Families of Adolescents and Adults with Autism: Uncharted Territory

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INTRODUCTION

There is a vast amount of uncharted territory about patterns of development in persons with autism beyond the childhood period, and even more uncharted territory regarding the impacts of parenting an adolescent or adult with autism. In con-
contrast to the proliferation of scholarly interest and research activity on the genetic causes, brain structure and function, and behavioral repertoire of young children with autism (McIlvane, Alexander, & Bristol, 1998), there is no comparable investment in research on either the impact on the family of lifelong caregiving or how the family environment may mediate the manifestation of the core deficits of autism. Given the centrality of the family in influencing the development and maintaining the quality of life of a person with autism, it is highly surprising that there is so little research on family well-being when the person with autism reaches adolescence and adulthood. For many older parents of adolescents and adults with autism, the legacy of blaming parents for their child’s disorder has yet to be replaced with more accurate information regarding the ways in which parenting demands and roles change over the life course. Relatedly, there is a paucity of investigations of the trajectory of the symptoms of autism across the full life course. Although the disability is lifelong, the research literature on families ends when the person leaves childhood. In contrast, over the last decade, much has been learned from taking a life-span perspective on the challenges and rewards of family-based care provided by families of children and adults with mental retardation (Heller, Hsieh, & Rowitz, 1997; Krauss & Seltzer, 1994). Thus, there is a critical gap in the scientific and public health literatures in understanding the ways in which families of adolescents and adults with autism are affected by and manage the challenge of lifelong parenting.

This chapter reviews the research on families of individuals with autism and examines the applicability of findings from studies of the early childhood period to adolescence and adulthood. Our purpose is both to summarize existing knowledge and to provide a framework for future research. The framework is based on a life-course perspective which clarifies that parenting is a commitment that endures even after the child has become an adult and regardless of where one’s children live (Lancaster et al., 1987). The life-course perspective assumes both continuities and changes in family functions, composition, and relationships, and investigates the extent to which patterns of individual and family interaction that occur during early periods of family life persist later in midlife and old age (Seltzer & Ryff, 1994).

We begin by providing a brief description of the major features of autism with particular emphasis on the characteristics of persons with autism that are most challenging for parents and other caregivers. In addition, we examine the research on the family genetics of autism, and the elevated risks that family members have for social, cognitive, communicative, and psychiatric difficulties. We then review the existing literature on the impact on families of having a son or daughter with autism, and the resources that parents use to ameliorate the strains they experience. We also review follow-up studies that provide insights both about the trajectory of the symptoms of autism through early adulthood and also residential placement patterns of adolescents and adults with autism. We supplement our review of the published literature with preliminary data from our pilot study of a small sample
II. DEFINITION OF AUTISTIC DISORDER

Autistic Disorder is one of several neurodevelopmental disorders classified together under the broad heading of Pervasive Developmental Disorders. Other disorders within this category include Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD–NOS). The disorders within this “autism spectrum” are characterized by qualitative impairments in social interaction and communication, as well as behavior, interests, and activities that are unusually restrictive and repetitive (American Psychological Association, 1994). Although autism and these related spectrum disorders were once thought to be rare, they are now known to be among the most common of the developmental disorders, with recent prevalence estimates indicating that autism spectrum disorders may be as high as 5–6/1000 (Bryson & Smith, 1998).

Autism occurs in 3 to 4 times as many males as females (Bryson & Smith, 1998). Approximately 75% of individuals with autism test in the mental retardation range on formal intelligence measures. The diagnosis of Autistic Disorder requires that the characteristic symptoms be present prior to 36 months of age, although this is not the case for Asperger’s Disorder or PDD–NOS (APA, 1994). Children with autism are typically diagnosed during the preschool years. The trajectories of developmental changes in communication, cognitive skills, social skills, and behaviors from childhood to adolescence to adulthood have yet to be described (see Sigman & Ruskin, 1999, as well as discussion within this chapter). We do know that as many as 30% of individuals with autism will develop seizures by early adolescence (Bryson & Smith, 1998). Although behavioral, educational, and pharmacological interventions can greatly improve the outcomes for individuals with autism, there is currently no cure, and ongoing research continues to identify biological markers and other genetic and neurological etiologies. As such, the lifelong emotional, social, and financial costs to individuals with autism, their families, and federal and state agencies continue to accrue (Bristol, McIlvane, & Alexander, 1998).

III. RELATED RISK FACTORS IN FAMILIES OF PERSONS WITH AUTISM

A growing body of research has questioned whether neurological, cognitive, communicative, and psychiatric difficulties appear more commonly in some fam-
ily members of individuals with autism than in the general population (for a review, see Bailey et al., 1998). Indeed, parents and other family members of persons with autism may face a dual challenge—the demands of caring for the individual with autism and, at the same time, dealing with an elevated risk of neurological, cognitive, communicative, and psychiatric difficulties in themselves, their spouse, and their other children. Although elevations in these areas of difficulty might be the result of shared environmental influences, they are most often interpreted from a family genetics perspective.

The earliest studies on this issue concluded that there was no elevation in such difficulties in family members of persons with autism (Cox et al., 1975; Cantwell, Baker, & Rutter, 1979; Kolvin, Garside, & Kidd, 1971; McAdoo & DeMyer, 1976). For example, Cox et al. (1975) found no differences in maternal depression, obsessional behavior, warmth, and emotional responsiveness between mothers of children with autism and mothers of children with a specific language disorder. Similarly, Cantwell et al. (1979) analyzed family life and interaction patterns of parents of children with autism compared with parents of children with a receptive developmental disorder of language and found very few differences between these two samples.

McAdoo and DeMyer (1976) took the research one step further, comparing the personality characteristics of parents of children with autism to a sample of parents participating in outpatient psychiatric treatment, as well as a sample of parents of children being treated in a child guidance center. These researchers, as well, found no striking differences in personality characteristics between the parents of the children with autism and the parents of children being treated in the child guidance center. Yet, these two groups of parents had more normative personality profiles (as measured by the Minnesota Multiphasic Personality Inventory) than did parents engaged in outpatient treatment for diagnosed psychiatric difficulties.

