintain that similar principles exist for adolescents with developmental disabilities. We propose that the timing of developmental changes often are delayed chronologically for youth with disabilities and that some adolescents with serious cognitive limitations may only partially make the transition into the adolescent phase. Nevertheless, the majority of adolescents with developmental disabilities will be faced with challenges during this period similar to those of other adolescents.

THE TASKS OF THE ADOLESCENT PERIOD: APPLICATIONS TO ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES

Adolescence is a time of transition, transformation, and realignment for adolescents, their parents, and their siblings. Among typically developing adolescents, becoming socially competent adults engenders several important tasks: autonomy, relatedness, and competence (Connell & Wellborn, 1991). These tasks clearly emerge from the developmental theory in that all require a sense of both identity and agency as well as require the developing adolescent to negotiate multiple interacting social systems. These tasks present unique but relatively unstudied challenges to adolescents with developmental disabilities (Glidden & Zetlin, 1992). These developmental accomplishments require individuation, which involves the disengagement from emotional dependence on adults and the development of a set of distinct views and belief systems (Steinberg & Silverberg, 1986) while maintaining connectedness to family and others (Grotevant & Cooper, 1986). Three small but growing knowledge bases related to the developmental endeavors of this phase exist on adolescents with disabilities: the formation of supportive peer relationships, the development of autonomy, and successful transitions in relationships with parents.

The Construction of Supportive Peer Networks

Constructing a supportive peer network is an important part of adaptive social adjustment. Indeed, poor social adjustment during adolescence is a predictor of adult psychopathology (East et al, 1992). Data indicate that most adolescents spend much more time with their peer network than with family members (Brown, 1990). From a psychosocial perspective, peer networks help the adolescent develop a sense of self and prepare for the development and maintenance of long-term intimate relationships.

In contrast to the complex and growing social networks of typically developing adolescents, studies of adolescents with developmental disabilities consistently point to high rates of social isolation (Richardson, Koller, & Katz, 1985). Anderson and Clarke (1982) conducted an extensive study in the United Kingdom of 119 adolescents with either cerebral palsy or spina bifida. They found that 31% reported seeing no friends outside of school hours (in contrast to 3% of their typically developing peers) and concluded that social isolation is the most common source of stress among this group of
adolescents. Such isolation is not restricted to adolescents with severe cognitive or physical limitations because those with learning disabilities also experience high rates of peer rejection (Zellin & Turner, 1985) and fewer, less stable, and more conflict-ridden friendships (Zellin & Murtaugh, 1988). Swanson and Malone (1992) conducted a meta-analysis of 39 studies of the social skills of children with learning disabilities. They concluded that on average, children with learning disabilities were reported to be at the 18th percentile in peer acceptance and at the 78th percentile for peer rejection.

Social isolation may be attributed to several factors. The social skills of many adolescents with developmental disabilities may be either unusual or delayed; this is likely because social and cognitive functioning, although they are not isomorphic, are integrated processes. In a study of 64 adolescents with moderate mental retardation, Siperstein and Bak (1989) found that those with higher cognitive performance were more frequently nominated to be friends by their peers. Leffert and Siperstein (2002) maintain that many aspects of social-cognitive processing critical to positive peer relationships are challenging for individuals with intellectual disabilities. These aspects include the encoding and interpretation of cues (e.g., reading facial expressions), consideration of goals (e.g., relinquishing an immediate goal to attain a long-term goal), and the generation and evaluation of strategies (e.g., determining alternative ways to enter a social group and selecting one that fits the group’s purpose).

Social perspective-taking is an important aspect of development that continues to be transformed during adolescence and appears to be reliant on sophisticated cognitive processes. Selman (1980; Selman, Beardslee, Schultz, Krupa, & Poderefsky, 1986) posits that during the adolescent period, self-reflection grows into mutual reflection and—eventually—to an understanding of a network of perspectives that support reciprocity, loyalty, and self-disclosure in friendships. Adolescents with certain disabilities, such as autism, have pronounced difficulty with social perspective-taking and thus tend to be limited in their ability to perceive the world through the eyes of others. This deficit has been attributed to an impairment in the theory of mind (i.e., in the ability to impute mental states to oneself and others, and thus to make inferences regarding the thought processes of others; Baron-Cohen, 1995). In contrast to adolescents with autism, those with other types of developmental disabilities, such as Down syndrome, may have limitations in other aspects of social interaction, such as communication, (Sigman & Ruskin, 1999), that affect their skills of social engagement. Thus, adolescents with different biologically based developmental disabilities may have distinct patterns of strengths and deficits related to social interaction, an observation that has been noted in studies of younger children (Hodapp, 1997).

In addition to unusual or delayed patterns of social cognitive processing, adolescents with disabilities may exhibit maladaptive behaviors that interfere with the construction of positive peer relationships. In a review of the social competence of students with mild disabilities, Gresham and MacMillan (1997) concluded that those who have difficulty regulating their own behavior also have the poorest social relationships (Merrell, Johnson, Merz, & Ring, 1992). Tonge (1999) noted that behavior problems are three to four times more likely to occur in children with developmental disabilities in comparison to other children. Furthermore, behavior problems in individuals with developmental disabilities appear to increase dramatically during the adolescent period (Jacobson, 1990). Thus, many adolescents with disabilities are hampered by either ex-
cessive withdrawal from others or excessive forms of acting-out behaviors that may diminish the desires of other adolescents to interact with them.

Furthermore, high rates of hospitalization and health care needs are characteristic of adolescents with severe intellectual disabilities and thus limit opportunities for social interaction with peers. Birenbaum and Cohen (1993) reported that children and young adults with severe mental retardation were hospitalized at eight times the national rate. Adolescents who are hospitalized or unable to attend school for long periods of time have the additional challenges of attempting reentry into peer groups that may have changed or realigned during their absence. The relation between health status and social competence of adolescents with disabilities has been seldom examined, however.

The Development of Autonomy

A second important task of adolescence, the development of autonomy, is receiving increasing attention among those studying adolescents with developmental disabilities. The development of autonomy may be a difficult task for such adolescents because of their compromised capacity to perform at a level consistent with their chronological age, coupled with restricted opportunities for exercising independence (Turnbull & Turabull, 1985). Nevertheless, the development of a sense of personal agency, or self-determination, appears to be as critical to their psychological well-being and personal growth as it is for other adolescents (Wehmeyer, 1994).

Autonomy implies the ability to act according to one's preferences, interests, and abilities, and therefore it involves a knowledge of self (Wehmeyer, 1994). How do adolescents with developmental disabilities regard themselves? Given current interest in issues of autonomy and self-determination, it is surprising that so few studies have been conducted on identity development in adolescents or young adults with developmental disabilities. In one of the few investigations on this topic, Davies and Jenkins (1997) conducted interviews with 53 young adults with intellectual impairments and their caregivers. They found that only 8 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 power over them.

Halpern (1985) proposed that success for the young adult with developmental disabilities involves the following: (a) employment, (b) living independently or with a friend, (c) paying at least a portion of living expenses, and (d) involvement in leisure pursuits. These activities all involve autonomous behavior and presume the development of optimal levels of independence during the adolescent period. The importance of self-agency, which is required for autonomous behavior, is a growing theme in the literature on children with developmental disabilities. In a longitudinal study of children with Down syndrome, motor impairment, or developmental delay (Hauser-Cram et al., 2001), we found that those who had higher levels of mastery motivation during the preschool years had greater development in the acquisition of skills of daily living (e.g., dressing, bathing, and self-care) through middle childhood. Thus, children's early striv-
ings for agency predict their adaptive skill development. Children and adolescents need to have varied opportunities for continued skill development, yet parents and other caregivers may limit such opportunities unknowingly. For example, Anderson and Clarke (1982) found that only 21% of adolescents with disabilities were given household chores compared to 69% of typically developing adolescents.

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 because through employment adolescents often develop a sense of responsibility, increased self-reliance, and expanded social networks. The majority of adolescents in the United States engage in employment opportunities (Mortimer, Shanahan, & Ryu, 1994), and in many communities some employment options exist for adolescents with developmental disabilities.