However, the weight of the evidence, especially from more recently conducted studies, suggests a different conclusion. Perhaps the strongest evidence for a genetic basis of autism comes from twin studies that show a high concordance for autism in monozygotic twins and relatively low concordance in dizygotic twins (Folstein & Rutter, 1977a, 1977b, 1988; Ritvo et al., 1985). In addition, whereas approximately 60% of monozygotic twins are concordant for autism, more than 90% are concordant for other social or cognitive difficulties (Bailey et al., 1995). Additional support for a genetic basis of autism comes from the higher recurrence risk for siblings of 4.5% (Jorde et al., 1991) compared to the general population risk (less than 1%).

Families with multiple children with autism may also be at a higher risk for lesser variants of autism, including language and cognitive difficulties (Piven et al., 1997a,b). For example, researchers have suggested a specific connection between autism and Asperger’s Disorder in other family members (Bowman, 1988). While research continues on the molecular mechanisms of these genetic associations (see
Cook, 1998, and Szatmari et al., 1998, for reviews), these findings have multiple implications for family members.

Much of the research on the family genetics of autism has focused on social impairments in family members. Researchers have reported that some parents of children with autism show deficits in social interaction in a general sense (Bolton et al., 1994; Gillberg, 1989; Landa et al., 1992; Piven et al., 1997a; Wolff, Narayan, & Moyes, 1988), while others have shown elevations in personality characteristics that lead to impaired social skills (Narayan, Moyes, & Wolff, 1990; Piven et al., 1994, 1997b; Wolff et al., 1988). Other research has indicated a higher prevalence of psychiatric disorders in parents of children with autism (Lobascher, Kingerlee, & Gubbay, 1970), including bipolar and other affective disorders (DeLong, 1994; DeLong & Dwyer, 1988; DeLong & Nohria, 1994; Lainhart & Folstein, 1994) than in the general population. Szatmari et al. (1995) used the family history study method to assess the prevalence of psychiatric disorder in parents, as well as second- and third-degree (collateral) relatives of children identified with a pervasive developmental disorder (PDD). They found that cognitive impairments and psychiatric problems were not more common in the families of individuals with PDD than in families of their control group, which included children with Down syndrome and children born at low birth weight. These researchers did find, however, several cases of PDD in maternal collateral relatives, as well as some mild social and communication differences in the family members of children with PDD.

A related line of research has examined communication and cognitive skills in family members of persons with autism. Here, the research suggests that some parents of children with autism may show pragmatic difficulties with language (Landa et al., 1992; Piven et al., 1997b) and communication (Landa, Folstein, & Isaacs, 1991; Wolff et al., 1988). Other researchers have found higher rates of learning disabilities, including reading, spelling, and language disorders (Bolton et al., 1994; Folstein & Rutter, 1977b; August, Stewart, & Tsai, 1981; Piven et al., 1990), and cognitive abilities in general (Boutin et al., 1997; Piven & Palmer, 1997; Tsai, Stewart, & August, 1981) in some relatives of individuals with autism. In particular, two studies have found that relatives of females with autism seem to be at greater risk for cognitive disabilities than relatives of males (Boutin et al., 1997; Tsai et al., 1981).

Research on siblings of individuals with autism has paralleled some of the findings on parental characteristics. Bolton et al. (1994) found higher rates of social deficits in siblings of individuals with autism as compared to siblings of individuals with Down syndrome. August et al. (1981) found that cognitive disorders (including disorders of speech, reading, spelling, language, and mental retardation) were more prevalent in siblings of children with autism compared to a group of siblings of children with Down syndrome. Finally, Piven et al. (1990) evaluated the psychiatric history of 67 adult siblings of individuals with autism, reporting that 2 siblings were identified as also having autism, 3 had "severe social dys-
function,” 10 had cognitive disabilities, and 10 had received treatment for affective disorders.

One explanation for the inconsistencies in the findings of studies investigating whether there is an elevated risk of other disorders in family members of persons with autism is the changing definition of autism. All of the studies which did not find elevations in neurological, psychiatric, communicative, or cognitive disorders were conducted in the 1970s, when the definition of autism was less precise and encompassed other types of childhood disabilities. In contrast, most of the studies finding evidence for the broader autism phenotype were conducted in the 1980s and 1990s, and thus likely had more focused and precisely defined samples. Thus, the weight of the evidence at the present time is that there is some indication of a broader autism phenotype, such that milder forms of the characteristics of autism are observed at an elevated level of frequency in some relatives of individuals with autism, although by no means in most or even many family members. These findings are important because they suggest a genetic basis for the etiology of autism, which may put parents and siblings at increased risk of experiencing stress as a result of providing care to their family member with autism.

IV. RESEARCH ON THE EFFECTS OF AUTISM ON THE FAMILY

Few disorders in children pose a greater threat to the psychosocial well-being of family members than autism. Gray and Holden (1992) describe four primary problems confronting parents. First, because autism is a relatively rare disorder, obtaining an accurate diagnosis is often the culmination of a long and protracted evaluation period. Second, the behaviors of children with autism are often extremely difficult to manage, and include temper tantrums, obsessional interests, and, in some cases, self-injury. Third, the public’s understanding of and tolerance for the aberrant behavior of children with autism is low. As a result, families may be socially isolated and wary of participating in public events. Fourth, there is no cure for autism and treatments or interventions entail tremendous investment of time, energy, and patience on the part of parents, other family members and friends, and professionals. In addition, the impairments in language and social skills that are among the core deficits of autism (Tager-Flusberg, 1994) strain the parent–child relationship. Collectively, these challenges can tax even the strongest family systems.

There are three major themes in the literature on the impacts on families of having a child with autism, each of which is reviewed below. First, the research literature shows that in comparison to parents of children with other types of developmental disabilities, parents of children with autism experience greater stress, depression, anxiety, and other negative mental health outcomes. Second, the con-
sequences for the family as a unit of having a member with autism are pervasive and lasting, but such consequences change from childhood to adolescence. Third, social support and the use of specific coping strategies can ameliorate or buffer the magnitude and impact of stress among such families.