Indeed, more has been written about employment than about any other aspect of this phase of life for adolescents and young adults with developmental disabilities. Findings from the National Longitudinal Transition Study (Blackorby & Wagner, 1996) indicate that only slightly more than one third of youth with intellectual disabilities are employed within 5 years of exiting secondary school. Employment tends to be at poverty-level wages but varies by ethnicity and gender. African American or Hispanic youth with disabilities are less likely to be employed than are their European American peers, and females are less likely to be employed than males. Although employment options may be limited for those with intellectual disabilities, postsecondary educational opportunities for such youth are even more restricted. The opportunity to attend college and possibly live away from home in a somewhat protected environment does not exist for most adolescents with developmental disabilities.

Involvement in other types of postsecondary programs, however, tends to be increasing. In a survey of community adjustment of former special education students in Iowa, Frank and Sitlington (2000) note a trend toward increasing attendance at community colleges and job training or apprenticeship programs. The need for such postsecondary programs is likely to grow in the next decade as adolescents with developmental disabilities who have experienced education in what Public Law 99-457 mandates as the least restrictive setting emerge from high schools and push for a range of future opportunities.

Transition in Relationships with Parents

Although self-determination is one dimension of autonomy, separation of emotional dependence from parents is another. Steinberg and Silverberg (1986) have conceptualized emotional autonomy as including individuation, nondependency, deidealization of parents, and perceptions of parents as people. Because several of these constructs require sophisticated cognitive processes, adolescents with developmental disabilities may be less well equipped to develop optimal levels of emotional autonomy. Therefore, it is not surprising that Zetlin and Turner's (1985) retrospective study of adolescents with developmental disabilities indicated that although more than one half reported having struggles with parents over issues of independence, only a third achieved emotional autonomy.
Examine the relation between the development of emotional autonomy and the climate of parental support is essential in predicting positive adolescent development (Lamborn & Steinberg, 1993). Developing autonomy and self-reliance but also maintaining connected relationships to parents is important to the well-being of typically developing adolescents (Grotevant & Cooper, 1986; Youniss & Smollar, 1985) and also critical for those with disabilities (Field, Hoffman, & Posch, 1997). In a study of adults with mild mental retardation living independently, Winik, Zetlin, and Kaufman (1985) found that those with the greatest independence and self-esteem had parents who had promoted independence and autonomy.

Because adolescents with disabilities, in comparison to their peers, have fewer friendships and higher levels of behavior problems (Glidden & Zetlin, 1992), parents may become more rather than less protective during the adolescent period. Such 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 that protected a son or daughter from difficulties and exploitation led to more successful employment outcomes of young adults with mild intellectual disabilities. The nature of parental protection and how it is enacted warrants careful study.

Furthermore, many adolescents with developmental disabilities will continue to live with their parents for many years (Fujiura & Braddock, 1992; Seltzer & Krauss, 1994). In a study of individuals with mild handicaps who had attended special education programs in Maryland, Scuccimarra and Speece (1990) found that the majority resided with their parents, although more than 75% of those individuals said they would prefer to live independently. Parents and other family members serve as a potentially strong support network for individuals with developmental disabilities but may also substitute for friends. McGrew, Johnson, and Bruininks (1994) studied young adults with mild to severe disabilities and reported that an inverse relation occurs between the number of family and nonfamily members in their social networks. Therefore, the parent-child relationship, although it is always complex, becomes increasingly so for adolescents with developmental disabilities, especially for those who rely on parents for many aspects of their daily living and social activities.

FAMILIES OF ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES

Until recently, most theorists of adolescent development focused on the conflict between parents and their adolescent children, especially in relation to the adolescent tasks of identity and autonomy (Schutze, 1989). As a consequence, the role of the family was conceptualized as one of departure (Douvan & Adelson, 1966), in order to give way to the dominating influence of peer groups, to accommodate to the adolescent’s sexual maturity, and to permit autonomous behavior. More contemporary studies have focused on factors affecting parenting competence during the adolescent period, suggesting that parents can exert an active (rather than departing) influence on how their adolescent child develops.