A. Differences between Parents of Children with Autism and Parents of Children with Other Disabilities

Holroyd and McArthur (1976) were among the first researchers to compare levels of stress among mothers of young children with autism, Down syndrome, and a clinical group. Based on a sample of 22 mothers of children with autism, 22 mothers of children with Down syndrome, and 32 mothers of children evaluated in a clinic setting (some of whom had mental retardation), they found that mothers of children with autism scored significantly higher than the other two groups on a variety of indices of parenting stress. Specifically, mothers of children with autism reported higher levels of stress than mothers of children with Down syndrome, with respect to being more upset and disappointed with their child, more concerned about the child's dependency and behavior management needs, more concerned about the effect of the child on the rest of the family, and more anxious about obtaining appropriate services. These findings were replicated in recent research by Bouma and Schweitzer (1990), who found higher stress levels among mothers of children with autism as compared with mothers of children with cystic fibrosis and of typically developing children, and by Kasari and Sigman (1997), who found that parents of children with autism were more likely to perceive that their child had a difficult temperament than parents of children with mental retardation or parents whose children were developing typically.

Other recent research has extended this line of investigation by including fathers as well as mothers. A comparison of mothers and fathers of children with autism, children with Down syndrome, and developmentally typical children (Fisman, Wolf, & Noh, 1989; Wolf et al., 1989) found that mothers and fathers of children with autism displayed significantly higher levels of stress and lower levels of marital intimacy than did the other two groups, and that mothers (but not fathers) of children with autism had greater depressive symptoms than the other groups. Rodrigue, Morgan, and Geffken (1990, 1992) compared parents of children with autism, children with Down syndrome, and developmentally typical children on a variety of indices of adaptational competencies and resources. They found that mothers of children with autism reported less parenting competence, less marital satisfaction, and less family adaptability than did mothers in the other two groups, whereas for fathers in these families, few significant differences were found. Dumas et al. (1991) assessed differences in parental reports of parenting stress, child behavior problems, and dysphoria among 150 families of children with autism, behavior disorders, Down syndrome, or typical development. Both mothers and fa-
thers of children with autism and behavior disorders had higher parenting stress than the other two groups of parents, but only the mothers in these two groups had elevated levels of depression. Thus, the combined results of these studies suggest that mothers may be affected more negatively than fathers as a result of parenting a child with autism.

One explanation for the elevation in maternal distress, in particular, was investigated by Hoppes and Harris (1990) who found that, as compared to mothers of children with Down syndrome, mothers of children with autism perceived more limited feelings of attachment and closeness from their children, although child responsiveness to the mother increased with age. More recently, however, Dissanayake and Crossley (1996) suggested that attachment might not be impaired in children with autism. In studying the actual behaviors of children with autism, children with Down syndrome, and typically developing children toward their mothers, they concluded that although children with autism were less likely to display sociable behaviors such as eye gaze and smiling, they were rated by trained observers as equally attached to their mothers as children in the other groups. These studies point out the complexity of assessing attachment when it is based on parental perceptions versus observational data.

Several reports are available that document the heightened levels of stress among parents of adolescents and adults with autism in comparison to parents of adolescents with other types of disabilities. Donovan (1988) found that mothers of adolescents with autism had higher levels of stress than mothers of adolescents with mental retardation, particularly with respect to parent and family problems, behaviors and attitudes of the adolescent, and greater dependency of the adolescent on the mother. In one of the few studies focusing specifically on families of adults, Holmes and Carr (1991) compared the pattern of care of adults with autism and Down syndrome who continued to live at home with their aging parents. They found that among both groups of families, the majority of hands-on caregiving continued to be provided by mothers, despite the increased physical size of their children. They also found that parents of adults with autism were more likely to give in to their children’s demands than parents of adults with Down syndrome, in an attempt to avoid physical confrontation. Parents of adults with autism also reported that the most difficult aspect of care was managing their child’s behavior problems, whereas parents of adults with Down syndrome were more stressed by the restrictions on their social lives of ongoing caregiving responsibilities. Finally, while 4 of the parents of adults with Down syndrome said their son or daughter was easier to care for as an adult, almost half of the parents of adults with autism described their child as being more difficult to care for at this stage of life. The primary reasons for the more adverse situation over time were increases in behavior problems, increasing age of the parents, and fewer siblings available to help with caregiving.

Diagnostic group differences have been observed not only in the parent–child relationship but also in siblings. Knott, Lewis, and Williams (1995) observed that
rates of social interaction between siblings and their brother or sister with autism were lower than among similar pairs of siblings of children with Down syndrome. Fisman et al. (1996) studied differences in internalizing and externalizing symptoms in siblings of children with Pervasive Developmental Disorder (PDD), children with Down syndrome, and developmentally typical children. They found significantly higher levels of both internalizing and externalizing behavior problems among the siblings of children with PDD than the other two groups (based on both maternal and teacher reports). These findings are consistent with an earlier investigation of Rodrigue, Geffken, and Morgan (1993), who compared internalizing and externalizing behavior problems among 19 siblings of children with severe autism, 20 siblings of children with Down syndrome, and 20 siblings of developmentally typical children. Siblings of children with autism had higher scores on both dimensions of behavior problems than did siblings in the other two groups, although their mean scores fell within the normative range.

Several features of these comparison studies warrant comment. First, all were conducted using small samples of families, the representativeness of which is unknown. Second, most were conducted with parents of young children and adolescents (usually under age 12), and only a few were based on samples of adolescents and adults. Thus, firm generalizations of the findings to families at later stages of the life course cannot be made. Third, the consistency of the contrast between parents of children with autism and parents of children with Down syndrome is remarkable, with parents of children with autism reporting higher levels of distress and a more distant relationship with their child in all studies. There is an obvious need to extend this line of comparative research to families of adults with autism in order to gauge directly whether these diagnostic differences persist during the second half of the family life course.

B. Changes in the Extent of Family Impacts in Adolescence and Adulthood

The research literature indicates that there are periods of intensification and abatement of the symptoms of autism as the child grows up. Whereas the symptoms tend to be less severe during the middle childhood period (i.e., age 10 or older) than in younger children (Ando & Yoshimura, 1979; Ando, Yoshimura, & Wakabayashi, 1980; Bebko, Konstantareas, & Springer, 1987), there is an increase in symptoms during adolescence and young adulthood (Bristol & Schopler, 1983; DeMyer & Goldberg, 1983). A common set of themes in the literature on family impacts underscores the pervasiveness of the accommodations that families make to manage the care of a child with autism in adolescence, the struggle to maintain positive family relationships and activities, and the social isolation that often accompanies a family's efforts (Harris, 1984; Harris & Powers, 1983; Norton & Drew, 1994).

Bristol and Schopler (1984) noted that parents of children with autism must
adapt to a range of specific challenges during the early childhood period, including the chronic fatigue that results from the need for constant vigilance and supervision. Many young children with autism have difficulty sleeping through the night, eat only a limited range of foods, are oblivious to danger, and tantrum easily and unexpectedly. They also noted the developmental progression of family stresses, with early concerns focusing on simply managing the often overwhelming needs of the child, subsequent concerns focusing on self-help training and family stability, and later family concerns focusing more squarely on community acceptance issues and securing critical services. Their review is instructive in noting the different types of concerns and tasks facing families who maintain primary responsibility over the life course in securing a high quality life for their son or daughter with autism.

DeMyer and Goldberg (1983) discussed their findings from clinical work with 23 families of adolescents with autism regarding the impacts on the family system. The greatest impact, as reported by parents, was on family recreation activities, which were often sacrificed because of the difficulties of managing the adolescent's behavior in public places. Other areas of severe impact included finances, physical and mental health consequences for parents, meeting the needs of siblings, relations with friends and neighbors, marital relationships, and personal development of family members. DeMyer and Goldberg noted that during early childhood, most families exert tremendous efforts to get the most and best help available. As the child ages, even if the daily management demands abate somewhat, parental realization of the permanency of the child's handicaps makes adolescence a difficult period.

Bristol and Schopler (1983) also found that family impacts increase in severity as the child reaches adolescence, primarily attributable to the realization of the permanency of the child's handicaps and the emergence of deep worries about the child's future and the services that will be needed. Fong, Wilgosh, and Sobsey (1993) examined parental concerns during adolescence and identified six major themes based on intensive parent interviews: behavioral concerns (obsessions, aggression, tantrums), social and communicative concerns (inappropriate or inadequate social skills), family-related concerns (restriction in family life, need for constant supervision), education and related services (choosing integrated versus specialized schools, accessing behavior management services), relationships with professionals (ineffective communication, blaming messages from professionals), and independence and future concerns (vocational, leisure, and residential services). Parental stress during adolescence is a persistent theme in clinical and empirical reports (Harris, 1984; Koegel et al., 1992; Marcus, 1984). Whether this trajectory of family distress continues, escalates, or abates when the child reaches adulthood is not currently known and warrants direct examination in future research. Moreover, research is needed to examine whether family or parental stress is a function of the atypical demands placed on family members throughout the
life course or, alternatively, is more directly linked to the severity of symptoms of
the member with autism at a particular point in time.

C. Social Support and Coping

A variety of studies have been conducted to identify the factors that mediate or
buffer the stress associated with having a child with autism, particularly social
support and psychological resources of the parent (Anderson, Thibadeau, & Chris-
tian, 1994; Morgan, 1988). Bristol (1987) utilized the Family Adjustment and
Adaptation Model proposed by McCubbin and Patterson (1981, 1983) to test hy-
potheses regarding differential predictors of healthy adaptation among a sample of
45 families of children with autism or communication impairments. She found that
family adaptation was predicted by the adequacy of social support. Importantly,
she also found that the severity of the child’s condition was not a significant pre-
dictor of family adaptation, but was a predictor of marital adjustment. Unexpect-
edly, the more severely impaired the child, the less adverse the effect on the mar-
riage. Among the risk factors for poorer adaptation were having a “pile-up” of
other life stressors, maternal self-blame, and defining having a child with a hand-
icap as a family catastrophe, suggesting that parental appraisal of the situation is
a greater factor in adjustment than are the specific caregiving stresses presented
by the child.

Further evidence of the critical role of social support is provided by a study re-
ported by Sharpley, Bitsika, and Efremidis (1997). They surveyed over 200 par-
ents of children with autism in Australia and found that the vast majority (82%)
said they were sometimes “stretched beyond their limits” because of their child’s
dependency needs. However, they found that parents had significantly lower lev-
els of anxiety and depression if other family members felt comfortable with the
child’s disability and provided caregiving assistance. They recommended that ex-
tended family members be included in parent training and information sessions re-
garding autism, in order to enlarge the array of caregivers for the child. Bristol,
Gallagher, and Holt (1993) confirmed the positive effects of psychoeducational in-
terventions in reducing maternal depression. Their longitudinal study of 28 moth-
ers of children with autism found significant differences in maternal depression fa-
voring the 14 mothers who participated in an intervention program designed to
facilitate child learning and manage difficult behavior. Their research suggests that
formal support, provided by professionals and agencies, can make a significant im-
 pact on parental well-being.

Spousal support is another influence on the adjustment of parents of children
with autism. Bristol, Gallagher, and Schopler (1988) found that among mothers of
children with autism, the husband’s degree of instrumental and expressive sup-
portiveness predicted lower maternal depression, more positive ratings of marital
adjustment, and higher parenting competence. Fisman et al. (1989) found a recip-
rocal influence of depression between husbands and wives. If one spouse is depressed, that is likely to affect the quality of the marital relationship, with a consequent loss of spousal support.

In addition to formal and informal social support, parental psychological resources have been found to buffer the effects of stress or to account for the manner in which the stress of parenting a child with autism takes a toll on psychological well-being. Bristol (1987), in the study of family adaptation referred to earlier, reported that the use of active coping patterns predicted favorable outcomes in mothers. The type of cognitive appraisals used by mothers of adolescents with autism is another psychological resource that mediates the manifestation of stress. Fong (1991) reported that mothers of adolescents with autism who are high in stress tend to use “threatening” appraisals (i.e., the tendency to assess situations with worry or concern), whereas mothers low in stress tend to use more benign appraisals. Similarly, Gill and Harris (1991) studied the role of “hardiness” and social support as ameliorators of stress in mothers of children with autism. The concept of hardiness, as developed by Kobasa (1979), is used to describe people who are less vulnerable to deleterious outcomes in the face of stressful situations because of personal attributes such as a strong internal locus of control and an ability to see difficulties as opportunities for change and growth. In the Gill and Harris (1991) study of 60 mothers of children (ages 2 to 18 years) with autism, they found that mothers with higher scores on the hardiness measure and who perceived social support as more available had fewer somatic complaints and fewer depressive symptoms than did those who perceived less social support and had lower hardiness scores.