For example, Bogenschneider, Small, and Tsay (1997), drawing from Belsky’s (1984) research on parenting competence in the early childhood period, examined the role of
parent characteristics, contextual sources of support, and adolescent characteristics on parenting competence during the adolescent period among typically developing youth. Whereas Belsky (1984; Belsky, Robins, & Gamble, 1984) found that parent characteristics were most influential in predicting parenting competence in the early childhood period, Bogenschneider et al. (1997) found that during adolescence, adolescent characteristics (e.g., adolescent openness to parental socialization, parent-child stress, and support from the social network) were the most important predictors of parenting competence. Clearly, recognition is emerging that the interactions among family members during the adolescent period constitute a fertile ground for understanding both adolescent and parental outcomes and that there are changing dynamics in the influence of parents on their children and children on their parents.

Although there is a paucity of research on the interactions and 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. 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 both undeniable stresses on parental well-being and health, as well as positively regarded accommodations to family life and values (Heller, Hsieh, & Rowitz, 1997; Krauss & Seltzer, 1994).

It is widely acknowledged that the adolescent period for typically developing children is often accompanied by heightened turmoil for their families, who must cope with the effects of the biological, cognitive, social, and psychological maturation of their adolescent. Part of the transition from childhood to adulthood includes the push and pull of relinquishing parental roles of protectiveness, close supervision, and authority and 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).

There has been a surge of research in the last 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., Hauser-Cram et al., 2001; Keogh, Garnier, Bernheimer, & Gallimore, 2000; Mink, Nihira, & Meyers, 1983; Seltzer & Heller, 1997). This body of research has roots in transactional theories of human development (Lerner, 2002b; Sameroff & Fiese, 2000), models of the ecology of human development (Bronfenbrenner, 1979), family systems theory (Olson, Russell, & Spenkle, 1983), and family life cycle theory (Carter & McGoldrick, 1980). Common to all these theoretical roots are three core propositions. First, 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. Second, changes in the individual and his or her environment affect other members of the indi-
individual's environment in reciprocal and iterative ways. Third, 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 or 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.

Family Life Cycle Theory

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 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 et al., 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 reflects 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, during the adolescent stage, there is a greater emphasis on letting go and in reducing child dependency.

Challenges for Families During the Adolescent Period

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 enumerated the following stressors:

- Adjusting emotionally to the chronicity of the handicapping condition
- Identifying issues surrounding emerging sexuality
- Dealing with peer isolation and rejection
- Making role adjustments based on skill development
- Future planning for vocational development
• Arranging for leisure-time activities
• Participating in individualized education planning (IEP) conferences
• Dealing with physical and emotional changes of puberty

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 later in this chapter, 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.

Substantial evidence indicates 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, and trepidation over the end of federally guaranteed rights to services as children leave the special education system.

Baine, McDonald, Wilgosh, and Mellon (1993) conducted quantitative and qualitative research on families of adolescents with severe disabilities. Their research included the development of major categories of family stress and, within those categories, subthemes that identified the general and unique stressors reported by parents. The most stressful issues were a mixture of 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 were related to family interpersonal dynamics (i.e., between adolescents with disabilities and their siblings, 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 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”). Baine et al. (1993, 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) note 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 more clearly viewed awareness of the child's developmental horizon. 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) notes 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. Her work supports the idea that transition periods are particularly problematic for families. 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 deviant 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.

**Parent-Child and Sibling Relationships in the Adolescent Period**

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 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., Kaufman, 1999; Park, 2001).
Zetlin and Turner (1985) conducted an ethnographic study of 25 young adults with mild mental retardation 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 mental retardation 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 restriction, rejection, expectancies-discrepancies—contributed to their uneasiness and discontent. (p. 578)

Although sibling relationships during adolescence between brothers and sisters without disabilities and their siblings with disabilities have been studied less extensively, there is evidence that this can be a period in which new social and emotional strains develop (McHugh, 1999). Krauss and Seltzer (2001) report 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. For example, non-disabled siblings worry about what their future role will be regarding the care and support of their brother or sister with a disability. Furthermore, embarrassment about odd behaviors of a sibling with a developmental disability may result in avoidance of public social activities and greater social isolation for non-disabled adolescent siblings.