To summarize, parents of children with autism experience elevated levels of distress. Their parenting stresses appear to increase and intensify after the child reaches adolescence. Nevertheless, the availability of informal and formal social support and the use of personal psychological resources such as active coping, positive appraisals, and the personality characteristic of hardiness, can ameliorate the stresses of parenting a child with autism, at least during the childhood and adolescent stages of family life. However, virtually no attention has been paid to the unique stresses and coping strategies experienced by these families across the life course. This is all the more remarkable given the fact that many studies of families who have a young child with autism have identified worries about the future as a significant source of current stress (Bouma & Schweitzer, 1990; Donovan, 1988; Koegel et al., 1992).

V. THE MANIFESTATION OF AUTISM IN ADULTHOOD AND THE ROLE OF THE FAMILY

Most of the research reviewed thus far in this chapter was based on samples of families of children with autism. Although there is very little research on families
after the person with autism has reached adulthood, a few studies are available describing how autism is manifested in adulthood and how the impact of autism on the family may change across the life course.

Piven et al. (1996) followed 38 high-functioning (IQs of 65 or higher) children with autism who had been diagnosed by age 5. The follow-up assessment was conducted when they were between the ages of 13 and 30 (mean age = 17.6 years). The Autism Diagnostic Interview–Revised (ADI–R; Lord et al., 1994) was used at both points of data collection to assess the symptoms of autism. It was found that all but five individuals continued to meet DSM–IV criteria for autism in adolescence or adulthood, and even these five continued to have some persistent autistic characteristics. The dominant pattern of change in ADI–R domains from childhood to adolescence and adulthood was improvement in functioning, with 82% having improved in communication, 82% having improved in social interaction, and 55% having reduced ritualistic and repetitive behaviors. The authors concluded that autism is a “lifelong disorder whose features change with development” (Piven et al., 1996, p. 527). A similar pattern was reported by Venter, Lord, and Schopler (1992) in a study of 58 high-functioning teens and young adults with autism who continued to have significant limitations in adaptive behavior but whose IQ scores increased by almost 10 points from childhood to adolescence and adulthood. Mesibov and his colleagues (Mesibov et al., 1989) have also documented significant improvement and decreased symptomatology over time using the Childhood Autism Rating Scale (CARS) with adolescents and adults.

These studies suggest that although most individuals diagnosed with autism in childhood continue to manifest the core deficits of autism in adulthood, the symptoms of autism appear to abate in severity over time, and the best outcomes are found for those with higher IQ scores and more advanced language ability. These patterns have important implications for family members. Although they face lifelong caregiving responsibilities, the challenges of parenting an adult with autism may be less stressful, or stressful in different ways, than when their son or daughter was a young child or adolescent and may have a different outcome depending on the initial cognitive abilities of the child, as well as on the capacities of the parents to manage their own reactions and adaptations to their atypical parenting careers.

One factor that appears to moderate this pattern of symptom abatement is residential setting. Individuals placed in institutional settings tend to deteriorate from childhood to adulthood (Kanner, 1971; Wolf & Goldberg, 1986), whereas those who live with their families have shown improvements (Mesibov et al., 1989; Piven et al., 1996; Venter et al., 1992). It is not clear from the available evidence, however, whether the more favorable outcomes manifested by those who lived at home are the result of the positive effect of family living or that less impaired children are more likely than those who were more impaired to remain living at home. In addition, very little is known about the effects of living in the community, either in group homes or supported apartments, as contrasted with family co-residence.
Finally, the impact on the family of decades of co-residence has not been assessed and, hence, the relative benefits for the individual with autism and his or her parents are not yet known. Nevertheless, given the significance of where the individual with autism lives for outcomes in adulthood, and the implications for the extended family of out-of-home placement versus continued residence with the parents, it is valuable to review trends in living arrangements of adolescents and adults with autism reported in the follow-up study literature.

In 1971, Leo Kanner published a paper documenting the current status of the first 11 children he had diagnosed 28 years earlier. Of the 11, one was lost to follow-up and another died, leaving 9 children from his original cohort. Of these, only 3 lived with their families, 5 lived in institutional settings, and 1 lived in a foster home. Only one of those who lived with the family had lived at home continuously throughout the follow-up period. In another follow-up study published at around the same time, DeMyer et al. (1973) found that of 120 adolescents with autism age 12 and over, 58% lived either with their parents or with foster parents, while the other 42% lived in institutions.

As the rate of institutionalization has decreased since the 1970s, the proportion of adolescents and adults with autism who have remained with their families has increased. For example, Rumsey, Rapoport, and Sceery (1985) followed up 14 men with a mean age of 28 years, and found that 9 continued to live with their parents, 1 lived independently, and 4 lived in supervised residential settings. The Rumsey et al. (1985) sample included 9 individuals who were quite high-functioning (IQs above 80), and thus the likelihood of living outside of the residential service system might have been higher than for the majority of persons with autism. Wolf and Goldberg (1986) reported that of the 64 adolescents with autism they were able to locate, only 31% lived with parents, foster parents, or independently, whereas 69% lived in group homes or institutions. Gillberg and Steffenberg (1987) reported follow-up data on the cohort with autism and associated disorders born in Goteburg, Sweden, between 1961 and 1968. Of the 40 members of this cohort who had reached age 20 by the time of the follow-up, 50% continued to live with their parents and 50% in institutional settings.

The most recent data show an even higher rate of co-residence with parents. Szatmari et al. (1989) found that 10 of 16 high-functioning adults with autism (mean IQ = 92) continued to live with their parents, one lived in a group home, and the others lived independently. Similarly, Venter et al. (1992) found that 16 of the 18 high-functioning adolescents and adults they followed up lived with their parents, and the other two lived independently.

However, all of the follow-up studies, with the exception of the Gillberg and Steffenberg Swedish study, may yield misleading conclusions about the likelihood that adolescents and adults with autism will continue to live with their parents because these studies are based on small, highly selected samples that were drawn initially from clinic populations. In addition, none of the studies extended beyond
the early adulthood period, and several were restricted to relatively high-functioning individuals who have a different pattern of development than children with autism who also have mental retardation (Burack & Volkmar, 1992), who constitute the majority of the population with this disorder.

To update these findings with a more representative population and across a wider age range, we obtained data from state MR/DD agencies in New York and Massachusetts regarding the living arrangements of the populations of adolescents and adults with autism that they serve. These data suggest that most adolescents still live with their families, but the percentage drops precipitously in adulthood. Specifically, of the 7941 persons with autism served in 1998 by the New York State Office of Mental Retardation and Developmental Disabilities, 85% of those between the ages of 10 and 19 still lived with their parents, as compared with 54% of those between the ages of 20 and 29 years, and only 34% of those between the ages of 30 and 39 (Matthew Janicki, personal communication). In Massachusetts, of the 1198 adults with autism served by the Department of Mental Retardation in 1997, 42% of those between the ages of 18 and 30 lived at home with their families, as compared with only a quarter (23%) of those over age 30 (Amy Nazaire, personal communication). If the New York and Massachusetts data are representative of national patterns, then it can be concluded that only about 1 to 3 of adults with autism in their 30s continue to live with their parents, a rate substantially below that of adults with mental retardation (Fujiura, 1998).

Little is known about the toll on the parents of caring for a son or daughter with autism for three or four decades or about the accommodations that these families have had to make to manage a household that includes an adult with highly specific needs. Similarly, little is known about the factors that precipitate out-of-home placement or the consequences of placement for families who now live physically separate, although not necessarily emotionally separate, lives from their son or daughter with autism.

VI. UNCHARTED TERRITORY: PILOT STUDY ON FAMILIES OF ADULTS WITH AUTISM

As part of our longitudinal study of 461 aging families of adults with mental retardation (Krauss & Seltzer, 1999; Seltzer & Krauss, 1989, 1994), we have had the opportunity to learn from 13 families in which the adult has a diagnosis of autism as well as mental retardation. This is a unique group of families, in that their sons or daughters were members of the first generation to be diagnosed with autism, and thus they provide insights about the life-course trajectories of adults with autism and their families. In 1988, when our study began, the men (n = 8) and women (n = 5) with autism in our sample ranged from 25 to 40 years (mean = 31 years) and their mothers ranged in age from 58 to 70 years (mean = 62 years).
The design of our study involves multiple interviews conducted with the mothers in these families. We collect quantitative and qualitative data about the characteristics of the son or daughter with the disability, the services he or she receives and needs, family characteristics, and maternal physical, social, and psychological well-being. Although the sample is very small, the data offer insights about the functional abilities, behavior problems, and social life of the person with the disability, the closeness of the relationship between the person with the disability and his or her parents, the frequency of contact with siblings, and the well-being of individual family members.

In the sections that follow, we first present two case studies of adults with autism and their aging families in order to illustrate the types of challenges and changes they experience during adulthood. Next, we describe the small subgroup of adults with autism in our sample (n = 13) and their families. In order to contextualize these descriptions, we contrast the adults with autism with adults with Down syndrome in our study (n = 120), as these represent distinct diagnostic groups that have been compared in past research on the early childhood period.

A. Longitudinal Case Studies

The two individuals\(^1\) portrayed in the case studies below illustrate a number of the challenges faced by adults with autism: preference for sameness, behavior problems, limited social relationships, and medical problems. In addition, they illustrate sources of support for these individuals: their families and the service system.

1. CASE STUDY 1: PAUL

When our study began in 1988, Paul was 23 years old. He had been diagnosed during childhood with autism and mild mental retardation. Paul's primary autistic behaviors as a young adult were pacing, hand-flapping, and repetitive speech. He lived with his parents, Mr. and Mrs. D., ages 63 and 64, respectively. Paul has two brothers and a sister: Gregory, Jr., age 37, Sam, age 35, and Francie, 21. Paul is independent in almost all areas of daily living. In addition, he is able to read paragraphs and write on a somewhat limited basis. Paul's social network included his family members and one friend, John.

During the day, Paul attended a sheltered workshop. His father insisted that he wear formal clothing to work every day—dress pants and a white shirt. Paul repeatedly refused opportunities for supported employment, preferring to remain in the sheltered workshop. By 1993, however, Paul finally accepted a supported employment trial doing clerical work at a small office. After two years at this job, he reached a high level of independence, relying only on infrequent check-ins by his

\(^1\) The names of the individuals in the case studies and identifying details have been altered to protect confidentiality.
job coach. Overall, his family was very pleased because this job met Paul’s needs to do precise work in a quiet setting.

In 1996, Paul’s residential status changed. For four days each week, Paul lived with his sister Francie, her husband and child, and for the other three days he lived with his parents. This arrangement worked because Francie and her husband lived in the next town. It was seen as an opportunity for Paul to live more independently, for Francie to try out her long-held expectation that Paul would eventually live with her, and for the parents to have more free time yet still be closely involved with Paul.

This move increased Paul’s opportunities for independence and resulted in new growth and personal development for him. For example, Paul no longer wore formal clothes to work, now varying his attire with jeans and a t-shirt. Also, he overcame his dislike of using the telephone and regularly called his parents on the days he was at Francie’s. In addition, he developed a limited friendship with Francie’s husband’s brother and still maintained contact with his friend, John.

2. CASE STUDY 2: DONALD

Donald is a 37-year-old man with autism and moderate mental retardation. He lives with his parents, Mr. and Mrs. F., who are in their early 70s. He has four siblings. Donald is independent in major activities of daily living, but needs assistance with transportation and household chores. He does not read or write. Donald attends a sheltered workshop five days a week. His mother noted that he doesn’t have any friends, but she has arranged for paid advocates to take him out about three or four times a week. A one-on-one social situation is all that he can handle. However, Mrs. F. was very dissatisfied with the services provided by the advocates, and she felt that they should try to do more to improve Donald’s skills.

When our study began, Donald’s behavior problems were severe and persistent. He stamped his feet when upset and was demanding and repetitious verbally, according to his mother. He talked to and about imaginary friends who were “very real to him.” His father felt that Donald was abusive to family members, always trying to control them, “to conquer us.” Donald took antipsychotic medication. Mr. and Mrs. F. were very interested in finding a residential placement for Donald, as the strain of living with him was increasingly difficult for them.

This situation continued without much change from the beginning of the study in 1988 until 1992, when a supported living situation was found for Donald. However, he was only able to sleep in his new apartment one night, when his sister stayed there with him. He and his advocate would go to the apartment every afternoon, but Donald would call home four or five times, and then would insist on returning to his parents’ home to sleep. This lasted for 3 months and then the placement was terminated.