Many have hypothesized that siblings of children with disabilities are exposed to extra demands for caregiving (serving as aides to their parents), to expectations for greater emotional sensitivity, and to higher levels of social involvement with their brother or sister with a disability (Grissom & Borkowski, 2002; Lobato, 1983; McHale & Gamble, 1987). Nixon and Cummings (1999) studied whether young adolescent brothers and sisters who have a sibling with a disability evidence greater emotional distress and behavioral reactivity to family conflicts. They found that siblings of children with developmental disabilities were more sensitive to family stress, utilized more active coping strategies, and had lower thresholds of conflict intensity for responding in comparison to siblings of children without disabilities. They concluded that "children growing up with a disabled sibling may be exposed to learning histories that sensitize them to conflict in multiple social contexts... These children have learned to become alert to potential problems in family dynamics and are inclined to do something about it" (p. 282).

The durability of the sibling relationship has also been noted in empirical studies (Krauss, Seltzer, Gordon, & Friedman, 1996). In a survey of adult siblings of persons with mental retardation, about a quarter indicated that they planned to co-reside with their brother or sister when their parents could no longer take care of the family member. In addition, despite having experienced increased interpersonal turmoil during the
adolescent period (based on retrospective assessments), 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. Indeed, the majority of studies on sibling relationships when one sibling has a disability have found them to be more positive and nurturing than relationships between typically developing siblings (Stoneman, 2001).

Parental Tasks in the Adolescent Period

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. A recent study examined the most common dilemmas reported by parents of adolescents with developmental disabilities (Thorin, Yovanoff, & Irvin, 1996). The six most common dilemmas were the following:

- Wanting to create opportunities for independence for the young adult and wanting to assure that health and safety needs are met
- Wanting a life separate from the young adult and wanting to do whatever is necessary to assure a good life for him or her
- Wanting to provide stability and predictability in the family life and wanting to meet the changing needs of the young adult and family
- Wanting to create a separate social life for the young adult and wanting to have less involvement in his or her life
- Wanting to avoid burnout and wanting to do everything possible for the young adult
- Wanting to maximize the young adult’s growth and potential and wanting to accept the young adult as he or she is

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.

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. Considerable evidence indicates that the prospect of losing the mandated educational and related services guaranteed by 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 more than 5 million chil-
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dren ages 6-21 receive special education services under IDEA (U.S. Department of Education, 2001). Of these children, approximately 200,000 exit the school system each year and enter the adult world (Wehman, 1996).

A component of IDEA requires that no later than age 16, an individualized transition plan be crafted as part of a student’s IEP that identifies needed transition services. The scope of the plan may include instruction, community experiences, development of employment and other postschool adult living objectives, and acquisition of daily living skills and functional vocational evaluation, where appropriate. The planning process is undertaken by a team of individuals, including the student, his or her parents, and personnel from community and adult service agencies who will be involved when the adolescent becomes an adult (Frank & Sillington, 2000).

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 recent study, most commonly in a day activity center or sheltered workshop (Kraemer & Blacher, 2001). 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 & Redcliff, 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.

CONCLUSIONS: SETTING A RESEARCH AGENDA FOR THE NEXT DECADE

Despite the increased visibility of individuals with disabilities in our society, knowledge about their development—especially during the adolescent phase—is meager. This limited knowledge base exists in contrast to the growing sophisticated and complex knowledge about adolescent development more generally. Although research on parental adaptation to raising a child with disabilities has been informed by theoretical models of family systems and the family life cycle, studies on the development of adolescents with disabilities have been for the most part descriptive in nature. Furthermore, most studies have failed to consider the multiple bidirectional relations among adolescents with disabilities and their parents, siblings, and other family members. Finally, studies have not focused on the multiple contexts in which adolescents develop and learn. Descriptive studies are important for foundational knowledge, but theories of adolescent
development and family change can lend valuable perspectives that will help the knowledge base grow in ways that reflect the complexity of the human experience.

The tasks of the adolescent period are particularly challenging for many adolescents with developmental disabilities and their families, and empirical knowledge guided by theoretical perspectives can be applied to those challenges. Psychosocial models of development emphasize the importance of identity development during the adolescent period, yet few researchers have undertaken work on identity development in youth with disabilities. Researchers operating from the narrative tradition (e.g., Davies & Jenkins, 1997; Kaufman, 1999) report that youth with intellectual impairments, like all youth, develop a sense of self through activities they find meaningful and through positive social relationships with others. Research could offer an even richer analysis of the various paths to identity development among youth with disabilities.

In contrast to the paucity of studies on identity development, investigations on social relationships of youth with disabilities are increasing. Models of social cognition have stimulated a deeper understanding of the limitations unique to specific disabilities, such as autism, which may thwart the construction of a supportive peer network. Therefore, further research on the development of social cognition in adolescents with varying disabilities is particularly important and may lead to the construction of interventions that assist with the development and maintenance of friendships. Although some interventions are promising in this area, especially for school-age children (e.g., Campbell & Siperstein, 1994), few have been developed for adolescents. A greater understanding is needed of the mechanisms by which social cognitive functioning advances during the adolescent period as well as how such functioning differs by type of disability, level of cognitive impairment, and types of supports provided by families, schools, and communities. Investigations guided by the selection, optimization, and compensation model of Baltes and colleagues (Baltes et al., 1998) could add a valuable perspective to our understanding of the development of social relationships in youth with disabilities by focusing attention on how such adolescents can optimize social functioning.

Compensation models do not necessarily imply that the individual alone is responsible for creating novel approaches. Vygotskian perspectives suggest that we also should focus on the social community can support alternative developmental routes for youth with disabilities. In terms of educational goals, this view is currently being advanced by those who advocate the use of universal design for learning (Rose & Meyer, 2002). They maintain that barriers to learning are not inherently within the student but rather reside in our methods of providing instruction. For example, students who have difficulty with comprehension can have purposefully designed prompts built into complex text material provided digitally on a computer, just as youth who are visually impaired can have text augmented or read to them through the computer. From a developmental systems perspective, it is also important that research on children with developmental disabilities and their families pay much greater attention to the increasing ethnic and cultural diversity of American society (Hauser-Cram & Howell, 2003). There is a stunning lack of attention in the literature on adolescence and developmental disabilities to the impact of cultural beliefs and norms. Particularly given the prominence of contextual influences in most contemporary theoretical approaches to the study of development, it is surprising that culture is not used as an organizing principle of development (Valsiner, 1989). As Garcia Coll and Magnuson (2000) note, most interventions
and programs for children with developmental disabilities are permeated with the values and goals of mainstream European American culture and are insensitive to the differing world views, parenting practices, social views, and belief systems of other cultures. Given the prominence of the family as an enduring context in which adolescents with developmental disabilities live, more focused research on the experiences of families and adolescents from various ethnic and cultural groups is a critical challenge for the future.

Another essential area of research involves the examination of adolescent-parent relationships. Adolescents with developmental disabilities in general are more reliant on their parents for a range of support features, including sometimes that of the sole source of friendship. At this time the adolescent may be striving toward greater self-determination and autonomy and his or her parents may be recognizing that their life cycle as parents differs from that of their family and friends. The task of developing independence within a connected relationship may take on different forms for adolescents with developmental disabilities, depending on their type of disability and level of adaptive functioning. Furthermore, research on the bidirectional effects of the parent-child relationship and their changes during the transition from childhood to adulthood among youth with disabilities are unstudied. Such research would yield important information about the extent to which models based on typically developing adolescents apply more broadly.

It is also imperative that research designs include adolescents with developmental disabilities as key informants about their lives. A variety of methodologies have been successful in including persons with developmental disabilities, including participant observation, in-depth and over-time interviewing, and ethnographic techniques. These individuals have much to teach us about how they view their own development socially and emotionally and about how their relationships with their parents, siblings, and peers change (for better or for worse) during this critical life stage.

In sum, the adolescent period for individuals with developmental disabilities is an understudied area but one that may be critical for our understanding of the continuities and discontinuities of their development over time. As is true for all adolescents, this period is fraught with enormous challenges as youngsters move towards greater individuation, increasing independence from their parents, more autonomy, and deeper capacities to form complex interpersonal relationships. For adolescents with developmental disabilities, these tasks are also prominent, but may be more difficult to master in light of their biological and cognitive impairments. The role of the family is thus increasingly important and—in contrast to families of typically developing adolescents—may become more intensified and consequential in shaping the future of their adolescent with a disability. As inquiries about the full range of human development—including that of persons with developmental disabilities—proceed, the opportunity to deepen our knowledge by including consideration of both typical and atypical development during adolescence should be seized.

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