In 1996, it was discovered that Donald had an overactive thyroid, which was treated with medication. As a result, his behavior problems decreased substantial-
ly, and the antipsychotic medication was discontinued. His parents were delight-
ed with the change in Donald and now feel that they would like him to live at home
as long as they are able to care for him. His mother also felt that he was learning
more from the advocates than in the past. In fact, Mrs. F. said, “I can’t say enough
about them. This agency has done so much for Donald. It’s been a whole new life
for him. They have done wonders!” His parents no longer felt the sense of physi-
cal and emotional exhaustion that they had lived with for so many years, and they
were much more satisfied with the services Donald received. They now look for-
ward to continued co-residence rather than to an out-of-home placement.

In both of these cases, substantial gains were made by the adults during the study
period. These gains are consistent with the pattern reported in many follow-up
studies, namely, “gradual symptomatic improvement with persistent residual so-
cial impairments” (Rumsey et al., 1985, p. 465). Paul’s autonomy and social world
expanded as he gradually made the transition to a more independent adulthood.
The diagnosis and treatment of Donald’s thyroid problem changed the quality of
life for Donald and his family, as his behavior problems abated substantially and
his social skills improved. These cases point to the changing balance of challenges
and resources in the lives of adults with autism as they and their families age.

In order to complement and contextualize these case studies, we compared the
characteristics of the families of adults with autism in our study with families of
adults with Down syndrome. With the exception of sociodemographic character-
istics which were measured when our study began, these comparisons reflect the
circumstances of the families in 1996. Differences up to the $p < .10$ level are re-
ported, due to the small size of the sample with autism and the very limited statis-
tical power. We caution that these findings are highly tentative and, at best, give
us avenues to investigate in future research.

B. Adults with Autism versus Down Syndrome

The adults with autism and the adults with Down syndrome in our study were
similar in gender distribution (about 60% male) and age (an average of 39 years
for the adults with autism and 38 years for the adults with Down syndrome). How-
ever, the adults with autism had poorer functional skills than the adults with Down
syndrome, and a greater number of behavior problems (an average of three be-
behavior problems for the adults with autism versus one for the adults with Down

\(^2\) When the study began in 1988 (Time 1), 15 families identified their son or daughter as having
autism, and 171 had a child with Down syndrome. The following analyses were conducted using the
Time 6 data (1996), including 13 families whose son or daughter has autism and 120 whose son or
daughter had Down syndrome. The 2 families of adults with autism who did not participate at Time 6
included 1 in which the mother was deceased and 1 in which the mother dropped out of the study. Of
the 51 nonparticipating families whose son or daughter had Down syndrome, in 8 families the son or
daughter had died during the course of the study, in 21 families the mother had died, in 8 there was in-
complete data, and in another 14 the mother dropped out of the study.
FAMILIES OF PERSONS WITH AUTISM

syndrome), both factors that we have found in our research to put caregiving mothers at risk of elevated levels of psychological distress (Seltzer, Greenberg, & Krauss, 1995). The mothers of adults with autism were much more likely to feel as if they are “walking on eggshells” around their adult child than were mothers of adults with Down syndrome and to feel that their son or daughter’s behavior problems often “come out of nowhere.” The particular problematic behaviors that differentiated the two groups were being hurtful to self, socially offensive, and withdrawn, all higher in adults with autism than those with Down syndrome. Indeed, over 80% of the sample of adults with autism were characterized by their mothers as being withdrawn, whereas only 20% of the adults with Down syndrome behaved this way.

Also more characteristic of the adults with autism than the adults with Down syndrome was a more constrained and limited pattern of social activities. They were less likely to spend time with relatives, coworkers, or neighbors than were the adults with Down syndrome. They also were less likely to be seen by their mothers as being “good company” (60%) than their counterparts with Down syndrome (94%).

Although both adults with autism and the adults with Down syndrome received about five or six discrete services, there were three types of services more likely to be received by the adults with autism: psychological services, occupational therapy, and nonvocational day services (i.e., day activity or day habilitation services rather than sheltered or supported employment). Their parents also perceived a higher level of unmet need for physical and occupational therapy, as contrasted with the perceptions of the parents of persons with Down syndrome. Thus, parents of adults with autism may perceive a continuing need for therapeutic intervention well into adulthood.

Another notable difference between the two groups was their residential placements. All but two of the adults with autism were living with their parents in 1996. In contrast, of the sample of adults with Down syndrome, 25% had moved out of the parental home. Of the adults with Down syndrome who were placed, 82.2% lived in various types of community settings, whereas one of the two placed adults with autism lived in a private institution. These data may suggest that there is an easier match between the available residential options and the needs of adults with Down syndrome than their counterparts with autism. It is also possible that the higher placement rate of adults with Down syndrome reflected their earlier age-related declines in cognitive and functional abilities. However, given the small size of the sample, we await future research to address this issue directly.

C. Mothers of Adults with Autism vs Down Syndrome

We also contrasted the well-being of the mothers of the adults with autism with the mothers of adults with Down syndrome. The mothers of adults with autism in our sample averaged 70 years of age in 1996, whereas the mothers of adults with
Down syndrome averaged 3 years older—about 73 years of age. The two groups of mothers did not differ in their level of education, marital status, or family income. Thus, their sociodemographic profiles were very similar.

We compared the two groups of mothers with respect to their social and psychological well-being. We found that the mothers were similar in their level of global well-being, as indicated by their self-rated health, level of depressive symptoms, size of social support network, overall life satisfaction, and positive psychological well-being. These findings differ from the results of research contrasting mothers of young children with Down syndrome and mothers of young children with autism, reviewed earlier. The absence of significant differences in our measures of global well-being may be the result of the small sample of mothers of adults with autism (and the resultant loss of statistical power to detect differences), may be due to the fact that the adults with autism were also diagnosed as having mental retardation and, thus, similar in this respect to mothers of adults with Down syndrome, or, more speculatively, may suggest an abatement in social and psychological stress among mothers of adults with autism after decades of caregiving. Further investigation of these alternative explanations awaits future research.

The two groups of mothers were found to differ in two measures of role-specific well-being: the mother's degree of pessimism about the son or daughter's future and her feelings of closeness with the son or daughter. The mothers of the adults with autism were more pessimistic about their son or daughter's future and had a less emotionally close relationship with their son or daughter than did mothers of persons with Down syndrome, mirroring findings reported in studies of families at an earlier stage of the life course (e.g., Hoppes & Harris, 1990).

D. Siblings of Adults with Autism vs Down Syndrome

There was also an interesting pattern of differences between the siblings of the adults with autism and the siblings of the adults with Down syndrome in our sample. Siblings of adults with autism were less likely to be married (44% versus 80%) and, consequently, had substantially lower household incomes (averaging between $25,000 and $35,000) than siblings of adults with Down syndrome (who averaged earnings of between $40,000 and $50,000). In addition, the siblings of adults with autism felt less close emotionally to their brother or sister than siblings of adults with Down syndrome. They also were less likely to participate together in social activities, such as going out for a meal, shopping or running errands, participating in a recreational activity, going out to visit relatives or friends, and going to doctors' appointments. Thus, there may be an intergenerational pattern of more distant relationships between family members and the person with the disability in the case of autism as compared with Down syndrome, which is consistent with studies reported earlier of more impaired sibling relationships in childhood (e.g., Knott et al., 1995).
VII. SUMMARY AND CONCLUSIONS

Research on families of persons with autism provides a detailed view of the challenges faced during the early stages of the family life course. Parents often struggle to obtain an accurate diagnosis for their child's aberrant behavior and development. The elevated frequency of highly disruptive behavior, such as tantrums, sleep problems, and physical safety concerns, may exhaust parental energies and severely curtail social, vocational, and familial life. Sorting out the range of therapeutic options that may be offered and managing the extraordinary effort many treatment programs require of families may initially be welcomed as a means of trying to provide the best opportunities to the child with autism for more responsive and normal functioning. However, in adolescence, many families recognize that their child's level of functioning or capacity for independence may not change dramatically in the years ahead. Adolescence, normally a time of increased independence and autonomy for boys and girls, may exacerbate family relationships for parents of adolescents with autism. Transitions from adolescence to adulthood require parents to confront the reality that access to publicly supported services, such as special education, will cease and that entry into the adult service system is fraught with uncertainty. The task of parenting a person with autism throughout the first two decades of life is marked by extraordinary effort, major accommodations in the family's daily life, frustrations and successes in obtaining needed services, and management of the psychological and physical toll these challenges extract on the family.

Our review of the extant literature described that, in contrast to other types of disabilities, parents of children with autism appear to be at greater risk for depression, social isolation, fatigue, and frustration in obtaining accurate diagnoses and services. There is considerable and consistent evidence that mothers experience greater impacts than fathers, that some siblings are at risk for psychological and behavioral difficulties, and that having other family members who are capable of providing caregiving assistance is a boost for the family. The pervasiveness of the accommodations families must make to manage the behavioral and social needs of a child with autism presents a staggering challenge. Yet, the evidence also points to the importance of coping, positive appraisals, and "hardiness" in ameliorating the stresses these families experience and in maintaining positive well-being profiles.

We know much less, however, about the life experiences of families of adolescents and adults with autism. In part, this reflects the fact that autism as a syndrome was first diagnosed as recently as 1943. Thus, many adults who might be correctly diagnosed with autism may have acquired other diagnostic labels in their childhood and are thus "unavailable" for current identification and recruitment for follow-up studies. It also reflects the more general trend for studies of families to concentrate on the early stages of the family life course, with studies of older families only more recently appearing in the literature (Seltzer & Krauss, 1994).
The fact that there are very few existing studies that consider issues relevant to families of adults with autism is striking, but the relative paucity of these studies only points out the need for future research. There are several important areas that remain virtually unstudied. For example, researchers have come to view the experiences of caregivers as dynamic and evolving over time. Such a perspective is needed in future research on families of persons with autism. There is considerable variability in the types of life stressors that caregivers experience from year to year. Some are thrust into additional caregiving roles, such as caring for an aging parent or spouse, or must deal with their own health difficulties that may be exacerbated by the physical and emotional toll of caring for a child with aberrant behaviors. Others experiencing unnerving ups and downs in the quality of services available for their son or daughter, affecting parental decision making about such fundamental decisions as where their adult child with autism should live. Research on how these types of normative and nonnormative changes tax the family’s capacity to provide care and, consequently, affect their psychological well-being is needed. Studies on the mechanisms by which families manage their caregiving tasks, such as the role of social support and coping strategies, are also needed, as such resources have been found in many other studies of family caregiving to play a critical role in buffering the effects of extraordinary caregiving challenges.

Further, more research needs to be conducted on the common set of concerns faced by families of adults, as opposed to children or adolescents with autism. The existing literature suggests that planning for the future care of an adult with autism is a major issue confronted by families. How do families resolve this issue? What role do adult siblings of persons with autism anticipate or adopt as they, too, confront the future care needs of their brother or sister? How do coping strategies acquired during the early years of caring for a youngster with autism affect the well-being of parents during the child’s adulthood? What personal, familial, or societal resources are important in maintaining a high quality of life for the person with autism and his or her family during adulthood? There are a host of additional questions that need investigation, not only to better describe the life-span developmental pathways of persons with autism and their families, but also to inform the service delivery systems that ultimately will provide the needed care and supervision after parental caregiving ends.

Despite an overwhelming perception in mothers of young children with autism that something is missing in their relationship with their child, as these children age, some mothers have reported that their child with autism has become more responsive (Hoppes & Harris, 1990). There is emerging evidence that the cardinal manifestations of autism, such as obsessive behaviors, social unresponsiveness, and communication difficulties, abate in some individuals over time. The implications of this pattern of abatement in manifestation of autistic behaviors for the long-range caregiving arrangements of adults with autism is cause for optimism and warrants additional investigation. In particular, because so little has been stud-
ied regarding the emotional and social relationships between adolescents and adults with their parents or other family members, additional research would be especially useful, especially focused on the gratifications as well as difficulties that characterize these relationships.

Finally, we noted earlier that some family members of persons with autism face a dual challenge, namely meeting the caregiving needs of the member with autism and dealing with manifestations of a broader autism phenotype that may affect other family members. The results of current investigations into the genetics of autism warrant careful scrutiny from a family systems perspective. Much needs to be understood about how variants of autism affect family groups over the life course. As information is accumulated about the life trajectories of persons at various points along the spectrum of autism, we need to understand how the environments in which they live, particularly the family environment in which more than one member may be affected, is altered by and accommodates to these atypical circumstances. As has been true in research on families of persons with other types of disabilities, it is probable that the experiences of families dealing with autism have much to teach us about the varieties of ways in which individuals and families equip themselves to survive, if not master, the consequences of one of life’s most complex and taxing challenges.

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